

THE UNIVERSITY OF HULL

The Experiences of Hospice Nurses: An Exploration of
Compassion and Interventions to Support Wellbeing

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Overview

The portfolio has three parts. Part one is a systematic literature review, in which empirical papers investigating the effectiveness of interventions for supporting and promoting wellbeing in palliative care staff are reviewed. A systematic database search identified 10 studies to be reviewed. A narrative synthesis of the findings related to effectiveness is provided, alongside a review of methodological quality of the research in this area. The clinical implications for healthcare services and directions for future research are also discussed. Part two is an empirical paper, which uses Interpretative Phenomenological Analysis to explore the experiences of nurses working within hospice settings and how compassion is experienced and understood in their work. The findings are discussed in relation to theory and implications for clinical practice and recommendations for future research are considered. Part three comprises the appendices supporting the systematic literature review and the empirical paper but also includes a reflective statement focusing on the research process. Part three also includes an epistemological statement.

Overall word count (excluding appendices) 20,820

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Part One: Systematic Literature Review

This paper is written in the format ready for submission to the journal, BMJ Supportive & Palliative Care. Please see Appendix C. for Guidelines for Authors.

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The Effectiveness of Interventions for Palliative Care Staff Wellbeing: A Systematic Literature Review

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ABSTRACT

Background Staff in palliative care settings have been found to experience psychological distress such as stress and burnout, which may be related to the demands of their work. Interventions have been designed and implemented to address the emotional impact of their work. However, the effectiveness of these interventions remains unknown.

Aim To explore the effectiveness of interventions aimed at improving wellbeing in palliative care staff by examining quantitative studies.

Method A systematic review was conducted. PsychINFO, CINAHL, MEDLINE and Academic Search Premier databases were searched up to February 2016. Of 2310 potentially eligible articles, 54 full texts were screened resulting in 10 eligible for review. Methodological quality was assessed. Findings of study effectiveness are synthesised using narrative synthesis and methodological quality is assessed using an adapted quality assessment tool.

Results Outcome measures focused on psychological distress, job related burnout, stress and compassion fatigue, wellbeing and quality of life. Interventions varied considerably, comprising of a mixture of support groups, relaxation, education and cognitive training. There was no significant improvement on wellbeing outcomes for any of the reviewed studies. The methodological quality of the studies was generally poor, with only one Randomised Controlled Trial study included in the review.

Conclusions There is limited research of adequate quality therefore it is not feasible to form meaningful conclusions about the effectiveness of interventions in improving

wellbeing of palliative care staff. More research is needed, of high quality design, along with better development of interventions.

INTRODUCTION

Professionals working in healthcare are at risk of experiencing work-related stress. Within the UK, some of the highest rates of work-related stress have been in the healthcare sector.¹ Stressors outside work, combined with an unsupportive work environment and work stress, can result in mental health difficulties such as symptoms of anxiety and depression.² The main sources of distress within nursing have been identified as: workload, leadership style, professional conflict and the emotional cost of caring.³

In recent years there has been a government drive to address the health and wellbeing of National Health Service (NHS) staff. An independent review commissioned by the Department of Health, The Boorman NHS Health and Wellbeing Review (2009)⁴ found that when organisations focused on the wellbeing of their staff, there was a positive impact on staff performance, levels of staff retention and reduced absence due to sickness. Furthermore, patient satisfaction improved. The wellbeing of healthcare staff is an influential factor in quality of care for patients and, importantly, has an impact upon patients' subjective experience of their care.⁵

Wellbeing as a concept and as a measurement has also been difficult to define. Some have argued that wellbeing is a construct,³⁰ whereas others have argued that wellbeing should be considered as a state.³¹ Dodge et al. (2012)³¹ offered a new definition of wellbeing: "the balance point between an individual's resource pool and the challenges faced".^{31(p229)} Most researchers believe that wellbeing is multi-dimensional³² which may be a contributing factor in the lack of standardised measures

designed to assess wellbeing. Quality of life appears to be a dimension of wellbeing rather than an all-embracing definition³¹.

Despite the fact that research has investigated the impact of psychosocial interventions for patients at end-of-life^{19 20} and their family caregivers,²¹ there has been less focus on addressing psychological wellbeing of the professionals who care for them. Yet the importance of Hospice staff wellbeing has recently been emphasised by Hospice UK (2015)²² in their published framework intended to advise hospice leaders and managers on how to promote staff resilience in stressful times.

Only a limited number of reviews have investigated interventions directed at stress prevention within the healthcare profession population.^{6,7,8} Compared with other healthcare professions, the literature that explores interventions for supporting staff wellbeing in the palliative care profession appears to be even more limited and, perhaps due to the nature of the services, tends not to meet quality inclusion criteria for large-scale Cochrane reviews.⁸

There is evidence that professionals who care for the dying are at risk of various stress-related problems. Even though recent reviews have shown that, despite the challenges associated with working with death and dying, palliative care nurses are no more stressed than those in other nursing professions, this does not lessen the particular challenges they face and the risks to their wellbeing.^{9,10} Furthermore, the psychosocial risk factors for palliative care staff have remained relatively constant over the last four decades.¹¹

The risk of burnout in this group of professionals is still a live issue. Sixty-three per cent of palliative and oncology professionals have been found to show symptoms of chronic stress.⁹ Burnout has been investigated internationally and has shown varying rates of

prevalence. A recent study identified a 33% per cent prevalence of burnout in Singaporean palliative care professionals.¹² Prevalence rates of burnout in palliative care workers, from international studies, vary from 14% in US hospice workers¹³ to 24% in Australian palliative care Physicians¹⁴ and 21% Canadian.¹⁵ Previous research has also shown palliative care nurses to be at high risk of substance misuse, alcohol abuse, anxiety and depression.¹⁶

Psychological distress can be defined in several terms. Burnout has been associated with symptoms of stress, depression and anxiety and has been a focus of research within the helping professions²³. The concept of burnout has been defined according to three characteristics: emotional exhaustion, depersonalisation and reduced perceived personal accomplishment.²⁴ Burnout is purported to be an effect of a prolonged discrepancy between the individual's input of resources and the workplace's reciprocal input of resources,^{25 26} breaching a psychological contract between the employee and the employer.²⁷ Another consequence related to working in the helping profession is the concept of compassion fatigue, a phenomenon conceptualised by Figley (1995)²⁸, whereby helping professionals experience a cumulative effect of repeated exposure to suffering of those they care for, resulting in a reduced ability to empathise with their patients.

Recommendations have been made that either preventative interventions or stress-reducing interventions are devised in order to enhance the psychological wellbeing of palliative care staff.¹⁷ The issue of staff wellbeing is important as employers have a moral and legal obligation to ensure employee wellbeing. Self-reported self-care strategies (e.g. promotion of physical wellbeing, talking to others, 'time away' from work, hobbies and maintaining personal and professional boundaries) have been

identified by palliative care physicians.¹⁸ However, it has not been investigated whether or not the implementation of these strategies was associated with agreeable prevention or stress-reduction outcomes (e.g. Burnout measures).¹⁷

There is ambiguity in the concepts of compassion fatigue and burnout as they are often used interchangeably in the literature and are both associated with stress, anxiety and depression. Within palliative care literature, psychological distress of professional care givers is commonly operationalised as stress and burnout⁹ and compassion fatigue.²⁹

Although the impact of palliative care work on staff stress has been explored and some literature has discussed some coping strategies that may help hospice staff, there is little reference made to the use of structured interventions to support hospice nurses' wellbeing. More specifically, there are no reviews that have systematically reviewed research into the types of interventions that have been tried out with hospice nurses as potential ways for managing with their work and how effective these interventions have been. By reviewing the literature in relation to the impact of interventions on the wellbeing of hospice nurses, it may inform understanding about both what 'works' and what does not in terms of reducing staff stress and improving their wellbeing. Furthermore, it may identify areas for future development in the implementation and design of interventions to best prevent and reduce hospice nurses stress and improve their wellbeing. Not only may it inform directions for future research it may offer insights into how to support effectively other healthcare professionals.

The research question:

How effective are interventions for hospice nurses that are aimed at enhancing wellbeing/reducing negative symptoms associated with their work?

METHODS

Search protocol

The following four online databases, accessed via the EBSCOhost service, were selected and searched up to and including February 2016: CINAHL, MEDLINE, PsycINFO and Academic Search Premier. Search terms were generated by listing alternatives to 'intervention', 'palliative care', 'occupational health' and 'care professionals'. EBSCOhost thesaurus was used to identify alternative words. The 'All text' field was selected to ensure the inclusion all relevant papers. Retrieved articles were searched manually for additional relevant references.

Search terms used for the online database search:

Palliative OR "terminal care" OR "end of life care" OR hospice*

AND

("occupational health" OR stress OR burnout OR "compassion fatigue" OR distress*
OR resilience*) N3 (nurse* OR "care profession*")

AND

Intervention* OR Strategy* OR prevent OR support of supervision* OR "self care" OR
program* OR therapy*

Inclusion and exclusion criteria

Inclusion:

- The study reports an intervention
- Participants are nursing or health-care based professionals involved in patient care working within a palliative care setting
- A quantitative measure relating to staff wellbeing/distress is applied pre- and post-intervention.
- Articles are from peer reviewed journals

Exclusion:

- Not reported in the English language
- Distress/wellbeing as an outcome is reported qualitatively only
- None of the participants are healthcare professionals working in a palliative care setting
- The participants are patients or families of patients.
- Review or discussion papers
- No intervention reported or evaluation of an intervention targeted at outcome of wellbeing/distress
- No quantitative measure relating to staff wellbeing/distress is applied pre- and post-intervention

For the purpose of this review, psychological outcomes encompass both positive and negative states: both the level of psychological distress and the extent to which a person experiences psychological wellbeing. Thus this review has included both research that has used outcomes focused on measures of distress or symptoms of

distress, as well as measures associated with the concept of wellbeing such as quality of life and job satisfaction, and self-compassion.

All identified journal articles were initially screened by title and abstract. Articles were discarded if they clearly provided information to show they failed to meet all of the inclusion criteria or met one or more of the exclusion criteria. However articles were retrieved in full if it was unclear from the title and abstract alone or if they did not meet one or more exclusion criteria. Once articles were retrieved, articles were read in full and inclusion and exclusion criteria were applied. A final sample of 10 studies remained. Figure 1. Summarises the article selection process.

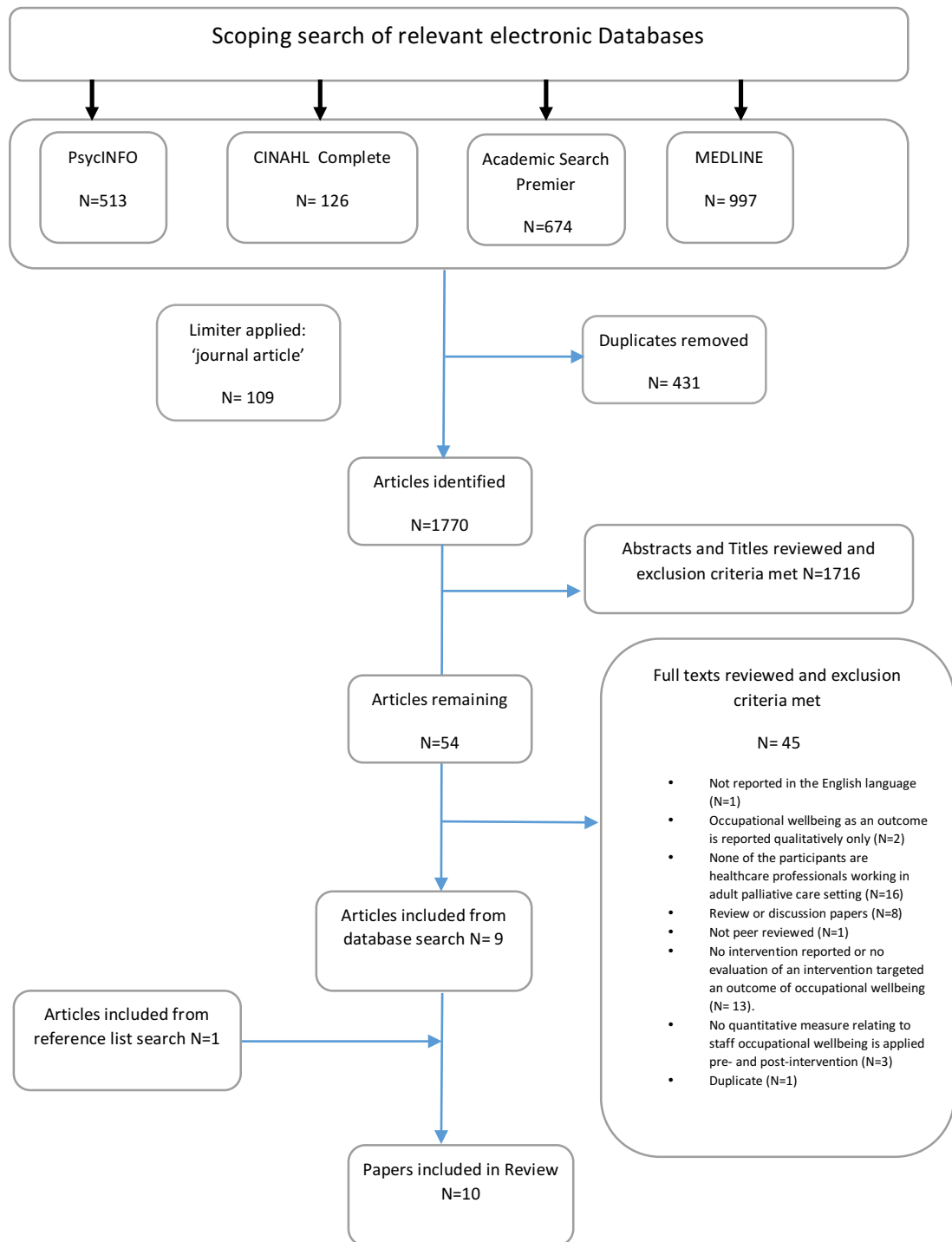


Figure 1. Summary of article selection process

Data Extraction

Data was extracted using a data extraction form designed specifically for the current review (see Appendix D), which included the following domains.

Research Aims and design

Characteristics of participants (e.g. gender, age ratio, professions, sample size)

Type of intervention (duration, mode of delivery, description of content)

Findings/results relating to staff wellbeing and how this was measured.

Quality Assessment

To measure study quality, a checklist was devised by the author (see Appendix E) which incorporated items from the Downs and Black (1998)³³ checklist, Strengthening the reporting of observational studies in epidemiology (STROBE)³⁴, Mixed Methods Appraisal tool MMAT³⁵ and NICE quality appraisal tools.³⁶ The checklist was adopted in this format to ensure that all aspects of methodological quality were reviewed adequately.

The scores were calculated in percentages with the highest possible score being 100% and the lowest possible score being 0%. Six studies (2 higher quality, 2 middle quality and 2 lowest quality scores) were reviewed by another researcher to assess inter-rater reliability. A calculation of Cohen's kappa showed inter-rater reliability to be good ($k=0.71$). However, any discrepancies between the two researchers' ratings were discussed until a consensus was reached.

Data analysis

A narrative approach to synthesis was chosen to analyse the results of the studies. This method was chosen due to the heterogeneity of the studies (both in outcome data and study design)³⁷ which meant a meta-analysis was not appropriate.

RESULTS

Overview of included studies

The main characteristics of the 10 included studies are summarised in Table 2.

Characteristics of participants

The studies were conducted in a range of countries but over half the studies were carried out in North America (5 U.S.A.^{38,39,40,41,42}; 1 Canada⁴³). The other countries were: Brazil,⁴⁴ Germany,⁴⁵ Hong Kong (China),⁴⁶ U.K.⁴⁷

Sample sizes ranged from nine participants³⁸ to the largest sample of 132 participants,⁴⁶ with the median sample size of 20 participants.^{41,42}

The majority of the professionals recruited in the studies were palliative care nurses although other professional groups were sometimes included e.g. social workers^{42,45,46}, physicians,^{39,46} counsellors⁴⁶, chaplains^{39,46}, volunteers.^{46, 41}

The majority of participants were female, with the percentage of female participants ranging from 64.70% of participants³⁹ to 100%^{40,47} with a median of 92.25% of participants being female.⁴⁶

Intervention type

Most of the interventions were group-based in nature but no two studies used the same intervention. The majority of the studies use a mixture of techniques and strategies, including CBT for insomnia³⁸, general CBT techniques,³⁹ psychoeducation^{39,45,30} relaxation^{39,46} and counselling/active listening skills training for managing suffering and bereavement.^{40, 41, 45} Creative approaches were also employed, for example, music and art-based therapy,⁴⁶ which varied in content between studies.

One intervention was physical education and 10 minutes of daily exercise as a workplace activity program (WPA)⁴⁴ One study used a quilt-making activity, where participants worked in pairs to produce a quilt panel (to contribute to a team quilt) to represent what being part of a hospice team meant to them.⁴² Whereas another study used improvisation with musical instruments.³⁹ Fillion et al.⁴³ used a manualised meaning-centered intervention based on Logotherapy. The five principles of Logotherapy were covered over four sessions: characteristics of meaning; sources of meaning; experiences of creative values and accomplishments at work; suffering as a source of attitudinal change; and the use of affective experiences and humour to find meaning.⁴³ The duration and frequency of the interventions varied considerably between studies.

Study design

The majority of studies used a one-group pre-post design, which is a limitation in terms of determining whether effectiveness was due solely to the intervention itself. Three used control groups.^{40,43,42,45, 41} However, Fillion et al. (2009)⁴³ was the only study to use a randomised controlled design, where a wait-list control group was employed. A limitation of the Salzano et al.⁴² study design was the use of the same participants to serve as the control group; participants completed outcome measures before and after both a staff meeting (control) and the art-making session (experimental group). Gray-Toft (1986)⁴⁰ also used a within-subjects control group but a staggered continuous design was used whereby the team was split into two groups based on nurses' shift patterns. The evening/night shift group were controls for the first six weeks, then the day shift group were controls for the last six weeks.

There was considerable variability in both the timing and frequency of the administration of pre and post measures. This general variability makes it difficult to draw direct comparisons between studies.

Measurements of psychological outcome

All the measures were standardised and/or validated outcome measures, with the exception of the author-devised Numeric Rating Scale.⁴⁵

The studies used a variety of different measures to assess psychological distress and wellbeing. Table 1. provides more descriptive information on the wellbeing outcome measures. These broadly fell into three domains:

Psychological distress

The Hospital Anxiety and Depression Scale (HADS)⁴⁸ and the Center for Epidemiological Studies-Depression (CES-D)⁴⁹ scales were used to directly measure psychological distress.

