

## UNIVERSITY OF PAVIA

Department of Brain and Behavioral Sciences Doctoral Program in Psychology, Neuroscience and Data Science Research Doctorate in Psychology *Cycle XXXIII; years 2017-2020* 

# Wellness and distress in healthcare professionals dealing with end-of-life and bioethical issues (WeDistress HELL): An observational, multicentre, cross-sectional research project

# with a multimethod design

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Dedicated to who is supporting me along my never-ending personal growth journey.

Ab imo pectore...

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PREFACE

#### PREFACE

This dissertation tries to lead the reader to critically understand the research project that I developed along three years for undergoing my research doctorate program in Psychology. With the precious support of valid collaborators and mentors, I attempted to enrich the knowledge regarding risk and protective factors for the wellbeing of healthcare professionals employed in highly sensitive and complex medical disciplines, namely palliative care and neurorehabilitation medicine.

These research themes appear particularly valuable in the present and future healthcare landscape. Indeed, medical, scientific and technological advancements are raising numerous changes. On one hand, manifold conditions that were lethal in the past are now chronic and manageable. On the other hand, comorbidities are also increasing due to the aging of world population. These upheavals request more professionals trained to manage complex life-threatening and long-lasting conditions. New challenges and bioethical issues broke in the healthcare scenario, paving the way to psychological malaise, moral distress, burnout and, as a consequence, to a relevant impoverishment of wellbeing. This statement is even more true for who work in palliative care and neurorehabilitation medicine contexts where the contact with high demanding and challenging clinical conditions is on a daily basis. In these medical disciplines further researches are needed in order to provide practical suggestions to prevent burnout and distress, as well as to discover, reinforce and enhance protective factors characterizing these specialties.

Overall, it has to be underlined that an ill healthcare workforce is a defeat not only for the single individual, but also for the entire society. Professionals suffering from burnout are more likely to medical errors, high sanitary expenses and worse quality of care provided. Thereby, finding effective solutions for preventing malaise and fostering wellbeing of the healthcare workforce is a sound urgency and a crucial moral dictate. In this vein, the current project seeks to shed light on risk and protective factors, as well as their relationships among professionals employed in palliative care and neurorehabilitation medicine disciplines.

Specifically, the present dissertation is divided into three sections.

The *first section (A)* provides the state of the art concerning the existing literature on the topic and it offers a rationale to conduct the following studies. It includes the first two chapters:

*Chapter One* starts from providing a comprehensive overview of the theoretical background characterizing the healthcare landscape, posing attention to the specific criticisms of this context. The perspective of the Positive Psychology as an approach to investigate and valorize resources is described too. The focus is put on outlining the characteristics of palliative care professionals and

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their colleagues employed in neurorehabilitation medicine discipline. Then, their specific risk and protective factors are also considered.

*Chapters Two* deepens the theoretical overview provided in the first chapter, reviewing the main variables investigated within the current research project, that are burnout, moral distress, wellbeing, meaning in life, ethical climate, affectivity and resilience. Moreover, the COR theory is presented as a useful theoretical framework for interpreting and linking in a functional and parsimonious way the variables investigated and the consequent results.

The *second section (B)* is called WeDistress HELL Project, that is the research acronym "WEllness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues". This part of the dissertation is constituted by the *Chapter Three* which describes in detail the research. In particular, an in-depth description of the objectives, quantitative and qualitative methods and procedures, as well as data analysis is provided. Then, ethical considerations are also exposed.

The *third section (C)* includes seven chapters and it provides all the findings unveiled by the different studies comprised in the research project.

Specifically, *Chapter Four* shows the descriptive and preliminary inferential statistics of healthcare professionals involved in the quantitative part of the research, offering the bases for enabling a full understanding of the further analyses.

*Chapter Five* reports findings concerning the instrument called SMiLE (Schedule for Meaning in Life Evaluation) considered one of the most used way to assess the construct of Meaning in Life (MIL). Differences and similarities regarding MIL are investigated between palliative care and neurorehabilitation medicine professionals. Moreover, the main areas providing MIL to these professionals are explored and exhaustively discussed.

*Chapter Six* accommodates the first psychometric Italian validation of HECS (Hospital Ethical Climate Survey). This instrument is considered the gold standard worldwide for the assessment of ethical climate in nursing. However, to the best of my knowledge, a version of this instrument for the Italian context still lacks. Thereby, this study contributes to bridge this gap, providing a first validation and adaption of this instrument for assessing ethical climate across all kinds of healthcare professionals employed in palliative care and neurorehabilitation medicine disciplines.

*Chapter Seven* describes the quantitative findings unveiled by the mediation and moderated mediation analysis. Specifically, the first study addresses healthcare professionals working in neurorehabilitation medicine and it investigates the impact that ethical climate, intended in its nuances of "ethical vision of patient care" and "managerial support in dealing with bioethical issues" may have on emotional exhaustion. Moral distress is considered a possible mediator of this

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relationship, as well as resilience and positive affectivity are intended as personal conditions which may enhance the effect detected.

Then, the second study involves professionals working both in palliative care and neurorehabilitation medicine specialties. It discloses whether resilience may impact on wellbeing and professional efficacy. Within this relationship, the "ethical vision of patient care" is considered as a possible mediator, while "managerial support in dealing with bioethical issues" as possible moderator.

*Chapter Eight* reports the interviews conducted with some palliative care professionals. First, a qualitative study reports the risk and protective factors perceived by palliative care professionals on a daily basis, trying to suggest resources to invest for preventive and supportive interventions fostering wellbeing. Then, a second qualitative study shows palliative care professionals' perceptions regarding the recent Italian law n° 217/2019 on advance directives. Their subjective feedbacks are investigated and critically discussed as this legislative act is the first formal attempt to regulate the patient's will on end-of-life and life-sustaining treatments in the Italian context. Positive and negative aspects of this law are underlined, as well as suggestions for future amendments are also collected.

*Chapter Nine* discloses the subjective feedbacks of medical students dealing with complex patients suffering from life-threatening conditions taken in care during their clinical placements. The focus is put on risk and protective factors perceived by students along their educational path. This study has to be considered an ancillary research attempting to detect factors which may be exploited to foster wellbeing and counterattack distress since the beginning of the healthcare profession. Adopting a preventive approach, the aim is to gain – through the lens of qualitative research – inputs and suggestions for actions which may safeguard the healthcare professionals, starting from the very beginning, which is their educational path.

Finally, *Chapter Ten* provides a general discussion of the findings unveiled by the quantitative and qualitative studies previously described. This general discussion brings together the contributions of the whole dissertation by developing a theoretical framework inspired by COR theory which provides practical suggestions for preventive and supportive interventions fostering the wellbeing of professionals employed in palliative care and neurorehabilitation medicine disciplines. Future research directions, limitations and strengths are also discussed. Then, suggestions and guidelines for practice are offered, hoping to effectively contribute to foster the wellbeing of the healthcare workforce.

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# SECTION A State of the art

"Although wood is the strength and substance of a tree, allowing its branches and leaves to flourish despite harsh weather, wood also predisposes a tree to burn"



M. Heenan (2020). Burnout. AMA Journal of Ethics, 22(1): E61-62. doi: 10.1001/amajethics.2020.61. Pallet wood sculpture of a lateral cerebrum with a gradient of burned wood visually representing a crisis among healthcare professionals

## Chapter One

### Theoretical background characterizing the healthcare landscape

#### 1.1. The malaise of the modern healthcare professionals

The modern healthcare landscape is even more characterised by unstoppable changes, as well as by medical and technological upheavals. The pace of these changes is frenetic, and it is expected to accelerate in the future as tools, opportunities and knowledge increase day-by-day (Johnston, 2018).

There is no doubt that these advancements contributed to increase the health-related quality of life and the life-expectancy of the world population, despites differences among countries (Mathers, Sadana, Salomon, Murray, & Lopez, 2001). Indeed, manifold diseases, that were lethal in the past, are becoming chronic such that, ever more frequently, medicine has to deal with chronicity and multimorbidity issues (Allotey, Reidpath, Yasin, Chan, & de-Graft Aikins, 2011; Yarnall et al., 2017), also due to the concomitant population aging (Denton & Spencer, 2010; Van Leuven, 2012). However, the other side of the coin is that healthcare professionals are requested to face with increasing challenging situations arising from a context of growing complexity. They need to provide cutting-edge care to suffering dying people and to daily cope with diseases, demanding relationships, challenging communications which slowly erode energies and resources (Maslach & Leiter 2016; West, Dyrbye, & Shanafelt, 2018; Samson & Shvartzman, 2018). This complex context is a fertile ground for burnout and distress which are well known forms of malaise in healthcare professionals all around the world, regardless differences among various healthcare workforces (Koh et al., 2015; Moss, Good, Gozal, Kleinpell, & Sessler, 2016; van Mol, Kompanje, Benoit, Bakker, & Nijkamp, 2015). This issue is internationally considered relevant and deserves high priority. To this regard, it is noteworthy to say that physicians have 36% more probability of developing burnout with respect to the American high school graduated population (Shanafelt et al., 2012) and, in general, medical students, residents/fellows, and early career physicians are more likely to suffer from burnout compared to the general population (Dyrbye et al., 2014). Also, between 2011 and 2014, the trend of job satisfaction and burnout was getting worse within healthcare workers (Shanafelt et al., 2015).

Moreover, healthcare professionals are increasingly exposed to the threat of moral distress due to manifold ethical issues occurring in their daily clinical practice. The term "moral distress" underlines the distressing malaise raising from a fracture between personal values and actions due to external constraints such that an individual has to act against her/his beliefs (Jameton, 1984;

Lamiani, Borghi, Argentero, 2017; see also chapter two). For instance, a nurse may experience a relevant amount of moral distress if she is requested by a physician to provide a life-sustaining therapy that she considers to be futile and aggressive for the patient. Currently, healthcare professionals have to deal with a growing spread of challenging ethical issues which arise from the advances in biomedical sciences, technologies and care practices (Leuter et al., 2018). In fact, the healthcare professionals' mandate is not merely to prolong as more as possible the life thanks to technologies and scientific progress, rather to guarantee the more updated and ethical care possible (Cheon, Coyle, Wiegand, & Welsh, 2015). Differently said, the best quality of life has to be considered one of the main outcomes until the individual's last breath of life. Factors that can trigger moral distress are manifold. For instance, according to two surveys, one conducted in Europe and the other one in the U.S., the most frequent ethical dilemmas characterising the medical practice are the decision making and the management of end-of-life treatments, the patients' inability to decide for themselves and the relationship problems which may occur with colleagues, patients and caregivers (Hurst et al., 2007; DuVal, Clarridge, Gensler, & Danis, 2004). Similarly, in an Italian survey conducted among physicians and nurses, the most relevant ethical issues are the managing of the patients' incapacity of self-determination, the perception of providing futile care as far as the decision making of the best care options in a context of poor facilities and resources (Leuter et al., 2018). Moreover, it may occur that the healthcare professionals have to mediate the family' requests that are in contrast with the patient's will (Cheon et al., 2015) or they are requested to agree with institutional and organizational constraints, too (Lamiani et al., 2017).

Thus, the healthcare professionals' condition deserves growing attention as a distressed system means not only poor quality of life and distress for the individual (Chan, Chan, Chuang, Ng, & Neo, 2015), but also a negative impact on the society too (Bodenheimer & Sinsky, 2014). In fact, the "*care of the patient requires care of the provider*" (Bodenheimer & Sinsky, 2014, p. 573). The healthcare professionals' distress may deplete the quality of care provided, as well as the relationship with the patient and, in turn, also the quality and the adherence to the treatment, besides to an unnecessary increase of healthcare expense (Bodenheimer & Sinsky, 2014; Moss et al., 2016).

This rapid overview depicts a healthcare scenario ever more complex and multifaced, characterised by manifold risk factors for the onset of healthcare professionals' malaise. Each medical specialty is requested to deal with a different clinical population so that some distressing situations and factors may occur in some disciplines more frequently than in other ones. In this dissertation, the focus is posed on healthcare professionals employed in palliative care and neurorehabilitation medicine specialties as they are more frequently exposed to challenging and demanding patients and clinical situations. The attempt is to better investigate and understand factors and mechanisms which may sustain or challenge the healthcare workforce in order to provide suggestions and tools for navigating the multifaceted landscape of healthcare and bioethics, intended as a sensitive discipline bridging medical knowledge (bio-) with the system of human values (-ethics) (Potter, 1970).

#### 1.2. Positive psychology and healthcare professionals' wellbeing

Besides the thorny issues discussed above, it is also possible to detect positive facets and processes that may support the healthcare professionals along their occupational path. This recognition appeared recently in the research landscape. Indeed, in the past the mainstream psychological research has put the attention on dysfunctional aspects and mechanisms, considering wellbeing and positive facets as natural consequences of the absence of negative aspects (Duckworth, Steen, & Seligman, 2005). This unbalance on what is dysfunctional (and which needs to be somehow repaired) was a topic characterizing psychology since the beginning. This approach was even more accentuated by the consequences of World War II, which pushed psychology even more to become a science for healing sufferance and trauma. However, the interest to wellbeing and optimal functioning has drawn growing attention in the international landscape during the last decades, such that a movement called "positive psychology" was born (Seligman, 1999; Alex Linley, Joseph, Harrington, & Wood, 2006; Snyder, & Lopez, 2009). "The aim of positive psychology is to catalyse a change in psychology from a preoccupation only with repairing the worst things in life to also building the best qualities in life" (Seligman, 2006, p. 3). The message is that what is pathological should not catalyse all the attention with the risk of neglecting the interest for fulfilled and thriving people. The foundation is the awareness that the "positive" is not something simply derived by the absence of the "negative", rather a multifaceted and independent concept. Indeed, "If the positive were just the absence of the negative, we would not need a positive psychology, just a psychology of relieving negative states. Similarly, if the positive were just the obverse of the negative, we could deduce everything we needed to know about the positive merely by attaching a negation sign to what we discover about the negative. [...] We believe that many of the positive states and traits add factors that cannot be deduced from the mere absence of their negative counterparts. Most centrally, we suggest that the mere relief of suffering does not lead to well-being; it only removes one of the barriers to well-being. Well-being is a process over and above the absence of depression, anxiety, and anger" (Duckworth et al., 2005, p. 634). The official advent of Positive Psychology has to be traced back to the American psychologist Martin E. P. Seligman who was the chief of the American Psychology Association at the end of XX century (Seligman, 1999; Alex Linley et al., 2006; Snyder, & Lopez, 2009). Then, it was energized also by other eminent scientists such as Mihaly Csikszentmihalyi, Ed Diener, Kathleen Hall Jamieson, Chris Peterson, and George Vaillant constituting the first Positive Psychology Steering Committee (Alex Linley et al., 2006; Snyder, & Lopez, 2009). However, unstructured and spontaneous attempts of research in this field may be traced back to the humanistic psychology, posing emphasis on the fully functioning individual of Carl Rogers (1961), as well as on the self-actualization and the study of healthy and motivated people investigated by Maslow (1954; 1968). Nevertheless, it was only with Seligman that the interest and awareness for positive and optimal functioning of human being obtained the welcome and approval in the scientific community as a structured and well-formalised psychological movement. Its definition is still arduous because manifold levels of interpretation can be unveiled. Overall, positive psychology may be considered a psychological approach posing interest in investigating conditions, factors and processes that can contribute to the flourishing, fulfilment and optimal functioning of people and societies in order to build resilience and resources for the individual's wellbeing (Gable & Haidt, 2005; Alex Linley et al., 2006). Thus, the potentiality of positive psychology has drawn increasing attention worldwide as it enables to focus not only on dysfunctional aspects, but also to shed lights on factors and mechanisms that can foster wellbeing and health. The aim is to reach a more balanced and integrated approach in which risk and protective factors are equally considered relevant. This perspective may be useful in all fields of research and practice, including researches on distress. To this regard, adopting a positive psychology framework may allow to understand and treat distress with a more "balanced and equally weighted focus on the positive and negative aspect of life" (Wood & Tarrier, 2010, p. 819). Positive factors may be used to deepen the understanding of phenomena, to buffer risk factors and negative events, as well as to build and promote resources. The scientific literature unveiled manifold protective factors for healthcare professionals, concerning both organizational and personal characteristics. For instance, among organizational factors, climate may make the difference and may contribute to preserve the healthcare professionals' wellbeing. To this regard, the literature pointed out that a positive and fair climate may favour psychological wellbeing and provide the individual with a sense of job satisfaction, engagement and professionals achievement as the environment adequately scaffold the worker and offer a pleasant work experience (Leitão, McCarthy, & Greiner, 2018; West et al., 2018). Similarly, a positive climate regarding the dealing with the ethical issues occurring during the daily care activity may sustain wellbeing and professional efficacy because the professionals have valuable guides and information to manage possible ethical dilemmas (Koskenvuori, Numminen, & Suhonen, 2019). Thus, a positive climate may prevent burnout (Dzeng & Curtis, 2018; West et al., 2018) and moral distress (Pauly, Varcoe, Storch, & Newton, 2009; Silén, Svantesson, Kjellström, Sidenvall, & Christensson, 2011; Hamric, Borchers, & Epstein, 2012). Moreover, receiving an effective support from superiors and colleagues is another pivotal protective factor as it enables the professionals to

communicate, exchange perspectives and experiences, as well as to search help for facing daily difficulties at work (Pereira, Fonseca, & Carvalho, 2011; Pereira & Fonseca, 2011; Velando-Soriano et al., 2020). Similarly, family and informal support may buffer negative experiences and risk factors, too (Pereira et al., 2011; Pereira & Fonseca, 2011; Velando-Soriano et al., 2020). Indeed, spending time with family may recharge the healthcare professionals and renew their resources (Pereira et al., 2011).

Going on with some examples, there are also personal facets which may foster wellbeing. Among protective factors, resilience was described to foster the healthcare professionals' wellbeing as it is a personal resource which may counterattack the onset of psychological malaise (Brennan, 2017; Rothenberger, 2017; Joyce et al., 2018; Ng, Chahine, Lanting, & Howard, 2019). In fact, resilient healthcare professionals are able to cope with problems and negative events as they have the necessary and adequate coping strategies and resources to find solutions as well as to adapt to each situation (Zwack, & Schweitzer, 2013; Hobfoll, Stevens, & Zalta, 2015). This capacity sustains professionals and may provide them with a sense of professional efficacy (Rushton, Batcheller, Schroeder, & Donohue, 2015; Guo, Luo, Lam, Cross, Plummer, & Zhang, 2018). Positive affectivity may be another important protective factor because positive emotions foster the healthcare professional to cope difficulties with a more positive and active overlook on life, predisposing them to take advantage to resources (Watson et al., 1988; Grigorescu, Cazan, Grigorescu, & Rogozea, 2018). Indeed, individuals with higher level of positive affectivity are able to find resources to cope with challenging circumstances, to stay positive, as well as to better exploit available resources in the environment such preserving themselves from the risk of burnout (Rouxel, Michinov, & Dodeler, 2016; Grigorescu et al., 2018). Positive affectivity can also predict job satisfaction impacting on job control (Rouxel et al., 2016). Similarly, meaning of work is another crucial element to foster wellbeing as it promotes satisfaction and engagement (Pereira et al., 2011; Moreno-Milan, Cano-Vindel, Lopez-Dóriga, Medrano, & Breitbart, 2019). In particular, meaning of work provides the healthcare professionals with an inner sense of fulfilment and gratitude derived by the acknowledge of the importance linked to what they have done such that this perception helps to buffer negative events and adversities (Pereira et al., 2011; Pereira & Fonseca, 2011). Moreover, meaning of work may mediate the effect of stress on subjective vitality, personal growth, as well as life satisfaction (Moreno-Milan et al., 2019).

Overall, these factors may be used in preventive and supportive interventions for promoting healthcare professionals' wellbeing. For this reason, it is of paramount importance to do research with the attempt to investigate and discover possible organizational and personal protective factors, as well as mechanisms that may support the professionals to buffer the negative events occurring during their professional careers. This understanding inspires the present dissertation.

#### 1.3. Palliative care professionals

#### 1.3.1. Definition

Since palliative care came into clinical practice thanks to the nurse Cicely Saunders' enlightened thought, a great deal of progress has been made. From a quite unknown practice of caring, palliative care ran through different transformations and gained ever-increasing importance, playing now an essential role in many healthcare systems (Aldridge, & Bradley, 2017; Meier, 2018). It is "*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*" (WHO, 2011). Thus, the intention of palliative care is not to cure the disease, but to care for the person of any age and her/his family, in order to guarantee the best quality of life until existence naturally expires. It is an intervention characterised by a holistic, patient/family-centred and relationship-driven approach, which considers not only physical but also the psychological, emotional and spiritual needs of the patient (Cassel et al., 2018). Indeed, each patient is first of all a person with own convictions and wishes that deserve respect until the last day of life.

According to the World Health Organization, each year about 40 million people from all around the world are in need of palliative care and this estimation is going to increase in the future (WHO, 2018). Other estimations confirm the critical role of palliative care in healthcare management. For example, forecasts based on age, sex and disease mortality rates from 2006 to 2014, have estimated an increase in the need of palliative care between 25% and 47% by 2040 in England and Wales (Etkind et al., 2017). So, assuming as constant the current proportion of 75% of dying people in need of palliative care, more than 470.000 British people will need this kind of care approach in 2040 (Etkind et al., 2017). The main reason of this focus on end-of-life and sufferance treatments is linked to the unstoppable demographic and epidemiological transformations characterizing population worldwide. Above all, it has to be underlined the necessity to face with an ever-growing increment of non-communicable diseases and ageing rates (Etkind et al., 2017; Costa, Giardini, & Monaco, 2017; WHO, 2018). Even more in the future, the typical patient will be an old person suffering with one or more chronic diseases and with a family to be taken in care (Giardini, Maffoni, Kardas, & Costa, 2018). So, clinicians are requested to support these persons to turn off more and

more candles with the best possible quality of life or at least containing symptoms and pain until the last breath.

The medical advancements and the general population aging have led to a structural rethinking of the organization of the healthcare systems (WHO, 2011). Thus, palliative care will be a future pivotal care practice to be implemented worldwide in different healthcare contexts. Consequently, providing adequate expertise in palliative care and safeguarding the providers' wellbeing is not only an ethical imperative but also an urgent social necessity (Harrison et al., 2017).

#### 1.3.2. Palliative care professionals' risk and protective factors

Considering present and future changes of healthcare systems, the attention to palliative care professionals' wellbeing has a growing importance. "*More than ever, the current increasing need for palliative care leads to health professionals providing this type of care which further leads to multiple challenges, and stressful and demanding situations*" (Parola, Coelho, Cardoso, Sandgren, & Apóstolo, 2017; p. 1905). To grasp the extent of the problem, just think that a recent review estimated a prevalence of burnout in palliative care professionals of 17.3%, despite differences among studies exist (Parola et al., 2017). This state of malaise threatens their psychological and physical health, which may undermine the quality of care (Bodenheimer T & Sinsky, 2014), as well as the professional quality of life (Samson & Shvartzman, 2018). A deeper discussion on this sound issue is provided in the paragraph 1.3.3 of this chapter.

Manifold kind of stressors challenge the wellbeing of healthcare workforce employed in the palliative care specialty. First of all, the exposure to death and to human sufferance on a daily basis may erode the emotional resources of individuals pushing them to a state of emotional exhaustion (Maslach &Leiter, 2016). The constant and prolonged contact with patients on the verge of death is described in the international literature as a relevant risk factor for emotional and psychological distress and burnout in this workforce (Sandgren, Thulesius, Fridlund, & Petersson, 2006; Pereira et al., 2011; Pereira & Fonseca, 2011). The contact with human sufferance threatens the healthcare professionals on an emotional level as they emphatically suffer with the patient, potentially experiencing feelings of helplessness and grief each time a patient dies (Back, Rushton, Kaszniak, & Halifax, 2015). Indeed, "when the brutality of illness outstrips the powers of medical technology, part of the fallout lands squarely on front-line clinicians" (Back et al., 2015; p. 26).

Moreover, these professionals are requested to make fundamental ethical decisions impacting on patient's life (Pereira et al., 2011; Pereira & Fonseca, 2011; Parola et al., 2017). The decision-making regarding withholding and withdrawing life-prolonging medical treatment is the most relevant example of high distressing and challenging facets. Withholding means to decline a treatment,

whereas withdrawing means to discontinue a therapy considered not useful any more. From a psychological point of view, it seems to be easer withhold a treatment than to withdraw it (BMA, 2008). To discontinue a therapy implies indeed to stop something that has been previously started, subjectively experiencing to be the active protagonist in hastening the individual' life. "*There can be an impression attached to a decision to withdraw treatment which can be interpreted as abandonment or 'giving up on the patient'; conversely, without a therapeutic trial of a treatment there can be a feeling that the patient has been denied the chance of improvement*" (BMA, 2008; pp. 19-20). However, sometimes it is necessary to start a cure and then to accept that it needs to be stopped at a certain time. Furthermore, this kind of decision requests to deeply know the regulation and the cutting-edge practices regarding end-of-life (Cartwright, White, Willmott, Williams, & Parker, 2016; Parola et al., 2017). These bioethics decisions might be taken against personal values and beliefs in order to be compliant to some patient/caregiver, institutional and moral constraints (BMA, 2008; Pereira et al., 2011; Pereira & Fonseca, 2011; Parola et al., 2017; Rainer, Schneider, & Lorenz, 2018). Day by day, these contrasts deplete resources, paving the way to the onset of psychological malaise.

Another highly demanding task is the breaking of bad news regarding poor diagnosis and prognosis (Pereira et al., 2011; Pereira & Fonseca, 2011). Palliative healthcare professionals stated both a lack of self-confidence in their own communication skills and the need of proper education in effective communication strategies (Pereira et al., 2011). Studies have underlined that the communication and the management of bad news are pivotal issues by medical students and proper trainings are suggested in educational curricula for being equipped to deliver palliative care (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010; Ranse, Ranse, & Pelkowitz, 2018). Indeed, the interpersonal relationships and the communication with patient and caregivers, as well as the management of their emotions are extremely energy consuming and emotionally draining.

Risk factors are also organizational features of the workplace, such as time pressure, conflicts with colleagues and superiors as well as resources shortage and excessive bureaucracy (Pereira et al., 2011). Similarly, personal characteristics, such as affectivity or coping strategies, may predispose the professionals to experience more malaise and distress (Pereira et al., 2011).

However, burnout and distress are not something unavoidable for who works in palliative care specialty. To this regard, it is noteworthy to underline that palliative care professionals do not show higher burnout levels than other colleagues (Martins Pereira, Teixeira, Carvalho, Hernández-Marrero, & InPalIn, 2016), probably thanks to the presence of some protective factors that may counterbalance the constant dealing with death and pain (Pereira et al., 2011; Sansó et al., 2015; Samson & Shvartzman, 2018). Among these protective factors, there is the meaning of work for what is done daily. This aspect may alleviate patient's pain as far as support and foster the best

quality of live until the last breath (Pereira et al., 2011; Sansó et al., 2015; Back et al., 2015; Samson & Shvartzman, 2018; Moreno-Milan, Cano-Vindel, Lopez-Dóriga, Medrano, & Breitbart, 2019). Thus, caring for patients facing their last days may be an enriching, personal gratifying and beneficial experience as the professional may make the difference for those people perceiving full satisfaction for their work activity (Sinclair, 2011; Pereira et al., 2011).

Also, the professionals' inner sense of spirituality may sustain the clinical practice providing the individual with a meaning of work (Sinclair, 2011; Sansó et al., 2015). Similarly, finding a meaningful sense to human sufferance and defining active strategies and rituals after death were described to help professionals to deal with the loss of the patients (Pereira & Fonseca, 2011).

Another protective factor described in the literature is the presence of formal and informal support (Pereira et al., 2011). Specifically, having the possibility to speak and having a confrontation with colleagues and superiors, as well as being able to spend time with families may reinforce the healthcare professionals' resources such counterbalancing the tough and constant experience of death and sufferance.

Moreover, some personal characteristics may support the healthcare professionals, too. For instance, some intervention studies described that teaching resilience skills to professionals may help them to thrive in the face of burnout and distress (Perez et al., 2015; Back, Steinhauser, Kamal, & Jackson, 2016; Hlubocky, Rose, & Epstein, 2017). Indeed, they may acquire skills and competence to manage difficulties occurring in their clinical practice, such as self-regulating emotions, recognizing cognitive distortions and developing realistic expectations (Back et al., 2016). However, it has to be underlined that only recently the literature has focused on positive and protective factors which may support the palliative healthcare professionals (Pereira & Fonseca, 2011; Pereira et al., 2011). The main focus has been put on risk factors and dysfunctional mechanism which may create the fertile ground for distress and burnout. Nevertheless, detecting protective factors and discovering positive processes may be equally important as these aspects may be the bases to implement tailored interventions for sustaining the professionals along their professional career as well as to help them to find and develop useful resources against distressing situations. For this reason, the project presented in this dissertation put preliminary attention to possible resources and protective factors in order to provide suggestions for clinical practice, in an attempt to foster and sustain the professionals' wellbeing.

#### 1.3.3. Further considerations on the risk of burnout for palliative care professionals

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#### Editorial

# Palliative medicine physicians: doomed to burn?

Julia Hynes,  $^1$  Marina Maffoni,  $^2$  Piergiorgio Argentero,  $^2$  Ines Giorgi,  $^3$  Anna Giardini  $^4$ 

On the first day of term, we academics and clinicians watch our first-year physician students file into the lecture theatre full of joy and altruistic dynamism. They have a burning passion to gain the knowledge, expertise and practical wisdom to cure and care for their fellow humans in times of sickness and decline. Our hope is that each of their dreams and aspirations are realised, to the full, in a healthy educational and work setting. This should be one which openly appreciates, values and rewards their contribution, in the service of life in a practical and verbal fashion. That environment must support them when their bodies fatigue, hearts break and minds become overburdened watching (at times) unnecessary suffering and respond to challenging situations regarding life and death. We hope that the flame of their passions does not burn out due to lack of provision and time for self-care and that they never utter the words, 'I have nothing more to give'.

However, if we are realistic, concrete evidence from both past and current medical literature indicates that some medical students' stories will not end well if changes to healthcare practice, including institutional ones, are not forthcoming.

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A cursory search reveals that it is steeped in evidence of depersonalised clinicians who begin to suffer themselves. They watch helplessly as the flame of passion dies only to be replaced by anxiety, compassion fatigue and depression.<sup>1</sup> They can no longer give the care their patients need, as they just about function themselves. Some continue on and in their compromised state. mistakes are made, which in turn may ignite lengthy Fitness-to-Practise or similar investigations. The guilt and shame of one mistake, especially when morality and ethics are involved, covers the physicians' self-perception of their life and work like a heavy, dark blanket. It blocks out all their success; stories of how they cared for and restored the health and well-being of sometimes thousands of patients. A clinician who is unwell is a loss for the entire society; everybody loses.

#### BIOETHICS AND HIGH-RISK PHYSICIANS

If burnout, distress and fatigue are worldwide relevant concerns in general medical practice, they are even more significant in palliative care and other clinical settings characterised by complex daily bioethical problems. It is a grave task for any physician who deals with the burden of emotions and decisions around end of life or life-sustaining therapy; simultane-ously juggling relatives' wishes and institutional and moral constraints. These demanding and distressing experiences may produce an inner conflict. A 'moral outrage'<sup>2</sup> against self-values develops if one feels prevented from doing what it is believed to be morally required. This, in turn, is a breeding ground

for moral distress.<sup>3</sup> In the past, dying coalmine birds were an alarm to prevent miners from harmful consequences of inadequate oxygen or toxic gases.<sup>4 5</sup> Physicians' negative health status similarly need to be seen as a warning signal and an 'ethical canary'.

#### A CALL FOR ACTION

We need more research regarding the specific experience of burnout, distress and fatigue, particularly that related to end of life and other bioethical issues in everyday clinical working life. We should consider bioethics as a discipline bridging medical knowledge (bio-) with the system of human values (-ethics).6 Indeed, the chronic nature of many diseases (thanks to contemporary medical advancements and societal transformations) inevitably imply an ever-growing need for those involved in palliative care and chronic disease. In addition, ever-proliferating bioethical quandaries impact physicians' wellness. This is even more relevant considering that such physician distress implies unnecessary increases in healthcare costs.<sup>8</sup> It also pauperises both the patient relationship and treatment adherence. Indeed, patient engagement can only result from their physicians' health and engagement. Thus, future research and interventions for healthier societies should also maintain the view that 'care of the patient requires care of the provider'.

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<sup>&</sup>lt;sup>1</sup> The BMJ Author Licence allows authors to use their articles for their own non-commercial purposes without seeking permission from BMJ and providing a full reference or link to the original article is included.

#### Editorial

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Section A: Chapter 1 - Theoretical background characterizing the healthcare landscape

#### 1.4. Healthcare professionals employed in neurorehabilitation medicine

#### 1.4.1. Definition

The concept of "rehabilitation" is intended as the process of restoration after injury or disease, aiming to maximize an individual's function ability and fostering the reintegration into the social, community and vocational activities (WHO 2001; Chua et al. 2007; Aadal, Kirkevold, & Borg, 2014). This process starts when the diagnosis is made and continues as long as the person needs interventions (Lexell, 2012) and it is constituted by four main steps: assessment, goal setting, interventions and outcome measurement (Lexell et al, 2015). The goal is to recovery as much as possible a certain function or ability to guarantee the best health-related quality of life and autonomy to an individual. In this vein, it is easy to understand why rehabilitation is becoming more and more grounded in the ICF - The International Classification of Functioning, Disability, and Health (WHO, 2001; Playford, 2015; Lexell, & Brogårdh, 2015; Giardini & Pistarini, 2019). This classification was provided by the World Health Organization in 1999 in order to offer a practical framework for the description of health and health-related conditions based on a biopsychosocial perspective. Specifically, ICF considers in an integrated way the body functions and structure, as well as individual's activities and participation so that the grade of disability is given by the interaction of the person within her/his environment and subjective needs. For instance, a pavement slope may be facilitator for people using wheelchairs, whereas it may turn in a physical hindrance for blind users with canes (Playford, 2015). For these characteristics, ICF may be successfully used in the rehabilitation field as it "provides a shared language within the multidisciplinary teams supporting a comprehensive assessment of an individual with a disability and facilitating treatment planning, which may aim to improve physiological function, maximize activity, alter the environment or support patient adjustment, all with a view to reaching a goal focused on participation" (Playford, 2015; p.5). To reach this aim, the patient's engagement is pivotal as physicians and patients may be considered to be in a "community of practice" where professionals need to understand the experience of the patients and support them in the process of learning and accepting the acquired changes, and reaching optimal recovery of functions (Aadal et al., 2014).

Different kinds of rehabilitation exist on the bases of individual diagnosis and injury. A wellrecognized typology is neurorehabilitation which puts the focus on the neuromotor system. It may be intended as composed by two main processes: the optimal adaptation to disability (e.g. the prescription of a wheelchair, cane) and a positive alteration of disability in type or degree by the manipulation of the physical abilities or anatomic-physiological structure (Cole, 1988). The neurorehabilitation practice started to steal the spotlight in the healthcare scenario thanks to a constant transformation of the neurologic care paradigm: the scientific findings moved from believing that a brain injury is something quite permanent and unrecoverable to the discovery of the brain's regenerative potential and, at least partial, recovery of functions (Barrett, Oh-Park, Chen, & Ifejika, 2013).

As medicine and technology grow, the healthcare scenario will increasingly need of professionals prepared to provide neurorehabilitation care to patients, offering solution to recovery lost functions or to successfully adapt to a certain disability occurred at a certain point of life.

## 1.4.2. Risk and protective factors for professionals in neurorehabilitation medicine

Similarly to other medical specialties, neurorehabilitation is a high demanding discipline characterized by different distressing factors. Besides common risk factors characterizing the healthcare professionals, the personnel employed in neurorehabilitation units has to deal with ethical challenges and with a relevant amount of distress given by patients suffering from severe and usually irreversible disfunctions who request long hospital stays and interdisciplinary needs (Körner, 2010; Mazlina & Engkasan, 2011; Koerner, 2011). These facets make employees in rehabilitation medicine units at increased risk of psychological malaise. According to the literature, moral distress and burnout are relevant issues throughout the specialty of physical medicine and rehabilitation (Carpenter, 2010; Gosseries et al., 2012; Sliwa et al., 2019; Bateman & Viana, 2019). Regarding this, a recent systematic review reported that burnout ranges from 48% to 62%, despite the incidence of burnout in this specialty varies among studies and kinds of rehabilitation (Bateman & Viana, 2019). According to an Italian study conducted with professionals involved in different kinds of rehabilitations, overall 14% of participants were described to be at high risk of developing burnout (Bruschini, Carli, & Burla, 2017). Consequently, these specialists are referred as one of the most "burned out" healthcare workforce (Shanafelt et al., 2015; Rothenberger, 2017; Sliwa et al., 2019; Shanafelt et al., 2019).

It is noteworthy to summarize the existing literature on this issue. Between the main self-reported risk factors for burnout in the rehabilitation specialty, there are various organizational characteristics and job demands (Koerner, 2011; Mazlina & Engkasan, 2011; Sliwa et al., 2019). Specifically, according to an American national survey, the three main causes of burnout were the increasing amounts of regulatory demands (documentation, insurance authorizations), workload and job demands (number of patients to taking care, institutions and patient/caregiver expectations, productivity targets), and practice inefficiency or lack of resources (lack of support, shortage of work force) (Sliwa et al., 2019). Another relevant issue is the emotional weight of

challenging patients involved in rehabilitation processes after some catastrophic accidents (Sliwa et al., 2019). To this regard, Belgian professionals employed in neurorehabilitation units and providing care to patients in a vegetative state and in a minimally conscious state reported symptoms related to emotional exhaustion and depersonalization (Gosseries et al., 2012). Moreover, professionals working more hours per week showed higher level of burnout and malaise compared to their colleagues (Bruschini et al., 2017; Sliwa et al., 2019).

The literature has also described that professionals working in rehabilitation units may experience moral distress and psychological malaise due to the ethical issues occurring in the daily clinical practice (Kirschner, Stocking, Wagner, Foye, & Siegler, 2001; Mukherjee, Brashler, Savage, & Kirschner, 2009; Carpenter, 2010; Mazlina & Engkasan, 2011). In particular, a survey conducted in Malaysia, described the healthcare professionals' perceptions of different ethical issues, such as the disclosure of patient's confidential information to colleagues, the allocation of scare resources, the difficulties regarding the decision-making process and the optimal discharge planning (Mazlina & Engkasan, 2011). Similarly, other studies described the following relevant stressors: healthcare reimbursement pressures, corporate culture constraints, the conflicts regarding goal-setting and discharge planning among colleagues and patient/caregivers, as well as the patient confidentiality management and the assessment of patient's decision-making capacity (Kirschner et al., 2001; Mukherjee et al., 2009). Another study unveiled that nurses employed in neurorehabilitation medicine specialty have to deal with high-acuity patients, poor interprofessional collaboration as far as heavy workload (Miller & Kontos, 2013) which comprises not only direct hands-on patient care, but also indirect care (reports, meetings and documents writing regarding the care to provide) and non-patient related activities (housekeeping, clerical errands) (Williams, Harris & Turner-Stokes, 2009). Also, an Italian study described the risk of developing burnout linked to the following organizational variables: control (workers' autonomy), management support (support and resources provided by the superiors), relationships (organizational climate and conflicts management), role (workers' awareness of their roles) and change (management and communication of organizational changes) (Bruschini et al., 2017).

The literature regarding protective factors for the wellbeing of healthcare professionals employed in rehabilitation and neurorehabilitation medicine specialty is still scant. Overall, the literature suggests to foster protective factors and interventions that seem to be effective to maintain wellbeing in healthcare professionals, regardless of the specific medical disciplines (Shanafelt & Noseworthy 2017; Sliwa et al., 2019). Specifically, for promoting wellbeing and counterattacking burnout, it is suggested to pay attention to maintain adequate workload, efficiency and resources, to provide meaning of work, to foster fair culture and values, to guarantee professionals' control and flexibility, as well as to sustain social support and work-life balance (Shanafelt & Noseworthy 2017). Moreover, healthcare professionals working in rehabilitation medicine pointed out the relevance of educational courses and programs teaching them how to deal and manage ethical issues that may occur in the clinical practice and that may pave the way to burnout and moral distress (Mazlina & Engkasan, 2011). In addition, cooperation and interprofessional practice and education have been described by medical students in rehabilitation field to be pivotal elements for their wellbeing (Gustafsson et al., 2016).

Overall, the literature focusing on this medical discipline is still scarce. Thus, it is of paramount importance to deepen the investigation within this specialty in order to better understand mechanisms and factors that can support or undermine the professionals' wellbeing. This dissertation contributes to bridge the gaps on risk and protective factors within this healthcare workforce.

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# Chapter Two

# Focus on the main constructs investigated in this project

# 2.1. Burnout

The psychiatrist Herbert Freudenberger was the first who started to speak about burnout syndrome among the healthcare workforce in the 1970s, posing the attention on specific stressors and work conditions of the helping professions (Freudenberger, 1974). Specifically, he investigated some volunteers in a free medical clinic and described burnout as a condition resulting from unresolvable, long-standing job stressors characterizing professionals in touch with suffering and demanding people (Freudenberger, 1974). Later, in the 1980s, research on burnout garnered growing attention, becoming more and more rigorous and detailed. The American psychologist Christina Maslach and her colleague Michael Leiter deepened the investigation, describing this syndrome as a resources-draining condition, that is an "erosion in values, dignity, spirit and will—an erosion of the human soul. It is a malady that spreads gradually and continually over time, putting people into a downward spiral from which it is hard to recover" (Maslach & Leiter, 1997, p. 16).

Three main symptoms are considered the core of this work-related syndrome (Leiter, Maslach, & Frame 2015; Maslach, & Leiter, 2016; West, Dyrbye, & Shanafelt, 2018):

- *Emotional exhaustion*: it includes feeling of "used up" and depletion of energies at the end of a workday. The professionals perceive that their emotional resources are drained up and nothing is left for the patient from an emphatic standpoint. It is the most common manifestation and it is considered the core symptom as the other ones can be seen as consequences of this state of emotional depletion (Taris, Le Blanc, Schaufeli, & Schreurs, 2005).
- *Depersonalization/Cynicism*: it describes the tendency to treat patients as objects rather than human beings. The focus is managing the disease, neglecting the people who is suffering from the disease. Thus, the professionals become more callous towards patients, lacking of empathy and human connection.
- *Poor professional efficacy*: it is a sense of reduced personal accomplishment resulting from feelings of ineffectiveness and failure in helping patients. Besides this sense of helplessness, the professional perceives a lack of value, competence and meaning of work-related activities. The choice of her/his profession is called into questions as the feeling of self-efficacy at work is lost.

The great relevance of this work-related syndrome is recognized worldwide such that burnout has been described as a "global crisis" or as an "holocaust in medicine" because it reached global epidemic levels with consequences not only on the individual but also on the entire healthcare system (The Lancet, 2019; Bhatnagar, 2020). Regarding this, it has to be said that the estimates of the problems differ among studies and methods used to collect data, as well as among countries and medical specialties considered (Rothenberger, 2017; Rotenstein et al., 2018; Shanafelt et al., 2019).

As concerns the palliative care professionals, a review including 1406 palliative health professionals from eight different studies, pointed out that the prevalence of burnout among these workers is 17.3% (Parola, Coelho, Cardoso, Sandgren, & Apóstolo, 2017). A recent Italian study involved 275 professionals of a nonprofit organization providing home palliative care and it unveiled that 11% of professionals reported emotional exhaustion and 20% of them referred poor professional accomplishment. Moreover, the most part of the sample (67%) complained depersonalization (Ercolani et al., 2020). Although these professionals are not more in burnout in respect to colleagues employed in other medical disciplines probably thanks to some protective factors (Pereira, Fonseca, & Carvalho, 2011; Sansó et al., 2015; Martins Pereira, Teixeira, Carvalho, Hernández-Marrero, & InPalIn, 2016; Samson & Shvartzman, 2018), these percentages deserve attention and full consideration to support professionals and to contain the problem. To this regard, the experience of burnout was described as an insidious and vary dangerous problem by American palliative care professionals participating in a focus group study (Kavalieratos et al., 2017). For example, one of the respondents stated that "I think it's like heart failure. I think it's chronic, and it's there, and if you don't take care of it, it will kill you.... And it gets to a point that you can't reverse it". (Kavalieratos et al., 2017; p. 5).

Considering the literature on burnout among the neurorehabilitation specialty, it has to be stated that it is still scant and there is evidence of some studies only focusing on the overall rehabilitative sector (Bateman & Viana, 2019; Bruschini, Carli, & Burla, 2017). To this regard, a recent systematic review including 5 studies examining 1886 American professionals and trainees employed in physical medicine and rehabilitation unveiled that burnout ranges from 48% to 62%, with a weighted mean prevalence of 51.6%. Moreover, this review showed that the prevalence of burnout between 2012 and 2015 increased by 29% amongst this healthcare workforce, that is 1.5 times the rate for all specialists (Bateman & Viana, 2019). According to an Italian survey recruiting 391 different rehabilitative therapists employed in various public and private healthcare institutions in the Centre of Italy, the emotional exhaustion was referred as a high risk by the 32.2%, as a medium risk by 25.3% and as a low risk by 42.5%. Moreover, dependent of the state of the st

by the 13.8%, as a medium risk by 21.7% and as a low risk by 59.1% (Bruschini, Carli, & Burla, 2017).

As already mentioned in the previous chapter, the principal causes of burnout reported by these two medical specialties are manifold, despite research in neurorehabilitation medicine specialty is still scarce. For instance, the main risk factors for the grounding of burnout are the requests to deal with suffering patients on the verge of death or involved in rehabilitation processes after some catastrophic accidents, as well as being exposed to dying, sufferance and ethical dilemmas on a daily basis (Sandgren, Thulesius, Fridlund, & Petersson, 2006; Pereira et al., 2011; Pereira & Fonseca, 2011 Mazlina & Engkasan, 2011; Koerner, 2011; Shanafelt, & Dyrbye, 2012; Sliwa et al., 2019). These conditions slowly but constantly drain the professionals from an emotional standpoint. Other organizational facets which may prepare fertile ground for burnout are the constant increase in responsibility, higher professional qualifications, time pressure, excessive bureaucracy and less autonomy, increasing workload, as well as shortage of human workforce and resources characterizing in particular the modern times (Pereira et al., 2011; Pereira & Fonseca, 2011; Koerner, 2011; Shanafelt, & Dyrbye, 2012; Shanafelt, Dyrbye, & West, 2017; Bruschini et al., 2017; Sliwa et al., 2019). Moreover, another relevant stressor is linked to interpersonal aspects such as possible team conflicts and lack of support by superiors and colleagues such that the professional is left alone to cope difficulties (Pereira et al., 2011; Pereira & Fonseca, 2011). It is also worthwhile to underline that poor communication skills and scarce practical communication trainings, as far as difficulties in breaking bad news are other important risk factors for developing burnout as these factors expose the healthcare professional to cope with emotionally high-demanding and challenging situations (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010; Pereira et al., 2011; Pereira & Fonseca, 2011; Shanafelt, & Dyrbye, 2012; Ranse, Ranse, & Pelkowitz, 2018).

Conversely, some organizational, interpersonal and personal aspects may be considered pivotal protective factors for palliative care or neurorehabilitation medicine professionals to counterattack the onset of burnout. For instance, good organizational climate, engagement and an effective job-task organization were described in the literature to be relevant supportive factors helping the professionals to buffer the negative events occurring during their working days (Pereira et al, 2011). Cooperation and adequate formal and informal social support (Pereira et al. 2011; Gustafsson et al., 2016), meaning in life and meaning of work, as well as job satisfaction are points of strengths, too (Sinclair, 2011; Sansó et al., 2015; Back, Rushton, Kaszniak, & Halifax, 2015; Samson & Shvartzman, 2018; Moreno-Milan, Cano-Vindel, Lopez-Dóriga, Medrano, & Breitbart, 2019). Indeed, perceiving the value of what is done refuels the professionals with energy and resources to counterattack burnout and to pursue aims despite problems and adverse events. Furthermore, good

communication skills and resilience are personal capacities, which may be considered other examples of pivotal resources to manage job difficulties and bad news and, in turn, to avoid the risk of burnout (Pereira et al., 2011; Perez et al., 2015; Back, Steinhauser, Kamal, & Jackson, 2016). Focusing on consequences, burnout reverberates its effects on multiple levels. On one hand, the main negative consequences are on the single healthcare professional who perceives a decrease of resources and energies, and an increase of psychological malaise (Maslach and Leiter, 2016; Bodenheimer & Sinsky, 2014; Back, Rushton, Kaszniak, & Halifax, 2015; Sliwa et al, 2019). In particular, professionals may start to suffer from depression, anxiety, substance abuse and suicide ideation (Harrison et al., 2017). Thus, burnout creates a serious condition of vulnerability of the professionals themselves (Pereira et al., 2011). On the other hand, there are other relevant consequences on organizational and social levels as a burned-out workforce is exposed to higher rates of medical errors, poor productivity and higher turnover, as well as higher expenditure (Harrison et al., 2017). Besides this, burnout impact on patients, too. To this regard, it was unveiled that burned out professionals usually provide a lower quality of care, show poor empathy and more cynicism which, in turn, worse the patient's satisfaction and security (Shanafelt, & Dyrbye, 2012; Harrison et al., 2017). So, this condition causes a relevant degree of vulnerability of the patient, too (Pereira et al., 2011).

Thus, burnout is to be considered a threat that cannot be ignored. It "has been recognized as a public health crisis in many high-income countries because it not only affects physicians' personal lives and work satisfaction but also creates severe pressure on the whole healthcare system—particularly threatening patients' care and safety" (The Lancet, 2019).

# 2.2. Moral distress

Among the different forms of malaise that the healthcare professionals may experience, there is the so called "moral distress". This term was introduced in the scientific literature by the American philosopher and bioethicist Andrew Jameton who fistly described a subjective painful state of inner fracture and eroding dilemma emerging from a contrast between moral values and actions to be done (Jameton, 1984). Differently said, moral distress is given when someone is forced to behave against her/his beliefs because of different organizational, legal, personal constraints. The definition is related to the assumption that healthcare professionals are guided by moral values (e.g. respect, dignity, honesty, integrity) which, if not addressed, may cause an inner and subjective experience of distress and loss of personal and professional integrity (Storch, Rodney, & Starzomski, 2004; Carpenter 2010). During the decades, manifold definitions have been provided by authors who investigated moral distress, trying to put attention on different nuances and to better define this construct (Musto, Rodney, 2018). A synoptic table of the different interpretations and understandings of moral distress developed during the time is provided in Table 1.

Table 1. Definitions	of moral	distress	(Musto,	Rodney,	2018, modified)
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Authors (date)	Definitions
Jameton (1984)	State arising when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.
Wilkinson (1987)	Psychological disequilibrium and negative feeling state experienced when a person makes a moral decision but does not follow through by performing the moral behavior indicated by that decision.
Jameton (1993)	<i>Initial moral distress</i> involves the feelings of frustration, anger and anxiety people experience when faced with institutional obstacles and conflict with others about values. <i>Reactive moral distress</i> is the distress people feel when they do not act upon their initial distress.
Hanna (2002)	State that occurs in the context of situations that have moral implications embedded within them, where the moral end, an inherent rightness or goodness, is understood to exist and understood to be or have been threatened, harmed or violated.
Austin et al. (2003)	The state experienced when moral choices and actions are thwarted by constraints.
Kälvemark et al. (2004)	Traditional negative stress symptoms that occur due to situations that involve ethical dimensions and where the healthcare provider feels she/he is not able to preserve all interests and values at stake.
Nathanial (2006)	Pain affecting the mind, the body, or relationships that results from a patient care situation in which the nurse is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action, yet, as a result of real or perceived constraints, participates, either by act or omission, in a manner he or she perceives to be morally wrong.
Mitton et al. (2011)	The suffering experienced as a result of situations in which individuals feel morally responsible and have determined the ethically right action to take, yet due to constraints (real or perceived) cannot carry out this action, thus committing a moral offence.
Varcoe et al. (2012)	The experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards.

Rodney et al. (2013)	What nurses (or any moral agents) experience when they are constrained from moving from moral choice to moral action—an experience associated with feelings of anger, frustration, guilt, and powerlessness.
Crane et al. (2013)	The experience of psychological distress that results from engaging in, or failing to prevent, decisions or behaviors that transgress, or come to transgress, personally held moral or ethical beliefs.
Barlem & Ramos (2014)	The feeling of powerlessness experienced during power games in the micro- spaces of action, which lead the subject to a chain of events that impels him or her to accept imposed individualities, have his or her resistances reduced and few possibilities of moral action; this obstructs the process of moral deliberation, compromises advocacy and moral sensitivity, which results in ethical, political and advocational expressiveness and a series of physical, psychical, and behavioral manifestations.
Campbell et al. (2016)	One or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that one perceives to be morally undesirable.

Considering the patient population taken in care by these professionals, it is not difficult to understand that palliative care professionals are particularly exposed to moral distress. Indeed, they are requested to manage tough emotions and challenging ethical decisions for the care of patients on the verge of death (Cherny, Werman, & Kearney, 2015). To this regard, a systematic review was conducted in order to summarize studies investigating causes and effects of moral distress among palliative care professionals. This systematic synthesis of the literature is provided in the next paragraph.

# 2.2.1. A systematic review on moral distress in palliative care professionals

Maffoni, M., Argentero, P., Giorgi, I., Hynes, J., & Giardini, A. (2019). Healthcare professionals' moral distress in adult palliative care: a systematic review. *BMJ supportive & palliative care*, *9*(3), 245-254. https://spcare.bmj.com/content/9/3/245.long<sup>2</sup>

NOTE: This paper has been awarded the first prize "Young Researcher Best W/O Psychology Paper - 2020" by the Italian Psychology Association - Section of Work and Organizational Psychology, 19th-20th November, 2020.

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# Healthcare professionals' moral distress in adult palliative care: a systematic review

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#### ABSTRACT

**Objectives** Palliative care providers may be exposed to numerous detrimental psychological and existential challenges. Ethical issues in the healthcare arena are subject to continual debate, being fuelled with ongoing medical, technological and legal advancements. This work aims to systematically review studies addressing the moral distress experienced by healthcare professionals who provide adult palliative care. **Methods** A literature search was performed on PubMed, Scopus, Web of Science and PsycINFO databases, searching for the terms 'moral distress' AND 'palliative care'. The review process has followed the international PRISMA statement guidelines.

Results The initial search identified 248 papers and 10 of them were considered eligible. Four main areas were identified: (1) personal factors, (2) patients and caregivers. (3) colleagues and superiors and (4) environment and organisation. Managing emotions of self and others, witnessing sufferance and disability, caring for highly demanding patients and caregivers, as well as poor communication were identified as distressing. Moreover, the relationship with colleagues and superiors, and organisational constraints often led to actions which contravened personal values invoking moral distress. The authors also summarised some supportive and preventive recommendations including self-empowerment, communication improvement, management of emotions and specific educational programmes for palliative care providers. A holistic model of moral distress in adult palliative care (integrating emotional, cognitive, behavioural and organisational factors) was also proposed.

**Conclusions** Cognisance of risk and protective factors associated with the moral distress phenomenon may help reframe palliative healthcare systems, enabling effective and tailored actions that safeguard the well-being of providers, and consequently enhance patient care.

#### INTRODUCTION

Healthcare providers are in contact with illness, emergencies and highly demanding people on a daily basis in their place of work. Besides the awareness and altruistic satisfaction of making a difference, the complexity of managing suffering and interpersonal relationships with the patients and the caregivers is often an everyday challenge. Burnout and common mental disorders are a well-known and a relevant issue for worldwide healthcare providers, with differences when considering various healthcare professional groups.<sup>1–3</sup>

If this is true for the general healthcare practitioner, it is even more real for those healthcare professionals working in the end of life landscape. Palliative care providers are in contact with death and with people who are dying on a daily basis, and are therefore constantly exposed to potential psychological and existential challenges, as well as to emotional distress.<sup>4</sup> Indeed, moral dilemmas frequently arise constituting an additional burden to manage in the workplace.

#### Moral distress

The expression 'moral distress' was coined by the American philosopher and bioethicist Andrew Jameton<sup>5</sup> who described it as a negative state experienced by a person dealing with a fracture between moral choice and moral actions due to external constraints. During the years, the authors defined the term differently and, still now, the meaning remains 'nebulous' and 'under construction'.<sup>6-8</sup> However, in general terms, moral distress is intended as a particular form of distressing and demanding feeling that arises when a person is obliged to act contrary to her/his beliefs and values.9 This negative effect may impact on the mind, the body and

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social relationships.<sup>9 10</sup> It generates painful sensations of frustration, sadness, anger, helplessness and psychophysical suffering.<sup>11</sup> The subject cannot do what she/ he thinks ought to be done and this awareness is ethically disturbing.

A healthcare provider may experience this feeling when prevented to perform in an ethical manner which accords with her/his own point of view.<sup>12</sup> An example of this may be when a nurse is requested by a doctor to draw blood to test from a patient on the verge of death. The nurse may consider this action futile and burdensome for the patient, however the physician may hold a different perspective.

