MARGO VAN MOL

BALANCING COINCIDENT WORLDS

The emotional impact of patients' relatives and professionals in the intensive care

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Financial support for the publication of this thesis by Ambidexter Management, the department of Intensive Care Medicine Erasmus MC, and Maquet the Netherlands B.V. is gratefully acknowledged

Cover design and lay out: Rik Tazelaar and Margo van Mol

Printed by: Optima Grafische Communcatie BV

ISBN: 978-94-92683-34-2

Balanceren In Samenvallende Werelden

de emotionele impact
voor naasten van de
patiënt en professionals
op de intensive care

Balancing Coincident Worlds

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Thesis

to obtain the degree of Doctor from the
Erasmus University Rotterdam
by command of the
rector magnificus

Prof. dr. H.A.P. Pols

and in accordance with the decision of
the doctorate Board.

The public defense shall be held on

Wednesday 21 June 2017
At 9.30 hours by

Martina Maria Cornelia van Mol
Born in Veldhoven

Erasmus University Rotterdam

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FOREWORD

BALANCING COINCIDENT WORLDS

THE EMOTIONAL IMPACT OF PATIENTS′ RELATIVES AND PROFESSIONALS IN THE INTENSIVE CARE

World has a broader overall meaning than planet Earth; especially, together with the life it supports, or the universe, in a broader philosophical context. This world is connected to other planets (e.g., the sun, the moon); however, the influence and closeness might vary by days, months or years. More figuratively, the word world also has the connotation of a group of people with common characteristics or pursuits, for example, the world of musicians, or a particular realm, such as the world of imagination. World can also refer to a particular way of life, all that relates to the life of a person, or a state of existence. In this thesis, I consider the worlds in these symbolic senses.

An intensive care unit (ICU) is a world of monitors, mechanical ventilators, infusion pumps, and other life-supporting technical devices, all with bleeps and alarming noises. A tangible atmosphere of hectic and urgent issues often controls the organizational processes. Patients stay in this ICU world with life threatening illnesses, totally dependent on the care of the professionals. Most of the time, they are comfortably sedated, sometimes awake, and sometimes they are in an imaginary matrix, a surrealistic delirious world. Patients´ relatives also stay in the ICU, living in a world of hope and fear; they are numb, stuck to a glimmer of faith, and weighing every word of the professionals. Intensivists and ICU nurses work in the ICU with all of their domain-specific knowledge and scientific methods to treat the patients´ diseases and complications. These coincident worlds, from different perspectives and mainly in harmonized balance, are working intensively together to provide the best care to the patient.

Staying and working in the ICU can be two sides of the same coin; patients and their relatives on the one side and healthcare professionals on the other side, are strongly connected to each other. Acting as separate and distinct entities, with their own interests and values, they might mutually influence personal life experiences. Staying in the ICU is never desirable; nevertheless, working in the ICU is challenging and versatile with all the required technical competences, providing emotional support, enlarging medical knowledge, comprehensive understanding and responsibilities. The ICU is a beautiful world in which to work, but it may be too much of a good thing; having to be present and empathic at all times with distancing or dehumanization as the result. The continuous weighing and balancing in professional proximity is an individual equilibrium, a personal world of engagement and detachment, which varies by days, months, and years.

The nursing profession is predominantly a practical domain; traditionally, a world with a holistic vision for patient care and executing protocols or medical orders from other disciplines. However, this world is increasingly subject to change. Nursing leadership is the effectuation of a pivotal role and qualified knowledge in advocacy to patient care. It can contribute in delivering person-centered care, patient safety, teamwork, and clear communication; thus, optimizing the quality of care for patients. Particularly in the ICU, nurses should present leadership in the complex care to frail patients and their relatives. In a valuable addition, health psychology brought tools to further deepen comprehension and insight in human experiences in the ICU to me personally. In a broader sense, it also offers profound health behavior theories and approaches to occupational health, which may support patients, their relatives, and the professionals as well. Furthermore, psychology provides sound methods to implement new interventions and to invest in their effectiveness. Similar expert skills are essential in both psychology and the ICU for professionals to provide optimal care. For example, support and communication, which are core elements in both fields, require the awareness and empathy of caregivers. Therefore, combining psychological theoretical viewpoints with daily ICU practice may integrate the best of these two intertwined worlds.

In contrast, the scientific worlds of medicine and psychology sometimes seem miles away from each other, with in each domain hidden "do´s and don´ts" for conducting research and their respective publications. For example, an ICU article needs a short introduction, whereas psychology articles require extended explanations, theories and hypotheses. It is a challenge, and a pleasure, to bridge the differences between these two worlds and join them together in an optimal balance.

This thesis reflects all these coincident worlds. An interrelationship may be reinforcing and powerful, leading to positive consequences, such as excellent quality of care and a healthy alliance between professionals and patients. A connection also may be too suffocating, for example, generating a heavy emotional workload and the inextricable negative emotions of a burnout. Personally, I prefer to start with an encouraging approach and to let the sunshine come into the world.

Margo van Mol

I can’t change the direction of the wind,
but I can adjust my sails to always reach my destination.

(Jimmy Dean)

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General introduction

Healthcare is changing, partly influenced by demographic, societal, economic, and technological trends[1]. First, an increasing aging population is a critical worldwide trend, due to longer life expectancy and lower birth rates[2]. This development is associated with rising rates of chronic diseases and comorbidities. Furthermore, a free market system and questions regarding the costs of treatment with respect to efficacy have intrusive effects on the delivering of care[3, 4]. Value, defined as outcomes relative to costs, should meet the overarching goals of the patient. These goals direct the choices and combined efforts of healthcare providers in the full circle of care[4]. Additionally, medical treatment is expanding with ongoing technical improvements[5]. Among other areas, these changes are evident in the environment of an intensive care unit (ICU)[6], the hospital ward that cares for patients with severe and life-threatening illnesses and injuries.

Essential characteristics of an ICU include support from highly trained staff, continuous monitoring, specialist equipment, exhaustive administration of medications, and innovative technical treatment. Intensive care or critical care has evolved from the historical recognition that the treatment of patients with acute, life-threatening diseases was better organized when such patients were grouped together in specific areas in the hospital. Florence Nightingale (1820-1910) is considered to be the first to utilize this idea[7]. During the Crimean War (1850-1854), she brought the most heavily wounded soldiers into the "Monitoring Unit", an area close to the nursing station. In this area Nightingale and her colleagues maintained continuous observation and provided immediate care when needed. She wrote in 1852, "It is valuable to have one place in the hospital where post-operative and patients needing close attention can be watched"[8]. However, since the 18th century, systems have distributed healthcare among wounded and sick soldiers in field hospitals during war[9]. Grouping together critically ill patients does not constitute an ICU. According to current definitions, there is no ICU without profound understanding of disease pathophysiology, without unambiguous measuring and monitoring, and without lifesaving interventions to react to the deterioration of patients (such as reanimation, blood transfer, vasoactive medication, or organ function replacement treatments)[10, 11]. Two crucial elements of ICU care are the prevention of and the rapid response to life-threatening complications in critically ill patients and the temporary substitution for the physiological function of one or more organ systems that have failed. Automatic artificial ventilation of the lungs during chest surgery was not known before 1896[12]. Therefore, linking Nightingale to the ICU seems artificial, romantic, and inaccurate according to its current definition. In 1926, Dr. W. E. Dandy opened a three-bed unit for critically ill postoperative neurosurgical patients[7, 13]. In 1953, Dr. B. Ibsen established the first medical and surgical ICU during the worldwide epidemic of poliomyelitis under the guidance of Mogens Björneboe[14]. These ICUs began as a technologic system of tools, knowledge and highly trained skills, where nurses´ traditional practices of intensive observation and triage provided the model for caring for the most critically ill patients[15]. In recent decades, the success of mechanical ventilation has spread quickly[13] and intensive care medicine has grown as a bastion of technology and advanced treatments[6]. Currently, providing intensive care also means utilizing an extensive multidisciplinary approach, which includes the use of teamwork to deliver care to patients and valuable discussions when making treatment desicions[16]. The necessity of working together to achieve the goal of providing safe and excellent patient care involves interconnected activities and interventions among diverse healthcare providers. Each professional's skills, knowledge, and expertise must be valued, and cooperation and the realistic division of tasks in order to achieve a unified goal are also necessary.

Finally, in addition to the generally changing trends, the current World Health Organization definition of health has been proposed for reformulation in a more positive direction[17]. Two main aspects considered to integrate are 'adaptation' and 'human balance in nature'. This new idea is positively expressed as "Health as the ability to adapt and to self-manage in the face of social, physical and emotional challenges"[18]. Therefore, it is essential to involve the individual as an active partner in professional care and treatment.

PERSON-CENTERED CARE

This alignment of partnership, which is labeled 'person-centered care', subsequently implies the shifting thoughts and attitudes of the healthcare professionals[19]. Person-centered care stresses patients and healthcare professionals as equal partners in planning, developing and monitoring care to ensure that it meets patients´ needs. It includes elements such as respecting individual values and preferences, compassion, optimal communication, physical comfort, and emotional support[20, 21]. Patients admitted to an ICU are typically less able to receive information or to make deliberate decisions regarding medical treatment due to the severity of their medical conditions or the administration of sedative medications. Therefore, clinical decision-making in the ICU should occur as part of a collaborative process with the relatives acting as representatives for the patients[22].

Professionals in the ICU increasingly view the patient as an integral component of a family unit and therefore include the relatives in their caring activities[23, 24]. A competent healthcare professional with appropriate skills and attitude can utilize person-centeredness. Not only during direct treatment but also by employing dignity, sharing information concerning the medical treatment and condition of the patient, and showing empathy towards patients and their relatives. Although there is an ongoing debate on the theories of compassion and empathy[25-27], in this thesis those are considered as two different constructs. Compassion includes noticing when someone is suffering and experiencing a mutual emotional reaction to this suffering, subsequently stimulating meaningful action in the relationship[25]. Empathy is the cognitive understanding and consideration of the perspective of other human beings in distress, leading to support[28], even though caregivers do not have to feel the pain and suffering of these individuals[29]. Person-centeredness requires awareness and knowledge by the professionals of all relevant and important aspects of the caring process together with empathy for the needs and preferences of patients and their relatives. Overall, today's challenge is to create an organizational culture based on person-centered care, thus contributing to an excellent quality of care.

QUALITY OF CARE FOR THE RELATIVES OF PATIENTS: STAYING IN THE ICU

An ICU is an uncertain and stressful place for ICU patients and their relatives[30], which may result in long-term physical, cognitive, and psychological distress[31]. Recently, the Post Intensive Care Syndrome (PICS) has been defined to emphasize the total impact of an ICU admission; the new or worsening impairments in health status arising and the persistence of critical illness after hospitalization[31, 32]. In addition to the challenges of recovering from the underlying disease and physical revalidation, the emotional distress needs to be addressed. Patients' relatives may suffer from PICS as well, although it may be restricted to emotional consequences over the long term[33]. The ability to adapt and self-manage their emotional turmoil might weaken and negatively affect their health. Many researchers have suggested that the relatives of patients need accessibility, support, and information to best cope with their anxiety and imbalance[34]. Healthcare professionals usually respond to these needs intuitively rather than based on evidence[35]. Therefore, it is necessary tailor the delivery of care to relatives in agreement with their perspectives, also named the 'Patient/Person Reported Experience Measures' (PREMs). Communication is one of the most important factors in the perceived quality of care from the point of view of the relatives[36]. The Dutch Society of Intensive Care (NVIC) acknowledges the relevance of optimal communication and suggests that every ICU needs to monitor this quality of care[37]. However, an evidence-based, valid, and reliable Dutch instrument that evaluates actual experiences and the perceived quality of care from the perspective of the relatives was lacking until 2014[38]. Therefore, it was desirable to develop a new measurement instrument as a logical follow-up to all previous international studies.

The development process of this measurement instrument is based on standards for determining the experiences with provided care from the perspective of a client group, according to the Consumer Quality Index (CQI) method[39]. In the Netherlands, the CQI method is a scientific and standardized process for developing measurement instruments in healthcare quality to promote person-centered care. The development process is generally prescribed in a manual[40], guided and controlled by an external scientific advisory board. The content validity of newly developed instruments are ascertained during a qualitative phase including a literature search, in-depth interviews, and focus groups[38, 41]. The CQI method is characterized by combining perceived actual experiences with the relative importance of each aspect of care, resulting in a list of priorities for improvement of the quality of care. Until now, several CQIs have been conducted in a variety of care settings and condition-specific patients' groups such as in cataract[42], palliative[43], and general hospital care[44]. The newly developed questionnaire regarding the quality of care in the ICU was labeled CQI 'Relatives in Intensive Care Unit' (CQI 'R-ICU')[45].

The CQI instruments are theoretically founded by the CAHPS® instruments and QUOTE® methodology, both of which are based on a discrepancy model[46]. To deliver a sufficient quality of care, the expectations regarding the quality should be in agreement with the perceptions of the actual experiences according to these methodologies. It is preferable to measure experiences rather than satisfaction, as it results in more objective and specific information for quality improvement[47]. An important step in the development of a CQI is determining the measurable aspects of care (quality indicators), for which many authors have adopted structure, process and outcome indicators[48-50]. Concerning the relatives of ICU patients, the structure indicators refer to the organization of the ICU, including the waiting room, visiting hours, coordination of care, and the availability of healthcare professionals. Process indicators primarily concern communication, with a distinction toward 1) providing information, for example about treatment and prognosis, and 2) affective aspects, such as the attitudes of healthcare professionals, honesty, and respect. Outcome indicators include the overall judgement of support provided by the ICU staff.

DELICATE EMOTIONAL BALANCE OF HEALTHCARE PROFESSIONALS: WORKING IN THE ICU

On the one hand, the ICU work environment is changing, as high-tech medical care requires more expert technical skills. The increased use of treatments such as advanced life-sustaining medical therapies for patients with poor long-term expectations may lead to disproportionate care[51]. On the other hand, delivering person-centered and value-based healthcare requires a focus on the patient as a human being in their own values[3]. This includes empathy from the healthcare providers, in open and meaningful communication with the person who needs care. In the ICU, the most stressful interactions for the professionals occur with the relatives rather than with the patients[52]. Therefore, an essential skill for reducing work-related stress, particularly when supporting relatives of the ICU patient, is the ability to respond with empathy. However, unwarranted immersion with ICU patients and their relatives or excessive proximity may lead to numbness and emotional exhaustion. To care for ICU patients and their relatives with empathy is about finding a delicate emotional balance for each individual professional. However, it is still unclear how proceeding this emotional investment affects work engagement, quality of work life, and sustained employability among ICU professionals.

WORK-RELATED STRESS, A HEALTH IMPAIRMENT PROCESS

Stress reactions are the first indications of emotional trauma. These reactions are defined as a set of conscious and unconscious behaviors, cognitions and emotions, developed to cope with the stressor[53]. It has been suggested that ICU professionals could be emotionally affected by end-of-life issues[54], the continuous suffering of patients[55], ethical decision making[56], miscommunication[57], disproportionate care[58], and demanding family members[59]. Additionally, workload[60, 61], alarm fatigue[62], conflicts[63], and the role of supervisors[64] could also provoke work-related stress. The stress process could ultimately cause poor individual health and less successful working. This might also lead to professionals leaving their jobs, thus impacting society through lost economic investment[65, 66]. It might even reduce the quality of care for patients and relatives [67] thereby threatening patient safety[68].

A growing body of evidence suggests that burnout among ICU healthcare professionals is a result of the demanding and continuously high-stress work environment[69]. Burnout has been defined as a combination of three factors: emotional exhaustion, depersonalization, and personal accomplishment[70]. A closely related concept, compassion fatigue, has been described as a loss of compassion due to repeated exposure to suffering during work[71, 72]. Furthermore, both post- and secondary traumatic stress include the persistent, deliberate avoidance of distressing trauma-related stimuli[73]. All of these concepts in the health impairment process are considered together in this thesis as ‘emotional distress’ because they underscore the same causes and consequences of work-related stress.

WORK ENGAGEMENT, A MOTIVATIONAL PROCESS

In the past, several studies have focused on the negative emotions of work stress and burnout in the ICU[74, 75]. However, studies on positive emotions may provide valuable perspectives as well. In relation to the proposed definition of health, which is represented as the ability to adapt and self-manage, the focus has shifted towards employees adapting to their work environment. Positive occupational health psychology aims to understand and foster the factors that allow individuals and communities to flourish. It seems of utmost importance to focus research on the motivational process affecting personal health and successful working[76-78]. Flourishing (or engaged) employees believe in themselves, generate positive feedback, set higher goals, have values that match with the organization, and can maintain long-lasting personal health. Work engagement, with its positive labeled elements, is a counterbalance to work-related stress[78, 79]. It is operationalized as a positive work-related state of mind and characterized by vigour, dedication, and absorption[80]. Vigour represents the level of energy and mental resilience while working; dedication refers to experiencing a sense of significance, enthusiasm, and challenge; and absorption is characterized by being focused and absorbed by work. In general, work engagement is influenced by job autonomy, social support, performance feedback, and personal resources such as self-efficacy, flexibility and adaptability[80]. Work engagement is firmly grounded in the Job-Demands-Resources (JD-R) theory.

THE JOB-DEMANDS-RESOURCES THEORY

The JD-R theory describes both the health impairment process and the motivational process in its relationship to the influencing factors in adapting to and self-managing stress[81, 82]. Many previous models and theories have inclined the JD-R theory, including early burnout models (Leiter, 1993), stress models (Seyle, 1976), the demands-control model (Karasek, 1979), job characteristics theory (Hackman & Oldham, 1980), and conservation of resources theory (Hobfoll, 2001)[83]. The therefrom derived JD-R model (Fig. 1) encompasses the negative aspects of work-related stress (ultimately resulting in burnout) as well as the positive aspects (resulting in work engagement). This JD-R model has been used in many studies of healthcare workers, and it is assumed that every occupation has its own demands, resources and associated factors[83, 84]. Thus, ICU professionals may have different aspects of their jobs related to work engagement compared to general employees. Until now, the JD-R model and work engagement have not been applied to ICU professionals.

The stressful environment in which both ICU nurses and intensivists work is increasingly challenging in physical, cognitive and emotional terms[52, 74, 85]. These job demands, together with the workload, might negatively affect an individual´s level of energy while working. Recent research has shown that the level of work engagement is primarily related to job resources[80], that is, the social aspects (i.e., team spirit, team efficacy and social support from colleagues); the aspects personal of grow (i.e., autonomy and performance feedback); and the organizational aspects (i.e., peer communication). Employees with adequate job resources will feel efficacious, important to the organization, and optimistic about their future[86]. The JD-R model includes personal resources as well, which refer to the perception of employees regarding their ability to successfully control

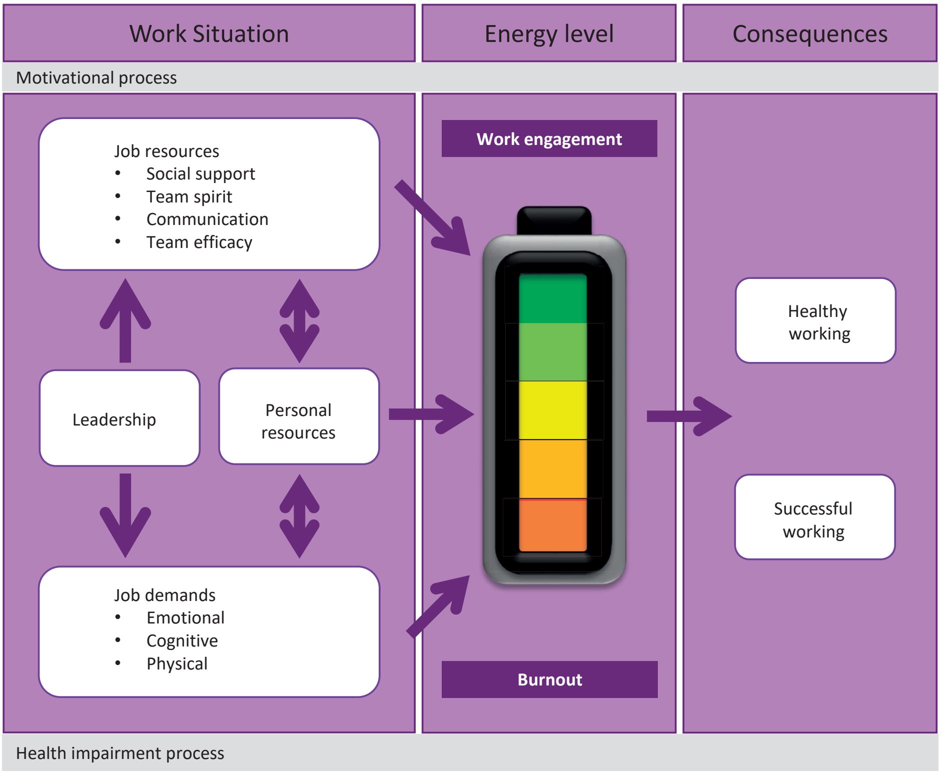

Figure 1. *JD-R model, adapted from Triple i Human Capital, Schaufeli and Schaufeli*[93, 94]

and have an impact on their work environment[80, 86]. Personal resources interact with job resources, as employees who score high on optimism, hope, self-efficacy, resilience, and self-esteem succeed more often in mobilizing their job resources. This boosting effect may change the relationship between job resources and work engagement[87]. Personal resources, such as personality traits, may partly explain different reactions to work-related stress and the level of work engagement[88-90]. Another personal resource, specifically applicable to healthcare, is the ability to respond with empathy to a person in distress or suffering[52, 91]. Traditionally, healthcare professionals interact with their clients. Strong relational skills are needed to contact and impact people who need care. There is some evidence that relational job characteristics, such as empathy, may be associated with work engagement[92].

OVERALL PURPOSE AND RESEARCH QUESTIONS

The overall purpose of this thesis is to gain a better understanding of the emotional challenges in ICU practices from the perspectives of both patients' relatives and healthcare professionals. The ultimate goal is to provide recommendations to further improve staying and working in the ICU.

This thesis will answer six central questions:

- Is the Consumer Quality Index 'Relatives in the Intensive Care Unit', which measures the experiences of ICU patients' relatives regarding the quality of care, evidence based, valid and reliable? (Chapter 2)
- What is the effect of additional supportive interventions to ICU patients' relatives on the perceived quality of care in the context of person-centered care? (Chapter 3)
- Which aspects are most relevant to providing person-centered care, and what will be the effects on the healthcare professionals? (Chapter 4)
- What is the prevalence of emotional distress (i.e., burnout, compassion fatigue, secondary traumatic stress) among ICU professionals? Which preventive strategies have been successfully applied to reduce this emotional distress? (Chapter 6)
- What is the historical perspective regarding work-related stress reactions, and which current trends need (no) further exploration. (Chapter 7)
- How are job resources and job demands associated with work engagement? Is empathy, acting as a personal resource, related to work engagement among ICU professionals? (Chapter 8)

SCOPE AND OUTLINE OF THE THESIS

The main content of this thesis is divided into two parts. The first part (Section 1) presents studies related to the quality of care and person-centered care. The world of ICU patients, and especially the experiences of their relatives (e.g., informational aspects of the healthcare providers, organizational aspects regarding their stay the ICU, and an overall judgment of the quality of care) contribute to these overarching themes. The studies underscore the relevance of Patient/Person-reported experience measures (PREMs) to further improve the care provided in the ICU. In the second part (Section 2), work-related stress and work engagement become the central themes. Working in an ICU may influence the worldview of ICU professionals, with both positive and negative consequences. The studies describe and analyze this theme and provide state-of-the-art reflections that can be applied to ICU professionals. Finally, a summary and discussion of the main findings of these parts follows in Section 3.

Chapter 2 examines the potential of the Consumer Quality Index ´Relatives in the intensive care unit´ questionnaire (CQI 'R-ICU'), to assess the quality of care from the perspective of relatives in the ICU. This newly developed instrument, measuring PREMs, can be used to provide feedback to healthcare professionals and policy makers in order to evaluate quality improvement projects concerning relatives in the ICU.

In *Chapter 2bis* we formulate a reaction to an article by Jensen et al., in Journal of Critical Care. The authors present the development of another Dutch questionnaire addressing the needs of relatives in the ICU, which might be helpful to provide high valued care in ICUs. However, to our opinion, there are some relevant theoretical and methodological problems concerning this study that we explained in this letter.

Chapter 3 describes the evaluation of a bundle of additional support specifically designed for relatives, such as intake interviews, encouragement to keep a diary, and weekly psychosocial rounds. The CQI ´R-ICU' was used for the assessment of these interventions in Erasmus MC. Additionally, person-centered care still requires a change in the mindset of healthcare professionals. This new point of view should overcome perceived barriers and foster a culture of partnership with the relatives of ICU patients.

Chapter 4 presents the joined forces of a Dutch national network, thus combining the strengths of different disciplines, scientists, and involving patient-experts and their relatives to reduce the emotional impact of an ICU admission. This approach is the core of person-centered care; the views, values, and needs of the experts are the sources of change in ICU policies. We extensively describe the key-concepts of person-centered care, such as respect, empathy, and compassion while considering that this person-centeredness puts additional weight on the shoulders of the ICU professionals. The needs of the healthcare professionals should be recognized as well.

In *Chapter 5.1* we deliberate if intensive care professionals will become more empathic by watching films and documentaries about suffering. Furthermore, *chapter 5.2*, involves a provoking consideration of dehumanizing patients in the ICU, which seems to contrast with an attitude of empathy by the healthcare professionals. This dehumanizing process may be inevitable, adaptive, and even morally and psychologically acceptable.

Chapter 6 concludes with the prevalences of burnout, compassion fatigue, secondary traumatic stress and vicarious trauma among ICU professionals. We suggest in this systematic review that the true magnitude of work-related stress remains unclear due to a lack of unified concepts, related measurement instruments, and cut-off points. Additionally, a thorough exploration of emotional distress concerning communication skills, ethical rounds, and mindfulness may provide an appropriate starting point for the development of further preventive strategies.

Chapter 7 provides a historical impression and trends in work-related stress responses among ICU professionals, such as burnout. In this book chapter we also address current opinions on post- and secondary traumatic stress and compassion fatigue among healthcare professionals.

Chapter 8 aims to explore the relationship between job demands, job resources, personal resources (i.e., personality traits and empathic ability), and work engagement among ICU professionals. The relatively high workload in the ICUs, with a high emotional burden in particular, may be acknowledged as an integral part of ICU work. Although it is essential to take care of the professionals, we emphasize that working in the ICU can be inspiring as well, as long as they adapt and self-manage the challenges.

REFERENCES

1. Joling W, Maas van der R, de Jong M. [Beleidsplan 2016-2020 Kennis maken op maat, samen met betrokken partners] Strategyplan 2016-2020 Customize knowledge, along with relevant partners: ZonMw, 2016.
2. United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing 2015; (ST/ESA/SER.A/390)
3. Moriates C, Arora V, Shah N. Understanding Value-Based Healthcare: McGraw-Hill Education, USA, 2015. ISBN 97800071816984
4. Porter ME. What is value in health care? New England Journal of Medicine 2010;363(26):2477-81.
5. Grimes SL. The challenge of integrating the healthcare enterprise. IEEE Engineering in Medicine and Biology Magazine 2005;24(2):122-24.
6. Price AM. Caring and technology in an intensive care unit: an ethnographic study. Nursing in Critical Care 2013;18(6):278-88.
7. Scales DC. The organization of Critical Care An Evidence Based Approach to Improving Quality: Springer, New York 2014. ISBN 9781493908110.
8. Skretkowicz V. Florence Nightingale's Notes on Nursing and Notes on Nursing for the Labouring Classes: Commemorative Edition with Historical Commentary: Springer Publishing Company 2010.
9. Iserson KV, Moskop JC. Triage in medicine, part I: concept, history, and types. Annals of Emergency Medicine 2007;49(3):275-81.
10. Ferdinande P. Recommendations on minimal requirements for intensive care departments. Intensive Care Medicine 1997;23(2):226-32.
11. Halpern NA, Bettes L, Greenstein R. Federal and nationwide intensive care units and healthcare costs: 1986-1992. Critical Care Medicine 1994;22(12):2001-07.
12. Takrouri M. Intensive care unit. The internet journal of Health 2004;3(2):2-4.
13. Kelly FE, Fong K, Hirsch N, Nolan JP. Intensive care medicine is 60 years old: the history and future of the intensive care unit. Clinical Medicine 2014;14(4):376-79..
14. Reisner-Sénélar L. The birth of intensive care medicine: Björn Ibsen's records. Intensive Care Medicine 2011;37(7):1084-86.
15. Farinman J. Watchful vigilance: nursing care, technology, and the development of intensive care units. Nursing Research 1992;41(1):56.
16. Berghout M, van Exel J, Leensvaart L, Cramm, Jane M. Healthcare professionals' views on patient-centered care in hospitals. BMC Health Services esearch 2015;15(1):1.
17. Charlier P, Coppens Y, Malaurie J, et al. A new definition of health? An open letter of autochthonous peoples and medical anthropologists to the WHO. European Journal of Internal Medicine 2016: doi.org/10.1016/j.ejim.2016.06.027
18. Huber M, Knottnerus JA, Green L, et al. How should we define health? BMJ 2011;343
19. Barnsteiner J, Disch J, Walton M. Person and Family Centered Care: Sigma Theta Tau International, Indianapolis USA. 2014. ISBN 9781938835070
20. Frampton SB, Guastello S. Time to Embrace a New Patient-Centered Care Rallying Cry:"Why Not?". The Patient-Patient-Centered Outcomes Research 2014;7(3):231-33.
21. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press 2001. ISBN 9780309072809
22. Netzer G, Sullivan DR. Recognizing, Naming, and Measuring a Family Intensive Care Unit Syndrome. Annals of the American Thoracic Society 2014;11(3):435-41.
23. Azoulay E, Pochard F, Chevret S, et al. Meeting the needs of intensive care unit patient families: a multicenter study. American Journal of Respiratory and Critical Care Medicine 2001;163(1):135-39.
24. Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the in-

tensive care unit: a literature review. Journal of Clinical Nursing 2013;22(13-14):1805-17.

25. Youngson RA. Time to care: How to love your patients and your job: Rebelheart Publishers 2012. ISBN 9789036808569.
26. Kiosses VN, Karathanos VT, Tatsioni A. Empathy promoting interventions for health professionals: a systematic review of RCTs. Journal of Compassionate Health Care 2016;3(1):7.
27. Singer T, Klimecki OM. Empathy and compassion. Current Biology 2014;24(18):R875-R78.
28. Halpern J. What is clinical empathy? Journal of general internal medicine 2003;18(8):670-74.
29. Hein G, Singer T. I feel how you feel but not always: the empathic brain and its modulation. Current opinion in neurobiology 2008;18(2):153-58.
30. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. Critical Care Medicine 2007;35(2):605-22.
31. Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference*. Critical Care Medicine 2012;40(2):502-09.
32. Elliott D, Davidson JE, Harvey MA, et al. Exploring the Scope of Post–Intensive Care Syndrome Therapy and Care: Engagement of Non–Critical Care Providers and Survivors in a Second Stakeholders Meeting. Critical Care Medicine 2014;42(12):2518-26.
33. Harvey MA, Davidson JE. Postintensive Care Syndrome: Right Care, Right Now… and Later. Critical Care Medicine 2016;44(2):381-85.
34. Verhaeghe S, Defloor T, van Zuuren F, Duijnstee M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. Journal of Clinical Nursing 2005;14(4):501-09.
35. Söderström IM, Benzein E, Saveman BI. Nurses' experiences of interactions with family members in intensive care units. Scandinavian Journal of Caring Sciences 2003;17(2):185-92.
36. van Mol M, Boeter T, Verharen L, Nijkamp M. 610: To communicate with relatives; an evaluation of interventions in the intensive care unit. Critical Care Medicine 2014;42(12):A1506-A07.
37. Advies Commissie Kwaliteit. [Kwaliteitstandaard Organisatie van Intensive care] Quality Standard of Intensive Care: Zorginstituut Nederland, 2016.
38. Rensen A, van Mol M, Menheere I, et al. Quality of care in the intensive care unit from the perspective of patient's relatives: development and psychometric evaluation of the consumer quality index 'R-ICU'. BMC Health Services Research 2017;17-7. doi:10.1186/s12913-016-1975-4
39. Zuidgeest M. Measuring and improving the quality of care from the healthcare user perspective: the Consumer Quality Index: Tilburg University 2011.
40. Koopman L, Sixma H, Hendriks M, de Boer D, Delnoij D. [Manual CQI development. Guideline and prescription in the development of a CQI measuring instrument] Utrecht: Nivel. 2011.
41. Bos N, Sturms LM, Schrijvers AJ, van Stel HF.The consumer quality index (CQ-index) in an accident and emergency department: development and first evaluation. BMC Health Services Research 2012;12(1):1.
42. Nijkamp M, Sixma H, Afman H, et al. Quality of care from the perspective of the cataract patient: the reliability and validity of the QUOTE-cataract. British journal of ophthalmology 2002;86(8):840-42.
43. Claessen SJJ, Francke, A. L., Sixma, H., et al. [On the road to a CQ-index Palliative Care: the development of a measuring instrument]: Utrecht: NIVEL. 2009
44. Sixma H. Zuidgeest M, Rademakers J. [CQ-index Ziekenhuisopname: meetinstrumen-

tontwikkeling] CQ-index Hospital Admission Measurement development: Utrecht 2009. ISBN 978906905947.

45. van Mol M, Bakker E, Rensen A, Menheere I, Verharen L. Quality of care in the ICU from the perspective of relatives. Critical Care 2013;17(Suppl 2):P543.
46. Babakus E, Mangold WG. Adapting the SERVQUAL scale to hospital services: an empirical investigation. Health Services Research 1992;26(6):767.
47. Cleary PD, Edgman-Levitan S. Health care quality: incorporating consumer perspectives. Jama 1997;278(19):1608-12.
48. Wollersheim H, Bakker P, Bijnen A, Gouma D, Wagner C, Weijden T. [Kwaliteit en veiligheid in patiëntenzorg] Quality and Safety in the Care for Patients. 2011 Bohn Stafleu van Loghum ISBN 9789031382354
49. Harteloh PPM, Casparie AF. [Kwaliteit van zorg: van een zorginhoudelijke benadering naar een bedrijfskundige aanpak] Quality of care: from a care-related approach to a managerial approach: VUGA 1991. ISBN 9789035219519.
50. Rademakers J, Delnoij D, de Boer D. Structure, process or outcome: which contributes most to patients' overall assessment of healthcare quality? BMJ Quality & Safety 2011:bmjqs.2010.042358.
51. Kompanje EJO, Piers RD, Benoit DD. Causes and consequences of disproportionate care in intensive care medicine. Current Opinion in Critical Care 2013;19(6):630-35.
52. Sprung CL, Cohen R, Marini JJ. Excellence in Intensive Care Medicine. Critical Care Medicine 2016;44(1):202-06.
53. Figley CR. Trauma and its wake: Routledge 2013. ISBN 9781134843855.
54. Todaro-Franceschi V. Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life. Dimensions in Critical Care Nursing 2013;32(4):184-90.
55. Todaro-Franceschi V. Compassion fatigue and burnout in nursing. Enhancing professional quality of life. New York: Springer 2013. ISBN 9780826109774.
56. Teixeira C, Ribeiro O, Fonseca AM, Carvalho AS. Ethical decision making in intensive care units: a burnout risk factor? Results from a multicentre study conducted with physicians and nurses. J Med Ethics 2013
57. Curtis JR, Sprung CL, Azoulay E. The importance of word choice in the care of critically ill patients and their families. Intensive Care Medicine 2014;40(4):606-08.
58. Kompanje EJ, Piers RD, Benoit DD. Causes and consequences of disproportionate care in intensive care medicine. Current Opinion in Critical Care 2013;19(6):630-35.
59. Epp K. Burnout in critical care nurses: a literature review. Dynamics 2012;23(4):25-31.
60. Embriaco N, Azoulay E, Barrau K, et al. High level of burnout in intensivists: prevalence and associated factors. American Journal of Respiratory & Critical Care Medicine 2007;175(7):686-92.
61. Klopper HC, Coetzee SK, Pretorius R, Bester P. Practice environment, job satisfaction and burnout of critical care nurses in South Africa. Journal of Nursing Management 2012;20(5):685-95.
62. Cvach M. Monitor alarm fatigue: an integrative review. Biomedical Instrumentation & Technology 2012;46(4):268-77.
63. Fassier T, Azoulay E. Conflicts and communication gaps in the intensive care unit. Current Opinion in Critical Care 2010;16(6):654-65.
64. Galletta M, Portoghese I, Coppola RC, Finco G, Campagna M. Nurses well-being in intensive care units: study of factors promoting team commitment. Nursing in Critical Care 2014;21(3).
65. Aiken LH, Clarke SP, Sloane DM, Sochalski J, Silber JH. Hospital nurse staffing and patient mortality, nurse burnout, and job dissatisfaction. JAMA 2002;288(16):1987-93.
66. Viotti S, Converso D, Loera B. Job satisfaction, job burnout and their relationships with work' and patients' characteristics: A comparison between intensive care units (ICU)

and not- Intensive care units (non-ICU). G Ital Med Lav Ergon 2012;34(2 suppl. B):B52-B60.

67. Rochefort CM, Clarke SP. Nurses' work environments, care rationing, job outcomes, and quality of care on neonatal units. Journal of Advanced Nursing 2010;66(10):2213-24.

68. Laschinger HKS, Leiter MP. The impact of nursing work environments on patient safety outcomes: The mediating role of burnout engagement. Journal of Nursing Administration 2006;36(5):259-67.

69. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. Current Opinion in Critical Care 2007;13(5):482-88.

70. Leiter MP, Bakker AB, Maslach C. Burnout at Work: A Psychological Perspective: New York, Psychology Press 2014. ISBN 9781848722286.

71. Joinson C. Coping with compassion fatigue. Nursing 1992;22(4):116, 18-9, 20.

72. Sinclair S, Norris JM, McConnell SJ, et al. Compassion: a scoping review of the healthcare literature. BMC palliative care 2016;15(1):1.

73. Americal Psychological Assosiation. Diagnostic and statistical manual of mental disorders, (5th ed.). Washington DC, USA 2013. ISBN 9780890425541.

74. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement—burnout syndrome in critical care health-care professionals: a call for action. CHEST Journal 2016;150(1):17-26.

75. van Mol MM, Kompanje EJ, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units: A Systematic Review. PloS one 2015;10(8):e0136955.

76. Fredrickson BL. The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. American psychologist 2001;56(3):218.

77. Csikszentmihalyi M, Seligman ME. Positive psychology: An introduction. American Psychologist 2000;55(1):5-14.

78. Schaufeli WB. Engaging leadership in the job demands-resources model. Career Development International 2015;20(5):446-63.

79. Bakker AB, Schaufeli WB, Leiter MP, Taris TW. Work engagement: An emerging concept in occupational health psychology. Work & Stress 2008;22(3):187-200.

80. Schaufeli WB, Taris TW. A critical review of the Job Demands-Resources Model: Implications for improving work and health. Bridging occupational, organizational and public health: Springer 2014:43-68.

81. Schaufeli WB, Bakker AB. Job demands, job resources, and their relationship with burnout and engagement: A multi-sample study. Journal of organizational Behavior 2004;25(3):293-315.

82. Demerouti E, Bakker AB, Nachreiner F, Schaufeli WB. The job demands-resources model of burnout. Journal of Applied psychology 2001;86(3):499.

83. Bakker AB, Demerouti E. Job Demands–Resources Theory: Taking Stock and Looking Forward. 2016 Journal of Occupational Health Psychology doi.org/10.1037/ocp0000056

84. Bakker AB, Demerouti E, Taris TW, Schaufeli WB, Schreurs PJ. A multigroup analysis of the Job Demands-Resources Model in four home care organizations. International Journal of stress management 2003;10(1):16.

85. Donchin Y, Seagull FJ. The hostile environment of the intensive care unit Review. Current Opinion in Critical Care 2002;8(4):316-20.

86. Xanthopoulou D, Bakker AB, Demerouti E, Schaufeli WB. The role of personal resources in the job demands-resources model. International journal of stress management 2007;14(2):121.

87. Seppälä P, Hakanen J, Mauno S, Perhoniemi R, Tolvanen A, Schaufeli W. Stability and change model of job resources and work

engagement: A seven-year three-wave follow-up study. European Journal of Work and Organizational Psychology 2015;24(3):360-75.

88. Swider BW, Zimmerman RD. Born to burnout: A meta-analytic path model of personality, job burnout, and work outcomes. Journal of Vocational Behavior 2010;76(3):487-506.

89. Geuens N, Braspenning M, van Bogaert P, Franck E. Individual vulnerability to burnout in nurses: The role of type D personality within different nursing specialty areas. Burnout Research 2015;2(2):80-86.

90. Alarcon G, Eschleman KJ, Bowling NA. Relationships between personality variables and burnout: A meta-analysis. Work & Stress 2009;23(3):244-63.

91. Pedersen R. Empirical research on empathy in medicine—A critical review. Patient Education and Counseling 2009;76(3):307-22.

92. Santos A, Chambel MJ, Castanheira F. Relational job characteristics and nurses' affective organizational commitment: the mediating role of work engagement. Journal of Advanced Nursing 2016;72(2):294-305.

93. Schaufeli WB, Schaufeli E. [Nederland anno 2013. Energie op de werkvloer.] The Netherlands anno 2013. Energy on the workplace. Report 2013.

94. Schaufeli WB, Schaufeli E. [Medische professionals anno 2014. Werkplezier en Energie.] Medical professionals anno 2014. Work pleasure and Energy. Report 2014.

SECTION 1

STAYING IN THE ICU

2

Relatives' perspectives on the quality of care in an intensive care unit: The theoretical concept of a new tool

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ABSTRACT

Objective

To examine the potential of a questionnaire (CQI 'R-ICU') to measure the quality of care from the perspective of relatives in the Intensive Care Unit (ICU).

Methods

A quantitative survey study has been undertaken to explore the psychometric properties of the instrument, which was sent to 282 relatives of ICU patients from the Erasmus MC, an academic hospital in Rotterdam, the Netherlands. Factor-analyses were performed to explore the underlying theoretical structure.

Results

Survey data from 211 relatives (response rate 78%) were used for the analysis. The overall reliability of the questionnaire was sufficiently high; two of the four underlying factors, namely 'Communication' and 'Involvement', were significant predictors. Two specific aspects of care that needed the most improvement were missing information about meals and offering an ICU diary. There is a significant difference in mean communication with nurses among the four wards in Erasmus MC.

Conclusions

The CQI 'R-ICU' seems to be a valid, reliable and usable instrument. The theoretical fundament appears to be related to communication.

Practice implications

The newly developed instrument can be used to provide feedback to health care professionals and policy makers in order to evaluate quality improvement projects with regard to relatives in the ICU.

Keywords: Consumer Quality Index, CQI, Quality of Care, Quality Assessment, Satisfaction, Communication, Intensive Care Unit, Critical Care, Relatives, Family Support, Health Care Surveys.

INTRODUCTION

Severe illness and subsequent admission of a family member or friend to an intensive care unit (ICU) can have a serious impact on the psycho-social well-being of the relatives/friends. They can become confused and anxious, may experience severe sadness and depression or even develop a 'Post intensive care syndrome-family'[1-3]. The mental distress may be caused by the gravity of the situation, uncertainty about the course of the medical situation or the unexpected death of the patient. In addition, the ICU environment with a multitude of unfamiliar equipment, sounds, smells, staff and other patients might contribute to the level of stress. Health care providers should develop the skills to observe this stress to address the needs of relatives.

Relatives could have an important role in the physical and psycho-social recovery process of the ICU-patient[4, 5]. They can support their loved ones in an emotional, cognitive and practical way, provided that they themselves are able to cope with the stressful situation. They also might enhance the trust of the patient, a significant aid in the recovery process[6]. Most ICU-patients are not able to receive information or make decisions, due to the severity of their medical condition and/or the administration of sedative medication, leaving the relatives as surrogate decision makers[7]. This role requires a careful communication process that begins immediately after hospitalization.

Both nurses and doctors seem to underestimate the relatives' need for information[8-10]. Inadequate communication might lead to dissatisfied patients and/or relatives, resulting in formal and informal complaints about the provided care[11]. Moreover, ideally patient and family communication leads to an elevated level of knowledge, less fear and decreases in insecurity and stress[12]. From the relatives' perspective, communication is assumed to be one of the most important factors in the perceived quality of care in the ICU, whereas most caregivers think the physical aspects of patient care are the most important factors for the relatives of ICU patients.

Currently, there is insufficient insight into the quality of care offered to relatives in the ICU because an evidence-based measurement tool is missing in the Netherlands[13]. The 'Family Satisfaction in the ICU Survey' (FS-ICU)[14] and the 'Critical Care Family Satisfaction Survey' (CCFSS)[15] were developed previously to measure the satisfaction of relatives in the ICU. However, these instruments were developed in non-Dutch situations. It seems reasonable that some items will be experienced as more or less important by relatives from different countries or even continents[16]. Moreover, although these instruments proved to be valid and reliable, the utilized concept of satisfaction might raise some bottlenecks such as ceiling effects, cognitive dissonance and socially desirable answers[17].

A discrepancy model, which describes satisfaction as a result of expectation minus the perceived experience, could overcome these problems[18]. Accordingly, developing a measurement instrument to establish the quality of care to relatives in ICUs in the Netherlands is a logical follow-up of these previous studies.

The development of the new instrument was built upon the Consumer Quality Index (CQI), which is a scientific and standardized method to determine the experiences of customers with the provided care[19-21]. The CQI instruments are theoretically founded by the CAHPS® instruments and QUOTE® methodology[22], both based on a discrepancy model[23]. To meet a sufficient quality of care, the expectations regarding the quality should be in accordance with the perceptions of the actual experiences according to these methodologies[24, 25]. Although this method judges the quality of care, there is no instrument under the umbrella of the CQI instruments available addressed to relatives in the ICU. Therefore, a CQI 'Relatives on Intensive Care Unit', in short CQI 'R-ICU', was accordingly developed within the Netherlands as a co-creation among HAN University of Applied Sciences, three hospitals (Erasmus MC, Rotterdam, Gelderse Vallei and Kennemer Gasthuis), and Open University of the Netherlands[26].

The theoretical framework of the CQI 'R-ICU' is partly derived from the 'Theoretical Model for Patient Focused Communication'[27], which is applied to the communication between relatives and caregivers. This model distinguishes between an instrumental need, 'the need to know and to understand', and in an emotional need, 'the need to be known and understood'. Subsequently, the caregivers should respond appropriately to these needs to influence coping mechanisms of the relatives. Communication is stated to consist of content aspects, such as information on medical treatment or visiting hours, and relational aspects such as respectfulness and hopefulness[28]. Both clusters of elements are expected to influence the quality of care given to relatives. This manuscript describes the theoretical framework and developmental process of the CQI ´R-ICU´ instrument and explores the psychometric properties of this new tool.

METHODS

The research protocol for the study was approved by the Medical Ethics Committee (MEC) of Erasmus MC, Rotterdam (MEC-2011-189). The committee judged that the study complied with the Dutch law on Medical Research in Humans (WMO).

STUDY DESIGN

The total process of development and validation was performed by the HAN University of Applied Sciences. The overall research plan, which was based on the Manual CQI, consisted of qualitative and quantitative survey studies[21]. This method, as shown in figure 1, contains four phases: the preparation, performance, psychometric and discriminatory phases.

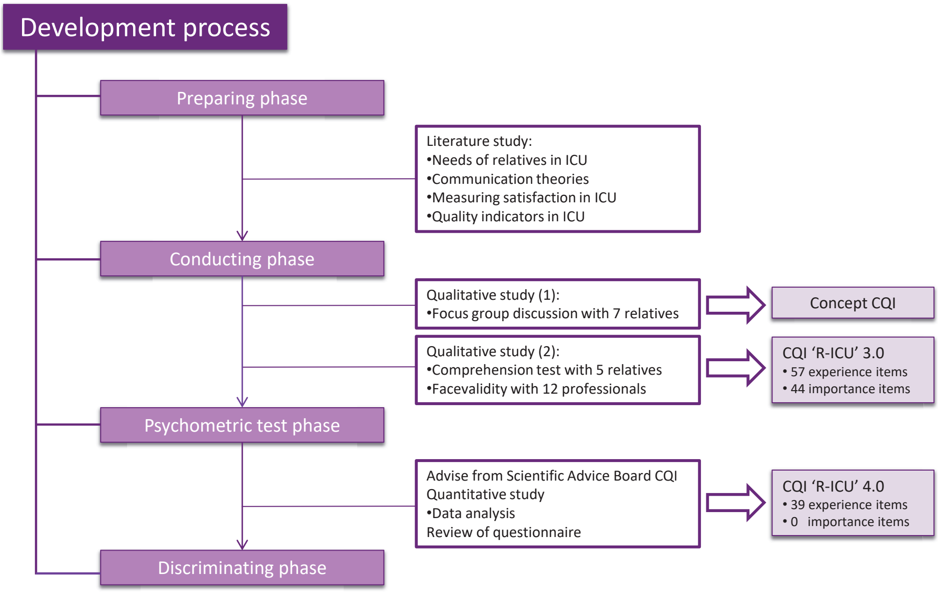

Figure 1. *Flow chart of the total development process which is carried out by the HAN University of Applied Sciences in order to meet the CQI method*

The preparation phase started with a literature research to create a list of quality of care domains for the relatives of ICU-patients. To determine relevant topics, some previous questionnaires were studied for useful content, including the 'Critical Care Family Needs Inventory' (CCFNI)[29, 30], the FS/ICU, the CCFSS and the CQI-palliative care Relatives[31]. Subsequently, in the performance phase, focus group interviews with relatives were held to verify the quality items according to their perceptions. The answers and spontaneous statements formed the foundation of the items in the concept questionnaire. Some aspects in the draft of the CQI 'R-ICU' were prescribed by the CQI Manual, such as obligatory general questions and the layout. Questions relating to the experiences of relatives with communication, already clustered by subject, formed the core of the instrument. These experience items (57) were formulated with respect to how often the quality aspect occurred; 'never', 'sometimes', 'often' or 'always' (e.g., "The caregiver takes me seriously"). Other questions referred to more general aspects of care (e.g., "Communication by nurses") using a scale from 1 (poor) to 10 (excellent). Finally, the respondents scored the relative importance of the quality of care aspects; these important items (44) were rated as 'not important', 'somewhat important', 'important' or 'very important'. The questionnaire was subsequently tested for comprehensiveness by the relatives and face validity by the health care professionals. With all the feedback, the concept CQI was revised in version 3.0 of the CQI 'R-ICU' which consists of 116 items in total. Then, in the psychometric phase, this questionnaire was tested among the relatives of patients. The resulting quantitative dataset provided insight into the validity and reliability of the CQI 'R-ICU'. Finally, in the last phase, the instrument will be tested with respect to its discriminatory power. The total process of development, including the qualitative study results, and validation of the instrument will be described in a separate article. The current study, which was conducted from October 2011 to April 2012 in Erasmus MC, Rotterdam, comprises data from the quantitative psychometric phase to pretest the potential of the questionnaire and support the theoretical foundation.

STUDY POPULATION

Erasmus MC is a university medical center with one of the largest ICUs in the Netherlands. The level III ICU for adult patients contains 32 operational beds and is divided into four units: the cardiological ICU (ICCU), thoracic surgery ICU (ICV-1) and two mixed units for neurological, neurosurgical, transplantation surgery and medical patients (ICV-2 and ICV-3). Relatives who were included in the psychometric phase met the following criteria: older than 18 years, understanding the Dutch language and related to an ICU patient who did not die within 24 hours after admission. Figure 2, the study flowchart, illustrates that a total of 420 relatives met the inclusion criteria. All relatives were recruited based upon availability, and a convenience sample of 282 respondents (67.1%) agreed to participate.

The CQI 'R-ICU', accompanied by a cover letter, was sent to the home address after receiving Informed Consent and discharge of the patient from the ICU. According to the Total Design Method this contact was followed by first and second reminders when there was no response after two and four weeks respectively[32]. A strict separation between the files with research data and with personal data files was maintained throughout the entire process, and the completed questionnaires included no traceable private data.

STATISTICAL ANALYSIS

The data were analyzed using Microsoft SPSS (version 18.0). An item was removed when a single answer category accounted for more than 90% of its score[21]. In addition, the non-response per item revealed the relevance and understanding by the respondents; if the non-response rate was higher than 5%, the item was considered for removal. For

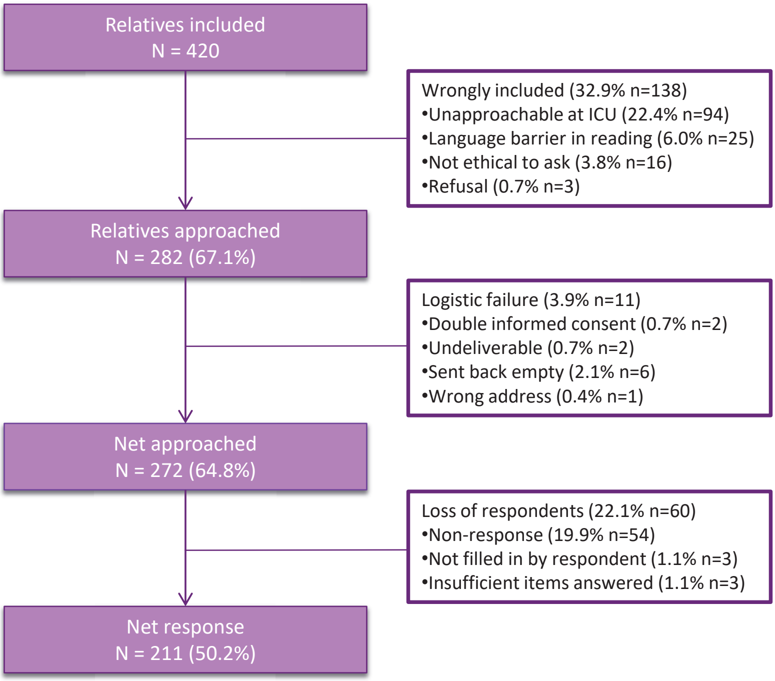

Figure 2. *Flowchart of the respondents in Erasmus MC, Rotterdam*

an inter item correlation between two items of greater than .85, one of the items was removed because of a non-unique contribution. Subsequently, an explorative factor analysis, a Principal Component Analysis (PCA), was conducted to examine the coherence of the items with respect to certain factors. An oblique rotation was used because some factors were presumed to potentially be related to each other. The oblique rotation was also meant to load a larger number of items into one factor. The aim of this analysis was to explore the underlying theoretical structure of the questionnaire. The preliminary requirements were a Kaiser-Maier-Olkin Measure of Sampling Adequacy (KMO-value) ≥ 0.60 and significant results of Barlett's test of sphericity ($p > .05$), indicating that the number of respondents was sufficiently large and the correlations between the variables was high enough to detect a factor loading[33]. All factors with eigenvalue ≥ 1.0 and factor loadings ≥ 0.40 were considered important. The internal consistency of the different subscales was analyzed using Cronbach's alpha, with $\alpha \geq 0.70$ indicating that a subscale was sufficiently reliable, an Item Total Correlation (ITC) ≥ 0.40 indicated that an item belonged to a certain subscale.

Furthermore, a Multiple Regression Analysis (MRA) to explain the relative importance of the variables was performed with the established factors and the demographic items as independent variables and ‘Total quality assessment’ as the dependent variables. The ‘Total quality assessment’ was computed by ‘What rating on a scale of 1 to 10 would you give nurses for communication?’, ‘What rating on a scale of 1 to 10 would you give doctors for communication?’ and ´What rating on a scale of 1 to 10 would you give for support and care in general?´. Then, an analysis of variance (One Way ANOVA) was conducted to compare the total quality assessment among the four ICUs. Finally, the Quality Improvement Scores (QIS) were computed with the formula ([mean importance item y]*[%‘negative’ experience item y])/100 to explore the usability of the new tool[34].

RESULTS

RESPONDENT CHARACTERISTICS

The CQI ‘R-ICU’ was sent to 282 relatives of ICU patients treated at Erasmus MC, Rotterdam. Due to logistic failure, 11 questionnaires (3.9%) were unusable for the analysis. With a loss of 60 respondents (22.1%), merely through a non-response rate of 19.9% (*n* = 54), the final sample included 211 questionnaires (a response rate of 77.9%) as shown in Figure 2.

The female-male ratio was 66/34%. Partners of the patients accounted for 56% of the respondents and individuals in the age group of 45-64 years accounted for 49.7%. The mean average of the patient’s length of stay in the ICU was 18.93 days, with 43.9% of all patients were still in the hospital and 21.5% were deceased at the time of the survey. Other characteristics are presented in Table 1.

Table 1 *Characteristics of respondents Erasmus MC, Rotterdam*

		Respondents (%) N = 211
Relation to patient		
	Partner	56.0
	Father/mother	12.4
	Son/daughter	22.5
	Brother/sister	5.3
	Other	3.8
Woman		65.6
Age		Modus 55-64
	18-24	3.3
	25-34	7.7
	35-44	17.2

Table 1 *Characteristics of respondents Erasmus MC, Rotterdam (continued)*

		Respondents (%) N = 211
	45-54	23.9
	55-64	25.8
	65-74	17.7
	75 and older	4.3
Health indication		
	Excellent	18.7
	Very good	23.4
	Good	49.3
	Reasonably well	8.1
	Bad	0.5
Education		
	Non/Primary school	3.4
	GCSE	37.7
	A-levels	30.4
	College/university	27.0
	Other	1.4
Ethnic background		
	The Netherlands	89.9
	Other	10.1
ICU Erasmus MC		
	ICV-1	14.3
	ICV-2	36.7
	ICV-3	38.3
	ICCU	10.2
IC-indication		
	Planned	41.3
	Not planned	58.7
Length of stay (mean in days, St. Dev.)		18.93 (26.64)
	ICV-1	12.46 (range 1-99)
	ICV-2	18.08 (range 1-99)
	ICV-3	22.66 (range 1-167)
	ICCU	8.75 (range 1-28)
Current situation of the patient		
	Hospital	43.9
	At home	30.2
	Deceased	21.5
	Other	4.4

FACTOR AND RELIABILITY ANALYSIS

Of all the items only 'Did you receive information by digital means?' and 'Did the hospital offer you peer support?' showed a skewed distribution. These items were disregarded in the analyses due to non-applicability. Furthermore, it turned out that 16 items had a non-response rate > 5%, with five being obligatory and another four rated as very important to the relatives according to the focus group interview; therefore these items were retained for the analysis. The other seven items with high non-response rates were excluded from further analysis. None of the importance items were deleted. 'Peer support through the hospital' seemed to be the least important item from the perspective of the relatives; altogether 82.0% scored this item as 'not' or 'somewhat' important (n=169). This was followed by 'Contact with clergy', 'Contact with psychologist' and 'Contact with social worker'; 64.3% (n=133), 63.1% (n=130) and 56.5% (n=117) respectively. In contrast, as presented in Table 2, the most important to the relatives was 'Conflicting information'.

