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Care about care for healthcare professionals providing palliative care

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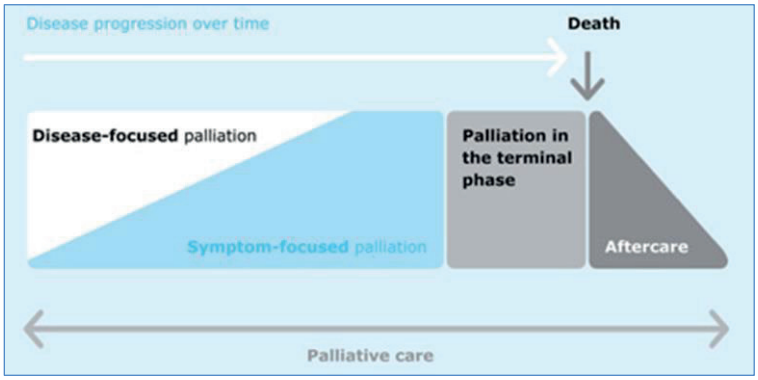
General introduction

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:

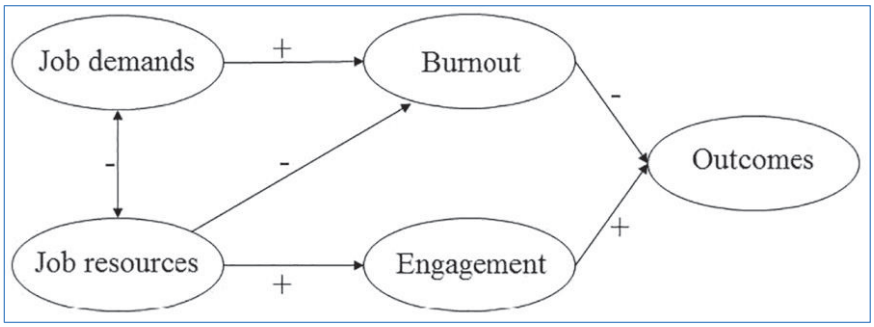
- *feelings of energy depletion or exhaustion;*
- *increased mental distance from one's job, or feelings of negativism or cynicism related to one's job; and*
- *reduced professional efficacy.*

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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