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## **Review Article**

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# Palliative care nurses' experiences of stress, anxiety, and burnout: A thematic synthesis

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#### Abstract

**Objectives.** This systematic literature review aimed to critically appraise empirical evidence investigating palliative care (PC) nurses' experiences of stress, anxiety, and burnout. **Methods.** Six databases (PsycINFO, MEDLINE, Scopus, CINAHL, PubMed, and Web of Science) covering literature within psychology, medicine and healthcare, and social sciences were searched from inception until December 2020. Studies were eligible if they included qualitative literature reporting on experiences of nurses working in a PC setting of stress, anxiety, or burnout, and were published in English. Eighteen studies satisfied the review's inclusion criteria and were considered relevant to the review aims. Critical appraisal was undertaken using the Critical Appraisal Skills Programme Qualitative Checklist.

**Results.** Thematic synthesis identified three main themes: *When work becomes personal, The burden on mind and body*, and *Finding meaning and connection*. The findings suggested that stress, anxiety, and burnout are deeply personal feelings experienced by nurses both on an emotional and physical level. Additionally, PC nurses' experiences can differ in meaning and strength depending on their relationships with patients, patients' families, and colleagues. **Significance of the results.** The synthesis highlighted that PC nurses' experiences are complex, encompassing clinical and organizational challenges, and the personal impact their work has on them. Having a greater understanding of the factors that contribute to PC nurses' experiences may help in PC nurses' core training and continuing professional education, as well as the provision of effective supervision and staff support.

# Introduction

Palliative care (PC) work involves absorption of negative emotional responses, breaking bad news, challenges to personal beliefs, coping with the inability to cure, immersion in emotional clashes, poorly defined roles, recurrent exposure to death, working in an area of uncertainty, patient suffering, and secondary trauma (Rokach, 2005; Breen et al., 2014). Healthcare professionals in PC settings can face a range of challenging situations while emotional demands on staff can lead to poor psychological well-being (Martins Pereira et al., 2012; Hill et al., 2016). Specifically, nurses working in PC have a demanding role, requiring time and continual contact with patients and caregivers who are suffering. The nature of this work, often involving prolonged contact with people during the end stages of serious illnesses, predisposes PC nurses to significant physical, emotional, spiritual, and psychological distress (Cross, 2019).

Four systematic literature reviews have been conducted to date synthesizing available literature in the area of PC. Martins Pereira et al.'s (2011) review included 15 studies published between 1999 and 2009 and exploring burnout in PC staff. Their findings suggested that burnout levels in PC do not seem to be higher than in other health contexts. However, a limitation of this review is that most of the studies included were not from PC settings, and half were from staff working in oncology services. Similarly, Parola et al.'s (2017) review of the prevalence of burnout in PC professionals included eight cross-sectional studies with a variety of healthcare professionals, such as nurses, physicians, and social workers. Hill et al.'s (2016) review included nine quantitative studies investigating psychosocial interventions to improve the well-being of staff who work in PC settings. They found no meaningful conclusions could be drawn about effective interventions for staff due to the poor quality of the research, furthermore, their study was undertaken with a range of participants (paid or voluntary) with no restrictions to any one profession (Hill et al., 2016). Finally, Zanatta et al.'s (2020) review of six quantitative studies on resilience in healthcare professionals providing PC to adults, found resilience moderates and facilitates nurses' adaptation to death anxiety, traumatic experiences, stress, and burnout. Zanatta et al.'s review (2020) proposed a theoretical model of resilience experience and suggested that further research was required to validate their findings.

There have been several recent systematic reviews undertaken in related areas. Dijxhoorn et al. (2020) investigated interventions for burnout in healthcare professionals providing PC in various settings. Their meta-analysis of 59 studies found a wide range of burnout in various



healthcare settings with lower rates in specialist services. They also highlighted that a greater understanding of burnout among healthcare professionals in PC was needed (Dijxhoorn et al., 2020). Lagentu et al. (2017) undertook a systematic literature review of burnout in PC nursing; however, their review only included four quantitative studies. Lastly, Powell et al.'s (2020) systematic literature review of eight qualitative and mixed-methods studies focused on the resilience in inpatient PC nurses. They suggested that research on developing a greater understanding of PC nursing staff experiences of stress and burnout from a qualitative perspective is missing (Powell et al., 2020).

To date, most research on stress, anxiety, and burnout in PC has been with patients and families. Moreover, much of the research that has been undertaken with healthcare professionals has focused on psychological interventions, developing resilience, or the prevalence of common mental health issues. Where systematic reviews have been undertaken into nurses' experiences in PC, these have mainly been done in home care settings (Sekse et al., 2018). As such, this systematic literature review will address the question: "What are palliative care nurses' experiences of stress, anxiety, and burnout?".

#### Methodology

#### Literature search

The review was registered on the systematic review protocols in the international prospective register (PROSPERO; ID number CRD42020221645). Searches for studies that have investigated PC nurses' experiences of stress, anxiety, and burnout were undertaken in December 2020. The databases used included PsycINFO, MEDLINE, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and Web of Science. The SPIDER tool was used to identify studies for inclusion in the review (Carroll et al., 2013) as it provides an

organizing framework by which to list search terms and main concepts (Methley et al., 2014). The main concept terms, and synonyms, were searched for within titles, abstracts, keywords, and the main text of studies to increase the probability of identifying relevant research. The truncation operator "\*" was also employed to avoid relevant search results being excluded due to minor word differences. An overview of search terms is presented in Table 1.

A Boolean search strategy was used, and each search performed using the following search terms: ("nurs\*" or "healthcare professional" or "health personnel" or "staff") AND ("palliative care" or "terminal care" or "end of life") AND ("stress" or "anxiety" or "burnout" or "vicarious trauma" or "compassion burnout" or "anticipatory grief") AND ("questionnaire" or "survey" or "interview" or "focus group" or "case study" or "observational study") AND ("perception\*" or "coping") AND ("qualitative" or "mixed methods").

#### Inclusion and exclusion criteria

An overview of the inclusion and exclusion criteria is presented in Table 2.

Studies were included if they were published in the English language, focused on the experience of stress, anxiety, or burnout and had nurses working in PC settings as participants. Also included were qualitative research, or mixed-methods studies where qualitative data were extractable. No limits were placed on study sample size, recruitment method, or date of publication. Initial screening of study titles and abstracts against inclusion and exclusion criteria was completed by both the lead researcher and a co-author. Relevant studies were retained, and the full text of each study was then screened independently by both the main author and the co-author. Any differences were managed by a moderating discussion between the two authors focusing on the aims of this literature review. Subsequently, it was decided that all studies with settings described as providing PC would be included.