Job related burnout, stress and compassion fatigue

The Maslach Burnout Inventory²⁴ and The Maslach Burnout Inventory-General Survey (MBI-GS),^{25,26} the Burnout Measure,⁵⁰ the Job Stress Scale⁵¹ and The Nurses Stress Scale (NSS)⁵² all measured the impact of the working environment.

Wellbeing and quality of life

The Five Facet Mindfulness Questionnaire (FFMQ).⁵³ The Numeric Rating Scale⁴⁵ measured general quality of life, self-compassion and contentment relating to the job. The subscale of Compassion Satisfaction/Fatigue Self-Test for Helpers (CFS)⁵⁴ The

vigour/activity subscale of the Shortened Profile of Mood States (POMS-37)⁵⁵ measured emotional quality of life.

Table 1. description of wellbeing outcome measures employed by the reviewed studies

Outcome measure	Description	Study which employed measure
Centre for Epidemiological Studies-Depression Scale (CES-D) ⁴⁹	A short self-report measure of symptoms associated with depression in the general population.	Carter , Dyer and Mikan (2013) ³⁸
Subscale of Compassion Satisfaction/Fatigue Self-Test for Helpers (CFS) ⁵⁴	This self-test estimates the respondents compassion status: risk of burnout and compassion fatigue and also the degree of satisfaction with helping others. Three separate scales: compassion satisfaction (pleasure derived from being able to do work well); Burnout (feelings of hopelessness and difficulties with job effectiveness); Compassion Fatigue (work related, secondary exposure to extremely stressful events).	Hilliard (2006) ³⁹
Hospital Anxiety and Depression Scale (HADS) ⁴⁸	Self-report measures of anxiety and depression in non-psychiatric population. 2 subscales (anxiety and depression) of 7 items each. Respondents rate relative frequency of symptoms over the past week on a four-point Likert scales (0 being not at all to 3 being very often indeed).	Freitas, Carneseca, Paiva & Paiva (2014) ⁴⁴
Maslach Burnout Inventory (MBI) ²⁴	Three-dimensional conceptualisation of Burnout: emotional exhaustion, depersonalisation and reduced personal accomplishment	Freitas, Carneseca, Paiva & Paiva (2014) ⁴⁴
Maslach Burnout Inventory-General Survey(MBI-GS) ^{25,26}	MBI-GS is a developed version of the MBI - it has three subscales that parallel the MBI: exhaustion, cynicism, professional efficacy. The exhaustion items are generic without the MBI's emphasis on emotions and without direct reference to service recipients.	Potash et al. (2014) ⁴⁶

Job Stress Scale ⁵¹	Assesses stress from three dimensions: psychological demands, control and social support and classifies as follows: high strain (high demand/ low control); low strain (high control/low demand); active work (high demand/high control); and passive work(low control/low demand).	Freitas, Carneseca, Paiva & Paiva (2014) ⁴⁴
Shortened Profile of Mood States (POMS-37) ⁵⁵	Measure of psychological distress, yields a Total Mood Disturbance score and sub-scores for 6 subscales: Fatigue-Inertia; Vigor-Activity; Tension-Anxiety; Depression-Dejection; Anger-Hostility; Confusion-Bewilderment. List of 37 adjectives: respondents indicate degree to which each adjective describes themselves in the last week on a 5-point Likert scale.	Fillion et al. (2009) ⁴³
Nursing Stress Scale (NSS) ⁵²	34-item measure: describe situations that have been identified as causing stress for nurses in the performance of their duties. It provides a total stress score as well as scores on each of seven subscales that measure the frequency of stress experienced by nurses in the hospital environment.	Gray-Toft (1980) ⁴⁰ ; Burneau and Ellison (2004) ⁴⁷
Five Facet Mindfulness Questionnaire (FFMQ) ⁵³	This instrument is based on a factor analytic study of five independently developed mindfulness questionnaires. The five facets are: Observing, Describing, Acting with awareness, Non-judging of inner experience, and Non-reactivity to inner experience. Statements are rated on a 5-point Likert scale (1 = never or very rarely true, 5 = very often or always true)	Potash et al. (2014) ⁴⁶
Burnout Measure (BM) ⁵⁰	21-item measure unidimensional measure of burnout of exhaustion: 7-point rating scale ranging from 'never' to 'always'	Larson (1986) ⁴¹

Methodological quality

Quality assessment percentage scores are reported in Table 2. For a more detailed breakdown of scores see Appendix F. Scores ranged from 38%⁴¹ to 85%.⁴³ The key methodological limitation identified related to the generalisability of the findings as sample sizes were small, interventions were frequently focussed on an individual staff team in a single location and study designs did not account for confounding variables. The long-term effectiveness of interventions could not be established in the majority of studies as follow up measures were not taken.

Effectiveness of interventions on outcomes

Psychological Distress

Two studies used direct measures of psychological distress. Both studies were one group pre-post designs. The Carter et al. (2013)³⁸ pilot study investigated the effect of an adapted CBT for insomnia intervention⁵⁶ on nurses' mood. Mean scores reduced from 17 (SD=12) to 12 (SD=11) from baseline to week 3 but increased to a mean score of 14 (SD=11) at week 5. Due to the small sample size, descriptive not inferential statistics were used and four participants did not complete the measures at all time-points. Therefore, data from 13 participants at baseline was compared to data of nine participants at week three and five. Mean scores on the CES-D were reported; therefore, it is not possible to determine if changes in scores were statistically significant. The meaningfulness of these results is limited because the clinical descriptors of these scores is not indicated. Furthermore, given the small sample size, it may have been more meaningful to have analysed individual scores on the CES-D for

each participant. The exact nature of the participants' depressive symptoms is not possible to determine as item scores are not reported.

Freitas et al. (2014)⁴⁴ used a workplace physical activity (WPA) programme of regular short activity over a three-month period. For both anxiety and depression, as measured using the Hospital Anxiety and Depression Scale (HADS)⁴⁸ the percentage of participants experiencing clinical levels of anxiety and depression decreased but this change was not a statistically significant effect. They reported only the proportion of participants who were classified as clinically anxious or depressed (a score of eight or higher on the HADS⁴⁸ was considered positive) at pre and post intervention. Nurses whose average attendance at the groups was less than twice a week were excluded from analysis. Therefore, the remaining nurses might have had more motivation or reasons for their involvement may have been different, which was not accounted for. The possible sampling bias towards a more motivated sample of nurses further highlights the ineffectiveness of the WPA because, even with a potentially more engaged sample, there was no significant effect of the intervention.

Burnout

Eight of the 10 studies used a measure related to the impact of the job - burnout or stress or compassion fatigue - which may indirectly relate to psychological distress.

Alongside their measure of direct psychological distress, Freitas et al. (2014)⁴⁴ also investigated the impact of their WPA program on job-related burnout, and occupational stress using the Maslach Burnout Inventory (MBI)²⁴ and Job Stress Scale.⁵¹ The pre and post outcomes from the MBI²⁴ were reported as the proportion of

nurses experiencing low, high and moderate levels of the MBI's three dimensions: emotional exhaustion, depersonalisation and personal accomplishment. There were no statistically significant changes in proportions from pre to post intervention. Of particular note was that the proportion of participants experiencing self-reported high levels of depersonalisation was high and remained so from pre (47.6%) to post (52.4%) intervention. This indicates that the WPA was not effective in ameliorating symptoms of burnout. However, as mentioned earlier, it would have been more informative to have analysed individual changes in scores rather than proportions. A Portuguese language-adapted shortened version of the Job Stress Scale⁵¹ measured occupational stress. Participants were categorised as either high or low in 'demand', 'control' and 'social support'. From pre to post there was a trend showing an increase in proportion of participants categorised as high for control and demand. However, this was not a statistically significant difference. This indicates no significant effect of WPA on occupational stress or burnout.

The MBI-GS^{24,25,26} was also used by Potash et al. (2014)⁴⁶ for evaluating the effectiveness of art-therapy based supervision compared to a skills-based supervision group for palliative care staff in a hospice. There was a reduction in emotional exhaustion for both groups but only a significant reduction in emotional exhaustion for participants in the art-therapy-based supervision group. This indicates that the art-therapy intervention was effective in reducing symptoms of emotional exhaustion. However, there are several limitations of the study, which preclude any firm conclusions. There are various confounding variables unaccounted for, including having no control group.

In the Salzano et al. (2013)⁴² study, participants' scores on the MBI were significantly lower from pre to post-collaborative quilt-making exercise. This contrasted with significantly increased scores from pre to post-monthly staff meeting, which acted as the control condition. Considering this finding in isolation, the collaborative art-making exercise appeared to bring about significant improvements in burnout symptoms. However, this finding must be interpreted with caution because the ecological validity of the findings is compromised by the timing of when the outcome measures were administered; immediately before and after the 1-hour session. The content of the staff meeting may have been, by its very nature, more stress-inducing than a supportive art-making group. Participants' expectations about the purpose of the groups, prior to being in the group, might have influenced their responses and perceived levels of burnout. Furthermore, the lack of an adequate control group makes it hard to determine what factors contributed to the positive change.

Larson (1986)⁴⁰⁴¹ used Pine and Aronson's (1981) 21-item Burnout Measure⁵⁰ to evaluate the effectiveness of a 12-week Support Group training programme. There were no significant differences in mean burnout scores from pre to post.

Stress

The Nurses Stress Scale⁵² was used in Gray-Toft's (1980)⁴⁰ evaluation of the impact of a counselling support program on levels of stress in nurses on an 11-bed hospice unit. This self-report measure assessed frequency of self-reported stress with 3 subscales: death and dying, conflict with physicians and work load. There was a decrease in mean scores of total stress but this was not statistically significant. At the subscale level, there was a significant reduction in scores for both nursing groups on the workload subscale. There was only a statistically significant reduction in death and

dying scores for the evening and night shift nurses. It appears that positive effects were more apparent for evening and night shift staff than day shift staff. However, due to the multiple group staggered continuous single-treatment design there are several confounding variables which were not accounted for which reduced the validity of the study. There may have been factors related to the individual characteristics of the nurses between the groups or changes in service context or differences in the clinical work related to the different time frames in which the intervention was administered compared to the day shift group which contributed to this difference. It is not possible to determine whether or not it was the counselling support group specifically which resulted in the changes.

Bruneau and Ellison (2004)⁴⁷ used the Nurses Stress Scal⁵² to assess the impact of their two-session stress-reduction programme. Participants completed the NSS at 4 time-points, twice before the programme and twice after at 2 and 3 week intervals before and after. There was no significant change in score from pre to post-programme. However, it was notable that the mean scores at the 1st and 2nd pre-programme indicated the participants were not particularly stressed at the outset, with means of 34 and 35 respectively (0= no stress, 170 (maximum score) = extreme stress). This may, in part, explain the lack of change found.

Compassion fatigue

Hilliard (2006)³⁹ was the only study to use a compassion fatigue measure. The study acknowledged it considered compassion fatigue and burnout to be interchangeable concepts. A subscale of the Compassion Satisfaction or Fatigue Self-Test for Helpers (CFS)⁵⁴ was used to compare the effectiveness of a didactic music therapy group with an ecological music therapy group. There were no statistically significant differences

in scores from pre to post intervention for either group. The small sample sizes of the groups limited the statistical power of the study and limits the generalisability of findings. The sample was also a mixture of different hospice professionals which may have influenced the results; it is difficult to know if music therapy may be more compatible or relevant to the needs of some professionals over others perhaps due to the differences in work demands. Similarly to the other studies, there was a lack of control groups.

Wellbeing and quality of life

Only three studies used measures related to wellbeing. The measures assessed quality of life, self-compassion and emotional regulation.

Fillion et al. (2009)⁴³ is the only study of high methodological quality, having used an RCT design and a well-developed manualised meaning-centred intervention (based on Victor Frankl's Logotherapy, the four weekly meetings focused on the development of skills to cope with emotional and existential demands). Emotional quality of life was assessed using the six-item Vigor/Activity subscale of the Shortened Profile of Mood States (POMS-37).⁵⁵ Confounding variables were identified, accounted for and statistically reduced using regression models. Participants' socio-demographic variables were found to be comparable between groups. Despite this study's rigorous methodology, there was no statistically significant difference in mean scores on the POMS-37⁵⁵ at pre, post or at 3-month follow up. This indicates there is no evidence for effectiveness of a meaning-centred intervention on emotional quality of life. However, this may be explained, in part by the recruitment of 'healthy' participants at baseline. The voluntary recruitment may have compromised the representativeness of the sample. Despite the POMS-37⁵⁵ having reportedly excellent internal consistency, only

one eight-item subscale of the POMS-37⁵⁵ was administered to measure emotional quality of life. This brings in to question whether this was the most informative/appropriate, holistic or ecologically valid measure of emotional quality of life.

Wasner (2005)⁴⁵ was the only study which used a measure relating directly to psychological wellbeing that was not standardised. Instead it was a researcher-devised numeric rating scale (NRS) which had 10 items to test general attitudes about work. The items of relevance to wellbeing were: quality of life, self-compassion and contentment with job. It is worth noting that the NRS was not the only primary measure. Spiritual wellbeing and other spirituality related validated measures were also used but they were not reported here because they were not deemed to be directly associated with psychological wellbeing and therefore within the scope of this review. Statistically significant increases in scores (indicating a positive change in self-ratings) occurred for all three items and this improvement was sustained at six-month follow up. This finding was also true for the overall NRS score of all 10 items. However, these findings can only be considered as indications as they were not corrected for statistical error.

Alongside measuring burnout, Potash et al.⁴⁶ also used the Five Facet Mindfulness Questionnaire (FFMQ)⁵³ to examine the interventions effects on 'emotional regulation'. The art-therapy-based supervision group showed statistically significant increases in scores for the subdomains of acting with awareness and non-judging of inner experiences. In contrast, there were no significant differences on the FFMQ for participants in the skills-based supervision group. Potash et al. suggest that this enhancement in emotional awareness may be in part responsible for the reduced

emotional exhaustion self-reported on the MBI.²⁴ However, the relationship between these measures was not statistically analysed therefore conclusions about the causal relationship or mechanisms of change cannot be made.

Summary

In summary, the interventions which were evaluated in relation to their effect on nurses' symptoms of anxiety and depression appeared to show a trend of a reduction in symptoms but this was not significant⁴⁴ or was not tested.³⁸ The two studies were not comparable as one intervention was based on CBT for insomnia,³⁸ whereas the other intervention was a physical activity programme.⁴⁴ Both studies had limitations in terms of size and design.

There were mixed findings for outcomes related to burnout, stress and compassion fatigue but generally there was little evidence for the effectiveness of the interventions. Studies that used burnout measures provided mixed evidence for the effectiveness of interventions aimed at reducing symptoms of burnout. Most studies showed no significant change in burnout scores. Although the two studies which used art-based interventions^{42,46} showed significant reductions in symptoms from pre to post, these findings are limited by problems in study design, incomparable interventions and lack of external and internal validity. As for the studies that used stress measures, there were no significant reductions in self-reported symptoms. Again, there were issues with study designs that resulted in uncontrolled confounding variables. Finally there was no evidence for the effectiveness of music therapy-based interventions on symptoms of compassion fatigue, satisfaction and burnout.³⁹

There are mixed findings for outcomes related to wellbeing. In the only RCT study,⁴³ which therefore had the most rigorous study-design, there was no significant effect of

the intervention on emotional quality of life. Two studies showed improvements in scores relating to self-compassion⁴⁵ and mindfulness⁴⁶ which may indicate that interventions aimed at enhancing emotional regulation and self-compassion have some positive impact on palliative care staffs' self-perceived emotional wellbeing but the design of these studies limits conclusions that can be drawn. Furthermore, the heterogeneity of the interventions and measures make it hard to draw comparisons. It is not possible to determine clear evidence that demonstrates the effectiveness of interventions on measures related to wellbeing.