Table 2 *Ten most important aspects of care to relatives (all items with median = 4)*

		Importance score	
Description of item	Mean (St. Dev)	Important (%)	Very important (%)
Conflicting information	3.71 (0.52)	23.4	74.2
Health care providers take you seriously	3.69 (0.46)	30.8	69.2
Information doctors understandable	3.69 (0.54)	23.6	72.6
Information nurses understandable	3.66 (0.54)	29.2	68.4
Nurses listen carefully	3.62 (0.53)	34.1	63.9
Doctors listen carefully	3.59 (0.55)	35.6	61.5
Health care provider at first entrance	3.49 (0.71)	30.1	60.3
Enough time for you	3.46 (0.60)	43.5	51.2
Professional contact person in reach	3.46 (0.64)	44.4	52.2
Involved in decision making	3.45 (0.68)	36.2	55.1

Factor analyses were conducted on 27 experience items (all using a 4 point Likert scale) to determine the underlying structure of the newly developed questionnaire. The PCA met all the requirements, with KMO being excellent (.84) and Bartlett's test of sphericity being significant ($N = 163$ en $p < .000$). The first analysis contained seven factors with an eigenvalue ≥ 1.0, and 61.19% explained the total variance. The scree-plot presented a first drop after two factors and stabilized after four factors. These factors were 'Communication', 'Involvement', 'Organization of care' and 'Nuisance'. Table 3 shows that the factor 'Nuisance' was skewed to the left and had a high kurtosis value, reflecting that most of the respondents did not report any nuisance at all. As also shown in Table 3, the internal consistency of all items together amounts to .89 with a range between .51 and .87 for the separate subscales.

Table 3 *Descriptive statistics of the four factors and the mean 'Total quality assessment'*

	N	Mean (St. Dev)	Minimum-Maximum	Cronbach's alpha	Skewness	Kurtosis
Communication	176	3.37 (0.49)	1.90-4.00	.85	-0.76	0.06
Involvement	184	2.39 (0.76)	1.11-4.00	.86	0.35	-0.81
Organization of care	192	2.03 (0.79)	1.00-4.00	.54	0.50	-0.71
Nuisance	200	3.64 (0.39)	1.50-4.00	.51	-1.74	5.15
Total quality assessment	198	7.36 (1.83)	1.00-10.0	.87	-1.02	1.51
Overall	163	2.91 (0.47)	1.78-3.89	.89	0.10	-0.57

TOTAL SCORES

The correlation between the 'Total quality assessment' and the factor 'Communication' was very strongly positive ($r = .82$, $p > .000$). In addition, the factor 'Involvement' was strongly positive ($r = .69$, $p > .000$), with the factor 'Organization of care' was moderately positive ($r = .33$ $p > .000$), and with the factor 'Nuisance' was weakly positive ($r = .30$ $p > .000$). Hierarchic MRA, with the standardized Z-scores of the four factors as independent variables and 'Total quality assessment' as a dependent variable in step one, presented a significant model (F (4, 155) = 102.69, $p < .000$). The explained variance was 72.6% ($R^2 = .73$). The beta coefficients for the factors 'Communication' ($\beta = .64$) and 'Involvement' ($\beta = .28$) were significant and contributed the most to the 'Total quality assessment'. The factors 'Organization of care' and 'Nuisance' were not significant. In step two, the socio-demographic dummy variables of gender, age, ethnic background, education, relationship to patient, health of relative, current situation and length of stay, were added as covariables (see Table 4). This model was also significant (F (12,141) = 38.07, $p < .000$), and the explained variance was barely changed (R^2 *change* = .03 with F_{change} (8,141) = 2.06, $p < .05$) with only a significant contribution from level of education. However, the mean score for the ´Total quality assessment´ for the level of education showed no significant difference ($M_{\text{high educated}} = 7.29$ and $M_{\text{low educated}} = 7.43$, $t(173.05) = -.51$ *ns*).

Subsequently, the total quality assessment was compared among the four ICUs of the Erasmus MC: ICV-1, ICV-2, ICV-3 and ICCU (see Table 5). The cardiological ICU, ICCU, yielded the highest mean scores for the 'Total quality assessment' ($M_{\text{ICCU}} = 8.46$), whereas the thoracic surgery ICU, ICV-1, yielded the lowest mean scores for the 'Total quality assessment' ($M_{\text{ICV-1}} = 7.11$). Table 5 also reveals that the scores for communication were higher for nurses than doctors. The scores for 'Total quality assessment' where not different between men and women ($M_{\text{women}} = 7.38$ and $M_{\text{man}} = 7.31$, $t(194) = -.25$ *ns*).

The item analysis showed some remarkable results, such as 58.3% answering 'sometimes' or 'never' in response to 'Did health care providers pay attention to what you needed?'.

Table 4 *Results MRA; Total quality assessment as dependent variable with four factors in step 1 and eight socio-demographic as dummy variables in step 2 (N=154)*

Variable	B	SE	β	t	p
Step 1					
(Constant)	7.45	.07		106.92	.00
Factor communication	1.07(*)	.10	.64	11.27	.00
Factor Involvement	.46(*)	.09	.27	4.92	.00
Factor Organization of care	-.03	.08	-.02	-.42	.67
Factor Nuisance	.12	.07	.07	1.61	.11
Step 2					
(Constant)	6.27	.82		7.63	.00
Factor Communication	.99(*)	.10	.59	10.14	.00
Factor Involvement	.51(*)	.09	.30	5.47	.00
Factor Organization of care	-.03	.08	-.02	-.44	.66
Factor Nuisance	.13	.08	.08	1.68	.10
Gender	.16	.15	.05	1.09	.30
Age	.39	.23	.07	1.57	.12
Ethnic background (Dutch to non-Dutch)	-.06	.25	-.11	-.25	.80
Education (low to high)	.55(*)	.15	.17	3.74	.00
Relationship with patient (partner to non-partner)	-.14	.15	-.04	.90	.37
Health of relative (good to bad)	-.32	.27	-.05	-1.18	.24
Current situation (home to not-home)	.08	.17	.02	.47	.64
Length of stay (less or more than one week)	-.06	.15	-.02	-.42	.68

(*) Significant

Table 5 *Mean 'Total quality assessment' and marks on communication and support divided per ICU*

ICU	Communication with nurses (mark 1-10) Mean (St. Dev)	Communication with doctors (mark 1-10) Mean (St. Dev)	General support (mark 1-10) Mean (St. Dev)	Total quality assessment Mean (St. Dev)
ICV-1 (n=28)	7.96 (1.80)	6.77 (3.13)	7.04 (2.39)	7.11 (2.31)
ICV-2 (n=72)	7.59 (1.67)	7.30 (2.02)	6.93 (1.92)	7.30 (1.65)
ICV-3 (n=76)	7.86 (1.66)	6.86 (2.62)	6.92 (2.27)	7.19 (1.95)
ICCU (n=20)	9.11 (0.90)[*]	8.33 (1.24)	7.85 (1.14)	8.46 (0.98)[**]
Total	7.90 (1.64)	7.17 (2.38)	7.06 (2.07)	7.58 (1.72)

ICCU = cardiological ICU, ICV-1 = thoracic surgery, ICV-2 and ICV-3 are two mixed units with neurological, neurosurgical, transplantation surgery and medical patients

[*] The test results with an analysis of variance (ANOVA) showed a significant difference for ICCU compared to ICV-1, ICV-2 and ICV-3, $F(3,185) = 4.20\ p < .05$), $\eta^2 = .064$

[**] The test results with an analysis of variance (ANOVA) showed a significant difference for ICCU compared to ICV-2 and ICV-3, $F(3,179) = 2.60\ p < .05$), $\eta^2 = .042$

The respondents seemed most satisfied with (no) nuisance of noise from visitors (*M* = 3.82) and (no) nuisance of noise from employees (*M* = 3.75). Both information given by doctors (*M* = 3.69) or nurses (*M* =3.66) and careful listening by doctors (*M* = 3.59) or nurses (*M* =3.62) also scored high. The respondents seemed to be least satisfied with the provision of information by digital means such as email or a website (*M* = 1.09), information on meals (*M* = 1.69) and offering to write in an ICU diary (*M* = 1.85). The latter two, together with participating in taking the care of the patient, also represented the highest Quality Improvement Scores.

DISCUSSION

The aim of this study was to develop and provide a theoretical framework for a new instrument to measure the experiences of relatives with the quality of care in the ICU. This tool, the CQI 'R-ICU', has been elaborated by the HAN University of Applied Sciences using a standardized scientific approach and has resulted in a tailor-made questionnaire for the relatives of ICU patients. Two strengths of the CQI 'R-ICU' questionnaire are that it attempts to overcome the conceptual and methodological problems associated with satisfaction surveys and that the relatives were directly involved in the instrument's development. The questionnaire focuses on "reports" of the quality of care rather than on highly subjective ratings of satisfaction. With a focus on the data from Erasmus MC, Rotterdam, the internal consistency of the questionnaire overall and of most subscales was satisfactory except for the 'Organization of care'. Reconsidering this four-item subscale appears necessary[35]. A highly internal consistency was found for both the 'Total quality assessment' and all the items in the questionnaire combined. Therefore, the CQI 'R-ICU' promises to be a reliable measurement instrument.

The correlation between the 'Total quality assessment' and the factors 'Communication' and 'Involvement' appeared to be (very) strongly positive. Inevitably, 'Communication' explained most of the ´Total quality assessment´ and was hence the most important predictor of the quality of care given to the relatives, followed by 'Involvement'. The different items within these two factors all belong to the process indicators, which was in accordance with the expectations[35]. At the same time, the relative importance of communication items in quality improvements is in line with the results of previous studies and seems applicable to various health care professionals[36]. The respondents judged the items of controversial information and being taken seriously as very important. These findings illustrate that the Theoretical Model in Communications conveyed in the questionnaire - both as instrumental needs, such as providing understandable information, and emotional needs, such as carefully listening - clearly emerged.

The established QIS provided insight into a ranking of improvement points, merely based on individual weighting of aspects of care combined with their experience. In accordance with the discrepancy model and the promising results of a new method to measure satisfaction[20], it has become clear that importance questions should be a permanent part of this questionnaire. The QIS takes into account the real weighting of the respondents, and strikingly showed information about meals as one of the highest requiring improvement. The potential for a relationship between some demographic variables and how relatives experience their needs was previously mentioned[13, 37]. Nevertheless, the present study demonstrated no significant influence of age or education on the respondents' total quality assessment of care. Thus, it is conceivable that a difference in neediness is not reflected in the perspective of relatives in their judgment of communication. This outcome is in line with the indicated theory stating that a difference between expectations and experiences determines satisfaction. Needs may control the quality aspects in some ways but are not predominantly decisive. Thus, it might be established that women are familiar with other needs that arise during the stressful ICU period, but that these other needs will not result in a significant deviance in their judgment of communication.

In accordance with the Expectation Violence Theory, a considerable part of how positive or negative an experience with a communicator is assessed to be will be based on physical attractiveness, task expertise and knowledge, similarity and other non-verbal items[38]. This bias means that the same behavior by different professionals might be interpreted in different ways. In small sample sizes, such as in current study, this effect could influence the mean total quality assessment.

LIMITATIONS

This study was performed in one hospital with four ICUs, resulting in a relatively small number of respondents. Therefore, the results are not generally applicable. A multicenter study, which has already been conducted, is necessary to confirm or disapprove the identified results. Another restriction must be made regarding the development process; which will continue until the discriminatory phase has finished. To address these issues, a subsequent study is already in progress in 21 regional and 2 academic hospitals in the Netherlands.

Additionally, some statistical decisions were made with respect to the used guideline despite valuable completeness to current practice and the real world of an ICU. For example, some items were formulated as screener questions with an answer category of 'if no, then go to question *xx*'. This set-up appeared very confusing for respondents and resulted in a high percentage of missing values, which were subsequently not analyzed. However, those items could have revealed some important information.

CONCLUSIONS

As noted in the discussion, it is clear that the CQI 'R-ICU' appeared to be a valid, reliable and usable instrument. Thus, further development and large-scale implementation are recommended. Professionals can learn from the experiences of relatives by using this instrument. Moreover, the measurement instrument will provide insight into the points requiring improvement with respect to the care for relatives. The relatives' quality judgment on communication and support by the health care professionals in ICUs has a value to the establishment and/or maintenance of good interventions in caring. It is rather unlikely that demographic variables have any influence on this judgment. The results indicate that the theoretical framework of the CQI 'R-ICU' has a sound basis that there is a good possibility of a sufficient discriminatory power. More research on this aspect is needed.

PRACTICAL IMPLICATIONS

The newly developed questionnaire will provide feedback to health care professionals and policy makers for the evaluation of quality improvement projects with regard to relatives in the ICU. The tool is expected to measure the effects of upcoming interventions in the policy on relatives in the ICU (e.g., open visiting policies, participation in patient care and adherence to doctor's rounds). The identified Quality Improvement Scores are especially useful indicators to strive for professional progression in the care given to relatives. This instrument identifies and sets priorities regarding specific aspects that need improvement in the quality of care given to relatives. For these reasons, the new tool is not a goal in itself but mainly a practical instrument in the care given to relatives.

ACKNOWLEDGMENTS

We are grateful to all the relatives who participated in the study. Furthermore, we would like to thank Erna Deitmers, Lobke Hazelaar, Helma van Hilten, Annemare van Koeveringe, Ilse Menheere, Hildelies van Oel, Ans Rensen,Trees van der Puil and Jantine in 't Veld for their practical input in this research process. This study was funded by RAAK, Regional Attention and Action for Knowledge circulation, Ministry OCW, the Netherlands. The authors have no conflicts of interest.

We confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the provided details.

REFERENCES

1. Ågård AS, Harder I. Relatives' experiences in intensive care - Finding a place in a world of uncertainty. Intensive and Critical Care Nursing 2007;23(3):170-77.
2. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. Critical Care Medicine 2012;40(2):618-24.
3. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo A. Psychological symptoms of family members of high-risk Intensive care unit Patients. American Journal of Critical Care 2012;21(6):386-94.
4. Bailey JJ, Sabbagh M, Loiselle CG, Boileau J, McVey L. Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care. Intensive and Critical Care Nursing 2010;26(2):114-22.
5. Verhaeghe S, Defloor T, van Zuuren F, Duijnstee M, Grypdonck M. The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. Journal of Clinical Nursing 2005;14(4):501-09.
6. Thüm S, Janssen C, Pfaff H, Lefering R, Neugebauer EA, Ommen O. The association between psychosocial care by physicians and patients' trust: a retrospective analysis of severely injured patients in surgical intensive care units. GMS Psycho-Social-Medicine 2012;9.
7. Commissie Indicatorontwikkeling NVIC. [Kwaliteitsindicatoren voor de Intensive Care en High Care afdelingen] Quality indicators to Intensive Care Units and High Care wards. Netherlands Journal of Critical Care, 2004;8:423-8.
8. Blom H, Gustavsson C, Sundler AJ. Participation and support in intensive care as experienced by close relatives of patients - A phenomenological study. Intensive and Critical Care Nursing 2013;29(1):1-8.
9. El-Masri MM, Fox-Wasylyshyn SM. Nurses' roles with families: perceptions of ICU nurses. Intensive and Critical Care Nursing 2007;23(1):43-50.
10. De Rouck S, Leys M. Information needs of parents of children admitted to a neonatal intensive care unit: A review of the literature (1990–2008). Patient Education and Counseling 2009;76(2):159-73.
11. Roter D, Hall JA. Doctors talking with patients/patients talking with doctors: improving communication in medical visits. JAMA:2007;297(7):748-752.
12. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Education and Counseling 2009;74(3):287-94.
13. Nederlandse Vereniging voor Anesthesiologie. [Richtlijn. Organisatie en werkwijze voor Intensive Care afdelingen voor Volwassenen] Guideline. Organization and procedure in Intensive Care Units for adults in The Netherlands. Alphen aan den Rijn: Van Zuiden Communications B.V, 2006.
14. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey. Critical Care Medicine 2007;35(1):271-79.
15. Hickman RL, Daly BJ, Douglas SL, Burant CJ. Evaluating the critical Care Family Satisfaction Survey for chronic critical illness. Western Journal of Nursing Research 2012;34(3):377-95.
16. Groenewegen PP, Kerssens JJ, Sixma HJ, van der Eijk I, Boerma WGW. What is important in evaluating health care quality? An international comparison of user views. BMC Health Services Research 2005;5(1):16.
17. Lechner L, Mesters I, Bolman C. [Gezondheidspsychologie bij patienten] Health psychology in patients: Assen: Koninklijke Van Gorcum, 2010. ISBN 9789023246206.
18. Janssen C, Ommen O, Scheibler F, Wirtz M, Pfaff H. Importance weighting, expectation fulfilment and satisfaction: an integrative and

innovative approach to measuring patient satisfaction with hospital stays. International Journal of Public Health 2013;58(6):955.

19. Koopman, Sixma H, Hendriks M, de Boer D, Delnoij D. [Handleiding CQI ontwikkeling. Richtlijn en voorschriften in de ontwikkeling van een CQI meetinstrument] Manual CQI development. Guideline and prescription in the development of a CQI measuring instrument. Utrecht: Nivel, 2011.
20. Nijkamp M, Sixma H, Afman H, et al. Quality of care from the perspective of the cataract patient: the reliability and validity of the QUOTE-cataract. British Journal of Ophthalmology 2002;86(8):840-42.
21. Kollen BJ, Groenier KH, Berendsen AJ. Patients' experiences with continuum of care across hospitals. A multilevel analysis of Consumer Quality Index Continuum of Care. Patient Education and Counseling 2011;83(2):269-72.
22. Berendsen AJ, Groenier KH, de Jong GM, et al. Assessment of patient's experiences across the interface between primary and secondary care: Consumer Quality Index Continuum of care. Patient Education and Counseling 2009;77(1):123-27.
23. Babakus E, Mangold WG. Adapting the SERVQUAL scale to hospital services: an empirical investigation. Health Services Research 1992;26(6):767.
24. Sixma HJ, Kerssens JJ, van Campen C, Peters L. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. Health expectations 1998;1(2):82-95.
25. De Boer D, Delnoij D, Rademakers J. The importance of patient-centered care for various patient groups. Patient Education and Counseling 2013;90(3):405-10.
26. van Mol M, Bakker E, Rensen A, Menheere I, Verharen L. Quality of care in the ICU from the perspective of relatives. Critical Care 2013;17(Suppl 2):P543.
27. Bensing B, Dulmen S, de Haes H. [Communicatie tussen patiënten en hun hulpverleners] Communication between patients and their caregivers] In Lechner, L., Mesters, I., & Bolman, C., [Gezondheidspsychologie in patiënten] Health psychology in patients (p109-134). Assen: Koninklijke Van Gorcum/ Open Universiteit, 2010.
28. Kahana E, Kahana B. Patient proactivity enhancing doctor–patient–family communication in cancer prevention and care among the aged. Patient Education and Counseling 2003;50(1):67-73.
29. Leske JS. Needs of relatives of critically ill patients: a follow-up. Heart & lung: the Journal of Critical Care 1986;15(2):189.
30. Molter NC. Needs of relatives of critically ill patients: a descriptive study. Heart & lung: the Journal of Critical Care 1978;8(2):332-39.
31. Claessen SJJ, Francke, AL, Sixma H, van der Brandt JA, de Veer AJE, Deliens L. [Op weg naar een CQ-index Palliatieve Zrog: de ontwikkeling van een meetinstrument] On the road to a CQ-index Palliative Care: the development of a measuring instrument: Utrecht: NIVEL, 2009.
32. Dillman D, Smyth J, Christian L. Internet, mail, and mixed-mode surveys: the total design method: John Wiley & Sons, New Jersey, 2009.
33. Field. Discovering Statistics Using SPSS. Second Edition ed, 2005. ISBN 9780761944522
34. Bos N, Sturms LM, Schrijvers AJ, van Stel HF. The consumer quality index (CQ-index) in an accident and emergency department: development and first evaluation. BMC Health Services Research 2012;12(1):1.
35. Rademakers J, Delnoij D, de Boer D. Structure, process or outcome: which contributes most to patients' overall assessment of healthcare quality? BMJ Quality & Safety 2011:bmjqs. 2010.042358.
36. Bensing J. Doctor-patient communication and the quality of care. Social Science & Medicine 1991;32(11):1301-10.
37. Høghaug G, Fagermoen MS, Lerdal A. The visitor's regard of their need for support, comfort, information proximity and assur-

ance in the intensive care unit. Intensive and Critical Care Nursing 2012;28(5):263-68.

38. Burgoon JK. Interpersonal expectations, expectancy violations, and emotional communication. Journal of Language and Social Psychology 1993;12(1-2):30-48.

2bis

In response to: Families´ experiences of ICU quality of care: development and validation of a European questionnaire (euroQ2)

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Journal of Critical Care,

2015;30:1408-1409

Dear Editor

With great interest we read the article by Jensen, et al.,[1]. Addressing the needs of relatives in the Intensive Care Unit (ICU) is a contemporary issue, and measuring their experiences is an important work assessment for healthcare providers and organizations. Therefore, the work from Jensen et al. might be helpful to provide high valued care in ICUs. However, to our opinion, there are some relevant theoretical and methodological problems concerning this study that we would like to explain in this letter.

As stated by the authors, the euroQ2 is based on items from the ´Quality of Dying and Death´ (QODD) questionnaire[2] and the 'Family Satisfaction in the ICU survey' (FS-ICU)[3]. However, only 32% of the original items in the QODD and 37% of the FS-ICU have been used as originally formulated. The euroQ2 should therefore be considered as a new questionnaire. The development process is not well described by the study, leading to indistinct questions. For example, the initial draft of the euroQ2 was primarily reviewed in English, then adjusted, and subsequently translated into Danish and Dutch. Items corresponding to end-of-life often elicit a semantic discussion, for that reason it seems difficult to judge these items in English for non-native speakers. Yet, another striking disadvantage of these instruments is the elaboration in ICUs outside Denmark and The Netherlands. It seems reasonable that items will be experienced as more or less important by relatives from different countries or even different continents[4]. The authors argue that the items have been adapted to the European environment, although it remains a mystery how and what they have done to scientifically underpin this proposition. The validation of the euroQ2 in two countries of different cultures and language requires a profound analysis of sensitivity and specificity.

Moreover, there is no reasoning behind the choice for the aforementioned measurement instruments. For example, why did the authors not use the 'Critical Care Family Needs Inventory' (CCFNI), which measures the needs of relatives in the ICU[5] or the 'Care Family Satisfaction Survey' (CCFSS) to measure the satisfaction of relatives[6]. Both have been assessed in former studies as reliable and valid. Furthermore, the QODD has been recognized with many limitations; the developers themselves even stated that the questionnaire was not ready for use as a primary outcome measure in intervention studies after studying over 4,000 patient deaths[7]. Then, the items of the FS-ICU were based on an existing framework to measure patient satisfaction, in a combination with items related to end-of-life care. Quite apart from the fact that satisfaction of patients might not at all correlate with the satisfaction of the relatives, it is preferable to measure experiences rather than satisfaction as they give more objective and specific information for quality improvement[8]. The authors misuse the concepts of ´satisfaction´, ´experiences´ and ´quality of care´ as one and the same and without further explanation.

In the Netherlands, the government introduced a national framework for evaluating quality of care that contains a set of indicators referring to experiences of consumers of care[9]. A Consumer Quality Index (CQI) was subsequently developed as the measurement standard, and since then it has been applied to the experiences of special target groups. The recently established Consumer Quality Index 'Relatives in the ICU', which has been developed according to these national standards to assess the quality of care through the perspectives of relatives in the ICU, proved to be valid and reliable in a pretest[10]. A sample of 564 respondents from six ICUs and nearly 1400 respondents of more than 20 ICUs in general and academic hospitals in the Netherlands, has been analysed to establish the psychometric characteristics and discriminative power, in respective. The authors do not mention this European instrument focussing on the same topic and target group, nor discuss why it was not integrated in the euroQ2 instead of the American FS-ICU.

Undoubtedly, it is basic knowledge that professionals should meet and integrate relatives´ needs in the provided care. Assessing these policies from the perspective of relatives is necessary to consolidate and further improve the process of caring. However, the items of the euroQ2 mostly relate to the care for the patient, for example ´pain under control´, ´emotional support for patient´, and ´end-of-life care according to wishes´. The authors do not explain how these items correspond to the needs of the relatives themselves. Furthermore, the assumption that these items correlate with post-ICU symptoms of anxiety, depression, and post-traumatic stress disorder (PTSD) of relatives, is short-sighted and need further theoretical explanation.

The PTSD diagnostic criteria were revised in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and require persistence of symptoms for more than one month[11]. Thus, three weeks after discharge from the ICU or the death of a relative is far too early to assess PTSD. In the same way, to measure some symptoms of anxiety or depression in mourning relatives, is within the normal range of emotions after three weeks and not a psychopathological process. The impact of the ICU period can indeed have negative consequences in the long run, which are currently described in the Post Intensive Care Syndrome-Family[12].

In conclusion, we agree with the authors that assessing the needs of relatives of ICU patients is of utmost importance. However, due to the abovementioned arguments, we question the added value of the euroQ2 above existing, validated instruments, like the Consumer Quality Index 'Relatives in the ICU'. Especially as the instrument is only validated in two European countries in relatively small samples with several methodological errors.

REFERENCES

1. Jensen HI, Gerritsen RT, Koopmans M, Zijlstra JG, Curtis JR, et al. Families' experiences of ICU quality of care: development and validation of a European questionnaire (euroQ2). Journal of Critical Care 2015;30(5):884-890.
2. Downey L, Curtis JR, Lafferty WE, Herting JR, Engelberg RA. The Quality of Dying and Death Questionnaire (QODD): empirical domains and theoretical perspectives. Journal of pain and symptom management 2010;39(1):9-22.
3. Wall RJ, Engelberg RA, Downey L, Heyland DK, Curtis JR. Refinement, scoring, and validation of the Family Satisfaction in the Intensive Care Unit (FS-ICU) survey*. Critical Care Medicine 2007;35(1):271-79.
4. Groenewegen PP, Kerssens JJ, Sixma HJ, van der Eijk I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. BMC Health Services Research 2005;5(1):16.
5. Molter NC. Needs of relatives of critically ill patients: a descriptive study. Heart & lung: the Journal of Critical Care 1978;8(2):332-39.
6. Hickman RL, Daly BJ, Douglas SL, Burant CJ. Evaluating the critical Care Family Satisfaction Survey for chronic critical illness. Western Journal of Nursing Research 2012;34(3):377-95.
7. Curtis JR, Downey L, Engelberg RA. The quality of dying and death: is it ready for use as an outcome measure? CHEST Journal 2013;143(2):289-91.
8. Cleary PD, Edgman-Levitan S. Health care quality: incorporating consumer perspectives. JAMA 1997;278(19):1608-12.
9. Ten Asbroek A, Arah O, Geelhoed J, Custers T, Delnoij D, Klazina N. Developing a national performance indicator framework for the Dutch health system. International Journal for Quality in Health Care 2004;16(suppl 1):i65-i71.
10. Van Mol M, Bakker EC, Nijkamp MD, Kompanje EJ, Bakker J, Verharen L. Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool. Patient education and counseling 2014;95(3):406-13.
11. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Arlington: American Psychiatric Publishing 2013. ISBN 9780890425541
12. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. Critical Care Medicine 2012;40(2):618-24.

3

Patient- and Family-Centered Care in the intensive care unit, a challenge in the daily practice of healthcare professionals

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Journal of Clinical Care Nursing,

2016 DOI: 10.1111/jocn.13669

ABSTRACT

Aims and objectives

The aim of this study was to evaluate the impact of supportive interventions, such as deferred intake interviews for providing information and discussing the emotional impacts, encouragement to keep a diary, and the introduction of weekly psychosocial rounds, as perceived by both the ICU patients´ relatives and the healthcare providers.

Background

Patient- and family-centered care is gaining interest, with a shift from provider-centric norms to care arranged around patients´ and relatives individual beliefs and needs. This is expected to have a positive influence on the quality of care. Communication is one of the most important factors impacting the perceived quality of care in the intensive care unit from the perspective of patients´ relatives. New interventions have been introduced to help the patients´ relatives in order to meet their communication needs.

Design and methods

A time-trend quantitative design was used to analyse the perceived quality of care. Two convenience samples of relatives were included (in 2012 and 2013) in four different intensive care units from a large university medical centre in the Netherlands.

Results

Survey data from 211 relatives (75% net response rate in 2012) and 123 relatives (66% net response rate in 2013) were used for the analysis. The second measurement showed significant improvements regarding informational aspects of care, clarification of roles in participatory caretaking, and shared-decision making.

Conclusion

The results suggest that the additional support offered to patients´ relatives increased perceived quality of care, particularly with respect to informational needs. However, patient- and family-centred care still requires a change in the mindset of healthcare professionals. This new point of view should overcome perceived barriers and foster a culture of partnership with patients´ relatives in the ICU.

Relevance to clinical practice

Training in providing psychosocial support for the needs of relatives leads to a stronger perception of patient-centredness.

Keywords: Communication, Patient and family centered care, Critical Care, Family Support, Intensive Care Unit, Nurses, Quality of Care, and Relatives

INTRODUCTION

Patient- and family-centered care (PFCC) is gaining interest, with a shift from traditional provider-centric norms to care that meets individual beliefs and needs[1]. PFCC includes elements such as respect and communication, which may improve the overall quality of care[2]. To strive for and to maintain an excellent quality of care is essential for effective care, improving patient outcomes, and aligning care to what healthcare users need[3]. There is no universally accepted definition of quality of care and the different aspects, mainly due varieties in opinion on the valuation of different stakeholders such as patients, relatives, caregivers and managers[4]. Subsequently, PFCC needs to respect, value and understand how patients may perceive the different aspects of quality of care improvements[5, 6]. These patient-reported measures are essential to quality improvement programs as they will provide feedback regarding patient-centeredness in daily practice to healthcare professionals and policy makers. The Institute of Medicine (IOM) recognizes six patient-centeredness aspects in defining qualitatively good healthcare: 1) it is respectful to patients' values, preferences, and expressed needs, 2) it is coordinated and integrated, 3) it provides information, communication, and education, 4) it ensures physical comfort, 5) it provides emotional support, and 6) it involves family and friends[6, 7]. This IOM patient-centered framework provides the theoretical background in caring of this article.

BACKGROUND

Professionals in the Intensive Care Unit (ICU) are increasingly approaching the relatives as an integral part of the family unit and subsequently expanding the care provided from the patient to their relatives (i.e., family members and close friends visiting the patient) as well[8, 9]. Most ICU patients are not able to receive information or make decisions due to the severity of their medical condition and/or the administration of sedative medication, leaving their relatives as surrogate decision makers. Therefore, the clinical decision making in the ICU should occur as part of a collaborative process with the relatives acting as representatives for the patients[10]. However, relatives can become confused and anxious due to the stressful environment of the ICU[11, 12]. Both daytime sleepiness, reported by more than half of respondents[13], and a 'Family ICU Syndrome´, which describes cognitive blunting with associated impairments in decision-making during an ICU stay, have been suggested as cognitive dysfunctions in relatives resulting from ICU stays[10]. In addition, a fair number (i.e. 30-42% at three months and even 32-80%

after twelve months) of relatives have developed posttraumatic stress[14], with depressive symptoms increasing from 20% to 34% in wives of patients hospitalized with severe sepsis[15], and 52% responded having had a significant degree of learned helplessness[16]. These symptoms were addressed as a 'Post intensive care syndrome-Family'[11]. Therefore, in accordance with PFCC, there is a need to develop and implement interventions to support patients´ relatives in this tumultuous period.

Several supportive interventions for relatives have been introduced in the last decade to improve the quality of care throughout hospitals in the USA and Western Europe, such as family rounds, adjusting the environment to meet family needs, an intensive communication structure, and the introduction of a family support specialist[17-21]. Although the problems in communication and life-support decisions are well recognized[22-24], there is still a lack of large scale evidence-based interventions directed at these problems[21]. Communication skills of healthcare professionals are key factors of the quality of care in the ICU in the perception of the relatives[23]. Relatives have a need for general information as well as medical information related to the specific situation of the patient[8, 25]. Moreover, this information should be unambiguous, devoid of inconsistencies, and presented in an effective, intelligible way[26]. To meet these communication needs of relatives in the ICU, and ultimately improve the quality of care, new supportive interventions have been introduced in the current study. These interventions include a deferred intake interview to provide information and discuss the emotional impact, encourage the relatives to keep a diary, and the introduction of weekly psychosocial rounds. A change in professional attention by introducing these interventions is desirable in the highly technical ICU environment and potentially leads to positive feedback from the patients´ relatives.

Involving ICU professionals in PFCC has posed some challenges. Although empathy and a holistic perspective of the patients has been applied for very long times now, PFCC requires more than that. A paradigm change from a paternalistic attitude ("I know what is best for you") to a supporting role ("What can I do for you to help?) means a challenging adjustment in attitude and vision on caring in daily practice. It may be a difficult problem to combine a service-oriented attitude in the fast-paced ICU environment. Healthcare providers moving quickly to beeping machines and deteriorating patient situations, leaving less time to interact with patients and relatives[27]. Other barriers implementing new interventions in the light of PFCC might play a role as well.

DESCRIPTION OF THE MULTI-INTERVENTION PROGRAM

The usual procedure for supporting the relatives of patients in the ICUs of Erasmus MC, a large medical centre in the Netherlands, consists of general information leaflets, visiting hours from 11 am to 8 pm, daily updates from the nurses, and regular meetings with the physicians. Although the professionals certainly value the communication process as an important part of their work, a structured and constant approach is lacking. To address this practical problem, an intake interview with the relatives on the second day of admission into the ICU was implemented. This deferred intake interview is performed by nurses in a quiet room away from the bedside. The conversation, semi-structured using a checklist, provided general information such as the visiting policy, organization of the ICU, contact with the physician(s), restaurant facilities, parking, and the meditation centre[28-30]. In addition, this intake interview also provided time and space on the emotional impact of the situation. ICU nurses were trained to react to feelings of anxiety, frustration or grief[29, 31]. Two of the researchers (MvM and TB) trained most of the 175 nurses (92%) in a half-day course on how to perform this intake interview. The training consisted of education about the needs of relatives, using the checklist, and practicing communication skills activities. It was emphasized being present, allow silence, use of touch and being sensitive to worries of the relatives. The nurses were not specifically assessed on their practical skills to perform this deferred intake interview.

In addition to oral communication realized by the intake interview, relatives were offered written information. This included a detailed brochure with information about the possible physical, cognitive and emotional effects in the long run of the ICU period[32], specific leaflets about social work, parking, meals, and lodging in the hospital, and a diary. The relatives were encouraged to keep this handwritten diary, they were instructed to write liberally in the diaries without guidance from the ICU professionals. Journaling can be valuable for both patients and their relatives in documenting the presence of visitors, describing the timeline of the situation, and expressing feelings and emotions[33, 34]. It can be beneficial for the patients in their understanding of the ICU experience while recovering. Moreover, relatives who keep a journal might look at the stressful situation from a less upsetting point of view, thus improving their coping abilities[33].

At the same time, a weekly psychosocial round was introduced as a component of this multi-stage intervention program. In these rounds, the situations of all of the relatives were discussed by a multidisciplinary collaborative team involving a social worker, a spiritual care worker, the nurse in charge of the patient and a staff nurse. Intensivists aimed to participate, however, most of the time their workload did not allow for their presence in this meeting. If deemed necessary from the perspective of one of the psychosocial team members, the relatives could be approached for further counselling with the psychosocial service of the hospital. This service from a social worker, a clergy or a psychologist, provide standard care to patients if needed. In case of the ICU this is expanded to the relatives as well. The counselling included some ´small talk´, listening, or additional appointments. All of the nurses were instructed to consult the psychosocial service providers using a digital form to arrange additional support for the relatives in an easily accessible way.

The development, implementation, and sustainability of the new measures was an iterative and active process in the development of the multi-intervention programme. The model of Wensing and Grol (2010) was used to develop a successful plan[35]. First, the goals (which were Specific, Measurable, Acceptable, Realistic, and Timely), priorities, and a risk management strategy were determined by a joint workforce composed of nurses, a psychosocial worker, an intensivist and a quality manager from the four ICUs. A mix of implementation strategies was then chosen. These included informing strategies, such as a newsletter and team discussions; motivating strategies, such as personal contact, positive feedback, and champions of PFCC; educational strategies, such as training and bedside teaching; logistic strategies, such as adaptation of the electronic patient data management system with reminders; and facilitating strategies, such as time management. These strategies were adapted to the culture-specific environment of each ICU. The multi-intervention programme and used implementation strategies have been supported by the management team, including the medical staff, and the nursing staff at each ICU. Some dedicated nurses coached their colleagues through on-the-job training.

STUDY AIM

The aim of this study is to evaluate the effects of new PFCC interventions, such as deferred intake interviews for providing information and discussing the emotional impacts, encouragement to keep a diary, and the introduction of weekly psychosocial rounds, as perceived by both the ICU patients´ relatives and the healthcare providers.

METHODS

The research protocol for the study was approved by the Medical Ethics Committee (MEC) for the medical centre (MEC-2011-189). The committee judged that the study complied with the Dutch law on Medical Research in Humans (WMO). All personal identifiers have been removed or disguised so the persons described cannot be recognized through the provided details.

STUDY DESIGN

A quantitative survey study in using a time-trend design was applied to analyse the perceived quality of care before (2012) and after (2013) the interventions were introduced. In the Netherlands, the government introduced a national framework for evaluating quality of care that contains a set of indicators which includes each person´s experiences[36]. The Consumer Quality Index (CQI) questionnaires are methodologically founded by the CAHPS® instruments and QUOTE® questionnaires[37], which are both theoretically based on the discrepancy (GAP) model[38]. For sufficient quality of care, the expectations regarding quality should be in accordance with the perceptions of the person´s actual experiences according to these methodologies[39]. This CQI was subsequently developed as the measurement standard and since then, has been applied to the experiences of special target groups[40]. The newly developed Consumer Quality Index 'Relatives in the ICU' (CQI 'R-ICU') has been proven to be a valid, reliable and feasible instrument with a sound basis in communication factors[41]. The first part of the questionnaire consists of 44 items divided into six categories, namely: introduction (e.g., "Was the hospitalization of your relative unexpected to you?"), support (e.g., "Was a professional present during your first contact with the patient?"), communication (e.g., "Have you been taken seriously?"), provided information (e.g., "Did the professionals talk to you about keeping a diary?"), organization (e.g., "Did the visiting hours sufficiently serve your needs?") and general judgment (e.g., "If you could change one thing about the support of the professionals, what would that be?"). The second part of the survey was related to demographic items. The internal consistency of the items was sufficient, with a Cronbach´s alpha of 0.89 for all the items together (in a range of 0.51 to 0.87 in four established factors). The CQI 'R-ICU' (version 4.0) was used for measurements in 2012 and 2013.

STUDY POPULATION

The study was undertaken in four ICUs in a large university medical centre in the Netherlands. The level III ICU for adult patients contains 32 operational beds in total and is divided into three units: the thoracic surgery ICU and two mixed units for neurological, neurosurgical, transplantation, general and trauma surgery, and medical patients. The cardiology ICU contains 16 beds, 8 of which have ventilation available. Eligible relatives met the following criteria: relation to an ICU patient who did not die within 24 hours of admission, age of at least 18 years, and understanding of the Dutch language.

The CQI 'R-ICU' was accompanied by a cover letter and sent by digital link to a given e-mail address or to a postal address after Informed Consent was given and after the patient was discharged from the ICU. According to the Total Design Method, first and second reminders were sent after two and four weeks, respectively[42]. To guarantee anonymity, strict separation of the research data and personal data files was maintained throughout the entire process, and the completed questionnaires included no traceable private data. Two convenience samples (2012 and 2013) of relatives of ICU patients in the four different ICUs were included, with a total of 282 and 187 respondents, respectively. The final samples included 211 (response rate 75%) and 123 (response rate 66%) questionnaires, respectively (see Figure 1).

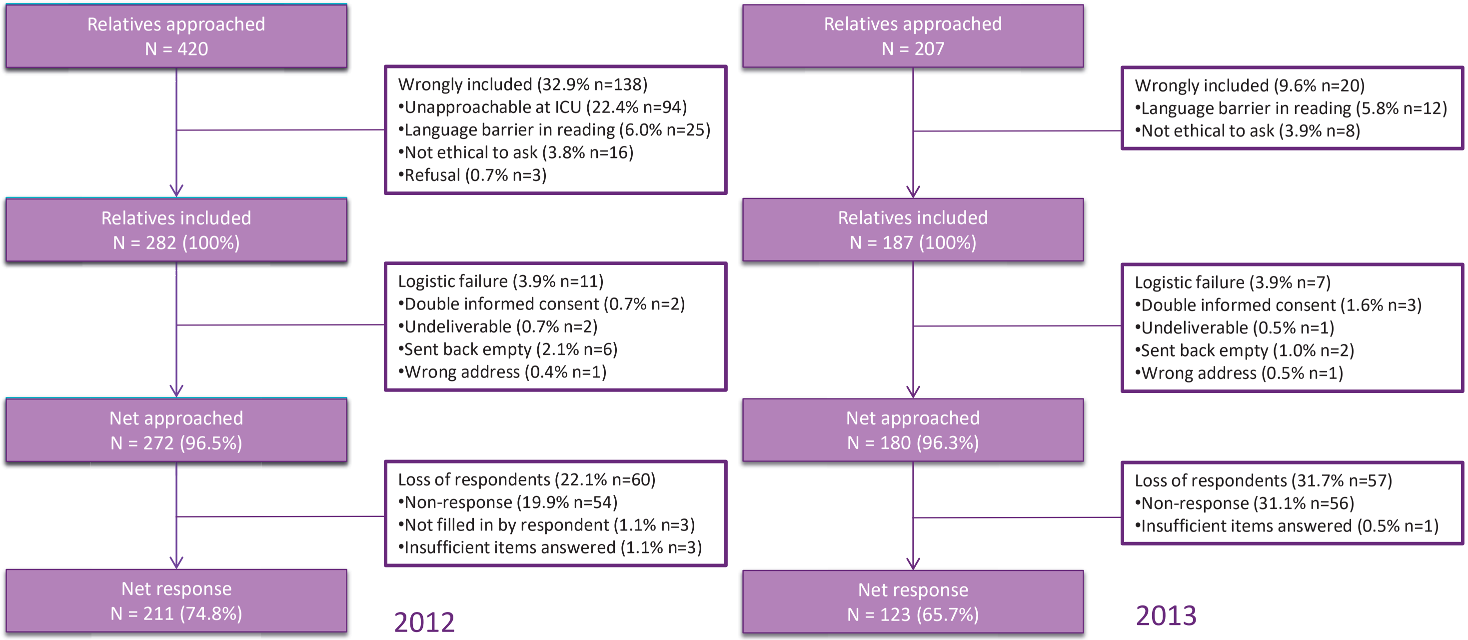

Figure 1. *The study flowcharts of respondents in 2012 and 2013*

STATISTICAL ANALYSIS

The data were analyzed using Microsoft SPSS (version 22.0), with the classical definition of $p < .05$ applied for statistical significance[43]. The characteristics of the respondents were presented as counts and percentages or mean values with standard deviations. Normality was first assessed by kurtosis, skew and histogram analyses. Additionally, a Kolmogorov-Smirnoff test and the Shapiro-Wilk test were performed with visually inspections of the Normal Q-Q plots for deviations. Descriptive statistics (means, standard deviations, and percentages) were calculated for responses to the items of the questionnaire. A two sample t-test for the normally distributed variables was used to compare the data from the first and second measurements, a Mann-Whitney test was used in case of non-normal distributed variables[43]. An analysis of variance (one way ANOVA) was conducted to compare the ´Total quality assessment´ among the four ICUs. This variable was computed by averaging the items 'What rating on a scale of 1 to 10 would you give the nurses for communication?', 'What rating on a scale of 1 to 10 would you give the doctors for communication?' and ´What rating on a scale of 1 (worst) to 10 (best) would you give for the support and care you received in general?´, altogether. An a priori power calculation, with t tests ´difference between two independent means´ ($1-\beta = 95\%$, $p < .05$, two-tailed, $d = .5$), indicated that a total of 210 respondents were needed to detect a medium effect size on the total quality judgment between 2012 and 2013[44]. The observed effect was analyzed as the combination of all the applied interventions together. No stratification of unique measures could be performed because the measuring instrument was too general for this purpose.

RESULTS

All of the questionnaires were sent by post in 2012, in contrast to 72% being sent with a link to the survey by email in 2013. No difference in response rates was observed between mailed and digital questionnaires, although the respondents to the digitally-completed surveys were slightly more likely to be men, of a younger age, and with more education. The respondents at both times were significantly similar in their relationships to the patients, gender, age, own health, education, and ethnic background, as presented in Table 1. The current status of the patient, e.g., still in the hospital or at home, refers to the time of completion of the CQI ´R-ICU´ by the relative. More than 20% of the relatives in 2012 and 16% in 2013 made efforts to complete this questionnaire after the death of their loved ones.

A significant difference in the two groups of respondents was found for ICU hospitalization, with 41% planned in 2012 and 23% in 2013, and in mean length of stay, at 19

Table 1 *Characteristics of the respondents in 2012 and 2013*

	Number of respondents (%)	
	2012* N = 211	2013* N = 123
Relation to patient		
Partner	117 (55.5)	68 (55.3)
Father/mother	26 (12.3)	18 (14.6)
Son/daughter	47 (22.3)	23 (18.7)
Brother/sister	11 (5.2)	12 (9.8)
Other	8 (3.8)	2 (1.6)
Female	137 (64.9)	78 (63.4)
Male	72 (34.1)	45 (36.6)
Age	Modus 55-64 Range 18-75	Mean 52.8 (SD 11.8) Range 22-77
Health indication		
Excellent	39 (18.5)	17 (13.8)
Very good	49 (23.2)	30 (24.4)
Good	103 (48.8)	66 (53.7)
Reasonably well	17 (8.1)	8 (6.5)
Bad	1 (0.5)	2 (1.6)
Education		
Non/Primary school	7 (3.3)	3 (2.4)
GCSE	78 (37.0)	39 (32.0)
A-levels	63 (29.9)	36 (29.0)
College/university	56 (26.5)	43 (35.3)
Other	3 (1.4)	1 (0.8)
Ethnic background		
Caucasian	187 (89.6)	110 (89.4)
Other ethnicities	22 (10.4)	13 (10.6)
ICU Erasmus MC**		
ICV-1	28 (13.3)	4 (3.3)
ICV-2	72 (34.1)	38 (30.9)
ICV-3	75 (35.5)	58 (47.2)
ICCU	20 (9.5)	23 (18.7)
ICU hospitalization		
Planned	86 (41.3)	28 (22.8)
Not planned	122 (58.7)	95(77.2)
Length of stay (mean in days) Median [Q1,Q3]	18.93 (SD 26.6) 9.0 [4.0, 21.0]	15.43 (SD 17.8) 8.5 [4.0, 21.0]
Current situation of the patient		
In the hospital	90 (42.7)	62 (50.4)

Table 1 *Characteristics of the respondents in 2012 and 2013 (continued)*

	Number of respondents (%)	
	2012[*] N = 211	2013[*] N = 123
Back at home	62 (29.4)	33 (26.8)
Deceased during/after the ICU	44 (20.9)	20 (16.3)
Other, e.g nursing home	9 (4.3)	8 (6.5)

[*] The respondents were not significantly different among the four ICUs ($p > .05$)

[**] ICV-1, the thoracic surgery ICU; ICV-2 and ICV-3, the mixed ICUs; ICCU, the cardiology ICU

and 15 days, respectively. This difference is explained by the study ending for logistic reasons after one month in the thoracic surgery ICU which is characterized by planned and short-stay hospitalizations. During the first two months no more than four eligible relatives could be included due to the high patient turnover. Therefore, in mutual agreement with the nursing staff, it was decided to concede no further inclusions or relatives in this ICU.

Most quality of care aspects as measured by the CQI ´R-ICU´ improved between 2012 and 2013. For example, the item "Did the professionals pay attention to what you needed?" increased from 39% of the respondents stating "always" or "mostly" in 2012 to 80% in 2013. On average, respondents experienced significantly ($t(304.229) = -7.13$, $p<.05$) more attention to their needs in 2013 ($M = 3.09$, $SE = .08$) than in 2012 ($M = 2.33$, $SE = .8$) with a medium effect size ($r = .38$). Additionally, significant improvements were observed in 2013 with regard to the provided information, such as keeping a diary, opportunity to participate in the care of the patient, and to be involved in clinical decisions on medical targets in the recovery process of their beloved one. Other items, such as nurses and doctors giving comprehensive information and taking the relatives seriously, scored equally high in both measurements. A few items, such as attentive listening by doctors and not receiving contradictory information, declined in 2013 (see Table 2).

Although not statistically significant, the mean scores for communication with nurses and intensivists and general support increased in 2013. The highest score was given to communication by nurses (M_{2013}= 8.20 and M_{2012}= 7.90), followed by communication by doctors (M_{2013}= 7.41 and M_{2012}= 7.17) and general support (M_{2013}= 7.42 and M_{2012}= 7.06). Relatives with higher education levels scored lowest on ´Total quality judgment´ (M_{High}= 7.26, $M_{A\text{-}Level}$= 8.12 and M_{Low}= 7.39). No differences were observed in ´Total quality judgment´ for the relationship to the patient, age, gender, and ethnic background. Moreover, the current status of the patient showed no difference as well. Relatives of patients who died during or soon after the ICU period evaluated the ´Total quality judgment´ and

Table 2 *Summary per item related to experiences of relatives in the CQI ´R-ICU´*

Item (short description)	Percentage ´always´ or ´mostly´		Mean Difference (SE)***	95% Confidence Interval of the difference		Mann-Whitney (Z)****
	2012	2013		Lower	Upper	
Support						
Support at first contact moment	89.4%	88.4%	1.46 (.09)*	1.28	1.64	
Prepared to first contact with patient	56.1%	65.0%	-.22 (.23)	-.46	.02	
Information to contribute to patient care	24.0%	53.7%				7330.0 (-6.57)*
Opportunity to contribute to patient care	36.2%	56.9%				9199.0 (-4.19)*
To be present during visiting rounds	48.0%	63.1%				10070.5 (-2.98)*
Felt listened to in decision-making**	44.3%	73.2%				9153.5 (-4.18)*
Sounds in the ICU explained	52.2%	72.4%				9739.0 (-3.19)*
Attention to the relative	39.0%	79.6%	-.76 (.11)*	-.97	-.55	
Contact with professional after ICU	30.6%	37.1%				7917.0 (-3.68)*
Communication						
Understandable information by doctors	80.6%	87.8%	-.19 (.10)	-.38	.01	
Understandable information by nurses	88.2%	94.3%	-.13 (.08)	-.28	.02	
No contradictory information	94.4%	92.7%				1074.5 (-14.42)*
Relatives feel taken seriously	88.5%	90.2%	-.07 (.08)	-.24	.09	
Professionals enough time to relatives	77.5%	86.1%	-.07 (.09)	-.24	.11	
Listening attentively by doctors	82.9%	81.1%				9388.0 (-3.43)*
Listening attentively by nurses	87.9%	93.5%	-.10 (.08)	-.30	.06	
Nuisance in changes medical team	94.0%	94.3%				1162.5 (-14.43)*
Provided information						
Written information leaflet given**	27.2%	95.8%	-.04 (.09)	-.17	.17	
Information through digital means**	3.0%	12.3%	-.04 (.05)	-.12	.05	
To know function of professionals	68.8%	82.1%	8.77 (1.64)*	5.14	12.40	
Information on keeping a diary	25.0%	51.2%	.34 (.10)*	.15	.53	
Information on parking policy	51.9%	73.8%	.90 (.10)*	.71	1.1	
Information on meals	21.1%	44.3%	.24 (.09)*	.07	.42	
Informed about translocation patient	61.7%	75.2%	5.58 (8.61)	-11.36	22.51	
Organization						
Accessible professional contact person**	42.8%	39.9%				4931.5 (-9.53)*
Sufficient privacy in the situation	94.4%	96.7%	4.11 (1.33)*	1.48	6.73	
Nuisance of other visitors	1.5%	1.6%				120.5 (-16.5)*
Family room supports needs of relatives	66.2%	54.5%	13.19 (2.31)*	8.64	17.74	
The visiting hours according the needs	95.0%	97.6%	-.02 (.07)	-.16	.12	

Table 2 *Summary per item related to experiences of relatives in the CQI ´R-ICU´ (continued)*

Item (short description)	Percentage ´always´ or ´mostly´		Mean Difference (SE)***	95% Confidence Interval of the difference		Mann-Whitney (Z)****
	2012	2013		Lower	Upper	
General judgement						
Recommending this ICU	91.6%	95.1%				10261.0 (-2.97)*
Marks for communication doctors			-.24 (.26)	-.74	.26	
Marks for communication nurses			-.31 (.17)	-.64	.02	
Marks for general support			-.36 (.22)	-.79	.07	

* Significant p < .05

**Other formulation of the item in the second measurement

***Mean Difference of Independent Samples T-Test (Standard Error), grouping variable ´time´ 2012 and 2013

**** Mann-Whitney U with Z test statistic, grouping variable ´time´ 2012 and 2013

communication aspects similarly as relatives with their beloved ones at home. No data on severity of illness were measured in current study. The test results with an analysis of variance (ANOVA) on ´Total quality judgement´ showed a significant difference for the cardiology ICU compared to the two mixed ICUs ($F(2,114) = 4.27$, $p = .02$) with means 8.35 (±0.91), 7.60 (±1.20), and 7.41 (±1.44) in respective for 2013. Similarly, communication with doctors, 7.96 (±1.30), 7.29 (±2.00), and 7.14 (±2.16) in respective. Although not significant, communication with nurses resulted in higher means in the cardiology ICU as well, 8.96 (±1.02), 7.84 (±1.59), and 8.24 (±0.91) in respective.

DISCUSSION

In comparing the measurements in 2012 and 2013, almost all of the quality of care aspects as measured by the CQI ´R-ICU´ showed a more positive valuation. These results might reflect the effectiveness of the interventions, including the intake interview to provide information and discuss the ICU's emotional impact, the encouragement to keep a diary, and the weekly multidisciplinary psychosocial rounds. In respect to the Institute of Medicine (IOM) recommendations, the results of the current study suggest a preliminary contribution to the six endorsed patient-centeredness aspects applied to the field of intensive care.

1) RESPECTFUL TO A PERSONS' VALUES, PREFERENCES, AND EXPRESSED NEEDS

Relatives themselves are most knowledgeable about whether organizational policies aligns with their needs[6, 7]. As an example, the CQI ´R-ICU´ is an instrument to express the relatives' values and assess their experiences in the quality of care. Measuring these experience provides insight into the impact of the provided services and focuses on efforts around what matters to them. Therefore, these measurements meet the first domain in PFCC and correspond to respectfulness of the needs of patient´ relatives. The training of the nurses in the relevance of PFCC and the emphasis on psychosocial support might have led to a stronger awareness of the needs of patients' relatives. This is shown through the more positive valuation of most items on the questionnaire. Although it is impossible to specify exactly which measure best conveys the impact for the implementation of this set of interventions, it certainly encourages the continuation of this new process.

2) COORDINATED AND INTEGRATED CARE

This domain refers mainly to timely and up-to-date medical information[7], which was not measured in this study.

3) INFORMATION, COMMUNICATION, AND EDUCATION

This domain describes that information should be clear, accurate, and understandable, with attentive listening by the healthcare professionals[7]. It also intends for the relatives in the ICU to be taken seriously and feeling involved in the care of their beloved ones. The results of this study suggest that the provided additional support offered to the patients´ relatives increase their perceived quality of care, particularly with respect to informational aspects. For example, the significant increase of the items related to information on keeping a diary, parking and meals, as well as information on contributing to patient care, demonstrate the positive effect of the intake interview and the folder with informational materials. This article focuses primarily on the interventions and communication with nurses, however, intensivists also play an important role in the support of relatives. The assessment of communication with both nurses and doctors showed an increase in 2013, although the results might suggest that communication was already highly appreciated in 2012. Communication regarding palliative care is perceived as being very important to relatives[45, 46]. Not only are the timing and frequency of the conversations important to the perceived quality of care, but the ability of providers to respond and listen to relatives has an impact as well[23]. However, this study did not take this particular factor into account because the CQI ´R-ICU´ is not suitable for measuring the experiences of relatives with regard to palliative care.

4) PHYSICAL COMFORT

IOM recommends providing appropriate pain relief and attending to physical symptoms[7]. At first sight, this domain is hardly applicable with regard to patient´s relatives. However, taking the possible stress reactions of the relatives into account, ICU-professionals should recognize the physical components of stress in the relatives. Subsequently, the ICU environment could be adjusted with comfortable chairs for the relatives to relieve muscle tension or low back pain due to stress and long waiting. Investing and improving the facilities would also help the relatives to feel more at ease and comfortable in their precarious situation.

