Care about care for healthcare professionals providing palliative care

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CARE ABOUT
CARE FOR HEALTHCARE PROFESSIONALS
PROVIDING PALLIATIVE CARE

Anne-Floor Dijxhoorn

Care about care for healthcare professionals providing palliative care

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Care about
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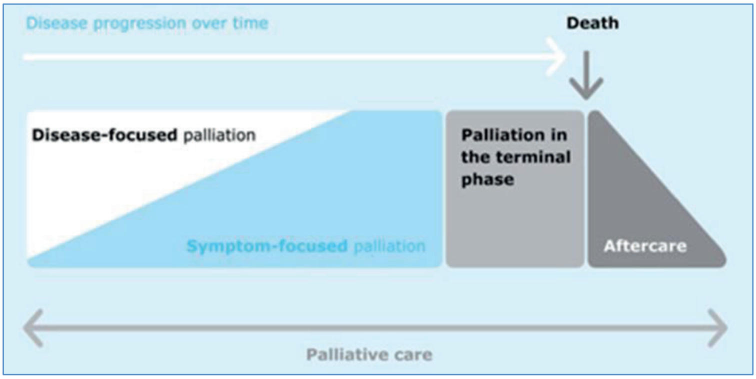
1

General introduction

Palliative care

Palliative care is an approach that aims to improve the quality of life of patients with a life-threatening condition or frailty and their family, through the prevention and relief of suffering. This is done by early identification, assessment and treatment of physical, psychological, social and spiritual problems.[1] The intention of palliative care is neither to hasten nor postpone death, but to accept dying as a normal process. It intends to offer a support system to help patients and their family.[2]

Figure 1 Disease trajectory based on the model of Palliative Care by Lynn and Adamson[3]



Palliative care is associated with better quality of life and lower symptom burden. It can and should be initiated early in the course of a life-threatening condition, along with therapies aimed at prolonging life (see figure 1). In practice, this means that, in addition to treatment of the life-threatening condition, conversations should take place about the wishes of patients in future situations. Such advance care planning as a part of palliative care helps patients to define their goals and preferences for future medical treatment and care and address their physical, psychological, social and spiritual concerns.[4] The use of advance care planning is associated with less unwanted hospitalisations, increased end-of-care discussions between patient and healthcare professionals, and increased compliance with patient wishes.[5,6]

In the Netherlands, palliative care is organised within a combined model of generalist and specialist palliative care. In this model, the primary palliative care needs are met by all healthcare professionals involved such as the primary care physician, home care nurses, treating medical specialist or other involved healthcare professionals with basic palliative care training and often few patients in need of palliative care. When more complex palliative care needs arise, generalist healthcare professionals can consult palliative care specialists. Palliative care specialists are trained in more complicated palliative care and provide palliative care as a substantial part of their work.[1] However, it is known that a significant part of healthcare professionals feel inadequately equipped to provide generalist palliative care.[7,8] In addition, training in palliative care is not yet standard part of the basic curricula of Dutch medical faculties and a Dutch study among final-year medical students shows that almost two thirds (59,6%) did not feel confident in providing generalist palliative care.[9,10] Also in Dutch nursing schools education in generalist palliative care is insufficiently provided with only in 17% of nursing schools providing mandatory palliative care courses.[11]

To improve the availability and access to high-quality palliative care in a generalist-specialist palliative care model, in 2017 the Netherlands Quality Framework for Palliative Care was launched.[1,12] This integration of generalist palliative care into the total care for patients with a life-threatening disease is important as research has shown that timely access to palliative care is associated with positive effects on quality of life, symptom burden and potentially inappropriate end-of-life care. The landmark publication of Temel and colleagues in the NJEM marked the start of a number of publications on randomized controlled trials showing the benefit of palliative care on the quality of life among cancer patients.[13] Several reviews and meta-analyses in this regard show better quality of life and lower symptom burden in patients who have received palliative care compared with patients who had received usual care.[14-17] Patients with an incurable illness other than cancer, such as heart failure, chronic obstructive pulmonary disease, or dementia, also benefit from palliative care as this is associated with reduced emergency department use, fewer hospitalisations and slightly lower symptom burden compared with receiving usual care.[18] There are no similar studies performed in the Netherlands. In Belgium, which has a similar healthcare system as the Netherlands, a randomised controlled trial among patients with advanced cancer showed that early integration of palliative care improved patient's quality of life.[19] Although there are no Dutch randomised trials, other research in the Netherlands has also found benefits for patients who received palliative care. A questionnaire study among relatives of cancer patients who died in a single Dutch hospital showed positive results of the use of the hospitals specialist palliative care teams.[20] Relatives reported significantly less pain and fatigue in patients for whom the specialist palliative care team was consulted. They also rated the quality of dying as higher when the specialist palliative care team was involved compared to cancer patients in the same hospital for whom the team was not consulted. Providing palliative care in the primary care setting is also associated with positive results. In 2010, PaTz groups (palliative care at home groups based on the Gold Standards Framework) were introduced in the Netherlands. In these groups, community nurses and general practitioners hold structural interprofessional meetings with support of a palliative care specialist (clinician with formal training and experience in palliative care) to identify and discuss patients with palliative care needs. Observational research in 37 PaTz groups showed that for 188 patients who were included in the PaTz register their preferred place of death was more likely to be known and that these patients more often had conversations on life expectancy, physical complaints, existential issues and possibilities of palliative care than patients who were not included.[21] Additionally, a retrospective, population-based study of more than 43,000 patients showed that cancer patients who received palliative care before the last month of life were substantially less likely to receive potentially inappropriate end-of-life care, such as admission to intensive care in the last month of life or to die in the hospital.[22] For most of these patients, the received palliative care probably consisted of mostly generalist palliative care.

Growing demand for palliative care

Worldwide the number of older people and their proportion in the population is expected to increase in the coming decades.[23,24] By 2050, one in six people in the world will be 65 years or older.[24] The number of people with chronic diseases and multimorbidity is also expected to increase over the next two decades.[23] Likewise, globally the number of people with cancer is rapidly growing from 19.3 million in 2020 to an estimated 28.4 million by 2040, an increase of 47%.[25] This increase in the number of people living with long disease courses, complex symptoms or frailty will lead to an increase in palliative care needs in populations in the near future.[23,26]

This growing demand for palliative care also applies to the Netherlands. In 2019, there were 1.4 million people over the age of 75 in the Netherlands, by 2040 there will be approximately 2.6 million, an increase of 86%. The number of people aged 90 and over is expected to increase by 151% to 318,000 by 2040.[27] Furthermore, the number of people with multiple chronic conditions will increase by about 21%, from 5.4 million in 2018 to approximately 6.5 million in 2040. The number of deaths caused by dementia are expected to increase by 154% over these years, and the number of deaths from cancer is expected to increase from almost 46.000 people in 2019 to more than 54,000 in 2032.[27,28]

These changes in the age structure and the increase of chronic and life-threatening diseases in the Dutch population will have an impact on the healthcare. The aging of the population will lead to an increase in the use of healthcare services and in mortality. In addition, with the higher proportion of people with chronic diseases, there will be a further shift from acute mortality (sudden deaths) to expected mortality (anticipated deaths), meaning patients living longer with life-threatening diseases, and following, with it the demand for palliative care will rise.[29] In the Netherlands it is estimated that approximately 70% of all people who die require palliative care.[30] Palliative care will increasingly involve patients with multimorbidity and multiple complex care needs, which will not only have a physical impact on patients, but also has consequences for their psychological, social and spiritual wellbeing. And it will affect those around the patient: their family, friends, social network, and the involved healthcare professionals.

The importance of healthy healthcare professionals

Many European countries are currently facing a shortage of healthcare workers.[31] For the countries in the European Union this shortage is expected to increase over the next decade, mainly due to a shortage of nurses.[32] Several calculations for the Netherlands also all predict a shortage of healthcare professionals in the coming years, although the extent of the predicted shortage varies. A recent study commissioned by the Dutch Ministry of Health, Welfare and Sports predicts a shortage of healthcare professionals of almost 138,000 persons by 2031.[33] Categorized by healthcare setting, the greatest shortages will be in nursing homes. Categorized by profession, the biggest shortage will be among nurses and nursing assistants. The Dutch Nurses' Association (Verpleegkundigen & Verzorgenden Nederland /V&VN) has even calculated that up to 2025 around 125,000 additional nurses and nursing assistants will be needed to meet the expected demand for care.[34] Currently, 1 in 6 employees in the Netherlands works in healthcare. If we leave our policies unchanged, by 2040, 1 in 4 employees will have to work in the healthcare sector to meet the demand for care.[35]

Reasons that might contribute to this current and forecasted workforce shortage include:

1) ageing of the current workforce,
2) low inflow and retention of new healthcare professionals, and
3) outflow and dropout due to high work-related stress.[31, 36]

With regard to the ageing workforce, the WHO has calculated that in 2020, in all WHO regions combined, the median proportion of medical doctors and nurses aged 55 and older was 30% and 18% respectively. In the Netherlands, this was roughly 25% (in 2019) and 22% (in 2016) respectively.[31] This means that in the coming decade, around a quarter of the current physicians and nurses in the Netherlands will retire.

At the same time, too few healthcare professionals are entering the healthcare workforce to replace these retiring healthcare professionals. The WHO reports that the nursing workforce in the American and European regions is relatively old and that an increase in the number of nursing graduates is necessary.[37] To address the nursing shortage by 2030, the total number of nursing graduates in Europe will need to increase by at least 7% per year on average.[37] At the same time in the Netherlands the number of applications for nursing education dropped by 15% in 2022 compared to the previous year.[38,39] Additionally, the eight Dutch medical schools received fewer applications in 2023 for the second year in a row.[40] Even if the absolute number of new healthcare professionals were to remain the same (instead of declining as it has in recent years), it would still be insufficient to meet the increasing demand for care.

Another problem regarding inflow of young healthcare professionals is the high dropout rate among resident/junior physicians, nurse students and novice nurses. An international indication of novice nurse turnover is difficult to provide, since there are few, up-to-date, figures on this topic. For the Netherlands it is reported that in 2021 dropout of nursing students after one year was 12% and after three years was 15%.[41] Furthermore, Kox et al stated that after one year roughly 10% of novice nurses no longer work in the field of nursing.[42] Dropout from nursing education in the Netherlands is due to, among other reasons, a mismatch between expectations about their future work and reality.[43] For example, former nursing students interviewed in this study mentioned that they felt there was little attention paid to the individual needs of patients. Other reasons for dropping out were a lack of psychological support and not feeling safe during the clinical placements.[43] Another Dutch qualitative interview study among nurses who left the nursing profession within two years after their graduation suggests that reasons for leaving included a lack of perceived competence and lack of job satisfaction.[42] The nurses in this study felt that the workload was heavy, work requirements were excessive and that there was little or no support from experienced colleagues as a result of staff shortages. A study among nursing students and novice nurses on their experiences with providing palliative care shows that participants felt insufficiently prepared to provide palliative care and that confrontation with patients in need of palliative care had a great emotional impact on them.[44] A questionnaire in 2022 among resident physicians shows that 44% experience the workload as too high and 35% are (very) dissatisfied with their work-life balance. Almost a quarter (24%) of resident physicians had burnout related symptoms, which is an increase of 10% compared to 2020.[45] The most reported causes for burnout symptoms were work-life balance (41%) and work-related issues (35%). The number of resident physicians that considers quitting their training is 26%.

Not only novice healthcare professionals consider leaving their jobs. Dissatisfaction among healthcare professionals in general about their work is common and organisations have difficulties retaining healthcare professionals. A survey including nurses in ten European countries showed that overall 9% of nurses intent to leave their profession, in the Netherlands this was relatively low with 5% of nurses.[46] A study among nursing assistants and registered nurses working in nursing homes in France showed that 27% of nursing assistants wanted to leave their work with the elderly.[47] An integrated review reported a range of 12% to 22% of physicians having an intention to leave direct patient care within five years.[48] A recurrent survey among healthcare professionals shows that workload and emotional strain have increased over time.[49] In 2019, 48% of all healthcare professionals considered their workload to be (much) too high. Absenteeism in the healthcare sector has been on average 1.5 points higher than in the economy as a whole for years, but has even increased more sharply since 2014 in particular.[50]

Overall, the growing and changing demand for care on the one hand, and the low inflow and high numbers of drop out on the other hand, are reinforcing the growing shortage of healthcare professionals and increasing work pressure. Therefore, attention must be paid to the recruitment of new and retention of current healthcare professionals and how to support them to maintain balanced in such a demanding profession.

Work-related stress and burnout in healthcare professionals

One of the reasons for dropout among healthcare professionals is related to the physical and mental work-related stress. Healthcare professionals are known to be exposed to various work-related stressors. These stressors may have an occupational nature, such as high workload, long working hours, high administrative burden, and a low sense of control over the work environment.[51-54] In addition, healthcare professionals often also experience psychosocial stressors such as moral distress, the feeling of providing futile or potentially inappropriate care, and the need to cope with death and the pain and suffering of patients and their families.[51, 55-58]

Persistent work-related stress can result into dissatisfaction with work and eventually in burnout. The concept of burnout was first described in the 1970s. It was explained as a construct related to individuals working within the human services consisting of emotional exhaustion, depersonalization, and reduced personal accomplishment.[59] There is currently no widely accepted definition, but there are some principles on which there seems to be agreement. For instance, the idea of burnout being solely a condition that can occur among employees in the human services sector has been abandoned.[60] It is also generally accepted that job stressors are an important cause for the development of burnout symptoms.[60] The World Health Organization has included burnout in the International Categorization of Diseases (IDC-11) as an occupational phenomenon and is defined as follows:

"Burn-out is a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed. It is characterized by three dimensions:

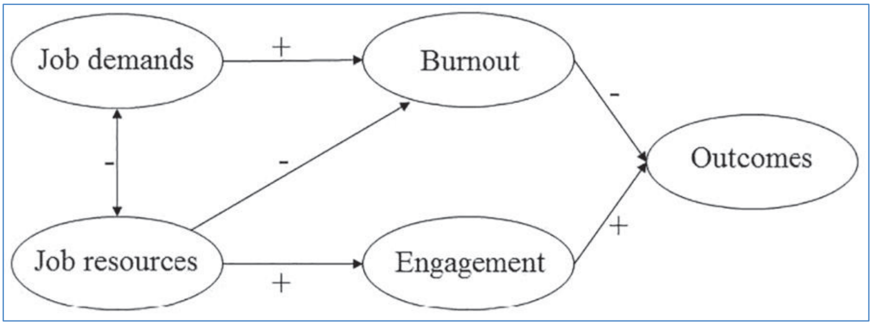
- *feelings of energy depletion or exhaustion;*
- *increased mental distance from one's job, or feelings of negativism or cynicism related to one's job; and*
- *reduced professional efficacy.*

Burn-out refers specifically to phenomena in the occupational context and should not be applied to describe experiences in other areas of life".[61]

The developments above show that after 50 years the three original dimensions of burnout (exhaustion, depersonalization and reduced accomplishment) are still, in a slightly different form, endorsed as exemplifying burnout.

A frequently used theory for the development of burnout is the Job Demand-Resources (JD-R) model (Figure 2).[60] This model suggests two processes that lead to the development of burnout. there are physical, social, or organisational aspects of the job that on the one hand are associated with physiological and psychological costs, these are the job demands. On the other hand, there these aspects of the job may help achieve work goals, help reduce the aforementioned costs or stimulate personal growth and development, these are the job resources. High job demands is positively related to exhaustion and a lack of resources has been associated with withdrawal behaviour and can therefore play a role in the development of burnout.[60]

Figure 2 Job Demands-Resources Model



Work-related stress and burnout in palliative care

To provide high quality palliative care as described in the Netherlands Quality Framework for Palliative Care, it is important to be aware of the emotional impact that providing palliative care can have on healthcare professionals. The expert panel, consisting of patient representatives and healthcare professionals, that developed the Netherlands Quality Framework for Palliative Care felt it was so important that the emotional impact of providing palliative care was included in the first domain of the framework; core values and principles, which serves as the basis for all subsequent domain.[1]

Healthcare professionals who provide palliative care are often exposed to (unbearable) suffering of the dying patient and grieving relatives. Repeated exposure to death and dying, complicated symptom management, emotionally demanding conversations about end-of-life care, and inadequate coping with the loss of a patient are considered as risk factors for the development of work-related stress and burnout related to providing palliative care.[62-66] On the other hand, other aspects of providing palliative care such as contributing to a good death, a deep sense of personal reward, personal growth, and a conscious choice to provide palliative care, may have a protective effect on the emotional well-being of healthcare professionals.[54,63,67] The balance between the additional exposure to work-related stress and the rewarding nature of providing care remains unclear, as do the personality traits of healthcare professionals who choose a career in palliative care. However, the question is to what extent healthcare professionals consciously and voluntarily choose to provide palliative care. Due to the integrated generalist-specialist palliative care model in the Netherlands all healthcare professionals are expected to provide generalist palliative care, making the idea of providing palliative care being a conscious choice unlikely.

Aims and outline of this thesis

The overall aim of this thesis is to gain more insight into the emotional impact of providing palliative care on healthcare professionals in the Netherlands. Furthermore, we aim to explore the strategies and needs of healthcare professionals in maintaining or regaining emotional stability while providing palliative care.

To achieve these aims, the following research questions are addressed:

- What are the rates of burnout among healthcare professionals providing palliative care and what are the effects of interventions to reduce symptoms of burnout among healthcare professionals providing palliative care?

- How is the emotional impact of providing palliative care experienced by Dutch healthcare professionals?
- What are the experiences regarding work-related stress among healthcare professionals providing palliative care in the Netherlands and what are their strategies and needs in relation to maintaining a healthy work-life balance?
- Can a Peer Support program be an effective instrument to help healthcare professionals deal with the emotional impact of their work?

Outline

Chapter 2 presents the outcome of a systematic literature review on the prevalence of burnout among healthcare professionals providing palliative care and reports on the effects of interventions aimed at addressing burnout symptoms in this population.

Chapter 3 reports a cross-sectional online survey on work-related stress among healthcare professionals providing palliative care in the Netherlands and addresses both their current strategies and needs in relation to maintain a healthy work-life balance.

Chapter 4 and 5 explore the experiences and perceptions of Dutch healthcare professionals on the emotional impact of providing palliative care, the strategies they use in dealing with the emotional impact and their needs regarding this. The results stemming from qualitative interview studies with physicians and nurses, both palliative care generalists and specialists, (**Chapter 4**) and with nurse assistants (**Chapter 5**).

Chapter 6 describes a pilot intervention study to assess the feasibility and applicability of a Peer Support Program to support healthcare professionals who provide palliative care in their personal wellbeing.

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2

Prevalence of burnout in healthcare professionals providing palliative care and the effect of interventions to reduce symptoms: A systematic literature review

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ABSTRACT

Background

In recent years there has been increasing attention for the prevalence and prevention of burnout among healthcare professionals. There is unclarity about prevalence of burnout in healthcare professionals providing palliative care and little is known about effective interventions in this area.

Aim

To investigate the prevalence of (symptoms of) burnout in healthcare professionals providing palliative care and what interventions may reduce symptoms of burnout in this population.

Design

A systematic literature review based on criteria of the PRISMA statement was performed on prevalence of burnout in healthcare professionals providing palliative care and interventions aimed at preventing burnout.

Data sources

PubMed, PsycInfo and CINAHL were searched for studies published from 2008-2020. Quality of the studies was assessed using the method of Hawkers for systematically reviewing research.

Results

In total 59 studies were included. Burnout among healthcare professionals providing palliative care ranged from 3%-66%. No major differences in prevalence were found between nurses and physicians. Healthcare professionals providing palliative care in general settings experience more symptoms of burnout than those in specialised palliative care settings. Ten studies reported on the effects of interventions aimed at preventing burnout. Reduction of one or more symptoms of burnout after the intervention was reported in six studies which were aimed at learning meditation, improving communication skills, peer-coaching and art-therapy based supervision.

Conclusions

The range of burnout among healthcare professionals providing palliative care varies widely. Interventions based on meditation, communication training, peer-coaching and art-therapy based supervision have positive effects but long-term outcomes are not known yet.

INTRODUCTION

Being a healthcare professional is demanding and often leads to work-related stress.[1] Persistent work-related stress can ultimately result into burnout.[2,3] Burnout consists of three core aspects: emotional exhaustion, depersonalisation and feelings of reduced personal accomplishment. It is seen as a complex process that develops gradually ranging from absence of symptoms into mild and eventually severe symptoms of burnout.[4,5]

It is known that burnout is common in healthcare professionals and often is higher than burnout in the general population. Shanafelt and colleagues showed a significant increase in symptoms of burnout among physicians in the U.S. from 45.5% in 2011 to 54.4% in 2014, whilst burnout among the general population remained similar over the years (28.4% vs. 28.6%).[6] A meta-analysis of Zhang et al. on the prevalence of burnout among nurses working in various departments, such as neurology, psychiatry, gynaecology and oncology, found a burnout rate of 58.6%.[7]

In recent years there has been increasing attention for (symptoms of) burnout among healthcare professionals for several reasons. Symptoms of burnout not only affect personal well-being of staff, but are also associated with poor quality of patient care and increases the risk of making mistakes.[8-11] Furthermore, healthcare organisations are impacted by burnout due to increased absenteeism and increased intention to quit employment, resulting in shortage of staff and extra workload for those remaining. On a macro level, there is an increasing problem of shortages of healthcare professionals and due to the ageing population the demand on healthcare is likely to increase.[12,13] Drop out of healthcare professionals cannot be afforded in this time of staff shortage. As preventing burnout in healthcare professionals is essential to maintain good quality of care various interventions to prevent (symptoms) of burnout in healthcare professionals have been developed, such as meditation and mindfulness, communications skills training and selfcare efforts.[14] These interventions have shown to have a positive effect on symptoms of burnout.[15]

Little is known about the impact of providing palliative care on the development of symptoms of burnout in healthcare professionals. There are various ideas regarding the relation between providing palliative care and the development of burnout. On the one hand, some aspects of providing palliative care, such as repeated exposure to death and dying, complicated symptom management, difficulties in communication with patient and families, and inadequate coping with one's own emotional response to the loss of patients are seen as risk factors for the development of burnout.[16-18,] On the other hand, it is thought that other aspects of palliative care such as being able to contribute to the quality of life and a good death, profound personal rewards, and personal growth can have a protective effect on the healthcare professional regarding the development of burnout.[19, 20] The study of Dougherty et al. showed that staff who deliberately decided to work in palliative care had significantly lower perceived stress compared to colleagues for whom this was not a conscious choice.[21] Possibly, interventions especially designed for healthcare professionals who provide palliative care are needed to address the specific challenges of providing care to incurable and terminally ill patients.

In recent years studies have been conducted into the prevalence of burnout among healthcare professionals working in different specialised palliative care settings, mainly in Europe, the United States and Asia.[22-24] These literature reviews focused on the prevalence of burnout in specialised palliative care healthcare professionals only, they did not investigate possible effective interventions and included studies until 2015. Therefore an updated synthesis of the current literature on 1) the prevalence of burnout in healthcare professionals providing palliative care and on 2) interventions to reduce early symptoms of burnout is necessary. Especially in the light of the growing shortage of healthcare professionals it is of importance to have a clear understanding of the risk of (symptoms of) burnout in this group and into preventive interventions. The aim of this systematic literature review is to provide an up-to-date overview of burnout rates among healthcare professionals providing palliative care and of interventions on reducing their burnout symptoms.

METHODS

We conducted a narrative systematic literature review on quantitative research and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[25] The objective of this review was to answer to following questions:

1) What are the burnout rates among healthcare professionals providing palliative care
2) What are the effects of interventions on reducing burnout among healthcare professionals providing palliative care.

Search strategy

An electronic search of the databases PubMed, PsycInfo, and CINAHL was performed to identify studies about the prevalence of burnout among healthcare professionals providing palliative care and interventions to reduce the symptoms of burnout that were published in English or Dutch between January 2008 and April 2020. A search strategy was developed for finding relevant studies in electronic literature databases. The computerised search was conducted to find studies on burnout in healthcare professionals providing palliative care including the following key constructs: 'burnout', 'palliative care', and 'healthcare professional'. Palliative care was operationalised using a standardised search procedure for palliative care developed by Rietjens et al.[26] The complete search string of all keywords and MeSH terms can be found in supplement 1. The search string was initially developed for PubMed and later adapted for the other databases. Additionally, the reference lists of selected articles were screened to retrieve additional relevant publications which had not been found in the computerised search. The focus of this review was on studies among healthcare professionals providing palliative care and not only specialists in palliative care in order to also include those healthcare professionals who take care of patients with life-threatening illness but may not necessarily have received a training in this area.

Selection process

A stepwise procedure was used to select all relevant studies. Titles and abstracts were screened by one reviewer (AD) using the following predetermined criteria: (i) target population of the study includes healthcare professionals working with adult human patients, (ii) area of study is palliative care, (iii) subject of the study includes burnout, (iv) quantitative research, (v) full-text article should be written in English or Dutch. Duplicates and studies published before 2008 were excluded. The title and abstracts of the remaining potential relevant studies were assessed by two reviewers (AD and NR) to include quantitative studies and exclude systematic literature reviews. Studies had to report on the prevalence of burnout in healthcare professionals providing palliative care and/or the effects of burnout interventions for healthcare professionals in palliative care. Healthcare professionals providing palliative care include those working in fields of non-acute care in which it is common that patients die due to life threatening illness and frailty. Articles referring to terms such as palliative care, end of life care and terminally/critically ill patients in their research were included. Titles were discussed until consensus was reached. Reasons for exclusion were listed for all studies that did not pass the selection process (flowchart figure 1). All remaining (potential relevant) studies were full text screened (AD) for which again the aforementioned criteria were used.

Data extraction

Appropriate information for data abstraction was determined based on the research question using a standard extraction form. For each included study the following details were abstracted: country of research, participant characteristics, setting, study design, used measurements including cut-off scores, relevant results (prevalence rates of burnout, effects of interventions on burnout) and conclusions. Type of intervention and effects were also registered for intervention studies. Results of the studies were reported in a descriptive manner. All the relevant outcome measures were described in tables.

Quality assessment

Methodological quality of the included studies was established using the quality assessment tool developed by Hawker et al.[27] This tool consists of nine questions and is rated on a four-point scale from 4 (good) to 1 (very poor), total range 9-36. Scores were categorised into three groups: very poor to poor (9-17), poor to fair (18-26) and fair to good (27 to 36). The nine topics are as follows: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalizability, implications and usefulness.

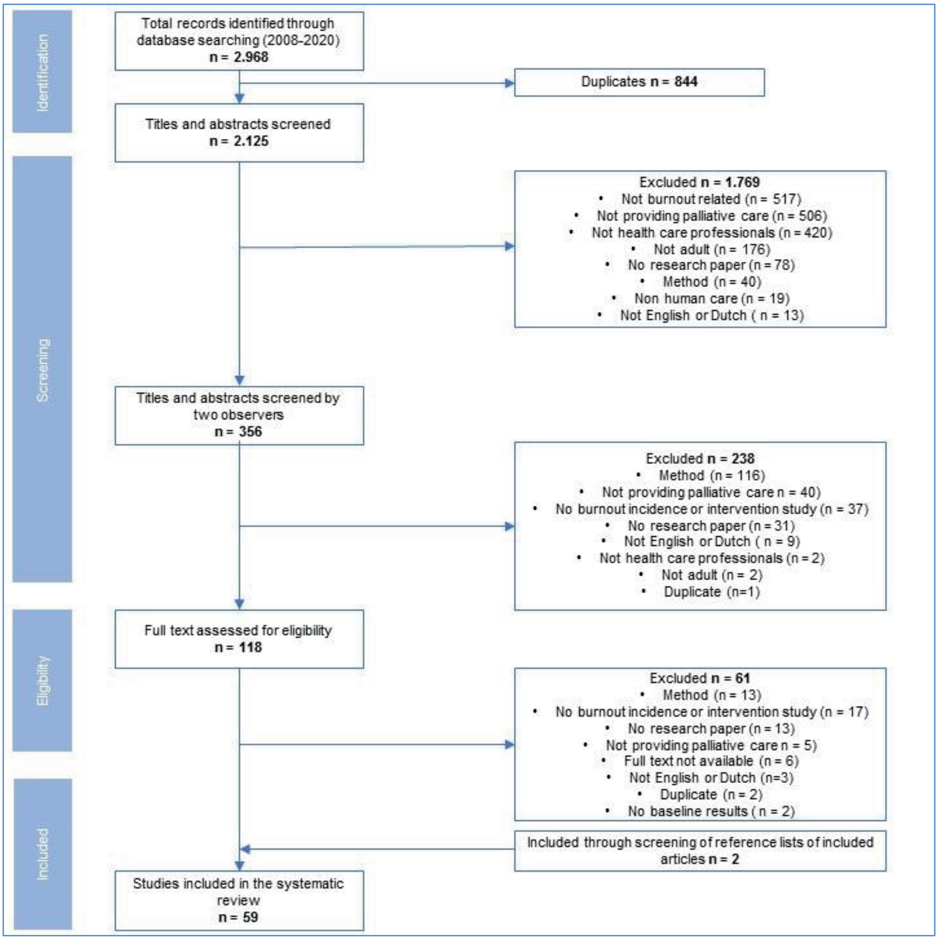
To guarantee uniformity in the quality assessment, the methodological quality of six studies was assessed by both reviewers (AD and NR). Results of the reviewers were compared and discussed. This procedure was repeated three times. After 12 studies, the interobserver reliability was good, both assessors scored the quality comparable. After that, one researcher assessed the quality of the remaining studies. In case of doubt the quality of the paper was discussed with the second reviewer until consensus was reached.

RESULTS

Study selection

In total, 2.968 studies were identified after the electronic search (see figure 1). After removing the duplicates, 2.125 articles remained for screening. Based on the title 1.769 articles were excluded as not being relevant for this research. The abstracts of the remaining 356 studies were assessed on relevance by two reviewers (NR and AD) and 238 were excluded based on the abstract. In total, 118 studies were full text articles assessed for eligibility and 57 studies were included. Main reasons for excluding the 61 studies were: no information present on burnout prevalence or effect of interventions (n=18), qualitative studies (n=13), no research paper (n=13) and not addressing professionals who provide palliative care (n=5). A manual search of the reference lists of all 57 included studies was conducted, resulting in two extra studies. In total, 59 studies were included in this systematic literature review.

Figure 1 PRISMA flowchart



Study characteristics

In total, 13.845 participants were included and the number of participants ranged from 17 to 1.156 participants. The included studies were conducted in North America (United States of America (n=19), Canada (n=3)), Europe (Portugal (n=6), Spain (n=5), Italy (n=1), Czech Republic, France, Germany, United Kingdom, Poland, Romania (all n=1)), Asia (Japan (n=3), China (n=2), Hong Kong, India, Singapore (all n=1)), Oceania (Australia (n=3), New Zealand (n=2)), Central and South America (Brazil (n=2), Mexico (n=1)), South Africa (n=2) and Israel (n=1). Quality of the papers was assessed as ‘fair’ to ‘good’ in 29 papers.[21, 28-55] Thirty studies were rated ‘poor’ to ‘fair’.[56-85] Ten studies were intervention studies, the quality of seven of these was assessed between ‘poor’ to ‘fair’. Studies were conducted mostly in hospitals, hospices and in palliative care teams. Most participants were physicians and nurses, but also research containing other healthcare professionals such as social workers and chaplains and others such as volunteers were included.