Table 2. Summary of the main characteristics of included studies

Study Authors (Year) Country	Aim (s) of study	Characteristics of Participants Organisation Profession(s) Sample size (n) Gender	Control/ Comparison group	Intervention	Wellbeing outcome measure How/when measured?	Other measures	Key findings	Quality score (%)
Carter, Dyer and Mikan (2013)³⁸ <i>Texas, USA</i>	Pilot study to test the feasibility and acceptability of CBT for insomnia in chronically bereaved hospice nurses.	<i>Non-profit Hospice agency</i> Hospice nurses n=9 (baseline n= 13) 1 Male, 8 Female	None	2 1-hour education sessions) CBT for Insomnia. Provided nurses with information and skills to identify thoughts and beliefs that negatively affected sleep quality. Set personal goals for change. Cognitive therapy, stimulus control, sleep hygiene and relaxations techniques. Session 1 occurred in week 2 and session 2 occurred in week 4.	CES-D ⁴⁹ Measures given at Baseline, Week 3 and Week 5.	PSI ⁵⁷ Goal attainment scale.	Average scores on CES-D at baseline was 17 (indicating major increased risk for major depression diagnosis). Week 3 mean score = 12 Week 5 mean score = 14. No statistical analysis. No significant correlation between sleep components and depressive symptoms.	53%

<p>Hilliard (2006)³⁹ U.S.A</p>	<p>Evaluate effects of ecological and didactic music therapy on compassion fatigue and team building.</p>	<p><i>Hospice</i> Nurses, social workers and chaplains n= 17 64.7% female</p>	<p>none</p>	<p>Two different group music therapy sessions run by Music Therapist and intern.</p> <p>Ecological group: open format for musical and verbal expression, facilitators took supportive and grounding role rather than leading. Primary technique was improvisation.</p> <p>Didactic group: psychoeducational approach, planned and structured sessions, music therapy within cognitive behavioural and humanistic framework. Guided meditation, relaxation and stress management.</p> <p>Six 1-hour sessions, weekly.</p>	<p>CFS⁵⁴ (subscale) Completed pre-test (session 1 before music group) and post-test (after session 6)</p>	<p>Team-building questionnaires (researcher devised)</p>	<p>No significant differences on the CFS scores from pre-to post- test within either group or in the post-tests between groups.</p>	<p>61%</p>
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Freitas, Carneseca, Paiva & Paiva (2014)⁴⁴ Brazil	To assess the effects of WPA on levels of anxiety, depression, burnout, occupational stress and and work-related quality of life	<i>Palliative Care Unit</i> Palliative care professionals: 19 assistants; 2 registered nurses n= 21 95.2% Female	none	WPA conducted by Physical Education professional 10-minute session, 5 days per week, over 3 months.	HADS ⁴⁸ MBI ²⁴ JSS ⁵¹	n/a	No significant effects of WPA on mood disorders, burnout or occupational stress.	59%
Fillion et al. (2009)⁴³ Canada	To test efficiency of a meaning-centred intervention to improve job satisfaction and quality of life.	<i>Hospital units, homecare services and long-term care facilities.</i> Palliative care nurses n=109 99.1% female	Randomised wait-list control group (n=53) Intervention group (n=56)	Manualised Meaning Centred Intervention: 4 weekly meetings	POMS-37 ⁵⁵ (Vigor-Activity Scale) Pre-, post-test, and 3-month follow-up.	JDS ⁵⁸ Benefit finding instrument ⁵⁹ FACIT-sp ⁶⁰	No significant effect on emotional Quality of life	85%
Wasner, Longaker, Fegg, Borasi (2005)⁴⁵ Germany	Evaluating the effects of spiritual care program on changes in attitudes, spiritual well-being and	Palliative care professionals: 51% nurses;16% hospice volunteers; 14% physician; 5% social workers; 5% pastoral	No control	3.5 days of training in 'Wisdom and Compassion in Care for the Dying'	Numeric Rating Scale (author-devised) Pre-, post-, and 6-month follow up.	IIR ⁶¹ STS ⁶² FACIT-sp ⁶⁰	Significant and sustained improvements in ratings of single attitudes (NRS)	55%

	work-related stress.	counselling; 9% other n=63 91% female						
Gray-Toft (1980)⁴⁰ U.S.A.	Design, implement and evaluate a counselling support program among nurses.	<i>11-bed hospice unit</i> 8 registered nurses, 5 licenced practical nurses, 4 senior nursing assistants n=11	Multiple-group, staggered continuous single-treatment design. Group 1: control group for last 6 weeks (evening and night shift nurses) Group 2: control group for first 6 weeks (day shift nurses)	Counselling support program staggered for two groups over 15 weeks. Group program 1-hour every week for 9 weeks.	NSS ⁵²	JDS ⁵⁸	Reduction in self-reported stress, increased job satisfaction and reduced staff turnover.	54%
Potash et al. (2014)⁴⁶ Hong Kong	Effectiveness of art-therapy-based supervision in reducing burnout and death anxiety in EOLC	<i>Field of death, dying and bereavement.</i> Nurses, social workers, counsellors, clergy, physical therapists, occupational	Control group: Skills-based supervision 3x 6-hour daily sessions. n=63	6 x weekly, 3-hour art-therapy-based supervision sessions. n=69	MBI-GS ^{25,26} FFMQ ⁵³ Pre and post intervention.	Generated art, reflective writings, discussions, and evaluations. DAP-R ⁶³	MBI: both groups decrease in exhaustion. Only art-therapy based group had significant mean reduction from baseline to post intervention.	61%

	workers	therapists volunteers					FFMQ: significant increase for art-therapy group from baseline to post.	
		n=132					Significant increases for acting with awareness and non-judging of inner experiences for art-therapy group. No significant changes for skills based group.	
		93% female						
Larson (1986)⁴¹ U.S.A.	Pilot test of the effectiveness of a support group training program for hospice nurses	<i>Hospice and the Visiting Nurse Association Hospice Program</i> Group A: 9 volunteers, 1 director of volunteers Group B: 4 nurses, 4 home health aides, 1 physical therapist, 1 hospice manager n=20	no	12-week Support Group training program: The Common Concern program (audiotape and print) teaching communication skills and group management.	Pre and post intervention BM ⁵⁰	Self-reported satisfaction/perceived expectations. JMCC ⁶⁴	No significant difference in mean burnout scores from pre- to post-intervention in either group. No meaningful pre-post analysis was possible for the JMCC.	38%
Salzano, Lindeman and Tronsky (2013)⁴²	Effectiveness of collaborative art-making	<i>Hospice</i> 10 social workers 10 members of the art	Participants served as their own control	Collaborative art-making: group produced a quilt. Pairs created a quilt panel to 'express what it means	MBI-GS ^{25,26}	SAWS ⁶⁵ Measured at the start and	Statistically significant two way interaction between time and condition:	67%

U.S.A.	task on reducing burnout and increasing social support in hospice caregivers	department n=20 80% female	Control group: staff meeting Experimental group: art-making activity.	to be part of the hospice team'		end of each group.	MBI-GS increased from pre-to post for the control condition but decreased pre-to post intervention for the experimental condition. Decreased burnout post art intervention.	
Bruneau & Ellison (2004)⁴⁷ U.K.	To quantify work-related stress and explore how well nurses cope. To evaluate the impact of a stress reduction programme	<i>Hospital in-patient palliative care ward</i> Registered nurses n=18 100% female	none	2 x 2-hr sessions, 4 weeks apart. Session 1: cognitive coping skills and relaxation techniques Session 2: practice relaxation, reflect on recent stressful event	NSS ⁵² Administered twice before and after, 3 weeks apart.		No significant difference between mean scores pre-post. No statistical association between programme and improvements in stress or coping.	75%
<p>CES-D-Centre for Epidemiological Studies-Depression Scale⁴⁹; PSI- Pittsburgh Sleep Quality Index⁵⁷; CFS- Compassion Satisfaction/Fatigue Self-Test for Helpers⁵⁴; HADS- Hospital Anxiety and Depression Scale⁴⁸; MBI- Maslach Burnout Inventory²⁴; JSS- Job Stress Scale⁵¹; POMS-37- Shortened Profile of Mood States⁵⁵; FACIT-sp- Functional Assessment of Chronic Illness Therapy- spirituality subscale⁶⁰; IIR- Idler Index of Religiosity⁶¹; STS-Self-transcendence Scale⁶²; NSS-Nursing Stress Scale⁵²; JDS-Job Diagnostic Survey⁵⁸; MBI-GS-Maslach Burnout Inventory- General Survey^{25,26}; FFMQ-Five Facet Mindfulness Questionnaire⁵³; DAP-R Death Anxiety Profile- Revised⁶³; BM-Burnout Measure⁵⁰; JMCC-Jenkins Means of Coping Checklist⁶⁴; SAWS-Support Appraisal for Work Stressors inventory⁶⁵</p>								

DISCUSSION

This review used a systematic approach with the aim to evaluate the effectiveness of interventions that aimed to improve palliative care staff wellbeing. Overall, there were mixed findings for the effectiveness of studies on outcomes related to staff distress and wellbeing.

A variety of different outcome measures were used to assess the impact of intervention on changes in staff wellbeing. Due to the heterogeneity of outcome measures used by the 10 studies in this review,^{38,39,40,41,42,43,44,45,46,47} evidence of effectiveness was explored by organising outcomes into three domains: psychological distress; job related burnout, stress and compassion fatigue; wellbeing and quality of life. There was no convincing evidence for the effectiveness of either a workplace physical activity intervention nor a CBT for insomnia based intervention on direct self-report measures of psychological distress, namely Depression and Anxiety. In the studies that used job-related stress outcomes, there were mixed findings, but overall there was limited evidence for the effectiveness of the interventions for reducing symptoms of burnout, stress and compassion fatigue. Finally, for outcomes related to wellbeing, there was one RCT which demonstrated no significant effect of the meaning-centred intervention on emotional quality of life. Two studies showed some improvements on self-compassion and aspects of mindfulness but the quality of this evidence is poor due to limitations in study design.

The choice of outcome measures used focused mainly on symptoms of distress. The literature has generally explored the psychological impact of working in palliative care in relation to burnout, staff stress and compassion fatigue which is represented within the outcomes of some of the studies reviewed. However, even then, a range of different outcome measures have been used. This makes it difficult to compare findings directly and also questions what should be considered the most meaningful outcome measure for assessing wellbeing in palliative care staff. Furthermore, the definition of wellbeing is still unclear, which has probably contributed to the fact that there is limited research that has used wellbeing-focused

outcomes. Continued research is needed to determine what the most valid markers of wellbeing are. More research that investigates other aspects of psychological wellbeing in palliative care staff may contribute to a better understanding of what outcomes to target in order to facilitate enhanced staff wellbeing. In order to meaningfully compare the effectiveness of interventions on palliative care, there would need to be increased research, of higher quality, which uses standardised interventions and outcome measures that target wellbeing.

Quality of the evidence

In this review, quality of the studies was assessed. The scientific rigour of the reviewed studies is generally very low. Only one out of the 10 studies was a randomised controlled design. The lack of control groups used in the study designs means that causal relationships between the treatment interventions and the outcomes cannot be determined fully, because confounding variables are not accounted for. Instead, only associations can be observed. Due to the sample sizes of the reviewed studies being relatively small, the statistical power of the studies is compromised. The generalisability of the findings to other palliative care staff is also limited due to small sample size and selection bias. A relative strength of the studies is the use of validated self-report measures.

Even though the majority of the studies used group-based interventions, no two interventions were the same. This lack of consistency between any of the studies makes it difficult to form any direct comparisons regarding the effectiveness of the interventions on wellbeing. Furthermore, the theoretical mechanisms of the interventions generally appears unclear, with the exception of one study, which used a theoretically underpinned manualised intervention.⁴⁵ Although various psychological techniques, such as CBT-specific techniques, have been described within some interventions, the extent to which these approaches adhered to the psychological models is difficult to determine. This, combined with the lack of controls for

confounding variables in the majority of the studies, means it is not possible to differentiate any particular mechanism that contributes to enhancing wellbeing, as for the majority of the other interventions.

Critique of review

A significant limitation of this review is that only 10 studies were identified which met inclusion criteria, which highlights the lack of research in this area and limits the scope of the findings. Several qualitative studies were identified in the selection process but were excluded as they did not specifically address the research question in relation to effectiveness. However, it may be useful to analyse studies which explored palliative care staffs' subjective experiences of interventions, to better understand what was perceived to be most meaningful and satisfactory, in order to aid future development of interventions.

As far as the author is aware, there are no reviews that have looked specifically at this population of healthcare professionals, but we can refer to reviews that have looked at interventions for occupational stress in health care workers more generally. Most recently, Ruotsalainen et al. (2015)⁸ conducted a metaanalytic Cochrane review to evaluate the effectiveness of work and person- directed interventions in preventing stress at work in healthcare workers. One obvious difference that Ruotsalainen et al. used was a meta-analytic approach that followed rigorous methodology and had a more specific inclusion criteria limited to RCTS. However, a meta-analysis was not appropriate or feasible for the current review, due to the heterogeneity of the studies in terms of outcome measures used and variability in study design.

A limitation of this review is that a customised checklist was devised to assess quality, which means the reliability and validity of this assessment process is uncertain. However, to check reliability of the quality assessment, a second reviewer independently assessed a subsample of studies. The process of study selection for this review was conducted only by the primary

author. Reliability of the selection process could have been enhanced by having a second reviewer.

Future directions

There are some preliminary indications that studies which assessed outcomes related to self-compassion and mindfulness showed some self-reported increases in self-compassion and mindfulness but the studies in this review are limited by their design.^{46, 39} A recent review has highlighted that mindfulness-based interventions are effective in enhancing self-compassion, reducing stress and increasing quality of life in healthcare professionals more broadly.^{50 51} (ref 66,67) A future focus on compassion and mindfulness-based interventions for palliative care staff may be worthy of exploration for increasing the evidence-base in relation to wellbeing outcomes.

Better development of interventions that draw on the literature that focuses on what makes a support group successful is needed. Different contexts might require different interventions, but interventions need to be developed with sound theoretical underpinnings and involving pilot studies and healthcare professionals input on what would be considered most pertinent to their needs. Finally, longitudinal studies are needed to determine whether or not strategies learnt from the interventions can be applied and whether or not the effects of which can be sustained within the context of ongoing clinical practice.

Conclusion

Conclusions about the overall effectiveness of supportive interventions for palliative care staff are very limited. It is not possible to compare directly any of the papers as no two interventions are the same and the types of outcome measures are heterogeneous. Overall, no conclusive recommendations can be made as to what psychosocial interventions effectively enhance psychological wellbeing for palliative-care staff. More research is needed to

determine both what the most effective interventions are for supporting palliative care staffs' wellbeing, and what measures are most relevant to assess wellbeing in this population.

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Part Two: Empirical Paper

This paper is written in the format ready for submission to the journal, Qualitative Health Research. Please see Appendix G. for the Guideline for Authors.

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The Lived Experiences of Hospice Nurses: An Exploration of Compassion

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Abstract

Existing literature has focused mainly on the negative impact of caring for people at the end of life. However, less attention has been paid to nurses who hold positive beliefs about such work. The concept of compassion has not been previously explored in research investigating the subjective experience of hospice nurses. Semi-structured interviews were carried out with nine hospice nurses. Interpretative Phenomenological Analysis was used to explore their subjective experiences of their work and how they understood and experienced compassion. The analysis generated five major themes of 'the motivation to care for others', 'the preciousness of death', 'shared humanity in death', 'the collective sense of caring' and 'self-awareness'. Central to the themes was a respect and dignity for the person within the dying patient and the dying process itself. There was a strong sense of awareness of their own personal and professional boundaries, which helped them to sustain their caregiving role. Compassion was experienced as an intrinsic part of their make-up as hospice nurses rather than a tangible skill that could be taught. The themes were related to existing models of compassion as one way of understanding how the participants might maintain a caring mentality in their work. The implications of the findings, on the drive to improve compassionate care in healthcare contexts more widely, are discussed.

Key words: hospice nurses, compassion, end-of-life-care, healthcare professionals

Short title: Experiences of Compassion in Hospice Nurses

Background

In England, approximately 500,000 people die each year. Of those people, up to 170,000 receive specialist palliative care (National Council for Palliative Care, 2014). Our ageing population, the inevitable increase in co-morbidity, expectations and aspirations for high quality end-of-life-care by both public and professionals, all mean that the demands on both generalist and specialist palliative care will increase (National Institute for Health and Care Excellence; NICE, 2011). Palliative care aims to optimise quality of life for patients and their families, by preventing and relieving suffering (Ferrell & Coyle, 2008). Nurses use evidence-based interventions to assess, diagnose, support and adapt to the needs of patients with acute or chronic, potentially life-limiting illnesses. This aims to achieve positive outcomes that maximize quality of life and alleviate suffering for patients as well as their families (Lynch, Dhalin, Hultman & Coakley, 2011). Palliative care not only addresses an individual's physical needs, but also responds to their emotional, spiritual and social needs. Carers, family members and close friends are also supported. Although Hospice work can be a fulfilling experience, workers also face a range of work and client related stressors (Sardiwalla, VandenBerg, & Esterhuyse, 2007). It is commonplace within Hospices that staff not only confront mortality but also deal with issues that "lie beyond the conventional boundaries of medical practice or social services, requiring a rare mixture of interpersonal skills, compassion and professional acumen" (DiTullio & McDonald, 1999, p.641).

In 2012, as part of a push towards more patient-centred and compassionate care for patients in the NHS, a 3-year plan for Compassion in Practice was launched by the Chief Nursing Officer of the NHS (Department of Health [DH], 2012; Cummins & Bennett, 2012). The values and behaviours of this plan were conceptualised as the 6Cs: Care, Compassion, Competence, Communication, Courage and Commitment (DH,

2012). In the wake of the failings of Mid Staffordshire NHS Foundation Trust and the findings from the public Inquiry (Francis, 2013), the nursing profession has been driven to regain the trust of the public by focusing on encouraging a compassionate care culture (Francis, 2013). There has been a drive for this vision to be implemented into the recruitment strategy and practice for nurses, and other care professionals within the NHS, to ensure compassionate care is delivered (Department of Health NHS Commissioning Board, 2012).

A new term, Compassion Literacy, has been conceptualized and discussed in relation to general practice nursing settings (Winch, Henderson, Kay & BurrIDGE, 2014). It is proposed that to be compassion literate, key skills are required: recognition of compassion as a core value; knowing how to deliver compassionate care; having capacity to deliver compassionate care; self-care skills; awareness of factors that deplete or create barriers to the delivery of compassion; strategies for navigating such barriers; and commitment to compassionate care. However, this concept and the skills that embody compassion literacy, imply compassion is something that needs to be taught, and can be lost/gained rather than being an innate characteristic within nurses. The concept is highlighted as a vital requirement for practice nurses to ensure the delivery of quality health care (Winch et al.) though it is acknowledged that compassion is difficult to document as part of standard reporting practice (Francis, 2013). However, its absence is detectable by patients and colleagues.

Competency in compassion literacy has been argued as vital for facilitating and maintaining compassionate care, through nurses regularly renewing their commitment to compassionate care and practicing self-compassion so as to protect against compassion fatigue (Winch et al., 2014). However, the process used to determine the concept appears to be based on the limited literature of concept analyses about compassion, without basis in evidence from research that has examined lived

experiences of nurses demonstrating this skill set. Thus, in order to understand how to deliver the best service and care to patients and staff, more needs to be known about the process of compassion from the perspective of the lived experiences of nurses working in the field.

Nurses' experiences of exposure to death and dying

Caring for dying people is often considered to be one of the more stressful aspects of nursing work as staff are faced with the pain and suffering of people with incurable diseases (McWhan, 1991; Ablett & Jones, 2007). A British Psychological Society report highlights the challenge for staff working in a palliative care setting, stating that “the contagion of distress from patient to professional is probably intrinsic to the work [in end of life care]” (Kalus et al. 2008, p.21). For palliative care teams, witnessing and active involvement in people dying is a daily experience. The phenomenon of ‘accumulated loss’ (Adams et al., 1991), whereby staff may experience repeated loss through death over an extended period of time, may be a likely experience in a palliative work context. Wakefield (2000) explored the lived experiences of nurses caring for the dying and identified that they practice ‘relentless self-care’ to cope with feelings of loss.

There is little research into palliative care staff’s experiences in relation to death and dying. Katz and Johnson (2006) suggest that nurses’ own experiences of death, trauma and loss in their lives may motivate them to choose end-of-life care as their profession. What is not understood is whether or not the motivation for entering the profession acts as a protective factor for maintaining wellbeing. The personal experience of the death of someone close may create a personal-professional interface for the nurse between their own life events and professional relationships (Genevay & Katz, 1990).

Age appears to influence reported levels of death anxiety and attitude towards caring in nurses. Loisel and Stirling (2012) found younger nurses reported a stronger fear of death and more negative attitudes towards end-of-life patient care than older ones. Although this suggests that fear of death in nurses may potentially influence attitudes towards patient care and the quality of that care, this study was explorative therefore the consequences of these attitudes were not determined. The impact of these feelings of relief and sadness was less in nurses who were more experienced and, for newly trained nurses, lessened by providing an open dialogue. Recounting workplace narratives may facilitate sharing of workplace experiences, contributing to a sense of openness, belonging and support in healthcare (Loiselle & Sterling). This study highlights the importance of supportive interventions for mediating the emotional impact of hospice work for newly trained nurses to prevent staff distress and to improve caring for patients.