5) EMOTIONAL SUPPORT

The IOM states that healthcare should also address emotional distress, such as insecurity and anxiety[7]. To meet this need in particular, the intake interview was introduced to discuss the emotional impact of the situation to relatives and spend some one-to-one time supporting their feelings of worrying, frustration or grief.

6) INVOLVE FAMILY AND FRIENDS

Research has extensively established that relatives play a significant role in ICU patients´ recovery and accordingly, must be involved in patient care[47]. The presence of relatives is not an issue of ´why´, but merely ´to what extent´ relatives want to be involved. The results of this study are inconclusive with regards to this aspect. For example, the item ´Opportunity to contribute to patient care´ showed a significant increase, although the measure did not specify how to do this. Under the condition that a relative wanted to contribute to the provision of care, this contribution might have varied between moisturizing the lips of the patient, reading the news out loud, feeding, or taking care of the patient´s hair and nails. There was no specific change in this usual practice during the study. The relatives likely felt that they had more time and space to be involved in caring for their loved ones due to the professional´s higher awareness of the relative´s needs. Involving the relatives could also mean rooming-in for 24/7 or allowing pets to visit the patient. Other encouraging interventions to implement in the context of PFCC include having family presence at visiting rounds, medical interventions or resuscitation, and assisting with technical interventions such as suctioning. However, further discussion on how to meet the preferences of the relatives in the involvement of patient care is certainly needed. The management staff of the ICUs are currently considering how to adjust the family policy based on the results of the current study. It seems important to create opportunities for relatives to choose the role they need. One approach does not fit all.

PERCEIVED BARRIERS IN THE IMPLEMENTATION OF THE INTERVENTIONS

The process evaluation from the perspective of the healthcare professionals was predominantly informal. Talking with the key users brought some insights on the barriers to implement patient-centered interventions. A multifaceted implementation strategy was followed to introduce the multi-intervention program[35], however, the adoption of the intake interview was difficult. Although it should have worked well, this did not mean it actually worked well overall. Contextual factors, which were not well understood from previous studies, may have influenced the effectiveness of the quality improvement interventions[48]. Time constraints, daily rushed workloads, and competing priorities might be key barriers to performing intake interviews. This also might have influenced the recruitment of eligible relatives, as the intake interview provides could have a side effect of a trustful relationship asking to participate in the study. Lack of motivation to complete the intake interview, such as what might result from a sceptical attitude towards quality improvement, could also be an influencing and conditional factor[48]. The expression of feelings might be considered to be one of the least important tasks within the technical ICU setting[9], which suggests that interpersonal relationships are less relevant than critical medical care[49]. While not specifically studied, the researchers (MvM and TB) observed a low degree of intake interview completion. Nurses appeared to have reservations about initiating structured conversations with relatives away from the patient's bedside. They are used to answering questions and having daily informal discussions, however, performing the intake interview requires a new, more proactive role. This hesitation might be explained by perceived barriers such as over involvement with relatives with a conflicting professional and personal role in treatment as a consequence[47]. This tension between distance and proximity is a matter of individual consideration and has been reflected in a different level of connections with relatives each day. The presence of relatives could also cause work stress for ICU-professionals[50]. Professionals might perceive to have less time to accomplish tasks, might not want emotional interference in the technical requirements of their work, or may even feel threatened. Moreover, they might feel uncertain to ask a colleague to look after their patient during their time away while performing the intake interview, or feeling too busy to spent their time with relatives. Sometimes there was no-one available to watch their patient, which made them unable to leave the ward. Insufficient training in relevant communication skills might also play an important role, which is a learning curve that could not be measured in this study. For these reasons, the utility of the intake interview remains a work in progress.

The results of the current study are preliminary and can be considered as a pilot for further research. This could be done using a process of Intervention Mapping, with a first step of in-depth interviews with relatives to extensively explore their views and values. This process could evoke more meaningful and richer data to rely on. Thereafter, one intervention could be chosen and the best applied methods known from literature could be selected for implementation, taking into account the perceived barriers identified in the current study. Finally, a thorough evaluation of the intervention itself and the process followed should be conducted with a longitudinal design to draw conclusions regarding the causal effect(s) of the applied interventions.

While we do not claim that these results represent all relatives across the country, or even more broadly in Europe or worldwide, our research provides insights into potential improvements to the daily practice of PFCC that could be applied to ICUs at an international level. On the whole, today's challenge is to create an organizational culture based on PFCC. This approach changes the relationship between professionals and the relatives from ´caring for´ to ´collaborating with´. PFCC requires a multidisciplinary cultural change, broadly supported by all professionals.

LIMITATIONS

Although the current study found no worth mentioning barriers to overcome, it has some limitations. To begin with, it was performed in one hospital with four ICUs, resulting in a relatively small number of respondents. Especially the difference in sample sizes and variances on some of the items in 2012 and 2013 gave rise to concern in evaluating the results. Therefore, the external validity of the study is open to question. An international multicenter study is necessary to confirm or disprove the presented results. Another restriction is the study design, which was a non-random cross-sectional design with pre- and post-intervention measurements. It was not a totally well performed intervention study, because of the lack of reproducible product and process evaluation. The total multi-intervention programme was evaluated as a bundle of interventions. It is not known if one part had a stronger effect than others because the outcome was measured as an assessment of the entire programme. Therefore, a clear sight on the effect of each measure could not be established. For ethical reasons, no control group was used, therefore, the effectiveness of the interventions remains open for discussion. Additionally, the data were collected retrospectively by sending out questionnaires three to six days after patients were discharged to the general ward. For this reason, some bias could occur due to other experiences during the hospital stay. However, distributing the questionnaires during treatment in the ICU might result in socially desirable answers. Another shortcoming of this study is a lack of personality variables. It is conceivable that different levels of introversion and different coping mechanisms among relatives might influence their personal needs for social support[51]. This, in turn, might affect their judgment of the care provided by the professionals in the ICU. Finally, this study was performed in four ICUs with completely different patient categories, such as a cardiologic versus a mixed population, numbers of ICU beds ranging from 8 to 16, severities of patient conditions in a range from post-operative to dying, staff composition, and cultural backgrounds. All of these factors may influence the experiences of the relatives and lead to variances in the outcomes.

CONCLUSION

This study presented new supportive interventions for patients´ relatives in the ICU. The results suggest that the bundle of additional support specifically designed for relatives, such as intake interviews, encouragement to keep a diary, and weekly psychosocial rounds, increases the perceived quality of care, particularly with respect to informational factors. Consequently, the continuation and further development of interventions related to PFCC could lead to improvements in the quality of care as perceived by patients' relatives. Moving towards PFCC requires a challenging shift in the mindset of the healthcare professionals. This new point of view should overcome perceived barriers and foster a culture of partnership with patients´ relatives in the ICU.

RELEVANCE TO CLINICAL PRACTICE

The concept of patient- and family centered care has been described and studied in different healthcare settings, however, in the ICU it might be difficult to operationalize this framework in daily practice. Further research is needed to identify factors that act as barriers or facilitators in the organizational cultural change of professionals in taking care from the perspective of PFCC. Training in providing psychosocial support to the needs of relatives leads to stronger awareness in patient-centeredness. Continuous efforts to change the mindset of professionals will contribute to an optimal quality of care in the ICU.

ACKNOWLEDGMENTS

We are grateful to all the relatives who participated in the study. Furthermore, we recognize the valuable contributions of Annet Eenhuizen, Helma van Hilten, Wim Nederlof, Hildelies van Oel, Bert Ruit, Henny van der Star, AnneMare van Steenbeek, Gerrie van der Veen and Annelies van Wiltenburg for their role in recruiting study participants. We also appreciate the efforts of Ilse Menheere and Ans Rensen to administer the data in SPSS. Finally, we thank Dr. Hester Lingsma, epidemiologist, for her appreciated advice in the statistical analysis.

REFERENCES

1. Frampton SB, Guastello S. Time to Embrace a New Patient-Centered Care Rallying Cry:"Why Not?". The Patient-Patient-Centered Outcomes Research 2014;7(3):231-33.
2. Starfield B. Is patient-centered care the same as person-focused care? The Permanente Journal 2011;15(2):63.
3. Campbell S, Braspenning J, Hutchinson A, Marshall M. Research methods used in developing and applying quality indicators in primary care. Quality and Safety in Health Care 2002;11(4):358-64.
4. Campbell SM, Roland MO, Buetow SA. Defining quality of care. Social Science & Medicine 2000;51(11):1611-25.
5. Renedo A, Marston C. Developing patient-centred care: an ethnographic study of patient perceptions and influence on quality improvement. BMC Health Services Research 2015;15(1):122.
6. Tzelepis F, Sanson-Fisher RW, Zucca AC, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. Patient preference and adherence 2015;9:831.
7. Arcrcitvij N. Crossing the Quality Chasm: A New Health System for the 21st Century. Journal for Healthcare Quality 2002;24(5):52
8. Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. Journal of Clinical Nursing 2013;22(13-14):1805-17.
9. O'Connell E, Landers M. The importance of critical care nurses' caring behaviours as perceived by nurses and relatives. Intensive and Critical Care Nursing 2008;24(6):349-58.
10. Netzer G, Sullivan DR. Recognizing, Naming, and Measuring a Family Intensive Care Unit Syndrome. Annals of the American Thoracic Society 2014;11(3):435-41.
11. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. Critical Care Medicine 2012;40(2):618-24.
12. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological symptoms of family members of high-risk Intensive care unit Patients. American Journal of Critical Care 2012;21(6):386-94.
13. Verceles AC, Corwin DS, Afshar M, et al. Half of the family members of critically ill patients experience excessive daytime sleepiness. Intensive Care Medicine 2014:1-8.
14. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. Critical Care 2016;20(16):1-8.
15. Davydow DS, Hough CL, Langa KM, Iwashyna TJ. Depressive symptoms in spouses of older patients with severe sepsis. Critical Care Medicine 2012;40(8):2335.
16. Sullivan DR, Liu X, Corwin DS, et al. Learned Helplessness Among Families and Surrogate Decision-Makers of Patients Admitted to Medical, Surgical, and Trauma ICUsLearned Helplessness in the ICU. CHEST Journal 2012;142(6):1440-46.
17. Daly BJ, Douglas SL, O'Toole E, et al. Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. CHEST Journal 2010;138(6):1340-48.
18. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. Critical Care Medicine 2007;35(2):605-22.
19. Jongerden IP, Slooter AJ, Peelen LM, et al. Effect of intensive care environment on family and patient satisfaction: a before–after study. Intensive Care Medicine 2013;39(9):1626-34.
20. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. CHEST 2011;139(3):543-54.
21. White DB, Cua SM, Walk R, et al. Nurse-led intervention to improve surrogate decision

making for patients with advanced critical illness. American Journal of Critical Care 2012;21(6):396-409.

22. Azoulay E, Chevret S, Leleu G, et al. Half the families of intensive care unit patients experience inadequate communication with physicians. Critical Care Medicine 2000;28(8):3044-49.
23. Curtis JR, Engelberg RA, Wenrich MD, et al. Studying communication about end-of-life care during the ICU family conference: development of a framework. Journal of Critical Care 2002;17(3):147-60.
24. De Rouck S, Leys M. Information needs of parents of children admitted to a neonatal intensive care unit: A review of the literature (1990–2008). Patient Education and Counseling 2009;76(2):159-73.
25. Molter NC. Needs of relatives of critically ill patients: a descriptive study. Heart & lung: the Journal of Critical Care 1978;8(2):332-39.
26. Azoulay E, Pochard F, Chevret S, et al. Meeting the needs of intensive care unit patient families: a multicenter study. American Journal of Respiratory and Critical Care Medicine 2001;163(1):135-39.
27. Wyskiel RM, Weeks K, Marsteller JA. Inviting families to participate in care: a family involvement menu. Joint Commission journal on quality and patient safety/Joint Commission Resources 2015;41(1):43-46.
28. Azoulay E, Pochard F, Chevret S, et al. Impact of a family information leaflet on effectiveness of information provided to family members of intensive care unit patients: a multicenter, prospective, randomized, controlled trial. American Journal of Respiratory and Critical Care Medicine 2002;165(4):438-42.
29. Orcutt TA. Developing family support groups in the ICU. Nursing2013 Critical Care 2010;5(5):33-37.
30. Verharen L, Mintjes J, Kaljouw M, Melief W, Schilder L, van der Laan G. Psychosocial Needs of Relatives of Trauma Patients. Health & Social work 2015:hlv039.
31. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. CHEST journal 2008;134(4):835-43.
32. ICU-steps. Intensive Care. [Een gids voor patienten en hun naasten] A guide for patients and their relatives. 2013. Available from: http://www.icusteps.org/assets/files/booklet/languages/dutch.pdf.
33. Garrouste-Orgeas M, Périer A, Mouricou P, et al. Writing In and Reading ICU Diaries: Qualitative Study of Families' Experience in the ICU. PloS ONE 2014;9(10):e110146.
34. Nydahl P, Knueck D, Egerod I. Extent and application of ICU diaries in Germany in 2014. Nursing in Critical Care 2014;20 (3):155-162.
35. Wensing M, Bosch M, Grol R. Developing and selecting interventions for translating knowledge to action. Canadian Medical Association Journal 2010;182(2):E85-E88.
36. Ten Asbroek A, Arah O, Geelhoed J, Custers T, Delnoij D, Klazinga N. Developing a national performance indicator framework for the Dutch health system. International Journal for Quality in Health Care 2004;16(suppl 1):i65-i71.
37. Berendsen AJ, Groenier KH, de Jong GM, et al. Assessment of patient's experiences across the interface between primary and secondary care: Consumer Quality Index Continuum of care. Patient Education and Counseling 2009;77(1):123-27.
38. Babakus E, Mangold WG. Adapting the SERVQUAL scale to hospital services: an empirical investigation. Health Services Research 1992;26(6):767.
39. Sixma HJ, Kerssens JJ, Campen CV, Peters L. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. Health expectations 1998;1(2):82-95.
40. Kieft RA, de Brouwer BB, Francke AL, Delnoij DM. How nurses and their work environment affect patient experiences of the quality of care: a qualitative study. BMC Health Services Research 2014;14(1):249.

41. van Mol MM, Bakker EC, Nijkamp MD, Kompanje EJ, Bakker J, Verharen L. Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool. Patient Education and Counseling 2014;95(3):406-13.
42. Dillman D, Smyth J, Christian L. Internet, mail, and mixed-mode surveys: the total design method: John Wiley & Sons, New Jersey, 2009.
43. Field. Discovering Statistics Using SPSS. Fourth edition. London: SAGE Publications, 2014. ISBN 9781446249185.
44. Faul F, Erdfelder E, Lang A-G, Buchner A. G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. Behavior Research Methods 2007;39(2):175-91.
45. Aslakson RA, Curtis JR, Nelson JE. The Changing Role of Palliative Care in the ICU. Critical Care Medicine 2014;42(11):2418-28.
46. Kirchhoff KT, Walker L, Hutton A, Spuhler V, Cole BV, Clemmer T. The vortex: families' experiences with death in the intensive care unit. American Journal of Critical Care 2002;11(3):200-09.
47. McConnell B, Moroney T. Involving relatives in ICU patient care: critical care nursing challenges. Journal of Clinical Nursing 2015;24(7-8):991-98.
48. Kringos DS, Sunol R, Wagner C, et al. The influence of context on the effectiveness of hospital quality improvement strategies: a review of systematic reviews. BMC Health Services Research 2015;15(1):277.
49. Söderström IM, Benzein E, Saveman BI. Nurses' experiences of interactions with family members in intensive care units. Scandinavian journal of caring sciences 2003;17(2):185-92.
50. Al Mutair A, Plummer V, Paul O'Brien A, Clerehan R. Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study. Journal of Clinical Nursing 2014;23(5-6):744-55.
51. Boerboom W, Jacobs EA, Khajeh L, van Kooten F, Ribbers GM, Heijenbrok-Kal MH. The Relationship of Coping Style with Depression, Burden, and Life Dissatisfaction in Caregivers of Patients with Subarachnoid Haemorrhage. Journal of Rehabilitation Medicine 2014;46(4):321-26.

4

Joined forces in person-centered care in the intensive care unit: A case report from the Netherlands

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Journal of Compassionate Healthcare,

2016; 3:5

ABSTRACT

Aim
First, to describe the state of the art of joined forces in person-centered care of professionals and patients with their relatives, in the context of intensive care units (ICUs) in the Netherlands. Second, to explore the aspects that are relevant to the professionals providing this compassionate care.

Background
Person-centered care is gaining increasing interest, with the shift from provider-centric norms to care arranged around individual beliefs and needs. Current daily practice in the ICU corresponds increasingly to this idea of person-centered care.

Case presentation
The realization of ´best practices´ in the emotional support of ICU patients´ relatives in three hospitals in the Netherlands enables the sharing of the successful ICU quality improvements nationwide. While other organizations have implemented similar evidence-based interventions, it seemed that professionals were sometimes inclined to reinvent the wheel as they were not aware of other successful initiatives and results. The ´Family and patient Centered Intensive Care´ (FCIC) foundation acts as a center of expertise, aiming to exchange knowledge, to maintain (inter)national contacts, and is an inspirational force in reducing the emotional effects of ICU admission on patients and their relatives.

Conclusion
Quality improvement programs to support the emotional distress of an ICU admission are ideally designed combining the strengths of different disciplines and involving patient-experts and their relatives. This approach is the core of person-centered care; the views, values and needs of the experts are the basis of change in ICU policies. FCIC ensures that these joined forces of professionals and experts improve the quality of care during and after ICU admission. However, person-centered care puts an additional emotional effort on the shoulders of the ICU professionals. This needs to be recognized as well.

Keywords person-centered care, patient-centeredness, compassion, intensive care unit, patient-experts, ICU professionals

BACKGROUND

Person-centered care is gaining increasing interest, with the shift from provider-focused norms to care that is focused on individual beliefs and needs[1-3]. So called "paternalistic healthcare" focuses on an ´I know what is the best for you´ approach, whereas person-centered care emphasizes an equal relationship with the patient and a holistic approach that can be summarized as ´What can I do to improve your health?[4]. It is therefore essential to involve the individual as an active partner in professional care and treatment[5]. However, patients admitted to the intensive care unit (ICU) are typically not able to receive any information or make decisions due to the severity of their medical conditions or the administration of sedative medications. Thus leaving their relatives as surrogate decision makers. For this reason, professionals in the ICU increasingly view the patient as an integral part of a family unit and subsequently include the care provided to the patient with the experiences of their loved ones as well (i.e., family members and close friends visiting the patient)[6-9]. Person-centered care considers patients and their relatives as equal partners in planning, developing and monitoring care to make sure it meets their needs. It includes elements such as respect, compassion, involvement of close relatives, communication, physical comfort and the supply of emotional support[10]. Current daily practice in the ICU increasingly corresponds to this idea of person-centered care, although occasionally, terms such as person-focused care, patient- and family-centered care, relationship-centered care, humanizing care, individualized-care, or family-oriented care, are used interchangeably[4, 11-13]. The central objective of all of these concepts is the inclusion of the persons´ individual experiences to preserve or improve the quality of care[14, 15]. This means seeing them as valuable persons, working alongside professionals to get the best outcome.

Communication is a complex two-way process in which the relatives must be respected as a part of the team. Not only to provide information on the severity of illness and targeted medical treatment goals, also to discuss the preferences and values in personal life of the patient. For example, a relative providing the intensivist personal information on the health status of her husband before admission into the ICU, might be valuable for targeting the medical aims of treatment. Cronenwett and colleagues (2007) defined person-centered care as follows: "recognize the patient or designee as the source of control and a full partner in providing compassionate and coordinated care based on respect for patient´s preferences, values and needs"[4,16]. It is foreseen that in the near future communication and sharing of treatment goals will be considered as important as technical targets in the ICU[15]. This shared decision making might be burdensome for relatives as well. The importance of clear communication in a timely and understandable manner to the person being treated and their relatives, might support the coping mechanism managing the stressful surroundings and critically unstable situation. For example, to the patients, professionals can respect individual preferences and choices in bathing, waking and sleep times, visiting hours and privacy[13]. Professionals can support the relatives discussing on general information, talking over possible emotional and cognitive consequences, recovering from a delirium or the revalidation process of their loved ones ahead. As this conversations particularly provide time and space on the emotional impact of the situation, ICU professionals can react to feelings of anxiety, frustration or grief. Being present, allowing silence, using of touch and being sensitive to worries of the relatives are important attitudes to relieve the burdens.

Because the patient´s survival has priority, person-centered care in the ICU requires a high level of clinical expertise, far-reaching knowledge, and extensive ´soft-skills´ on the parts of the professionals. A change in professional attention is desirable in the highly technical ICU environment and could potentially lead to positive feedback from the patients and relatives[10, 17]. This feedback might increase satisfaction with healthcare and the assessments of the overall quality of care in the ICU[13, 18, 19].

STUDY AIM

The aims of this case report are 1) to describe the state of the art of joined forces in person-centered care of professionals and patients with their relatives, in the context of intensive care units (ICUs) in the Netherlands, and 2) to explore the aspects that are relevant to the professionals providing compassionate care.

KEYS CONCEPTS IN PERSON-CENTERED CARE

HOLISTIC, INDIVIDUAL, RESPECTFUL AND EMPOWERING

Morgan and Yoder (2011) identified in a concept analysis of person-centered care the four most associated attributes in a post-acute healthcare setting, namely: holistic, individual, respectful and empowering[13]. This framework provides the context of current study. Providing holistic care allows the professionals to better understand the entire person and how to respond to their needs. Through individualized care, the professionals recognize and meet the unique personality of people and their perspectives. Being respectful is approaching the patients and their relatives as active health care consumers with own choices in receiving support and care. Effective communication and collaboration are needed for a person to sincerely feel empowered to be involved in healthcare decisions[13].

COMPASSION

Another key concept in person-centered care is compassion[20, 21]. Compassion is a relational caring activity for other human beings. It involves experiencing an emotional reaction and noticing when someone is suffering, thus stimulating meaningful action in the relationship. Compassion has traditionally been related to most major religions[22]. It can be described as the sensitivity to another´s pain, concerns or distress coupled with a deep desire taking action to ameliorate them[3, 22]. A compassionate attitude requires attention to cultural aspects, beliefs, behaviors and personal needs. According to Youngson (2012), compassion is *feeling* the pain as your own; it is mutual[23]. The provider and receiver are one, similar to the concept of 'open-hearted compassion with non-attachment'[23]. However, healthcare professionals trying to alleviate that pain, should not claim ownership. Additionally, this mutual feeling might have a too demanding emotional effort on the ICU professionals, which needs to be recognized as well.

EMPATHY

As a closely related concept, empathy is the cognitive *understanding* of other human beings in which caregivers do not have to *feel* the pain and suffering of their patients[24, 25]. Acknowledgements of the patient´s pain and suffering with understanding, kind words of sympathy, and the display of a profound interest in the person lying in the hospital bed are factors that are as important as the medical and nursing care per se. The meaning of empathy begins from the philosophy of aesthetics and was first applied by German philosophers as ´Einfühling´[26]. It characterizes the human ability to get ´inside´ a beautiful piece of art, for example a painting or a piece of music. It was the psychologist Tichener who adapted this word and first used empathy in 1909[27]. The idea of getting into a feeling is vital in human nature, particularly to see and feel the world form the other´s perspective trying to understand and relate with those in the nearby surroundings[26]. Empathy covers three dimensions[28]: 1) cognitive empathy is the ability to perceive, recognize and discriminate emotional states in the other person; 2) affective empathy is the feeling or the experience of the other´s emotional state; 3) perspective taking, also known as Theory of Mind, metalizing and mind-reading, is seeing things from the other person´s point of view[29].

A critical review stated that the majority of the 38 identified measurement instruments lacked a clear definition of empathy and were based on aspects relatively far away from daily healthcare practice[30]. For example, an item used in the Jefferson Scale of Physician Empathy is: ´I do not enjoy reading non-medical literature or experiencing the arts´. The majority of the explored studies in the critical review applied neither a cognitive nor an affective perspective of empathy, although some studies explicitly adhered to a cognitive process. From a phenomenological background, empathy is the one-sided cognitive awareness and imaginative perspective taking of others in contrast to the two-sided sharing of affects[31].

Studies in neuroscience have explored brain regions related to empathy[29]. The results indicate an activation in special areas, e.g. the anterior insula and anterior cingulate cortex, when participants empathized with people in pain. However, some factors might modulate empathy[29]. These factors are the intensity of displayed emotion, attention, situational context, features of the target, and characteristics of the empathizer. These characteristics in particular might play a role in healthcare providers. It is shown that physicians, compared to naive participants, have reduced empathic brain responses when seeing animated pictures of needles being inserted into the human body[29]. To conclude, empathy is resonating with another person´s feelings. It is the basic of holistic, individualized and respectful caring in an empowering way. In contrast, sympathy is "an emotional response stemming from another´s emotional state or condition that is not identical to the other´s emotion, but consist of feelings of sorrow or concern for another´s welfare"[32]. Therefore, sympathy is me-oriented while empathy is you-oriented. In addition, persons who feel sympathy might have difficulty to detach own feelings from the others´ while persons experiencing empathy are able to detangle themselves from others[33, 34].

CASE PRESENTATION

JOINED INITIATIVE

Citation: "Last year, my father was acutely admitted to the ICU with a septic shock, resulting from an anastomotic leak following bowel tumor surgery. His situation remained instable for two weeks. This period was a rollercoaster for our family, constantly juggling with hope and fear. It was also a time where we had to rely on each other in order to cope with the stressful events, understand the provided information, make choices and to look for ways to continuously supporting my father while keeping ourselves afloat."[35].

Relatives can become confused and anxious due to the stressful environment of the ICU[36-38]. The admission into the ICU may have physical, cognitive, and psychological consequences in the long term for patients and psychological consequences for relatives as well. Therefore, three ICUs in the Netherlands jointly implemented new interventions in a quality improvement program to support relatives in the ICU (Spaarne Hospital in Haarlem, Gelderse Vallei in Ede, and Erasmus MC in Rotterdam). Some examples of these interventions are: prolonged visiting hours, encouragement of the relatives to keep a diary, a deferred intake interview with a close relative to provide information and discuss the emotional impact, a personalized poster with pictures and other personal facts of the patient, an individual tailored ICU-webportal, and the introduction of weekly multidisciplinary psychosocial rounds. The effects of these interventions on the quality of care as perceived by the relatives were measured using the Consumer Quality Index ´Relatives in the ICU´, which is a validated Dutch questionnaire for measuring person-reported outcomes[18, 39]. It is important to involve all disciplines, including nurses, physicians, social workers, chaplains, psychologists, quality advisors, and a clinical ethicist, in this process of person-centeredness in the ICU.

KNOWLEDGE EXCHANGE AND PATIENT-EXPERTS

Citation: "Fantastic, to feel so much energy [throughout the ´Open Space meeting´] to formalize the recognition, facts and improvements during and after an ICU admission. It brought up a lot in me, I needed some time to react. The ICU period has more impact on daily life than you can think of. Powerful, all of us together!"[40].

Best practices in the support of ICU patients´ relatives in three hospitals in the Netherlands enables the sharing of the successful ICU quality improvements with colleagues at national symposia. Other organizations have similarly implemented several evidence-based interventions[17, 41-44]. However, during these symposia it seemed that professionals were occasionally inclined to reinvent the wheel because they were not aware of other successful initiatives and results. For example, the provision of a general information leaflet about the effects of an ICU admission has been an isolated effort in many hospitals, although the contents were similar across hospitals. Extensive knowledge exchange regarding daily practices is therefore desirable; however, a useful communication platform was lacking.

The original joint initiative also provided an impetus to the development and implementation of evidence based interventions to reduce the emotional influence of ICU admission for both patients and relatives in a nationwide collaboration. For example, to gather, improve and disseminate professional activities to prepare and support the visit of children to their loved ones in the ICU. Additionally, this initiative was the beginning of a structural involvement of field-experts, active and passionate ex-ICU patients and relatives, which has not been set up in this style previously.

FOUNDATION FAMILY AND PATIENT CENTERED INTENSIVE CARE

The nationwide collaboration of professionals and field-experts resulted in the Family and patient Centered Intensive Care (FCIC) foundation in January 2015. The FCIC acts as a center of expertise, aiming to exchange knowledge, maintain (inter)national contacts, and to inspire the professionals reducing the impact of an ICU admission in patients and their relatives. Moreover, other professionals and field-experts disseminate additional empirical examples and informational material via the FCIC. A strength of the FCIC is this structural collaboration, the exchange of knowledge and daily practices with field-experts.

FUTURE TARGETS OF THE FCIC

Citation: "It wasn´t easy, those weeks. So much grief in me about my lost health and my dark and uncertain future. About my former work which I loved so dearly. Grief over the critical days in the ICU of which I know only from hearsay, about the bewildering and scary events during the following days. Grief about my prednisone face and moth-eaten hair, the incredible fatigue and about all my thoughts 'What: if-then´. About the long, heavy, and tough beautiful year in the medical rehabilitation center. About the worries and sorrows for my family, my kin and parents. My tears come in waves; minutes, hours, days, weeks in succession. I gave way to it, knowing I need time to shed all those tears and to bury my grief with love and tender care. Again, I count my blessings; there are so many people wanting to listen, willing to help, and really being able to help me to come over all the incredible events of the past one and a half year."[45].

Recently, Post Intensive Care Syndrome (PICS) has been recognized as a syndrome to emphasize the long term consequences of admission into the ICU[46, 47]. In addition to challenges in recovering from the underlying critical illness and physical rehabilitation, emotional distress also needs to be addressed. Sustained support for both the patients and their relatives after the ICU period is frequently lacking[15]. This gap might be due to insufficient knowledge about the physical, emotional, and cognitive consequences of the ICU experience in general ward nurses, general practitioners and the healthcare insurance companies. In general, quality improvement programs of ICU aftercare are ideally designed combining the strengths of different disciplines and involving patient-experts. This approach is the core of person-centered care; the views, values and needs of the experts are the basis of change in ICU policies. For example, patient-experts in FCIC have launched a powerful lobby to introduce aftercare inside and outside the direct work field. This raised the awareness of healthcare organizations, as stated in personal correspondence, to address the long term health problems.

Another target is the involvement of field-experts through innovative methods, such as social media or web applications. Inspiring examples are the communication app ´voICe´ for intubated patients[48], the general support app ´MyICU´, which serves as a communication tool to better engage ICU patients and family members in decisions[49], and the webportal ´IC Portal´ in which relatives and family members receive tailored information, can keep a journal, plan visits, and request family conversations[50]. These applications should relate to the person´s cultural background, health literacy level and communication needs. An important point is understanding and speaking the same language as expert and professional. The development of a well-designed, easy accessible, safe and wide-ranging web application to support and mobilize field-experts is a work in progress for the FCIC.

The FCIC ensures that field-experts are heard via story-telling and active participation in a fully integrated network. The FCIC will convey the idea of person-centered care.

DISCUSSION

Citation: "I don't think the word 'dehumanize' is an intentional action. It is a result of doctors and nurses being so committed to numbers and treatment that there can be a disconnection with the patient. In my own experience in the MICU [medium intensive care unit], I was in a nowhere bubble with no past, present, future, or hope. I could only imagine what their world was like not being in my condition. I knew nothing and felt I was being told nothing and it was the lowest I have ever felt. But then my physical therapist introduced himself with an everyday greeting and his name. I was here, and I was real, and I was a person! Hope had found its way to me. That one action improved my mood like nothing else. There was much to be done and my understanding was still nowhere to be found but that greeting was the initial cut in that bubble. The doctors and nurses were amazing, they saved me, and here I am and able to type this because of them. Maybe dehumanizing is the base effort to get someone living again and the focus and efforts surrounding that. However, once that base effort is no longer needed humanizing should come once again to the fore."[51].

FCIC foundation expresses person-centered care with an empathic attitude in holistic, individualized and respectful caring in an empowering way. FCIC foundation stimulates the professionals to better understand the ICU patients and their relatives through storytelling and intensive cooperation. As a consequence, the professionals recognize and meet the unique personality of people and their perspectives. FCIC foundation is the binding factor between professionals and the patients and their relatives. These joined forces are empowering the frail persons to speak up and feel listened to. A few aspects that are relevant to the professionals providing compassionate care need more discussion. The presented case study provides some grasp on person-centered care based on the transformation towards the holistic vision and application of an empathic attitude in daily practice. An adjustment of the current common approach to patients and relatives in terms of a change toward an organizational culture based on person-centeredness is needed. This approach will alter the relationship between professionals and patients and their relatives from ´caring for´ to ´collaborating with´. A starting point is to acknowledge and respect the person in the whole. Still, professional attitudes in person-centered care require a multidisciplinary cultural change, that is broadly supported by all professionals[4, 52].

Too much compassion might upset healthcare providers emotionally, sometimes leading to burnout and compassion fatigue[53, 54]. This process, in turn, can lead to professionals ultimately leaving their job and influence society via lost economic investment[55]. A concept at the other end of the spectrum is dehumanization, or deindividuation[56]. This process emphasizes the need of caregivers to regulate the negative emotions linked to human suffering, deterioration, and dying[57]. Subtle dehumanization of patients may be a protective mechanism with which professionals cope with negative and devastating inhuman situations[58]. To dehumanize a person has a dark meaning; however, it is not meant to emphasize a malicious intent on the part of the professionals. In this case report, dehumanization refers to an unconscious cognitive functioning, a manner in which humans´ evolved minds interact with the social practices and functional requirements of hospitals[57]. Especially in an ICU, work is incredibly demanding both physically and emotionally, due to the need to continuously and vigilantly monitor of the patient, the unpredictable life-threatening changes in patient conditions, the use of life-sustaining highly technological strategies, and obtrusive family presence[59]. Although dehumanization never must be encouraged, it is a known side-effect of working in an ICU and a common practice in the work of physicians and nurses. At the same time, solutions to reduce dehumanization have to be stimulated. For example, practitioners should talk to patients and relatives not only about the atelectasis, blood values, and failing organs, but also about how the patient feels, what his/her values and desires are, and what type of work he/she does (or did). Talk among professionals not merely about the disease or ´the interesting X-ray in box one´, but call the patient by name in acknowledging the person he/she is. Thus, the goal is to personalize the patient in an environment in which professionals who focus on failing organs and organ systems are busy with life-saving work. Relatives can re-humanize their loved ones as well through reassurance, trust, telling personal stories or news reading.

Empathic concern, as opposed to detached concern, which has been promoted among nurses and physicians in previous decennia[60], refers to the motivation to care for persons in need[61]. Empathic concern allows professionals to change their perspectives and fit the provided care to the specific values, preferences, and needs of the individuals. The ability to feel concern has deep evolutionary roots that are anchored in interacting neural circuits, including the brainstem, amygdala, hypothalamus and somatosensory cortex[62]. According to Decety and colleagues (2014), the patterns of neural response is highly flexible and can be modulated by a number of contextual, cognitive, social and interpersonal factors[61, 62]. For example, the neurophysiological response to the perception of another person´s pain involves significantly less arousal in brain areas in physicians than in non-physicians. Therefore, not feeling patients' misery might be a natural, unconscious coping process in healthcare professionals. Consequently, compassionate caring in the definition of sharing mutual feeling might not be desirable in the stressful environment of ICU professionals. Additionally, sympathy must be restrained in clinical situations whereas empathic communication should be used in all patient related contacts. Although some authors will disagree, the same difference might be true for compassion[29, 33, 34]. Knowing a person´s suffering, without specifically feeling the distress, and alleviating that suffering to the best of a practitioner's professional ability through presence and the provision of support is a valuable contribution to person-centered care.

Both compassionate caring as well as the all-encompassing process of dehumanization might have negative consequences for ICU professionals themselves; therefore, supportive strategies to protect the health of the professionals are necessary. To meet the needs of professionals and to acknowledge their emotional well-being is a key aspect when providing person-centered care in the ICU[10,63]. The most important factor might be an open communication to explore emotional experiences among the professionals. This goal can be achieved by informal talks, interventions from social workers or psychologists, and discussion groups regarding topics such as a moral deliberation. Additionally, training in ´soft-skills´, including relationship-building and communication capabilities, is an essential element for the development of an empathic attitude in ICU professionals. Furthermore, recognition on the parts of management and policymakers of the efforts to provide person-centered care is a well-intentioned condition. These strategies will improve the better balance for professionals between highly technical ICU care and seeing the patient as the person he/she is.

CONCLUSION

The FCIC foundation is a beautiful example of person-centered care in the world of ICU care. On the one hand, professionals must respond to the suffering and needs of patients and relatives with empathy, compassion, and sensitivity inherent for person-centered care. They need to do more than simply *know* persons are suffering; they have to alleviate that suffering to the best of their abilities and should be able to *be* there as a witness and to provide support through their presence. On the other hand, excessive immersing with ICU patients and their relatives or an overload of proximity might lead to numbness and emotional exhaustion. Empathic caring is about finding a delicate balance for each individual professional.

ACKNOWLEDGMENTS

We are grateful to the core members of FCIC for their contribution and support; Ilona Blauw (Organizational expert, ´Veilig Veranderen´), Nikk Conneman (Neonatologist, Erasmus MC, Rotterdam), Ruud Klercks (Expert), Grietje Marten-van Steijn (After-care nurse, RadboudUMC, Nijmegen), Hanneke Oonk (Health care coach), Willem Roudijk (Patient coach, RadboudUMC, Nijmegen), Marike van der Schaaf (Associate professor, Revalidation AMC, Amsterdam), Marjolein Siebel (Expert), Idelette Nutma (Expert), Marijke van der Steen (Intensivist, Gelderse Vallei, Ede), Lisbeth Verharen (Associate Professor LAIZ, Nijmegen), John van Vlijmen (Quality advisor and ICU nurse, Ziekenhuis Rivierenland, Tiel), Gijs de Vos (Expert), Peter Westerduijn (ICU nurse, Admiraal de Ruyter Ziekenhuis, Goes).

Furthermore, we gratefully acknowledge Herma Speksnijders (ICU nurse Erasmus MC) and Arie den Ouden (Project ´Surgeon´, Ambidexter Management) for advice and comments on this case report.

REFERENCES

1. Frampton SB, Guastello S. Time to Embrace a New Patient-Centered Care Rallying Cry:"Why Not?". The Patient-Patient-Centered Outcomes Research 2014;7(3):231-233.
2. Starfield B. Is patient-centered care the same as person-focused care? The Permanente Journal 2011;15(2):63.
3. Lown BA, McIntosh S, Gaines ME, McGuinn K, Hatem DS. Integrating Compassionate, Collaborative Care (the"Triple C") Into Health Professional Education to Advance the Triple Aim of Health Care. Academic medicine: journal of the Association of American Medical Colleges 2016;91(3):310-316.
4. Barnsteiner J, Disch J, Walton M. Person and Family Centered Care. Indianapolis USA: Sigma Theta Tau; 2014. ISBN 9781938835070.
5. Ekman I, Swedberg K, Taft C, et al. Person-centered care - Ready for prime time. European Journal of Cardiovascular Nursing 2011;10(4):248-251.
6. Al-Mutair AS, Plummer V, O'Brien A, Clerehan R. Family needs and involvement in the intensive care unit: a literature review. Journal of Clinical Nursing 2013;22(13-14):1805-1817.
7. Azoulay E, Pochard F, Chevret S, et al. Meeting the needs of intensive care unit patient families: a multicenter study. American Journal of Respiratory and Critical Care Medicine 2001;163(1):135-139.
8. Jacobowski NL, Girard TD, Mulder JA, Ely EW. Communication in critical care: family rounds in the intensive care unit. American Journal of Critical Care 2010;19(5):421-430.
9. O'Connell E, Landers M. The importance of critical care nurses' caring behaviours as perceived by nurses and relatives. Intensive and Critical Care Nursing 2008;24(6):349-358.
10. Jakimowicz S, Perry L. A concept analysis of patient-centred nursing in the intensive care unit. Journal of Advanced Nursing 2015;71(7):1499-1517.
11. American Academy of Pediatrics. Policy Statement. patient- and Family-Centered Care and the Pediatrician´s Role. In: Pediatrics. vol. 129; 2012: 394 -404
12. Bardes CL. Defining "patient-centered medicine". New England Journal of Medicine 2012;366(9):782-783.
13. Morgan S, Yoder LH. A concept analysis of person-centered care. Journal of Holistic Nursing 2012;30(1):6-15.
14. Tzelepis F, Sanson-Fisher RW, Zucca AC, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. Patient preference and adherence 2015;9:831.
15. Cabrini L, Landoni G, Antonelli M, et al. Critical care in the near future: patient-centered, beyond space and time boundaries. Minerva Anestesiologica 2015.
16. Cronenwett L, Sherwood G, Barnsteiner J, et al. Quality and Safety Education for Nurses. Nursing outlook 2007;55(3):122-131.
17. Davidson JE, Powers K, Hedayat KM, et al. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004–2005. Critical Care Medicine 2007;35(2):605-622.
18. van Mol M, Bakker EC, Nijkamp MD, Kompanje EJ, Bakker J, Verharen L. Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool. Patient Education and Counseling 2014;95(3):406-413.
19. Heyland DK, Rocker GM, Dodek PM, et al. Family satisfaction with care in the intensive care unit: Results of a multiple center study. Critical Care Medicine 2002;30(7):1413-1418.
20. McCormack B, McCance TV. Development of a framework for person-centred nursing. Journal of advanced Nursing 2006;56(5):472-479.
21. Todres L, Galvin KT, Holloway I. The humanization of healthcare: A value framework for qualitative research. International Journal of

Qualitative Studies on Health and Well-being 2009;4(2):68-77.

22. Papadopoulos I, Shea S, Taylor G, Pezzella A, Foley L. Developing tools to promote culturally competent compassion, courage, and intercultural communication in healthcare. Journal of Compassionate Health Care 2016;3(1):1.
23. Youngson RA. Time to care: How to love your patients and your job: Rebelheart Publishers; 2012. ISBN 9789036808569.
24. Pedersen R: Empathy. A wolf in sheep's clothing? Medicine, Health Care and Philosophy 2008;11(3):325-335.
25. Halpern J. What is clinical empathy? Journal of general internal medicine 2003;18(8):670-674.
26. Howe D. Empathy: What it is and why it matters: Palgrave Macmillan; 2012. ISBN 9781137276421.
27. Titchener EB. Lectures on the experimental psychology of thought processes. In.: JSTOR; 1910.
28. Feshbach ND. 12 Parental empathy and child adjustment/maladjustment. In: Empathy and its development. Edited by N. Eisenberg and J Strayer. 1987:Press Syndicate of the University of Cambridge, New York, USA;271-291. ISBN 0521409861.
29. Hein G, Singer T. I feel how you feel but not always: the empathic brain and its modulation. Current Opinion in Neurobiology 2008;18(2):153-158.
30. Pedersen R. Empirical research on empathy in medicine - A critical review. Patient Education and Counseling 2009;76(3):307-322.
31. Zahavi D, Rochat P. Empathy≠ sharing: Perspectives from phenomenology and developmental psychology. Consciousness and Cognition 2015;36:543-553..
32. Eisenberg N, Miller PA. The relation of empathy to prosocial and related behaviors. Psychological Bulletin 1987;101(1):91.
33. Neumann M, Bensing J, Mercer S, Ernstmann N, Ommen O, Pfaff H. Analyzing the "nature" and "specific effectiveness" of clinical empathy: a theoretical overview and contribution towards a theory-based research agenda. Patient Education and Counseling 2009;74(3):339-346.
34. Batson CD, Eklund JH, Chermok VL, Hoyt JL, Ortiz BG. An additional antecedent of empathic concern: valuing the welfare of the person in need. Journal of personality and social psychology 2007;93(1):65.
35. Marjan. (patients´ relative-expert). www.opeenicliggen.nl; 2013.
36. Ågård AS, Harder I. Relatives' experiences in intensive care—Finding a place in a world of uncertainty. Intensive and Critical Care Nursing 2007;23(3):170-177.
37. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. Critical Care Medicine 2012;40(2):618-624.
38. McAdam JL, Fontaine DK, White DB, Dracup KA, Puntillo KA. Psychological Symptoms of Family Members of High-Risk Intensive Care Unit Patients. American Journal of Critical Care 2012;21(6):386-393.
39. Menheere I, Rensen A, Rutjens R, Verharen L, Vloet L. [Kwaliteitsrapportage Consumer Quality Index ´Naasten op de intensive care´] Quality report Consumer Quality Index ´Relatives in the intensive care unit´. In.: Lectoraat Acute Intensive Zorg, Hogeschool van Arnhem en Nijmegen; 2015.
40. Jacqueline. (patient-expert). In. www.opeenicliggen.nl; 2013.
41. Jongerden IP, Slooter AJ, Peelen LM, et al. Effect of intensive care environment on family and patient satisfaction: a before–after study. Intensive care medicine 2013;39(9):1626-1634.
42. Daly BJ, Douglas SL, O'Toole E, et al. Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. CHEST Journal 2010;138(6):1340-1348.
43. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in

intensive care: a systematic review. CHEST 2011;139(3):543-554.

44. White DB, Cua SM, Walk R, et al. Arnold RM. Nurse-led intervention to improve surrogate decision making for patients with advanced critical illness. American Journal of Critical Care 2012;21(6):396-409.

45. Brackel M. [Raakt hij mijn voeten aan? Dat is ten strengste verboden!] Is he touching my feet? It is stricktly forbidden!. Medisch Contact 2009;64(50).

46. Needham DM, Davidson J, Cohen H, et al. Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. Critical Care Medicine 2012;40(2):502-509.

47. Davidson JE, Harvey MA, Schuller J, Black G. Post-intensive care syndrome: what is it and how to help prevent it. American Nurse Today 2013;8(5):32-38.

48. Radboudumc. Retrieved 14-11-2015 from https://www.radboudumc.nl/Zorg/Afdelingen/IntensiveCare/Pages/CommunicatieAppvoICe.aspx.

49. Beth Israel Deaconess Medical Center. Retrieved 14-11-2015 from https://healthmanagement.org/c/icu/news/myicu-app-introduced.

50. Funatic. Retrieved 14-11-2015 from http://www.funatic.nl/wps/portal/healthcare/icportaal

51. Hoover H. (patient-expert). In. www.linkedin.nl; 2015.

52. van Lieshout F, Titchen A, McCormack B, McCance T. Compassion in facilitating the development of person-centred health care practice. Journal of Compassionate Health Care 2015;2(1):1.

53. van Mol MM, Kompanje EJ, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units: A Systematic Review. PloS ONE 2015;10(8):e0136955.

54. Stamm BH. Measuring Compassion Satisfaction as Well as Fatigue: Developmental History of the Compassion Satisfaction and Fatigue Test. In: In: Treating Compassion Fatigue. edn. Edited by Figley CR. New York: Routledge; 2002:107 - 117.

55. Böckerman P, Ilmakunnas P. Interaction of working conditions, job satisfaction, and sickness absences: evidence from a representative sample of employees. Social science & medicine 2008;67(4):520-528.

56. Haque OS, Waytz A. Dehumanization in medicine causes, solutions, and functions. Perspectives on Psychological Science 2012;7(2):176-186.

57. Vaes J, Muratore M. Defensive dehumanization in the medical practice: A cross-sectional study from a health care worker's perspective. British Journal of Social Psychology 2013;52(1):180-190.

58. Kompanje EJ, van Mol MMC, Nijkamp MD. 'I just have admitted an interesting sepsis'. Do we dehumanize our patients? Intensive Care Medicine 2015:41(12);2193-2194

59. Ciufo D, Hader R, Holly C. A comprehensive systematic review of visitation models in adult critical care units within the context of patient-and family-centred care. International Journal of Evidence-Based Healthcare 2011;9(4):362-387.

60. Cadge W, Hammonds C. Reconsidering Detached Concern: The Case of Intensive-Care Nurses. Perspectives in Biology and Medicine 2012;55(2):266-282.

61. Decety J, Smith KE, Norman GJ, Halpern J. A social neuroscience perspective on clinical empathy. World Psychiatry 2014;13(3):233-237.

62. Decety J, Norman GJ, Berntson GG, Cacioppo JT. A neurobehavioral evolutionary perspective on the mechanisms underlying empathy. Progress in Neurobiology 2012;98(1):38-48.

63. Slatore CG, Hansen L, Ganzini L, et al. Communication by nurses in the intensive care unit: qualitative analysis of domains of patient-centered care. American Journal of Critical Care 2012;21(6):410-418.

SECTION 2

WORKING IN THE ICU

5.1

Will we become more empathic intensive care professionals by watching films and documentaries about suffering?

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Intensive Care Medicine,

2017; DOI 10.1007/s00134-017-4693-4

‘*Extremis*’ is a 24-minute, documentary about end-of-life care in the intensive care unit at Highland Hospital in Oakland, California. It was made and directed by Dan Krauss in 2016 and it can be watched on Netflix® [1]. The film provides insight in the daily ethical dilemmas which physicians, nurses, patients and their relatives face in the inevitability of death. The documentary follows dr Jessica Zitter, who is a palliative care specialist helping patients without hope on recovery. She prepares her patients to die. It shows, among others, a ventilated patient desperately trying to write her last wishes on a piece of paper. And Donna, a woman with myotonic muscular dystrophy who is eventually freed from her endotracheal tube so she can peacefully die in the presence of her loved-ones. We also see the daughter of Selena who will not stop looking for another miracle, but her mother suffered severe cerebral damage after a circulatory arrest making such hope in vain. However, her daughter feels that stopping the mechanical ventilator is taking an active role in Selena´s death. The way of filming, the editing, the music, the emotions shown and deliberations make this film heavy and heart-breaking to watch.

In our intensive care, we have five days a week, half an hour of teaching during lunchtime. One day we showed *‘Extremis’* to a group of twenty-five intensivists, fellows, interns, and researchers. They gathered together in the conference room. Some of them enjoying a good cup of coffee or a sandwich. During the documentary they all were quiet, so we observed them for nonverbal behaviour. We watched their facial expressions. We tried to read them. In the hours before they joined their colleagues in the conference room and before watching the documentary, most of them were confronted with severely ill patients on the ward, facing disturbed and emotional confused relatives, and making treatment decisions. Now they were watching the same situations, but on a screen with music, from a distance.

Empathy can be divided in three forms: cognitive empathy, emotional empathy and compassionate empathy. With cognitive empathy we know how the other person feels and what he/she might be experiencing or thinking. Emotional empathy means that you can feel physically and emotionally along with the other person, as though the emotions are contagious. In compassionate empathy we understand and feel the same emotions, but we are spontaneously moved to help the other[2].

‘Extremis’ is emotionally provocative, as we observed on the faces of some of the attending (mostly female) doctors. But is watching a movie even more emotionally provocative than actual working with patients and their relatives on the intensive care? Do we, as professionals working on the intensive care, experience more mental pain when we are watching a film or documentary or reading a fictional book about suffering than when we experience this in real life? No, a different form of empathy is in action. In patient-care almost all healthcare workers use cognitive empathy in coping with the experience of suffering. While watching a movie, a documentary and reading a novel we experience emotional empathy.

Why do we want to read a novel or watch a movie about the pain and suffering of others in the first place? That we appreciate experiencing the kinds of emotions that we tend to consider unpleasant in daily life, like death, end-of-life, suffering, may seems rather illogical[3]. This is called the '*tragic paradox*'[4, 5]. Hanich and colleagues[4] formulated the '*being moved hypothesis*'. People experience a positive experience of feeling emotionally moved, for that reason they seek out such films or read such books. The watcher or reader opens his/her mind for feeling to be moved for experiencing an '*overall positive emotional state*'. Something we do not allow ourselves when confronted with the same feelings during our real work on the intensive care. We '*simply liked to be moved*' with fiction or a documentary. We identify ourselves emotionally with the characters (emotional empathy), but obviously we do not identify ourselves emotionally with most of the patients and their relatives we care for on the intensive care (cognitive empathy).

Empathy is needed in every healthcare provider-patient relationship[2]. We suppose that readers (of a novel on suffering) or watchers (of a movie or documentary) of suffering can become unsettled and after that consider the same suffering in real life in a different (more empathic) way. Possibly this leads to better empathic understanding of events in real life[2]. Exposure to films, documentaries and fictional literature can have a positive effect on empathic understanding[6]. In combination with sad music the effect is even stronger[7].

To conclude, we strongly believe that including reading fiction and watching movies or documentaries on suffering can make healthcare professionals more empathic persons [2]. Watching such documentaries and movies should be included in educational programs of ICU professionals.

REFERENCES

1. Watch trailer: https://www.youtube.com/watch?v=TJiY8duVgz0 Wt.
2. Dehning S, Reiß E, Krause D, et al. Empathy in high-tech and high-touch medicine. Patient Education and Counseling 2014;95(2):259-64.
3. Koopman E. Reading suffering: an empirical inquiry into empathic and reflective responses to literary narratives. 2016; PhD Thesis, Erasmus University Rotterdam.
4. Hanich J, Wagner V, Shah M, Jacoben T, Menninghaus W. Why we like to watch sad films. The pleasure of being moved in aesthetic experiences. Psychology of Aesthetics, Creativity, and the Arts 2014;8(2):130.
5. Oliver MB. Exploring the paradox of the enjoyment of sad films. Human Communication Research 1993;19(3):315-42.
6. Mar RA, Oatley K, Peterson JB. Exploring the link between reading fiction and empathy: Ruling out individual differences and examining outcomes. Communications 2009;34(4):407-28.
7. Eerola T, Vuoskoski JK, Kautiainen H. Being moved by unfamiliar sad music is associated with high empathy. Frontiers in psychology 2016;7;1176

5.2

‘I just have admitted an interesting sepsis’. Do we dehumanize our patients?

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2015;41(12):2193-2194

'I just admitted an interesting sepsis'; 'Do you have the lactate of that oesophagectomy on ICU-2?'; 'I asked the neurosurgeon to take a look at that bad-looking subarachnoid haemorrhage (SAH) in box three'. Three examples the first author overheard physicians talking to each other about patients on the intensive care. They were talking about Mr B. a 63-year old male patient ('*the interesting sepsis*'), Mrs C. a 69-year old frail woman ('*the oesophagectomy*'), and Mrs D. a 49-year old mother of three ('*the bad-looking SAH*'). We wondered, would the young doctors also talk about '*an interesting sepsis*', '*an oesophagectomy*' or '*a bad looking SAH*' when it concerns their father, mother, sister, colleague or spouse? Probably not, that would be seen as impropriate. It would be less empathic. But why do we so often talk about patients as if they were just diseases, operation techniques or organs? Why do we depersonalize or dehumanize them?

Another example. An 18-year old girl was run over by a car when the driver neglected a red stopping light. She was admitted to the hospital with severe traumatic brain injury. Her pupils were fixed and dilated, 3 on the Glasgow Coma Scale. One of us saw the senior intensivist, a resident and a nurse entering the family room to bring the bad news to the parents that their daughter was going to die. One hour later the intensivist and the resident were seen in the hospital restaurant, laughing, making jokes and enjoying lunch. Where they indifferent of the immense catastrophe the parents just had to deal with?

Every experienced healthcare provider will recognize these examples. Over time, most healthcare providers become desensitized to the physical and emotional pain, the distress, anxieties, fears and death of their patients, but usually retain the ability to *know* when a patient is in pain or distress. The dulling of their empathic sense is essential for practicing medicine[1, 2]. A region in our frontal lobes, the medial prefrontal cortex (MPFC) ensures that we can make inferences about the state of mind of others. When you think about how you can please someone, you use your MPFC. The intensivist speaking to the parents of the young dying girl did not really *feel* the pain of parents, but he calmly inferred their pain[1, 3]. When people are unlike us, or more distant from our personal social networks (as our patients are), they become less likely to engage our MPFC, making us more indifferent about the pain and suffering of others. That doesn't make bad healthcare providers. We don't want the healthcare providers to be suffering with the patients, but we want them to *know* that they suffer. Nothing more, nothing less.

Healthcare providers who are sometimes speaking about patients in terms of diseases, organs or operation techniques do so because it is practical. It is easier to remember in communication about the patient than using their real names. Because our primary interest lay in the disease, the failing organ, the patho-physiological puzzle, and not in the person behind this, it is easier to communicate with colleagues in terms like 'the interesting sepsis' or the ´bad-looking SAH'. Furthermore, the patients do not engage our MPFC, because of social-economic differences; conditions resulting from lifestyle choices that are not ours, sometimes even true disgust and because they, most importantly, are very distant from our social network. Thirdly; disease, pain, suffering and death is a daily part of the work on the ICU. The healthcare providers expect it, are not shocked or surprised to see it every day, 24/7/365. Through the partly dehumanization of our patients we can deal with this.

An additional explanation can be found in the theory of cognitive dissociation. According to Festinger (1957), a person can holds two cognitions that are inconsistent with one another; he will experience the tension of an aversive motivational state, a pressure that he will seek to remove, among other ways, by altering one of the two dissonant cognitions[4, 5]. How do they reduce this tension? By changing his/her attitudes so that they are in line with our behaviour ('dehumanising' patients so they don't feel the pain and suffering). Failing to do so can lead to burnout, compassion fatigue or even post-traumatic stress disorder.

So, yes, we dehumanize some of our patients. But this is inevitable and even adaptive, and even morally and psychologically acceptable. As long as healthcare providers *know* their patients are suffering and in pain, they don't have to *feel* it.

REFERENCES

1. Epley N. Mind wise: Why we misunderstand what others think, believe, feel, and want: Vintage Books Trade Paperback, 2014. ISBN 9780385351676.
2. Smith DL. Less than human: Why we demean, enslave, and exterminate others: Macmillan, St. Martin's press, New York: 2011. ISBN 9780312532727.
3. Cheng Y, Lin C-P, Liu H-L, et al. Expertise modulates the perception of pain in others. Current Biology 2007;17(19):1708-13.
4. Festinger LA. Cognitive theory of dissonance. Row Petersen, Evanston, IL. Stanford University Press 1957. ISBN 9780804709118.
5. Sturman ED. Dehumanizing just makes you feel better: The role of cognitive dissonance in dehumanization. Journal of Social, Evolutionary, and Cultural Psychology 2012;6(4):527-531.