Instruments to detect symptoms of burnout

All 59 included studies reported on the prevalence of burnout in healthcare professionals providing palliative care, mainly measured by two validated instruments. Thirty-six studies used the Maslach Burnout Inventory (MBI) and 14 used the Professional Quality of Life Scale (ProQOL). The MBI was used in English, Spanish, Portuguese, Japanese, Chinese, French, German, Polish and Italian. The ProQOL was used in English, Spanish and Hindi. The Hindi questionnaire was not validated.[68] Four studies used another tool to measure burnout: three studies used a single item burnout query and two studies a self-developed tool. The original MBI measures burnout and consists of 22 questions representing three constructs of burnout: emotional exhaustion, depersonalisation and personal accomplishment. The ProQOL measures the professional quality of life of healthcare professionals on three subscales: secondary traumatic stress (previously known as compassion fatigue), burnout and compassion satisfaction.

Prevalence of (symptoms of) burnout in healthcare professionals providing palliative care

The studies using the MBI were mainly conducted in Europe (Table 1). High emotional exhaustion ranged from 3% to 48.7%, with an outlier of 93% in Australia.[86] High depersonalisation ranged from 1.3% to 48%, with an outlier of 67% in Italy and 87% in Australia.[51] Low personal accomplishment ranged from 3% to 85%. Twelve studies reported an overall burnout rate among participants, varying from 3% to 38.7% with an outlier of 51% in China.[41]

Table 1 Incidence of burnout among healthcare professionals working in palliative care – MBI

first author, year	country	type of study	setting/ population	N	type of healthcare professional	measure	% BO[a]	emotional exhaustion (EE)	depersonalisation (DP)	personal accomplishment (PA)	quality
Anderson, et al., 2011	USA	cross-sectional study	nursing homes	380	other healthcare professional = 100%	MBI	*not specified*	mean = 2.0 (0.6)	mean = 0.8 (0.8)	mean 1.5 (0.5)	27
Boerner, et al., 2017	USA	cross-sectional study	nursing homes and home care	220	other healthcare professional = 100% (64% = nursing assistant, 36% = home care worker)	MBI	*not specified*	**certified nursing assistants** mean = 18.12 (10.9) **home health aides** mean = 12.94 (10.4)	**certified nursing assistants** mean = 4.74 (5.9) **home health aides** mean = 3.71 (4.6)	**certified nursing assistants** mean = 38.89 (8.0) **home health aides** mean = 40.54 (6.9	24
Davhana-Masalesele, et al., 2008	South Africa	cross-sectional study	hospitals	174	nurses = 100%	MBI	*not specified*	median = 33	median = 29	median = 52	24
Dreano-Hartz, et al., 2016	France	cross-sectional study	pcu[b] & palliative care mobile team	309	physician = 100%	MBI	*not specified*	high EE = 9%	high DP = 4%	low PA = 23%	30
Ercolani, et al., 2020	Italy	cross-sectional study	home palliative care teams	207	physician = 50.2% nurse = 36.2% other healthcare professional = 13.5%	MBI	*not specified*	**HCP** mean = 13.8 high = 11% **physicians** mean = 14.5 high = 14% **nurses** mean = 12.7 high = 7%	**HCP** mean = 10.2 high = 67% **physicians** mean = 10.4 high = 66% **nurses** mean = 19.9 high = 65%	**HCP** mean = 33,6 low = 20% **physicians** mean = 33,2 low = 19% **nurses** mean = 33,4 low = 27%	31
Fernández-Sánchez, et al., 2018	Spain	cross-sectional study	pcu[b] of a single hospital	64	physician = 10.14% nurse = 43.48% other healthcare professional = 46.38%	MBI - HSS	26.09%	high = 26.1% moderate = 29% low =44.9% mean = 17.03 (9.46)	high = 21.7% moderate = 27.5% low = 50% mean = 5.15 (5.02)	low = 7.2% moderate = 23.2% high = 69.6% mean = 41.57 (5.43)	28

Table 1 (continued)

Freitas, et al., 2014	Brazil	quasi-experimental pre-post intervention study	pcu[b] of a single hospital	21	nurse = 100%	MBI	*not specified*	high = 33.3% moderate = 33.3% low = 33.3%	high = 47.6% moderate = 38.1% low = 14.3%	low = 14.3% moderate = 28.6% high = 57.1%	24
Gama, et al., 2014	Portugal	cross-sectional study	hospitals	360	nurse = 100%	MBI	*not specified*	mean total = 16.52 palliative care = 13.03	mean total = 5.43 palliative care = 3.42	mean total = 37.67 palliative care = 38.63	22
Gomez-Cantorna, et al., 2015	Spain	cross-sectional study	various hospital and nonhospital pcu[b]	162	nurse = 100%	MBI	*not specified*	high = 30.4% moderate = 24.2% low = 45.3%	high = 25.5% moderate = 23.6% low = 50.9%	low = 23.6% moderate = 18% high = 58.4%	25
Guo, et al., 2019	China	cross-sectional design	hospitals	279	nurses = 100%	MBI	*not specified*	mean = 25.73 (10.48) high = 48.7%	mean = 9.70 (5.42) high = 45.4%	mean = 31.79 (6.06) reduced = 65.1%	34
Hernandez - Marrero, et al., 2016	Portugal	cross-sectional mixed methods study	pcu[b] for inpatients; home care teams; and hospital support team	88	physician = 20% nurse = 80%	MBI-HS	in burnout = 3% high risk = 13%	median (P25-P75) = 18 (11-25) high = 28% moderate = 28% low = 43%	median (P25-P75) = 3 (1-7) high = 10% moderate = 34% low = 56%	median (P25-P75) = 38 (32-43) high = 26% moderate = 31% low = 43%	27
Hunnibell, et al., 2008	USA	cross-sectional study	members of Oncology Nursing Society and Hospice and Palliative Nurses Association	563	nurse = 100%	MBI - HSS	*not specified*	**hospice nurses** M = 17.04 (SD = 9.46) high = 18% moderate = 21.7% low = 60.2%	**hospice nurses** M = 2.94 (SD = 3.23) high = 4.5% moderate = 11.5% low = 84%	**hospice nurses** M = 42.60 (SD = 20.12) low = 2.9%, moderate = 18.9% high = 78.3%	25
Kalicińska, et al., 2012	Poland	cross-sectional questionnaire survey	hospital and hospices	117	nurse = 49.6% other healthcare professional = 50.4%	MBI	*not specified*	M = 16.83 (9.78)	M = 4.29 (4.04)	M = 21.64 (12.78)	20
Kamal, et al., 2020	USA	cross-sectional study	members of the American Academy of Hospice and Palliative Medicine	1056	physicians = 68% nurse = 21% other healthcare professional = 12 %	MBI-HSS	38.7% [c]	high EE = 34.8%	high DP = 8.8%		27
Koh, et al., 2015	Singapore	prospective, cross-sectional study	hospital pcu[b] palliative home care services;	273	physician = 28.1% nurse = 58.3%	MBI-HSS	**all respondents** = 33.3%[c]	high EE **all respondents** = 26.4%	high DP **all respondents** = 15.8%	Low PA **all respondents** = 40.3%	27

			inpatient hospices		social worker = 13.6%		**doctors** = 41.9%^{c} **nurses** = 31.2%^{c} **social workers** = 27.8%^{c}	**doctors** = 31.1% **nurses** = 26% **social workers** = 22.2%	**doctors** = 20.3% **nurses** = 14.3% **social workers** = 13.9%	**doctors** = 29.7% **nurses** = 44.8% **social workers** = 44.4%	
Lobb, et al., 2010	Australia	cross-sectional study	an in home palliative care service	59	nurse = 85% other healthcare professional = 14%	MBI	*not specified*	M = 17.56 (10.8), range 0-54	M = 2.93 (3.57), range 0-30	M = 38.72 (7.053), range 12-48	29
Ma, et al., 2019	China	cross-sectional field survey	Chinese Society of Clinical Oncology and the Chinese Committee of Rehabilitation and Palliative Care	1620	physician = 100%	MBI-HSS	51%^{c}	mean (SD) = 23.18 (12.17) high = 39% moderate = 21 % low = 27.5%	mean (SD) = 8.62 (6.38) high =37% moderate = 24.8 % low = 36.2%	mean (SD) = 30.7 (9.74) high = 20.9% moderate = 19.1% low = 57.2%	27
Mampuya, et al., 2017	Japan	cross-sectional study	hospitals	87	physician = 100%	MBI-HSS	3.4% 20.6%^{c}	high = 14% moderate = 25% low = 61%	high = 10% moderate = 10% low = 79%	low = 20% moderate = 24% high = 56%	25
Martins Pereira, et al., 2014	Portugal	cross-sectional survey study	palliative care teams	88	physician = 20% nurses = 80%	MBI	3% 13% at high risk of deve-loping burnout	median = 18 (11-25)	median = 3 (1-7)	median = 38 (32-43)	27
Moreno-Jiménez, et al., 2008	Spain	cross sectional study	hospitals and health centres	130	physicians = 100% (23.8% terminal adults hcp)	MBI-HSS	*not specified*	mean (SD) = 20.37 (9.7)	mean (SD) = 7.96 (5.17)	mean (SD) = 38.3 (9.44)	24
Morita, et al., 2009	Japan	single institution randomised controlled study using a	a single general hospital	40	nurse = 100%	MBI and self develope d VAS	66.1^{d}	Emotional exhaustion (1-7) = 4.11	Depersonalization (1-7) = 1.96	Personal accomplishment (1-7) = 4.16	25

Table 1 (continued)

		waiting list control								
Morita, et al., 2014	Japan	RCT using a waiting list control	pcu^{b} inpatient hospices; palliative care consultation teams; general medical wards	76	nurse = 100%	MBI and self-developed VAS	**Group 1** overall mean^{d} = 46 (24) **Group 2** overall mean^{d} = 50 (26)	**Group 1** mean = 32 (9.5) **Group 2** mean = -	**Group 1** mean = 8.0 (3.0) **Group 2** mean = 6.8 (2.1)		27
Orellana-Rios, et al., 2017	Germany	observational pre-post mixed method pilot study	community hospital	28	physician = 3.6% nurse = 67.8% other healthcare professional = 14.3% other = 14.3%	MBI-HSS	*not specified*	M=14.85 (9.07)	M=2.72 (2.85)	M=39.27 (4.88)	29
Ostacoli, et al., 2010	Italy	cross-sectional survey	hospitals hospices	92	nurse = 100%	MBI	*not specified*	**hospice nurses** M=11.28 (6.69) high = 3% moderate = 24.2% low 72.8%	**hospice nurses** M=1.76 (2.25) high = 3% moderate = 18.2% low = 78.8%	**hospice nurses** M=40.88 (4.87) low = 84.9% moderate = 12.1% high = 3%	25
Pattison, et al., 2020	UK	cross-sectional survey	critical care and palliative care teams in a specialist tertiary cancer centre	61	nurse n = 36 physician n = 19 other healthcare professional n = 3 other n = 2	MBI	*not specified*	mean (SD) = 7.8 (5.3) high = 3.4% moderate = 6.9% low = 89.7%	mean (SD) = 9.9 (6) high = 20.3% moderate = 25.4% low = 52.3%	mean (SD) = 37.4 (7.2) high = 3.2% moderate = 44.4% low = 44.4%	28
Pereira, et al., 2012	Portugal	cross-sectional mixed methodology study	palliative care teams	73	nurse = 100%	MBI	*not specified*	median = 19.63	median = 4.95	median = 36.06	26

Pereira, et al., 2016	Portugal	Cross-sectional survey	pcu[b] and intensive care units	392 PCU = 92	**total** physician = 26% nurse = 74% **PCU** physician = 20% nurse = 80%	MBI-HSS	**PCU** in burnout = 3%, high risk = 13%, high level of burnout = 16%	**PCU** high = 28% moderate = 29% low = 43%	**PCU** high = 10% moderate = 36% low = 54%	**PCU** low = 43% moderate = 30% high = 27%	29
Podgurski, et al., 2019	USA	pre-, post-intervention survey assessment	palliative care section at an academic medical centre	29	physician = 61% nurse = 21% other hcp = 18%	MBI-HSS	18.5%[c]	mean (SD) = 18.9 (9.2) high = 17.2%	mean (SD) = 5.7 (4.4) high = 3.7%	mean (SD) = 37.1 (8.0) low = 24.1%	25
Popa-Velea, et al., 2019	Romania	longitudinal intervention study	hospitals	69	physicians = 100%	MBI	**study group** M (95%CI) = 69.80 (64.24–75.37) **control group** M (95%CI) = 71.89 (67.96–75.82)	**study group** M (95%CI) = 29.45 (25.96–32.94) **control group** M (95%CI) = 29.97 (27.55–32.39)	**study group** M (95%CI) = 11.77 (9.83–13.70) **control group** M (95%CI) = 11.78 (10.40–13.17)	**study group** M (95%CI) = 28.58 (26.53–30.62) **control group** M (95%CI) = 30.52 (28.78–32.26)	27
Potash, et al., 2014	Hong Kong	quasi-experimental pre-post intervention study	various settings	132	**art therapy group** nurse = 33.3% other healthcare professional = 20% other = 34.8% **skills based group** nurse = 41.4% other healthcare	MBI-GS	*not specified*	Exhaustion **art group** M=15.46 (5.93) **skills-based group** M=15.19 (6.22)	Cynicism **art group** M=10.84 (5.17) **skills-based group** M=11.63 (4.71)	Professional efficacy **art group** M=26.29 (6.46) **skills-based group** M=24.80 (6.02)	23

Table 1 (continued)

					professional = 30.2% other = 27%					
Puyat, et al., 2019	Canada	cross-sectional study	Long term care facilities	203	physicians and psychologists = 3.9% nurses = 23.2% other healthcare professionals = 48.8% other = 15.8% unknown = 8.4%	MBI	31.8% experienced EE and/or DP	31%	7%	low = 20%	25
Quinn-Lee, et al., 2014	USA	cross-sectional study	hospices	290	other healthcare professionals (hospice social workers) = 100%	MBI-HSS	*not specified*	mean =18.09 (8.73) = moderate high = 15% moderate = 42% low = 42%	mean =3.87 (3.21) = low high = 1.3% moderate = 17.9% low = 80%	mean = 41.16 (5.10) = low high = 6% moderate = 18% low = 76%	25
Rizo-Baeza. et al., 2018	Mexico	cross-sectional study	hospitals and health facilities	185	nurse = 100%	MBI	34.6% presented overall burnout (95% CI: 27.7%–41.4%)	high = 37.3% (95% CI: 30.3%–44.3%)	high = 35.1% (95% CI: 28.3%–42.0%)	low = 37.8% (95% CI: 30.8%–44.8%)	26
Singh, et al., 2017	Australia	cross-sectional online survey	members of the Australian Society of Medical Imaging and Radiation Therapy	200	physician = 100%	MBI	*not specified*	high = 93% mean 38.5, SD 8.2	high = 87% mean 17.5, SD 4.7	low = 61% mean 30.5, SD 4.3	28
Turner, et al., 2009	Australia	quasi-experimental design	hospital	32	nurse = 100%	MBI	*not specified*	**T1** 19 (range 5-43) **T2** 20 (range 4-38)	**T1** 3.0 (range 0-20) **T2** 3.5 (range 0 -15)	T1 37.0 (range 19-48) **T2** 37.0 (18-48)	23

Valjee, et al., 2014	South Africa	cross-sectional, exploratory mixed-design study	palliative care organisations	28	physician = 7.1% nurse = 32.1% other healthcare professional = 60.9%	MBI	Frequency M = 2.0724 (0.61841), range 1.14 - 3.27	Frequency M = 2.4856 (1.09525) range 1.00 - 4.56	Frequency M = 1.2963 (0.53312), range 1.00 - 3.00	Frequency M = 5.8973 (1.17608), range 1.00 - 7.00	26

[a] MBI defines Burnout as high EE, high DP and low PA
[b] PCU = palliative care unit
[c] other method of defining burnout than defined by MBI
[d] overall burnout based on VAS (0-100)

Table 2 Incidence of burnout among healthcare professionals working in palliative care – ProQOL

first author, year	country	type of study	setting	N =	type of healthcare professional	measure	Compassion fatigue / Secondary Traumatic Stress	Burnout	Compassion satisfaction	Quality
Alkema, et al., 2008	USA	cross-sectional study	two home hospice care agencies	37	nurse = 45.9% other healthcare professional = 37.8% other = 16.2%	ProQOL-RIII	M = 17.5	M = 23.8	*not administered*	26
Al-Majid, et al., 2018	USA	cross-sectional survey design	hospital	48	nurse = 100% (direct care nurse n = 38 charge nurse n = 10)	ProQOL V ^{a}	**direct care nurse** mean = 47.6 (9.6) high STS = 21% **charge nurse** mean = 57.2 (7.4) high STS = 20%	**direct care nurse** mean = 48.6 (6.6) high = 21% **charge nurse** mean = 49.5 (7.4) high = 10%	**direct care nurse** mean = 50.3 (10.10) high = 23.7% **charge nurse** mean = 52.9 (6.2) high = 0%	29
Frey, et al., 2018	New Zealand	cross-sectional study	New Zealand Nurses Organisation	157	nurse = 100%	ProQOL^a	**all** high STS = 22.9% moderate STS = 51.6% **specialisation PC** mean (SD) = 21.93 (4.58) **other** mean (SD) = 22.01 (5.54)	**all** high = 26.8% moderate = 48.4% **specialisation PC** mean (SD) = 20.91 (4.65) **other** mean (SD) = 23.89 (5.29)	**all** moderate = 48.4% high = 28.8% **specialisation PC** mean (SD) = 42.17 (3.98) **other** mean (SD) = 39.71 (5.16)	27
Galiana, et al., 2017	Brazil and Spain	two surveys with cross-sectional design	hospitals, hospice, home based care	546 B = 161 S = 385	**Spain** physician = 40.3% nurses = 33.3% other healthcare professional = 23% other = 0.8% **Brazil** physician = 21.1% nurses = 19.3% other healthcare	ProQOL V	**Spain** M=12.42 (5.79), range 0-40. High = 16.80%, Medium = 62.7%, Low = 20.50% **Brazil** M=14.24 (6.47), range 1-34 High = 29.30%, Medium = 56.60%,	**Spain** M=15.62 (5.13), range 0-31. High = 1.8%, Medium = 32.5%, Low = 65.7% **Brazil** M=15.05 (6.34), range 2-32. High = 3.30%, Medium = 28.30%,	**Spain** M=41.05 (4.70), range 24-50. Low = 4.3%, Medium = 47.4%, High = 48.30% **Brazil** M=41.63 (6.61), range 23-50. Low = 12.6%, Medium = 27.4%,	20

					professional = 41.6% other = 18%		Low = 14.10%	Low = 68.50%	High = 60%	
Hayuni, et al., 2019	Israel	cross-sectional study	Israeli Society for Clinical Oncology and Radiation Therapy, and the Israel Society of Haematology and Blood Transfusion	71	physicians = 100%	ProQOL	M = 17.24, SD = 7.35, range 3-39	M = 26.64, SD = 6.82, range 4-41),	*not administered*	26
Heeter, et al., 2017	USA	pre-post intervention study	hospice and palliative care healthcare professionals of a healthcare network	36	physicians = 11% nurses = 39% other healthcare professional = 12% other = 39%	ProQOL[a, b]	mean = 21.34 (4.14) very low = 81% low = 14% neutral = 5%	mean = 22.22 4.52) very low = 94% low = 3% neutral = 3%	*not administered*	22
Kaur, et al., 2018	India	cross-sectional study	hospitals and hospices	65	physicians = 21.5% nurses = 32.3% other healthcare professional = 46.1%	ProQOL-version 5[a]	M = 70 (6.97)	M = 54.9 (6.01)	M = 54.6 (6.55)	24
Klein, 2018	USA	exploratory pre-post interventional pilot study	academic medical centre (inpatient palliative care department and neonatal advanced practice)	17	physicians = 11.8% nurses = 70.6% other healthcare professional = 17.6%	ProQOL - version 5[c]	M = 26.1 (10.5) 95%CI: 19.4 - 32.8	M=27.3 (6.0) 95%CI: 23.5 -31.0	M=35.2 (5.3) 95%CI: 31.8 - 38.5	23

Table 2 (continued)

Montross-Thomas, et al., 2016	USA	cross-sectional study	hospices	390	hospice staff and volunteers	ProQOL-version 5	M = 19	M = 20	M = 43	28
O'Mahony, et al., 2018	USA	cross-sectional survey	professionals participating in a continuing education program on palliative medicine	66	physicians = 33.3% nurses = 36.3% other healthcare professional = 28.8%	ProQOL-5	M = 20.70 (4.13)	M = 20.30 (4.17)	M = 42.70 (4.20)	18
Pelon, et al., 2017	USA	cross-sectional survey	hospice organisations	55	other healthcare professional (social work clinicians) = 100%	ProQOL-5[a, b]	M = 50 (10), range = 33.3 - 76.4 high = 21.8% moderate = 56.4% low = 21.8%	*not administered*	M = 50 (10), range 31.3 - 63.5, low = 20% moderate = 43.6% high = 36.4%	27
Sanso, et al., 2015	Spain	cross-sectional survey	members of the Spanish Society of Palliative Care	385	physicians = 43.6% nurses = 33.2% other healthcare professional = 23.2%	ProQOL	M = 12.42 (5.59)	M = 15.62 (5.13)	M = 41.05 (4.79)	26
Slocum-Gori et al.,	Canada	cross-sectional survey	hospices and palliative care organisations	480	physician = 6.9% nurses = 42.3% other healthcare professional = 17.7% other = 33.1%	ProQOL	total = 18.6 medicine = 17.6 nursing = 20.1 integrative medicine = 17.3	total = 20.8 medicine = 22.4 nursing = 22.3 integrative medicine = 17.5	total = 43.9 medicine = 44.6 nursing = 43.4 integrative medicine = 48.1	27
Whitebird, et al., 2013	USA	cross-sectional survey	hospice programs	547	nurses = 37.3% other healthcare professional = 39.2% other = 22.2%	ProQOL - RIII	M = 9.9 (6.6)	M = 13.9 (7.2)	*not administered*	29

[a] Raw scores were converted to T-scores.

[b] Scale 1-5 was used, all other studies used 6 point Likert scale (0-5)

Fourteen studies, mainly from the USA, used a version of the ProQOL (Table 2). Six studies showed a mean on secondary traumatic stress (compassion fatigue) ranging between 21.34 and 70. These studies converted the raw scores into standardized t-scores according to the ProQOL manual.[87] The standardised mean t-scores for all three scales is 50 with a standard deviation of 10. The remaining eight studies used raw mean scores (scale ranges from 0-50 with higher scores indicating greater risk of burnout) and showed a mean secondary stress score ranging from 9.9 to 17.5.
Five studies used the burnout scale of the ProQOL with mean standardised scores between 22.22 and 54.9. Eight studies reported the raw mean burnout scores ranging from 13.9 to 26.6 (total range: 0 – 50 per scale). Higher scores equals greater risk of burnout.

In total 11 studies used a different measure to assess the level of burnout among healthcare professionals such as single item burnout queries, abbreviated versions of the MBI, self-developed burnout measures, and The Burnout Measure developed by Pines et al. and The Burnout Measure -short version (Table 3). Two studies used a VAS for burnout in addition to the MBI (Table 2). These studies show a range of burnout prevalence between 6% and 66%.

Burnout in dedicated palliative care settings compared to other healthcare settings
Three European studies compared the prevalence of burnout in general healthcare settings with dedicated palliative care units and reported better results in the latter. Pereira et al. reported that healthcare professionals working in intensive care units had a significant higher likelihood of developing high levels of burnout than their colleges in palliative care units (31% vs 16%, p=.006).[49] Gama et al. reported significantly lower symptoms of burnout in nurses working in palliative care units than in other departments.[62] Nurses working in palliative care units had lower levels of emotional exhaustion compared to nurses working in oncology units (m=13.03 vs. m=18.4, t = 2.71, <.008), in haematology (m = 13.03 vs. m=19.03, t=3.47, p<.001) and in internal medicine (m=13.03 vs. m=16.42, t =2.62, p<.009). When comparing hospice and hospital nurses Ostacoli et al. reported that nurses working in hospitals showed significantly higher mean levels of burnout symptoms than nurses working in hospice (emotional exhaustion m=19.65 vs m=11.28, depersonalisation m=5.15 vs m=1.76, personal accomplishment m=34.58 vs m=40.88, p <0.001).[75] The authors state that the precise identification of factors contributing to this significant difference is not yet possible.

Table 3 Incidence of burnout among healthcare professionals working in palliative care - Other

first author, year	country	type of study	setting	N =	type of healthcare professional	measurement instrument	% BO	Outcome	Outcome	Outcome	Quality
Frey, et al., 2015	New Zealand	Cross-sectional study	residential care facilities	431	nurse = 25.5% other hcp = 60.8% other = 11%	Burnout Measure-Short Version	mean = 2.8 (SD = .96)				23
Chamberlin, et al., 2019	USA	Cross-sectional study	hospitals	333	physician = 41.7% nurse = 56.1% missing = 2.1%	single item screen	43%				27
Clayton, et al., 2019	USA	cross-sectional study	hospices	175	nurse = 100%	abbreviated version of the Maslach Burnout Inventory (12 items)	mean (SD) 33.98 (5.71) median (range) 33 (19-50)	emotional exhaustion mean (SD) 8.97 (3.6) median (range) 9 (3-19)	depersonalisation mean (SD) 4.16 (1.8) median (range) 3 (3-11)	personal accomplishment mean (SD) 18.81 (2.2) median (range) 20 (12-21)	27
Dougherty, 2009	Canada	cross-sectional study	a single oncology centre with an inpatient unit and a pcu[a]	60	nurses = 71.1% other healthcare professional = 28.9%	53-question survey (self-developed)		55.9% feeling emotionally drained			28
Lambden, et al., 2018	USA	cross-sectional study	hospitals	333	physician = 41.7% nurse = 56.1%	Single item question	43%				28
Marchalik, et al., 2019	USA	cross-sectional study	members of the American Academy of Hospice and	709	physician = 75% nurse = 8% other healthcare professional = 12.8% other = 1.7%	validated abridged 2-item version of the Maslach Burnout Inventory (MBI)	18.2%	high emotional exhaustion = 16.6%	high depersonalisation = 6.3%	*Not administered*	27

			Palliative Medicine							
Melo, 2011	Portugal	mixed methods study using a control group	pcu[a] and other settings (participants worked with dying patients but not in a pcu[a])	total = 176 intervention n = 150 control = 26	physician = 5% nurses = 58% other healthcare professional = 12%	self-developed questionnaire based on MBI	**Participants above cut-off point** emotional exhaustion = 30.0% depersonalisation = 1.3% professional fulfilment = 89.3%	emotional exhaustion total: 3.10 (.80) outside PCU: 3.31 (.83) control group: 3.21 (.57)	depersonalisation total: 1.82 (.60) outside PCU: 1.85 (.59) control group: 1.98 (.64)	professional fulfilment total: 4.44 (.60) outside PCU: 4.40 (.64) control group: 4.35 (.59)	22
Pavelkova, et al., 2015	Czech Republic	Cross-sectional observational study	hospices	241	physician = 0.8% nurse = 57.7% other healthcare professional = 41.5%	Burnout Measure	burnout = 5.8% alarming levels = 28.2% mean burnout score = 2.8 (0.8) median = 2.7, range = 1–5.3)				21
Yoon, 2017	USA	self-administered questionnaire	members of the American Medical Association	1156	physicians = 100%	single item burnout query	**overall** = 23% **end-of-life specialities** = 20% **general specialties** = 24%				35

[a] PCU palliative care unit

Table 4 The effect of interventions aimed to decrease burnout among healthcare professionals working in palliative care

first author, year	country	type of study	setting	N =	type of healthcare professional	intervention	measurement instrument	effect	outcome	effect size	quality
Heeter, et al., 2017	USA	pre-post intervention study	a healthcare network	36	physicians = 11% nurses = 39% other healthcare professionals = 12% other = 39%	a technology - assisted meditation program	ProQOL	+	**Compassion fatigue** significant effect (paired t-test, p= .034) Mean = 21.34 M = 20.00 (pre-post) **Burnout** significant effect (paired t-test, p= .047) M = 22.22 vs M = 20.64 (pre-post)	**Compassion fatigue** Delta pre-post = 1.34 CI 95% = -2.57 - 0.12 **Burnout** Delta = 1.58 CI 95% 0.03 – 3.14	22
Orellana-Rios, et al., 2017	Germany	observational pre-post mixed method pilot study	community hospital	28	physicians = 3.6% nurses = 67.8% other healthcare professionals = 14.3% other = 14.3%	mindfulness and compassion-oriented meditation training for interdisciplinary teams	MBI-HSS	+/-	**Emotional exhaustion** significant effect (t = -3.13, p=0.005) M = 14.85 (9.07) vs M = 11.29 (7.63) (pre to post) **Depersonalisation** no significant effect (t = 0.71, p = 0.48) M = 2.72 (2.85) vs M = 2.53 (2.80) **Personal Accomplishment** significant effect (t = -2.71, p=0.012) M = 39.27 (4.88) vs M = 41.22 (4.03)	Cohen's d **Emotional exhaustion** = 0.41 **Depersonalisation** = 0.07 **Personal Accomplishment** = 0.43	29

Podgurski, et al., 2019	USA	pre-, post--intervention survey assessment	palliative care section at an academic medical center	29	physician = 61% nurse = 21% other healthcare professional = 18%	Mindfulness	MBI-HSS	-	Emotional Exhaustion **Pre** mean (SD) = 18.9 (9.2) **7 month post** Mean (SD) = 17.6 (8.9) p = 0.479 Depersonalisation **Pre** Mean (SD) = 5.7 (4.4) **7 month post** Mean (SD) = 4.8 (4.5) p = 0.243 Personal accomplishment **Pre** Mean (SD) = 37.1 (8.0) **7 month post** Mean (SD) = 38.8 (6.9) p = 0.348	Emotional exhaustion Delta = - 1.3 Depersonalisation Delta = - 0.9 Personal accomplishment Delta = 1.7	25
Melo, et al., 2011	Portugal	mixed methods study using a control group	palliative care units and other settings* *participants worked with dying patients but not in a pcu^{a}	intervention = 150 control = 26	physician = 5% nurses = 58% other healthcare professional = 12%	training in communication, in offering emotional and spiritual support to patients, and in personal introspection on death anxiety	self-developed questionnaire based on MBI	+	**Emotional exhaustion** *total*: significant effect (p <0.001) M = 3.10 (.80) vs M = 2.89 (.81) (pre vs post) *experimental group, outside PCU*: significant effect (p <0.001) M = 3.31 (.83) vs M = 2.90 (.81) *control group*: not significant M = 3.21 (.57) vs M = 3.18	**Emotional exhaustion** total group Delta = -0.21 **Depersonalisation** total group Delta = -0.18 **Personal accomplishment** total group Delta = 0.18	22