Burnout has been well described among palliative care physicians and nurses, though there is mixed evidence around the prevalence of burnout and stress in palliative care nurses compared to other professions. Although there is evidence that palliative care staff do experience symptoms of stress and burnout (Vachon, 1995; Payne 2001), two recent reviews of studies within palliative care units, hospices and oncology services found that, despite work demands being a common cause of stress, burnout levels in health professionals working in these settings were not any higher than in other contexts (Pereira et al. 2011; Peters et al. 2012). These recent reviews highlight that the processes by which palliative care nurses mitigate stress, or navigate what is considered widely to be a difficult working environment, in order to maintain wellbeing, needs to be better understood.

There may be a positive impact of repeated exposure to death and dying. Canadian end-of-life-care clinicians reported their work gave meaning to life and taught them many life affirming lessons, highlighting the more positive effects on hospice staff lives (Sinclair, 2011). The experiences and personal growth of hospice workers during encounters with death have also been explored (DeArmond, 2012). A theme of interconnectedness emerged, referring to hospice nurses' full involvement in the experience of death and dying. Through interconnectedness, it appeared that hospice workers learned to become intimate with death and described overcoming fear of death and dying through working at a hospice. DeArmond also found that 53-88% of hospice workers experienced elements of personal growth, suggesting that caring for the dying may help prepare staff for their own death and create a sense of life renewal (DeArmond). This study highlights the importance of education and development for hospice workers, in order to promote empathy as a facilitator of personal growth.

To try and explain the finding that palliative care staff do not report higher levels of psychological distress, and report lower levels of burn out compared to other specialties (Pereira et al., 2011; Peters et al., 2012), Ablett and Jones (2007) used Interpretative Phenomenological Analysis (IPA). Central themes from the interviewing of palliative care nurses related to a high level of commitment and sense of purpose about their work and an awareness of their own mortality and spirituality. Personality constructs of hardiness and a sense of coherence, were identified as interpersonal factors that help promote resilience in palliative care staff. However, what is not known, is the understanding of the emotional regulation processes that contribute to wellbeing to enable staff to provide compassionate care.

In summary, there is evidence to suggest that palliative care staff experience no higher levels of stress than other nursing professions and there is an indication that there

may be a positive impact of such work. The finding that palliative care staff experience similar levels of psychological distress and lower levels of burnout than staff working in other specialities needs more empirical study for an adequate explanation. Considering that working in a stressful job does not inevitably lead to psychological distress, more exploration of factors that contribute to a sense of wellbeing is required.

Compassion in Palliative Care

Halifax (2011) emphasises the role of compassion in palliative care, in particular in relation to suffering. She highlights the importance of engaging in strategies to support compassionate action toward the dying patient, colleagues and self. However, within the literature there is no clear consensus on how compassion is conceptualised. Dewar (2011) highlights that several challenges face the measuring of compassion, including that it is rarely articulated and means different things to different people. There are differing views on whether compassion is an evolved emotion (Goetz, Keltner, Simon-Thomas, 2010), a behaviour (Gilbert, 2009) or a moral virtue (Dietz & Orb, 2000). However common themes across definitions within the literature are that compassion involves sympathy for and recognition of distress and an intention to alleviate suffering of self or others (Burnell, 2009; Gilbert, 2009; McCaffrey & McConnell; Shantz, 2007; Lama, 1995; Jazaieri et al. 2013). The Dalai Lama (Gyatso, 1995) defines compassion, “As a sensitivity to the suffering of self and others with a deep commitment to try to relieve it” (p.16).

The compassionate mind approach integrates the scientific study of compassion and affiliative behaviour. Gilbert (2009) suggests that compassion derives from skills that primates evolved for parenting and to form affiliative and cooperative relationships with others in order to survive as a group. He suggests that compassion is not simply an emotion or motivation, but a complex combination of attributes and qualities. Gilbert

(1989, 2005, 2009, 2014) developed a theory of the compassionate mind within which he constructed a framework for understanding how the human mind regulates emotion. This framework suggests there are three systems of emotional regulation: the threat and self-protection system; the incentive and resource-seeking system; and the affiliative system. As far as this author is aware, this model has not been empirically studied in relation to healthcare professionals.

The threat and self-protection system identifies threats quickly and creates feelings of anger, anxiety and disgust to alert us to take action against them. The incentive resource-seeking system primarily gives us positive feelings, such as excitement and pleasure, to motivate us to seek out resources for the survival and prosperity of ourselves and others. Provided this system does not become over-excited, and remains balanced with the other two systems, it can motivate and guide us towards important life goals. The affiliative system facilitates feelings of contentment and is linked to feelings of affection and kindness which helps soothe us when we are distressed and provides a sense of safeness. The soothing system responds to kindness and focusing on kindness to self and others can help to stimulate it. The theory suggests that we become stressed when these systems become unbalanced and our incentive resource-seeking and threat/self-protection systems are overactive whilst our soothing and contentment system is underactive.

Gilbert (2009) suggests key attributes of compassion are motivation, distress tolerance, sympathy, non-judgement and empathy. Our capacity for empathy has been linked to the personal quality of self-compassion (Neff, Kirkpatrick & Rude, 2006). Neff (2003) defines self-compassion in terms of three main constituents: kindness, a sense of common humanity, and mindfulness. Self-compassion enhances wellbeing because it helps individuals to feel cared for, connected, and emotionally calm (Gilbert, 2005).

Using Gilbert's model (Gilbert, 1989) it is postulated that self-compassion counteracts and deactivates the threat system and activates the self-soothing system.

Gilbert (1989; 2005; 2009; 2014) proposed the concept of a caring-mentality. This refers to a specific motivation to form social relationships that, when activated, shifts our attention to the needs of others/self (Liotti & Gilbert, 2011). It involves thoughts and feelings relating to helpfulness, kindness, empathy, sympathy, concern and warmth. Whilst this social mentality facilitates compassion for self and others it is suggested that it can be easily disrupted and restricted by other emotions such as stress, fatigue and anger (Gilbert, 2009). No existing literature explores the lived experiences of hospice workers in relation to their experiences and understanding of compassion and the care-giving mentality and how this is maintained.

Rationale for Study

Previous research has predominantly focused around the negative impact of working with death and dying but there is a lack of literature that explores the experiences of nurses who hold positive beliefs about their work. The finding that palliative care staff experience similar levels of psychological distress and lower levels of burnout than staff working in other specialities (Pereira et al., 2011; Peters et al., 2012), needs more empirical study for an adequate explanation. Considering that working in a stressful job does not inevitably lead to psychological distress, more exploration of factors that contribute to a sense of wellbeing is required. In nursing, compassion is considered to be a fundamental component of the profession (Winch et al., 2014; Burnell, 2009), yet in the literature it is not clearly defined or researched in the context of modern nursing practice (Shantz, 2007). Further research is needed, that extends research on palliative care nurses' wellbeing (Ablett & Jones, 2007), to explore up-to-date subjective experiences of hospice nurses within the current healthcare

context in the UK. Furthermore, the Compassionate Mind Theory (Gilbert, 2009, 2010) has not been used before as a framework for understanding lived experiences of any client or professional population, to the author's knowledge. Moreover, an understanding of the subjective experience of working as a palliative care nurse and an understanding of how they make sense of their own subjective experiences of compassion, may enhance our understanding of the phenomenon that underpins compassion: "nursing's most precious asset"(Shantz, 2007, p 48).

Aims

This study aimed to better understand the lived experience of palliative care nurses in the current UK healthcare context, and explore how compassion and the caregiving mentality is experienced and understood by nurses in palliative care clinical practice. This study hopes to contribute to an explanation of the relative wellbeing of palliative care nurses, who work with dying and suffering, which is widely assumed to be difficult and distressing. A greater understanding may inform the development of training and support to facilitate resilience and compassion in staff newly entering palliative care and to foster staff wellbeing (which will be increasingly pertinent given the ageing workforce and foreseeable changes in how hospices function in the future). It may inform or aid interventions for facilitating compassionate nursing environments. Relevant thoughts and ideas around support and training may be disseminated more widely across nursing professions within the NHS with potential future benefit for the wellbeing of staff and patients. Due to the exploratory nature of this investigation, a qualitative methodology was used. Specifically, the study aimed to explore the following questions:

- What are palliative care nurses' subjective experiences of their work?

- How do palliative care nurses experience and understand compassion in their clinical practice?

Method

Design

A qualitative study using semi-structured interviews explored the concept of compassion in hospice nurses. Interview data was transcribed and analysed using Interpretative Phenomenological Analysis ([IPA]; Smith, Flowers & Larkin, 2009).

Sample

A purposive sampling method was used to develop a suitably homogenous sample for the in-depth analysis. Individuals were therefore only included if they had worked as either a qualified nurse or unqualified care assistant (or equivalent title) at a hospice for a minimum of one year, they were a fluent English speaker, and at least 50% of their role involved face-to-face patient care. Participants were excluded if they did not meet the above criteria.

Nine registered nurses were recruited from two adult hospices in the north of England (East Yorkshire and North Lincolnshire) and one adult hospice in the south east of England (East Sussex).

Two participants volunteered after being informed via emailed advertisement, directly from the researcher. Three participants responded after receiving an information sheet (see Appendix J.) sent directly to all in-patient nursing staff. Four participants responded to emailed advertisements, forwarded to all nursing staff, via the ward manager.

All nine participants were women, whose ages ranged from 28-66 years (mean= 57.38). Eight participants were white British and one participant was originally from

New Zealand, though had British citizenship at the time of the interview. The number of years worked in the hospices ranged from 2-29 years (mean= 12.17). The years of experience of working in palliative care more generally ranged from 3-31 years (mean= 16.56). Participant demographics are reported in Table 3. Participants have been given Pseudonyms to protect anonymity.

Table 3. Participant demographics

Participant	Age	Gender	Nationality	Ethnicity	Years in palliative care	Years at current Hospice	Job title
'Amanda'	62	F	British	White	18	16	Staff Nurse
'Trish'	48	F	British	White	24	24	Senior Sister
'Jenny'	-	F	British	White	24	24	Senior Sister
'Alison'	54	F	British	White	28	3	Registered Nurse
'Dorothy'	66	F	British	White	31	29	Staff Nurse
'Jane'	54	F	British	White	9	3	Registered Nurse
'Claire'	34	F	British	White	3.5	3.5	Staff Nurse
'Fiona'	65	F	New Zealander	White	5	5	Staff Nurse
'Lucy'	28	F	British	White	7	2	Senior Registered Nurse

Ethics

The study was reviewed and granted approval by a local Research Ethics Committee (see Appendix H.) All data collected were anonymized to maintain participant confidentiality and audio-recordings were deleted. Hard copies of transcripts, consent forms and participant demographics were stored in accordance with the Data Protection Act 1998. Full written informed consent was gained prior to interviews commencing (see Appendix K. for consent form). Participants were informed of their

right to withdraw at any time without any negative implications. Post interview, participants were provided with information about available sources of support (see Appendix N.)

Data collection

A semi-structured interview schedule (see Appendix M.) guided the interviews and was used flexibly to accommodate individuals' different experiences. Participants were informed that the researcher was interested in hearing about their experiences of their work, experiences that had been both satisfying and challenging, and their understanding and experiences of compassion towards themselves and others in the context of their clinical work. Prompts related to emotional responses to their interactions with patients, families or friends of patients, and colleagues.

Interviews were conducted in locations most convenient and/or preferred by the participants. Six interviews were conducted in private rooms within the hospices. One interview took place at a participant's home. Two interviews occurred at the researcher's home. Interviews were audio-recorded and transcribed verbatim. Interview duration ranged from 25 to 90 minutes.

Data analysis

Interpretative Phenomenological Analysis (IPA; Smith et al., 2009) was the selected method for analysing the interview transcripts. The principle of hermeneutics within IPA acknowledges the influence of a researcher's preconceived ideas upon the analysis (Smith et al., 2009).

The author is a young, white British, educated female. The author considered how both her Clinical Psychology Doctoral training and prior experience of working for six months as a healthcare assistant at a hospice may have shaped her experiences and

influenced the data collection and analysis process. The author made use of a reflective group with colleagues and kept a reflective journal to help her awareness of her own reactions and feelings about the interview and analysis process. (See Appendix A. and B. for a full discussion of epistemology and full reflective statement respectively.)

The analysis was an iterative, reflexive process comprising four main processes:

Step 1: The author immersed herself in the data by reading and re-reading the transcripts. Immediate reflections about how the author felt and initial reactions to the data were noted down to refer to at the next stage.

Step 2: A detailed line-by-line analysis was conducted. The semantic content and language use was examined and initial exploratory comments were recorded next to each line of transcript, in order to arrive at an interpretative understanding.

Step 3: The initial notes were examined and emergent themes were developed and recorded.

Step 4: Emergent themes were grouped further. These themes were compared and contrasted across all transcripts. Connections across themes were explored and an overarching conceptual framework was created (see Table 4.). An example of the transcript analysis process can be found in Appendix O.

Results

Thirteen themes emerged with five high order themes: ‘the preciousness of death’, ‘the motivation to care for others’, ‘shared humanity’, ‘the collective sense of caring’ and ‘self-awareness’. The themes and subthemes, developed from participants’ accounts, are presented in Table 4.

Table 4. Superordinate and subordinate themes

Superordinate Theme	Subordinate Theme
The Motivation to Care for Others	Caring is innate
	A profession that honours, values and respects; aligning personal and professional values
The Preciousness of Death	A good death
	A privileged position
Shared Humanity in Death	Getting alongside, under the same blanket
	Identifying, valuing and facilitating wishes
	Honest communication
	Building rapport
The Collective Sense of Caring	Working together
	Looking after the team
Self-awareness	Doing your best
	Personal and professional conflict
	Self-protection

The Motivation to Care for Others

This theme encompasses two sub themes that represent how nurses reflected on their motivation to work in hospice care. There was a sense that personal values seemed to be matched to the ethos and values of the hospice movement and that caring was something that was innate and intrinsic to them. Compassion was not necessarily a word they recognised as something they consciously engaged in within their work.

Caring is Innate

This theme describes the nature and motivation of care and compassion as an intrinsic part of being a nurse, whereby the drive to care is considered to be an innate process. There seemed to be an internal sense, a process of 'knowing' how to be that is intangible and unteachable. Amanda described using her instinct in interactions with a patient:

“It was just a gut instinct..., I knew that although she was saying she was alright, she wasn't really...” (Amanda)

Dorothy also referred to having an ability to care that is in-built:

“It's just, basically caring and, I think it probably is something that's within you” (Dorothy)

There was a strong sense that the notion of compassion was not something recognised as being easy to define:

“Compassion is so important in our work, but to define it is extremely difficult.” (Dorothy)

It appeared that 'compassion' was not a word readily used or explicitly available within the language used by nurses to describe their experience of caregiving, as highlighted by Jane:

“... I wouldn't know that it's a term that I'm hearing much, on a day to day basis. So are you saying that it's a term that's around more?” (Jane)

A Profession that Honours, Values and Respects; Aligning Personal and Professional Values.

This theme refers to how the participants' motivation is underpinned by their personal values and sense of identity as hospice nurses. Working at the hospice appears to enable them to align their work with their own beliefs about quality care and they are able to enact their beliefs of protecting humanness at end of life. For example, Dorothy described how:

“It allowed me to do, to really care for the patients, erm, body mind and spirit, the whole patient, treating patients as individuals” (Dorothy, P5)

Having previous experiences in other settings seemed to influence participants' reasons for pursuing hospice nursing. Claire described an experience of having witnessed someone dying in hospital, which challenged her ideal of care at end of life:

“I thought it shouldn't be like that you know, she should be, you know her and her dad should be somewhere totally private where they can be alone, and she can grieve if she needs to” (Claire)

It seems that finding an area of nursing which aligned with their beliefs about providing ideal care at end of life helped to eliminate the tension of having previously been unable to provide the care they aspired to give. The mismatch between the care she hoped to offer and the reality she had experienced appeared to motivate Amanda to consider an alternative way of fulfilling her aspirations:

“At that point, palliative care was, was negligible. We did our best and you muddle through. And I just thought there must be something better than this” (Amanda)

The Preciousness of Death

This higher order theme refers to how participants seemed to regard the end of life stage as a special process for patients, relatives and themselves. There was strong belief that it was important that death should be the best it can be and that their role in this is a privileged one. This gave the sense that death was a precious time for all involved in it.

A Good Death

A good death refers to how participants talked about and emphasised that there was this unique opportunity of being able to “make death as good as it can be” (Claire), an occasion where you have ‘only one chance to get it right’. It seemed that within this realisation, there came a high expectation upon themselves to acknowledge the importance of getting death right, with this seeming mutually important for the nurses, patients and relatives. Lucy refers to the impact of enabling a good death on the nurses and patients’ families:

“We pride ourselves on giving good deaths and a lot of the feedback we get, and things like that, is surrounding good deaths and ‘thank you for making those last days comfortable.” (Lucy)

Alison expressed a sense of the enormity of the personal impact of getting it right:

“I think you can’t really explain what that does for you as a person, to know that hopefully you’ve sort of got that right.” (Alison)

It seemed that, by providing a ‘good’ death was meaningful because it might facilitate the bereavement process and protect it from being a traumatic or difficult transition. There was almost a sense that the bereavement process is happening on different levels with differing intensity for the nurses, families and patients.

“...they would think back and think about what his last time was, and it's difficult to actually explain how that makes you feel, because actually what it makes you feel is that, what you hoped was you doing a good job, actually is making a difference to people.” (Alison)

Nurses expressed how they take an active role in being able to help families and themselves make sense and give meaning to the dying process. This lasting legacy of the ‘good’ death seemed really important for nurses; it helped them believe that they had enabled relatives to move forward and to experience their loved one’s death as a process that respected the life of the person who died. Alongside this, there seemed to be pressure put upon themselves to actualise ideal care at this important stage:

“...you only have one chance to get it right for that patient, because you can’t, you know, they can’t come back and you can’t redo it. You are always, I think in the back of your mind, what best can I do for this person.” (Amanda)

A Privileged Position

This ties in to the sense that it is a privileged position because it is a unique experience. Hospice nursing staff are in a rare position; they are the only ones who get to be with people at this stage in their life in comparison to the extent of the involvement of other nursing professionals in a person’s journey through illness and ultimately death. They have the luxury of time to spend with the patients to meet their needs, in a way that aligns with their personal values. Jenny describes a real sense of

this stage being something to appreciate, and feeling honoured to bear witness to people being at their most vulnerable:

“I felt very privileged that I’d been with her through certain times, I’d been, I think, until you’ve actually, been with somebody, when they’re going through that, you can’t explain it to somebody, I think it’s such a special part of somebody’s life, sometimes it’s a privilege, that they’re letting you be there at that time.” (Jenny)

Shared Humanity in Death

This higher order theme refers to a shared sense of humanity. The process of being alongside the patient and families in their experience connects the nurses with patients and relatives. The nurses value separating the person from the process of death itself and recognising and acknowledging the individual person within the ill patient. This theme relates to their motivation to care and their appreciation for the profoundness and specialness of death. There is a sense that common humanity can get lost in other settings at the end of life but this is the place where relational person-to-person, human-to-human care is facilitated. Shared humanity involves the subthemes of ‘Getting alongside; under the same blanket’, ‘Identifying, valuing and facilitating wishes’, ‘Honest communication’, and ‘Building rapport’.