Table 1. Key search terms

| SPIDER                 | Main concept               | Synonyms  | Location                                   |
|------------------------|----------------------------|---|--|
| Sample                 | Nurses                     | "nurs*", "healthcare professional", "health personnel", "staff"                                   | Title<br>Abstract<br>Keywords<br>Main text |
| Phenomenon of Interest | Working in palliative care | "palliative care", "terminal care", "end of life"   | Title<br>Abstract<br>Keywords<br>Main text |
|                        | Stress and anxiety         | "stress", "anxiety", "burnout", "vicarious trauma", "compassion", "burnout", "anticipatory grief" | Title<br>Abstract<br>Keywords<br>Main text |
| Design                 |                            | "questionnaire", "survey", "interview", "focus group", "case study", "observational study"        | Title<br>Abstract<br>Keywords<br>Main text |
| Evaluation             | Experiences                | "perception*, "coping"  | Title<br>Abstract<br>Keywords<br>Main text |
| Research Type          | Qualitative research       | "qualitative", "mixed methods"  | Title<br>Abstract<br>Keywords<br>Main text |

Table 2. Inclusion and exclusion criteria

| Criteria     | Inclusion   | Exclusion  |
|--------------|---|--|
| Language     | English   | Any other language   |
| Participants | Registered nurses working in palliative care (PC) setting                             | Other healthcare professionals, patients, families, carers                     |
| Experience   | Focus on stress, anxiety, or burnout  | Focus on any other mental health condition                                     |
| Methodology  | Qualitative research, or mixed-methods studies where qualitative data are extractable | Quantitative only, mixed-methods where qualitative data could not be extracted |
| Time period  | Any time period   | N/A  |

#### Classification of studies

Study selection was recorded on a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (Moher et al., 2009; Figure 1).

A total of 655 articles were identified following database searches. Four additional studies were identified after reference checking. After eliminating 36 duplicates, the remaining 623 article titles and abstracts were screened excluding a further 573 articles. The full texts of the remaining 50 articles were independently reviewed again by both authors and 32 articles not meeting inclusion criteria were excluded (Figure 1). The final result was 18 studies eligible for inclusion in the review.

# Quality assessment

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018) was used to assess study quality as it is the most used tool for quality appraisal in health-related qualitative evidence syntheses (Long et al., 2020). To enhance reliability, the co-author conducted an independent quality assessment check on all included studies using the same framework. Inter-rater reliability was assessed using Cohen's kappa ( $\kappa$ ). The overall kappa score was 0.877, suggesting very good inter-rater reliability (Altman, 1999).

Quality assessment using the CASP resulted in scores ranging from 12 to 19, with an average score of 17. There were three main limitations of the included studies identified during the current review: sample diversity, researcher's reflexivity, and data analysis. A detailed description of the quality assessment of studies included in this review can be found in the Supplementary materials document.

## Characteristics of the literature

The author(s), date of publication, country, aim(s), sampling method, sampling characteristics, data collection, data analysis, and main findings were extracted from the original articles. A detailed description of the characteristics of studies included in this review can be found in the Supplementary materials document. A summary of the characteristics of the literature is presented in Table 3.

#### Analytic review strategy

Thematic synthesis was used to develop descriptive and analytical themes that extend the primary research studies to generate new interpretations (Thomas and Harden, 2008). During Stage One (Coding Text), each study was read with sections highlighted

and codes created inductively to capture meaning and content. This resulted in 38 initial codes, such as *Coping Strategies*, *Families Causing Stress*, and *Feeling Helpless*. In Stage Two (Developing Descriptive Themes), the initial codes were grouped according to similarities and differences and descriptive codes were created to capture the meaning of these new groups. Stage Three (Developing Analytical Themes) involved addressing the review question by "going beyond" the original data and inferring PC nurses' experiences of stress, anxiety, and burnout based on the descriptive themes from Stage Two. Through this process, the final three analytical themes emerged. To ensure rigor in the analysis (Thomas and Harden, 2008; Houghton et al., 2017) NVivo 1.4 was used in each of its three stages of analysis (see Supplementary materials for screenshots and examples from each stage).

#### Results

Thematic synthesis identified three main themes: When work becomes personal, The burden on mind and body, and Finding meaning and connection. An overview of themes and subthemes is provided in Table 4. Additional quotes are provided in the Supplementary materials document.

A summary of each paper's contribution to each main theme and subtheme is shown in Table 5.

## When work becomes personal

This main theme describes how PC nurses' experiences of stress, anxiety, and burnout were linked with the personal impact of their work. Nurses in all studies apart from four (Källström Karlsson et al., 2008; Rose and Glass, 2009; Tunnah et al., 2012; Harris, 2013) stated their relationships with a patient's family could be personally challenging and a source of stress. PC nurses "found it particularly stressful when relationships [within the family] were strained" (Wilkes et al., 1998, p. 17) and/or when they were expected "to be the mediator" (Seed and Walton, 2012, p. 5). In addition, some nurses also found it stressful when family members were experiencing difficult and distressing emotions, such as the lack of understanding, or denial, of a patient's palliative medical status. Others saw dealing with a families' or patient's denial of illness prognosis as the most challenging task (Wilkes et al., 1998, p. 17).

Caring for PC patients requires specialist knowledge and skills to balance the needs of patients and families. Nurses are often the first and main contact for many families. For some, it was a feeling of being under pressure from families for answers that led to their work being experienced as more stressful, "... a lot of relatives involved in the families ... all looking to you for an answer

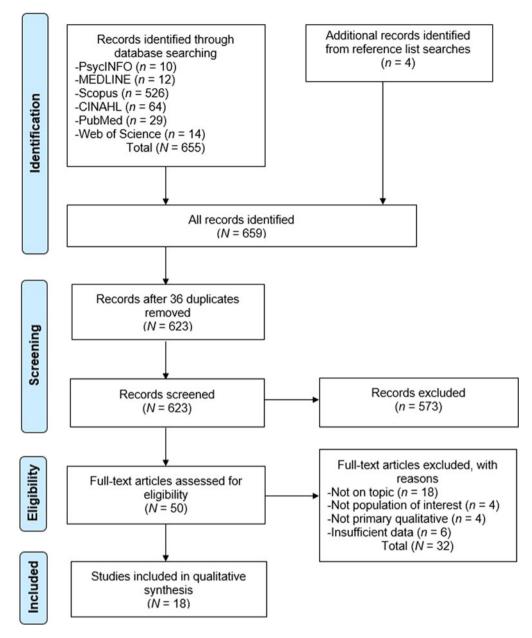


Fig. 1. PRISMA flow diagram (adapted from Moher et al., 2009).

... it is more stressful" (Reid, 2013, p. 543). Nurses also reported that "families get very needy, and they start needing [the nurse] for every little part from getting [their] father up to poop, to everything that's going on in their personal life" (Seed and Walton, 2012, p. E5).

Having good professional relationships with a patients' family was seen as important to providing good quality care. However, where nurses had built up a good rapport with families, this was also seen to contribute to increasing stress in some situations (Wilkes et al., 1998, p. 17).

In order to cope with pressure from families, some nurses had developed strategies that allow them to focus on the needs of their patients. Some learnt to "close the door, get [the family] out of the room, out of [their] personal space" (Badger, 2005, p. 67). For others, this meant not allowing themselves to get too close to the patient and thus needing to "restrict [themselves] in the

relationship" (Johansson and Lindahl, 2012, p. 2,037) to be able to continue to deliver professional support.

## The burden on mind and body

This main theme describes how nurses found their work to be both emotionally and physically difficult. Two subthemes are discussed, *Emotional impact* and *Physical impact*.