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The prevalence of compassion fatigue and burnout among healthcare professionals in intensive care units: A systematic review

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PLoS ONE,

2015;10(8): e0136955

ABSTRACT

Background

Working in the stressful environment of the Intensive Care Unit (ICU) is an emotionally charged challenge that might affect the emotional stability of medical staff. The quality of care for ICU patients and their relatives might be threatened through long-term absenteeism or a brain and skill drain if the healthcare professionals leave their jobs prematurely in order to preserve their own health.

Purpose

The purpose of this review is to evaluate the literature related to emotional distress among healthcare professionals in the ICU, with an emphasis on the prevalence of burnout and compassion fatigue and the available preventive strategies.

Methods

A systematic literature review was conducted, using Embase, Medline OvidSP, Cinahl, Web-of-science, PsychINFO, PubMed publisher, Cochrane and Google Scholar for articles published between 1992 and June, 2014. Studies reporting the prevalence of burnout, compassion fatigue, secondary traumatic stress and vicarious trauma in ICU healthcare professionals were included, as well as related intervention studies.

Results

Forty of the 1623 identified publications, which included 14,770 respondents, met the selection criteria. Two studies reported the prevalence of compassion fatigue as 7.3% and 40%; five studies described the prevalence of secondary traumatic stress ranging from 0% to 38.5%. The reported prevalence of burnout in the ICU varied from 0% to 70.1%. A wide range of intervention strategies emerged from the recent literature search, such as different intensivist work schedules, educational programs on coping with emotional distress, improving communication skills, and relaxation methods.

Conclusions

The true prevalence of burnout, compassion fatigue, secondary traumatic stress and vicarious trauma in ICU healthcare professionals remains open for discussion. A thorough exploration of emotional distress in relation to communication skills, ethical rounds, and mindfulness might provide an appropriate starting point for the development of further preventive strategies.

Keywords Burnout, Compassion fatigue, Vicarious trauma, Secondary Traumatic Stress

INTRODUCTION

An Intensive Care Unit (ICU) can be full of stressful situations for patients, relatives and healthcare professionals. A growing body of evidence suggests that burnout among ICU nurses[1] and ICU physicians[2] is a remarkable result of the demanding and continuously high-stress work environment. It has been suggested that ICU professionals could be emotionally affected by end-of-life issues[3], ethical decision making[4], observing the continuous suffering of patients[5], disproportionate care or medical futility[6], miscommunication[7], and demanding relatives of the patients[8]. Moreover, many patients in the ICU lack decision-making capacity; therefore, the healthcare professionals depend on communication with relatives for decision making, which can complicate the communication process[9]. In addition, the ICU work environment has become increasingly technical, which requires extended skills in advanced life sustaining medical therapies. These aspects may lead to moral distress or avoidance behavior[10], and consequently increase emotional distress. This job stress can have a negative effect on an individual´s enjoyment of work. It might even result in long-term absenteeism or a threatening brain and skill drain if the professionals leave their jobs prematurely to preserve their own health, ultimately leading to economic burdens[11]. In addition, these processes may even reduce the quality of care for patients and relatives[12].

Work-related stress with the accompanying emotions provoked specifically in ICU is well documented over the previous years[12-15]. The high-stakes, high stress environment that ICU professionals practice in, are incredibly demanding intellectually, physically, and emotionally. Both physical warning signs (such as headaches, sleeping disturbances, low back pain and stomach problems) and mental responses (such as irritability or hostility, loss of concentration, low self-confidence and emotional instability) could indicate individual stress reactions[16-18]. However, these are non-specific symptoms which cannot depict the origin of stress and subsequently constrain effective coping mechanisms or the developing of preventive strategies for this ongoing process.

Stress reactions are the first indication of the presence of an emotional trauma. These reactions are defined as a set of conscious and unconscious behaviors, cognitions and emotions, to deal with the stressor[19]. In the research field of traumatization, which focuses on the process and origin of developing stress symptoms, there is a distinct difference in primary and secondary traumatization[20]. Primary traumatization is the process that can occur from having persistent, intense and direct contact with a traumatic event, such as a situation of war, violence or sexual abuse. This process can lead to posttraumatic stress disorder[21]. Secondary traumatization is the process via an indirect exposure, which may develop from hearing about a traumatic event or caring for someone who has experienced a traumatic event. This process may lead to burnout, compassion fatigue, vicarious trauma, and secondary traumatic stress[20, 22].

BURNOUT

Burnout (BO), an emotional and behavioral impairment that results from the exposure to high levels of occupational stress, has been described as a combination of three factors: emotional exhaustion, depersonalization and personal accomplishment[23]. Individuals who are at risk of a BO, usually have some level of perfectionism and feel guilty if they do not perform as well as they would like to. This goal-oriented mindset could cause an extreme imbalance in work-related situations and might lead to long-term absenteeism. Although BO can be severe, it has also been viewed as a contagious syndrome[24]. The social context, and especially the interaction with complaining colleagues, might play an important role in the development of BO. Furthermore, BO has been mentioned as a fashionable diagnosis because a clear and standardized definition is lacking[8, 25]. A substantial number of studies on BO in a broad range of professions were published and a peak in media coverage occurred since the first description[26]. However, since its origination, the operationalization and measurement of BO have differed enormously.

COMPASSION FATIGUE

Compassion fatigue (CF) has been defined as a state of physical or psychological distress in caregivers, which occurs as a consequence of an ongoing and snowballing process in a demanding relationship with needy individuals[27, 28]. It has been associated with a ‘helper syndrome’ that results from continuous disappointing situations and leads to moral distress[29]. CF was described for the first time in the early nineties as the loss of compassion in result of repeated exposure to suffering during work[30]. A little later, CF was defined as secondary traumatic stress (STS) resulting from a deep involvement with a primarily traumatized person, because of the “more friendly framing”[29]. From this time on, CF has interchangeably been referred to as secondary- and posttraumatic stress (S/PTS) or vicarious trauma (VT)[27-29, 31]. CF consists of two parts. The first part contains issues such as exhaustion, frustration, and depression, typical associated with BO. The second part is the negative feeling driven by concerns such as hyper-vigilance, avoidance, fear and intrusion, which are also characteristics of S/PTS.

RELATIONSHIPS OF CONCEPTS

Although BO is closely related to CF, the underlying mechanism most likely differs. BO is believed to be related to occupational factors, such as workload, autonomy, and rewarding, rather than personal relationships[32]. In contrast, an inability to engage, or enter into a caring relationship, is considered to be the core of CF[33]. What becomes more and more apparent is the level of complexity in the various concepts and mutual relationships. Besides the already mentioned interchangeably usage of CF and STS, a significant positive correlation between CF and BO was found in some studies, suggesting an overlay in one or more of the components of these phenomena[20, 22]. According to Elkonin and Lizelle, BO illustrates the end result of traumatic stress in the professional life of the caregiver and could be an extreme case of CF[22]. Conversely, Sabo suggested BO as a pre-condition for CF[33], and Aycock proposed that CF replaces the outdated notion of BO in describing the phenomenon in oncology nurses[34]. This review explores all mentioned concepts because of the same range of causes, coping mechanisms, and consequences in the field of traumatization.

AIM OF THE STUDY

The main purpose of this review was to evaluate the literature on emotional distress among professionals in the ICU according the PRISMA method, with an emphasis on the prevalence of burnout and compassion fatigue. We enhanced some new knowledge in this field to assess the current literature precisely and compare the measuring instruments and the results of the studies. Furthermore, while the sometimes devastating personal and organizational consequences of BO and CF have been published previously, very few studies have addressed the effectiveness of preventive strategies. This review aims to provide a starting point for clinical practice guideline developers and summarizes interventions to prevent the negative consequences of emotional distress among healthcare professionals in the ICU. The following research questions have been addressed:

1. What is the prevalence of compassion fatigue and burnout among healthcare professionals in the ICU?
2. Which preventive strategies have been successfully applied to reduce emotional distress among ICU professionals?

METHODS

A systematic review of the scientific literature was conducted to obtain original articles for appraisal. Pre-determined search strategies were followed and quality criteria were applied as guidelines to conduct the review process[35]. The current study was performed in accordance with the PRISMA statement (PRISMA 2009 Checklist)[36]. This review study did not need ethical approval nor was individual consent needed.

SEARCH STRATEGY

A systematic search in the computerized databases of Embase, Medline OvidSP, Cinahl, Web-of-science, PsychINFO, PubMed publisher, Cochrane and Google Scholar has been performed. The following Medical Subject Headings (MeSH) were used: burnout, empathy and fatigue. This search was supplemented with compassion fatigue and secondary traumatic stress as free text words. The Boolean indicator 'AND' was used to select the studies applied to the ICU healthcare professionals. All terms were tailored to the thesaurus of each database, the complete search strategy is recorded in the protocol (Additional File S1). Local unpublished surveys, unpublished reports and academic theses were not included. All references were retrieved, organized and stored with EndNote X7.1 version 17.

ELIGIBILITY CRITERIA

In the first round, the references from each database were screened by the title and abstract for relevancy. We included studies that 1) dealt with the prevalence as described in the article or calculated from the presented data, or 2) described an intervention on BO, CF, VT or S/PTS. All studies were set within an ICU, Critical Care Unit, Neonatology Intensive Care Unit or Pediatric Intensive Care Unit, and were applicable to healthcare professionals i.e. nurses or physicians. We were particularly interested in effects of the interventions on the professional quality of life of the individual workers. We chose 1992 as the initial search year because the first article on CF in nurses was published that year[30], the search included original articles written in the English language all years through 30 June 2014. We excluded studies on coping with work stress and the causes and consequences of BO.

After the full text was read in the second selection round, the articles were limited to the prevalence presented as percentages or numbers of BO, CF, VT or S/PTS and intervention studies in which respondents are being pre- and post-tested or compared in two groups in different regimes. Finally, the included articles were manually checked for new references until no further studies were identified.

QUALITATIVE DATA EXTRACTION

A set of quality criteria was developed to assess the methodological soundness[27, 35], see Table 1. The total study quality has been computed as 12.5% for each positive scored criterion, at least six of eight criteria should be applicable. Three of the authors (MvM, MN and EK) independently extracted qualitative information from each article. The following information was determined: ´bibliographic information´ (e.g., first author, year of publication), ´aim of the study´, ´definition of concepts´, ´setting´ (e.g., general or academic hospital), ´population and sample size´ (e.g., nurses or physicians), ´method design´, ´measuring instrument, validation and reliability´, and ´prevalence´. Disagreements between the three reviewers were discussed until a consensus was reached.

Table 1. *Set of criteria used to appraise the study quality*

	Quality criterion	Yes/No
1	Clear research questions and objectives	
2	A definition of the measured concept(s)	
3	Valid and reliable measuring instrument(s)	
4	Method description in detail	
5	Information on the size and type of the target population	
6	Information on the number and characteristics of the subjects who agreed to participate	
7	Addressing missing values	
8	Appropriate statistical analysis	

RESULTS

The review process, which is illustrated in Figure 1, began with 2580 references retrieved from the electronic databases. Deleting duplicate references (*n*=1620) and a manual search (*n*=3) resulted in 136 relevant publications after the first selection round. Subsequently, the references only published as an abstract (*n*=39) or non English (*n*=30) were removed. A few studies were excluded because prevalence could not be calculated from the data[37-39] or effects of the intervention were not measured[17]. Finally, a sample of 30 eligible articles on the prevalence of emotional distress and 10 associated intervention studies were appraised as methodologically sound and included for extensive review[20, 22, 40-77]. The assessment of all articles which were read in full text, as indicated in additional file S2, had an excellent inter-rater agreement using Cohen´s kappa (*k*=0.912).

An overview of the included publications, with the study characteristics such as setting, sample size, sample characteristics and quality assessment, is provided in Table 2. Most of the studies were conducted in Europe and North-America (70%), nine studies were conducted in an academic or tertiary hospital setting (22.5%) and other study settings included small, large or a mix of hospital samples. The number of respondents varied between 25 and 3,052; in most studies female respondents were over-represented. The response rates varied between 24.8%[50] and 98.8%[77]. In Table 3 all the sample characteristics are summarized.

PREVALENCE

Studies on the prevalence of CF and S/PTS in the ICU were less frequent than studies of BO, as shown in Table 4, and only one study mentioned VT[22]. The Professional Quality of Care (ProQOL) questionnaire, which was used in some of the reviewed studies, was developed to measure both CF and BO[78]. Additionally, this questionnaire distinguishes also the positive effects of caring, referred to as compassion satisfaction. Over time, this tool has been validated in various healthcare work environments and has proven to be reliable and feasible for medical staff[27, 79]. According to the ProQOL-revisited V, two different studies showed 7.3%[20] and 40%[22] of the respondents who scored high on CF compared with 1.2% and 23%, respectively, who had severe BO. Two other studies, which were using the ProQOL, measured a 0% high risk for BO, as well as S/PTS, as stated by the authors[57, 76]. However, succeeding studies described the prevalence of S/PTS as 17%, using the Posttraumatic Diagnostic Scale[44], and 38.5% using the Davidson Trauma Scale[72]. Additionally, 24% of 230 full-time working ICU nurses in a university hospital experienced some symptoms of S/PTS, such as nightmares, according to results from the Post Traumatic Stress Syndrome 10 Questions Inventory, compared to 14% in general nurses and 29% in the control group[60].

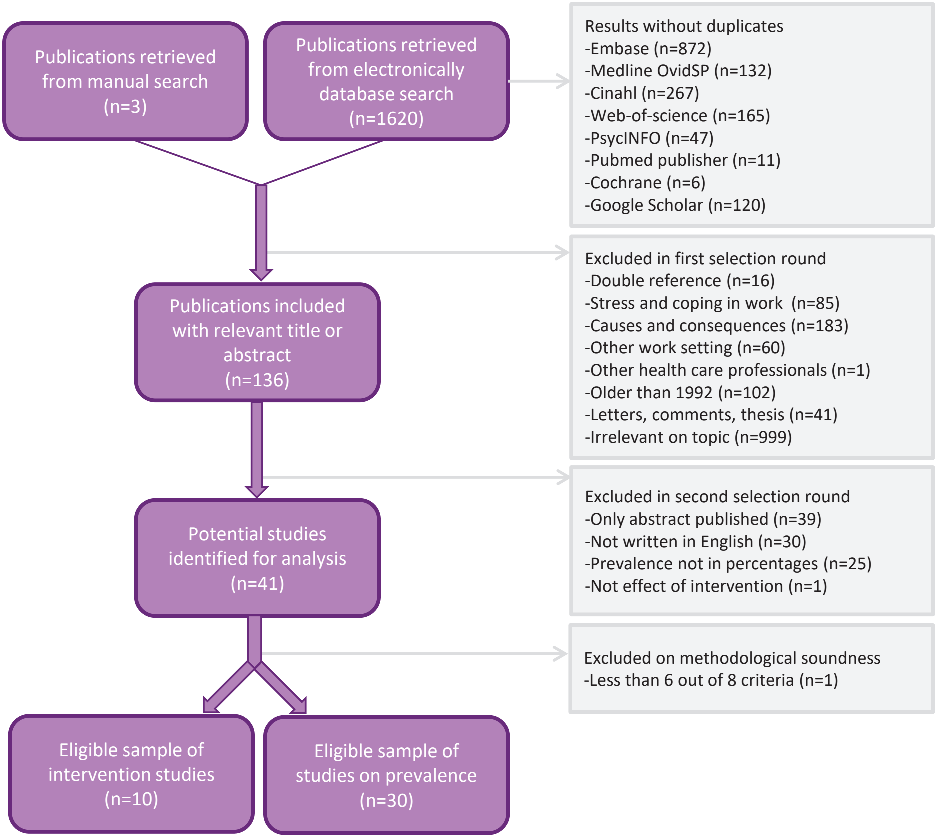

Figure 1. *An adapted PRISMA flowchart of the total review process on the prevalence of compassion fatigue and burnout among healthcare professionals in the intensive care unit.*

Table 2 *An overview of the included articles with the study characteristics*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
Ali, et al., 2011	5 ICUs in the United States	39 86.7%	Intensivist Female 24%; Mean age 41 years Comparison of a continuous staffing schedule in half month rotation, and an interrupted schedule with weekend cross-coverage by colleagues, on the level of burnout.	Prospective, cluster-randomized, alternating trial	75
Barbosa, et al., 2012	6 ICUs in Brazil	76	Physicians Female 55.22%; Mean age 43.9 years; mean length of time since graduation 19.4 years	Cross-sectional observational descriptive study	87.5
Bellieni, et al., 2012	NICUs in Italy	110 (84.6%)	Neonatologist Female 60.0%; Age 35-50 (78.2%); Years of service <5 (30%), 5-10 (33.6%), >15 (36.4%)	Cross-sectional study	100
Cho, et al., 2009	65 ICUs in Korea	1365 (93%)	Charge and staff Nurses Female 98.9%; Plan to leave 26.3%	Cross-sectional study	100
Czaja, et al., 2012	A tertiary-care PICU In the USA	173 (43%)	Nurses Female 93.0%; Mean age 35 years; Considering change in careers 31%	Cross-sectional study	100
Eagle, et al 2012	PICU in New Orleans	T_1 28 and T_2 22	Physicians and nurses Work experience modus 1-5 years (57%) Measuring the effect of an educational session and skills training of coping, grief and peer support on the level of burnout.	Pre- post design	87.5
Elkonin, et al., 2011	Three ICUs in Africa	30 (40%)	Nurses Female 93.33%; Mean age 38.7 years; Years of ICU experience 1-10 (63%), 11-20 (23.33%)	Quantitative exploratory descriptive study	87.5
Embriaco, et al., 2007	189 ICUs in France	978 (82.3%)	Physicians, fellows, interns or residents Female 28%; Mean age 40 years; Mean working hours per week 59 ± 12	Observational survey study	100

Table 2 *An overview of the included articles with the study characteristics (continued)*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
Galvan, et al., 2012	All PICUs of Argentina	162 (60%)	Physicians with a workload equal or more than 24 hours/week Female 57%; Mean age 42 years; No plans to continue with PICU activity 31%	Observational cross-sectional study	100
Garland, et al., 2012	2 ICUs in the United States	37 (94.9%)	Intensivist Female 8%; Age 41-60; ICU training > 10 years ago 56% Comparison of a standard model, where one intensivist worked for 7 days, taking night call from home, and the shift work model, where one intensivist worked 7 day shifts, while other intensivist remained in the ICU at night, on the level of burnout.	Alternating cross-over design	87.5
Goetz, et al., 2012	1 ICU in Germany	86 (54.4%)	Nurses; ICU (n=57) and IMC (n=29) Female 76.7%; Age between 25 and 34 years (56.1%)	Cross-sectional study	100
Guntupalli, et al., 1996	ICUs in the USA	248 (24.8%)	Physicians Female 11.3%; Mean age 41.6 years, 47.3% indicated they would wind down critical care component in 9.9 ± 4.7 years	Cross-sectional study	87.5
Guntupalli, et al., 2014	ICU in Houston	213	Nurses (n=151) and Respiratory therapist (n=62) Female 72.2%	Cross-sectional study	75
Karanikola, et al., 2012	ICUs in 8 general hospitals in Greece.	152 (60.0%)	Nurses Female 78.8%; Mean age 31.8 years, Mean work experience in ICU 5.0 years	Descriptive correlational design	100
Lederer, et al., 2008	Five ICUs in Austria.	183 (59%)	Nurses (n=150) and physicians (n=33) Female 56.8%; Age 20-29 (28.4%), 30-39 (55.7%), >40 (15.8%), Years of employment <1-5 (41.0%), 5-10 (28.4%), >10 (30.6%)	Prospective cross-sectional study	100
Liu, K., et al., 2012	Adult general, specialty medical, surgical and ICU in China.	1104 (95.5%)	Nurses Female 97.8%; Mean age 28.55 years; Years of employment <5 (41.0%), 5-10 (28.4%), >10 (30.6%)	Cross-sectional study	87,5

Table 2 *An overview of the included articles with the study characteristics (continued)*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
Liu,Y., et al., 2013	12 CCUs in Shanghai.	215 (97.7%)	Nurses Female 98.6%; Age <30 (62.3%), 30-39 (34%), >40 (3.7%); Years of CCU experience <5 (57.2%), 5-9 (23.3%), >10 (19.6%)	Cross-sectional study	87.5
Loiselle, et al., 2011	ICU in Canada	T_1 44 and T_2 27 (45% and 28%)	Nurses Female 91.9%; Age modus 25-34 (62.2%) Measuring the effect of the Adler/Sheiner Programme (structural elements on information and support in Family Centered Care) on emotional distress.	Pre-experimental mixed design using quantitative and qualitative methods	87.5
Mason, et al., 2014	ICU in the United States	26 (77%)	Nurses Modus 21-30 years ICU experience (61.5%)	Non-experimental, descriptive, correlational design	87.5
Meadors, et al., 2008	PICU, NICU and PEDS in the United States	185	Nurses and other (e.g social worker) Female 96.8%; Mean age 35.3 years; Mean current position 7.4 years Measuring the effect of a 4 hours educational seminar dealing with compassion fatigue, management of stress and factors associates with grief, on personal stress.	Pre- post design	87.5
Meadors, et al., 2010	All PICUs and NICUs in the United States	167	Nurses (23), Physicians (21), Chaplains (22), Child life specialist (87) and other (8) Female 82.0 %; Average working experience in their unit 6-10 years	A correlational design	100
Mealer, et al., 2007	3 ICUs and 3 general wards in America	351 (47%)	Full-time nurses ICU (n=230) and general ward (n=121) Female 86.6; Mean age 37.6 years	Cross-sectional study	87.5

Table 2 *An overview of the included articles with the study characteristics (continued)*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
Mehrabi, et al., 2012	ICU in Iran	34 94.4%	Nurses Female 100%; Mean age 33.5 years Measuring the effect of an 8 weeks yoga class on stress coping strategies.	Quasi experimental pre-post design	75
Merlani, et al., 2011	74 of the 92 certified ICUs in Switzerland.	3052 (71%)	Nurses (n=2587) and physicians (n=465) Female76 %; Age <40 years (70%); Mean years of ICU experience 7.5	Prospective, multicenter, observational survey	100
Nooryan, et al 2011	ICU, CCU, PICU, psychiatry and burn wards in Armenia	106 70.7%	Physicians and nurses Mean age case group 33.2 and control group 31.6 years; Measuring the effect of a training programme dealing with emotional intelligence on situational and personality anxiety.	Cross interventional, pre- and post, case and control group design	87.5
Nooryan, et al 2012	ICU, CCU, PICU, psychiatry and burn wards in Iran	150	Physicians and nurses Mean age case group 38.8 and control group 39.7 years; Average work experience nurses 7.4 and physicians 4.4 years Measuring the effect of a training programme dealing with emotional intelligence on situational and personality anxiety.	Cross interventional, pre- and post, case and control group design	87.5
Poncet, et al., 2007	165 ICUs in France	2392 (95.8%)	Nurses Female 82.1%, Mean age 31 years, Mean months in ICU 40 (17 to 96)	Cross-sectional study	87.5
Quenot, et al., 2012	1 ICU in France	Period 1 n=53 (85%) and period 2 n=49 (79%)	Nurses (49 and 45) and physicians (4 and 4) Female 40% and 36% in respective, Mean age 27 and 26 years in respective, ICU experience > 5 years 63% and 65 % in respective	Longitudinal, monocentric, before-and-after interventional study	100
Raftopoulos, et al., 2012	ICU, general and emergency department in Cyprus	1482 (98.6%)	Nurses during the provision of a training program for upgrading from diploma to bachelor level Female 80.8%, Mean age 36.68 years, Mean working experience 14.53 years	Cross-sectional study	100

Table 2 *An overview of the included articles with the study characteristics (continued)*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
Raggio, et al., 2007	Two ICUs in Italy	50	Nurses (n=25) and physicians (n=25) Female 40.0% Mean age men 42.2 and woman 38.1 years	Observational study by administration of psychometric test	100
Rochefort, et al., 2010	9 NICUs Canada	339 (61.3%)	Registered nurses Female 98.5%, Mean age 39.4 years; Mean of NICU experience 12.4 years	Cross-sectional study	100
Saini, et al., 2011		25	Nurses Female 92.0%, Mean age 27.9 years; Mean of ICU experience 3.2 years	Cross-sectional mixed method design	75
Shehabi, et al., 2008	Australian ICUs	115 (36%)	Intensivists No demographic data	Cross-sectional study	87.5
Sluiter, et al., 2005	PICU in the Netherlands	50 and 36 55% overall	Physicians and nurses Mean age 41 years; Mean of PICU experience 11 years Measuring the effect of a structured multidisciplinary work shift evaluation on the level of burnout.	Prospective, repeated measurements design	87.5
Su, et al., 2007	The Veterans General Hospital in Taipei City, China	102	Nurses SARS regular (n=44), SARS ICU (n=26), neurology (n=15) and CCU (n=17) Female 100%; Mean age 29.8, 31.5, 25.4 and 32.7 years in respective	A prospective and periodic follow-up design study	87.5
Teixeira, et al., 2013	10 ICUs Portugal	300 (67%)	Physicians (n=82) and nurses (n=218) Female 65.0%; Mean age 32 years	Cross-sectional study	100
Verdon, et al., 2008	ICU in Switzerland	97 (91%)	Nurses (n = 86) and nurse-assistants (n=11) Female 61%	Cross-sectional study	100

Table 2 *An overview of the included articles with the study characteristics (continued)*

First author Year of publication	Setting	Sample size (response rate)	Sample characteristics	Design	Study quality (%)*
West, et al., 2014	ICU in the United States	74 study and 350 non-study 75% overall	Physicians Female 33.8% Measuring the effect of a 19 biweekly facilitated discussion groups incorporating elements of mindfulness, reflection, shared experience and small-group learning on the level of burnout.	Randomized clinical trial testing an intervention	100
Young, et al., 2011	CCU and IMC in the USA	70	Nurses ICU (n=45) and IMC (n=25) No demographic data	Exploratory descriptive study	75
Zhang, et al 2014	14 ICUs in Liaoning, China	426 (98.8%)	Nurses Female 88.5%; Median age 25 years	Cross-sectional observational study	100

ICU = Intensive care Unit, IMC = Inter Mediate Care, CCU = Corony Care Unit, PICU =Pediatric Intensive Care Unit, NICU = Neonatal Intensive Care Unit

* Study Quality is computed as 12.5% for each positive scored quality criterion (see Table 1), at least six of eight criteria should be applicable

Table 3. *The sample characteristics of the included studies*

Variable	Number (percentage)
Continent	
Europe	14 (35.0%)
North-America	14 (35.0%)
Asia	8 (20.0%)
South-America	2 (5.0%)
Australia	1 (2.5%)
Africa	1 (2.5%)
Hospital setting	
Academic or tertiary hospital setting	9 (22.5%)
Other	31 (77.5%)
Specialism	
Intensive care unit	25 (62.5%)
Corony care unit	2 (5.0%)
Neonatology intensive care unit and pediatric intensive care unit	8 (20.0%)
Comparison of different wards	5 (12.5%)
Occupation	
Nursing profession	20 (50.0%)
Medical profession	8 (20.0%)
Mix of nurses and physicians	11 (27.5%)
Other	1 (2.5%)
Range in number of respondents	25 to 3,052
Total respondents	14,770
Response rate	24.8% to 98.8%
Range in percentage of female respondents	8.0% to 100.0%

Table 4. *Amount of articles on the prevalence of emotional distress and prevalence range*

	Mentioned in studies n (%)	Prevalence range (%)
Burnout	28 (93.3%)	0.0 – 70.1
Emotional exhaustion		7.6 – 52.0
Depersonalization		3.3 – 41.8
Personal accomplishment		6.0 – 75.9
Compassion fatigue	5 (16.7%)	7.3 – 40.0
Secondary- and post-traumatic stress	6 (20.0%)	0.0 – 38.5
Vicarious trauma or stress	1 (3.3%)	

BO is mostly assessed with the Maslach Burnout Inventory (MBI), according to some authors as the standard tool for measuring the severity of BO[2, 41, 66]. The MBI is a highly reliable and validated 22-item self-report questionnaire that evaluates the three domains of BO in independent subscales: emotional exhaustion, depersonalization and personal accomplishment. The MBI was predominately used (*n*=22, 70.0%), including the French (*n*=4), the Portuguese (*n*=2), the Chinese (*n*=2), the Korean (*n*=1) and the German (*n*=1) validated versions, in addition to the original English version.

The reported prevalence rate of BO in the ICU, measured with the MBI, varied from 14.0%, after a preventive intervention[65], to 70.1% when BO was defined as a high score on only one subscale[41]. The latter study also stated that the prevalence would be 17.7% if BO had been defined as a high score on the combined subscales. Similarly, Czaja *et al*. reported a prevalence rate of 68.0% with BO defined as a high score on any BO symptom, and 45% for the emotional exhaustion subscale[44]. Some other studies defined a high risk for BO by a cut-off score in the emotional exhaustion subscale, leading to estimates of prevalence varying from 25.0% to 51.9%[50, 51, 55, 67, 70]; four studies defined BO by a total MBI score of > -9 and reported the prevalence in the range of 28.0% to 46.5%[46, 61, 64, 74].

One study presented a significantly lower prevalence of BO in ICU healthcare professionals (*n*=121); 14.5% in the ICU compared to 21.9% in the oncology department (*n*=82), 17.5% in the operating theatre (*n*=88), 17.2% in the surgical department (*n*=134), and 12.4% in the medical department (*n*=109)[66]. No difference for the Neonatology Intensive Care Unit or Pediatric Intensive Care Unit, with the prevalence ranging from 1.2%[20] to 41%[47], was found compared to the adult ICU, with the prevalence ranging from 16%[77] to 46.5%[46], measured with the MBI. Correspondingly, no clustering of prevalence rates was identified for specific hospital settings (i.e., an academic or regional hospital), professional role (i.e., doctors or nurses), or number of respondents in the study group.

A summary of the diverse measurement instruments, cut-off scores and reported prevalence, are shown in Table 5.

The included studies reported a broad range of variables related to emotional distress, see Table 6. Work environment[22, 46, 68, 74], professional role[61, 67] and conflicts[46, 64] were significantly and positively related to the measured phenomenon. However, some studies stated opposite results. Most confusing variable was the female sex, with an increasing[46, 66] versus a decreasing[61] effect, and no significantly measured influence[42, 50, 52, 64] on emotional distress.

Table 5 *A summary of the diverse measuring instruments, cut-off scores and found prevalences*

Concept*	Measuring instrument	Applied in	Prevalence of high risk
CF	Professional Quality of Care – Revision IV, CF subscale CF > 17 high, 8-17 average and <8 low risk	Elkonin 2011 Meadors 2010	40.0% 7.3%
S/PTS	Professional Quality of Care – Revision V, CF subscale BO >56 high, 55-43 moderate and < 42 low risk	Young 2011 Mason 2014	0.0% 0.0%
	Posttraumatic Diagnostic Scale	Czaja 2012	17.0%
	Post Traumatic Stress Syndrome 10 Questions Inventory	Mealer 2007	24.0%
	Davidson Trauma Scale	Su 2007	38.5%
BO	Professional Quality of Care – Revision IV, BO subscale BO >27 high, 18-27 moderate and < 18 low risk	Elkonin 2011 Meadors 2010	23.0% 1.2%
	Professional Quality of Care – Revision V, BO subscale BO >56 high, 55-44 moderate and < 43 low risk	Young 2011 Mason 2014	0.0% 0.0%
	Maslach Burnout Inventory with three subscales; EE**(9 items), DP**(5 items) and PA**(8 items)		
	A high score on EE subscale EE ≥ 27 high, 19-26 moderate and ≤ 19 low score	Cho 2009 Liu 2012	53.0% 37.3%
	A high score on EE, cut-off score not defined	Rochefort 2010	35.7%
	A high score in one subscale EE ≥ 27 high, 19-26 moderate and ≤ 19 low score, DP ≥ 12 high, 6-11 moderate and < 6 low score, PA 0-33 high, 34-39 moderate, and ≥ 40 low score	Barbosa 2012 Galvan 2012	70.1% 41.0%
	A high score in one subscale EE > 24, DP > 9 or PA < 29	Raggio2007	EE 32.0%
	A high score in one subscale EE ≥ 27, DP ≥ 10 or PA ≤ 33	Liu 2013	EE 51.9%
	A high score in one subscale or a total score > -9 EE > 30, DP >12 or PA < 33	Quenot 2012	28.0% before 14.0% after
	A high score on EE and DP EE ≥ 30 high, 18-29 moderate and ≤ 17 low score, DP ≥ 10 high, 6-9 moderate and ≤ 6 low score, PA 0-33 high, 34-39 moderate, and ≥ 40 low score	Raftopoulos 2012	14.5%
	A high score in two of the three subscales EE ≥ 25 high, 15-24 moderate and ≤ 14 low score, DP ≥ 190 high, 4-9 moderate and ≤ 3 low score, PA 0-32 high, 33-39 moderate, and ≥ 40 low score	Teixeira 2013	31.0%
	A high score on EE and DP with a low score on PA subscales EE ≥ 27 high, 17-26 moderate and ≤ 16 low score, DP ≥ 14 high, 9-13 moderate and ≤ 8 low score, PA 0-30 high, 31-36 moderate, and ≥ 37 low score	Guntupalli 2014	EE 25.0%
	A high score on EE and DP with a low score on PA subscales EE ≥ 30 high, 18-29 moderate and ≤ 17 low score, DP ≥ 10 high, 6-9 moderate and < 6 low score, PA 0-33 high, 34-39 moderate, and ≥ 40 low score	Karanikola 2012	25.0%

Table 5 *A summary of the diverse measuring instruments, cut-off scores and found prevalences (continued)*

Concept[*]	Measuring instrument	Applied in	Prevalence of high risk
	A high score on EE and DP with a low score on PA subscales EE > 31 high, 21-30 moderate and <20 low score, DP > 11 high, 6-10 moderate and < 5 low score, PA 0-35 high, 36-41 moderate, and > 42 low score	Guntupalli 1996 Zhang 2014	EE 29.0% 16.0%
	A moderate to high score one subscale EE ≥ 17, DP ≥ 7 and PA ≤ 39	Czaja	68.0%
	A total MBI score > -9	Embriaco 2007	46.5%
		Merlani 2011	28.0%
		Poncet 2007	32.8%
		Verdon 2008	28.0%
	High level not defined	Shehabi 2008	EE 42.0%
	Maslach Burnout Inventory, with four subscales; EE (9 items), DP (5 items), PA (7 items) and consternation (4 items)	Lederer 2008	34.4%
	Link Burnout Questionnaire	Bellieni 2012	30.0%
	The Arbeisbezogene Verhaltens- und Erlebensmuster (Burnout pattern)	Goetz 2012	17.7%

[*] CF = Compassion fatigue, S/PTS = Secondary- and post-traumatic stress, BO = Burnout

[**] EE = Emotional exhaustion, DP = Depersonalization, PA = Personal accomplishment

PREVENTIVE STRATEGIES

A wide range of intervention strategies to reduce emotional distress among ICU professionals emerge from the recent literature, see Table 7. Ten studies measured the effect of an intervention, such as different intensivist work schedules[40, 48], educational programs on emotional distress[45, 58], improving elements of family-centered care and communication skills[56, 65, 71], strategies regarding personality and coping[62, 63], and relaxation exercises[59, 75] such as yoga and mindfulness. In addition, seven of the included studies suggested preventive strategies, varying from improving the work environment[49, 55, 68], focussing more on social support and individual coping strategies[54], changing team composition to include a greater number of women[61], developing teambuilding and periodic job rotation[42], and a mix of all these elements[67].

According to Quenot and colleagues [65], the implementation of a set of active, intensive communication strategies regarding end-of-life care in the ICU has been associated with significantly lower rates of BO after the intervention. These strategies comprised elements in the organization, (i.e., the introduction of unrestricted visiting hours and the availability of a staff psychologist for consultation on demand), communication, (i.e., daily meetings of the caregiving team with the patient and/or their family and the discussion of palliative care options), ethics, (i.e., a special section in every patient´s medical record or ethical rounds), and stress debriefings and conflict prevention. Reductions of almost 50% and

Table 6 *Relationship of a variable with emotional distress, pro and con*

Variable	Pro: significantly related to emotional distress	Con: significantly not related to emotional distress
High workload	Embriaco 2007 Poncet 2007	Barbosa 2012
Short work experience	Bellieni 2012 Liu 2012 Zhang 2014	Karakinola 2012
Work environment	Elkonin 2011 Embriaco 2007 Verdon 2008 Rochefort 2010	
Nurse/patient ratio	Cho 2009	
Professional role (nurse-doctor)	Raggio 2007 (nurse) Merlani 2001 (nurse ass)	
End-of-life care	Poncet 2007	Czaja 2012
Mortality rate	Merlanie 2011	Embriaco 2007
Demographic variables	Poncet 2007 (age) Raftopoulos 2012 (age) Bellieni 2012 (age) Merlanie 2011 (age) Liu 2012 (age)	Czaja 2012 Karakinola 2012 Lederer 2008 Guntupalli 1996 (age) Guntupalli 2014 (age)
Having children	Bellieni 2012	
Female sex	Embriaco 2007 (increased) Raggio 2007 (increased EE) Merlani 2011 (decreased) Raftopoulos 2012 (increased)	Poncet 2007 Bellieni 2012 Guntupalli 1996 Karakinola 2012 Guntupalli 2014
Conflicts	Embriaco 2007 Poncet 2007	
Number of ICU beds		Guntupalli 1996

60% were reported in the relative risk of BO and depression, respectively, after some of these interventions. Another promising preventive strategy is mindfulness training. West and colleagues[80] measured a positive effect of 19 biweekly discussion groups, which included elements of mindfulness, reflection and shared experience, on physician well-being. Furthermore, Lederer and colleagues[53] mentioned a positive influence on the prevalence of a fully developed BO due to the support of a facilitator. An external psychologist provided support whenever needed in two of the five ICUs included in this study; more specifically, individuals with a high risk of BO were less likely to consult the psychologist. In contrast, peer support had no significant effect on BO[45]. Finally, educational seminars on CF increased both awareness and resources for the prevention of emotional distress in the future[58]. The participants in that study felt significantly less tense and reported being more calm and peaceful after the intervention.

Table 7. *Summary of the interventions on emotional distress*

Type of intervention		Description of intervention	Study
Organization-directed interventions			
		Work schedules of intensivist	Ali *et al.* 2011
			Garland *et al.* 2012
		Improving work environment	Goets *et al.* 2012
			Liu *et al.* 2013
			Rochefort *et al.* 2010
		Change team composition	Merlani *et al.* 2011
		Teambuilding and job rotation	Bellieni *et al.* 2012
Person-directed interventions			
	Practical		
		Educational programs, seminars	Eagle *et al.* 2012
			Meadors, *et al* 2008
			West *et al.* 2014
		Improve communication skills	Loiselle *et al.* 2012
			Quenot *et al.* 2012
			Sluiter *et al.* 2005
		Relaxation exercises	West *et al.* 2014
			Mehrabi *et al*. 2012
		Mindfulness	West *et al.* 2014
	Personal		
		Personality and coping	Nooryan *et al.* 2011
			Nooryan *et al.* 2012
		Social support and individual coping	Liu *et al.* 2012
		Counselling	Lederer *et al.* 2008

DISCUSSION

This comprehensive systematic review identified thirty studies that investigated the prevalence of BO, CF, VT or S/PTS among healthcare professionals working in ICUs. It is clear that working at an ICU correlates with a substantial risk of emotional distress, all of the included studies underscored the stressful environment in the ICU. From this perspective, it is even more strikingly to find contradictory results with lower percentages or means on BO, CF or S/PTS in the ICU compared to other wards[20, 44 66, 72], which is also esthablished in supplementary studies[79, 81]. This anomaly might be explained through unique personal qualities, such as resilience or emotional intelligence, and environmental factors, such as training, mental support, organizational culture or the differences between cultures and countries.

Although the risk of emotional distress has been recognized in this review, the true magnitude of the explored phenomena remains unclear for several reasons. First, the definitions of the types of distress have been used interchangeably across studies; more specifically, CF has been measured with the same subscale of the ProQOL as S/PTS[20, 22, 76]. One of the key elements in the ProQOL model is the empathic ability of the caregivers and the therapeutic relationship with clients. However, a profound analysis has shown that STS and CF really differ regarding their content validity[82]. In contrast to STS, which refers to symptoms related to a process of indirect traumatization, CF is stressing the diminished sympathy to someone´s suffering, and the lessened desire to help in a broad context through the meaning of compassion[20, 83]. The loss of this compassionate energy is also mentioned in a conceptual analysis of CF, in which is stated that the synonymous use of CF with STS is far removed from Joinson´s original meaning[28]. In addition, Sabo suggested that the binary dimension of CF in the ProQOL (i.e., you either have it or not), is not congruent human nature, which is characterized by gradual responses similar to slightly, moderately or severely. More fundamentally, the model also failed to clearly conceptualize empathy, thus making it difficult to understand the background of CF[33]. Therefore, Coetzee and Klopper[28p237] distinguished CF again as a loss of the nurturing ability that is vital to compassionate care. The essential issue of the caring professionals is to deliver themselves; being present and empathic. If this process stagnates, the emotional price of caring can become a burden in personal life, manifested by emotional distress such as CF.

The Secondary Traumatic Stress Scale is the only instrument that is designed to assess the symptoms of STS by a 17-item Likert scale[18], however, this questionnaire has not been used among ICU professionals. The ProQOL has been used in many healthcare settings, is profoundly tested, and marked as a valid and reliable instrument[84]. However, the STS/CF subscale is fundamentally based on the concept of STS, with items explicitly pointing at traumatic stress reactions such as a startle reflex, intrusive and frightening thoughts, re-experiencing situations, and avoidance. To sum up, there is no measurement instrument to assess CF in the meaning of a lost ability to care.

Second, the reported prevalence of emotional distress differed based on the applied measurement instruments. The ProQOL seemed incapable of detecting a risk for severe burnout, which is illustrated with prevalence rates around zero[20, 57, 76], in comparison, the prevalence with the MBI ranged from 14.0% up to 70.1%. Meadors and colleagues provided a valuable and comprehensive overview of the mental trauma literature in the non-adult ICUs, and found a low prevalence of CF (7.3%) and BO (1.2%) with the ProQOL[20]. They suggested that drop out by the already over-exhausted individuals participating in the study to explain their results; this reason of self-selection bias may have a substantial role in all of the studies on this topic. In contrast to these results, another study among 162 intensivists working at a paediatric intensive care in Argentina described a 41% BO prevalence measured by the MBI[47], and a study of 173 nurses working at a tertiary children´s hospital found that 68% of respondents had at least one BO symptom[44]. In short, the MBI is characterized by a more discriminative power than the ProQOL. Nevertheless, the highest prevalence of CF, defined by the authors as such and measured by the ProQOL, was 40.0% and reported in a study of 30 registered nurses in two ICUs in South Africa[22]; a 23% prevalence of BO was found in the same study. It was stated that there was a noteworthy shortage of ICU nurses in that country, and most of the participants were not trained for nursing critically ill patients. Thus, the work environment might have been particularly stressful due to a lack of appropriate nursing skills and ICU knowledge. The highest prevalence of S/PTS, 38.5%, was measured with the Davidson Trauma Scale in a study of 26 ICU-nurses in a SARS unit in Taiwan; this group was compared to 17 critical care and 15 neurology nurses working in two non-SARS units[72]. However, a study using the ProQOL in an academic hospital with 68 nurses in the United States did not find a severe risk for S/PTS[76]. This difference might be explained partially by the extreme working conditions associated with the SARS outbreak and the difference in measuring instruments. Although the last two studies addressed relevant issues, it may be difficult to identify changeable determinants in the work setting to prevent the consequences of emotional distress.

Third, the outcome scales or cut-off points used to indicate the prevalence of burnout measured with the MBI have a wide range, as presented in Table 5. A great deal of work has been done with the MBI, both conceptualizing and measuring BO in a valid and reliable way[85]. However, it should be used uniformly, with an evaluation of all three subscales together. As shown, Czaja and colleagues[44] used a moderate to high score in one subscale with emotional exhaustion above 17 to establish the prevalence of BO, with 68% as a result. In contrast, Zhang and colleagues[77] found a prevalence of 16%, with BO defined a high score on emotional exhaustion (above 31), depersonalization (above 11), and a low score on personal accomplishment (above 42). Schaufeli and Van Dierendonk (1995) stated that caution is needed when cut-off points are used to classify the severity of BO, which could also be nation specific[86]. All in all, the prevalence might be affected by the used measuring instrument as well as the different cut-off points and subscales. Finally, the variety of research variables, i.e., whether the variables are significantly related to emotional distress in the ICU, perpetuates the lack of clarity.

Therefore, the true prevalence of BO, CF, S/PTS and VT in ICU-professionals remains open for discussion, which might emphasize the need for a ´gold standard´ which will be used in all future research. To begin, the concepts specifically related to the ICU healthcare environment have to be defined by a wide-ranging consensus committee, e.g., by conducting a Delphi study. Subsequently, more agreement is needed to address the discrepancies in measurement issues, and to better investigate emotional distress with a large international quantitative observational multicenter study. Only one such study has been published to date[24], from which an impressive amount of data on burnout were already gathered in 1994. The results were reported not sooner than 2005 because they formed part of a larger study on the organizational influence on the effectiveness and efficiency of ICUs. This study is still of importance because of the focus on fundamental psychological processes, such as emotional contagion in burnout, and the relationships between variables. However, the prevalence of BO among ICU professionals might change over time and a broader view on emotional distress would be preferable.

It is highly recommended to further investigate and compare the consequences of emotional distress in the ICU in a valid comparative manner to indicate the relevance of the problem. However, cross-sectional study designs cannot reveal causal relationships between contributing variables, individual coping mechanisms or organizational preventive strategies to emotional distress. A prospective longitudinal study design would be recommended to bridge this gap. In addition, a pitfall of these approaches is the focus on questionnaires and scoring systems because of the reliance on a cut-off points intended to ´establish´ a phenomenon and socially desirable or exaggerated answers of the respondents. Besides quantitative research, in-depth semi-structured interviews are required to stress the deeper driving forces in an individual to provide more insights into the thoughts and behaviors in reaction to a stressful work environment.

To develop adequate preventive strategies for emotional distress, it is essential to know the individual´s incentive to choose a caring profession in addition to ones unconsciously chosen coping strategies to deal with the stressful work settings. Some encouraging preventive strategies to combat emotional distress in ICU professionals have been developed recently[53, 65, 75]. A review study of intervention programs for BO found that most of the person-directed interventions, such as cognitive behavioural training, counselling, and relaxation exercises, led to a significant reduction in BO lasting for at least 6 months after the intervention. Although the organization-directed interventions, such as primary nursing, management skills, and social support, were classified by this study as having less study evidence, they were also significantly effective[87]. Combined person- and organization-directed multifaceted interventions with refresher courses reported the best results. At this point, it might be interesting to investigate the effect of a combination of relevant and changeable determinants, such as communication skills, educational sessions in stress management, and mindfulness training for ICU professionals.

The improvement of communications skills might support the interaction with patients and relatives, and reduce conflicts with colleagues or management[7, 64]. An intensive three-day training for oncologists resulted in the integration of many of the key communication skills in their daily practice, for up to 15 months post-course[88]. Furthermore, significantly more expressions of empathy were reported in this study and successively interpreted as an increase of self-efficacy. This, in turn, could enhance compassionate care and increase personal well-being. Educational sessions in stress management might expand the awareness of emotional distress and methods to apply in response to this distress[45, 58, 62]. The awareness of stressful situations and knowing the vital signs of BO or CF, are the first steps in maintaining a healthy work life. In a lack of awareness the ongoing devastating process may continue until a total mental or physical breakdown. Personality[39] and emotional intelligence[62], especially the meta-cognitive capacity of the individual, might provide some clues for the energy in trying to change things in the ´here and now at the bedside´ within their level of responsibility. Mindful meditation might be a source of strength for preventing the hidden effects of stress, and gives the individual healthcare professional the ability to pay attention in the present moment and respond wisely, instead of reacting later with negative feelings[89, 90]. Balancing human intimacy and professional distance, and remaining appropriately present and compassionate, may be recognized as a valuable personal ability. This ability could be taught, and effectively enhanced, through self-awareness and mindful meditation which is potentially useful in promoting well-being and stress management in healthcare professionals[89-91].

STRENGTHS AND METHODOLOGICAL LIMITATIONS

The main strengths of this review were the systematic approach and reproducible method. It was based on explicit search strategies, eight applicable databases and unambiguous criteria for selecting suitable and high-quality studies. Because randomized controlled trials or rigorous observational studies are rare in this area, a meta-analysis could not be performed[35].

Although measures in the included studies have been taken to prevent social desirability (e.g. guaranteed anonymity), the internal validity might be threatened due to self-report questionnaires. Furthermore, the Hawthorne effect could have biased the results of the reported studies. Some of these studies tried to limit this bias by explicitly not mentioning the measured concept to the respondents[44, 60]. Moreover, the response rates in the very low ends, e.g. selection bias, and high ends, e.g. mandatory participation, could be questioned.

This literature review aimed to be highly sensitive in order to be as comprehensive as possible, and therefore had a lower precision. Thus, many irrelevant references were included in the beginning of the review process. This could lead to an erroneous exclusion of a relevant reference. Further, the search was limited to original articles, which suggests the potential to miss information on the topic. However, because of the focus on the prevalence rather than the causes or consequences, this approach was a justified decision. The restriction in language could also have caused an incomplete overview of the relevant studies. As in every review, a publication bias may have occurred. Positive results are more likely to be submitted and published in scientific journals than inconclusive or negative results, and insignificant outcomes will probably not be mentioned in an abstract[92, 93], accordingly putting too much emphasis on the significant mental effects of stress in the ICU. Moreover, negative or inconclusive results remain unpublished; consequently, there might be an over reported prevalence of burnout or compassion fatigue.

CONCLUSIONS

Working in the ICU environment is an emotionally charged challenge, and the emotional price of caring might become a burden for professionals' personal lives, possibly manifested in compassion fatigue or burnout. This study adds some new viewpoints in the lack of common understanding of the theoretical constructs, which is reflected by the variously defined (and interpreted) negative outcomes of providing care in the ICU setting among the included studies. The true magnitude of the emotional distress in the ICU healthcare professionals remains unclear due to a lack of unity in measurements as well. This study also suggests that policymakers should introduce interventions to prevent the negative consequences of emotional distress. A longitudinal experimental study is needed to examine the emotional distress among ICU professionals in relation to their communication skills, educational sessions on stress management, and mindfulness. Only in this way evidence-based best practice interventions can be formulated.

ACKNOWLEDGEMENTS

We would like to thank W.M. Bramer, biomedical information specialist Erasmus MC, for his assistance in the data-gathering process.

REFERENCES

1. Schaufeli WB, Keijsers GJ, Reis Miranda D. Burnout, technology use, and ICU-performance. In: Organizational risk factors for job stress. Sauter SL, Murphy LR eds. APA Books, Washington. 1995 pp 259-271.
2. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. Current Opininions in Critical Care 2007;13:482-488.
3. Todaro-Franceschi V. Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life. Dimensions in Critical Care Nursing 2013;32:184-190.
4. Teixeira C, Ribeiro O, Fonseca AM, Carvalho AS. Ethical decision making in intensive care units: a burnout risk factor? Results from a multicentre study conducted with physicians and nurses. Journal of Medical Ethics 2013;40(2):97-103.
5. Todaro-Franceschi V. Compassion fatigue and burnout in nursing. Enhancing professional quality of life. Springer, New York 2013. ISBN 9780826109774.
6. Kompanje EJ, Piers RD, Benoit DD. Causes and consequences of disproportionate care in intensive care medicine. Current Opinion in Critical Care 2013;19:630-635.
7. Curtis JR, Sprung CL, Azoulay E. The importance of word choice in the care of critically ill patients and their families. Intensive Care Medicine 2014;40:606-608.
8. Epp K. Burnout in critical care nurses: a literature review. Dynamics 2012;23:25-31.
9. Curtis JR, Ciechanowski PS, Downey L, et al. Development and evaluation of an interprofessional communication intervention to improve family outcomes in the ICU. Contemporary Clinical Trials 2012;33:1245-1254.
10. De Villers MJ, DeVon HA. Moral distress and avoidance behavior in nurses working in critical care and noncritical care units. Nursing Ethics 2013;20:589-603.
11. Böckerman P, Ilmakunnas P. Interaction of working conditions, job satisfaction, and sickness absences: evidence from a representative sample of employees. Social Science Medicine 2008;67:520-528.
12. Donchin Y, Seagull FJ. The hostile environment of the intensive care unit Review. Current Opinion in Critical Care 2002;8:316-320.
13. Crickmore R. A review of stress in the intensive care unit. Intensive Care Nursing 1987;3:19-27.
14. Grzeskowiak M, Bartkowska-Sniatkowska A, Rosada-Kurasinska J, Kielbasiewicz-Drozdowska I, Janicki PK. Stress assessment by anaesthesiologists and nurses working in paediatric intensive care units. East Journal Medicine 2011;17:59-66.
15. Hays MA, All AC, Mannahan C, Cuaderes E, Wallace D. Reported stressors and ways of coping utilized by intensive care unit nurses. Dimensions in Critical Care Nursing 2006;25:185-193.
16. Marcial L, Brazina M, Diaz A, Jaramillo C, Marentes G, Mazmanian N. A brief article: is this the cost of caring? A student perspective on compassion fatigue. Dimensions in Critical Care Nursing 2013;32:18-21.
17. Caine RM, Ter-Bagdasarian L. Early identification and management of critical incident stress. Critical Care Nursing 2003;23:59-65.
18. Beck CT. Secondary traumatic stress in nurses: a systematic review. Archives of psychiatric nurs 2011;25:1-10.
19. Figley CR. Trauma and its wake: Routledge. New York 2013. ISBN 9781134843855.
20. Meadors P, Lamson A, Swanson M, White M, Sira N. Secondary traumatization in pediatric healthcare providers: Compassion fatigue, burnout, and secondary traumatic stress. Omega Journal of Death and Dying 2010,60:103-128.
21. National Center for Post Traumatic Stress Disorder. For Professionals; PTSD overview and Assessment. Retrieved on 25-04-2014 from http://www.ptsd.va.gov/

22. Elkonin D, Lizelle. Positive and negative emotional responses to work-related trauma of intensive care nurses in private health care facilities. Health SA Gesondheid 2011;16:1-8.
23. Schaufeli W, Bakker A. [De psychologie van arbeid en gezondheid. Derde geheel herziene druk ed.] The psychology of labor and health, 3th ed. Bohn Stafleu van Loghum, Houten 2013. ISBN 9789031350698.
24. Bakker AB, Le Blanc PM, Schaufeli WB. Burnout contagion among intensive care nurses. Journal of Advanced Nursing 2005;51:276-287
25. Kaschka WP, Korczak D, Broich K. Burnout: A fashionable diagnosis. Deutsches Ärzteblatt International 2011;108:781.
26. Freudenberger H. Burnout: The Cost of High Achievement. Anchor Press, New York 1980.
27. Nimmo A, Huggard P. A Systematic Review of the Measurement of Compassion fatigue, Vicarious Trauma, and Secondary Traumatic Stress in Physicians. Australas J Disaster Trauma Stud 2013;1:37-44.
28. Coetzee SK, Klopper HC. Compassion fatigue within nursing practice: A concept analysis. Nursing and Health Science 2010;12:235-243.
29. Figley CR. Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized. Routledge, New York 1995. ISBN 9780876307595
30. Joinson C. Coping with compassion fatigue. Nursing 1992;22:116,118-119.
31. Jenkins B, Warren NA. Concept analysis: Compassion fatigue and effects upon critical care nurses. Critical Care Nursing Quarterly 2012;35:388-395.
32. Whitebird RR, Asche SE, Thompson GL, Rossom R, Heinrich R. Stress, Burnout, Compassion Fatigue, and Mental Health in Hospice Workers in Minnesota. Journal of Palliative Medicine 2013;16:1534-1539.
33. Sabo B. Reflecting on the concept of compassion fatigue. Online Journal Issues of Nursing 2011 16: 1.
34. Aycock N, Boyle D. Interventions to manage compassion fatigue in oncology nursing. Clinical Journal of Oncology Nursing 2009;13:183-191.
35. Fink A. Conducting research literature reviews: from the Internet to paper. 3rd ed. SAGE Publications Inc, Thousand Oaks 2010. ISBN 9781412971898.
36. Liberati et al. The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration. PloS Medicine 2009;6:e10000100..
37. Losa Iglesias ME, Becerro de Bengoa Vallejo R. Prevalence and relationship between burnout, job satisfaction, stress, and clinical manifestations in spanish critical care nurses. Dimensions in Critical Care Nursing 2013,32:130-137.
38. Klopper HC, Coetzee SK, Pretorius R, Bester P. Practice environment, job satisfaction and burnout of critical care nurses in South Africa. Journal of Nurse Management 2012;20:685-695.
39. Myhren H, Ekeberg O, Stokland O. Job Satisfaction and Burnout among Intensive Care Unit Nurses and Physicians. Critical Care Research Practice 2013:786176.
40. Ali NA, Hammersley J, Hoffmann SP, et al. Continuity of care in intensive care units: a cluster-randomized trial of intensivist staffing. American Journal of Respiratory and Critical Care Medicine 2011;184:803-808.
41. Barbosa FT, Leao BA, Tavares GMS, dos Santos JGRP. Burnout syndrome and weekly workload of on-call physicians: Cross-sectional study. Sao Paulo Med J 2012;130:282-288.
42. Bellieni CV, Righetti P, Ciampa R, Lacoponi F, Coviello C, Buonocore G. Assessing burnout among neonatologists. J Matern -Fetal Neonatal Med 2012;25:2130-2134.
43. Cho S, June KJ, Kim YM, et al. Nurse staffing, quality of nursing care and nurse job outcomes in intensive care units. Journal Clinical Nursing 2009;18:1729-1737.