Table 4 (continued)

(.74)
Depersonalisation
total: significant effect (p <0.001)
M = 1.81 (.62) vs 1.63 (.60) (pre vs post)
experimental group outside PCU: significant effect (p <0.001)
M = 1.85 (.59) vs 1.59 (.57)
control group: not significant
M = 1.98 (.64) vs M = 1.85 (.54)
Professional fulfilment
total: significant effect (p<0.001)
M = 4.44 (.60) vs M = 4.62 (.58) (pre vs post)
experimental group outside PCU: significant effect (p<0.005)
M = 4.40 (.64) vs M = 4.61 (.60)
control: not significant
M = 4.35 (.59) vs M = 4.50 (.51)

Morita, et al., 2009	Japan	single institution randomised controlled study using a waiting list control	a single general hospital	40	nurses = 100%	Education about communication skills, the conceptual framework of meaninglessness and the use of the Spiritual Conference Summary Sheet.	MBI and self-developed VAS	+/-	**Emotional exhaustion** significant effect (p=0.012) M = 4.11 vs M = 3.62 (pre-post) **Depersonalisation** no significant effect (p = 0.15) M = 1.96 vs M = 1.67 (pre-post) **Personal Accomplishment** significant effect (p = 0.024) M = 4.16 vs M = 4.70 (pre-post)	Change ratio **Emotional exhaustion** = -12% **Depersonalisation** = –15% **Personal accomplishment** = 13%	25
Potash, et al., 2014	Hong Kong	quasi-experimental pre-post intervention study	various settings	132	**art therapy group** nurses = 33.3% other healthcare professional = 20% other = 34.8% **skills based group** nurses = 41.4% other healthcare professional = 30.2% other = 27%	**art-therapy-based supervision group**: breathing exercise, guided visualisation, making art, reflective writing, group discussions **standard skills-based supervision group** learn new clinical skills, share case material,	MBI-GS	+/-	**Exhaustion** *Artgroup* significant effect (t = 2.64, p=0.011) M = 15.46 5.93) vs M = 13.73 (5.40) (pre to post) *Skills based group* no significant effect (t = 0.82, p =0.42) M = 15.19 (6.22) vs M = 14.74 (6.15) **Cynicism** *Art group* no significant effect (t = -1.08, p = 0.29) M = 10.84 (5.17) vs M = 11.58 (4.83) (pre to post)	**Exhaustion** Artgroup Delta = -1.73 Skills based group Delta = - 0.45 Cynicism Art group Delta = 0.74 Skills based group Delta = 1.31	23

Table 4 (continued)

						engage in case analysis			*Skills based group* significant effect (t = -2.60, p=0.012) M = 11.63 (4.71) vs M = 12.94 (3.65)		
Popa-Velea, et al., 2019	Romania	longitudinal intervention study	hospitals	69	physicians = 100%	Balint groups	MBI	+	**Burnout** T0 study vs control group M = 69.80 vs M = 71.89, p = 0.52 T1 study vs control group M = 65.66 vs M = 76.06, p=0.003 **Emotional exhaustion** T0 study vs control group M = 29.45 vs M = 29.97, p = 0.79 T1 study vs control group M = 26.86 vs M = 33.00, p=0.004 **Depersonalisation** T0 study vs control group M = 11.77 vs M = 11.78, p = 0.98 T1 study vs control group M = 10.63 vs M = 13.80, p=0.005 **Low personal accomplishment** T0 study vs control group M = 28.58 vs M = 30.52, p = 0.14	**Burnout** Study group T0 vs T1 Delta = - 4.44 Control group T0 vs T1 Delta = 4.17 **Emotional exhaustion** Study group T0 vs T1 Delta = - 2.59 Control group T0 vs T1 Delta = 3.03 **Depersonalization** Study group T0 vs T1 Delta = - 1.14 Control group T0 vs T1 Delta = 2.02 **Low personal accomplishment** Study group T0 vs T1 Delta = - 0.42 Control group T0 vs T1 Delta = - 0.96	27

									T1 study vs control group M = 28.16 vs M = 29.56, p=0.30		
Klein, et al., 2018	USA	exploratory pre-post interventional pilot study	a medical centre	17	physicians = 11.8% nurses = 70.6% other HEALTHCARE PROFESSIONAL = 17.6%	an educational resiliency program about CS, CF, vicarious trauma, self-care, resilience and quality of life	ProQOL - version 5	-	No significant differences *1st survey compared to 2nd* **Secondary traumatic stress** M = 26.1 vs M = 26.3 (pre-post) **Burnout** M = 27.3 vs M= 26.5 **Compassion Satisfaction** M = 35.2 vs M= 36.8 *1st survey compared to 3rd* **Secondary traumatic stress** M = 26.1 vs M = 26.0 **Burnout** M = 27.3 vs M = 26.6 **Compassion Satisfaction** M = 35.2 vs M = 36.4	Effect size Secondary traumatic stress = 0.03 Burnout = 0.14 Compassion satisfaction = 0.35	23
Morita, et al., 2014	Japan	randomised controlled study using a waiting list control	palliative care units, inpatient hospices palliative care consultation teams and general medical wards	76	nurses = 100%	interactive education program focused on working with the Spiritual Pain Assessment Sheet	MBI and self-developed VAS	-	**Emotional exhaustion** No significant effect Group 1 M = 32 (9.5) vs M = 32 (11), Group 2 M = 34 (8.5) vs M = 32 (8.1), **Depersonalisation** No significant effect Group 1: M = 8.0 (3.0) vs M = 8.0 (3.3),	**Emotional Exhaustion** Group 1 ES = 0.0, 95% CI = -0.3 - 0.2 Group 2 ES = 0.1, 95% CI = -0.3 - 0.1 **Depersonalisation** Group 1	27

Table 4 (continued)

								Group 2: M = 6.8 (2.1) vs M = 6.9 (2.5),	ES = 0.0, 95% CI = -0.4 - 0.4 Group 2 ES = 0.1, 95% CI = -0.2 - 0.4	
Freitas, et al., 2014	Brazil	quasi-experimental pre-post intervention study in a single setting	hospital palliative care unit	21	nurse = 100%	Workplace physical activity program	MBI	-	**Emotional exhaustion** no significant effect (p =0.61) high = 33.3% vs 19.0% (pre-post) **Depersonalisation** no significant effect (p=0.88) high = 47.6% vs 52.4% (pre-post) **Personal accomplishment** no significant effect (p = 0.54) low = 14.3% vs 4.8% (pre-post)	High emotional exhaustion = -14.3% High Depersonalisation = 4.8% Low Personal accomplishment = -9.5%	24

[a] PCU = palliative care unit

Interventions to reduce early symptoms of burnout

Ten studies reported on interventions to reduce early symptoms of burnout in healthcare professionals providing palliative care, including 11 interventions (such as meditation, workplace activity, (communication) education and art-therapy based supervision) (Table 4). Most interventions were aimed at the individual healthcare professional. One intervention was aimed at the interdisciplinary team, in order to integrate the learned skills into their work.[46] Two were offered to the entire team, but they were not necessarily developed as a team intervention.

Six studies reported a significant positive effect post-intervention on at least one of the administered dimensions of the questionnaire that was used to measure burnout. Effective interventions on reducing burnout symptoms were meditation (n=2), communication training (n=2), peer-coaching (n=1) and art-therapy based supervision (n=1).[46,65,71,73,79] The meditation focused interventions consisted of a group programme provided by an experienced meditation teacher and a technology assisted meditation program focusing on body, breath and mind.[46,65] The communication skills intervention used by Melo et al. consisted of 2 modules; 1 focused on personal introspection on death anxiety in order to improve the capacity of healthcare professionals to empathize with patients.[71] The second module was about improving communication skills and understanding psychological and spiritual needs of patients. The study of Morita et al. aimed at developing basic communication skills and working with the Spiritual Conference Summary Sheet.[73] The peer-coaching intervention regarded six Balint group meetings run by moderators with a medical background.[50] The art-therapy-based supervision used by Potash et al. used breathing exercises, guided visualisation, making art, reflective writing and small and large group discussions related to themes such as self-care and stress management, care sharing and clinical skills and grief and bereavement.[79]

The four remaining studies reported no positive significant post-intervention effect, these studies included an educational program (n=2), a mindfulness program (n=1) and a workplace physical activity program (n=1).[45,69,59] One study showed a negative effect: the skills-based intervention studied by Potash et al. led to more cynicism.[79] Possible reasons for the lack of a positive significant effect given by the authors are the absence of a social or emotional component in the intervention and a low level of burnout at baseline.

DISCUSSION

Main findings

This systematic literature review has synthesized studies on burnout rates among healthcare professionals providing palliative care and the effects of interventions aimed at reducing symptoms of burnout in this group of healthcare professionals. Overall burnout prevalence among healthcare professionals providing palliative care ranges from 3% to 66%, with most studies reporting a prevalence of 18% or higher. Burnout was measured by using mostly the Maslach Burnout Inventory (MBI). Symptoms of burnout as measured in the MBI showed wide ranges of 'high emotional exhaustion' (3%-49%), 'high depersonalisation' (1%-48%) and 'low sense of personal accomplishment' (3%-85%). Healthcare professionals providing palliative care working in general healthcare settings report higher rates on (symptoms of) burnout compared to healthcare professionals providing palliative care working in specialised palliative care settings.

Few interventions to reduce symptoms of burnout for healthcare professionals providing palliative care were found. Moreover, only six studies showed positive effects of such interventions. These interventions mainly aim at awareness and spirituality using a form of meditation, communication training, peer-coaching and art-therapy based supervision.

Some findings need to be highlighted. First, burnout seems to be prevalent in almost one fifth of healthcare professionals providing palliative care, although the range of burnout prevalence rates found in this systematic literature review is very wide. This seems comparable with the prevalence of burnout among physicians and nurses in general and somewhat higher compared to healthcare professionals working in specialised palliative care settings.[22,88,89,90] This is in line with our results showing a lower burnout rate among healthcare professionals providing palliative care in specialised settings compared to those providing palliative care in general settings. However a recent study showed a positive association between the number of suffering patients healthcare professionals see on a daily basis and reduced emotional wellbeing.[91] This could indicate that there is a maximum amount of suffering one can cope with on a daily basis.[92]

Furthermore, all studies show a wide range. Due to this wide range in prevalence it is difficult to compare the prevalence of burnout among healthcare professionals providing palliative care with other healthcare professionals and to get a clear understanding of the unique impact of providing palliative care in relation to developing (symptoms) of burnout.

Second, the included intervention studies showed little improvement. This is in line with other research on improving wellbeing of healthcare professionals providing palliative care. A systematic literature review of Hill et al. on this subject found little improvement in the psychological wellbeing of healthcare professionals working in palliative care settings after the use of psychosocial interventions such as music therapy, art therapy, (psycho)existential interventions and stress reduction.[93] Most of these interventions were focused on the individual healthcare professional.

Thirdly, there were few interventions found that aim at reducing symptoms of burnout for healthcare professionals providing palliative care. Most interventions were directed at the individual healthcare professional. However, research has shown that interventions directed at organisational level are more effective in reducing symptoms of burnout than interventions directed at the individual healthcare professional.[14,94] Since the development of burnout is related to work conditions, interventions aimed solely at the individual do not seem sufficient to bring permanent changes in the situation.[3]

Lastly, the use of measurement instruments to assess burnout is diverse and not according to the published manuals of the two mainly used validated measurement instruments as already indicated by Rotenstein et al.[87, 88, 95] In the studies using the MBI different cut-off scores were used for defining burnout. Maslach et al. define burnout as having high emotional exhaustion, high depersonalisation and low sense of personal accomplishment.[95] However several studies defined burnout as having an unfavourable score on two out of three subscales. Also the use of the ProQOL varied. Several studies used a 6-point response scale instead of the (renewed) 5-point scale as described in the manual.[87] Moreover not all studies computed t-scores but instead reported the raw scores. Rotenstein et al. also showed that the use of burnout measurements varies among studies.[88] This methodological issue combined with the wide range of burnout rates complicates the estimation of the magnitude of the problem.

Strengths and limitations

This study has strengths and limitations. To our knowledge, this is the first systematic literature review on burnout specific among healthcare professionals providing palliative care in all settings. It addresses an important topic and shows that limited knowledge is present about the prevalence of symptoms of burnout among these healthcare professionals and about the prevention of these symptoms.

A limitation of this review is by definition of its search string, which solely addresses burnout and within the field of palliative care. Burnout is related to concepts such as (work-related) stress, compassion fatigue and job satisfaction and these concepts even may have some shared components. In order to focus it was decided to use burnout to have a demarcated search area. Therefore some relevant studies might have been missed. The findings from this review could be complemented with results from reviews on work-related stress, job satisfaction and compassion fatigue to get a broader understanding of the work-related wellbeing of healthcare professionals providing palliative care. Despite the use of the standardised search string for palliative care of Rietjens et al, the operationalisation of palliative care varies among the included studies.[26] It was also difficult to distinguish between healthcare professional who are generalist in palliative care and those who are specialist palliative care, which limits the insights of burnout in different subgroups. To minimalize the impact of these limitations references from included articles were screened and only two articles were added. Moreover, a reporting bias might be present regarding the interventions to reduce (symptoms of) burnout, as studies with positive outcomes are more likely to be published.

Another limitation is that the included studies were conducted in different countries with a variety of healthcare systems, settings and among different types of healthcare professionals. Therefore it is difficult to compare the outcomes. No meta-analysis was performed due to the heterogeneity in type of healthcare professional, gender, setting and measurement.

What this paper adds

Prevalence of burnout in healthcare professionals providing palliative care seems similar to healthcare professionals in general and affects a substantial amount of healthcare professionals. Due to the aging population, combined with the increase in patients with multimorbidity and living longer with a life-threatening illness, an increasing need for palliative care is expected.[96] This increasing need, combined with the already existing shortages of healthcare professionals, has the risk of leading to a vicious circle; healthcare professionals will have to work harder due to the increasing demand for care, which contributes to the risk of getting burned out, leading to a higher workload for the remaining healthcare professionals. Apart from general work-related stressors, providing palliative care has some specific stress factors. Many healthcare professionals are exposed to the deaths of patients and its related risk factors. Especially those healthcare professionals providing palliative care in a non-specialised setting experience a higher burden of burnout symptoms.

The concept of burnout is developing. Research into the theoretical description of burnout and an empirical inventory of burnout characteristics has resulted in a new measurement instrument to assess burnout; the burnout assessment tool (BAT). The new definition of burnout, on which the BAT is based, constitutes of four dimensions: exhaustion, emotional impairment, cognitive impairment and mental distance. In addition, burnout is accompanied by psychological distress, psychosomatic complaints and depressed mood.[97] More research into the concept of burnout among healthcare professionals (proving palliative care) is needed. Also more research is needed to develop effective interventions on different levels of support (e.g. peer support service, team-meetings, individual therapies) to prevent burnout among healthcare professionals. Interventions aimed at preventing burnout found in this review almost all focus on the individual healthcare professional based on mindfulness and improving communication skills. This is in line with the article of Harrison et al. who state that the way burnout interventions are currently designed might suggest that healthcare professionals are personally accountable for burnout. However it is known that the development of burnout among healthcare professionals also has an organisational component.[98] In line with this previous studies have advocated an integrated approach of burnout in which both the level of the individual healthcare professional and the organisational level is included.[94, 99] Further research is needed on interventions aimed at both organisational changes and individual support to achieve strong positive and long-term effects.

Also, it seems wisely to incorporate specific issues regarding providing palliative care in general interventions aimed at preventing (symptoms of) burnout, as most healthcare professionals will provide care for patients with incurable diseases.

Conclusion

This systematic literature review identified 59 studies that investigated the prevalence of burnout among healthcare professionals providing palliative care. Ten of these were intervention studies. The range of burnout found is wide and was conducted among different types of healthcare professionals in various settings. The prevalence of burnout among healthcare professionals providing palliative care in specialised settings seems lower compared to those providing palliative care in general settings. Few interventions aimed at preventing burnout in healthcare professionals providing burnout were found. Although interventions on meditation, communication, peer-coaching and art-therapy based supervision aimed at the individual healthcare professional seem worthwhile, interventions aimed at team and organisational changes are likely to have a stronger effect. Further research on interventions aimed at both team and organisational changes and at individual healthcare professionals is needed.

DECLARATIONS

Authorship

AD and NR participated in the design of the review. AD, LB and NR were involved in the data collection, analysis and interpretation. AD drafted the manuscript. All authors were involved in the critical revision of the manuscript and approved the final version of the manuscript.

Declaration of conflicts of interest

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

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Data management and sharing

The data that support the findings of this study are available on request from the corresponding author.

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SUPPLEMENT 1. Keyword search string

#1	Burnout[tiab] OR emotional exhaustion[tiab] OR mental exhaustion[tiab] OR compassion fatigue[tiab] OR depersonalization[tiab] OR depersonalisation[tiab] OR cynicism[tiab] OR personal accomplishment[tiab] OR mental health[tiab] OR stress[tiab] OR work-related stress[tiab] OR resilience[tiab] OR self management[tiab] OR selfcare[tiab]
#2	"Burnout, Professional"[Mesh] OR "Occupational Stress"[Mesh]
#3	#1 OR #2
#4	Care provider[tiab] OR clinician[tiab] OR health care professional[tiab] OR physician[tiab] OR nurse[tiab] OR doctor[tiab] OR palliative care team[tiab]
# 5	"hospice social workers" [tiab] OR "hospice workers" [tiab]
#6	"Health Personnel"[Mesh]
#7	#4 OR #5 OR #6
#8	Palliative[tiab] OR hospice[tiab] OR end of life[tiab] OR end-of-life[tiab] OR advanced disease[tiab] OR advanced oncology[tiab]
#9	"Palliative Care"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice Care"[Mesh] OR "Terminal Care"[Mesh]
#10	"Terminal Care" [mh] OR bereave* OR hospice*[tw] OR "advanced cancer"[tiab] OR "end of life" OR "terminally ill"[tw] OR palliative*[tiab] OR "Palliative Care"[mh]
#11	#8 OR #9 OR #10
#12	#3 AND #7 AND #11

3

Healthcare professionals' work-related stress in palliative care: A cross-sectional survey

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ABSTRACT

Context

Providing palliative care can lead to work-related stress and ultimately to burnout. The need for palliative care will further increase due to population aging and people living longer with life-threatening diseases. Therefore, a healthy palliative care workforce is vital.

Objectives

This study aims to get insight into the experienced work-related stress among healthcare professionals providing palliative care in the Netherlands and their strategies and needs in relation to maintaining a healthy work-life balance.

Methods

A cross-sectional online survey among members of the Dutch Association for Palliative Care Professionals was conducted between February and March 2020. Burnout was assessed by the validated Burnout Assessment Tool. Self-constructed questions assessed strategies and needs of healthcare professionals providing palliative care regarding work-related stress.

Results

In total 179 eligible respondents responded (response rate 54%). Respondents were mostly female (79%) and older than 50 years (66%). Most respondents were nurses (47%) and physicians (39%). Two-thirds of respondents (69%) experienced a median level of burnout and 2% a (very) high level. Furthermore, 7% had been on sick leave due to burnout. Although healthcare professionals engage on average in 3.7 coping activities, a quarter (23%) felt that these activities were not sufficient to maintain balanced. Respondents feel a need for activities aimed at the team and organisation level such as feeling emotionally safe within their team.

Conclusion

Symptoms of burnout are quite prevalent among healthcare professionals providing palliative care in the Netherlands. Healthcare professionals have a need for team and organisation approaches to maintain a healthy work-life balance.

INTRODUCTION

Healthcare professionals providing palliative care address the physical, psychological, social and spiritual care needs of patients with a life-threatening illness and their relatives. They often perceive providing palliative care as rewarding, derive meaning-in-life experiences from providing this care and experience personal growth as a result of caring for terminally ill patients.[1-4] However, repeated exposure to suffering and death and dying can be demanding and may be experienced as emotionally challenging.[5] It can also lead to work-related stress that ultimately can result in burnout.[6] Burnout founds its origin in caring occupations which due to its aim to help people in need can be experienced as emotionally stressful.[7] One of the early and common used definitions of burnout by Maslach et al describes burnout as a psychological syndrome involving emotional exhaustion, depersonalization, and a diminished sense of personal accomplishment that occurred among professionals who work with other people in challenging situations.[7] These constructs are also represented in the widely used Maslach Burnout Inventory (MBI).[8] Some criticism regarding the MBI are present regarding difficulties in the practical use of the MBI and psychometric flaws. Therefore the concept of burnout has further evolved and this has recently resulted in a new burnout measurement; the Burnout Assessment Tool (BAT).[9] The BAT includes four constructs: exhaustion, mental distance, emotional impairment and cognitive impairment.[10]

A recent systematic literature review on the prevalence of burnout among healthcare professionals providing specialist palliative care showed that 17% of these healthcare professionals suffered from a burnout.[11] In other words, almost one in five healthcare professionals providing specialist palliative care are at risk of dropping out as a result of work-related stress. At the same time, as a result of a decrease in the working-age population and a growing need for palliative care in coming years due to people getting older and having more co-morbidities, the workload for healthcare professionals will likely further increase.[12-14] To be able to manage this rapid growth of palliative care needs, healthcare systems must adapt by focusing on integration and boosting of palliative care across healthcare disciplines on the one hand, and by fostering professionals providing palliative care by reducing work-related stress on the other.

As providing palliative care has unique aspects, it is of interest to develop interventions specifically aimed at reducing symptoms of burnout among healthcare professionals in palliative care. A recent systematic literature review showed a relatively small number of such tailored interventions to reduce symptoms of burnout among healthcare professionals providing palliative care.[15] Furthermore, another systematic literature review on interventions improving the psychological wellbeing of palliative care healthcare professionals showed little effect of the interventions on their psychological wellbeing.[16]

Current research is mainly focused on the specialist palliative care setting. In the context of current and future challenges palliative care is facing, it is important to gain insight into the work-related stress of healthcare professionals providing palliative care, in both the specialist and generalist setting. Furthermore, to develop effective interventions to reduce work-related stress and symptoms of burnout for these professionals, it is necessary to understand their needs regarding the physical and emotional impact of providing palliative care. Therefore, the aim of our research is to get insight into the experienced work-related stress among healthcare professionals providing palliative care in the Netherlands and what their strategies and needs are in relation to maintaining a healthy work-life balance.

METHODS

Study design

A cross-sectional survey was conducted to assess symptoms of burnout among healthcare professionals providing palliative care in the Netherlands and their (copings) strategies and needs regarding work-related stress. We have used the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendation for cross-sectional studies in order to ensure accurate and complete reporting of this observational study.[17]

Setting and participants

In the Netherlands all healthcare professionals are expected to provide generalist palliative care to patients with a life-threatening illness. They are supported by palliative care specialists when necessary. Therefore, in this study all members of the Dutch Association for Palliative Care Professionals (Palliactief) were invited to complete an online questionnaire. Palliactief is a multidisciplinary association including physicians, nurses and other professionals working in generalist and specialist palliative care. Members were eligible for the survey if they were healthcare professionals. Non-healthcare providers (researchers, policy makers) were excluded. In February 2020 an invitation to the online questionnaire was sent to all members of Palliactief, of whom 358 were healthcare professionals. A reminder followed 4 weeks after the invitation and the questionnaire closed 6 weeks after the start, at the end of March 2020, due to the outbreak of Covid-19.

Measures

Burnout was assessed by the validated Burnout Assessment Tool (BAT). This is a newly developed instrument based on recent research on the concept of burnout. After careful consideration among all authors it was decided to use the BAT and not the frequently used MBI. Main reason for this was the experienced difficulties in the use of the MBI which have been tried to resolve in the BAT.[9] The BAT consists of 33 questions and includes four core constructs: exhaustion, mental distance, emotional impairment and cognitive impairment. Total burnout is determined based on the four constructs. The BAT also assesses secondary symptoms, namely psychological distress and psychosomatic complaints. A 5-point Likert scale was used. Cut-off scores for low (1.00–1.55), median (1.56–2.79), high (2.80– 3.64) and very high (3.65–5.00) total burnout scores were used.[10]

To assess how healthcare professionals deal with the physical and emotional impact of providing palliative care and their needs in relation to this theme self-constructed questions were used. Furthermore, sociodemographic characteristics were obtained including age, gender, profession, level of palliative care education and work-related information. Level of palliative care education was divided into three categories: no postgraduate palliative care education, postgraduate palliative care training and postgraduate specialist palliative care education. Palliative care training comprises a wide range of types of palliative care education ranging from short to extensive courses. Specialist palliative care education only includes educational programs that are directed at the specialist palliative care level.

Data analysis

All data of respondents was analysed using STATA (version 16.1, StataCorp Texas). Respondents who completed all four core constructs of the BAT were included in the analysis. Descriptive analysis was used to describe sociodemographic characteristics, work characteristics and prevalence of (symptoms of) burnout. The nonparametric Kruskal Wallis test was used to assess significant differences in total burnout scores between type of profession, setting, age, years of experience in palliative care, palliative care education and number of patients dying on average per month. A p-value of 0.05 was considered to be statistically significant. All open questions were analysed by AD and if needed new categories were added after discussion with NR and LB.

Ethical considerations

In the Netherlands, according to the Central Committee on Research involving Human Subjects (CCMO) this type of study is exempt from approval of a medical ethics committee, therefore no application was submitted.[18] The online questionnaire was administered anonymously and participation was voluntary. Invitation to the survey was sent by the office manager of Palliactief in order to comply to the General Data Protection Regulation (GDPR).

RESULTS

The online questionnaire was completed by 192 respondents (53.6% response rate) of which 179 were eligible for inclusion in the analysis (Supplement 1). Seventy-nine percent was female and most respondents were older than 50 years (66%). Nearly half of the respondents were nurses (47%), 39% were physicians and 13% were other healthcare professionals such as chaplains, physiotherapists or psychologists (Table 1).

Table 1 sociodemographic characteristics of study population (n=179)

Healthcare professionals' sociodemographic characteristics*	**% (n)** **n (= 179)**
Gender	
Male	20 (35)
Female	79 (141)
Age	
≤ 30	1.7 (3)
31-40	9.5 (17)
41-50	22 (39)
51-60	40 (72)
≥ 61	26 (46)
Profession	
Nurse	47 (85)
Physician	39 (69)
Other healthcare professional[a]	13 (23)
Work setting	
Homecare	23 (42)
Nursing home	7.8 (14)
Hospital	39 (69)
Hospice	20 (36)
Other[b]	8.9 (16)

[a] *Other professions include chaplains, physiotherapists and psychologists*
[b] *Other work settings includes mainly healthcare professionals working in several settings*
**Missing data did not exceed 5%*

The majority of respondents reported more than 20 years of work experience in healthcare and more than 11 years of work experience in palliative care. Most respondents reported additional palliative care training: 84% of nurses and 94% of physicians. In addition, 60% of nurses and 90% of physicians had received specialist palliative care education (Table 2).

Table 2 Work experience and education characteristics of respondents by profession

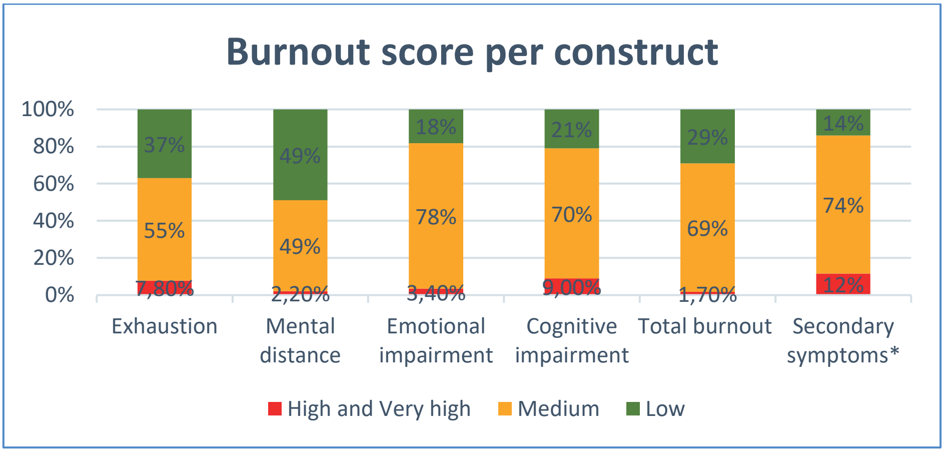
	Nurses (n= 84)	**Physicians (n= 69)**	**Other HCP (n= 23)**
	% (n)	% (n)	% (n)
Experience in healthcare (years)			
0-10	4.8 (4)	7.2 (5)	17.3 (4)
11-20	12 (10)	28 (19)	26 (6)
≥ 21	83 (70)	65 (45)	57 (13)
Experience in palliative care (years)			
0-5	26 (22)	15 (10)	22 (5)
6-10	20 (17)	23 (16)	8.7 (2)
11-20	25 (21)	32 (22)	30 (7)
≥ 21	27 (23)	30 (21)	39 (9)
Education in palliative care			
Yes, postgraduate specialist PC education*	60 (50)	90 (62)	27 (6)
Yes, postgraduate PC training	24 (20)	4.3 (3)	45 (10)
No postgraduate PC education	17 (14)	5.8 (4)	27 (6)
Mean number of patients in the palliative phase in care (per month)			
≤5	8.3 (7)	13 (9)	23 (5)
6-20	50 (42)	57 (39)	54 (12)
21-50	33 (28)	25 (17)	23 (5)
≥51	8.3 (7)	5.8 (4)	0 (0)
Mean number of patients that die in which the healthcare provider is involved (per month)			
0-1	3.6 (3)	15 (10)	14 (3)
2-5	48 (40)	58 (40)	64 (14)
6-10	36 (30)	17 (12)	18 (4)
≥11	13 (11)	10 (7)	4.5 (1)

** healthcare professionals with one of the following specialist palliative care education: Palliative Medicine for Health Care Professionals at the Cardiff University, UK., Palliative Care Education of the Dutch College of General Practitioners, Short course palliative care of the Dutch College of General Practitioners, Post graduate education palliative care for nurses.*

Prevalence of symptoms of burnout

Sixty-nine percent of respondents scored a median level of burnout, with 2% reporting a high or very high burnout score. Most respondents showed median levels on the four main constructs: exhaustion (55%), mental distance (49%), emotional impairment (78%), and cognitive impairment (70%). Furthermore, 8% of the respondents reported high or very high levels of exhaustion and 9% of the respondents had a high or very high level of cognitive impairment. Most respondents (74%) had a median level of secondary symptoms and 12% reported a high level of secondary symptoms (Figure 1).