#### **Emotional** impact

All but one study (Becker et al., 2017) reported the emotional impact that PC work had on nurses. A range of factors were seen to increase the emotional impact that nurses felt, such as having close relationships with patients and their families, the complexity of PC clinical care, and how PC work connected with their personal values:

 Table 3.
 Characteristics of the literature

|   | Main findings with themes          | Three coping strategies were identified:  1. Cognitive — putting up with it, visualizing, learning from experience, reminiscing, and putting things into perspective  2. Affective — laughter, externalizing feelings, and emotionally compartmentalizing  3. Behavioral — retreating, avoiding, and distancing behaviors Difficulties were primarily seen as the result of conflicts with families and physicians  Providing futile care, the perception of "torturing" the patient, and conflict with families caused the greatest distress to staff | Emergency nurses develop expertise in end-of-life care giving by progressing through stages of development. Three stages/ themes were identified:  1. Investment of the self in the nurse-patient relationship —  Nurses could see the value in investing the therapeutic self into the relationship but were also concerned about boundaries between professional and personal relationships with patients.  2. Management of emotional labor — Nurses were concerned about the emotional impact of caring for patients near the end of life and their relatives. Some develop distancing behaviors to protect them from grief; however, this can be more stressful over a prolonged period of time.  3. Development of emotional intelligence — Self-awareness is central for nurses to develop emotional intelligence. It allows them to reflect on past experiences, core values, and identify strengths and weaknesses in their practice  Barriers that prevent the transition to expertise contribute to occupational stress and can lead to burnout and withdrawal from practice. | Three main concepts/themes describing the nurses' definition of dying well:  1. Emotional and spiritual support for the patient and family 2. Patient and family control 3. Promotion of a peaceful environment Eight categories of nursing actions to promote dying well were identified, which included: 1. Communication with disciplinary team/nursing staff 2. Provision of optimal physical care 3. Demonstration of caring and compassion 4. Supporting dignity in death for patient/family 5. Education of patient/family to support dying well 6. Emotional support for patient/family, advocacy for dying well 7. Fostering a peaceful environment Symptoms of distress among nurses and actions for relief were also indicated by participants. This included: Sadness, anxiety, |
|---|------------------------------------|--|--|---|
|   | Data collection<br>Data analysis   | Data collection Focus group interviews, informal conversations, and selective participant observation Data analysis Three phases of analysis described: data reduction, data display, and conclusion drawing   | Data collection Unstructured observations of practice and semi-structured interviews Data analysis Thematic analysis   | Data collection<br>Semi-structured questionnaires<br>Data analysis<br>Grounded theory   |
|   | Sample characteristics             | N = 24 nurses n = 19 female (79%) n = 5 male (21%) N = 24 identified as white (100%) Aged 24 to 57 years (M = 38.7) Nursing experience ranged from 1 to 35 years (M = 13.37) MICU experience ranged from 1 month to 35 years (M = 9.44)  | N=10 No other demographic information provided   | N = 49 nurses n = 42 female (86%) n = 7 male (14%) All registered nurses who had worked in an acute care environment for at least 12 months   |
|   | Sampling method                    | Purposive sampling from a medical intensive care unit  | Purposive sampling from a hospital emergency department  | Purposive sampling<br>from medical-<br>oncology, surgical,<br>progressive, and<br>intensive care<br>nursing units   |
|   | Aim(s)                             | To describe Medical<br>Intensive Care Unit<br>(MICU) nurses'<br>coping behaviors   | To explore how emergency nurses manage the emotional impact of death and dying in emergency work   | To identify perceptions of nurses regarding their actions to provide quality endof-life care for dying patients, their definitions of dying well, and their symptoms of distress and actions they took for relief   |
| Author(s), Date, Country<br>Ouality Rating (OR) | Inter-rater Reliability<br>(Kappa) | Badger, 2005, USA<br>QR 80%<br>Kappa <i>K</i> = 1.00   | Bailey et al., 2011, UK<br>QR 70%<br>Kappa <i>K</i> = 1.00   | Becker et al., 2017, USA<br>QR 90%<br>Kappa <i>K</i> = .615   |

(Continued)

Table 3. (Continued.)

|   | ess,<br>ment,   | im less optional. In skills, parents at illness cation and illness cation leir of the new page of the home sed and ies with ach support also an sharing; useful.   | f,<br>oort and<br>ies and<br>g with<br>, lack of  |
|---|---|--|---|
| es  | crying, feeling helpless, physical symptoms (sleeplessness, headache, heart racing, nausea), fatigue, guilt, bewilderment, betrayal, and anger. | Two categories were identified:  1. Challenges with four themes:  • Communication — Conversations with children were challenging, as their thought processes and actions seem less logical than adults and they were found to be more emotional. All nurses acknowledged their inadequate communication skills.  • Training and knowledge — They felt challenged when parents wanted information about complications of the medical illness and prognosis. Clinical examination and doses of medication were also different from adults. The majority welcomed further training to improve their knowledge and skills.  • Personal suffering — Providing care to children and their families was found to be a very emotive experience, compounded if they were mothers or had close relatives of the same age. Seeing a young child die was tough on them spiritually and being present with grieving parents and extended families overwhelmed some nurses. Parents with seemingly unrealistic expectations also challenged them in providing care for their child.  • Systemic — Busy workloads made it difficult to juggle home visits and to deal with pediatric procedural emergencies.  2. Coping with three themes:  • Intrapersonal — Nurses coped by being mentally focused and emotionally prepared, maintaining professional boundaries with family enhanced their confidence and resilience.  • Intrapersonal — Colleagues are a source of emotional support and guidance. Sharing with close family members was also an important way to cope.  • Systemic — Nurses valued teamwork, while reflective sharing and debriefing sessions in a safe work environment were useful.  | Three categories of stressors were found: organizational, professional, and emotional.  1. Organizational stressors included a lack of a PC approach, interprofessional difficulty, lack of continuity in life-support and treatment plans, and conflicting demands.  2. Professional stressors included lack of PC competencies and difficulty communicating with families and collaborating with the medical team.  3. Emotional stressors were described as value conflicts, lack of emotional support, and dealing with patient and family suffering.   |
| Main findings with themes   | al symptoms<br>a), fatigue, g   | Two categories were identified:  1. Challenges with four themes:  • Communication — Conversations with children were challenging, as their thought processes and actions so logical than adults and they were found to be more eath nurses acknowledged their inadequate communication of the media and prognosis. Clinical examination and doses of mewere also different from adults. The majority welcome training to improve their knowledge and skills.  • Personal suffering — Providing care to children and families was found to be a very emotive experience, compounded if they were mothers or had close relatives are seeing a young child die was tough on the spiritually and being present with grieving parents and families overwhelmed some nurses. Parents with seen unrealistic expectations also challenged them in prov for their child.  • Systemic — Busy workloads made it difficult to jugg visits and to deal with pediatric procedural emergence.  • Intrapersonal — Nurses coped by being mentally for emotionally prepared, maintaining professional bound compassion. Nurses felt the learning experience from family enhanced their confidence and resilience.  • Intrapersonal — Colleagues are a source of emotiona and guidance. Sharing with close family members was important way to cope.  • Systemic — Nurses valued teamwork, while reflective and debriefing sessions in a safe work environment we   | Three categories of stressors were found: oprofessional, and emotional.  1. Organizational stressors included a lack interprofessional difficulty, lack of continuit treatment plans, and conflicting demands.  2. Professional stressors included lack of Prdifficulty communicating with families and the medical team.  3. Emotional stressors were described as veemotional support, and dealing with paties suffering.   |
| Main finding  | pless, physic<br>acing, nause<br>er.  | ree identifiee  Conversati eir thought is and they weledged their mical examir nical examir nical examir t from adult is thoo g — Providir d to be a vee ey were mot a young chi ng present w med some n a young chi ng present w werkloads I with pediati ee themes: Nurses cope red, maintai ees felt the le es  | of stressors variational. stressors inclificulty, lacing conflictions on the confliction of caring with caring with care were defect, and dealing the care of the |
|   | crying, feeling helple<br>headache, heart raci<br>betrayal, and anger.  | Two categories were identified:  1. Challenges with four themes:  • Communication — Conversation challenging, as their thought prological than adults and they were the company of the com | Three categories of stressor professional, and emotional.  1. Organizational stressors in interprofessional difficulty, I treatment plans, and conflit.  2. Professional stressors incl difficulty communicating withe medical team.  3. Emotional stressors were emotional support, and deal suffering.  |
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| Data collection<br>Data analysis  |   | interviews<br>is   |   |
| Data co<br>Data a   |   | Data collection Semi-structured interviews Data analysis Thematic analysis   | Data collection<br>Focus groups<br>Data analysis<br>Content analysis  |
|   |   |  |   |
| Sample characteristics  |   | ears<br>nce ranged t   | 5%)<br>Pears<br>ranged from   |
| Sample ch   |   | N=16 (all female) Aged 24 to 62 years (M=29.5) Nursing experience ranged from 1 to 25 years (M=5) PC experience ranged from 1 to 18 years (M=2.5)  | N = 42<br>n = 40 female (95%)<br>n = 2 male (5%)<br>Mean age 35.4 years<br>ICU experience ranged from 6.6<br>to 14.1 years  |
| pod   |   |  | bū  |
| Sampling method   |   | Purposive sampling from clinical services in greater Kuala Lumpur  | Purposive sampling<br>from nurses working<br>in ICU   |
| Sa  |   | From in g in g Lum   |   |
| Aim(s)  |   | To explore the experience of community PC nurses providing home care to children   | To describe stressors experienced by nurses in providing end-of-life palliative care (EoL/PC) in intensive care units (ICUs)  |
| try   |   |  | To des experir nurses end-of care (fintens) (ICUs)  |
| Author(s), Date, Country<br>Quality Rating (QR)<br>Inter-rater Reliability<br>(Kappa) |   | Chong and Abdullah,<br>2017, Malaysia<br>QR 85%<br>Kappa K = 1.00  | Gélinas et al., 2012,<br>Canada<br>QR 80%<br>Kappa <i>K</i> = 1.00  |
| Author(s),<br>Quality Ra<br>Inter-rater<br>(Kappa)                                    |   | Chong and Ab<br>2017, Malaysia<br>QR 85%<br>Kappa <i>K</i> =1.00   | Gélinas et al., 3<br>Canada<br>QR 80%<br>Kappa K=1.00   |