Moral distress is a phenomenon characterising healthcare professionals with different rates across worldwide healthcare settings<sup>13</sup> and it may have a deteriorating effect on healthcare providers' well-being and their quality of work.<sup>9</sup> <sup>11</sup> Indeed, it undermines provider's core values and beliefs and, perhaps, in turn her/his professional responsibility and integrity.<sup>11</sup> <sup>12</sup> Moral distress implies moral conflicts directly deriving from the provider's commitment and from the effort to alleviate suffering despite constraints.<sup>6</sup>

#### Moral distress in palliative care

Palliative care providers are not immune to develop moral distress<sup>14</sup>; on a daily basis they have to attend to people with a limited life expectation, as well as cases characterised by relevant ethical and moral implications and conflicts. Many factors could contribute in the management of morally distressing and conflicting clinical situations, such as advancements in medicine and technology, complexity and diversity in cultures, necessity to provide constant attention to the patient, as well as shortage of resources.<sup>15</sup> In end-of-life management, to negotiate with all the stakeholders involved in order to reach an agreed consensus on the best intervention to be performed is not always simple. Indeed, one may not agree with a treatment because it is perceived as useless or even detrimental, nonetheless one may have to carry it out.<sup>16</sup><sup>17</sup> Moreover, to routinely witness suffering and pain and to consequently manage the negative emotions of oneself are challenging and consuming issues.<sup>18</sup> <sup>19</sup> Palliative care providers complained of the frequent sense of powerlessness when dealing with end-of-life issues and the complexity of disclosing fatal information to patients and families, in other words trying to be 'professional over emotional<sup>20</sup> (p 29). The complex management of these sensitive issues along with external constraints, workload and possible interpersonal conflicts with colleagues may create a breeding ground where moral distress could escalate. This negative personal setting is detrimental for both the individual in particular and society in general, as it affects both care and productivity.<sup>1 21</sup> Indeed, surveys report that burnout, dissatisfaction and moral distress prevent healthcare professionals to adequately fulfil their work, and furthermore contribute to their intention to quit their current positions which in turn generates a relevant ongoing shortage of qualified personnel.<sup>22,23</sup>

There exist a wide range of research studies on moral distress in healthcare professionals<sup>24,25</sup>; however, there is a dearth of studies which focus specifically on this phenomenon in relation to the providing of palliative care to adult patients. With regard to neonatal and paediatric palliative care, a review reported that providers' moral distress may be related to personal factors, family's denial, providing futile care and/or false hope, infant's clinical status fluctuation, as well as inefficacious symptom management and healthcare professionals' treatment disagreement.<sup>26</sup> In addition, the risk to provide disproportionate and aggressive care, the sense of powerlessness and a poor prognosis communication were highlighted as challenging and highly demanding also.<sup>27</sup> However, it was found that educational intervention and the implementation of palliative care protocols may lead to a reduction in moral distress.

An overview of literature on moral distress strictly relating to providing palliative care to adult patients still lacks. Thus, the aim of this paper is to report about a systematic review of studies, both of the qualitative and the quantitative types, which have investigated moral distress concerning adult palliative care. The authors will endeavour to summarise issues related to this phenomenon and to provide possible ameliorative and preventive recommendations.

#### **METHODS**

A systematic review of the literature related to moral distress in adult palliative care was conducted. Before starting, registered and/or work in progress studies on this topic were searched for in the International Prospective Register of Systematic Reviews. Since no recent comparable research was found, the systematic review protocol was recorded in this register ( ref. CRD42018090073).

The review was conducted and reported according to the international Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines.<sup>28</sup>

#### Search strategy and data extraction

An electronic literature search was performed on four databases publicly available: PubMed, Scopus, Web of Science and PsycINFO. The terms 'moral distress' AND 'palliative care' were used, detecting them in the title, abstract and keyword sections. The search included articles published from 1984—when the term 'moral distress' appeared for the first time<sup>5</sup>—to April 2018. A reference management and bibliography creating software (EndNote Web) were used to support the review process.

After the electronic search was completed, two reviewers (MM, PA) independently performed the

screening of the records retrieved, starting from the titles considered possibly relevant. The records considered eligible were screened by means of abstract reading. Papers without abstracts were automatically excluded and deemed not suitable to correctly perform the screening process. Finally, the selection by full text of the retrieved records was conducted in order to identify papers relevant and informative to the review. Doubts and concerns about inclusion and exclusion criteria were discussed by a third reviewer (AG) until a full consensus was reached.

#### Inclusion and exclusion criteria

Studies were considered suitable for inclusion if written in English and published by peer-reviewed journals. Grey literature, editorials, commentaries, dissertations, opinion or theory pieces, as well as reviews were excluded. Articles reporting studies on healthcare providers' moral distress related to adult palliative care were considered. Research studies focusing on patients and/or family points of view were excluded. No limitations to methodology were adopted: both qualitative and quantitative articles were considered eligible and relevant to the present review. Moreover, as no strong consensus and empirical evidence are available, no quality scales to screen the articles were implemented.<sup>29</sup>

#### RESULTS

Merging the databases, the initial search identified 248 papers. After removal of duplicates, 149 titles were screened for compliance with the study criteria. Based on title and abstract screening, 105 studies were excluded from consideration. Of these, 44 full-text articles were assessed for eligibility and, finally, 10 studies met all the criteria and were included in the present review (figure 1). Of these, 80% were

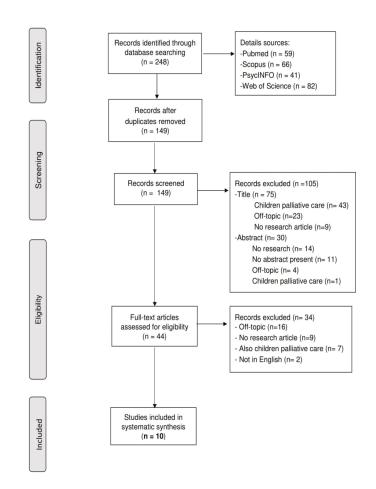


Figure 1 Flow diagram of records identified, screened and included in the systematic review, according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) reporting guidelines.

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Table 1 Articles included in the systematic review					
Author(s), year	Country (HDI*)	Setting (RPC, HPC)†	Subjects	Data collection	Data analysis
Popejoy <i>et al</i> , <sup>30</sup> 2009	USA (0.920)	ICU, not-for-profit university community hospital (RPC)	22 staff nurses from the medical ICU (n=10), surgical ICU (n=6) and neuroscience ICU (n=6) caring for patients with critical illness and are dying	5 audio-recorded and verbatim transcribed focus groups (from 2 to 7 participants)	Analysis of psychosocial setting and themes and subthemes emerged by two investigators
Brazil <i>et al</i> , <sup>16</sup> 2010	Canada (0.920)	5 home visiting organisations (HPC)	18 healthcare professionals providing home-based palliative care (10 nurses, 2 personal support workers, 2 social workers, 2 occupational therapists, 1 physiotherapist, 1 speech language pathologist)	Qualitative one-on-one semistructured interview through critical incident approach	Thematic content analysis to analyse the audio-recorded verbatim transcripts
Browning, <sup>33</sup> 2013	USA (0.920)	Online (RPC)	277 critical care nurses registered on the American Association of Critical-Care Nurses' (AACN) email newsletter who have cared dying adults	A cross-sectional descriptive online survey constituted with 32-item Moral Distress Scale— MDS and 16-item Psychological Empowerment Instrument—PEI	Statistical analysis (correlations and multiple linear regression)
Funk <i>et al</i> , <sup>20</sup> 2013–2014	Canada (0.920)	3 residential care facilities (RPC)	11 certified resident care aides (RCA) who had worked full time for at least 1 year in a residential care facility and had experience providing end-of-life care to dying persons	Audio-recorded, face-to-face, in-depth, semistructured interview (1–2 hours per person)	Interpretative analysis of the transcripts
McAndrew and Leske, <sup>31</sup> 2015	USA (0.920)	ICU, academic hospital (RPC)	7 nurses from surgical, neuroscience, cardiovascular and medical ICUs and 4 attending physicians who all practised in a medical ICU	One-on-one unstructured, audio- recorded and verbatim transcribed interview (19–65 min per person) and field notes for behaviours and non-verbal communication	Grounded theory method
Zheng <i>et al</i> , <sup>18</sup> 2015	China (0.738)	Cancer hospital (RPC)	28 nurses who have been taking care of patients with terminal illness	Face-to-face semistructured, audio-recorded and verbatim transcribed interview (30–60 min)	Qualitative thematic analysis through NVivo V.10.0 software
Leboul <i>et al</i> , <sup>19</sup> 2017	France (0.897)	2 palliative care units (PCU) in a PC hospital and one PCU in a university hospital (RPC)	35 medical and paramedical providers	3 multiprofessional focus groups (two 3-hour sessions) and 14 personal narratives	Grounded theory method
Bublitz <i>et al</i> , <sup>32</sup> 2017	Australia (0.939)	Haemodialysis units at a tertiary-level hospital (RPC)	55 nephrology nurses caring for adult end-of-life patients	Writing of narratives guided by reflective questions to develop a core summary story	Qualitative narrative inquiry methods
Browning and Cruz, <sup>12</sup> 2018	USA (0.920)	ICU, urban hospital with palliative care team across all units, serving low- income population (RPC)	43 ICU nurses considering experimental and control group (group size varied according to the type of analysis)	Reflective debriefing protocol to alleviate moral distress through regular debriefings (45–60 min session once per month across 6 months) and Moral Distress Scale- Revise—MDS-R at the beginning and at the end of the intervention	Relationship between variables was statistically analysed with SPSS software (SPSS version not mentioned)
Lokker <i>et al</i> , <sup>17</sup> 2018	Netherlands (0.924)	Healthcare institutions (RPC)	36 nurses working in hospital, nursing home or primary care and having experience of palliative sedation	Audio-recorded and verbatim transcribed semistructured interview (30–65 min)	Constant comparative method

knowledge and a decent standard of living. †Types of palliative care provided: HPC, home palliative care; RPC, residential palliative care (hospital or hospice).

ICU, intensive care unit; PC, palliative care.

qualitative research studies  $^{16-20}$   $^{30-32}$  whereas 20% reported quantitative research studies.  $^{12}$   $^{33}$ 

As a synthesis, the authors extracted for each article different kind of information: country and setting, subjects, methods to collect and analyse data, as well as main results (table 1; see also online supplementary Table 1). To give a more informative indication about the context, they reported also the Human Development Index of each country, as monetary measures are no more considered adequate proxies of development.<sup>34</sup>

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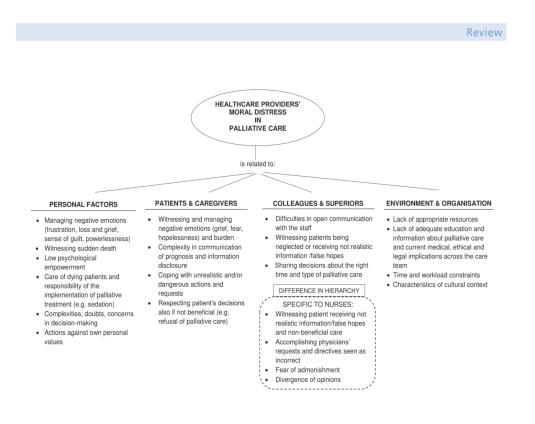


Figure 2 Maps of the themes emerged.

The authors read the articles included in the review and found an agreement on the main results to report, as well as on a thematic framework that could be used to analyse data. Thus, they identified four main areas reporting native aspects and causes of healthcare providers' moral distress in adult palliative care: personal factors, patients and caregivers, colleagues and superiors, environment and organisation (figure 2). Author JH reviewed all of the tabulated data for accuracy and clarity.

#### **Personal factors**

The experience of negative emotions—like frustration, sense of guilt and powerlessness, loss and grief—is a spontaneous and human response to caring for patients who are dying and this interpersonal experience may contribute to moral distress.<sup>12</sup> <sup>17–20</sup> <sup>30–32</sup> Moreover, witnessing sudden death during a shift is reported as a challenge also.<sup>16</sup> Psychological empowerment is negatively correlated with moral distress frequency (r=-0.194, p=0.01) and it is predicted significantly by moral distress frequency ( $\beta$ =0.222, p<0.01).<sup>33</sup>

In addition, nurses underlined that the caring behaviour for patients who are dying is a risk factor for moral distress,<sup>20</sup> as well as the responsibility and the pressure for treatment implementation,<sup>12</sup> <sup>19</sup> in

particular related to palliative sedation<sup>17 19</sup> and to inefficacy of pain management.<sup>16</sup>

Clinical and care activities in palliative care triggered doubts, fears, concerns and existential questions on the correctness and ethics of personal behaviour and these challenging experiences are related to moral distress.<sup>18–20</sup> In addition, to act or to witness someone else perform actions against her/his own personal values and beliefs may be relevant to experiencing distress and discomfort.<sup>12 16 17 32 33</sup>

#### Patients and caregivers

Caring for a patient who is dying is a challenging situation due to the constant and continuous exposition to sufferance and suffering persons close to death.<sup>20</sup> One risk factor is to witness and manage the burden and the negative emotions—as grief, loss, pain, fear, hopelessness—experienced by the patient and the family.<sup>16 20 30</sup> Communication is another matter of distress for health-care professionals. Communication on prognosis and information disclosure were reported as complex, difficult and feared; that is, not easy to manage.<sup>16 20 30</sup> Constantly coping with family's unrealistic requests and/or detrimental behaviour was reported also as another demanding aspect.<sup>12 16 17 19 31 33</sup> To witness and to accept a patient's decision is challenging and

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is related to moral distress if her/his actions are not beneficial, as for example refusing palliative care when no other options are available.<sup>16,32,33</sup>

#### **Colleagues and superiors**

Healthcare providers complained about difficulties in maintaining an open communication with colleagues and a collaborative climate,<sup>12 31 33</sup> as well as referred complex negotiations about the right time and type of palliative care to offer to the patient.<sup>12 17 19 32</sup> In addition, witnessing a colleague neglecting a patient or giving her/him unrealistic information and false hopes was reported as challenging too.<sup>16 17 30</sup>

Another situation described as morally distressing was the witnessing of a patient receiving unrealistic information or even treatments not in line with their values and beliefs, because considered detrimental and uselessness.<sup>12 16 17 30 32</sup> Having divergence of opinions without margin of disagreement and fear of physicians' admonishment was reported by nurses as related to moral distress.<sup>12 17 30 32</sup> Furthermore, nurses experienced constraints and pressure to accomplish superiors' not shared request and directives, leading to the experience of moral distress.<sup>17 30</sup>

#### Environment and organisation

Healthcare providers complained of the lack of appropriate human and instrumental resources in offering effective palliative care to the patient,<sup>16 33</sup> as well as an insufficiency in training about specific skills on palliative care and current medical, ethical and legal implications.<sup>16 18</sup> Time and workload constraints, conflicting with the necessity of the grieving process, contributed to moral distress in palliative care providers also.<sup>18 20</sup> Cultural context may influence both caring and the experience of moral distress, due to a social taboo surrounding these topics which in turn may contribute to the complex management as regards death and dying.<sup>18</sup>

#### Suggested recommendations

The first four authors collated positive factors and suggestions for coping with moral distress which were reported in the examined articles and a synthesis of recommendations was proposed (box 1).

From this review emerged the necessity of actions to promote an effective and open communication with patients, their families<sup>18</sup> <sup>19</sup> <sup>30</sup> and with other colleagues, in order to minimise misunderstandings and negative emotions and to facilitate a supportive climate. <sup>12</sup> <sup>17-19</sup> <sup>31</sup> <sup>32</sup> Indeed, collaborative and respectful relationship with colleagues and superiors was reported as helpful to handle day-to-day job demands in palliative care. <sup>12</sup> <sup>16</sup> <sup>19</sup> <sup>31</sup> <sup>32</sup> Occasions to have confrontations and an exchange of experiences may support the providers too. <sup>12</sup> <sup>16</sup> <sup>20</sup> Moreover, interventions to improve personal psychological empowerment<sup>12</sup> <sup>33</sup> and the management of emotions<sup>18</sup> <sup>20</sup> are suggested as

# Box 1 Suggestions from the articles in the systematic review

- Training for effective communication with patient and her/his family; colleagues and healthcare staff.
- Encourage the construction of a collaborative and respectful relationship.
- Share experiences and foster confrontations (briefing, breaks, memorial events, and so on).
- ► Improve personal psychological empowerment.
- Training programmes to provide nurses with emotion and meaning-making strategies and specific knowledge on palliative care (medical, ethical, legal aspects).
- Presence of bereavement and psychological support structures and specialists.
- Development of a transdisciplinary and holistic approach to palliative care.
- Research on moral distress in palliative care, analysing patterns and protective factors.

effective ways in which to counterattack the development of moral distress.

Besides supportive interventions, it underlined the necessity to implement and propose educational programmes to all healthcare providers, in particular to nurses, giving specific knowledge about medical, clinical and ethical features, as well as meaning-making strategies in palliative care.<sup>16 17 32 33</sup> Indeed, it is suggested as relevant to become aware of sources of distress and conflict to prevent them.<sup>16</sup>

Articles included in this review also recommended the presence of structures and specialists (psychologists, counsellors) to psychologically support providers with death, dying and with the other challenging and demanding issues characterising adult palliative care.  $^{16\,17\,20\,31}$ 

Furthermore, it is suggested the development of a transdisciplinary and holistic approach able to respond to patients' and providers' care necessity.<sup>30</sup>

At the same time, further research studies in this field are recommended in order to analyse specific patterns of protective factors.  $^{31\,33}$ 

#### DISCUSSION

The findings of this systematic review reported an informative overview of the studies addressing healthcare professionals' moral distress in adult palliative care, with the aim to provide a stimulus for future research and suggestions to clinical practice too. In this regard, the first four authors identified four main areas that may synthetise the features involved in this phenomenon: personal factors, patients and caregivers, colleagues and superiors, environment and organisation.

As to personal aspects, moral distress appeared to be related to death and negative emotions, as well as to coping with decision-making and doubts regarding the care of the patient. Indeed, experiencing and seeing

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sufferance and disability on a daily basis may challenge the person and lead him or her to a distressed experience.<sup>4</sup> Empathy is a resourceful character trait which enables good quality of care, but the prolonged and continuous exposure to negative emotions may erode the inner moral life of an individual, leading to a path of burnout, compassion fatigue and moral distress.<sup>2</sup> Moreover, distress levels may be raised in palliative care settings due to coping with moral and ethical issues. The responsibility of care-taking and decision-making regarding the final days of a patient's life and the balancing between external constraints is a relevant burden to manage. The consequent sense of dissatisfaction and powerlessness frequently experienced as a result may become a sort of 'moral outrage' offending self-values and feeling prevented from doing what it is morally required.<sup>35</sup> Therefore, facing up to actions and constraints divergent from their own values and beliefs may challenge the person and bring distress, as already reported in neonatal and paediatric palliative care.<sup>26</sup>

Sometimes, the treatment provided and/or witnessed is believed to be not even dangerous but indeed useless.<sup>12</sup> <sup>16</sup> <sup>17</sup> <sup>30</sup> <sup>32</sup> The same experience is reported in adult palliative care, and in neonatal and paediatric palliative care.<sup>26 27</sup> Indeed, the boundaries between palliative care and futile care are often thin and elusive. Futile care is offered as treatment with very low odds of success and a high possibility to be detrimental.36 On the contrary, palliative care aims to improve quality of life when no other curative treatments are possible and, as a consequence, palliative interventions are introduced as a means through which reducing futile cares, as well as to cut needless healthcare costs.<sup>37</sup> Thus, the believed 'appropriateness' or 'potentially inappropriateness' of a treatment determines whether we are in the landscape of palliative or futile care. This evaluation inevitably comes with moral and ethical dilemmas due to the lack of clear definition and the consequent reliability on clinical experience and personal values.<sup>31</sup>

Dealing with palliative care patients and suffering caregivers is challenging too. Besides the witnessing of such suffering and the complex management of their negative emotions, this review highlighted also the diagnosis communication as highly demanding and distressing, as already reported in neonatal and paediatric palliative care.<sup>26</sup> <sup>27</sup> Difficulties in prognosis communication are often present in all fields of medicine, in particular when the clinician is asked to report a life-threatening condition or critical findings in the best possible way to the patient and her/ his family.<sup>39–41</sup> These complexities are particularly relevant in palliative care medicine where effective skills in communication are crucial to adequately manage the situation and to maintain hope.<sup>42</sup> Moral distress is an issue that emerges also from the interpersonal relationships with colleagues and superiors.

# Review

As mentioned above, a shared decision on the palliative treatment is a complex procedure considering what is futile or aggressive instead of beneficial for the patient is, in some clinical cases, a concept which relies on personal evaluations and values.<sup>38</sup> In addition, the difference in professional hierarchy may be demanding and complex. Indeed, the present review reported that nurses complained to be sometimes forced to complete physicians' requests for fear of admonishment.<sup>12,17,30,32</sup> Difficulties and different perceptions in communication and collaborations between nurses and physicians are already well documented in literature<sup>9,43</sup> and the role asymmetry is reported as a focal point particularly distressing for nurses.<sup>44</sup>

Moral distress may be also linked to intrapersonal and interpersonal features, and to environmental and organisational issues characterising the healthcare workplace.9 Indeed, poor ethical climate, inadequate support from colleagues, as well as lack of appropriate resources and intensive workload may be factors facilitating the development of moral distress.9 Moreover, research studies included in this review underlined the lack of effective educational programmes focused on palliative care implications and characteris-tics.<sup>16</sup> <sup>18</sup> Although only two studies addressed preventive suggestions in an explicit way, focusing on subjective protective factors<sup>20</sup> and on beneficial behaviour for containing moral distress,<sup>12</sup> all research studies in this review provided suggestions and recommendations to cope with moral distress experienced in caring for palliative care patients. In this regard, different kinds of preventive and supportive interventions were proposed. In particular, the importance of interventions to improve communication skills with patients and colleagues was underlined.<sup>12 17-19 30-32</sup> A workplace characterised by open communication may be a relevant added value to both the individual and the society. Indeed, it is known that poor communication between healthcare professionals may result in relevant negative outcomes, compromising quality of care, patient satisfaction and entailing a bleeding of resources and growing caring costs.45

Equally important are educational and training programmes to provide specific skills and strategies to cope with difficulties characterising palliative care,<sup>16 17 32 33</sup> as well as actions supporting the adoption of meaning-making strategies.<sup>20</sup> Similarly, neonatal and paediatric palliative care have already stated the positive impact of educational interventions to decrease moral distress, allowing providers to become more comfortable with the management of their work and its emotional and ethical implications.<sup>26</sup> These kinds of interventions provide skills and know-how useful in clinical practice. Indeed, knowing what to do and how to manage in sensitive clinical situations is a significant protective factor, considering as low empowerment and autonomy are reported to be tightly related to moral distress.

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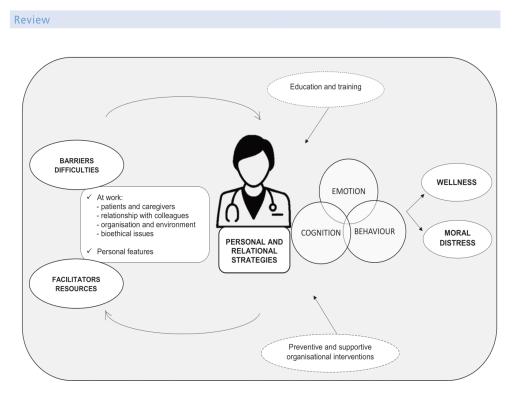


Figure 3 Moral distress in adult palliative care—theoretical holistic model.

Moreover, it is important to support the providers with a time and space for experience sharing and, bereavement, in order to sustain the maintenance of psychological and physical health.<sup>16 17 20 31</sup> Indeed, the well-being of the patient and the quality of care is also an often forgotten result of the provider's well-being.<sup>1</sup>

# A holistic model to deal with moral distress in palliative care

In the light of the findings emerged from this review, it is clear that moral distress experienced in providing adult palliative care may be considered a multidimensional phenomenon. Different kinds of factors contribute to create a breeding ground for the development of distress when facing constraints, in the expression of, and contradictions as regards personal moral values. However, it is possible to identify some protective factors too. That is, there is a sort of balance between barriers and resources which are the two sides of the same coin.

Starting from these findings, the authors propose a theoretical frame that may explain moral distress in adult palliative care (figure 3).

In this theoretical holistic model, personal, relational and environmental factors are presented as both constraints and resources. For example, it is possible to encounter demanding difficulties concerning personal characteristics, as well as organisational features (environmental issue, quality of the relationship with colleagues and with the patient and the caregivers). On the other hand, patients and caregivers, personal features and organisational characteristics may become facilitators for managing complicated clinical situations. Indeed, disability is no more intended as a matter only linked to the individual's functionality level and health status, but as a consequence of the encounter between the person and her/his physical and social environment, according to the WHO International Classification of Functioning, Disability and Health.<sup>46</sup> That is, personal, relational and environmental factors may become relevant resources, with a positive impact on perceived quality of life.<sup>47</sup>

All these aspects are not compartmentalised but rather tightly interconnected. Indeed, healthcare providers put into action their own personal and relational strategies to manage situations that need an ethical decision, as usually happens with caring for end-of-life patients in need of a treatment preserving as much as possible a satisfying quality of life. Thus, the outcome of every working day life may be both wellbeing and moral distress, depending on the appropriateness and richness of strategies implemented, as well as the integration reached.

In this complex process it is possible to find room for manoeuvre. Preventive and supportive organisational interventions, mediation, training and education may improve strategies and skills, empowering

the healthcare providers and allowing them to contain or resolve ethical dilemmas and possible divergences between acts and values associated to moral distress. Moreover, a relevant protective factor may be the betterment of healthcare professionals' knowledge of parameters, guidelines and new legislation. Indeed, the normative framework may be a compass to provide further indications to move correctly in the palliative care background.

#### Limitations, strengths and implications

Worldwide differences between healthcare systems and cultures on palliative care may make it difficult to compare the research studies. Thus, findings of this review may be biased by the lack of some nuances of meanings associated to different cultures; for example, African countries are not present in this review. The choice of the search terms may potentially have added another bias too.

However, to the best of the authors' knowledge this is the first systematic review addressing moral distress experienced by healthcare professionals providing adult palliative care. Factors contributing to the moral distress in this particular category of workers are displayed and a holistic model to explain the phenomenon addressing personal, interpersonal and environmental levels is suggested. Moreover, suggestions extracted by the reviewed papers are summarised in order to provide a set of recommendations to counterattack the phenomenon of moral distress in adult palliative care.

To this summary of recommendations, four further proposals from the point of view of a healthcare educationalist and clinical ethicist are: (1) to place further emphasis on clinical communication in nursing and medical schools and in addition to merge such sessions in an interdisciplinary fashion; (2) to reignite and reinforce the discussion on introducing the topics of death and dying into schools, with a view to establishing it as a core subject into high school curricula; (3) to introduce continual professional development sessions on clinical communication and mediation for healthcare professionals working in a palliative care setting; (4) to promote, establish and encourage the use of clinical ethics committees to assist with the moral distress and with clinical ethical dilemmas in the area of palliative care for patients, relatives and healthcare professionals; and (5) to improve the healthcare professional's knowledge of normative framework that, in many countries, legitimates the palliative care action and clearly defines the roles of the subjects involved in the taking care process.

#### CONCLUSION

Moral distress is a grey zone, a phenomenon which still remains elusive, one which is not yet completely or commonly defined. However, this issue is becoming ever more relevant and medical and technological advancements are fuelling ethical dilemmas in terms of complexity and number. Indeed, these changes introduce more challenges and pressure to healthcare professionals and in particular to palliative care providers.48 In end-of-life management, it is not easy to fulfil professional duties, manoeuvring the self between external constraints, ethical concerns and stakeholders' requests. Thus, moral distress may be a warning signal, as an 'ethical canary' in a coalmine to prevent harmful consequences.<sup>49 50</sup> Cognisance of factors negatively and positively associated with this phenomenon may help better reframe healthcare processes and take effective and tailored actions when required and in understanding and paying attention to who is involved in providing care. This is even more relevant in the field of palliative care, considering the worldwide ageing population and the increasing of non-communicable diseases.48 Indeed, these trends will require a growing number of qualified and health professionals with the ability to adequately address clinical situations when no further curative treatments can be provided. To conclude, moral distress can become obstructive and dangerous because it may impoverish healthcare providers' physical, psychological and relational well-being,<sup>10</sup> impacting indirectly on society and on the general well-being of the population.

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# 2.2.2. Additional information: moral distress in neurorehabilitation medicine specialty

The literature on moral distress in the neurorehabilitation discipline is still scarce in respect to other research field and mainly focused on the rehabilitation setting in general, despite the specific type of rehabilitation offered. However, these professionals have to manage very challenging situations such as providing care to patients with severe injuries derived by accidents or carrying on complex rehabilitation processes (Sliwa et al, 2019). Growing attention is put on the ethical issues occurring in the daily clinical practice (Kirschner, Stocking, Wagner, Foye, & Siegler, 2001; Mukherjee, Brashler, Savage, & Kirschner, 2009; Carpenter, 2010; Mazlina & Engkasan, 2011). In particular, an American survey investigated possible ethics issues affecting rehabilitation professionals along their daily clinical practice. The respondents of this study reported 543 ethics issues that can be categorized in the following areas: health care reimbursement policies, culture constraints, divergences on both goal-setting and discharge planning among colleagues and patient/caregivers, the patient confidentiality management, withdrawal of life-sustaining treatments and the assessment of patient's decision-making capacity (Kirschner et al., 2001). The survey was repeated some years later and it confirmed the same results. Also this time, three main sources of moral distress were unveiled: institutional ethics (e.g. health care reimbursement pressures and corporate culture), professional practice (e.g. codes of behavior, patient confidentiality/privacy), and clinical decision-making (e.g. conflicts regarding goal-setting and discharge planning, assessment of decision-making capacity) (Mukherjee et al. 2009). Similarly, another survey conducted in Asia, unveiled different ethical issues which may pave the way to the onset of moral distress among rehabilitation professionals. In particular, the respondents pointed out the disclosure of patient's confidential information to colleagues, the allocation of scare resources, the difficulties regarding the decision-making process and the optimal discharge planning as relevant matter of concern (Mazlina & Engkasan, 2011).

Furthermore, Carpenter (2010) wrote an interesting discussion paper on the theoretical concept of moral distress in the context of physical and rehabilitation therapy practice. He underlined the necessity to reflect on the moral and ethical dimension characterizing the modern clinical practice of professionals employed in the rehabilitation context. He described how these professionals have to deal with complex patients who suddenly get worse or are unable to recover. In these cases, they are asked to take ethical decisions very quickly regarding treatments or to suggest which other medical consultation are needed. They also need to find the right words to engage the patient or to disclosure a bad prognosis (Carpenter, 2010).

Overall, all these ethical issues unveiled by the literature may trigger the unpleasant condition of moral distress in the healthcare professionals employed in the rehabilitation setting. Like for the

other professionals, this morally distressing condition may threaten the sense of professional efficacy and the personal integrity of the individual, impoverishing the quality of care provided, the job satisfaction as well as preparing fertile ground for the onset of burnout, too (Kirschner et al., 2001; Mukherjee et al., 2009; Carpenter, 2010).

# 2.3. Wellbeing

Wellbeing has been the focus of many researches and it is still a growing area of research as it may be considered the final life goal of everyone. Additionally, wellbeing is the core component of the concept of "health" in the definition provided by the World Health Organization, stating that health is not the passive result of the lack of illnesses, rather a state derived by a full psychophysical wellbeing (WHO; 1948). However, this concept remains difficult to define and even harder to assess due to its intangible and multifaced nature (Conceição, & Bandura, 2008; Dodge, Daly, Huyton, & Sanders, 2012). A simple, comprehensive and practical definition is provided by Dodge et all (2012). In an attempt to summarize previous studies on this theme, they described wellbeing as "*the balance point between an individual's resource pool and the challenges faced*" such that the individual self-perceive sufficient fulfillment and capacities to live life (Dodge et al, 2012, p. 230). From this perspective, investigations on variables potentially increasing wellbeing may play a pivotal role, suggesting protective factors and good practices.

Professionals' wellbeing is getting increasing attention in the healthcare landscape, too. It was stated that it is necessary to shift form the triple aim of the healthcare system (enhancing patient experience, improving population health and reducing costs) to a quadruple aim including also the attention to improving the professionals' work-life (Bodenheimer, & Sinsky, 2014; Horn, & Johnston, 2020). Indeed, professionals are threatened by different individual (e.g. personality traits, dysfunctional coping strategies), professional (e.g. workload, emotionally charged-situations) and organizational (e.g. bureaucracy, shortage of resources) factors which may result in negative consequences such as burnout, distress, psychiatric morbidities, substance abuse and relationship conflicts (Wallace, Lemaire, & Ghali, 2009, Schrijver, 2016; West et al, 2018). Additionally, poor healthcare professional's wellbeing does not affect only the individual, but it also reverberates on the society as the quality of care is depleted (Bodenheimer, & Sinsky, 2014). Systematic reviews showed that in most of the studies, poor wellbeing and burnout were associated to poorer patient safety, potential medical errors and suboptimal delivery of high-quality health care as the professionals is deprived of energies and resources (Wallace et al., 2009; Hall, Johnson, Watt, Tsipa, & O'Connor, 2016). Moreover, the decreasing of professional's wellbeing means increasing costs for the healthcare system in terms of reduced productivity and efficiency, as well as expensive staff recruitment and retention (Wallace et al, 2009). To this regard, Arnetz (1999) provided reliable measures assessing physician wellbeing at a system level which encompasses specific components concerning organizational and staff wellbeing including mental energy, work climate, work-related exhaustion, skill development, organizational efficacy and leadership. According to Arnetz (2005), subjective indicators might lead to both individual wellbeing and organizational performance improvement.

As concerns palliative care professionals, the previous literature highlighted protective factors for preserving the professionals' wellbeing and allows self-care (Pereira et al., 2011; Pereira & Fonseca, 2011; Mills, Wand, & Fraser, 2018; Moreno-Milan et al, 2019; Horn, & Johnston, 2020). In fact, as stated by palliative care professionals taking part in the study conducted by Mills et al. (2018), "Balancing care for yourself and others is essential [...] It's looking after me to look after patients, so to speak; if I'm not of a good healthy physical state or emotional state, I'm hardly likely to be able to support someone" (Mills et al., 2018; p. 4). The wellbeing is a positive health status resulting from different aspects which enable a functional living. For instance, meaning in life and satisfaction and meaning of work are milestones in palliative care as the professionals perceive a sense of fulfillment and achievement which refuel energy and motivation (Pereira et al., 2011; Pereira & Fonseca, 2011; Moreno-Milan et al., 2019; Horn, & Johnston, 2020). That is, the professionals perceive to be able to make the difference, alleviating sufferance and improving the quality of patients' last days of life. This awareness is a trigger and a constant recharger for the professionals. Moreover, a good support provided by the team is described as essential for subjective wellbeing (Pereira et al., 2011; Gustafsson et al., 2016; Mills et al., 2018). In fact, in a supportive environment it is possible to share responsibilities and emotional burden through effective and authentic communication, to foster good self-care practices and to refuel personal resources as optimism and humor (Mills et al., 2018). Some personal resources as resilience, sense of humor, optimism, and subjective vitality are personal facilitators for maintaining wellbeing, too (Hulber & Morrison, 2006; Back et al., 2016; Pereira et al., 2011; Moreno-Milan et al, 2019). In fact, the individual uses these personal resources as buffer against adverse events and going on. Moreover, it is essential taking time for themselves and having rest and relaxation to relieve stress and find new resources and energies (Pereira et al., 2011; Mills et al., 2018). Similarly, spending time with families and friends was described to be of great benefit as allows the professionals to be supported and to avoid the feeling of loneliness (Pereira et al., 2011; Mills et al., 2018). Finally, in line with aforementioned findings, Swetz and colleagues (2009) conducted a qualitative study to identify promotion strategies for wellbeing adopted by U.S. physicians employed in hospice and palliative medicine. Responding physicians reported manifold strategies, including physical wellbeing (60%), professional relationships (57%),

taking a transcendental perspective (43%), talking with others (43%), hobbies (40%), clinical variety (37%), personal relationships (37%), personal boundaries (37%), "time away" from work (27%), passion for one's work (20%), realistic expectations and use of humor and laughter (13%), and remembering patients (10%).

As concerns neurorehabilitation medicine specialty, it has to be underlined that studies regarding protective factors for wellbeing among this workforce still lacks. Thereby, suggestions for their support and wellbeing are derived from the literature addressing burnout in these professionals (Bruschini et al., 2018; Bateman & Viana, 2019; Sliwa et al., 2019) or in the general healthcare workforce, despite the specific discipline (Rothenberger, 2017; Shanafelt et al., 2017; Shanafelt et al., 2019). What can be inferred by subjective experiences in the rehabilitation landscape is that the satisfaction for own work and the sense of achievement contribute to a feeling of wellbeing (Crisci & Arnone, 2017). Moreover, the capacity to engage the patient and to cooperate with her/him to reach the rehabilitative aims is an additional element fostering a sense of achievement for own profession and, in turn, promoting wellbeing (Aadal, Kirkevold, & Borg, 2014). The cooperation among the team members seems to be another protective factor promoting wellbeing as the professionals may share the burden derived by the taking care of challenging patients (Miller & Kontos, 2013; Gustafsson et al., 2016). Concerning organizational factors, a study conducted with professionals employed in Belgian neurorehabilitation centers suggested that less hours per week spent in touch with vegetative and minimally conscious patients is associated with higher selfperceived personal accomplishment and, in turn, with wellbeing (Gosseries et al., 2012).

Overall, the aforementioned factors may be considered effective weapons usable by palliative care or neurorehabilitation medicine professionals to cope with difficulties and emotionally challenging situations, safeguarding and promoting the individual wellbeing.

# 2.4. Meaning in life

Meaning in life (MiL) is a construct who is drawing increasing attention. In particular, researchers adopting the positive psychology approach consider this construct a pivotal element for wellbeing in private life as well as at work (Pratt & Ashforth, 2003; Dik, Duffy, & Eldridge, 2009; Heintzelman & King, 2014; Allan, Duffy, & Douglass, 2015). Indeed, it was written that "*personal meaning is important not only for survival but also for health and well-being*" (Wong & Fry, 1998, p. xvii). The inspirational founder of the research on MIL is Viktor Frankl who argued that people can live in a functional way when they are able to perceive a sense of meaning and when they possess a life purpose or mission fostering them to go on their existences (Frankl, 1963). Moreover, he described three core values for MIL: creativity (e.g., work, dedication to causes), experience (e.g., art, nature,

relationships) and attitude (one's standpoint toward suffering and existential problems) (Frankl, 1976).

However, to provide a unique and shared definition of MIL is not an easy task as different descriptions of this construct have been provided according to the field of research, the researcher's approach and the instruments used to analyze it (Steger, 2012; Czekierda, Banik, Park, & Luszczynska, 2017). For instance, Park and Folkman (1997) proposed a model in which MIL may indicate two dimensions: a) the beliefs about the world, self, and the relationships between self and the world (sense of significance regarding existence), b) one's life goals and purposes. Other researchers have differently deepened and strengthen these two interpretations. So, on one hand, Ryff and Singer (1998) interpreted MIL as goal directedness in life. On the other hand, Steger, Frazier, Oishi and Kaler (2006) defined it as 'the sense made of, and significance felt regarding, the nature of one's being and existence' (p. 81). Again, Martela and Steger (2015) provided a deepen conceptualization of MIL, unveiling the three following dimensions: coherence (sense of comprehensibility and one's life making sense), purpose (core goals and direction in life), significance (sense of worth-living life and life values). Overall, MIL may be considered a process encompassing cognitive, motivational and emotional facets allowing individuals to give sense and coherence to life events (Reker, 2000). That is, MIL is the lens through which individuals find a sense to what happens in the environment around them, thus finding a purpose in life and reaching a sense of fulfillment and significance to own existence. This sense of coherence and meaning triggers positive mechanisms and processes which promote wellbeing through life. To this regard, it has to be mentioned that researches on MIL associated this construct with life and career satisfaction (Steger et al., 2009; Steger et al., 2011), resistance to stress (Park & Baumeister, 2017), quality of life and psychological wellbeing (Melton & Schulenberg, 2008; Heintzelman & King, 2014), as well as with health (McKnight & Kashdan, 2009; Heintzelman & King, 2014; Czekierda et al., 2017) and lower psychopathological manifestations such as depression and anxiety (Mascaro & Rosen, 2006).

Considering the palliative care specialty, MIL was investigated in particular from the patient's perspective, probably because of the activation of a meaning-based coping processes useful to face the poor clinical conditions (Park & Folkman, 1997; Folkman & Greer, 2000). However, a study tried to measure MIL in palliative care professionals in order to detect possible differences with colleagues employed in maternity wards, a medical discipline usually not requested to deal with death (Fegg, L'hoste, Brandstätter, & Borasio, 2014). In this study, palliative care professionals listed spirituality and nature experience as MIL areas more often than colleagues working at maternity units. Moreover, they reported higher values of stimulation, as well as self-direction and openness to change. The authors read these results in line with Frankl's theory such recognizing

the importance of creativity, experience and attitude to reach MIL. These values and attitudes may be considered facets pushing towards the decision to work in the specific field of palliative care, maintaining and fueling MIL. The capacity to give a meaning to difficult events and to accept them provides a sense of control, bolstering self-worth and wellbeing (Park, 2010; Fegg et al., 2014). Regarding this, in another studies, MIL was described as an antecedent of positive emotions like vigor (Desbiens & Fillion, 2007).

To the best of my knowledge, no studies focusing on MIL in rehabilitation and neurorehabilitation medicine discipline has been conducted to now. Thus, one aim of this project is to start bridging this gap, providing findings on MIL as perceived by healthcare professionals employed in neurorehabilitation specialties compared to palliative care colleagues. A complete discussion of this study is provided in chapter five of this dissertation.

# 2.5. Ethical climate

The construct of ethical climate is attracting growing attention in the present and future healthcare landscape as manifold ethical concerns are emerging day after day. Ethical climate may be considered a subtype of organizational climate, namely the pool of meanings and perceptions on procedures, policies and practices shared by workers regarding their workplace, as well as the behaviors rewarded, supported, and expected at work (Schneider & Barbera, 2014). The employees' perceptions provide a compass to act in a successful way within the organization and to be adequately rewarded. In other words, the organizational climate is to be intended as the "personality" of an organization, suggesting people the expected behavior (Olson, 1998).

A specific nuance of organizational climate is the ethical climate. It has been mainly studied in relation to nurses as they are potentially more exposed to daily ethical dilemmas and constraints because of the setting-bound nature of nursing practice (Olson, 1989; Hamric & Blackhall, 2007; Koskenvuori, Numminen, & Suhonen, 2019). Two pioneers of research in this field described this construct as the "*shared perceptions of what is ethically correct behaviour and how ethical issues should be handled*" (Victor, & Cullen, 1987, p. 51). Again, they defined further this construct as the "*prevailing perceptions of typical organizational practices and procedures that have ethical content*" (Victor & Cullen, 1988, p. 101). These definitions describe how the organization may play a role in shaping the ethical behavior of employees and how ethical issues are managed. Differently said, ethical climate is the sum of workers' perceptions regarding what is expected to be an ethically behavior to pursue. Along the times, researchers forwarded alternative definitions, trying to better describe this construct (Newman, Round, Bhattacharya, & Roy, 2017). For instance, Olson provided a more comprehensive and general description, defining ethical climate as "*the context in which ethical behavior*.

and decision-making occurs" (Olson, 1998, p. 346). Another author tried to broaden the definition, suggesting that ethical climate has to be intended as "a molar concept reflecting the content and strength of the prevalent ethical values, norms, attitudes, feelings, and behaviors of the members of a social-system" (Arnaud, 2010, p. 125).

The complexity of reaching a comprehensive definition is derived by the fact that ethical climate is a multifaced concept. For instance, the healthcare professionals' approach to patient care may be described as a nuance of ethical climate. To this regard, it has been reported that the provision of respectful care may increase nurses' professional efficacy and job satisfaction (Peery, 2010; McClendon, 2017). However, there is still scant in-dept knowledge on this theme and other researches are needed to investigate this dimension of ethical climate. Moreover, social support may be considered a positive facet of ethical climate, too (Velando-Soriano et al., 2020). Indeed, the support provided by colleagues and superiors in dealing with ethical issues contribute to define the quality of ethical climate. Regarding this, growing evidences suggest the protective role of managerial support in preventing healthcare professionals' burnout (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020). However, only few studies concentrated on the role of managerial support in supporting healthcare professionals in dealing with ethical dilemmas (Storch et al, 2009; Poikkeus, Suhonen, Katajisto, & Leino-Kilpi, 2018).

Despite the manifold definitions and interpretations provided, the literature has underlined that a positive ethical climate may be associated to a higher level of wellbeing experienced at work by healthcare professionals (Storch et al, 2009). In fact, ethical climate affects different variables which contribute to a pleasant work experience (Koskenvuori et al., 2019). Specifically, a recent systematic review stated that a positive ethical climate is related to a better experience of professional efficacy in the nursing workforce (Koskenvuori et al., 2019). Overall, according to a recent review, a positive ethical climate was described to be related with different important outcomes, such as positive work attitudes (e.g. organizational commitment, job satisfaction, commitment to quality), ethical behaviours (e.g. moral awareness, personal justice norms, ethical intentions), psychological wellbeing (e.g. health, mindfulness), performance outcomes (e.g. job performance, customer satisfaction, team work) (Newman et al., 2017). Moreover, the authors identified also organizational and individual factors as antecedents of ethical climates (Newman et al., 2017). Among the first ones, there are the organizational type and culture, the organizational and managerial practices as well as the leadership style. Among individual characteristics, job tenure, education hierarchical and the fit between personal and organizational values may make the difference.

Ethical climate is particularly important for healthcare professionals working in units at high risk of moral distress and burnout, such as palliative care and neurorehabilitation medicine specialties.

For this reason, the current project focused on these specialties because their job characteristics may potentially threaten healthcare professionals' wellbeing and their work experience. What is known from researche focusing on palliative care is that ethical climate was described as negatively associated with moral distress in nursing providing care to dying patients such that higher perception of moral distress was related to more negative ethical climate (Hamric & Blackhall, 2007). More in detail, the perception of ethical climate was also different among organizations and linked to the hospital attitude and policies towards life-sustaining therapies such suggesting a relation among organizational culture, moral distress and ethical climate perception (Hamric & Blackhall, 2007). Moreover, compared to physicians, for nurses the caring for dying patients is linked to poorer ethical climate, probably due to the setting-bounding nature of the nursing activity (Hamric & Blackhall, 2007). Furthermore, it was stated that a supportive ethical climate characterized by a strong team spirit is an essential element in a palliative care setting as the healthcare workforce have to become a sort of family to face with the critical aspects encountered during their clinical practice (Meier & Beresford, 2008; Fernando & Hughes, 2019). Indeed, "the successful functioning of the palliative care team is often described in terms of collaborative practice, characterized by self-awareness, cohesiveness, shared decision-making, trust, respect, accountability, mutual support, self-care, positive work environment, recognition for a job well done, and attention to retention and job satisfaction" (Meier & Beresford, 2008, p. 677).

Regarding neurorehabilitation discipline, the literature on the ethical climate is still scant and further researches are urgently needed as these workers are increasingly exposed to ethical issues resulting from the taking care of complex patients. To now, the climate characterized by poor supportive relationships was associated with burnout and malaise in an Italian neurorehabilitation setting (Bruschini et al., 2018). Moreover, studies on moral distress in rehabilitation and neurorehabilitation settings suggested that moral distress finds fertile ground in contexts characterized by negative climate which lacks support and ethical approaches (Kirschner et al., 2001; Mukherjee et al., 2009; Carpenter, 2010).

# 2.6. Affectivity

Among the personal characteristics attracting the attention of psychologists, there is "affectivity" which may "color" in bright or dark nuances the individual's life experiences.

In general terms, an affect represents the phenomenological experience of "feeling," that is the human affective experience, which usually is described through terms related to positive or negative emotions (Watson, 2000). Affectivity is constituted by two separate unipolar dimensions according to the Watson and colleagues' approach, which may be considered the predominant framework

both in the organizational researches (Burke, Brief, & George, 1993; Spector, Fox, & Van Katwyk, 1999) and in psychology in general (Schimmack & Grob, 2000). Generally, these two dimensions may be described as follows: "Positive Affect (PA) reflects the extent to which a person feels enthusiastic, active, and alert. High PA is a state of high energy, full concentration, and pleasurable engagement, whereas low PA is characterized by sadness and lethargy. In contrast, Negative Affect (NA) is a general dimension of subjective distress and unpleasurable engagement that subsumes a variety of aversive mood states, including anger, contempt, disgust, guilt, fear, and nervousness, with low NA being a state of calmness and serenity" (Watson, Clark, & Telleoen, 1988; p. 1063). The literature shown that PA and NA are two factors independent of one another (Burke, et al. 1993; Kaplan, Bradley, Luchman, & Haynes, 2009) as these two dimensions work through different biological and behavioral mechanisms (Watson, 2000) and differently correlate with other constructs (Watson & Pennebaker, 1989).

Furthermore, it is noteworthy to remind that affectivity may be considered as a transient factor (state affect), encompassing moods and emotions, or as a stable factor (trait affect) which is a personality feature as it refers to the individual tendency to experience life events through a certain pattern of positive or negative emotions (Watson & Clark, 1984).

A very influential paper stated that for a long time "*research has generally neglected the impact of everyday emotions on organizational life*" (Ashford & Humphrey, 1995; p. 97). However, in recent times, the researchers from all over the world are paying an increasing attention on affectivity in order to promote positive emotions and minimize negative ones. Indeed, it has been demonstrated that satisfied and happier workers increase their productivity (Kaplan et al., 2009), such that the relation between satisfaction and performance was described to be the "Holy Grail" of industrialorganizational psychology (Landy, 1989). In particular, PA seems to be related to important personal and professional outcomes (King, Hicks, Krull, & Del Gaiso, 2006; Hu & Kaplan, 2015). For instance, PA promotes a state of wellbeing and health (Fredrickson, 2003), cognitive flexibility and purpose in life (King et al., 2006). Also, PA fosters better task performance, more prosocial behavior (Dalal, 2005) more favorable job attitudes and reactions (Thoresen, Kaplan, Barsky, Warren, & de Chermont, 2003; Xanthopoulou, Bakker, Demerouti, & Schaufeli, 2012).

In palliative care setting, affectivity was more studied taking the perspective of patients, aiming to describe emotions linked to their disease illnesses and to promote interventions to cope with stress (Montross-Thomas et al., 2015; Warmenhoven et al., 2016). Thus, studies on affectivity experienced by palliative care healthcare professionals are still scant. Desbiens & Fillion (2007) unveiled that, among a sample of Canadian nurses, PA like vigor was associated with living with others and was predicted by the capacity to give meaning to death and, in turn, it contributed to successfully cope with stress characterizing their profession. Furthermore, PA reported by

palliative care professionals enhanced after a specific relaxation and resiliency program lasted two months, despite the fact that this improvement was not found to be statistically significant probably due to the little size of the sample (Mehta et al., 2016).

As concerns neurorehabilitation medicine specialty, to the best of my knowledge, no studies investigated the affectivity dimension and mechanisms in this healthcare workforce. Thus, the current project tries to contribute in bridging this gap.

# 2.7. Resilience

Today resilience is a flourishing field of research. The growing interest for this construct is in line with the revolution of positive psychology which pushed researchers to "*move from a deficit, 'glass half empty' view of human nature to a positive, salutogenic, 'glass half full' approach*" (Pooley & Cohen, 2010).

To provide a shared definition of resilience is not an easy task as a lot of researchers has provided different views across the time. For instance, resilience was first described as a stable trait of an individual (Hu, Zhang, & Wang, 2015) and, in more recent times, as a multidimensional capacity which can be learned and improved to protect the individual from burnout and distress (Fletcher & Sarkar, 2013). Again, recently resilience is described as a coping characteristic of groups and environments (Alliger, Cerasoli, Tannenbaum, & Vessey, 2015).

In general terms, resilience may be considered the individual dynamic ability to adapt positively to life events, overcoming setbacks and recovering from adversity, crisis and trauma (Sisto, Vicinanza, Campanozzi, Ricci, Tartaglini, & Tambone, 2019). Thus, it is considered a fundamental resource and dynamic process to adapt to events, as well as to react and cope with difficulties occurring during the life-span. It is the capacity to persist, to bounce back and to thrive after adverse events and stressors (Bonanno, 2004). Overall, borrowed by the natural sciences in which it denotes the capability of a strained body to recover its size and shape after deformation caused by a compressive stress, in psychology the term resilience describes the human ability to overcome adversities without being overwhelmed and damaged.

Masten and Wright (2010) stated that research on resilience passed through four waves: firstly research focused on the definitions and descriptions of resilience; secondly the attention was put on the variables associated with resilience, thirdly researchers sought to test resilience interventions; and finally in the modern area, research aims to advance resilience studies with an integrative approach in order to "*better understand the complex processes that lead to resilience*" (p. 214).

Resilience was largely investigated in the healthcare sector (Hart, Brannan, & De Chesnay, 2014; Robertson et al., 2016) as it is a fundamental resource to counterattack burnout and foster wellbeing and professional efficacy (Ablett & Jones, 2007; Rothenberger, 2017; Ng, Chahine, Lanting, & Howard, 2019).

As concerning the palliative care discipline, a systematic review was conducted to summarize knowledge within this healthcare workforce. The paper of this research is presented in the following paragraph.

# 2.7.1. A systematic review on resilience in palliative care professionals

See pages 56-63 of the current dissertation: Zanatta, F., Maffoni, M., & Giardini, A. (2020). Resilience in palliative healthcare professionals: a systematic review. Supportive care in cancer: official journal of the Multinational Association of *Supportive Care in Cancer, 28*(3), 971–978. doi:10.1007/s00520-019-05194-1.<sup>3</sup>

# 2.7.2. Additional information: resilience in neurorehabilitation medicine specialty

As concerns the rehabilitation and neurorehabilitation medicine, resilience was studied mainly regarding the patient (Neils-Strunjas et al., 2017). The general aim of these researches was to analyze resilience as a useful resource to sustain the rehabilitative process. To the best of my knowledge, no specific study was conducted to investigate resilience and its mechanisms in healthcare professionals working in rehabilitative settings. What is known is that professionals who are able to promote and sustain resilience in patients and along the entire rehabilitative process reach better rehabilitative outcomes as resilience is a pivotal resource for helping the patient to face adversities and success in the rehabilitation (Neils-Strunjas et al., 2017). Thus, the present project may be considered a first attempt to provide evidences on resilience processes also within this healthcare workforce.

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**REVIEW ARTICLE** 



# Resilience in palliative healthcare professionals: a systematic review

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#### Abstract

**Purpose** Exposure to end-of-life and chronic illness on a daily basis may put palliative healthcare professionals' well-being at risk. Resilience may represent a protective factor against stressful and demanding challenges. Therefore, the aim is to systematically review the quantitative studies on resilience in healthcare professionals providing palliative care to adult patients. **Methods** A literature search on PubMed, Scopus, Web of Science and PsycINFO databases was performed. The review process

has followed the international PRISMA statement guidelines.

**Results** At the initial search, a total of 381 records were identified. Twelve articles were assessed for eligibility and, finally, 6 studies met all the inclusion criteria. Of these, four researches were observational and two interventional pilot studies. From the systematic synthesis, palliative care providers' resilience revealed to be related to other psychological constructs, including secondary traumatic stress, vicarious posttraumatic growth, death anxiety, burnout, compassion satisfaction, hope and perspective taking.

**Conclusions** The current systematic review reported informative data leading to consider resilience as a process modulator and facilitator among palliative care professionals. A model on palliative healthcare providers' experience and the role of resilience was proposed. Further studies may lead to its validation and implementation in assessment and intervention contributing to foster palliative healthcare professionals' well-being.

Keywords Resilience · Palliative care · Burnout · End-of-life · Chronicity · Healthcare professionals

# Introduction

The concept of resilience has significantly changed over the past two decades [1]. To date, there is no accepted universal definition. Originally, it was conceptualized as a trait, thus as a stable attribute determined by personality [2–5]. More recently, resilience has been considered as a result of multiple factors protecting individuals from the negative effects of stress and adversity [6]. This approach includes internal factors such as (epi)genetics, personal traits or beliefs [7–9] and external and environmental factors like social, material or energy resources [10]. Finally, resilience has been intended as a contextual and dynamic process of adaptation, considering temporal aspects

Anna Giardini anna.giardini@icsmaugeri.it like pre-adversity functioning and trajectories of postadversity adjustment [11, 12].

As a result, over the years, researchers have approached the study of resilience from different perspectives. Aburn et al. [13] conducted an integrative review examining how resilience is defined in empirical research. According to the authors, resilience describes and explains the complexity of the responses-given by a person or a group-to traumatic and challenging circumstances [13]. However, further definitions were provided. On the one hand, several authors considered resilience as a process of overcoming adversity and rising above in front of crisis and trauma [14-17]. On the other hand, resilience was explained too as the ability to adjust or successfully adapt to challenging situations [18-20]. Moreover, some researchers referred to resilience as the result of personal strength originating from previous experiences and social support throughout a demanding and a stressful period [19, 21-24]. In addition, others considered good mental health as a 'proxy' for resilience [16, 25, 26]. Based on this definition, a resilient individual may present a stable trajectory of healthy functioning after adverse or traumatic events. Finally, resilience was described as the ability to 'bounce back' too. In

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other words, resilient individuals or groups may be able to recover from traumatic or difficult events jumping back to a baseline condition of health or well-being [27].

In a broad sense, resilience is therefore intended as the individual and group positive responses to adversity, trauma, tragedy, threats or any significant source of stress [28].

Research on resilience has focused on a variety of study populations and disciplinary areas so far, including healthcare settings [13]. Since health care may represent a stressful and demanding challenge, resilience has been recently recognised as a potential resource for healthcare professionals. Indeed, in a recent review, a strong correlation between resilience, high persistence, high-self-directedness and low avoidance of challenges was identified suggesting that resilience may represent a protective factor in terms of maintaining an adaptable and effective workforce [29]. Moreover, diverse studies considering healthcare professionals identified resilience as a positive attitude towards patient population, as well as a competence to be developed or strengthened [30-33]. Resilience was described as a personal resource, leading to positive adaptation [29] and a protecting factor against burnout [34]. Studies on healthcare professionals working in critical care units were conducted too, showing the mediating role of resilience between burnout conditions and health-related quality of life, buffering the impact of negative outcomes of work-related stress [35, 36].