Getting Alongside; Under the Same Blanket.

This theme refers to the process of developing a shared understanding between nurses and their patients, which emphasises a sense of shared humanity. Nurses described the importance of getting alongside and being there with patients. It seemed to be a process that is pivotal to their role but is also a highly emotive yet rewarding experience. Jane described joining her patients in their emotional states, whether good or bad:

“To get alongside them in their despair and their sadness or their joy”

(Jane)

Amanda described how a personal relationship taught her how to be compassionate in her clinical work:

“It was somebody that said, ‘if you really want to help me, when I’ve got my mental health problems, you know, if I’m laid on the floor with the blanket laid over my head get down on the floor with the blanket over you as well’ and I think that’s probably one of the biggest things that [relative’s name] taught me about compassion and about understanding, is that what I think might make it better for her, is not what might make it better for her and the important thing is always ask, you know. “what can I do for you, that’s gonna make it better for you””

(Amanda)

Being attuned to the needs of patients seemed to be an active process but did not necessarily mean intervening or ‘doing to’. Instead, being alongside seemed to involve learning to tolerate suffering together when the relief of suffering was not possible; truly connecting to the shared humanity of suffering. In order to know how to be alongside it seemed they had to attune themselves to the individual. To facilitate this, the participants expressed how they used their own personal experiences to help them to empathise:

“Having had first-hand experience of losing a close family member, I think you can draw on those experiences and...you have more of an idea of what it feels like to be a relative watching somebody dying or that sort of confusion of what does this mean or what's going on?” (Claire)

Jenny reflected on the emotional demands of being alongside and how experiences that resonated on a personal level were very challenging:

“When things hit home and you can put yourself in somebody else’s shoes, I think, that’s when it’s very difficult, because I was thinking, I wouldn’t want to leave my daughter” (Jenny)

Identifying, Valuing and Facilitating Wishes

This theme refers to how identifying what is important to the person is highly valued by the nurses. This seems underpinned by a value of seeing the person and the humanity within the ill patient. Fiona describes the importance for her in learning about the person before their illness:

“You don't want to put on Heart radio, for somebody who's spent all their life listening to Radio 4. You don't want to give someone the Sun newspaper when they've always read the Telegraph. You know what I'm meaning? You've got to try and work out who they've been before they came to you”. (Fiona)

Her concern may reflect empathy for how she might feel if her individual preferences/interests weren’t considered.

Valuing what is meaningful to the individual and respecting the patients’ choices and wishes is considered to be a crucial aspect of their work. The nurses seemed to enact their person-centred values through small but meaningful acts, connecting relating to their patients as human-to-human with a shared appreciation of what it is to be human. Trish talks about how the simple things are valued by patients:

“It was only a simple thing that we did for him, but for him that was everything.” (Trish)

Jenny described the meaningfulness of being able to achieve simple, yet taken-for-granted acts.

“We’ve had a lady admitted today, she’s been in hospital for three weeks and she’s never had her own nightie on. Now, how difficult is it putting somebody’s nightie on? I don’t understand that, I can’t - and she said ‘could I have my nightie on?’, ‘course you can’. So it’s little things like that make such a difference to people and I think we have got the luxury of that little bit of extra time.” (Jenny)

Having time seems to be an important enabler for enacting these simple but humane acts of caring.

Honest Communication

This theme represents a sense that honesty is highly valued and it is an expectation of their work that they communicate with patients in an open and honest way. It seems related to offering good care. It is not only acceptable to be honest about dying, it is in fact an expected part of their role as hospice nurses:

“...you've got to be honest, you know, because people will ask you questions you can't answer, and you just have to say, you know, ‘I wish I could give you an answer to that.’” (Alison)

Encouraging and modelling openness and honesty in talking about feelings associated with death and dying is a crucial part of their work in providing total care. Jenny describes how not being afraid to talk openly about death with patients is important:

“It’s about having the time to speak to somebody, being honest with them, and erm, if they want to talk about it, it’s erm, it’s not being frightened to go and talk about it” (Jenny)

Trish expresses how the cultural context of the hospice offers a safe place to explore these feelings:

“We want people to be able to be honest and say what they want to feel, you know say what they feel, you know in a safe environment really.”

(Trish)

Acknowledging their difficulties seems to be regarded as a positive thing that shows strength rather than weakness. The sense of collective caring seems to enable a sense of safety within the team to express honestly their personal reactions to the work, within a professional-to-professional context.

Building Rapport

This theme refers to the relational aspect of shared humanity as a fundamental and satisfying part of the nurses’ work. Trish describes the satisfying nature of building rapport with families and patients:

“You can get involved so much with the relatives and you can build up such a good rapport with the patient and I just really got such a lot of job satisfaction out of doing that” (Trish)

Part of their role is to build rapport with patients and families in order to offer ongoing support for them. By developing trust and learning about the patient, the nurses may feel better equipped to offer support and help. This may result in patients and families feeling more comfortable about dying away from home. Developing relationships with the nurses may enable patient and family to feel valued and

understood which may also validate the nurses' own identities as care-givers. It seems to require time for a relationship to develop and flourish and there is a sense of continuity:

“She slowly began to trust us, and, and I think because we, we took a step back, I think we let her know what we could offer, but didn't impose on her and didn't insist she had anything done, and over time, getting to know us.” (Claire)

Fiona describes a proactive stance to getting to truly know the person:

“Try and remind yourself constantly that they've been bright, intelligent people and now they're struck down with this dreadful disease, and you get windows of opportunity or lucidity to talk to them.” (Fiona)

It may be protective for the nurses to build the relationship as this may enable them to see the person within the ill dying patient and be reminded of humanity.

The Collective Sense of Caring

This theme refers to being a team and being alongside each other as colleagues. There is a collective approach to achieving the shared aims of the hospice.

By looking after the team as a collective it preserves the functioning and wellbeing of the team and enables the maintenance of professional boundaries. The nurses seemed to identify as a team and had a strong sense of shared responsibility. This theme comprises the subthemes: 'Working together' and 'Looking after the team'.

Working Together

Nurses talked about helping each other out to manage the workload and being flexible in order to support one another. By knowing each other's strengths and weaknesses they are able to collectively maintain the standard of care and the palliative

care values. Amanda described the closeness of the team and acknowledges and values the different parts that make the whole team work together:

“It’s about your colleagues, we have a very tight team. We are all very supportive of each other, mostly. You know, we recognize that we’ve all got different needs and different strengths and weaknesses and we work with those together.” (Amanda)

Looking After the Team

This theme represents the sense of shared responsibility for each other’s wellbeing, and privileging their colleagues’ needs over their own. Alison illustrated this when recounting a situation where she acted on her beliefs about placing her concern for her colleagues’ wellbeing above her own:

“I couldn’t sleep because all I could see was this man’s face, but obviously for me, I had to put that to one side to make sure the other staff were okay.” (Alison)

Nurses also described how team support seemed to be a social and reciprocal process where emotional reactions were shared experiences within the team. Dorothy described the comfort in having a simple but social ritual of a cup of tea:

“We tend to just have time out with a cup of tea or a coffee and discuss the situation with each other, and give each other mutual support, because we all recognise that at times we all cry together, we all laugh together... “(Dorothy)

Claire also described making use of informal moments to check-in with each other and reflect together on shared experiences:

“You will kind of talk to each other about what you've just come out of, good or bad, and we do, we share a lot with our colleagues.” (Claire)

Self-awareness

This theme refers to a strong sense that the nurses have of their position in all of this, the reactions, thoughts and feelings that they experience and the limitations of their work. How they are able to know when things are difficult for them enables them to be attuned with the team and also manage the personal and professional boundaries required to maintain separateness between their work life and personal life. This is seen as necessary in order to maintain their wellbeing so they are able to provide compassionate care.

Doing Your Best

Doing your best is related to a motivation for caring. Nurses often talked about having high standards of how they deliver care themselves and respecting and valuing the palliative care approach. However, in order to manage the demands of the work, there is an awareness of what is realistic within their role. The nurses recognise that they cannot fix everything.

“I think we should strive to relieve peoples’ suffering as much as possible, but equally to protect ourselves, we've got to acknowledge that there are times when we won’t be able to relieve it and we shouldn’t see that as a failing” (Claire)

Although this comes with difficult feelings, they are able to reassure themselves by having the awareness that they have done the best they could within the circumstances. Dorothy talked about acknowledging the limits of her work:

“I think in this job we've got to realise in this job, there are some people, you've got limitations, as so long as you know you've done your best for the person, then, there is no more you can do, and I think you've got to face that sometimes.” (Dorothy)

Personal and Professional Conflict

This theme refers to an awareness of an ongoing balance between maintaining a professional boundary as nurses and expressing their humanness as people. On the one hand, Jenny describes how experiencing emotional reactions is an important barometer of being human. It seemed that if these feelings were lost, it would indicate a loss of the humanity that she values. On the other hand, she seems unsure about what is acceptable to share with patients from a professional point of view:

“The time I wouldn't shed tears would be the time for me to leave really, because I think if I haven't got that hum- even though I'm a nurse, we're all still human aren't we? And I think if you can't have that human side to you, to me I would be, that would be a hardness, do you know what I mean? And there is times that I've got upset about patients and I've cried, but I wouldn't, try not to do it in front of the patients them self or the relative...” (Jenny)

Jane described a struggle in allowing themselves to express feelings of sadness or distress in front of patients:

“They don't need to know that you're distressed by their situation, so much. It's getting the balance.”(Jane)

Self-protection

This theme refers to recognition of the need to take care of oneself. The nurses talked about developing an awareness of the need to manage the separation of their personal and professional selves. Jenny illustrated how she learnt, with experience, to recognise and act when the personal professional boundary was being crossed:

“...I think I’ve learnt now, that when I go home and I take my uniform off, that I’m Jenny the Mum and I’m Jenny the Wife, do you know what I mean, because if I don’t, you’ve got, that’s sort of like a bit of self-preservation really” (Jenny)

Having an awareness and noticing the need to step back seemed to develop over time. Nurses also described ways of protecting themselves from the emotional impact of the work to maintain professionalism by “distancing,” “detaching”, or “switching off”. Lucy described how she detaches herself from her work:

“...it's difficult to kind of detach yourself, but I have always been quite good in, you know, my work stays at work and my home life is home life.” (Lucy)

Claire described how this ability to distance herself was facilitated by reminding herself of having a separate personal and professional life:

“I think a lot of the time you're able to disconnect and they're not your loved ones. As much as you build up a working relationship, you can take a step back and go, 'they're not mine’” (Claire)

Self-protection appeared to be less important to the nurses than caring for and giving to patients, families and colleagues. It seemed that the collective sense of caring is valued above self-protection. As natural caregivers, it may be harder to consider receiving care from themselves or others and affording themselves the same values of care they afford their patients.

Discussion

This study aimed to describe hospice nurses' experience of their work and more specifically, how they experienced and understood compassion while working with terminally ill patients and their families. Central to the themes revealed was a respect and dignity for both the person within the dying patient and the dying process itself. There was also a strong sense of awareness of their own role within this and of those they worked with which helped them sustain their care giving role. The notion of compassion was experienced as an intrinsic part of their individual make-up rather than a skill that could be taught.

This study identified that nurses held positive beliefs about the preciousness of death and strived to develop relationships with patients and their families, which led to a sense of shared humanity. This adds to previous findings that nurses who work with people who are dying can experience positive effects such as sense of connectedness, preparedness for their own death (DeArmond, 2012) and a sense of meaning in life (Sinclair, 2011, Ablett & Jones, 2007).

Nurses described how personal experiences of loved ones dying motivated them to enter the profession. It also helped foster a sense of connection and enhanced empathy towards patients and relatives. Furthermore, some nurses' decisions to enter the profession were based on wanting to actualise their personal and professional values about patient care at end-of-life. This supports and may help to explain Katz and Johnson's (2006) suggestion that nurses' own experiences of death, trauma and loss in their lives may motivate them to choose end-of-life care as their profession.

Ablett and Jones (2007) also identified a theme of personal and professional issues and boundaries, which is similar to the findings from this study. This highlighted

the conflict experienced between striving for a sense of shared human experience and human-to-human connecting versus the need to protect themselves from emotional harm. This also corresponds to the person-professional interaction that is described by Genevay & Katz (1990). The current study highlights how this interaction can impact on the process of caregiving: nurses experienced a dilemma about the extent to which they could express their emotions in front of the patient. Nurses described how learning to navigate this boundary required time and experience, which may explain Loiselle and Sterling's (2012) finding that younger nurses are more vulnerable to death anxiety.

It seems that the nurses valued highly the times when they were able to offer small but meaningful acts of kindness. Considering the apparent pressure to do their best and the risk of not being able to relieve suffering, it is interesting that the nurses held on to their values of patient centred care, and perhaps more importantly, enacted them through the simple but meaningful acts that were important to the individual. The essence of person-centred care has not been lost, but is in fact the core of their work.

The collective sense of caring, whereby participants described a shared sense of responsibility and reliance on each other, may help to explain the finding that palliative care nurses are no more stressed than other nursing professions (Pereira et al. 2011; Peters et al. 2012). Loiselle & Sterling (2012) found that the process of sharing workplace narratives created a sense of openness, belonging and support. Working as a collective may offer protection against individual symptoms of stress and burnout.

In Neff's (2003; 2007) three-part conceptualisation of self-compassion, one domain is common humanity versus isolation. The theme of shared humanity relates to the component of common humanity outlined in Neff's definition of self-compassion. Fostering the human-to-human relationship seems crucial to the nurses' work. Having a sense that the good and bad times are shared together may help the nurses to know they

are not alone in their feelings and their work. The balance of personal and professional boundaries that were perhaps modified by self-awareness seem to relate to the construct of mindfulness versus over-identification within Neff's model of self-compassion. Nurses tussled with the challenge of being mindful and avoiding over identification. The concept of self-kindness versus self-judgement was less clear within the findings. The nurses seemed to learn about themselves and recognize and accept their limits, not as failures but as doing their best. However, notably, some nurses found it hard to identify experiences of receiving compassion themselves. This may relate to their motivation to care for others being privileged over motivation to care for themselves and perhaps highlights an area of vulnerability. It may not be that compassion is missing within the work they do, but directing the flow of compassion towards the self is a challenge.

Nurses in the study often described their interactions with patients in terms of caring and relieving suffering and being alongside. However, the word compassion itself was not used by any of the participants until the researcher introduced the word into the interview. Interestingly, despite the descriptions of their experiences relating to identifiable constructs within definitions and models of compassion (Burnell, 2009; Gilbert, 2009; Jazaieri et al. 2013; Lama, 1995; McCaffrey & McConnell; Neff, 2003; Shantz, 2007), nurses reported finding it difficult to define compassion despite them considering it vital to the work that they do. This raises questions about the conceptualisation and utility of compassion in hospice nurses' experiences.

Maintaining care giving and the compassionate mind perspective

One way of thinking about the findings is via Gilbert's (1989; 2005; 2009; 2014) compassionate mind theory of how emotions are regulated. Humans are social beings motivated by a desire to be helpful and guided by emotions towards their social goals.

The emotional regulation system therefore plays a vital role in achieving the care-giving social goals in the hospice environment. The diagram in figure 2. uses Gilbert’s model of the emotion regulation systems to formulate how emotions might be regulated in the hospice context based on the findings of nurses’ lived experiences from this study.

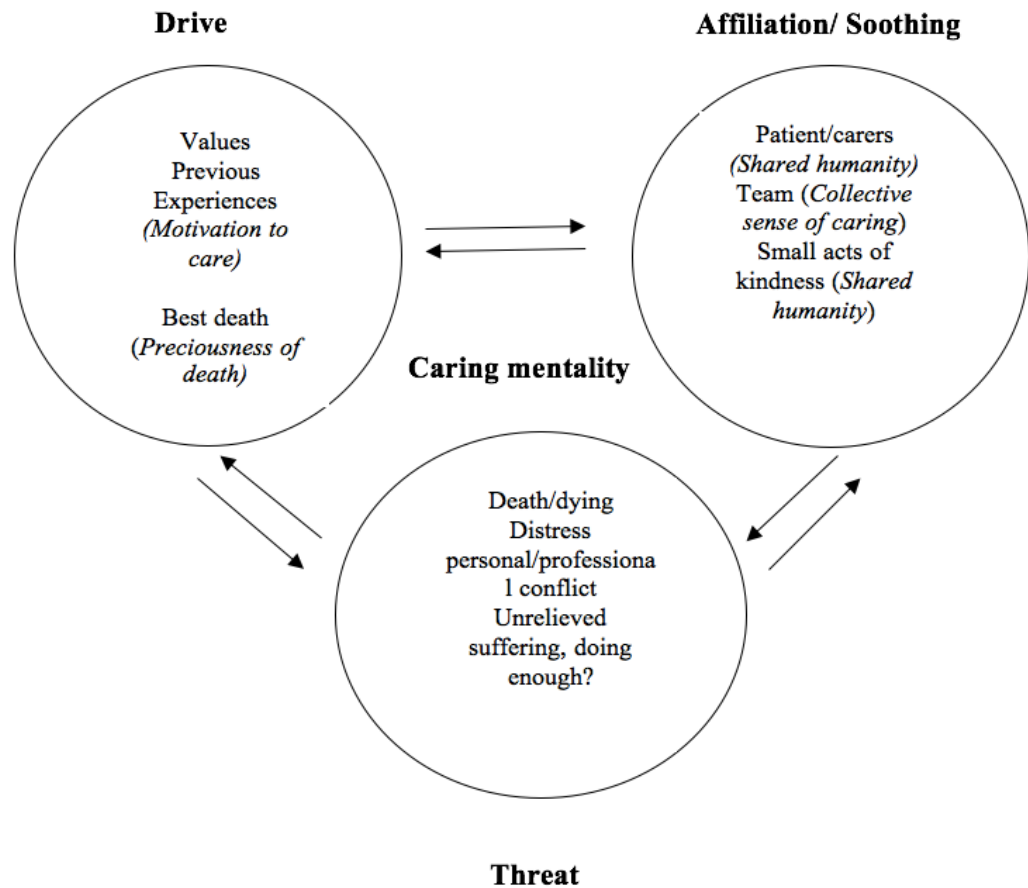


Figure 2. A formulation of hospice nurses’ emotional regulation systems for maintaining care-giving using Gilbert’s (2009) model.