| To understand Propries coping from process and in adequacy of workplace coping resources | Purposive sampling<br>from nurses working<br>in hospices | N=19 n=18 female (95%) n=1 male (5%) n=1 (84%) were white women, ranging in age from 45 to 54 years Average nursing experience was over 10 years; however, most participants had 5 years or less experience in hospice care | Data collection<br>Focus groups<br>Data analysis<br>Content analysis                | Three major themes were identified:  1. Social support — The most helpful and most frequently used coping mechanism was talking with and/or venting to others. In particular, they relied most heavily on their co-workers in times of stress. Although sharing with spouses or significant others was cited, many believed that their colleagues were the best outlet because they could speak freely about the situation.  2. Humor — All participants spoke of the importance of laughing and believed that humor helped to take their minds off distressing thoughts or stressful situations. It was not uncommon for them to use it in their practice for those very same reasons.  3. Prayer/meditation — Taking time for meditation or reflection seemed to be discussed interchangeably with the concept of prayer. A majority perceived prayer and/or spirituality to be an essential part of their coping process.   |
|--|--|---|---|--|
| Purposive from acut and medi and medi settings in hospitals hospitals                    | e surgical<br>cal care<br>n two                          | N=8 (All female) Nursing experience ranged from 3 to 32 years None of the nurses had any special education in PC  | Data collection Semi-structured interviews Data analysis Thematic analysis          | Seven themes were identified:  1. Being grateful to be able to share in the end of another's life — Constantly working towards the goal of achieving the best care for patient and loved ones.  2. Being touched by physical and existential meaning —  2. Being touched by physical and existential meaning —  2. Being touched by physical and existential meaning —  3. To exist in place and space — A desire to have a separate unit for PC and "long for a special and sheltered place" (p. 2038) with the resources to satisfy the needs of the patients and their family.  4. To give and receive energy — Working with terminally ill patients costs the nurses much energy, however, caring for the terminally ill and their families means getting a lot back in return.  5. Being open in relation to patients and colleagues — Availability and closeness are prerequisites for being able to see and get to know the patients and families to meet and deliver care to them 6. Being in embodied knowledge — The need is not always for new external knowledge but knowledge of oneself as a person and how to use one's lived knowledge.  7. Time that does not exist — Being unable to keep up with the work as they would like evokes feelings of stress and dissatisfaction. |
| Purposive : from an int care unit o healthcare institution                               | sampling<br>tensive<br>f a private                       | N=9 (All female) All permanently employed. All with experience of end-of-life issues in the intensive care unit   | Data collection<br>Semi-structured interviews<br>Data analysis<br>Thematic analysis | Four major themes were identified:  1. Conflicting emotions — Nurse's experience conflicting emotions and inability to function as a patient's advocate when faced with withdrawal of life-sustaining treatment.  2. Family relations — A supportive relationship with family members was formed when caring for end-of-life patients and members was formed family involvement was evident.  3. Multidisciplinary team relations — A need for more effective team collaboration was expressed.  4. Supportive strategies when dealing with end-of-life issues — Supportive strategies, for instance, debriefing, use of a counselor, education, were recognized.  |

Table 3. (Continued.)

| Main findings with themes   | Three descriptive claims were identified in 1993:  1. Deeper insight — Realization that death would come to them 2. Changed values — Life today is here and now 3. Not thinking of death — Creating a barrier against death in leisure time Four descriptive claims were identified in 2004: 1. Adapted to death — Being in close proximity to death 2. Integrated values — In-depth living in the here and now 3. Not thinking of death — Maintaining a barrier against death in leisure time 4. Feelings of confidence — Feeling confident about changes in themselves   | Three main themes were identified:  1. Significance — Experiences of significance included feeling admiration for the patients, becoming invigorated by their encounters with their patients, and getting confirmation that they did well.  2. Stress related to the profession — Participants described how they were affected by external influences such as meetings with patients and their families. Psychological stress, and stress-related symptoms including exhaustion, headaches, dizziness, and stomach pains.  3. Coping strategies — Their own family was an important source of new energy outside the job, and many of the informants described that they had very active lives with friends and with physical training. Participants stressed the importance of having a smooth-running team and having support on an organizational level through the head nurse. | Four core themes were identified: work demands; relationships, maintaining control, and support and roles. Of particular note were stressors associated with the subthemes of relationships, emotional demands, and ethical conflicts.  1. Demands — This theme is based upon workload, work patterns, and the work environment.  2. Relationships — The dominant discourse within this theme is related to relationships between the nurse and the child and/or family.  3. Maintaining control — Nurses from across the three settings identified maintaining control as a stressor. The HNs recounted the unpredictable nature of their working day, the juggling of competing demands, the need to re-prioritize their caseload, and lone working as stressful consequences of their role  4. Support and roles — Two clear subthemes emerged, managerial support, and role ambiguity. |
|---|--|---|--|
| Data collection<br>Data analysis  | Data collection Semi-structured interviews (in 1) 1993 and 2004) Data analysis Interpretive descriptive method Interpretive descriptive de | Data collection Semi-structured interviews Data analysis Systematic text condensation (STC) and abductive analysis t t t t p p p  | Data collection Focus groups Data analysis Thematic content analysis Content analysis Thematic content analysis  |
| Sample characteristics  | N = 5<br>No other demographic<br>information provided  | N=14 (All female) Aged 42 to 60 years Palliative experience ranged from 1 to 25 years   | N= 18<br>No demographic information<br>provided  |
| Sampling method   | Purposive sampling from an inpatient hospice ward based at a university hospital.  | Purposive sampling from specialized palliative home care teams  | Purposeful sampling<br>from three children's<br>PC services  |
| Aim(s)  | To discern the nurses' thoughts, feelings, and attitudes towards death and dying   | To highlight nurses' experiences of caring for patients in PC at mid-life and describe their coping strategies  | To explore the experience of occupational stress from the perspective of nurses contributing to the PC of children   |
| Author(s), Date, Country<br>Quality Rating (QR)<br>Inter-rater Reliability<br>(Kappa) | Källström Karlsson et<br>al., 2008, Sweden<br>QR 85%<br>Kappa K= 0.630   | Kaup et al., 2016,<br>Sweden<br>QR 90%<br>Kappa <i>K</i> = 1.00   | McCloskey and Taggart, 2010, UK<br>QR 75%<br>Kappa K= 1.00   |