Resilience may play an important role for palliative healthcare professionals, too. Working in such settings can put healthcare professionals' well-being at risk, since exposure to death and dying, and legal and bioethical issues, as well as caring for patients with serious illness on a daily basis, may represent a challenge and a source of moral distress [37, 38], burnout [39] and impoverishment of professional quality of life [40].

Recently, a qualitative systematic review on palliative care nursing has been conducted [41]. However, as far as our knowledge, an overview of the quantitative studies on resilience in healthcare professionals providing palliative care and dealing with end-of-life among adult patients still lacks. Thus, the aim of the current research is to systematically review the studies concerning this issue.

## Methods

A systematic review of the literature on resilience in healthcare professionals providing palliative care to adult patients was carried out. A prior search on registered and/or work in progress studies on this topic through the International Prospective Register of Systematic Reviews (PROSPERO) was conducted. The register provided no similar results. Thus, the systematic review protocol was recorded (ref. CRD42019126648).

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The current research is part of a broader project called WeDistress HELL Project (WEllness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues) approved by Ethical Committee of ICS Maugeri - Institute of Pavia (June 2018, Protocol No. 2211CE). PRISMA statement guidelines were followed [42].

#### Search strategy and data extraction

The primary search of literature was conducted on four public databases: PubMed, Scopus, Web of Science and PsycINFO. Relevant articles were identified on 1 February 2019 by querying the following string: (resilience) AND ('palliative care'), (resilience) AND ('end of life' OR 'end-of-life'). A reference management and bibliography-creating software (EndNote Web) were included in the review process.

As for the data extraction, the eligibility of each record was independently assessed by the reviewers. Progressive exclusion was conducted starting from the title, then the abstract and finally the full text. Inclusion and exclusion criteria were discussed and accepted after full consensus.

#### **Eligibility criteria**

Researches to February 2019 concerning healthcare providers' resilience related to adult palliative care were included. No date range restriction was considered. Studies focusing on patients and/or family/caregivers and/or healthcare professionals providing only paediatric palliative care were not considered. Limitations to document type were adopted: grey literature, editorials, case studies and theoretical and discussion papers, as well as reviews, were not taken in account. Only English research articles published on peer-reviewed journals were included. As for the methodology, only articles providing quantitative data were considered eligible to the current review.

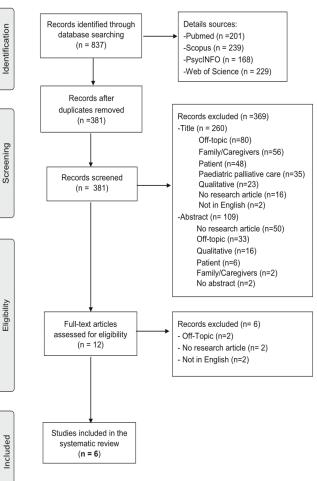
#### Results

The database searches resulted in 837 titles. After removal of duplicates (n = 456), a total of 381 records were identified. Twelve articles were assessed for eligibility (369 studies excluded) and, finally, 6 studies met all the inclusion criteria (Fig. 1).

For each article included in the systematic review, different kinds of information were extracted, including country, study design, participants and measures as well as main results (Table 1). Each country was listed with the corresponding Human Development Index (HDI), which is a summary measure of average achievement in three key dimensions of human development: 'long and healthy life' (life expectance at birth), 'knowledge' (expected years of schooling and mean Section A: Chapter 2 – Focus on the main constructs investigated in this project

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Fig. 1 Flow diagram of records identified, screened and included in the systematic review, according to PRISMA reporting guidelines



years of schooling) and 'a decent standard of living' (Gross National Income per capita) [43]. Three researches were conducted in the USA [44–46] and three in Europe (Spain, Poland and the UK) [47–49]. As for the design, two studies were cross-sectional and correlational [44, 47], two were interventional pilot studies [45, 46], one was a correlational study [49] and one conducted a tool development and validation [48]. Finally, as regards the participants, all studies included nurses. Of these, two included also physicians [45, 46] and three other healthcare professions, such as social workers, counsellors, consultants, mental health workers and occupational therapists [45, 46, 48]. All studies included healthcare professionals providing exclusively adult palliative care, with the exception of one study involving paediatric palliative care providers also [44].

The quantitative data provided in the six studies described the relationship between palliative care professionals' resilience and other constructs such as the following: secondary traumatic stress, vicarious posttraumatic growth, death anxiety, burnout, compassion satisfaction, hope and perspective taking.

#### Resilience, death anxiety and traumatic experiences

Edo-Gual et al. [47] showed that death anxiety was negatively correlated with resilience (r = -0.22, p < 0.1). Moreover, a stepwise multiple linear regression analysis indicated that resilience and attention to feelings and self-esteem were significant predictors of death anxiety ( $R^2$ adj = 0.15, p < 0.01). This suggested that social and emotional competencies associated with positive coping may modulate fear of death.

Moreover, resilience revealed to be negatively correlated with secondary traumatic stress (r = -0.36, p < 0.01) and openness to new experiences and sense of humour resulted

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Author (year)	Country (HDI*, ranking)	Study design	Subjects (N°, mean age $\pm$ SD, age range)	Measures	Main results
Edo-Gual et al. (2015) [47]	Spain (0.891, 26)	Cross-sectional and correlational study	Nursing students ( $N = 760$ , 22–44 ± 5.24)	Collett-Lester Fear of Death Scale (CLFDS) Death anxiety Inventory-Revised (DAI-R) Brief Resilient Coping Scale (BRCS) Trait Meta-Mood Scale (TMMS-24) Rosenberg Self-Esteem Scale (RSES)	Death anxiety showed a negative significant correlation with resilience ( $r = -0.22$ ; p < .01). Through stepwise multiple linear regression analysis, attention to feelings, resilience and self-esteem are significant predictors ( $R^2$ adi = 0.15).
Klein et al. (2017) [46]	USA (0.924, 13)	Exploratory, pre-post, interventional pilot study	Nurses, physicians and counsellors/social workers ( <i>N</i> = 17, > 20)	A copyrighted resiliency development program Professional Quality of Life Scale (ProQOL5)	At 6 months following the completion of the educational program, only 8 participants completed all surveys. Post-intervention data showed an increase of compassion satisfaction (CS; 1.12, $p = 0.67$ ), a decrease of burnout (BO; $-0.63$ , $p = 0.50$ ) and a minimal change in secondary traumatic stress (STS; $-0.13$ , $p = 0.96$ ).
Oginska-Bulik (2018) [49]	Poland (0.865, 33)	Correlational study	Nurses ( <i>N</i> = 72, 46.01 ± 10.69, 22–72)	Secondary Traumatic Stress Scale (STSS) Posttraumatic Growth Inventory (PTGI) Resiliency Assessment Scale (SPP-25)	Results showed a negative relationship between resilience and secondary traumatic stress (STS; $r = -0.36$ , $p < 0.01$ ) and a positive relationship with vicarious posttraumatic growth (VPTG; $r = 0.50$ , $p < 0.001$ ). Regression analysis showed resilience to be a predictive factor of STS and VPTG. STS and VPTG correlated negatively ( $r = -0.27$ , p < 0.05)
Mehta et al. (2016) [45]	USA (0.924, 13)	Interventional pilot study	Physicians, nurses practitioners, nurses and social workers $(N = 16, 44 \pm 8.1)$	Relaxation Response Resiliency Program for Palliative care Clinicians (3RP-PCC) Perceived Stress Scale (PSS) Positive and Negative Affects Schedule (PANAS) Interpersonal Reactivity Index (IRI) Life Orientation Test-Revised (LOT-R) Brief Satisfaction with Life Scale (SWLS) General Self-Efficacy scale (GSE)	Following the 3RP-PCC intervention, participants showed significant reduction in perceived stress ( $z = -2.17$ , $p = 0.03$ ; $d = 0.65$ ) and increase in perspective taking ( $z = -1.66$ , $p = 0.10$ ; $d = 0.67$ ).
Pangallo et al. (2016) [48]	United Kingdom (0.922, 14)	Tool development and validation	Nurses, consultants, social workers, mental health workers, occupational therapists ( $N = 284$ , $45, 53 \pm 9.35$ , 18-54)	Michigan Organizational Assessment Questionnaire (MO AQ) Single-Item Measures of Personality (SIMP) Connor-Davidson Resilience Scale (CD-RISC-10) Ego-Resiliency-89 scale (ER-89) Psychological Capital (PsyCap) Brief Resilience Scale (BRS) World Health Organization Well-Being Index (WHO-5)	Situation Judgement Test (SJT) provided acceptable test-retest scores $(0.71, p = <0.001)$ and high internal consistency ( $\alpha = 0.91$ ). It was positively correlated with resilience self-report measures: PsyCap ( $r = 0.51$ , $p < 0.001$ ); CD-10 ( $r = 0.35$ , $p < 0.001$ ); BRS ( $r = 0.34$ , $p < 0.001$ ) and ER-89 ( $r = 0.37$ , $p < 0.001$ ).
Rushton et al. (2015) [44]	USA (0.924, 13)	Cross-sectional survey	Nurses ( <i>N</i> = 114, 32, 22–67)	Maslach Burnout Inventory (MBI) Moral Distress Scale (MDS) Perceived Stress Scale (PSS) Connor-Davidson Resilience Scale (CD-RISC) Meaning Scale State Hope Scale	Resilience revealed to be a protective factor against emotional exhaustion $(r = -0.31, p < 0.01)$ contributing to personal accomplishment $(r = 0.59, p < 0.01)$ . Higher scores of resilience were associated with high level of hope $(r = 0.51, p < 0.01)$ and low level of stress $(r = -0.44, p < 0.01)$

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as the main predictive resilience factor of secondary traumatic stress symptoms, including intrusion ( $\beta = -0.47$ ,  $R^2 = 0.09$ ), avoidance ( $\beta = -0.35$ ,  $R^2 = 0.25$ ) and arousal ( $\beta = -0.41$ ,  $R^2 = 0.22$ ) [49]. In addition, after completion of a resiliency development program, secondary traumatic stress scores minimally changed (-0.13, p = 0.96) [46].

Nevertheless, experiencing secondary traumatic stress may lead to positive changes, to the so-called vicarious posttraumatic growth. Indeed, Oginska-Bulik et al. [49] showed that resilience was positively correlated with vicarious posttraumatic growth (r = 0.50, p < 0.001) and regression analysis showed two resilience factors (i.e. openness to new experiences and sense of humour,  $\beta = -0.46$ , p < 0.01; personal competencies and tolerance of negative emotions,  $\beta = 0.34$ , p < 0.05) to be significant predictors of vicarious posttraumatic growth.

#### **Resilience, stress and burnout**

According to Rushton et al. [44], resilience may help individuals to reduce burnout: resilience is revealed to be a protective factor against emotional exhaustion (r = -0.31, p < 0.01) contributing to personal accomplishment (r = 0.59, p < 0.01). Moreover, higher scores of resilience were associated to low levels of perceived stress (r = -0.44, p < 0.01) and with high levels of hope (r = 0.51, p < 0.01).

#### **Resilience in assessment and interventions**

Pangallo et al. [48] developed and validated within palliative care context the Situational Judgement Test (SJT). The tool aimed to measure behaviours associated with resilience among palliative care providers. Results provided acceptable test-retest scores (0.71, p < 0.001) and high internal consistency ( $\alpha = 0.91$ ). Situational judgement was positively correlated with self-report measures of resilience.

Two interventional studies were included in the systematic synthesis [45, 46]. Klein et al. [46] proposed a copyrighted resiliency development program. At 6 months following the completion, post-intervention data were collected. Resilience influenced the change in the survey scores, increasing compassion satisfaction (1.12, p =0.67) and decreasing burnout (-0.63, p = 0.50). Some limits of the studies, as described by the researchers too, are the small sample size, being pilots and the absence of a control group. Mehta et al. [45] implemented the Relaxation Response Resiliency Program for Palliative care Clinicians (3RP-PCC). Following the intervention, participants showed significant reduction in perceived stress (z = -2.17, p = 0.03; d = 0.65) and increase in perspective taking (z = -1.66, p = 0.10; d =0.67).

#### Discussion

The studies included in the systematic synthesis reported informative quantitative data concerning palliative care professionals' resilience. Three researches showed resilience to be significantly correlated to different constructs, including death anxiety, secondary traumatic stress, vicarious posttraumatic growth, burnout, stress, attention to feelings, self-esteem and hope [44, 45, 49]; two studies proposed specific interventions on resilience reporting informative changes in burnout, secondary traumatic stress, stress, compassion satisfaction and perspective taking [45, 46]; and one study conducted the development and validation of a test measuring resilience in palliative care workers [48].

Palliative care professionals are exposed to death and dying on a daily basis. Their attitude toward death may influence their well-being as well as the quality of care they offer to terminally ill patients and their families [50]. Edo-Gual et al. [47] showed that higher scores on resilience indicated lower levels of death anxiety. As a result, fostering resilience among palliative care professionals may help them to manage experiences of loss and grieve exposure. Moreover, the contact with such touching experiences potentially represents an opportunity to grow as individuals.

Exposure to death and being constantly in contact with people who directly experienced trauma or suffering may lead healthcare professionals to develop secondary traumatic stress [51]. However, some positive changes resulting from secondary traumatic stress may occur in the individual's psychological functioning, including self-perception, interpersonal relationship and philosophy of life [52]. This effect is known as vicarious posttraumatic growth. In this scenario, resilience represents an important protective factor against secondary trauma avoiding the development of secondary traumatic stress as well as promoting positive changes [49].

Absenteeism, increased medical errors, poor communication and teamwork are some of the negative effects of stress exposure among palliative care professionals [53]. High levels of stress may lead providers to experience burnout [44]. That includes emotional exhaustion, depersonalization and reduced personal accomplishment [54]. In particular, emotional exhaustion revealed to be the main predictor, as it is considered the first step in burnout [55]. Rushton et al. [44] showed a strong association among resilience, hope and burnout. In particular, resilience as well as hope supported the development of strategies aimed to reduce vulnerability to emotional exhaustion contributing to personal accomplishment. This suggested that both constructs may contribute to increase work satisfaction among healthcare professionals.

To date, little research has been conducted toward resilience assessment among palliative care professionals [48]. The validation of the Situational Judgement Test (SJT) represented an attempt to develop a specific questionnaire tailored

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to palliative care workers. The scale revealed to be a reliable and valid measure. As to the practical implications, its implementation in multidisciplinary teams and using a reflective learning approach may represent for the healthcare professional an opportunity to debrief about the emotional impact of jobrelated adversities and to reach peer support [48].

The interest on treatments aimed to promote providers' wellness and resilience has increased, too [45]. The two interventional studies, included in this systematic review, were pilot, had a small sample size and involved no control group. Nevertheless, both reported informative data on resilience following the completion of an educational program [45, 46]. Mehta et al. [45] implemented a program based on the principles of cognitive behavioural therapy and positive psychology. In fact, the intervention aimed to evoke a relaxation response through breath awareness exercises, to reduce overall stress reactivity and to increase connection with others. The intervention led participants to a reduction in perceived stress and an increase in perspective taking. Klein et al. [46] proposed an intervention consisting of sessions aimed to educate participants about compassion satisfaction, compassion fatigue, vicarious trauma, self-care, resilience and quality of life completing self-assessments and participating to group discussions. Post-intervention data showed in all participants an increase of compassion satisfaction and a decrease of burnout. In summary, the two interventional studies suggest that resiliency development programs based on cognitive stimulation and/or social support may lead palliative care professionals to gain self-awareness fostering their well-being.

#### Resilience as a process modulator and facilitator

A recent qualitative systematic review focusing on resilience in palliative care inpatient nursing workforce identified exposure to death, stress and coping as informative subthemes [41]. According to the emerged results, resilience occurs when adversity and stressful experiences lead nurses to adapt through a meaning construction process. Therefore, the cognitive ability to give meaning and shape to stress appears to determine resilience development or maintenance. Similarly, in the current systematic review, resilience appeared to be an influencing construct in palliative care professionals' well-being. In particular, it seems to modulate death anxiety, traumatic experiences, stress and burnout predicting vicarious posttraumatic growth, compassion satisfaction, hope and increased perspective taking. As a result, while in the model of Powel et al. [41] resilience may be seen as originating from adverse experiences and the result of abilities aimed to overcome challenging situations, in the present model we propose, resilience could be considered as a process modulator and facilitator that may help palliative care professionals to reach positive adaptation (Fig. 2). Summing up, both two models focus on healthcare professionals' well-being within a context where end-of-life and chronicity reveal to be influencing aspects. Specifically, stressful experiences, trauma, exposure to death and growth appear to be common aspects included in the systematic synthesis. As for the differences, while Powel et al.'s [41] model adopted a qualitative approach and considered coping and meaning construction, the current research adopted a quantitative approach identifying burnout, compassion satisfaction and positive thinking (i.e. hope, perspective taking) as factors to be included in the data analysis. Thus, the two models may be integrated in order to orient future researches to develop a mixed-methods model explaining resilience in this population, as well as to promote resilience as a factor in support of palliative care professionals' personal growth.

#### Limitations and strengths

The current systematic review presents some limits. First, the included studies were exclusively conducted in the USA or in European countries. Thus, data on resilience in palliative care professionals belonging to other cultures (e.g. Asian or African) were not provided. Second, the interventional studies included in the analysis, as described by the researchers too, were pilot, had a small sample size and involved no control group.

However, it is noteworthy that the analysed data were recent, as the included studies range from 2015 to 2018. Moreover, to the best of the author's knowledge, this is the first quantitative systematic review addressing resilience in healthcare professionals providing adult palliative care.

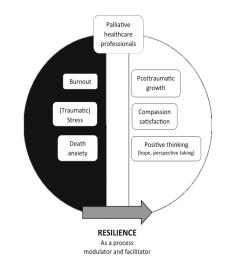


Fig. 2 Palliative care providers' experience and the role of resilience

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#### Future directions and clinical implications

The results allowed the authors to develop a model concerning the role of resilience in palliative care providers' personal and professional growth. Further studies to validate this proposed framework should be conducted considering wider sample sizes and the presence of a control group. In addition, further correlational and regressional studies aimed to examine in depth the predictive role of resilience on positive constructs like self-esteem and attention to feelings [47], posttraumatic growth [49], compassion satisfaction [46] and hope [44] are recommended. Also, interventional studies on this topic should take into account specific cognitive and behavioural stimulation exercises [45], social support and educational sessions on themes connected to psychological well-being in work setting, as main strategies to enhance resilience [46].

#### Conclusion

Since resilience has no accepted universal definition, it remains a construct difficult to quantify. Nevertheless, the current systematic review reported informative data leading to consider resilience as a process modulator and facilitator among palliative care professionals. From the analysis of the included studies, particular attention on research concerning palliative care providers' resilience should be taken into account, as working in contact with end-of-life and chronic illness on a daily basis may put their well-being at risk. The validation of the proposed model on the role of resilience may lead to its implementation in assessment and intervention contributing to foster palliative care professionals' well-being.

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#### Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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# 2.8. A framework to understand healthcare professionals' risk and protective factors: COR theory

Over the years, many theories were developed to put in order and better interpret the knowledge generate by research. Theoretical frameworks may offer a reading key to understand the research findings and to suggest practical applications. As concerns the current project, a useful theory within the broaden framework of positive psychology may be the Conservation of Resources (COR) theory (Hobfoll 1989, 2001). In fact, this theory is both an integrated and comprehensive model of stress based on resources and a motivational theory. Developed to analyze distress in response to major stressful or traumatic events and chronic and/or acute illnesses (Benight et al., 1999; Hobfoll, Tracy, & Galea, 2006), in the last decades it has become one of the gold-standard theoretical frameworks within work and organizational psychology. It has been successfully adopted across manifold workplaces as it is a parsimonious comprehensive conceptual model to explain human behaviour and reaction to stressful events (Hobfoll, Halbesleben, Neveu, Westman, 2018).

According to COR theory (Hobfoll, 1989, 2001; Hobfoll et al., 2018), the main tenet is that each individual strives to obtain, retain, foster and protect those things that have a pivotal importance for survival, following an evolutionary-based built-in strong bias which pushed to overweight resource loss and underweight resource gain. At the end of the 1980s, 74 different resources were identified and classified in four main categories (Hobfoll, 1989):

1. *Object resources*: physical items which are worthy due to their utility, rarity or symbolism (e.g., tools for work, material goods);

2. Condition resources: states of being which are generally desirable (e.g., job status, safety at work);

3. *Personal resources*: characteristics, key skills and personal traits helping to face stress (e.g., self-efficacy, resilience);

4. Energy resources: valuable sources of other resources (e.g., efforts, knowledge).

Resources are the core of this theory and the existence is characterized by loss and gain of resources. On this core element, four principles were proposed to explain the COR theory.

The first one reports that the resource loss is disproportionate than resource gain in term of impact. This means that the magnitude and lasting of resource loss tends to affect people more rapidly and deeply over time (Hobfoll, 1988; Hobfoll et al., 2018).

The second principle of COR theory posits that it is necessary to invest resources in order to cope with resource loss, to recover from losses, and to gain further resources. Indeed, individuals are motivated to acquire resources to achieve goals in the present and preserve resources for the future (Hobfoll, 1988; Hobfoll et al., 2018). Consequently, people invest their resources with the purpose

of earning a "return of investment", "develop resource surpluses" which generate positive feelings of eustress and "offset the possibility of future loss", which would otherwise provoke the negative feelings of stress (Hobfoll, 1989, p. 517).

The third principle points that resource gain paradoxically increases in importance in context of resource loss. That is, when the resource loss is massive, the possibility to gain further resources to cope with the loss become of paramount relevance (Hobfoll, 1988; Hobfoll et al., 2018).

The last principle affirms that when resources are outstretched or exhausted, people adopt dysfunctional coping strategies, entering a defensive mode to preserve the self that is often aggressive and may become irrational (Hobfoll, 1988; Hobfoll et al., 2018).

From these four easy but full comprehensive principles three corollaries are derived. The first one posits that individuals with fewer resources are more vulnerable and less likely to engage in resource investment because they either possess appropriate resources to invest or have to conserve resources in a reservoir which they could use for emergency contingencies; thereby, resulting in fewer resources over time (Hobfoll, 1988; Hobfoll, 2001; Hobfoll et al., 2018). Conversely, individuals with more resources are better positioned for resource gain and less vulnerable to resource loss. As a result, they will invest more resources in their work and develop higher levels of personal accomplishment.

The second corollary points that resource loss has a spiraling nature. This means that resource loss brings to further depletion of resources such that iteration by iteration a loss cycle is triggered (Hobfoll, 1988; Hobfoll et al., 2018). Indeed, stress emerges when individuals experience or anticipate a threat to or an actual loss of resources or fail to gain resources after significant resource investment or loss (hobfoll, 1989). In this condition, an individual has no resources to offset the resource loss, paving the way to malaise. This means also that distress is not something that appears suddenly, rather it is usually the result of a long period of resource loss without a successful removal. Thus, burnout may be intended as the end state of a long-term process of resource loss which gradually developed over time and which exhausted one's energy resources (Hobfoll & Freedy, 1993).

The third corollary posits that resource gain also has a spiraling nature. However, this positive cycle is of less magnitude and slower than resource loss such that resource gain spirals are weak and take time to develop. Hopefully, resource gain increased in saliency in high-loss contexts such that motivation to acquire new resources becomes stronger (Hobfoll, 1988; Hobfoll et al., 2018).

Moreover, COR theory does not consider the individual only, rather it is interested in parsimoniously explaining resources loss and gain mechanisms in the interaction with the environment. For this reason, Hobfoll (2011) formulated the concept of "resource caravans",

explaining that resources do not exist individually but travel in packs (i.e. caravans) in individuals and organizations. Resources are sort of co-travelers as they derived by nurturance and learned adaptation (Hobfoll, 2011; Hobfoll et al., 2018). For instance, self-esteem, optimism, and selfefficacy are highly correlated as they are fueled by the same supportive environment. This strong interconnection of resources allows also the exchange of resources based on the so called "crossover model" (Hobfoll 1989, 2001; Hobfoll et al., 2018). "Crossover acts as one of the mechanisms of resource exchange within resource caravans" (Hobfoll et al., 2018; p. 108). This means that resources are transferred within social and organizational contexts, offering a further interindividual level of analysis which encompass dyads, teams and organizations (Westman 2001). Differently said, this theory suggests that resources tend to produce other resources, therefore generating resource caravans, which, in turn, prompt a gain cycles toward better wellbeing (Hobfoll 1989, 2001; Hobfoll et al., 2018). Greater wellbeing fosters the acquisition of further job resources, generating gain spirals (Salanova, Schaufeli, Xanthopoulou, & Bakker, 2010). Empirical evidence has been provided to support a long-term effect of resources on wellbeing, wherein resources and well-being reinforce each other reciprocally (Hakanen, Bakker, & Jokisaari, 2011). For instance, a study among Dutch workers revealed that numerous job and personal resources were positively associated with wellbeing over an eighteen-month period (Xanthopoulou et al., 2009).

Furthermore, Hobfoll (Hobfoll, 2011; Hobfoll et al., 2018) introduced the concept of "resource caravan passageways" which states that individual's resources are nested in the environment and the ecological conditions may sustain or block resource creation. This concept is of paramount importance as it enables to put emphasis both on the individual level and on the environment, suggesting the impact that contextual elements may have. In fact, "social and environmental conditions create resilience or fragility" (Hobfoll et al., 2018, p. 107), facilitating or obstructing the resource gain.

One of the points of strength of COR theory is that it allows to generate a wide range of specific hypotheses which are much broader than those provided by other theories. Moreover, this theory recognizes some personal characteristics as "*resources to the extent that they generally aid stress resistance*" (Hobfoll, 1989, p.517), suggesting that certain characteristics can be treated as personal coping resources. In addition, by including the concept of "resource caravan passageways", COR theory claims that individual resources exist in ecological conditions that either enforce or block resource creation and sustenance. Finally, this conceptual framework is a motivational theory that offers explanations for human behavior based on the evolutionary need of species conservation.

Bearing in mind these advantages, this theory may be suitable for the current dissertation as it allows to investigate possible risk and protective factors intended as resources or lack of them. In this vein, it is possible to interpret the health and professional outcomes, grounding the findings in strong theoretical bases and, in turn, suggesting practical implications to ameliorate the work experience and wellbeing of professionals employed in palliative care and neurorehabilitation medicine specialties. The application of COR theory framework to investigate the variables and mechanisms considered in this project is provided in more details in chapter ten of the current dissertation.

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# **SECTION B**

WeDistress HELL Project: WEllness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues

> Do the research. Ask questions. Find someone doing what you are interested in! Be curious! (Katherine Johnson, American mathematician)

# Chapter Three The project

## 3.1. Introduction to the project

The project presented in the present PhD dissertation is called WeDistress HELL which is the acronym of *WEllness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues.* It started in the October 2017 thanks to the fruitful collaboration between the Department of Brain and Behavioural Sciences of the University of Pavia and the ICS Maugeri Institute of Pavia. What inspired the project was the awareness that contemporary medical practice implies an increasing amount of bioethical issues to manage and this fact may constrain physicians and healthcare professionals to experience relevant distressing and high demanding situations that urge a better understanding and suggestions for the daily practice (Genuis, 2006; for a review: Kompanje et al, 2013; Ulrich & Grady, 2018).

In this chapter, the objectives and the methods of this research will be presented in detail.

#### 3.2. Main objective

The general object of this research was to detect and quantify a set of variables (meaning of life, burnout, moral distress, ethical climate, resilience, positive and negative affects) that may impact on professionals dealing with end-of-life and bioethics issues in their working life by quantitative and qualitative methods. Specifically, the main aim was to detect some variables already addressed in the literature which can act as risk and protective factors for two specific medical specialties, namely neurorehabilitation and palliative care.

The above-mentioned variables ware evaluated among the two samples of healthcare professionals in light of the Positive Psychology (Seligman & Csikszentmihalyi, 2014) and COR theory (Hobfoll 1989) described in the Section A of this dissertation.

A better explanation of the specific objectives set by this project will be provided in chapters five, six, seven, eight, nine of this dissertation which exhaustively present each studies conducted.

## 3.3 Ethical considerations

The WeDistress HELL Project was presented to the Italian Ethical Commitee of Istituti Clinici Scietifici (ICS) Maugeri - Institute of Pavia as the most part of the Institutions involved in this research are affiliated with the ICS Maugeri Spa Società Benefit - I.R.C.C.S. The project was revised according to the suggestions provided by the above-mentioned Ethical Committee and it was approved on 19 June 2018. The identification protocol number is 2211CE.

Healthcare professionals were orally and written informed about the aims and procedures of this research, as well as they were advised regarding the participants' anonymity and the aggregated data analysis in accomplish to the norms for the protection of personal data and the right to privacy (Legislative Decree 196 of 30.06.2003 and subsequent amendments/ additions) and to the EU General Data Protection Regulation 2016/679. On the consent form, the contacts of researchers were provided for asking clarifications and more details. The participation was on a voluntary basis without any form of reimbursement and the possibility to withdraw from the study at any moment without providing explanations was always guaranteed. Moreover, it is worthwhile to be said that meetings during the shift-changes was arranged in each Institute to orally present the research to participants. In this way, they were further reassured by a researcher and/or their clinical supervisors about the anonymity of data collection and no repercussions of their responses on their job. The possibility to have clarifications was facilitated, too.

Each participant who agreed to participate in the research project was asked to sign and date the consent form which should be inserted in an anonymous envelope. She/he was also asked to place the completed questionnaires and the signed consent form in two different cardboard boxes located in a common area inside each institute involved in the research.

#### 3.4. Method and procedures

#### 3.4.1. Study design

The project is an *observational multicentre cross-sectional study*. The principal investigators are ICS Maugeri IRCCS and the Department of Brain and Behavioural Sciences, University of Pavia. Specifically, this project has to be intended as an observational multicentre cross-sectional study *with a multimethod design* as a single time quantitative and qualitative evaluation was carried out within professionals employed in different hospitals.

However, in case that there were funds to deepen the project, future follows might be also conducted. Regarding this point, it is also noteworthy that it will be possible to match the responses provided by the healthcare professionals participating both in the present evaluation and in the future ones in order to evaluate the changes in the aforementioned variables over the time and within subjects. To leave this possibility open, the participants of the present evaluation were requested to create a univocal self-generated identification code (also known as *Hogben number*, Honig 1995; Winchester et al. 1996) linking the person's answers across evaluation in an anonymous way (see *Annex 1*). Specifically, the generation of this identification code involves answering the same set of researcher-constructed enquiries based on personal information (e.g. initial of mother's first name, initial of month of birth) at each data collection time. This process is

very used in longitudinal research as it enables people to develop their own unique identifier which is used to anonymously track the respondents across time (Honig 1995; Winchester et al. 1996; Yurek, Vasey, & Sullivan Havens, 2008; Schnell, Bachteler, & Reiher, 2010; Direnga, Timmermann, Lund, & Kautz, 2016).

#### 3.4.2. Method

#### 3.4.2.1. Background of the method design adopted

The research project presented in this dissertation used a *multimethod design* which makes use of both quantitative and qualitative methods to collect and analyse data.

The adoption of both quantitative and qualitative approaches came into wide use in the landscape of healthcare research as it enables to capitalize on the respective points of strength of the two methods, overcoming their weaknesses in an attempt to provide an integrated comprehensive understanding of a complex context (Andrew & Halcomb, 2009; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011; Strudsholm, Meadows, Robinson Vollman, Thurston, & Henderson; 2016). In the American context, Coyle et al. (2018) showed as the mixed methods research studies receiving funding nearly doubled from 2009 to 2014 (n = 535; 2009-2014) and increased modestly from previous trends (n = 226; 1997-2008). The healthcare system is, indeed, a very complex and multifaceted context due to the different protagonists involved and the sensitivity of the healthcare issues. For these reasons, all kind of strategies to collect information are welcomed in order to better understand the real meaning of phenomena, grasping the perspective of who live inside the healthcare context, as well as the mechanisms underlying the daily practice. Thus, adopting both quantitative and qualitative approaches means "to attack a research problem with an arsenal of methods that have non overlapping weaknesses in addition to their complementary strengths" (Brewer and Hunter, 1989, p. 17). That is, studying the research problem by different perspectives allows the researcher to gain a completer and more detailed picture of human behaviour and real experience (Morse, 2003). Researches adopting quantitative and qualitative methods are labelled as *mixed methods* or *multimethod* design studies. In the literature these terms are frequently used as synonymous as the different meaning nuances are nebulous and not unanimously shared (Morse, 2003; Hesse-Biber & Johnson, 2015). With a metaphor, it can be said that "to engage in multimethod and mixed methods research (MMMR) requires working at the borders of disciplines and navigating across a turbulent MMMR landscape characterized by deep epistemic, theoretical, and methods divides" (Hesse-Biber, 2015; p. xxxiii). Doing border work entails to consider borders as "contact zones" (Higonett, 1994), as "sites of innovation, of rupture, connection, transmission  $[\ldots]$  and those working at the borders begin to move beyond one-way questions" (Hesse-Biber, 2015;

p. xxxiii; see also Higonett, 1994, pp. 3-4). Thus, regardless the small differences among definitions and epistemic foundations, mixed methods and multimethod design have in common the adoption of more than one methods to address a research inquiry in order to maximise the source of information, as well as the chance of reaching a full and complete understanding of phenomena. In this dissertation, I chose the term *multimethod design* in line with the conceptualization provided by Morse (2003). It is important to clearly specify this choice as it is necessary to be cognizant of the characteristics and rational of the use of different methods, in order to avoid "muddling methods" (Stern, 1994). Indeed, mixing methods without respecting a shared terminology and procedures undermine the validity of methodological assumptions and, in turn, the reliabilities of findings (Stern, 1994; Morse, 2003).

#### 3.4.2.2. Specific multimethod chosen

The present research project is based on a "*quantitative and qualitative simultaneous design with a deductive theoretical drive*" (also identified with the shorten form QUAN + qual; Morse, 2003). Specifically, quantitative studies have been conducted in order to test hypothesised relationship between the above-mentioned variables on the basis of previous research. Concurrently, qualitative studies have been carried on in order to collect nuances of meanings provided by the subjective experience of healthcare professionals.

According to Morse's theorization, the multimethod design is characterised by conducting "two or more research methods, each conducted rigorously and complete in itself, in one project. The results are then triangulated to form a comprehensive whole" (Morse, 2003; p. 190). The main strength of this strategy is the possibility to address the research question from different perspectives which are complete in themselves. That is, this design offers "different lens" as provided by a crystal in order to see manifold nuances of phenomena (Sandelowski, 1995). Each multimethod design project has a principal theoretical drive, that is the main goal of discovering or testing. Thus, the *inductive theoretical drive* is chosen when the main goal is discovery phenomena and processes so that the guiding inquiry is the following: "what is going on?" Conversely, the deductive theoretical drive is given when the major aim is to test hypotheses to determine relationships, thus the research question is the following: "how much or how many?" (Morse, 2003). This latter drive is the bases of this project. However, each study which will be thereafter presented has a particular goal that may be more focused on discovering or testing. To this regard, it has to be said that, in multimethod design, each method adopted may be characterised by a more inductive or deductive direction as each study is complete itself. Indeed, the theoretical drive is given by the most important and dominant study of the multimethod project.

As for the pace chosen for carry on the project, the studies were conducted in parallel. Indeed, in multimethod design, the pace of the project may be different, such that the studies may be conducted in a sequential or in a concurrent way, so resulting in sequential or simultaneous design, respectively (Morse, 2003).

In multimethod research design is also pivotal to define a moment of integration of the findings provided by the different studies, that is to frame *triangulation*. This term describes "*the combination of the results of two or more rigorous studies conducted to provide a more comprehensive picture of the results than either study could do alone*" (Morse, 2003, p. 190). The metaphor of triangle helps the comprehension of the relationships between quantitative and qualitative data. That is, points of the triangle may be seen as empirical findings provided by the different studies, while the sides of this geometrical form represent the relationship occurring, such that we can design a convergent triangle (i.e. quantitative and qualitative findings are in line), a complementary triangle (i.e. quantitative and qualitative findings provide contradictory conclusions) (Östlund et al., 2011). In this project, triangulation was performed at the end in order to integrate the findings of each single study in a comprehensive understanding of the phenomena investigated.

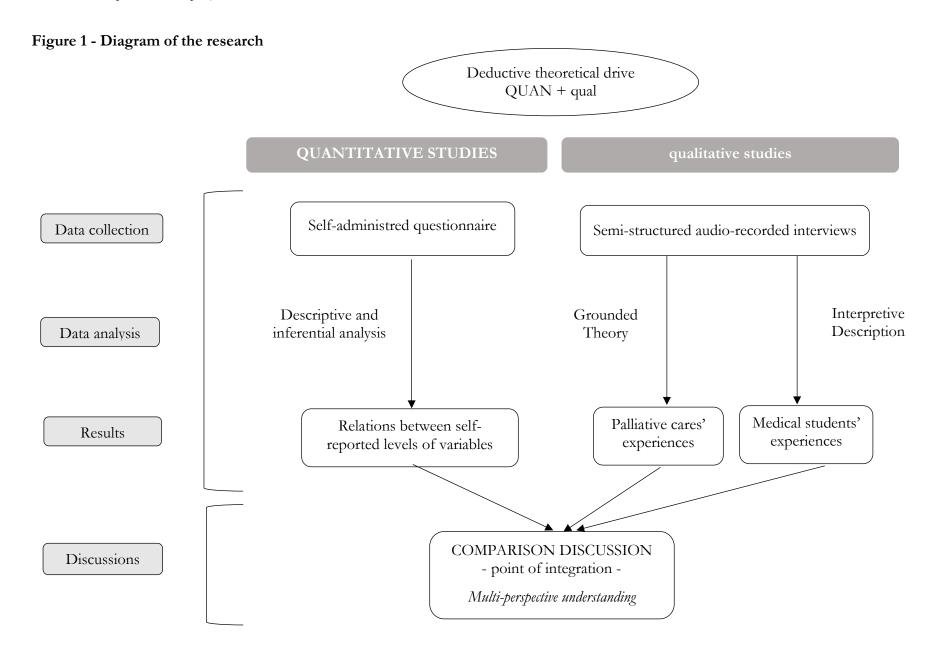
The details of the quantitative and qualitative investigations are provided in chapters four, five, six, seven, and in chapters eight and nine, respectively. Furthermore, the triangulation of results is provided in the Discussion of the present dissertation (see chapter ten).

The Figure 1 provides a graphical and summary representation of the multimethod design adopted for the present project.

# 3.4.3. Procedure and phases

To develop a proper study design addressing the aims of the study, a review of the existing and updated literature was conducted (see Section A). Consequently, the instruments constituting the *ad-hoc* questionnaire were chosen as well as the main areas to be qualitatively investigated were detected.

After the preparation of the study design and the Ethical Committee approval, two qualitative studies were carried out, one in Italy (see chapter eight) and the other one in Cyprus (see chapter nine). Concurrently, the administration of the anonymous paper-pencil questionnaire was proposed to eligible professionals employed in the Italian hospitals involved in the research, according to agreements with the management of each organization. The research was orally and written presented and copies of the paper-pencil questionnaire were placed in a common area



situated in the eligible wards of each hospital in order to allow the healthcare professionals to bring the questionnaire and to self-administer it. They were also instructed to place the filled and signed questionnaire and consent form in two separate card-boxes.

The data collection and analysis were conducted separately for qualitative and quantitative data. Afterward, the quantitative and qualitative findings were considered together to reach a comprehensive integration and providing suggestions for clinical and managerial practice.

Specifically, the study phases and activities have been the following:

#### Phase 1

During this initial period, a literature review was conducted to learn more about the updated knowledge regarding the variables under investigation and to better focus the areas to be analysed through interviews. Two systematic reviews and an editorial were produced (see Section A). Moreover, the suitable instruments for addressing the research aims were detected according to literature suggestions and periodic meetings between the partners of the ICS Maugeri and the University of Pavia. When necessary, the requested permissions for the instruments were obtained, as well as the translation and adaptation of the *Hospital Ethical Climate Survey* was conducted as it was not available in Italian. The translation of this instrument was provided following the standard guidelines for translating questionnaires (Sousa & Rojjanasrirat, 2011) and a more detailed description is provided in chapter six.

In addition, the topic guides for the semi-structured interviews were defined according to literature suggestions and they were discussed and approved by the partners of the ICS Maugeri and University of Pavia.

The research protocol and the consent form were also prepared and presented to the Ethical Committee for approval.

## Phase 2

In this phase, the collection of qualitative and quantitative data was performed.

Specifically, palliative healthcare professionals (see chapter eight) and medical students (see chapter nine) were interviewed. The qualitative analysis of the interviews conducted in Italy also started in this phase in order to guarantee theoretical sampling and saturation of concepts as requested by Grounded theory (see chapter eight). Concurrently, the administration and collection of the questionnaires took place in the different hospitals participating in the research (see chapters four, five, six, seven).

The conceptualization and writing of scientific article reporting the qualitative and quantitative findings started, too. Preliminary findings were also disseminated to national and international congresses.

# Phase 3

In this phase, the qualitative data analysis of interviews conducted with palliative healthcare professionals were sharpen and concluded (see chapter eight). Then, the analysis of interviews conducted with medical students (see chapter nine) were performed at the university of Alberta, Canada. Moreover, the quantitative data analysis was also conducted (see chapters four, five, six, seven).

The writing of scientific papers and the dissemination of scientific findings in national and international congresses were also carried on.

# Phase 4

In the last phase, the data analysis proceeded, aiming to conceptually integrate qualitative and quantitative findings and to suggest practical implications (see chapter ten).

The writing of scientific papers was concluded, and the last papers are now in press (see chapter six) or under revision of editors (see chapters seven and nine). The dissemination of findings to scientific congresses was reduced by to the worldwide sanitary crisis of COVID-19.

The Gantt diagram (see Figure 2) displays the timing of the above-mentioned phases and activity.

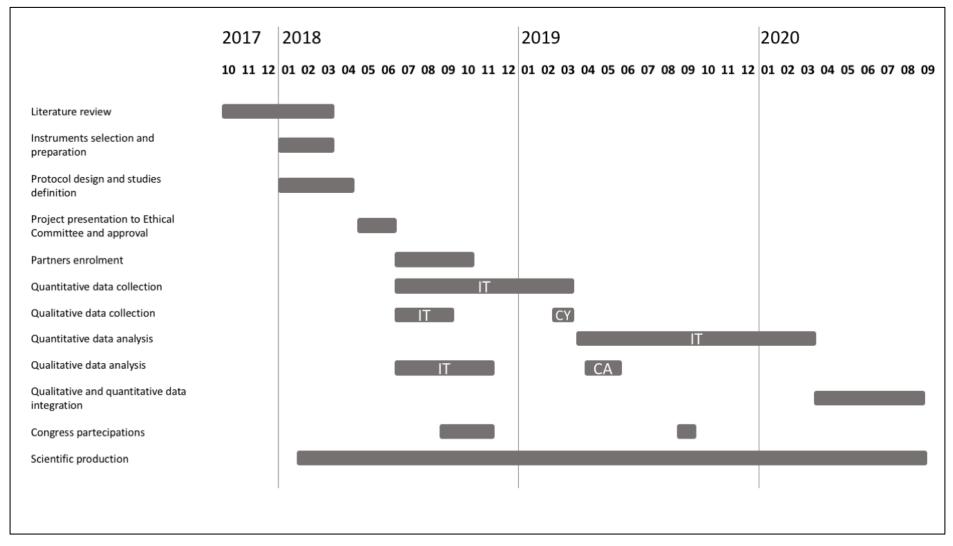
# 3.4.4. Participants

Being a multicentre study, different hospitals took part in this project. Specifically, the Italian centres involved for the data collection were the following:

- ✤ ICS Maugeri Spa Società Benefit I.R.C.C.S:
  - U.O. di Cure Palliative Pavia (PV, via Boezio),
  - U.O. di Cure Palliative Ospedale San Martino di Mede (PV)<sup>4</sup>
  - U.O. di Riabilitazione Specialistica Neuromotoria Pavia (PV, via Maugeri)
  - U.O. Unità Operativa Neuromotoria Montescano (PV)
  - U.O. di Riabilitazione Neuromotoria Telese Terme (BN)

<sup>&</sup>lt;sup>4</sup> This unit has been merged with the U.O. di Cure Palliative – Pavia (PV, via Boezio). Thus, the qualitative part of the study took place in the U.O. di Cure Palliative – Ospedale San Martino di Mede (PV), while the quantitative part took place in the U.O. di Cure Palliative – Pavia (PV, via Boezio). The healthcare professionals were the same.

# • Figure 2 - Gantt diagram of research activities



*Note.* IT =Italy; CY= Cyprus; CA= Canada

- Humanitas Research Hospital Rozzano (MI):
  - Unità di Cure Palliative Domiciliari Humanitas Cancer Center
  - U.O. Oncologia Medica Humanitas Cancer Center
- I.R.C.C.S. Santa Lucia Centro Riabilitativo Roma (RM)

Moreover, at the beginning the participation of other European organizations was also expected. Specifically, the institutions which signed a partnership agreement concerning the present research are the following:

- Medical Ethics and Law Lead St George's University, London Medical Programme, Nicosia, Cyprus (Coordinator: Dr Julia Hynes).
- ✤ Faculdade de Medicina Universidade do Porto, Pourtugal (Coordinator: Francisca Rêgo).
- Medical University of Lodz (Coordinators: Prof. Przemyslaw Kardas, Dr. Marta Kurczewska-Michalak).
- Universitas Studiorum Catholica Croatica Catholic University of Croatia (Coordinators: Dr. Anto Čartolovni).

Concerning the foreign partners, it has to be underlined that, during the research, only the Medical Ethics and Law Lead – St George's University, London Medical Program, Nicosia and the Faculdade de Medicina – Universidade do Porto continued to collaborate. Specifically, the first one collaborated for the qualitative part of the research (see chapter nine) and the second partner agreed to participate in the quantitative part. Unfortunately, in this dissertation the Portuguese data are missing as the research is still in progress in this country.

The other organizations encountered different hindrances in the implementation of the research protocol in their country. In particular:

- The Universitas Studiorum Catholica Croatica withdrawn its participation as the coordinator was no more available.
- Medical University of Lodz withdrawn its participation due to the expense for a professional translation of the instruments not available in Polish language.

Thus, the present dissertation displays the data collected in the above-mentioned Italian institutions participating in the project.

Regarding the sample presented in this dissertation, the study participants encompassed healthcare professionals employed in palliative care and neurorehabilitation specialties. The participation was on voluntary bases and without any form of reimbursement. As the healthcare profession – whatever the specific role – requires a dedicated education and an adequate use of the language to deal with patients, no exclusion criteria regarding alphabetization and the mastery of the Italian

language were considered. Thus, all the different professionals were considered eligible as the scope of this project was to better analyse possible risk and protective factors for all healthcare professionals of the above-mentioned medical specialties. For this reason, the research was extended to physicians, psychologists, nurses, physiotherapists and other therapists (dieticians, speech therapists, occupational therapists) as well as social-healthcare practitioners (in Italian *Operatore Socio Sanitario – OSS<sup>5</sup>*).

Moreover, only for the qualitative part of the present project, some interviews were conducted also with international medical students recruited in Cyprus. For more details on this subsample, please see chapter nine of this dissertation.

#### 3.4.5. Qualitative Instruments

The present research adopted two different type of instruments for data collection. As concerns the qualitative part of the project, a topic-guide for healthcare professionals' semi-structure interviews were developed according to both the clinical experience of the researchers involved in this project and the scientific literature findings.

The first part of the topic-guide interview aimed to collect the subjective experience regarding professionals' risk and protective factors of working in palliative care specialty. Specifically, the interviewees were requested to think to some difficult situations occurred in their work and to focus on helping factors, as well as on the most difficult aspects to manage in that situations. Moreover, they were asked to provide a feedback on the perceived support received by colleagues and superiors to carry on the working activity. Some questions asked also on possible disagreements with colleagues and patients or caregivers, requesting to provide some examples. As it was a semi-structure interview, other specific issues were investigated if they emerged during the conversation. The questions of the first part of the topic-guideline are provided in the paper "Underneath the white coat: risk and protective factors for palliative care providers in their daily work", reported in chapter eight of this dissertation.

The second part of the interview focused on healthcare professionals' first impressions on the recent law n. 217/2019 on advance directives. Specifically, they were asked to provide a subjective feedback and say if the law may protect or obstacle their work activity according to them. Moreover, they were asked to suggest possible changes to tune and ameliorate this regulation. Other issues related to this regulation were discussed if they emerged during the conversation. The

<sup>&</sup>lt;sup>5</sup> In the Italian healthcare system, the "social-healthcare practitioner" is a qualified healthcare assistant who addresses the basic needs of a person (washing, feeding, etc.) in both social and healthcare contexts (European Commission, Regulated Professions Database).

complete topic-guideline for this part of interview is provided in the paper "Healthcare professionals" perceptions about the Italian law on advance directives", showed in chapter eight of this dissertation.

Similarly, another guide for interviewing medical students was prepared, too. Again, the focus was unveiling the subjective perceptions of risk and protective factors encountered during the student's clinical placements in touch with patients suffering from life-threatening illness. Thus, they were asked to explain the reasons for choosing to become a physician and to describe some difficulties encountered during their educational path. Moreover, they were invited to describe the most subjective difficult aspects to manage, as well as to report some helping factors encountered during their clinical placements. Some questions of the interview analysed also the experience of possible disagreements occurred with superiors and colleagues or with patients/caregivers. The perception of support received by the other students and by their superiors were investigated too. Also in this case, other emerging issues were discussed if they emerged during the interview. The complete guide is provided in chapter nine of this dissertation.

#### 3.4.6. Quantitative Instruments

The quantitative part of the research was conducted through an ad-hoc self-administered questionnaire. It was constituted by a socio-demographic schedule asking for demographic data (e.g. gender, age) and professional details (e.g. professional role, tenure in the current position). Despite the collection of these data for statistical purposes, the anonymity of the respondents was always guaranteed. The *Appendix 2* reported the complete socio-demographic schedule. Beside this schedule, the questionnaire included some well-know and validated instruments used in the national or international literature in order to measure the variables considered: meaning of life, burnout, moral distress, ethical climate, resilience, positive and negative affects. The questionnaires were all provided in Italian language. Table 3 displays a summary of the chosen instruments which are better described below and further mentioned in chapters four, five, six, seven.

#### 3.4.6.1. Schedule for Meaning in Life Evaluation (SMiLE)

The Schedule for Meaning in Life Evaluation (SMiLE; Fegg, Kramer, L'hoste, & Borasio, 2008) is a self-generated, idiographic measure for the assessment of individual meaning in life.

The respondents are asked to provide an open answer, listing three to seven areas which provide meaning to their existence, considering the present time. Fegg et al. (2008) identified 15 clusters comprising similar areas listed by a representative sample of 1,004 Germans. The categories highlighted are the following: family, partnership, social relations, occupation/work, leisure

Instrument	Construct	Score	Subscales (nº items)	Scoring interpretation
SMiLE Schedule for Meaning in Life Evaluation	Meaning in Life	One open answer Satisfaction subscale: -3= not at all, +3= extremely Importance subscale: 0= not at all, 5= extremely	from 3 to 7 items for open answer question (to be chosen by respondent) Satisfaction and importance subscales: from 3 to 7 items depending from what is chosen in	open answer: subjective areas providing meaning in life The higher the score, the higher are the satisfaction and the importance for each of the above-mentioned areas
MASI-R Maugeri Stress Index - Revised	Eustress/Wellbeing	1= not at all 5= extremely	the open answer Resilience (16) Wellness (7) Social Support (5) (Negative) Coping (5) Lie (4) Total (37)	Higher scores indicate the perception of eustress/wellbeing For the Coping-subscale only: the higher the score, the more dysfunctional is the coping
Moral Distress Scale - Revised Moral Distress		Frequency subscale: 0= never, 4= very frequent Intensity subscale: 0= none, 4= great extent	Futile care (3) Ethical misconduct (5) Deceptive communication (3) Poor teamwork (3) Total (14)	The higher the score, the higher are the perception of moral distress
MBI – GS Maslach Burnout Inventory General Survey	Bu <del>r</del> nout	0= never 6=daily	Emotional Exhaustion (5) Cynicism (5) Professional Efficacy (6)	The higher the score, the higher are the perception of emotional exhaustion, cynicism and professional efficacy
HECS Hospital Ethical Climate Scale	(positive) Ethical Climate	1= almost never true 5= almost always true	Peers (4) Patients (4) Managers (6) Hospital (6) Physicians (6) Total (26)	The higher the score, the more positive is the perception of ethical climate
PANAS Positive Affects and Negative Affects Schedule	Positive and negative affects	1= very slightly or not at all 5= extremely	PA – positive affects (10) NA – negative affects (10)	The higher the score, the higher is the perception of positive or negative affect
CD-RISC 10 Connor and Davidson Resilience Scale	Resilience	0 = not true at all 4= true nearly all the time	Total (10)	The higher the score, the higher is the perception of resilience

## Table 3. Summary of the instruments included in the questionnaire

time/relaxation, home/garden, finances, spirituality, religion, health, satisfaction, nature/animals, social commitment, hedonism, art/culture, growth.

For each area listed, the person is instructed to rate the level of satisfaction and importance (called weight). The level of satisfaction ranges from -3 (*very unsatisfied*) to 3 (*extremely satisfied*), whereas the level of importance ranges from 0 (*not important*) to 7 (*extremely important*). Both the index of total satisfaction (IoS) and the index of total weighting (IoW) range from 0 to 100. Levels of importance and satisfaction assigned to specific areas are independent such that a person may be unsatisfied about a certain area considered extremely important. Conversely, another person may be satisfied in an area but may assign little importance to it. Also, a third one may indicate high level of both importance and satisfaction for a certain area.

It is also possible to compute a comprehensive index called weighted satisfaction (IoWS) ranging from 0 to 100. This last index results from the combination of satisfaction and importance ratings according to the syntax provided in the author's manual (Fegg, 2019). A higher score on this index indicates higher Meaning in Life.

Additionally, for each category listed in the first open answer question, a mean value of satisfaction may be calculated by summing up the satisfaction outcomes for the areas belonging to one category and dividing that by the number of the areas. Similarly, it is possible to obtain a mean value of weight and weighted satisfaction through an analogue procedure.

The psychometric properties of SMiLE have been assessed and satisfactory values were reported (Fegg et al., 2008). As for reliability, the satisfaction ratings showed a Cronbach's alpha of 0.71 and the importance ratings displayed a Cronbach's alpha of 0.49. Good results were obtained for testretest in the IoS (0.71), in the IoW (0.60) and in the IoWS (0.72). The test-retest reliability was 0.71 (p<0.001) for the IoS, 0.60 (p<0.001) for the IoW, and 0.72 (p<0.001) for the IoWS. Of the areas listed at the baseline, 85.6% were mentioned again at seven day after the initial assessment. Convergent validity was assessed though other measure of the same construct, that is the Purpose in Life test (Crumbaugh, 1968; r = 0.48, p < .0001), the Self-Transcendences Scale (Reed, 1991; r = 0.34, p < .001), and a general numeric rating scale on MiL (Fegg et al., 2008; r = 0.53, p < .001). The SMiLE was adopted within a representative sample of Germans, French, and Italians (Fegg, Kramer, Bausewein, & Borasio, 2007; Bernard, Braunschweig, Fegg, & Borasio, 2015), in community-dwelling older adults with depression (Volkert et al., 2019), as well as in different population of patients suffering from the following clinical conditions: amyotrophic lateral sclerosis (Fegg et al., 2010a), progressive supranuclear palsy (Fegg, Kögler, Abright, Hensler, & Lorenzl, 2014), congestive heart failure (Mello & Ashcraft, 2014), cancer or palliative care patients (Fegg et al., 2008, Fegg et al., 2010b; Stiefel et al., 2008; Bernard et al., 2017). Moreover, this instrument has been implemented with bereaved informal caregivers (Brandstätter et al., 2014) with healthcare professionals employed in palliative care and maternity care specialties (Fegg, L'hoste, Brandstätter, & Borasio, 2014).

This instrument is available in different languages (German, English, French, Italian, Spanish, Japanese, Hindi, Dutch, Persian and Turkish) on the instrument' site (http://www.meaninginlife.info).

#### 3.4.6.2. Maugeri Stress Index-Revised (MASI-R)

The Maugeri Stress Index - Reduced form (MASI-R; Massidda et al., 2017; Giorgi et al., 2014; Giorgi et al., 2011) is a self-report questionnaire assessing the self-perceived distress/wellbeing. Specifically, the impact of work-related psychological distress is investigated through 37 items to be rated on a Likert scale from 1 = not at all to 5 = extremely. It is composed by the following subscales: Wellness, Resilience, Perception of social support, Negative coping styles, Lie index. Specifically, the subscale of Wellness is composed by seven items describing a condition of wellbeing, characterized by energy, satisfaction and optimism (e.g. I have done things that interested me; I feel full of energy). The subscale Resilience comprises 16 items assessing some personal resources which may support in dealing with requests and problems occurring in the workplace (e.g. I always face adversities and I gradually manage to overcome them; I usually succeed in managing job-related problems). The third subscale, that is Perception of social support, is constituted by five items analysing the perception of social support provided by people at the workplace (e.g. In difficult moments, I find people willing to help me; I can count on the support of my colleagues at work when I need it). The Negative coping styles subscale is composed by 5 items which describe dysfunctional personal strategies or behaviours to face difficulties (I tend to isolate myself from others when I find myself in difficulty; On the job, I get easily irritated). The four items of the Lie index detect attempts of deception (e.g. All of my habits are good and acceptable; I always put what I say into practice). A high score on the subscales indicates perceived eustress, except for the negative coping scale. A high score in this subscale highlights indeed dysfunctional coping strategies and, in turn, possible distress. These several dimensions determine also a total index, that is obtained as the sum of responses, performing the reverse coding for the coping subscale. A high score means perception of eustress, that is wellbeing.