44. Czaja AS, Moss M, Mealer M. Symptoms of Posttraumatic Stress Disorder Among Pediatric Acute Care Nurses. Journal of Pediatric Nursing 2012;27:357-365.
45. Eagle S, Creel A, Alexandrov A. The effect of facilitated peer support sessions on burnout and grief management among health care providers in pediatric intensive care units: A pilot study. Journal of Palliative Medicine 2012;15:1178-1180.
46. Embriaco N, Azoulay E, Barrau K, et al. High level of burnout in intensivists: prevalence and associated factors. American Journal of Respiratory and Critical Care Medicine 2007;175:686-692.
47. Galvan ME, Vassallo JC, Rodriguez SP, et al. Physician's burnout in pediatric intensive care units from Argentina. Arch Argent Pediatrics 2012;110:466-473.
48. Garland A, Roberts D, Graff L. Twenty-four–Hour Intensivist Presence: A Pilot Study of Effects on Intensive Care Unit Patients, Families, Doctors, and Nurses. American Journal of Respiratory and Critical Care Medicine 2012;185:738-743.
49. Goetz K, Beutel S, Mueller G, Trierweiler-Hauke B, Mahler C. Work-related behaviour and experience patterns of nurses. International Nursing Review 2012;59:88-93.
50. Guntupalli K, Fromm Jr RE. Burnout in the internist-intensivist. Intensive Care Medicine 1996 22: 625-630.
51. Guntupalli KK, Wachtel S, Mallampalli A, Surani S. Burnout in the intensive care unit professionals. Indian Journal of Critical Care Medicine 2014;18:139-143.
52. Karanikola MN, Papathanassoglou ED, Mpouzika M, Lemonidou C. Burnout syndrome indices in Greek intensive care nursing personnel. Dimensions in Critical Care Nursing 2012;31:94-101.
53. Lederer W, Kinzl JF, Traweger C, Dosch J, Sumann G. Fully developed burnout and burnout risk in intensive care personnel at a university hospital. Anaesth Intensive Care 2008;36:208-213.
54. Liu K, You L-M, Chen S-X, et al. The relationship between hospital work environment and nurse outcomes in Guangdong, China: a nurse questionnaire survey. Journal of Clinical Nursing 2012;21:1476-1485.
55. Liu Y, While A, Li SJ, Ye WQ. Job satisfaction and work related variables in Chinese cardiac critical care nurses. Journal of Nurse Management 2013;Doi: 10.1111/jonm.12161
56. Loiselle CG, Gelinas C, Cassoff J, Boileau J, McVey L. A pre-post evaluation of the Adler/Sheiner Programme (ASP): a nursing informational programme to support families and nurses in an intensive care unit (ICU). Intensive Critical Care Nursing 2012;28:32-40.
57. Mason VM, Leslie G, Clark K, et al. Compassion fatigue, moral distress, and work engagement in surgical intensive care unit trauma nurses: a pilot study. Dimensions in Critical Care Nursing 2014;33:215-225.
58. Meadors P, Lamson A. Compassion Fatigue and Secondary Traumatization: Provider Self Care on Intensive Care Units for Children. Journal of Pediatric Health Care 2008;22:24-34.
59. Mehrabi T, Azadi F, Pahlavanzadeh S, Meghdadi N. The effect of yoga on coping strategies among intensive care unit nurses. Iran Journal Nursing Midwifery Research 2012;17 421-424.
60. Mealer ML, Shelton A, Berg B, Rothbaum B, Moss M. Increased prevalence of post-traumatic stress disorder symptoms in critical care nurses. American Journal of Respiratory Critical Care Medicine 2007;175:693-697.
61. Merlani P, Verdon M, Businger A, Domenighetti G, Pargger H, Ricou B. Burnout in ICU caregivers: a multicenter study of factors associated to centers. American Journal of Respiratory Critical Care Medicine 2011;184:1140-1146.
62. Nooryan K, Gasparyan K, Sharif F, Zoladl M. The effect of teaching emotional intelligence (EI) items on job related stress in physicians and nurses working in ICU wards in hospitals,

Yerevan, Armenia. International Journal of Collaboration Research Internal Medicine Public Health 2011;3:704-713.

63. Nooryan K, Gasparyan K, Sharif F, Zoladl M. Controlling anxiety in physicians and nurses working in intensive care units using emotional intelligence items as an anxiety management tool in Iran. International Journal General Medicine 2012;5:5.

64. Poncet MC, Toullic P, Papazian L, et al. Burnout syndrome in critical care nursing staff. Americal Journal of Respiratory in Critical Care Medicine 2007;175:698-704.

65. Quenot JP, Rigaud JP, Prin S, et al. Suffering among carers working in critical care can be reduced by an intensive communication strategy on end-of-life practices. Intensive Care Medicine 2012;38:55-61.

66. Raftopoulos V, Charalambous A, Talias M. The factors associated with the burnout syndrome and fatigue in Cypriot nurses: a census report. BMC Public Health 2012**;12:** 457doi:10.1186/1471-2458-12-457

67. Raggio B, Malacarne B. Burnout in Intensive Care Unit. Minerva Anestesiologica 2007;73:195-200.

68. Rochefort C, Clarke SP. Nurses' work environments, care rationing, job outcomes, and quality of care on neonatal units. Journal of Advance Nursing 2010;66:2213-2224.

69. Saini R, Kaur S, Das K. Assessment of stress and burnout among intensive care nurses at a tertiary care hospital. Journal of Mental Health Human Behavior 2011;16(1):43-47.

70. Shehabi Y, Dobb G, Jenkins I, Pascoe R, Edwards N, Butt W. Burnout syndrome among Australian intensivists: a survey. Critical Care Resuscitation 2008;10:312-315.

71. Sluiter JK, Bos AP, Tol D, Calff M, Krijnen M, Frings-Dresen MHW. Is staff well-being and communication enhanced by multidisciplinary work shift evaluations? Intensive Care Medicine 2005;31:1409-1414.

72. Su TP, Lien TC, Yang CY, et al. Prevalence of psychiatric morbidity and psychological adaptation of the nurses in a structured SARS caring unit during outbreak: A prospective and periodic assessment study in Taiwan. Journal of Psychiatric Research 2007;41:119-130.

73. Teixeira C, Ribeiro O, Fonseca AM, Carvalho AS. Burnout in intensive care units - a consideration of the possible prevalence and frequency of new risk factors: A descriptive correlational multicentre study. BMC Anesthesiology 2013;13:38.

74. Verdon M, Merlani P, Perneger T, Ricou B. Burnout in a surgical ICU team. Intensive Care Medicine 2008;34:152-156.

75. West CP, Dyrbye LN, Rabatin JT, et al. Intervention to Promote Physician Well-being, Job Satisfaction, and Professionalism: A Randomized Clinical Trial. JAMA Internal Medicine 2014;174:527-533.

76. Young JL, Derr DM, Cicchillo VJ, Bressler S. Compassion satisfaction, burnout, and secondary traumatic stress in heart and vascular nurses. Critical Care Nurs Quarterly 2011;34:227-234.

77. Zhang XC, Huang DS, Guan P. Job burnout among critical care nurses from 14 adult intensive care units in northeastern China: a cross-sectional survey. BMJ Open 2014;4: e004813

78. Stamm BH. Measuring Compassion Satisfaction as Well as Fatigue: Developmental History of the Compassion Satisfaction and Fatigue Test. In: Figley CR, editor. In: Treating Compassion Fatigue. New York: Routledge 2002 pp107-117. ISBN 9781583910535

79. Smart D, English A, James J, et al. Compassion fatigue and satisfaction: A cross-sectional survey among US healthcare workers. Nursing Health Science 2013;Doi:10.1111/nhs.12068.

80. West CP, Dyrbye LN, Rabatin JT, et al. Intervention to Promote Physician Well-being, Job Satisfaction, and Professionalism: A Randomized Clinical Trial. JAMA Internal Medicine 2014 Doi:101001/jamainternmed.2013.14387.

81. Kerasiotis B, Motta RW. Assessment of PTSD symptoms in emergency room, intensive care unit, and general floor nurses. International Journal of Emergy Mental Health 2004;6:121-133.
82. Jenkins SR, Baird S. Secondary traumatic stress and vicarious trauma: A validational study. Journal of traumatic stress 2002;15:423-432.
83. Yoder EA. Compassion fatigue in nurses. Applied Nursing Research 2010;23:191-197.
84. Stamm BH. The concise ProQOL manual. Pocatello, 2010;ID: ProQOL org.
85. Leiter MP, Bakker AB, Maslach C. Burnout at Work: A Psychological Perspective. Psychology Press 2014. ISBN 9781848722286.
86. Schaufeli WB, van Dierendonck D. A cautionary note about the cross-national and clinical validity of cut-off points for the Maslach Burnout Inventory. Psychological reports 1995;76:1083-1090.
87. Awa WL, Plaumann M, Walter U. Burnout prevention: A review of intervention programs. Patient Education and Counseling 2010;78:184-190.
88. Fallowfield L, Jenkins V, Farewell V, Solis-Trapala I. Enduring impact of communication skills training: results of a 12-month follow-up. British Journal Cancer 2003;89:1445-1449.
89. Davies WR. Mindful meditation: healing burnout in critical care nursing. Holistic nursing practice 2008;22:32-36.
90. Lan HK, Subramanian P, Rahmat N, Kar PC. The effects of mindfulness training program on reducing stress and promoting well-being among nurses in critical care units. Australian Journal of Advanced Nursing 2014;31(3):22-31.
91. Kearney MK, Weininger RB, Vachon MLS. Self-care of physicians caring for patients at the end of life: “Being connected... a key to my survival”. JAMA 2009;301(11):1155-1164
92. Sackett DL. Bias in analytic research. J Chronic Diseases 1979;32:51-63.
93. Rosenthal R. The file drawer problem and tolerance for null results. Psychological Bulletin 1979;86:638.

SUPPORTIVE INFORMATION S1

PRISMA 2009 CHECKLIST

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	3 - 5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6 Additional file S1
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6 - 7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Additional file S1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	6 Table 1
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Inapplicable
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	6 - 7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Inapplicable

Section/topic	#	Checklist item	Reported on page #
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	6
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	Inapplicable
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	15
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Inapplicable
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	7 Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	8 Table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Inapplicable
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	7 - 10 Table 3-7
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Inapplicable
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Inapplicable
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	Inapplicable
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	11 - 16
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	11 - 16
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	17
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	17

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

SUPPORTIVE INFORMATION S2

SEARCH PROTOCOL

Number of found references

Database	References	Without duplicates
Embase	875	872
Medline OvidSP	513	132
Cinahl	493	267
Web-of-science	335	165
PsycINFO	138	47
PubMed publisher	12	11
Cochrane	14	6
Google Scholar	200	120
Total *	**2580**	**1620**

* Results of systematic searching in electronical databases until 30 June, 2014

SEARCH STRATEGIES

EMBASE 872

(‘posttraumatic stress disorder’/de OR ((‘emotional attachment’/de OR empathy/de OR ‘emotional stress’/de OR ‘nurse patient relationship’/de OR ‘doctor patient relation’/de OR ‘coping behavior’/de OR ‘runaway behavior’/de OR ‘stress management’/de OR ‘adaptive behavior’/de) AND (fatigue/de OR exhaustion/de OR burnout/de OR Workload/de OR ‘job stress’/de)) OR (((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) NEAR/6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR ‘post traumatic’) NEAR/3 stress)):ab,ti) AND (((‘health care personnel’/exp OR nursing/exp OR ‘health personnel attitude’/exp OR (personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff):ab,ti) AND (‘intensive care’/exp OR ‘intensive care unit’/de OR (‘intensive care’ OR ‘critical care’ OR icu OR picu OR nicu OR icus OR picus OR nicus):ab,ti)) OR ‘intensive care nursing’/exp)

MEDLINE OVIDSP 132

(“Stress Disorders, Post-Traumatic”/ OR ((empathy/ OR “Stress, Psychological”/ OR exp “Professional-Patient Relations”/ OR “Adaptation, Psychological”/ OR “runaway behavior”/) AND (exp fatigue/ OR “Burnout, Professional”/ OR “Workload”/)) OR (((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) ADJ6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR "post traumatic") ADJ3 stress)).ab,ti.) AND (((exp "health personnel"/ OR exp nursing/ OR nursing.xs. OR exp "Attitude of Health Personnel"/ OR exp "Professional Role"/ OR (personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff).ab,ti.) AND (exp "Critical Care"/ OR exp "intensive care units"/ OR ("intensive care" OR "critical care" OR icu OR picu OR nicu OR icus OR picus OR nicus).ab,ti.)))

COCHRANE 6

((((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) NEAR/6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR 'post traumatic') NEAR/3 stress)):ab,ti) AND ((((personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff):ab,ti) AND (('intensive care' OR 'critical care' OR icu OR picu OR nicu OR icus OR picus OR nicus):ab,ti)))

WEB-OF-SCIENCE 165

TS=(((((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) NEAR/6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR "post traumatic") NEAR/3 stress))) AND ((((personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff)) AND (("intensive care" OR "critical care" OR icu OR picu OR nicu OR icus OR picus OR nicus)))))

PSYCINFO OVIDSP 47

("Posttraumatic Stress Disorder"/ OR ((empathy/ OR "Psychological Stress"/ OR "Adaptation"/ OR "runaway behavior"/) AND (exp fatigue/ OR "Occupational Stress"/ OR "Work load"/)) OR (((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) ADJ6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR "post traumatic") ADJ3 stress)).ab,ti.) AND (((exp "health personnel"/ OR exp nursing/ OR "Health Personnel Attitudes"/ OR (personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff).ab,ti.) AND (exp "intensive care"/ OR ("intensive care" OR "critical care" OR icu OR picu OR nicu OR icus OR picus OR nicus).ab,ti.)))

CINAHL 267

(MH "Stress Disorders, Post-Traumatic+" OR ((MH empathy+ OR MH "Stress, Psychological+" OR MH "Professional-Patient Relations+" OR MH "Adaptation, Psychological+") AND (MH fatigue+ OR MH "Burnout, Professional+" OR MH "Workload+")) OR (((compass* OR empath* OR vicarious OR attach* OR emotion* OR coping OR runaway) N6 (fatigue* OR satisf* OR stress OR trauma* OR exhaust* OR burnout* OR tired*)) OR ((secondar* OR posttraumat* OR “post traumatic”) N3 stress))) AND (((MH “health personnel+” OR MH “Attitude of Health Personnel+” OR MH “Professional Role+” OR (personnel* OR nurs* OR doctor* OR physician* OR caregiver* OR provider* OR paramedic* OR profession* OR staff)) AND (MH “Critical Care+” OR MH “intensive care units+” OR (“intensive care” OR “critical care” OR icu OR picu OR nicu OR icus OR picus OR nicus))) OR MH “Critical Care Nursing+”)

PUBMED PUBLISHER 11

((((compass*[tiab] OR empath*[tiab] OR vicarious[tiab] OR attach*[tiab] OR emotion*[tiab] OR coping[tiab] OR runaway[tiab]) AND (fatigue*[tiab] OR satisf*[tiab] OR stress[tiab] OR trauma*[tiab] OR exhaust*[tiab] OR burnout*[tiab] OR tired*[tiab])) OR ((secondar*[tiab] OR posttraumat*[tiab] OR post traumatic[tiab]) AND stress[tiab]))) AND ((((personnel*[tiab] OR nurs*[tiab] OR doctor*[tiab] OR physician*[tiab] OR caregiver*[tiab] OR provider*[tiab] OR paramedic*[tiab] OR profession*[tiab] OR staff)) AND ((intensive care[tiab] OR critical care[tiab] OR icu[tiab] OR picu[tiab] OR nicu[tiab] OR icus[tiab] OR picus[tiab] OR nicus[tiab])))) AND publisher[sb]

GOOGLE SCHOLAR 120

“compassion|empathy|vicarious|attachment|emotional fatigue|satisfaction|stress|exhaustion”|ptss|ptsd personnel|nursing|nurses|doctors|physicians|caregivers|providers|paramedics|professional|staff icu|picu|nicu|icus|picus|nicus

SUPPORTIVE INFORMATION S3

ASSESSMENT OF ARTICLES

Box S3.1. Inclusion criteria

Inclusion criteria first selection round on title abstract:

Studies dealing with the prevalence of burnout, compassion fatigue, vicarious trauma or secondary traumatic stress, and intervention studies on these kind of emotional distress.

Studies in the Intensive Care Unit, Critical Care Unit, Neonatology Intensive Care Unit, Pediatric Intensive Care Unit,

Studies on nurses or physicians,

Studies published from 1992 until 23 May 2014,

Inclusion criteria second selection round after whole article inspection:

Studies in English (or Dutch) language,

Original and review articles available in complete form

Inclusion criteria on methodological soundness:

Prevalence defined as percentages of burnout or compassion fatigue

At least six of eight criteria on soundness must be available:

- Research questions and objectives are described precisely
- Clear definition of compassion fatigue
- A valid and reliable measuring instrument
- Method is described in detail
- Information given on size and type of the target populations
- Information given on number and characteristics of subjects who agreed to participate
- Drop out/missing values are addressed
- Statistical analysis appropriate

Table S3.1. *References included/excluded after whole text reading*

#	Include/exclude	Author(s)	Year	Title of article	Journal
Studies dealing with the prevalence of burnout, compassion fatigue, vicarious trauma or secondary traumatic stress					
1	Include	Galvan, M. E., J. C. Vassallo, et al.	2012	Physician's burnout in pediatric intensive care units from Argentina	Arch Argent Pediatr 110(6): 466-473
2	Include	Barbosa, F. T., B. A. Leao, et al.	2012	Burnout syndrome and weekly workload of on-call physicians: Cross-sectional study.	Sao Paulo Med J 130(5): 282-288.
3	Exclude, not prevalence	Rama-Maceiras, P., S. Parente, et al.	2012	Job satisfaction, stress and burnout in anesthesia: Relevant topics for anesthesiologists and healthcare managers?	Eur J Anaesthesiol 29(7): 311-319
4	Include	Bellieni, C. V., P. Righetti, et al.	2012	Assessing burnout among neonatologists	J Matern -Fetal Neonatal Med 25(10): 2130-2134.
5	Include	Shehabi, Y., G. Dobb, et al.	2008	Burnout syndrome among Australian intensivists: a survey.	Crit Care Resusc 10(4): 312-315.
6	Exclude, other work setting	Kholdebarin, R., R. M. Helewa, et al.	2011	Evaluation of a regional acute care surgery service by residents in general surgery.	J Surg Educ 68(4): 290-293.
7	Include	Embriaco, N., E. Azoulay, et al	2007	High level of burnout in intensivists: prevalence and associated factors.	Am J Resp Crit Care Med 175(7): 686-692
8	Exclude, other work setting	Chiron, B., E. Michinov, et al.	2010	Job Satisfaction, Life Satisfaction and Burnout in French Anesthetists.	J Health Psych 15(6): 948-958.
9	Exclude, other work setting	Shanafelt, T. D., C. M. Balch, et al.	2010	Burnout and Medical Errors Among American Surgeons	Annals of Surgery 251(6): 995-1000.
10	Include	Elkonin, D. and Lizelle	2011	Positive and negative emotional responses to work-related trauma of intensive care nurses in private health care facilities.	Health SA Gesondheid 16(1): 1-8
11	Exclude, only fatigue not CF	Ruggiero, J. S	2003	Correlates of fatigue in critical care nurses.	Res Nurs Health 26(6): 434-444
12	Exclude, not prevalence	Todaro-Franceschi, V.	2013	Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life	DCCN 32(4): 184-190
13	Exclude, not prevalence	Marcial, L., M. Brazina, et al.	2013	A brief article: is this the cost of caring? A student perspective on compassion fatigue.	DCCN 32(1): 18-21.

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
14	Include	Mealer, M. L., A. Shelton, et al.	2007	Increased prevalence of post-traumatic stress disorder symptoms in critical care nurses.	Am J Respir Crit Care Med 175(7): 693-697
15	Include	Raftopoulos, V., A. Charalambous, et al.	2012	The factors associated with the burnout syndrome and fatigue in Cypriot nurses: a census report.	BMC Public Health 12
16	Exclude, not prevalence	Smart, D., A. English, et al.	2013	Compassion fatigue and satisfaction: A cross-sectional survey among US healthcare workers.	Nurs Health Sci
17	Include	Su, T. P., T. C. Lien, et al.	2007	Prevalence of psychiatric morbidity and psychological adaptation of the nurses in a structured SARS caring unit during outbreak: A prospective and periodic assessment study in Taiwan.	J Psychiatr Res 41(1-2): 119-130
18	Include	Young, J. L., D. M. Derr, et al.	2011	Compassion satisfaction, burnout, and secondary traumatic stress in heart and vascular nurses.	Crit Care Nurs Q 34(3): 227-234
19	Exclude, not prevalence	Sluiter, J. K., A. P. Bos, et al.	2005	Is staff well-being and communication enhanced by multidisciplinary work shift evaluations?	Intens Care Med 31(10): 1409-1414
20	Exclude, not prevalence	Meadors, P. and A. Lamson	2008	Compassion Fatigue and Secondary Traumatization: Provider Self Care on Intensive Care Units for Children.	J Pediatr Health Care 22(1): 24-34
21	Include	Czaja, A. S., M. Moss, et al.	2012	Symptoms of Posttraumatic Stress Disorder Among Pediatric Acute Care Nurses.	J Pediatr Nurs 27(4): 357-365
22	Exclude, not prevalence	Ayala, E. and A. M. Carnero	2013	Determinants of Burnout in Acute and Critical Care Military Nursing Personnel: A Cross-Sectional Study from Peru.	PLoS ONE 8(1).
23	Include	Liu, Y. E., A. While, et al.	2013	Job satisfaction and work related variables in Chinese cardiac critical care nurses.	J Nurs Manag
24	Include	Teixeira, C., O. Ribeiro, et al.	2013	Ethical decision making in intensive care units: a burnout risk factor? Results from a multicenter study conducted with physicians and nurses.	J Med Ethics

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
25	Exclude, not prevalence	Losa Iglesias, M. E. and R. Becerro de Bengoa Vallejo	2013	Prevalence and relationship between burnout, job satisfaction, stress, and clinical manifestations in behavior critical care nurses.	DCCN 32(3): 130-137.
26	Exclude, not prevalence	Epp, K.	2012	Burnout in critical care nurses: a literature review.	Dynamics 23(4): 25-31.
27	Include	Karanikola, M. N., E. D. Papathanassoglou, et al.	2012	Burnout syndrome indices in Greek intensive care nursing personnel."	DCCN 31(2): 94-101.
28	Include	Goetz, K., S. Beutel, et al.	2012	Work-related behavior and experience patterns of nurses."	Int Nurs Rev 59(1): 88-93.
29	Include	Liu, K., L.-M. You, et al.	2012	The relationship between hospital work environment and nurse outcomes in Guangdong, China: a nurse questionnaire survey.	J ClinNursi 21(9/10): 1476-1485.
30	Exclude, not prevalence	Klopper, H. C., S. K. Coetzee, et al.	2012	Practice environment, job satisfaction and burnout of critical care nurses in South Africa.	J Nurs Manage 20(5): 685-695.
31	Include	Merlani, P., M. Verdon, et al.	2011	Burnout in ICU caregivers: a multicenter study of factors associated to centers."	Am J Resp Crit Care Med 184(10): 1140-1146.
32	Exclude, not original article	Azoulay, E. and M. Herridge	2011	Understanding ICU staff burnout: The show must go on.	Am J Respir Crit Care Med 184(10): 1099-1100.
33	Include	Rochefort, C. M. and S. P. Clarke	2010	Nurses' work environments, care rationing, job outcomes, and quality of care on neonatal units.	J Adv Nurs 66(10): 2213-2224.
34	Include	Cho, S., K. J. June, et al.	2009	Nurse staffing, quality of nursing care and nurse job outcomes in intensive care units.	J ClinNurs 18(12): 1729-1737.
35	Include	Verdon, M., P. Merlani, et al.	2008	Burnout in a surgical ICU team.	Intens Care Med 34(1): 152-156.
36	Include	Lederer, W., J. F. Kinzl, et al.	2008	Fully developed burnout and burnout risk in intensive care personnel at a university hospital.	Anaesth Intens Care 36(2): 208-213.

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
37	Include	Raggio, B. and P. Malacarne	2007	Burnout in Intensive Care Unit.	Minerva Anestesiol 73(4): 195-200.
38	Include	Poncet, M. C., P. Toullic, et al.	2007	Burnout syndrome in critical care nursing staff.	Am J Resp Crit Care Med 175(7): 698-704.
39	Exclude, not original article	Embriaco, N., L. Papazian, et al.	2007	Burnout syndrome among critical care healthcare workers.	Curr Opin Crit Care 13(5): 482-488.
40	Exclude, not prevalence	Bakker, A. B., P. M. Le Blanc, et al.	2005	Burnout contagion among intensive care nurses.	J Adv Nurs 51(3): 276-287.
41	Exclude, not prevalence	Buhler, K. E. and T. Land	2004	Burnout and personality in extreme nursing: An empirical study.	Schweiz Arch Neurol Psychiatr 155(1): 35-42.
42	Exclude, not prevalence	Chen, S. M. and A. McMurray	2001	"Burnout" in intensive care nurses."	J Nurs Res 9(5): 152-164.
43	Exclude, not prevalence	Tekindal, B., M. A. Tekindal, et al.	2012	Nurses' burnout and unmet nursing care needs of patients' relatives in a Turkish State Hospital.	Int J Nurs Pract 18(1): 68-76.
44	Include	Quenot, J. P., J. P. Rigaud, et al.	2012	Suffering among carers working in critical care can be reduced by an intensive communication strategy on end-of-life practices.	Intens Care Med 38(1): 55-61.
45	Exclude, not prevalence	Cubrilo-Turek, M., R. Urek, et al.	2006	Burnout syndrome – Assessment of a stressful job among intensive care staff	Coll Antropol 30(1): 131-135.
46	Exclude, not prevalence	Kerasiotis, B. and R. W. Motta	2004	Assessment of PTSD symptoms in emergency room, intensive care unit, and general floor nurses.	Int J Emerg Ment Health 6(3): 121-133
47	Exclude, not prevalence	Ozden, D., S. Karagozoglu, et al.	2013	Intensive care nurses' perception of futility: Job satisfaction and burnout dimensions.	Nurs Ethics 20(4): 436-447.
48	Exclude, case study	Pardoe, P.	2011	Psychological support for nurses on pediatric intensive care units	Nurs Child Young People 23(8): 27-29
49	Exclude, not prevalence	Ifeagwazi, R. F.	2005	The influence of marital status on self-report of symptoms of psychological burnout among nurses.	Omega: J Death Dying 52(4): 359-373.

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
50	Include	Meadors, P., A. Lamson, et al.	2010	Secondary traumatization in pediatric healthcare providers: Compassion fatigue, burnout, and secondary traumatic stress	Omega J Death Dying 60(2): 103-128
51	Include	Guntupalli, K. K. Fromm, r. E.	1996	Burnout in the internist-intensivist	Intens Care Med 22: 625-630
52	Exclude, not prevalence	Aytekin, A., et al.	2013	Burnout levels in neonatal intensive care nurses and its effects on their quality of life.	Australian Journal of Advanced Nursing 31(2): 39-47.
53	Include	Guntupalli, K. K., et al.	2014	Burnout in the intensive care unit professionals.	Indian J Crit Care Med 18(3): 139-143.
54	Exclude, not prevalence	Myhren, H., et al.	2013	Job Satisfaction and Burnout among Intensive Care Unit Nurses and Physicians	Crit Care Res Pract 2013: 786176.
55	Include	Saini, R., et al.	2011	Assessment of stress and burnout among intensive care nurses at a tertiary care hospital	J. Mental Health Human Behav 16(1) 43-48
56	Include, same data as # 24	Teixeira, C., et al.	2013	Burnout in intensive care units - a consideration of the possible prevalence and frequency of new risk factors: A descriptive correlational multicentre study."	BMC Anesthesiol 13:38
57	Include	Zhang, X. C., et al.	2014	Job burnout among critical care nurses from 14 adult intensive care units in northeastern China: a cross-sectional survey.	BMJ Open 4(6): e004813.
58	Include	Mason, V. M., et al.	2014	Compassion fatigue, moral distress, and work engagement in surgical intensive care unit trauma nurses: a pilot study.	DCCN 33(4): 215-225.
59	Exclude, not prevalence	Neville, K. and D. A. Cole	2013	The relationships among health promotion behaviors, compassion fatigue, burnout, and compassion satisfaction in nurses practicing in a community medical center.	JONA 43(6) 348-354
60	Exclude, not prevalence	Mealer, M. and J. Jones	2014	Methodological and ethical issues related to qualitative telephone interviews on sensitive topics.	Nurse Res. 21: 32-37.

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
61	Exclude, not prevalence	Lin, F., et al.	2009	Burnout among hospital nurses in China	J. Nurs Manag 17 294-301
Intervention studies on emotional distress					
62	Include, comparison of two groups	Ali, N. A., et al.	2011	Continuity of care in intensive care units: a cluster-randomized trial of intensivist staffing.	Am J Respir Crit Care Med 184(7): 803-808.
63	Exclude, not effect of intervention measured	Caine, R. M. and L. Ter-Bagdasarian	2003	Early identification and management of critical incident stress.	Crit Care Nurse 23(1): 59-6
64	Include, comparison of two groups	Garland, A	2012	Twenty-four-Hour Intensivist Presence A Pilot Study of Effects on Intensive Care Unit Patients, Families, doctors, and Nurses	Am J Respir Crit Care Med 185 (7) 738-743.
65	Exclude, abstract	Hartshorn, J. C.	1992	Evaluation of a critical care nursing internship program	J Cont Educ Nurs 23(1): 42-48.
66	Exclude, abstract	Iskra-Golec, I., et al.	1996	Health, well-being and burnout of ICU nurses on 12- and 8-h shifts.	Work Stress 10(3): 251-256.
67	Include, pre- and post-measurement	Loiselle, C. G., et al.	2012	A pre-post evaluation of the Adler/Sheiner Programme (ASP): a nursing informational programme to support families and nurses in an intensive care unit (ICU).	Intens Crit Care Nurs 28(1): 32-40.
68	Exclude, abstract	Schwarzkopf, D., et al.	2012	A survey of ICU medical staff on interdisciplinary communication about END-of-life care and burnout.	Intens Care Med38: S70-S71.
69	Include, pre- and post-measurement (Nr 19 first review, not prevalence)	Sluiter, J. K., et al.	2005	Is staff well-being and communication enhanced by multidisciplinary work shift evaluations?	Intens care Med 31(10): 1409-1414.
70	Include, pre- and post-measurement	Beumer, C. M.	2008	Innovative solutions: the effect of a workshop on reducing the experience of moral distress in an intensive care unit setting	Dimens Crit Care Nurs 27(6): 263-267.
71	Include, pre- and post-measurement	Eagle, S., et al.	2012	The effect of facilitated peer support sessions on burnout and grief management among health care providers in pediatric intensive care units: A pilot study.	J Pall Med 15(11): 1178-1180.

Table S3.1. *References included/excluded after whole text reading (continued)*

#	Include/exclude	Author(s)	Year	Title of article	Journal
72	Include, pre- and post-measurement (Nr 20 first review, not prevalence)	Meadors, P. and A. Lamson	2008	Compassion Fatigue and Secondary Traumatization: Provider Self Care on Intensive Care Units for Children.	J Pediatr Health Care 22(1): 24-34.
73	Include, pre- and post-measurement	Mehrabi, T., et al.	2012	The effect of yoga on coping strategies among intensive care unit nurses.	Iran J Nurs Midwifery Res17(6): 421-424.
74	Include, pre- and post-measurement	Nooryan, K., et al.	2011	The effect of teaching emotional intelligence (EI) items on job related stress in physicians and nurses working in ICU wards in hospitals, Yerevan, Armenia.	Int J Collab Res Intern Med Public Health 3(10): 704-713.
75	Include, pre- and post-measurement	Nooryan, K., et al.	2012	Controlling anxiety in physicians and nurses working in intensive care units using emotional intelligence items as an anxiety management tool in Iran.	International journal of general medicine 5: 5.
76	Include	West, C. P., et al.	2014	Intervention to Promote Physician Well-being, Job Satisfaction, and Professionalism: A Randomized Clinical Trial.	JAMA internal medicine 174(4): 527-533
Manual found					
77	Exclude, not ICU	Mealer, M & Jones, J	2013	Posttraumatic Stress Disorder in the Nursing Population: A concept Analysis	Nursing Forum, 48(4)
78	Exclude, not ICU	Nimmo, A & Huggard, P	2013	A Systematic Review of the measurement of Compassion fatigue, Vicarious Trauma, and Secondary Traumatic Stress in Physicians	Austral J Disaster Trauma Studies
79	Exclude, not ICU	Kaschka, W. P. Korczak, D., & Broich, K.	2011	Burnout: a Fashionable Diagnosis.	Deutsches Ärzteblatt International 108(46): 781-1

Table S3.2. *Methodological criteria*

#	Research questions and objectives are described precisely	Clear definition of concept(s) has been given	A valid and reliable measuring instrument has been used	Method is described in detail	Information given on size and type of the target populations	Information given on number and characteristics of subjects	Drop out/missing values are addressed	Statistical analysis are appropriate	**Total amount of criteria on soundness**
1	Y	Y	Y	Y	Y	Y	Y	Y	**8**
2	Y	Y	Y	Y	Y	Y	N	Y	**7**
4	Y	Y	Y	Y	Y	Y	Y	Y	**8**
5	Y	Y	Y	Y	Y	N	Y	Y	**7**
7	Y	Y	Y	Y	Y	Y	Y	Y	**8**
10	Y	Y	Y	Y	Y	Y	N	Y	**7**
14	Y	N	Y	Y	Y	Y	Y	Y	**7**
15	Y	Y	Y	Y	Y	Y	Y	Y	**8**
17	Y	N	Y	Y	Y	Y	Y	Y	**7**
18	Y	Y	Y	Y	Y	N	N	Y	**6**
21	Y	Y	Y	Y	Y	Y	Y	Y	**8**
23	Y	N	Y	Y	Y	Y	Y	Y	**7**
27	Y	N	Y	Y	Y	Y	Y	Y	**8**
28	Y	Y	Y	Y	Y	Y	Y	Y	**8**
29	Y	N	Y	Y	Y	Y	Y	Y	**7**
31	Y	Y	Y	Y	Y	Y	Y	Y	**8**
33	Y	Y	Y	Y	Y	Y	Y	Y	**8**
34	Y	N	Y	Y	Y	Y	Y	Y	**7**
35	Y	Y	Y	Y	Y	Y	Y	Y	**8**
36	Y	Y	Y	Y	Y	Y	Y	Y	**8**
37	Y	Y	Y	Y	Y	Y	Y	Y	**8**
38	Y	Y	Y	Y	Y	Y	N	Y	**7**
44	Y	Y	Y	Y	Y	Y	Y	Y	**8**
50	Y	Y	Y	Y	Y	Y	N	Y	**7**
51	Y	Y	Y	Y	Y	Y	N	Y	**7**
53	Y	Y	Y	N	Y	Y	N	Y	**6**
55	Y	N	Y	Y	Y	Y	N	Y	**6**
56	Y	Y	Y	Y	Y	Y	Y	Y	**8**
57	Y	Y	Y	Y	Y	Y	Y	Y	**8**
58	Y	Y	Y	Y	Y	Y	N	Y	**7**
62	Y	N	N (not for burnout)	Y	Y	Y	Y	Y	**6**
64	Y	N	Y	Y	Y	Y	Y	Y	**7**

Table S3.2. *Methodological criteria (continued)*

#	Research questions and objectives are described precisely	Clear definition of concept(s) has been given	A valid and reliable measuring instrument has been used	Method is described in detail	Information given on size and type of the target populations	Information given on number and characteristics of subjects	Drop out/missing values are addressed	Statistical analysis are appropriate	**Total amount of criteria on soundness**
67	Y	N	Y	Y	Y	Y	Y	Y	**7**
69	Y	N	Y	Y	Y	Y	Y	Y	**7**
70	Y	Y	N	Y	Y	N	Y	N	**5**
71	Y	N	Y	Y	Y	Y	Y	Y	**7**
72	Y	Y	Y	Y	Y	Y	N	Y	**7**
73	Y	N	Y	Y	Y	Y	N	Y	**6**
74	Y	Y	Y	Y	Y	Y	N	Y	**7**
75	Y	Y	Y	Y	Y	Y	N	Y	**7**
76	Y	Y	Y	Y	Y	Y	Y	Y	**8**

7

Reflections on work-related stress among intensive care professionals, a historical impression

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Annual Update in Intensive Care and Emergency Medicine,

2017; Springer International Publishing 527-538.

INTRODUCTION

Medical doctors have experienced significant changes in delivering healthcare over time. Long and tensed working hours, increased administrative burden, impaired work-life balance, and frequent burden of liability and lawsuits have changed daily practice[1]. In addition, increased expectations from patients and families, and a complex process of shared decision-making, lead to severe stress in healthcare providers[2]. This work-related stress can have a negative impact on an individual´s joy in work, increase chances of medical errors, and jeopardize quality of care[3, 4]. It might even result in long-term absenteeism or a threatening brain and skill drain if the professionals leave their jobs prematurely to preserve their own health, ultimately leading to economic burdens[5]. Reports have indicated that this increased work-related stress might cause suicide among doctors[6]. Physicians appeared to be more likely to die by suicide than other healthcare professionals and twice as many compared to the general population, although, it is still a quit rare occurrence. Each year approximately 400 physician in the USA die by suicide, which is more than by motor vehicle, drowning, homicide, and plane crashes together[7]. Historically, various healthcare professionals have been acknowledged as particularly vulnerable to work-related stress, with a number of prevalent stress responses such as burnout, compassion fatigue, and traumatic stress. See table 1 for an overview.

Table 1. *Types of stress responses experienced by various healthcare professionals*

Anxiety	Moral distress
Burnout	Posttraumatic stress
Compassion fatigue	Secondary traumatic stress
Countertransference	Secondary victimization
Depression	Substance abuse
Empathic distress/strain/fatigue/overload	Suicide
Emotional distress	Vicarious trauma/stress
Exhaustion	Wounded healer

A 2014 study on the prevalence of burnout among physicians in the USA found that more than 54% reported at least one symptom of burnout, measured with the Maslach Burnout Inventory (MBI)[8]. Among all domains, the field of critical care scored highest in the prevalence of burnout (55%)[9]. However, during the same period, a nationwide study on burnout among Dutch intensivists found a very low burnout rate with a prevalence of only 4.4%[10]. In a recent systematic literature review on emotional distress among intensive care professionals we suggested that the true magnitude of work-related stress remains unclear due to a lack of unity in concepts, related measuring instruments, and cut-off points[11]. In this book chapter we provide a historical impression and trends in the work-related stress responses among intensive care professionals.

THE ORIGIN OF STRESS

Stress describes a person’s response to a threat or some other change in its environment which go beyond one´s resources for coping with the obstacles (events, people, and situations). Similarly, in a psychological definition, stress is: “the condition in which person – environment transactions lead to a perceived discrepancy between the physical or psychological demands of a situation and the resources of the individual´s biological, psychological, or social systems”[12].

Stress increases immediately if a defiant change or threat occurs. A certain amount of stress is necessary and important to perform activities and work tasks[13], also called eustress. The pathogenic role of stress was identified by physiologist Walter B. Cannon (1871-1945) in the ´fight-or-flight´ response, as this mobilizes an individual to combat the threat or to flee in face of the stressful event[14]. This process could have negative consequences if the burden exceeds the individual’s capacity or when it becomes a chronic stress. A little later, this theory was expanded to the General Adaption Syndrome by Hans Selye (1907-1982), a medical doctor at Johns Hopkins University. He showed that environmental stressors activate the HPA axis (hypothalamus, pituitary gland, and adrenal cortex) and consequently increase cortisol levels associated with an immediate increase in blood pressure and heart rate. In a chronic phase, these cortisol levels can lead to cell damage and depletion of the body´s energy reserves[15]. Finally, the psychologist Richard Lazarus (1922-2002) found that cognitive appraisal processes can influence both the stress and the emotional experience[16]. The appraisal of a situation causes an emotional, or affective, response that is going to be based on that appraisal. An important aspect of this appraisal theory is that it accounts for individual variances of emotional reactions to the same event. Therefore, work-related stress might have different effects in individual healthcare professionals even in situations of equal stress. Both physical warning signs (headaches, sleeping disturbances, low back pain and stomach problems) and mental responses (irritability or hostility, loss of concentration, low self-confidence and emotional instability) could indicate individual stress reactions[12]. However, these are non-specific symptoms that won´t depict the origin of stress and subsequently constrain effective coping mechanisms and the developing of preventive strategies.

EXHAUSTION AND BURNOUT

The Roman physician Galen (129-269?) wrote one of the earliest discussions on exhaustion, which he believed was an imbalance of the four humors blood, yellow bile, black bile and phlegm. An increase of black bile “slowed the body’s circulation and clogged up the brain’s pathways, bringing about lethargy, torpor, weariness, sluggishness and melancholy”[17]. Although this idea found no scientific basis, even today many people with exhaustion, and subsequent foggy thinking, experience their brains filled with a tar-like liquid causing an extreme mental tiredness. Many people throughout history have felt overtired, suggesting that fatigue and exhaustion could be part of the human condition.

Burnout has first been described by Herbert J. Freudenberger (1926–1999). He borrowed the term from the drug scene where it originally referred to the catastrophic influence of chronic drug abuse, and applied this concept to volunteers of the St Mark´s Free Clinic in New York´s East Village who felt a gradual emotional depletion, loss of motivation, and reduced commitment[18]. At the same time, burnout was used by Maslach in a description of social workers who felt emotionally exhausted and developed negative perceptions about their clients. From 1970 a considerable body of knowledge about the nature of burnout, its causes and consequences, and its prevalences in specific domains has emerged[19].

Burnout is currently seen as the most prevalent career crisis of the twenty-first century. Nowadays, it is characterized by a combination of three factors: emotional exhaustion, depersonalization and personal accomplishment[18, 19]. An official Critical Care Societies Collaborative statement provides an extensive summary of the symptoms, the causative factors and consequences of burnout in the intensive care unit[20]. Some of the risk factors for burnout include individual characteristics, such as perfectionism, a compromised work-life balance, and a neurotic personality. However, organizational aspects such as an increased workload and too many work hours, are related to high rates of burnout as well. Although some contradictions exists, younger professionals are at higher risk of burnout compared to older and more experienced professionals[11]. Some studies reported female ICU professionals to be at higher risk[4, 21], whereas others found no effect[22, 23].

The Maslach Burnout Inventory (MBI) is seen as the standard tool for measuring the severity of burnout[21, 24, 25]. The MBI is a highly reliable and validated 22-item self-report questionnaire that evaluates the three domains of burnout in independent subscales[26]. However, since its origination, the operationalization and measurement of burnout have differed across studies[11, 20]. Measuring only exhaustion, as an equivalent to burnout, is not sufficient and induces erroneously high prevalence rates. The high burnout rates as currently reported in public discussions is also confounded by the limited methodologic quality of the majority of the studies[27]. Cross-sectional studies might suffer from reverse causation thus mixing cause and effect of work related stress to burnout and emotional exhaustion. In addition, the low response rates as seen in some studies to be as low as 19% [8], could result in selection bias. Therefore, this cost of caring is overestimated. The concept of burnout might be misused to indicate an overall exhaustion with life; fatigue and tiredness may result as a part of the human condition. It is highly recommended to further investigate burnout with longitudinal international studies in a valid and comparative manner, with clear cut-off points in all three domains, to indicate the relevance of the problem among intensive care professionals.

POSTTRAUMATIC STRESS DURING WAR

Crocq and Crocq (2000) provided an all-encompassing historical overview on the diseases that are currently labeled as Post-Traumatic Stress Disorder (PTSD)[28]. The authors stated that the first phenomena of psychological consequences after witnessing terrifying situations emerged during early battles as: "The first case of chronic mental symptoms caused by sudden fright in the battlefield is reported in the account of the battle of Marathon by Herodotus, written in 440 BC". Hippocrates (460?-377 BC) also mentioned frightening battle dreams, and centuries later, Shakespeare wrote a line of poetry in his ´Romeo and Julia´ on the awakening of soldiers by re-experiencing past battles in their dreams. In 1678, a Swiss physician identified ´Nostalgia´, which was followed by the ´Traumatic neurosis´ of the German physician Oppenheim in 1884, to label similar psychological signs. In 1871, the physician Jacob Mendes Da Costa (1833-1900) described psychological war symptoms as the so-called 'Irritable heart'. He studied over 300 servicemen during the American Civil War (1861-1865) with complaints about chest pain, fatigue, dyspnea, palpitations, headaches and dizziness. He assumed a somatic cause in excessive marching [29]. However, later on, the irritable heart was also observed in civilians, especially young women who performed strenuous work and who were highly emotional. 'Neurasthenia' or 'Nervous exhaustion' was introduced in 1880 by the neurologist George Beard (1839-1883) [30] who assumed for the first time that there was a certain predisposition in soldiers, which could be recognized before they were sent to battle.

After the First World War (1914-1918), the cardiologist Thomas Lewis (1881-1945) described 'The soldier's heart' and the 'Effort syndrome' [31]. Complaints, again, were shortness of breath, dizziness, headache, sighing, palpitations, chest pain, fatigue, confusion, forgetfulness and lack of concentration. The condition was explained to be somatically caused, such as from lack of sleep in the trenches and the effects of poisonous gas. Another term used during this war was, 'Shell shock' (also named 'trench neurosis', 'gas neurosis' and 'buried-alive neurosis'), which differed from the above mentioned syndromes by also giving rise to symptoms such as irritation, speech disorders, forgetfulness and other cognitive complains. Soldiers with a history of a ´weak´ personality, family psychiatric disorders and a fragile physical constitution were predisposed to develop this condition. In the Second World War (1939-1945), once again, soldiers were suffering from the previously described symptoms. The terms ‘Combat neurosis’, ‘Battle fatigue’, ‘Operational fatigue’ and ‘Combat exhaustion’ were introduced to name these complex of symptoms. Obviously, these conditions were more a psychological or a psychiatric condition than that it could be related to somatic stresses. The symptoms were supposed to disappear after the war, but the phrase “You can take the man out the war, but you can never take the war out of the man” proved to be more truthful than expected. Even the term ‘The old sergeant syndrome’ was introduced when it became evident that veterans might chronically suffer from their war experiences. During the Vietnam War (1955-1975), the incidence was much lower than in the previous wars, but still soldiers suffered from ‘Combat stress’ and ‘Battle stress reactions’.

POSTTRAUMATIC STRESS IN HEALTHCARE

In 1952, the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-1) was developed by the American Psychiatric Association (APA). This manual included ´Gross stress reaction´ to mention a stress syndrome that is a response to an exceptional physical or mental stress, such as a natural catastrophe or battle. In DSM-II (1968), this category disappeared, perhaps because of the peaceful era in which the manual was revised, only to be re-entered in DSM-III (1980), after the Vietnam War, as ´Posttraumatic Stress Disorder´. The PTSD diagnostic criteria were again revised in DSM-5, and are presented in table 2, including the persistent effortful avoidance of distressing trauma-related stimuli among others[32]. A structured interview, such as the Clinician-Administered PTSD Scale for DSM-5 or the PTSD Symptom Scale-Interview, establishes the PTSD diagnose. Disadvantages of these interviews are the prolonged administration time and the special training to guarantee the validity of the diagnosis. Although a number of self-report measurement instruments, such as the Davidson Trauma Scale or the Impact of Event Scale-Revised, assess the symptoms of PTSD, these measures do not accomplish a diagnose of PTSD because of too much biased responses[33]. The estimated lifetime prevalence of PTSD in the National Comorbidity Survey Replication among adult Americans was 6.8% and a twelve-month prevalence of 3.5%[34].

Some researchers have suggested that intensive care professionals experience a traumatic work environment; these studies have found that 21%-29% of the respondents tested positive for symptoms of PTSD[35, 36]. Most of the traumatic events presented in

Table 2. *Criteria of Posttraumatic Stress Disorder, adopted from DSM-5 manual*

Criterion A: stressor

The person was exposed to: death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence, as follows: (one required)

1 Direct exposure.

2 Witnessing, in person.

3 Indirectly, by learning that a close relative or close friend was exposed to trauma. If the event involved actual or threatened death, it must have been violent or accidental.

4 Repeated or extreme indirect exposure to aversive details of the event(s), usually in the course of professional duties (e.g., first responders, collecting body parts; professionals repeatedly exposed to details of child abuse). This does not include indirect non-professional exposure through electronic media, television, movies, or pictures.

Criterion B: intrusion symptoms

The traumatic event is persistently re-experienced in the following way(s): (one required)

1 Recurrent, involuntary, and intrusive memories. Note: Children older than six may express this symptom in repetitive play.

2 Traumatic nightmares. Note: Children may have frightening dreams without content related to the trauma(s).

3 Dissociative reactions (e.g., flashbacks) which may occur on a continuum from brief episodes to complete loss of consciousness. Note: Children may reenact the event in play.

4 Intense or prolonged distress after exposure to traumatic reminders.

5 Marked physiologic reactivity after exposure to trauma-related stimuli.

Criterion C: avoidance

Persistent effortful avoidance of distressing trauma-related stimuli after the event:(one required)

1 Trauma-related thoughts or feelings

2 Trauma-related external reminders (e.g., people, places, conversations, activities, objects, or situations).

Criterion D: negative alterations in cognitions and mood

Negative alterations in cognitions and mood that began or worsened after the traumatic event: (two required)

1 Inability to recall key features of the traumatic event (usually dissociative amnesia; not due to head injury, alcohol, or drugs).

2 Persistent (and often distorted) negative beliefs and expectations about oneself or the world (e.g., "I am bad," "The world is completely dangerous").

3 Persistent distorted blame of self or others for causing the traumatic event or for resulting consequences.

4 Persistent negative trauma-related emotions (e.g., fear, horror, anger, guilt, or shame).

5 Markedly diminished interest in (pre-traumatic) significant activities.

6 Feeling alienated from others (e.g., detachment or estrangement).

7 Constricted affect: persistent inability to experience positive emotions.

Criterion E: alterations in arousal and reactivity

Trauma-related alterations in arousal and reactivity that began or worsened after the traumatic event: (two required)

1 Irritable or aggressive behavior

2 Self-destructive or reckless behavior

3 Hypervigilance

Table 2. *Criteria of Posttraumatic Stress Disorder, adopted from DSM-5 manual (continued)*

4	Exaggerated startle response
5	Problems in concentration
6	Sleep disturbance
Criterion F: duration	
Persistence of symptoms (in Criteria B, C, D, and E) for more than one month.	
Criterion G: functional significance	
Significant symptom-related distress or functional impairment (e.g., social, occupational).	
Criterion H: exclusion	
Disturbance is not due to medication, substance use, or other illness.	
Specify if: With dissociative symptoms. In addition to meeting criteria for diagnosis, an individual experiences high levels of either of the following in reaction to trauma-related stimuli:	
1	Depersonalization: experience of being an outside observer of or detached from oneself (e.g., feeling as if "this is not happening to me" or one were in a dream).
2	Derealization: experience of unreality, distance, or distortion (e.g., "things are not real").
Specify if: With delayed expression. Full diagnosis is not met until at least six months after the trauma(s), although onset of symptoms may occur immediately.	

these studies on PTSD, such as verbal abuse, massive bleeding in the patient, or stress related to feeling overextended due to an inadequate professional to patient ratio, do not meet the DSM-5 criteria for PTSD. Although these situations may be stressful and may result in negative personal effects, this should not lead to the medicalization of normal human emotional responses or turn to over-diagnosis with potential overtreatment[37]. Witnessing a person´s death, which is stated as a potential risk for PTSD, and providing palliative care might raise feelings of grief and pain in intensive care professionals, in particularly if that person is of a younger age or in a comparable situation to the professionals´ own surroundings. These feelings should be considered as regular human reactions and part of the normal process of dealing with one´s emotion. The majority of individuals recover spontaneously after a traumatic situation[38]. Many people are exposed to loss or potentially traumatic events throughout their life span. However, most of them successfully endure the temporary emotional disturbance, with no apparent interference in functioning at work or in close relationships[39]. This process typically occurs because many individuals show resilience, which is the capacity to stay mentally healthy and to positively adapt after experiencing profound events. Intensive care professionals may have adapted their individual coping strategies to the demanding work environment to find emotional balance. Thus, apart from some exceptional cases, such as being involved in a medical error, a natural disaster, or a war situation, it is very unlikely that intensive care professionals are traumatized by their emotionally demanding work. PTSD, and its related symptoms stemming from war veterans, is completely different from work-related stress in ICU professionals.

THE FOUNDATION OF COMPASSION FATIGUE

In the early 1980s, the term 'compassion fatigue' was used in American policy documents in reference to immigration, and in the early 1990s to describe the lack of interest with homeless people by the general public. In 1992, Carol Joinson, a nurse educator in Texas, USA, described compassion fatigue as the loss of compassion due to repeated exposure to suffering during work[40]. Slightly later, the psychologist Charles Figley, defined this phenomenon as secondary traumatic stress resulting from a deep involvement with a primarily traumatized person because of the "more friendly framing"[41]. Figley proposed in 1995 that compassion fatigue is an excessive empathic reaction after witnessing another´s suffering, resulting in symptoms such as anxiety, irritability, intrusive thoughts, hypervigilance or startle reactions, and avoidance of patient care. Although conceptually different, since then compassion fatigue and secondary traumatic stress have been used interchangeably, with suggested similarities between vicarious traumatization and burnout[11]. While compassion fatigue predominantly has been studied in the nursing field[42, 43], high risks were also found in physicians ranging from 9% to 20%[44, 45].

Some scientists posed critical notes on the empirical understanding of *compassion* as a fundamental element of compassion fatigue, which is not equivalent to *empathy,* as used by Figley[46, 47]. His model identifies empathic ability as the capacity of healthcare providers to notice pain in others, and in a response, project themselves into this emotional energy, thus feeling the pain, grief, desperation, or anger. However, a fundamental and profound theory on the concept of compassion is lacking. Thus, perhaps, it is too much of a good thing being empathic all of the time, with distancing or dehumanization as the result. Additionally, The Professional Quality of Life Scale, the newest modified measuring instrument on compassion fatigue, evaluates items responding to secondary stress[48]. This seems to be insufficient for meeting the concept of compassion in the first place. In the last two decades, compassion fatigue has become a fashionable hype that should be critically reexamined or erased in favor of a new debate on work-related stress among intensive care professionals.

THE POSITIVE APPROACH OF WORK ENGAGEMENT

In 1990 Robert Louis Kahn, an American psychologist, first described ´personal engagement´. He stressed the psychological conditions of personal engagement and disengagement at work. In optimal engagement, the individual's values coincide with the role of performance in all aspects (physical, cognitive, and emotional) while working[49]. In a further development, work engagement has been defined as a positive, fulfilling, work-related state of mind, which is characterized by vigor, dedication, and absorption [26]. Wilmar Schaufeli et al., (2002) stated that "Vigor is characterized by high levels of energy and mental resilience while working, the willingness to invest effort in one's work, and persistence even in the face of difficulties; dedication by being strongly involved in one's work, and experiencing a sense of significance, enthusiasm, inspiration, pride, and challenge; and absorption by being fully concentrated and happily engrossed in one's work, whereby time passes quickly and one has difficulties with detaching oneself from work" [26]. Engaged employees believe in themselves, generate their own positive feedback, set higher goals, have values that match with the organization, and show a sustained healthy state. As illustrated in Figure 1, work engagement with its positive labeled elements is the counterbalance to work-related stress. In general, work engagement is influenced by job autonomy, social support, performance feedback, and personal resources such as self-efficacy, flexibility and adaptability. Work engagement is firmly grounded in the Job-Demands-Resources Model [26].

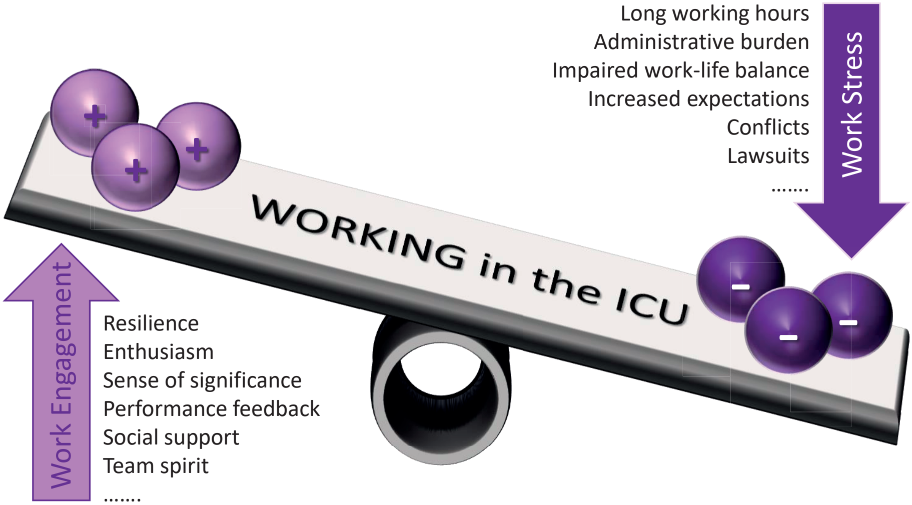

Figure 1. *Work engagement in a counterbalance to work-related stress*

FROM HISTORICAL FACTS TO FUTURE DIRECTION

Healthcare organizations should think of improvements and provide support in daily practice, in addition to the individual activities promoting their well-being, such as self-care in nutrition, sleep, exercise, and spending time with family or friends[4, 8]. The urge of a call for action has been heard and endorsed by all healthcare providers now. Evidence-based interventions are needed to address the most effective contributing factors; however, persuasive randomized controlled trials in this domain have not been performed until now[20]. Probably, there is not one simple or brilliant solution that will fit all. Stimulating a healthy work environment is a multidimensional challenge, a traffic map with multiple roads leading to the same point of interest. Some promising suggestions are regulating the environment and workload, having adequate administrative support systems, and finding meaning in work [4]. Education and early recognition of the stress-related consequences among intensive care professionals could provide some answers as well. Furthermore, the personal development of resilience might provide the basic adaptability to flourish in the hectic and ever demanding intensive care unit. ICU professionals have learned to respond in these emotionally difficult situations. Indeed, we must take care of ourselves[50], however, we should not forget that working in the intensive care unit can be inspiring and pleasurable too.