| Five sources of stress were identified:  1. Societal values and reaction — Hospice nurses agree that dying and death are still subjects that most people would rather not discuss.  2. Organization of the work environment — Many of the difficultities and stresses that hospice nurses experience in their care of those who are dying relate to the structural conditions of their work.  3. Exchanges between nurses and the patients and their families, and nurses validates nurses' sense of self-worth and values.  4. Exchanges between nurses and their families, friends, and colleagues — Nurse's personal networks developed between family, friends and colleagues feature most strongly as both a source of stress and support for hospice nurses.  5. Personally facing death — Hospice health professionals must deal with the realities of death and dying within the context of their daily activities. Inevitably these contacts with the dying trigger personal responses  Many of the stresses encountered by hospice nurses relate to the sensitive nature of their work. Not only are their patient's frail, iil, and frightened, the patient's families and friends are themselves vulnerable, unwillingly thrust into the act of final parting and entering the grieving process even before the death of a loved one. | Four interrelated and overlapping themes were identified, illustrating the complexity of delivering PC to CYP.  1. Emotional preparedness — Most described being underprepared to deal with the emotional impact of the death of a CYP. Rather than the younger participants or those with least experience, it appeared to be those without a child nursing qualification who struggled to reconcile themselves with the concept of child death.  2. Navigating the "professional road" — Many reported difficulties with discharge planning, late introduction and inclusion of families, and multi-agency input confusing their own perceptions of their roles, boundaries, and responsibilities.  3. Becoming part of the family — Over half of the participants found working in balance with the extended family, parents, and the CYP unusual. All described some challenges in maintaining professional boundaries, with some portraying themselves as a "pseudo-member" of the family.  4. It's everybody's business — Small teams meant the ability to rest and relinquish practical and emotional responsibilities were limited. While working in small communities also meant there were risks of prejudging the family, potential breaches of confidentiality, lack of nursing anonymity, and the pressure of being a supportive pillar for the entire community. |
|---|--|
| Data collection<br>Interviews and participant<br>observation<br>Data analysis   | Data collection Semi-structured interviews Data analysis Content analysis and thematic analysis  |
| N = 22 n = 20 female (91%) n = 2 male (9%) Aged 25 and 62 years PC experience ranged from 6 months to 11 years  | N = 10 (No gender details provided) Nursing experience ranged from 15 to 42 years (M = 29.5) Four had PC qualifications, and four had children's experience  |
| Purposeful sampling from inpatient and community-based hospice services   | Purposive sampling from community nursing teams  |
| To demonstrate how hospice nurses perceive stress in their work environment and cope with caring for dying patients   | To highlight challenges perceived by nurses when delivering PC to children and young people (CYP) in the home  |
| McNamara et al., 1995,<br>Australia<br>QR 60%<br>Kappa K = 1.00   | Reid, 2013, UK<br>QR 85%<br>Kappa <i>K</i> = 1.00  |

Table 3. (Continued.)

| Author(s), Date, Country<br>Quality Rating (QR)<br>Inter-rater Reliability<br>(Kappa) | Aim(s)  | Sampling method                                       | Sample characteristics   | Data collection<br>Data analysis   | Main findings with themes  |
|---|---|---|--|--|--|
| Rose and Glass, 2009, 1 Australia QR 90% Kappa K=.706  V                              | To explore nurses' experiences of providing PC with a focus on emotional well-being and its relationship to professional practice | Purposive sampling<br>from community<br>nursing teams | N=15 (All female)<br>No other demographic<br>information provided                    | Data collection<br>Semi-structured interviews and<br>reflective journaling<br>Data analysis<br>Hierarchical content data<br>analysis | Two main themes and four subthemes were identified. Feeling balanced was used to depict nurses' experiences of well-being while the theme Out of balance captured the complexity of feeling emotionally unwell.  1. Feeling balanced — Balance was intrinsically linked to their well-being and their emotional, physical, and spiritual health. It included four subthemes of Being self-aware, Coping, Feeling spiritually enriched, and Settling boundaries.  2. Feeling out of balance — This theme discussed interconnectedness between their emotional, physical, and spiritual selves to describe feeling out of balance. Physical tension, distress sadness, restlessness, and irritability were reported. Mind racing, sleeplessness, and worrying caused ongoing effects leaving some nurses depleted of energy.   |
| Seed and Walton, 2012, 1 USA QR 95% Rappa K=1.00                                      | To gain an understanding of the challenges faced by nurses and to explore how they cope with these challenges                     | Purposive sampling from four hospices                 | N = 12 n = 11 female (92%) n = 1 male (8%) No other demographic information provided | Data collection Semi-structured interviews Data analysis Grounded theory   | The core category was Caring for Self with two supporting categories: Facing the Challenges and Implementing Ways of Coping.  Caring for Self included spirituality, social support, hobbies, having fun outside work, building relationships, and keeping work and home life separate. It also involved nurturing the physical, spiritual, social, and psychological self. Participants talked of healthy self-care practices such as yoga and meditation and the ability to self-soothe and relieve stress, as well as identifying self-care deficits.  Facing the Challenges: All participants expressed difficulty in managing their time effectively. Being drawn into family dynamics and setting boundaries were a challenge for most participants. Many participants stated that setting boundaries is nearly impossible but being aware of stepping over boundaries and knowing when to step back are necessary to prevent burnout and excessive emotional grief.  Implementing ways of coping: Being able to ask team members for help is integral in dealing with burnout and a healthy team, who cares for self, is more able to cope with stress and burnout. Maintaining therapeutic relationships and having formal closure processes after death occurs are vital. If missing, guilt and the additional stress can be a burden. Finally, finding a balance between the multifaceted workplace challenges and personal life stressors was crucial to their own health and well-being. |