For the nurses in this study, the threat system may be activated by being alongside and bearing witness to unrelieved suffering or distress. Nurses also described finding it upsetting to hear patients’ experiences that connected with their own personal experiences.

The nurses' experiences involved being motivated to care and actualise their personal and professional values. This may explain how the drive system may be active in their work. There also seemed to be a pressure about the preciousness of death, as there is only one chance to 'get death right'. For the nurses, their threat system may become activated if they are unable to fulfil their motivation to care in line with their values.

The contentment, soothing and safeness system helps to regulate the drive and threat system to keep them in balance. Based on the nurses' experience in this study, this system appeared to be activated in their interactions with patients, families and colleagues, as well as when they were supported by their own loved ones. The sense of shared humanity and development of relationships and the collective sense of caring may create affiliative bonds which may have a soothing effect on the nurses.

Without the soothing system the nurses are likely to become stuck in the drive and threat system. It may be that the experiences which relate to the affiliative/soothing system maintain a balance, more often than not, between the drive and threat system to enable the nurse to regulate their emotions to maintain a sense of wellbeing and caring mentality/motivation to care, despite the emotional challenges they may come across.

Limitations of the Study

The findings need to be considered within the context of the study's limitations. First, this study design was exploratory and qualitative therefore causal relationships are not the aim. This study does not attempt to generalise findings due to the small sample size and idiographic nature of IPA. Although the recruitment was aimed at both qualified and unqualified nursing staff, only registered nurses responded, therefore this study did not capture the voices of nursing assistants or healthcare assistants who also have considerable involvement with patients and families and have a valuable

contribution within the hospice team. Although this highlights a potential response bias, it also implies that the nurses who volunteered to participate represented the target population of nurses who were able to regulate their emotions to maintain caregiving. These findings are based on participants who identified as white British therefore exploring compassion in hospice nurses from other cultures may offer a different perspective.

Clinical Implications

The research findings highlight the importance of a supportive, safe team culture which facilitates hospice nurses to express and process difficult feelings in order to maintain their caregiving roles and the personal and professional boundary that accompanies this. The wider healthcare system could learn how to instil the hospice culture within hospital settings. Additionally, the finding that nurses considered experience to be helpful in learning to better manage the personal/professional boundaries within interactions with patients has potential implications for preparing and training newly qualified nurses who are new to the profession or have had limited interactions with patients at the end of life. This is the first study to use Gilbert's model of emotional regulation to offer an understanding of how hospice nurses maintain their wellbeing in order to care. This could be applied in practice to support staff's wellbeing.

The finding that compassion is experienced by the nurses in this study as an intangible and innate process and is not explicitly used within the nurses' language, has wider implications for the drive to ensure nurses practice compassionately within NHS contexts (Francis, 2013). It challenges the ideas of Compassion Literacy (Winch et al. 2014) and that compassion is a tangible entity that can be taught, gained or lost. It also highlights a possible discrepancy between what is perceived as most pertinent and clinically relevant to nurses' work and the reality. Just because the hospice nurses were

not explicitly referring to the concept of compassion does not mean it does not exist in their interactions with patients and colleagues. Furthermore, whether or not the concept is readily available in the nurses' lexicon does not necessarily mean it has any bearing on enhancing their clinical practice. Indeed, this study suggests that the introduction of the word is unlikely to change the way nurses deliver their care. These nurses did not seem to be explicitly aware of compassion within their work, therefore introducing interventions to teach compassionate care may run the risk of the intrinsic nature of compassion being exploited and its essence and meaningfulness lost.

Future directions for research

The nurses within this study had a substantial number of years' experience in the profession. Exploring the experiences of compassion in less experienced hospice nurses may provide useful insight into how best to support nurses who are new to the profession. Moreover, future research should consider the lived experiences of compassion in other healthcare professionals in order to develop a better understanding of the relevance of compassion to professionals at different organizational levels within the healthcare settings.

Conclusion

The purpose of this study was to explore the subjective experience of hospice nurses and how they experience and understand compassion in their work. The experiences of these participants suggest that working with death and dying is held in high esteem, as is having respect and dignity for the person within the patient. The nurses experienced satisfaction in being able to align their personal and professional values in their caregiving role. Participants had an awareness of balancing their personal and professional selves and working together to sustain their roles. Findings were related to the compassionate mind model to explore how nurses maintained their caring mentality.

Compassion was experienced as an innate and intrinsic part of the nurses' makeup and the notion was not considered easy to explicitly define. This raises questions about how the concept is thought about and has implications for wider healthcare contexts in relation to policies and staff training.

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The Authors declare that there is no conflict of interest.

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Part three: Appendices

Appendix A. Epistemological statement

Epistemological statement

This statements intends to convey the researcher's understanding of ontology and epistemology, to explain the assumptions that underpin the Systematic Literature Review and the Empirical paper which comprise this portfolio.

Ontology is the nature of the social world and what can be know about it (Snape & Spencer, 2003). Epistemology is the nature of knowledge and how it can be gained (Snape & Spencer).

The epistemological stance is the justification for the knowledge obtained from a research method, based on a 'theory of knowledge' (Carter & Little, 2007). Underlying assumptions about what reality is, and what is possible for us to know about 'reality' and how this knowledge is obtained, influences the approach taken to answer a research question.

Epistemological stances tend to become polarised between positivism and interpretivism.

From the positivist perspective, the research can be conducted by the researcher, independently, objectively and value-free. In contrast, the interpretivist position holds that the researcher has to explore and understand the social world through participant' and their own perspectives (Snape & Spencer, 2003). The influence of the process of the researcher studying a person is itself acknowledged; there is an interaction between the researcher and the social phenomena (Snape & Spencer).

Qualitative methodologies broadly reflect interpretivist principles that hold that interpretation and observation are important in understanding the social world (Snape & Spencer, 2003).

Quantitative methodology is normally rooted in the epistemological stance of positivism, whereby reality is determined by the object of study. The influence of the researcher is limited as much as possible (Onwuegbuzie, 2000).

The SLR in this portfolio included only quantitative papers and is underpinned by positivist principles. The choice of methodology was made based on what was most appropriate for

answering the question. Exploring the effectiveness of interventions for supporting wellbeing seemed to be best achieved using quantitative research which can enable causality, generalisations and the direct of effect to be determined.

For the empirical paper, a qualitative methodology was adopted to capture the subjective experiences of nurses working in a hospice context. The use of a quantitative approach was not considered appropriate for the purpose of this empirical paper because of the topic of compassion in hospice nursing was intended to explore subjective experiences and to obtain an understanding of how a particular group nurses experienced compassion.

Interpretative Phenomenological Approach is underpinned by methodological assumptions of phenomenology, hermeneutics and idiography (Smith, Flowers, & Larkin, 2009).

Phenomenology is the study of people's experiences and the ways in which they view the world (Smith, Flowers, & Larkin). IPA fits with subjective experience rather than objective truths or 'reality' and it focuses on the individual nature of experiences which seems relevant to the researcher's research aims.

My previous experience of having worked as a healthcare assistant in a hospice, led me to develop the expectation that hospice nurses view their work positively and are compassionate in their care and my own experiences of interactions with patients and families may have coloured my impression of the accounts shared by participants. My influence during the interviewing process will have co-created the content of the interview. There may have been a bias in the interview process as my positive beliefs about the work may have led me to ignore negative responses in following up questions or in analysing the data. I attempted to address this potential bias by creating a balanced interview schedule which allowed for the exploration of both positive and negative perspectives/experiences and I tried to replace the word compassion with the words they used to describe it, in subsequent compassion-related questions, in order to stay true to their understanding. I was aware of being mindful during the analysis. However, the method of IPA holds the principle of hermeneutics, where the

influence of the analyst's own experiences and assumptions on the interpretation of experience are acknowledged (Smith, Flowers, & Larkin, 2009).

The epistemologies and methodologies of the component parts of this thesis are contradictory. However, Onwuegbuzie and Leech (2005) argue that epistemological belief should not limit the use of research methods. The philosophical position of pragmatism considers knowledge to be of value if it has useful practical consequences. This means method selection is considered to be needs-based to attain findings that are useful. Onwuegbuzie (2000) contests the assertion that quantitative and qualitative paradigms are not compatible and encourages new researchers to employ mixed methods in research, identifying a range of advantages of a pragmatic stance to research. The polarised perspective of epistemology is challenged with the suggestion that positivist and non-positivist philosophies fall on a continuum of epistemology instead (Onwuegbuzie).

The researcher considers herself to not subscribe wholly to either end of the epistemological continuum. The researcher comes from an ontological stance of critical realism where an external reality exists independent of our beliefs and understanding but reality is only knowable through the human mind and socially constructed meaning (Snape & Spencer, 2003). The researcher gives equal value to both quantitative research from a positivist stance and qualitative research from an interpretative stance and appreciates the usefulness of both approaches dependent on the research question that needs answering. Therefore, the pragmatist stance guided the choice of methodology and research for the two papers in this portfolio and this stance explains the contrasting approaches used for the SLR and Empirical papers.

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Appendix B. Reflective statement

Reflective statement

Choosing my research area

When I initially started to consider a topic area for my research, I immediately drew upon my own recent experience of having worked as a healthcare assistant at a hospice during a year gap between graduating and starting the doctorate. Prior to working at the hospice I had never stepped foot in such a place, let alone had I any experience of physical patient care. However, I found the experience extremely powerful, emotionally intense but very rewarding. Observing how the nursing team engaged with the patients and their loved ones, with what I perceived as such care and compassion was truly inspiring to me. I had never experienced witnessing a person die before and it was a really big shock to the system. However, I began to appreciate, in my six months there, how uplifting and profound it was to support people in their final stages of life. I also have a personal interest in mindfulness and self-compassion, having attended various Buddhist meditation classes to help me with my own personal difficulties with being self-compassionate. So for me, I had quite a clear vision of the initial topic area for research exploration.

In first year of training, a research fair is held within the department, where trainees are introduced to the research topics available within the department. Initially I found this quite a daunting experience. Despite having ideas up my sleeve beforehand, I approached it with openness and found myself becoming inspired by lots of different topics and I felt quite a lot of pressure to make the 'right' decision. Although we'd been advised by staff and trainees in the years above that the process of deciding research area has several stages and opportunities to alter the idea, this did not take

away from the feeling that I needed to choose something that I would be prepared to invest emotionally and academically in for the next three years.

When I learned of Philip and Tim's research interests at the research fair were related to compassion, I was keen to think about how this could be explored in relation to my interest in hospice nursing. I was keen to hold on to the essence of nurses' experiences and the person beyond a large dataset.

My relationship with research

In all honesty the research component of the doctoral program was the aspect of the training I was least looking forward to when starting the course, not because I don't find learning and discovering new knowledge a fascinating process, but because of 'imposter syndrome' where I did not feel 'clever enough to be an academic and an ongoing personal challenge of finding academic writing an emotional struggle.

However, I have gradually developed way of managing and challenging the internal self-critics and I've developed ways to tolerate the anxiety enough to persist with the research process and I have found several pockets of enjoyment from it.

Tim and Philip have provided a constant reminder to me that their role is of a supportive, not judgemental position and I have found my relationship with them throughout this process has been crucial to me staying grounded in the ups and downs of it all.

Enthusiasm has waxed and waned, juggling the different demands of the course and life but I really noticed my passion reigniting after my initial interview with a participant. I remember being really apprehensive about what to expect but came out having spent the best part of 2 and half hours at the participant's home. I was so

energised and inspired, I had this urge to tell my friends and families how amazing it had been. It really reminded me why I had chosen this area for my research and spurred me on.

Recruitment became a bit stagnated after the first response. I teetered on the edge of not wanting to push myself onto the hospice team, which I got the impression was very busy, versus also needing to make myself know and heard. I ended up having to branch out to other hospices including the hospice I had worked at. Luckily this led to a flow of responses. In hindsight I think I had been too complacent and overly enthusiastic about the likelihood of recruiting all my participants from one site.

I found the gap between finalising my research topic and actually meeting the people who inspired it all along was really long, and contributed to a loss of interest. I felt I had drifted from what inspired me most and felt I had lost that connection. However, this interest came flooding back to me once the interview started happening in close succession.

Design and data analysis

I was perhaps over ambitious about my timeline for research and maybe part of that was driven by a fear of not having enough time to do this process. Data analysis ended up taking place at a much later stage than I had anticipated or hoped. This was partly due to the recruitment trajectory: my last interview did not take place until 18th March 2016. I also had a flurry of responses which took me from having three participants, for a long part of my recruitment phase, to nine in a short space of time. This meant I had nine interviews to transcribe.

I discovered that I found it very difficult to split my attention between SLR and empirical and I also realised that realistically, I could not split my mindset from transcribing to analysis intermittently. Therefore I resigned myself to the fact that I would need to have all my interviews transcribed before attempting the analysis stage. Now that I have been through the analysis process I believe I would be able to do things differently. I think it would be helpful to start jotting down initial comments for each participant, as and when the interviews were transcribed. Again, I think my ability to 'juggle' has definitely improved over the course of this program.

When choosing which methodology to use, I was unsure of which direction to take. As an undergraduate undergrad, I had enjoyed the quantitative nature of the the research and I found some comfort in there being more 'black and white' to results and it being quite a systematic process. However, I felt as though qualitative research fitted with the values of being a clinical psychologist in terms of having an interest in and connecting with people. I was keen to have the opportunity to try an approach I had never used before. I remember the dilemma of feeling that if I didn't do something quantitative, it would be a case of 'use it or lose' on the statistical skills front. But, I at the same time I had a 'fear of missing out' on the opportunity to learn about a whole new approach. I felt this dilemma paralleled the conflict in clinical training, with regards to learning about lots of different therapeutic approaches but, rather than being an expert in one, we are trained to be a 'jack of all trades'.

Excited to really 'get to know' the participants as people not just numbers. In terms of my pragmatic side, I was also swayed by perhaps my inaccurate assumption (as I later discovered) that it would take the pressure off to only have to interview a small sample of participants compared to collecting and analysing data for hundreds of people.

I was overwhelmed at the prospect of starting the analysis phase but once I'd overcome this I quickly became focused and engrossed in the process and, for the first time, I really felt I connected emotionally with the content of the interviews. I spent several evenings where I had to pause every so often, as I welled up and reflected on the moving experiences the nurses talked about. I was glad to be in the privacy of my own home as I sat at my laptop, headphones on, transcribing through tears. I hadn't really expected the transcription process to bring so many emotions up to the surface. I found myself remembering the meaningful and emotional encounters I had during my time as a hospice healthcare assistant and I felt sad that they had passed on, but also privileged to have been part of that stage of their lives and to be let into such an intimate and vulnerable time of their lives. Having analysed the data I can see parallels in my own beliefs about working at a hospice and being with patients and the themes that have come out of the data. However, I also became aware during the interviews themselves of how I'd barely scratched the service and had only been a healthcare assistant for a speck in time compared to the nurses I interviewed.

The interviewing process

I felt pressure, put on myself, to do justice to the nurses' experiences and their generosity in sharing them with me. Some of the interviews felt quite reserved and and I noticed that at times it felt like a professional-professional meeting rather than a person to person relationship (which is what I'd hoped for). It didn't always have an ease to it. I wondered about the impact of meeting at the hospice, either before or after a shift, in the family room, still in their uniforms. On the one hand they may have remained in their professional role, which maybe contributed to a feeling of not connecting fully on a human to human level. On the other hand, I suppose that's what

I wanted to capture in the first place: nurses' experiences of their work. I was unsure about my role: being an interviewing researcher was new to me and I felt confused about my position in it all? Maybe they were unclear about the expectations of the interview as well? I'm still pondering about this now. I was also aware of my age, being significantly younger, and how that may have impacted on the sense of connection I felt was lacking sometimes. I wonder how my continued anxiety about my 'performance' as a researcher might have influenced the process too. Was I 'doing it right?' Interestingly, whilst I'm writing I've noticed some parallels in my description of the interviews with some of the themes that came out of my research.

IPA analysis was conflicted experience due to various factors. It was a phase where I felt most engrossed and passionate and inspired, but was also tainted by the very real time-pressure of looming thesis deadline rapidly approaching. This dampened my enjoyment of this stage: I felt resentment that I didn't have more time to revel in the enjoyment of this part. However, at the same time, I wondered if the time pressure worked in my favour to enable me to be more focused and efficient and it prevented me from becoming too entangled in my data to the point of potential paralysis or losing my way too far off track from the real experiences of the participants. I think this was the time when I was really aware of my ability to channel my anxiety in a positive way and is possibly the phase that I am proudest of, in terms of my level of focus and productivity in a time of such pressure.

One of the hardest parts was piecing together the findings and representing them in a way where I felt I had fully captured the richness of my participants' experiences. I felt a sadness and disappointment when picking quotes and had to learn to not become as

attached to quotes which had really struck an emotional chord when listening to the transcripts.

Compassionate mind

Throughout this research journey, I have become more aware of my own tussle between the threat and drive system and the times I've become stuck in drive or threat. It's been a struggle to be apart from my family who are based over 250 miles away. I have tried to maintain regular opportunities to be with them. But this has become much harder in the last few months in the run up to the hand-in of this thesis. I have become aware of the negative impact this has had on my affiliative soothing system. To some extent the source of affiliation has been replaced by the strong supportive relationships I have with my peers on the course and I have found ways to foster contact to help me balance my threat and drive system. Luckily three of us have found it much more effective for our productivity and sanity to work together at the university library to keep focused but at the same time feel less alone in what can feel like a very isolating process. I have also found it hugely helpful to check in with peers and family and friends with telephone contact regularly. I hugely appreciate the importance of nurturing and not neglecting the relationships that matter in times of stress. I find this particularly pertinent to reflect when Mental Health Awareness Week has recently reminded us of the important of relationships in fostering wellbeing. I feel lucky to have had so much support to call upon in my times of need but also to be relied upon in order to feel part of something more communal and in touch with reality again.