Furthermore, this instrument is also accompanied by two visual scales asking the respondent to estimate from 0 to 100 the self-perceived satisfaction level regarding the own private and occupational life in the last six months.

This instrument has been developed considering the Job Content Questionnaire – JCQ (Karasek, 1979), the Work Organisation Assessment Questionnaire – WOAQ (Griffiths, Cox, Karanika,

Khan, & Tomás, 2006) and the Effort-Reward Imbalance – ERI (Siegrist, 1996). The factorial structured has been evaluated and it was administrated to a normative sample (Giorgi et al., 2011). The first version was constituted by 51 items to be rated on a 5-point Likert scale. The analysis of the internal consistency and of the factorial structure of the MASI led the authors to develop a reduced form of the instrument, the MASI-R used in this research and above described (Giorgi et al. 2014; Massidda et al., 2017).

As concerns the psychometric characteristics, according to the Rasch model, the item properties and the reliability of the instrument appear good for Wellness (R=0.89) and Resilience (R=0.89). Conversely, the subscales for the Perception of social support (R=0.70) and Negative coping styles (R=0.50) show a lower internal consistency (Massidda et al., 2017). The internal consistency in terms of Cronbach's  $\alpha$ , appeared good for the scales Wellness ( $\alpha$ =0.94) and Resilience ( $\alpha$ =0.89). While, for the scales Perception of social support ( $\alpha$ =0.64) and Negative coping styles ( $\alpha$ =0.65), the values were acceptable (Massidda et al., 2017). As for the discriminant validity, a research study unveiled that workers who experienced mobbing reveal higher work stress levels compared to the control group in all aspects measured (Giorgi et al. 2014).

To now, the instrument provided significant results in perceived work stress assessment in the healthcare sector (Giorgi et al., 2011; Giorgi et al., 2014; Massidda et al., 2017). Specifically, Giorgi et al. (2014) showed that workers perceiving mobbing revealed higher work stress levels than the control group in all subscales. Moreover, Raglio et al., (2019) implemented this instrument in a research within the healthcare sector, showing a significant reduction trend in stress levels in professionals listening a daily 30-min-playlist for 3 weeks at home.

#### 3.4.6.3. Moral Distress Scale-Revised (MDS-R)

Moral Distress Scale-Revised (MDS-R; Hamric, Borchers, & Epstein, 2012; Italian version of Lamiani, Setti, Barlascini, Vegni, & Argentero, 2017) is an instrument assessing the self-perception of moral distress. This scale includes four dimensions: Futile care, which analyses the situation in which treatments and cares are perceived as inappropriate because of their harmfulness or uselessness (3 items; e.g., *Initiate extensive life-saving actions when I think they only prolong death; Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient*); Deceptive communication, unveiling unclear forms of communication, like for example giving "false hopes" or not communicate a poor prognosis with a patient and/or a caregiver (3 items; e.g., *Witness healthcare providers giving "false hope" to the patient or family; Follow the family's request not to discuss death with a dying patient who asks about dying*); Ethical misconduct, referring to ethically questionable behaviours occurring in everyday clinical practices (5 items; e.g., *Take no action about an observed ethical issue because* 

the involved staff member or someone in a position of authority requested that I do nothing; Feel pressure from others to order what I consider to be unnecessary tests and treatments); Poor teamwork, which investigates situations lacking of trust and cooperation among medical staff members (3 items; e.g., Watch patient care suffer because of a lack of provider continuity; Witness diminished patient care quality due to poor team communication). Respondents are asked to rate each item in terms of frequency (e.g., how frequently the situation was experienced) and intensity (e.g., to what extent the experienced situation was perceived as disturbing). The items are rated on a 5-point Likert scale ranging from 0 (never) to 4 (very frequently) and from 0 (none) to 4 (great extent) for the frequency and intensity scales, respectively. As concerns the Italian validation, a score for each subscale was calculated by summing the frequency for intensity scores and dividing the total by the number of items. Such subscale score ranges from 0 to 16. However, it is also possible to obtain a total index and higher the score higher the perception of moral distress (Lamiani et al., 2017).

The first version of this scale, namely Moral Distress Scale – MDS (Corley, Elswick, Gorman, & Clor, 2001), arose from the conceptualization of moral distress provided by Jameton (1984), from the role conflict theory proposed by House and Rizzo (1972) and from beliefs, attitudes, and values theory stated by Rokeach (1968). This scale included 32 items describing morally distressing situations. Hamrich et al. (2012) developed a revised shorter version of the MDS (MDS-R) which is composed with 21 items. The aforementioned Italian version is based on MDS-R (Hamrich et al., 2012). The Italian validation has shown good psychometric properties (Lamiani et al., 2017). Specifically, CFA of the Italian MDS-R showed good fit indices (RMSEA = 0.06; CFI = 0.95; TLI = 0.94; WRMR = 0.65). The internal consistency of the Italian MDS-R was good (Cronbach *a* = 0.81), with Cronbach *a* of the sub-scales ranging from 0.55 to 0.73 (Lamiani et al., 2017). Moreover, as concerns the convergent validity, the scale score positively correlated with the score provided by the Italian version of the Beck Depression Inventory-Second Edition (Sica & Ghisi, 2007) (*r* = 0.293; *p* = 0.000).

The MDS-R has been used by previous studies on healthcare professionals (Whitehead, Herberston, Hamric, Epstein, Fischer, 2014; Lamiani et al., 2017; Fumis, Amarante, de Fátima Nascimento, & Junior, 2017; Lamiani, Dordoni, & Argentero, 2018; Browning & Cruz 2018, Bosshardt, Coyne, Marsden, Su, & Melvin, 2018). Such for example, Browning and Cruz (2018) used the MDS-R in assessing moral distress before and after a Reflective Debriefing Protocol for healthcare professionals. Another recent research implemented this scale to evaluate changes in moral distress among nurses after implementation of a policy helping them in patient care (Bosshardt et al., 2018). In another research, the MDS-R was used to define the relationship between moral distress, end-of-life care and pain management in acute care settings (Whitehead et

al. 2014). In the Italian context, this scale has been widely used by previous studies on healthcare professionals working in intensive care units (Lamiani et al., 2017; Lamiani, et al., 2018).

#### 3.4.6.4. Maslach Burnout Inventory – General Survey (MBI-GS)

The gold-standard to assess burnout is the Maslach Burnout Inventory (MBI) which is based on the Christina Maslach's theory describing burnout as a syndrome characterized with three main symptoms, that are emotional exhaustion, cynicism (also called depersonalization) and professional efficacy (Maslach, Jackson, Leiter, Schaufeli, & Schwab, 1986; Maslach, Schaufeli, & Leiter, 2001; Schaufeli, Leiter & Maslach, 2009). Different versions of this instrument have been developed. In the present research, the Maslach Burnout Inventory - General Survey (MBI-GS; Schaufeli, Leiter, Maslach, & Jackson, 1996) was adopted. The Italian validation of MBI-GS is included in another instrument called Organizational Checkup System and it was provided by Borgogni, Galati, & Petitta (2005). The MBI-GS is a 16-item self-report scale composed of three subscales: Emotional Exhaustion referring to feeling emotionally drained at work (5 items; e.g. I feel emotionally drained by my work; I feel used up at the end of the workday), Cynicism describing a negative attitude towards the organization and service recipients (5 items; e.g., I have become less interested in my work since I started this job; I doubt the significance of my work) and Professional Efficacy assessing the feeling of work achievement given by the perception of being able to perform effectively one's own job tasks (6 items; e.g., I feel I am making an effective contribution to this organization; I can efficiently solve problems at work). Each item is rated on a 7-point Likert frequency scale ranging from 0 (never) to 6 (daily). High scores on the emotional exhaustion and cynicism subscales, as well as low scores on the professional efficacy subscale indicate the presence of burnout (Maslach & Leiter, 2008).

It has to be underlined that, in respect to other existing versions, the MBI-GS is shorter and capable to describe broader occupational contexts, having a universal applicability (Maslach, Leiter, & Schaufeli, 2008). For these reasons, it turned to be the most preferred version of MBI (Mäkikangas, Hätinen, Kinnunen, & Pekkonen, 2001). Although MBI-GS is not specifically addressed to healthcare professionals, it was referred to be effectively usable also with these workers (Borgogni et al., 2005). Validation studies (Bria, Spânu, Băban, & Dumitrașcu, 2014) provided more convergent results for MBI-GS than for the version tailored for healthcare professionals that is the Maslach Burnout Inventory for Human Services Survey - MBI-HSS (Maslach & Jackson, 1981). Moreover, in the literature MBI-GS was preferred for mixed samples including ancillary healthcare staff (Bria et al., 2014). Similarly, in this project, the social-healthcare practitioners (*OSS*) were considered eligible participants.

The psychometric properties of the Italian MBI-GS have been referred to be satisfactory. Specifically, as concerns the internal validity of the scales, the following Cronbach's alpha were reported: Emotional Exhaustion:  $\alpha$ =.85; Cynicism:  $\alpha$ =.72; Professional Efficacy:  $\alpha$ =.74. (Borgogni et al., 2005).

The MBI-GS has been extensively used in the international landscape of research focusing on burnout within healthcare professionals (Schutte, Toppinen, Kalimo, & Schaufeli, 2000; Schaufeli et al., 2009; Kitaoka & Masuda, 2013; Bria et al., 2014; Laschinger & Fida, 2014; Kawamura et al., 2018).

#### 3.4.6.5. Hospital Ethical Climate Survey (HECS)

The Hospital Ethical Climate Survey (HECS; Olson, 1998) is a 26-item self-administrated instrument evaluating hospital nurses' perceptions of the ethical climate within their workplace. This scale consisted of five subscales analysing the different kind of relationships between the people and the organization involved in the care pathway. Specifically, the five subscales are the following: Peers (4 items, e.g., *My peers help me with difficult patient care issues/problems; I work with competent colleagues*), Patients (4 items, e.g., *Patients know what to expect from their care; The patient's wishes are respected*), Managers (6 items, e.g., *My manager supports me in my decisions about patient care; When my peers are unable to decide what's right or wrong in a particular patient care situation, I have observed that my manager helps them*), Physicians (6 items, e.g., *Physicians ask nurses for their opinions about treatment decisions; Nurses and physicians here respect each other's opinions, even when they disagree about what is best for patients*) and Hospital (6 items, e.g., *The feelings and values of all parties involved in a patient care issue/problem are taken into account when choosing a course of actions; Conflict is openly dealt with, not avoided*).

Respondents are asked to consider its current job position and its current unit in the hospital in order to answer to each item which is rated on a 5-points Likert scale from 1 (*almost never true*) to 5 (*almost always true*). It is possible to obtain a mean score for the instrument as a whole as well as for individual factors too (Olson, 1998). The greater the HECS score, the more positive the ethical climate.

Starting from conducting a literature review and collective manifold experiences in nursing practice and administration, Olson (1998) developed this scale with the main purpose to provide a valid and reliable instrument to measure how nurses employed in hospital may perceive the climate of their work setting, paying particular attention to ethical concerns and issues. To this regard, it has to be said that the organizational ethical climate may affect ethical practice, job satisfaction, and quality of care (Redman, 2002). This instrument was administered for the first time to 360 American registered nurses employed in two acute care hospitals in one midwestern city (Olson, 1998). It shown good construct and internal validity (e.g., Olson, 1998; Redman, 2002). Specifically, the construct validity was supported by the relationship of this instrument with another tool called Integrity Audit (White and Wallace, 1988) used to assess the ethical climate in non-healthcare settings. As concerns internal consistency, the following Cronbach's alphas were referred: Peers (0.73), Patients (0.68), Managers (0.92), Hospital (0.77), Physicians (0.81), as well as Total score (0.91) (Olson, 1998). To date, HECS has been adopted in many different settings. In particular, it was administered in pediatric cancer units (Bartholdson, Sandeberg, Lützén, Blomgren, & Pergert, 2016) and adult cancer care settings (Charalambous et al., 2018), in older people care institutes (Suhonen, Stolt, Katajisto, Charalambous, & Olson, 2015), as well as in psychiatric units (Lützen, Blom, Ewalds-Kvist, & Winch, 2010; Claeys et al., 2013).

In chapter six is discussed the validation of this instrument for the Italian context.

#### 3.4.6.6. Positive and Negative Affect Schedule (PANAS)

Positive and Negative Schedule (PANAS; Watson et al. 1988; Italian validation of Terraciano, McCrae, & Costa, 2003) encompasses two self-reported scales: Positive Affects (PA) and Negative Affects (NA). Each scale presents 10 items which are words describing different emotions and feelings. The PA scale describes the extent to which a person feels a pleasant condition characterised by enthusiasm, excitement, activation and resolution. Conversely, the NA scale describes a general dimension of unpleasant engagement characterized by manifold adverse affects. In more detail, respondents are asked to indicate how frequently they usually felt each of the listed positive emotional states (e.g. *interested, inspired*) and negative emotional states (e.g. *distressed, irritable*). To do so, they have to mark next to the word the appropriate number describing the intensity of perception of a certain emotional state. The Likert scale ranges from 1 (*very slightly or not at all*) to 5 (*extremely*), both for PA and NA scales.

A mean score is calculated for PA and NA scales, and higher scores indicate higher levels of positive affectivity and negative affectivity, respectively. PANAS can be administered using a slightly different instructions differentiating the state-like and trait-like characteristics of affectivity. In the present research, the focus was put on the person's trait, so asking people to describe the extent they "usually" perceive the emotions mentioned.

The terms used in this instrument have been empirically selected in order to create two scales correlating negatively and the selection proceeded until results suggested stable reliability and validity of the scale (Watson et al., 1988). The Italian translation of the items was completed

through exploratory factor analysis and some terms were adapted to the Italian context. For example, the item "ashamed" was translated using the noun (*vergogna*) instead of the adjective (*vergognoso*), as it presents a slightly different nuance of meaning in the Italian language (Terracciano et al., 2003).

Watson et al. (1988) showed good internal consistency and an excellent convergent and discriminant validity of this instrument. Specifically, both PANAS scales showed high reliability (for PA,  $\alpha = 0.88$ ; for NA,  $\alpha = 0.87$ ) and the correlation between the two scales is invariably low (r= - 0.17). As concerns the Italian validation, Terracciano et al. (2003) unveiled solid psychometric properties. Particularly, the exploratory factor analysis provided congruence coefficients describing good factor structure. Moreover, results showed stable internal validity for both scales (PA:  $\alpha = .83$ ; NA:  $\alpha = .87$ ).

Thanks to its brevity and robust psychometric characteristics, PANAS has become the most widely and frequently used scale in researches assessing affectivity in clinical and not-clinical population (Crawford & Henry, 2004; Díaz-García et al., 2020). The scale has been employed in some studies on healthcare professionals too. Such for example, a study focused on emotions of oncologists administered this scale (Lazányi et al., 2011). Another research examined positive and negative affects as possible mediating factors in the associations of mindfulness, resilience and burnout among primary care physicians (Montero-Marin et al., 2015). Also, a Spanish cross-sectional study adopted PANAS in a research focusing on burnout within primary healthcare professionals (general practitioners, nurses and medical residents) (Montero-Marin et al., 2016).

#### 3.4.6.7. Connor-Davidson Resilience Scale (CD-RISC-10)

The ten-item Connor-Davidson Resilience Scale (CD-RISC-10; Davidson & Connor, 2007; Campbell-Sills & Stein, 2007; Italian validation of Di Fabio, & Pallazzeschi, 2012) is a self-report instrument to assess resilience intended as a monodimensional "*measure of stress coping ability and, as such, could be an important target of treatment in anxiety, depression, and stress reactions*" (Connor & Davidson, 2003, p. 76).

Participants are invited to address ten items asking the level of agreement with ways of facing problems and reacting to stressful situations (e.g., *I try to see the humorous side of things when I am faced with problems; Having to cope with stress can make me stronger*). Each item is rated on a five-point Likert scale ranging from 0 (*almost always false*) to 4 (*almost always true*). A total score is calculated, and it ranges from a minimum of 0 to a maximum of 40. Greater scores indicate greater resilience levels. The median score varies with setting as it appears to be influenced by various factors, in particular by the region where data were collected and the nature of the sample (Davidson & Connor, 2007).

For instance, scores are generally lower in the psychiatric population and in younger adults (Davidson & Connor, 2007). A median score in a community sample was 32, with lowest to highest quartiles being 0-29, 30-32, 33-36 and 37-40 (Campbell-Sills, Forde, & Stein, 2009).

This ten-item scale was developed from a longer version of the same authors encompasses 25 items (Connor & Davidson, 2003). To date, different versions of this scale are available having two, 10 and 25 items (Davidson & Connor, 2007).

The psychometric characteristics of the CD-RISC-10 have been assessed by Campbells-Sills and Stein (2007), three undergraduate samples were involved to conduct exploratory and confirmatory factor analysis. The scale shown good internal consistency (Cronbach's alpha = .85) and a further study also showed good test retest reliability (r = 0.81; Sarubin et al. 2015). The Italian validation unveiled similar psychometric properties too ( $\alpha = .85$ ; Di Fabio, & Pallazzeschi, 2012).

The CD-RISC-10 has been extensively used by international researchers in clinical and not-clinical population (Davidson & Connor, 2007) and it has provided relevand data on resilience among health professionals so far. For instance, a study using the 10-item version of CD-RISC referred that resilience may be a significant protective factor for nurses (Arrogante & Aparicio-Zaldívar, 2017). Similarly, CD-RISC-10 described resilience as a predictive factor for psychological well-being among intensive care nursing staff (Arrogante, Pérez-García, & Aparicio-Zaldívar, 2016). Moreover, CD-RISC-10 was adopted to measure resilience levels among health professionals took place in Alabama after a tornado disaster (Turner, 2015). The CD-RISC-10 has been also provided to Danish hospital staff (Lauridsen, Willert, Eskildsen, & Christiansen, 2017).

#### 3.5. Data analysis

Being a multimethod research project, different kinds of analysis approach and relative tools were adopted. Specifically, as for the quantitative part, descriptive statistics were carried on through the use of IBM SPSS – Statistics 22 (Allen, Bennett, & Heritage, 2014; see chapter four). Moreover, inferential analyses were also conducted. In particular, mediation and moderated mediation models were proposed, and analyses were carried on through Hayes's (2013) PROCESS macro (Model 4 for mediation models, Model 7 for moderated mediation models) and Mplus Version 7 statistical software (Muthèn & Muthèn, 2012, see chapter seven). The value of p. < .05 was considered statistically significant.

As concerns the qualitative part of the project, Grounded Theory (Corbin & Strauss, 2008) and Interpretive Description (Thorne, 2016) approaches were used to collect and analyse interview data within healthcare professionals (see chapter eight) and medical students (see chapter nine), respectively. More details of the data analyses performed are provided in the following chapters in which is described each study conducted.

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## SECTION C The studies

Research is creating new knowledge. Neil Armstrong

## Chapter Four

## Descriptive and preliminary inferential statistics of Italian healthcare professionals

This chapter describes the socio-demographic characteristics of the participants taking part in the quantitative part of the present project. Moreover, the main descriptive and preliminary inferential statistics are displayed, too. More in-depth analysis and inferential statistics are presented in the chapters five, six, seven.

#### 4.1. Response rate

The overall questionnaires collected were 318, corresponding to a response rate of 57,2%. However, the final sample included 315 healthcare professionals (222 neurorehabilitation, 93 palliative care). Two participants were excluded since they did not complete at least the sixty percent of the survey and one other case was deleted because it was identified to be a multivariate outlier. The response rate for each single institute is reported in Table 1.

Institute	Questionnaire collected	Response rate
U.O. Unità Operativa Neuromotoria – Montescano (PV)	73	51.0 %
U.O. di Riabilitazione Specialistica Neuromotoria – Pavia (PV, via Maugeri)	53	76.8 %
U.O. di Riabilitazione Neuromotoria – Telese Terme (BN)	37	58.7 %
U.O. di Cure Palliative – Pavia (PV, via Boezio)	21	40.4 %
Oncology and Hematology Unit, Humanitas Clinical and Research Center – IRCCS, Rozzano (MI)	72	52.6 %
I.R.C.C.S. Santa Lucia - Centro Riabilitativo – Roma (RM)	61	67.8 %

#### Table 1 – Response rates

#### 4.2. Socio-demographic and occupational characteristics

Of the 315 healthcare professionals who participated in the present research, most of them were female (67.0%) nurses (40.6%) with bachelor's degree (48.6%) who did shift work (64.7%) and had open-ended contracts (78.9%). Respondents were employed in neurorehabilitation medicine (70.5%) and palliative care (29.5%) specialties. Most subjects were under 40 years old (46.0%), an overall job tenure above 16 years (43.5%) and a tenure in the current position above 10 years (44.7%). More than half of participants (63.3%) did not report any extra-work stressful event occurred in the last year.

To unveil significant differences between the two specialties, Chi-square analyses were performed. Palliative care professionals were younger ( $X^2=15.16$ ; p=.001) and more of them had less than five years of both overall seniority ( $X^2=21.38$ ; p=.0001) and seniority in the current position ( $X^2=23.68$ ; p=.0001) than colleagues employed in neurorehabilitation discipline. In palliative care specialties, there were more physicians and psychologists, as well as nurses; conversely more physiotherapists and therapists were employed in the neurorehabilitation discipline ( $X^2=50.13$ ; p=.0001). Fewer professionals in palliative care specialty reported to have shift work ( $X^2=4.95$ ; p=.026), while neurorehabilitation professionals had more open-ended work contracts.

Table 2 reports more in detail the socio-demographic and occupational characteristics of the sample considered in this project.

#### 4.3. Research variables

#### 4.3.1 Cronbach's Alpha

Cronbach's Alpha (see Table 3) were calculated for all subscales and scales since this index is the most widely used objective measure of internal reliability (Tavakol & Dennick, 2011).

Of note, it has to be specified that SMiLE enables to calculate Cronbach's alpha for the Index of Satisfaction and the Index of Weighting, but not for the Index of Weighted Satisfaction. Indeed, this latter combines the ratings for satisfaction and weighting, no longer considering the single item (Fegg, SMiLE manual).

	Tot N= 315	Neurorehabilitation medicine n= 222 (70.5%)	Palliative care n= 93 (29.5%)		
		n (% within	n (% within		
	N (%)	specialization)	specialization)	$\mathbf{X}^2$	p.
Gender				.51	.477
Female	211 (67.0)	146 (65.8)	65 (69.9)		
Male	104 (33.0)	76 (34.2)	28 (30.1)		
Age				15.16	.001
$\leq$ 40 years old	144 (46.0)	88 (39.8) *	56 (60.9) *		
41-50 years old	101 (32.3)	74 (33.5)	27 (29.3)		
$\geq$ 51 years old	68 (21.7)	59 (26.7) §	9 (9.8) §		
Missing	2 (0.6)				
Professional role				50.13	.0001
Physician and Psychologist <sup>A</sup>	65 (20.8)	30 (13.6) *	35 (38.0) *		
Nurse	127 (40.6)	81 (36.7) §	46 (50.0) §		
Physiotherapist and others <sup>B</sup>	69 (22.0)	68 (30.8) °°	1 (1.1) °°		
Social-healthcare practitioner	52 (16.6)	42 (19.0)	10 (10.9)		
Missing	2 (0.6)	12 (19.0)	10 (10.5)		
Education	2 (0.0)			26.89	.0001
Middle school diploma	17 (5.4)	16 (7.2)*	1 (1.1) *	20.07	.0001
*					
High school diploma	59 (18.8)	48 (21.7) §	11 (12.0) §		
Bachelor's degree	152 (48.6)	114 (51.6)	38 (41.3)		
Master's degree	9 (2.9)	6 (2.7)	3 (3.3)		
PhD, masters, other specialization	76 (24.3)	37 (16.7) #	39 (42.4) #		
Missing	2 (0.6)				
Shift work				4.95	.026
Yes	198 (64.7)	147 (68.7) *	51 (55.4) *		
No	108 (35.3)	67 (31.3) §	41 (44.6) §		
Missing	9 (2.9)				
Work contract				14.55	.001
Open-ended	240 (78.9)	179 (83.3)*	61 (68.5) *		
Fixed-term	44 (14.5)	29 (13.5)	15 (16.9)		
Temporary, VAT registration, Co-op	20 (6.6)	7 (3.3) §	13 (14.6) §		
Missing	11 (3.5)				
Overalll tenure				21.38	.0001
$\leq$ 5 years	79 (25.2)	40 (18.1) *	39 (42.4) *		
6-15 years	98 (31.3)	74 (33.5)	24 (26.1)		
16-25 years	83 (26.5)	63 (28.5)	20 (21.7)		
$\geq 26$ years	53 (16.9)	44 (19.9) §	9 (9.8) §		
Missing	2 (0.6)		× /		
Tenure in current occupation	x7			23.68	.0001
$\leq 5$ years	99 (31.8)	53 (24.2) *	46 (50.0) *		
6-10 years	73 (23.5)	51 (23.3)	22 (23.9)		
$\geq 10$ years	139 (44.7)	115 (52.5) §	24 (26.1) §		
Missing	4 (1.3)	115 (52.5) 3	27 (20.1) <sup>3</sup>		
Extra work stressful events in last year	+ (1. <i>J</i> )			.49	.483
· · ·	107 (62 2)	136 (62.1)	(1 (66 2))	.49	.400
No Yes	197 (63.3)	136 (62.1)	61 (66.3) 31 (33 7)		
1 05	114 (36.7) 4 (1.3)	83 (37.9)	31 (33.7)		

Table 2 - Socio-demographic and profession	al characteristics of the study sample
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*Note.*  $X^2$  value with  $p \le .05$  are considered significant. For each level of the variable, the values that do differ significantly from each other share the same subscript symbol (based on adjust p- value, Bonferroni method,  $p \le .05$ ). <sup>A</sup> Psychologists have been merged with physicians because of small sample size. Specifically, there are 7 psychologists in medical

rehabilitation unit and 1 psychologist in palliative care unit.

<sup>B</sup> Others includes dieticians, speech therapists and occupational therapists.

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Scales and Subscales	Cronbach's Alpha
SMiLE - IoS	.76
SMiLE - IoW	.69
MASI-R (total)	.89
MASI-R Wellness	.80
MASI-R Resilience	.87
MASI-R Social Support	.74
MASI-R Coping	.51
MDS-R (total)	.88
MDS-R Futile Care	.76
MDS-R Ethical Misconduct	.63
MDS-R Deceptive Communication	.55
MDS-R Poor Teamwork	.83
MBI-GS Emotional Exhaustion	.91
MBI-GS Cynicism	.79
MBI-GS Professional Efficacy	.82
HECS (total, italian version – see chapter six)	.88
HECS Ethical vision of patient care	.87
HECS Managerial support (in dealing with ethical issues)	.95
PANAS PA	.85
PANAS NA	.84
CD-RISC 10	.87

Table 3 - Cronbach's Alpha values

Note. SMiLE – IoS = Schedule for Meaning in Life Evaluation – Index of total Satisfaction; SMiLE – IoW = Schedule for Meaning in Life Evaluation - Index of total Weighting; MASI-R= Maugeri Stress Index - Revised; MASI-R Wellness= Maugeri Stress Index - Revised, subscale Wellness; MASI-R Resilience= Maugeri Stress Index - Revised, subscale Resilience; MASI-R Social Support= Maugeri Stress Index - Revised, subscale Social Support; MASI-R Coping= Maugeri Stress Index - Revised, subscale Coping; MDS-R= Moral Distress Scale - Revised; MDS-R Futile Care= Moral Distress Scale - Revised, subscale Futile Care; MDS-R Ethical Misconduct= Moral Distress Scale -Revised, subscale Ethical Misconduct; MDS-R Deceptive Communication= Moral Distress Scale – Revised, subscale Deceptive Communication; MDS-R Poor Teamwork= Moral Distress Scale – Revised, subscale Poor Teamwork; HECS= Hospital Ethical Climate Survey; HECS Ethical vision of patient care= Hospital Ethical Climate Survey, subscale Ethical vision of patient care; HECS Managerial support (in dealing with ethical issues)= Hospital Ethical Climate Survey, subscale Managerial support (in dealing with ethical issues); MBI-GS Emotional Exhaustion= Maslach Burnout Inventory - General Survey, scale Emotional Exhaustion; MBI-GS Cynicism= Maslach Burnout Inventory - General Survey, scale Cynicism; MBI-GS Professional Efficacy= Maslach Burnout Inventory - General Survey, scale Professional Efficacy. PANAS PA= PANAS Positive and Negative Schedule, scale Positive Affectivity; PANAS NA= Positive and Negative Schedule, scale Negative Affectivity; CD-RISC 10= Connor-Davidson Resilience Scale, ten items.

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#### 4.3.2 Descriptive statistics

The table 4 reports the mean and standard deviation of the variables if considering the total sample, along with skewness and kurtosis values. Normality of the data was considered acceptable when skewness < |3.0| and kurtosis < |8.0| (Kline, 2011).

Since this condition was respected by the data collected, the distribution of data was assumed to be normal and proper statistical analyses were carried on.

	N	Response	Mean	Std.	Ske	wness	Ku	ırtosis
	IN	range	Mean	Deviation	Statistic	Std. Error	Statistic	Std. Error
SMiLE - IoWS	288	0-100	77.63	17.81	-1.43	.14	2.99	.29
SMiLE - IoS	290	0-100	77.15	17.59	-1.30	.14	2.60	.29
SMiLE - IoW	289	0-100	83.69	12.04	73	.14	.74	.29
MASI-R Overall score	261	1-5	3.50	.40	14	.15	.31	.30
MASI-R Wellness	314	1-5	3.37	.66	11	.14	36	.27
MASI-R Social Support	314	1-5	3.53	.65	17	.14	14	.27
MASI-R Resilience	293	1-5	3.72	.47	12	.14	.18	.28
MASI-R Coping (reversed)	293	1-5	3.70	.58	41	.14	.17	.28
MDS-R Overall score	305	0-16	3.11	2.45	.96	.14	.56	.28
MDS-R Deceptive Comm.	303	0-16	2.86	2.79	1.28	.14	1.52	.28
MDS-R Futile Care	298	0-16	3.85	3.64	1.07	.14	.48	.28
MDS-R Misconduct	303	0-16	2.02	2.13	1.35	.14	1.68	.28
MDS-R Poor Teamwork	299	0-16	4.56	3.94	.90	.14	.21	.28
MBI-GS E. Exhaustion	309	0-6	2.55	1.52	.61	.14	36	.28
MBI-GS Prof. Efficacy	309	0-6	4.33	1.01	55	.14	.35	.28
MBI-GS Cynicism	309	0-6	1.72	1.34	1.12	.14	1.18	.28
HECS Overall score	309	1-5	3.74	.67	58	.14	.03	.28
HECS Ethical vision pt. care	309	1-5	3.52	.70	23	.14	52	.28
HECS Managerial Support	308	1-5	4.08	.86	-1.13	.14	.97	.28
PANAS Positive Affectivity	307	1-5	3.54	.61	36	.14	.19	.28
PANAS Negative Affectivity	307	1-5	1.74	.59	.98	.14	.73	.28
CD-RISC-10	308	0-4	2.65	.72	75	.14	1.11	.28

#### Table 4 – Descriptive statistics

*Note.* SMiLE – IoSW = Schedule for Meaning in Life Evaluation – Index of Weighted Satisfaction; MDS-R Deceptive Comm. = MDS-R Deceptive Communication; MBI-GS E. Exhaustion = MBI-GS Emotional Exhaustion; MBI-GS Prof. Efficacy = MBI-GS Professional Efficacy; HECS Ethical vision pt. care = HECS Ethical vision of patient care; HECS Managerial Support = HECS Managerial support in dealing with ethical issues.

#### 4.3.3 Correlations among all variables

Firstly, data were explored by conducting Pearson's correlations among all variables, considering both the overall scores and the sub-scale scores of variables investigated in the present research. Table 5 shows these correlations.

All correlations were in the expected directions according what suggested by the previous literature. Thus, overall index of meaning in life (IoWS) was statistically significantly and positively associated to wellbeing (MASI-R Overall score; r = .38, p < .01), professional efficacy (MBI-GS Professional Efficacy; r = .15, p < .05), ethical climate (HECS Overall score; r = .22, p < .01), positive affectivity (PANAS Positive Affect; r= .29, p < .01) and resilience (CD-RISC-10; r= .14, p < .05). Whereas, it was statistically significantly and negatively related to moral distress (MDS-R Overall score; r = -.16; p <.01), emotional exhaustion (MBI-GS Emotional Exhaustion; r = -.22; p <.01), cynicism (MBI-GS Cynicism; r = -.14; p < .05) and negative affectivity (PANAS Negative Affect; r = -.22, p <.01). Additionally, wellbeing (MASI-R Overall score) were statistically significantly and positively associated with professional efficacy (MBI-GS Professional Efficacy; r= .55, p <.01), ethical climate (HECS Overall score; r= .37, p <.01), positive affectivity (PANAS Positive Affect; r= .64, p <.01) and resilience (CD-RISC-10; r = .59, p <.01). Whereas, the same index of wellbeing was statistically significantly and negatively related to moral distress (MDS-R Overall score; r = -.18; p <.01), emotional exhaustion (MBI-GS Emotional Exhaustion; r = -.35; p <.01), cynicism (MBI-GS Cynicism; r = -.35; p < .01) and negative affectivity (PANAS Negative Affect; r = -.48, p < .01). Furthermore, moral distress (MDS-R Overall score) was statistically significantly and positively associated with emotional exhaustion (MBI-GS Emotional Exhaustion; r=.23; p <.01), cynicism (MBI-GS Cynicism; r = .13; p < .05) and negative affectivity (PANAS Negative Affect; r = .32, p <.01); whereas it was statistically significantly and negatively related to professional efficacy (MBI-GS Professional Efficacy; r = -.12, p < .05) and ethical climate (HECS Overall score; r = -.25, p <.01). Also, emotional exhaustion (MBI-GS Emotional Exhaustion) was statistically significantly and positively associated with cynicism (MBI-GS Cynicism; r = .54; p < .01) and negative affectivity (PANAS Negative Affect; r = .38, p < .01); whereas it was statistically significantly and negatively related to ethical climate (HECS Overall score; r = -.23, p < .01), positive affectivity (PANAS) Positive Affect; r = -.25, p < .01) and resilience (CD-RISC-10; r = -.15, p < .01). Similarly, cynicism (MBI-GS Cynicism) was statistically significantly and positively associated with negative affectivity (PANAS Negative Affect; r = .35, p < .01), whereas it was statistically significantly and negatively related to ethical climate (HECS Overall score; r = -.30, p < .01) and positive affectivity (PANAS Positive Affect; r = -.28, p <.01). Considering professional efficacy (MBI-GS Professional Efficacy), it was statistically significantly and positively associated with ethical climate (HECS Overall score;

 Table 5 - Correlations

	IoWS	MASI-R	MASI-R Wellness	MASI-R Social Supp	MASI-R Resilience	MASI-R Coping	MDS-R	MDS-R Dec. Com.	MDS-R Futile care	MDS-R Misconduct	MDS-R Poor team.	MBI-GS E. Exhaust.	MBI-GS Prof.Eff.	MBI-GS Cynicism	HECS	HECS Ethical vision	HECS Man. Supp	PANAS Pos. Affect.	PANAS Neg. affect.	CD-RISC-10
IoWS	-																			
MASI-R Overal score	.38**	-																		
MASI-R Wellness	.46**	.82**	-																	
MASI-R Social Sup	.30**	.72**	.49**	-																
MASI-R Resilience	.24**	.91**	.61**	.51**	-															
MASI-R Coping (score revised)	.15*	.47**	.26**	.20**	.30**	-														
MDS-R Overall Score	16**	18**	12*	16**	09	17**	-													
MDS-R Dec Com.	17**	15*	10	12*	07	12*	.85**	-												
MDS-R Futile care	.00	13*	03	04	09	14*	.82**	.60**	-											
MDS-R Misconduct	16**	18**	14*	17**	09	22**	.82**	.62**	.67**	-										
MDS-R Poor team.	20**	13*	16**	22**	06	11	.83**	.64**	.45**	.57**	-									
MBI-GS E. Exhaust	22**	35**	28**	26**	25**	28**	.23**	.18**	.26**	.24**	.14*	-								
MBI-GS Prof. Eff	.15*	.55**	.38**	.40**	.58**	.18**	12*	13*	07	12*	11	07	-							
MBI-GS Cynicism	14*	35**	22**	31**	22**	20**	.13*	.07	.15**	.15**	.11	.54**	14*	-						
HECS Overal score	.22**	.37**	.23**	.54**	.27**	.10	25**	20**	09	19**	37**	23**	.37**	30**	-					
HECS Ethical Vision	.23**	.33**	.23**	.43**	.21**	.10	24**	19**	09	19**	36**	23**	.36**	33**	.85**	-				
HECS Menag. Support	.14*	.29**	.17**	.54**	.18**	.09	16**	15*	03	17**	24**	21**	.25**	24**	.84**	.54**	-			
PANAS Pos. Affect.	.29**	.64**	.53**	.43**	.62**	.25**	07	05	02	13*	06	25**	.53**	28**	.27**	.27**	.17**	-		
PANAS Neg. Affect.	22**	48**	40**	28**	31**	51**	.32**	.26**	.20**	.32**	.30**	.38**	24**	.35**	24**	28**	18**	28**	-	
CD-RISC-10	.14*	.59**	.41**	.33**	.60**	.33**	04	03	.02	09	04	15**	.51**	11	.23**	.21**	.18**	.60**	40**	-

Note. \*\* Correlation is significant at the 0.01 level (2-tailed), \* Correlation is significant at the 0.05 level (2-tailed)

r= .37, p <.01), positive affectivity (PANAS Positive Affect; r= .53, p <.01) and resilience (CD-RISC-10; r= .51, p <.01), whereas it was statistically significantly and negatively related to cynicism (MBI-GS Cynicism; r= -.14; p <.05) and negative affectivity (PANAS Negative Affect; r= -.24, p <.01). Additionally, ethical climate (HECS Overall score) was statistically significantly and positively associated with positive affectivity (PANAS Positive Affect; r= .27, p <.01) and resilience (CD-RISC-10; r= .23, p <.01), whereas it was statistically significantly and negatively related to negative affectivity (PANAS Negative Affect; r= -.24, p <.01). Finally, positive affectivity (PANAS Negative Affect; r= .27, p <.01) and resilience (CD-RISC-10; r= .60, p <.01) and negatively related to negative affectivity (PANAS Negative Affect; r= -.28, p <.01); whereas negative affectivity (PANAS Negative Affect) was statistically significantly and negatively related to resilience (CD-RISC-10; r= .40, p <.01).

#### 4.3.4 Differences by groups regarding research variables

Independent t-tests and one-way ANOVA tests were conducted to detect possible differences in the self-perception of variables, and significant differences were displayed by tables 6 to 14.

Although scores of all variables did not unveiled any critical areas, focusing only on the overall scores of research variables, manifold differences emerged.

As concerns the *indexe of meaning in life (SMiLE)*, statistically significant differences were detective regarding shift work such that who has this kind of work reported higher levels of weighted satisfaction (IoWS; M=79.54, SD=7.87) compared to whom has no shift work (M= 73.59, SD= 17.30; t(279)= 2.71, p=.007. Additionally, who did not experience extra-work stressful events reported higher levels of weighted satisfaction (IoWS; M=79.85, SD=16.66) compared to whom experience these such of events (M= 73.84, SD= 19.23), t(284)= 2.78, p=.006.

Regarding the *index of eustress/distress (MASI-R Overall score)*, who has a shift work reported higher levels of wellbeing (M=3.56, SD=.39) compared to whom has no shift work (M= 3.41, SD= .38; t(253)= 2.85, p=.005. Moreover, social-healthcare practitioners stated higher levels of overall wellbeing (M=3.68, SD= .33) in respect to both physicians/psychologists (M=3.40, SD= .39) and physiotherapists/other therapists (M= 3.41, SD=.39), F(3,308)=5.58, p=.001.

Considering *moral distress (MDS-R Overall score*), physiotherapists/other therapists (M= 2.13, SD=1.70) reported higher levels of moral distress compared to physicians/psychologists (M=3.48, SD= 2.37) and nurses (M=3.67, SD=2.61), F(3,261)=6.41, p<.001. Furthermore, professionals having a work tenure in the current position of 6-10 years (M=3.90, SD=2.50) described higher levels of moral distress compared to colleagues with more than 10 years of work tenure in the current position (M=2.73, SD=2.44), F(2,261)=4.53, p=.012.

As concerns *burnout (MBI-GS)*, the only statistically significant difference unveiled regarded cynicism, such that professionals having a shift work (M= 1.84, SD= 1.46) reported higher levels of this dimension in respect to colleagues without shift work (M= 1.48, SD=1.09), t(298)= 2.49, p=.014.

Putting attention on *ethical climate (HECS Overall scores)*, it has to be highlighted that who has not a shift work (M=3.85, SD=.62) reported higher levels of positive ethical climate in respect to other colleagues having shift works (3.67, SD=.69), t(298)=-2.23, p=.027. Additionally, physicians/psychologists (M= 3.97, SD=.53) reported higher levels of positive ethical climate in respect to physiotherapists/other therapists (M=3.53, SD=.74), F(3,303)=5.15, p=.002. Also, professionals with higher specializations (M=3.93, SD=.56) stated a more positive ethical climate in respect to colleagues with bachelors' degree (3.64, SD=.66), F(4,302)=2.66, p=.033.

Finally, as concerns *affectivity* (*PANAS*), professionals who experienced extra-work stressful events (M=1.85, SD=.61) reported more negative affectivity levels (PANAS NA) in respect to others who did not experience such events (M=1.67, SD=.56), t(301)=-2.65, p=.009. Moreover, professionals with a fixed-term work contract (M= 3.76, SD= .56) stated higher levels of positive affectivity (PANAS PA) compared to colleagues with an open-ended work contract (M=3.51, SD=.60), F(2,293)=3.12, p=.046.

#### Table 6 - Differences regarding gender

	Gen	ıder			
Scales	Male	Female	t	df	Sig.
MASIR Resilience	3.80±.43	3.68±.49	2.10	291	.036
MDSR Poor Teamwork	$3.86 \pm 3.35$	4.88±4.16	-2.03	284	.043

	Shift	work			
Scales	Yes	No	t	df	Sig.
IoWS	79.54±17.87	73.59±17.30	2.71	279	.007
IoS	79.21±17.74	72.75±16.83	2.98	280	.003
MASI-R Overall score	3.56±.39	3.41±.38	2.85	253	.005
MASI-R Wellness	3.45±.67	3.21±.61	3.05	303	.003
MASI-R Resilience	3.77±.46	3.62±.47	2.68	284	.008
MDS-R Futile Care	4.37±3.90	$2.97 \pm 2.96$	3.21	273	.002
MBI-GS Cynicism	1.84±1.46	$1.48 \pm 1.09$	2.49	298	.014
HECS Overall score	3.67±.69	3.85±.62	-2.23	298	.027
HECS Ethical vision	3.43±.74	3.65±.60	-2.59	298	.010

## Table 7 - Differences regarding shift work

## Table 8 – Differences regarding extra-work stressful events

	Extra-work s	stressful events			
Scales	Yes	No	t	df	Sig.
IoWS	73.84±19.23	79.85±16.66	2.78	284	.006
IoS	73.38±19.25	79.36±16.27	2.81	286	.005
MASI-R Wellness	3.25±.69	3.46±.64	2.72	308	.007
PANAS - NA	1.85±.61	$1.67 \pm .56$	-2.65	301	.009

## Table 9 – Differences regarding age

		Age (age)				
Scales	<b>≤</b> 40	41-50	≥ 51	F	df	Sig.
MASI-R Coping (reverse)	3.66±.63 <sup>A</sup>	3.84±.49 <sup>A B</sup>	3.60±.57 <sup>B</sup>	4.21	2,288	.016

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		0	ccupation				
Scales	Physician/ psychologist	nurse	Physiotherapist/ other therapist	Social- healthcare practitioner	F	df	Sig.
IoS	73.32±14.13 <sup>A</sup>	79.15±17.42	73.00±18.26 <sup>B</sup>	83.64±19.24 <sup>A B</sup>	4.96	3,284	.002
MASI-R Overall score	3.40±.39 <sup>A</sup>	3.53±.40	3.41±.39 <sup>B</sup>	3.68±.33 <sup>A B</sup>	5.58	3,308	.001
MASI-R Wellness	3.21±.62 A	3.39±.69	3.28±.63 <sup>в</sup>	3.65±.64 <sup>A</sup> <sup>B</sup>	4.93	3,308	.002
MASI-R Resilience	3.63±.43 <sup>A</sup>	3.69±.47 <sup>в</sup>	3.65±.47 <sup>C</sup>	3.99±.42 <sup>АВС</sup>	7.01	3,287	.000
MDS-R Overall score	3.48±2.37 A	3.67±2.61 <sup>B</sup>	2.13±1.70 <sup>A B</sup>	2.83±2.71	6.41	3,261	.000
MDS-R Deceptive C.	3.49±2.83 <sup>A</sup>	3.37±3.00 <sup>B</sup>	1.62±1.66 <sup>A B</sup>	$2.54 \pm 3.03$	7.35	3,280	.000
MDS-R Futile care	3.77±3.04 A	5.14±4.04 <sup>B</sup>	1.99±2.33 <sup>АВ</sup>	3.54±3.78	11.68	3,277	.000
HECS Overall score	3.97±.53 <sup>A</sup>	3.74±.65	3.53±.74 <sup>A</sup>	3.75±.69	5.15	3,303	.002
HECS Ethical vision	3.72±.66 A	3.50±.69	3.37±.66 A	3.50±.79	2.86	3,303	.037
HECS Managerial S.	4.35±.70 <sup>A</sup>	4.09±.80	3.76±1.08 <sup>A</sup>	4.13±.72	5.53	3,302	.001

Table 10 – Differences regarding occupational role	Table 10 – Differences	regarding	occupational	role
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## Table 11 – Differences regarding education level

Education								
Scales	Middle school	High school	Bachelor's degree	Master's degree	Higher specialization	F	df	Sig.
IoS	91.05±10.73 <sup>A B</sup>	79.34±19.38	76.72±17.43 <sup>A</sup>	75.63±32.51	73.97±14.40 <sup>B</sup>	3.30	4,285	.012
HECS Overall	3.80±.88	3.70±.74	3.64±.66 <sup>A</sup>	3.93±.64	3.93±.56 <sup>A</sup>	2.66	4,302	.033

## Table 12 – Differences regarding work contract

Work contract								
Scales	Open- ended	Fixed- term	Temporary/ Co-op/VAT	F	df	Sig.		
HECS Managerial support	4.00±.91 <sup>A</sup>	4.42±.53 <sup>A</sup>	4.46±.63	6.44	2,294	.002		
PANAS - PA	3.51±.60 <sup>A</sup>	3.76±.56 <sup>A</sup>	3.51±.76	3.12	2,293	.046		

Overall tenure (years)							
Scales	< 5	6-15	16-25	≥ 26	F	df	Sig.
MASI-R Coping (reverse)	3.55±.64 <sup>A</sup>	3.77±.57	3.86±.46 <sup>∧ B</sup>	3.55±.62 <sup>в</sup>	5.33	3,287	.001
MDS-R Poor teamwork	4.74±4.07	5.36±3.93 <sup>A</sup>	4.53±4.11	2.99±3.08 <sup>A</sup>	3.89	3,280	.010
HECS Managerial support	4.29±.69 <sup>A</sup>	3.98±.90	3.89±.94 <sup>A</sup>	<b>4.24±.</b> 80	4.00	3,302	.008

#### Table 14 – Differences regarding tenure in current occupation

Tenure in current occupation (years)								
Scales	≤ 5	6-10	≥ 10	F	df	Sig.		
MASI-R Social Support	3.62±.62 <sup>A</sup>	3.62±.56	3.40±.68 <sup>A</sup>	4.68	2,307	.010		
MDS-R Overall score	3.10±2.36	3.90±2.50 <sup>A</sup>	2.73±2.44 <sup>A</sup>	4.53	2,261	.012		
MDS-R Deceptive Comm.	$2.88 \pm 2.63$	3.77±3.05 <sup>A</sup>	2.38±2.69 <sup>A</sup>	5.47	2,280	.005		
MDS-R Poor teamwork	<b>4.59±3.7</b> 0	5.72±4.25 <sup>A</sup>	3.98±3.88 <sup>A</sup>	4.23	2,280	.015		
HECS Social Support	4.24±.70 <sup>A</sup>	4.25±.73 <sup>в</sup>	3.87±.98 <sup>A B</sup>	7.59	2,302	.001		

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Section C: Chapter 5 - The Meaning in Life for palliative and neurorehabilitation medicine professionals

## Chapter Five

## The Meaning in Life for palliative and neurorehabilitation medicine professionals

#### 5.1. An introduction to the investigation of MIL

The psychological construct of meaning in life (MiL) has gained interest among researchers in positive psychology due to its potential protective role. It was defined as a process comprising cognitive, motivational and emotional components sustaining individuals to provide sense to life events (Reker, 2000). This construct is positively associated with life satisfaction (Steger, Oishi, & Kesebir, 2011), self-esteem (Routledge et al., 2010), resistance to stress (Park & Baumeister, 2017), higher quality of life, psychological wellbeing (Melton & Schulenberg, 2008), adequate coping styles (McKnight & Kashdan, 2009), and with lower depression and anxiety (Mascaro & Rosen, 2006). Furthermore, MiL seems to be related with age, since older people reported more meaning in life than younger and, regardless of life stages, high perceived meaning in life was associated with higher wellbeing (Steger, Oishi, & Kashdan, 2009). For instance, studies analyzing gender differences revealed that females considered more important a general feeling of fulfilment in life compared to males who, instead, valued as more relevant their leisure time (Grouden & Jose, 2014). Also, females considered more relevant the wellbeing, while self-actualization was more worthful for males (Schnell, 2009).

Among different protective factors promoting wellbeing in healthcare professionals, MiL may play a relevant role as it showed associations with lower levels of psychological distress, negative affect and burnout (Taubman-Ben-Ari & Weintroub, 2008; Loffler, Knappe, Joraschkt, & Pohlmann, 2010; Hill et al., 2017; Tsai et al., 2018; Barnett, Moore, Garza, 2019). However, this construct is still scarcely studied. Thus, the present research aims to investigate MiL in palliative care and neurorehabilitation professionals, as they frequently are asked to face with demanding situations paving the way to burnout, moral distress and impoverishment of quality of life (Horn & Johnston, 2020; Sliwa et al., 2019; Samson & Shvartzman, 2018). Indeed, both these medical disciplines, even addressing different care needs, have to deal with demanding issues coming from patients affected by very severe health conditions.

The instrument called SMiLE may be considered one of the best tool to assess this kind of construct as it adopts an idiographic approach which enables to valorize the subjective perspective. For this reason, it was chosen in this project.

Previously, SMiLE was implemented only among palliative healthcare professionals and professionals employed in maternity, demonstrating the usability of this instrument also with

healthcare professionals (Fegg, L'hoste, Brandstätter, & Borasio, 2014) and not only with patients (Fegg, Kramer, L'hoste, & Borasio, 2008; Stiefel et al., 2008; Fegg et al., 2010; Fegg, Kögler, Abright, Hensler, & Lorenzl, 2013; Mello & Ashcraft, 2014; Bernard et al., 2017; Volkert et al., 2019). However, no previous research investigated possible MiL differences among different medical disciplines which are requested to face highly demanding clinical situations. Although each medical discipline address different medical needs, some professionals have in common the management of clinical conditions that are particularly emotionally demanding.

Thus, the paper presented in this chapter describes the implementation of SMiLE among palliative care and neurorehabilitation professionals, detecting differences and commonalities and providing suggestions for preventive and supportive interventions.

# 5.2. The current investigation of MIL in palliative care and neurorehabilitation medicine professionals

Maffoni Marina, Zanatta Francesco, Setti Ilaria, Giorgi Ines, Laura Velutti, Giardini Anna. SMiLE to life: Meaning in Life within healthcare professionals working in palliative care and rehabilitation medicine. *Manuscript submitted for publication on 2<sup>nd</sup>December 2020 to Supportive Care in Cancer, under review*.

In the healthcare landscape, manifold protective factors are identified, such as meaning in life (MiL) namely what gives sense to life events. However, still little is known on this construct in the healthcare population. Thus, the aim of the current study is to describe MiL among healthcare professionals employed in palliative care and neuro-rehabilitation medicine, unveiling possible differences related to medical speciality and socio-demographic characteristics. In this cross-sectional and multicentre study, palliative care and neurorehabilitation professionals were recruited. MiL was evaluated with the Schedule for Meaning in Life Evaluation (SMiLE) which provides a list of meaningful areas, as well as related overall indexes of satisfaction (IoS), weighting (IoW), weighted satisfaction (IoWS). Descriptive statistics, t-test, chi-square, linear and binary logistic regressions were performed. Overall, 297 healthcare professionals completed the evaluation. Palliative care professionals were younger than neuro-rehabilitation professionals (p<0.001). The sample resulted heterogeneous for occupation (p<0.0001). Conversely, no significant group differences emerged in MiL indexes comparisons, nor in the number of MiL listed areas. As for MiL areas, the category "family" increased IoWS index, while terms related to "finances" contributed to decrease it. Palliative care professionals were more likely to report areas like "partnership", "social commitment", and "satisfaction". Nurses, social-healthcare practitioners and therapists were more likely to mention health-related terms (e.g. health, physical wellbeing) than physicians and psychologists. This study highlighted MiL areas among professionals employed in palliative care and neuro-rehabilitation specialties, providing informative suggestions for tailored health prevention programs which should pay particular attention to social and family relationships, socio-economic status and health.

Key words. Meaning in life; healthcare professionals; chronicity; palliative care; rehabilitation.

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## Introduction

The growing number of chronic and incurable diseases led palliative care and rehabilitation professionals to face an increasing number of demanding challenges (James et al., 2018). Specifically, palliative care professionals are constantly in contact with death and dying patients and this condition may expose them to potential moral and existential dilemma (Sansó et al., 2015; Maffoni, Argentero, Giorgi & Giardini, 2019). Similarly, working in rehabilitation medicine exposes to patient suffering from critical and chronic illnesses of different nature. Thus, these professionals are exposed to challenging clinical situations, emotional burden, as well as to legal and bioethical issues (Maffoni, Argentero, Giorgi, Hynes, et al., 2019; Sliwa et al., 2019; Maffoni et al., 2020). These aspects may represent for healthcare professionals a fertile ground for burnout, moral distress and impoverishment of quality of life (Maffoni, Argentero, Giorgi & Giardini, 2019; Maffoni, Argentero, Giorgi, Hynes, et al., 2019; Sliwa et al., 2019; Hynes et al., 2019). Among different kinds of protective factors, there is Meaning-in-life (MiL), namely all the cognitive, motivational and emotional components sustaining individuals to give sense to life (Reker, 2000). It plays a crucial role as working in such settings may activate a process of "meaning making" concerning life and work issues, aiming to maintain a protective work-life balance (Maffoni et al., 2020; Allan et al., 2015) and a broader wellbeing (Steger et al., 2009). Researches focusing on healthcare professionals, suggested the positive influence of MiL on both health and professional outcomes (Taubman-Ben-Ari & Weintroub, 2008; Loffler et al., 2010; Hill et al., 2017; Tsai et al., 2018; Barnett et al., 2019). Despite its relevance, little is known on the relationship between subjective characteristics and MiL in healthcare professionals. To the best of our knowledge, it is possible to report only one study indicating that higher MiL is associated with higher age among nurses, and with greater exposure to death during previous six months among physicians (Taubman-Ben-Ari & Weintroub, 2008). Thus, the present study aims to shed light on some sociodemographic features related to MiL in healthcare professionals.

As MiL refers to subjective perspectives, measurements basing on standardized models and preselected domains may not adequately explain the complexity of this construct (Carr & Higginson, 2003; Fegg et al., 2008). Considering this, The Schedule for Meaning in Life Evaluation (SMiLE) may be a promising instrument (Fegg et al., 2008), since it provides an individualized assessment of MiL, focusing not only on personal meaning areas, but also

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on perceived intensity and weight. These characteristics led to choose this instrument in the present study.

As for instrument implementation, the SMiLE was adopted in a representative sample of Germans, French, and Italians (Fegg et al., 2007; Bernard et al., 2015), different clinical populations (Fegg et al., 2008; Volkert et al., 2019; Fegg, Kögler, et al., 2010; Fegg et al., 2013; Mello & Ashcraft, 2014; Fegg, Brändstatter et al., 2010; Stiefel et al., 2008; Bernard et al., 2017) and with bereaved informal caregivers (Brändstatter et al., 2014). One study only implemented the SMiLE among palliative healthcare professionals, providing results from a comparison with professionals which were working in a very different medical unit such as maternity wards (Fegg et al., 2014). However, no previous research investigated MiL among different medical disciplines which are requested to face highly demanding situations.

Thus, a first aim of the current study is to investigate MiL areas in professionals working in palliative care and in neuro-rehabilitation, exploring possible differences related to two specialties coping with patients suffering from severe conditions. Moreover, a second aim was to detect possible differences in MiL area linked to professional role, age and gender.