REFERENCES

1. Sprung CL, Cohen R, Marini JJ. Excellence in Intensive Care Medicine. Critical Care Medicine 2016;44(1):202-06.
2. Curtis JR, Ciechanowski PS, Downey L, et al. Development and evaluation of an interprofessional communication intervention to improve family outcomes in the ICU. Contemp Clin Trials 2012;33(6):1245-54.
3. West CP, Huschka MM, Novotny PJ, et al. Association of perceived medical errors with resident distress and empathy - A prospective longitudinal study. Jama-Journal of the American Medical Association 2006;296(9):1071-78.
4. Spickard Jr A, Gabbe SG, Christensen JF. Mid-career burnout in generalist and specialist physicians. JAMA 2002;288(12):1447-50.
5. Böckerman P, Ilmakunnas P. Interaction of working conditions, job satisfaction, and sickness absences: evidence from a representative sample of employees. Social Science and Medicine 2008;67(4):520-28.
6. Legha RK. A history of physician suicide in America. Journal of Medical Humanities 2012;33(4):219-44.
7. Gunter TD. Physician Death by Suicide: Problems Seeking Stakeholder Solutions. Available at SSRN 2761854 2016.
8. Changes in burnout and satisfaction with work-life balance in physicians and the general US working population between 2011 and 2014. Mayo Clinic Proceedings; 2015. Elsevier.
9. Medscape. Lifestyle Report 2016 2016 [Available from: http://www.medscape.com/features/slideshow/lifestyle/2016/public/overview#page=2.
10. Meynaar I, van Saase J, Feberwee T, et al. Burnout among dutch intensivists. Neth. Journal of Critical Care, 2015;24(1):12-17
11. van Mol MMC, Kompanje EJO, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units: A Systematic Review. PloS one 2015;10(8):e0136955.
12. Sarafino EP. *Health Psychology. Biopsychosocial Interactions*. 4th ed. New York: John Wiley & Sons, INC., 2002.
13. Piquette D, Reeves S, Leblanc VR. Stressful intensive care unit medical crises: How individual responses impact on team performance. Critical Care Medicine 2009;37(4):1251-55.
14. Cannon WB. Bodily changes in pain, hunger, fear and rage. 1929.
15. Selye H. The stress concepts. Past, present and future In Stress Research(Ed By Cooper CL) United Kingdom: John Wiley 1983.
16. Lazarus RS. From psychological stress to the emotions: A history of changing outlooks. Annual review of psychology 1993;44(1):1-22.
17. Schaffner AK. *Exhaustion: A History*: Columbia University Press, 2016.
18. Schaufeli WB, Leiter MP, Maslach C. Burnout: 35 years of research and practice. Career development international 2009;14(3):204-20.
19. Leiter MP, Bakker AB, Maslach C. *Burnout at Work: A Psychological Perspective*: Psychology Press, 2014.
20. Moss M, Good VS, Gozal D, et al. An official critical care societies collaborative statement—burnout syndrome in critical care health-care professionals: a call for action. CHEST Journal 2016;150(1):17-26.
21. Embriaco N, Azoulay E, Barrau K, et al. High level of burnout in intensivists: prevalence and associated factors. American Journal of Respiratory and Critical Care Medicine 2007;175(7):686-92.
22. Bellieni CV, Righetti P, Ciampa R, et al. Assessing burnout among neonatologists. J Matern-Fetal Neonatal Medicine 2012;25(10):2130-34.
23. Guntupalli KK, Fromm Jr RE. Burnout in the internist-intensivist. Intensive Care Medicine 1996;22(7):625-30.
24. Barbosa FT, Leao BA, Tavares GMS, et al. Burnout syndrome and weekly workload of

on-call physicians: Cross-sectional study. Sao Paulo Medical Journal 2012;130(5):282-88.

25. Galvan ME, Vassallo JC, Rodriguez SP, et al. Physician's burnout in pediatric intensive care units from Argentina. Arch Argent Pediatr 2012;110(6):466-73.
26. Schaufeli WB, Salanova M, González-Romá V, et al. The measurement of engagement and burnout: A two sample confirmatory factor analytic approach. Journal of Happiness studies 2002;3(1):71-92.
27. Seidler A, Thinschmidt M, Deckert S, et al. The role of psychosocial working conditions on burnout and its core component emotional exhaustion–a systematic review. Journal of Occupational Medicine and Toxicology 2014;9(1):1.
28. Crocq M-A, Crocq L. From shell shock and war neurosis to posttraumatic stress disorder: a history of psychotraumatology. Dialogues in clinical neuroscience 2000;2(1):47-55.
29. Da Costa JM. On irritable heart: a clinical study of a form of functional cardiac disorder and its consequences. The American Journal of Medicine 1951;11(5):559-67.
30. Beard GM. A Practical Treatise on Nervous Exhaustion,(Neurasthenia;) Its Symptoms, Nature, Sequences, Treatment. American Journal of Psychiatry 1880;36(4):521-a-26.
31. Lewis T. The" effort syndrome," its signs and symptoms, contrasted with those with heart disease. Soldier's heart and effort syndrome London: Shaw and Sons 1918:10-26.
32. American Psychology Association, (APA), Diagnostic and statistical manual of mental disorders (DSM-5®). 2013: American Psychiatric Pub.
33. National Center for Post Traumatic Stress Disorder (2014). For Professionals; PTSD overview and Assessment. Retrieved on 02-09-2016 from http://www.ptsd.va.gov/
34. Kessler RC, Berglund P, Demler O, et al. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Archives of general psychiatry 2005;62(6):593-602.
35. Czaja AS, Moss M, Mealer M. Symptoms of posttraumatic stress disorder among pediatric acute care nurses. Journal of pediatric nursing 2012;27(4):357-65.
36. Posttraumatic stress disorder in the nursing population: a concept analysis. Nursing forum; 2013. Wiley Online Library.
37. Nimmo A, Huggard P. A Systematic Review of the Measurement of Compassion fatigue, Vicarious Trauma, and Secondary Traumatic Stress in Physicians. Australasian Journal of Disaster and Trauma Studies 2013;2013:1.
38. Sijbrandij M, Olff M, Reitsma JB, et al. Treatment of acute posttraumatic stress disorder with brief cognitive behavioral therapy: a randomized controlled trial. American Journal of Psychiatry 2007.
39. Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? American psychologist 2004;59(1):20.
40. Joinson C. Coping with compassion fatigue. Nursing 1992;22(4):116, 18-9, 20.
41. Figley CR. *Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized*. New York: Routledge, 1995.
42. Young JL, Derr DM, Cicchillo VJ, et al. Compassion satisfaction, burnout, and secondary traumatic stress in heart and vascular nurses. Critical Care Nursing Quarterly 2011;34(3):227-34.
43. Elkonin D, Lizelle. Positive and negative emotional responses to work-related trauma of intensive care nurses in private health care facilities. Health SA Gesondheid 2011;16(1):1-8.
44. Huggard P, Dixon R. Tired of Caring": the impact of caring on Resident Doctors. Australasian Journal of Disaster and Trauma Studies 2011;3:105-12.
45. El-bar N, Levy A, Wald HS, et al. Compassion fatigue, burnout and compassion satisfaction among family physicians in the Negev area-a cross-sectional study. Israel journal of health policy research 2013;2(1):1.

46. Sinclair S, Norris JM, McConnell SJ, et al. Compassion: a scoping review of the healthcare literature. BMC palliative care 2016;15(1):1.
47. Van Mol MM, Brackel M, Kompanje EJ, et al. Joined forces in person-centered care in the intensive care unit: a case report from the Netherlands. Journal of Compassionate Health Care 2016;3(1):1.
48. Sabo B. Reflecting on the concept of compassion fatigue. Online J Issues Nurs 2011;16(1):1.
49. Kahn WA. Psychological conditions of personal engagement and disengagement at work. Academy of management journal 1990;33(4):692-724.
50. Pastores SM. Burnout Syndrome in ICU Caregivers: Time to Extinguish! CHEST Journal 2016;150(1):1-2.

8

Counterbalancing to work-related stress; work engagement among intensive care professionals

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2017 Minor revision.

ABSTRACT

Background and objectives

Working in an Intensive Care Unit (ICU) is increasingly complex and is also physically, cognitively and emotionally demanding. Although the negative emotions of work-related stress have been well studied, the opposite perspective of work engagement might also provide valuable insight. This study focuses on the work engagement of ICU professionals and aims to explore how job resources and demands are associated with work engagement while determining the advantageous personal resources required for work engagement.

Methods

This was a cross-sectional survey study among ICU professionals in a single-centre university hospital. Work engagement was measured by the Utrecht Work Engagement Scale, which included items about opinions related to the respondent's work environment. Additionally, 14 items based on the Jefferson Scale of Physician Empathy were included to measure empathic ability. A digital link to the questionnaire was sent in October 2015, and the sample size included 262 ICU nurses and 53 intensivists.

Results

The overall response rate was 61% (n=193). Work engagement was negatively related both to cognitive demands among intensivists and to emotional demands among ICU nurses. No significant relationship was found between work engagement and empathic ability; however, agreeable, conscientious and emotionally stable persons showed strong correlations with work engagement. Only the number of hours worked per week remained as a confounding factor, with a negative effect of workload on work engagement after controlling for the effect of weekly working hours.

Conclusion

Work engagement counterbalances work-related stress reactions. The relatively high workload in ICUs, coupled with an especially heavy emotional burden, may be acknowledged as an integral part of ICU work. This workload does not affect the level of work engagement, which was high for both intensivists and nurses despite the known high job demands. Specific factors that contribute to a healthy and successful work life among ICU professionals remain to be discovered.

Keywords Empathy, ICU professionals, personality, well-being, work engagement, work-related stress

INTRODUCTION

Working in an Intensive Care Unit (ICU) is increasingly complex and is also physically, cognitively and emotionally demanding for the professionals[1-3]. In addition to being confronted by end-of-life issues, ethical decision making, continuous human suffering, disproportionate care, miscommunication, and demanding family members, the ICU work environment has become increasingly technical[4]. All these aspects require that ICU professionals maintain an extended skill-set (e.g., advanced life sustaining medical therapies, extended communication skills, and ethical deliberations). Furthermore, the changing perspective on healthcare (from provider-focused norms to person-centered care) often requires new competencies in ICU staff[5]. These raising demands, together with persistent work-related stress, reduce individual job satisfaction, and augment the risk of stress reactions, long-term absenteeism and burnout[6-8]. This stress process could ultimately result in poor individual health and less successful working, leading to professionals leaving their jobs and impacting society due to lost economic investment[9-12].

In a recent systematic literature review on emotional distress among ICU professionals it was suggested that the true magnitude of work-related stress, and burnout in particular, remains unclear due to a lack of unity in concepts and related measurements[4]. Until now, most research on work –related stress in ICUs has been directed at organizational and job-related factors[13]. Although the negative emotions of work-related stress have been well studied, an opposite perspective might also provide valuable insight. It seems of utmost importance to focus research on the motivational process affecting personal health positively[14-16]. Work engagement is operationalized as a positive work-related state of mind and is characterized by vigour, dedication, and absorption[16, 17]. Vigour represents a high level of energy and mental resilience while working; dedication refers to experiencing a sense of significance, enthusiasm, and challenge; and absorption is characterized by being fully focused and absorbed in work[18]. Exploring and understanding personal factors might provide insights into new interventions that affect personal health and promote successful working. Therefore, we commenced to study the work engagement of ICU professionals in relationship to personal resources.

STUDY AIMS

This study focuses on the work engagement of ICU professionals and aims to 1) explore how job resources and job demands are associated with work engagement, and 2) determine the advantageous personal resources required for work engagement. Based on previous findings, five hypotheses (Table 1) were formulated for work engagement (1 and 2)[18, 19] and for personal resources (3, 3a, and 3b)[20-22]. The conceptual model is illustrated in Figure 1.

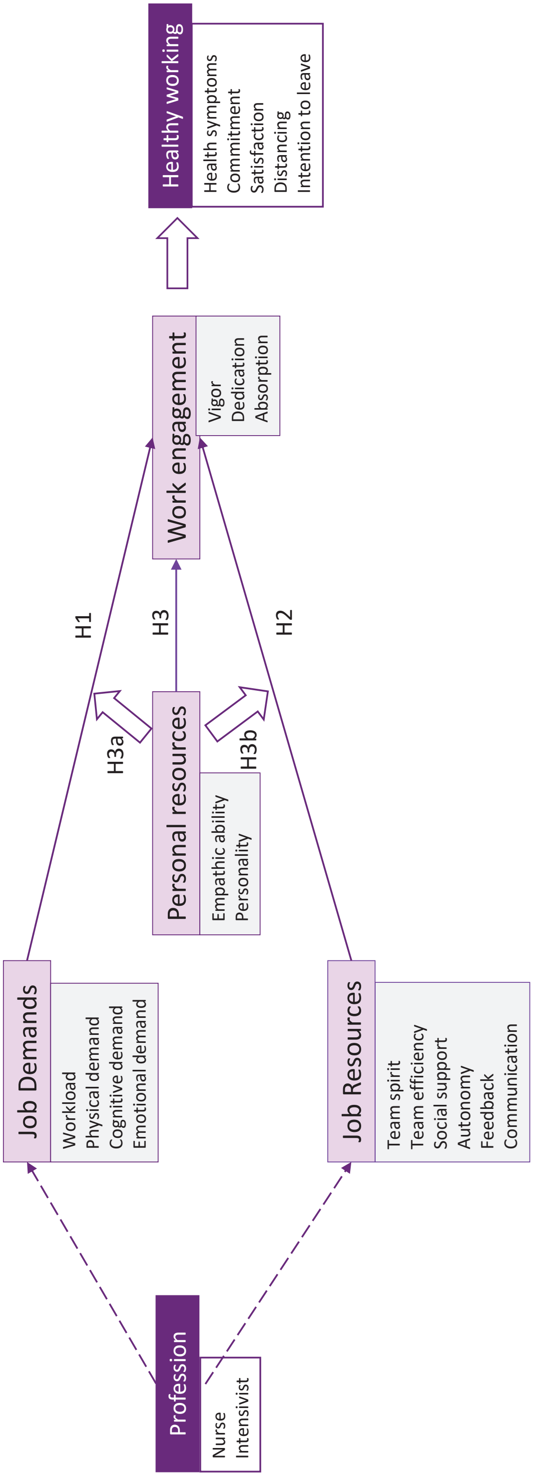


Figure 1. *Conceptual model*

Table 1. *Study Hypotheses*

1	Job demands are negatively related to work engagement; when experiencing higher physical, cognitive and emotional demands the level of work engagement is decreased.
2	Job resources are positively related to work engagement; when experiencing higher team spirit, team efficacy, social support, autonomy, performance feedback, and better peer communication, the level of work engagement is increased.
3	Personal resources, i.e., personality traits and empathic ability, have main effects on work engagement; agreeableness, extraversion, conscientiousness, openness, and empathic ability have positive effects, neuroticism has a negative effect.
3a	Personal resources have a moderating effect on the relationship of job demands and work engagement; having more favorable personal resources decrease the negative main effect of job demands on work engagement.
3b	Personal resources have a moderating effect on the relationship of job resources and work engagement; having more favorable personal resources increase the positive main effect of job resources on work engagement.

METHODS

Approval by the Medical Ethics Committee was not needed as the rules laid down in the medical Research Involving Human Subjects Acts (also known by its Dutch abbreviation WMO) did not apply to this study. All participants consented to participate through completion of the survey.

STUDY DESIGN

The design of this study was a cross-sectional online survey study of ICU professionals at a single-centre university hospital with one of the largest adult ICUs in the Netherlands. A short introduction and a plain hyperlink to the tailored questionnaire were distributed in October 2015 to the work email addresses provided by ICU management. Data were gathered during four consecutive weeks. Weekly individual reminders and general feedback on the response rates were provided twice to encourage ICU professionals to participate. To guarantee confidentiality, a strict separation of the research data and personal data files was maintained throughout the entire process.

STUDY POPULATION

The ICU setting under study contains 48 operational beds, divided into four units: two mixed units for neurological, neurosurgical, transplantation, general and trauma surgery, and medical patients; the cardio-thoracic surgery ICU; and the cardiology ICU. All professionals, i.e., 162 nurses/students in the mixed ICUs, 46 nurses/students in the thoracic ICU, 54 nurses/students in the cardiac ICU and 53 intensivists/medical doctors, who worked for at least 12 hours/week (0.3 full time equivalent), were eligible to participate in the study. Professionals not regularly working in the ICU were excluded from the study.

MEASURES

The questionnaire used was based on a composition of existing validated reliable questionnaires and reflected the diverse concepts of interest. Most items on job demands (9 items) and job resources (21 items) stemmed from the Questionnaire on the Experience and Evaluation of Work[23] and the National Working Conditions survey[24], both generally used in the Netherlands for psychosocial risk evaluation at work[16]. The subscales have proven good scale reliabilities, for example, social support of coworkers with three items (e.g., ´Do you feel recognized and appreciated by colleagues?´) with $\alpha = .85$, performance feedback with three items (e.g., ´Do you get enough information about the results of your work?´) with $\alpha =. 80$, and autonomy with seven items (e.g., ´Do you have enough freedom and independence in your work?´) with $\alpha = .90$. The Revised NEO Personality Inventory, with 60 self-rated items on a five-point Likert-type scale (1=totally disagree; 5=totally agree), was added to measure the Big V personality traits: neuroticism, extraversion, openness, agreeableness, and conscientiousness [25]. The internal consistencies of the NEO-PI-R (the 60 item domain only version) as reported in the manual were satisfactory (ranging from .79 to .83). Furthermore, the test retest reliability has been proven to suffice for all five dimensions. The Jefferson Scale of Physician Empathy was partly included, with 13 self-rated items on a five-point Likert-type scale (1=never; 5=always), to measure empathic ability in three subscales[26]. Cognitive empathy with five items (e.g., ´Understanding the feelings of patients and their relatives is important in caring.´), emotional empathy with six items (e.g., ´I do not allow myself to be affected by intense emotional relationships with patients or their relatives.´), and perspective taking with two items (e.g., ´It's hard for me to see things from the perspective of the patient or the patient's family.´ All items related to empathy were rephrased and applied to the ICU environment and were thereafter pilot tested for comprehensiveness ($n = 5$) so that the professionals could better understand the statements provided. Validity nor reliability is known on these adapted subscales. Work engagement was measured using the Utrecht Work Engagement Scale with 17 self-rated items on a five-point Likert-type scale (1=never; 5=always) in three subscales[27]. Cronbach´s alpha of vigour (6 items, e.g., ´At work, I feel like I am bursting with energy.´) ranged between .81 and .90, dedication (5 items, e.g., ´I am enthusiastic about my job.´) ranged between .88 and .95, and absorption (6 items, e.g., ´I get carried away when I am working.´) ranged between .70 and .88. Five items on sleeping quality, health quality and sickness absence were taken together to measure a healthy state. Successful working (five items) was measured as satisfaction in work, team commitment, institute commitment, self-distancing, and intention to leave work. Although ordinal Likert-type rating scales were used in all subscales, e.g., 'Never' to 'Always' with corresponding numbers one through five, these were considered as rational scales[28]. Previous studies have shown this method as feasible, using parametric statistical tests to provide subgroup analyses and to compare with benchmarks[29]. All items were in the Dutch language.

A representative study sample (*n* = 1,213) of the Dutch working population was used as a benchmark[16]. This benchmark reflected the total industry according to the classifications of the National Bureau of Statistics. The largest groups were ´health and welfare´ (17.4%), ´commercial services´ (14.4%), and ´retail and repair´ (13.1%). The employees in the general benchmark working in ´health and welfare domain ´ acted as the benchmark for empathic ability.

DATA ANALYSIS

The data were analyzed using Microsoft® SPSS version 22 with the classical definition of $p<.05$ applied for statistical significance. Reliability was tested with Cronbach´s alpha, descriptive statistics (means, standard deviations, and percentages) were calculated[30]. The relationships between the means of subscale scores as independent variables and work engagement as the outcome variable were analyzed by Pearson's (i.e., normally and linear distributed variables) and Spearman´s (i.e., ordinal scale or non-normally distributed variables) correlation coefficients. Variable correlations below .3 were considered weakly, between .3 and .5 moderately, and between .5 and 1.0 strongly associated[30]. Furthermore, linear regression models of work engagement as a function of potential personal and professional risk factors were constructed using a stepwise method. The total model was built after checking the assumptions of non-zero variance and multicollinearity of the variables, homoscedasticity from the graph of residual terms, and independent errors with the Durbin-Watson test. An analysis of covariance was performed (ANCOVA) to control the bias of confounding variables. To run the ANCOVA, workload was split into three categories based on frequencies (approximately 25% low, 50% middle and 25% high workload). Two additional assumptions were checked: the independence of the covariate and the independent variable; and the homogeneity of regression slopes[30]. Finally, moderation was tested with the PROCESS-tool.

RESULTS

DESCRIPTIVE STATISTICS AND SCALE RELIABILITY

The overall response rate was 61.3% (n=193) and none of the responses had to be excluded because of an incomplete questionnaire. Seven respondents were excluded from further analysis because of limited working hours or because they had an administrative or supporting staff occupation. Most respondents were female, ICU nurses, middle-aged, Dutch, college-level educated and living with a partner and children. Table 2 presents all background characteristics of the respondents. The respondents from the four ICUs showed the same characteristics however, the characteristics between ICU nurses and intensivists differed in the male-female ratio (0.39 versus 1.13, p<.05), educational level

Table 2 *Demographic characteristics of respondents*

	Respondents N = 193	
	Count (%)	Mean (St. dev) range
Woman	132 (68.4)	
Age		44.5 (11.79) 22-67
Ethnic background Dutch	188 (97.4)	
Family situation		
Families with children	82 (42.5)	
Single with children	6 (3.1)	
Married/living with partner	68 (35.2)	
Single	37 (19.2)	
Education		
Non/Primary school	11 (5.7)	
GCSE	11 (5.7)	
A-levels	31 (16.1)	
College	103 (53.4)	
University	37 (19.2)	
Occupation		
Nurse	146 (75.6)	
Doctor	32 (16.6)	
Other	15 (7.6)	
Working hours per week (contract)		31.1 (9.1) 0-48
Working hours per week (reality)		33.6 (11.7) 0-90
Years working in the ICU		14.1 (10.1) 1-41
ICU team, working in		
Cardio-thoracic surgery ICU	29 (15)	
Mixed ICU, unit 1	41 (21.2)	
Mixed ICU, unit 2	44 (22.8)	
Cardiology ICU	43 (22.3)	
All units	36 (18.7)	
Health indication		
Excellent	10 (5.2)	
Very good	49 (25.4)	
Good	116 (60.1)	
Reasonably well	17 (8.8)	
Bad	1 (.5)	
Good sleeping quality		
Disagree	37 (19.2)	
Neutral	32 (16.6)	
Agree	124 (64.3)	

(mostly college versus all university, p<.001 respectively), mean number of years working in ICU (15.4 ±10.1 versus 8.1 ±8.02, p<.001), and the mean overtime hours worked (0.20 ±3.0 versus 11.97 ±15.9).

The scale reliability, represented as Cronbach's *α*, and the means of job demands, job resources, personal resources, work engagement, and healthy work are shown in Table 3. The Cronbach´s *α* values were 0.86 for vigour, 0.89 for dedication, and 0.82 for absorption, which indicated reliable subscales. Only emotional empathy (*α*=0.65) and the ICU-specific subscale (*α*=0.58) showed limited internal consistency, while most other variables exceeded 0.70.

INDEPENDENT VARIABLES: JOB DEMANDS AND JOB RESOURCES

The mean job demands were 2.4 (±0.7), 2.9 (±0.6), and 2.5 (±0.6) for the physical, cognitive and emotional domains respectively (Table 3). These job demands exceeded the general Dutch benchmark, with 2.0, 2.5, and 1.8, respectively. However, 89.7%, 98.8%, and 94.3% of the participants reported rarely having problems with the physical, cognitive, and emotional demands, respectively. Only 3.1% of the ICU professionals reported the workload to be too high, which was considerably lower when compared to the 3.6% reported by the benchmark.

As also shown in Table 3, the job resources of social support, communication, team efficacy, and team spirit resulted in similar means in the ICU professionals compared to the benchmark, while both performance feedback (2.3±0.7) and autonomy (2.5±0.7) scored lower than the average for Dutch employees (2.7 and 2.9 respectively, non-significant). ICU professionals showed equal scores on the cognitive component (3.9 compared to a 4.0 benchmark, non-significant) and a lower score on the emotional component (3.0 compared to 3.8 benchmark, p<.05).

OUTCOME VARIABLES: WORK ENGAGEMENT AND HEALTHY WORK

Regarding work engagement, ICU professionals scored the same on vigour (3.5±0.7), higher on dedication (3.9±0.7) and lower on absorption (2.8±0.7) compared to the average Dutch employee (3.7, 3.5, and 3.4, respectively). Although the results for the intensivists and ICU nurses were predominantly the same, a statistically significant higher mean for physical demand was observed in nurses. In addition, the nurses scored lower on dedication and absorption.

The same results were found for healthy work among intensivists and ICU nurses. Both professions reported only few stress-related symptoms such as self-distancing, health complaints and sleeping disorders. Almost 55% of the respondents reported absenteeism in the past year, with a statistically significant difference of 60% for ICU nurses and 31% for intensivists. Further details on absenteeism were not analysed because of high non-response rates. Six percent of participants were planning to leave their job in the upcoming year.

THE EFFECT OF AGE, YEARS OF EXPERIENCE, AND WORKING HOURS

The covariates of age and years of experience showed non-significant results. Only the number of hours worked per week remained as a confounding factor, with a negative effect of workload on work engagement after controlling for the effect of the number of hours worked per week (F(1,179)=5.40, p=.02, 95% confidence interval [0.00;0.02], η^2=.03). The estimated means were 3.49 (±0.08), 3.46 (±0.05), and 3.23 (±0.74) for the low, middle, and high workload, respectively.

HYPOTHESIS TESTING

A weak negative correlation was found for total job demands and work engagement (*r*=-.20, p<.01) for all respondents combined. However, the cognitive demands for intensivists only (*r*=-.46, p < .001) and the emotional demands for ICU nurses only (*r*=-.27, p<.00) were moderately and weakly related to work engagement. Moderately positive correlations between job resources and work engagement were found for team efficacy (r=.37 p<.00) and team spirit (r=.36 p<.00), whereas the personal resource of empathy was non-significant and personality was moderately negatively correlated for Neuroticism (r= -.38 p<.00).

In all ICU professionals, the personality traits showed significant correlations to work engagement and the subscales of vigour, dedication and absorption. Mean cognitive empathy correlated weakly to work engagement (*r*=.18, p<.05). However, emotional empathy, perspective taking nor the ICU specific items were statistically significant. The model summary of multiple linear regression analysis on work engagement is shown in Table 4. Highly work-engaged respondents were more likely to experience good team efficacy (β=0.14, p=.01), to feel higher team spirit (β=0.13, p=0.03), to be more conscientious (β=0.21, p=.00), to be more agreeable (β=0.35, p=.00), and to have an emotionally stable personality (neuroticism) (β=-0.23, p=.00). The most confined multiple linear regression model was found to have an explained variance of 34% (adjusted r^2=.32).

Furthermore, no moderation effect was found for the personality factors of conscientiousness, agreeableness or neuroticism in the relationship between job demands and work engagement. Although the conditional effects of workload moderated by the personality factors were found to be statistically significant for team efficacy and team spirit, no interaction terms produced an effect on workload [30].

Table 3 *Scale reliabilities and means (± Standard deviations) on job demands, job resources, personal resources, work engagement, and healthy working*

	Scale reliability	Overall n=186	Nurses n=146	Doctors n=32	Bench mark#
Job demands	.74				
Workload	n.a	3.47 (±0.6)	3.49 (±0.6)	3.53 (±0.6)	
Physical demand	n.a	2.40 (±0.7)**	2.54 (±0.7)*	1.84 (±0.7)	2.0
Cognitive demand	n.a	2.94 (±0.6)**	2.95 (±0.6)	2.98 (±0.7)	2.5
Emotional demand	n.a	2.51 (±0.6)**	2.53 (±0.6)	2.57 (±0.7)	1.8
Job resources					
Social support	.76	3.73 (±0.8)	3.79 (±0.7)	3.55 (±0.8)	3.5
Feedback	.77	2.32 (±0.6)**	2.30 (±0.7)	2.36 (±0.6)	2.7
Autonomy	.87	2.53 (±0.7)**	2.53 (±0.7)	2.34 (±0.8)	2.9
Communication	.71	3.14 (±0.6)	3.11 (±0.6)	3.17 (±0.7)	3.3
Team efficiency	.80	3.37 (±0.7)	3.37 (±0.7)	3.41 (±0.7)	3.5
Team spirit	.85	3.88 (±0.7)	3.99 (±0.7)	3.53 (±0.7)	3.8
Personal resources					
Empathic ability	.73				
Cognitive empathy	.87	3.95 (±0.6)	4.00 (±0.6)	4.02 (±0.6)	4.0
Emotional empathy	.65	3.03 (±0.5)**	3.05 (±0.4)	3.04 (±0.5)	3.8
Perspective taking	n.a	2.67 (±0.4)	2.68 (±0.4)	2.73 (±0.3)	
ICU-specific	.58	2.27 (±0.5)	2.30 (±0.5)	2.16 (±0.5)	
Personality factors					
Neuroticism	.83	2.34 (±0.6)	2.30 (±0.6)	2.32 (±0.5)	2.5
Extraversion	.80	3.62 (±0.5)	3.64 (±0.5)	3.61 (±0.6)	3.6
Openness	.76	3.82 (±0.5)**	3.76 (±0.5)*	4.11 (±0.6)	3.4
Agreeableness	.70	3.93 (±0.4)	3.95 (±0.4)	3.87 (±0.5)	3.9
Conscientiousness	.78	3.98 (±0.4)	3.99 (±0.4)	4.00 (±0.4)	3.8
Work engagement					
Vigor	.86	3.53 (±0.7)	3.51 (±0.6)	3.70 (±0.6)	3.7
Dedication	.89	3.87 (±0.7)**	3.83 (±0.7)*	4.11 (±0.6)	3.5
Absorption	.82	2.83 (±0.7)**	2.74 (±0.6)*	3.26 (±0.6)	3.4
Healthy working					
Health symptoms	n.a	1.76 (±1.0)	1.71 (±1.0)	1.81 (±1.0)	
Work satisfaction	n.a	3.97 (±0.7)	3.97 (±0.7)	4.00 (±0.8)	
Team commitment	n.a	3.89 (±0.7)	3.90 (±0.6)	3.94 (±0.7)	
Institute commitment	n.a	3.30 (±0.7)	3.24 (±0.7)	3.41 (±0.9)	
Intention to leave	n.a	1.76 (±1.0)	1.75 (±0.9)	1.81 (±1.1)	2.2
Self-distancing	.74	1.65 (±0.5)	1.70 (±0.5)*	1.51 (±0.4)	1.5

n.a not applicable

General Dutch employees served as benchmark, except for cognitive and emotional empathy which were general healthcare practitioners.

[*] Difference is significant at 0.05 level (2-tailed) between nurses and doctors

[**] Difference is significant at 0.05 level (2-tailed) overall respondents compared to benchmark

Table 4 *Model summary of multiple linear regression analysis on work engagement*

	β (±SE)	95% CI	P
Model 1, $r^2 = 0.341$, adjusted r^2=.32, p=0.000			
Team efficacy	0.14 (±0.06)	0.05; 0.28	0.006
Team spirit	0.13 (±0.06)	0.01; 0.24	0.029
Agreeable personality	0.35 (±0.09)	0.08; 0.42	0.004
Conscientious personality	0.21 (±0.08)	0.09; 0.42	0.003
Emotionally instable personality	-0.23 (±0.07)	-0.34; -0.09	0.001
Model 2, $r^2 = 0.407$, adjusted r^2=.38, p=0.001			
Step 1			
Team efficacy	0.09 (±0.06)	0.04; 0.37	0.016
Team spirit	0.09 (±0.06)	-0.00; 0.33	0.055
Agreeable personality	0.20 (±0.08)	-0.26; 0.01	0.075
Conscientious personality	0.16 (±0.08)	-0.03; 0.22	0.144
Emotionally instable personality	-0.12(±0.07)	-0.03; 0.21	0.133
Step 2, enter			
IC-specific	-0.29 (±0.08)	-0.44; -0.14	0.000
Resilience	0.03 (±0.07)	-0.11; 0.17	0.661
Social support	0.02 (±0.06)	-0.10; 0.14	0.721
Autonomy	0.06 (±0.05)	-0.04; 0.15	0.254

Abbreviations: SE (Standard Error), CI (confidence interval), P (p-value, significant at 0.05 level)

DISCUSSION

The overall aim of this study was to explore the relationships between job demands, personal resources and work engagement among the ICU professionals. Job demands were negatively related to work engagement; however, no significant relationship was found between personal resources and work engagement.

The results showed that there were relatively high physical, cognitive and emotional job demands in the ICU; in contrast, these job demands were not found to be problematic for most respondents. It seemed that a workload with a high emotional burden is acknowledged as an integral part of ICU work. This was also reflected by minimally reported symptoms of stress in the current study. Both ICU nurses and intensivists responded within normal limits for vigour and were highly dedicated to their jobs. A longitudinal study indicated similar results, with relatively high or average levels of work engagement[31]. A low absorption in nurses was identified in the current study which might be explained by the type of their work situation, including having many different tasks, facing sometimes hectic and life-threatening demands, experiencing continuous alarms, needing to divide their attention between technical and psychosocial aspects of work, and dealing with multidisciplinary requests for help or information. Thus, it might be difficult to experience flow while working in an ICU.

Overall, the relationships between the independent variables (i.e., job demands and job resources), and the primary outcome (i.e., work engagement) confirmed the findings in previous studies[16, 18, 20, 29]. As outlined in the introduction, it was assumed that job demands were negatively related to work engagement (Hypothesis 1). The results that were found partly supported this assumption, in that a cognitive demand for intensivists and an emotional demand for ICU nurses were negatively related to the work engagement. Therefore, the level of work engagement decreased if higher physical, cognitive and emotional demands were experienced. Job resources were assumed to relate positively with work engagement (Hypothesis 2). The results mainly supported this assumption, since both intensivists and ICU nurses showed positive relationships between job resources and work engagement. The level of work engagement increased when experiencing higher team spirit, team efficacy, social support, autonomy, performance feedback, and better peer communication. These findings were consistent with recent research, stating that employees with sufficient job resources will feel an increased sense of self-efficacy, important to the organization, and optimistic about their future [18 20]. Therefore, with good team spirit and optimal team efficacy, ICU professionals will be able to flourish and focus on the provision of excellent care[1, 32].

The importance of personal resources becomes clear when considering that employees in one working unit or hospital are exposed to the same organizational and job-related circumstances, sometimes demonstrating differences in their reactions to work-related stress and their level of work engagement. Personal resources, such as personality traits, might partly explain these differences[33]. The personality traits in the ICU professionals reflected the normal population[25, 34]. As expected, the personality traits of agreeableness and conscientiousness had positive main effects while neuroticism had a negative main effect (Hypothesis 3). However, none of these personal resources had a moderating effect on the relationship between job demands and work engagement (Hypothesis 3a) or on the relationship between job resources and work engagement (Hypothesis 3b). The relationships between neuroticism on both work engagement and a healthy states showed moderately negative correlations. These associations could be explained by the general likelihood of persons with higher levels of neuroticism to experience negative emotions or the probability that they will perceive their environment as more stressful than can be managed by their poor coping abilities. For instance, neuroticism has been linked to burnout in ICU nurses[35], as they view their work as being more stressful and are less likely to seek help from friends or colleagues. This finding is consistent with studies on work-related stress in physicians[36]. Contrary to the negative impact of neuroticism, the personality traits of agreeableness and conscientiousness contributed substantially and positively to work engagement. This finding might help establish an employee profile that has a low vulnerability to stressful situations and that is particularly responsive with a compassionate attitude towards other persons[37]. Although the data mostly support the hypotheses, it might be argued to be more about the hospital culture than the ICU professionals themselves[38]. A study on team climate suggested a positive relationship between a team-satisfaction-oriented culture and a low level of work-related stress[39]. Since team spirit, team efficacy, and social support scored high in current study, this might also be reflective of the high scores on work engagement.

ICU professionals showed remarkably low scores in emotional empathy, whereas their cognitive empathy matched those of general healthcare providers. Consequently, they understood the patients and relatives but kept themselves at a certain emotional distance. This might be interpreted as being a protective reaction for one´s own emotional health[40]. Excessive empathy also has another side, leading to over-engagement, which can be damaging to the professionals´ well-being[41]. Revealing diminished emotional empathy is of the utmost importance in the performance of intensive and invasive treatments[5, 42]. Although preliminary, it seemed that ICU professionals used this strategy to cope with the emotional demands of their work environment.

In contrast to the previously reported work-related stress levels and prevalence of burnout, in this study, a high work engagement and low levels of the symptoms of stress were observed. Apparently, ICU professionals learned to cope with the stress of their work environment. Because burnout has not been measured, conclusions based upon burnout cannot be drawn. These results were not consistent with the current tendency to emphasize the stress levels in healthcare; however, these results might be somewhat disproportionate. In addition, resilience might also decrease the development of work-related stress in ICU professionals[43]. Resilience is considered as the ability to maintain mental equilibrium, which is an active and flexible process of the adaptation to life changes, and operates as a protective factor against psychological distress and mental disorders[44]. It is closely related to vigour, energy, motivation, and personal strength, which enables one to cope with stressful situations when confronted with danger or suffering. Subsequently, this ability to adopt and self-manage the challenging situations in an ICU, might positively influence the emotional health of the clinical professionals.

PRACTICAL IMPLICATIONS

If ICU professionals have the personality traits that match the job, this might result in improved workplace efficiency, work engagement and staff retention. Agreeable, conscientious and emotionally stable persons might personify the characteristics needed to implement the appropriate interventions and coping strategies that address workplace stressors. Accordingly, providing management team input to create a stable and engaged team may help address the high emotional demands of the ICU. Thus, the quality of care may improve. However, a team composed of professionals with the 'right' profile is difficult to establish and maintain. Due to work-related stress, even the most resilient employees might potentially and gradually lose their positive mind-setting and emotions while working. Therefore, preventive strategies that support the professionals are needed to underscore the importance of their (emotional) health[4].

STUDY LIMITATIONS

There are certain limitations that need to be acknowledged in the present study. First, because of the cross-sectional design, an interpretation of the causality in the relationships between variables is not possible. Longitudinal studies are needed to understand the causal and reciprocal relationships between the constructs and to validate the findings over time. Second, some of the non-responses might have been due to apathy, a negative work attitude or even burnout. It could be speculated, in the context of this healthy worker effect, that healthy professionals had a greater tendency to participate. This might have led to more optimistic results. Third, the data were obtained exclusively by self-report questionnaires, which could have led to socially desirable answers and presents common method variance problems[45]. Approaches other than self-report have rarely been applied to measure the used constructs[46]. Fourth, the items measuring empathy were adapted to the specific culture of the ICU (i.e., some linguistic changes were made). Therefore, more research on empathy using cross-cultural and psychometrically validated instruments is needed. Finally, the data were collected exclusively from a convenience sample of professionals working in the ICUs of a single university hospital; thus, generalization of the study results is not warranted. Future research plans have been made to replicate this study in various clinical settings and in an international context.

CONCLUSIONS

Work engagement, which recognizes positively labelled elements, is the counterbalance to work-related stress. The relatively high workload in ICUs, coupled with an especially high emotional burden, may be acknowledged as an integral part of ICU work. This workload does not affect the level of work engagement, which was high for both intensivists and nurses despite the known high job demands. Both the job demands and personal resources seemed to be sufficient for the respondents. Although there was no influence of empathy on work engagement, the results of this study suggest that

ICU professionals understand the feelings of patients and their families but remain at a certain emotional distance. This finding may be interpreted as a protective reaction for their own emotional health; however, specific factors that contribute to a healthy and successful work life among ICU professionals remain to be discovered.

REFERENCES

1. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement—burnout syndrome in critical care health-care professionals: a call for action. CHEST Journal. 2016;150(1):17-26.
2. Sprung CL, Cohen R, Marini JJ. Excellence in Intensive Care Medicine. Criticical Care Medicine. 2016;44(1):202-206.
3. Donchin Y, Seagull FJ. The hostile environment of the intensive care unit Review. Current Opinion Critical Care. 2002;8(4):316-320.
4. van Mol MMC, Kompanje EJO, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units: A Systematic Review. PloS ONE. 2015;10(8):e0136955.
5. van Mol MMC, Brackel M, Kompanje EJO, Gijsbers L, Nijkamp MD, Girbes ARJ, et al. Joined forces in person-centered care in the intensive care unit: a case report from the Netherlands. Journal of Compassionate Health Care. 2016;3(1):1.
6. Embriaco N, Papazian L, Kentish-Barnes N, Pochard F, Azoulay E. Burnout syndrome among critical care healthcare workers. Current Opinion Critical Care. 2007;13(5):482-488.
7. Epp K. Burnout in critical care nurses: a literature review. Dynamics. 2012;23(4):25-31.
8. Leiter MP, Bakker AB, Maslach C. Burnout at Work: A Psychological Perspective: New York, Psychology Press 2014. ISBN 9781848722286.
9. Aiken LH, Clarke SP, Sloane DM, Sochalsku J, Silber JH. Hospital nurse staffing and patient mortality, nurse burnout, and job dissatisfaction. JAMA. 2002;288(16):1987-1993.
10. Castle NG, Engberg J. Staff turnover and quality of care in nursing homes. Medical Care. 2005;43(6):616-626.
11. Leiter MP. Maslach C. Nurse turnover: the mediating role of burnout. Journal of Nursing Management 2009;17(3):331-339.
12. Viotti S, Converso D, Loera B. Job satisfaction, job burnout and their relationships with work' and patients' characteristics: A comparison between intensive care units (ICU) and not- Intensive care units (non-ICU). G Ital Med Lav Ergon. 2012;34(2 SUPPL. B):B52-B60.
13. Meynaar IA, van Saase JLCM, Feberwee T, Aerts TM, Bakker J, Thijsse W. Burnout among dutch intensivists. Netherlands Journal of Critical Care. 2015;24(1):12-17.
14. Csikszentmihalyi M. Seligman ME. Positive psychology: An introduction. American Psychology. 2000;55(1):5-14.
15. Fredrickson BL. The role of positive emotions in positive psychology: The broaden-and-build theory of positive emotions. American Psychology. 2001;56(3):218.
16. Schaufeli WB. Engaging leadership in the job demands-resources model. Career Development International. 2015;20(5):446-463.
17. Bakker AB, Schaufeli WB, Leiter MP, Taris TW. Work engagement: An emerging concept in occupational health psychology. Work and Stress. 2008;22(3):187-200.
18. Schaufeli WB, Taris TW. A critical review of the Job Demands-Resources Model: Implications for improving work and health. In: Bridging occupational, organizational and public health. 2014; Springer 43-68.
19. Bakker AB, Demerouti E, Taris TW, Schaufeli WB, Schreurs PJ. A multigroup analysis of the Job Demands-Resources Model in four home care organizations. International Journal of Stress Management. 2003; 10(1):16.
20. Xanthopoulou D, Bakker AB, Demerouti E, Schaufeli WB. The role of personal resources in the job demands-resources model. International Journal of Stress management. 2007;14(2):121.
21. Seppälä P, Hakanen J, Mauno S, Perhoniemi R, Tolvanen A, Schaufeli W. Stability and change model of job resources and work engagement: A seven-year three-wave follow-up study. European Jounal of Work

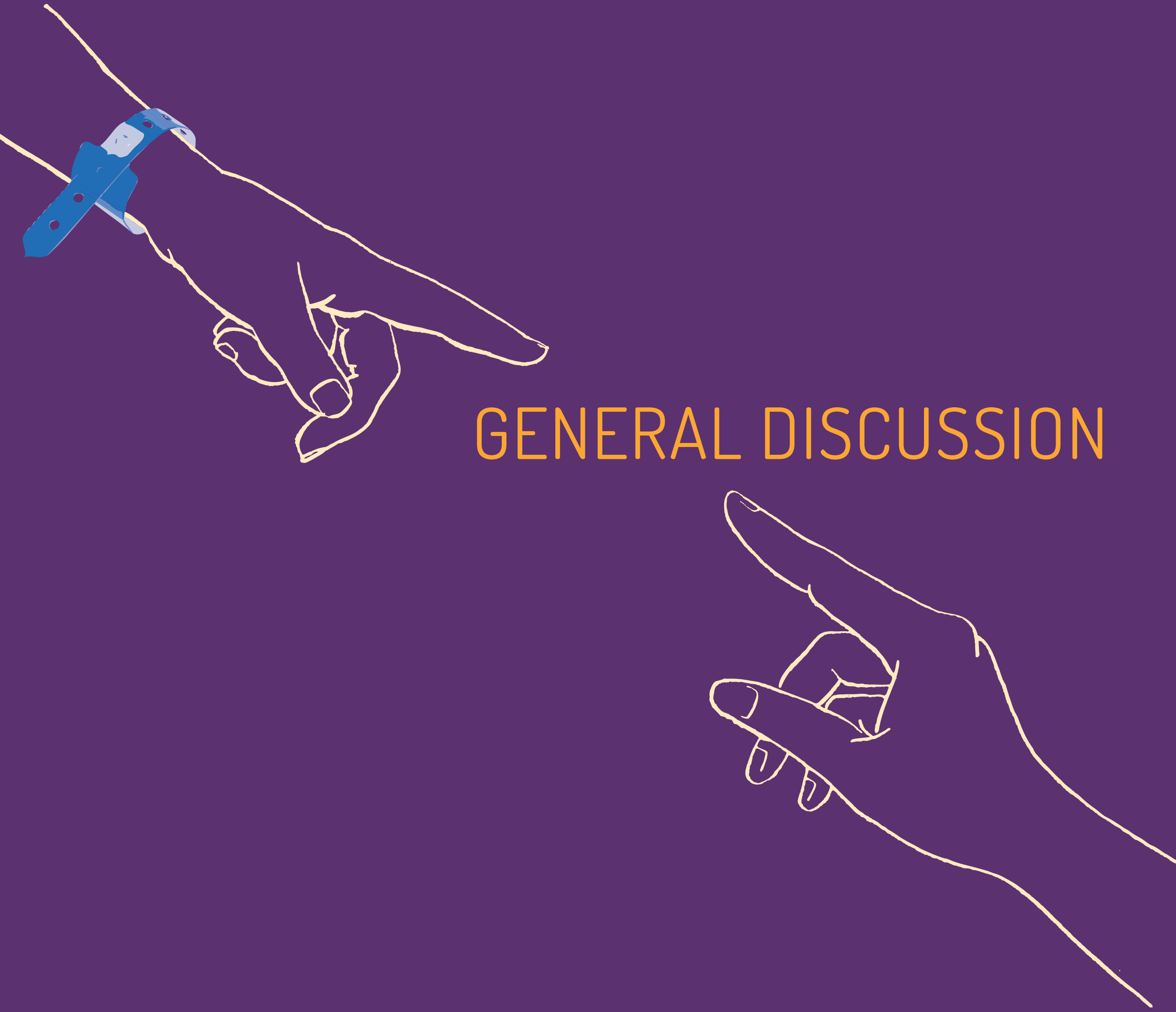
Organizational Psychology. 2015;24(3):360-375.

22. Geuens N, Braspenning M, van Bogaert P, Franck E. Individual vulnerability to burnout in nurses: The role of type D personality within different nursing specialty areas. Burnout Research. 2015;2(2):80-86.
23. Veldhoven M van, de Jonge J, Broersen S, Kompier M, Meijman T. Specific relationships between psychosocial job conditions and job-related stress: A three-level analytic approach. Work and Stress. 2002;16(3):207-228.
24. Hooftman W, Houtman I, Kwantes J. Netherlands EWCO CAR on Working conditions in the retail sector–National contribution. 2012, In:European Foundation for the Improvement of Living and Working Conditions.
25. Costa Jr P, McCrae RR. Neo personality inventory–revised (neo-pi-r) and neo five-factor inventory (neo-ffi) professional manual. Odessa, FL: Psychological Assessment Resources, 1992.
26. Hojat M, Gonnella JS, Nasca TJ, Mangione S, Vergare M, Magee M. Physician empathy: definition, components, measurement, and relationship to gender and specialty. American Journal of Psychiatry. 2002;159:1563–1569.
27. Schaufeli WB, Bakker AB, Salanova M. The measurement of work engagement with a short questionnaire a cross-national study. Educational Psychology Measurement. 2006;66(4):701-716.
28. Carifio J. Perla RJ. Ten common misunderstandings, misconceptions, persistent myths and urban legends about Likert scales and Likert response formats and their antidotes. Journal of Social Sciences. 2007;3(3):106-116.
29. Schaufeli WB, Bakker AB. Job demands, job resources, and their relationship with burnout and engagement: A multi-sample study. Journal of Organizational Behaviour. 2004;25(3):293-315.
30. Field. Discovering Statistics Using SPSS. Fourth edition. London: SAGE Publications, 2014. ISBN 9781446249185.
31. Mäkikangas A, Kinnunen U, Feldt T, Schaufeli W. The longitudinal development of employee well-being: A systematic review. Work and Stress. 2016;1-25.
32. Pastores SM. Burnout Syndrome in ICU Caregivers: Time to Extinguish! CHEST journal. 2016;150(1):1-2.
33. Alarcon G, Eschleman KJ, Bowling NA. Relationships between personality variables and burnout: A meta-analysis. Work and stress. 2009;23(3):244-263.
34. Costa PT, McCrae RR. Normal personality assessment in clinical practice: The NEO Personality Inventory. Psychology Assessment. 1992;4(1):5.
35. Burgess L, Irvine F, Wallymahmed A. Personality, stress and coping in intensive care nurses: a descriptive exploratory study. Nurse Critical Care. 2010;15(3):129-140.
36. McManus I, Keeling A, Paice E. Stress, burnout and doctors' attitudes to work are determined by personality and learning style: a twelve year longitudinal study of UK medical graduates. BMC Medicine. 2004;2(1):1.
37. Kennedy B, Curtis K, Waters D. Is there a relationship between personality and choice of nursing specialty: an integrative literature review. BMC Nursing. 2014;13(1):1.
38. Bakker AB, Le Blanc PM, Schaufeli WB. Burnout contagion among intensive care nurses. Journal of Advanced Nursing. 2005;51(3):276-287.
39. Guidet B, González-Romá V. Climate and cultural aspects in intensive care units. Critical Care. 2011;15(6):312.
40. Bühler KE, Land T. Burnout and personality in intensive care: an empirical study. Hospital Topics. 2003;81(4):5-12.
41. Santos A, Chambel MJ, Castanheira F. Relational job characteristics and nurses' affective organizational commitment: the mediating role of work engagement. Journal of Advanced Nursing. 2016;72(2):294-305.
42. Kompanje EJO, van Mol MMC, Nijkamp MD. 'I just have admitted an interesting sepsis'. Do

we dehumanize our patients? Intensive Care Medicine. 2015;41(12):2193-2194.

43. Mealer M, Jones J, Newman J, McFann KK, Rothbaum B, Moss M. The presence of resilience is associated with a healthier psychological profile in intensive care unit (ICU) nurses: Results of a national survey. International Journal of Nursing Studies. 2012;49(3):292-299.
44. Montero-Marin J, Tops M, Manzanera R, Demarzo MMP, de Mon MÁ, García-Campayo J. Mindfulness, Resilience, and Burnout Subtypes in Primary Care Physicians: The Possible Mediating Role of Positive and Negative Affect. Frontiers in psychology. 2015;6.
45. Podsakoff PM, MacKenzie SB, Lee JY, Podsadoff NP. Common method biases in behavioral research: a critical review of the literature and recommended remedies. Journal of Applied Psychology. 2003;88(5):879.
46. Mäkikangas A, Kinnunen U, Feldt T. Self-esteem, dispositional optimism, and health: Evidence from cross-lagged data on employees. Journal of Research Personality. 2004;38(6):556-575.

SECTION 3



GENERAL DISCUSSION

9

General discussion

Staying and working in the ICU can be two sides of the same coin: patients and their relatives, on the one side, and healthcare professionals, on the other side, are connected to one another. Acting as separate and distinct entities, with their own interests and values, they might mutually influence personal life experiences. Both staying and working in the ICU can have an emotional impact on one's personal well-being. The overall purpose of this thesis was to gain insight in the emotional challenges in ICU practices from the perspectives of both the patients' relatives and the healthcare professionals. The six central questions regarding the emotional impact of staying and working in the ICU, described in the introduction of this thesis, have certainly been answered in six individual studies. This chapter discusses the main findings of these studies, the methodological considerations, suggestions for further research, and implications for clinical practice.

EMOTIONAL CHALLENGES IN ICU PRACTICE FROM THE PERSPECTIVE OF THE PATIENTS' RELATIVES

Admission into an ICU is associated with short- and long-term physical impairment, cognitive deterioration, and emotional consequences for patients and their relatives[1-4]. Fewer than 10% of patients who received mechanical ventilation for more than four days are alive and fully independent one year later[5]. Recently, a large population-based cohort study found that 23% of ICU survivors were admitted to emergency departments within 30 days of discharge, thus emphasizing that post-ICU care should be improved[6]. Additionally, a considerable number (i.e. 30 to 42% at three months and even 32 to 80% after twelve months) of relatives have developed posttraumatic stress[7]. Depressive symptoms have raised from 20% to 34% in partners of patients hospitalized with severe sepsis[8], and 52% of the relatives showed signs of learned helplessness[9]. These symptoms have been labelled and acknowledged together as 'Post Intensive Care Syndrome-Family' (PICS-F)[10]. For these reasons, it is of utmost importance to develop and implement interventions to support patients´ relatives in this tumultuous period (Chapters 3 and 4).

First, the potential of a newly developed questionnaire, the consumer Quality Index ´Relatives in the intensive care unit´ (CQI 'R-ICU') has been examined to assess the quality of care from the perspective of relatives in the ICU (Chapter 2). This instrument, measuring Patient/Person Reported Experience Measures (PREMs), aimed to provide feedback and identify bottlenecks regarding the quality of care to healthcare professionals and policymakers. The goal was to establish evidence-based quality improvement projects to serve relatives in the ICU. It seemed that the CQI 'R-ICU' is a valid, reliable and usable instrument with a sound theoretical basis, which sets priorities regarding the aspects that need improvement[11]. The CQI method is fundamentally and methodologically grounded in a discrepancy model, which describes the satisfaction of the target group, i.e., the relatives of ICU patients, with the provided care evaluated as expectation minus the perceived experience. The utilized concept of satisfaction in another newly developed Dutch questionnaire related to the relatives in the ICU, the euroQ2, might contain several methodological misconceptions. The euroQ2 appears to be developed and preliminary validated with some bias, such as ceiling effects, cognitive dissonance and socially desirable answers (Chapter 2). Therefore, in a letter to the editor, the added value of this questionnaire in addition to the CQI 'R-ICU' has been questioned[12]. From an international perspective, no gold standard currently exists to evaluate the satisfaction of relatives in the ICU[13]. Defining family satisfaction is a complex and multifactorial process, and it is possible that not all aspects have been included and accurately measured. Nevertheless, to determine the discriminative power of the CQI 'R-ICU,' a follow-up study, which has not been published, was conducted in 21 hospitals nationwide[14]. Although the original measurement instrument was developed in the Dutch language, the translated English version of the CQI 'R-ICU'[15] might be valuable from an international perspective as well.

Subsequently, the effect of additional supportive interventions specifically designed for ICU patients' relatives, including intake interviews, encouragement to keep a diary, and weekly psychosocial rounds, has been examined using the CQI 'R-ICU' questionnaire (Chapter 3). The results suggested that the implementation of these interventions increased the perceived quality of care, particularly with respect to informational factors[16]. Other studies also found that clear and complete information, good communication, and good decision-making, were key determinants of the satisfaction of the relatives[17]. Moreover, adequate communication promotes relationship building between the patients' relatives and healthcare professionals. Several studies evaluated the effectiveness of supportive interventions that aim to increase the satisfaction of relatives with inconclusive results[18]. A communication strategy that included a family conference and a written summary afterwards to document the main topics, found no significant improvements[18]. It has been difficult to find evidence supporting these multifactorial quality improvement and communication strategies, which underpins the results using the CQI 'R-ICU'. Another study found that some of the main limitations in communication voiced by patients were vulnerability, a paternalistic manner when deciding on the treatment plan, and limited discussion of psychosocial factors due to the time constraints of the professional[19]. A positive experience in communication was centered on a tailored approach and individualized care, which emphasizes the importance of feeling personally understood in one´s context[19]. However, moving toward person-centered care requires a challenging shift in the mindset of the healthcare professionals[20]. During the study it appeared that this paradigm shift remained a work in progress. Although multifaceted implementation strategies were followed to introduce the intervention program during the project[21], the adoption and effectuation appeared difficult at some points. This was similar to another study among pediatric healthcare providers from three different countries on their perceptions towards policies in family-centered care[22]. A significant discrepancy in preference was found between caring for the child and working with the parents, thus suggesting that even if the child's hospital claimed to provide family-centered care in vision and strategy, daily practice appeared more restrictive in true collaboration on policies and practices with the parents. Management teams who want to implement person-centered care should therefore emphasize these values and dimensions in their stated policies and concrete support of the professionals[23]. Evaluation and retrospective explanations of the challenges might include: the difficulty of changing the behavior and prevailing practices of the involved professionals, a limited commitment from the organization, non-systematic approaches for transforming problems into tailored solutions, and insufficient or intuitively chosen intervention strategies[24]. In a scoping review of patient discharge from the ICU, thirty patients, providers, and institutional factors in different phases of the transfer process were identified[25]. This review reflected the complex overall process in changing attitudes of healthcare professionals describing facilitators (e.g., the use of best practices) and barriers (e.g., provider workload, family anxiety). Therefore, it is unlikely that a simple universal answer will be found to stimulate the adoption of person-centered interventions.