Figure 1 Symptoms of burnout scores per scale



** Secondary symptoms includes psychological distress and psychosomatic complaints*

Univariate differences in burnout

Older healthcare professionals scored significantly lower compared to younger healthcare professionals regarding burnout score (1.78 (.42) versus 2.06 (.44), $p<0.05$), exhaustion, (1.98 (SD.59) versus 2.35 (SD .55), $p<0.05$), and emotional impairment (1.68 (SD.45) versus 1.94 (SD.51), $p<0.05$). Furthermore, the burnout score differed between healthcare professionals with more than 10 years of experience in palliative care with those with less experience (1.77 (.43) versus 1.87 (.43), $p<0.05$). The burnout score did not significantly differ between professions, settings, type of palliative care education and number of patients who die under their care per month (Table 3).

Table 3 Univariate comparison of the total burnout score between different characteristics

BAT-scales (M (SD)	N	Total BO score (Mean and SD)	p-value
Profession			
Nurse	85	1.81 (.42)	**p=0.6107**
Physician	69	1.82 (.42)	
Other	23	1.79 (.55)	
Setting			
Homecare	42	1.9 (.39)	**p=0.3688**
Hospital	69	1.9 (.45)	
Nursing home	14	1.8 (.44)	
Hospice	36	1.7 (.47)	
Age			
<40 years	20	2.06 (.44)	**p=0.0048**
≥41 years	157	1.78 (.42)	
Years of experience in palliative care			
0-5	37	1.9 (.45)	**p=0.0097**
6-10	35	1.8 (.41)	
11-20	50	1.9 (.35)	
> 21	54	1.7 (.49)	
Education in palliative care[a]			
Postgraduate PC training	23	1.81 (.42)	**p=0.9645**
Specialist PC education	112	1.81 (.42)	
No PC education	18	1.86 (.44)	
Mean number of patients that die in which the healthcare provider is involved (per month)			
0-10	156	1.8 (.43)	**p=0.6196**
≥11	19	1.8 (.50)	

[a] *only nurses and physicians were included in this analysis due to predefined specialised palliative care education options in survey.*

Impact of providing palliative care on healthcare professionals' wellbeing

The majority (64%) of the respondents reported no consequences of their work for their own wellbeing. One fifth of the respondents (20%) reported having experienced a period of stress symptoms such as insomnia, rumination, irritability and/or crying easily. Furthermore, 16% of the respondents had felt overloaded for a longer period (>four weeks) as a result of their work and 6.7% of the respondents reported to have been on sick leave due to burnout symptoms.

Coping strategies regarding work-related stress

Almost all respondents (97%) reported engaging in activities for dealing with work-related stress, with an average of 3.7 (SD 1.7) activities. These activities included mainly: talking to colleagues about impactful events (84%); leisure activities such as sports, walking, gardening or listening to music (84%); peer coaching (50%); and team consultation (40%) (Table 4). Overall, 23% of the respondents felt that their activities were not sufficient for them in coping with work-related stress.

Table 4 Coping activities used by healthcare professionals providing palliative care (n=179)

Activity	Frequency (%)
Talk to colleagues about impactful events	151 (84)
Leisure activities (sports, walk, gardening)	151 (84)
Peer coaching	90 (50)
Team consultation	71 (40)
Variation in work activities	62 (35)
Distraction (education for example)	49 (27)
Mindfulness, meditation and yoga	40 (22)
Support by manager	33 (18)
Individual coaching	18 (10)
Getting support at home	7 (3.9)
Other	5 (2.8)

Table 5 Experienced problems related to work-life balance by healthcare professionals providing palliative care (n= 179)

Problem	Frequency (%)
Workload	81 (45)
Burden of administration	78 (44)
Long working hours	59 (33)
Working alone/little contact with colleagues	33 (18)
Lack of knowledge regarding work-life balance	11 (6.2)
Lack of palliative care knowledge	7 (3.9)
Lack of palliative care knowledge among colleagues	6 (3.4)
Other	35 (20)
No problem	29 (16)

Work-life balance problems and needs

Most respondents (84%) experienced multiple problems with their work-life balance, with an average of 1.9 (SD 1.02) problems. Reported problems in maintaining a healthy work-life balance were high workload (45%), administrative burden (44%), and long working days (33%) (Table 5). The majority of respondents expressed a need to maintain or restore their work-life balance (87%). Most frequent mentioned needs were: time to talk with colleagues about impactful events (55%); feeling emotionally safe within the team (39%); and less work pressure (34%). Almost one fourth of the respondents (23%) reported that paying more attention to the emotional impact of providing palliative care is important (Table 6).

Table 6 Work-life balance related needs (n=179)

Work-life balance related needs	Frequency (%)
Time to talk to colleagues about impactful events	98 (55)
Feeling safe within the team	70 (39)
Less work pressure	60 (34)
More attention for emotional impact	42 (23)
Peer coaching	4 (2.2)
Variate in work activities	4 (2.2)
Other	31 (17)
Nothing	24 (13)

DISCUSSION

This first nationwide survey among healthcare professionals providing palliative care in the Netherlands had a high response rate and shows that more than two-thirds experience a median level of burnout. Some healthcare professionals even experience high levels of burnout, indicating a severe burnout. Furthermore, a significant number has felt being overloaded as a result of their work or even has been absent from work due to burnout. Being older and having more experience in providing palliative care is associated with a lower risk of (symptoms of) burnout. Almost all healthcare professionals providing palliative care are engaged in several activities to maintain a healthy work-life balance. Nevertheless, nearly a quarter of all healthcare professionals feel that these activities are not sufficient to maintain a healthy work-life balance. They encounter mainly organisational problems such as high workload, administrative burden and long working days. Important needs are related to sharing impactful events within the team, such as having more time to talk to colleagues and feeling emotionally safe within the team.

The levels of burnout found in this study are lower compared to those of healthcare professionals in the Netherlands who do not provide palliative care on a regular basis. Houkes et al. showed that approximately 20% of general practitioners in the Netherlands experienced a clinical burnout.[19] Similarly, a survey among members of the Dutch Anaesthesia Society demonstrated a prevalence of burnout of 18% among anaesthesiologists in the Netherlands.[20] The low percentage of high level of burnout in our study might be explained by multiple reasons. Firstly, the majority of respondents in this study had received specialist palliative care education. Therefore, they might be better equipped to provide palliative care and to cope with the emotional impact of providing this care than healthcare professionals providing generalist palliative care.

This is in line with a study among palliative care teams in Portugal showing that healthcare professionals with postgraduate palliative care education have less symptoms of burnout compared to colleagues without this education. Additional palliative care education seems to be a protective factor for burnout.[21] Secondly, in our study most respondents had ample experience in providing palliative care, which also seems to be a protective factor. A US study among healthcare professionals providing palliative care showed that more experienced professionals were in less danger of developing burnout.[22] This might also be explained by the fact that more resilient healthcare professionals are more likely to continue working in this profession.[23] Interestingly, in our study no relation was seen between level of burnout and exposure to a higher number of dying patients per month. This is in line with a recent study on the level of exposure to death and levels of burnout among nurses and physicians in Israel, that showed no significant differences between healthcare professionals with high level of exposure to death and those with a lower exposure.[24] However, a study among German palliative care teams showed that the mean critical number of deaths per week was 4.4, indicating that there is a maximum of suffering and dying one can cope with.[25] The assessment of level of exposure to dying patients in our study was not specific enough to be compared with these studies.

Our study also shows that healthcare professionals are engaged in many activities to maintain a healthy work-life balance, predominantly talking to colleagues about impactful events, leisure activities, peer coaching, and mentorship. Similar activities were also seen in other studies.[26,27] A US study showed that hospice and palliative medicine physicians engage on average in four activities to prevent burnout. Most common reported activities by these physicians were: promoting their physical well-being by for example exercising; nurturing professional relationships with a focus on teamwork and collegiality and taking a transcendental perspective by engaging in spiritual exercises such as meditation. Furthermore, talking with colleagues and loved ones was an important need.[27] However, in our study respondents felt that these activities were not sufficient to maintaining a healthy work-life balance. This might indicate that the current activities individuals engage in do not fully match the needs of healthcare professionals providing palliative care. Moreover, healthcare professionals feel that it is important to share impactful events with colleagues. However, a frequent reported need is having time to talk to colleagues and a safe team culture in which it is possible to share impactful experiences. Therefore, more attention to the emotional impact of providing palliative care seems warranted.

It is important to address both the needs within the sphere of influence of the healthcare professionals themselves (individual level) as the needs related to team culture and policy within healthcare organisations. This whole-system approach to prevent burnout has also been emphasized by other studies.[4,28-30] Harrison et al. state that current efforts to mitigate burnout in palliative care are mainly focused on the individual but should evolve to a system-level approach.[28] Although the individual level interventions remain important for decreasing the risk of burnout, placing the responsibility solely on the individual healthcare professional is not appropriate since it fails to address the structural causes of burnout. A dual approach on both individual and structural or organisational level is necessary to decrease the risk of burnout effectively.[4]

Strengths and limitations

This study is the first Dutch survey to assess the level of symptoms of burnout among healthcare professionals providing palliative care in the Netherlands. The response rate (54%) was fairly good and also a good distribution of nurses and physicians was present. However, recent research showed that surveys may provide valid burnout estimates despite low response rate.[31] Other limitations of this study were that, firstly, healthcare professionals who currently experience (symptoms of) burnout are more likely to reply to the survey invitation emails. This probably has resulted in some selection bias due to the 'healthy worker' effect. Secondly, the generalisability of our results to other countries is limited as the organisation of palliative care in the Netherlands deviates from other countries.

Implications for practice and future research

Work-related stress is common among healthcare professionals providing palliative care and currently used coping strategies do not seem to be sufficient for fully dealing with the emotional impact of providing this type of care. Clearly, due to the predicted shortage of healthcare workers in palliative care, it is important to better understand work-related stress in this field. Moreover, awareness of risk of burnout when providing palliative care and the importance of prevention is needed both at the individual level, the team level, and the organisation level.

As a result of the current coronavirus (COVID-19) pandemic awareness of the importance of the psychosocial wellbeing of healthcare professionals has increased.[32] Moreover, many healthcare organisations have started psychosocial support for healthcare professionals during this outbreak. For example, several hospitals in the Netherlands introduced a program for peer support or access to a psychological support team in dealing with the impact of Covid-19.[33,34] Hopefully this increased awareness will contribute to a sustainable change in mindset of healthcare organisations about their responsibility in addressing the psychosocial wellbeing of their healthcare professionals. It is essential to evaluate this support for its effectiveness and appropriateness to sufficiently address the emotional impact of providing palliative care.

Conclusion

Symptoms of burnout are quite prevalent among healthcare professionals providing palliative care in the Netherlands and some even experience a high level of burnout. Most healthcare professionals providing palliative care are actively engaged in multiple coping activities. Nevertheless, currently used activities are not adequate to prevent median levels of burnout and healthcare professionals have a need for supporting activities at team level and organisation level. Due to the foreseen increasing demand for healthcare professionals providing palliative care, it is vital to keep a healthy workforce in palliative care. Therefore, it is of utmost importance to develop support that transcends the individual level, such as activities within the team and on the organisation level.

DISCLOSURE

Authorship

All authors participated in the design of the questionnaire. AD did the data collection. AD, LB and NR were involved in the analysis. Interpretation of the data was discussed among all authors. AD drafted the manuscript. All authors were involved in the critical revision of the manuscript and approved the final version of the manuscript.

Declaration of conflicts of interest

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4

Clinicians' perceptions of the emotional impact of providing palliative care: A qualitative interview study

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ABSTRACT

Objectives

Many aspects of palliative care, such as managing (complicated) symptoms, conducting goals-of-care conversations, and repeated exposure to loss, can be stressful to clinicians . Previous research on the emotional impact of providing palliative care was mainly done in specialist settings. However, the majority of palliative care is provided by clinicians who are not specialised in palliative care, and can be supported by palliative care specialists only when needed. Therefore, this study aimed to gain insight into the emotional impact of providing palliative care on clinicians, both palliative care generalists and specialists.

Methods

A qualitative interview study among 21 clinicians (11 doctors and 10 nurses) working in hospitals, homecare or nursing homes in the Netherlands was conducted. Between February to June 2019, 13 palliative care generalists and 8 specialists were interviewed. Interviews were thematically analysed by two researchers.

Results

All clinicians considered the emotional impact of providing palliative care to be substantial and experienced both positive and negative aspects of providing palliative care. Several aspects of providing palliative care can support or undermine emotional stability. These so-called facilitators and barriers, such as practicing self-care and complexity of palliative care, were found at three different levels: individual, team and organisation.

Significance of results

Although clinicians experience providing palliative care as meaningful and valuable, the emotional impact is considerable. Negative and positive aspects often co-exist. Further insight into the dynamics and magnitude of the emotional impact of providing palliative care is needed in order to create a healthy working environment and develop adequate interventions.

INTRODUCTION

Clinicians providing palliative care are confronted with several impactful aspects such as complicated symptom management, complex and emotional conversations with patients and their family, and repeated exposure to death and dying.[1-3] These specific aspects of palliative care can attribute to work-related stress, which in turn may lead to burnout.[4,5] Meanwhile nurses and doctors are also confronted with a high workload (including administration and working long hours), greater staff shortages and treat more patients than ever before (and face increasing patient expectations).[6, 7] In addition, there is a growing need for palliative care due to people getting older and having more co-morbidities.[8] In addition, unexpected developments can have a major impact on the emotional wellbeing of clinicians, as experienced with the outbreak of Covid-19. A meta-analysis of 65 studies on the psychological impact of Covid-19 on healthcare professionals all over the world showed a prevalence for clinical depression, PTSS and burnout of respectively, 31%, 40% and 37% since the outbreak of the pandemic.[9] The growing demand for palliative care, combined with an increasing shortage of healthcare professionals and high workload, means that drop-out of clinicians should be avoided. This calls for attention to the wellbeing of clinicians in order to retain them in the healthcare field.

Existing research on the emotional impact of providing palliative care is inconclusive. Firstly, most research focuses only on the specialised palliative care settings such as palliative care units and palliative care teams.[10,11] Secondly, some studies suggest that healthcare professionals providing palliative care consciously choose to work in the field of palliative care, which is seen as a protective factor for work-related stress.[12] However, providing palliative care might not be a deliberate choice for all clinicians, especially those providing generalist palliative care. In the Netherlands, palliative care generalists provide care during the whole disease trajectory including both curative and palliative care. These palliative care generalists often do not have any formal palliative care training.[13]

Thirdly, there is unclarity about the impact of the confrontation with suffering and dying on a regular basis. Some studies state that there is a ceiling effect in the amount of dying patients a clinician can deal with.[14] Other studies found no negative relation between level of exposure to death and burnout. They state that being able to help patients and their relatives in such an important part of their lives helps them cope with work-related stress.[15]

To our knowledge limited studies have been conducted to assess the emotional impact of providing palliative care in both palliative care generalists and specialists. Therefore, this study aimed to gain insight into the emotional impact of providing palliative care on both types of clinicians.

METHODS

Study design

A qualitative study using semi-structured interviews was performed. This study design allowed the examination of the perceptions of clinicians providing generalist and specialist palliative care in the Netherlands regarding the emotional impact of caring for patients in need of palliative care. For reporting the COnsolidated criteria for REporting Qualitative research (COREQ) checklist was used.[16]

Participants and setting

We aimed at including a heterogeneous group of clinicians providing palliative care with a fair distribution regarding type of clinician (nurse and doctor, both palliative care generalists and specialists) and setting, using a matrix of setting and profession.

In the Netherlands, palliative care generalists, such as general practitioners, medical oncologists, home care nurses, and oncology nurses provide care during the whole disease trajectory including palliative care. They are supported by palliative care specialists if required. Palliative care specialists were defined as clinicians with additional education in palliative care and working as a palliative care consultant, either in the home care setting, or in a hospital palliative care consultation team.

Recruitment

Participants were recruited through convenience sampling. Colleagues of the Netherlands Comprehensive Cancer Organisation were asked to act as an intermediary to contact clinicians from their local network for this study. Those clinicians who gave permission to be contacted received an e-mail from the researcher (AD) inviting them to a face-to-face interview at their place of preference.

Data collection

All interviews were conducted between February 2019 and June 2019 by AD, a female PhD with a background in psychology. Interview duration ranged between 29 and 65 minutes. A semi-structured topic list was used to guide the interview, with some separate questions for palliative care specialists (Supplement I). Participants also completed a short self-administered questionnaire on socio-demographics. The semi-structured topic list was developed by AD and LB, based on previous research on burnout among clinicians.[17-19] The topic list was approved by all authors and tested on a clinician. Two main themes were included; 1) experiences and views of the clinicians related to the emotional impact of providing palliative care, 2) activities undertaken by the clinician and their organisation to maintain emotional stability. Aim of the study, the role of AD and main themes of the interview were explained beforehand. All interviews were audio-recorded and transcribed verbatim. Interviews were held until saturation per type of clinician was reached.

Data analysis

Interviews were analysed according to the thematic analysis approach using Atlas.ti version 8.4.18. Data analysis started during data collection so new themes that emerged from the interviews could be added to the topic list. Two researchers (LB and AD) independently coded three randomly selected transcripts using an open coding procedure and results were compared. This procedure was repeated two times, with in total three new manuscripts, to confirm uniformity among researchers. Disagreements between the researchers over codes and categories were resolved via discussion. Based on the codes, categories were derived by two researchers (LB and AD) and clustered into themes and discussed with the research group.

Ethical consideration

In the Netherlands, according to the Central Committee on Research involving Human Subjects this type of study is exempt from approval of an ethics committee due to the fact that there was no invasive intervention nor were there vulnerable patients involved (CCMO, 2020).[20] The interviewer explained the purpose of the study and anonymity of participants was guaranteed. For all participants written informed consent was obtained and participants were informed that they could withdraw from the study at any time.

RESULTS

Participant characteristics

In total, 21 clinicians were interviewed, including 13 palliative care generalists and 8 palliative care specialists. Ten participants were nurses and eleven were doctors. The clinicians worked in hospitals (n=9), home care (n=7) and nursing homes (n=5). Participants were mostly women (81%) and had a median age of 49 (26-67) (Table 1).

Table 1 Healthcare professionals' sociodemographic characteristics

	Palliative care generalists (n=13) N (%)*	**Palliative care specialists** (n=8) N (%)***
Gender		
Women	11 (85)	6 (75)
Men	2 (15)	2 (25)
Age (median, range)	48 (26-66)	49,5 (35-67)
< 35	3 (23)	0 (0)
35 – 55	5 (38)	6 (75)
>55	5 (38)	2 (25)
Profession		
Doctor***	6 (46)	5 (63)
Nurse	7 (54)	3 (37)
Setting		
Home care	5 (38)	2 (25)
Nursing home	3 (23)	2 (25)
Hospital	5 (38)	4 (50)
Years of experience in healthcare in general		
<10 years	4 (31)	0 (0)
10– 20 years	4 (31)	4 (50)
>20 years	5 (38)	4 (50)

*due to rounding the numbers do not always/necessarily add up to 100%

**having received a specific training in palliative care and working as a consultant or in a palliative care team

*** GP, medical oncologist, pulmonologist, elderly care physician

Emotional impact of providing palliative care

All clinicians considered the emotional impact of providing palliative care to be substantial. When elaborating on this impact, many participants mentioned both positive and negative aspects affecting their emotional stability. These positive and negative aspects of their work often coexist, as illustrated in the following quote: *"As a nurse, I think it is almost like you torment yourself a little, […] because it is beautiful, it brings you a lot, but it comes at a higher expense. And I think it is important that you keep a balance in that."* Palliative care generalist (hospital nurse)

Reported positive aspects were 1) having a fulfilling and rewarding job and 2) experiencing personal growth as a result of providing palliative care. Several clinicians said that, although providing palliative care can be difficult and burdensome, they felt strongly motivated in their work by being able to help patients during this difficult part of their life: *"It [providing palliative care] concerns not only medical technical and pharmacological matters, but, above all, also the phenomenon that people end up in an* *existential crisis [...]. Yes, that can keep you awake at night, but it also gives you a lot of satisfaction."* Palliative care specialist (elderly care physician)

Personal growth was described in relation to learning valuable personal lessons as a result of providing palliative care. It made clinicians aware of what is really important in life and helped them realise that every person has different viewpoints and backgrounds. This resulted in becoming more open minded: *"It turns out that life is not so malleable. It [providing palliative care] has taught me to live in the moment. [...] I used to be very forward-looking and almost always just yearned for what was yet to come, while I forgot to enjoy the present. And that has very much changed."* Palliative care specialist, (hospital nurse)

Feelings of powerlessness were mentioned as having a negative emotional impact. Clinicians found situations in which helping a patient was beyond their control such as relatives getting upset due to a patient's death rattle, to be emotionally burdensome. One participant described a situation in which she was unable to relieve a patient's pain: *"I think mainly the sense of powerlessness. We are of course focused on helping [patients], on supporting them, on solving something. And in these situations you often can't do much anymore. Yes, you can be there, and often that is enough. But I think the powerlessness, the feeling of powerlessness... [...] When the family looks at us like 'what can you do to make this easier or more pleasant?' And you do not always have a solution."* Palliative care generalist (home care nurse)

Facilitators and barriers of providing palliative care regarding emotional stability

Several aspects of providing palliative care can support or undermine emotional stability; they function as so-called facilitators and barriers. These facilitators and barriers for emotional stability of the individual clinician were found at three different levels: individual, team and organisation (Table 2).

Individual level

Aspects of providing palliative care at the individual level included elements that are associated with personal attitudes, coping and actions of clinicians. Two facilitators of emotional stability on the individual level were mentioned: 1) attitude towards the inevitability of death as part of life and 2) practicing self-care. Also three barriers of emotional stability in relation to providing palliative care were mentioned: 1) patient-related aspects, 2) conflicting personal values between the patient and the clinician, and 3) lack of experience with loss and dying.

Table 2 Facilitators and barriers of providing palliative care regarding emotional stability

Level	Facilitator	*Description*	Barrier	*Description*
Individual	Attitude towards the inevitability of death as part of life	*realising illness and death are part of life* *being aware of what you can and cannot change about the patients' situation*	Patient-related aspects	*young patients* *involvement of young children* *a long lasting therapeutic relationship*
	Practicing self-care	*taking a deep breath after having seen a patient* *going for a run* *consciously distancing yourself from work after a workday*	Conflicting personal values	*different perspectives on the best possible care* *having to choose between attend to patient wishes or sticking to one's own values and personal boundaries*
			Lack of experience with loss and dying	*having little experience in witnessing loss and dying increases the emotional impact*
Team	Supportive team culture	*receiving support from colleagues* *feeling safe within the team to be open and honest about the impact*	Colleagues not experienced in palliative care*	*experiencing stress as a result of colleagues not recognizing what is needed to provide adequate palliative care*
	Having role models in self-care	*having experienced clinicians to set the right example how to practice self-care* *observing different types of self-care activities helps less experienced clinicians develop their own coping strategies*		

Organisation	Opportunity to reflect on (impact of) care	*structurally discuss impactful situations among colleagues*	Care as usual is under pressure	*experiencing a high workload*
				not having the extra time that is needed to provide good palliative care
			Complexity of palliative care	*providing four dimensional care is mentally and emotionally demanding*

*only experienced by palliative care specialists

Some clinicians mentioned that it was helpful to realise illness and death are an inevitable part of life and that you cannot prevent this from happening. They mainly focused on their potential contribution to providing high quality of care for patients in their last phase of life. Some clinicians said that recognizing the difference between what they can and cannot change about the patients' situation can prevent feelings of frustration and powerlessness: "*I also notice awareness of what you do have, and what you can do for someone and what you cannot change. This may also have a protective effect. It's like a circle of influence: on what aspects can I exert influence and how do I do that, and which aspect cannot be changed?*" Palliative care specialist (General practitioner)

Engaging in self-care activities or rituals was also mentioned to be a helpful coping mechanism. These took place during the workday (after contact with a patient, or after death of a patient), or at the end of the day. Examples were taking a deep breath after having seen a patient, going for a run, never working from home after working hours or consciously distancing themselves from work after a workday. Some clinicians became aware of this during the interview and engaged in these activities unconsciously. Others were already aware of needing activities to maintain emotional stability. "*I have been practicing mindfulness for years and it has brought me a lot. And by applying mindfulness in my daily life as a doctor, I actually build in moments of recovery all the time: When I walk to the waiting room I use that walk to get out of my head and focus my attention on my legs and feet. This way I get close to myself for a moment. I find these moments promote my recovery, they give me energy.*" Palliative care generalist (General practitioner)

Several patient-related characteristics or situations were frequently mentioned as emotionally undermining aspects of palliative care, including caring for a young patient, involvement of young children and having had a therapeutic relationship with the patient for many years. *"It really depends on what kind of patient I have in front of me and probably also a bit on my own identification with the patient. For example age, what kind of disease, their family and how the relationship with family members is."* Palliative care generalist (hospital nurse)

Another barrier was conflicting personal values between the patient, their family and the clinician, resulting in different perspectives on the best possible care. Conflicting values can lead to difficult situations for clinicians as they must choose between letting go of their personal values to meet the needs and wishes of the patient. Or protecting their personal boundaries and telling the patient that they cannot comply to their wishes.

Furthermore, some participants said that their lack of experience in witnessing loss and dying increased the emotional impact. With time and experience they found a way to deal with it and the impact declined. This was also observed by a palliative care specialist among her colleagues from other departments: *"In departments where they are not so used to dealing with [dying patients], I notice that the impact is substantial. People almost drown in the feeling that the appropriate care should be delivered, immediately, because the patient is dying. [...] and the impact in those departments seems to be greater than in a department in which it is more common for people to die."* Palliative care specialist (hospital nurse).

On the contrary, it was also mentioned that witnessing many patients die may have a cumulative effect, in which case the clinician appears to reach some sort of limit: *"Well, I think you can reach a saturation level in terms of grief. And for some that level may be different than for others, but overall I think that after a certain period you have to say 'life is more than just this'. So it's self-protection..."* Palliative care specialist (elderly care physician)

Team level

On the team level two facilitators supporting emotional stability of the individual clinician arose: 1) supportive team culture and 2) having role models in self-care. Having colleagues who are not experienced in providing palliative care was experienced as a barrier undermining emotional stability. The team level included those colleagues with whom a clinician works together in the care for patients.

Many participants reported receiving support from colleagues and feeling safe within the team to be open about the impact of providing palliative care to be an important facilitator in dealing with the impact of providing palliative care. Respondents also found other collaborative practices, such as sharing the care for patients when a colleague had a heavy patient load to be supportive: *"What I find very important is that you and your team are very collegiate. So you have to be flexible if you have terminal clients in care. And palliative care is of course much broader, but especially that last part, that dying phase, you have to be very flexible among each other. So if someone works in the evening shift, they must be able to call a colleague and ask 'hey, extra care is needed, can you go or do you want to take over my work?'."* Palliative care generalist (home care nurse)

Furthermore, having role models in self-care was mentioned as an important facilitator. Experienced clinicians should set the right example so that less experienced colleagues can observe different types of self-care and coping. This way less experienced colleagues can learn what self-care activities fit their personality and develop their own coping strategies. *"You learn by watching how others do it [self-care activities]. And then by doing it yourself and when you gain experience, you will learn: this may also work for me. You also experience: this does not suit me, I shouldn't do that. [...] And just a good division between that the beginners are in a good surrounding, that they have enough examples where they can compare themselves to and can pick from what suits them. And be able to not use what does not suit them."* Palliative care specialist (medical specialist).

Having colleagues who are not sufficiently educated in providing palliative care was mentioned as a barrier regarding the impact of providing palliative care. This was solely mentioned by palliative care specialists working in a team with mainly palliative care generalists. The palliative care specialists mentioned it can be emotionally stressful when your colleagues do not always recognize what is needed to provide adequate palliative care: "*They give the care that is needed and then they leave again. And the next care-visit they come again and think: what needs to be done this time? But they are not looking ahead: the weekend is coming up, shouldn't we already discuss what pain medication should be available? Suppose something happens, what should we do? And then you feel very responsible.*" Palliative care specialist (home care nurse)

Organisational level

One facilitator of emotional stability on the organisational level was mentioned, namely peer support. Also two barriers of emotional stability in relation to providing palliative care were mentioned: 1) care as usual is under pressure and 2) the complexity of providing palliative care.

Many participants mentioned the possibility of structurally reflecting on the impact of palliative care and especially impactful situations as beneficial for emotional stability. An often mentioned example was peer coaching sessions. Several clinicians mentioned that such peer coaching sessions should be guided by a trained professional to make sure feelings are being addressed adequately and prevent the conversation from remaining superficial: "*Good peer coach sessions with a good supervisor once every two months. I don't even think every month is necessary. But you must attend them and share your experiences. I think, that way, things will come out sooner rather than when it is actually already too late."* Palliative care generalist (medical specialist)

An aspect that undermines the emotional stability is that clinicians felt the whole healthcare system is under pressure due to a high workload. Some participants mentioned that they feel it is impossible to take some extra time that is needed to provide good palliative care. "*That the formation of care is not sufficient, that there are people who do not look carefully at what is happening, that they call you in too late so that someone, in your opinion, suffers unnecessarily. [...] You know, all those things that I, as a simple doctor, can't influence. Or at least to a limited degree, in my experience. And that also costs energy, because it is precisely the things that you have no influence on, that cause the most frustration and by now I learned that frustration is a killer."* Palliative care generalist (elderly care physician)

Furthermore, the complexity of palliative care was also mentioned as an important barrier. When providing palliative care, clinicians address not only physical care, which can sometimes be complex, but also pay attention to the psychological, social and spiritual dimensions of palliative care. This not only requires time, but is also perceived as mentally and emotionally demanding as the following quote demonstrates: " *It just makes an appeal to you as a doctor, because at that point everything comes together. You are dealing with people who are in a very intensive period of their lives, who are vulnerable, yet can also be very strong because of it. There are so many emotions involved and the four pillars of palliative care [...] yes in every area it is just pulling all the stops and that is intense. Yes, that does something to you as a doctor.*" Palliative care specialist (general practitioner)

Overall, in the above mentioned results there were no substantial differences in the perceived facilitators and barriers between doctors and nurses and both palliative care generalists and specialists experience needs on the individual, team and organisational level.. Only having colleagues who are not sufficiently educated in providing palliative care was mentioned solely by palliative care specialists. It means that they feel they cannot rely on the quality of the care their colleagues provide, and are hesitant to go on holiday. *"Well you know how hectic the care in the end-of-life can be. So I already arranged a lot of things and everything was well put in order because I knew I was going on holiday, now I have to hand it over to the team, with all palliative care generalists so to speak. Is that going well? And then I felt that responsibility very strongly. Are things going well? Are they handling this well now? Can I leave this to my team?"* Palliative care specialist (home care nurse)

DISCUSSION

Main findings

This interview study shows that both palliative care generalists and specialists experience substantial emotional impact of providing palliative care and that providing this care can simultaneously positively and negatively affect their emotional stability. This coinciding positive and negative impact can be attributed to facilitators and barriers on the individual, team and organisational level. Facilitators include practicing self-care, having role-models in self-care and having the opportunity to reflect on the impact of providing palliative care. Barriers include conflicting personal values, palliative care not being integrated in care as usual, the complexity of providing four dimensional palliative care, and repeated exposure to death and dying

Some findings deserve attention. Firstly, aspects of palliative care that undermine or support emotional stability occur simultaneously. It seems these factors do not balance out as a scale but coexist regardless of the degree of presence of the opposite factor. This was also seen in an Italian interview study among nurses and doctors who worked in a palliative care unit [21]. The authors concluded that some factors, such as work experience, may be supporting emotional stability in one clinician, but undermine stability in another. Likewise, in our study we found different views amongst the 21 clinicians about repeated exposure to dying. If a person perceives certain work aspects as stressful and how they respond to this stress can be explained by many factors, for example working conditions, not working in a team, personality or age.[5, 22-24]

Secondly, our study showed that repeated exposure to dying patients can have different effects on the emotional stability of clinicians, whereby having some experience of patients in the dying phase and witnessing death seems to help in coping. Whereas frequent exposure to death and suffering can have a cumulative negative effect on emotional stability. Similar findings have been described in an Israeli study by Granek and colleagues.[25] In their study, 53% of the oncologists indicated that exposure to patients' death had normalized death and dying for them. While other participants indicated that exposure to a patient's death had made death more frightening (24%) and/or sadder (28%) for them.