| Tunnah et al., 2012, UK QR 95% Kappa <i>K</i> = 1.00 Wilkes et al., 1998, Australia OR 80% | To explore the feelings and experiences of hospice at home nurses when providing palliative nursing care for patients in the community  To describe nurses' personal constructs of stress | Purposive Purposive sampling from community nursing teams  | N= 7 (all female) No other demographic information provided  N= 21 (all female) No other demographic information provided  | Data collection Semi-structured interviews Data analysis Grounded theory  Data collection Open-ended questionnaire and semi-structured interviews. | Four categories were identified:  1. Job satisfaction — Identified as an important determinant of nurses' stress levels.  2. Stressors — Included conflict with colleagues from outside the team and difficulty communicating with GPs and district nurses as sources of stress.  3. Coping strategies — Nurses identified the need to "switch off" after work. Their strategies included walking and exercise, television, music, and craft.  4. Support—Nurses identified support from colleagues as being important for their coping.  Four themes were identified:  1. Lack of control, lack of time — Nurses found it particularly stressful when relationships with families were strained leading   |
|--|---|--|--|--|--|
|  |   | בפק ביים אינים אינ | חסיוומנים אינים אי | semi-surdictured interviews. Data was coded, categorised and themes identified   | to conflict in care. Time was too short due to workload and lead to overload on nurses.  2. Inadequacy/overload — Some nurses felt useless and overloaded. Stress was generated for the nurses by the expectations of many stakeholders including themselves.  3. Inability to cope — Some nurses felt unable to cope. Coping strategies included talking and sharing experiences with another nurse, with the bereavement counselor, with the PC team or reflecting on their experience alone.  4. Lack of knowledge — Some nurses felt they had a lack of knowledge to give proper answers. An overwhelming expectation that caused a number of nurses' stress was the demands of family or client to go beyond what the nurses considered the boundaries of their role, for example, to be a counselor when nurses felt it was beyond their skill.  |
|  | To explore the experiences of intensive care nurses caring for patients who are dying.  | Purposive sampling within ICUs   | N = 10 (No gender details provided) Aged 22 to 32 years. ICU nursing experience ranged from 2 to 12 years.   | Data collection<br>Semi-structured interviews<br>Data analysis<br>Colaizzi's descriptive<br>Phenomenological analysis                              | Analysis identified 13 main themes, categorized into three groups: Nurses' attitudes, Stressors, and Coping strategies.  1. Nurses' attitudes — The most common feelings that emerged from the data analysis were those of fear and guilt. This sense of fear and guilt was coupled with a sense of powerlessness and frustration relating both to nurses' inability to alter the ultimate outcome for patients or take away the family's grief.  2. Stressors — ICU nurses have many diverse demands made on them, which they reported as being stressful. Four themes were identified: the relationship between physician and nurse, family's emotional reactions, concealing illness or prognosis from patients, and do not resuscitate orders.  3. Coping Strategies — ICU nurses are often confronted with stressel in studenting and they must learn to cope and manage stresses in order to function effectively in the ICU setting. Providing good nursing care and religion and beliefs were highlighted in this study. |

Table 4. Main themes and subthemes

| Main theme                     | Subthemes              |
|--------------------------------|------------------------|
| When work becomes personal     | -                      |
| The burden on mind and body    | Emotional impact       |
|                                | Physical impact        |
| Finding meaning and connection | Feeling fulfilled      |
|                                | Connection with others |

"The majority of the participants expressed mixed emotions of sadness, grief and anger when caring for patients who presented with end-of-life issues. One participant explained it as follows: "Guilt, anger... helplessness, because... you want to fix it, but you can't. That's kind of sadness obviously...extreme sadness..."

(Jordan et al., 2014, p. 78)

Rose and Glass (2009, p. 188) highlighted nurses felt "out of balance" as a result of an inability to provide the kind of care they wished to give and the need to maintain high professional and personal standards. This for some led to them feeling "stressed, restless, angry. Not content, not happy not all the things that you wish you were. Very short tempered..." and for others to making "rash decisions that [they] wouldn't do", putting themselves "in the firing line" and even behaving "like [they are] a victim" (Rose and Glass, 2009, p. 189–190). While the emotional impact could lead to feelings of sadness, grief, and anger, positive emotional experiences, such as "the feeling of being needed, appreciated, and confirmed through the caring activities in which they engaged with patients", which could be protective against stress, were also reported (Källström Karlsson et al., 2008, p. 230).

In 9 of the 18 studies, nurses specifically discussed the impact that patients' deaths had on them (McNamara et al., 1995; Källström Karlsson et al., 2008; McCloskey and Taggart, 2010; Bailey et al., 2011; Seed and Walton, 2012; Tunnah et al., 2012; Jordan et al., 2014; Kaup et al., 2016; Chong and Abdullah, 2017). Nurses found it particularly difficult when patients died suddenly and unexpectedly (Källström Karlsson et al., 2008); however, it was also recognized that "... personally facing death was an issue that could not be ignored, but that [they] did get used to the idea of death". (McNamara et al., 1995, p. 233).

Some nurses reported certain patient groups to be more challenging to work with, such as children (Chong and Abdullah, 2017) or mid-life patients (McNamara et al., 1995; Kaup et al., 2016), while others talked about the impact of having close relationships with patients and their families (Bailey et al., 2011). Annette reflected on how a patient's death had affected her:

"I think it is more the emotional side of what happens. You just think [about the loss of life] and because the family told me so much personal stuff [information], you just feel for them so much. You are putting yourself in their shoes so much that it makes you emotional. It was just so rotten." (Bailey et al., 2011, p. 3,367)

Nurses formed close bonds with their patients and reported finding it particularly difficult when "many patients died within a short period or if death came quickly and unexpectedly" (Källström Karlsson et al., 2008, p. 230). In addition, for some nurses, "providing care to children and their families" was identified as presenting them with personal challenges "if [the nurses] are mothers or have close relatives of the same age" (Chong and Abdullah, 2017, p. 128).

Table 5. Summary of paper contribution to each theme

|                                  |                            | The burden on r  | mind and body   | Finding mea       | ning and connection    |
|----------------------------------|----------------------------|------------------|-----------------|-------------------|------------------------|
| Studies                          | When work becomes personal | Emotional impact | Physical impact | Feeling fulfilled | Connection with others |
| Badger (2005)                    | ✓                          | ✓                |                 |                   | ✓                      |
| Bailey et al. (2011)             | ✓                          | 1                |                 |                   | ✓                      |
| Becker et al. (2017)             | ✓                          |                  | 1               |                   |                        |
| Chong and Abdullah (2017)        | ✓                          | 1                | 1               | 1                 | ✓                      |
| Gélinas et al. (2012)            | ✓                          | ✓                |                 | ✓                 | ✓                      |
| Harris (2013)                    |                            | ✓                |                 | 1                 | ✓                      |
| Johansson and Lindahl (2012)     | ✓                          | ✓                |                 | ✓                 |                        |
| Jordan et al. (2014)             | ✓                          | ✓                |                 |                   | ✓                      |
| Källström Karlsson et al. (2008) |                            | 1                |                 | 1                 | ✓                      |
| Kaup et al. (2016)               | ✓                          | 1                | 1               | 1                 | ✓                      |
| McCloskey and Taggart (2010)     | ✓                          | ✓                | ✓               |                   | ✓                      |
| McNamara et al. (1995)           | ✓                          | ✓                | ✓               |                   | ✓                      |
| Reid (2013)                      | ✓                          | 1                |                 | 1                 | ✓                      |
| Rose and Glass (2009)            |                            | ✓                | ✓               | <b>√</b>          |                        |
| Seed and Walton (2012)           | ✓                          | 1                |                 | 1                 | ✓                      |
| Tunnah et al. (2012)             |                            | 1                |                 | 1                 | ✓                      |
| Wilkes et al. (1998)             | ✓                          | <b>✓</b>         | ✓               |                   | ✓                      |
| Yang and Mcilfatrick (2001)      | 1                          | 1                |                 | 1                 |                        |

Two studies also reflected on some of the protective factors against burnout. Seed and Walton (2012, p. E6) identified the "importance of closure.... being able to be there for the death and see death in that moment" was seen as "optimal", while Källström Karlsson et al. (2008, p. 227) highlighted that "being present at the moment of death and taking care of the bodies seemed to result in less anxiety about [the nurses'] own death."