RECOMMENDED ICU POLICY ON "RELATIVES INCLUDED"

How should person-centered care be further adopted in the ICU setting? In addition to the previously discussed interventions (Chapter 3 and 4), additional ICU policies involving patients' relatives might further increase the provided quality of care. The evidence-based ABCDEF-bundle (A: Assessment, prevention, and management of pain, B: Both Spontaneous Awakening Trials and Spontaneous Breathing Trails, C: Choice of analgesia and sedation, D: Delirium assess, prevent, and manage, E: early mobilization and exercise, F: Family engagement and empowerment) suggests guidelines to improve family participation[26]. Recently, it was found that higher compliance with the total bundle was independently associated with improved patient survival and cognitive functioning, with a dose-related effect of a partial implementation[27]. Therefore, the involvement of relatives in the ICU should be targeted in every ICU. In the context of person-centered care, a novel research approach engaging patients and relatives as researchers has been suggested to explore and identify opportunities for ICU improvements[28]. The main findings from this study include, among others, extensive emotional support for relatives during the tumultuous period and effective communication that is consistent for all healthcare providers. Wide-ranging information should be provided orally, in written material, and in digital form[29]. Digital user-friendly web portals with general information on ICU treatments, several disease descriptions, long-term consequences of ICU admission, and tailored patient details might meet the informational needs of the relatives. The utility of a web portal lies in its free and continuous availability 24/7[30], although it should never replace face-to-face communication between healthcare professionals and relatives. Furthermore, a culture that integrates patients and their relatives as members of the care team could be fostered, for example by inviting relatives to be present during visiting rounds or (medical) interventions, encouraging shared decision-making, and helping at the bedside if appropriate[26, 28, 31]. Open visiting guidelines allowing patient-tailored visitation is recommended to meet the relatives' needs of proximity[32, 33]. A review study in this domain found similarities and differences across countries and disciplines. It seemed that nurses predominantly perceived open visiting hours with doubts and organisational challenges, although, the benefits for patients and their relatives were confirmed consistently[34]. Ideally, aftercare commences during ICU admission. There is an increased awareness regarding the importance of alleviating the discharge process from the ICU to the general ward[33, 35]. However, continued emotional support after the ICU period is frequently lacking or insufficient from the perspectives of former ICU patients[36-38]. This gap is primarily due to insufficient knowledge about the possible consequences of the ICU experience[35, 39]. Thus, an increase of provider awareness on the fragility of relatives and the long-term consequences of critical illness should be addressed[28]. Because there is an increasing number of ICU survivors, PICS and PICS-F are becoming public health issues[2]. Stakeholders, such as GPs, should be considered to involve in the ongoing recovery chain of post ICU care. An extensive information package, education, and resources enabling optimal treatment are required to understand and support individuals in their search for retrieval. ICU professionals might play an important role in this public responsibility. Finally, a dedicated family liaison nurse could provide all warranted care and profound emotional support for the relatives during and after ICU admission[1,8 40, 41].

PSYCHOLOGY PRACTICE IN THE ICU

A case study of the joint efforts of the Dutch national network and the Family and Patient Centered Intensive Care (FCIC) foundation is presented as an example of person-centered care (Chapter 4). The FCIC combines the strengths of different disciplines (e.g., nurses, doctors, psychologists, health counselors, and social workers), scientists, former ICU patients, and their relatives, to exchange knowledge on reducing the emotional impact of an ICU admission. In the ICU, with the priority on patient´s survival and the technological aspects of treatment, person-centered care requires a high level of clinical expertise, far-reaching knowledge, and extensive ´soft-skills´ on the part of the professionals. However, providing care with an excess of empathy might have negative consequences for the ICU professionals themselves; therefore, supportive strategies to protect the health of the professionals are also necessary[42]. Psychological support might be effortful to the patients and their relatives as well as the professionals.

The role of psychologists in the ICU is still an area to explore. Despite the acknowledged psychological symptoms in former ICU patients and their relatives, health service psychologists have been minimally involved in the multidisciplinary treatment plans utilized in the ICU[43]. Furthermore, occupational psychologists might be able to support the emotional distress awareness and teaching activities of the professional staff. A recent survey study in the US found that less than 35% of de psychologists in hospital settings were involved in critical care on a weekly or daily basis[43]. Half of them had worked less than 5 years in critical care, and most had seen patients with brain injury or other neurological disorders such as delirium. Psychological practice in the ICU is seemingly a relatively new area; however, it might fill a need for active guidance in quality improvement related to the experiences of the patients and their relatives. It might also increase the program development of preventive strategies for those working in emotionally demanding situations.

AN INTERMEZZO ON EMPATHY

In a guest blog, Neil, a former ICU patient, commented on the case study[42]:

"I experienced all of these [delirious thoughts and frightening nightmares] during my time in the ICU, and yet there were no discussions about my mental condition between care staff and myself or my relatives. […] From a technical perspective, the care that I received was superb, but I felt that there was a general lack of awareness, and unwillingness by the care staff to accept that I had been through some terrifying nights in ICU. […] I agree with van Mol that some communication to me and my relatives before the operation might have made it easier to cope with the stressful situation afterwards. Personally, I am sure that I would have benefited from a more patient-centered approach to my care in ICU, specifically regarding communication of information to enable me and my relatives to understand and cope with the symptoms experienced during my highly unpleasant period of delirium."[44]

From a nursing perspective, empathy and a holistic vision in caring for patients have been applied for a long time. The special care administered to critically ill patients, specified as watchful vigilance, set the tone for patient-centered care[45]. Bien van den Brink Tjebbes (1924-2014), who wrote the first nursing theory in The Netherlands, stated that the relationship between care taker and provider should address 'focused-on the other', with the aim of supporting that person in his/her self-management and life course[46]. In the last twenty years, healthcare has become so complex that humanity might be threatened in a business market model[47]. In "Crossing the Quality Chasm: A New Health System for the 21st Century " the Institute of Medicine identified a medical model of patient (person) centered care as the ideal, with a focus on interpersonal skills in communication and clinical empathy[48]. In turn, current renewal of the holistic view, similar to the concept of person-centeredness, has been used in many organizations and healthcare settings to stimulate an attitude of hospitality in all healthcare professionals (Chapter 4). A way of providing individual attention with dignity and respect, thus taking responsibility to find meaning in caring for others, is an essential competence in every healthcare provider. Professionals identified "treating patients with dignity and respect" as one of the most important elements in providing right care[23]. Empathy, respect for a person´s values, needs, and preferences, and optimal communication are core aspects of person-centered care. Another important challenge has been how to best engage patients and their relatives in medical treatments and general policies, helping them to discover their strengths and weaknesses that might influence their own health[49].

Whether empathy is an innate competence derived from prosocial behavior[50] or whether it can be taught during medical and nursing training[51] is not a black or white issue. For example, readers (of a novel) or watchers (of a movie or documentary) who read about or view suffering can become unsettled and may thereafter consider the same anguish in real life in a different (more empathic) way (Chapter 5.1). This feeling may lead to a better empathic understanding of events in real life. Nevertheless, a systematic behavioral training in this domain appears difficult to develop because of concerns that empathy is a mysterious and intuitive process[51, 52]. Nearly all healthcare professionals use cognitive empathy in daily patient management when coping with the experience of suffering. They understand and respect the turmoil that patients and their relatives experience (Chapter 8). Controversially, it is also stated that when it comes to decision making, empathy works contra productively[53]. Instead of improving the lives of others, empathy might be a capricious and irrational emotion that appeals to narrow prejudices. Without empathy, decisions would be clearer, fairer, and ultimately more moral. Individuals differ in their disposition to feel empathy[53].

ICU professionals might have adapted their individual coping strategies to maintain their own emotional balance and to avoid being overwhelmed by the intense emotional workload while supporting the patients and their relatives (Chapter 4, 5.1, 5.2, 7, and 8). However, while watching a movie or documentary or reading a novel, they may experience emotional empathy that serves another aim in their personal life[54]. In that case, they want to be touched and they want to identify themselves with the individuals in the film or book. In contrast to responding with empathy to ICU patients and their relatives, dehumanization also occurs. Healthcare providers who sometimes speak about patients in terms of specific diseases, organs or operation techniques do so because it is practical. This appeared inevitable, adaptive, and even morally and psychologically acceptable (Chapter 5b). As long as healthcare providers *know* that their patients are suffering and in pain, they do not have to *feel* it[55]. This suggestion is questioned by Sinclair and colleagues who stated that compassion is "extolled as a cornerstone of quality healthcare,". Compassion was emphasized as a virtuous response of *suffering with* another person coupled with actions to diminish this person´s distress[56, 57]. Since 2012, a sharp increase in published articles on compassion has emerged, dealing with conceptualization, key dimensions, relational factors, and the development of compassion among others[56]. The idea of authentic emotional resonance with a person in distress is described as a distinguishing feature of compassion. Thus, compassionate clinicians do not distance themselves emotionally from patients, but rather integrate these emotions into the patient-clinician relationship[58]. According to this reasoning, the purpose and depth of this relationship should extend beyond simply acknowledging, understanding, and relating to this person as a human being. An extensive empirical understanding of compassion has been studied in a qualitative study among patients with cancer in the palliative care setting[57]. Although the added value of the developed Compassion Model and the three broad categories "seeking to understand, relational communicating, and attending to needs" may be acknowledged[57], the vulnerable role of the healthcare professionals when deeply feeling another person´s distress and engaging in this suffering must be considered. Clinicians and patients may differ in their perceptions of compassionate care. For example, "going the extra mile" and "putting themselves out there, you know, it could be their brother or sister" as exemplars of compassionate action from a patient´s perspective[57], represent a pure and beautiful interaction between two people. Of course, that may happen and it is a valuable occurrence in time, place, and person. However, if healthcare providers must respond in an extraordinary way exceeding their own (emotional) boundaries and feelings at any time, this is doomed to result in work-related stress.

Compassion may overlap with affective empathy; the seven identified dimensions associated with compassion (attentiveness, listening, confronting, involvement, helping, presence, and understanding)[59] do not differ from with empathic behaviour. Furthermore, qualities such as honesty, fairness, kindness, dedicated presence, demonstrating respect and dignity, relate to both concepts and are expected to be performed by every healthcare provider daily. Therefore, professionals should address the suffering and needs of patients and relatives with the sensitivity inherent to person-centered care. They need to do more than simply *know* persons are suffering; they have to alleviate that suffering to the best of their abilities, and should be able to *be* there as a witness and to provide support through their presence (Chapter 4 and 6). Both caring with an excess of (affective) empathy and the all-encompassing process of dehumanization might have negative consequences for ICU professionals themselves; therefore, supportive strategies for protecting the health of these professionals are imperative (Chapter 6). Meeting the needs of professionals and acknowledging their emotional well-being are important aspects for providing person-centered care in the ICU. A study among nurses caring for critically ill non-sedated mechanically ventilated patients underpinned the delicate process between closeness and distance[60]. No strict boundaries can be formulated, depending on individual psychological capital. Caring with empathy and compassion involves finding a delicate balance for each individual professional.

EMOTIONAL CHALLENGES IN ICU PRACTICE FROM THE PERSPECTIVES OF THE HEALTHCARE PROFESSIONALS

Traditionally, various healthcare professionals have been acknowledged as particularly vulnerable to work-related stress, with several prevalent stress responses such as burnout, compassion fatigue, and traumatic stress (Chapter 6 and 7). Thirty percent of the respondents reported high emotional exhaustion measured using the Maslach Burnout Inventory (MBI) in a 2016 cross-sectional study among 13,077 nurses throughout Europe[61]. A 2014 study on the prevalence of burnout among physicians in the USA found that more than 54% reported at least one symptom of burnout, also measured using the MBI[62]. Moreover, working in an ICU is increasingly complex and physically, cognitively and emotionally demanding[63-65]. In addition to being confronted with end-of-life issues, ethical decision-making, continuous suffering of patients, disproportionate care, miscommunication, and demanding relatives of the patients, the ICU work environment has become increasingly technical[66]. Among all domains, the field of critical care scored highest in the prevalence of burnout (55%)[67]. However, the systematic literature review on emotional distress among ICU professionals (Chapter 6) suggested that the true magnitude of work-related stress such as burnout remains unclear because of a lack of unity in concepts, related measuring instruments, and cut-off points[66]. For example, the reported prevalence rates of burnout in the ICU, measured using the MBI, varied from 14.0%, after a preventive intervention[68] to 70.1% when burnout was defined as a high score on only one subscale on the same MBI[69] (Chapter 6, Table 4 and 5). The latter study also stated that the prevalence would be 17.7% if burnout had been defined as a high score on the combined subscales. A comparable systematic review conducted one year later found, for the most part, similar results [70]. This study also identified risk factors for ICU burnout, which included age, sex, work experience in nursing, and excessive workload. Contrasting results have been found in the broad range of related variables among the studies on burnout (Chapter 6, Table 6). The most confusing variable was the female sex, with an increasing, a decreasing, and no significantly measured influence on emotional distress. Other risk factors included individualities, such as perfectionism, a compromised work-life balance, and a neurotic personality (Chapter 8). However, organizational aspects such as an increased workload and excessive work hours, were related to high rates of burnout as well[71]. The interference of work-life and home activities due to increased work hours might result in difficulties to "switch-off" from work responsibilities and ruminative thoughts[72]. The ability to detach from work is essential for employee to recover from daily stressors and challenges.

From a historical perspective, exhaustion during work life has been common (Chapter 7). Therefore, the concept of burnout might be a trend misused to indicate an overall exhaustion with life; fatigue and tiredness may result as a part of the human condition. Other researchers have suggested that ICU professionals experience a traumatic work environment with posttraumatic stress responses or far-reaching depletion of compassion as a consequence. However, ICU professionals have adapted their individual coping strategies to the demanding work environment to find an emotional balance (Chapter 4, 5a, 5b, 7, and 8). To underscore the positive process of dealing with ICU challenges, we further explored work engagement as a counterbalance to the negative values of emotional distress. The relatively high workload in ICUs, with a high emotional burden, may be acknowledged as an integral part of ICU work. This workload does not affect the level of work engagement; work engagement was high for both intensivists and nurses despite the acknowledged high job demands (Chapter 8). Although there was no influence of empathic ability on work engagement, the results of this study suggested that ICU professionals understood and respected the patients and relatives but remained at a certain emotional distance. This process of self-management and adaptation may be interpreted as a protective reaction for their own emotional health and well-being while working[73].

Founded by the JD-R theory, an exploration of the relationships between job demands, job resources, personal resources and work engagement among the ICU professionals was made (Chapter 8). All job resources (i.e., autonomy, team spirit, social support, and performance feedback) showed positive correlations with work engagement (Chapter 8, table 5), as expected according to the JD-R theory, although some differences were found for nurses and intensivists. Job demands were negatively related to work engagement, which was not predicted according to the model. Emotional workload among ICU professionals was found higher than in the healthcare benchmark. This might relate to personal resources such as empathic ability or resilience, which, in turn, could affect work engagement. Furthermore, no interaction effects were found between personal resources (i.e., empathy and personality traits) and work engagement, which appeared to contrast with our reasoning. Personal resources are assumed to control and affect the work environment successfully as mediators between job resources and work engagement. Similarly, empathy, considered a type of emotion regulation among healthcare providers, might positively affect their well-being[74]. The JD-R theory is heuristic and flexible in its meaning; however, this situation could also be the Achilles' heel of the model as this points to the specificity and the quality of the predictions[75]. Therefore, it is essential to establish an undisputable idea regarding the role of each job characteristic in the setting under study. Empathy may create individual ambiguity whether it acts as a job demand or a job resource, thus, influencing the health impairment process or the motivational process. This may even fluctuate across situations, timing, human interactions, and may be influenced by other job demands, such as workload. However, the JD-R theory is generally applied, and most organizations are interested in the demands, resources, and subsequent well-being of entire departments instead of individual scores[76]. Only when there is ample unanimity, can scores be interpreted as reflecting the common view of the quality of the specific job characteristic. Another consideration should be observed: consistent with the appraisal of job demands, which can be both challenging and hindering[77], empathy might be too complex to include straight forward into the model. The psychological processes involved with work engagement in the JD-R theory merit additional exploration[75]. To conclude, some unsettled questions should be addressed regarding this theory.

The study also suggests that policymakers should introduce interventions to prevent the negative consequences of emotional distress (Chapter 8). To develop adequate preventive strategies for emotional distress, it is essential to know the individual´s incentive for choosing a caring profession in addition to unconsciously chosen coping strategies for addressing stressful work settings. Some encouraging preventive strategies for combating emotional distress in ICU professionals have been developed recently[68, 74, 78]; nevertheless, not one 'golden standard intervention program' has been found until now. Combined person- and organization-directed multifaceted interventions with refresher courses have reported the best results in preventing emotional distress[79]. Balancing human intimacy and professional distance, remaining appropriately present, and responding with empathy, may be recognized as a valuable personal abilities. These abilities should be taught and effectively enhanced in striving for well-being at work.

SUSTAINABLE EMPLOYABILITY

The idea of well-being at work has diverse meanings within and between organizations and countries[80]. The International Labour Organisation relates well-being "to all aspects of working life, from the quality and safety of the physical environment to how workers feel about their work, their working environment, the climate at work and work organization"[81]. Occupational well-being is originally accompanied by feeling energized, focused, and optimistic. In healthcare professionals, dedication and attentiveness to achieving optimal patient care has been described as well[82]. Work engagement, with its influencing factors, is a promising concept regarding establishing occupational well-being among ICU professionals. Sprung and colleagues (2016) stated that "setting new goals, life-long learning, acquiring new skills, and meaningful collaborations with colleagues in new projects confer a sense of personal growth and can keep the pot boiling"[65]. It is indeed important to express the joy of practicing excellent ICU care, even in today´s challenging work environment. The urgent call for action in preventing emotional distress has been heard and has now been endorsed by all healthcare providers[71]. The question is: How do we become or stay engaged while growing older and becoming more affected by working in an emotionally demanding environment?

The overall aging of people has increased rapidly due to longer life expectancy and lower birth rates[83], which also influences the contribution in the workforce. In Europe and Northern America, participating in the labor force beyond the age of 65 years has increased gradually since 1990, and it is expected to further increase in the future[83]. Because of this foreseeable demographic shift, employers should adopt a proactive approach to align their policies to an ageing population. To encourage employees to maintain a healthy lifestyle, stay engaged, and work productively until retirement, exploring sustainable employability is critical[84, 85]. Although still under discussion, sustainable employability may refer to "the degree to which employees are able to work throughout their entire working lives, and their work context enables them to do so"[86]. It is a multidimensional construct, in which both employer and employee are equally responsible for maintaining the ability to work. Various work-related factors, both physical and psychosocial, influence sustainable employability[87, 88]. Motivational factors might influence sustainable employability as well, for example, by allocating meaning in work[89] and work engagement[90]. Whereas previous research has focused on a general population[84, 85], in healthcare professionals this domain is still relatively understudied. More specifically, in the ICU the need to explore factors related to maintaining professionals´ work ability in the ICU is warranted.

METHODOLOGICAL CONSIDERATIONS AND FUTURE RESEARCH

This thesis explored the emotional challenges in ICU practices from two perspectives. Regarding the patients' relatives, the newly established measurement instrument has been used to assess the overall quality of care provided to the target group. Although this questionnaire seemed valid and reliable, it was still in the development process during the research process. Looking back now, it turned out to be a risky and preliminary choice, but it was the optimal choice. A limitation of the study organization was the researcher' role as an active member of the ICU team at that time. This situation might have led to a tunnel vision, excessive endeavors to implement the interventions, or a bias because of the role as a nurse-colleague. Long-term monitoring of the effectiveness of interventions reducing the impact of ICU admission with respect to patients and their relatives is important. The overall judgement of the quality of care to relatives should be performed using the CQI 'R-ICU'; however, specific interventions may better be evaluated with a tailor-made short questionnaire. It is still questionable if the CQI 'R-ICU' is sensitive enough to detect a change due to this intervention[13]. Because of a lack of adequately powered multicenter trials, a network including large numbers of ICUs worldwide should be established to study more extensive policies in person-centered care in the ICU[33]. New studies should not only be conducted from the perspectives of the ICU patients and their relatives, but they must also be in charge during the entire research process[28]. This means, patient- and relatives-led research, from questioning to reporting the results. Furthermore, to overcome barriers in implementing new policies in person-centered care, procedures should be developed according to an intervention-mapping process. This is an iterative six-step method, aiming to systematically develop an intervention with explicit user involvement[91]. Cost-effectiveness studies can be performed and deliberately considered to maintain the supportive interventions after pilot testing. In addition, the role of psychologists in an ICU setting should be explored in the context of communication and shared decision-making, rehabilitation of former ICU-patients, and preventive strategies in the emotional support of the professionals[43].

More research, e.g., a grounded theory approach in qualitative design, is necessary to address the fundamental questions on the complex nature and relationships of empathy and compassion from the perspectives of healthcare professionals in different healthcare settings. This research should be extended with a randomized controlled trial to assess the effect of training empathy and communication skills. Regarding the discussion as to whether empathy should be taught in isolation or embedded in a more general training[52], the latter will increase a broader acceptance of person-centeredness in healthcare provision.

Regarding the healthcare professionals, it is recommended that the contradictory results in variables affecting burnout be clarified in a meta-analysis in order to quantify the effect sizes by statistically pooling the data of the systematic review studies. Furthermore, the scope of this part on work engagement was narrowed to a limited number of measured variables based on previous literature and preferences of the researchers. This situation might have led to exclude important associations, for example the relationship of various types of leadership and work engagement, an extended exploration of the role of social support, habituation to ICU work, resilience, and self-selection or the profile of professionals working in the ICU. Authentic leadership, professional empowerment, and satisfying relationships with colleagues were suggested to be protective for burnout[92], which therefore might also be of utmost influence to work engagement. Additionally, the current hospital policy on stimulating well-being was not considered, which might have biased the professionals' focus on vitality and energy while working. It is, therefore, highly recommended to more broadly explore and investigate the costs of emotional distress in healthcare professionals and evaluate the meaning of sustainable employability in a valid comparative manner to define the relevance of the problem. A prospective longitudinal study design could bridge the gap in fundamental knowledge on preventive strategies to stimulate occupational well-being of the care providers. The follow-up period should extend over a one-year period and include at least two measurement points after completing the intervention[80]. Furthermore, insight into coping strategies used by the participants may uncover what individuals do to modify the impact of job characteristics on their own well-being. In addition to quantitative research, in-depth semi-structured interviews are required to stress the deeper driving forces in an individual to provide more insight into the thoughts and coping behaviors in reaction to the ICU work environment.

Finally, all data in this thesis were gathered in one university medical center limiting the external validity and should be interpreted with caution regarding other ICU settings. The empirical study designs were observational and cross-sectional in nature. Consequently thereof, causal inferences from the data could not be drawn.

IMPLICATIONS FOR CLINICAL PRACTICE

Concerns about the gap between science and practice are longstanding, with considerable distance between the mind of a scientist and the mind of a practitioner. However, small steps can be taken, one by one, to bridge the worlds of research and daily practice in the ICU healthcare. During the last decade, more importance has been assigned to use evidence derived from scientific studies and applying the results in clinical practice[93]. This thesis, in the coinciding research fields of the ICU, psychology, and nursing, supports the necessary empirical changes in practice by accessible and applied science, thus, providing meaning to warranted changes. Striving for improvement corresponds with continuously changing the world in which individuals live and work in, as Steven

Covey revealed: “If we keep doing what we have been doing, we are going to keep on getting what we have been getting”[94].

PROVIDING MEANING TO SUSTAINABLE EMPLOYABILITY

Healthcare organizations and ICU policy makers must develop, adopt, and implement interventions in daily practice aimed to prevent emotional distress and establishing sustainable employability among professionals. Evidence-based interventions are required to address the most effective contributing factors; however, persuasive randomized controlled trials in this domain have not been performed until now[71, 80]. The organizational improvements, in addition to individual activities promoting the well-being of the professionals, including self-care in nutrition, sleep, exercise, spirituality, and spending quality time with family or friends, should target an increase of personal fulfillment, meaning in work life, and subsequently work engagement[62, 95]. These organizational efforts and the financial funding of a multiannual program on well-being and vitality have been demonstrated to generate a positive return of investment[96, 97]. Another factor to target is autonomy, or the feeling of being in control and being able to influence the work environment[98]. The personal experience of being in control is psychologically beneficial in itself, even without an actual manifestation of the phenomenon. By contrast, perceptions of a lack of control result in more work-related stress. Therefore, organizational interventions should increase perceived autonomy as well. Resilience also might decrease the development of mental distress in ICU healthcare professionals[99]. Resilience is considered the ability to maintain mental equilibrium, an active and flexible process of adaptation to life changes, operating as a protective factor against psychological distress and mental disorders[100, 101]. This ability to ´bounce back´ may vary during one’s life course[102]. It is closely related to vigour, energy, motivation, and personal strength, enabling one to cope with stressful situations when confronted with danger or misfortune. Subsequently, this ability to adopt and self-manage the challenging situations in an ICU, can positively influence the health of ICU professionals[103]. Individual growth in autonomy and resilience might provide the basic skills to flourish in the hectic and ever-demanding ICU environment, thereby successfully improving sustainable employability.

The recently developed model of sustained employability includes the value-related aspects of work to assess individual well-being as a quality of one’s working life[89]. Work has become a life domain in which employees want to achieve important goals and fulfill personal ambitions and values, in addition to having income security. This means that an individual´s work situation should enable the execution of valued tasks, aiming for goals that are both personally significant and valued by the organization[89]. The model suggests that for contemporary employees, it is not sufficient to have a good balance between job demands and job resources; the employees should also have a good fit with the values important to their work. In turn, this could lead to personal growth, a healthy work life, and sustained work engagement. Making a positive change in the lives of frail people might provide significance and purpose for the employees' own effort while working, which may stimulate and contribute to the employees´ dedication[104]. For ICU professionals in particular, this might generate some ideas in improving the working climate. The severity of illnesses, the emotional workload, and the often complex situations with relatives cannot be changed. However, the perspectives and goalsetting regarding medical therapies should be a topic of regular multidisciplinary discussion to help professionals maintain their values in accordance with the implemented policies and working climate.

OVERALL CONCLUSIONS; BALANCING COINCIDENT WORLDS

Staying in the uncertain world of the ICU is never desirable for patients and their relatives; however, the negative impact of this stay might be diminished if they experience receiving optimal and quality care. Interventions that focus on person-centered care and encompass respect, dignity, and empathy will have a positive influence on the users' experiences. If it is only being present, listened to and knowing to be taken seriously by the professionals. Healthcare providers in the ICU may play a crucial role and make a difference in the lives of the patients and their relatives. Working in the ICU can be exciting in a positive way. The diverse proceedings that require various technical skills, such as increasing one's medical knowledge, providing emotional support, managing intense treatment courses, and trying interesting new interventions, might satisfy an individual's work-related ambitions and life fulfillment. This may give meaning to the work of ICU professionals. Both comprehensive insights into the patients´ diseases and circumstances as well as thoughtful discussions and subsequent patient care decisions may offer ICU professionals ample opportunity to grow and to enjoy their work. In their unsolicited role, patients and their relatives may contribute to this fulfillment. Overall, the ICU is an inspiring world in which to work. We should keep it that way and strive for a healthy and successful working environment.

REFERENCES

1. Davidson JE, Harvey MA. Patient and Family Post–Intensive Care Syndrome. AACN Advanced Critical Care 2016;27(2):184-86.
2. Elliott D, Davidson JE, Harvey MA, et al. Exploring the Scope of Post–Intensive Care Syndrome Therapy and Care: Engagement of Non–Critical Care Providers and Survivors in a Second Stakeholders Meeting. Critical Care Medicine 2014;42(12):2518-26.
3. Griffiths JA, Morgan K, Barber VS, Young JD. Study protocol: the Intensive Care Outcome Network ('ICON') study. BMC Health Services Research 2008;8(1):1.
4. Parker AM, Sricharoenchai T, Raparla S, Schneck KW, Bienvenu OJ, Needham DM. Posttraumatic stress disorder in critical illness survivors: a metaanalysis. Critical Care Medicine 2015;43(5):1121-29.
5. Harvey MA, Davidson JE. Postintensive Care Syndrome: Right Care, Right Now… and Later. Critical Care Medicine 2016;44(2):381-85.
6. Hill A, Fowler R, Pinto R, Herridge M, Cuthbertson B, Scales D. Long-term outcomes and healthcare utilization following critical illness–a population-based study. Critical Care 2016;20(1):1.
7. van Beusekom I, Bakhshi-Raiez F, de Keizer NF, Dongelmans DA, van der Schaaf M. Reported burden on informal caregivers of ICU survivors: a literature review. Critical Care 2015;20(1):1-8.
8. Davydow DS, Hough CL, Langa KM, Iwashyna TJ. Depressive symptoms in spouses of older patients with severe sepsis. Critical Care Medicine 2012;40(8):2335.
9. Sullivan DR, Liu X, Corwin DS, et al. Learned Helplessness Among Families and Surrogate Decision-Makers of Patients Admitted to Medical, Surgical, and Trauma ICUsLearned Helplessness in the ICU. CHEST Journal 2012;142(6):1440-46.
10. Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: Postintensive care syndrome–family. Critical Care Medicine 2012;40(2):618-24.
11. van Mol MMC, Bakker EC, Nijkamp MD, Kompanje EJ, Bakker J, Verharen L. Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool. Patient Education and Counseling 2014;95(3):406-13.
12. van Mol MMC, Bakker E, Kompanje EJO, Nijkamp M. In response to: Families' experiences of ICU quality of care: development and validation of a European questionnaire (euroQ2). Journal of Critical Care 2015 DOI: 10.1016/j.jcrc.2015.07.006
13. van den Broek JM, Brunsveld-Reinders AH, Zedlitz A, Girbes A, de Jonge E, Arbous MS. Questionnaires on Family Satisfaction in the Adult ICU: A Systematic Review Including Psychometric Properties. Critical Care Medicine 2015;43(8):1731-1744
14. Rensen A, van Mol M, Menheere I, et al. Quality of care in the intensive care unit from the perspective of patient's relatives: development and psychometric evaluation of the consumer quality index 'R-ICU'. BMC Health Services Research 2017 17:77. doi:10.1186/s12913-016-1975-4
15. Univeristy of Applied Sciences Arnhem and Nijmegen. Consumer Quality Index 'Relatives in the intensive care unit' English translation. 2016 Available from www.laiz.nl [accessed 10-01-2017].
16. van Mol M, Boeter G, Verharen L, Kompanje E, Bakker J, Nijkamp M. Patient-and family-centered care in the intensive care unit, A challenge in the daily practice of healthcare professionals. Journal of Clinical Nursing 2016 doi:10.1111/jocn.13669
17. Schubart JR, Wojnar M, Dillard JP, et al. ICU family communication and health care professionals: A qualitative analysis of perspectives. Intensive and Critical Care Nursing 2015;31(5):315-321.
18. Pagnamenta A, Bruno R, Gemperli A, et al. Impact of a communication strategy on

family satisfaction in the intensive care unit. Acta Anaesthesiologica Scandinavica 2016;60(6):800-806.

19. Rocque R, Leanza Y. A systematic review of patients' experiences in communicating with primary care physicians: intercultural encounters and a balance between vulnerability and integrity. PloS ONE 2015;10(10):e0139577.
20. McConnell B, Moroney T. Involving relatives in ICU patient care: critical care nursing challenges. Journal of Clinical Nursing 2015;24(7-8):991-98.
21. Wensing M, Bosch M, Grol R. Developing and selecting interventions for translating knowledge to action. Canadian Medical Association Journal 2010;182(2):E85-E88.
22. Feeg VD, Paraszczuk AM, Çavuşoğlu H, Shields L, Pars H, Al Mamun A. How is Family Centered Care Perceived by Healthcare Providers from Different Countries? An International Comparison Study. Journal of Pediatric Nursing 2016;31(3):267-76.
23. Berghout M, van Exel J, Leensvaart L, Cramm JM. Healthcare professionals' views on patient-centered care in hospitals. BMC Health Services Research 2015;15(1):1.
24. Hesselink G, Zegers M, Vernooij-Dassen M, et al. Improving patient discharge and reducing hospital readmissions by using Intervention Mapping. BMC Health Services Research 2014;14(1):1.
25. Stelfox HT, Lane D, Boyd JM, et al. A scoping review of patient discharge from intensive care: opportunities and tools to improve care. Chest Journal 2015;147(2):317-27.
26. SCCM. ABCDEF bundle. Available from http://www.iculiberation.org/Bundles/Pages/default.aspx [accessed 30-01-2017].
27. Barnes-Daly MA, Phillips G, Ely EW. Improving Hospital Survival and Reducing Brain Dysfunction at Seven California Community Hospitals: Implementing PAD Guidelines Via the ABCDEF Bundle in 6,064 Patients. Critical Care Medicine 2017;45(2):171-178.
28. Gill M, Bagshaw SM, McKenzie E, et al. Patient and family member-led research in the intensive care unit: a novel approach to patient-centered research. PloS ONE 2016;11(8):e0160947.
29. Brown SM, Bell SK, Roche SD, et al. Preferences of Current and Potential Patients and Family Members Regarding Implementation of Electronic Communication Portals in Intensive Care Units. Annals of the American Thoracic Society 2016;13(3):391-400.
30. Mistraletti G, Umbrello M, Mantovani ES, et al. A family information brochure and dedicated website to improve the ICU experience for patients' relatives: an Italian multicenter before-and-after study. Intensive Care Medicine 2016:1-11.
31. Berwick DM, Kotagal M. Restricted visiting hours in ICUs: time to change. JAMA 2004;292(6):736-37.
32. Chapman DK, Collingridge DS, Mitchell LA, et al. Satisfaction With Elimination of all Visitation Restrictions in a Mixed-Profile Intensive Care Unit. American Journal of Critical Care 2016;25(1):46-50.
33. Cabrini L, Landoni G, Antonelli M, et al. Critical care in the near future: patient-centered, beyond space and time boundaries. Minerva Anestesiologica 2015 (PMID:26474269).
34. Cappellini E, Bambi S, Lucchini A, Milanesio E. Open intensive care units: a global challenge for patients, relatives, and critical care teams. Dimensions of Critical Care Nursing 2014;33(4):181-193.
35. Bench S, Day T, Heelas K, Hopkins P, White C, Griffiths P. Evaluating the feasibility and effectiveness of a critical care discharge information pack for patients and their families: a pilot cluster randomised controlled trial. BMJ open 2015;5(11):e006852.
36. Myhren H, Ekeberg O, Toien K, Karlsson S, Stokland O. Posttraumatic stress, anxiety and depression symptoms in patients during the first year post intensive care unit discharge. Critical Care 2010;14(1):R14.

37. Bench S, Day T. The user experience of critical care discharge: a meta-synthesis of qualitative research. International Journal of Nursing Studies 2010;47(4):487-99.
38. McKinney AA, Deeny P. Leaving the intensive care unit: a phenomenological study of the patients' experience. Intensive and Critical Care Nursing 2002;18(6):320-31.
39. Paul F, Hendry C, Cabrelli L. Meeting patient and relatives' information needs upon transfer from an intensive care unit: the development and evaluation of an information booklet. Journal of Clinical Nursing 2004;13(3):396-405.
40. Chaboyer W, Thalib L, Alcorn K, Foster M. The effect of an ICU liaison nurse on patients and family's anxiety prior to transfer to the ward: an intervention study. Intensive and Critical Care Nursing 2007;23(6):362-69.
41. Athifa M, Finn J, Brearley L, et al. A qualitative exploration of nurse's perception of Critical Outreach Service: A before and after study. Australian Critical Care 2011;24(1):39-47.
42. van Mol MMC, Brackel M, Kompanje EJ, et al. Joined forces in person-centered care in the intensive care unit: a case report from the Netherlands. Journal of Compassionate Health Care 2016;3(1):1.
43. Stucky K, Jutte JE, Warren AM, Jackson JC, Merbitz N. A survey of psychology practice in critical-care settings. Rehabilitation psychology 2016;61(2):201.
44. Brunton N. A personal experience of ICU care in the UK Available from http://blogs.biomedcentral.com/on-health/2016/12/19/a-personal-experience-of-icu-care-in-the-uk/19-12-2016 [accessed 30-12-2016] 2016.
45. Fairman J. Watchful vigilance: nursing care, technology, and the development of intensive care units. Nursing Research 1992;41(1):56.
46. Brink-Tjebbes JA, Keij JA. [Verplegen in verbondenheid. De verpleegde centraal–gevolgen voor verplegingspraktijk en verplegingswetenschap] The caretaker central-implications for nursing practice and nursing science: Uitgeverij Kavanah 1997.
47. ZonMw. [Signalement over Zingeving in zorg] Advisary Report Meaning in healthcare. Ed: Wijgergnags L, Reijmerink W. ZonMw, 2016.
48. Richardson WC, Berwick DM, Bisgard JC, et al. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academy Press 2001. ISBN 9780309072809
49. Clay A, Parsh B. Patient-and Family-Centered Care: It's Not Just for Pediatrics Anymore. AMA journal of ethics 2015;18(1):40-44.
50. Decety J, Smith KE, Norman GJ, Halpern J. A social neuroscience perspective on clinical empathy. World Psychiatry 2014;13(3):233-37.
51. Buckman R, Tulsky JA, Rodin G. Empathic responses in clinical practice: Intuition or tuition? Canadian Medical Association Journal 2011;183(5):569-71.
52. Kiosses VN, Karathanos VT, Tatsioni A. Empathy promoting interventions for health professionals: a systematic review of RCTs. Journal of Compassionate Health Care 2016;3(1):7.
53. Bloom P. Against Empathy The Case for Rational Compassion. 2016. Ecco Press new York, ISBN 9780062339331
54. Kompanje EJO, van Mol MMC, Weigel J. Will we become more empathic intensive care professionals by watching films and documentaries about suffering? Intensive Care Medicine 2017; DOI 10.1007/s00134-017-4693-4
55. Kompanje EJ, van Mol MMC, Nijkamp MD. 'I just have admitted an interesting sepsis'. Do we dehumanize our patients? Intensive Care Medicine 2015;41(12):2193-94.
56. Sinclair S, Norris JM, McConnell SJ, et al. Compassion: a scoping review of the healthcare literature. BMC palliative care 2016;15(1):1.
57. Sinclair S, McClement S, Raffin-Bouchal S, et al. Compassion in health care: An empirical

model. Journal of pain and symptom management 2016;51(2):193-203.

58. Graber DR, Mitcham MD. Compassionate clinicians: Take patient care beyond the ordinary. Holistic Nursing Practice 2004;18(2):87-94.

59. van der Cingel CJM. Compassion in care: A qualitative study of older people with a chronic disease and nurses. Nursing Ethics 2011:0969733011403556.

60. Laerkner E, Egerod I, Hansen HP. Nurses' experiences of caring for critically ill, non-sedated, mechanically ventilated patients in the Intensive Care Unit: A qualitative study. Intensive and Critical Care Nursing 2015;31(4):196-204.

61. Aiken LH, Sloane D, Griffiths P, et al. Nursing skill mix in European hospitals: cross-sectional study of the association with mortality, patient ratings, and quality of care. BMJ Quality & Safety 2016:bmjqs-2016-005567.

62. Shanafelt TD, Hasan O, Dyrbye LN et al. Changes in burnout and satisfaction with work-life balance in physicians and the general US working population between 2011 and 2014. Mayo Clinic Proceedings; 2015. Elsevier; 2015: 1600-1613.

63. Crickmore R. A review of stress in the intensive care unit. Intensive Care Nursing 1987;3(1):19-27.

64. Donchin Y, Seagull FJ. The hostile environment of the intensive care unit Review. Current Opinion Critical Care 2002;8(4):316-20.

65. Sprung CL, Cohen R, Marini JJ. Excellence in Intensive Care Medicine. Critical Care Medicine 2016;44(1):202-06.

66. van Mol MMC, Kompanje EJ, Benoit DD, Bakker J, Nijkamp MD. The Prevalence of Compassion Fatigue and Burnout among Healthcare Professionals in Intensive Care Units: A Systematic Review. PloS ONE 2015;10(8):e0136955.

67. Medscape. Lifestyle Report 2016. 2016 [Available from http://www.medscape.com/features/slideshow/lifestyle/2016/public/overview#page=2 accessed 18-8-2016].

68. Quenot JP, Rigaud JP, Prin S, et al. Suffering among carers working in critical care can be reduced by an intensive communication strategy on end-of-life practices. Intensive Care Medicine 2012;38(1):55-61.

90. Barbosa FT, Leao BA, Tavares GMS, dos Santos JGRP. Burnout syndrome and weekly workload of on-call physicians: Cross-sectional study. Sao Paulo Med J 2012;130(5):282-88.

70. Chuang C-H, Tseng P-C, Lin C-Y, Lin K-H, Chen Y-Y. Burnout in the intensive care unit professionals: A systematic review. Medicine 2016;95(50):e5629.

71. Moss M, Good VS, Gozal D, Kleinpell R, Sessler CN. An official critical care societies collaborative statement—burnout syndrome in critical care health-care professionals: a call for action. CHEST Journal 2016;150(1):17-26.

72. Smit BW, Barber LK. Psychologically detaching despite high workloads: The role of attentional processes. Journal of Occupational Psychology 2016;21(4):432-442.

73. van Mol MMC, Nijkamp MD, Bakker J, Schaufeli WB, Kompanje EJO. Counterbalance to work-related stress; work engagement among intensive care professionals. Australian Critical Care 2017 Minor revision.

74. Buruck G, Dörfel D, Kugler J, Brom SS. Enhancing Well-Being at Work: The Role of Emotion Regulation Skills as Personal Resources. 2016;21(4):480-493

75. Bakker AB, Demerouti E. Job Demands–Resources Theory: Taking Stock and Looking Forward. 2016;doi.org/10.1037/ocp0000056

76. Jong J, Ford MT. The Lagged Effects of Job Demands and Resources on Organizational Commitment in Federal Government Agencies: A Multi-Level Analysis. Journal of Public Administration Research and Theory 2016:muv040.

77. Searle BJ, Auton JC. The merits of measuring challenge and hindrance appraisals. Anxiety, Stress, & Coping 2015;28(2):121-43.

78. West CP, Dyrbye LN, Rabatin JT, et al. Intervention to Promote Physician Well-being, Job Satisfaction, and Professionalism: A

Randomized Clinical Trial. JAMA Internal Medicine 2014;174(4):527-33.

79. Awa WL, Plaumann M, Walter U. Burnout prevention: A review of intervention programs. Patient Education and Counseling 2010;78(2):184-90.

80. Romppanen J, Häggman-Laitila A. Interventions for nurses' well-being at work: a quantitative systematic review. Journal of Advanced Nursing 2016

81. International Labour Organisation. Workplace well-being. ccupational safety and health. available from http://www.ilo.org/safework/areasofwork/workplace-health-promotion-and-well-being/WCMS_118396/lang--en/index.htm2009 [accessed 28-12-2016].

82. Scheepers RA, Boerebach BC, Arah OA, Heineman MJ, Lombarts KM. A systematic review of the impact of physicians' occupational well-being on the quality of patient care. International Journal of Behavioral Medicine 2015;22(6):683-98.

83. United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing 2015; (ST/ESA/SER.A/390)

84. Leijten FR, van den Heuvel SG, van der Beek AJ, Ybema JF, Robroek SJ, Burdorf A. Associations of work-related factors and work engagement with mental and physical health: a 1-year follow-up study among older workers. Journal of Occupational Rehabilitation 2015;25(1):86-95.

85. van der Meer L, Leijten FR, Heuvel SG, Ybema JF, de Wind A, Burdorf A. Company Policies on Working Hours and Night Work in Relation to Older Workers' Work Ability and Work Engagement: Results From a Dutch Longitudinal Study with 2 Year Follow-Up. Journal of Occupational Rehabilitation 2016;26(2):173-81.

86. Fleuren BP, de Grip A, Jansen NW, Kant I, Zijlstra F. Critical reflections on the currently leading definition of sustainable employability. Scandinavian Journal of Work, Environment and Health 2016;42(6):557-560.

87. Burdorf A, Jansen J. Predicting the long term course of low back pain and its consequences for sickness absence and associated work disability. Occupational and Environmental Medicine 2006;63(8):522-29.

88. Leiter MP, Bakker AB, Maslach C. Burnout at Work: A Psychological Perspective: Psychology Press 2014. ISBN 9781848722286.

89. van der Klink JJ, Bültmann U, Burdorf A, et al. Sustainable employability–definition, conceptualization, and implications: A perspective based on the capability approach. Scandinavian Journal of Work Environmental Health 2016;42(1):71-79.

90. Schaufeli WB, Bakker AB. Job demands, job resources, and their relationship with burnout and engagement: A multi-sample study. Journal of organizational Behavior 2004;25(3):293-315.

91. Bartholomew LK, Kok G, Markham CM. Planning health promotion programs: An intervention mapping approach. Fourth edition 2016. John Wiley and Amp; Sons Inc. ISBN 9781119035497.

92. Bienvenu OJ. Is this critical care clinician burned out? Intensive Care Medicine 201;42(11):1794-1796.

93. Walshe K, Rundall TG. Evidence-based management: from theory to practice in health care. Milbank Quarterly 2001;79(3):429-57.

94. Covey S. Quote Availabale from https://www.brainyquote.com/quotes/quotes/s/stephencov636483.html; [accessed 03-01-2017].

95. Spickard Jr A, Gabbe SG, Christensen JF. Mid-career burnout in generalist and specialist physicians. JAMA 2002;288(12):1447-50.

96. Serxner S, Alberti A, Weinberger S. Medical cost savings for participants and nonparticipants in health risk assessments, lifestyle management, disease management, depression management, and nurseline in a large financial services corporation. American Journal of Health Promotion 2012;26(4):245-52.

97. Baicker K, Cutler D, Song Z. Workplace wellness programs can generate savings. Health affairs 2010;29(2):304-11.
98. Ng TW, Sorensen KL, Eby LT. Locus of control at work: a meta-analysis. Journal of organizational Behavior 2006;27(8):1057-87.
99. Mealer M, Jones J, Newman J, McFann KK, Rothbaum B, Moss M. The presence of resilience is associated with a healthier psychological profile in intensive care unit (ICU) nurses: Results of a national survey. International Journal of Nursing Studies 2012;49(3):292-99.
100. Montero-Marin J, Tops M, Manzanera R, Demarzo MMP, de Mon MÁ, García-Campayo J. Mindfulness, Resilience, and Burnout Subtypes in Primary Care Physicians: The Possible Mediating Role of Positive and Negative Affect. Frontiers in psychology 2015;6
101. Bonanno GA. Loss, trauma, and human resilience: have we underestimated the human capacity to thrive after extremely aversive events? American psychologist 2004;59(1):20.
102. Windle G, Bennett KM, Noyes J. A methodological review of resilience measurement scales. Health and quality of life outcomes 2011;9(1):1.
103. Charlier P, Coppens Y, Malaurie J, et al. A new definition of health? An open letter of autochthonous peoples and medical anthropologists to the WHO. European Journal of Internal Medicine 2016: doi.org/10.1016/j.ejim.2016.06.027
104. Santos A, Chambel MJ, Castanheira F. Relational job characteristics and nurses' affective organizational commitment: the mediating role of work engagement. Journal of Advanced Nursing 2016;72(2):294-305.

10.1

Summary and Conclusions

The overall aim of this thesis was to gain insight into the emotional challenges associated with intensive care practice from the perspectives of both the patients’ relatives and the professionals. The ultimate goal was to provide recommendations to further improve staying and working in the intensive care unit (ICU).

First, the potential of a questionnaire, the Consumer Quality Index ´Relatives in the intensive care unit´ (CQI ‘R-ICU’) has been examined to assess the quality of care from the perspective of relatives in the ICU (Chapter 2). This instrument, which measures ‘Patient/Person Reported Experience Measures’ (PREMs), is aimed to provide feedback and identify bottlenecks regarding the quality of care to policy makers and healthcare professionals. The CQI ‘R-ICU’ appears to be a valid, reliable and usable instrument with a sound theoretical basis, that establishes priorities regarding the aspects that need improvement. Professionals can learn from the experiences of relatives by using this instrument. For these reasons, the new tool is not a goal in itself but mainly a practical instrument to assess the care given to relatives.

Two years later, Jensen et al. presented the development of another new Dutch questionnaire addressing the needs of relatives in the ICU, namely, the euroQ2, which might prove helpful to provide high-quality care in ICUs. Assessing the needs of relatives of ICU patients is of the utmost importance; however, the authors treated the concepts of ´satisfaction´, ´experiences´ and ´quality of care´ as one and the same without further explanation. In addition, the euroQ2 appears to have been developed and preliminary validated using methodological errors. Most importantly, the utilized concept of satisfaction might raise some biases due to ceiling effects, cognitive dissonance and socially desirable answers. A discrepancy model, which describes satisfaction as a result of expectations minus the perceived experience, could overcome these problems. Therefore, in a letter to the editor, the added value of this questionnaire in addition to the CQI ‘R-ICU’ has been questioned (Chapter 2bis).

Subsequently, the effect of additional supportive interventions specifically designed for ICU patients’ relatives, such as intake interviews, encouragement to keep a diary, and weekly multidisciplinary psychosocial rounds, has been examined using the CQI ‘R-ICU’ questionnaire (Chapter 3). The results suggested that the implementation of these interventions increased the perceived quality of care, particularly with respect to informational factors. However, moving toward person-centered care requires a challenging shift in the mindset of healthcare professionals. Training in providing psychosocial support to meet the needs of relatives might lead to a stronger awareness of person-centered care. Therefore, ongoing efforts to change the mindset of professionals will contribute to an optimal quality of care in the ICU.

A case study of the joint efforts of the Dutch national network and the Family and Patient Centered Intensive Care (FCIC) foundation is presented as an example of person-centered care (Chapter 4). The FCIC combines the strengths of different disciplines and input from scientists, former ICU patients and their relatives to exchange knowledge about how to reduce the emotional impact of an ICU admission. This approach is the core of person-centered care; the views, values and needs of experts are fundamental to create changes in ICU policies. Empathy, respect to a person´s values, needs and preferences, and comprehensive communication are key aspects of person-centered care. In the ICU, with the priority on patient´s survival and the technological aspects of treatments, a high level of clinical expertise, far-reaching knowledge, and extensive ´soft-skills´ are required on the parts of the professionals. Although there is an ongoing debate on the theories of compassion and empathy, in this thesis those are considered as two different constructs. Compassion includes noticing when someone is suffering and experiencing a mutual emotional reaction to this suffering, subsequently stimulating meaningful action in the relationship. Empathy is the cognitive understanding and consideration of the perspective of other human beings in distress, leading to support, even though caregivers do not have to feel the pain and suffering of these individuals. However, providing care with an excess of empathy might have negative consequences for ICU professionals themselves; therefore, supportive strategies to protect the health of the professionals are necessary. This goal can be achieved by informal talks, interventions from social workers or psychologists, and discussion groups regarding topics such as a moral deliberation. Additionally, training in relationship-building and communication capabilities is an essential element for the development of empathy in ICU professionals. Furthermore, recognition of and support for person-centered care on the part of managers and policymakers is a well-intentioned condition. These strategies will provide a better balance for professionals in terms of providing highly technical ICU care while remaining emotionally distant and avoiding becoming overloaded by exhaustive feelings and attachment.

Whether empathy is an innate competence derived from prosocial behavior or whether it can be taught during medical and nursing training is not a black or white issue. Readers (of a novel) or watchers (of a movie or documentary) who read about or view suffering can become unsettled and may thereafter consider the same anguish in real life in a different (more empathic) way (Chapter 5.1). This may lead to better empathic understanding of events in real life. Nearly all healthcare professionals in their daily patient management use cognitive empathy when coping with the experience of suffering. However, while watching a movie or documentary or reading a novel, they may experience emotional empathy that serves another aim in their personal life. In that case, they want to be touched and identify themselves with the individuals in the film or book. In contrast to responding with empathy to ICU patients and their relatives, dehumanization also occurs. Healthcare providers, who sometimes speak about patients in terms of specific diseases, organs or operation techniques, do so because it is practical. It seems easier to communicate using these patient characteristics than using their real names. Therefore, it was provocatively stated that ICU professionals dehumanize some of their patients. However, this appeared inevitable, adaptive, and even morally and psychologically acceptable (Chapter 5.2).

Inevitably, working in the ICU environment can be an emotionally charged challenge. The emotional price of caring might become a burden for professionals' personal lives, which may possibly be manifested in compassion fatigue or burnout. However, a systematic review study showed that the true magnitude of the emotional distress of the ICU professionals remains unclear due to a lack of unity in concepts, measurements, and cut-off points (Chapter 6). Policymakers should introduce interventions to prevent the negative consequences of emotional distress. Training communication skills, educational sessions on stress management, and mindfulness might be helpful to prevent emotional distress among ICU professionals.

Traditionally, various healthcare professions have been acknowledged as particularly vulnerable to work-related stress, with a number of prevalent stress responses such as burnout, traumatic stress, and compassion fatigue. Burnout is currently seen as the most prevalent career crisis of the twenty-first century. However, since the emergence of this issue, the operationalization and measurement of burnout has differed across studies. The concept of burnout might be misused to indicate an overall exhaustion with life. Fatigue and tiredness may result as a part of the human condition. Other researchers have suggested that ICU professionals experience a traumatic work environment, and consequently, posttraumatic stress responses. By contrast, it was suggested that ICU professionals have adapted their individual coping strategies to the demanding work environment to find emotional balance (Chapter 7). Apart from some exceptional cases, such as being involved in a medical error, a natural disaster, or a war situation, it is very unlikely that ICU professionals are traumatized by their emotionally demanding work. Post-traumatic stress disorder and its related symptoms in war veterans are completely different from work-related stress in ICU professionals. Compassion fatigue, which has been described as a loss of compassion due to repeated exposure to suffering during work, raised conceptual confusion and questioning of symptoms. In the last two decades, compassion fatigue has become a trending topic that should be critically reexamined or abandoned in favor of a new debate on work-related stress among ICU professionals. Work engagement, with its positively labeled elements, is the counterbalance to work-related stress. Engaged employees believe in themselves, generate their own positive feedback, set higher goals, have values that match those of the organization, and show a sustained healthy state.

In an empirical study among ICU professionals, the relatively high workload and especially the high emotional burden, was acknowledged as an integral part of ICU work (Chapter 8). The emotional, cognitive and physical job demands did not affect the level of work engagement; work engagement was found high for both intensivists and nurses. In addition, there was no influence of empathic ability on work engagement. The results of this study also suggested that ICU professionals understand their patients and relatives but remain at a certain emotional distance. This self-management and adaptation to the work environment may be interpreted as a means for professionals to protect their emotional health. It is essential to take care of the professionals and their emotional balance while working to support their health and allocate successful management of care to patients and their relatives.

GENERAL DISCUSSION AND CONCLUSIONS

Healthcare organizations and ICU policy makers must develop, adopt, and implement interventions in daily practice that are aimed to prevent emotional distress and establish sustainable employability among professionals. Organizational improvements, in addition to individual activities to promote the well-being of the professionals, including self-care in nutrition, sleep, exercise, spirituality, and spending quality time with family or friends, should aim to increase personal fulfillment, meaning in work life and subsequently work engagement. Work has become a life domain in which employees want to achieve important goals and fulfill their personal ambitions and values, in addition to having income security. Therefore, an individual´s work situation should enable the execution of valued tasks, aiming for goals that are both personally significant and valued by the organization. Making a positive change in the lives of frail people might provide meaning and purpose while working, which may stimulate and contribute to employees´ dedication.

Staying in the uncertain world of the ICU is never desirable; however, the negative impact of this stay might be diminished if patients and their relatives perceive that they are receiving optimal and quality care. Interventions that focus on person-centered care and encompass respect, dignity, and empathy will have a positive influence on the patients' and relatives' experiences. Healthcare providers in the ICU may play a crucial role and make a difference in the lives of the patients and their relatives. Working in the ICU can be exciting in a positive way. The diverse proceedings that require various technical skills, such as increasing one's medical knowledge, providing emotional support, managing intense treatment courses, and trying interesting new interventions, might satisfy an individual's work-related ambitions and life fulfillment. This may give meaning to the work of ICU professionals. Both comprehensive insights into the patients´ diseases and circumstances as well as thoughtful discussions and subsequent patient care decisions may offer ICU professionals ample opportunity to grow and to enjoy their work. In their unsolicited role, patients and their relatives may contribute to this fulfillment. Overall, the ICU is an inspiring world in which to work. We should keep it that way and strive for a healthy and successful working environment.

10.2 Samenvatting en Conclusies

Dit proefschrift beoogt inzicht te verkrijgen in de emotionele uitdagingen in intensive care (IC) zorg vanuit het perspectief van zowel de patiënt en diens naasten als de professionals, in het bijzonder de intensivisten en verpleegkundigen. Het uiteindelijke doel was om aanbevelingen op te stellen voor verdere verbetering van het verblijven en werken op de IC-afdeling.