#### Methods

The current study is part of the research project *Anonymised* approved by the Ethical Committee of *Anonymised* 

#### Study design, Sample and Procedures

This research had a cross-sectional, observational and multicentre study design. Healthcare Professionals (physicians, psychologists, nurses, physiotherapists, dieticians, speech therapists, occupational therapists and social-healthcare practitioners) working in palliative care or in neuro-rehabilitation medicine were recruited on a voluntary basis in six Italian hospitals. The participants were asked to paper-pencil complete the questionnaire and to place it in a cardboard box located in a common hall. To guarantee anonymity, few socio-demographic data were collected (gender, age and professional role).

Written informed consent was provided from all participants before joining the study and any form of reimbursement was given.

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## Measure

Subjects were assessed with the Schedule for Meaning in Life Evaluation (SMiLE; Fegg et al., 2008). In the Schedule, respondents are asked to list three to seven relevant areas providing meaning to their lives in their current situation. Next, rates on the satisfaction level (-3: *very unsatisfied*, +3: *very satisfied*) and on importance of each listed area (0: *not important*, 7: *extremely important*) are requested. Importance ratings were collected with an 8-point Likert scale in order to avoid ceiling effects (Bernard et al., 2017; Fegg et al., 2014), differently from previous publications (Fegg et al., 2008; Fegg, Kögler, et al., 2010; Fegg, Brändstatter et al., 2010).

Three overall scores are obtained:

- Index of Satisfaction (IoS): indicating the mean satisfaction or dissatisfaction with the individual areas, in which the higher the score the higher the satisfaction level (IoS range: 0-100);
- Index of Weighting (IoW): indicating the mean weighting of the MiL, where higher scores indicate higher levels of importance (IoW range: 0-100);
- Index of Weighted Satisfaction (IoWS): resulting from the combination of satisfaction and importance ratings (IoWS range: 0-100). Higher scores reflect higher MiL.

Levels of satisfaction and importance in each area are independent from each other and may change independently: an individual may be satisfied in a particular area assigning no importance to it, whereas in another area levels may be higher both in satisfaction and in importance. The IoWS, as a comprehensive index, takes in consideration both satisfaction and importance ratings expressed in each MiL area (Fegg et al., 2008).

The validation of the instrument provided good psychometric properties, including test-retest reliability, convergent and discriminant validity (Fegg et al., 2008). The Italian version of the SMiLE was administered in this study following the author's manual prescriptions (Fegg, n.d.).

### Statistical Analysis

Chi-squared test was used to observe potential differences within the levels of the sociodemographic variables (i.e. gender, age and occupation).

Frequencies of the emerged categories - both for the total sample and for the two subsamples - were reported. In addition, Chi-squared tests were run to detect possible differences in

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frequency of categories mentioned by palliative care as compared to neuro-rehabilitation professionals.

Student's *t*-test was used to both identify differences of SMiLE total indexes within the two subsamples and to compare the number of MiL areas listed.

To identify differences in the likelihood in listing each MiL area (dependent variable), binary logistic regressions were conducted assuming all sociodemographic variables (i.e. gender, age, specialty and professional role) as independent variables. For all MiL categories, the odds ratio Exp(B) along with its p-value of each sociodemographic variable were reported.

Moreover, linear model regression analyses were performed to analyze which MiL areas (independent variables) may contribute to IoWS (dependent variable). Socio-demographic variables (i.e. gender, age and professional role) were considered control variables. The total explained variance ( $R^2$ ) and the unstandardized regression coefficient (*B*) for each independent variable with its respective P-value were reported.

For undergoing linear and binary logistic regressions, dummy variables were created for categorical non-binary variables. Statistical significance was set at p < 0.05. Due to the exploratory character of the results, no p-value adjustment was performed.

#### Results

## Socio-demographic Characteristics

The socio-demographic characteristics are presented in Table 1. Significant differences between the two subsamples emerged only for age ( $X^2=14.7$ , p=0.001) and for occupation ( $X^2=50.9$ , p=0.0001).

[Table 1 near here]

#### MiL Areas and Indexes

The MiL areas were subsumed under 15 categories reported in the manual and in previous literature within European countries, including Italy (Fegg et al., 2007; Bernard et al., 2015) and a new category labelled "universal values" was included, encompassing terms linked to universal rights and values (e.g. respect, trust, honesty, peace, dignity).

In Table 2, means and standard deviations of satisfaction (S) and weight (W) for both subsamples are displayed. The percentages of professionals mentioning each category are reported in Table 3. Specifically, the categories "partnership", "satisfaction", "social

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commitment" and "universal values" are significantly more mentioned by palliative care professionals, while "family" were significantly more reported by neuro-rehabilitation medicine professionals.

Furthermore, the two groups of professionals did not differ in terms of the numerosity of MiL areas listed, IoW, IoS and IoWS (Table 4).

[Table 2 near here] [Table 3 near here] [Table 4 near here]

## Likelihood in listing MiL Areas

Binary logistic regressions revealed the impact of different variables on the likelihood that healthcare professionals would report a certain category (Table 5). Professionals working in palliative care were more likely to report areas falling within the categories "partnership", "satisfaction" and "social commitment" in respect to colleagues employed in neuro-rehabilitation medicine. Female were over five times more likely to mention terms linked to the categories "family" and "social relations" than male. Moreover, 41-50 years old professionals and professionals over 51 years old colleagues. Also, the professionals older than 51 years were less likely to report terms related to "leisure time and relaxation". Considering the professional role, nurses were more likely to report areas linked to "finances" and "health" than physicians and psychologists. Similarly, physiotherapist and other therapists were more likely to mention terms related to the category "back to mention terms related to the category "back to report the category "cocial relations" more likely to report the category "back to mention terms related to the category "back to "finances" and "health" than physicians and psychologists. Similarly, physiotherapist and other therapists were more likely to mention terms related to the category "back to report the category "back to report the category "back to report the category "back to mention terms related to the category "back to report the category "back to report the category "back to report the category "back to physicians and psychologists, too. Finally, social-health practitioners were less likely to report the category "back to physicians and psychologists.

[Table 5 near here]

#### **Linear Regressions**

After controlling for gender, age and professional role, the category "family" contributed to increase IoWS index (p=0.013). Conversely, the category "finances" tended to reduce this index (p=0.0001) (Table 6).

[Table 6 near here]

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#### Discussion

This research aims to investigate MiL in palliative care and neuro-rehabilitation professionals, as their chance to face burnout, moral distress and impoverishment of quality of life is widely recognized (Maffoni, Argentero, Giorgi & Giardini, 2019; Maffoni, Argentero, Giorgi, Hynes, et al., 2019; Sliwa et al., 2019; Hynes et al., 2019). Specifically, considering the crucial and understudied role that MIL may have to foster healthcare professionals' wellbeing, the current research identified what may promote MiL among workers involved in healthcare settings dealing with multimorbid and complex patients by analyzing sociodemographic variables.

The two subsamples appeared heterogeneous regarding socio-demographic characteristics. Similar with a previous study (Fegg et al., 2014), significant group differences were found for age and professional role. This may be ascribable to the diversity of the two specialties. Firstly, palliative care units are more recent in Italy in respect to neuro-rehabilitation units, therefore the professionals are often younger than in the rehabilitation discipline (Casale & Calvieri, 2014). Secondly, the difference in professional role between the two specialties may origin from a different work force organization. For instance, physiotherapists are professionals not usually largely employed in palliative care.

Conversely, no differences emerged in the number of MiL areas listed and in the SMiLE indexes between groups. It is possible that dealing with critical care patients and tasks may activate a similar process of meaning definition. Additionally, the nature of the profession characterised by providing care may prevail whatever the specific specialty. This hypothesis is supported by the study comparing palliative care providers with professionals working in the maternity unit, where no differences in the MIL indexes was unveiled (Fegg et al., 2014).

As for categories mentioned, palliative care professionals listed significantly more terms related to "partnership", "satisfaction", "social commitment" and "universal values", while neuro-rehabilitation medicine professionals reported significantly more the category "family". Binary logistic regressions strengthened almost totally these data, unveiling that palliative care professionals are more likely to mention the categories "partnership", "satisfaction", and "social commitment" than neuro-rehabilitation colleagues. Regarding this, previous literature showed that job satisfaction and relational aspects are protective factors for palliative care professionals' wellbeing (Maffoni et al., 2020). Thus, it is conceivable that these professionals are more likely to list these factors as they self-perceive the crucial role of these aspects in providing MiL to their life.

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Furthermore, the binary logistic regressions revealed the impact of gender, age, and professional role on the likelihood that professionals would report a certain MiL category.

Regarding gender, females were more likely to mention "family" and "social relations" than males. This result may need a sociological and neurobiological interpretations. On one hand, in the Mediterranean area the role of females has historically been connected to the family (Viazzo, 2003). On the other hand, a recent study underlines as females considered social and relational aspects to be more rewarding than males probably due to oxytocin release (Borland et al., 2018).

Furthermore, binary logistic regressions suggested that the professionals aged under 41 were more likely to report the category "partnership" and "leisure time and relaxation" in respect to their older colleagues. This data could be supported by Erik Erikson's theory of psychosocial development explaining that people generally pass through a series of stages centred on social and emotional development (Erikson, 1998). Consistently to the current finding, during the young adulthood stage (i.e. between 19 and 40) individuals generally tend to search partnership and to develop intimate relationships, while with increasing age the focus is on leaving a contribution to society, such as a meaningful work (Erikson, 1998). Additionally, younger people are more prone to find a partner due to biological and hormonal reasons (Porges & Carter, 2010).

Regarding the professional role, nurses were more likely to mention terms linked to "finances" and "health" than physicians and psychologists. Regarding this, previous literature reported that nurses are not satisfied with their salary (Bressi et al., 2008) and they are at high risk of psychological malaise (Bridgeman et al., 2018). Thus, they may deserve more attention to financial and health-related issues than other healthcare professionals. In addition, therapists were more likely to report terms related to "health" area than physicians and psychologists, too. Finally, social-health practitioners were less likely to list "social relationship" and more likely to indicate "health" as meaningful areas in respect to physicians and psychologists. It is possible that they are more likely to mention the "health" category as these professionals, and in particular nurses, are usually the closest to patients (Dinç & Gastmans, 2013). However, these findings regarding the professional role need further investigations. To the best of our knowledge, there are only few studies regarding the role of sociodemographic variables on MiL, no one referring to possible differences among the professional roles (Steger et al., 2009; Grouden & Jose, 2014; Schnell, 2009). Therefore, this research is the first attempts to unveil the impact of different socio-demographic

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characteristics on MiL, as well as the first study investigating this construct within palliative care and neuro-rehabilitation medicine specialties.

The linear regressions unveiled that the category "family" contributed to increase the overall index of IoWS. This category, which is also the most frequently reported by all participants, is therefore confirmed to be one of the most relevant MiL area (Fegg et al., 2008; Fegg, Kögler et al., 2010; Fegg et al., 2013; Fegg, Brändstatter et al., 2010; Bernard et al., 2017; Brandstätter et al., 2014). It was already reported that family support contributes to better health and increases professional outcomes (Ma et al., 2020). Moreover, family plays a central role for individuals living in the Italian and Mediterranean area than in other cultures (Viazzo, 2003). Moreover, the category "finances" significantly reduced the overall index of IoWS. In addition, when asked to attribute a subjective score of satisfaction and importance on the finance area, professionals reported lower mean scores on satisfaction than in levels of weight. Since these two indexes contribute to the overall index, IoWS may be low because the "finances" are considered important but not adequately satisfied. Regarding this, researches suggested that individuals considered their annual income and household economic wellbeing to be of the utmost importance for them, being positively associated with job satisfaction (Sansoni et al., 2016) and with satisfaction in life (Gallagher et al., 2015). Previous literature has also unveiled that Italian healthcare professionals complained their low and frozen salary (Porges & Carter, 2010; Petmesidou et al., 2014). It has to be considered that the present investigation has been conducted after the 2008 global financial crisis: the European healthcare sector has been subject to tough austerity measures comprising salary cuts, downsizing and freezing (Petmesidou et al., 2014; Correia et al., 2015). Thus, further investigations are suggested to better interpret these data in the actual socio-political and economic scenario.

This study presented some limits too. First, a sample constituted by two medical specialties was considered; data generalization in healthcare population is therefore difficult. Secondly, since MiL strictly refers to individual's experiences, the presented data could be considered contextually biased and, therefore, intercultural studies are needed in order to corroborate them. Meanwhile, there are some strength points too. Above all, this study implemented a specific idiographic instrument for MiL area, enabling to detect areas that are important for an individual but where satisfaction may lack as well (Fegg, Brändstatter et al., 2010). Another added value is a further comparison of palliative care providers with another sample (i.e. neuro-rehabilitation professionals) facing similar clinical and bioethical issues, taking in consideration socio-demographic facets too.

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## Conclusion

This study shed light on MiL areas among professionals employed in palliative care and neuro-rehabilitation specialties. The emerged results may provide informative suggestions for health prevention programs. For instance, giving space of confrontation on MiL among healthcare professionals may enhance wellbeing, by providing the roots for a supportive environment allowing the sharing of personal concerns and emotions with colleagues and superiors. Moreover, since these findings described social relationships, socio-economic status and health as relevant meaningful areas in healthcare professionals' life, trainings should pay particular attention on these aspects.

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		Table 1							
Socio-demographic characteristics of the study sample									
Characteristics	Total (%) n = 297	PC n = 89 (30%)	NR n = 208 (70%)	$\mathbf{X}^2$	p-value				
Gender				0.51	0.474				
Male	99(33.3)	27(30.3)	72(34.6)						
Female	198(66.7)	62(69.7)	136(65.4)						
Age				14.71	0.001				
<u> 40 years old </u>	139(47.0)	55(61.8)*	84(40.6)*						
41-50 years old	96(32.4)	26(29.2)	70(33.8)						
$\geq$ 51 years old	61(20.6)	8(9.0)^	53(25.6)^						
Missing	1(0.3)								
Occupation				50.93	0.0001				
Physician and Psychologist *	65(22.0)	35(39.8)*	30(14.5)*						
Nurse	116(39.3)	44(50.0)^	72(34.8)^						
Physiotherapist and others b	67(22.7)	1(1.1)°	66(31.9)°						
Social-health practitioner °	47(15.9)	8(9.1)§	39(18.8) <sup>§</sup>						
Missing	2(0.7)								

Note. PC - Palliative care; NR - Neuro-Rehabilitation medicine

 Psychologists were merged with physicians due to small sample size (7 psychologists in neurorehabilitation medicine and 1 in palliative care)

<sup>b</sup> Dieticians, speech therapists and occupational therapists

<sup>c</sup> In the Italian healthcare system, qualified healthcare professional who address the basic needs of a person (washing, feeding, etc.).

For each level of the variable, the values that do differ significantly from each other share the same subscript symbol (based on adjust p- value, Bonferroni method,  $p \le .05$ ).

## Table 2

# Means and standard deviations of satisfaction and weight

	PC (n	= 89)	NR (n = 208)			
SMiLE areas	s	w	s	w		
	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)		
1. Family	2.1 (1.3)	6.7 (0.7)	2.2 (1.2)	6.7 (0.7)		
2. Partnership	1.6 (1.8)	6.1 (1.2)	1.8 (1.8)	6.1 (1.2)		
<ol><li>Social relations</li></ol>	1.6 (1.5)	5.6 (1.2)	2.0 (1.2)	5.7 (1.2)		
4. Occupation/work	1.3 (1.3)	5.5 (1.2)	1.2 (1.5)	5.6 (1.3)		
5. Leisure time/relaxation	0.7 (1.9)	4.4 (1.2)	1.3 (1.4)	4.7 (1.4)		
6. Home/garden	2.8(0.5)	5.8 (1.3)	1.8 (1.2)	5.7 (1.5)		
7. Finances	- 0.1(0.8)	6.0 (1.4)	- 0.5 (1.9)	5.1 (1.4)		
8. Spirituality/religion	2.0 (1.4)	6.6 (0.8)	2.4 (0.9)	6.0 (1.1)		
9. Health	1.7 (1.1)	6.4 (1.1)	1.8 (1.4)	6.6 (0.9)		
10. Satisfaction	1.1 (1.5)	5.8 (1.3)	0.8 (1.9)	6.3 (1.2)		
11. Nature/Animals	0.5 (2.2)	5.0 (1.3)	2.2 (0.8)	5.3 (0.8)		
12. Social commitment	2.0 (1.2)	5.7 (1.0)	1.4 (1.5)	4.7 (1.6)		
13. Hedonism	0.4 (1.8)	5.4 (1.3)	1.5 (1.6)	5.4 (1.5)		
14. Art/culture	2.0 (1.4)	5.4 (1.0)	2.0 (1.1)	5.0 (1.3)		
15. Growth	1.2 (1.1)	5.7 (1.4)	1.5 (1.1)	5.2 (1.6)		
16. Universal values	1.9 (0.9)	6.0 (1.0)	1.3 (1.7)	6.5 (0.9)		

Note. PC - Palliative care; NR - Neuro-Rehabilitation medicine; S - satisfaction; W - weight

SMiLE areas	Total (n = 297)	PC (n = 89)	NR (n = 208)	X <sup>2</sup>	p-value
	%	%	%		•
1. Family	91.6	86.5*	93.8*	4.230	0.039
2. Partnership	28.3	44.9*	21.2*	17.392	0.0001
<ol><li>Social relations</li></ol>	58.9	59.6	58.7	0.021	0.886
4. Occupation/work	82.2	83.1	81.7	0.085	0.770
5. Leisure time/relaxation	34.0	25.8	37.5	3.774	0.052
6. Home/garden	3.7	5.6	2.9	1.306	0.253
7. Finances	7.4	9.0	6.7	0.463	0.496
8. Spirituality/religion	5.7	9.0	4.3	2.510	0.113
9. Health	27.9	21.3	30.8	2.747	0.097
10. Satisfaction	9.4	14.6*	7.2*	3.992	0.046
11. Nature/Animals	4.4	6.7	3.4	1.698	0.193
<ol><li>Social commitment</li></ol>	5.1	9.0*	3.4*	4.110	0.043
13. Hedonism	17.8	19.1	17.3	0.136	0.712
14. Art/culture	12.1	14.6	11.1	0.737	0.391
15. Growth	11.8	14.6	10.6	0.974	.324
<ol><li>Universal values</li></ol>	7.1	12.4*	4.8*	5.410	0.020

Table 3 Percentage of respondents listing each MiL area

Table 4 Mean scores of SMiLE indices and comparisons between the two subsamples									
	Total (n = 297)	PC (n=89)	NR (n = 208)						
	Mean (SD)	Mean (SD)	Mean (SD)	t	df	p-value			
n. of MiL areas listed	4.4 (1.5)	4.7 (1.6)	4.3 (1.5)	-1.78	295	0.08			
IoW IoS	83.7 (12.0) 77.0 (17.7)	83.2 (10.7) 74.1 (18.1)	83.9 (12.6) 78.3 (17.5)	.046 1.85	288 289	0.65			
IoWS	77.5 (18.0)	75.1 (18.1)	78.6 (17.9)	1.53	287	0.13			

Table 4

Note. PC - Palliative care; NR - Neuro-Rehabilitation medicine; IoW - Index of Weighting; IoS - Index f Satisfaction; IoWS - Index of Weighted Satisfaction; t - t Student's value; df - degree of freedom

eer R

	Snor	ialty		Gender Age				Professional role						
MiL areas	-	ve care)		nder nale)	41-5	0 years	> 51	years	N	urses	-	therapists herapists		al-health titioner
	ExpB	р	ExpB	р	ExpB	р	ExpB	р	ExpB	р	ExpB	р	ExpB	р
l. Family	0.40	0.095	5.60	0.0001	0.72	0.533	1.02	0.980	2.27	0.144	1.53	0.545	2.71	0.182
2. Partnership	2.14	0.019	1.08	0.801	0.37	0.002	0.24	0.001	0.72	0.358	0.60	0.272	0.54	0.216
3. Social relations	0.86	0.620	1.71	0.043	1.04	0.882	0.89	0.734	0.70	0.289	0.70	0.391	0.30	0.004
<ol><li>Occupation/work</li></ol>	0.72	0.396	1.32	0.402	0.84	0.638	0.47	0.067	0.44	0.088	0.35	0.060	0.36	0.066
5. Leisure time/relaxation	0.53	0.053	0.72	0.239	0.94	0.823	0.39	0.013	0.69	0.280	1.17	0.698	0.44	0.074
6. Home/garden	2.33	0.277	0.70	0.584	0.53	0.452	1.23	0.797	0.33	0.217	0.76	0.791	1.40	0.693
7. Finances	1.93	0.222	1.32	0.614	1.87	0.239	2.31	0.194	10.69	0.026	8.33	0.068	3.61	0.309
8.Spirituality/religion	2.17	0.178	3.32	0.124	1.63	0.412	1.83	0.403	1.42	0.586	0.81	0.822	0.98	0.984
9. Health	0.77	0.448	0.67	0.179	1.38	0.320	1.70	0.170	7.73	0.0001	3.28	0.041	7.82	0.0001
10. Satisfaction	3.78	0.011	0.44	0.056	0.93	0.892	1.56	0.431	1.30	0.644	3.02	0.112	1.37	0.664
<ol> <li>Nature/Animals</li> </ol>	2.64	0.156	1.43	0.607	1.64	0.458	1.95	0.403	1.37	0.673	1.87	0.514	0.65	0.724
12. Social commitment	6.39	0.012	2.40	0.207	1.26	0.721	1.73	0.457	0.26	0.126	2.79	0.261	2.59	0.231
13. Hedonism	1.17	0.679	0.71	0.292	1.08	0.843	1.97	0.098	1.18	0.695	1.00	0.992	0.91	0.860
14. Art/culture	1.92	0.153	1.05	0.899	1.45	0.389	1.82	0.225	0.68	0.434	1.49	0.483	0.64	0.490
15. Growth	1.46	0.410	0.67	0.288	0.52	0.164	0.85	0.746	0.70	0.449	1.11	0.854	.412	0.217
<ol><li>Universal values</li></ol>	2.01	0.189	0.58	0.268	0.35	0.115	1.03	0.970	1.86	0.285	0.52	0.481	0.32	0.315

Table 5 Results from binary logistic regressions

Note. References categories for regressions: neuro-rehabilitation medicine (specialty), male (gender), < 40 years (age), physician/psychologist (professional role) Boldfaced numbers underline significant p-value < .05

MiL areas	Total R <sup>2</sup>	В	p-value
1. Family	0.08	9.57	0.013
2. Partnership	0.06	-1.09	0.652
3. Social relations	0.06	0.99	0.650
<ol><li>Occupation/work</li></ol>	0.06	0.29	0.918
5. Leisure time/relaxation	0.07	-2.92	0.199
6. Home/garden	0.06	4.90	0.375
7. Finances	0.11	-15.59	0.0001
8. Spirituality/religion	0.07	5.94	0.200
9. Health	0.06	1.71	0.488
10. Satisfaction	0.06	-2.52	0.492
11. Nature/Animals	0.06	-4.10	0.437
12. Social commitment	0.06	1.84	0.711
13. Hedonism	0.07	-4.30	0.114
14. Art/culture	0.07	5.15	0.108
15. Growth	0.06	-4.04	0.219
16. Universal values	0.06	0.26	0.950

# Table 6 Linear Regression Model Predicting IoWS

*Note.* Linear regression model predicting IoWS considering categories as independent variables and controlled for sociodemographic variables (age, gender, occupation). Boldfaced numbers underline significant p-value < .05

# Chapter Six

# The Italian version of the Hospital Ethical Climate Survey

# 6.1. An introduction to the validation study of the Hospital Ethical Climate Survey

In the international literature the construct of ethical climate has been extensively investigated in hospital setting, specifically within the nursing professional role (Olson, 1989; Koskenvuori, Numminen, & Suhonen, 2019). Only in recent time a new instrument for ethical climate has been proposed in Swedish language with an inter-professional focus (Grönlund, Söderberg, Dahlqvist, Andersson, & Isaksson, 2019). The authors highlighted the fact that in the worldwide healthcare landscape are still missing both a tailored tool for each profession and a multi-professional instrument to assess ethical climate. Italy is not an exception: it still does not exist an Italian gold-standard instrument which assesses the perception of hospital ethical climate among physician or other healthcare professionals other than nurses.

However, growing researches are trying to investigate the ethical climate also within physicians and other healthcare professionals (Hamric & Blackhall, 2007; Hamric, Borchers, & Epstein 2012; Bartholdson, Sandeberg, Lützén, Blomgren, & Pergert, 2016; Pergert, Bartholdson, & af Sandeberg, 2019). In fact, it was unveiled a correlation between a non-supportive ethical climate and higher moral distress in both nurses and physicians (Hamric, et al., 2012) and, in general, a negative influence of a poor ethical climate on healthcare professionals' wellbeing and professional outcomes (Pauly, Varcoe, Storch, & Newton, 2009; Silén, Svantesson, Kjellström, Sidenvall, & Christensson, 2011; Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2014; Dzeng, & Curtis 2018; Koskenvuori, et al., 2019).

These scientific findings suggest the necessity to develop inter-professional instruments and approaches to detect ethical climate among all the healthcare workforce in order to foster and maintain professionals' wellbeing. To contribute to bridge this gap in the Italian context, the paper described in this chapter provides a first Italian version of the Hospital Ethical Climate Survey. This instrument originally was tailored for nurses, however it was supposed that it could be extended to other healthcare professionals, too. To this regard, it has to be said that the decision of little rewording the original items in order to extend the instrument to all healthcare professionals was taken by consensus of all authors who scheduled a meeting in order to discuss this option. Finally, the decision to adapt the instrument for the entire healthcare workforce was taken because the content of the items appeared to be common to all professionals. Although the explicit items address nurses, they depict in fact situations which may occur to the other healthcare

professionals too. Some examples are the following: My peers help me with difficult patient care issues/problems; The feelings and values of all parties involved in a patient care issue/problem are taken into account when choosing a course of actions; My manager is someone I can trust; item Conflict is openly dealt with, not avoided. Prof. Linda Olson, the author of the original instrument, was also informed through mail and she expressed her consent.

In addition, previous attempts to use a little revised version of this instrument also with physicians and nursing assistant were already reported in the pediatric cancer care settings in Sweden (Bartholdson et al., 2016; Pergert et al., 2019).

Thus, in this chapter is described in more detail the assessment of a preliminary Italian version of the Hospital Ethical Climate Survey (HECS), checking its factor structure through exploratory factor analysis (EFA) and confirming the emerged factor structure using confirmatory factor analysis (CFA).

# 6.2. The validation study of Hospital Ethical Climate Survey

Maffoni, M., Sommovigo, V., Giardini, A., Argentero, P., & Setti, I. The Italian version of the Hospital Ethical Climate Survey: first psychometric evaluations in a sample of healthcare professionals employed in neuro-rehabilitation medicine and palliative care specialties. *Manuscript accepted for publication, 6<sup>th</sup> October 2020*.

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**Title:** The Italian version of the Hospital Ethical Climate Survey: first psychometric evaluations in a sample of healthcare professionals employed in neuro-rehabilitation medicine and palliative care specialties

Running head: The Italian validation of the Hospital Ethical Climate Survey

In the field of psychology, the term "climate" was proposed for the first time by Lewin, Lippitt and White (1939) to describe how people develop an overall meaning regarding their social settings that is mainly affected by the leadership style experienced inside it. The first studies on organizational climate came to light in the late 1960s (Schneider, Ehrhart, & Macey, 2011; Schneider, & Barbera, 2014). These first researches lacked both a clear definition of "organizational climate" and a conceptual agreement regarding proper instruments and procedures to directly assess this construct. Therefore, according to the general approach called "molar approach", the knowledge about climate as a general experience was inferred from the measurement of organizational facets and dimensions (e.g. job satisfaction, leadership) that were believed to be in relation to climate itself (Schneider et al., 2011; Schneider & Barbera, 2014). After that, to better tailor the research on climate, Schneider (1975) proposed to assess specific outcomes of interest, looking for a "climate of something", such as "climate for productivity" or "climate for turnover". In this way, each research may address a specific type of climate, with regards to the causes and consequences of a particular aspect of the construct. Apart these specifications, the overall literature regarding organizational climate is focused on the shared meaning and perceptions that workers derive from procedures, policies and practices that are endorsed and expected at their workplace (Schneider & Barbera, 2014). These employees' perceptions provide some sorts of guidelines to act in a successful way inside the organization. In other words, the organizational climate is to be intended as the "personality" of the organization (Olson, 1998). Since it determines the work and social environment in which people conduct their own activity, climate may enhance employees' motivation and satisfaction (Mathew & Selvi, 2007; Schneider et al., 2011; Schneider & Barbera, 2014) which, in turn, may positively affect workers' efficiency and performance (Mathew & Selvi, 2007; Schneider et al., 2011; Schneider & Barbera, 2014; Berberoglu, 2018).

## THE ETHICAL CLIMATE

One of the most studied aspect of organizational climate is related to the moral and ethical dimension of this construct. The seminal researches conducted by Victor and Cullens (1987, 1988) paved the way, focusing on the workers' shared meaning and common perception of "what is correct behaviour, and how ethical situations should be handled in an organization" (Victor & Cullen, 1988, p. 135). Thus, the ethical climate may be defined as workers' perceptions of ethics-related organizational practices, procedures and policies that may have ethical content and moral consequences due to the potential influence on ethics-related attitudes and behaviours (Treviño, 2008; Parboteeah, Martin, & Cullen, 2011). In other words, the ethical climate refers to employees' perception of ethical standards and norms for the management of ethical decisions or behaviours. The quality of the ethical climate may change among various organizations and work units. According to literature, different kinds of national, organizational, and occupational cultures may be considered as antecedents of ethical climate (Parboteeah et al., 2011). Moreover, the leadership style may impact on subordinates' ethical climate perceptions, so that, an ethical leadership style may positively affect such perceptions, thanks to a virtuous cycle triggered by the good example provided by the leader's honest and trustworthy behaviour (Demirtas & Akdogan, 2015). The importance of ethical climate is related to its effects

on organizational outcomes. Indeed, ethical climate may positively influence job satisfaction (Elçi & Alpkan, 2009; Parboteeah et al., 2011), organizational commitment (Parboteeah et al., 2011; Demirtas & Akdogan, 2015), employees' job attitudes and behaviours (DeConinck, 2010) as well as positive extra-role behaviours (Leung 2008).

## THE ETHICAL CLIMATE IN THE HEALTHCARE SYSTEM

The construct of ethical climate has been mainly investigated in healthcare settings due to the higher possibility of ethical and moral implications related to the provision of patient care. Nowadays, the medical and technological advancements are letting arise complex ethical issues among healthcare professionals; thereby, potentially affecting their wellbeing and, in turn, the quality of care provided (Bodenheimer & Sinsky, 2014; Harrison et al., 2017; Hynes, Maffoni, Argentero, Giorgi, & Giardini, 2019; Maffoni, Argentero, Giorgi, Hynes, & Giardini, 2019; Maffoni, Argentero, Giorgi, & Giardini, 2019; Maffoni, Argentero, Giorgi, & Giardini, 2020). Paying attention to healthcare professionals' wellbeing is now an ever-growing ethical imperative, as well as an urgent necessity (Harrison et al., 2017; Hynes et al., 2019). To this regard, the ethical climate is of paramount importance in healthcare systems because of its potential impact on personal and organizational outcomes. Indeed, according to a recent review, the ethical climate was positively associated with positive individual self-perceptions, such as professional competence and efficacy; individual skills, including abilities to manage disagreements and to cooperate with colleagues; positive job-related outcomes, such as job satisfaction and work engagement; healthcare professionals' wellbeing and their satisfaction for cares provided (Koskenvuori, Numminen, & Suhonen, 2019). The ethical climate is also positively associated with the perception of social and organizational support (Silén, Kjellström, Christensson, Sidenvall, & Svantesson, 2012; Abou Hashish, 2017; Koskenvuori et al., 2019). In particular, the perception of positive climate is promoted by providing mutual support among intraorganizational members (e.g., supervisors, coworkers) and by sharing information with colleagues (Silén et al., 2012). Moreover, the ethical climate is negatively associated with moral distress (Pauly, Varcoe, Storch, & Newton, 2009; Silén, Svantesson, Kjellström, Sidenvall, & Christensson, 2011; Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2014; Dzeng, & Curtis 2018; Koskenvuori et al., 2019), in particular it is described as a potential antecedent of moral distress and burnout (Dzeng & Curtis, 2018). For these reasons, it is important to provide instruments to examine the ethical climate inside healthcare organizations. Indeed, understanding ethical facets of the work climate allows to implement tailored and effective interventions to manage, change and improve organizational practices and procedures on ethical aspects, positively influencing healthcare professionals' work experience and wellbeing (Olson, 1998; Pauly et al., 2009; Schwatka, Hecker, & Goldenhar, 2016).

To date, the ethical climate within healthcare settings has been mainly explored considering nurses' perspectives: nurses constitute the largest professional group of the health workforce of our countries (WHO, 2018) and they are exposed to different kinds of ethical issues on a daily basis during their work activity (Ulrich et al., 2010). In the 1990s, Olson provided a definition of ethical climate from nurses' point of views (Olson, 1995, 1998), described as the result of institutional practices and policies regarding ethical content and

decisions, such as the possibility to disagree with one another or to have a debate on ethical issues, as well as the opportunity to access to information for making informed decisions (Olson, 1998). It may be assessed by asking the healthcare professionals to provide their perceptions regarding situations and facts characterized by ethical contents that may happen inside their institution. For instance, the management of ethical decisions or the possibility to engage in ethical reflections are matter of interest (Olson, 1998; Redman, 2002). Starting from considering literature review and the experience in nursing practice and administration, Olson developed a 26-item instrument called Hospital Ethical Climate Survey (HECS) to assess nurses' perceptions of ethical climate through five subscales focusing on their relationships with Peers, Patients, Managers, Physicians and within the Hospital (Olson, 1998). This instrument, which has shown a good internal consistency and construct validity (e.g., Olson, 1998; Redman, 2002), has been translated in different languages, including Greek (Charalambous, Cloconi, Papastavrou, & Theodoula, 2018), Persian (Khalesi et al., 2014), Japanese (Hwang & Park, 2014), Dutch (Claeys et al., 2013), Turkish (Bahcecik & Oztürk, 2003), Swedish (Silén et al., 2011) and Finnish (Suhonen, Stolt, Katajisto, Charalambous, & Olson, 2015). The instrument maintained good psychometric properties across countries and numerous translations confirmed a five-factor structure as the original American version (Bahcecik & Oztürk, 2003; Silén et al., 2011; Claeys et al., 2013; Hwang & Park, 2014; Khalesi et al., 2014; Suhonen et al., 2015; Charalambous et al., 2018).

With the author's permission, it has been developed also a shorter version with 14 items in the English language (Hamric, Borchers & Epstein, 2012), translated and further modified in Swedish as well (Pergert, Bartholdson, Wenemark, Lützén, & af Sandeberg, 2018). The shorter version included the following five dimensions: 1) health-care personnel relationships with the hospital, the immediate manager and the patients/parents; 2) relationships between professionals; 3) team interactions; 4) identifying and dealing with ethical issues and 5) care as it should be provided (Hamric et al., 2012; Pergert et al., 2018). Furthermore, as HECS was originally designed for nurses, some studies utilized parallel versions which were constructed for specific professional groups (e.g., see Hamric et al., 2012; Pergert et al., 2018; Pergert, Bartholdson, & af Sandeberg, 2019 for physicians; see Whitehead et al., 2014 for physicians, therapists, dieticians and social workers). For instance, using the shortened HECS modified version in a Swedish healthcare population, Pergert et al. (2019) found some differences in relation to certain items of the HECS between physicians and nurses. In particular, medical doctors reported significantly higher scores than nurses on items regarding relationships with team members and managers. In addition, males reported significantly greater scores on the item focusing on the physician's availability to ask for nurses' opinions than female, while females reported significantly higher scores than their male counterparts on the item referring to hospital guidelines. Conversely, other studies made minor revisions (e.g., different wording of scale items) to make HECS suitable for multiple professions (e.g., Bartholdson, Sandeberg, Lützén, Blomgren, & Pergert, 2016; de Boer, van Rosmalen, Bakker, & van Dijk, 2016; Silén, Haglund, Hansson, & Ramklint, 2015; Ulrich et al., 2007), as the content of the original items has been considered to be potentially extendible to all healthcare professionals. For instance, Bartholdson et al. (2016) adapted the Swedish version of the shortened Hospital Ethical Climate Survey (HECS-S) to analyse the overall perception of the paediatric hospital ethical climate among healthcare professionals (i.e.,

physicians, nurses, and nurse-aides) caring for children with cancer, while Ulrich et al. (2007) administrated an adapted version of Olson's 26-item HECS (1998) to American nurses and social workers employed in intensive care units. Additionally, De Boer et al. (2016) translated the HECS into the Dutch language and slightly adapted it to the neonatal intensive care unit situation, administrating it to both nurses and physicians. The authors showed that the perceived ward ethical climate reduced the intensity of morally distressing situations in both professional groups (De Boer et al., 2016). Similarly, Silén and colleagues (2015) adapted the HECS by using a different wording for scale items to evaluate whether ethics rounds (i.e., an alternative to traditional ethics committee where healthcare professionals from different disciplines can reflect on ethically difficult facets of patient's cases) could improve the ethical climate perceived by healthcare professionals (i.e., nurses, therapists, physicians) working in psychiatric outpatient clinics.

The instrument has been adopted in many different settings, such as: paediatric cancer units (Bartholdson et al., 2016) and adult cancer care settings (Charalambous et al., 2018), older people care institutes (Suhonen et al., 2015), psychiatric units (Lützen, Blom, Ewalds-Kvist, & Winch, 2010; Claeys et al., 2013;). Moreover, since previous investigations revealed differences in ethical climate perceptions across care settings (Bahcecik and Oztürk, 2003) and since healthcare may have diverse organizational features (e.g., number of patient beds per each nurse; Hwang & Park, 2014), the assessment of psychometric properties of HECS was encouraged across contexts and professional groups (Koskenvuori et al., 2019). Indeed, the strength of the HECS is both its well-established international adoption and its focus on specific factors influencing the ethical climate, considering the perspective of healthcare professionals across specific work settings.

Overall, previous investigations suggest that each professional group has its own identity and codes of ethics and meets patients in diverse circumstances (Jameton, 2013), so that perceptions of ethical climate may vary as a function of differences in professional roles, which involve specific tasks, more or less influence and discretion in decision-making (e.g., Hamric & Blackhall, 2007; Pergert et al., 2019). On the other hand, several healthcare professionals from different disciplines are involved in daily patient care (Grönlund, Söderberg, Dahlqvist, Andersson, & Isaksson, 2019) and ethical climate is a form of organizational climate that embraces shared perceptions about what constitutes the correct behaviour, which in turn affects ways ethical issues and decision-making are addressed (Martin & Cullen, 2006). More specifically, ethical climate is particularly important for healthcare professionals employed in specialties at high risk of moral distress. Among these, neuro-rehabilitation medicine and palliative care specialties represent explicative examples as healthcare provides working in these specialties are frequently confronted with numerous challenges, such as high demands related to the treatment of patients with complex care needs, the urgency of making decisions, the dehumanizing effect of technology, the elevated incidence of patient mortality and the presence of organizational policies, priorities, pressures to reduce costs as well as fear of litigation which conflict with care needs (Bakker, Le Blanc, & Schaufeli, 2005; Epp, 2012; Koerner, 2011; Meltzer & Huckabay, 2004). All these factors make employees at neuro-rehabilitation medicine and palliative care specialties at increased risk of developing moral distress and burnout symptoms, so that they are defined as one of the most "burned-out" healthcare professional groups (Rothenberger, 2017; Sliwa et al., 2019). Additionally, previous studies showed that unit climate was associated with numerous therapeutic outcomes, such as drop out-, release-, and readmission rates (Moos, Shelton, & Petty, 1973), patient satisfaction (Bressington, Stewart, Beer, & MacInnes, 2011), motivation for treatment (van der Helm, Beunk, Stams, & van der Laan, 2014) and therapeutic alliance (Long et al., 2011). Therefore, it seems to be particularly important to create and maintain a good ethical climate not only for nurses, but also for the other healthcare providers employed in specialties at high risk of moral distress. To this end, it seems crucial to encourage healthcare professionals from different disciplines to reflect on ethically difficult facets and to promote multi-professional dialogue about care provided to improve ethical practices (Schmitz et al., 2018). To facilitate practitioners in the achievement of this, the Italian context needs an instrument suitable for different healthcare professionals working in units at high risk of moral distress.

## AIMS AND HYPOTHESES

As far as our knowledge, an Italian version of the HECS is still missing. To fill this gap, the main purpose of the present research was to perform exploratory and confirmatory factor analyses to select the best items and test their factorial structure in order to provide a brief version of the HECS in the Italian language. In doing so, although the existence of a shorter version (i.e., 14 items), we decided to explore the psychometric properties of the original version (i.e., 26 items) since it was widely used in literature (Bahcecik & Oztürk, 2003; Lützen et al., 2010; Silén et al., 2011; Claeys et al., 2013; Hwang & Park, 2014; Khalesi et al., 2014; Suhonen et al., 2015; Bartholdson et al., 2016; Charalambous et al., 2018). A further goal of the current study was to examine the nomological validity of the questionnaire. Moreover, a further objective was to provide a psychometric evaluation of the HECS by testing its model of measurement not only with nurses, but also with other healthcare professionals employed in palliative care and neuro-rehabilitation medicine specialties. Despite some differences, both neuro-rehabilitation medicine and palliative care are at particular risk of moral distress and burnout as the care of patient in life-threatening conditions may expose healthcare professionals to numerous ethical issues, influencing their perceptions of ethical work climate. Therefore, a further purpose of this study was to analyse whether the factor structure of the HECS concept would be invariant across specialties (i.e., neuro-rehabilitation medicine vs palliative care specialties).

We expected to find that the Italian version of the HECS would display a five-factor model of measurement, similar to the original structure proposed by Olson (1998). Moreover, we hypothesized that all dimensions of HECS would correlate positively with social support and wellbeing and that such dimensions would be negatively associated with moral distress and burnout. Moreover, we hypothesized that there might be differences in HECS perceptions between males and females and between healthcare providers employed in palliative care and those in neuro-rehabilitation medicine specialties, even if the factor structure of the HECS concept would be invariant across gender and specialties. Finally, we hypothesized that there might be differences in HECS perceptions between professionals having different professional roles.

### METHOD

## Participants and Procedure

Our research population consists of healthcare professionals from six hospitals in Northern and Central Italy. In each hospital, a coordinator and a researcher presented the research project to healthcare professionals during shift changes. After being reassured of the confidentiality and anonymity of their responses, participants provided their written informed consent and completed paper-pencil questionnaires. It took approximately 20 minutes to fill in the questionnaire. Participants did not receive any form of incentive. To further guarantee the anonymity, participants were instructed to place the completed questionnaires in a cardboard box. These boxes were placed at the front of a common area in each hospital taking part in the research. This survey is part of a broader research project called WeDistress HELL (WEllness and DISTRESS in HEalthcare professionals dealing with end of Life and bioethicaL issues) which has been approved by the Ethical Committee of ICS Maugeri - Institute of Pavia (Protocol No. 2211CE, 19 June 2018). Moreover, the present study was conducted in the agreement with the ethical norms laid down by the Italian National Psychological Association. In total 318 employees completed the survey. We excluded two participants since they did not complete at least the sixty percent of the survey, which reduced the sample size from 318 to 316. Additionally, one case was deleted because it was identified to be a multivariate outlier (as described below), leaving a total sample of 315 respondents. The average percentage of missing values ranged from 0.6% (for well-being and support scales) to 1.6% (for burnout symptoms and moral distress scales). More specifically, it was 1% for HECS. We replaced each of the missing values with the mean of the observed values for that variable in order to keep our sample size up to the full sample size.

Most participants were female (67.0%) nurses (40.6%) who did shift work (64.7%) and had openended contracts (78.9%). Respondents were employed in neuro-rehabilitation medicine (70.5%) or palliative care (29.5%) specialties. Most subjects were under 40 years old (46.0%), an overall job tenure above 16 years (43.5%) and a tenure in the current position above 10 years (44.7%).Participants were randomly divided into two groups to conduct Exploratory Factor Analysis (EFA group, n=158) and Confirmatory Factor Analysis (CFA group, n=157). Table 1 shows the characteristics of the two groups in terms of the HECS total mean, age, gender, occupational status, overall job tenure.

#### [Please insert Table 1 here]

## Measurements

The *Hospital Ethical Climate Survey* (HECS; Olson, 1998) is a 26-item self-administrated scale which was originally developed to evaluate hospital nurses' perceptions of the ethical climate within their workplace. This scale consisted of five subscales including: relationships with Peers (4 items, e.g., "My peers listen to my concerns about patient care"), Patients (4 items, e.g., "Patients know what to expect from their care"), Managers (6 items, e.g., "When I'm unable to decide what's right or wrong in a patient care situation, my

manager helps me"), Physicians (6 items, e.g., "Physicians ask nurses for their opinions about treatment decisions") and Hospital (6 items, e.g., "Hospital policies help me with difficult patient care issues/problems"). Responses are obtained on a 5-point Likert scale ranging from 1 (*almost never true*) to 5 (*almost always true*). The greater the HECS score, the more positive the ethical climate. The HECS has a good reliability as well as a good construct validity (Olson, 1998; Redman 2002).

Two subscales from *The Maugeri Stress Index–Reduced form* (Giorgi et al., 2011; Giorgi et al., 2014; Massidda et al., 2017) were used to evaluate wellbeing and social support perceptions. Participants were invited to report how frequently they tended to experience a condition of wellbeing, serenity, satisfaction for their work experience (7 items; e.g., "I have done things that interested me") and how often they perceived to receive adequate support from their colleagues or superiors (5 items; e.g., "My superiors at work are willing to help me in difficult moments; I can count on the support of my colleagues at work when I need it."). All items were measured on a 5-point Likert scale ranging from 1 (*never*) to 5 (*very much*), where greater scores indicate greater levels of wellbeing and social support. This instrument has been widely utilized by previous studies on Italian healthcare professionals and it has shown satisfactory psychometric properties (Massidda et al., 2017).

*Maslach Burnout Inventory-General Survey* (Schaufeli, Leiter, Maslach, & Jackson, 1996; Italian validation of Borgogni, Galati, & Petitta, 2005). This 16-item instruments includes the following three dimensions: Emotional exhaustion, namely feelings of chronic fatigue and lack of emotional resources as a result of overtaxing work (5 items; e.g., I feel emotionally drained by my work); Cynicism, namely cynical attitudes and feelings toward the organization and service recipients (5 items; e.g., I have become less interested in my work since I started this job); Professional efficacy, namely personal accomplishment and perceptions of being able to perform effectively one's own job tasks (6 items; e.g., I feel I am making an effective contribution to this organization). All items were scored on a 7-point Likert scale ranging from 0 (*never*) to 6 (*always*). A reversed score for Professional efficacy subscale was obtained. Then, a total score was calculated by averaging all item scores, where greater scores indicate greater levels of burnout symptoms. This scale is particularly suitable to healthcare professionals and has shown a good internal consistency (Borgogni et al., 2005).

*Moral Distress Scale-Revised* (Hamric, Borchers, & Epstein, 2012; Italian version of Lamiani, Setti, Barlascini, Vegni, & Argentero, 2017) was used to analyse moral distress, namely the painful and distressing experience resulting from the necessity to behave against own personal beliefs and values. This scale included four dimensions: Futile care, which refers to all provided treatments and cares that are perceived as inappropriate because of their harmfulness or uselessness (3 items; e.g., Initiate extensive life-saving actions when I think they only prolong death); Deceptive communication, that refers to unclear forms of communication, such as giving "false hopes" or not discussing a poor prognosis with a patient and/or a caregiver (3 items; e.g., Witness healthcare providers giving "false hope" to the patient or family); Ethical misconduct, namely ethically questionable behaviours that may occur in everyday clinical practices (5 items; e.g., Take no action about an observed ethical issue because the involved staff member or someone in a position of authority requested that I do nothing); Poor teamwork, which regards situations where there is a lack of trust and cooperation among medical staff members (3 items; e.g., Watch patient care suffer because of a lack of provider continuity). Each item was scored in terms of frequency (e.g., how frequently the situation was experienced) and intensity (e.g., to what extent the experienced situation was perceived as disturbing). All items were rated on a 5-point Likert scale ranging from 0 (*never*) to 4 (*very frequently*) and from 0 (*none*) to 4 (*great extent*) for the frequency and intensity scales, respectively. A score for each subscale was calculated. This subscale score is obtained by summing the frequency for intensity scores and dividing the total by the number of items. Such subscale score ranges from 0 to 16. However, to make this measure easily comparable with the other instruments, the scale of measurement was transformed by dividing by a constant in a scale ranging from 0 to 10, where higher scores indicate greater levels of moral distress dimensions. This scale has been widely used by previous studies on healthcare professionals working in intensive care units (Lamiani et al., 2017; Lamiani, Dordoni, & Argentero, 2018), showing a high degree of internal consistency (Lamiani et al., 2017).

#### Translation

Dr. Olson, the original designer of HECS, was contacted and permission was obtained to translate and culturally adapt HECS to develop an Italian version of this instrument. The translation of the HECS followed the standard guidelines for translating questionnaires (Sousa & Rojjanasrirat, 2011). One native Italian-speaking researcher translated the items. Then, to address at inadequate expressions of the translation, the forward translation was reviewed by a bilingual (in English and Italian) expert panel which identified acceptable alternatives. All items were translated back to English by an independent translator who was not involved in the initial translation. Finally, a comparison of the back-translated version and of the original version of the scale was performed by both Italian- and English-speaking natives, and further amends were made. Although the original version included a specific wording which was referred to "nurses" only, we decided to use the more general term "healthcare professionals" to extend the use of the questionnaire to all kind of providers. This revised wording was approved by the author of the original scale, too.

## Statistical Analyses

Preliminary analyses were conducted for the EFA and CFA groups following Tabachnick and Fidell' (2013) recommendations. We evaluated descriptive statistics of items (means, standard deviations, skewness, and kurtosis) to support the robustness of further analyses. Normality of the data was considered acceptable when skewness <[3.0] and kurtosis <[8.0] (Kline, 2011). Multivariate outliers were identified among the cases using p>.001 criterion for Mahalanobis distance. Before conducting exploratory factor analysis (EFA), we also verified the statistical assumptions (Kaiser-Meyer-Olkin measure of sampling adequacy and Bartlett test groups). All descriptive analyses were performed using IBM SPSS Statistics 23 (George & Mallery, 2016). Then, using Mplus 7 (Muthén & Muthén, 2012), a parallel analysis, which according to Henson and Roberts (2006) provides the most accurate approach as it avoids to over-extract factors, was performed to determine

the number of factors to retain from EFA. Then, we conducted several EFAs on the EFA group (n=158) with a progressively lower number of items using the maximum likelihood (ML) extraction with Geomin rotation. Each EFA was followed by a Promax rotation. Eigenvalues, communalities, and factor loadings for each item, as well as item-total correlation coefficients and item discrimination ability, were checked to delete the worst items. In line with the recommendations from Howard's review (2016) of EFA decisions, we repeated factor analysis until a factor structure was detected in which all items (a) loaded onto their primary factor above .40, (b) loaded onto alternative factors below .30, and (c) had a difference between their primary and alternative factor loadings of at least .20. 20. For each EFA conducted in Mplus, we performed the corresponding principal component analysis in SPSS (George & Mallery, 2016) to check that the items retained were those with the highest explained variance for each factor. More generally, in the early stages and throughout the entire process, the factor patterns of different analyses were compared with each other on interpretability in the attempt of understanding the data as good as possible also in the light of the context of the research. Additionally, we considered satisfactory a factor structure when an item-total correlation was higher than .30 and all items had a communality higher than .20 (Fabrigar et al., 1999; Tabachnick & Fidell, 2013; Balboni, Perrucci, Cacciamani, & Zumbo, 2018). Moreover, as a measure of reliability, McDonald's omega (McDonald, 1999) was computed for each factor and for the developed total scale (Dunn, Baguley, & Brunsden, 2014) using JASP (JASP Team, 2018). An examination of the scree plot of eigenvalues and total variance explained by retained factors was performed to confirm the total number of factors to retain using SPSS 23.

To check the percentage of variance explained by each factor and by the total scale, a confirmatory factor analysis (CFA) was performed on the CFA group (n=157) to validate the factor structure of the dimensions emerged from the previous EFA analysis using Mplus 7 (Muthén & Muthén, 2012). Factors were taken as latent variables and their items as observed indicators. All latent constructs were allowed to covary. We utilized maximum likelihood (ML) estimation method for factor extraction. A non-significant chi-square is the prime indicator for evaluating model fit in structural equation modelling (SEM) analysis (Cheung & Rensvold, 2002). However, this index is affected from the sample size (Bollen, 1990). Therefore, in accordance with common suggestions in the field of CFA (Cheung & Rensvold, 2002; Hu & Bentler, 1999; McDonald & Ho, 2002), the model goodness of fit was tested considering the following indices: Comparative Fit Index (CFI, Bentler, 1990; values above .90 are generally considered to be indicative of a good model fit), Tucker-Lewis index (TLI, Tucker & Lewis, 1973; values above .90 are generally considered to be indicative of a good model fit), Root Mean Squared Error of Approximation (RMSEA, Steiger, 1990; values less than .08 and .05 suggest an adequate and good model fit) and Standardized Root Mean Square Residual (SRMR; Jöreskog & Sörbom, 1993; values of .05 are taken as good fit, .05-.07 as moderate fit). Additionally, the goodness of the twodimensional model was assessed by comparing it in terms of Bayesian Information Criterion (BIC) and Akaike Information Criterion (AIC) comparative indices with two competing models (i.e., the corresponding onedimensional structure and the original five-factor structure). Lower values of AIC and BIC indicate a better fit and the model with the lowest AIC and BIC is the best fitting model. Additionally, Cronbach's alphas were computed. Internal reliability >.70 were considered acceptable (Cronbach & Meehl, 1955). Furthermore, to

test measurement invariance across gender, four multigroup confirmatory factor analyses (MGCFA) were conducted using Mplus 7. Similarly, four MCCFA were performed to test measurement invariance across specialties. This study utilised maximum likelihood estimation with robust standard error to ascertain statistical fit. To determine statistical differences between models, the  $\chi^2$  of the baseline model was subtracted from the  $\chi^2$  value of the nested comparison model, computing the Satorra-Bentler scaled  $\chi^2$  (Satorra & Bentler, 2010). Moreover, as  $\chi^2$  values are influenced by sample size, to evaluate the goodness of the nested models, the difference in CFIs (CFI, Bentler, 1990) between the freely estimated model and the constrained model was used. In fact, it is considered a robust statistic for testing the between-group invariance of CFA models, indicating invariance when this value is .01 or less (Cheung & Rensvold, 2002). Furthermore, fit was examined using RMSEA and CFI indices. Moreover, to examine the nomological validity of the Italian version of the HECS, the correlations (Pearsons' r) between the two dimensions of the Italian version of HECS and other constructs that literature highlighted to be associated with HECS were analysed in the total sample (N=315). In particular, the other constructs considered in association with ethical climate were wellbeing, burnout, social support, and moral distress (McAndrew, Schiffman, & Leske, 2019; Atabay, Çangarli, & Penbek, 2015; Abou Hashish, 2017; Pauly et al., 2009). Moreover, independent sample t-test analyses were performed to detect differences in HECS subscale scores across gender and specialties, also considering Cohen's d values. Internal reliability, nomological validity and t-test analyses were carried out using SPSS 23 (George & Mallery, 2016).

## RESULTS

### Exploratory Factor Analysis

Skewness and kurtosis indexes showed a normal distribution of the items. An examination of the Mahalanobis distance scores indicated the presence of one multivariate outlier which was removed. The Barlett's Test of Sphericity was significant (p<.001) and the Kaiser-Meyer-Olkin measure was very satisfactory (.92), therefore making the factor analysis possible. A first EFA (n=158) was run with the responses for all the HECS items. Then, to determine the number of factors to retain from EFA, a parallel analysis was performed using Mplus 7. We extracted the number of factors for which the real eigenvalue was higher than the parallel one (mean), namely two factors. Items 1, 2, 4, 6, 9, 10, 13, 16, 17, 18 and 23 were eliminated since they did not meet all the required criteria. This led to select, from the original set, 15 items having a factor loading higher than 0.40 on only one factor, a factor loading on the second factor lower than .30, and a difference between the primary and alternative factor loading(s) higher than .20 (Howard, 2016). Next, to detect a factor solution from the 15 items, a second EFA with an oblique Geomin rotation was carried out on these items. Using the same criteria described above, a two-factor solution followed by a Promax rotation was extracted and 15 items were selected. The indexes of the EFA for the two-factor solution met the criteria for a good fit ( $\chi^2$ =135.66, df=76, p=.00, CFI=.95, TLI=.94, RMSEA=.07, SRMR=.04). To further support the two-factor solution, a principal component analysis was conducted using SPSS in conjunction with

a scree plot of eigenvalues. An examination of the scree plot of eigenvalues and total variance explained by retained factors confirmed that the total number of factors to retain were two.

The first factor, labelled *Ethical vision of patient care*, included nine items concerning a general attitude to carry on the job characterized by mutual respect, collaboration, and a sharing mission. The second factor, labelled *Managerial support*, included six items regarding the perception of support that healthcare professionals receive from their managers in dealing with ethical issues. Therefore, the chosen solution resulted composed by 15 items (see *Table 2*): Ethical vision of patient care (9 items,  $\alpha$ =.87) and Managerial support (6 items,  $\alpha$ =.95). The factor loading for the 15-item solution ranges between |.71| and |.96| for Managerial support, and between |.49| and |.83| for Ethical vision of patient care, proposing that all items were substantially contributing in respective factors (Hair, Hult, Ringle, & Sarstedt, 2016). The average interitem correlation was .80 and McDonald's omega of the 15 items was .98 (.97 for managerial support and .98 for ethical vision of patient care) and the internal consistency of the total scale was .93. Furthermore, the item-total correlation was higher than .30 (i.e., .58) and all items had a communality higher than .20 (i.e., all items ranged from .28 to .86). The same structure was confirmed by conducting the same EFA analysis using SPSS 23. The factor solution absorbed 62.13% of the total variance (Ethical vision of patient care explained 49.91% of the variance and Managerial support explained 12.22%).