I had heard previous trainees talking of huge hurdles during their application for ethical approval, or speaking of real difficulties in recruiting or having to change

research question/ design, but no one really spoke of the challenge of the write up. I feel that for me this stage of the project has been the toughest. Particularly in terms of managing a work-life balance, switching modes between research and clinical placement and keeping the self-critical demons at bay. Balancing the drive and threat systems has definitely been tested most at this point.

I've been driven by not wanting to let others down, pressure upon myself to do the participants justice as well as to honour the effort put in by my research supervisors and also to make sure I can become a qualified Clinical Psychologist of course!

There has been an ongoing challenge for me which has been a theme throughout the training process as a whole and before then too. My more general long-term relationship with academia as felt like an emotional rollercoaster and double edged sword. On the one side is the satisfaction that comes with completion of academic work and the passion interest in learning. On the other side comes the anxiety and internal critics that join me in this process. I have engaged in personal therapy which has helped me to develop ways of managing better and I'm on a journey which I hope to continue, in figuring out how to truly be there for myself and be kind to myself. I have found ways to tolerate uncertainty and trust in my own decision making. I hope I have grown as a researcher, clinician and human being and I hope to continue to grow in the future.

During the course of interviews, I fell a little bit out of love with my focus on compassionate mind because I became aware that during the interviews it was not something that was talked about spontaneously. At times I felt embarrassed to try to make explicit something that seemed obviously part of their make-up and identity. Perhaps this reflects my initial position in all of this, of having been an observer during

my short stint as a healthcare assistant noticing possibly, from a more outsider perspective, a process that is seemingly intrinsic to the hospice nursing team.

Systematic Literature Review

I felt as though the process of doing my SLR was made up of three phases in terms of the nature of my relationship with the process. The first phase felt overwhelming. The task of pinpointing a specific research question was such a long and arduous process and was tinged with the fear that at any moment along this process I might come across a review which had already answered my question. I had to put this fear to one side though. I quite enjoyed the more practical tasks within the SLR process and feeling as though there was a clear process to follow, which was a nice change and contrasted with the more iterative nature of IPA analysis.

I had concerns about my research question being 'too simple' and not 'interesting enough' or 'hard enough'. Initially I had some ideas about exploring the conceptualisation of compassion. However, as I did preliminary explorations of the literature it felt less feasible for a systematic review approach. The area felt quite abstract and I was unsure how to do this systematically. I didn't feel very confident and I also felt very overwhelmed at the possibility of doing a meta synthesis or meta ethnography, which I had never attempted before and felt very unfamiliar with. I also found very few studies which could be included so there was not substantial enough literature to conduct a systematic review. In discussions with my supervisors we agreed it would be best to change tack and revert to an older idea which was presented within my initial research proposal. I felt frustrated that I could have been much further ahead with my SLR if I had started with this research question to begin with, but I learnt that it was a useful and necessary part of the process. Once I had

committed to my question and determined my search terms, I moved in to the next phase of my relationship with my SLR. This second phase felt much more enjoyable and rewarding. I had been aware from the start that the process of doing the SLR would be much more time-consuming than I could anticipate, so I was keen not to avoid it and to break it down into manageable sections/tasks. I enjoyed the process of working through the methodical steps, and found comfort in the more black and white nature of the paper selection process and data extraction. However, the write up stage was my final of the three phases and within this phase I experienced a mix of emotions. On the one hand I enjoyed the process of critiquing and understanding the literature, but the actual process of determining a way of structuring the results and 'knowing' what to include in my discussion brought up a lot of self-evaluation and the self-critics were back with a vengeance. With the support from my research supervisors, my peers and learning to apply my own ways of coping with the self-critics I got through this phase.

I approached it by doing little and often over the summer period of 5th year. I believe the SLR process has taught me a lot about learning to trust in my decisions and develop in my journey to become a more autonomous researcher. My research supervisors have adapted to my needs and have supported me in line with the zone of proximal development.

Final thoughts

I've learned that it's okay to express my emotions and to give myself time to rest and relax but it is an ongoing process of making peace with my inner critics. I'm proud that I've managed to get to the end of this research journey. I've learned to balance trusting in the process with my own responsibility to face the things I find difficult and

develop ways of helping myself through them. I've found the support of my peers invaluable. I believe the hand-in will be a milestone, not a finite end to my relationship with academia. I've no doubt I will be drawn back into it as I progress in my clinical psychology career, and I hope I can look back on this time and remind myself of the lessons I have learned.

Appendix C. Author guidelines for submission to BMJ Supportive and Palliative Care

Preparing your manuscript

All material submitted is assumed to be submitted exclusively to the journal unless otherwise stated. Submissions may be returned to the author for amendment if presented in the incorrect format.

Manuscript documents are deleted from our systems 6 months after completion of the peer review process.

[Cover letter](#)

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[Statistics](#)

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Cover letter

Your cover letter should inform the Editor of any special considerations regarding your submission, including but not limited to:

Details of related papers by the same author(s) already published or under consideration for publication.

Details of previous reviews of the submitted article.

Copies of related papers, previous Editors' and reviewers' comments, and responses to those comments can be submitted using the File Designation "Supplementary file for Editors only". Editors encourage authors to submit previous communications as doing so is likely to expedite the review process.

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The title page must contain the following information:

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Full name, postal address, e-mail and telephone number of the corresponding author.

Full name, department, institution, city and country of all co-authors.

Up to five keywords relevant to the content of your manuscript. This will enable us to identify the most suitable reviewers for your manuscript.

Word count, excluding title page, abstract, references, figures and tables.

Manuscript format

The manuscript must be submitted as a Word document. PDF is not accepted.

The manuscript should be presented in the following order:

Title page.

Abstract, or a summary for case reports (Note: references should not be included in abstracts or summaries).

Main text separated under appropriate headings and subheadings using the following hierarchy: BOLD CAPS, bold lower case, Plain text, Italics. Tables should be in Word format and placed in the main text where the table is first cited.

Tables must be cited in the main text in numerical order.

Acknowledgments, Competing Interests, Funding and all other required statements. Reference list.

Images must be uploaded as separate files (view further details under the Figures/illustrations section). All images must be cited within the main text in numerical order and legends should be provided at the end of the manuscript. Appendices should be uploaded using the File Designation "Supplementary File" and cited in the main text.

Please remove any hidden text headers or footers from your file before submission.

Style

Abbreviations and symbols must be standard. SI units should be used throughout, except for blood pressure values which should be reported in mm Hg.

Whenever possible, drugs should be given their approved generic name. Where a proprietary (brand) name is used, it should begin with a capital letter.

Acronyms should be used sparingly and fully explained when first used.

Figures/illustrations

Images must be uploaded as separate files. All images must be cited within the main text in numerical order and legends should be provided at the end of the manuscript.

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Colour images and charges

For certain journals, authors of unsolicited manuscripts that wish to publish colour figures in print will be charged a fee to cover the cost of printing. Refer to the specific journal's instructions for authors for more information.

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File types

Figures should be submitted in TIFF or EPS format. JPEG files are acceptable in some cases. A minimum resolution of 300 dpi is required, except for line art which should be 1200 dpi. Histograms should be presented in a simple, two-dimensional format, with no background grid.

During submission, ensure that the figure files are labelled with the correct File Designation of "Mono Image" for black and white figures and "Colour Image" for colour figures.

Figures are checked using automated quality control and if they are below the minimum standard you will be alerted and asked to resupply them.

Please ensure that any specific patient/hospital details are removed or blacked out (e.g. X-rays, MRI scans, etc). Figures that use a black bar to obscure a patient's identity are NOT accepted.

Tables

Tables should be in Word format and placed in the main text where the table is first cited. Tables must be cited in the main text in numerical order. Please note that tables embedded as Excel files within the manuscript are NOT accepted. Tables in Excel should be copied and pasted into the manuscript Word file. Tables should be self-explanatory and the data they contain must not be duplicated in the text or figures. Any tables submitted that are longer/larger than 2 pages will be published as online only supplementary material.

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You may submit multimedia files to enhance your article. Video files are preferred in .WMF or .AVI formats, but can also be supplied as .FLV, .Mov, and .MP4. When submitting, please ensure you upload them using the File Designation "Supplementary File - Video".

References

Authors are responsible for the accuracy of cited references and these should be checked before the manuscript is submitted.

Citing in the text

References must be numbered sequentially as they appear in the text.

References cited in figures or tables (or in their legends and footnotes) should be numbered according to the place in the text where that table or figure is first cited. Reference numbers in the text should be inserted immediately after punctuation (with no word spacing)—for example, [6] not [6].

Where more than one reference is cited, these should be separated by a comma, for example, [1, 4, 39]. For sequences of consecutive numbers, give the first and last number of the sequence separated by a hyphen, for example, [22-25]. References provided in this format are translated during the production process to superscript type, and act as hyperlinks from the text to the quoted references in electronic forms of the article.

Please note that if references are not cited in order the manuscript may be returned for amendment before it is passed on to the Editor for review.

Preparing the reference list

References must be numbered consecutively in the order in which they are mentioned in the text.

Only papers published or in press should be included in the reference list.

Personal communications or unpublished data must be cited in parentheses in the text with the name(s) of the source(s) and the year. Authors should request permission from the source to cite unpublished data.

Journals from BMJ use a slightly modified version of Vancouver referencing style (see example below). The style template is available via [Endnote](#). Note that [The BMJ](#) uses a different style.

BMJ reference style

List the names and initials of all authors if there are 3 or fewer; otherwise list the first 3 and add 'et al.' (The exception is the Journal of Medical Genetics, which lists all authors). Use one space only between words up to the year and then no spaces. The journal title should be in italic and abbreviated according to the style of Medline. If the journal is not listed in Medline then it should be written out in full.

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Example references

Journal article

13 Koziol-McLain J, Brand D, Morgan D, et al. Measuring injury risk factors: question reliability in a statewide sample. *Inj Prev* 2000;6:148–50.

Chapter in book

14 Nagin D. General deterrence: a review of the empirical evidence. In: Blumstein A, Cohen J, Nagin D, eds. *Deterrence and Incapacitation: Estimating the Effects of Criminal Sanctions on Crime Rates*. Washington, DC: National Academy of Sciences 1978:95–139.

Book

15 Howland J. *Preventing Automobile Injury: New Findings From Evaluative Research*. Dover, MA: Auburn House Publishing Company 1988:163–96.

Abstract/supplement

16 Roxburgh J, Cooke RA, Deverall P, et al. Haemodynamic function of the carbomedics bileaflet prosthesis [abstract]. *Br Heart J* 1995;73(Suppl 2):P37.

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Electronic journal articles

Morse SS. Factors in the emergency of infectious diseases. *Emerg Infect Dis* 1995 Jan-Mar;1(1). www.cdc.gov/nciod/EID/vol1no1/morse.htm (accessed 5 Jun 1998).

Electronic letters

Bloggs J. Title of letter. *Journal name* Online [eLetter] Date of publication. url eg: Krishnamoorthy KM, Dash PK. Novel approach to transseptal puncture. *Heart* Online [eLetter] 18 September 2001.
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1. Alwick K, Vronken M, de Mos T, et al. Cardiac risk factors: prospective cohort study. *Ann Rheum Dis* Published Online First: 5 February 2004.
doi:10.1136/ard.2003.001234

How to cite articles with a DOI once they have appeared in print

1. Vole P, Smith H, Brown N, et al. Treatments for malaria: randomised controlled trial. *Ann Rheum Dis* 2003;327:765–8 doi:10.1136/ard.2003.001234 [published Online First: 5 February 2002].

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Additional figures and tables, methodology, raw data, etc may be published online only as supplementary material. If your paper exceeds the word count you should consider if any parts of the article could be published online only. Please note that these files will not be copyedited or typeset and will be published as supplied, therefore PDF files are preferred.

All supplementary files should be uploaded using the File Designation "Supplementary File". Please ensure that any supplementary files are cited within the main text of the article.

Some journals also encourage authors to submit translated versions of their abstracts in their local language, which are published online only alongside the English version. These should be uploaded using the File Designation "Abstract in local language".

Statistics

Statistical analyses must explain the methods used.

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Authors are encouraged to use the relevant research reporting guidelines for the study type provided by the EQUATOR Network. This will ensure that you provide enough information for editors, peer reviewers and readers to understand how the research was performed and to judge whether the findings are likely to be reliable.

The key reporting guidelines are:

Randomised controlled trials (RCTs): [CONSORT guidelines](#)

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Manuscript length and formatting: Have you checked that your manuscript doesn't exceed the requirements for word count, number of tables and/or figures, and number of references? Have you provided your abstract in the correct format? Have you supplied any required additional information for your article type, such as key messages?

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Details of any co-authors (name, institution, city, country and email address)

Details of preferred reviewers (name and email address)

Word count, number of figures, number of tables, number of references and number of supplementary files for online only publication

Competing interest statement

Contributorship statement

Additional information that can be provided or may be required when submitting certain article types to certain journals:

Name of the research funder(s)

ORCID number(s) for all authors

Names of any collaborators

Details of non-preferred reviewers (name and email address)

Clinical trial registration number

Patient consent form

Details of ethical approval

Research reporting checklist (or a reason why one has not been provided)

Data sharing statement

Permission from the copyright holder to re-use previously published material

Title of an alternate BMJ journal to which your manuscript can be

automatically submitted if rejected from your first choice journal

Please check the specific journal's instructions for authors prior to submitting your manuscript.

Appendix D. Data extraction form

Study Title:
General
Author(s)
Year of Publication
Title of Study
Peer reviewed
Research Aims
Research Design
Participants
Gender
Age
Profession
Country
Sample size
Intervention
Name/title
Duration
Mode of Delivery? (who, how?)
Description of content
Control/Comparison?
Randomised?
Outcomes
Measurement of wellbeing
Other outcome measures
When measured
Statistical Analysis
Main Findings
Conclusions
Of Authors
Notes of review
Quality Score

Appendix E. Quality assessment Checklist devised from NICE STROBE MMAT DOWNS AND BLACK

Study author and date:		Score				
Item	Criteria	yes	partly	no	Unable to determine	n / a
		2	1	0	0	
Reporting						
Introduction						
Background	1. Are the relevant key concepts explained/defined in the literature review?					
Objectives	2. Is the hypothesis/aims/objectives of the study clearly described? Is it clear what the study is investigating and what its parameters are?					
Context	3. Does it provide a clinical rationale? (a real world issue that justified the study?)					
Method						

Participant Characteristics	4.Are the characteristics of the participants included in the study clearly described?					
	5.Eligibility criteria and the sources and methods of selection and follow up reported?					
Sample	6.Explanation of how the sample size was arrived at?					
Study design	7.Are the key elements of study design presented e.g. design, procedure, and methods?					
	8.Is the study design appropriate? Is a rationale given for the design and methods used?					
Intervention	9.Are the interventions of interest clearly described?					
Analysis	10.Did the report provide an adequate description of the methods used in data collection?					
Statistical methods	11. Describe all statistical methods, including those used to control for confounding					
Data sources /measures	12.Is the main outcome measure/ measure of the variables of interest clearly described in the Introduction or Method section?					
Bias	13.Describes any efforts to address potential sources of bias					
Results						

Participants	14.Report number of participants at each stage of the study (potentially eligible, examined for eligibility, included/excluded, completing follow-up, analysed.					
	15.Reasons provided for non participation.					
	16.Provides characteristics of study participants: demographics, clinical, social and potential confounders.					
Findings	17.are the main findings clearly described					
	18.are the findings presented clearly.					
	19.are the findings relevant to the aims of the study?					
	20.Are estimates of the random variability in the data for the outcomes relating to wellbeing provided?					
	21.Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability variable is less than 0.001?					
Discussion						
Key results	22.Are the key results summarised with reference to the study objectives?					
Limitations	23.Are limitations discussed that take into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.					

Interpretation	24.Gives a cautious overall interpretation of results considering objectives, limitations, results from similar studies and over relevant evidence?					
Generalisability	25.Discusses generalisability (external validity) of the study results.					
Methodological quality criteria						
Quantitative Randomised controlled (trials)	26.Is there a clear description of the randomisation?					
	27.Is there a clear description of the allocation concealment?					
	28.Are there complete outcome data (80% or above)					
	29.Is there low withdrawal/drop out (below 20%)					
Quantitative non-randomised	30.Are participants recruited in a way that minimised selection bias?					
	31.In the groups being compared, are the participants comparable or do researchers take account (control) for the difference between these groups.					
	32. are there complete outcome data (80% or above) and when applicable an acceptable response rate (60% or above) or					

	an acceptable follow up rate for cohort studies.					
Validity						
External validity	33. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?					
	34. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?					
Internal validity	35. In trials and cohort studies, do the analyses adjust for different lengths of follow up of participants or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?					
	36. Were the statistical tests used to assess outcomes related to wellbeing appropriate?					
	37. Was compliance with the intervention(s) reliable?					
	38. Were the main outcome measures used accurate (valid and reliable)?					
Internal validity confounding (selection bias)	39. Were participants in different intervention groups or were the cases and controls recruited from the same					

	population? (between/within)					
	40. Were study subjects in different intervention groups for trials and cohort studies or for case-control studies, were the cases and control recruited over the same period of time?					
	41. Were study subjects randomised to intervention groups?					
	42. Was there adequate adjustment for confounding in the analyses from which the main outcome findings were drawn?					
	43. Were losses of participants to follow-up taken into account?					
Power	44. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%					

Appendix F. Quality assessment: breakdown of individual scores for each checklist item*and total scores and percentages