Furthermore, apart from individual aspects undermining and supporting emotional stability, our results also revealed important elements on the team and organisational level. Similar results were found in a systematic literature review on moral distress experienced by healthcare professionals providing palliative care.[26] This review identified four main areas: 1) personal, 2) patients and caregivers, 3) colleagues and superiors and 4) environment/organisation. The authors state that these factors may both support or undermine the emotional stability of clinicians and remark that moral distress is a multidimensional phenomenon and a complex process. They suggest that not only training and education is necessary to empower clinicians, but also preventive and supportive organisational interventions. Although the reaction to stress is different in every individual, increased attention is being paid to the need for a system approach to properly address work-stress and burnout among healthcare professionals. This system approach advocates a shift from a focus on individual oriented interventions towards a combined approach in which attention is also paid to interventions at team and organisational level [27, 28] This is in line with our findings in which clinicians plea for group interventions such as peer coaching.

Strengths and limitations

A limitation of the study is that the participants were almost all woman with a Dutch cultural background. Therefore, this study does not provide insight into sex and cultural differences in dealing with the impact of providing palliative care. Also, it is plausible that there has been some degree of self-selection when recruiting the participants, whereby participants with interest in the emotional impact of their work were more likely to participate in this study. This may have led to a restricted impression of the experienced impact of providing palliative care. This study also has strengths to be mentioned. Firstly, by including both palliative care generalists and specialists we aimed to broaden the research on the impact of providing palliative care, unrelated to work setting or level of palliative care education. Secondly, the interviews might have worked as an intervention in itself, the so-called therapeutic effects of qualitative research.[27] During the interviews it became apparent that many clinicians, especially palliative care generalists, were not used to talking about the emotional impact of their work. The interview itself might have helped them become aware of the importance of addressing this topic, both personally as within the team and organisation.

Implications for practice and policies

This study shows that clinicians experience the emotional impact of providing palliative care as substantial. Its impact related to providing palliative care, on top of the general work-stressors experienced by clinicians, requires attention, in light of the call of the World Health Organisation for equal access to palliative care and to integrate palliative care into existing health services.[30] With both the expected increase of need for palliative care in the near future, and in light of unforeseen situations such as the outbreak of a pandemic, more clinicians will be involved providing care for patients in their last phase of life. This would not only make the case to train clinicians in palliative care skills, as advocated in the context of the integration of palliative care, but also to pay specific attention to learning to reflect on the personal emotional impact of providing palliative care to maintain emotional balanced.[31]

Furthermore, this study shows the importance of addressing the emotional impact of providing palliative care on clinicians at both the individual, team and organisational level. However, most interventions aimed at reducing burnout are on the individual level.[32] This implies that the impact of providing palliative care is only an individual problem, while there are also important aspects regarding the team and organisational level.[28] Addressing these aspects are often beyond the personal influence of clinicians. Therefore, it is important that healthcare organisations support solutions such as peer coaching and provide the opportunity, both in time and in addressing the work culture related to this topic, to maintain and improve emotional stability for both palliative care generalists and specialists.

Conclusions

Providing palliative care has a substantial emotional impact on clinicians, both for palliative care generalists as palliative care specialists. Clinicians simultaneously experienced positive and negative impacts on their emotional stability. The impact of providing palliative care can be mitigated by facilitators and barriers on the individual, team and organisational level. Structured attention towards dealing with this impact on all these levels should be implemented. More knowledge on adequate interventions to maintain emotional stability is needed to enable clinicians to provide excellent palliative care for a growing population.

DECLARATIONS

Authorship

All authors participated in the design of the topic list. AD conducted the interviews. AD and LB and NR were involved in the analysis of the interviews. Interpretation of the data was discussed among all authors. AD drafted the manuscript. All authors were involved in the critical revision of the manuscript and approved the final version of the manuscript.

Declaration of conflicts of interest

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SUPPLEMENT I: Topic list

Introduction of the interview

Emotional impact of providing palliative care

- How are you involved in the care of patients in the palliative phase?
- What is the emotional impact of caring for patients in the palliative phase on you as a healthcare professional? *Can you give an example of a situation where caring for a patient in the palliative phase was difficult for you? What caused that? What did you do then?*
- [palliative care specialist] In your opinion, is there a difference in how the emotional impact of providing palliative care is experienced between palliative care generalists and specialists.
- [palliative care specialist] What do you think is different in providing palliative care compared to working in another healthcare setting in relation to the emotional impact?
- Palliative care includes care on the physical, psychological, social and spiritual domain. When you think about delivering those aspects of care, what is the impact on you?
- What do you see in colleagues in your field (palliative care generalists) with regard to the emotional burden of caring for patients in the palliative phase? *Can you explain this? Can you give an example of this? What are causes for imbalance?*

Complaints that precede emotional overload are for example poor sleeping, irritability, crying easily, worrying and feeling agitated.

- Which complaints do you recognize in your colleagues (palliative care generalists) a result of providing care to patients in the palliative phase?

Stress elements related to providing palliative care are: exposure to death and dying, insufficient time for dying patients, not being able to cope well with one's own emotions regarding the patient's death, feeling helpless/powerless.

- What makes / How come that providing palliative care specifically contributes to these complaints/emotional burden? *Is there a difference between how you perceived this when you first started working and how you perceive this now?*

Elements of Burnout

Such complaints can result in emotional overload, also known as burnout. Burnout consists of three elements: emotional exhaustion, depersonalization, and a sense of diminished accomplishment.

- Emotional exhaustion is described as a feeling of extreme fatigue (reserves are depleted and the battery can no longer be charged). Do you recognize this in yourself or your colleagues? *If you think about it, how is this linked to providing palliative care?*
- Depersonalization involves becoming alienated from others. People develop a negative, cynical and distant attitude towards their patients, colleagues and work. Do you recognize this in yourself or your colleagues? *If you think about it, how is this linked to providing palliative care?*
- The third dimension of burnout is sense of diminished accomplishment; it feels like you can't perform as you are used of yourself in the past. It's a tendency to judge yourself negatively. Do you recognize this in yourself or your colleagues? *If you think about it, how is this linked to the provision of palliative care?*
- Up to now we have mainly discussed the burden of palliative care. The literature suggests that working in palliative care settings can also be a protective factor against emotional stress. What is your opinion on this? *What do you think can be protective factors of providing palliative care?*

Needs and support

In addition to how caring for patients in the palliative phase impacts you as a healthcare professional, we are also interested in the policy with regard to this theme.

- How do you try to protect yourself from the potential burden of caring for patients in the palliative phase? *Is this helpful? How do your colleagues do this?*
- What is done within your organisation when someone is emotionally overloaded or experiences related complaints? *What does your manager/supervisor do? What is the policy of the organisation?*
- What specific interventions are there for healthcare professionals who care to many patients in the palliative phase? *If there are interventions: how are they offered; focused on the individual, the team or the organisational level?*
- In what way does your organisation pay attention to prevention with regard to this theme?
- Which aspects do you think should be given (more) attention to prevent or reduce burnout within your organisation?

5

Nursing assistants' perceptions and experiences with the emotional impact of providing palliative care: A qualitative interview study in nursing homes

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ABSTRACT

Aim

To gain insight into the perceived emotional impact of providing palliative care among nursing assistants in Dutch nursing homes, their strategies in coping with this impact and associated needs.

Design

Exploratory qualitative study.

Methods

In 2022, seventeen semi-structured interviews with nursing assistants working in Dutch nursing homes were conducted. Participants were recruited via personal networks and social media. Interviews were open coded by three independent researchers following thematic analysis approach.

Results

Three themes emerged regarding the elements that contribute to the emotional impact of providing palliative care in nursing homes: Impactful situations (e.g. witnessing suffering, sudden deaths), Interactions (e.g. close relationship, receiving gratitude), and Reflection on provided care (e.g. feeling fulfilment or feeling inadequate in caring). Nursing assistants used different strategies to cope, including emotional processing activities, their attitude towards death and work and gaining experience. Participants experienced a need for more education in palliative care and organised peer group meetings.

Conclusion

Elements that play a role in how the emotional impact of providing palliative care is perceived by nursing assistants can have a positive or negative impact.

Implications for the profession and/or patient care

Nursing assistants should be better supported in coping with the emotional impact of providing palliative care.

Impact

In nursing homes, nursing assistants are most involved in providing daily care to residents and have a signalling role in recognizing deteriorating conditions of residents. Despite their prominent role, little is known about the emotional impact of

providing palliative care among these professionals. This study shows that although nursing assistants already undertake various activities to reduce the emotional impact, employers should be aware of the unmet needs in this area and the responsibility they have in this regard.

Reporting method

The QOREQ checklist was used for reporting.

Patient or public contribution

No Patient or Public Contribution

INTRODUCTION

In the U.S., 44% of decedents stayed in a nursing home in the last 90 days of life and approximately 25% of older adults are cared for in a nursing home until they die.[1] In the Netherlands in 2019, out of a total population of 18 million inhabitants, more than 115,000 people lived in a nursing home or care home and 27% of deaths in the Netherlands occurred in a nursing home.[2,3] A nursing home is 'a facility with a domestic-styled environment that provides 24-hour functional support and care for people who need assistance with activities of daily living and who often have complex health needs and increased vulnerability'.[4] Care in these nursing homes is provided by a wide range of healthcare professionals, including care assistants, nursing assistants, nurses and elderly care physicians. In the Netherlands, more than one-thirds of employees in nursing homes are certified nursing assistants of which the majority has completed a three-year practice-oriented training allowing them to support residents in daily living - such as bathing, dressing and preparing breakfast -, nursing care activities - such as giving injections, dressing wounds and administering medication - and psychosocial care of residents.[5-8] In addition, certified nursing assistants have a signalling function for other healthcare professionals involved such as nurses and elderly care physicians. With this, Dutch certified nursing assistants (hereafter referred to as nursing assistants) are trained to a higher level than e.g. US nursing assistants, who typically receive a maximum of 75 hours of training.[9] However, despite their important role in providing palliative care, palliative care education for nursing assistants varies between educational institutions in the Netherlands and often focuses only on the care in the terminal phase.[10]

Worldwide, more and more people have complex chronic conditions and multimorbidity. It is estimated that by 2060 47% of all deaths will be people with serious health-related suffering.[11] This burden of health-related suffering is partially due to people getting older and is expected to lead to an increase in need for long-term care. Also the Dutch population is aging; the number of people older than 90 is expected to grow from 127,000 in 2019 to 318,000 in 2040.[12] Meanwhile, we are confronted with an aging labour force which will create a growing shortage of healthcare professionals delivering care. The shortage of professionals in long-term care facilities in the Netherlands is expected to rise to 90,000 employees by 2030.[13]

In many Western European countries the long-term care systems have changed in the last decades.[14] Most of these reforms focused on changing the access of care by focusing more on those most in need. Also in the Netherlands changes were made, making nursing home care only accessible for clients with high-level care needs who need 24-hour care or supervision.[15] A cross-sectional study of deceased residents in six European countries showed that 33% of residents in Dutch long-term care facilities die within one year of admission and 73% of residents need assistance with eating or drinking.[16] As a result, care provided in nursing homes is often intensive and complex and includes to a large extent care for patients in their last phase of life, palliative care.[16] Palliative care aims to improve the quality of life of patients with a life-threatening illness and their family by preventing and relieving of physical, psychological, social and spiritual suffering.[17] Because of the close personal contact that nursing assistants have with residents and the amount of time they spent with residents as a result of their work, they also have an important, signalling role in recognizing deteriorating conditions of residents.[18]

An international literature review showed that a substantial amount of healthcare professionals who provide palliative care experience symptoms of burnout, especially those working in non-specialized palliative care settings.[19] Moreover, the emotional impact of providing palliative care is often experienced as rewarding and fulfilling, but also as demanding, as research among Dutch physicians and nurses showed.[20] Although providing palliative care is a substantial part of their daily work, little is known about how nursing assistants experience the personal emotional impact of providing palliative care. The few studies present on this topic show that nursing assistants experience providing palliative care both as meaningful as well as emotionally distressing. A Swedish focus group study showed that nursing assistants experience providing palliative care as upsetting and have a need for support in encountering death.[21, 22] Furthermore, a study among nursing assistants in the U.S. indicates that direct care staff often experience grief symptoms similar to those experienced by family.

THE STUDY

The aim of this study was to gain insight into the perceived emotional impact of providing palliative care among nursing assistants in Dutch nursing homes. The specific aims were to get insight into: 1) what elements play a role in the perceived emotional impact of providing palliative care among nursing assistants 2) what are their strategies in coping with this emotional impact and 3) what are their associated needs?

METHODS

Study Design

An exploratory qualitative research using semi-structured interviews was conducted. This study design allowed to investigate in a broad sense how nursing assistants perceive the emotional impact of providing palliative care, their coping strategies and needs. Using interviews allowed the researchers to get a close understanding of the perceptions of the nursing assistants.

Recruitment and participants

Nursing assistants were eligible for inclusion when they (1) were working in a nursing home in the Netherlands, (2) had an IG3 educational level and (3) were older than 18 years.[5, 9] An IG3 education is a European Qualification Framework (EQF) level 3 practice oriented training of three years for nursing assistants. This training addresses palliative care to a limited extent.[10] Participants were recruited between February and April 2022 by means of convenience sampling. Colleagues of the Netherlands Comprehensive Cancer Organisation and the Netherlands Association for Palliative Care were asked to send out a priorly constructed recruitment text to nursing homes in their network. Also, a recruitment text was posted on the Netherlands Association for Palliative Care social media accounts. Interested individuals could respond by sending an email to the researcher (YH), after which they received more information on the content and purpose of the study. When they decided to participate, an appointment for the interview by videocall was planned. Additionally, for further recruitment we asked participants at the end of the interview if they knew other potential participants.

A total of 17 nursing assistants were interviewed, with a mean age of 50, ranging from 23 to 67 years. The majority had more than 25 years of experience as a nursing assistant, ranging from 2 to 50 years working in the nursing profession. Most participants cared for an average of one to two residents in need of palliative care per month (Table 1).

Data collection

A semi-structured topic list was developed to guide the interviews, ensuring to cover all relevant topics (see Appendix A). The topic list was developed by YH based on previous research on the emotional impact of providing palliative care, and discussed with AD and LB.[20, 23] Prior to the interview, participants gave written consent and completed a questionnaire on socio-demographic characteristics (see Appendix B). All interviews were conducted via videocall by two researchers (YH and AD) and took

Table 1 Certified nursing assistants' sociodemographic characteristics (n=17)

	N (%)*
Gender	
Female	16 (94)
Age (mean, range) (years)	50 (23-67)
< 35	3 (18)
35-55	8 (47)
> 55	6 (35)
Professional work experience as certified nursing assistant (years)	
< 10	5 (29)
10-25	4 (24)
> 25	8 (47)
Working hours as certified nursing assistant (per week)	
< 20	1 (6)
20-24	5 (29)
25-28	5 (29)
29-32	5 (29)
>32	1 (6)
Mean amount of nursed residents with palliative care needs (per month)**	
1-2	5 (29)
3-5	4 (24)
6-10	4 (24)
11-20	3 (18)

*due to rounding the numbers do not always add up to 100%

** missing data of 1 respondent

place between March and May 2022. YH, a female master student in Health Science, held 16 interviews and one was held by AD, a female PhD student with a background in psychology. During the interviews, the participants were asked a) about their perceived emotional impact of providing palliative care, b) how they coped with this impact and c) their experienced needs related to dealing with the emotional impact of providing palliative care. Interviews were audio-recorded and transcribed verbatim by YH. Duration of the interviews ranged from 35 to 60 minutes. Analysis of the interviews started during the data collection to monitor what topics emerged from the interviews. This enabled the researchers to discuss both whether the topic list needed to be adjusted based on these initial analyses and whether data saturation had been reached. Data saturation was based on the description of Boeije: 'researchers may stop collecting data when analysis of the newly selected cases yields no further information with regard to the selected research topics'.[24] When no new topics emerged from the interviews, researchers concluded data saturation was approached and no new participants were recruited.

Data analysis

Atlas.ti version 22 was used for analysing the data. The thematic analysis approach was used to identify, analyse and report patterns found in the data. The following steps as described by Braun and Clarke were carried out.[25] First, each transcript was read to familiarize with the data. Meaningful information, such as key phrases, was then identified and initial codes were created. Based on a relationship between codes, themes and sub-themes were formulated. A check was done to compare if codes properly fit the themes and if all meaningful data were reflected in the themes, and themes and sub-themes were named. The last step was to writeup the findings and select quotes to support our findings. To increase confirmability, three researchers (YH, AD and LB) independently coded three randomly selected transcripts and generated initial codes. These initial codes were compared and discussed until consensus on the codes was reached. A constant comparative method was used to compare codes within and between interviews. This process was repeated with two more transcripts to confirm uniformity between researchers. All remaining transcripts were coded by YH after which the researchers YH, AD and LB through discussion jointly identified the main factors and themes. Member checking was not applied. Participants did receive a summary of the results, but were not asked to provide feedback on the findings. Weekly debriefing, the iterative process of examining the data several times and comparing our findings to earlier studies and the literature added to the dependability and confirmability. The Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used for reporting this study.[26]

Ethical consideration

The study was conducted according to the declaration of Helsinki. The Medical Ethical Committee (METC) of Leiden Medical Center (LUMC, N22.017) in the Netherlands reviewed the study protocol and has decided to exempt this qualitative interview study from ethical review. This was done in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). Data analysis and collection were done in accordance with the Dutch Personal Data Protection Act. Prior to the scheduled interview, participants received an information letter and informed consent form. Before the start of the interview, participants were informed about the study aim, anonymity and the possibility to withdraw from the study at any time without any consequences. Written informed consent was obtained from all participants.

FINDINGS

In this study, the participants were asked about the elements that play a role in the perceived emotional impact of providing care, the strategies they use to cope with it, and what needs nursing assistants have regarding dealing with the emotional impact. Analysis of the results identified three broad themes for the elements and three themes related to coping strategies. Furthermore, two themes related to the needs of nursing assistants emerged.

Elements that contribute to the emotional impact of providing palliative care

Three themes have been identified regarding how the emotional impact of providing palliative care was perceived: 1) impactful situations, 2) interaction with residents and relatives and 3) reflecting on personal contribution to the care provided. Table 2 shows the elements that were mentioned relating to how the emotional impact of providing palliative care was perceived and the identified themes and sub-themes.

Table 2 Factors affecting the perceived emotional impact of providing palliative care

Factors	Relates to	Examples of rewarding aspects	Examples of demanding aspects
Impactful situations	Residents	-	Witnessing suffering of resident
		-	Witnessing family grief
		-	Young palliative care residents
	Process	-	Many deaths in a short time period
		-	Sudden deaths
Interactions with residents and relatives	Residents	Good understanding through personal relationship	Experiencing grief due to having a personal relation
	Relatives	Gratitude from families	Misunderstanding of families
		-	Incompatible family demands
Reflecting on personal contribution to the care provided	Feelings of fulfilment	Contributing positively to wishes of family/residents	-
	Feelings of powerlessness	-	Lack of time/staff
		-	Disagreement with policy of doctors
	Feelings of inadequacy	-	Insecurity how to act
		-	Insecurity about quality of provided care

Theme 1: Impactful situations

Some situations surrounding the care for residents in their last year of life were experienced as emotionally impactful. These situations concerned emotionally burdensome circumstances that nursing assistants were confronted with in their daily work and on which they personally had no influence. This theme consists of four sub-themes: 1) dealing with suffering and grief, 2) unfairness of life, 3) accumulation of deaths, 4) unexpectedness of deaths.

Witnessing the suffering of residents and grief of relatives greatly affected nursing assistants. Participants indicated that being confronted with residents who are in pain or experience shortness of breath, but not being able to alleviate this suffering led to feelings of sadness for the resident that they have to go through this:

"Last week we had a woman who passed away. And that woman was really anxious. And then I notice…, then I find it…, then I would really like to help her and take that away from her, but that's not possible. So that's just…, yes, I find that very difficult; that you can't just take over something from someone. You know, you see it and you can do your best by talking about it or by getting a doctor, but still, that fear remains, and I find that difficult sometimes." (R20)

When nursing assistants had to care for a young resident in the palliative phase, they often experienced feelings of unfairness of life, feeling that such a young resident should not yet die. Accumulation of deaths occurred when many residents died in a short time period and was also experienced as an impactful situation relating to how the emotional impact of providing palliative care was perceived. Furthermore, several participants reported that it was emotionally burdensome when a resident died suddenly. Nursing assistants indicated that such unexpected deaths preoccupied them because they did not understand exactly what had happened:

"Well, those are usually situations [sudden death of a residence] where I can't really put my finger on it. Because when you can't put your finger on it, you're also not really sure of your own actions. And so that's for example when someone just dies or has a cardiac arrest and that is stressful for me, to not be able to do anything." (R15)

Theme 2: Interactions with residents and relatives

The second theme that plays a role in the perceived emotional impact of providing palliative care related to the interactions nursing assistant had with residents and relatives. It involved the interaction both between the nursing assistant and the resident and their relatives, but also witnessing the interactions between the resident and their family. Three sub-themes were identified: 1) closeness of the relation with residents, 2) receiving gratitude, and 3) struggles with relatives.

To develop a personal relationship with residents was viewed as a beautiful aspect of providing palliative care. Nursing assistants experienced that when there was a close personal relationship, residents felt safe and opened up to the nursing assistant, leading sometimes to in-depth conversations. It implies that nursing assistants really know the resident and their specific wishes and needs:

"And the moment that [a resident] enters the dying phase, then I try to give that person what he needs [...] With some, for example, you take into account that in the room, it's just as quiet as possible. And with someone else you make sure that voices are still present, because that person is more sensitive to that. And so with that other person the silence is necessary." (R17)

On the other hand, having a close personal relationship with a resident increased the emotional impact of providing palliative care compared to residents with whom nursing assistants felt less connected. The emotional impact of this personal relationship was especially felt when a resident dies:

"There was a resident who died last year, a woman with whom I had very good contact. So the last time I cried like that was when my own mother died. So ... off course that feeling can come very close. It doesn't always happen, but this was really an exception. It was really like I lost my eh... second mother, definitely, yes" (R06)

Receiving gratitude, both from residents and from their relatives meant a lot to nursing assistants. On the other hand, nursing assistants mentioned struggles with relatives of residents as being impactful for them. In these situations the wishes of the relatives did not match the care wishes of the resident or relatives made demands in the resident's last phase of life that were not in line with policy or were unrealistic in the view of the nursing assistants. Such contradictions in wishes can lead to an inner conflict among nursing assistants about how to act. When relatives did demand that such incompatible wishes be carried out, then nursing assistants experienced a sense of sadness or anger:

"And the children can also have quite an ... impact of, ... there's still this and there's still that, and then this has to be done and then that. While the father or the mother no longer wants all that. But that for the children, [...] well that the children are, well, annoying, and difficult about it. What we [healthcare professionals] think and what they [the children] think, [...] and that the one who lies in bed doesn't have much to say about it anymore. I find that a very difficult situation." (R06)

Theme 3: Reflecting on personal contribution to the care provided

This third theme included nursing assistants looking back at the palliative care provided and evaluating their own role in this process. It consists of three subthemes: 1) feelings of fulfilment 2) feelings of powerlessness, and 3) feelings of inadequacy.

Nursing assistants mentioned that providing palliative care often gives them a sense of fulfilment. Of knowing that they contribute to good care in such an important part of someone's life:

"Then we put an extra blanket over the bed, we went outside, and we stood by the Christmas tree and we sang a Christmas carol. That's a matter of fifteen, twenty minutes, but that was so precious. That lady absolutely loved it. And for me that gave a lot of satisfaction, that I can do that for someone. (R12)

On the other hand, nursing assistants also experienced feelings of powerlessness. This occurred for example when nursing assistants had a vision on how they wanted to provide palliative care, but were unable to do so due to situational factors or preconditions that were not met, such as not having enough time and staff to provide good palliative care.

'and sometimes, you sit hand in hand with [a resident] because you just have to, and then your alarm goes off. I find that very difficult, to split up then and to say: "I have to leave you for a moment, but I will be back soon" You know, sometimes you just can't. And I find that very difficult' (R07)

Participants also experienced powerlessness when nurses or physicians gave conflicting instructions. Moreover, also when nursing assistants felt they were dependent of the policy of the physician or nurse and they did not have a say in this feelings of powerlessness were experienced:

"I have experienced, once, that a doctor for example did not want to prescribe morphine. And yeah, then I can get very angry… and think; why does this woman have to suffer like this, while the morphine is available, you know, to give her that peace. Well, eventually I talk with that doctor, and then finally I do get the morphine. But yes, I have to fight for it very hard and sometimes I just don't understand that. Yes, that makes me angry" (R08)

A sense of inadequacy happened due to nursing assistants' insecurities regarding their personal competence on how to act in certain situations and whether the care provided by the team was qualitatively sufficient. Some participants mentioned feeling guilty due to a self-perceived shortcoming towards residents and questioned whether they had done the right thing:

"Uhm, yes it [caring for residents in their last year of life] can also make you sad sometimes or, uncertain.… That you… if you're doing it right…, if you're giving the right care." (R09)

Coping strategies to deal with emotional impacts of providing palliative care

When asked about how they cope with the emotional impact of providing palliative care, nursing assistants mentioned several helpful strategies. Three themes arose from this 1) engaging in activities, 2) adopting a helpful attitude and 3) gaining experience. Table 3 shows the different strategies nursing assistants use regarding coping with the emotional impact of providing palliative care and the identified themes and sub-themes.

Theme 1: Engaging in activities

Nursing assistants mentioned a variety of activities for dealing with impactful experiences. This has been divided in two sub-themes: 1) releasing work-related stress and 2) consciously saying goodbye to a resident.

Activities that were aimed at processing and releasing of impactful situations and work-related stress were leisure activities (for example doing sports, walking or meeting with friends), talking with colleagues or a supervisor about what has happened, or seeking professional help. Sharing their experiences with colleagues helped nursing assistants in managing their emotions. A nursing assistant indicated that by crying, she was able to let go of the experienced emotions and therefore was better able to cope with these emotions. Nursing assistants also mentioned that this sharing of experiences led to mutual understanding among colleagues.

Table 3 Strategies regarding coping with the emotional impact of providing palliative care

Strategies	Themes	Examples
Engaging in activities	Releasing of work-related stress	Hobbies
		Collegial support
		Talking with supervisor
		Seeking professional help
	Consciously saying goodbye to a resident	Providing final care
		Funeral attendance
		Cleaning room of deceased
Adopting a helpful attitude	Peace with death	Acceptance of death
		End to suffering
	Professional vs personal attitude	Expressing personal emotions in the presence of residents
	Work-life balance	Not working outside working hours
Gaining experience	Experience with death	Feeling more at peace in providing palliative care due to gained experience

Another important coping activity that was mentioned by participants was consciously saying goodbye to deceased residents. This was done by activities such as laying off the body, attending the funeral or cleaning the room of the deceased resident. This helped participants to figurately close the chapter of caring for this resident:

[when a resident died before the nursing assistant could say goodbye] "Well, that's kind of a weird, a strange thing I'm going to say now, but then I'm very happy that I get to clean up a room and leave it tidy for the family. That's just for the last time still being able to do something so to say. [...] But lately we are allowed to do that [washing & laying out] again, so then you are, so to speak, the last person who has cared for someone, and that embodies the closing of for me. Like okay, I make sure someone is neatly groomed for the family and things like that" (R15)

Theme 2: Adopting a helpful attitude

This theme consists of thee sub-themes: 1) having peace with death, 2) balancing between having a professional or a personal approach towards residents, and 3) monitoring the balance of work versus private life. These attitudes served for many as a psychological coping mechanism through which they prevented becoming emotionally overwhelmed.

Having peace with death represents an attitude of acceptance that death is a natural part of life. Participants also mentioned it as a helpful attitude to realise that for many residents, dying means an end to pain and suffering. This yields a feeling of relieve among nursing assistants:

"Well, I think at some point, some people are obviously in a lot of pain or are expressing dissatisfaction. And then I think, well, of course you don't want to see someone in constant pain and things like that. So yes, sometimes I think, it's okay, you know. Like well, the body is drained, ...that resident is drained so to say. So yes, that way you can actually make peace with it" (R14)

Another helpful attitude many participants mentioned was to find a balance between being professional and being personal in relation to the residents. Most participants viewed personal emotional expression as unprofessional. They were very aware of their attitude towards residents and their relatives and the impact their personal expression of emotion may have on them. Many nursing assistants mentioned to try to allow some emotions whilst simultaneously suppressing them among residents and relatives. However, finding this balance remained difficult for most:

"With some people [residents] you always try to have a professional attitude; you try not to cry in front of the family because, well, that is not professional. Although I always say; you are not made of stone. You are not made of stone, but you should still try not to ... because well, it is not your mother, it is not your ..., but that is still difficult sometimes yes" (R05)

Many nursing assistants mentioned that monitoring their work-life balance was an important way of coping with the emotional impact of their work. Not working outside working hours, such as not reading their work e-mail or not being available for questions, was an often mentioned method to keep this balance.