## [Please insert Table 2 here]

### Confirmatory Factor Analysis

As preliminary analyses, no univariate outliers were identified. We normalized the HECS total score distribution (equal to the sum of the score of the 15 items selected utilizing the EFA) and checked for multivariate outliers. None was found. Multinormality of the data was considered acceptable. The two-factor model selected in the EFA and tested on the CFA sample (n=157) with ML method meet the criteria for a good fit ( $\chi^2=138.97$ , df=89, CFI=.94, TLI=.93, RMSEA=.06, RMSEA 95% CI= [.04,.08], probability  $RMSEA \le .05=.16$ , SRMR=.05, AIC=5193.16, BIC=5330.41; see Figure 1 and Table 3). Then, we estimated the goodness of fit of two alternative models obtained by collapsing the two factors into one (i.e., Managerial-Ethical vision of patient care) and by considering the original composition of factors (i.e., Peers, Patients, Manager, Hospital, Physicians subscales). The two-factor model showed better fit indices than all

alternative nested models. Cronbach's alphas were .88 for the total scale. Moreover, the Cronbach's alpha coefficients were between .85 (CFA group) and .87 (EFA group) for Ethical vision of patients care, whereas the internal consistency of Managerial support subscale ranged between .87 (CFA group) and .95 (EFA group).

[Please insert Figure 1 and Table 3 here]

Measurement invariance across gender

First, two CFA's were performed for men ( $\chi^2$ = 121.74; CFI=.95; RMSEA=.06), and women ( $\chi^2$ = 169.54; CFI=.94; RMSEA=.06), separately. Next, we tested for measurement invariance across gender. To this end, four MGCFA were run. The first was the configural model, which evaluates whether the number of factors and pattern of indicator-factor loadings is equivalent across groups (Brown, 2006). Results for this CFA indicated an adequate model fit (see Table 4), suggesting that the two-factor ethical climate model and the factor pattern loadings were equivalent across gender. The second CFA evaluated the equality of factor loadings. This procedure "entails specification of equality constraints for all freely estimated factor loadings that are similarly specified in both baseline models" (Byrne, 2006, p. 238). To this end, factor loadings were constrained to be equal across the comparison groups. The difference in the  $\chi^2$  statistic for the configural and metric factorial invariance models was not statistically significant ( $\Delta \chi^2 = 5.08$ ,  $\Delta df = 13$ ) and the difference in CFIs was below .01 ( $\Delta$ CFI=.004). The statistically nonsignificant result indicates that the constraints tested were equivalent across gender. Then, the scalar invariance (or equivalence of item intercepts) was tested by constraining the item intercepts to be equivalent in the two groups, in addition to retaining the constraints applied in the metric invariance model. The difference in the  $\chi^2$  statistic for the metric factorial invariance and the scalar invariance models was not statistically significant ( $\Delta \chi^2 = 23.30$ ,  $\Delta df = 15$ ) and the difference in CFIs was below .01 ( $\Delta$ CFI=.004).The statistically nonsignificant result shows that "mean differences in the latent construct capture all mean differences in the shared variance of the items" (Putnick & Bornstein, 2016, p. 5). Therefore, since scalar invariance was supported, the residual variance (or equivalence of item residuals of metric and scalar invariant items) was tested by constraining the item residuals to be equivalent in the two groups, in addition to retaining the constraints applied in the scalar invariance model. The difference in the  $\chi^2$ statistic for the scalar invariance and the residual invariance models was not statistically significant ( $\Delta \chi^2 =$ 22.77,  $\Delta df = 15$ ) and the difference in CFIs was below .01 ( $\Delta CFI=.004$ ). This indicates that "the sum of specific variance (variance of the item that is not shared with the factor) and error variance (measurement error) is similar across groups" (Putnick & Bornstein, 2016, p. 6). Overall, these results indicated that the factor structure of the HECS concept was invariant across gender.

## [Please insert Table 4 here]

#### Measurement invariance across specialties

First, two CFA's were conducted for the neuro-rehabilitation medicine group ( $\chi^2$ = 148.94; CFI=.96; RMSEA=.05), and the palliative care group ( $\chi^2$ = 155.71; CFI=.93; RMSEA=.07), separately. Next, we tested for measurement invariance across specialties. To this end, four MGCFA were run. The configural model indicated an adequate model fit (see *Table 5*), suggesting that the two-factor ethical climate model and the factor pattern loadings were equivalent across specialties. The difference in the  $\chi^2$  statistic for the metric factorial invariance and the scalar invariance models was statistically significant ( $\Delta \chi^2 = 27.15$ ,  $\Delta df = 15$ ). Then, since the full scalar invariance was rejected, partial scalar invariance could still be explored (Byrne, Shavelson, & Muthén, 1989; Millsap & Meredith, 2007), leaving at least two fixed factor loadings plus

intercepts in one factor as the HECS construct was composed by two factors. To this end, the intercepts noninvariance was analysed by relaxing constraints on the intercepts one by one based on modification indices (Byrne et al., 1989; Millsap & Meredith, 2007). One item intercept (item 21) was relaxed for achieving partial scalar invariance. Indeed, the difference in the  $\chi^2$  statistic for the metric factorial invariance and the partial scalar invariance (where the intercept of item 21 was freely estimated) models was not statistically significant  $(\Delta \chi^2 = 22.52, \Delta df = 14)$ , and the difference in CFIs was below .01 ( $\Delta CFI=.004$ ). Therefore, since partial scalar invariance was supported, the partial residual variance was tested by constraining all item residuals except from that of item 21 to be equivalent in the two groups, in addition to retaining the constraints applied in the partial scalar invariance model. The difference in the  $\chi^2$  statistic for the partial scalar invariance and the partial residual invariance models was not statistically significant ( $\Delta \chi^2 = 13.30$ ,  $\Delta df = 14$ ) and the difference in CFIs was below .01 ( $\Delta$ CFI=.000). This means that a change in the latent variable produces the same effect on the score of the observed variables across specialties (except for item 21) and that the differences in all item scores are uniquely attributable to the latent variable. Moreover, except for item 21, it is possible to compare the observed scores at the scale means level (i.e., sums of the item scores) as well as their variances and covariances, making reasonable to make comparisons among means at the latent level across specialties. Overall, since at least partial scalar invariance was reached, HECs scores were comparable across specialties (i.e., neuro-rehabilitation medicine and palliative care; Byrne et al., 1989; Milfont & Fischer, 2010; Sommovigo, Setti, O'Shea, & Argentero, 2018).

## [Please insert Table 5 here]

#### Nomological validity

Results of correlations between the two dimensions of the Italian version of the HECs, Social support, Wellbeing, Burnout and Moral distress dimensions are shown in *Table 6*. Ethical vision of patient care was positively and significantly associated with perceptions of Social support (r=.42, p<.01) and Wellbeing (r=.23, p<.01), whereas this dimension was negatively related to Burnout symptoms (r= -.16, p<.01), Deceptive communication (r= -.19, p<.01), Misconduct (r= -.19, p<.01), Poor team work (r= -.36, p<.01) and Futile care (r= -.09, p<.01), although this latter correlation was not significant. Similarly, Managerial support dimension showed positive and significant associations with perceptions of Social support (r=.54, p<.01) and Wellbeing (r=.17, p<.01), while it was negatively and significantly related to Burnout symptoms (r= -.15, p<.01), Deceptive communication (r= -.15, p<.01), Misconduct (r= -.17, p<.01), Poor team work (r= -.24, p<.01) and Wellbeing (r=.17, p<.01), while it was negatively and significantly related to Burnout symptoms (r= -.24, p<.01) and Futile care (r= -.03, p<.01), while it was negatively and significantly related to Burnout symptoms (r= -.24, p<.01) and Futile care (r= -.03, p<.01), even though this latter correlation was not significant. Therefore, overall, the two factors showed a similar pattern of results, as expected.

#### [Please insert Table 6 here]

Further analyses were conducted to detect whether there were differences across gender and specialties on the two dimensions of the Hospital Ethical Climate Survey. No significant differences were found for

gender (see *Table 7*). Conversely, there were significant differences in the scores of both dimensions for healthcare professionals employed in neuro-rehabilitation medicine specialty (M=3.45, SD=.73; M=3.66, SD=.57, for Ethical vision of patient care and Managerial support, respectively) and those who were working in palliative care specialty (M=4.01, SD=.90; M=4.25, SD=.72, for Ethical vision of patient care and Managerial support, respectively), so that the latter reported higher levels of both Ethical vision of patient care and Managerial support than the first (see *Table 7*). Then, to detect whether there were differences across professional roles on the two dimensions of the HECS, an analyses of variance (ANOVA) was conducted (see *Table 8*). Bonferroni post-hoc comparisons showed that physicians and psychologists (M=3.72; SD=.66) perceived the ethical vision of patient care as significantly more positive than physiotherapists and other therapists (M=3.37; SD=.65). Additionally, physicians and psychologists (M=3.76; SD=.70) reported to receive more managerial support than physiotherapists and other therapists (M=3.76; SD=1.07). No other statistically significant differences were found among professional groups.

[Please insert Table 7 here]

[Please insert Table 8 here]

## DISCUSSION

The purpose of this study was to assess, through psychometric evaluations, a preliminary version of the Hospital Ethical Climate Survey (HECS; Olson, 1998) in the Italian language and to investigate its dimensionality in a sample of healthcare professionals employed in neuro-rehabilitation medicine and palliative care specialties. Based on the results from exploratory factor analysis, the scale was reduced from 26 to 15 items. The number of items constituting the Italian validation is in line with the English 14-item version of the instrument proposed by Hamric et al. (2012). Although previous versions in other languages maintained the five-factor structure as the original (Bahcecik, & Oztürk, 2003; Silén et al., 2011; Claeys et al., 2013; Hwang & Park, 2014; Khalesi et al., 2014; Suhonen et al., 2015; Charalambous et al., 2018), our findings revealed a different structure. Indeed, we found that a two-factor model provided the best fit for the data, indicating the presence of two independent dimensions labelled (1) Ethical vision of patient care and (2) Managerial support. The first dimension is a new factor that resulted from the aggregation of nine items which originally belonged to Patients, Physicians and Hospital subscales identified by Olson (1998). This factor underlines the presence - or the absence - of mutual respect and collaboration among colleagues, in addition to the sharing of a mission in terms of the provision of a patient care which is made according to quality standards and in compliance with ethical values and practices. The second dimension, called Managerial support, included six items regarding the relationships that healthcare professionals may have in their workplace with managers who may - or not - provide adequate support in dealing with ethical issues. It should be noted that this factor remained unchanged from that included in the original version. This is not surprising, considering that in the Persian version of HECS, the subscale Manager scored the highest scores (Khalesi et al., 2014), indicating the relevance of this dimension. Furthermore, these results underline the pivotal role of 15

hospital managers in maintaining a positive ethical climate. Additionally, a possible explanation for the different factor structure we found might be attributable to dissimilarities existing in the healthcare system between Italy and North America (Winter, 2016; Hennes, Kieselbach, Klädtke,Wirsching, & Zucchinali, 2015). On the one hand, although the presence of different private hospitals, the Italian healthcare system is a public-based model in which health assurances are not a prerequisite to have access to cares because healthcare represents an inalienable right that, as such, is guaranteed to each citizen. On the other hand, the American healthcare system is largely privatized, and healthcare expenses depend on citizens' private assurances. These differences may impact on both healthcare professionals' daily work practices and hospital policies, invalidating some items of the original subscales Hospital and Patient. Moreover, the original subscale Peers - which was at the beginning developed to investigate relationships among nurse colleagues - was completely deleted probably because it was unsuitable to our sample since the questionnaire was administrated not only to nurses, but also to other healthcare providers (i.e., physicians, physiotherapists, social operators).

The correlation between the two dimensions resulted positive both in the exploratory and in the confirmatory factor analysis. Such positive correlation is in line with what expected based on the results from other validation studies (Suhonen et al., 2015; Khalesi et al.; 2014; Olson 1998). The correlations in the entire sample between the two dimensions of HECS and wellbeing, social support, burnout, and moral distress dimensions are in the hypothesized directions as a support to the concurrent validity. Both dimensions are positively correlated with wellbeing and social support, confirming the fact that a positive ethical climate is positively associated with wellbeing (Koskenvuori et al., 2019) and perceptions of social support (Silén et al., 2012; Abou Hashish, 2017; Koskenvuori et al., 2019). Additionally, both Ethical vision of patients care, and Managerial support are negatively associated with moral distress dimensions and burnout in accordance with findings from previous studies (Pauly et al., 2009; Silén et al., 2011; Dzeng & Curtis 2018; Koskenvuori et al., 2019). Overall, these results highlight the importance for healthcare professionals to perceive a good ethical climate to maintain their wellbeing and counterattack distress (Pauly et al., 2009; Schwatka et al., 2016; Koskenvuori et al., 2019). Moreover, the current research did not show any significant differences between women and men in the perception of HEC, differently from what predicted based on previous studies (Luthar DiBattista, & Gautschi, 1997; Pergert et al., 2019). A possible explanation might be related to our sample that was not well balanced with respect to gender. Conversely, significant differences in HECS scores were revealed for specialty, so that healthcare professionals employed in palliative care specialty reported higher levels of both Ethical vision of patient care and Managerial support than those working in neuro-rehabilitation medicine specialty. These results are in accordance with the study conducted in Turkey, showing differences across different care settings (Bahcecik & Oztürk, 2003). Additionally, our results indicated that physicians and psychologists reported higher levels of both ethical vision of patient care and managerial support than physiotherapists and other therapists, whereas no other statistically significant differences were detected among professional groups. These findings may partly be explained by the fact that physicians and psychologists have more decision-making authority than other healthcare professionals, so that they can more freely behave in line with their ethical values in the provision of care. Moreover, having more responsibilities,

physicians have usually many procedures and occasions for discussing tough clinical cases (Pergert et al., 2019), therefore they may perceive to be more supported by the management in dealing with demanding ethical issues. In literature it has been argued that these discrepancies in the autonomy and responsibility linked to the various professional roles may explain why physicians reported a better perception of ethical climate than nurses (Hamric & Blackhall, 2007; Bartholdson et al., 2016; Pergert et al., 2018; Pergert et al., 2019) and other healthcare professionals, too (Whitehead et al., 2014). In the present study, this difference was statistically significant only between physicians and psychologists in respect to therapists.

Our analyses confirmed item adequacy and a good internal consistency of the subscales. Looking at the reliability of the two dimensions, they turned out to be satisfactory, in accordance with what previously found (e.g.,  $\alpha$ =.81, Olson, 1998;  $\alpha$ =.94, Silén et al., 2011;  $\alpha$ =.95, Hwang & Park, 2014;  $\alpha$ =.73, Khalesi et al., 2014;  $\alpha$ =.84, Charalambous et al., 2018). The reliability for the total scale ranged between .88 (CFA group) and .93 (EFA group), similarly to the reliabilities found by previous investigations (e.g.,  $\alpha$ =.91, Olson, 1998;  $\alpha$ =.89, Bahcecik & Oztürk, 2003;  $\alpha$ =.92, Silén et al., 2011;  $\alpha$ =.95, Hwang & Park, 2014;  $\alpha$ =.94, Khalesi et al., 2014;  $\alpha$ =.90, Suhonen et al., 2015).

Overall, our results revealed that the Italian version of HECS represents a user-friendly instrument to measure healthcare professionals' perceptions of ethical climate within their work setting.

### Limitations and future perspectives for research

The contributions of this study need to be interpreted in the light of its limitations.

Although our sample was constituted by healthcare professionals from six hospitals, we did not collect information about participants' hospital location in order to further guarantee the anonymity and confidentiality of subjects' responses. This was aimed to diminish respondents' evaluation apprehension and social desirability concerns (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). As a result, data were analysed in aggregated form and our results were based on a single sample which was split through a random sampling technique into two small subsamples (i.e., EFA group and CFA group). The total sample was mainly composed of female nurses. However, gender and professional status distribution in our sample is representative of these employee cohorts within the Italian healthcare context (WHO, 2018). Therefore, future research should replicate the findings of this study using samples that are more balanced in terms of gender and professional roles. Moreover, even if we could demonstrate that the factor structure of the HECS concept was invariant across gender, the results supported full metric invariance, but only partial scalar invariance across specialties, given the existence of one non-invariant item intercept. This was from the ethical vision of patient care factor and referred to the questioning and looking for creative solutions to patient care problems, meaning that this affirmation had a different connotation for professionals working in medical rehabilitation in comparison with those working in palliative care. This difference might be explained by the different types of patients treated and specific clinical practices allowed in these two critical specialties. Said differently, professionals might interpret with different nuances the content of this item in accordance with the kind of needs and demands posed by the patients. Thus, questioning and looking for creative solutions may elicit different meanings in a

palliative care professional adopting a more holistic approach when compared with a colleague who is mainly focused on rehabilitative outcomes. Future studies should investigate more in depth the connotations attributed to this item by professionals working in different critical specialties. Additionally, we could not test measurement invariance across different professional roles because of our relatively small sample size. Therefore, future studies using a larger population will make it possible to have enough participants to examine the invariance of the HECS factor structure for participants differing in professional roles. In doing so, also the stability of the model will be corroborated.

Additionally, standardization investigations could identify normative scores to cluster individual profiles. Furthermore, the self-report nature of our study and the cross-sectional design of our research raise issues of common method bias. Although common method bias is seldom severe enough to compromise the validity of the results (Spector, 2006), we followed Podsakoff and colleagues' (2003) recommendations regarding questionnaire design to decrease this bias. Future research should collect information from other sources (e.g., interviews with professionals) and adopt a longitudinal design to verify test-retest reliability of the Italian version of HECS.

A further limitation of this research was the lack of convergent and discriminant validity tests which is justifiable to light of the absence of other Italian validated scales analysing similar constructs and the avoidance of excessive survey length to prevent low response rates. Despite this limitation, nomological validity was confirmed by showing that the correlations of the measure with other relevant variables (i.e., Wellbeing, Social support, Burnout and Moral distress dimensions) were in the hypothesized direction. Only the Futile care dimension of moral distress did not reach statistical significance. Moreover, the reliability of the Deceptive communication subscale was poor. As the moral distress scale was validated on a sample of healthcare professionals working in intensive care units (Lamiani et al., 2017), future investigations should further test the reliability of this scale by evaluating more deeply the content validity of its items within neuro-rehabilitation medicine and palliative care specialties.

Another possible limitation was that we decided to re-word HECS items by using the more general term "healthcare professionals" instead of administrating parallel versions to each of the specific professional groups. Therefore, this might not have activated one's own professional group identity, making more difficult for healthcare providers to think about peculiar professional group-relevant events. As a result, this might have hindered the appraisal of such events, limiting the emersion of specific differences among professional roles. Additionally, this might have limited the opportunity to investigate relationships among healthcare professional sample. However, this choice was made in accordance with previous studies which made similar minor revisions to make the original scale suitable for multiple professions (e.g., Bartholdson et al., 2016; de Boer et al., 2016; Silén et al., 2015; Ulrich et al., 2007), in addition to being approved by the author of the original scale. Furthermore, the use of a label which related to a more inclusive ingroup (i.e., the healthcare providers themselves) might have facilitated the emergence of common perceptions about hospital ethical climate among different professional groups. This is in line with the theoretical assumption that the ethical

climate is a form of organizational climate that embraces shared perceptions about healthcare providers working within the same units. Additionally, from a practical point of view, this choice allows to provide practitioners with an instrument having a multi-professional applicability; thereby, facilitating the design of interventions addressed at professionals from different disciplines, whose involvement is crucial to cultivate a positive ethical climate.

A further limitation of this study was that we shorted the HECS without using a response theory (IRT)based methodology (i.e., a modern psychometric methodology which evaluates the relationships between a participant's response on an item and its corresponding level of the latent variable; Edelen & Reeve, 2007). In addition to detecting the most informative items among an item set, IRT techniques enable to successfully shorten scales by selecting items that cover all levels of a latent concept, without compromising assessment precision and making the shortened versions easily compatible with the original questionnaires (e.g., Reise, 2009). Despite of IRT advantages, our item selection was based on EFA indices rather than IRT because we were interested into the characteristics of the overall scale (i.e., IRT does not analyse a scale on the set of item level) and our relatively small sample size limited the possibility to reach sufficient accuracy of the estimates that may be obtained from the use of IRT. Future research efforts should strongly consider combining classical test theory (CTT) and IRT techniques to confirm on a larger population whether the best items with which to represent HECS were those that we selected.

Finally, the current validation of the HECS is restricted to neuro-rehabilitation medicine and palliative care specialties which are at high-risk contexts for ethical dilemmas due to the complexity of patient care. Although these specialties share numerous relevant characteristics with other ones, future investigations should replicate these results in other specialties to confirm the generalizability of the Italian version of HECS.

### CONCLUSION

Nowadays, the ethical climate plays a pivotal role for healthcare professionals' wellbeing due to the increasing ethical issues arising from the even growing complexity of patient care. The results presented in this paper are promising. Indeed, the preliminary Italian version of the HECS provides – to the best of our knowledge - for the first time in this country the opportunity to utilize a valid and reliable scale to evaluate hospital medical professionals' perceptions of the ethical climate within their workplaces which can be used by both researchers and practitioners. This is crucial to formulate preventive measures and tailored interventions that help healthcare professionals deal with ethical dilemmas.

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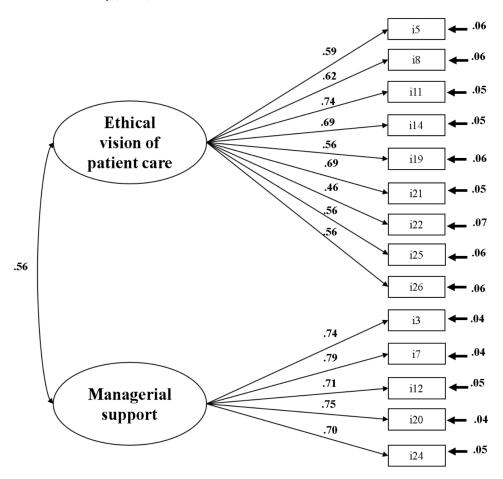
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**Figure 1.** Completely standardized coefficients of the two-factor model of the Italian version of the Hospital Ethical Climate Survey (HECS).

Note. p < .001 for all coefficients.

	All participants (n=315)	EFA group ( <i>n</i> =158)	CFA group ( <i>n</i> =157)
	<u>(n=515)</u> %	<u>(n=130)</u> %	<u>(n=137)</u> %
Gender			
Female	67.0	64.6	69.4
Specialty			
Neuro-rehabilitation medicine	70.5	68.4	72.6
Palliative care	29.5	31.6	27.4
Age			
< 40 years	46.0	44.9	47.1
41-50 years	32.3	31.4	33.1
>51 years	21.7	23.7	19.7
Occupation			
Physician and psychologist	20.8	24.2	17.3
Nurse	40.6	40.8	40.3
Physiotherapist and other therapist <sup>s</sup>	22.0	15.3	28.8
Social-health operator	16.6	19.7	13.5
Overall job tenure			
<5 years	25.2	25.6	24.8
6-15 years	31.3	30.1	32.5
>16 years	43.5	44.3	42.7
Job tenure in current position			
<5 years	31.8	30.8	32.9
6-10 years	23.5	25.0	21.9
>10 years	44.7	44.2	45.2
Shift work			
Yes	64.7	68.6	60.8
Contract			
Open-ended	78.9	74.8	83.0
Fixed term	14.5	17.9	11.1
Temporary	6.6	7.3	5.9
Average HECs score	M (SD)	M (SD)	M (SD)
Note <sup>a</sup> Other therapists includes disticions, speech t	3.71(.61)	3.76 (.55)	3.70 (.66)

# Table 1. Characteristics of the total participants and EFA and CFA groups

Note. <sup>a</sup> Other therapists includes dieticians, speech therapists and occupational therapists

		actor	
Items	Ethical vision of	Managerial	h <sup>2</sup>
	patient care	support	
3. Quando non sono in grado di decidere che cosa è giusto o sbagliato sulla cura	01	.88*	.81
di un paziente, il mio superiore mi aiuta <sup>a</sup>			
5. I professionisti sanitari si fidano gli uni degli altri <sup>b</sup>	.63*	.04	.48
7. Il mio superiore mi supporta nelle decisioni riguardanti la cura dei pazienti <sup>c</sup>	.00	.92*	.85
8. I professionisti sanitari condividono chiaramente la mission dell'ospedale <sup>d</sup>	.69*	.13	.66
11. Per risolvere i problemi legati alla cura dei pazienti i professionisti sanitari si	.53*	.04	.44
basano su dati pertinenti <sup>e</sup>			
12. Il mio superiore mi ascolta quando parlo di problemi legati alla cura dei	.03	.90*	.86
pazienti <sup>f</sup>			
14. Partecipo nelle decisioni di trattamento dei miei pazientig	.49*	.03	.28
15. Il mio superiore è una persona di cui mi posso fidareh	.10	.81*	.81
19. Le volontà dei pazienti sono rispettate <sup>i</sup>	.55*	.01	.47
20. Quando i miei colleghi non sono in grado di decidere cosa è giusto o sbagliato	.17	.72*	.76
in una particolare situazione di cura di un paziente, ho notato che il mio			
responsabile li aiuta <sup>1</sup>			
21. Nella cura dei pazienti, ci si pone delle domande e si ricercano soluzioni	.53*	.10	.42
creative <sup>m</sup>			
22. I professionisti sanitari si rispettano reciprocamente <sup>n</sup>	.84*	09	.72
24. Il mio capo è una persona che rispetto <sup>o</sup>	.12	.69*	.68
25. Nel mio reparto posso svolgere il mio lavoro nel modo in cui penso debba	.67*	04	.52
essere fatto <sup>p</sup>			
26. Nel mio ospedale, tutti i professionisti sanitari sono supportati e rispettati <sup>q</sup>	.72*	04	.56
Explained variance (%)	49.91	12.22	
McDonald's omega	.97	.98	
Interfactor correlations			
1. Manager		.58	

Table 2. EFA (n=158): factor loadings and communalities of the selected 14 items of the Hospital Ethical Climate scale, explained variance and reliability of the factors, and interfactor correlations

<sup>b</sup>Nurses and physicians trust one another

°My manager supports me in my decisions about patient care.

<sup>d</sup>A clear sense of the hospital's mission is shared with nurses. <sup>e</sup>Nurses use the information necessary to solve a patient care issue/problem <sup>f</sup>My manager listens to me talk about patient care issues/problems

I participate in treatment decisions for my patients.

<sup>h</sup>My manager is someone I can trust.

<sup>h</sup>Patients' wishes are respected.
<sup>h</sup>When my peers are unable to decide what's right or wrong in a patient care situation, I have observed that my manager helps them.
<sup>m</sup>There is a sense of questioning, learning, and seeking creative responses to patient care problems.
<sup>n</sup>Nurses and physicians respect each other.

°My manager is someone I respect.

PI am able to practice nursing on my unit as I believe it should be practiced.

9Nurses are supported and respected in this hospital

Model	$\chi^2$	df	CFI	TLI	RMSEA	RMSEA 90% CI	SRMR	AIC	BIC
2-factor	138.97	89	.94	.93	.06	[.04, .08]	.05	5193.16	5330.41
1-factor	311.78	90	.72	.67	.13	[.11, .15]	.10	5363.98	5498.24
5-factor	562.44	289	.82	.80	.08	[.07, .09]	.07	9085.21	9347.77
Cut-off			>.90	>.90	<.08		<.08		

 Table 3. Fit indices for structural models (n=157)

Note.  $\chi^2$  = chi-square test of model fit; CFI= Comparative Fit Index; TLI= Tucker-Lewis Index; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardized Root Mean Squared Residual; AIC= Akaike Information Criterion; BIC= Bayesian Information Criterion.

Model	$\chi^2$	df	$\Delta \chi^2$	Δ df	р	CFI	RMSEA	90% CI RMSEA	Δ CFI
Model men	121.76	89	-	-	-	.953	.06	[.03,.09]	-
Model women	169.54	89	-	-	-	.936	.06	[.05,.08]	-
Configural invariance	292.06	178	-	-	-	.942	.06	[.05,.08]	-
Metric invariance	297.14	191	5.08	13	.83	.946	.06	[.05,.07]	.004
Scalar invariance	320.43	206	23.30	15	.08	.942	.06	[.05,.07]	.004
Residual invariance	343.20	221	22.77	15	.09	.938	.06	[.05,.08]	.004

Table 4. MGCFA results for measurement invariance across gender

Note. df= degree of freedom;  $\Delta \chi^2$ = difference in chi-square between models; RMSEA= Root Mean Square Error of Approximation; 90% CI RMSEA= 90% confidence interval RMSEA; CFI= Comparative Fit Index;  $\Delta CFI$ = difference in CFI between models.

Model	$\chi^2$	df	$\Delta \chi^2$	Δdf	р	CFI	RMSEA	90% CI RMSEA	ΔCFI
Model neuro-rehab.	148.94	89	-	-	-	.959	.05	[.04,.07]	-
Model palliative care	155.71	89	-	-	-	.930	.07	[.05,.08]	-
Configural invariance	304.10	178	-	-	-	.934	.06	[.05,.08]	-
Metric invariance	313.46	191	9.36	13	.56	.936	.06	[.05,.08]	.002
Scalar invariance	340.62	206	27.15	15	.03	.930	.06	[.05,.08]	.006
Part. scalar invariance <sup>a</sup>	335.98	205	22.52	14	.07	.932	.06	[.05,.08]	.004
Part. residual invariance	349.28	219	13.30	14	.07	.932	.06	[.05,.07]	.000

**Table 5.** MGCFA results for measurement invariance across specialties

Note. Model neuro-rehab.= model neuro-rehabilitation medicine; df= degree of freedom;  $\Delta \chi^2$ = difference in chi-square between models; RMSEA= Root Mean Square Error of Approximation; 90% CI RMSEA= 90% confidence interval RMSEA; CFI= Comparative Fit Index;  $\Delta CFI$ = difference in CFI between models; <sup>a</sup>freely estimated the intercept of item 21.

	Μ	SD	Skewness	Kurtosis	1	2	3	4	5	6	7	8	9	10
1. Ethical vision of patient care	3.51	.70	23	52	.86									
2. Managerial support	4.08	.86	-1.13	.96	.54**	.92								
3. Social support	3.52	.65	17	14	.42**	.54**	.74							
4. Wellness	3.37	.66	11	35	.23**	.17**	.49**	.80						
5. Burnout	2.87	.86	.89	1.61	16**	15**	15**	13*	.85					
6. Futile care	2.35	2.26	1.07	.48	09	03	04	03	.21**	.76				
7. Deceptive communication	1.73	1.73	1.28	1.52	19**	15**	12*	09	.09	.60**	.55			
8. Misconduct	1.24	1.34	1.35	1.68	19**	17**	17**	14*	.17**	.67**	.61**	.63		
9. Poor teamwork	2.78	2.48	.90	.21	36**	24**	22**	16**	.09	.45**	.64**	.57**	.83	
10. Gender	-	-	-	-	05	02	01	07	07	02	.10	.01	$.14^{*}$	-
11. Specialty	-	-	-	-	$.14^{*}$	.13*	.09	06	13*	17**	.37**	$.11^{*}$	.16**	.04

**Table 6**. Descriptive statistics and intercorrelations in total sample (N=315)

Note. Boldfaced numbers on the diagonal represent Cronbach's alpha; M= means; SD= standard deviations; \*p<05; \*\*p<.01.

Mal	Males		Females			95% CI		Cohen's
(n=1	03)	(n=205)		t	р			d
М	SD	М	SD	-	1	LL	UL	-
3.57	.68	4.49	.70	.97	.33	09	.24	.12
4.10	.83	4.07	.87	.35	.73	16	.23	.04
Neuro-reha	bilitation	Palliative care				95% CI		Cohen's
(n=2	17)	(n=91)		t	р			d
М	SD	М	SD	-	•	LL	UL	-
3.45	.73	3.66	.57	-2.37	.02	35	06	.31
4.01	.90	4.25	.72	-2.31	.01	44	07	.30
	(n=1 M 3.57 4.10 Neuro-reha (n=2 M 3.45	(n=103)         SD           M         SD           3.57         .68           4.10         .83           Neuro-rehabilitation (n=217)           M         SD           3.45         .73	$\begin{array}{c ccccc} (n=103) & (n=2) \\ \hline M & SD & M \\ \hline 3.57 & .68 & 4.49 \\ \hline 4.10 & .83 & 4.07 \\ \hline Neuro-rehabilitation \\ (n=217) & (n=9) \\ \hline M & SD & M \\ \hline 3.45 & .73 & 3.66 \\ \hline \end{array}$	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	$\begin{array}{c c c c c c c c c c c c c c c c c c c $	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	$\begin{array}{c c c c c c c c c c c c c c c c c c c $

Table 7. Mean, standard deviations, t-values of the dimension of HECs acro	oss gender and medical specialty
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Note. CI= confidence interval; LL=lower limit; UL=upper limit

Dimension	Occupational group	Mean	SD	F	959	% CI
					LL	UL
Ethical vision of patient care	Physicians	3.72	.66	$2.86^{*}$	3.55	3.88
	Nurses	3.50	.70		3.38	3.62
	Therapists	3.37	.65		3.21	3.53
	Social health workers	3.50	.79		3.27	3.73
Managerial support	Physicians	4.35	.70	5.53**	4.17	4.52
	Nurses	4.09	.80		3.94	4.23
	Therapists	3.76	1.07		3.50	4.02
	Social health workers	4.13	.72		3.92	4.33

**Table 8.** ANOVA between groups for different kinds of professional groups regarding ethical vision of patient care and managerial support dimensions

Note. SD= standard deviations; LL=lower limit; UL=upper limit; \*p<05; \*\*p<.01.

### Abstract

This study aimed to assess, through psychometric evaluations, a preliminary Italian version of the Hospital Ethical Climate Survey (HECS), checking its factor structure through exploratory factor analysis (EFA) and confirming the resulting factor structure in a second sample using confirmatory factor analysis (CFA). This research included a total of 315 Italian healthcare professionals working in neuro-rehabilitation medicine and palliative care units from six hospitals. EFA revealed a two-factor structure, including *Ethical vision of patient care* and *Managerial support*. CFA on the second sample confirmed the factor structure extracted from EFA, displaying good internal consistencies. Correlations showed that both dimensions were positively associated with wellbeing and social support, while negatively related to burnout and moral distress, supporting construct validity. The Italian version of HECS represents a user-friendly instrument to evaluate the ethical climate perceptions of healthcare professionals which are increasingly at risk of facing ethical dilemmas due to the growing complexity of patient care.

Keywords: Italian validation; hospital ethical climate; rehabilitation medicine; palliative care; distress



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# Chapter Seven

# Mediation and moderated mediation models

# 7.1. An introduction to the mediation and moderation studies conducted

The intricate healthcare scenario of nowadays may deprive healthcare professionals of energies and resources, providing fertile ground to burnout, distress and moral distress (Hall, Johnson, Watt, Tsipa, & O'Connor, 2016; West, Dyrbye, & Shanafelt, 2018; Hynes et al. 2019; Maffoni et al, 2019; Maffoni et al, 2020). This is even more true for professionals employed in palliative care and neurorehabilitation medicine as their job tasks expose them to different challenging issues on a daily basis (Maslach, 2007; Rothenberger, 2017; Maffoni, Argentero, Giorgi, & Giardini, 2020; Sliwa et al., 2019).

However, as described in chapter one of this dissertation, manifold protective factors for wellbeing and professional outcomes were detected in the previous literature, too. In this context, it is of paramount importance to better define and understand the mechanisms and relations among factors which may contribute to foster wellbeing or pave the way to psychological malaise. In an attempt to provide evidence to address these relevant research questions, two studies were conducted to test hypotheses driven from COR theory (Hobfoll, 1989), focusing on palliative care and neurorehabilitation medicine specialties. The following pages will present these studies in detail.

The first study addresses healthcare professionals working in neurorehabilitation medicine. The aim was to disclose through which mechanisms and under what conditions emotional exhaustion may be reduced by ethical climate, intended in its nuances of "ethical vision of patient care" and "managerial support in dealing with bioethical issues". In addition, resilience and positive affectivity were investigated to check if these personal conditions may or not moderate the effect of ethical climate on emotional exhaustion through moral distress.

The second study focuses on healthcare professionals employed both in palliative care and neurorehabilitation medicine specialties with the aim of unveiling whether and under which conditions resilience may impact on health and professional outcomes. Moreover, managerial support was investigated to check if it may or not moderate the effect of resilience on wellbeing and professional efficacy through ethical vision of patient care.

Overall, these findings enable to formulate and suggest preventive measures to support healthcare professionals overcome the numerous challenges characterizing their profession. Some of such suggestions and recommendations will be better discussed also in chapter ten of this dissertation.

Section C: Chapter 7 - Mediation and moderated mediation models

# 7.2. The relationship between managerial support and emotional exhaustion

Marina Maffoni, Valentina Sommovigo, Anna Giardini, Stefano Paolucci, Ilaria Setti. Dealing with ethical issues in rehabilitation medicine: The relationship between managerial support and emotional exhaustion is mediated by moral distress and enhanced by positive affectivity and resilience. *Journal of Nursing Management, 28*: 1114–1125. <u>https://doi.org/10.1111/jonm.13059</u>.<sup>6</sup>

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ORIGINAL ARTICLE

# Dealing with ethical issues in rehabilitation medicine: The relationship between managerial support and emotional exhaustion is mediated by moral distress and enhanced by positive affectivity and resilience

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**Aims:** To analyse whether managerial support and ethical vision of patient care would be related to emotional exhaustion directly or through moral distress and whether these relationships would be conditional on individual levels of positive affectivity and resilience.

**Background:** Although some studies described the effects of ethical climate, moral distress, resilience and positive affectivity on emotional exhaustion, there are no attempts of explicative models containing these variables.

**Methods:** A total of 222 Italian professionals employed in neuro-rehabilitation medicine units participated in this cross-sectional study. Descriptive statistics, mediation and moderated mediation analyses were conducted using SPSS.

**Results:** Managerial support and ethical vision of patient care were negatively related to emotional exhaustion, directly and through moral distress. Professionals high in resilience and positive affectivity benefited more from the protective effect of managerial support on emotional exhaustion through moral distress.

**Conclusion:** Ethical climate represents a protective factor against moral distress and emotional exhaustion. Moreover, individual levels of positive affectivity and resilience may increase the beneficial effects deriving from managerial support in dealing with ethical issues.

**Implication for Nursing Management:** Health organisations may consider developing strategies to improve ethical climate, enhance managers' ability to support team in dealing with ethical issues and foster employees' positive affectivity and resilience.

#### KEYWORDS

affectivity, emotional exhaustion, ethical climate, moral distress, rehabilitation, resilience

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#### MAFFONI ET AL

## 1 | INTRODUCTION

Today's medical and technological advancements result in complex ethical concerns among health care professionals, which pose challenges for managers struggling for health care personnel safeguard (Hynes, Maffoni, Argentero, Giorgi, & Giardini, 2019; Maffoni et al., 2019, 2020; Sliwa et al., 2019). This particularly affects daily working life of professionals employed in rehabilitation units who are frequently confronted with numerous challenges, such as high demands related to patient-centred treatment and potential conflicts with organisational priorities. All these factors make these employees at increased risk of developing moral distress and emotional exhaustion (Sliwa et al., 2019). Therefore, more research is required to identify factors, which may protect health care professionals employed in medical rehabilitation specialties from emotional exhaustion. Emotional exhaustion, namely feelings of overwhelming exhaustion resulting from the depletion of personal resources due to prolonged work demands (Maslach & Leiter, 2016), represents "the central quality of burnout" (Maslach, Schaufeli, & Leiter, 2001; p. 402) as the other dimensions (i.e. depersonalization and reduced personal accomplishment) develop as a consequence of this state of exhaustion (Taris, Le Blanc, Schaufeli, & Schreurs, 2005). According to Conservation of Resources (COR) theory (Hobfoll, Halbesleben, Neveu, & Westman, 2018), stress emerges when individuals experience or anticipate a threat to or an actual loss of resources (i.e. things that individuals centrally value) or fail to gain resources after significant resource investment. From this perspective, emotional exhaustion represents the end state of a long-term process of resource loss, which gradually develops over time and which exhausts one's energy resources. In this regard, numerous studies have consistently demonstrated that this condition may engender mental and cognitive health problems, including depression (Wurm et al., 2016), suicidal ideation (Shanafelt et al., 2011), cognitive difficulties (Horvat & Tement, 2020) and negative organisational outcomes, including disengagement, job dissatisfaction and turnover (López-Cabarcos, López-Carballeira, & Ferro-Soto, 2019; Thanacoody, Newman, & Fuchs, 2014).

Besides emotional exhaustion, *moral distress* represents another threat to health care professionals' well-being. It refers to the experience of painful feelings that takes place when professionals are unable to act according to their own beliefs and values because of external constraints (Lamiani, Borghi, & Argentero, 2017; Maffoni, Argentero, Giorgi, Hynes, & Giardini, 2019). Drawing on COR theory, engaging in actions that contradict one's stated ethical values may negatively impact on psychological functioning as it leaves individuals confronted with the loss of critical resources (e.g. moral integrity) eventually leading to emotional exhaustion (Dzeng & Curtis, 2018; Fumis, Amarante, de Fátima Nascimento, & Junior, 2017; McAndrew, Schiffman, & Leske, 2019). Indeed, in attempting to deal with the consequences of moral distress, health care professionals need to invest further resources. If health care providers are not successful in doing so, they may further

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exacerbate their losses, entering an escalating spiral of losses, which leads to fewer resources and further health impairment (Hobfoll et al., 2018). In a situation of continued resource depletion, health care professionals may lack the energies to maintain their normal functioning at work, and finally, emotional exhaustion may occur. As a result, health providers may try to offset the loss of emotional resources by reducing their working efforts to meet patient care demands and by adopting withdrawal behaviours (Lamiani, Setti, Barlascini, Vegni, & Argentero, 2017; Maffoni, Argentero, Giorgi, Hynes, et al., 2019). This is particularly likely to occur when individuals have fewer resources as they are more vulnerable to resource loss (Hobfoll et al., 2018). Thus, health care professionals with fewer resources may more easily pass from moral distress to emotional exhaustion. Conversely, professionals with greater resources are less susceptible to resource loss as they have a tendency towards the accumulation of resources over time, namely a tendency towards resource caravans (Hobfoll et al., 2018). Resource caravans allow individuals to maintain high levels of well-being, which, in turn, foster the acquisition of additional job resources, leading to a so-called gain spiral. Such gain spiral may also be stimulated by resourceful work environments, known as resource caravan passageways (i.e. "environmental conditions that support, foster, enrich, and protect the resources of individuals"; Hobfoll, 2012; p. 229) to the extent to which workplaces provide individuals with protection against resource loss, thereby facilitating the creation of resource caravans. In this regard, several investigations showed the relevance of a positive organisational climate in contrasting emotional exhaustion and moral distress (Burston & Tuckett, 2013; West, Dyrbye, & Shanafelt, 2018). In particular, the research on hospital ethical climate is growing due to the increasing attention to ethical concerns related to care (Koskenvuori, Numminen, & Suhonen, 2019), Ethical climate refers to a general attitude characterized by ethical values and practices in the provision of patient care, along with a shared mission to comply with high-quality care standards (Treviño, 2008). It is relevant in preventing from emotional exhaustion (Dzeng & Curtis, 2018; West et al., 2018) and moral distress (Pauly, Varcoe, Storch, & Newton, 2009; Silén, Svantesson, Kjellström, Sidenvall, & Christensson, 2011), not only among nurses but also among physicians (Hamric, Borchers, & Epstein, 2012). A positive facet of ethical climate is the presence of social support. Although the protective role of managerial support in preventing health care professionals' emotional exhaustion is well known (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020), only a few studies concentrated on managerial support provided to health care professionals dealing with ethical issues (McAndrew et al., 2019; Rasoal, Skovdahl, Gifford, & Kihlgren, 2017). Throughout this paper, the term managerial support will refer to the support provided by managers in facing ethical issues.

Besides managerial support, the health care provider's approach to patient care may be another relevant nuance of ethical climate (Burston & Tuckett, 2013). Indeed, nurses' commitment to providing respectful patient care was found to reduce emotional exhaustion

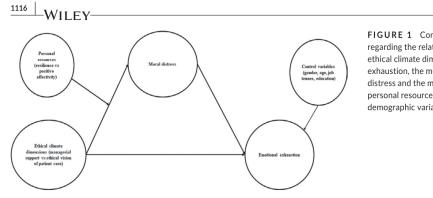


FIGURE 1 Conceptual model regarding the relationships between ethical climate dimensions and emotional exhaustion, the mediating role of moral distress and the moderating role of personal resources, while controlling for demographic variables

by increasing their personal accomplishment and job satisfaction (McClendon, 2017; Peery, 2010). However, to date, no previous studies have analysed *ethical vision of patient care* intended as the shared mission of providing high-quality patient care and engaging in ethically behaviours in patient treatment. In this regard, the Italian validation of the Hospital Ethical Climate Scale (Maffoni et al., submitted) revealed two independent dimensions of ethical climate: "managerial support" and "ethical vision of patient care". Thus, considering the current literature gaps, the present study moves an important step forward by analysing the potential role of these two ethical climate dimensions as caravan passageways.

Additionally, a closer look to the literature on the boundary conditions under which ethical climate may reduce moral distress and, in turn, emotional exhaustion reveals numerous shortcomings.

Evidence suggests that some psychological characteristics may predispose individuals to perceive their workplace more favourably, making some individuals better able to meet demanding job requests than others (Zeidner & Matthews, 2000). According to COR theory, personal characteristics represent resources to the degree which they generally aid stress resistance. Individuals who possess more resources are more likely to appraise problematic working conditions as challenges rather than as threats, thereby being more capable to adopt effective coping strategies to handle potential stressors. Among analysed personal characteristics, the current study focused on positive affectivity (i.e. the tendency to experience positive emotional states over time and across situations; Watson, Clark, & Tellegen, 1988) and resilience (i.e. the ability to cope with and positively adapt in the aftermath of stressful situations; Zanatta, Maffoni, & Giardini, 2020) as their role in protecting health care professionals from distress and emotional exhaustion has been widely documented. Therefore, drawing on COR theory, we expected that resilience, which represents a personal coping resource as it helps individuals effectively manage challenging situations, would foster the negative effect of ethical climate dimensions on moral distress as resilient health care professionals would perceive ethical issues related to patient care as challenging and they would easily utilize the resources available in the workplace to effectively find solutions to them. Similarly, positive affectivity may be considered as a personal resource because health care providers who experience more positive emotions may

"colour" their perceptions of the work characteristics in a rosier light and generate more social support from supervisors, possibly leading to more proactive strategies for positively resolve potential conflicts of values. Furthermore, the current research concentrated on resilience and positive affectivity as, differently from stable personality traits, they may be modifiable and learnable through specific trainings (Joyce et al., 2018; Lindsay et al., 2018), offering significant room of manoeuvre with manifold practical implications for health care professionals' well-being (Joyce et al., 2018; Lindsay et al., 2018). Moreover, to the best of our knowledge, there are no prior studies analysing whether resilience and positive affectivity might enhance the negative effect of ethical climate on moral distress and, then, on emotional exhaustion, thereby providing a unique theoretical contribution to the existing literature.

Therefore, our research questions were the following: Is managerial support directly and negatively related to emotional exhaustion? Is ethical vision of patient care directly and negatively associated with emotional exhaustion? Moreover, do these relationships occur also indirectly by reducing the levels of moral distress? Finally, can personal resources in terms of resilience and positive affectivity enhance these effects, such that individuals with higher levels of personal resources may be more likely to benefit from the effects of ethical climate dimensions in reducing moral distress and, then, lowering emotional exhaustion? As a conceptual framework, Figure 1 illustrates our proposed model, by incorporating our research questions.

### 2 | METHOD

### 2.1 | Design

This cross-sectional study is part of the research project called WeDistress HELL (WEIIness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues), which has been approved by the Ethical Committee of ICS Maugeri–Institute of Pavia (Protocol No. 2211CE, 19 June 2018). It was conducted through paper-and-pencil questionnaires in four hospitals in Northern and Central Italy between July 2018 and March 2018.

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### 2.2 | Sampling and data collection

By means of convenient sampling, four neuro-rehabilitation medicine units were chosen and all health care professionals working there were invited to take part in the study. To participate, professionals were required to be working in neuro-rehabilitation medicine units, be directly involved in patient care and sign the informed consent. In each hospital, professionals who met these criteria were informed about the aims of the research project and the voluntary nature of their participation without reimbursement by a coordinator and a researcher during shift changes. Respondents who voluntary agreed to participate provided their written informed and were assured about the anonymity and confidentiality of their responses. Participants took approximately 30 min to complete paper-and-pencil questionnaires and were instructed to place the completed questionnaires in cardboard boxes.

To further guarantee the anonymity, only a few socio-demographic variables were collected. Additionally, participants answered questions concerning their perceptions of resilience, positive affectivity, ethical hospital climate, emotional exhaustion and moral distress. We excluded two participants since they did not complete at least the 60% of the survey, which reduced the sample size from 224 (response rate: 61.4%) to 222.

#### 2.3 | Measures

# 2.3.1 | Ethical vision of patient care and managerial support in dealing with ethical issues

Ethical vision of patient care and managerial support was evaluated through nine and six items, respectively, from the Hospital Ethical Climate Survey (HECS: Olson, 1998: Italian adaptation by Maffoni et al., submitted). Participants reported how frequently they perceived the statements to be consistent with the situation at their work environment on a 5-point Likert scale (1 = almost never true. 5 = almost always true). Ethical vision of patient care includes statements, which refers to the presence of a shared mission to behave in an ethical manner in all matters relating to patient care (nine items, e.g. A clear sense of hospital's mission is shared with health care professionals). Managerial support includes statements that regard the degree to which health care professionals perceive to be supported by their managers in dealing with ethical issues (six items, e.g. When I'm unable to decide what's right or wrong in a patient care situation, my manager helps me). A mean score is calculated, and greater scores indicate more positive ethical climate perceptions. The internal consistencies of ethical vision of patient care and managerial support scales in this study were good ( $\alpha$  = 0.87 and  $\alpha$  = 0.93, respectively).

### 2.3.2 | Emotional exhaustion

Emotional exhaustion was measured through five items from the Maslach Burnout Inventory-General Survey (Schaufeli, Leiter,

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Maslach, & Jackson, 1996; Italian validation of Borgogni, Galati, & Petitta, 2005). Participants indicated how often they experienced a lack of emotional resources as a result of their work (e.g. *I feel used up at the end of the workday*) on a 7-point Likert scale (0 = *never*, 6 = *always*). A mean score is obtained, and higher scores indicate greater emotional exhaustion. The scale in the present study had a good internal consistency ( $\alpha$  = 0.92).

### 2.3.3 | Moral distress

Moral distress was measured through the 14-item Moral Distress Scale-Revised (Hamric et al., 2012; Italian version of Lamiani, Setti, et al., 2017). This scale instructs participants to answer to four factors: (a) futile care, which regards all provided treatments that are perceived as inappropriate because of their harmfulness or uselessness (three items, e.g. Initiate extensive life-saving actions when I think they only prolong death); (b) deceptive communication, which refers to misleading forms of communication (three items, e.g. Witness health care providers giving "false hope" to the patient or family); (c) ethical misconduct, which describes morally questionable behaviours (five items, e.g. Take no action about an observed ethical issue because the involved staff member requested that I do nothing); and (d) poor teamwork, which encompasses situations where there is a lack of cooperation within the teamwork (three items, e.g. Watch patient care suffer because of a lack of provider continuity). Each item was scored in terms of frequency (i.e. how frequently the situation was experienced) and intensity (i.e. to what extent the experienced situation was perceived as disturbing). All items were rated on a 5-point Likert scale (0 = never, 4 = very frequently and from 0 = none, 4 = great extent for the frequency and intensity scales, respectively). This instrument provides a total score ranging from 0 to 16, which is computed by summing the products of multiplying the frequency score by the intensity score for each of the 14 items and by dividing the resulting total by the number of items. To make this measure easily comparable with the other instruments, the scale of measurement was transformed by dividing by a constant (i.e. 1.6) in a scale ranging from 0 to 10, where higher scores indicate greater levels of moral distress. The internal consistency of the scale in the present study was satisfactory ( $\alpha = 0.87$ ).

### 2.3.4 | Positive affectivity

Participants' positive affectivity was measured with ten items from the Positive and Negative Affect Scale (Watson et al., 1988; Italian validation of Terraciano, McCrae, & Costa, 2003). Respondents indicated how frequently they usually felt each of the listed positive emotional states in their workplace (e.g. *enthusiastic*). The responses were obtained on a 5-point Likert scale (0 = *very slightly or not at all*, 5 = *extremely*). A mean score is calculated, and higher scores indicate higher levels of positive affectivity. The internal consistency of the scale in this study was adequate ( $\alpha = 0.85$ ).

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### 2.3.5 | Resilience

Resilience was evaluated through ten items from the Connor-Davidson Resilience Scale (Campbell-Sills & Stein, 2007; Italian validation of Di Fabio & Palazzeschi, 2012). Participants reported how much they agreed with each statement concerning ways of reacting to stressful situations (e.g. *I can achieve goals despite obstacles*) on a 5-point Likert scale (0 = *almost always false*, 4 = *almost always true*). A mean score is calculated, and greater scores indicate greater resilience. In this study, the reliability of this scale was good ( $\alpha$  = 0.88).

### 2.3.6 | Control variables

We controlled for gender (0 = male, 1 = female) and age (1=<40 years, 2 = 41-50 years, 3=>51 years) since prior investigations in the health care sector found that women and younger were more vulnerable to emotional exhaustion. Additionally, we recognized that job tenure (1 = <5 years, 2 = 6-15 years, 3 = 16-25 years, 4 =  $\geq$ 26 years) and educational status (0 = diploma, 1 = degree/higher specialization) might be inversely associated with emotional exhaustion since some studies showed that health care providers who had more years of experience or a higher level of education were less likely to experience emotional exhaustion.

### 2.4 | Statistical analyses

The data were first explored for descriptive statistics and correlations using IBM SPSS Statistics 23. Then, using the PROCESS macro (Hayes, 2013), mediation and moderated mediation models were conducted utilizing bootstrapping tests and a bias-corrected 95% confidence interval (CI) with a resample procedure of 1,000 bootstrap samples. Two separate mediation models were performed to calculate the indirect effects for each dimension of ethical climate on emotional exhaustion through moral distress, while controlling for gender, age, job tenure and educational status. To test whether the strength of the relationship between ethical climate dimensions and emotional exhaustion through moral distress was conditional on the values of positive affectivity and resilience, for each dimension, two moderated mediation models were run, while controlling for gender, age, job tenure and educational status. Indirect and conditional effects were considered significant when zero was not comprised of the 95% CI.

### 3 | RESULTS

# 3.1 | Demographic characteristics of the study sample and correlational analysis

Overall, 222 health care professionals took part in the study. Most participants were female (65.8%) nurses (36.5%) younger than 40 years (39.6%) who did shift work (66.2%) and had an

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**TABLE 1** Socio-demographic characteristics of the study sample (*n* = 222)

Variable	n (%)
Gender	
Female	146 (65.8)
Male	76 (34.2)
Age	
<40 years old	88 (39.6)
41-50 years old	74 (33.3)
>51 years old	59 (26.6)
Missing	1 (0.5)
Education	
Middle or high school diploma	64 (28.8)
Bachelor or master's degree/higher specialization	158 (70.7)
Missing	1 (0.5)
Occupation	
Nurse	81 (36.5)
Physiotherapist and others <sup>a</sup>	68 (30.6)
Social health care practitioner <sup>b</sup>	42 (18.9)
Physician and Psychologist <sup>c</sup>	30 (13.5)
Missing	1 (0.5)
Job tenure	
<5 years	40 (18.0)
6-15 years	74 (33.3)
16-25 years	63 (28.4)
≥26 years	44 (19.8)
Missing	1 (0.5)
Shift work	
Yes	147 (66.2)
No	67 (30.2)
Missing	8 (3.6)
Work contract	
Open-ended	179 (80.6)
Fixed-term	29 (13.1)
Temporary, VAT registration, Co-op	7 (3.2)
Missing	7 (3.2)

<sup>a</sup>Others include dieticians, speech therapists and occupational therapists.

<sup>b</sup>In the Italian health care system, 'social health care practitioner' is a qualified health care professional who addresses the basic needs of a person (washing, feeding, etc.) in both social and health care contexts. <sup>c</sup>Psychologists have been merged with physicians due to the small sample size (psychologists n = 7).

open-ended contract (80.6%). The descriptive statistics are reported in Table 1.

All correlations among variables were in the expected directions (see Table 2), but in contrast to our expectations, none of the demographic variables significantly correlated with emotional exhaustion.

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### 3.2 | The mediation analysis

First, a power analysis for a multiple regression analysis with seven predictors was conducted in G\*Power to determine whether our sample had a sufficient size using an alpha of 0.05, a power of 0.95 and a medium effect size. Results indicated that a sample of at least 153 subjects was required, suggesting that our sample size was adequate.