Study	Checklist Item Number																																																				
	1	2	3	4	5	6	7	8	9	10	11	12	13	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	33	34	42	43	44	45	46	47	48	49	50	51	52	53									
Carter et al. (2013)	2	1	2	2	1	0	1	1	2	2	0	2	0	2	0	2	1	1	1	2	2	1	1	1	0					0	0	0	2	0			0	2	2	2	0	0	2	5									
Fillion et al. (2009)	1	2	2	2	2	2	1	2	1	2	2	2	2	2	2	2	2	2	2	2	1	2	2	1	2	0	2	2	2			0	0	2	2	1	1	2	2	2	2	2	2	5									
Freitas et al. (2014)	1	2	2	1	2	2	2	0	0	1	2	2	1	2	2	2	0	1	1	2	2	2	2	2	0				0		0	0	0	0	0	1	2	2	0	1	0	5											
Gray-Toft (1980)	2	2	2	1	1	1	1	2	2	1	2	2	0	0	0	0	2	1	2	2	2	2	0	0	0				0	1	0	2	2	0	2	0	2	1	0	0	0	0	5										
Hilliard (2006)	2	2	2	2	1	1	1	1	1	1	2	2	1	1		1	2	2	2	2	0	1	2	1	0				0	1	2	2	0	2	2	1	1	0	0	0	0	4											
Larson (1986)	2	2	2	0	0	0	1	1	1	2	0	1	0	0	0	0	2	1	2	0	0	2	1	2	2				0	0	0	0	0		0	0	2	0	0	0	0	0	5										
Potash et al.(2014)	2	2	2	2	1	1	2	1	2	1	2	2	0	0	0	1	2	2	2	2	2	2	2	2	0				0	1	2	0	0	0	2	2	2	0	0	0	0	0	5										
Slozano et al.(2013)	2	2	2	2	2	1	2	1	2	1	1	2	1	1	1	2	1	1	2	0	2	2	2	2	2				0	2	2	0	0	2	2	2	2	0	0	0	0	0	5										
Wasner et al. (2005)	2	1	2	2	0	0	0	0	1	1	2	2	0	1	0	1	2	2	2	2	0	2	2	2	1				1		0	0		0	0	2	0	0	0	0	2	5											
Bruneau & Ellison (2004)	1	2	2	0	1	1	2	2		2	2	2	1	1		1	2	2	2	2	2	2	2	1	1				0	2	0	1		0	0	2	2	2	0	2	2	5											

*Blanks represent items not applicable to the study

Study	Total score	Max score	Percentage %
Carter et al. (2013)	45	83	53%
Fillion et al. (2009)	72	85	83%
Freitas et al. (2014)	47	85	59%
Gray-Toft (1980)	45	79	54%
Hilliard (2006)	48	83	61%
Larson (1986)	31	79	38%
Potash et al.(2014)	51	81	61%
Slozano et al.(2013)	56	83	67%
Wasner et al.(2005)	42	77	55%
Bruneau & Ellison (2004)	56	75	75%

Appendix G. Author guidelines for submission to Qualitative Health Research

Manuscript Submission Guidelines: Qualitative Health Research (QHR)

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR 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)

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/qhr> to manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types

2. Editorial policies 2.1 Peer review policy

2.2 Authorship 2.3 Acknowledgements 2.4 Funding 2.5 Declaration of conflicting interests 2.6 Research ethics and patient consent 2.7 Clinical trials 2.8 Reporting guidelines 2.9 Data

3. Publishing Policies 3.1 Publication ethics

3.2 Contributor's publishing agreement 3.3 Open access and author archiving 3.4 Permissions

4. Preparing your manuscript 4.1 Word processing formats

4.2 Artwork, figures and other graphics 4.3 Supplementary material 4.4 Journal layout 4.5 Reference style

4.6 English language editing services 5. Submitting your manuscript

5.1 How to submit your manuscript 5.2 Title, keywords and abstracts 5.3 Corresponding author contact details

6. On acceptance and publication 6.1 SAGE Production

6.2 Access to your published article

6.3 Online First publication 7. Further information

1. Article types

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience Experiences of caregivers Health and health-seeking behaviors Health care policy

Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Look Out for These Regular Special Features

Pearls, Pith and Provocation: This section fosters debate about significant issues, enhances communication of methodological advances and encourages the discussion of provocative ideas.

Computer Monitor: These are articles related to computers and qualitative research.

Book Review Section: Qualitative Health Research includes a book review section helping readers determine which publications will be most useful to them in practice, teaching and research.

Mixed Methods: This section includes qualitatively-driven mixed-methods research, and qualitative contributions to quantitative research.

Advancing Qualitative Methods: Here, qualitative inquiry that has used qualitative methods in an innovative way is described.

Evidence of Practice: Theoretical or empirical articles addressing research integration and the translation of qualitatively derived insights into clinical decision-making and health service policy planning.

Ethics: Quandaries or issues that are particular to qualitative inquiry are discussed.

Teaching Matters: Articles that promote and discuss issues related to the teaching of qualitative methods and methodology.

2. Editorial policies

2.1 Peer review policy

QHR strongly endorses the value and importance of peer review in scholarly journals publishing. All papers submitted to the journal will be subject to comment and external review. All manuscripts are reviewed initially by the Editors and only those papers that meet the scientific and editorial standards of the journal, and fit within the aims and scope of the journal, will be sent for outside review.

QHR adheres to a rigorous double-blind reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Please refer to the editorial on blinding found in the Nov 2014 issue: <http://qhr.sagepub.com/content/24/11/1467.full>.

2.2 Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check 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 and design, acquisition of data or analysis and interpretation of data,
- (ii) Drafted the article or revised it critically for important intellectual content,

(iii) Approved the version to be published.

Authors should meet the conditions of all of the points above. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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 fully meet the criteria for authorship.

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.

2.3 Acknowledgements

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

2.3.1 Writing assistance

Individuals who provided writing assistance, e.g. from a specialist communications company, do not qualify as authors and so should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance”).

It is not necessary to disclose use of language polishing services.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

QHR requires 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 not-for-profit sectors.

2.5 Declaration of conflicting interests

It is the policy of QHR 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 that '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](#)

2.6 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 Institutional Review Board 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.

In terms of patient privacy, authors are required to follow the [ICMJE Recommendations for the Protection of Research Participants](#). Patients have a right to privacy that should not be infringed without informed consent. Identifying information, including patients' names, initials, or hospital numbers, should not be published in written descriptions, photographs, and pedigrees unless the information is essential for scientific purposes and the patient (or parent or guardian) gives written informed consent for publication. Informed consent for this purpose requires that a patient who is identifiable be shown the manuscript to be published. Participant descriptors should not be listed individually. Because qualitative research is descriptive, it is recommended that participant quotations not be linked to identifiers in the manuscript.

2.7 Clinical trials

QHR conforms to the [ICMJE requirement](#) that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant [EQUATOR Network](#) reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed [Consolidated Standards of Reporting Trials \(CONSORT\)](#) flow chart as a cited figure, and a completed CONSORT checklist as a supplementary file.

Other resources can be found at [NLM's Research Reporting Guidelines and Initiatives](#).

2.9 Data

SAGE acknowledges the importance of research data availability as an integral part of the research and verification process for academic journal articles.

QHR requests all authors submitting any primary data used in their research articles alongside their article submissions to be published in the online version of the journal, or 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(s) may consider limited embargoes on proprietary data.] The editor(s) [can/will] also grant exceptions for data that cannot legally or ethically be released. All data submitted should comply with Institutional or Ethical Review Board requirements and applicable government regulations. For further information, please contact the editorial office at vshannonqhr@gmail.com.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#)

3.1.1 Plagiarism

QHR and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised

other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

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Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit our [Frequently Asked Questions](#) on the SAGE Journal Author Gateway.

3.3 Open access and author archiving

QHR offers optional open access publishing via the SAGE Choice programme. For more information please visit the [SAGE Choice website](#). For information on funding body compliance, and depositing your article in repositories, please visit [SAGE Publishing Policies](#) on our Journal Author Gateway.

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Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our [Frequently Asked Questions](#) on the [SAGE Journal Author Gateway](#)

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTeX templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#). Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our [Manuscript Submission Guidelines](#) page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for "APA format."

4.5 Reference style

QHR adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/qhr> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For

further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on [How to Help Readers Find Your Article Online](#)

5.3 Corresponding author contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly.

6.2 Access to your published article

SAGE provides authors with online access to their final article.

6.3 Online First publication

Online First allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be published online prior to their inclusion in a final journal issue which significantly reduces the lead time between submission and publication. For more information please visit our [Online First Fact Sheet](#)

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the QHR editorial office as follows:

Vanessa Shannon, Managing Editor, vshannonqhr@gmail.com.

Appendix H. Confirmation of ethics approval

REMOVED FOR HARDBINDING

Appendix I. Example recruitment poster

REMOVED FOR HARDBINDING

Appendix J. Participant information sheet

Title of study: Palliative Care Nurses' and Assistants' Understanding and Experience of Compassion in their Work.

We would like to invite you to take part in a research study, which is looking at the experiences of palliative care nurses and health care assistants. Before you decide if you want to participate we would like you to understand why this research is being done. We would also like you to understand what it will involve for you if you decide to participate. You can talk to others if you would like before you decide if you want to take part. The researcher will answer any questions you may have.

What is the study about?

This study is exploring the personal experiences of palliative care workers and their perspective on the role of compassion in their work to develop a better understanding of what it is like to work in the profession.

Why have I been invited?

We are asking nurses and health care assistants within Hospice settings to share their experiences of their work and how they experience and understand compassion in their role.

What will I have to do?

If you are interested in sharing your experiences of working in a hospice, you will be invited to participate in a one-to-one interview with the researcher. This interview would be arranged at a time and place that is convenient and most preferable to you and will take place privately outside of the Hospice.

During the interview the researcher will ask you questions about your personal experiences of working in palliative care, what compassion means to you and how you experience it. The interview will be audio recorded. The interview may last up to 60 minutes.

What will happen to the recording?

The audio recording will be securely stored electronically. Only the researcher will have access to it. They will listen to the recording of the interview and transcribe it. This transcript will be anonymous (people will not be able to identify you from it) and securely stored. The researchers will then read through the transcript of the interview in order to better understand your experiences. The audio recording will be destroyed following transcription.

Do I have to take part and what if I change my mind?

You are under no obligation to participate in this study. Participation is completely voluntary. If you decide to take part you will be asked to sign a consent form to indicate that you agree to take part. Even if you give consent to participate, you can still ask to withdraw at any time up to the point when the results are analysed without giving a reason for doing so. Deciding not to participate, or withdrawing your consent later, will have no impact on your role at the hospice or relationships with your employer.

Will other people know what I have said?

During the interview, you may talk about things that you do not want others to know about. Everything you speak about in the interview will remain anonymous and confidential. Non-anonymised information (e.g. signed consent forms and your personal information) will only be accessible to the researcher and will be securely stored at the University and kept separate to the recordings and transcriptions. Some direct quotes from your interview may be used in the write-up of the study but none of your personal details or any identifiable information will be included.

Confidentiality may have to be broken if you tell the researcher something which gives us concern for your own or someone else's safety. In these cases we would discuss this with you before any action was taken but in some cases the researcher may need to tell someone about these concerns without asking you first.

What will happen to the results of the study?

After the study is completed the results will be written-up as part of the researcher's thesis and may be submitted for publication in an academic journal or presented at conferences. Some direct quotes from your interview may be used in the write-up but none of your personal details or any identifiable data will be included.

Who is organizing and funding the study?

The researcher is a doctoral student in Clinical Psychology at the University who is also employed by the Humber NHS Foundation Trust. This study is part of her doctoral research project. Research expenses are being provided by the University of Hull.

Who has reviewed the study?

Independent Research Ethics Committees protect the interests of people who participate in research. This study has been reviewed and approved by the Faculty of Health and Social Care Research Ethics Committee at the University of Hull.

What if there is a problem?

If you have any concerns about the study, it might be helpful to discuss these with the researcher, who will do their best to answer your questions. You may also contact either of the researcher's supervisors at the University of Hull.

Expenses and Payments

Your participation in this study is voluntary; therefore there will be no payment for taking part. However, you will be reimbursed for any travel expenses should you wish to come to the University to take part in the study. If you choose to be interviewed at the University, you will receive a visitor parking permit prior to the interview to enable you to park easily on the University premises.

What are the possible disadvantages and risks of taking part?

The study will require you to give up 60 minutes of your own time, outside of working hours. People may, at times, find it upsetting talking about their experiences because it may bring to mind some difficult issues about your work. However, if this happens to you, the researcher

will offer support and will help you to gain access to further support and from your GP, if needed.

What are the possible benefits of taking part?

Although there will be no direct benefit or payment as a result of your involvement in this study, some people find it useful to talk about their experiences. It is hoped that the information you give us will contribute to understanding how hospice workers experience their work and how compassion is experienced and understood in this setting. This may help to improve support and training for palliative care and other nursing professions in the future.

I am interested in participating and would like further information

If you are interested in participating you can contact the researcher via the details on the next page.

Contact Details

Researcher: **Louise Durant**

Department of Psychological Health and Wellbeing
Clinical Psychology Programme
Hertford Building
University of Hull
Cottingham Road
Hull
HU6 7RX

Telephone: **REMOVED FOR HARDBINDING**(please leave a message if the call is not answered and the researcher will get back to you)

Email: **REMOVED FOR HARDBINDING**

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

Appendix K. Participant consent form

CONSENT FORM

Title of Project: Palliative Care Nurses' and Assistants' Understanding and Experience of Compassion in their Work.

Name of Researcher: Louise Durant

Please initial boxes

1. I confirm that I have read and understand the information sheet dated (insert date) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason up to the point of data analysis and transcription, without my role or relationship with my employer or colleagues being affected.

3. I confirm that direct quotes from the interview may be used in future publications or conference presentations and understand that they will be anonymised. Any quotes that risk breaching confidentiality will not be used in publications.

4. I agree to take part in the interview part of the study and understand that my interview will be audio recorded.

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file;

Appendix L. Demographics Sheet

INFORMATION ABOUT YOU

Please answer the following questions:

Participant number:.....

1. What is your age in years?.....

2. What is your gender? Male Female please tick

3. Ethnicity: White Asian
 Black Chinese
 Other (please state):

4. How many years have you worked in palliative care?

5. How many years have you been working at this Hospice?

6. What is your job title?

.....

Appendix M. Interview Schedule

Interview Schedule

Experiences of work

- What were your reasons for coming to work at a Hospice?
Prompt
 - *What is it about working with people with life-limiting illnesses?*
- How does that fit with your reasons for being here now?
- Please tell me about a situation that reflects typically what working in a hospice is like for you?
- What aspects of your work do you like?
 - *Why do you like them?*
- What aspects do you not like?
 - *Why don't you like them?*
- Tell me about a situation where you've felt good about an experience of caring for a patient or a time where the work that you did went well?
 - *What happened?*
 - *How did you feel at the time and afterwards?*
 - *How did the other person react?*
 - *What made you react in that way?*
 - *What did you think about the person?*
 - *How did you feel towards them?*
 - *What do you think influenced how you felt towards them?*
 - *How did you respond to those feelings?*
- Tell me about a time when you had a difficult/challenging experience of caring for a patient/at work?
 - *What happened?*
 - *How did you feel at the time and afterwards?*
 - *How did the other person react?*
 - *What made you react in that way?*
 - *What did you think about the person?*
 - *How did you feel towards them?*
 - *What do you think influenced how you felt towards them?*
 - *How did you respond to those feelings?*

Experiences and understanding of compassion

- Compassion is talked about a lot at the moment but I'm really interested to hear what your understanding of it is. What does it mean to you?
- Tell me about a time when you've been aware of being compassionate*
- Tell me about a time when you've been aware of experiencing compassion*:
 - Towards yourself
 - From others
- Tell me about a time when you think you've been compassionate* towards a colleague at work?
- Tell me about a time when you think you've been compassionate* towards a patient at work?
 - *What makes it difficult for you to be compassionate*?*
 - *What helps you to be compassionate?*

**replace 'compassion' with the participants own language used to describe what compassion means to them.*

Appendix N. Sources of Support sheet (example)

Sources of support and information

Sources of support at REMOVED FOR HARDBINDING

If you have been affected by anything that you have talked about today and feel you need to seek additional support or information, you are encouraged to initially make contact with your **Clinical Supervisor**.

If you would prefer to seek alternative support from this, please contact

[name removed for hard binding].

You are also welcome to raise any issues or concerns you may have with the **HR department**.

Sources of support outside of Dove House Hospice

If you would prefer to seek advice or support from outside of your work place, see below:

Cavell Nurses Trust offer help and advice to registered nurses and healthcare assistants

Advice line: 01527 595 999 or visit their website for more details

<https://www.cavellnursestrust.org/talk-to-us>

The **Time to Change** website offers advice on support for how to get support from your employer if you are finding work stressful.

<http://www.time-to-change.org.uk/your-organisation/support-workplace/getting-support-from-my-company>

Samaritans offer confidential support for people experiencing feelings of distress or despair.

24-hour helpline: 08457 90 90 90

www.samaritans.org.uk

Should you have any specific issues that taking part in this study has raised then you can call the **Researcher** on:

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You can also seek advice from your **GP**

Appendix O. excerpt of transcript and example analysis

1 <u>Transcription Participant (P) and Interviewer (I) – ‘Claire’</u>	<u>Comments</u>	<u>Emergent Themes.</u>
2 I: So <u>erm</u> , the question I usually start with is, what were your 3 reasons for coming to work at a hospice?		
4 P: <u>Erm</u> , quite personal reasons really. Before I went in to 5 nursing I went into hotel work, I worked in media sales, and 6 then my <u>mother got cancer</u> and was ill for a period of about 7 three years before she <u>died</u> and I think <u>it was the influence of</u> 8 <u>the palliative nurses we had</u> . She had community nurses 9 coming out to the home, she was in the hospice twice, so had 10 experience of those nurses and then finally at the end she had 11 Hospice at Home caring for her, <u>and I remember at the time</u> 12 <u>thinking what a fabulous job they did and how much I’d want</u> 13 <u>to do it</u> . So I started my nursing training about a year after she 14 died, and... I kept an open mind and thought, oh open to doing 15 any type of nursing if something else were to change my mind, 16 but by the end I was still dead set on doing palliative and went 17 straight in to working in a Hospice and have been there ever 18 since.	<p data-bbox="784 622 1523 678">Personal experience of mum having cancer and witnessing the care she had from hospice influenced her career choice.</p> <p data-bbox="784 861 1545 917">Had a strong vision of her desired role as a hospice nurse. Witnessed fabulous work of nurses personally.</p>	<p data-bbox="1590 606 1747 686">Influenced and motivated by personal experiences</p> <p data-bbox="1590 861 1747 917">Clear vision to pursue the hospice profession</p>
19 I: Oh wow, gosh, thank you for sharing that about your mum. It 20 sounds like, you had it in mind to pursue nursing after your 21 experience with your mum and then you came back to actually 22 yes, I definitely want to do the hospice work?		
23 P: It was tough I think a few people would say to me, 'oh don't 24 got straight into a hospice, go and work in sort of the acute 25 sector first, <u>erm</u> , but I, and I think, I just think, at the age I was 26 30 when I qualified and I thought, no I want to do what I want 27 to do and not, I don't think that's been to my detriment. I think 28 from life experience I was ready for it.	<p data-bbox="784 1149 1433 1173">Discouraged by peers to go directly into hospice nursing when newly qualified.</p> <p data-bbox="784 1236 1344 1260">Had entered her training with a purpose/ clear career path in mind.</p>	<p data-bbox="1590 1181 1747 1252">Feeling ready for the role, striving to be a hospice nurse</p>