Theme 3: Gaining experience

Gaining experience includes one sub-theme: exposure to dying and death. Participants mentioned how through practical experience with death and dying they had learned to cope both with their emotions and how to act in situations surrounding palliative care which also had an impact on the perceived impact. Some nursing assistants stated that through various palliative care experiences they became familiar with providing care to residents in their last phase of life, and therefore felt more at peace in these situations. More experience with providing palliative care led several participants to develop anticipation skills, making them quicker in identifying approaching death. For instance, becoming more alert in identifying the right time for preparing the family for the transition towards the death of their loved-one:

"I think that throughout the years I have seen that it is good to mention what is happening. If family members are present, ..., that's what I've learned for myself, that you can give them a bit of guidance, to eh... well, to put it into words what is happening, and what the expectations are. And also, practical things like, if someone indeed seems to be dying, then it's better to already say on the first day: maybe it's a good idea to start thinking about what kind of clothes you want your mother to wear, and about a funeral undertaker or ... those really practical things. I've learned to just, well, mention that right away" (R19)

Needs regarding dealing with the emotional impact of providing palliative care
Although participants named several coping strategies, they also mentioned unmet needs in dealing with the emotional impact of their work. These needs can be categorised into two themes: a need related to 1) obtaining knowledge and skills and 2) being supported in the emotional processing.

Theme 1: Obtaining knowledge and skills
Nursing assistants felt they need more practical and/or social knowledge. Desired education in social skills consisted for instance of ways on how to emotionally support and cope with residents and relatives. More practical needs were expressed regarding learning for example the various ways the palliative phase can develop and how they can act in different scenarios:

[Regarding needs] "Well, I think mainly all you have to think of, in the care, so to speak. So just practical things too actually, like moistening the mouth, that sort of things. Like how you can do that even better or in different ways, that sort of things, because, I know the basics, but I know there are also more things I don't know yet.... And..., a bit of guidance with family, I sometimes miss that a bit too here. What is the best way to guide the family, because that is also a question." (R20)

Nursing assistants felt this learning does not always have to be in the form of a training, but also can occur through learning from experienced colleagues, by learning from their perspectives and exchanging advice among each other in for example team meetings. They reasoned that experiences of others could support them in coping with palliative care situations and accompanying emotions.

Theme 2: Being supported in the emotional process

Participants expressed a need for organised collegial meetings to share experiences about palliative care situations and to vent their accompanying emotions to process them. They reasoned that it is important to feel safe to share your experiences and the related emotions whether it is anger, sadness or uncertainty with colleagues to help cope with the impact of their work:

"I think it might be good if there was some kind of training or meetings, so that people can, say, really pour their heart out if something bothers them, because there are of course plenty of colleagues who don't put it aside easily, but take it home with them. I think that's really something like, make it discussable, and it is not bad how you feel about it" (R15).

DISCUSSION

To our knowledge, this is one of the first exploratory studies on the emotional impact of providing palliative care among nursing assistants in the Netherlands. The findings of this study show that nursing assistants perceive the provision of palliative care as a valuable part of their profession, but also find this part of their work as personally demanding and difficult. Elements that play a role in how the emotional impact is perceived are impactful situations (such as witnessing suffering or residents who die suddenly), the interactions with the resident and/or their relatives, and by how the nursing assistants reflect on their work. Nursing assistants have multiple coping strategies for dealing with the emotional impact of their work, such as engaging in activities to release work, adopting a helpful attitude towards death and work, and gaining experience. Despite these efforts many nursing assistants feel the need for more knowledge and skills and desire organised sessions to share experiences with colleagues in order to learn how to better deal with the emotional impact of providing palliative care.

Many participants felt that the **relationship they had with residents** was an important factor in how they experienced the emotional impact of their work . Having a personal connection with residents makes their work meaningful and helps nursing assistants to provide better care. Several nursing assistants mentioned that, especially in the last phase of a resident's life, knowing a resident well allows them to provide personalised care and often leads to in-depth conversations. A study of healthcare assistants in New Zealand found that many participants felt that they had a familial relationship with residents and that this supported them to provide good quality, individualised care.[27] The downside of this personal relationship is that nursing assistants mentioned that the death of a resident they knew well affected them more than when there was less personal connection. This tension between building close relationship with residents and the associated feelings of loss and grief when a resident dies is also reflected in other studies. A US study showed nursing assistants working in nursing homes not only had a grief response after a patient's death, but that this response was similar to that of bereaved family caregivers, indicating a family-like feeling towards patients.[28] Therefore, it is important to recognize the impact of the relationship and possible subsequent grief, especially since grief over a patient's death play a role in the development of burnout symptoms in nursing assistants.[29] Although participants often mentioned that providing care to residents in their last year of life was fulfilling, many nursing assistants in this study mentioned that they regularly had feelings of inadequacy **in caring for these residents.** They expressed regular feelings of insecurity about the care they were able to provide to residents who were in need of palliative care. This insecurity and sense of falling short can have wider implications. Similar results were found in others studies, showing that nursing staff experience feelings of falling short and are hesitant to act in the care for residents who are in need of palliative care due to insufficient competence to for example have conversations with residents about death and dying.[22,30,31] Furthermore, studies show that such feelings threaten the staff's sense of self-respect and meaningfulness and lead to feelings of sadness, fear or shame.[21,31] This sense of falling short may be reflected in the need expressed by nursing assistants in this study for more knowledge and skills regarding palliative care. Another need frequently mentioned by nursing assistants in this study was being able **to share experiences with colleagues**. Although nursing assistants often engage in one-on-one informal collegial contact, they still expressed a need for organised collegial group meetings. Similar to our findings, a study of Danish nurses found that open collegial discussions to reflect on various emotions and situations were perceived as vital for coping with complex situations, but were still lacking at a formal organisational level.[27, 32]

Limitations

There are several limitations to the present study. The participants in this study do not form a very heterogeneous group: all but one of the participants were women, with almost half of them having more than 25 years of working experience as a nursing assistant. Another limitation of this study is that data saturation was based on initial analysis of the interviews and the researchers' impression that no new issues came up in the interviews. This may have led to recruitment being stopped prematurely. Furthermore, by recruiting through convenience sampling and placing invitations to participate on social media of a palliative care organisation, we might have a bias in nursing assistants who already have some affinity with palliative care and the personal impact this may have on them. Because of this self-selection bias and the homogenous group of women with many years of work experience, it may be that our participants have a different experience than if more men and nursing assistants with less work experience had been interviewed. However, across continents women constitute the large majority in the nursing profession and the aim of the study was not to generalize results, but to get a deeper understanding of the problem.[33] Although we chose to conduct this research in a single setting there is still much variation in the nursing home care setting. For example, within nursing homes there are often somatic, psychosomatic and rehabilitation units, all with their own characteristics and challenges. Further research on this may be interesting to gain insight into different aspects of providing palliative care in these units.

Implications for clinical practice

This study reflects a need of nursing assistants in support to better cope with the emotional impact of providing palliative care. Nursing assistants in this study expressed a wish for education in palliative care, both in practical and social skills, and structural meetings to reflect with and learn from colleagues. In light of the expected increase in elderly people and the associate need for palliative care and the important role of nursing assistants in this respect, nursing home managers should be aware that an active role to address these needs is necessary. The desire for more knowledge and skills highlights the importance of structurally embedding palliative care education in the primary training of nursing assistants. However, until this is implemented, organisations should assess the palliative care knowledge of their current nursing assistant workforce and additionally train them in providing palliative care. This will not only possibly enhance the quality of care for the residents, but might also reduce feelings of sadness and fear among nursing assistants and the need for support.[31, 34] However, also with firm knowledge on providing palliative care, nursing assistants can encounter impactful situations and still have a need to share the impact of these situations. To enable reflection among colleagues, address the doubts regarding the provided care and encourage peer learning, the CURA intervention could be effective.[35] CURA is an instrument providing a structure for ethical reflection on palliative care related moral challenges. It guides in reflecting on challenges, express doubts and vent emotions related to palliative care. This tool can also be used in collegial group settings by jointly reflecting and asking questions, which stimulates joint learning via the sharing of different perspectives on palliative care challenges. A Dutch study among nurses and nursing assistants showed positive results regarding feasibility of the instrument, but also that organisational preconditions need to be better addressed to help healthcare professionals use this intervention.[35]

Conclusion

When providing palliative care, nursing assistants experience both elements of providing palliative care that are emotionally demanding and elements that are rewarding. The emotional impact of providing palliative care on nursing assistants is underrecognized and deserves more attention. Although nursing assistants themselves already undertake several activities to cope with the emotional impact, employers must be aware of and take responsibility for unmet needs in this regard. Further research on how nursing assistants can be supported in dealing with this emotional impact is needed. In particular research on the duality of having a close personal relationship with residents while at the same time being able to cope with their personal feelings of loss may be interesting. In addition, it could be interesting to investigate whether educational interventions could be a valuable solution to diminish the emotional impact and foster emotional health among nursing assistants.

DECLARATIONS

Authorship

YH, AD and LB participated in the design of the topic list. YH conducted all but one the interviews; AD conducted one interview. YH, AD and LB were involved in the analysis of the interviews. Interpretation of the data was discussed among YH, AD, LB and NR. AD drafted the manuscript. All authors were involved in the critical revision of the manuscript and approved the final version of the manuscript.

Data availability statement

Data available on request due to privacy/ethical restrictions

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APPENDIX A: Interview guide

Introduction of the interview
Including introduction of interviewer, goal of the study, anonymity and confidentiality, the right to stop the interview at any time, and recording of the interview.

General question

- Can you talk a little about how you are involved in caring for residents in their last year of life?

Emotional impact of providing palliative care

- What does it do to you emotionally to care for residents in their last year of life?
- Do you remember any beautiful moments while providing care in the last year of life, can you tell something about them?
- Caring for residents in the last year of life is often perceived as a rewarding, beautiful experience from which you can personally also derive benefits. Do you recognize these positive effects or benefits in yourself? If yes: Which ones do you recognize?
- When providing care in the last year of life, difficult situations can arise such as sudden deaths, unenlightened suffering in the dying phase, many deaths in a short period of time. What do you personally find difficult of troublesome while providing this type of care?
- Does the care for residents in their last year of life sometimes preoccupy you outside working hours?
- Poor sleep, irritability, crying easily, and feeling agitated are examples of complaints that can be seen as precursors to emotional overload. Do you recognize such complaints as a result of providing care to residents in their last year of life? If yes: What kind complaints? Can you give an example of situations that may lead to such kind of complaints?
- There are several situations that can lead to stress in providing care during the last year of life of residents such as not having enough time to care for dying residents, not being able to cope well with your own emotions about a resident's death, dealing with the resident's emotions, feeling helpless or powerless in caring for residents who are about to die. Do you recognize these situations and feelings of stress? Can you explain a little more where exactly that (mentioned feeling) comes from? What makes a particular situation stressful for you?

Dealing with the emotional impact

- How do you personally deal with the emotions you experience as a result of providing care to residents in their last year of life?
- You may feel overwhelmed by emotions whilst providing care in the last year of life or care around death of residents, how do you express these emotions?
- Is there a difference in how you dealt with emotions you experienced as a result of providing care in the last year of life of residents when you just started this work compared to now? If yes: What changed?
- The activities you undertake at the moment, do they help you cope well with the emotional strain?
- What would you still need in this regard?
- Suppose the organisation wants to pay attention to the impact of palliative care provision on healthcare professionals what would you like or recommend to them?

Finishing the interview

APPENDIX B: Questionnaire socio-demographic characteristics of respondents

Age..

Gender..

Number of years of professional work experience in care:....................

On average, how many residents who are no longer getting better do you care for per month? ....

Number of residents dying per month: ....

How many hours in the week do you work as a nursing assistant: ....

5

Emotional impact of providing palliative care among nursing assistants

Peer Support Program for addressing work-related stress in healthcare professionals providing palliative care: A pilot study

6

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Submitted

ABSTRACT

Working as a healthcare professional (HCP) is demanding and can lead to work-related stress. Peer Support aims to support HCPs who are involved in an incident using conversations with a trained peer. Peer Support might also help HCPs who struggle with the impact of caring for patients with life-limiting diseases. This pilot study aimed to assess feasibility and acceptability of Peer Support to address work-related stress in HCPs providing palliative care in a single Dutch hospital. HCPs from three departments were invited to complete a questionnaire including the Burnout Assessment Tool, additional questions on work-related stress and an invitation to use Peer Support. After the intervention participants completed the questionnaire again, supplemented with evaluation questions. A total of 56 respondents completed the questionnaire (response rate 11%). One in seven respondents scored (very) high on various burnout subscales. On average, respondents engaged in almost four activities to manage their work-related stress, but 57% of all respondents still had needs in this regard. Respondents felt more attention should be paid to work-related stress and more support was needed from their supervisor and organisation. Four respondents participated in the Peer Support Program, they all experienced this as valuable. Although getting time to talk with colleagues about impactful events is desired by HCPs to cope with the emotional impact of their work, the approach used in this pilot study was not suitable to reach HCPs who experience high levels of burnout symptoms.

INTRODUCTION

Working as a healthcare professional is demanding and can lead to work-related stress. Known causes of work-related stress include high workload, long working days, night and weekend shifts, and administrative burden.[1,2] A study among healthcare professionals caring for patients with a life-limiting disease also found that repeated exposure to dying patients, difficulty in balancing between a personal or professional attitude towards patients and family, and disagreement about what care should be provided were stressors associated with providing palliative care.[3] Moreover, an interview study among healthcare professionals providing palliative care suggests that conversations about life-threatening illness and end-of-life care can lead to feelings of anxiety among healthcare professionals due to a lack of communication skills or anticipation of an emotionally charged response from the patient and family.[4]

Prolonged stress can lead to burnout.[5] The prevalence of burnout symptoms among healthcare professionals is considerable. A meta-analyses by Zhang and colleagues showed that almost two-thirds of nurses have symptoms of burnout, and a European study found similar numbers of burnout symptoms among young medical oncologists.[6,7] A systematic literature review among healthcare professionals who provide palliative care showed that, despite a wide range of burnout prevalence rates, most studies reported a prevalence of burnout of 18% or higher.[8] Several studies in this review showed that healthcare professionals working in general care settings such as hospitals had higher burnout rates compared to their colleagues working in dedicated palliative care settings such as hospices.

Previous research among healthcare professionals providing palliative care has shown that most healthcare professionals engage in various coping activities to lower their work-related stress, such as engaging in leisure activities or talking with colleagues.[9,10] However, almost a quarter of these healthcare professionals felt that this was not enough to deal with the emotional impact of their work and 55% felt that they needed more time to talk with colleagues about the impact of their work.[9] Brighton and colleagues also showed this importance, with all participants in their study mentioning the importance of reflecting on emotionally charged experiences in order to deal with their emotions, and having time to do so.[4] Barriers experienced in receiving social support from colleagues were fear of appearing vulnerable and not wanting to bother colleagues because they have their own emotional burdens.[10]

Research shows that physicians are more likely to seek help from a peer, a colleague physician, than they would access professional mental health support.[11] Peer Support as defined for the healthcare context is '*the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge for a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or actually stressed focal person*'.[12] In Peer Support programs healthcare professionals who are involved in a predefined adverse event or critical incident are contacted and offered a number of conversations with a trained colleague (peer).[13] Over the years, Peer Support has evolved and now is used also as a way to promote the personal wellbeing of healthcare professionals in the work environment and help them cope with stress and anxiety.[14] Peer Support Programs are organised in diverse ways such as in one-to-one sessions, in group meetings or as online support groups.[12,14,15] Important components of Peer Support conversations are reaching out to a clinician who is involved in an emotionally stressful event, giving an opening to talk about the event, listening, reflecting, discussing the coping strategies and support system.[13] Studies on Peer Support interventions after an adverse patient event show that healthcare professionals experience it as to be helpful and feel that it leads to recognition, less stress and offers an opportunity to a culture in which healthcare professionals feel safe to share experiences.[14,16,17]

Since most Peer Support Programs are thus focused on support after an incident or adverse event, it might also be beneficial for coping with emotional impact of providing palliative care, as this involves stressful and emotionally burdensome situations. A recent systematic literature review showed that, among nurses, good social support, such as support from the supervisor or peer, was associated with lower symptoms of burnout.[18] Therefore, we hypothesised that Peer Support Programs might be appropriate for healthcare professionals who struggle with work-related stress and their personal wellbeing as a result of providing palliative care. The aim of this study was to assess the applicability and feasibility of a Peer Support program to address personal wellbeing in healthcare professionals providing palliative care.

METHODS

Study design and setting

This pilot study aimed to assess feasibility and applicability of a Peer Support Program for addressing work-related stress and emotional wellbeing in healthcare professionals providing palliative care in the departments of Gynaecology/Obstetrics, Neurosurgery and Radiotherapy of the LUMC. In the Netherlands, primary palliative care is provided by all healthcare professionals and is supported by palliative care specialists when necessary. The pilot study was conducted between October 2022 and December 2022. For reporting the CONSORT checklist was used.[19]

Participants and recruitment

All 490 healthcare professionals working in the departments Gynaecology/Obstetrics, Neurosurgery and Radiotherapy of the LUMC were invited to complete an online questionnaire and invited to participate in the Peer Support Program. In these departments healthcare professionals care for patients with life-limiting illnesses from various ages. Managers of the participating departments gave their consent to conduct the study and were asked to inform healthcare professionals in their department about the pilot study.

Intervention and data collection

A Peer support program has been installed in LUMC since 2017 and offers one-on-one conversations when serious events have been reported to the department of Quality and Patient Safety (DKP, acronym for Directoraat Kwaliteit en Patiëntveiligheid). The LUMC has circa 25 healthcare professionals that conduct these Peer Support conversations. The members of the Peer Support team are all trained in having these conversations. In 2021, Peer Support conversations after serious events have been formally offered to 67 healthcare professionals, of which 13 (19%) have accepted this offer.

In this pilot study, all healthcare professionals working at the participating departments received a personal e-mail with information about this pilot study and were invited to participate. In the email, a link to an online questionnaire on symptoms of burnout was provided. After two weeks a reminder was sent. The questionnaire consisted of the validated Burnout Assessment Tool (BAT) and additional questions on work-related stress and work characteristics and socio-demographics.[20] The BAT is a validated instrument using a 5-point Likert-scale measuring four core subscales of burnout: exhaustion, mental distance, emotional impairment and cognitive impairment. In addition, the BAT assesses secondary symptoms, divided in symptoms regarding psychological distress and psychosomatic complaints.[21]

At the end of the questionnaire, participants could indicate if they wanted to have three Peer support conversations. If so, they gave consent for the Peer Support team to contact them to schedule a first meeting. They were offered thee conversations with a member of the Peer Support team of the LUMC to talk about work-related stress. Participants with high scores on the BAT subscales, and therefore seen as the intended target group for the Program, were also contacted by e-mail to offer them Peer Support. The match between the participant and Peer Support colleague was based as much as possible on similarity of function, but working in a different department. After completion of the Peer Support Program, participants again received the online questionnaire, supplemented with an evaluation form. Respondents who did not want to participate in the Peer Support program were asked about their reasons for not participating. Also the three Peer Supporters involved in these conversations received an evaluation questionnaire regarding their personal experiences of conducting Peer Support conversations in the context of this pilot study.

Data analysis

The results of participants who completed the Burnout Assessment Tool were included in the analysis. Descriptive analysis were used to describe sociodemographic characteristics, work characteristics, the prevalence of symptoms of burnout on the five constructs of the BAT and additional questions on work-related stress. Cut-off scores for low, median, high and very high scores on the BAT were used as provided in the manual [21]. All data were analysed using STATA (version 17.0, STATACorp LLC). Results of the evaluation questionnaires of the participants and Peer Supporters were discussed among researchers AD, LB and NR.

Ethical considerations

The Medical Ethical Committee (METC) of Leiden Medical Center (LUMC, N22.017) in the Netherlands reviewed the study protocol and has decided to exempt this pilot study from full ethical review. This was done in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). Data collection and analyses were done in accordance with the Dutch Personal Data Protection Act. Before the start of the questionnaire information was provided on the screen regarding the aim of the study, anonymity and the possibility to withdraw from the study at any time without any consequences. The contact details of the researcher were provided and informed consent was obtained through a statement declaring that by starting the questionnaire consent to participate in the study was given.

RESULTS

In total, 56 healthcare professionals completed the first questionnaire (11% response rate). Response rate differed per department: 24% for Radiotherapy, 7% for

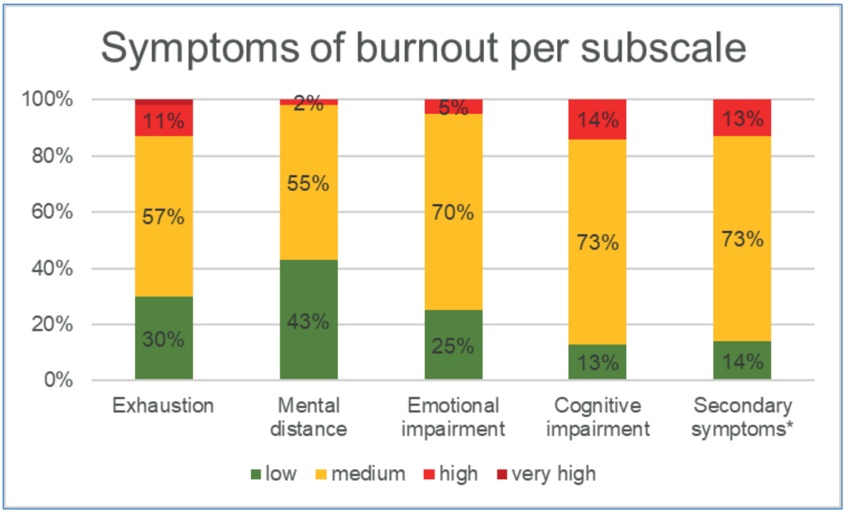
Gynaecology/Obstetrics and 5% for Neurosurgery. Most respondents were female (93%) and older than 40 year (58%) (Table 1). Of the 56 respondents, 31 worked at the department of Radiotherapy (55%), 23 at the department Gynaecology/Obstetrics (41%) and 2 worked at Neurosurgery (4%).

Slightly more than half of respondents (54%) regularly cared for patients who probably were in the last year of their life. All 10 healthcare professionals that indicated to see no patients in the last year of life work in the Gynaecology/Obstetrics department. Almost a quarter (23%) of respondents felt they have (completely) insufficient knowledge and experience to care for patients in their last phase of life. In this regard, 42% of respondents perceived themselves as (completely) sufficient.

Symptoms of burnout

Most healthcare professionals had medium levels on all subscales of the burnout inventory, namely exhaustion (57%), mental distance (55%), emotional impairment (70%), cognitive impairment (73%) and secondary symptoms (73%). Of all 56 respondents, 13% had a high or very high level of exhaustion, 14% had a high level of cognitive impairment and 13% a high level of secondary symptoms (Figure 1).

Figure 1 Symptom of burnout scores per subscale.



**Secondary symptoms includes psychological distress and psychosomatic complaints*

Table 1 Sociodemographic and work-related characteristics of healthcare professionals (n=56)

	% (n)
Gender	
Female	93 (52)
Age	
≤30	20 (11)
31-40	23 (13)
41-50	38 (21)
≥ 51	20 (11)
Department	
Gynaecology/Obstetrics	41 (23)
Neurosurgery	4 (2)
Radiotherapy	55 (31)
Profession	
Physician	36 (20)
Radiotherapy lab technician	23 (13)
Hospital midwife	13 (7)
Nurse specialist	9 (5)
Psychologist	4 (2)
Other	16 (9)
Years of working experience as healthcare professional	
1 – 5	18 (10)
6 – 10	16 (9)
11 – 20	29 (16)
>21	38 (21)
Number of serious situations last year (e.g. sudden death)	
0	29 (16)
1-2	27 (15)
3-5	25 (14)
>6	20 (11)
Percentage of patients you cared for who had a serious illness and are probably in the last year of their life?	
0%	18 (10)
1-10%	29 (16)
11-50%	43 (24)
>51%	11 (6)
To what extend do you have sufficient knowledge and experience to care for patients in their last phase of life?	
Completely insufficient	7 (4)
Insufficient	16 (9)
Neutral	36 (20)
Sufficient	29 (16)
Completely sufficient	13 (7)

Coping activities and support needs for work-related stress

The 56 healthcare professionals reported a mean of 3.7 activities that they do to remain balanced. The most commonly reported activities were seeking support from a partner or friends (80%), leisure activities such as sports, gardening and reading (80%), and seeking support from colleagues (79%) (Table 2). In total, 43% felt that these activities were enough to deal with work-related stress. Almost two third (57%) of respondents had one or more unmet needs, with a mean of 4 unmet needs, ranging from 1 to 13. These unmet needs included less work pressure (27%), more attention for work-related stress at work (25%), more support from their supervisor (25%), feeling safe within the team (23%) and more support from the organisation (21%) (Table 2). Half of all respondents (50%) stated they knew where to find help in dealing with work-related stress, but also almost a quarter (23%) reported they did not know where to find help.

Table 2 Work-related stress activities and needs

	Total (n=56)	Low/Medium score BO subscales (42)	High score on BO subscales (n=14)
	% (n)	**% (n)**	**% (n)**
Signed up for Peer Support	11 (6)	10 (4)	14 (2)
Secondary Symptoms	2.0 (.52)	1.9 (.45)	2.6 (.58)
Percentage of patients you cared for who had a serious illness and are probably in the last year of their life?	26	24	32
(Completely) Sufficient knowledge and experience to care for patients in their last phase of life	41	45	29
Mean number of Coping Activities	3.7	3.8	3.6
Activities			
I seek support from partner of friends	80 (45)	83 (35)	71 (10)
I spend time on my hobby (e.g. sports, hiking, reading, gardening)	80 (45)	81 (34)	79 (11)
I seek support from colleagues	79 (44)	81 (34)	71 (10)
I seek support from supervisor	30 (17)	29 (12)	35 (5)
I alternate my work activities	30 (17)	33 (14)	21 (4)
I get support from team meetings (sharing experiences)	23 (13)	29 (12)	7 (1)
I practice mindfulness/meditation	18 (10)	14 (6)	29 (4)
I make use of individual coaching/mentoring	16 (9)	12 (5)	29 (4)
I share my experiences in intervision meetings	11 (6)	14 (6)	0 (0)
I seek support from my employer/organisation	4 (2)	2 (1)	7 (1)
I am taking additional training/education	2 (1)	0 (0)	7 (1)
Not applicable	4 (2)	2 (1)	7 (1)
Mean number of needs	*4.0*	*3.6*	*4.7*

Needs			
Nothing, the current activities I undertake are sufficient	43 (24)	52 (22)	14 (2)
Less work pressure	29 (16)	21 (9)	50 (7)
More attention for work-related stress at work	25 (14)	19 (8)	43 (6)
Support from their supervisor/manager	25 (14)	21 (9)	36 (5)
Feeling safe within the team	23 (13)	12 (5)	57 (8)
Support from the organisation	21 (12)	19 (8)	29 (4)
Tools on how to deal with work-related stress	18 (10)	10 (4)	43 (6)
Time to talk to colleagues about event within work	18 (10)	17 (7)	21 (3)
Support from my team	14 (8)	14 (6)	14 (2)
Conversations with colleagues	11 (6)	10 (4)	14 (2)
Hobbies (e.g. exercising, walking, reading, gardening)	11 (6)	7 (3)	21 (3)
Individual coaching/mentoring	9 (5)	2 (1)	29 (4)
Alternate activities	7 (4)	7 (3)	7 (1)
Mindfulness or meditation	7 (4)	5 (2)	14 (2)
Conversations with partner or friends	5 (3)	2 (1)	14 (2)
Intervision	4 (2)	5 (2)	0 (0)
Training/education	2 (1)	0 (0)	7 (1)
I know where to find help in dealing with work-related stress			
Completely disagree	9 (5)	7 (3)	14 (2)
Disagree	14 (8)	12 (5)	21 (3)
Neutral	27 (15)	(24 (10)	36 (5)
Agree	32 (18)	33 (14)	29 (4)
Completely agree	18 (10)	24 (10)	0 (0)

High symptoms of burnout score

Of all respondent (n=56), 25% had high scores on one or more of the four burnout subscales, which indicates a potential risk for burnout. These healthcare professionals were considered as high risk group and potential participants for the Peer Support Intervention. These healthcare professionals cared on average for a patient population of which 32% was in need of palliative care and engaged on average in 3.6 activities (Table 2). The most frequently mentioned activities in the high risk group were the same as those mentioned by all respondents. Respondents in the intended target group had an average of 4.7 needs. Similar to all 56 respondents, the most common needs in the high risk group were to feel safe in the team (57%), less pressure at work (50%) and more attention to work-related stress (43%). They also reported a need for tools on how to deal with work-related stress (43%) and about one in three respondents in this group had a need for support from the organisation (29%) and individual coaching and mentoring (29%). Of the healthcare professionals with a high score on one of the subscales, 35% did not know where to find help in dealing with work-related stress.

Peer Support Program: Non participating respondents

Of the 56 respondents, 6 (11%) signed up for participation in the Peer Support Program and 50 did not (Figure 2). Of the latter group, 40% (n=20) reported their reason not to sign up for the Peer Support Program. They mainly stated that they did not experience any problems with the personal impact of their work (40%) or already talk to someone else about the personal impact of their work (20%). Other practical reasons for not signing up were that the timing of the pilot study (conversations were held in the two months following the questionnaire) (15%) or /and a too great time investment (15%) (Table 3).