Twelve of the 18 studies (Yang and Mcilfatrick, 2001; Badger, 2005; Källström Karlsson et al., 2008; Rose and Glass, 2009; Bailey et al., 2011; Gélinas et al., 2012; Johansson and Lindahl, 2012; Tunnah et al., 2012; Harris, 2013; Reid, 2013; Jordan et al., 2014; Kaup et al., 2016) discussed nurses' feelings of helplessness when working in complex care systems, within strict medical hierarchies, and when caring for patients who are not expected to recover from their condition. Jordan et al. (2014, p. 78) found that nurses "expressed feelings of helplessness when unable to do more for their patients" and when they engaged in "futile or unnecessary care ... when dealing with end-of-life issues".

Organizational pressures such as staff shortages (Kaup et al., 2016), system failures (Rose and Glass, 2009), and difficulties managing their time (Seed and Walton, 2012) were all mentioned as contributing to increased feelings of helplessness and stress. Stress for some nurses was also linked to a feeling that they were not working in the patients' best interests as were required to keep the diagnosis confidential for cultural reasons connected to a "moral tension that was emerging because they felt uncomfortable with their inability to disclose prognosis" (Yang and Mcilfatrick, 2001, p. 439).

#### Physical impact

Seven of the 18 studies (McNamara et al., 1995; Wilkes et al., 1998; Rose and Glass, 2009; McCloskey and Taggart, 2010; Kaup et al., 2016; Becker et al., 2017; Chong and Abdullah, 2017) discussed how nurses were physically impacted by their work; "Bad deaths however, are problematic as well as physically and emotionally exhausting for those who participate in the nursing care" (McNamara et al., 1995, p. 231). Common symptoms included physical tension, distress, sadness, restlessness and irritability, mind racing and worrying, and sleeplessness (Rose and Glass, 2009).

Physical symptoms of stress were particularly common in studies that looked at nurses working in the community (Wilkes et al., 1998; Rose and Glass, 2009; Kaup et al., 2016; Chong and Abdullah, 2017). Interestingly, some nurses reported the symptoms appeared only before or during certain patient encounters while other symptoms were more chronic and related to stress over a longer time period:

"...[nurses] described symptoms such as headache, dizziness, and stomach pain. Sometimes the symptoms appeared only in certain encounters; for example, stomach pain might occur on [a nurses] way to a specific patient where the participant knew it could be difficult. Other symptoms were more long lasting and were often related to stress over a longer period."

(Kaup et al., 2016, p. 567)

Further, Wilkes et al.'s (1998) participants reported that physical symptoms of stress and tension they experienced were a combination of work and home life stress.

## Finding meaning and connection

The main theme *Finding meaning and connection* is concerned with how nurses cope with PC work. Despite the work being emotionally demanding, it was common for nurses to want to reflect

on and find personal meaning in their roles rather than to distance themselves from it. Within this theme, two subthemes were identified, *Feeling fulfilled* and *Connection with others*.

#### Feeling fulfilled

Eleven of the 18 studies considered how nurses found meaning and reward in their work, giving them a sense of satisfaction and reward (Yang and Mcilfatrick, 2001; Källström Karlsson et al., 2008; Rose and Glass, 2009; Gélinas et al., 2012; Johansson and Lindahl, 2012; Seed and Walton, 2012; Tunnah et al., 2012; Harris, 2013; Reid, 2013; Kaup et al., 2016; Chong and Abdullah, 2017). Nurses' descriptions included their work being a privilege (Johansson et al., 2012; Tunnah et al., 2012), being professionally rewarding, and giving them a sense of satisfaction (Seed and Walton, 2012; Tunnah et al., 2012; Harris, 2013; Reid, 2013; Kaup et al., 2016).

PC nurses identified that job satisfaction came from feeling as thought they had made a difference; "If you can nurse someone at home and make them as comfortable as possible in their last days of life, it's a privilege to do it ... it's well worth everything you do." (Tunnah et al., 2012, p. 286). Nurses acknowledged that PC work is challenging, personally and professionally; however they felt it was rewarding to deliver care during such a private, personal, and devastating time: "It was a very privileged place to be" (Reid, 2013, p. 544).

Some nurses described being able to deliver care to the best of their ability as providing a sense of satisfaction and gratitude (Johansson and Lindahl, 2012). Others reported gaining strength and meaning in their roles after having affirming experiences and when they felt stimulated in their work (Källström Karlsson et al., 2008).

Several participants mentioned their spirituality and faith as ways of coping with the stress and impact of a patient's death. These seemed to enable some nurses to find a deeper meaning in their work that connected with their sense of faith. This is highlighted by one of Harris's (2013) participants who stated "it takes more of a toll than I think we know. You have to have a good spiritual base to deal with all" (p. 450).

## Connection with others

Fourteen of the 18 studies reported nurses sought the support of other people ("either with another nurse, with the bereavement counsellor, with the palliative care team"; Wilkes et al., 1998, p. 18) to cope with stress and the risk of burnout (McNamara et al., 1995; Wilkes et al., 1998; Badger, 2005; Källström Karlsson et al., 2008; McCloskey and Taggart, 2010; Bailey et al., 2011; Gélinas et al., 2012; Seed and Walton, 2012; Tunnah et al., 2012; Harris, 2013; Reid, 2013; Jordan et al., 2014; Kaup et al., 2016; Chong and Abdullah, 2017). For some nurses, this connection was related to them feeling socially connected to their colleagues at work, while seeking informal support was seen as an important coping strategy. Harris (2013) found that nurses identified talking to colleagues as a key coping strategy, "... the most helpful and most frequently used coping mechanism was talking with and/or venting to others. In particular, members of each of the focus groups reported that they relied most heavily on their coworkers in times of stress" (p. 449). Nurses felt it was important to use informal opportunities, to "chat with my colleague and the district nurses ... make sure we have lunch together in the office so that we can chat" (Tunnah et al., 2012, p. 288), at work to speak openly about their feelings.

Connections with colleagues were seen not just to help with symptoms of stress but were explicitly identified as preventing burnout. Nurses acknowledged that they relied heavily on their peers as a method of preventing burnout; "... the burnout is definitely there with all of us to a point. We all get to that point where I just, I just can't do it, but we bounce back real fast. We have a great team so we just work and talk among each other and help each other out" (Seed and Walton, 2012, p. E5). While colleagues were most commonly mentioned, family relationships and having contact with others outside of work were also reported as protective factors against the impact of nurses' work building up (McNamara et al., 1995; Källström Karlsson et al., 2008; Tunnah et al., 2012; Kaup et al., 2016). The concept of connection with others being a "release" is articulated here by a nurse working in a hospital inpatient setting:

"Stable and functioning family relationships were desirable so that the nurses could regain their strength during their leisure time. Spending time with children and adults outside the family or professional colleagues was understood as a shield against thoughts of death. Meeting other people who were full of life "and talking about something completely different" was like a release."