Managerial support was negatively associated with both moral distress ( $\beta$  = -0.30, SE = 0.12, p < .05, 95% CI [-0.54, -0.06]) and emotional exhaustion ( $\beta$  = -0.29, SE = 0.12, p < .05, 95% CI [-0.52, -0.06]). Moral distress was positively associated with emotional exhaustion ( $\beta$  = 0.21, SE = 0.07, p < .01, 95% CI [0.08, 0.34]) and partially mediated the relationship between managerial support and emotional exhaustion ( $\beta$  = -0.06, SE = 0.04, 95% CI [-0.14, -0.01]; see Figure 2a). The indirect effect was negative, suggesting that greater levels of managerial support reduced moral distress perceptions. This, in turn, led to lower emotional exhaustion.

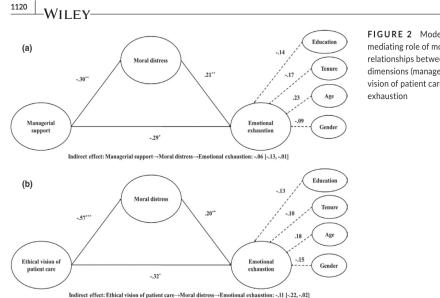
Ethical vision of patient care was negatively related to both moral distress ( $\beta = -0.57$ , SE = 0.15, p < .001, 95% CI [-0.86, -0.28]) and emotional exhaustion ( $\beta = -0.32$ , SE = 0.15, p < .05, 95% CI [-0.61, -0.03]). Moral distress was positively related to emotional exhaustion ( $\beta = 0.20$ , SE = 0.07, p < .01, 95% CI [0.06, 0.33]) and partially mediated the relationship between ethical vision of patient care and emotional exhaustion ( $\beta = -0.11$ , SE = 0.05, p < .05, 95% CI [-0.22, -0.02]; see Figure 2b). The indirect effect was negative, suggesting that greater levels of ethical vision of patient care lowered moral distress perceptions. This, in turn, resulted in lower emotional exhaustion.

### 3.3 | The moderated mediation analysis

Positive affectivity strengthened the negative association between managerial support and moral distress ( $\beta$  = -0.68, SE = 0.19, p < .001, 95% CI [-0.93, -0.30]; see Table 3 and Figure 3a). The moderated mediation effect of managerial support and positive affectivity through moral distress on emotional exhaustion was significant for health care professionals who had high ( $\beta = -0.17$ , SE = 0.08, 95% CI [-0.33, -0.03]) or moderate ( $\beta$  = -0.08, SE = 0.04, 95% CI [-0.16, -0.01]) positive affectivity, but not for those who had low positive affectivity ( $\beta = -0.01$ , SE = 0.03, 95% CI [-0.06, 0.07]). Examination of the interaction plot (see Figure 4a) showed that individuals with high positive affectivity reported a considerable decrease in moral distress at high managerial support levels. No change in moral distress was revealed for individuals with low positive affectivity in the passage from low managerial support to high managerial support condition. Conversely, the interaction of ethical vision of patient care and positive affectivity ( $\beta$  = 0.22, SE = 0.20, ns, 95% CI [-0.17, 0.60]; see Table 3 and Figure 3b) was statistically insignificant.

Resilience strengthened the negative effect of managerial support on moral distress ( $\beta$  = -0.43, SE = 0.15, p < .01, 95% CI [-0.73, -0.13]; see Table 3 and Figure 3c). The moderated mediation effect

<b>TABLE 2</b> Descriptive, internal consistencies and intercorrelations for study variables ( <i>n</i> = 222)	incies and	intercorrel	ations for stu	dy variables	(n = 222)							
	Σ	SD	Skewness	Kurtosis	1	2	ю	4	2	9	7	œ
1. Ethical vision of patient care	3.45	0.73	-0.11	-0.79	0.87							
2. Managerial support	4.01	0.90	0.90	0.50	0.57**	0.93						
3. Moral distress	1.73	1.55	1.21	1.39	-0.25**	-0.15*	0.87					
4. Emotional exhaustion	2.63	1.55	1.55	-0.42	-0.20**	0.18**	0.24**	0.92				
5. Positive Affectivity	3.53	0.61	0.61	0.56	0.25**	$0.17^{*}$	-0.05	-0.20**	0.85			
6. Resilience	2.65	0.74	0.74	10.18	0.21**	0.20**	-0.04	-0.12	0.59**	0.88		
7. Gender	,	,	,	,	-0.06	0.02	0.01	-0.05	-0.05	-0.02	ı	
8. Age	,	,	1	,	0.12	0.11	-0.01	0.02	-0.07	0.06	0.12	ı
9. Job tenure	,	,			-0.00	0.13	-0.05	-0.01	-0.07	0.03	$0.15^{+}$	$0.61^{*}$
10. Educational level		ı			0.01	0.03	-0.01	-0.07	0.02	0.04	0.00	-0.23**
<i>Note:</i> Boldfaced numbers on the diagonal represent Cronbach's alpha. M, means; <i>SD</i> , standard deviations.	present Cro	nbach's alp	ha.									
*p < 05; **p<.01.												



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FIGURE 2 Models analysing the mediating role of moral distress in the relationships between ethical climate dimensions (managerial support, ethical vision of patient care) and emotional

of managerial support and resilience through moral distress on emotional exhaustion was significant for health care professionals who had high ( $\beta$  = -0.14, SE = 0.07, 95% CI [-0.29, -0.02]) or moderate  $(\beta = -0.08, SE = 0.04, 95\%$  CI [-0.16, -0.01]) resilience, but not for those who had low resilience ( $\beta$  = -0.02, SE = 0.04, 95% CI [-0.08, 0.08]). Examination of the interaction plot (see Figure 4b) indicated that when highly resilient individuals perceived to be supported by their managers in dealing with ethical issues, they reported lower moral distress. Conversely, no change in moral distress was revealed for poorly resilient individuals in the passage from low managerial support to high managerial support condition. By contrast, the interaction of ethical vision of patient care and resilience on moral distress ( $\beta$  = -0.01, SE = 0.19, *ns*, 95% CI [-0.39, 0.36]) was statistically insignificant (see Table 3 and Figure 3d).

## 4 | DISCUSSION

As the complexity of ethical questions in health care is increasing. moral distress and emotional exhaustion represent phenomena of growing concern in everyday clinical practice. This study contributes to the existing literature by analysing whether managerial support and ethical vision of patient care are directly and indirectly-through moral distress-related to staff's emotional exhaustion. Furthermore, by identifying personal boundary conditions for ethical climate effects, this research reveals that both resilience and positive affectivity represent individual protective factors. Thus, several findings emerged from this research.

First, managerial support reduced health care professionals' emotional exhaustion. This suggests that a supportive leader may scaffold health care professionals dealing with ethical dilemmas arising from complex patient care. Thus, a climate, which is characterized by managerial support in dealing with ethical issues, may be a resource caravan passageway helping health care professionals counterbalance resource loss spirals, thereby protecting them from the onset of emotional exhaustion (Hobfoll et al., 2018). Indeed, a superior may set examples on how to provide appropriate care and resolve bioethical issues, in addition to providing health care professionals with a sense of protection, which signals also that the whole health care organisation cares about its employees (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020). Although the crucial role of supervisor support in preventing health care workers' emotional exhaustion is well known (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020), this is one of the first studies to demonstrate the protective role of managerial support in dealing with ethical concerns against emotional exhaustion.

Second, ethical vision of patient care was directly and negatively related to emotional exhaustion. This care approach may guide health care professionals in their daily practice, counterbalancing potential work difficulties and relieving the burden of job stressors. In this view, ethical vision of patient care can be interpreted as a resource caravan passageway, which provides health care professionals with feelings to be prepared and well equipped to respond to occupational demands posed by ethical issues, preventing emotional exhaustion. Accordingly, previous studies within the health care context showed that appropriate care may counterattack burnout because it provides health care professionals with an inner sense of professional accomplishment (McClendon, 2017; Peery, 2010; Shanafelt & Noseworthy, 2017). As far as our knowledge, this is the first study to show that ethical vision of patient care protects rehabilitation medicine professionals from emotional exhaustion.

Third, moral distress increased emotional exhaustion. This provides further empirical evidence to support that moral distress may predict emotional exhaustion (Fumis et al., 2017; Pauly et al., 2009; Silén et al., 2011) because it represents a job demand which may deplete individual resources, paving the way to emotional exhaustion.

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**TABLE 3** Conditional effects for moderated mediation models having moral distress as mediator in the relationship between ethical climate dimensions and emotional exhaustion and positive affectivity or resilience as moderators

Conditional effects Model a	В	SE	95% CI
Managerial support*Low PA $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.01	0.03	[-0.06, 0.07]
$Managerial\ support^*Moderate\ PA \to Moral\ distress \to Emotional\ Exhaustion$	-0.08	0.04	[-0.16, -0.01]
Managerial support *High PA $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.17	0.08	[-0.33, -0.03]
Index of moderated mediation	-0.15	0.08	[-0.31, -0.02]
Conditional effects Model b	В	SE	95% CI
Ethical vision of patient care*Low PA $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.14	0.09	[-0.34, 0.01]
Ethical vision of patient care*Moderate PA $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.12	0.06	[-0.25, 0.02]
Ethical vision of patient care*High PA $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.10	0.06	[-0.21, 0.01]
Index of moderated mediation	0.03	0.08	[-0.09, 0.23]
Conditional effects Model c	В	SE	95% CI
$Managerial\ support^*Low\ RES \to Moral\ distress \to Emotional\ Exhaustion$	-0.02	0.04	[-0.08,0.08]
$Managerial\ support^*Moderate\ RES \to Moral\ distress \to Emotional\ Exhaustion$	-0.08	0.04	[-0.16,-0.01]
Managerial support*High RES $\rightarrow$ Moral distress $\rightarrow$ Emotional Exhaustion	-0.14	0.07	[-0.29,-0.02]
Index of moderated mediation	-0.09	0.06	[-0.25, -0.01]
Conditional effects Model d	В	SE	95% CI
Ethical vision of patient care*Low $RES \to Moral\ distress \to Emotional\ Exhaustion$	-0.11	0.06	[-0.25, 0.01]
Ethical vision of patient care*Moderate $RES \to Moral\ distress \to Emotional\ Exhaustion$	-0.11	0.05	[-0.23, 0.02]
$Ethical\ vision^*High\ RES \to Moral\ distress \to Emotional\ Exhaustion$	-0.12	0.06	[-0.23, 0.01]
Index of moderated mediation	-0.01	0.04	[-0.07, 0.11]

Abbreviations:: Bold characters highlight statistically significant effects. 95% CI, bootstrapping lower and upper limit bias-corrected 95% confidence intervals; B, Effect; Managerial support, managerial support in dealing with ethical issues; PA, Positive Affectivity; RES, Resilience; SE, Standard Errors.

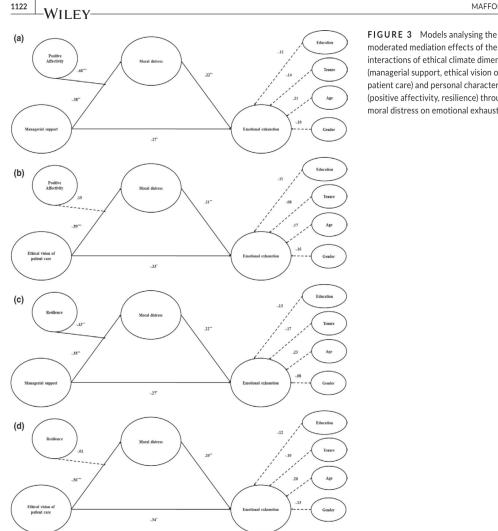
Indeed, moral distress may lead to the loss of critical resources, which may trigger an escalating spiral of losses, leading to emotional exhaustion (Hobfoll et al., 2018). In line with this reasoning, moral distress partially mediated the relationships between ethical climate dimensions and emotional exhaustion. In this regard, it has been previously speculated that a negative ethical climate may result in moral distress, which may lead to burnout (Fumis et al., 2017). This research corroborated this idea, demonstrating that both managerial support and ethical vision of patient care reduced moral distress. This negative effect, in turn, lowered emotional exhaustion. This is one of the first studies to analyse the mediating role of moral distress in the associations between ethical climate dimensions and emotional exhaustion, suggesting that addressing ethical dilemmas may reduce moral distress and, therefore, emotional exhaustion.

Fourth, this study deepens our understanding of personal boundary conditions for ethical climate by showing that professionals with high positive affectivity or resilience benefited more from managerial support. Given their positive overlook on life and their predisposition to adopt problem-focused coping strategies (Watson et al., 1988), high-positive affective individuals are more likely to benefit from managerial support. As a result, they may feel less threatened by ethical dilemmas and adopt more easily adaptive strategies for dealing with ethical demands, which, in turn, may reduce their emotional exhaustion. Similarly, as resilient individuals tend to thrive in challenging circumstances and to easily utilize available resources (Joyce et al., 2018), they are more likely to benefit from managerial support and respond to ethical issues with effective solutions, thereby perceiving lower emotional exhaustion. Overall, these findings are in line with previous investigations showing the role of positive affectivity and resilience in preserving health care professionals' well-being and suggest that these personal characteristics are important personal coping resources.

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Finally, ethical vision of patient care had a negative influence on both moral distress and emotional exhaustion, regardless of the individual levels of positive affectivity and resilience. Therefore, in the absence of moderation from such factors, we can suggest that, whatever the levels of positive affectivity and resilience possessed by health care professionals, a prediction of their well-being may be based on the presence of an ethical vision adopted in the provision of patient care. A plausible explanation might be that a climate characterized by a respectful approach to patient care represents a so powerful resource caravan passageway that all can benefit from it. This is the first study to show that fostering a positive ethical climate of patient care may entail beneficial effects for health care professionals' well-being.

This research is not without limits. This cross-sectional study relied on self-report measurements, which were collected on health care professionals employed in Italian neuro-rehabilitation medicine



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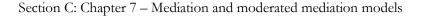
moderated mediation effects of the interactions of ethical climate dimensions (managerial support, ethical vision of patient care) and personal characteristics (positive affectivity, resilience) through moral distress on emotional exhaustion

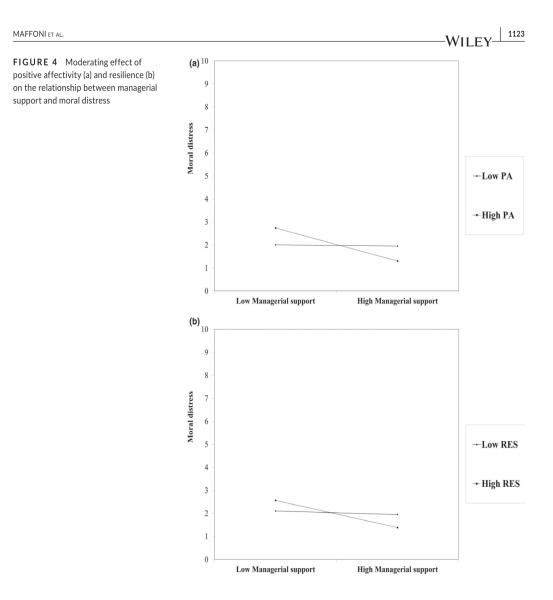
units only. Future studies should adopt longitudinal techniques and integrate different information sources. Additionally, replications should be conducted in other contexts to explore whether our results could be generalized to other specific health care working populations.

### 5 | PRACTICAL IMPLICATIONS

These findings suggest relevant implications for nursing management in terms of possible interventions for health care professionals and their managers (Gibiino, Rugo, Maffoni, & Giardini, 2020). To enhance managerial support, supervisors should be educated in providing support and in recognizing the signals that help is needed to professionals who are confronted with ethical dilemmas. Additionally, managers should consider handling daily work problems that may impact on health care professionals' ethical values. To this end, supervisors should support their subordinates through

periodic sharing and mentoring sessions where health care professionals are stimulated to openly share their negative feelings deriving from violations of personal values, but also their experiences of success to make them aware of one's own resources useful to deal with sensitive issues occurred in the clinical practice. Managers may consider organising "ethics rounds" where health care professionals from different disciplines can reflect on ethically difficult facets of patient's cases. Moreover, by strengthening the reflection about ethical issues, by promoting socializing and multi-professional communication about care provided and by holding ethical dialogue with senior professionals, supervisors may also foster a positive ethical climate. This is particularly important as maintaining an ethical patient care approach enables health care professionals to perceive themselves to be able to provide proper ethical care in line with their professional vocation, counterattacking the risk of resource depletion, which may lead to emotional exhaustion. In this regard, the management should involve team leaders in creating a formal written ethical code of conduct that can help health care professionals





navigate ethical conflicts by providing them with ethical procedures. Team leaders should also become the spokesperson of the organisational mission of maintaining high ethical standards to assure clinical excellence.

To strengthen the benefits of a sound climate in the work unit, professionals should be provided with psychological resilience programs to increase their resilience levels. Moreover, although positive affectivity is a quite stable disposition, it is possible to cultivate it through specific programs, such as brief present moment awareness trainings (Nasser & Przeworski, 2017). Managers could also foster this latter personal resource by encouraging an organisational culture, which promotes positive events by treating errors as learning opportunities and by supporting employees when critical events occur.

### 6 | CONCLUSIONS

This study addressed Italian health care professionals working in rehabilitation medicine, disclosing through which mechanisms and under what conditions ethical climate reduces emotional exhaustion. Our findings showed that managerial support and ethical vision of patient care reduce health care professionals' emotional exhaustion, directly and indirectly, as mediated by moral distress. Moreover, professionals high in resilience and positive affectivity benefit more from the protective effect of managerial support on emotional exhaustion through moral distress. Nowadays health care managers need to adequately support their subordinates, sustain a positive ethical climate and foster health care professionals' personal protective factors.

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### CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the study, authorship and publication of the present paper.

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# 7.3. The relationship between resilience and wellbeing/professional efficacy

Marina Maffoni, Valentina Sommovigo, Anna Giardini, Laura Velutti, Ilaria Setti. The role of resilience in promoting wellbeing and professional outcomes among healthcare professionals dealing with the challenges of bioethical issues. Manuscript submitted for publication on 1st June 2020 to Psychology and Health, under 2<sup>nd</sup> review.

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The role of resilience in promoting wellbeing and professional outcomes among healthcare professionals dealing with the challenges of bioethical issues.

Running title: Wellbeing and professional efficacy in healthcare

#### Abstract

Objective: Drawing on Conservation of Resources theory, this study aimed to analyse whether resilience would be a psychological resource which could help healthcare professionals dealing with ethical issues maintain their wellbeing and professional self-efficacy both directly and indirectly, as mediated by ethical vision of patient care and moderated by managerial support in dealing with bioethical issues.

Design: Overall, 315 Italian healthcare professionals employed in neuro-rehabilitation medicine or palliative care specialties participated in this multi-centred cross-sectional study.

Main Outcome Measures: resilience (ten-item Connor-Davidson Resilience Scale), wellbeing (Maugeri Stress Index-Reduced), professional efficacy (Maslach Burnout Inventory-General Survey), ethical vision of patient care and managerial support in dealing with ethical issues (nine and six items, respectively, from the Hospital Ethical Climate Survey, Italian version), positive affectivity and negative affectivity (Positive and Negative Affect Schedule).

34 Results: The findings disclosed that resilience improves healthcare professionals' wellbeing and 35 36 professional self-efficacy, directly and indirectly, as mediated by ethical vision of patient care. 37 Moreover, highly resilient professionals benefit more from the positive effect of ethical vision of 38 39 40 patient care on wellbeing in presence of high managerial support. 40 41 42

Conclusion: These findings provide suggestions for tailored interventions sustaining healthcare professionals along their daily activity characterized by high-demanding and challenging situations.

Keywords: resilience, health and professional outcomes, ethical climate, rehabilitation, palliative care, managerial support

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# INTRODUCTION

 In the nowadays scenario, ethical dilemmas are challenging the healthcare workforce (Singh et al., 2017; Hynes et al., 2019; Gibiino et al. 2020) and the professionals working in rehabilitation medicine and palliative care specialties too, since are constantly exposed to suffering and related ethical dilemmas (Maffoni, et al. 2019; Sliwa et al., 2019, Maffoni, et al. 2020). Frequently dealing with bioethical situations may deplete professionals' energies, paving the way to burnout and moral distress (West et al., 2018; Hynes et al., 2019; Maffoni et al., 2019; Maffoni et al., 2020). Poor healthcare professional's wellbeing does not affect the individual only, but reverberates also on the society (Bodenheimer & Sinsky, 2014), being associated to poor patient safety, potential medical errors, suboptimal quality and outcome of care (Wallace et al., 2009; Hall et al., 2016), as well as to increasing costs for the healthcare system (e.g. reduced productivity and efficiency, expensive staff recruitment and retention) (Wallace et al., 2009). Since the attention for safeguarding healthcare professionals' wellbeing is an urgent imperative (Walker, & Pine, 2018; Hynes et al., 2019), this study attempts to contribute with new knowledge which may aid to respond to this urgency.

Among the various proposals for facing this issue, this research adopted the positive psychology framework which places emphasis on the role of personal resources. This is consistent with the Conservation of Resources (COR) theory, which states that people strive to gain, retain, build and foster resources, which are crucial tools for resisting stress and alleviating strain associated with negative experiences, thereby boosting their wellbeing (Hobfoll, 1989, 2001; Hobfoll et al., 2018). In this vein, personal characteristics, which are one of the four resources identified by the COR theory (i.e., objects, conditions, personal characteristics, energies; Hobfoll, 1989; Hobfoll et al., 2018), represent "*resources to the extent that they generally aid stress resistance*" (Hobfoll, 1989, p.517). Said differently, certain personal characteristics can be treated as coping resources influencing healthcare professionals' reactions to stress (Zwack & Schweitzer, 2013). Thus, individuals with more personal resources are less vulnerable to stress, in addition to being better positioned for future resource gains (i.e., gain spirals; Xanthopoulou et al., 2007; De Cuyper et al., 2012). Therefore, they are more likely to have better protection against the development of psycho-physical malaise and the loss of professional self-efficacy.

In the healthcare context, literature has described the positive impact of some individual resources, such as emotional stability (Zaninotto et al., 2018; van Mol et al. 2018), optimism (Avvenuti et al., 2016; Fowler et al., 2020) and resilience (Brennan, 2017; Ng et al., 2019). Among these factors, resilience represents an interesting variable since it is a more modifiable resource than others: resilience may be developed through specific trainings, allowing important room of manoeuvre

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(Rogers, 2016; Joyce et al., 2018). Therefore, this study posed emphasis on resilience. Specifically, while prior research in the healthcare context has mostly focused on the role of resilience in preventing from negative consequences (Robertson et al., 2016; Zanatta et al., 2020), the present investigation discloses *whether* and *through which psychological* mechanism resilience may result simultaneously in improved wellbeing and greater professional self-efficacy among healthcare professionals, thus helping build new theoretical perspectives.

#### The role of resilience in promoting wellbeing

In line with COR theory (Hobfoll, 2001; Hobfoll et al., 2015), resilience is a personal resource which may help healthcare professionals face distressing work situations and decision making in their daily activity in touch with sufferance (Zwack & Schweitzer, 2013; Zanatta et al., 2020). Resilient healthcare professionals can draw from a reservoir of personal self-regenerating resources (Hobfoll, 2001). Specifically, COR theory (Hobfoll, 1989, 2001) assumes that resources tend to produce other resources, therefore generating resource caravans, which, in turn, function as pools that can be drawn from to enable people flourish, prompting a gain cycle toward better wellbeing (Hobfoll et al., 2003). Accordingly, resilience was found to be associated with decreased distress levels (Utsey et al., 2007), lower depression and anxiety symptoms (Melnyk et al., 2013) and greater wellbeing (Avey et al., 2009). As such, we hypothesized the following:

Hypothesis 1: Resilience will be positively related to healthcare professionals' well-being.

#### The role of resilience to promote professional efficacy

Healthcare professionals suffering from burnout complain three main symptoms, encompassing emotional exhaustion, feeling of detachment from their job and a sense of ineffectiveness and lack of competence in providing proper care (Maslach, 2007; West et al., 2018). Hobfoll, and Freedy (1993) applied COR theory to burnout and argued that job demands threaten the individual's resources and then produce strain, which eventually leads to emotional exhaustion. Conversely, personal resources, such as resilience, may help individuals foster professional self-efficacy which, in turn, counteracts burnout. Therefore, we focused on professional self-efficacy because, as predicted by COR theory and confirmed by empirical evidence, the three dimensions of burnout are differentially associated with job demands and resources, such that resources are more strongly related to professional self-efficacy than demands (Lee & Ashforth, 1996; Leiter, 2017).

Resilience may aid healthcare professionals to overcome the need for defensive coping and foster their professional efficacy as it allows them to positively adapt to their workplace and find effective

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solutions to complex patient care problems (Zwack & Schweitzer, 2013). Therefore, we expected the following:

Hypothesis 2: Resilience will be positively related to professional self-efficacy.

#### The mediating role of ethical vision of patient care

To avoid resource loss, individuals are motivated to acquire new resources by safeguarding their resources in preparation of times of trial and by strategically investing their resources to accumulate further ones (Hobfoll, 1989; Halbesleben et al., 2014). Investment decisions are also based on personal characteristics and depend on individual's personal resource levels (Halbesleben et al., 2014): only individuals having high personal resources can invest and, in turn, gain new resources (Hobfoll, 2001). On the one hand, resilience may predispose healthcare professionals to perceive their workplace more favourably, leading to better perceptions of ethical vision of patient care. On the other hand, highly resilient professionals may invest their resources to build a work setting characterised by ethical values and practices in the provision of high-quality care. In doing so, crossover processes may explain the mechanisms by which resilience may be transferred within organizational contexts: resilience could be transmitted between the colleagues via empathy or, alternatively, coping styles characterizing resilient people may transmit positive experiences (Hobfoll et al., 2018). Thus, a positive crossover processes triggered by resilience might facilitate a positive ethical climate (Westman, 2001, p.743). Ethical climate is described as the "shared perceptions of what is ethically correct behaviour and how ethical issues should be handled" (Victor, & Cullen, 1989, p. 52). It has been positively associated with healthcare professionals' wellbeing (Storch et al., 2009; Koskenvuori et al., 2019) and it may include two dimensions: managerial support in dealing with ethical issues and ethical vision of patient care (Anonymous et al., manuscript submitted). This latter dimension has been related to wellbeing (Anonymous et al., manuscript submitted). Additionally, the provision of respectful care increases nurses' professional efficacy (Peery, 2010; McClendon, 2017). Therefore, a workplace characterized by ethical vision of patient care can be conceptualized as a caravan passageway to the extent to which it enriches professionals' resource reservoirs (Hofboll, 2018). In this vein, healthcare professionals' resilience may contribute to ethical vision of patient care perceptions which, in turn, may lead to increased wellbeing and greater professional self-efficacy. Thus, the following hypotheses were postulated:

*Hypothesis 3: Ethical vision of patient care will mediate the relationship between resilience and wellbeing.* 

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*Hypothesis 4: Ethical vision of patient care will mediate the relationship between resilience and professional self-efficacy.* 

#### The moderating role of managerial support in dealing with bioethical issues

Growing evidences unveil the protective role of managerial support in preventing healthcare professionals' burnout as well as maintaining wellbeing and professional achievements, as the superior may guide and sustain also on behalf of the healthcare organization (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020). However, only few studies concentrated on the role of managerial support in sustaining healthcare professionals in dealing with ethical dilemmas (Storch et al., 2009; Poikkeus et al., 2018). The investigation on the possible role of superiors is crucial; managerial support may be a possible moderator on health and professional outcomes, even if findings are not consistent (Sawang, 2010; Mazzetti et al., 2019). Considering these evidences, it is conceivable that the managerial support offered to adequately deal with bioethical issues may enhance the effect of other protective aspects and may impact both on the proper approach to care and on professionals' wellbeing. Specifically, the following hypothesis were proposed:

Hypothesis 5: The effect of resilience on wellbeing through ethical vision of patient care will be conditional on the levels of managerial support in dealing with ethical issues, such that the effect of ethical vision of patient care on wellbeing ( $H_5a$ ) and professional self-efficacy ( $H_5b$ ) will be enhanced when managerial support will be high.

# METHOD

#### Participants and Procedure

Overall, 318 questionnaires were collected (response rate: 57.2%). However, two participants were excluded since they did not complete at least the sixty percent of the questionnaire and one other case was deleted because it was a multivariate outlier, such that the respondents considered for the study were 315. They were employed in neuro-rehabilitation medicine or palliative care specialties from six hospitals in Northern and Central Italy. Participants were provided with information about the research project, the voluntary nature of their involvement, anonymity and confidentiality of their responses and the possibility to end participation at any time. After providing written informed consent, participants completed paper-pencil questionnaires, which required approximately 20 minutes.

Most participants were female (67.0%) who did shift work (64.7%), were younger than 40 years (46.0%) and were employed in neuro-rehabilitation medicine specialty (70.5%); for more details see *Table 1*.

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#### Measurements

 *Resilience* was assessed using the ten-item Connor-Davidson Resilience Scale (Campbell-Sills & Stein, 2007; Italian validation of Di Fabio & Pallazzeschi, 2012). Respondents were invited to indicate to what extent they agreed with each statement regarding ways of responding to stressful circumstances (e.g., *I can achieve goals despite obstacles*) on a five-point Likert scale (0=almost *always false*, 4=almost *always true*), where greater scores signify higher resilience levels ( $\alpha=.87$ ).

Wellbeing was evaluated using a seven-item subscale from *The Maugeri Stress Index– Reduced form* (Giorgi et al., 2011; Giorgi et al., 2014; Massidda et al., 2017). Respondents indicated how frequently they experienced a condition of general well-being, characterized by energy, satisfaction and optimism (7 items; *I have done things that interested me*) on a five-point Likert scale (1 = never, 5 = very much), where higher scores correspond to greater wellbeing levels ( $\alpha = .80$ ).

Professional efficacy was assessed using six items from the Maslach Burnout Inventory-General Survey (Schaufeli et al., 1996; Italian validation of Borgogni et al., 2005). Participants indicated how frequently they experienced feelings of being able to perform effectively their job tasks (6 items; I feel I am making an effective contribution to this organization) on a seven-point Likert scale (0=never, 6=always), where higher scores indicate greater professional efficacy levels ( $\alpha$  =.82).

Ethical vision of patient care and managerial support in dealing with ethical issues were assessed using nine and six items, respectively, from the Hospital Ethical Climate Survey (HECS; Olson, 1998; Italian adaptation of *Anonymised*). Participants reported how often they perceived the statements to be consistent with the situation at their workplace on a five-point Likert scale (1=*almost never true*, 5=*almost always true*). Ethical vision of patient care comprises statements which regards the presence of mutual respect among colleagues and a shared mission in terms of adopting ethical behaviours and maintaining high-quality patient care (9 items; e.g., *A clear sense of hospital's mission is shared with healthcare professionals*). Managerial support in dealing with ethical issues (from now on mention only as "managerial support") refers to healthcare professionals' perceptions of being supported by their managers in dealing with ethical issues (6 items, e.g., *When I'm unable to decide what's right or wrong in a patient care situation, my manager helps me*). The greater the scores, the more positive the ethical climate ( $\alpha = .86$ ,  $\alpha = .92$ , respectively).

*Positive Affectivity* (PA) and *Negative Affectivity* (NA) were assessed by the Positive and Negative Affect Scale (PANAS) including ten positive and ten negative emotional states (e.g., *concentrating* for PA, *upset* for NA; Watson et al., 1988; Italian validation of Terraciano et al., 2003). Participants indicated how often they usually experience each of the listed mood states on a five-point Likert scale (0= *very slightly or not at all* to 5= *extremely*), where greater scores mean greater levels on the specific trait. PA and NA refer to pervasive predispositions that are expressed by the individual

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tendency to respectively experience positive or negative emotional states over time and across situations. We decided to use affectivity traits to test comparative moderation models, as such personal predispositions has been found to affect the development of employees' malaise due to work stressors (Van der Wal et al., 2018; Grigorescu et al., 2018;  $\alpha = .85$ ,  $\alpha = .84$ , respectively).

We controlled for the exposure to stressful extra-work events over the previous year (i.e. *Have you experienced extra-working stressful events in the last year of life?*). This information was measured with a dichotomous item (0=no, 1=yes).

#### Ethical considerations

This research is part of a broader research project called *Anonymised* which was approved by the Ethical Committee of *Anonymised* (Protocol No. *Anonymised*).

#### Statistical analyses

Before conducting analyses, the data were screened on outliers, multicollinearity and distribution of the data and explored for intercorrelations using SPSS 22. There was no multicollinearity as the highest variance inflation factor (VIF) was 2.01 and the lowest tolerance statistic was .49, which was far below the suggested cut-off of 10. Skewness (ranging from -1.13 to .98) and kurtosis (ranging from -.52 to 1.1.0) values were acceptable. Structural equation modelling (SEM) was utilised to evaluate the appropriateness and fit of our proposed theoretical models. We first performed confirmatory factor analyses (CFAs) with the maximum likelihood method comparing the measurement model with a series of competing models. After establishing a good fit for the measurement model, we tested our mediation model using bootstrapping analyses. We constructed bias-corrected confidence intervals by drawing 1000 random samples with replacements from the full sample; whereby an indirect effect was deemed significant if the 95% confidence interval from the bootstrap analysis did not include zero and then the p-value was deemed to be less than or equal to 0.05. This method is more robust against Type 1 and Type 2 errors, less biased and more powerful than other techniques (Hayes, 2013). Model fits were examined by examining the magnitude and statistical significance of factor loadings, the root mean square error of approximation (RMSEA), the standardized root mean square residual (SRMR), the comparative fit index (CFI) and the Tucker-Lewis index (TLI). To test our moderation hypothesis, we conducted a series of moderated mediation models and we evaluated their goodness by comparing them in terms of BIC (Bayesian Information Criterion) and AIC (Akaike Information Criterion). Lower values of AIC and BIC indicate a better fit and the model with the lowest AIC and BIC is the best fitting model. SEM analyses were conducted using Mplus Version 7 statistical software (Muthèn & Muthèn, 2012).

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# RESULTS

### Correlational analyses

Means, standard deviations and Pearson correlations are presented in *Table 2*. Resilience was positively related to both ethical vision of patient care (r=.21, p<.01) and managerial support (r=.17, p<.01), wellbeing (r=.41, p<.01) and professional efficacy (r=.51, p<.01). Moreover, both ethical vision of patient care and managerial support were positively related to wellbeing (r=.23, r=.17, p<.01, respectively) and professional efficacy (r=.36, r=.25, p<.01, respectively).

#### Confirmatory factor analyses

To assess the measurement part of our model, we conducted a CFA with the maximum likelihood method. Results from CFA (see *Table 3*) revealed that the five-factor model (i.e., resilience, ethical vision of patient care, managerial support, wellbeing, professional efficacy) outperformed all the alternative models ( $\chi^2$ [655]=1130.93, RMSEA=.05, SRMR=.05, CFI=.90, TLI=.90). However, to improve the fit indices of this model ( $\chi^2$ [652]=1054.98, RMSEA=.04, SRMR=.05, CFI=.91, TLI=.91), we correlated the errors of two pairs of items from the resilience scale because these items tapped into similar behaviours ("I am able to adopt to change" with "I can deal with whatever comes" and "I can stay focus under pressure" with "I am not easily discouraged by failure"), for two items from the managerial support scale ("My manager is someone I can trust" with "My manager is someone I respect") and two items from the professional efficacy scale ("I feel exhilarated when I accomplish something at work" with "At my work, I feel confident that I am effective at getting things done") due to high intercorrelations between them. The resulting models were built considering the modification indices which were used in this satisfactory model.

#### Mediation analyses

To test the research hypotheses (H<sub>1</sub>-H<sub>4</sub>), one mediation model was conducted. In the resulting mediation model ( $\chi^2$ [485]=780.17, RMSEA=.04, SRMR=.05, CFI=.91, TLI=.91; see *Table 4* and *Figure 1*), resilience was directly and positively associated with ethical vision of patient care ( $\beta$ =.22, p<.01, 95% CI [.04, .35]), wellbeing ( $\beta$ =.46, p<.001, 95% CI [.29, .60]) and professional efficacy ( $\beta$ =.46, p<.001, 95% CI [.33, .59]), while controlling for experience of extra-work stressful situations over the previous year. Ethical vision of patient care, in turn, was positively associated with both wellbeing ( $\beta$ =.18, p<.01, 95% CI [.06, .30]) and professional efficacy ( $\beta$ =.33, p<.01, 95% CI [.19, .44]). Therefore, ethical vision of patient care partially mediated the relationships that resilience had with both wellbeing ( $\beta$ =.04, p<.01, 95% CI [.01, .08]) and professional efficacy ( $\beta$ =.07, p<.01, 95%

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CI [.02, .12]). Overall, resilience was directly and indirectly - through ethical vision of patient care - related to both wellbeing and professional efficacy. Therefore, *Hypotheses 1, 2, 3* and *4* were confirmed.

#### Moderated mediation analyses

To test our moderation hypotheses, different moderated mediation models were conducted (see Table 5). The validity of the hypothesized models was assessed by comparing it (i.e., in terms of BIC and AIC comparative indices) with some competing models, as described in detail in Table 6. As shown, the model with managerial support as moderator in the relationship between ethical vision of patient care and wellbeing was the better-fitting model compared to those which used professional self-efficacy as outcome or those which included positive and negative affectivity traits as moderators. Although managerial support did not moderate the impact of ethical vision of patient care on professional self-efficacy, the effect of resilience on wellbeing though ethical vision of care was enhanced by managerial support, such that it strengthened the positive effect of ethical vision of patient care on wellbeing ( $\beta = .12$ , p<.05). The moderated mediation effect was significant for healthcare professionals who perceived high managerial support ( $\beta = .05$ , p<.05), but not for those who perceived moderate ( $\beta = .03$ , ns) or low ( $\beta = .01$ , ns) managerial support. Total effects indicated that the overall positive effect of resilience on wellbeing enhanced with the increasing of managerial support levels ( $\beta = .42$ ,  $\beta = .44$ ,  $\beta = .47$ , p<.001 for low, moderate, high managerial support levels, respectively). Examination of the interaction plot (see Figure 3) showed that healthcare professionals benefited more from high ethical vision of patient care levels when they perceived to be highly supported by their managers rather than when they experienced lower managerial support. Thereby, Hypothesis 5a was supported, whereas Hypothesis 5b was rejected.

#### DISCUSSION

Healthcare professionals working in palliative care and neuro-rehabilitation medicine specialties are often exposed to manifold challenging situations. The positive psychology framework may be crucial for fueling research on possible protective factors. To this regard, COR theory (Hobfoll, 1989, Hobfoll et al., 2018) suggests that personal resources, such as resilience, may trigger a "gain spiral" of coping resources renewal. This study enriches the existing literature by analyzing whether resilience is both directly and indirectly related to wellbeing and professional self-efficacy, as mediated by ethical vision of patient care and moderated by managerial support in dealing with bioethical issues. Thus, sundry findings worth to be discussed.

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3 Firstly, resilience was directly and positively related to both healthcare professionals' wellbeing and professional self-efficacy, in line with previous studies (Brennan, 2017; Rothenberger, 2017; Ng et al., 2019). Indeed, taking the perspective of COR theory, resilience may be a coping personal resource useful to face with distressing situations, as it promotes resources caravans and self-regenerating gain spiral (Hobfoll, 1989; Hobfoll, 2001; Hobfoll et al., 2018). Differently said, resilience may activate a pool of mental, physical and social resources and strategies aiding healthcare professionals not to be overwhelmed by events, maintaining wellbeing and allowing the achievement of professional goals (Zwack & Schweitzer, 2013). This is particularly important considering that personnel's wellbeing and professional self-efficacy may have a positive impact not only on the individual, but also on professional and patient outcomes (Wallace et al., 2009; Bodenheimer & Sinsky, 2014; Hall et al., 2016). This is one of the first studies showing that resilience may simultaneously result in improved wellbeing and greater professional self-efficacy among healthcare professionals. Secondly, ethical vision of patient care was found to partially mediate the effect of resilience on wellbeing and professional self-efficacy. Previous literature has already underlined that respectful care approach increased the perception of professional self-efficacy (Peery, 2010; McClendon, 2017). These findings may be explained in the light of COR theory (Hobfoll, 2001). On the one hand, since resilient individuals tend to have a positive view of themselves, a sense of control over their own life and an optimistic vision, they might be more likely to appraise a favourable ethical climate. On the other hand, highly resilient professionals might proactively challenge job demands by investing their energies in promoting the adoption of ethical care practices. In doing so, resilient professionals may contribute, through crossover processes, to cultivating a shared mission, ethical values and practices in the provision of high-quality care. In this context, ethical vision of patient care can function as a caravan passageway (Hofboll, 2018) which is fostered by resilience and, in turn, fosters healthcare personnel' wellbeing and professional self-efficacy. By examining, for the first time, whether ethical vision of patient care may shape the effects of resilience, this study contributes to understanding through which psychological mechanism resilience may foster both wellbeing and professional self-efficacy. Additionally, by extending the crossover process to positive experiences triggered by resilience, this study provides new insights to the positive psychology field. Thirdly, this research deepened our understanding of the moderating role of managerial support: professionals perceiving high managerial support benefited more from the positive effects of resilience on wellbeing- but not professional self-efficacy- through ethical vision of patient care. This 

finding is in accordance with previous studies underlining the pivotal role of managerial support to maintain psychological wellbeing and sustain professional achievements (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020), also acting as a moderator (Sawang, 2010; Mazzetti et al., 2019).

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Indeed, drawing on COR theory (Hobfoll, 2001), managerial support represents a social resource which may reinforce professionals' beliefs of being able to handle stressors and encourage them to engage in effective coping strategies, therefore, reducing the emotional burden of dealing with ethical issues and, then, promoting their wellbeing. By unveiling for the first time the enhancing effect of managerial support in the relationship of resilience on wellbeing through ethical vision of patient care, this study contributes to a limited but increasing body of empirical research showing the role of managerial support in sustaining healthcare professionals in dealing with ethical dilemmas (Storch et al., 2009; Poikkeus et al., 2018).

The fact that the enhancing role of managerial support in the relationship between ethical vision of patient care and professional self-efficacy was not confirmed, suggests that whatever is the level of received managerial support, a prediction of personnel' professional efficacy may be based on ethical vision adopted in providing care. It is possible to speculate that providing respectful care is so essential for helping professionals that it is rewarding and satisfying regardless of the presence of other social resources. Thus, the perception of an ethical approach to care is enough to guarantee the perception of professional self-efficacy. Regarding this, the awareness of the value of one's own job is a protective factor for professionals dealing with complex situations as the possibility to provide relief to patients is inner gratifying (Shanafelt & Noseworthy, 2017; Maffoni et al., 2020).

Although these findings have particular relevance in the actual healthcare scenario, they are subjected to some limitations. Firstly, this research is a cross-sectional study based on self-reported measurements. Secondly, the healthcare professionals involved were employed in hospitals located in Northern and Central Italy only, such that biases regarding the socio-cultural context cannot be excluded. To overcome these limits, future studies are recommended to adopt a cross-cultural longitudinal research design.

# PRACTICAL IMPLICATIONS

The practical implications of the present study are manifold. In light of the positive and direct impact of resilience on health and professional outcomes, the healthcare management should consider investing in psychological resilience training programs. In fact, resilience not only enables professionals to overcome the difficulties occurring in their daily activity, but it also triggers a gain spiral of self-renewing resources constantly empowering the individuals. Moreover, the mediating role of ethical vision of patient care suggests the relevance of the ethical approach to care. Thus, the provision of care based on shared ethical values is beneficial not only for the patient, but also for the healthcare professionals. In addition, the positive impact of the ethical vision of patient care might be enhanced by supportive superiors helping professionals deal with bioethical issues. Thus, educational

programs and trainings to tune the superior's support ability are suggested. Superiors may provide examples and guidance, transmit a sense of protection and support provided by the healthcare organization respectful of its employees (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020).

#### CONCLUSION

 This study focused on Italian healthcare professionals employed in palliative care and neurorehabilitation medicine specialties. The results disclosed that resilience improved healthcare professionals' wellbeing and professional self-efficacy, directly and indirectly, as mediated by ethical vision of patient care. Moreover, resilient professionals experiencing high managerial support benefited more from the protective effect of resilience on wellbeing through ethical vision of patient care. These findings enable to formulate preventive measures and tailored interventions to help healthcare professionals overcome the numerous challenges characterizing their profession.

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# **DECLARATION OF INTEREST**

The authors declare no conflicts of interest.

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	%
Gender	
Female-Male	67.0-33.0
Specialty	
Neuro-rehabilitation medicine-Palliative care	70.5-29.5
Age	
< 40 years	46.0
41-50 years	32.3
>51 years	21.7
Education	
Middle school diploma	5.4
High school diploma	18.8
Bachelor's degree	48.6
Master's degree	2.9
Further specialization	24.3
Occupation	
Physician and psychologist <sup>a</sup>	20.8
Nurse	40.6
Physiotherapist and other therapist <sup>b</sup>	22.0
Social-health practitioner <sup>c</sup>	16.6
Overall job tenure	
<5 years	25.2
6-15 years	31.3
>16 years	43.5
Job tenure in current position	
<5 years	31.8
6-10 years	23.5
>10 years	44.7
Shift work	
Yes- No	64.7-35.3
Stressful event	
Yes-No	36.7-63.3
Psychologist and physicians were considered together as psycho	

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	М	SD	Skewness	Kurtosis	1	2	3	4	5	6	7
1. Ethical vision of patient care	3.51	.70	23	52	.86						
2. Managerial support	4.08	.86	-1.13	.96	.54**	.92					
3. Resilience	2.65	.72	75	1.10	.21**	.17**	.87				
4. Wellbeing	3.37	.66	11	35	.23**	.17**	.41**	.80			
5. Professional efficacy	4.33	1.00	55	.34	.36**	.25**	.51**	.38**	.82		
6. Positive Affectivity	3.54	.61	36	.19	.27**	.17**	.60**	.53**	.52**	.85	
7. Negative Affectivity	1.73	.58	.98	.73	28**	18**	40**	40**	24**	28**	.84
8. Extra-work stressful events	-	-	-	-	10	07	10	15**	05	07	.15*

Note. Boldfaced numbers on the diagonal represent Cronbach's alpha; M= means; SD= standard deviations; \*p<05; \*\*p<01.

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Model	χ2	df	р	RMSEA	SRMR	CF
Five-factor model_mo <sup>h</sup>	1054.98	652	.00	.04	.05	.91
Five-factor model <sup>g</sup>	1130.93	655	.00	.05	.05	.90
Four-factor model <sup>f</sup>	1555.43	659	.00	.07	.07	.81
Three-factor model2 <sup>e</sup>	1884.73	662	.00	.08	.08	.74
Three-factor model1 <sup>d</sup>	1924.82	662	.00	.08	.08	.73
Two-factor model 2 <sup>c</sup>	2187.73	664	.00	.09	.09	.68
Two-factor model 1 <sup>b</sup>	2854.44	664	.00	.10	.14	.54
One-factor model <sup>a</sup>	3397.18	665	.00	.12	.13	.42

Error of Approximation; SRMR= Standardized Root Mean Square of freedom; Mean Square Residuals; CFI= Comparative Fit Index; TLI= Tucker-Lewis Index. <sup>a</sup> All indicators load on a single factor.

<sup>b</sup> All ethical hospital climate sub-scales load on one factor, resilience, professional efficacy and wellbeing load on a second factor. <sup>c</sup> Ethical vision of patient care, managerial support and resilience load on one factor; wellbeing and professional efficacy load on a second factor.

<sup>d</sup> Managerial support and ethical vision of patient care load on one factor; resilience and wellbeing load on a second factor, professional efficacy loads on a third factor.

e Managerial support and ethical vision of patient care load on one factor; professional efficacy and wellbeing load on a second factor, resilience loads on a third factor.

f Managerial support and ethical vision of patient care load on one factor; resilience loads on a second factor; wellbeing loads on a third factor; professional efficacy loads on a fourth factor. <sup>8</sup> Managerial support loads on one factor; ethical vision of patient care loads on a second factor; resilience loads on a third factor; 

wellbeing loads on a fourth factor; professional efficacy loads on a fifth factor.

<sup>h</sup> Prior model allowing correlations for two pairs of items from resilience scale (item 2 with 1, item 8 with item7) and for one pair of items from managerial support scale (item 6 with 4) and professional efficacy scales (item 6 with 4).

Table 4. Fit indices and standardized direct and indirect effects for mediation models analyzing the
impact of resilience on wellbeing and professional efficacy via ethical vision of patient care.

Model (outcome)	χ2	df	р	RMSEA	SRMR	CFI	TL
Model 1	780.17	485	.000	.04	.05	.91	.91
Standardized dire	ct and i	ndirec	t effect	S			
Effects- Model 1			Estim	ate S.	Е.	95% C	Л
Resilience $\rightarrow$ Ethical vision of patient care			.22	.0	7	[.04,.3	5]
Ethical vision of patient care $\rightarrow$ Wellbeing			.18	.0	6	[.06,.3	0]
Extra-work stressful events $\rightarrow$ Wellbeing			09	0. 0	5	[20,.0	)2]
Resilience $\rightarrow$ Wellbeing			.46*	** .0	7	[.29, .6	0]
Resilience $\rightarrow$ Ethical vision of patient care $\rightarrow$ Wellbei	ng		.04	* .0	2	[.01, .0	8]
Total effects on Wellbeing			.50*	** .0	7	[.32, .6	2]
Ethical vision of patient care $\rightarrow$ Professional efficacy			.33*	* .0	7	[.19,.4	4]
Extra-work stressful events $\rightarrow$ Professional efficacy			.04	.0	6	[20,.0	2]
Resilience $\rightarrow$ Professional efficacy			.46*	.0	6	[.33, .5	9]
Resilience $\rightarrow$ Ethical vision of patient care $\rightarrow$ Professi	onal effic	cacy	.07*	* .0	2	[.02, .1	2]
Total effects on Professional efficacy			.53*	** .0	7	[.40, .6	5]

Note. df= degree of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardized Root Mean

Square Residuals; CFI= Comparative Fit Index; TLI= Tucker-Lewis Index.

41 42 \*p<05; \*\*p<.01; \*\*\*p<.001 45

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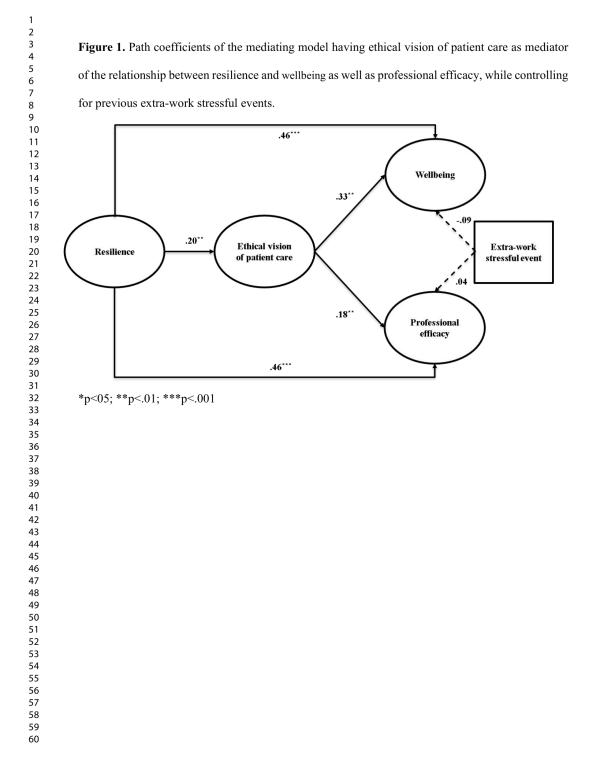
Table 5. Path coefficients and standardized conditional effects for the model with manager support as moderator of the association between resilience and wellbeing.

Model: $X \rightarrow M^*V \rightarrow Y$			Standardized conditional effects		
		Estimate	S.E		
Re	silience $\rightarrow$ Ethical vision of patient care	.22**	.07		
Eth	ical vision of patient care $\rightarrow$ Professional efficacy	.32**	.06		
Eth	ical vision of patient care $\rightarrow$ Wellbeing	.15*	.07		
Eth	ical vision of patient care*Managerial support	.12*	.06		
Re	silience $\rightarrow$ Professional efficacy	.46***	.06		
Re	silience $\rightarrow$ Wellbeing	.42***	.06		
Ma	nagerial support $\rightarrow$ Wellbeing	.08	.07		
Ext	ra-work stressful events $\rightarrow$ Professional efficacy	.04	.06		
Ext	tra-work stressful events $\rightarrow$ Wellbeing	08	.06		
Re	silience $\rightarrow$ Ethical vision of patient care*Low Managerial support $\rightarrow$ Wellbeing	.01	.02		
Re	silience $\rightarrow$ Ethical vision of patient care*Moderate Managerial support $\rightarrow$ Wellbeing	.03	.02		
Re	silience $\rightarrow$ Ethical vision of patient care*High Manager support $\rightarrow$ Wellbeing	.05*	.02		
Го	al effects for Low Managerial support	.42***	.09		
Го	al effects for Moderate Managerial support	.44***	.09		
Го	al effects for High Managerial support	.47***	.09		

3 5 Table 6. Goodness of fit indices for the selected mediation model and its competing models. Model:  $X \rightarrow M^*V \rightarrow Y$ AIC BIC Model **M1** Resilience  $\rightarrow$  Ethical vision of patient care\* Managerial support  $\rightarrow$  Wellbeing 28293.04 28768.66 M2 Resilience -> Ethical vision of patient care\* Managerial support -> Professional efficacy 28295.63 28768.66 M3 Resilience  $\rightarrow$  Ethical vision of patient care\* Positive Affectivity  $\rightarrow$  Wellbeing 31580.93 32097.11 15 Resilience  $\rightarrow$  Ethical vision of patient care\* Positive Affectivity  $\rightarrow$  Professional efficacy M4 31592.71 32108.89 Resilience  $\rightarrow$  Ethical vision of patient care\* Negative Affectivity  $\rightarrow$  Wellbeing M5 33472.96 33989.14 M6 Resilience  $\rightarrow$  Ethical vision of patient care\* Negative Affectivity $\rightarrow$  Professional efficacy 33492.96 33989.14 Note. In bold the selected model; X= I.V.; W= moderator; Y= D.V.; CI= customer incivility; BIC= Bayesian Information Criterion; AIC= Akaike Information Criterion; 

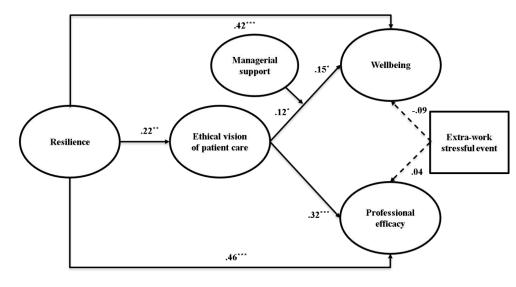
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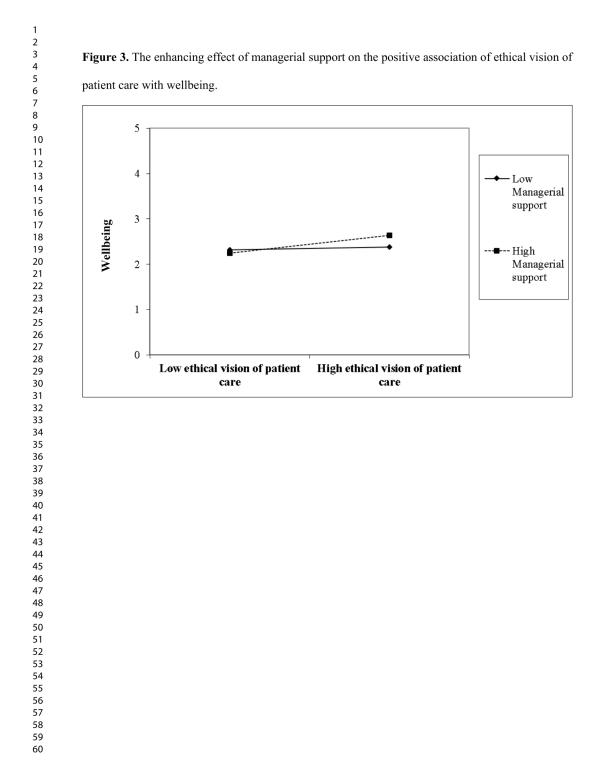
**Figure 2.** Path coefficients of the moderated mediation model having ethical vision of patient care as mediator of the relationship between resilience and wellbeing as well as professional efficacy and managerial support as moderator of the association between ethical vision of patient care and wellbeing.



<sup>\*</sup>p<05; \*\*p<.01; \*\*\*p<.001

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# Chapter Eight

# Interviews with palliative care professionals

# 8.1. An introduction to the interviews conducted with healthcare professionals

As described in the Section A of this dissertation, the literature has unveiled manifold risk factors for burnout and distress in the healthcare context. The daily exposure to death and suffering is one of the main factors which may cause distress, fatigue and impoverishment of professional life (Samson & Shvartzman, 2018). Moreover, facing with bioethical dilemmas related to end-of-life care and decision making, as well as communication difficulties of inauspicious diagnosis and poor prognosis, are other relevant aspects deserving attention (Flannery, Ramjan, & Peters; 2016). For these reasons, this research project provides a qualitative focus on palliative care professionals to collect their daily experience at work. These qualitative findings aim to enrich with further nuances and insights the quantitative data collected, in line with the main aim of the multi-method design chosen (see chapter three).

To carry on this qualitative part of the project, the Grounded Theory approach was chosen as it is a well-establish technique in healthcare research and it allows to generate a theoretical framework grounded in real data, providing practical implications (Corbin & Strauss, 2015). According to this method, data collection and preliminary data analysis were carried on in the same time until the reaching of saturation of categories, namely the full comprehension of the emerging themes was gained. Overall, 19 healthcare professionals were interviewed. These professionals were employed in a unit of palliative care located in a rural area in Northern Italy (Lombardy). Some months after, this healthcare team has been moved and merged with another palliative care unit of the same hospital organization in the city.