Figure 2 Flowchart participants Peer Support Program

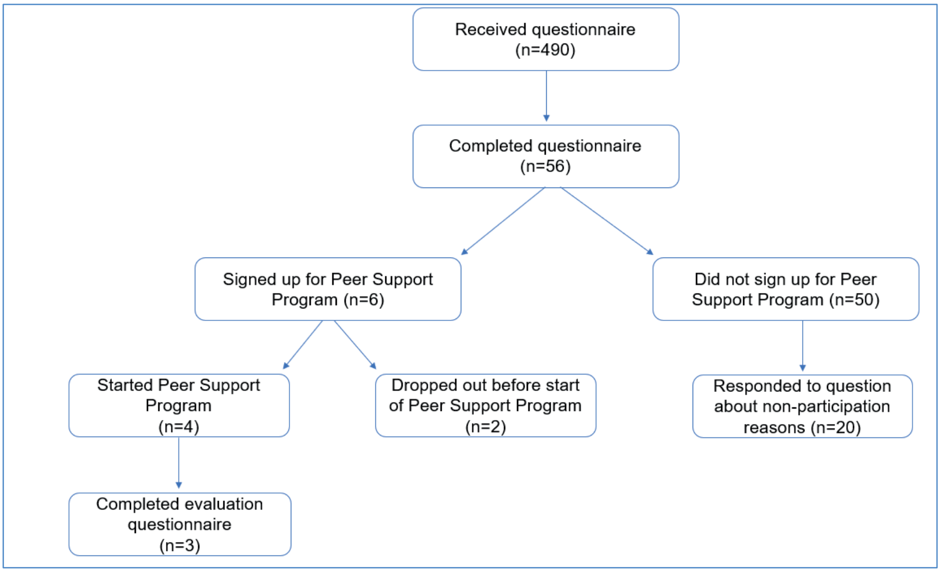


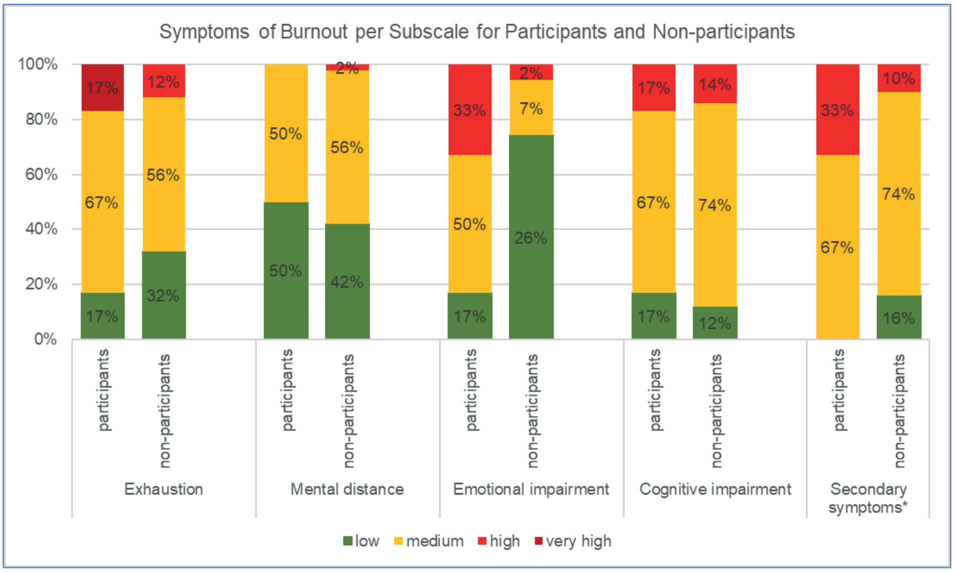
Table 3 Reasons for not signing up for Peer Support (n=20)

Reasons for not signing up for Peer Support	% (n)
I experience no problems with the personal impact of my work	40 (8)
I already talk to someone else about the personal impact of my work	20 (4)
The timing was not convenient, maybe at a later time	15 (3)
The time investment is too big	15 (3)
It does not feel safe to talk to a colleague about the personal impact of my work	10 (2)
Lack of time for such conversations	10 (2)
I prefer to solve it myself, outside of work	10 (2)
Three conversations seem too much to me, I prefer to start with one conversation and see what is needed	5 (1)
I don't want to do anything about the personal impact I experience from my work	5 (1)
Other, namely...	10 (2)

Feasibility of the Peer Support Program

The six respondents who did sign up for participation had on average median scores on symptoms of burnout. On both the subscales Exhaustion and Cognitive Impairment one participant scored (very) high, and on Emotional Impairment and on Secondary Symptoms two participants scored high (Figure 3).

Figure 3: Symptoms of burnout per subscale for participants and non-participants



**Secondary symptoms includes psychological distress and psychosomatic complaints*

These six healthcare professionals were contacted by the Peer Supporter that was matched to them. After this initial contact, two dropped out. One did not remember signing up and had no interest and one did not respond, despite repeated attempts by the Peer Supporter, either by phone or e-mail, to make an appointment. Four participants participated in the Peer Support intervention of which three completed the evaluation questionnaire.

All three participants that completed the Peer Support Program would recommend it to their colleagues, because they felt it had added value, they learned about themselves and it was easy to participate. The length of the Peer Support Program (three conversations) was perceived as enough and as good but also as "too big a tool to put in place for everyone". It seems to depend on the situation and needs of the individual. One participant mentioned that the encouragement of the supervisor was an important support to participate. Another participant highlighted the added value of sharing the same working environment.

The Peer Supporters providing the Peer Support Program felt it was nice and pleasant to offer Peer Support. They also felt it was useful for the participant and that they were able to support their colleague. The Peer Supporters experienced barriers related to time (busy schedules), especially within working hours. One Peer Supporter mentioned that it is important to have clear expectations of the Peer Support Program.

DISCUSSION

This pilot study aimed to assess the feasibility and applicability of a Peer Support Program to address the personal wellbeing of healthcare professionals providing care for patients in the last year of life. This pilot study did not reach the intended target group. The response rate to the questionnaire was low (11%). One in seven respondents scored high or very high on the burnout subscales of exhaustion and cognitive impairment, but the step to participate in the Peer Support Program was only followed by four healthcare professionals. Respondents engaged on average in almost four activities to deal with work-related stress, but more than half of respondents still has (unfulfilled) needs in this regard. A quarter of respondents indicated that more attention should be paid to work-related stress and that they needed more support from their supervisor and from the organisation.

A quarter of the respondents had a high score on one or more of the four subscales. These respondents were considered as the intended target group for the Peer Support Program. Healthcare professionals who fell in this group had similar outcomes to the other respondents regarding activities they undertake and their needs. However, respondents with a high score on one of the subscales had on average more unfulfilled needs. In addition to the needs mentioned above, they more often expressed a need for tools on how to deal with work-related stress and individual coaching.

Despite these expressed needs among respondents to the questionnaire, only six respondents signed up for the Peer Support Program (11%) and four actually started the program. Reasons for not signing up for the program included experiencing no problem with the personal impact of work, already receiving other support and practical issues including timing and time investment. The participants varied in their experiences with the Peer Support Program and this gave little insight into the applicability of the program. Due to the low response rate for the Peer Support Program, it cannot be concluded from this study if this intervention sufficiently fits the needs.

Overall, a considerable part of healthcare professionals participating in the questionnaire of this pilot study experience symptoms of burnout and have a need for more support. However, very few healthcare professionals with a high score on burnout symptoms were willing to participate in the Peer Support Programs. The reported needs ask for interventions to support healthcare professionals in dealing with the emotional impact of their work. Among all questionnaire respondents, 43% reported having no unmet needs. When looking at healthcare professionals with a high score on one or more burnout subscales, 86% reported having one or more needs. Apart from less workload (50%), most reported needs in this group were feeling safe within the team (57%), more attention for work-related stress at work (43%) and tools on how to deal with work-related stress (43%). These needs are mostly beyond the control of individual healthcare professionals and thus require organisation induced interventions.

The low response rate to this pilot study is likely to be multifactorial. It is known that healthcare professionals experience very high work pressure and this pressure on healthcare professionals is increased due to COVID-19.[22,23] The timing of the first questionnaire may therefore have contributed to a low response rate. In the autumn of 2022 healthcare professionals were cautious for a possible new increase in number of COVID-19 patients. Another possible reason for the low response rate is that the approach for this Peer Support Program may have been perceived as too much top-down. Previous studies have shown that healthcare professionals reported a need for support from their supervisors and organisation when it comes to talking about the emotional impact of their work.[9,24] Therefore, in this study supervisors of the participating departments were asked to send an e-mail to all healthcare professionals in their department to encourage them to sign up for the Peer Support Program. Yet, this approach might have been too much a top-down approach. A study in the U.S. on the needs of physicians in coping with emotional stressors showed that barriers for seeking support were perceived lack of time (89%), concerns about lack of confidentiality (68%), stigma of mental health care (62%) and not knowing who to go to (61%).[11] Also, in this current study respondents felt at that moment they did not have time to take part in the Peer Support Program or the time investment was too big. However, a Dutch study on a coaching intervention among paediatric medical residents and specialists was able to include 57 healthcare professionals in the intervention.[25] The intervention consisted of six individual coaching sessions with a professional, external, coach. Like in this current pilot study, participation was voluntary and there were limited regulations for the coaching process. The study by Solms and colleagues did differ in the method of approaching potential participants. Besides sending an e-mail, informative presentations were held in the participating departments, and it was not necessary to complete a questionnaire prior to signing up. Also, participants could choose from a selection of professional coaches, rather than being assigned to a trained colleague (Peer).

Strengths and limitations

A major limitation of this study is the way the potential participants for the Peer Support Program were approached. By approaching healthcare professionals by e-mail through a questionnaire, we may not have been able to reach the target group properly. Filling in the questionnaire may have been perceived as a barrier, as this requires an additional time investment prior to participation in the Peer Support Program and may also have distracted from the exact goal in the communication about the Peer Support Program. A more direct approach, for example through a presentation in the participating departments or asking team leaders to share the information about the possibility to participate in the Peer Support Program in an existing team meeting might have contributed to a higher response. Furthermore, the way healthcare professionals were approached in this pilot study was too one-sided. By only sending an email, too little attention was paid to the cultural and social barriers that healthcare professionals may face in discussing the personal impact of their work. Second, selection bias may have occurred. Healthcare professionals who did fill in the questionnaire might have more affinity with the theme than their colleagues who chose not to participate in this pilot study. This may have led to an overestimation of burnout symptoms in this study. On the other hand, healthcare professionals who experience (very) high burnout symptoms are unlikely to make time for a questionnaire. Therefore, it is difficult to state if the respondents are representative for the entire population in the partaking departments.

Implications for practice and future research

The limited number of people who were willing to participate in this pilot study combined with the expressed need for support in dealing with the impact of their work, suggests that further insight is needed into how to tailor the intervention to the needs of healthcare professionals, how to ensure that healthcare professionals have the time and space to participate in the interventions offered, and how these factors might interact. Furthermore, to increase the preparedness to participate in such interventions at the individual level, simultaneously interventions to the address the (team) culture should be addressed. Feeling save within the team; mutual trust to talk about impactful events but also a general consensus that addressing the personal impact of providing care is needed, can not only work as a protective, valuable factor in dealing with the personal impact of work but might also take away perceived barriers to participate in interventions on the individual level. Lastly, also simultaneously, certain preconditions should be ensured at the organisational level, such as scheduling time for the offered interventions.

Conclusion

In this study we found that the Peer Support Program, as offered in this pilot study, did not reach the target group and does not appear to adequately meet the needs of healthcare professionals who experience high levels of burnout symptoms. This may be due to the way in which participants were approached, the timing of the study post-COVID, the time investment, or the Peer Support program itself. However, healthcare professionals do have a need to address the personal impact of their work and more attention from their supervisor or within the organisation is wanted. More research is needed to understand the factors that lead to low use of Peer Support Programs and how to best meet the needs of healthcare professionals who care for patients in the last year of their life and how to prevent or limit burnout among healthcare professionals.

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General discussion

7

The aim of this thesis was to gain insight into the emotional impact of providing palliative care on healthcare professionals in the Netherlands and to explore the strategies and needs of healthcare professionals in this regard. This general discussion provides an overview of the main findings of the studies presented in this thesis and discusses the methodologies used. This is followed by an interpretation of the findings. Finally, recommendations for practice, education, policy, and research are considered.

7.1 MAIN FINDINGS

Symptoms of burnout among healthcare professionals providing palliative care and effect of interventions

To explore the wellbeing of healthcare professionals providing palliative care, a systematic literature review was conducted to synthesize the current literature on the prevalence of (symptoms of) burnout among these healthcare professionals and the interventions to alleviate burnout symptoms **(Chapter 2)**. In total, 59 studies were included. No Dutch studies were found. Although the prevalence of burnout varied widely (3% - 66%), most studies reported that about one in five healthcare professionals experienced burnout. The studies that compared the prevalence of burnout between settings showed that healthcare professionals providing palliative care in general healthcare settings reported more symptoms of burnout than colleagues in specialised palliative care settings. Only ten studies reported on interventions to reduce symptoms of burnout in healthcare professionals providing palliative care. Of these studies, six reported (small) positive effects on the prevalence of burnout symptoms in the short term. The interventions in these studies used meditation, communication training, peer coaching and art therapy-based supervision. Almost all the interventions were aimed at the individual healthcare professional.

No conclusions could be drawn for the Netherlands based on the systematic literature review. In order to gain insight into the current Dutch situation an online survey on burnout symptoms and work-related stress was conducted in the beginning of 2020, just before the first lockdown due to the COVID-19 outbreak **(Chapter 3)**. The respondents were members of the Dutch Association for Palliative Care Professionals (Palliactief), mostly nurses and physicians working in general healthcare settings such as hospitals and home care. The survey (53.6 % response rate) showed that more than two-thirds (69%) of the 179 respondents had medium levels of symptoms of burnout and 7% had taken sick leave because of burnout. Although most healthcare professionals actively engaged in an average of nearly four activities to manage the personal impact of their work, 23% of respondents expressed a need for supportive activities at a team and organisational level. The majority of the reported needs included allocating time to discuss impactful events with colleagues (55%) and feeling safe within the team (39%). The questionnaire study among 490 healthcare professionals, mainly generalists in palliative care, from three departments of an academic hospital **(Chapter 6)** showed similar results. Only 56 respondents (11% response rate) completed the questionnaire, and the majority had medium scores on the four subscales of the burnout questionnaire. They reported engaging in an average of almost four activities to remain balanced, but 57% of respondents still had unmet needs. This is substantially higher than in the survey of Palliactief members. The most frequently reported unmet needs were less work pressure (27%), more attention to work-related stress at work (25%), more support from their supervisor (25%), feeling safe within the team (23%) and more support from the organization (21%). Of the 56 respondents, 25% had a high score on one or more of the four subscales. These healthcare professionals had on average more unmet needs, in particular they were more likely to express a need for tools to deal with work-related stress and a need for individual coaching.

Perceptions and experiences of healthcare professionals regarding the emotional impact of providing palliative care

To gain a better understanding of the emotional impact of providing palliative care on healthcare professionals, two interview studies were conducted **(Chapters 4 and 5)**. The first interview study involved physicians and nurses, both palliative care generalists and palliative care specialists, working in hospitals, home care or nursing homes. The second interview study was conducted among nursing assistants working in nursing homes. All were palliative care generalists. Participants in both studies expressed positive emotional aspects of providing palliative care but also experienced a substantial emotional impact from it. Some differences were found between palliative care generalists and specialists such as a lack of experience with loss and death, or as a palliative care specialist to work with colleagues with little knowledge of palliative care.

In both studies, several factors were reported as contributing to coping with the emotional impact, such as receiving collegial support and having the opportunity to reflect on the (impact of) care with colleagues. At the same time, participants expressed experiencing barriers **(Chapter 4)** or having unmet needs **(Chapter 5)** regarding coping with the emotional impact of providing palliative care. Most of the reported facilitators and needs go beyond the personal influence of the individual healthcare professional and require action at a team and organisational level.

Peer support as potential instrument to support healthcare professionals providing palliative care

In response to the need of healthcare professionals as reported in **Chapter 3** for more time to reflect with colleagues on impactful events, a Peer Support pilot was conducted **(Chapter 6)**. Peer Support is an intervention in which healthcare professionals who are involved in an adverse event, are offered support through conversations with a trained colleague to help them cope with the stress and anxiety following the event. Many hospitals in the Netherlands have a Peer Support Program to support healthcare professionals after their involvement in pre-defined potentially traumatic events, such as a serious patient safety incident. As an accumulation of small events can also potentially lead to a traumatic emotional impact on healthcare professionals, this may be mitigated by timely intervention. The aim of this pilot study was therefore to assess the feasibility and applicability of a Peer Support Program to address the emotional wellbeing of healthcare professionals providing palliative care in a single academic hospital.

Of the 56 participants who responded to the questionnaire, 25% had a high score on one or more of the burnout subscales. They were considered to be the intended target group for the pilot study. In addition to the needs that emerged within group as a whole, they also reported a need for tools on how to deal with work-related stress and for individual coaching. Six healthcare professionals indicated that they would like to join the Peer Support Program but only four participated in the program and three completed the evaluation questionnaire. All three would recommend Peer Support to their colleagues. For those who chose not to join the Peer Support Program, the time investment and the inconvenient timing of the pilot were reported as practical reasons for not participating in the current program.

7.2 REFLECTIONS ON THE USED METHODOLOGIES

The studies in this thesis used a variety of observational methodological approaches, including a systematic literature review **(Chapter 2)**, cross-sectional surveys **(Chapter 3 and 6)**, qualitative interviews **(Chapter 4 and 5)** and a pilot intervention study **(Chapter 6)**.

Study selection

The results of the systematic literature review **(Chapter 2)** were largely determined by the search string and selection criteria. Although we developed a broad search, emotional impact is such a wide-ranging topic with many related concepts that we were not able to include all terms (see Appendix A). As a result, we may have missed some relevant studies. Because in the selection process we only included studies that reported on the prevalence of burnout we may have excluded studies that provide insight into a broader concept of the wellbeing of healthcare professionals. We intentionally made this demarcation to avoid comparing different outcomes.

Assessment of burnout

The Maslach Burnout Inventory (MBI) was the most commonly used instrument in the studies included in the systematic literature review **(Chapter 2)**. However, we found large variations in the use of this validated questionnaire, which made it difficult to compare the results and to conduct a meta-analysis. Limitations of the MBI include differences in interpretation of the response categories, and the absence of an overall score.[1] A systematic literature review on burnout among physicians illustrates the heterogeneity in the use of the MBI. This review included 182 studies, of which 156 used a version of the MBI to assess burnout. These 156 studies used more than 47 definitions of overall burnout prevalence.[2] In 2019 the Burnout Assessment Tool (BAT) was developed. This validated questionnaire aims to overcome the limitations of the MBI by creating items that refer directly to burnout symptoms, omitting reversed items, and providing a single burnout score.[3] Because the BAT is a relatively new instrument and norms for the Netherlands are not yet available, it is more difficult to compare the results with other target groups. Nevertheless, we decided that the BAT was the most appropriate questionnaire for our studies and therefore chose to use it in the two surveys **(Chapter 3 and 6)** to assess levels of (symptoms) of burnout.

Recruitment

Healthcare professionals for the interview studies **(Chapters 4 and 5)** were recruited via the network of colleagues working in the field of palliative care, using convenience sampling. This strategy may have introduced selection bias, because this network consists mainly of healthcare professionals who have an interest in palliative care. In addition, healthcare professionals who showed interest in participating in the interviews are also likely to have some affinity with the personal impact of providing palliative care. Furthermore, both interview studies were conducted among a fairly homogeneous group of female participants with a Dutch cultural background, which limits the generalisability of the results.

Regarding the recruitment for the pilot study of the Peer Support program **(Chapter 6)**, our chosen approach might have been a limitation. By asking potential participants via e-mail to complete a questionnaire might have been perceived as a barrier to join the program. Although there was support from the heads of the participating departments and the e-mail was sent by them, a more personal approach for example by means of presentations about the pilot at the different departments, could have helped to provide healthcare professionals with a better understanding of the intervention's content and the aim of the pilot study. Lastly, timing might have been unfortunate since a lot of attention was paid to work-related stress during the COVID-19 pandemic and its aftermath for example via the app Digital Stress Buddy at LUMC.[4] Healthcare professionals therefore may have been somewhat saturated regarding this subject.

Representativeness and generalisability

The representativeness of the study populations of the two surveys might be limited due to the specificity of the target group **(Chapter 3)** and the low response rate **(Chapter 6)**. This limits the generalisability of the studies. The survey among healthcare professionals providing palliative care **(Chapter 3)**, had a fairly good response rate of 54%, despite being sent at the start of the COVID-19 pandemic. This response rate and wide variety of healthcare professionals who participated, combined with the use of a validated instrument, led to valuable insights. Although it is still possible that those who responded are structurally different from those who did not respond, these results can be seen as an indication of all members of the Dutch Association for Palliative Care Professionals (Palliactief). However, by distributing the questionnaire only among members of Palliactief, and thus to healthcare professionals who are consciously involved in palliative care, the outcomes cannot be properly compared to other healthcare professionals in the Netherlands. In the pilot study on Peer Support **(Chapter 6)** the response rate for the questionnaire was low, with only 11% of invited healthcare professionals responding. Therefore, they do not accurately represent the total group of healthcare professionals working in their departments.

7.3 INTERPRETATION OF THE FINDINGS

Healthcare systems around the world are facing a growing demand for care. Meanwhile, the outflow of healthcare professionals has increased significantly in recent years. The results of a Dutch survey show that in 2022, almost 40% of healthcare professionals sometimes think about leaving the healthcare sector, and about 12% plan to actually change jobs to work outside the healthcare sector in the coming year.[5]

While 70% of healthcare professionals state they are passionate about their work, 16% regularly or often feel emotionally exhausted. With growing demands for care, the (emotional) care burden for all healthcare professionals involved in palliative care will increase. How are these healthcare professionals affected by the provision of palliative care? And how can they be supported to maintain or find balance in this regard? This section discusses the findings from the different studies in this thesis about how healthcare professionals are affected emotionally by providing palliative care, what their needs are and how they can be supported in this regard.

Elements of providing palliative care that have an emotional impact

Much attention has been paid to the high prevalence of (symptoms of) burnout among healthcare professionals in general. Frequently cited causes of work-related stress among healthcare professionals, which can ultimately lead to burnout, are high workload, high administrative burden and low autonomy.[6-8] During the COVID-19 pandemic, there has been a growing recognition of the emotional impact on healthcare professionals of caring for so many dying patients, and of the often intensive conditions in which healthcare professionals work. This has contributed to an awareness that caring for patients in the face of death requires something different than providing curative care. The studies in this thesis indeed show that caring for patients who are in need of palliative care, even outside a pandemic, is experienced as different from providing curative care, and involves some additional stressors on top of those already known of work-related stress. The interview studies demonstrated that providing palliative care is often perceived as beautiful, but also as something that affects the healthcare professionals personally **(Chapters 4 and 5)**. These positive experiences, such as feelings of fulfilment, receiving gratitude and personal growth and negative experiences, such as feelings of powerlessness coexist **(Chapter 4)**. An Australian interview study among 20 physicians working in a specialist palliative care service also found a wide range of strong work-related emotions.[9] The authors reported that many doctors felt providing palliative care was personally rewarding, but also led to feelings of exhaustion, anger or irritability outside of work. These emotions were provoked by specific elements of providing palliative care that are also identified as impactful in our studies, such as confrontation with death and grief and conflicting personal values **(Chapter 4 and 5)**.

In addition, interviews with nursing assistants working in nursing homes revealed that they felt torn between experiencing the added value of building a personal relationship with the residents and the greater emotional impact this has when a resident dies **(Chapter 5)**. Similarly, a qualitative study among 26 healthcare assistants working in residential care facilities in New Zealand reported that participants felt that the 'familial' relationship they had with residents was key to providing individualised, high-quality care, for dying patients, but also led to stronger feelings of bereavement after the death of a resident.[10] This duality when building a personal relationship also emerged in the interviews held with clinicians in this thesis **(Chapter 4)**. They mentioned that a long-term therapeutic relationship contributed to a greater emotional impact. This was also seen among junior doctors on a palliative care rotation who reported struggling with the balance between maintaining a professional distance and simultaneously being close to the patients to gain trust and remain human.[11] Genuine emotional understanding of patients is associated with increased personal wellbeing of healthcare professionals, higher levels of job satisfaction and lower levels of stress.[12, 13] In addition, the empathic processes underlying such relationships increase helping behaviour, promote good communication and a considerate social style.[12] Personal connection enhances the quality of care. On the other hand, the emotional and cognitive labour required for this is also demanding for healthcare professionals. Empathy is a multidimensional process, influenced by characteristics of the healthcare professional, the patient and the setting and has multiple levels of complexity.[12] However, because of the multifaceted process that empathy influences, it is difficult to determine the balance between the added value of empathy for both the patient and the healthcare professionals on the one hand, and the burden experienced by the healthcare professional on the other.

In summary:

- ➔ In the provision of palliative care, other stressors are experienced than in providing curative care;
- ➔ Providing palliative care gives simultaneously positive and negative feelings;
- ➔ Healthcare professionals experience a duality in building personal relationships with patients and the greater emotional impact this has when their patients die.

Differences in emotional impact between providing generalist palliative care and specialist palliative care

Zooming in on the differences in the emotional impact of providing palliative care, studies demonstrate that healthcare professionals providing care in general care settings report higher rates of burnout than their colleagues working in specialist palliative care settings, such as hospices or palliative care units **(Chapter 2)**. This may be explained by several reasons. For example, palliative care generalists are unlikely to have deliberately chosen to provide palliative care. Moreover, often they did not realise beforehand that providing palliative care is a substantial part of their work.

Other possible explanations are that in general settings there is little attention for the emotional impact of providing palliative care and that many healthcare professionals are not trained in palliative care. Furthermore, palliative care specialists indicated that they found it stressful when they were surrounded by colleagues with insufficient knowledge of palliative care **(Chapter 4)**. This made them reluctant to transfer the care to these colleagues because they feared that palliative care needs would be recognized too late, and this would compromise the quality of care.

Focusing on education, receiving palliative care training plays an important positive role in the stress experienced by healthcare professionals and the prevalence of burnout.[14,15] Studies have shown that healthcare professionals with more palliative care training are more aware of the purpose of the care they provide, resulting in less frustration or reduced feelings of failure.[15,16] Furthermore, when palliative care education focuses not only on the practical knowledge of providing palliative care, but also reflects on the potential personal impact of providing palliative care, it can create awareness in healthcare professionals. Awareness can be described as the tendency to be conscious of one's own experiences in daily life.[17] It consists of a combination of self-knowledge and empathy, enabling healthcare professionals to attend to both the needs of their patients and their own needs.[17] A cross-sectional study among Spanish palliative care professionals found that those with higher levels of awareness were better able to cope with death.[17]

In specialist palliative care settings, teams often actively pay attention to the potential emotional impact of providing palliative care. This is another possible explanation for the lower levels of burnout found in specialist palliative care settings compared to generalist settings.[18] In practice we see that in many hospices or palliative care units, standard team meetings are held to provide an opportunity to discuss how the healthcare professionals are personally affected by their work. Well-led group meetings can contribute positively to the wellbeing of healthcare professionals and have been associated with reduced burnout.[19]

In summary:

- ➔ Providing palliative care in general care settings is associated with higher burnout rates than in specialist palliative care settings;
- ➔ Possible reasons for this difference are that palliative care generalists may not have deliberately chosen this field, they have no specific education and in general settings there is little attention for the possible impact;

➔ Education and group meetings can create awareness and help reduce work-related stress.

Interventions to reduce emotional impact of providing palliative care

Various interventions have been developed to support healthcare professionals who provide palliative care in dealing with the emotional impact of their work. These interventions are often aimed at improving communication skills, meditation interventions or creative therapy. Unfortunately, studies most included in our literature review were of poor to fair quality and reported little to no effect (**Chapter 2**). Another literature review of psychological interventions to improve the wellbeing of healthcare professionals working in palliative care settings also revealed only small improvements in psychological outcomes in only two out of nine included studies.[20] Most of the included studies were methodologically weak. Almost all of the included studies in both literature reviews were aimed at the *individual* healthcare professional. This individual approach to dealing with the personal impact of work has several shortcomings. First, it does not match the needs of healthcare professionals to be supported on a team and organisational level. In this thesis **(Chapters 3 and 6)**, respondents reported they already engage in a range of self-care activities to cope with the emotional impact of providing palliative care but feel this is not enough. They express unmet needs at a team and organisational level, such as more attention from the organisation to work-related stress, more support from their supervisor, time to discuss impactful events with colleagues, and feeling safe within their team **(Chapters 3 and 6)**. This need for support at a team and organisational level also emerged from other studies. A study among 177 oncologists showed that the majority would find it helpful in coping with the death of a patient when emotions such as grief would be validated as a normal and acceptable part of their work in oncology.[21] Second, offering only individual-oriented interventions may send the message that burnout and the experienced work-related stress are an individual problem, both in terms of impact, cause and solution. Burnout and poor healthcare professional wellbeing are associated with poor patient safety outcomes and increased absenteeism.[22, 23] In addition, the youngest generations constituting and entering the workforce highly value work-life balance and having a supportive environment in their work.[24] Organisations should respond to these needs by developing and maintaining a stable workforce. Therefore, healthcare professionals' wellbeing is a shared responsibility of the individual healthcare professionals, managers/supervisors and healthcare organisations as a whole.

In summary:

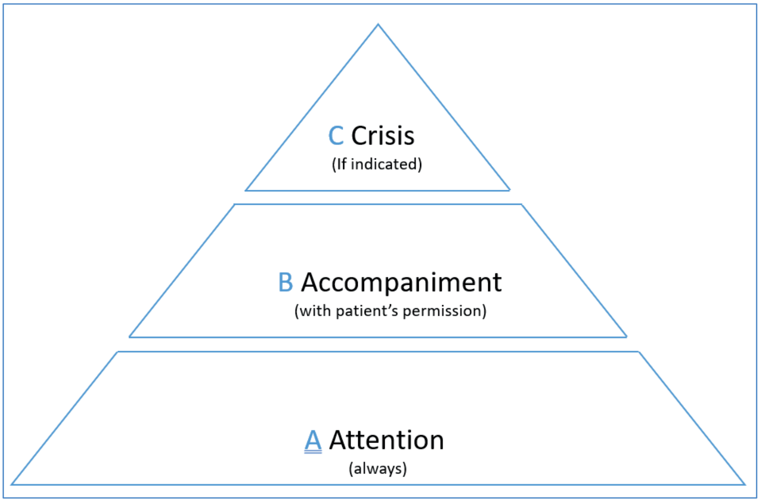
- ➔ Interventions to support with the emotional impact of providing palliative care often show small improvements;
- ➔ Most interventions are directed at the level of the individual and do not address two other important levels, namely the team and the organisation.

7.4 RECOMMENDATIONS FOR PRACTICE, EDUCATION AND ORGANISATION/ POLICY

Several recommendations to support healthcare professionals to maintain, gain or restore their personal emotional wellbeing while providing palliative care emerge from the main findings of this thesis.

To support the diverse needs of healthcare professionals in relation to the emotional impact of providing palliative care at the organisational, team, and individual levels, we advise using the ABC model (Figure 1). This model has its origin in spiritual and existential care to address the wellbeing of patients in the palliative phase. ABC stands for A) *Attention*, B) *Accompaniment* and C) *Crisis*.[25]

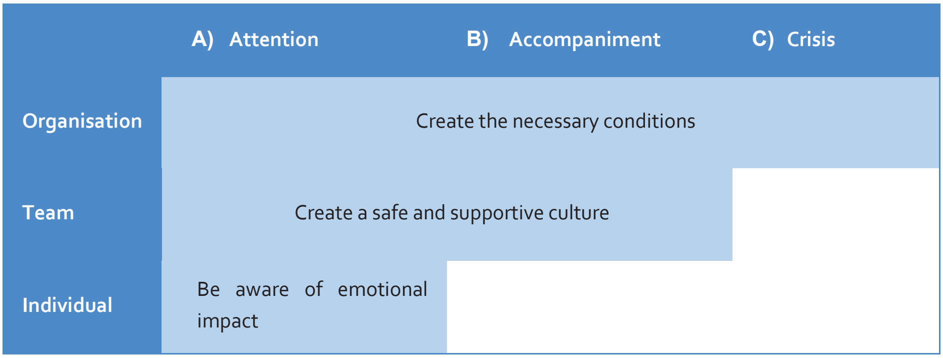
Figure 1 ABC model for spiritual and existential care



The National Guideline for Existential and Spiritual Aspects of Palliative Care advises that the first step (A) is that healthcare professionals pay *Attention* to existential/spiritual issues in the care of every patient receiving palliative care.[25] This can be done through an open attitude and/or a brief exploration of spiritual needs. If a patient indicates they would like *Accompaniment* regarding existential/spiritual care, the healthcare professional involved will do so by taking step B: talking with the patient about his/her existential/spiritual concerns and process, or by paying attention to any rituals that the patient or family might want. To be able to do step B, clinicians should have some basic knowledge of spiritual care. If there are indications for a spiritual *Crisis*, the patient needs specialized care and should be referred to a spiritual counsellor (step C).