Ten eerste zijn de eigenschappen onderzocht van een vragenlijst, de Consumer Quality Index ´Naasten op de intensive care afdeling' (CQI-Naasten op de IC') waarmee naasten van een IC-patiënt de kwaliteit van zorg kunnen beoordelen (Hoofdstuk 2). Dit instrument, dat de 'Patient/Person Reported Experience Measures' (PREMs) meet, streeft ernaar om knelpunten in de geboden kwaliteit van zorg te bepalen en geeft feedback aan beleidsmakers en professionals in de gezondheidszorg. De CQI 'Naasten op de IC' bleek een valide, betrouwbaar en nuttig instrument met een stevige theoretische basis. Deze vragenlijst geeft ook prioriteiten aan in de aspecten waar verbetering nodig is. Professionals kunnen van de ervaringen van naasten leren door het instrument te gebruiken. Daarom is dit tool niet een doel op zichzelf, maar vooral bedoeld als een praktisch instrument in de zorg voor de naasten.

Twee jaar later presenteren Jensen en collega´s de ontwikkeling van een andere Nederlandstalige vragenlijst ten aanzien van de naasten op de IC, de EuroQ2, welke van nut kan zijn om hoog gewaardeerde zorg op de IC te leveren. Het evalueren van de behoeften van naasten van een IC-patiënt is van groot belang, echter, de auteurs verwarren de concepten van ´tevredenheid´, ´ervaringen´, en ´kwaliteit van zorg´ in het gebruik door elkaar heen zonder verdere uitleg. Daarnaast lijken enkele methodologische fouten een rol te spelen in de ontwikkeling en validering van de EuroQ2. Meest zwaarwegend is dat het door hen gebruikte concept van tevredenheid bias kan geven als gevolg van plafondeffecten, cognitieve dissonantie en sociaal wenselijke antwoorden. Een discrepantie-model kan deze problemen voorkomen. Dit gaat uit van tevredenheid als resultaat van de verwachting minus de waargenomen eigen ervaring, In een ´letter to the editor´ werd getwijfeld aan de toegevoegde waarde van deze vragenlijst boven de bestaande CQI ´Naasten op de IC' (Hoofdstuk 2bis).

Vervolgens is met de CQI ´Naasten op de IC' het effect geëvalueerd van ondersteunende interventies die speciaal voor de naasten van IC-patiënten werden ontworpen, zoals een opnamegesprek, aanreiken en stimuleren om een dagboek bij te houden, en wekelijks multidisciplinair psychosociaal overleg (Hoofdstuk 3). De resultaten suggereren dat de implementatie van deze interventies de kwaliteit van zorg verhoogden, dit betrof vooral aspecten met betrekking tot het delen van informatie. Echter, een verschuiving naar persoonsgerichte zorg vereist een uitdagende verandering in de mindset van de professionals. Een training in psychosociale opvang van de behoeften van naasten zou kunnen leiden tot een grotere bewustwording van persoonsgerichte zorg. Een voortdurende inspanning om de mindset van de professionals te veranderen kan bijdragen aan een optimale kwaliteit van zorg op de IC-afdeling.

Een casestudie betreffende samenwerkende krachten in een nationaal Nederlands netwerk, stichting FCIC (Family and patient Centered Intensive Care), werd gepresenteerd als een voorbeeld van persoonsgerichtheid (Hoofdstuk 4). FCIC combineert de sterke kanten van diverse disciplines en wetenschappers, met voormalig IC-patiënten en hun naasten, om kennis te delen over hoe de impact van een IC-opname beperkt kan worden. Deze benadering komt overeen met de kern van persoonsgerichte zorg; de visie, de waarden en de behoeften van de experts vormen een fundamentele basis in veranderingen in IC-beleid. Empathie, respect voor de waarden, de behoeften en de voorkeuren van een persoon, alsmede uitgebreide communicatie zijn de belangrijkste aspecten van persoonsgerichte zorg. Op een IC-afdeling, met de prioriteit gericht op het overleven van de patiënt met technologische aspecten in de behandelingen, vraagt dit een hoog niveau van klinische expertise, ver reikende kennis, en uitgebreide sociale vaardigheden ('soft-skills') van de professionals. Hoewel er een voortdurende discussie is over de achterliggende theorieën over compassie en empathie, worden deze in dit proefschrift als twee verschillende begrippen beschouwd. Compassie omvat het opmerken van het lijden van een ander in een wederzijdse emotionele reactie (voelen) op dit lijden, gevolgd door een betekenisvolle handeling in deze relatie. Empathie is het cognitieve begrip en het overwegen van de situatie van een andere persoon in lijden of zorg, leidend tot ondersteuning, waarbij dit niet gepaard hoeft te gaan met het zelf voelen van het lijden van deze persoon. Een teveel aan emotioneel inleven kan negatieve gevolgen hebben voor de professionals. Daarom zijn er ondersteunende interventies nodig om de emotionele gezondheid van de professionals te waarborgen. Dit kan bereikt worden met informele gesprekken met collega´s of vrienden, intervisie door een medisch maatschappelijk werker of psycholoog, en teambesprekingen over casuïstiek met morele aspecten in de zorg. Daarnaast, een training in relatieopbouw en communicatieve vaardigheden vormen een essentieel element in de ontwikkeling van een empathische houding bij IC-professionals. De herkenning en begeleiding door managers en beleidsmakers van persoonsgerichte zorg is een noodzakelijke voorwaarde tot succes bij de implementatie van de interventies. Deze strategieën verbeteren de balans voor IC-professionals tussen hoog-technische IC zorg in emotionele nabijheid en jezelf verliezen in een overdaad van uitputtende gevoelens en nabijheid.

Of empathie een aangeboren vaardigheid afgeleid van pro-sociaal gedrag is, of dat het aangeleerd kan worden tijdens medische en verpleegkundige trainingen, is geen zwart-of-wit perspectief. Lezers (van een boek) of kijkers (naar een film of documentaire) van persoonlijke situaties met lijden, kunnen zich ontzet voelen om daarna in het reële leven dezelfde angst te overwegen op een andere (meer empathische) manier (Hoofdstuk 5.1). Waarschijnlijk leidt dit tot een meer empathisch begrip van werkelijke gebeurtenissen. Bijna elke zorgverlener in de dagelijkse zorg voor patiënten gebruikt cognitieve empathie in de omgang met situaties van lijden. Echter, tijdens het lezen van een boek, of het kijken naar een film of documentaire, kan emotionele empathie ervaren worden. Dit dient een ander doel in het persoonlijk leven. In dat geval willen mensen geraakt worden en willen zij zichzelf identificeren met de personages in het boek of de film. In tegenstelling tot het reageren met empathie bij IC-patiënten en hun naasten, is dehumanizatie eveneens herkenbaar. Zorgverleners spreken soms over patiënten in termen van ziektes, organen of operatietechnieken omdat het praktisch is. Het lijkt gemakkelijker om in de communicatie deze kenmerken van de patiënten te onthouden dan hun echte namen te gebruiken. In dit profschrift werd provocatief beweerd dat IC-professionals sommige van hun patiënten dehumaniseren, maar dat dit onvermijdelijk, adaptief, en zelfs moreel en psychologisch aanvaardbaar is (Hoofdstuk 5.2).

Het is onvermijdelijk dat werken op een IC-afdeling een emotioneel geladen uitdaging kan zijn. De emotionele prijs van zorg verlenen kan een last worden in het persoonlijke leven van de professional. Dit komt mogelijk tot uiting in compassie vermoeidheid of burnout. Echter, de systematische literatuurstudie liet zien dat de werkelijke omvang van emotionele (over)spanning in IC-professionals onduidelijk blijft als gevolg van een gebrek aan eenheid in concepten, meetinstrumenten, en afkappunten (Hoofdstuk 6). Beleidsmakers zouden interventies moeten introduceren om de negatieve gevolgen van emotionele (over)spanning te voorkomen. Het trainen van communicatieve vaardigheden, educatieve sessies over stress hantering, en mindfulness kunnen behulpzaam zijn in het voorkomen van emotionele (over)spanning bij professionals op een IC-afdeling.

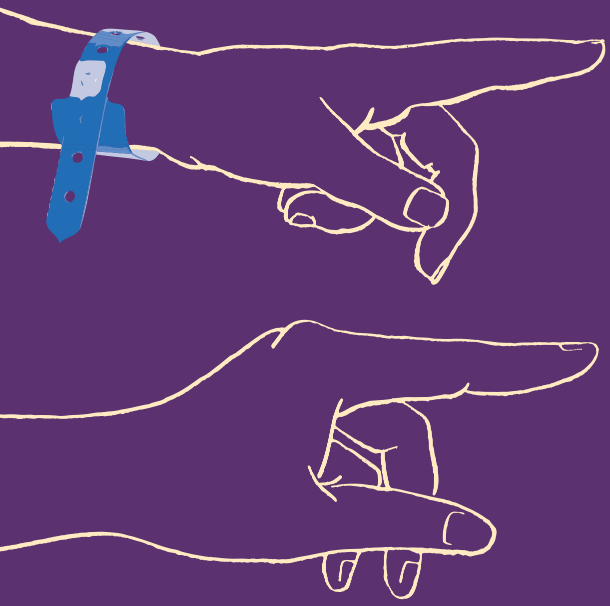
Van oudsher zijn zorgverleners vanuit diverse disciplines erkend in hun kwetsbare positie met betrekking tot werkstress, met een aantal meest voorkomende stress reacties zoals burnout, traumatische stress en compassie vermoeidheid. Vooral burnout wordt tegenwoordig gezien als de meest sterke carrière crisis van de eenentwintigste eeuw. Echter, in diverse studies is de operationalisatie en het meten van burnout is nogal verschillend gehanteerd. Het idee van burnout kan verkeerd of tendentieus gebruikt zijn om een algemene vermoeidheid in het leven te benoemen; uitputting en moeheid blijken een onderdeeldeel van het menselijke bestaan te zijn. Andere onderzoekers suggereren dat IC-professionals het werk als traumatiserend ervaren, met posttraumatische stress als gevolg. In deze thesis daarentegen, wordt gesuggereerd dat professionals op de IC hun individuele coping strategieën hebben aangepast aan de eisen van de werk omgeving om hun emotionele balance te behouden (Hoofdstuk 7). Afgezien van uitzonderlijke situaties, zoals betrokken zijn bij het maken van een medische fout, een natuurramp, of een oorlogssituatie, is het uitzonderlijk dat IC-professionals getraumatiseerd zijn door hun emotioneel veeleisende werk. Post-traumatische stress stoornis, en de gerelateerde symptomen afstammend van oorlog-veteranen, is totaal verschillend van werkstress bij IC-professionals. Compassie vermoeidheid, dat kan worden beschreven als een verlies van compassie als gevolg van herhaalde blootstelling aan lijden tijdens het werk, roept conceptuele verwarring en vragen ten aanzien van de symptomen op. Het is de laatste twee decennia een moderne hype geworden die kritisch her-beoordeeld of verwijderd moet worden ten gunste van een nieuwe discussie over werkstress bij IC-professionals. Werkbevlogenheid, met positief gelabelde elementen, is een tegengewicht voor werkstress. Bevlogen werknemers geloven in zichzelf, genereren hun eigen positieve feedback, stellen hogere doelen, hanteren waarden die overeenkomen met de organisatie, en laten langdurig een goede gezondheid zien.

In een empirische studie onder IC-professionals werd de relatief hoge werkdruk, met vooral een hoge emotionele last, erkend als een wezenlijk onderdeel van het werken op een IC-afdeling (Hoofdstuk 8). De emotionele, cognitieve en fysieke werkeisen beïnvloedden niet het nivo van werkbevlogenheid, die was voor zowel intensivisten als verpleegkundigen hoog. De resultaten van de studie suggereren ook dat IC-professionals een goed begrip hebben voor de situatie van de patiënten en hun naasten, maar dat ze op een bepaalde emotionele afstand blijven. Dit zelfmanagement en aanpassen aan de werkomgeving kan gezien worden als een beschermende reactie voor de eigen gezondheid. Het is essentieel om de professionals te helpen en zorg te dragen voor hun emotionele balans tijdens het werken, teneinde de persoonlijke gezondheid te ondersteunen en succesvolle zorg aan patiënten en hun naasten mogelijk te maken.

ALGEMENE DISCUSSIE EN CONCLUSIES

Gezondheidszorginstellingen en IC beleidsmakers moeten interventies ontwikkelen, adopteren, en implementeren in de dagelijkse praktijk met als doel emotionele (over) spanning van de professionals te voorkomen en duurzame inzetbaarheid mogelijk te maken. Naast individuele activiteiten om het welzijn te bevorderen zoals goede voeding, slaap, sporten, spiritualiteit, en tijd doorbrengen met familie en vrienden, moeten de verbeteringen vanuit de organisatie leiden tot het vergroten van persoonlijk voldoening, betekenis geven in het werkbare leven en daarmee werkbevlogenheid bevorderen. Werk is een levensdomein geworden, waarin werknemers naast inkomensveiligheid belangrijke doelen willen behalen en persoonlijke ambities en waarden nastreven. Dat betekent dat een individuele werksituatie het mogelijk moet maken om taken uit te voeren die zowel persoonlijk belangrijk zijn als van waarde voor de organisatie. Het verschil te kunnen maken in het leven van kwetsbare mensen kan precies die betekenis en het doel geven aan de eigen inspanningen tijdens het werk, zodat het kan bijdragen aan de toewijding van de werknemers.

Het is voor patiënten en hun naasten nooit wenselijk om in de onzekere wereld van de IC-afdeling te verblijven. Echter, de negatieve impact van dit verblijf zou verminderd kunnen worden als patiënten en hun naasten ervaren dat zij optimale kwaliteitszorg ontvangen. Interventies in de context van persoonsgerichte zorg, waarbij respect, waardigheid, en empathie de belangrijkste kenmerken zijn, oefenen een positieve invloed uit op de ervaringen van patiënten en hun naasten. Zorgverleners op de IC-afdeling kunnen een cruciale rol spelen en het verschil maken in het leven en de ervaringen van de patiënten en hun naasten. Werken op een IC-afdeling kan op een positieve manier uitdagend en afwisselend zijn. Een verscheidenheid aan procedures die een beroep doen op diverse technische vaardigheden, het vergroten van de medische kennis, het verstrekken van emotionele steun, het verloop van intensieve behandelingen, en interessante nieuwe interventies, kunnen invulling geven aan individuele werkgerelateerde ambities en voldoening in het leven. Zowel uitgebreid inzicht in de ziekten en situaties van de patiënt, alsmede de evenwichtige discussies en daaropvolgende beslissingen, kunnen betekenis geven aan het werk van de IC-professionals. Daarmee zijn er voldoende mogelijkheden om te groeien en met plezier te werken. In hun ongevraagde rol kunnen patiënten en hun naasten bijdragen aan deze vervulling. Over het algemeen kan gesteld worden dat de IC-afdeling een inspirerende wereld is om in te werken. Laten we dat zo houden en streven naar een gezonde en succesvolle werkomgeving.



ATTACHMENTS

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Dankbetuiging

LIST OF ABBREVIATIONS

ANOVA	Analysis of variance
BO	Burnout
CCFNI	Critical Care Family Needs Inventory
CCFSS	Critical Care Family Satisfaction Survey
CF	Compassion fatigue
CQI	Consumer Quality Index
CQI 'R-ICU'	Consumer Quality Index 'Relatives on Intensive Care Unit'
DSM-5	Diagnostic and Statistical Manual of Mental Disorders (fifth edition)
FCIC	Family and patient Centered Intensive Care foundation
FS-ICU	Family Satisfaction in the ICU Survey
ICCU	Intensive Cardiological Care Unit
ICU	Intensive Care Unit
ICV-1	Intensive Care Unit Adults-1
ICV-2	Intensive Care Unit Adults-2
ICV-3	Intensive Care Unit Adults-3
ITC	Item Total Correlation
KMO-value	Kaiser-Maier-Olkin Measure of Sampling Adequacy
M	Mean
MBI	Maslach Burnout Inventory
MEC	Medical Ethics Committee
MeSH	Medical Subject Headings
MICU	Medium intensive care unit
MPFC	Medial prefrontal cortex
MRA	Multiple Regression Analysis
n	Number
QIS	Quality Improvement Scores
PCA	Principal Component Analysis
PICS	Post Intensive Care Syndrome
PTSD	Post-traumatic stress disorder
ProQOL	Professional Quality of Care
QODD	Quality of Dying and Death
RAAK	Regional Attention and Action for Knowledge circulation
SAH	Subarachnoid haemorrhage
STS	Secondary traumatic stress
VT	Vicarious trauma
WMO	The Dutch law on Medical Research in Humans

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LIST OF PUBLICATIONS AND PRESENTATIONS

INTERNATIONAL PEER REVIEWED PUBLICATIONS

Relatives' perspectives on the quality of care in an Intensive Care Unit: The theoretical concept of a new tool.
van Mol MMC, Bakker EC, Nijkamp MD, Kompanje EJ, Bakker J, Verharen L.
Patient Education and Counseling 2014;95(3):406-413.

From the inside. ´I just have admitted an interesting sepsis´. Do we dehumanize our patients?
Kompanje EJO, van Mol MMC, Nijkamp MD.
Intensive Care Medicine 2015;41(12):2193-2194.

The Prevalence of Compassion Fatigue and Burnout among health care professionals in Intensive Care Units: A systematic review.
van Mol MMC, Kompanje EJO, Benoit DD, Bakker J, Nijkamp MD.
PLoS ONE 2015;8(10) e0136955.

Joined forces in person-centered care in the intensive care unit: A case report from the Netherlands.
van Mol MMC, Brackel M, Kompanje EJO, Gijsbers L, Nijkamp MD, Girbes ARJ, Bakker J.
Journal of Compassionate Healthcare 2016;3:5 DOI: 10.1186/s40639-016-0022-Y.

Patient and Family Centered Care in the intensive care unit; a challenge in daily practice of the healthcare professionals.
van Mol MMC, Boeter T, Verharen L, Kompanje E, Bakker J, Nijkamp MD.
Journal of Clinical Nursing 2016;doi: 10.1111/jocn.13669

Quality of care in the intensive care unit from the perspective of patient's relatives: development and psychometric evaluation of the consumer quality index 'R-ICU'
Rensen A, van Mol M, Menheere I, Nijkamp M, Verhoogt E, Maris B, & Verharen L.
BMC Health Services Research 2017;17(7). doi:10.1186/s12913-016-1975-4

Will we become more empathic intensive care professionals by watching films and documentaries about suffering?
Kompanje EJO, van Mol MMC, Weigel J.
Intensive Care Medicine 2017; DOI 10.1007/s00134-017-4693-4

Counterbalance to work-related stress; work engagement among intensive care professionals
van Mol MMC, Nijkamp MD, Bakker J, Schaufeli WB, Kompanje EJO
Australian Critical Care; Minor revision

Using an Intervention Mapping approach to develop a discharge protocol for intensive care patients
van Mol MMC, Nijkamp MD, Markham C, Ista E
BMC Health Services Research, Under review

BOOK CHAPTERS

Reflections on work-related stress among intensive care professionals, a historical impression
van Mol MMC, Kompanje EJO, Bakker J.
Annual Update in Intensive Care and Emergency Medicine 2017. Springer International Publishing, 527-538. ISBN978-3-319-51907-4

LETTERS

In response to: Families´ experiences of ICU quality of care: development and validation of a European questionnaire (euroQ2).
van Mol MMC, Bakker EC, Kompanje EJO, Nijkamp MD.
Journal of Critical Care 2015;30(6):1408-1409

NATIONAL PUBLICATIONS

Samenwerken in de zorg voor naasten op de IC-afdeling.
Janssen J, van Mol MMC, Verhoogt E, Verharen L.
Kritiek 2012;30(5):10-11.

Informatie op maat; IC-webportaal met informatie voor naasten van IC-patiënten.
van Mol MMC, Grootswagers B, Brouwer L, Postema T, Bakker J.
Critical Care 2013;2:20-22.

Het intakegesprek met naasten, een communicatieve interventie in het familiebeleid ontwikkeld en geïmplementeerd met Intervention Mapping.
van Mol MMC, Nijkamp MD.

Capita Selecta, Venticare 2014 http://www.venticare.nl/kennisbank/artikelen/het-intakegesprek-met-naasten-een-communicatieve-interventie-het-familiebeleid-ontwikkeld-en-geimplementeerd-met-intervention-ma

De patiënt centraal, worden IC-professionals er moe van?
van Mol MMC.
Capita Selecta, Venticare 2014 http://www.venticare.nl/kennisbank/artikelen/de-patient-centraal-worden-ic-professionals-er-moe-van

Een toolkit voor het begeleiden van familie op de intensive care.
Verharen L, Boeter T, Brunsveld E, Gijsbers L, van der Lingen L, van Mol M, Zegers E.
Kritiek 2014;32(3):8-9.

Reflectie op werkstress: gevolgen voor verpleegkundigen en mogelijke interventies.
de Boer C, van Mol MMC.
VIP Science 2014;1:8-9

Critical Appraised Topic. Relevante aspecten om de ervaringen van naasten op de intensive care te meten.
van Mol MMC, Nijkamp MD.
Venticare Magazine October 2015;28-29

Critical Appraised Topic. Emotionele disbalans bij intensive care professionals, een systematische review.
van Mol MMC, Kompanje EJO, Nijkamp MD.
Venticare Magazine April 2016;40-41

Persoonsgerichte zorg; een nieuwe trend?
Buis V, van Mol MMC.
VIP Science 2016;5:8-9

Naasten op de IC ´Was er aandacht voor wat u als naaste nodig had?’ Consumer Quality Index naar de ervaringen van naasten met de opvang en begeleiding op een intensive care te meten
Rutjens R, Rensen A, Menheere I, van Mol MMC, Verhoogt E, Maris B, Verharen L, Vloet L.

Venticare Magazine Januari 2017;44-45

Verpleegkundige 3.0! Een slimme verpleegkundige is op de toekomst voorbereid: nieuwe beroepsprofielen in 2020.
Buchner M, Kerpel J, van Mol MMC.
VIP Science 2017;6:10-11

ABSTRACTS

Quality of care in the Intensive Care Unit from the perspective of relatives.
van Mol MMC, Nijkamp MD, Bakker E, Rensen A, Menheere I, Verharen L.
Abstract presented at ISICEM 2013, Brussel.
Critical Care 2013:(Suppl 2)P543 doi:10.1186/cc12481

Compassion fatigue and burnout among health care professionals in the Intensive Care Unit.
van Mol MMC, Kompanje EJO, Bakker J, Nijkamp MD.
Abstract presented at ISICEM 2014, Brussel.
Critical Care 2014;18:(Suppl 1)P19 doi:10.1186/cc13209

To communicate with relatives; an evaluation of interventions in the Intensive Care Unit.
van Mol M, Boeter T, Verharen L, Nijkamp M.
Abstract presented at SCCM 2015, Phoenix, USA.
Critical Care Medicine 2015;42(12):A1506-pA1507 doi: 10.1097/01.ccm.0000458107.38450.d

Work engagement among healthcare professionals in the intensive care unit.
van Mol M, Nijkamp M, Kompanje E.
Abstract presented at ISICEM 2016, Brussel.
Critical Care 2016;20:(Suppl 2) P437

Personalized and person-centred care: how will the new design enhance possibilities for compassionate care in the Intensive Care Unit?
van Heel L, van Mol M.
Abstract accepted for European Healthcare Congress 2016, London UK.
Congress Book 2016;P37.

The professional nursing work environment: the experience of Dutch nurses in a university hospital.
Maassen SM, van Mol MMC, Dekker-van Doorn CM.
Abstract accepted for European Nursing Congress 2016, Rotterdam the Netherlands.
Congress Book 2016;D7-S259.

The influence of empathic ability and autonomy on sustaining work engagement among intensive care nurses.
van Mol MMC, Nijkamp MD, Kompanje EJO.
Abstract accepted for European Nursing Congress 2016, Rotterdam the Netherlands.
Congress Book 2016;D7-S259.

Right Care and Flourishing Nurses; a Comparison of the Intensive Care Unit and General Wards
van Mol MMC, Said T, Kompanje EJO, Nijkamp MD.
Abstract presented at SCCM, 2017 Honolulu Hawaii.
Critical Care Medicine 2016;44(12) Suppl.(828):283

POSTER PRESENTATIONS NATIONAL CONGRESSES

De Consumer Quality Index (CQI) Ervaringen van naasten op de Intensive Care.
van Mol MMC, Kompanje EJO, Maris B, Verhoogt E, Menheere I, Zeegers F, Nijkamp M, Verharen L.
Topics in Intensive Care 07-12-2011, Lunteren.

Family-centered Care op IC-Volwassenen in het Erasmus MC.
van Mol MMC, Kalkman N, Boeter T, Kompanje EJO.
WES 15-03-2012, Rotterdam.

De ontwikkeling en validering van de Consumer Quality Index ‘Ervaringen van naasten op de Intensive Care’.
van Mol MMC, Nijkamp MD, Maris B, Verhoogt E, Verharen L.
Venticare 07-06-2012, Utrecht.

Een evaluatie van communicatieve interventies om naasten op een Intensive Care afdeling te ondersteunen.
van Mol MMC, Boeter T, Kompanje E, Nijkamp M.
Venticare 04-06-2015, Utrecht.

Work engagement and empathic ability among healthcare professionals in the intensive care unit.
van Mol MMC, Nijkamp MD, Kompanje EJO.
COEUR-day 13-04-2016, Rotterdam.

ORAL PRESENTATIONS, INVITED SPEAKER

Consumer Quality Index. Tevredenheidmeting vanuit het perspectief van naasten op de IC
Topics, 12-12-2012, Lunteren.

Familiebegeleiding op de IC
Schakels in de Zorg, 12-03-2013 en 28-03-2013, Capelle aan den IJssel.

Op weg naar een valide meetinstrument, de CQI 'Naasten op de IC'
Symposium 'Family-centered Care… bijzaak of kerntaak?' 11-04-2013, Rotterdam.

Empathic studie; Waar staat de familie van de IC-patiënt?
Symposium 'Erasmus Critical Care Days', 12-06-2013, Rotterdam.

De patiënt centraal, worden IC-professionals er moe van?
Venticare, 16-05-2014, Utrecht.

IC-webportaal: informatie op maat voor naasten van IC-patiënten
Alumni dag Zorg Informatica, 11-06-2014, Amsterdam.

Eyes and ears to the relatives in the Intensive Care Unit
1st European Listening and health Care Conference, 30-10-2014, Nijmegen.

Persoonsgerichte zorg op de intensive care, de krachten gebundeld
Anna Reynvaan genomineerden bijeenkomst, 28-05-2015, Amsterdam.

Person-focused care, hoe ver ga je?
Venticare, 04-06-2015, Utrecht.

Hoe betrek je de familie erbij?
Venticare, 04-06-2015, Utrecht.

Persoonsgerichte zorg op IC volwassene
Lunchbijeenkomst Erasmus MC, 30-06-2015, Rotterdam.

Workshop: Familieparticipatie, mag het ietsje meer zijn?
Congres VIP^2 "Welke invloed heb jij?" 13-11-2015, Rotterdam.

IC Portal: een praktische toepassing van e-communicatie
VVIZV, 19-11-2015, Gent, België.

De familie beslist mee
Topics, 01-12-2015, Lunteren.

Patient and Family Centered Care; de juiste zorg nu en later
WES, "trAUma, na de klap de zorg" 11-03-2016, Rotterdam.

The influence of empathic ability and autonomy on work engagement among intensive care nurses
European Nursing Congress, 6-10-2016, Rotterdam.

Verpleegkundige Raad VIP^2; Waar staan we nu en wat gaan we het komende jaar doen?
Congres VIP^2 "Registratie; last of lust?" 02-12-2016, Rotterdam.

Using Intervention Mapping to develop a discharge protocol in the intensive care; needs assessment involving three perspectives
7th EfCCNa Congress, 17 -02-2017, Belfast

The evaluation of 'Balance-training'; a new method in the aftercare of intensive care patients
7th EfCCNa Congress, 17 -02-2017, Belfast

Visie op verpleegkundige dossiervoering in het Erasmus MC
Verpleegkundige Diagnosen met Linda Carpenito, 05-04-2017, Rotterdam

Stress en motivatie in het werk op de IC: last of lust?
23ste^{e} LVIZ symposium "Damage Control" 21-04-2017, Kerkrade.

PUBLIC MEDIA

“Starbucksgesprek”; Kan een patiënt zelf de regie voeren?
Interview met dr. Anneloes van Staa
VIP Science 2, May 2015.

Nurse power: Billenwassers.
Column in “Scanner”, August 2015.

Nurse power: Paraskevidekatriafobie.
Column in “Scanner”, September 2015.

Nurse power: Leermomentje!
Column in “Scanner”, November 2015

“Starbucksgesprek”; Functiedifferentiatie voor verpleegkundigen.
Gespreksverslag tussen Drs. J. Ensing, Drs. P. van Herk, J. Kerpel en I. Meima.
VIP Science 3, November 2015

“Jij en je ideale werkdag”
Interview met dr. Monique van Dijk.
VIP Science 3, November 2015.

IC-verpleegkundige belangrijk bij ondersteuning familie
Gastblog Nursing, 21 maart 2016,
http://www.nursing.nl/Verpleegkundigen/Blogs/2016/3/Gastblog-Erasmus/

Werkbevlogenheid op de IC
Gastblog Nursing, 21 maart 2016,
http://www.nursing.nl/Verpleegkundigen/Blogs/2016/3/Gastblog-Werkbevlogenheid-op-de-ic/

PHD PORTFOLIO

Name: Martina Maria Cornelia (Margo) van Mol
PhD period: 2013-2017
Erasmus MC Departments: Intensive Care Unit and Public Health
Research School: COEUR
Promotor: Prof. dr. J. Bakker
Copromotors: dr. E.J.O. Kompanje and dr. M.D. Nijkamp

1. PHD TRAINING

	ECTS	Year
General academic skills		
Academic writing in English for PhD-students (Taalinstituut EUR)	1	2013
Intensive course English (Regina Coeli, Vught)	4	2013
Schrijfmodule I. Zakelijk schrijven (Open Universiteit)	4.3	2013
Schrijfmodule II. Academisch schrijven (Open Universiteit)	4.3	2013
Toegankelijk, informatief schrijven (De Redactie)	0.3	2016
Didactische vaardigheden (Zorgacademie)	0.3	2016
Basiscursus Regelgeving en organisatie voor Klinisch onderzoekers, hercertificatie (BROK; Good Clinical Practice, Erasmus MC)	1	2016
Intensive Care Research (COEUR)	0.3	2017
Research skills		
Master Health Sciences, specialization Public health, NIHES	70	2014-2016
In-depth courses		
Klinische psychologie 3. De ambulante praktijk (Open Universiteit)	4.3	2013
E-mental health interventies (Open Universiteit)	4.3	2013

2. SEMINARS AND WORKSHOPS

	ECTS	Year
International congresses		
ISCEM, Brussel, Belgium	1	2013
ISCEM, Brussel, Belgium	1	2014
ESICM, Barcelona, Spain	1	2014
SCCM, Phoenix, USA	1	2015
VVIZV, Gent, Belgium	1	2015
ISCEM, Brussel, Belgium	1	2016
European Nursing Congress, Rotterdam, the Netherlands	1	2016
SCCM, Honolulu, Hawaii	1	2017
EfCCNa, Belfast, England	1	2017
National congresses		
Schakels in de Zorg, Capelle aan den IJssel	0.3	2013
Venticare, Utrecht	0.3	2013
Erasmus Critical Care Day, Rotterdam	0.3	2013
V&V Excellente zorg, Ede	0.3	2013
Nursing Experience, Ede	0.3	2013
Venticare, Utrecht	0.3	2014
Venticare, Utrecht	0.3	2015
Topics, Lunteren	0.3	2015
WES, Rotterdam	0.3	2016
Critical Care Nefrologie, Rotterdam	0.3	2016
FCIC, Meet and Greet, Putten	0.3	2016
Venticare, Utrecht	0.3	2016
V&VN, Zorgprofessional in balans, Ede	0.3	2016
Onderweg naar betaalbare persoonsgerichte zorg, Nijmegen	0.3	2016
V&VN, VAR netwerkdag, Nijmegen	0,3	2016
23ste^{e} LVIZ symposium 2017 *'Damage Control'*	0,3	2017
Workshops		
Research management for PhD students (Molecular Medicine Post Graduate School)	1	2013
Workshops Systematic Literature Retrieval and Endnote (Erasmus MC)	1	2013
Erasmus MC PhD-days, COEUR PhD-days, and associated workshops (Erasmus MC)	2	2013-2017
Scientific Integrity (Erasmus MC)	0.3	2014

Workshop 'Grant writing' (ZonMW)	0.3	2015
Workshop 'Grant writing' (Erasmus MC)	0.3	2017
Leiderschap en sturing (CC Zorgadviseurs)	0.3	2017
Ontwikkelen E-module (Erasmus MC)	0.1	2017

3. TEACHING AND OTHER ACTIVITIES

	ECTS	Year
Lecturing		
Diverse national workshops Theme: ´Family centered Intensive Care´	0,5	2012- 2014
Clinical lessons (Intensive Care Unit Adults, Erasmus MC) Themes: ´Person-centered care´, ´Work engagement´, and 'the Nursing Council, promoting leadership'	2	2012-present
Nursing Education Acute Care (Zorgacademie Erasmus MC) Theme: ´Patient and family Centered Care´	0.5	2016-present
Supervision		
Bachelor Students HBOV (Nurse education)	0.5	2014
Master student Health Care Management Erasmus University	1	2016
Other		
Member congress committee of: ■ Familiebegeleiding op de IC…. Meer dan een visitekaartje. ■ Family-centered Care…bijzaak of kerntaak? ■ 'On speaking terms' Verpleegkundigen in Dialoog. ■ 'Open Space' Family Centered Intensive Care.	3	2013-2014
President congress committee of: ■ Back to the future. Was vroeger alles beter? Onze kracht ligt in de toekomst. ■ De IC-verpleegkundige in 2025	0,5	2014-present
Coordinator Family-centered Care, Intensive Care Unit, Erasmus MC, several projects	4	2012-2014
Member of several committees supporting person-centered care	2	2012- present
Member of the jury of "Meijboom Zorgprijs" (an award for the most innovative nursing project in daily practice), Erasmus MC	1	2013-2015

Initiator and core member FCIC (Foundation Family and patient Centered Intensive Care)	2	2013- 2016
Member Nursing Council VIP[2], and president since June 2016	3	2010- present
Editor in Chief "VIP Science", scientific journal to and by nurses of Erasmus MC	3	2014- present
Editor "Jaarboek Verplegingswetenschappelijk Onderzoek", edition 2010-2014 and 2015-2016	1	2015-present
Member "Commissie Medisch Ethische Vraagstukken", Erasmus MC	1	2015- present
Peer reviewing of articles		
Pediatrics (2), Plos One (1), Journal of Evidence-Based Complementary & Alternative Medicine (1), BMJ open (1), SCCM abstract round (28), International Journal of Nursing (1), Traumatology (1), Netherlands Journal of Critical Care (1)	3	2015- present

4. GRANTS AND AWARDS

	Year
Grants	
Congress grant SCCM	2015
Travel Grant Specialty Sections (approximately € 500,00)	
Waivergrant Biomed Journal of Compassonate Healthcare	2015
A grant for free publishing, no open acces-fee (approximately €1.250,00)	
Evidence Based Care Nursing (EBCN)	2016
A grant to support nursing research in Erasmus MC (€ 50.000,-)	
Congress grant SCCM	2017
Snapshot Research Theater (approximately € 650,00)	
CON170362ABS	
Award	
"Anna Reynvaan Praktijkprijs"	2015
An award for the best nursing initiative to improve patient care (€ 5.000,-)	
"Best oral presentation for practice"	2017
At 7th EfCCNa Congress, held in Belfast.	

ABOUT THE AUTHOR

Martina Maria Cornelia (Margo) van Mol studied Health Psychology at the Faculty of Psychology and Educational Sciences, Open University of the Netherlands. She graduated cum laude in May 2013 on ´Quality of Care in the Intensive Care Unit from the Perspective of Relatives´. In addition to her function as an intensive care nurse, she started her PhD project at the department of Intensive Care Unit (ICU) Adults, Erasmus Medical Center.

Margo is particularly interested in supporting relatives, communication, medical-ethical dilemmas, person-centered care, and work engagement of ICU professionals.

Margo was born on 27th of April 1965 in Veldhoven, the Netherlands. In 1983 she finished Grammar school (VWO, Mgr. Zwijssen College, Veghel) and a year later she started her carrier as a registrated nurse (Carolus Hospital, ´s Hertogenbosch). Margo has worked in Erasmus MC (Academic Hospital Rotterdam in that time) since 1989. After three years as Specialist Nurse Obstetrics and Gynaecology, she started her training in the ICU in which she has now over 25 years' experience. Margo went astray in Nursing Informatics (University of Applied Sciences, Diemen) and graduated in 2002 on the implementation of a Patient Data Management System in her work department.

During Margo´s study of Health Psychology (2006-2013), she became inspired to improve the support of relatives in the ICU. This passion has led to the coordination of various projects in family-centered care in Erasmus MC, the relatedly participation in several committees supporting person-centered care, and the involvement in a national foundation of FCIC (Family and patient Centered Intensive Care). At the same time, Margo became aware of general nursing leadership and evidence based care. Therefore, she has been an active member of the Nursing Council VIP^2 of Erasmus MC from its beginning in 2010 and is president of VIP^2 since 2016. In her role as editor in chief of ´VIP Science´, she has contributed to disseminating nursing science within the organization.

Margo finished her Master of Science in Health Sciences, specialization Public Health, Institute for Health Sciences (NIHES, 2014-2016) on ´Work engagement among healthcare professionals in the intensive care unit´.

Margo is married with Arie den Ouden and lives in Spijk (Lingewaal).

DANKBETUIGING

In balans tussen samenvallende werelden; dat was voor mij ook zeker het geval als het gaat om het schrijven van dit proefschrift en mijn privé bezigheden. Aan de ene kant een prachtige kans om te groeien en nieuwe vaardigheden te ontwikkelen, aan de andere kant keuzes maken in alle andere leuke uitdagingen en sociale activiteiten. Het voordeel van promoveren halverwege je carrière, is het iets gemakkelijker relativeren in het afwegingsproces om in een optimale balans te blijven.

Promoveren doe je niet alleen. Velen hebben bijgedragen in mijn ontwikkeling tot de persoon en wetenschappelijk onderzoeker die ik nu ben. Daarvoor wil ik aan iedereen mijn oprechte dankbaarheid uitspreken! Ik prijs me gelukkig met de geweldige begeleiders, collega´s, vrienden en familie die mij bijstonden in deze periode. Aan hen wil ik meer specifiek mijn dank overbrengen.

Allereerst gaat mijn dank uit naar mijn promotor en copromotoren.

Geachte prof. dr. Jan Bakker, beste Jan. Wat was het een enorme verassing toen je mij, na het behalen van mijn Master Psychologie, uitnodigde om verder onderzoek te gaan doen. Het zaadje was gelegd, mijn gedachten en mogelijke onderwerpen buitelden over elkaar heen. Langzaam, en met lichte sturing, kwam de focus op 'Family-centered Care'. Je hebt daarin altijd laten zien dat het onderwerp steeds meer een prominente plek inneemt in de totale zorg op de IC-afdeling. Ik waardeer je zeer om je uitstekende feedback, kort en krachtig, zonder franje. Jan, bedankt dat je mij deze kans hebt gegeven.

Geachte dr. Marjan Nijkamp, lieve Marjan. Jij bent voor mij een kanjer; wat heb ik veel van je mogen leren. Ik heb je als een prettige en competente begeleider leren kennen bij het schrijven van mijn masterthesis, en we zijn meteen maar samen verder gegaan op mijn pad van onderzoek doen. Jouw enthousiasme, je kritische vragen als relatieve buitenstaander in de IC-wereld, de theoretische inbreng, en de zeer nauwkeurige feedback op al mijn schrijfproducten, is van ongekende waarde in mijn wetenschappelijke opleiding. Maar ook je voelsprieten als ik er doorheen zat, "zullen we donderdag even bellen?", en je opmonterende begrip waren een weldaad voor mij. We delen een interesse voor het gedachtengoed vanuit de positieve psychologie, waarbij een toepassing in de dagelijkse praktijk van professionals het centrale thema van onze verkenning is. Marjan, ik ben ervan overtuigd dat we samen nog mooie artikelen kunnen blijven schrijven. Dank je wel.

Geachte dr. Erwin Kompanje, beste Erwin. Jij kent mij al vanaf het moment dat ik als beginnend verpleegkundige mijn eerste stappen op de IC-afdeling zette, toen nog 7 zuid. Wat een plezier hebben we gekend, gesprekken in 'de salon', Terschelling met collega´s. Daarnaast was er de serieuze kant, verdieping, een hersendode jongedame, ogen als spiegels van de ziel. Wat doet dat met je als professional; je leerde mij ermee om te gaan. Zonder enige twijfel was je voor mij de aangewezen persoon om mijn promotietraject te superviseren en ik voelde me vereerd met je toezegging. Bij mijn eerste serieuze poging om terug te krabbelen schudde jij je hoofd en wees op ´mapje Margo´. Inderdaad stond daar een ordnermap, toen nog leeg, met mijn naam erop. Dat gaf me wel vertrouwen. Vele uren van gedachtenvormende discussies over uiteenlopende onderwerpen in de wetenschappelijke wereld volgden. 'Ineens' kwam de focus op het perspectief van de professional te liggen. Je hebt me de volledige vrijheid gegeven om mijn promotie traject in te richten op een manier zoals dat bij me past, maar altijd alert op niet ter zake doende zijpaden. Ik kijk ernaar uit om in "de emo-hoek" zoals je het zelf noemt, nog veel onderzoek samen op te pakken. Lieve Erwin, we hebben door de jaren heen ook ´lief en leed´ met elkaar gedeeld. Dat maakt het zo bijzonder om ook deze voor mij belangrijke gebeurtenis te kunnen delen. Dank voor alles.

De leden van de beoordelingscommissie, bestaande uit Prof. dr. Lex Burdorf, Prof. dr. Jos Latour en Prof. dr. Hans van der Hoeven, hartelijk dank voor uw expertise en tijd die is vrijgemaakt om het manuscript kritisch te beoordelen. Alle opponenten, Prof. dr. Monique van Dijk, Prof. dr. Jan Hazelzet, Prof. dr. Jan van Busschbach, en Prof. dr. Dominique Benoit, hartelijk dank voor het lezen van mijn proefschrift en uw aanwezigheid tijdens de promotieplechtigheid.

Mijn zeer speciale dank gaat ook uit naar mijn paranimfen, Natasja Kalkman RN en Drs. Carin van Mol.

Lieve Natasja. Vanaf het eerste moment dat wij elkaar leerden kennen voelde ik een prettige klik met jou. Eerst als verpleegkundigen op de 'Neuro-IC' 6 zuid, in de diverse afdelingsgebonden sociale activiteiten, en later de organisatie van een IC congres in het thema van Family-centered Care. Ook samen sparren in het 'werkhok' op 10 zuid of even bijkletsen in Kade 80 toen onze werkplekken wat verder uit elkaar kwamen te liggen. Onze gedeelde passie, de ontwikkeling en de ondersteuning van IC-professionals kent verschillende praktische uitwerkingen. Jouw visie als onderwijsdeskundige helpt mij om scherp te blijven in de kennisoverdracht aan collega´s. Natasja, bedankt dat jij als paranimf zowel letterlijk als figuurlijk achter mij staat.

Lieve Carin, allerliefste zus, wat ben ik trots en blij dat jij mijn paranimf wil zijn. Niet alleen als zus, maar ook vanwege onze innige vriendschap. Het is fijn dat je er altijd en onvoorwaardelijk voor me bent. We hebben al zoveel dingen samen meegemaakt, mooie en verdrietige situaties. Jij kent mijn onzekerheden en waar ik het meeste moeite mee had tijdens dit promotietraject. Altijd sta je klaar om mij te ondersteunen met adviezen, moed in te praten, of echt te luisteren. Sommige dingen zijn veel waardevoller om samen te beleven. Carin, bedankt voor je geweldige steun, warmte en interesse.

Daarnaast wil ik heel graag iedereen bedanken die de moeite heeft genomen om een concrete bijdrage te leveren waarvan de resultaten in dit proefschrift zijn beschreven.

Zonder de input van zovele naasten, zowel via vragenlijstonderzoeken als ook in focusgroep gesprekken, hadden we niet geweten hoe zij de kwaliteit van onze zorg op de IC beoordeelden. Ook de individuele gesprekken met verschillende patiënt-experts hebben bijgedragen aan een breder inzicht om de zorg te verbeteren. Alle collega´s die ik in de afgelopen jaren bestookt heb met enquêtes, klinische lessen, nieuwe interventies en proefballonnen, bedankt voor de medewerking. Met name Wilbert, Gerrie, Bert, Erna, Corné, Annette, Marja, Karin, Petra, Henny, Tilly en Thea als leidinggevenden van de meewerkende afdelingen wil ik bedanken voor hun enthousiaste bereidheid om als onderzoekseenheid te fungeren.

Prof. dr. Wilmar Schaufeli, het was voor mij een enorme eer dat ik met u mocht samenwerken. Als designer en leermeester van het Job-Demand-Resources Model, waarin zowel burnout als werkbevlogenheid zijn beschreven, is mijn proefschrift met behulp van uw waardevolle feedback naar een hogere verdieping gebracht. Verder wil ik graag alle auteurs in de verschillende artikelen danken voor hun bijdrage en vernieuwende inzichten.

Eveneens zijn er velen met wie ik in de afgelopen jaren heb mogen samenwerken en daarbij leuke dingen of projecten vormgeven in het licht van mijn wetenschappelijke ontwikkeling. Ook hen wil ik bedanken.

Met veel plezier heb ik gewerkt met collega verpleegkundigen en artsen van de intensive care afdeling van het Erasmus MC, voornamelijk van ICV-3. Velen toonden bij gelegenheid belangstelling voor mijn vorderingen. Dat heb ik enorm gewaardeerd. De internationale congressen, wat heerlijk was het om naast de educatieve sessies ook gewoon gezellig te kunnen ontspannen. Natasja, Erica, Marjolein, Steven, Janneke, Trudi, Petra en Kim, het was leuk om dit met jullie te mogen meemaken. Ik heb ook ondersteuning gekregen van Legisa met praktische secretariële tips en een fijn kletspraatje op onze werkplek, Els als agenda bewaker van aanvankelijk Jan en daarna Diederik, en Erna met de informatie en organisatie vanuit de onderzoeksschool COEUR.

Trudi en Bert, mijn maatjes vanaf het eerste uur in familiegerichte zorg, bij jullie heb ik ontzettend veel steun ervaren. Samen met Tamara, Jelle, en Jasper vormen we nu een denkgroep om het beleid rondom persoonsgerichte zorg goed neer te zetten op de IC-afdeling. Met jullie deel ik de interesse om dit beleid vervolgens concreet uit te werken. Vivi, 'partner in crime' in het Sofia Kinderziekenhuis, jouw ongebreidelde geestdrift werkt enorm aanstekelijk. Het is een genot om met je te klankborden over de lastige hobbels bij het implementeren van familiebeleid. Nikk, jij hebt me laten zien dat out-of-the-box denken tot prachtige resultaten kan leiden.

Alle kerngroep leden van stichting FCIC (Family and patient Centered Intensive Care), we stonden samen aan het begin van een landelijke aandacht om de psychosociale impact van een IC-opname te beperken voor de patiënt en diens naasten. In alle opzichten een bijzondere en inspirerende periode. Remy´s wijze woorden "Het zit allemaal al in je" hebben me diep geraakt en waren een mantra in mijn eigen zoektocht.

Alle Raadsleden van de Verpleegkundige Raad VIP^2, en speciaal Ilse, Susanne, George, Annelies, Karin, Marella, Lotte, en Jacqueline, we hebben hard gewerkt om te bereiken waar we nu staan. Het was boeiend en leerzaam om dit proces met elkaar door te maken. We zijn er nog lang niet, onze gemeenschappelijke stip op de horizon is ambitieus en vooruitstrevend. Ik verheug me om dit met jullie verder vorm te geven.

Het redactieteam van VIP Science, Herma, Helen, Iefke, Anne Margreet, Erwin, Marleen, Tom, Marly, Tilly, Ina en Annet, het is een voorrecht om in gezamenlijke inspanningen een wetenschappelijk tijdschrift voor verpleegkundigen van het Erasmus MC te maken. Jullie flexibele inzet, waardevolle kopij ideeën, prachtige foto´s van collega´s, en eigen initiatieven maken mij steeds weer super trots bij elke nieuwe editie.

Prof. dr. Jaap Verweij, hartelijk dank voor uw enthousiasme en steun in de positionering binnen de organisatie en de wetenschappelijke bijdragen van de verpleegkundige beroepsgroep. Dit heeft mij er persoonlijk van overtuigd dat er veel mogelijkheden zijn om een win-win situatie te creëren.

Prof. dr. Jos Latour, beste Jos, je bent voor mij een van de inspiratiebronnen bij het schrijven van dit proefschrift. In eerste instantie deelden we dezelfde passie om de kwaliteit van de zorg voor ouders en naasten in een valide vragenlijst te kunnen meten. Al tijdens jouw promotie dacht ik "Dat wil ik ook" omdat jij wetenschap en praktijk heel dicht bij elkaar brengt. Gaandeweg heb je mij veel waardevolle adviezen gegeven en gestimuleerd om verder te gaan. Je deur staat altijd open, ook nu je in Plymouth je werk voortzet. Jouw enthousiaste reacties zijn hartverwarmend voor me.

Prof. dr. Monique van Dijk, beste Monique, ook jij gaf mij een zetje in de rug. Mede door jouw feedback kreeg ik het vertrouwen om mijn eigen cognities bij te stellen. Jij hebt wetenschappelijk zorgonderzoek in het Sofia Kinderziekenhuis op de kaart gezet vanuit jouw achtergrond als verpleegkundige en psycholoog. Daarin bewonder ik je. In je nieuwe functie als eerste hoogleraar Verplegingswetenschappen in het Erasmus MC hoop ik samen met jou te mogen bouwen aan een solide netwerk voor zorgonderzoek dat stevig verankerd is in collegiale en interdisciplinaire samenwerking en verder reikt dan de fysieke muren van het Erasmus MC. Het is voor mij een eer dat je jouw nieuwe rol voor de eerste keer officieel vormgeeft tijdens mijn promotie.

Anne Margreet, we hebben al heel wat effectieve vergadermomenten in diverse clubjes doorgebracht. Maar je hebt ook geluisterd naar mijn verhalen, het zuchten en de karakteristieke worstelingen van promoveren. Je kon uit eigen ervaring putten en mij moed inspreken. Dat koester ik. Eveneens heb ik Erwin, Onno, Coby, Mirjam, Conny, Anneloes, Erika, Gerard, en Wendy leren kennen als gepromoveerde onderzoekers vanuit de verpleegkundige professie. Het was fijn om bij jullie een overeenkomstige gedrevenheid te herkennen, deze verbondenheid bracht al meerdere mooie samenwerkingsverbanden voort. Ik heb er alle vertrouwen in dat we ook in de toekomst nog vaak bij elkaar aankloppen. Daarnaast heb ik veel intercollegiale ‘PhD-wetenswaardigheden’ uit kunnen wisselen met Ineke, Zoran, Sandra, Mo, en Patrick. Jelle, jouw proefschrift was niet alleen inhoudelijk, maar evenzeer in lay-out en opmaak, een prachtig voorbeeld voor mij.

Promoveren is een veranderingsproces, in mijn geval van verpleegkundige naar wetenschappelijk onderzoeker. Aletta, jij hebt dit met jouw coaching vaardigheden in gang weten te zetten. Diederik, jij hebt me het vertrouwen en de erkenning gegeven om die transitie te kunnen maken. En Tamara, jij hebt mijn ontwikkeling gestimuleerd, gewaardeerd, en de ruimte gegeven. Je nam de tijd om echt te luisteren en in gezamenlijkheid naar de toekomst te kijken. Daarvoor ben ik jullie zeer erkentelijk.

Aan het begin van mijn promotie traject dacht ik dat het schrijven van een proefschrift analoog aan het lopen van een marathon zou zijn. Je stelt een ultiem maar haalbaar doel, maakt een enigszins flexibel trainingsschema, volhard in de uitvoering daarvan, en laadt jezelf mentaal op. Op de bewuste dag heb je steun van de mensen om je heen en je eigen rituelen, dan ren je ongeveer vier uur ´het snot voor de ogen´, en het is klaar. Echter, dat bleek een vergissing. Het schrijven van een proefschrift is veel meer overeenkomstig met het lopen van twee Vierdaagse Marsen, zoals eerst Apeldoorn en daarna Nijmegen achter elkaar. Je hebt een doel en focus nodig, prioriteren, tijdig je rust nemen, pijnlijke blaarbehandeling doorstaan, en vooral steeds weer opnieuw opladen. Ook de mensen om je heen hebben een lange adem nodig. Je neemt een voorbeeld aan andere, op het oog meer geoefende, wandelaars, en loopt misschien een stukje samen op. Ergens onderweg vindt er een omslag plaats in je hoofd. Precies die transitie bracht mij nieuwe inzichten in mijn eigen promotieproces toen ik in de wereld van het wandelen stapte.

Er zijn veel mensen om mij heen, niet direct aan dit proefschrift gerelateerd, die een plaats innemen in mijn leven. Misschien het minst zichtbaar, maar eigenlijk het meest belangrijke deel om waardevolle verbintenissen aan te gaan en betekenis te geven.

Mijn vrienden en familie, die ik niet bij name ga noemen, jullie zorgden voor een welkome afwisseling in de vorm van een etentje, een lunchafspraak of een gezellige avond samen. Maar ook een kort berichtje, bemoedigende woorden, verdiepende gesprekken en onverwachte ingevingen gaven sjeu aan het schrijven van dit proefschrift.

Mijn body-balance maatjes, Irene, Mary, Daniëlle, Anja, Annemiek, Irma, Veronique, Annet, Silvia en alle anderen, wat een energie heb ik steeds weer op mogen pakken tijdens onze wekelijkse lessen. In de "Sun salutation", de "Warrior" en de "Triangle" bijvoorbeeld, kon ik de rust vinden om mijn gedachten los te laten.

Alle muzikanten van de Politie Harmonie Vereniging in Rotterdam, wat een warm welkom heb ik recentelijk mogen ervaren na vier jaren van afwezigheid. Ik ben vast van plan om nog een hele tijd mijn steentje bij te dragen op dwarsfluit en het plezier te ervaren van samen muziek maken.

En niet te vergeten, Dik†. Op zijn onnavolgbare manier heeft hij ervoor gezorgd dat ik startte met de studie Gezondheidspsychologie. Ik begreep niets van de 'Existentiële fenomenologie' en het 'Symbolische Interactionisme', waar hij vanuit de sociologische wetenschap zo veelvuldig met mij over sprak. Een soortgelijke kennis, maar dan toegepast op één persoon of kleine groepen, wilde ik mezelf graag toe-eigenen. Zonder hem zou ik niet diegene zijn die ik nu ben.

Lieve Paul en Nel, ik heb het getroffen met zulke warme en behulpzame schoonouders. Fijn dat we dit kunnen delen.

Liefste pap en mam, jullie hebben mij mede gemaakt tot de persoon die ik nu ben. Alle energie en tijd die jullie zowel in mij als in mijn zus hebben gestoken ten tijde van de basis- en middelbare school werpt zijn vruchten af. Hoe trots zou mijn vader†, Jan, geweest zijn op zijn dochter. Ik kreeg van hem mee hoe belangrijk en leuk het is om te blijven leren, en de onderzoeksgeest om naar oplossingen te zoeken in een lastig vraagstuk. Maar vooral ook de eigenwijsheid om mijn persoonlijke ideeën te volgen.

Lieve Nanny, je hebt me gestimuleerd op eigen benen te staan, verantwoordelijkheid te nemen voor mijn eigen groeipad, en vooral geleerd om ook met tegenslagen om te gaan. Ik zal nooit vergeten dat ik als tiener een prachtige eigenhandig gebreide trui, na een week van intensieve arbeid, moest uithalen omdat ik letterlijk ergens een steekje had laten vallen. Het schrijven van dit proefschrift leek daar soms op. En ook: “Morgen is er weer een dag”, maar dat heb ik niet altijd kunnen volhouden. Je hebt steeds belangstellend mijn vorderingen gevolgd, en jouw gedachten en ervaringen met de gezondheidszorg onomwonden gedeeld. Mam, je bent geweldig.

Lieve, lieve Arie, het waren vier prachtige jaren. En meer hoef ik niet te zeggen, jij weet als geen ander wat het voor mij betekent!

Je hebt de zelfgekozen rol als “Opper-mopper-incasseerder” met verve op je genomen. Ook gaf je mij binnen onze relatie alle tijd en de ruimte om te groeien en de dingen te doen die ik nodig vond. De kruisbestuiving met jouw vakgebied was voor mij van onschatbare waarde, en de figuren in dit proefschrift had ik nooit voor elkaar gekregen zonder jouw input. Wij weten beiden, er zullen steeds weer nieuwe uitdagingen op mijn levenspad komen. Ik ben ontzettend blij dat jij naast mij over die weg wandelt.

This thesis explored the emotional challenges in ICU practices from two perspectives. STAYING and WORKING in the ICU can be two sides of the same coin; patients and their relatives on the one side and healthcare professionals on the other side, are strongly connected to each other.

Staying in the uncertain world of the ICU is never desirable for PATIENTS AND THEIR RELATIVES; however, the negative impact of this stay might be diminished if they experience receiving optimal and quality care. Interventions that focus on person-centered care and encompass respect, dignity, and empathy, will have A POSITIVE INFLUENCE on the users' experiences. Healthcare providers in the ICU may play a crucial role and make a difference in the lives of the patients and their relatives.

Although it should be emphasized that working in the ICU can be inspiring and pleasurable, it is essential to take care of the PROFESSIONALS and their emotional balance while working. An ICU is increasingly complex and physically, cognitively and emotionally demanding for the professionals, which might lead to distress while working. Occupational well-being is originally accompanied by feeling energized, focused, and optimistic. In their unsolicited role, patients and their relatives may contribute to this fulfillment of well-being. Overall, the ICU is a motivating world in which to work. We should keep it that way and strive for a HEALTHY and SUCCESSFUL working environment.