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Care about care for healthcare professionals providing palliative care

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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.