To use the ABC model to provide support in relation to the emotional impact of providing palliative care, it has been adapted (Figure 2). In addition to the level of treatment as known from the original ABC model (*Attention*, *Accompaniment* and *Crisis*), in this adapted model a distinction is also made for the organisational, team and individual level.

Figure 2. Model for care for healthcare professionals providing palliative care. Inspired by the ABC model of the national guideline Existential and spiritual aspects in palliative care



	A) Attention	B) Accompaniment	C) Crisis
Organisation	Create the necessary conditions		
Team	Create a safe and supportive culture		
Individual	Be aware of emotional impact		

The main focus of the model is on *Attention*. All three levels, the organisational, the team and the individual level, have an important role in this. Similar to the original ABC model, *Attention* should be given to the emotional impact of providing palliative care for every healthcare professional. If this is not sufficient, *Accompaniment* and *Crisis Intervention* should be available and the need for further support should be monitored. Due to the many differences in impactful situations, between healthcare professionals and between organisations, no single solution can be provided at all these levels. Therefore, this model should not only lead to stepped care, but also offer a range of interventions to meet the different possible needs.

The model also implies that addressing the emotional impact of providing palliative care is a shared responsibility, and the foundation for this lies within the organisation. Organisations should create the right conditions for individual healthcare professionals and teams to build on. Interventions should be part of a broader, system-wide approach. By taking responsibility as an organisation for the emotional wellbeing of healthcare professionals and creating the right conditions for interventions at the organisational, team and individual level, several goals can potentially be achieved. First, such a system-wide approach may be more effective than the individual approaches. An individual approach does not address the causes of stress at the team and organisational level and the related needs that are beyond the individual healthcare professionals control.[26] An approach that includes both individual oriented and team interventions and is embedded in an organisation that provides necessary conditions has potentially more impact.[27] The healthcare organisation and the team should therefore be part of the solution, leading to a system-wide approach.[28] Second, a more comprehensive approach might prevent *Crisis*, which is more desirable than treating work-related stress or symptoms of burnout as this is often accompanied by absenteeism of healthcare professionals. Third, when organisations convey work-related stress as a shared responsibility and provide the necessary conditions, it can empower healthcare professionals to take action regarding their personal wellbeing.

Create necessary conditions: organisation level

Include support for dealing with the emotional impact of providing palliative care in policy plans

It is recommended that organisations create the necessary conditions to ensure that the unmet needs of healthcare professionals can be met at the organisational, team and individual level. To create these conditions, it is necessary to include goals regarding support for dealing with the emotional impact of providing palliative care in the policy plans. Necessary conditions include making time available for activities, appointing employees with an assignment in drawing up a program regarding the emotional wellbeing of healthcare professionals and increasing knowledge within the organisation regarding the theme.

Design a Support program

Organisations should use a program-based approach to meet the various needs which may differ per healthcare professional and per situation. In such a program it is desirable not only to build in support for healthcare professionals who suffer from too great an emotional impact of providing palliative care (*Crisis Interventions*), but also to focus on prevention by through *Attention* and *Accompaniment*. It is advisable to simultaneously pay attention to the balance in the team. It is argued that burnout is contagious: the attitudes and emotions of burned out healthcare professionals impact the wellbeing of their colleagues.[29, 30] In addition to individual wellbeing, it is also essential to consider any imbalance in the team, which may require the implementation of other conditions than when solely focusing on the individual wellbeing. Also, for organisations that already have a good structure for the personal wellbeing of healthcare professionals, it is recommended to see whether there is sufficient recognition of the emotional impact of providing palliative care. After all, workload and long working hours require a different approach than dealing with the emotional impact of caring for people who have a life-threatening condition or frailty.

Implement a broad support program across the organisation

To gain ideas for interventions for a broad support program, organisations can learn from other professions and domains such as psychiatry or uniformed personnel (Military, fire brigade, police). The first guideline for Psychosocial Support for Uniformed Persons was drawn up in 2010. It took ten years and the COVID-19 pandemic before the initiative emerged for the first guideline Psychosocial Support for Healthcare Professionals.[31] Figure 3 shows some examples of interventions that can be implemented relating to *Attention*, *Accompaniment* and *Crisis*. One example is to discuss the experiences of healthcare professionals providing palliative care during progress meetings. Other potential interventions include ensuring that managers/supervisors are adequately equipped to recognise the emotional impact on employees and how to initiate conversations about this and clear communication within the organisation that there extra support is available when *Attention* is not enough.

Ensure continuous palliative care training for all healthcare professionals and availability of palliative care specialists

Besides a program for support in dealing with the emotional impact of providing palliative care it is also important that organisations ensure that healthcare professionals receive the appropriate palliative care education. Organisations that expect their healthcare professionals to provide (generalist) palliative care should take responsibility towards their healthcare professionals and their patients. This can be done through palliative care training and sufficient availability of palliative care specialists. In the Netherlands, the program Optimize Palliative Care Education (in Dutch: Optimaliseren Onderwijs PZ (O2PZ)) works on the integration of education in palliative care in the basic curriculum for different healthcare professions.[32] However, the current workforce often lacks fundamental knowledge to actually function as a palliative care generalist. This leads to feelings of inadequacy in providing palliative care among healthcare professionals and leads to stress. It is therefore recommended

Figure 3 Examples of interventions aimed at emotional support for healthcare professionals providing palliative care

	A) Attention	B) Accompaniment	C) Crisis
Organisation	• Include the emotional impact and related needs of healthcare professional as topic in the progress meetings of employees • Provide training about the emotional impact of providing palliative care	• Ensure that managers/supervisors are adequately equipped in recognising the emotional impact on employees • Make sure it is known that there is extra support available when Attention is not enough • Focus on timely involvement of a palliative care specialist in complex palliative care	• Appoint a psychologist within and/or outside the organisation
Team	• Arrange team trainings such as workshops on building team competencies • Organise teambuilding activities • Set an example as manager/supervisor regarding dealing impactful situations • Provide role models • Establish mentorship • Organise structural team discussions such as intervision or day start meetings	• Appoint a team member with signalling function • Organise the opportunity for reflection after impactful events	
Individual	• Know yourself • Ensure you have the right training • Reflect on the positive aspects of providing palliative care		

that organisations draw up a plan to train them appropriately in this regard. The O2PZ program offers teaching material on varying topics such as the use of measurement instruments or how to talk about death. Healthcare organisations can use these materials to train their staff. In addition, organisations must ensure that sufficient palliative care specialists are available so that palliative care generalists can consult them when the care for patients in the palliative phase becomes complex. Palliative care specialists can offer guidance, education, and support to palliative care generalists.[33] This is likely to alleviate stress experienced by palliative care generalists.

The possible emotional impact of providing palliative care should be an integral part of generalist palliative care education. After all, even with sound knowledge on providing palliative care, healthcare professionals can still be emotionally impacted by certain situations. Currently, education about self-care related to providing palliative care in the Dutch medical curricula is experienced as insufficient.[34] It is unclear to what degree self-care education regarding palliative care is included in other educational programmes in the Netherlands. To address self-care, palliative care education can learn from other disciplines. For example, in the Dutch psychiatry residency and in the postgraduate training to become psychotherapist personal therapy is included in order to develop the ability to identify, appoint, and control your own emotions and simultaneously address the emotions of others.[35,36] A study on coping strategies among a variety of healthcare professionals shows that psychologists report better self-care than physicians and nurses.[37] The authors suggest this may be explained due to psychologists being more aware of self-care as an effective coping strategy.

Create a safe and supportive culture: team level

It is recommended to create a safe and supportive work culture regarding the emotional impact of providing palliative care. Feeling safe in the team to share experiences of emotional impact and support from the manager/supervisor are important needs of healthcare professionals **(Chapter 3 and 6)**. Sharing experiences, support among colleagues and compassionate leaders are important aspects for realizing a healthy team culture.[38, 39] Achieving a healthy team culture is multifactorial and which interventions are appropriate differs per team and setting and cannot be achieved with one intervention. It is therefore important that the team members are involved in the decisions about which interventions are desirable with regard to *Attention* and *Accompaniment*. Examples of how to improve team culture include participating in relevant workshops or organising teambuilding activities.

Ongoing recognition of potential emotional impact of providing palliative care

Regarding *Attention*, it is recommended to implement interventions that support ongoing recognition of the potential impact of providing palliative care. Managers/supervisors play an important role in this as they influence the collective perception of values and priorities.[27] They can contribute to a safe, supportive and honest work culture by showing their own vulnerabilities, sharing losses and successes.

They can lead by example, for instance by taking time to reflect after a patient's death. Additional examples include having role models in the team in dealing with the emotional impact of providing palliative care, pairing less experienced healthcare professionals in palliative care with a more experienced mentor, and initiating team meetings in which emotionally impactful experiences can be shared. Such team meetings are preferably supervised by a trained professional who can ensure the emotional safety and quality of the meetings.[40] By encouraging healthcare professionals to talk to each other about the emotional impact of providing palliative care through such interventions, and by providing good examples, teams can work towards a culture in which this is normal. In addition to these recurrent meetings additional reflective meetings after an impactful event has occurred in the care of patients in the palliative care phase could be organised.

Signal the need for Accompaniment

To ensure that the transition from *Attention* to *Accompaniment* is initiated in a timely manner, managers/supervisors should ensure that an appropriate process is set up for this and that their team is equipped to recognize and validate a need for *Accompaniment*. This can be done, for example, by appointing members of the team for this purpose. On the one hand, these appointed team members can provide an accessible point of contact for colleagues who notice that *Attention* alone is insufficient for them. On the other hand, these appointed team members can also be the ones who actively monitor whether colleagues could use more support. This can be organised in various ways, for example by appointing one or two colleagues who are available for an entire team or by linking two colleagues to each other in a buddy system. Regardless of how this is organised, it is important that such a conversation can be conducted in an emotionally safe context and that a process of recognition, acknowledgement and formulation of needs and specific follow-up steps regarding *Accompaniment* can take place.

Be aware of emotional impact of providing palliative care: individual level

Know yourself

Being able to pay attention to the emotional impact of providing palliative care, begins with being aware of the possible impact. In the interviews held in this thesis **(Chapter 4)** it became apparent that many healthcare professionals, mostly palliative care generalists, had never or only to a limited extent previously consciously considered the emotional impact of providing palliative care on themselves. However, there seems to be an association between awareness and the use of protective self-care activities.[17] Hence, healthcare professionals should reflect on the emotional impact of providing palliative care, identify their preferred coping style and personal needs, undertake basic self-care activities and be aware of the subsequent support that is available to them.

Ensure you have the right training

Insufficient knowledge about providing palliative care can lead to feelings of uncertainty and therefore increase the experienced emotional impact. Healthcare professionals must ensure that they receive adequate training in relation to the care they are expected to provide to their patients. Organisations have a responsibility in offering such training, but healthcare professionals also have a responsibility in addressing their needs in this regard. In addition, they can also increase their knowledge on palliative care by using existing training materials, for example via O2PZ.

Reflect on the positive aspects of providing palliative care

Many healthcare professionals experience that providing palliative care is accompanied by feelings of fulfilment and experiencing personal growth **(Chapter 4 and 5)**. It is recommended that healthcare professionals identify and share such positive experiences regarding providing palliative care. This can help them and their colleagues to become aware of these positive sides of providing palliative care which can be beneficial in dealing with the emotional impact.

7.5 RECOMMENDATIONS FOR FUTURE RESEARCH

Several recommendations for future research can be formulated. First, healthcare professionals providing palliative care in general healthcare settings report higher symptoms of burnout than colleagues in specialised palliative care settings **(Chapter 2)**. However, an accumulation of confrontation with suffering and dying on a regular basis has also been associated with high emotional impact on healthcare professionals.[41] On the other hand, some experience with caring for patients in the palliative care phase and witnessing death is perceived as helpful in coping with these experiences **(Chapter 4)**. Further research should:

- ➔ Investigate the impact of generalist palliative care education on the experienced emotional impact of providing palliative care;
- ➔ Consider if there is a tipping point between gaining necessary experience and being too often confronted with suffering and dying.
- ➔ Gain insight into how healthcare professionals with little exposure to suffering and death can be supported in gaining experience in dealing with these emotional challenges.

Second, healthcare professionals experience a struggle between on the one hand developing a personal relationship with their patients and on the other hand maintain professional distance to prevent being too greatly emotionally impacted **(Chapter 4 and 5)**. Further research should:

➔ Focus on understanding this apparent contradiction and which factors play a role in this.

➔ Assess how healthcare professionals can be supported in this balance between personal involvement and professional distance.

Third, most interventions regarding the emotional wellbeing of healthcare professionals providing palliative care are aimed at the individual healthcare professional. But unmet needs among healthcare professionals in this regard find their origin on the team and organisational level **(Chapter 3 and 6)**. This argues for a system-wide approach at the organisational, team and individual level to improve the resilience of healthcare professionals who provide palliative care. Further research should:

➔ Develop interventions at both team and organisational level that address the needs of healthcare professionals regarding the emotional impact of providing palliative care

➔ Investigate the experiences with a program-based approach to support the emotional wellbeing of healthcare professionals providing palliative care

The interpretation and comparison of research findings on the emotional wellbeing of healthcare professionals is challenging due to a broad use of terms. Lack of a clear definition for burnout and diversity in the use of burnout measurements **(Chapter 2, 3 and 6)**. However, the many symptoms experienced by healthcare professionals and rates of healthcare professionals leaving healthcare show that the problem is major and deserves serious attention. Further research should:

➔ Provide more clarity on the definition of burnout, or an appropriate other related concept that encompasses the wide range of experiences of healthcare professionals;

➔ Examine the appropriate and practical use of measuring instruments used in burnout research.

8.6 CONCLUSION

Providing palliative care is often experienced as rewarding, but at the same time it is emotionally demanding for healthcare professionals. The experienced emotional impact of providing palliative care does not have to be problematic if healthcare professionals are aware of this emotional impact, know how to manage it in their daily work, and are supported by their team and organisation. Awareness and normalisation of the potential emotional impact of providing palliative care on healthcare professionals is needed to maintain a healthy healthcare workforce in the coming years. A system approach at the organisational, team and individual level that ensures the right *Attention*, *Accompaniment* and *Crisis Intervention* at the right time has the potential to increase the resilience of healthcare professionals so that they can care for patients in the palliative phase while maintaining their emotional wellbeing. There is no ‘one size fits all’ approach, but it is about recognizing, acknowledging and taking tailored shared responsibility and action in the care for healthcare professionals providing palliative care.

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APPENDIX A: Concepts related to burnout and work-stress

There are numerous concepts that describe a state of being affected by work-related experiences. In the table below the most encountered terms are presented. This list is not exhaustive but gives an idea of the variety of concepts. The concepts in blue were used in the search string of the systematic literature review **(Chapter 2)**.

Term
Burnout
Chronic stress
Compassion fatigue
Coping
Cynicism
Depersonalisation
Emotional distress
Emotional exhaustion
Emotional impact
Emotional labour
Emotional strain
Job demands
Job stress
Mental exhaustion
Mental health
Moral distress
Moral injury
Occupational stress
Personal accomplishment
Personal balance
Personal impact
Professional quality of life
Psychological wellbeing
Resilience
Secondary traumatic stress (compassion fatigue)
Self-care
Self-management
Stress
Work-life balance
Work-related stress

7

General discussion

Summary

8

Palliative care aims to improve the quality of life of those who are facing a life-threatening condition or frailty and of their family. It consists of care for the physical, psychological, social and spiritual wellbeing. In the Netherlands, palliative care is provided by all healthcare professionals involved in the care for these patients. If necessary, due to the complexity of palliative care needs, healthcare professionals with additional training and experience can be consulted. Despite this possibility to consult these so-called palliative care specialists, many healthcare professionals do not feel confident and adequately equipped to provide generalist palliative care.

In 2017, the Netherlands Quality Framework for Palliative Care was introduced to enhance the availability and accessibility of high-quality palliative care. The framework was developed by a panel of experts including patient representatives and various healthcare professionals. It emphasizes the importance of paying attention to the emotional impact of providing palliative care by including it in the first domain, which serves as the foundation of the framework. Healthcare professionals providing palliative care are often confronted with emotional experiences, such as witnessing the suffering of dying patients and grieving relatives, and facing their own mortality Factors such as repeated exposure to death, treating complex symptoms, engaging in emotionally challenging conversations about end-of-life care and struggling with the loss of a patient have been identified as potential causes of work-related stress and burnout. However, engaging in aspects of palliative care such as contributing to a good death, experiencing personal fulfilment and growth and making a conscious choice to provide palliative care, may act as protective factors regarding their emotional well-being.

The demand for palliative care is expected to increase in the coming years due to an ageing population and an increase in people living with chronic diseases and multimorbidity. Currently, many European countries, including the Netherlands, are facing a shortage of healthcare professionals. The ageing population will not only lead to more patients, but also to a reduction in the workforce due to retiring healthcare professionals and too few (young) healthcare professionals to succeed them. All this takes place in the context of an already high work demand. Because of the different nature of providing palliative care compared to curative care and the expected increase in demand for generalist palliative care, the focus of this thesis was to gain insight into the emotional impact of providing palliative care on healthcare professionals in the Netherlands.

A systematic literature review was conducted to explore the available evidence on the well-being of healthcare professionals providing palliative care (chapter 2). The review, which included 59 studies, focused on the prevalence of burnout symptoms among professionals providing palliative care and interventions to alleviate these symptoms. The prevalence of burnout varied widely (3% - 66%), with most studies suggesting that about one in five healthcare professionals experienced burnout symptoms. Comparisons between general healthcare settings and specialised palliative care settings showed higher burnout symptoms among professionals in general healthcare settings. Only ten studies addressed interventions, six of which showed small positive effects on burnout symptoms in the short term. These interventions used meditation, communication training, peer-coaching, and art-therapy-based supervision, and were mainly aimed at individual healthcare professionals.

The review did not include Dutch studies. To gain a deeper understanding of the situation in the Netherlands, an online survey on burnout symptoms and work-related stress was conducted among members of the Dutch Association for Palliative Care Professionals, focusing on burnout symptoms and work-related stress (chapter 3). The majority of participants were nurses and physicians in general healthcare settings such as hospitals and home care. Results showed that 69% of respondents experienced moderate levels of burnout symptoms, and 7% had taken sick leave due to burnout. Although most professionals were actively engaged in up to four different activities to manage the personal impact of their work, 23% expressed a need for supportive activities at both the team and organisational level. The main needs reported involved time to discuss impactful events with colleagues (55%) and to create a safe team environment (39%).

To further explore the personal emotional impact of providing palliative care, two interview studies were conducted. The first study (chapter 4) involved physicians and nurses working in hospitals, home care, or nursing homes, including both generalists and palliative care specialists. Participants reported experiencing a significant emotional impact of providing palliative care and identified both positive and negative aspects that affected their emotions. These aspects, termed facilitators and barriers to emotional stability, were observed at individual, team, and organisational levels. The second study (chapter 5) focused on nursing assistants in nursing homes, because of their crucial role in caring for residents in their last year of life. This study also identified positive and negative elements that influence the perceived emotional impact of providing palliative care. Participants in both studies reported using coping mechanisms, engaging in emotional processing activities and their attitude towards death. However, unmet needs were also reported, emphasizing the need for support that goes beyond their personal influence and such as support from supervisors to better manage the emotional impact.

After gaining insight into the impact of providing palliative care and the related needs of healthcare professionals, a pilot intervention study was conducted (chapter 6). This intervention, Peer Support, offers support to healthcare professionals who are involved in pre-defined adverse events through conversations with trained colleagues to help them cope with post-event stress and anxiety. Given that even small events can have an emotional impact on healthcare professionals, the pilot aimed to assess the feasibility and applicability of a Peer Support Program for enhancing emotional well-being of healthcare professionals providing palliative care in a single academic hospital. In the study, 490 healthcare professionals from three departments were invited to participate, 56 responded to the questionnaire and 6 expressed their interest in the Peer Support Program. The results of the survey results showed a need for more attention to the emotional impact of their work from managers and the organisation. However, the pilot struggled to include healthcare professionals with high levels of burnout symptoms in the intervention. Although the three participants who completed the evaluation questionnaire recommended Peer Support to their colleagues, time investment and timing of the pilot were identified as significant barriers to program engagement.

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Finally, chapter 7 discusses the findings of this thesis in a broader perspective and suggests recommendations for practice, education and policy. The findings of this thesis highlight that healthcare professionals face different challenges and emotional stressors in providing palliative care than when providing curative care. Building personal relationships with patients brings both rewarding and emotionally impactful experiences, especially when patients are dying. Higher rates of burnout are observed in general palliative care settings, possibly due to a lack of specific training, and insufficient attention to the emotional impact of providing palliative care. Education and group meetings are seen as crucial for raising awareness and reducing stress, particularly for generalist palliative care professionals. However, current interventions targeting the emotional impact of providing palliative care show limited improvement, highlighting the need for broader support at team and organisational level to adequately address the wellbeing of healthcare professionals in this important and growing field.

The ABC model, which stands for paying Attention (A), Accompaniment (B), and Crisis Intervention (C), could be used to address the emotional impact of providing palliative care. The steps should be well embedded at the organisational, team, and individual level. The primary focus is on paying Attention to the emotional impact for all healthcare professionals. Where Attention alone is not sufficient, Accompaniment and Crisis Intervention should be available, with ongoing monitoring for additional support needs. The model recognises the diversity of impactful situations, and, therefore, the use of a range of interventions rather than a one-size-fits-all approach. It emphasises the shared responsibility for addressing emotional impact, with organisations playing a crucial role in creating the necessary conditions for individuals and teams.

In order to maintain a healthy healthcare workforce in the coming years, which will be increasingly involved in providing palliative care, there is a need for awareness and normalisation of the potential emotional impact of taking care of seriously ill patients and their family. It is about recognizing, acknowledging and taking tailored shared responsibility and action in caring for healthcare professionals involved .
Organisations, teams and healthcare professionals jointly need to care about the care for healthcare professionals providing palliative care.

Appendices

Samenvatting
Curriculum Vitae
List of Publications
Dankwoord

SAMENVATTING

Palliatieve zorg is de zorg voor mensen met een levensbedreigende aandoening of kwetsbaarheid. De nadruk ligt op het verbeteren van de kwaliteit van leven van patiënten en hun naasten en omvat fysieke, psychologische, sociale en spirituele zorg.

In Nederland wordt palliatieve zorg verleend door *alle* zorgverleners die betrokken zijn bij de zorg voor patiënten in de laatste levensfase. Vaak zijn dit zorgverleners zonder veel ervaring of scholing in het verlenen van palliatieve zorg; we noemen hen generalisten in de palliatieve zorg. Indien de palliatieve zorgbehoeften van een patiënt te complex zijn, kunnen generalisten contact opnemen met een specialist palliatieve zorg. Dit zijn zorgverleners met een aanvullende opleiding en veel ervaring in het verlenen van palliatieve zorg. Het is bekend dat veel generalisten in de palliatieve zorg zich onzeker en niet adequaat toegerust voelen om goede palliatieve zorg te bieden.

Zorgverleners die palliatieve zorg verlenen, zowel generalisten als specialisten palliatieve zorg, worden geconfronteerd met emotionele ervaringen, zoals het lijden van ernstig zieke patiënten en verdrietige familieleden. Factoren zoals zorgen voor patiënten met complexe symptomen, het voeren van emotionele gesprekken over het levenseinde en het herhaaldelijk meemaken dat patiënten overlijden worden gezien als mogelijke oorzaken van werk-gerelateerde stress. Dit kan uiteindelijk tot een burn-out leiden. Het gevoel bij te kunnen dragen aan een goed levenseinde voor zieke mensen en het ervaren van persoonlijke vervulling en groei worden gezien als mogelijke beschermende factoren.

De behoefte aan palliatieve zorg in de komende jaren verder toenemen. Dit komt doordat de bevolking vergrijst en er meer mensen leven met chronische ziekten en multimorbiditeit. Dit proefschrift richt zich dan ook op de vraag hoe zorgverleners in Nederland de emotionele impact van het verlenen van palliatieve zorg ervaren en welke ondersteuning zij hierin nodig hebben.

Ten eerste hebben we internationale studies geanalyseerd die de mate van burn-out symptomen bij zorgverleners die palliatieve zorg verlenen hebben gemeten en de effecten hebben onderzocht van methoden om deze symptomen te verlichten **(hoofdstuk 2)**. Uit de meeste studies bleek dat ongeveer één op de vijf zorgverleners burn-out symptomen ervoeren. Bovendien hadden zorgverleners die palliatieve zorg verlenen in algemene settingen, zoals ziekenhuizen, een hogere mate van burn-out symptomen dan zorgverleners in gespecialiseerde palliatieve zorg settingen, zoals hospices. De interventies die werden onderzocht, waren voornamelijk gericht op individuele zorgverleners met burn-out klachten en lieten beperkte verbeteringen hierin zien.

Om een beeld te krijgen van de situatie in Nederland, werd een online vragenlijst over burn-out symptomen en werk-gerelateerde stress uitgestuurd onder leden van de Nederlandse Vereniging voor Professionals in de Palliatieve Zorg (Palliactief) **(hoofdstuk 3)**. Hieruit bleek dat 69% van de respondenten een zekere mate van burn-out symptomen ervoeren, en zelfs dat 7% zich ziek had gemeld vanwege burn-out. Bijna alle zorgverleners ondernamen zelf verschillende activiteiten om de emotionele impact van hun werk te beheersen. Toch gaf 23% aan extra ondersteuning nodig te hebben vanuit hun team of organisatie. Vooral tijd om impactvolle gebeurtenissen met collega's te kunnen bespreken en een veilige teamomgeving werden genoemd.

Er zijn twee interviewstudies uitgevoerd om beter inzicht te krijgen in wat de emotionele impact van het verlenen van palliatieve zorg op zorgverleners is. Het eerste onderzoek werd uitgevoerd onder artsen en verpleegkundigen. Dit waren zowel generalisten als specialisten palliatieve zorg, die werkzaam waren in ziekenhuizen, thuiszorg of verpleeghuizen **(hoofdstuk 4)**. Het tweede onderzoek richtte zich op verzorgenden die werkten in verpleeghuizen **(hoofdstuk 5)**. Deelnemers aan beide studies vertelden dat het verlenen van zorg aan ernstig zieke patiënten en hun naasten hen emotioneel raakt, en noemden zowel positieve als negatieve elementen van het verlenen van palliatieve zorg die van invloed waren op de ervaren emotionele impact. Net als in hoofdstuk 3 benoemden de zorgverleners in deze onderzoeken dat zij zelf verschillende activiteiten ondernamen in het omgaan met de emotionele impact, maar steun nodig hadden die verder reikte dan hun persoonlijke invloed.

Toen we inzicht hadden in de behoeften van zorgverleners, werd een pilot-interventiestudie uitgevoerd op drie afdelingen van een academisch ziekenhuis **(hoofdstuk 6)**. De interventie, Peer Support, biedt ondersteuning aan zorgverleners door drie gesprekken met hierin getrainde collega's om hen te helpen omgaan met stress en angst na een impactvolle gebeurtenis. De resultaten van de enquête onder zorgverleners toonden aan dat vanuit leidinggevenden en binnen de organisatie meer aandacht moet worden besteed aan de emotionele impact van het werk. In de pilot was het echter lastig om zorgverleners met hoge burn-out scores bij de interventie te betrekken. Hoewel de drie deelnemers na het programma aangaven Peer Support aan te bevelen aan hun collega's, werden tijdgebrek en de timing van de gesprekken genoemd als belemmeringen voor deelname aan de pilot van het Peer Support programma.

Ten slotte werden in **hoofdstuk 7** de onderzoeksresultaten in een breder perspectief geplaatst en werden aanbevelingen gedaan. De resultaten van dit proefschrift benadrukken dat zorgverleners uitdagingen en emotionele stress ervaren bij het verlenen van palliatieve zorg. We stellen voor het ABC-model te gebruiken om gelaagd te kijken naar de ondersteuning van zorgverleners in het omgaan met deze emotionele impact. Dit model legt de primaire focus op het besteden van Aandacht (A) aan de emotionele impact voor alle zorgverleners. Als Aandacht alleen niet voldoende is, moeten Begeleiding (B) en Crisisinterventie (C) beschikbaar zijn. Het model benadrukt de gedeelde verantwoordelijkheid voor het omgaan met de emotionele impact, waarbij organisaties een cruciale rol spelen bij het creëren van de noodzakelijke voorwaarden voor individuen en teams .

Het is nodig de komende jaren de beroepsgroep zorgverleners zo gezond mogelijk te houden en hen in staat te stellen zo goed mogelijke palliatieve zorg te verlenen. Bewustwording en normalisatie van de emotionele impact van het verlenen van zorg aan ernstig zieke patiënten en hun naasten is daarom nodig. Zorginstellingen, zorgteams en individuele zorgverleners dragen gezamenlijk verantwoordelijkheid voor de zorg voor de <u>zorg voor zorgverleners die palliatieve zorg verlenen</u>.

CURRICULUM VITAE

Anne-Floor Dijxhoorn was born on July 2, 1986 in Amersfoort, the Netherlands. In 2005 she graduated from secondary school (Herman Jordan Montessori Lyceum, Zeist) and from 2006 until 2010 she did a bachelor Psychology at the University of Amsterdam. During her bachelor she became interested in quality of life and happiness and worked at Stichting De Gelukskoffer, which offers lessons in personal development for primary school children. In 2010 she started her Master in Health Psychology at Leiden University and in 2011 she obtained her Master of science.

After completing her Master's degree, Anne-Floor started as freelancer and worked on several projects for C1000 and the Gelukskoffer Foundation. However, she missed her field of study, and sought a job at the intersection of healthcare and psychology. To gain experience in the healthcare sector, she worked as a care assistant in a nursing home in Amsterdam. It was during this time that the idea of working in palliative care began to take shape. In 2013, Anne-Floor started as a project assistant at IKNL, where she worked on various projects. Subsequently, she became Advisor Palliative Care at IKNL and was involved in the development of the first Dutch quality framework for palliative care.

In 2018 within IKNL the opportunity arose for PhD research, which started in 2019 in close collaboration with the Centre of Expertise in Palliative Care of LUMC, under supervision of Prof. dr. Yvette van der Linden, Dr. Natasja Raijmakers and Dr. Linda Brom. Alongside her PhD research, Anne-Floor was also involved in the research on integrated palliative care.

Anne-Floor currently works as senior advisor at Stichting Palliatieve Zorg Nederland.

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Submitted

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**both authors contributed equally*
Under review

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In Handboek psychiatrie in de laatste levensfase
Radboud Marijnissen, Kenneth Chambaere, Richard Oude Voshaar (redactie)
Boom uitgevers Amsterdam 2022

DANKWOORD

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