(Källström Karlsson et al., 2008, p. 288)

Others talked about finding it difficult to get support from outside of work due to the lack of understanding from those who do not work in PC; "Many nurses indicated that they thought people outside of the hospice "system" lacked an understanding of what was involved in caring for the dying" (McNamara et al., 1995, p. 229). Finally, nurses reflected on how their family members often did not want to hear about their work; "Could you change [the] subject?"... "It's depressing.". "Do you have to talk about this over dinner?" (Gélinas et al., 2012, p. 32)

## **Discussion**

This review addressed the question, "What are palliative care nurses' experiences of stress, anxiety and burnout?". Thematic synthesis identified three main themes.

## When work becomes personal

PC nurses described how difficult relationships with a patient's family were seen as potential sources of stress and burnout. Conversely, some nurses with close personal relationships with families also found this to be stressful.

While the current review supports previous findings on the impact of conflict (François et al., 2017), it also highlights how close personal relationships with families contributed to nurses' experience of stress and burnout. Specifically, it extends our understanding of the different ways nurses can be affected by relationships with patient's families, and the importance of supporting nurses to recognize the impact of their professional relationships with patient's families to reduce the potential for increased stress, anxiety, and burnout.

#### The burden on mind and body

PC nurses were emotionally and physically impacted by stress, anxiety, and burnout, experiencing sadness, grief, anger, guilt, frustration, unhappiness, and dissatisfaction with themselves. These findings are consistent with the existing literature (Peters

et al., 2013; Zheng et al., 2018; Powell et al., 2020; Zanatta et al., 2020). Furthermore, these findings are congruent with the work of Figley (1995, 2002) exploring stress and compassion fatigue as seen in nurses supporting patients suffering traumatic events. However, this review also highlighted how positive experiences can moderate stress, anxiety, and burnout which has been seen as a limitation of Figley's original model (Sabo, 2011).

Feelings of helplessness were reported in many of the current review's studies. These feelings were related to clinical, personal, and organizational issues and contributed to nurses' stress levels were also highlighted. This finding is supported by Powell et al. (2020) whose systematic literature review also found personal factors and organizational workload pressures to be key factors in PC nurses' stress levels.

Nurses in the current review described how patients' deaths affected them in deeply personal ways. This could be due to several factors including nurses' relationships with patients due to the patient's age, cultural background, or when patients suddenly and unexpectedly died. These findings are supported by Malone et al.'s (2016) systematic literature review which identified that patient factors, such as age and cultural background, can impact on how nurses cope with patients' deaths; however, their review was only looking at newly graduated nurses in PC.

Nurses also experienced physical symptoms of stress, anxiety, and burnout. Nurses consistently reported sleep difficulties, with tension and headaches common. This impacted them in several ways, including at home and work, with some nurses reported not being able to concentrate, feeling agitated, and unbalanced. These findings support Baqeas and Rayan's (2018) that PC nurses' sleep and physical well-being are significantly impacted by their work.

## Finding meaning and connection

Nurses' feelings of fulfillment and connection with others for support were discussed in relation to whether they experienced work to be stressful or not. Where nurses reported feeling fulfilled, a sense of satisfaction and pride in their work, they also talked about how this made the challenge of PC work worthwhile. Nurses also reported finding meaning in their spirituality and religion in six of the studies. A recent systematic review by Sekse et al. (2018), looking at nurses' roles in PC, found that feelings of fulfillment were present when nurses felt they were able to be "attentively present and dedicated" (Sekse et al., 2018, p. 33).

Nurses found seeking support from family and their colleagues helped them cope. Nurses identified that open and honest conversations about the impact of their work were important in reducing stress in the short-term and burnout in the longer-term. Spending time with others unconnected to their work was also important in helping them cope. This is consistent with other systematic reviews in PC nursing which have identified nurses' need to express their emotional responses to others, whether with colleagues, friends, or family (Powell et al., 2020; Zanatta et al., 2020).

#### Limitations

Efforts to synthesize findings meant trying to find a balance in papers' inclusion and exclusion decisions, given PC's definition in research varies depending on the workplace setting. While all participants were nurses engaged in providing PC as part of their main role, the homogeneity of participants should be considered when interpreting the review's conclusions. For example,

participants were recruited from inpatient, hospices, and community settings, and from countries with acknowledged cultural differences in attitudes to PC. Additionally, the search terms "compassion fatigue" and "secondary traumatic stress" were not included. These related concepts are well established in hospice and PC literature (Melvin, 2015) and their omission limits the search results and findings.

#### Clinical policy and practice implications

Findings from this review support and further demonstrate the complexity of feelings PC nurses have about their role, which may help both nurses and services take action to mediate against nurses' experiences of stress, anxiety, and burnout. The findings may also help expand our understanding of how patient deaths impact PC nurses and how to better support them in this critical aspect of their work. Two main policy and practice implications were identified within the reviewed studies: greater staff support and more relevant learning and development opportunities.

Harris (2013) highlighted that having someone to talk to would be beneficial on a particularly stressful or painful day or when nurses experienced loss. Similarly, staff support groups that were not specific to grief alone were "facilitated by someone outside of hospice" and having their content kept "confidential" would be welcome (Harris, 2013, p. 451). These findings are broadly consistent with research that has identified greater access to social support as protective against occupational stress in healthcare workers (Ta'an et al., 2020).

Seed and Walton (2012) suggested that nurse managers should regularly assess the stress and coping ability of their teams, to ensure nurses have/receive unscheduled time off because of undue stress and working with difficult families. Tunnah et al. (2012) similarly identified the need for further use of clinical supervision and reflection.

Further, staff training has been highlighted to support nurses having greater clarity on how to respond to challenging care situations as well as improving their abilities to identify stress and recognize their own emotional needs. This could include meaning-based reflective practice sessions which have been associated with greater self-awareness and less burnout in other healthcare professional groups (Heath et al., 2020). Finally, Becker et al. (2017) suggested training staff to better communicate with families regarding helpful and harmful care during the end of life.

# Further research

Research is needed to gain a more nuanced understanding of how PC nurses are affected by their work. For example, through exploring the experiences of nurses with a longer tenure working in PC, or by the use of longitudinal studies evaluating the emotional and physical impact of PC work. Finally, further studies could focus on helping education providers and employers better understand their role in training and staff support, for example when preparing newly qualified nurses who choose to work in PC.

Furthermore, recruitment of more diverse participant samples and reporting of relevant participant demographics could widen the range of views and experiences within the literature. Discussion of the relationship between researchers and participants and any conflicts, or potential bias, should also be included. Finally, research should be undertaken using appropriate research methods with clear reporting in methodological sections. Addressing these issues would improve the quality, replicability, and validity of research findings.

#### Conclusion

The current review explored PC nurses' experiences of stress, anxiety, and burnout. Three main themes were identified which suggest that PC nurses' experiences are complex, encompassing clinical and organizational challenges, and the personal impact their work has on them. The findings of this review highlighted that nurses' relationships with patients, patients' families, and colleagues, can be both a source of stress and strength. While many nurses describe their work as difficult, they also find it personally and professionally rewarding.

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