This qualitative part is described in detail in two already published papers presented in the following pages. The first one put the focus on professionals' daily work experience, aiming to reach a theoretic framework that can better explain what daily working in a palliative care unit means for healthcare professionals. The attention is on factors that may counteract distress and foster wellbeing in order to strengthen and find mechanisms unveiled with the quantitative part.

The second study put the focus on professionals' subjective perception of the recent Italian law n. 219/2017 (see Box 1). The main scope is investigating the practical implications of the novel law on Advance Directives according to healthcare professionals who have to adopt it in every day working life. To this regard, one has to be cognizant of the fact that bioethical decision-making processes may be a relevant source of distress for healthcare professionals, in particular when choices to be taken are in conflict with their own values and beliefs (Flannery et al., 2016; Rainer,

Schneider, & Lorenz, 2018). Bearing in mind this delicate issue, the project takes the occasion to explore through some open questions the first perceptions of providers regarding the new law which may be considered a tool for the professionals to navigate in the nebulous horizon of end-of-life care.

# Box 1- Italian law n. 219/2017

*Full name:* Norme in materia di consenso informato e di disposizioni anticipate di trattamento (Provisions for informed consent and advance directives), Law no. 219/2017. (Published on Gazzetta Ufficiale, Serie Generale no. 12, 16<sup>th</sup> Janury 2018).

*Legislative process:* On 14 December 2017, the Italian Senate approved the law with 180 votes in favor, 71 against and 6 abstentions. On 31<sup>st</sup> January 2018, the law entered into force.

*Background of the law:* There are manifold differences in the European country regarding endof-life and advance directive legislations. Within Europe, Italy is one of the last nation to regulate end-of-life decisions. The Italian delay has different roots associated to political, religious and cultural factors and this law has to be considered the culmination of a long process and heated cultural debate throughout Italian society.

# Essential structure (Di Paolo et al., 2019):

Art. 1 (informed consent): To establish clear rules on consent to and refusal of any medical treatment. To establish the form of informed consent. To establish the role of public and private healthcare facilities in the training of healthcare professionals in the field of relationships and communication with the patient;

Art. 2 (Pain therapy, prohibition of unreasonable obstinacy in treatment and dignity at the end of life): To avoid non-beneficial treatments and disproportionate means in end-of-life care.

Art. 3 (Minors and incompetent patients): To establish rules on the decision-making process in the case of minors and incompetent patients.

Art. 4 (Advance treatment directives): To establish rules on the value of prior requests placed by patients before becoming incapable of expressing their will

Art. 5. (Shared care plans): To improve the concept of the clinical relationship between patients and healthcare professionals

Art. 6-8: Administrative articles

# References:

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Section C: Chapter 8 - Interviews with palliative care professionals

# 8.2. Risk and protective factors experienced by palliative care professionals

Maffoni, M., Argentero, P., Giorgi, I., & Giardini, A. (2020). Underneath the White Coat: Risk and Protective Factors for Palliative Care Providers in Their Daily Work. *Journal of Hospital and Palliative Nursing*, *22*(2), 108-114. doi: 10.1097/NJH.000000000000023<sup>7</sup>.

1

#### Abstract

Palliative care practice is associated with risk factors linked to end-of-life, chronicity, personal, interpersonal, and work characteristics, as well as with protective factors, but how these are perceived by the healthcare providers themselves is not clear. This paper aims to elaborate a theoretic framework explaining the risk and protective factors for palliative care providers in their daily practice. Nineteen providers (16 nurses, 3 physicians) working in a palliative care unit of a clinical- research institute in Northern Italy were interviewed. A Grounded Theory qualitative approach guided the data collection and analysis. From the interviews, 28 codes, subsequently organized into 11 interconnected categories, emerged. They described both stressors (emotion management regarding death/dying, conflicts, communication and relationship with patients/caregivers, discrepancies between patients' and caregivers' needs, communication of poor diagnosis/prognosis, decision-making about treatment, and real-life and work interference) and protective factors (social support, positive approach and value of past experience, recognised value of/passion towards professional work, work-family balance). Experiencing these elements as positive or negative depends on the professionals' point of view, as well as their past and present experience.

Understanding what dealing with life-limiting illnesses means may suggest tailored interventions to improve professionals' wellbeing by fostering the protective elements and combatting the risk factors.

**Key-words:** healthcare professionals, palliative care, Grounded Theory, qualitative, risk and protective factors, distress, moral distress

<sup>&</sup>lt;sup>7</sup> This is a non-final version of an article published in final form in Maffoni, M., Argentero, P., Giorgi, I., & Giardini, A. (2020). Underneath the White Coat: Risk and Protective Factors for Palliative Care Providers in Their Daily Work. *Journal of Hospital and Palliative Nursing, 22*(2), 108-114. (Wolters Kluwer policies).

# **INTRODUCTION**

The future will see an increasing demand for healthcare professionals specialized in palliative care in order to assist the growing number of patients dealing with end-of-life or life-limiting illnesses, maintaining their quality of life as satisfactory as possible and reducing suffering. Hence, there is a crucial need to focus on the wellbeing of all palliative care professionals since they are potentially exposed to occupational risks concerning their psychological and physical health, which could also reflect on the quality of care provided.<sup>1,2</sup> For instance, a recent review estimated the prevalence of burnout in palliative care providers to be 17.3%<sup>3</sup> The risk factors are various and include work features, personal factors, and interpersonal relationships with colleagues, patients and caregivers.<sup>4,5</sup> According to quantitative analyses, exposure to death and dying can result in distress, fatigue and impoverishment of professional quality of life.<sup>6</sup> Managing the ethical dilemmas related to end-of-life care and the foregoing life-sustaining therapy appears to be a risk factor for burnout and moral distress, as also the difficulty in communicating diagnosis and poor prognosis.<sup>4,7,8</sup> Healthcare practitioners' endof-life decision-making may in itself contribute to the distress and burnout experience.9 A significant source of distress for physicians and nurses is the need to make bioethical decisions which are in conflict with their own personal values, as well as is the need to find a balance between family, institutional, legal and moral constraints.<sup>4,7,10</sup>

At the same time, it is well known that healthcare providers working in palliative care do not show higher burnout levels than other colleagues, probably thanks to the presence of protective factors and coping mechanisms that may influence the constant dealing with death and dying.<sup>6,11</sup> However, the positive and protective factors which may modulate the relationship between healthcare professionals and their job have been little investigated.<sup>4,6,12</sup>

The aim of this qualitative study was to develop a theoretic framework explaining what working daily in a palliative care unit means for healthcare professionals, focusing on the factors that may counteract distress and foster wellbeing.

## **METHODS**

# Design

A qualitative research design using semi-structured audio-recorded interviews was adopted. The study was conducted according to the "Consolidated Criteria for Reporting Qualitative Research" (COREQ).<sup>13</sup> This study is part of a broader observational multicentre crosssectional research project focusing on wellness and distress in healthcare professionals dealing with end-of-life and bioethical issues in their everyday working life (XXX Project, approved by the XXX Ethical Committee on XXX, Protocol N° XXX).

#### Sampling and participants

This study involved nurses and physicians working in a palliative care unit in Northern Italy. This hospital unit is specialized in taking care of patients suffering from life-limiting diseases. No exclusion criteria regarding gender or length of service were adopted since it was not possible for the authors to guarantee the reaching of an adequate size for each subsample. Participation was voluntary, and the only requirement was the knowledge of spoken Italian. No financial reimbursement was provided.

Potential participants were recruited through theoretical sampling according to the Grounded Theory methodology,<sup>14</sup> therefore the size of the sample was not decided before starting, but on the basis of the emerging theory. So, participants were enrolled up to a complete and fully comprehension of data. Indeed, being oriented to the generation of a

theoretic framework, the recruitment of participants ran parallel with data analysis and continued until saturation was reached (i.e. when the categories that emerged and their relationships were fully explored). Thus, the authors decided to stop the recruitment when they were confident that no additional relevant information could be obtained with further interviews.

### Ethical considerations

The study was conducted according to the principles of the Declaration of Helsinki.<sup>15</sup> Participants were informed by a researcher (MM) about the aim of the study, as well as about the anonymity of data management, and signed a written informed consent. The possibility to be provided with more clarifications or to withdraw from the study at any moment during the interview was guaranteed.

#### Data collection and analysis

The qualitative methodology guiding the study was Grounded Theory, one of the techniques most widely used to explain a phenomenon on the basis of data grounded in real-life experience.<sup>14</sup> Considering literature reports and clinical experience, the authors developed a semi-structured interview enquiring about the subjective experience of working in palliative care with a focus on perceived risks and protective factors for developing stress (Table 1). Interviews were audio-recorded and conducted face-to-face, transcribed verbatim and played back from audio-registration to guarantee reliability and integrity.

#### **INSERT HERE TABLE 1**

Data analysis was performed according to the indications of the Grounded Theory method, requiring codes (the simplest units of meanings) and identification of categories (i.e. the concepts including and organising the codes).<sup>14</sup> Thus, initially MM searched for the main

guiding concepts, carrying out the *open coding*. During the second phase (*axial coding*), all authors read the transcriptions and through discussion identified the main categories, subcategories and codes. In the third step (*selective coding*), all authors reviewed and redefined the codes and categories until a workable theoretic framework of the analysed experience was reached. During the process, the authors wrote memos and notes to help the critical and in-depth analysis. RQDA, a R-based qualitative analysis software application was used to support this process.<sup>16</sup>

At the end of data collection and analysis, the authors conducted a word frequency analysis of the transcriptions, identifying the 20 words most used by participants (excluding the interviewer words) in order to verify coherence with the categories that emerged. In the verbatim transcriptions, Italian "stop words" (articles, prepositions and all other semantically irrelevant terms) were filtered out. Plural and singular forms were merged into one term. A Python script, based on the module "word cloud", was used for textual analysis and to generate a word cloud (where word sizes are directly proportional to word frequency).<sup>17</sup>

# RESULTS

Data saturation occurred after 19 interviews (16 nurses and 3 physicians, 16 females and 3 males). Twenty-eight interconnected codes emerged (Table 2), which were subsequently organized into 11 categories, describing stressors and protective factors. These categories were constantly changing, with the potential to be either protective factors or stressors, and together they constituted the core category "the daily experience of working in palliative care unit" that summarizes these findings (Figure 1).

INSERT HERE TABLE 2

**INSERT FIGURE 1** 

#### Stressors

# Emotion management regarding death and dying

Healthcare providers underlined the complexity of managing their emotions linked to the care of patients on the verge of death. In particular, they described psychological suffering with repeatedly having to face the "experience of the end" and difficulty in finding the right balance between proximity to the patient and "maintaining a distance".

You never get used to death... (Nurse).

[...] there are people that get into your heart and you don't even know why...

losing him was like a wrench (Physician).

## Conflict

Providers, in particular nurses, described it as stressful having to deal with divergences and conflict among colleagues. The content of disagreements was linked mostly to the approach to the patient and the care provided (e.g. patient dressing and handling, palliative sedation).

There can be conflicts since we are all different, and we work in different manners... (Nurse).

They didn't want us to do the sedation, in particular there was a father who was completely shocked [...] because he was seeing us like the ones who were killing his son (Physician).

#### Communication/relationship with patients and caregivers

Respondents described the relationship with those in care as complex to manage. The main areas of difficulty related to communication and the relationship with patients (especially when they are young) and with the caregivers. Sometimes there are difficult situations regarding communication with the family,

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e.g. when there are under-age children involved (Physician).

For me, aggressive families are difficult to manage (Nurse).

In particular, if there are very young patients. It's the hardest thing to deal with.

It's not like normality, parents leaving their child, but instead children leaving

their parents, it's ... it's heavy (Nurse).

#### Discrepancies between patients and caregivers' needs

Healthcare professionals sometimes witnessed misunderstanding and disagreement between patients and their caregivers, discrepancies between conflicting life perceptions. Moreover, they sometimes had to be a mediator to ensure that the patient's will was understood by the caregivers.

The most difficult aspect is matching the patient's needs with the family will (Physician).

#### Communication of poor diagnosis and prognosis

Communicating a poor diagnosis and prognosis was also reported as a demanding act. The interviewees described the difficulties of breaking bad news to their patients.

Difficult aspects of this job are mainly related to communication of diagnosis and communication of prognosis above all, so I mean patients that, due to their illness path... need or openly ask... how much time remains for them to live ... (Physician).

Decision-making about treatment

Providers, especially physicians, described the decision-making process regarding patients' treatment as complex. To determine the "right" moment for the beginning of the palliative sedation was particularly stressful.

It's hard to know for us when we have reached the limit of over-treatment and we need to switch to another direction. It's not easy (Physician).

### Life and work interference

Some healthcare providers felt tired and overwhelmed due to bereavements experienced in private life that could be recalled to memory by patients. The continuous exposure to suffering, death and dying had changed their attitude towards work and life too.

Also the emotional burden, over the years, it starts to feel heavy after a while [...] in the last few years I have had a series of losses in my family and therefore, in one way or other, the difficulties weigh down on what was happening here (Nurse).

I feel different. After 13 years I am tired out... (Nurse).

### **Protective factors**

#### Social support

Social support is a significant protective factor, in that it allows one to share burdens and experiences.

[...] then talking with the others about those things helps, you reach a shared solution that gives you a bit of confidence (Physician).

Yes, we support each other. ... after all the difficulties, we are still able to sustain who falls (Nurse).

Moreover, the appreciation from patients and caregivers is a social support too.

When you came back he [the patient] was waiting for you, that is gratification... (Nurse).

Some families don't abandon us. And so they come back to visit us, because they consider us part of their family (Nurse).

### Positive approach and value of past experience

Healthcare professionals better coped with difficulties inside their work activity when they had a positive attitude towards life. They valued past experiences as an important instrument to learn from and gain new perspective.

I am lucky, I have quite a sunny personality [...] I go to say hello to them one by one in the room and... I make a joke... I sit down, sometimes chatting, so they can relax a little bit ... (Nurse).

I see things differently, I mean... I take things differently... in life [...] It was very useful to start working here, I appreciate more the present instead of the future (Nurse).

#### Recognised value of and passion for one's professional work

Another protective factor is the adoption of a positive approach towards work. Providers underlined the importance of being conscious of the value and significance of their profession.

We give dignity and we don't let them suffer. The fact that someone can die peacefully, without struggling with pain (Nurse).

Work-family balance

Healthcare professionals described their efforts to find a balance between work and family, staying focused on the present moment and trying to avoid too much 'contamination' between the two sectors.

What I learned here is that I need to find a "glass wall" to isolate myself... I should not bring work into the home, I mean, when my work shift is over, it's over. I have another life outside (Nurse).

#### Word frequency analysis

The 20 words most used by the interviewees (Figure 2) were coherent with the categories that emerged, and in line with the main themes characterizing the subjective perception of everyday life in the palliative care unit. The most frequent terms were: patient, person, caregivers, work, meaning, colleagues. These words were related to both stressors and protective factors.

**INSERT HERE FIGURE 2** 

#### DISCUSSION

This study provides a picture explaining what working daily in palliative care means for healthcare providers (physicians and nurses). The picture that emerged is of a demanding and challenging work experience characterized by both positive and negative aspects. The daily experience of healthcare providers is made up of elements which can be both stressors and protective factors (Figure 1). In other words, they seem to be two faces of the same coin: the same factor may be a trigger of wellness, but in the meantime, it may turn into a stressor too. In fact, an experience in the palliative care unit can become a protective element for one person and a distressing element for another. What makes the difference is the (previous) professional experience or the life period that the person is going through. Using a metaphor,

many elements of palliative care practice are potentially "stem cells" that may turn into either risk factors or protective ones. For example, in our interviews, work experience was described by some as a risk factor for burnout over the course of time but by others as a protective element providing meaning in life and work satisfaction. Hence, clinicians and researchers should take advantage of this, promoting interventions to orient workers' perception of the factors in a protective direction instead of in a distressing one. Indeed, personal, relational and environmental factors may be both constraints and resources, and need to be understood as part of a complex holistic unity in which the single person interacts with the external physical and social context that influences the subjective experience.<sup>4</sup>

Focusing on risk factors, besides work experience, the constant exposure to suffering, death and dying could be potentially distressing and highly challenging.<sup>6</sup> The palliative clinical setting gives rise to negative emotions that need to be adequately managed by the providers, who are in a never-ending search for balance between "stay close" and "maintain a distance". Reports in the literature also highlight the complex and exhausting effort required to cope with the emotional sphere, avoiding the risk of becoming dried up and morally distressed.<sup>4,12</sup> Similar experiences of moral distress, due to the perception of acting not perfectly in line with one's own values, are described not only by professionals taking care of adult patients in life-threatening, troubling clinical situations, but also by providers dealing with dying infants or children.<sup>18</sup> Equally emotionally demanding is the communication of diagnosis and poor prognosis to patients and caregivers because of the highly sensitive issue of death and loss, which requires expertise and skill to be handled adequately.<sup>4,7,18</sup> The relationship with colleagues and superiors may also be a source of distress, due to possible disagreements and divergent views on taking care. One has to deal with demanding clinical situations involving moral dilemmas and different possibilities of acting.<sup>4,7</sup> Thus, the complex decision-making process about life-sustaining treatments becomes a matter of conflict and

distress when it involves the need to find a consensus between different personal views, external and legal constraints and moral values.<sup>4,7,9,10</sup> In addition, staying in constant touch with life-limiting patients and caregivers is a demanding experience. The interviewees reported that they had to manage not only their inner feelings, but also had to mediate between requests and needs coming from both patients and caregivers, which were not always convergent.<sup>4,7</sup> Sometimes the clinicians had to become a mediator or interpreter of the patient's needs, in order to safeguard the person from their loved ones who could be (despite their best intentions) not supportive.

As said before, these personal and relational aspects can act as protective factors in daily palliative care practice, fostering the providers' wellbeing and, as a consequence, improving the quality of care too. Indeed, whilst on the one hand the relationships with other people may be highly demanding, on the other hand they can also provide a 'scaffolding' and help the professionals to cope with the difficulties faced in the workplace.<sup>7</sup> In this light, it is important to promote a serene and supportive climate within the team.<sup>4</sup> In addition to social support, a positive and meaningful approach to one's own work was reported as a protective factor in the daily practice. This is confirmed by literature reports showing that being aware of the value of one's work in alleviating suffering and fostering a better quality of life protected against distress and burnout.<sup>6,12</sup> In addition, respondents underlined the importance of taking care of themselves and their families, safeguarding the balance between work and private life.<sup>11</sup>

The elements - risk and protective - which emerged from this Grounded Theory analysis were confirmed by a word frequency analysis of the interviews' verbatim transcription performed by a Python script, based on the module "word cloud" (Figure 1). Indeed, the 20 most used words were the keywords of the main themes that emerged. Besides terms related to the workplace ("patient", "persons", "caregivers", "work"), another frequent

word was "meaning", highlighting the central role of *searching for a meaning* perceived by healthcare professionals. Less frequent but still important terms were: "life", "difficult", "mum", "manage" and "young". It is reasonable to suppose that all these terms are conceptual pins on the value map of providers working in palliative care practice.

### STRENGTHS AND LIMITATIONS

The qualitative methodology used<sup>14</sup> enabled us to construct a meaningful theoretical framework explaining the palliative care context from the perspective of healthcare providers. The rigor of the scientific research is testified by the credibility, authenticity and integrity of the findings.<sup>19</sup>

Nevertheless, the clinicians and nurses recruited for the study were from a single hospital center, introducing a possible bias in the findings. We thus recommend that future studies recruit the healthcare professionals in multiple units, as well as assessing for possible differences linked to culture, religious beliefs, healthcare systems and overall seniority.

### CONCLUSION

If a palliative care provider suffering from burnout, moral distress or other work-related conditions is not able to provide high-quality care because of the work-related stress, the issue becomes a social challenge.<sup>1,2,4,20</sup> Thus, trying to grasp the palliative care professionals' subjective point of view and understand what dealing with life-limiting illnesses means may enable tailored interventions to be implemented to improve both providers' wellbeing and the quality of the care they provide.

#### ACKNOWLEDGEMENTS

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## DISCLAIMER

This article is a part of the research XXX, approved by the XXX Ethical Committee on XXX, Protocol N° XXX.

### DECLARATION OF CONFLICTING INTERESTS

The authors declare that there is no potential conflict of interest.

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# Figure 1 – Theoretical framework of day-by-day work experience in a palliative care unit

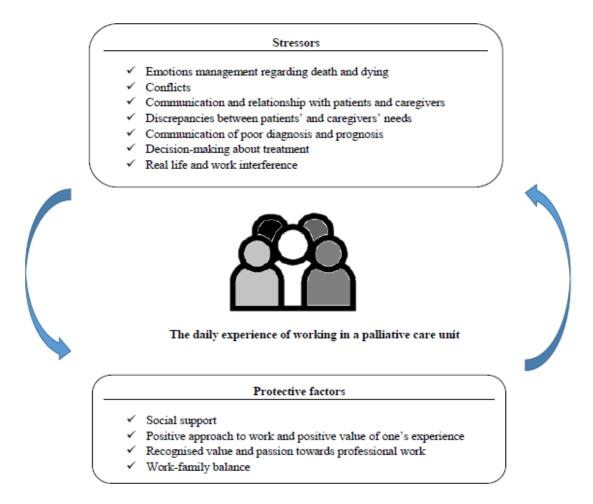


Figure 2 - Wordcloud and frequencies of the 20 words most used by the respondents

Word	Frequency	
Patient	174	looking for mum carogivors
Person	85	looking for mum caregivers
Caregivers	84	
Work	77	work bad
Meaning	75	difficult
Colleagues	56	home
Home	51	
Life	48	
Unit	48	manage 🗄
Difficult	43	colleagues <sup>young</sup>
Bad	42	0
Mum	38	problems clinicians
Time	38	problems
Manage	37	
End	34	
Young	34	
Situation	34	- PDO
Clinicians	30	situation meaning
Looking for	30	situation
Problems	27	

# Table 1. Open questions of the semi-structured interview

 Have you ever had to manage difficult situations, emotionally and morally, in your work? Could you give me an example?

2. Has the frequency of those events changed, e.g. increased or decreased, over the years?

3. In those complex situations, what for were you the most difficult aspects to manage? Why?

4. What are the factors that helped you in managing those complex situations?

5. In those complex situations, did you feel supported and free to talk about things with colleagues and superiors? Any examples?

6. Did you ever disagree with colleagues about those issues? Any examples?

7. Did you ever disagree with the will expressed by the patient's family? Any examples?

### Table 2. Codes that emerged and their frequencies within the total number of interviews (n=19)

Codes	n	%
Stressors/risk factors		
Disagreement with colleagues	16	84
Disagreement with caregivers	14	74
Emotional management linked to care of young patients	14	74
Relationship with caregivers	14	74
Management of personal psychological suffering	12	63
Discrepancies between the patient's and caregivers' needs	10	53
Subjective perception of increasing of complex clinical situations	9	47
Maintenance of the "need" for emotional distance	7	37
Management of the "end-of-life" experience	7	37
Communication of poor diagnosis and prognosis	6	32
Situations recalling personal experiences	6	32
Communication with caregivers	5	26
Disagreements with superiors	5	26
Caring and decision-making	4	21
Communication and relationship with the patient	4	21
Management of elderly caregivers	3	16
Management of elderly patients	2	11
Psychosomatic disorders	2	11
Real-life and work interference	2	11
Management of lonely patients	1	5
Protective factors		
Social support from colleagues	18	95
Social support from superiors	16	84
Positive approach towards work	10	53
Recognised value of one's own work	9	47
Patients' and caregivers' positive feedback	7	37
Positive value of past experience	7	37
Work-family balance	7	37
Social support from family	3	16

### 8.3. Palliative care professional' perspective on the Italian law on advance directives

Maffoni, M., Argentero, P., Giorgi, I., & Giardini, A. (2019). Healthcare professionals' perceptions about the Italian law on advance directives. *Nursing Ethics, 27*(3), 796-808. doi: 10.1177/0969733019878831<sup>8</sup>.



Original Manuscript

# Healthcare professionals' perceptions about the Italian law on advance directives



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#### Abstract

**Background:** In the variegated legislative framework on advance directives, the first specific regulation in Italy on this issue came into force only in 2018.

**Research objective:** This qualitative study aimed to investigate the implications of the new Italian law on advance directives in clinical practice from the perspective of those who deal with this delicate ethical issue on an everyday basis, that is, Italian healthcare professionals.

**Research design:** A qualitative research design using semi-structured audio-recorded interviews was adopted. The data collection and analysis were performed according to the Grounded Theory approach. **Participants:** Nineteen healthcare professionals (16 nurses, 3 physicians) working in a palliative care unit of a research and clinical institute in Italy.

**Ethical considerations:** The study is part of the WeDistress HELL Project (WEIIness and DISTRESS in HEalth care professionals dealing with end of Life and bioethicaL issues) approved by the Ethical Committee of ICS Maugeri - Institute of Pavia (Italy).

**Findings:** The authors identified a main overall category, 'Pros and Cons of the Italian law on advance directives', composed of six constituent categories: Positive welcome, Self-determination and protection, Prompts for future betterment, Uncertainties, Lack of knowledge, and Neutrality and no suggestions.

**Discussion:** The Italian law n. 219/2017 on advance directives was seen as a legal instrument possessing both strengths and weaknesses, but able to guarantee the patient's self-determination and support healthcare professionals in providing care according to patients' wishes.

**Conclusion:** An understanding of the healthcare providers' perspective may support the discussion on advance directives and bridge the gaps that currently persist in handling ethical issues.

#### Keywords

Advance directives, Grounded Theory, healthcare professionals, Italy, law

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#### Introduction

Planning advance care is a complex, relatively recent issue defined by expert panels as 'a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care'.<sup>1,2</sup> Despite the existence of the patient's written advance directives, the state of the art about the implementation of living wills is still globally heterogeneous and legally muddled, so it is quite difficult to trace effective parallelisms between countries.<sup>3</sup> Indeed, bioethical laws represent a controversial and sensitive issue because the nature of these regulations reveals an 'ambiguous necessity<sup>4,5</sup>. There is not only the need to guarantee universal rights during the never-stopping biomedical advancements but also the urge to safeguard the pluralism and specificities characterizing each country. Moreover, there are different issues in the landscape of end-of-life care, such as advance directive(s), euthanasia, assisted suicide and do-not-resuscitate orders. The legislation may address entirely or only in part these aspects, leaving relevant legislative vacuum to be discussed. To now, the existence of specific legislation regarding advance directive(s) is worldwide jeopardized and in constant evolution. For example, in Europe, the Netherlands led the way enacting a specific law on advance directive(s) in 1994 then followed by Denmark, Estonia, Belgium, Spain, Finland, France, United Kingdom, Austria, Slovenia, Germany, Hungary, Latvia, Luxemburg, Portugal and Ireland.<sup>5</sup> In the latest years, Czech Republic, Sweden and Italy enacted a national law on advance directive(s) too.<sup>6</sup>

Despite numerous differences, a common element worldwide is the increasing attention focused on this issue, particularly due to the growing need for effective measures to provide palliative care and end-of-life treatments.<sup>7</sup> In the last two decades, there has also been a steady rise in research on this topic. Indeed, a PubMed search of articles published worldwide on 'advance\* directive\*' shows an increase from 56 in 1998 to 125 in 2018 (Figure 1).

Concerning advance directive(s), many ethical and legal concerns arise. For instance, there are scant regulations advising clinicians what to do in cases where the patient's wishes are not clear or where surrogate decision-makers' interpretations of patients' wishes conflict with the living will.<sup>3</sup> In addition, different kinds of barriers and constraints exist making the implementation of advance directive(s) difficult in daily clinical practice: ethical and legal concerns,<sup>8,9</sup> healthcare providers' knowledge about and confidence in the law on end-of-life care,<sup>10</sup> the availability and access to advance directive(s),<sup>11–13</sup> the quality of the relationship and communication between patient and clinician,<sup>13,14</sup> as well as subjective perception, understanding and concerns about advance directive(s).<sup>13,15</sup> Despite these drawbacks, advance directive(s) are reported to improve the patient's quality of life in the last days<sup>16</sup> and may potentially reduce costs of care too.<sup>17</sup> Hence, planning medical care treatments in advance merits the attention of healthcare systems.

### Background

Since the first advance directive(s) proposed back in the late 1960s by an American lawyer, this kind of regulation has spread through the world at different rates according to the cultural and political climate of each country.<sup>18</sup> Only at the end of 2017 did Italy finally address the issue with a specific law on advance directive(s) (legislative decree n. 219/2017).<sup>19,20</sup> This delay with respect to other countries has different roots linked to political, religious and cultural factors characterizing the Italian context.<sup>21</sup> However, the debate on this issue was fervent for many years before becoming law, due to previous attempts at implementing regulations and various cases brought into the limelight through the media.<sup>20,21</sup> The Italian legal system has always paid attention to respect the person's will and their right to participate in the decisions about their care and treatment. There were previous attempts to regulate advance directive(s) in the Italian legislative corpus.<sup>22,23</sup> Nevertheless, the law adopted in 2017 must be considered the first one specifically stating the individual's right to express their personal values, to decide in advance what treatments to

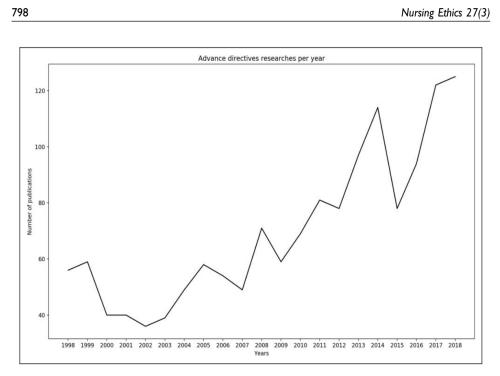


Figure 1. PubMed search showing annual trend in articles published on advance directive(s).

accept/not accept, as well as to nominate a surrogate decision-maker.<sup>19–21</sup> More in detail, the law introduces, for each person over the age of 18, the possibility of compiling their Advance Directives Declaration. It contains the instructions for the physicians regarding end-of-life treatments, such as vegetative state maintenance, pain management, cardiopulmonary resuscitation, blood transfusions and emergency treatment in general. The declaration can be written freely without a pre-defined structure (even though some associations already provide a general template) and must be delivered to a public officer in order to register it. The person can modify or withdraw her or his wills at any time. The declaration can also contain the indication of a trusted person, who has the duty to enforce the respect of the declaration's content. Physicians are obliged to respect the wills expressed by the patients regarding the treatments they would or would not allow for themselves, while in the past there was no specific law and end-of-life decisions were in most cases taken by physicians with or without the caregivers' involvement. According to this law (legislative decree n. 219/2017), the only cases where the physician – in agreement with the patient's trusted person – may partially or entirely disregard the patient's will is when new therapies are available. Moreover, assisted suicide and euthanasia remain illegal in Italy and are not addressed in this law, which has fuelled ongoing debates on physicians' right to autonomy as well as on their duty to protect human life.<sup>19–21</sup>

Up to now, a national database of Advance Directives Declaration is not available; therefore, it is not possible to estimate how many people already wrote their declaration. Moreover, little is known about healthcare providers' impressions on this recent law in clinical practice. Therefore, the aim of the present qualitative study was to collect initial feedback from palliative care professionals (the healthcare providers are potentially more affected by the Italian law n. 219/2017 on advance directive(s)), in an attempt to understand the implications of this regulation in clinical practice from the point of view of those who have to apply it in their everyday working life.

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 Table 1. Open questions of the semi-structured interview guide.

- I. What do you think about the new law on advance directives?
- (If the person doesn't know about the law) Are you planning to seek information about this law in the future? 2. Do you feel more protected or more obstructed by this law:

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- a. in your daily work?
- b. in your private life?3. Would you change anything in the current law?

### Methods

#### Participants

Participants were recruited in a palliative care unit of a research hospital in Italy between June and September 2018. Although every healthcare professional may be affected by this new law, we chose the providers working in a palliative care unit as research subjects since, in virtue of their dealing with end-oflife patients, they have more probability to be more often affected by this new law. All healthcare professionals (physicians and nurses) were invited to take part in the study regardless of their sex or length of service. In accordance with theoretical sampling, the authors considered to extend this qualitative study to other palliative care units in case it was necessary to reach the saturation of data. However, 19 participants were interviewed before the saturation was reached (the analysis were performed every four–five interviews) and therefore no other units were involved. Participation was voluntary and without any form of financial reimbursement.

#### Study design and procedure

The present study adopted a qualitative design based on the Grounded Theory (GT) approach, which aims to build an explanatory theoretical framework based on data grounded in real-life experience. Theoretical sampling was adopted for the participants' recruitment as prescribed by the GT methodology.<sup>24</sup> Data collection ran parallel to data analysis until theoretical saturation was reached, at which point sampling and analysis stopped as all concepts were sufficiently well understood and developed (i.e. no additional information could be obtained with further interviews).<sup>25</sup> As saturation was reached, no other healthcare professionals were recruited by other hospital palliative care units.

To collect data, a semi-structured interview guide was developed throughout a preliminary discussion with experts dealing with bioethical issues and palliative care. It included the open questions presented in Table 1. The interviews were conducted on a one-to-one basis and audio-recorded. They took place in a silent room inside the palliative care unit during the healthcare professionals' shift changes. The mean length of each interview was about 20 min. Soon after the conclusion of the interview, trainee psychologists made a verbatim transcription and each one was revised by one author at a time who listened again to the corresponding audio-registration.

Following the prescriptions of the GT approach, the authors analysed data looking for the simplest content units (codes) and then for more comprehensive concepts (categories) explaining how the law was experienced by providers.<sup>24</sup> At the beginning, M.M. started the preliminary *open coding*, reading line-by-line the transcripts to identify the main guiding topics. In the following phases (*axial coding* and *selective coding*), all authors carried out a deep recursive reading in order to detect meanings and to find links among codes and main categories, until a sufficiently workable framework was reached that could explain the

issues analysed. To better visualize the results, we developed a map constantly modified during the entire procedure. The entire analysis was supported by RQDA, an R-based software for qualitative data analysis.<sup>26</sup>

#### Ethical considerations

The study was conducted as part of a mixed-methods observational, multicentre and cross-sectional study on wellness and distress in healthcare professionals dealing with end-of-life and bioethical issues in their everyday working life (WeDistress HELL Project, approved by the Italian Ethical Commitee of ICS Maugeri - Institute of Pavia on 19 June 2018, Protocol No. 2211CE). A trained researcher (M.M.) informed each participant, both orally and in written form, about the study aims and protocol and data storage. Respondents were guaranteed their anonymity as well as the possibility to request clarifications or to withdraw from the study at any moment if they so wished. Before starting the interview, written informed consent was obtained from each participant.

There were no relationships between the authors and the participants. A.G. had previously worked in the unit but all the interviews were conducted by M.M. who never met the participants before.

#### Results

To reach the saturation of concepts, 16 nurses (1 male, 15 females) and 3 physicians (2 males, 1 female) were interviewed. Of these 19 interviewees, 4 female nurses (21%) affirmed to not know the new law on advance directive(s) and told if they were planning or not to seek information about this law. Fifteen healthcare providers who stated to have some knowledge of this new regulation answered to the second and third questions about the present law and some possible suggestions for future improvements.

Seventeen codes were detected, constituting six categories: *Positive welcome, Self-determination and protection, Prompts for future betterment, Uncertainties, Lack of knowledge*, and *Neutrality and no suggestions* (Table 2). These categories were summed up in a main category termed '*Pros and Cons of the Italian law on advance directive(s)*'. Figure 2 depicts the theoretical framework explaining the healthcare professionals' perception of the new law.

#### Main category 'pros and cons of the Italian law on advance directive(s)'

As a whole, the Italian law was perceived by healthcare professionals as a legal instrument which shows both strengths (Lights) and weaknesses (Shadows) in its present form, with room for future improvement. It was described as a tool to use in daily clinical practice characterized by both pros and cons as outlined in the six categories described below.

#### Lights

Category 1: Positive welcome. The interviewees appeared to positively welcome the law on advance directive(s). One nurse said 'It is definitely a step forward...I followed the law-making procedure, in particular when they gave the ok to the law in the courtroom...I was very happy, everybody was happy!' Healthcare professionals described the law as a useful instrument to guide themselves in carrying out their work. One physician described it as a new 'resource' to appropriately carry out the daily work. They affirmed that it is a good, positive and needed regulation to provide healthcare in accordance with the patient's will.

Category 2: Self-determination and protection. The healthcare professionals said this new law was a form of protection for the patient. The law could prevent futile treatments and safeguard the patient from the caregiver's will. For example, one nurse reported,

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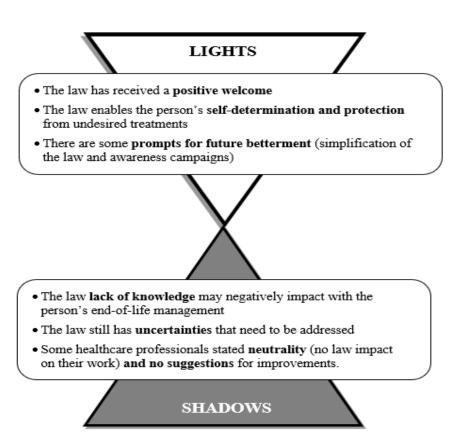
Table 2. Codes that emerged and their frequencies.

Codes	n/respondents to be considered <sup>a</sup>	% <sup>a</sup>
Lights		
Category 1. Positive welcome		
Positive feedback	15/15	100.0
Attitude to deepen one's knowledge of the law	6/19	31.6
Category 2. Self-determination and protection		
Guarantee of patient self-determination	10/15	66.7
Patient's protection against caregiver's contradictory will	9/15	60.0
More self-determination and protection against futile care for healthcare providers	9/15	60.0
(intended as potential users)	4/15	247
Patient's protection against futile care	4/15	26.7
Category 3. Prompts for future betterment	2/15	
Simplification and better definition of the law	3/15	20.0
Awareness campaigns and training are necessary (information and communication)	2/15	13.3
Shadows		
Category 4. Uncertainty		
Healthcare professional as a mediator or an executor?	5/15	33.3
Implementation difficulties	4/15	26.7
Do my current will be the same in the future?	4/15	26.7
Taboo of speaking about death (may hinder individuals from providing advance directives)	1/15	6.7
Category 5. Lack of knowledge		
No knowledge of the law (nurses)	4/19	21.0
Lack of law accessibility on the part of citizens	1/15	6.7
Category 6. Neutrality and no suggestions		•
Law's impact on healthcare professionals' work: no opinions or no proposed variations	s 5/15	33.3
Law's impact on healthcare professionals' work no opinions of no proposed variation. Law's impact on healthcare professionals' private life (providers as potential users): no		20.0
decisions taken or no proposed variations	, 5/15	20.0
No prompts or suggestions for improvement	6/15	40.0

<sup>a</sup>Frequencies and percentages are calculated considering that 19 healthcare providers answered the first question of the interview. Fifteen healthcare providers who knew the law answered to the second and third questions too.

I saw a patient asking not to suffer any more while on the other side the family wanted to see him awake [...] I tried looking at it from the point of view of my own personal experience. I understand the selfishness of the family because, when they told me that my mother was living her last moments, I absolutely did not want my mother to go [voice moved]. So, I understand how the family member – who may be a son or anyone, even a friend – can wish to stay close to the patient. I understand this selfishness, this wish. You are not able to accept the loss immediately.

Therefore, the patient's will of not suffering any more was in contrast with the caregivers' desire to stay close to the patient while she or he was awake, regardless of the related sufferance. Besides protection, the law was seen as a mean to guarantee the person's self-determination. Indeed, two nurses affirmed that 'this law allows the person to be able to choose in her/his future whether to be managed by another, in certain situations  $[\ldots]$  everyone is free to do what they want'. Indeed, 'I think that everyone has the right to choose how to live and even how to die, because death is part of life, isn't it? Why do others have to decide for me?'



Pros and Cons of the Italian law on ADs

Figure 2. Theoretical framework explaining healthcare professionals' perception of the law on advance directive(s).

Category 3: Prompts for future betterment. When requested for future suggestions to better the law, some healthcare professionals proposed to simplify it, as well as to clarify some controversial points that could lead to misunderstandings or misinterpretation. For example, according to one physician, one key benchmark issue to address was the definition and clarification of the difference between 'palliative care' and 'euthanasia'. The same physician also underlined the necessity to better define how to manage the informed consent issue in the case of patients with 'some form of cognitive impairment'.

Another suggestion made was to promote awareness and information campaigns about the law, explaining its characteristics, content and the boundaries of the law to both patients and caregivers, in order to minimize the risk of misunderstanding.

Moreover, the interviewees suggested training interventions specifically aimed to improve the provider's knowledge about the law prescriptions and to foster healthcare professionals' communication skills on end-of-life issues in general. In particular, a nurse underlined that

if you talk, you can do what is necessary in the right way and with respect for everyone. If you do not talk, you're only telling lies to each other to protect one another, but in the end you're not protecting anyone.

Some interviewees stated that, according to them, an open and honest communication by providers could lead the patient and caregivers to find the right way to understand and accept the clinical healthcare situation. In this regard, another nurse affirmed 'a patient and her or his relative must be informed in advance. That is, they must not arrive in palliative care without knowing the situation and the gravity of the situation'.

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#### Shadows

*Category 4: Uncertainties.* Some providers underlined some difficulties in implementing the law in clinical practice, in particular due to confusion and differences in the communication actions and to the accessibility of local officers for registering advance directive(s). Indeed,

the law can create a period of uncertainty, of misunderstanding... I have understood that now all Municipalities will have to ... or anyway all the Regions or Institutions will still have to clearly specify where it is possible to deposit these advance directives. They have to clearly communicate how is the procedure ... How is it possible to register this document? What kind of value can it have? [...] So it requires a greater commitment on the part of the health professional who has to reconstruct, recover the various wishes. (Physician)

In addition, the role of the healthcare provider did not always appear to be clear, shifting between that of being a mediator between constraints and the patient's will or that of an executor carrying out the person's wishes.

Furthermore, one physician underlined that the new law is not able to support the providers in those cases in which the patient's decisional and self-determination capacity cannot be taken for granted, like, for example, with 'patients suffering from some form of cognitive impairment'. Another problem concerned whether it was possible to make reliable predictions in the present about future treatments. In other words, some healthcare providers wondered if it is really possible to remain committed to a previously formed opinion right up to the last moment, because 'each situation has to be assessed in the present moment' (nurse). 'The future cannot be defined from the present [...] because what I am now is not what I will be at that moment...' (physician). In addition, a nurse reported that there might persist the taboo of speaking about death, because 'perhaps we are still a little bit backward on these things'. This taboo could be an obstacle to willingness to provide advance directive(s).

*Category 5: Lack of knowledge.* A minority of interviewees (21%), all nurses, affirmed that they did not know the law on advance directive(s) at the present time. One nurse reported, 'I haven't got any idea yet'. However, it is not clear how many interviewees have a deep and extensive understanding of the law, considering that some answers started with expressions such as 'I know something [about the law]' (nurse). Of note, it should be pointed out that some nurses stated that they wished to seek information about the law since they still do not fully understand it.

Moreover, a physician affirmed that, in his opinion, citizens (in particular in small towns) might not yet understand how to have access to this regulation. 'I do not believe that people yet know well where it is possible to leave these wishes, how it is possible to register them'.

Category 6: Neutrality and no suggestions. Some other respondents declared that they did not yet have an opinion about this law or had not perceived changes in their daily work routine, because 'as I think I work in the right way, it does not involve any changes...it does not give me any problem' (nurse). Similarly, some providers had uncertainties or no opinions about the implementation of the law for themselves as a citizen. In this regard, a nurse stated, 'I do not know, I really avoid thinking about it'.

Considering possible future improvements of the law on advance directive(s), some providers stated that they still do not have enough information and knowledge about the law to be able to make any suggestions. A physician also reported that it is difficult to improve the law because it is not possible to predict or regulate every aspect of the care process.

#### Discussion

The present qualitative study aimed to build a theoretical framework explaining the practical implications and significance of Italian law n. 219/2017 on advance directive(s),<sup>19,20</sup> from the point of view of healthcare professionals dealing with end-of-life issues in their everyday working life. The law, passed only recently in the Italian legislative framework, was described as an instrument with strengths and weaknesses for the present daily practice, as well as areas for future improvement.

Considering the European legislative framework, the Italian regulation on advance directive(s) is one of the last laws approved, indicating another important step towards harmonization with the European laws on this topic.<sup>20</sup> However, it is still difficult to find parallelisms between countries because of the unicity of each legal and social context.

Being long awaited by both the Italian patients and providers,<sup>20</sup> it is not surprising that the healthcare professionals, who stated in our research a certain knowledge of this regulation, welcomed this law in a positive way, considering it as a 'step forward' and a 'resource' to support them in their everyday practice in dealing with end-of-life issues. It might be regarded as a compass to navigate properly through complex and sensitive cases involving legal, moral and ethical issues that could potentially lead to healthcare providers' moral distress and worsening of wellness.<sup>27,28</sup>

The Italian law was described as a legal instrument that protects both sides, enhancing the empowerment of both patient and healthcare professionals, since its aim is to protect the position of each one. For the patient, it is a solid guarantee of self-determination in accordance with both the Italian Constitution and human rights.<sup>19,20</sup> Individuals can now establish their treatment preferences in line with their own existential convictions and be confident of a legal and accepted guarantee that their wishes be implemented.<sup>20</sup> Patients, hence, are now protected, at least at a legal level, from treatments proposed by others (caregivers and providers) and can self-determine their choices as regards care. On the contrary, this law protects providers too. The interviewees (healthcare providers) described it as a tool protecting both their private and work life. Indeed, considering themselves common citizens who will potentially also be in need one day of end-of-life treatments, the providers described the law as a guarantee of their wishes. Meanwhile, they recognized the value of the law as a legal standard supporting them in sensitive healthcare situations, promoting an appropriate management of resources and guaranteeing the patient's will.<sup>20</sup> In addition, the presence of a written patient advance directive(s) might enhance providers' engagement and confidence in dealing with end-of-life issues, even though further evidence on this aspect is required.<sup>29</sup>

Besides strengths, some critical points were also mentioned. First of all, the healthcare professionals reported uncertainty and difficulty in the implementation of advance directive(s) for a variety of reasons. Being a recent law, not always was it easy for the clinicians to trace a patient's advance directive(s) or for citizens to understand where and how to have their wishes registered. Indeed, interviewees perceived differences in the communication and accessibility of local offices authorized to collect advance directive(s). Moreover, some interviewed nurses declared that they did not know the contents of the Italian law on advance directive(s) and some of them expressed a wish to deepen their knowledge. In this regard, it should be underlined that lack of adequate knowledge about advance directive(s) on the part of clinicians was previously reported as a drawback for implementing the patient's wishes in clinical practice.<sup>10</sup>

Moreover, the healthcare professionals underlined that the regulations do not disambiguate all the controversial situations nor do they address some critical issues.

The law reflects the increasing attitude of modern medicine to put at the centre the patient and her or his wills throughout the whole care process.<sup>30–32</sup> This approach is promoted as a worldwide relevant point to ensure high quality of care.<sup>30,32</sup> However, in clinical practice, different constraints may not always allow the patient to have the possibility to make informed and shared healthcare decisions with the clinicians.<sup>30–32</sup> If this may be true in general, it is even more a concrete matter of fact when speaking about bioethical and

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moral issues. One sensitive theme is the right of conscientious objection in healthcare landscape that legitimates the healthcare professionals to refuse or impose interventions, restricting the patient's will.<sup>33</sup> Maybe the soundest example is the case of abortion. In Italy, gynaecologists and other ancillary providers refusing to perform abortion is about  $70\%^{34}$  and in the rest of Europe, the situation is jeopardized and complex.<sup>35</sup> Similar reflections have to be deserved for the end-of-life care. The previous literature has already reported the same critical points characterizing the Italian law on advance directive(s) and raised questions regarding the patient's capacity, provider's conscientious objection. Assisted suicide and euthansia warrant further investigation as well.<sup>20,21</sup>

A further aspect of concern was the possibility to make reliable predictions about future treatments based on the present: some providers suggested that it is not reasonable, or at least very hard, to imagine what the patient's real will would be when they are in an end-of-life situation. Indeed, it is necessary to pay attention to a person's capacity to overlook and make plans regarding wishes about treatments because of the discordance between present time and future contingencies.<sup>36</sup> So, the 'temporal dissonance' characterizing advance directive(s) has to be borne in mind when interpreting and implementing the patient's wishes in clinical practice since wills may change over the course of life.<sup>36</sup> However, the current law affirms the possibility of each person to change or revoke their advance directive(s) at any moment.<sup>19</sup>

Concerning future evolutions of the Italian law on advance directive(s), the healthcare providers underlined the need to simplify and better define the law. Moreover, they suggested promoting the divulgation and knowledge of this legal instrument among both healthcare providers and citizens. Interventions and training to improve healthcare professional's communication skills on end-of-life matters in general and advance directive(s) would be helpful too. Indeed, an open and clear communication may foster the therapeutic alliance with patient and caregivers; a relationship based on trust supports both the patient in properly choosing her or his advance directive(s) and the clinician to provide adequately tailored care right up until the patient's last breath. So, educational programmes appear to be a central element to open and facilitate the discussion on advance directive(s), as well as to try and bridge the gaps still present.<sup>20</sup>

### Strengths and limitations

This study adopted the well-established methodology of GT, allowing to construct a meaningful theoretical framework grounded in real-life experience. To our knowledge, it is the first study to collect feedback and perspectives from Italian healthcare professionals on the implementation of law n. 219/2017,<sup>19</sup> the first law focusing on advance directive(s) in Italy, in daily clinical practice. A better understanding of the healthcare professionals' perspective may suggest future improvements in order to adequately address some weaknesses present in the current Italian law, but also present in other laws adopted abroad.

Some possible limits have to be underlined too. Although the saturation was reached, the present study was based on healthcare professionals working in a single unit, restricting the possibility to generalize data to the national level. To address this limitation, further studies should be performed enrolling healthcare professionals in multiple sites throughout Italy. Moreover, it would be useful to perform a follow-up study to detect and understand possible changes in the perception and implementation of the law over time.

### Conclusion

Palliative care units are, without doubt, a challenging and demanding workplace due to the different kinds of legal, emotional, relational and institutional constraints with which healthcare professionals have to deal.<sup>27,28</sup> In this sensitive context, a well-established law supporting healthcare providers in the management of critical situations is of paramount importance. Italy has adopted a law on advance directive(s) only recently and the feedback from clinical practice is mandatory in order to understand how the law could be a

barrier or a facilitator for the empowerment of citizens and healthcare professionals. Our findings showed law n. 219/2017 as a legal instrument that both supports the clinicians in their work and guarantees patients' right to self-determination. However, some weaknesses appeared to persist and there is room for future improvement.

### **Authors' Note**

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# Chapter Nine

# Interviews with medical students

### 9.1. An introduction to the interviews conducted with medical students

The research project comprised also an additional qualitative research study with semi-structured interviews with medical students in order to describe their subjective experiences dealing with patients suffering from life-threatening complex clinical situations, focusing on risk and protective factors encountered along their educational path. The attempt is to detect possible threats or protective aspects since the beginning of the healthcare profession. To this regard, it has to be said that burnout and moral distress are a silent and deadly epidemic invading entirely the healthcare human resource arena and medical students are not excluded. The international literature in this field unveiled that medical students might be exposed to several problems, such as anxiety, depression, suicidal ideation, distress and burnout (Costa et al., 2012; Dyrbye et al., 2008; Ludwig et al., 2015; Rotenstein et al., 2016; Thurn & Anneser, 2019).

Thus, paying particular attention to the bioethical dimension, the study presented in detail in the following pages aimed to explore the medical student's subjective experiences dealing with life-threatening complex clinical situations. The focus is on their perceived risk and protective factors for their wellbeing characterizing their clinical experience during the educational path. The study took place at the Medical School at Nicosia (Cyprus). In particular, the study was addressed to students enrolled in the 6-Year Direct Entry University of Nicosia Medical School MD Degree and 4-Year Graduate Entry St George's MBBS Degree who had attended at least a clinical placement in touch with end of life or life-threatening patients. Medical School boasts a long and prestigious tradition in providing medical education, with different university locations spread around the world and hosting students coming from all around the world. For this reason, this context was thought to be particularly suitable for collecting meaningful data. The analysis approach chosen is Interpretive Description (Thorne, 2013; 2016). The main reason for this choice is given by the fact that this methods enables to reach an informative knowledge about main patterns and themes, avoiding fixed procedures of other approaches and suggesting tips for daily practice.

Taken together with healthcare professionals' perspectives, this qualitative study involving students may provide further insights to detect approaches and practices which are able to support healthcare practitioners and students before the onset of psychological malaise and resources depletion. Thus, understanding the current medical students' perceptions may be considered a tool to act from the roots for helping the tomorrow professionals, as preventing is the winning card to sustain healthcare professionals.

# 9.2. Risk and protective factors of medical students facing life-threatening illnesses

Marina Maffoni, Karin Olson, Julia Hynes, Piergiorgio Argentero, Ilaria Setti, Ines Giorgi, Anna Giardini. A journey through roses and thorns: becoming a physician by learning from patients with life-threatening illnesses. *Manuscript submitted for publication on 1<sup>st</sup> May 2020 to Qualitative Research in Education under review*.

# A journey through roses and thorns: becoming a physician by learning from patients with life-threatening illnesses

#### Abstract

The medical students' well-being may be threatened by various stressors associated with providing care to different kind of patients. This study aims to explore students' clinical experiences with patients who suffer from life-threatening illnesses, focusing on potential risk and protective factors. Audio-recorded and face-to-face interviews were conducted and transcribed verbatim. The interpretive description approach was used to analyse data. Overall, ten medical students with a mean age of 27.8 years old were interviewed. Wellbeing promoting factors were the following: therapeutic relationships, work-life balance, social support, communication, perception of improvement in knowledge, acceptance and availability of advanced directives. Whereas factors that may reduce well-being included managing tough emotions, communication difficulties, internal conflicts and disagreements, lack of knowledge feeling of powerlessness and subjective concerns. These findings shed light on facets that are inherent parts of clinical experience with patients suffering from a lifethreatening disease and that may turn in risk and protective factors for the medical students. Understanding the students' subjective experiences may aid in the improvement of the current educational programs as well as in the development of tailored supportive and preventative interventions to promote well-being and professional competencies among this kind of students.

**Keywords:** medical student, life-threatening disease, risk and protective factors, qualitative research, Interpretive Description.

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# QRE - Qualitative Research in Education, X(X)

# Introduction

Distress and burnout are worldwide matters of concern among healthcare professionals (Hynes et al., 2019; Maffoni et al., 2019; West et al., 2018). Medical students are affected by these issues too. Indeed, literature in this field indicates that medical students might experience anxiety, depression, suicidal ideation, distress, and burnout in response to stressful clinical experiences occurred during their internships (Costa et al., 2012; Dyrbye et al., 2008; Ludwig et al., 2015; Rotenstein et al., 2016; Thurn & Anneser, 2019). About half of USA medical students complained burnout (Dyrbye et al., 2008) and the prevalence of depressive symptoms ranged from 9.3% to almost 60% across studies with medical students (Rotenstein et al., 2016). Various reasons may undermine the medical students' health. For instance, the clinical education component of medical school requires students to manage demanding and emotionally tough situations related to the provision of care for ill individuals. Other factors that contribute to burnout among medical students include being male and young, lack of free time and dissatisfaction with one's educational path (Costa et al., 2012). In addition, difficulties regarding work-life balance, disproportionate workload, concerns related to career, and financial issues are also relevant self-reported stressors for medical students (Hill et al., 2018). Conversely, some protective factors, such as positive emotions, seem to strengthen self-efficacy, preserve students' wellbeing and assist in reaching their professional aims (Burr & Beck Dallaghan, 2019).

The students' clinical experience becomes even more demanding when caring for individuals suffering from life-threatening illnesses. For example, frequent exposure to death and suffering may pave the way for experiencing negative emotions that may affect not only the students' wellbeing but also their performance and sense of achievement (Burr & Beck Dallaghan, 2019; Costa et al., 2012; Thurn & Anneser, 2019). However, there is still scant literature focusing on the subjective experience of medical students regarding the taking care of life-threatening patients. Considering that the encounter with this kind of challenging patients may occur inevitably somehow during the clinical tranships, the understanding of student's experiences becomes a crucial aspect

# Medical students' risk and protective factors

that urges to be better investigated. In fact, the students may feel to be unprepared to effectively manage the patient and their caregivers, as well as their own emotions (Boland et al., 2019). Thus, it is important to further investigate the experience of medical students during their educational path in order to better tailor educational programs and effective professional curricula, trying to bridge the gaps between theory and practice (Kitto, 2019). Specifically, it may be useful to inquire both positive and negative facets, trying to reach a comprehensive understanding of the students' subjective experience. To this regard, qualitative research may be an effective way to reach new insights suggesting novel directions for further studies in a certain field (Bansal et al., 2018).

Therefore, we conducted a qualitative study exploring how medical students describe their clinical experience dealing with life threatening disease, with the goal of identifying subjective risk and protective factors.

# Method

# Study design

This study is part of a broader observational multi-centre cross-sectional mixed method research project focused on wellbeing and distress experienced by healthcare professionals who provide care for individuals with complex life-threatening illnesses (XXX, approved by the Ethical Committee of XXX, Protocol N° XXX).

In this exploratory qualitative study, the authors adopted the *Interpretive Descriptive* approach that helps the researchers to reach a preliminary understanding of the main patterns and themes, capturing the common and different points of view of those who experience a certain phenomenon on a daily basis (Thorne, 2016). Avoiding constraints and fixed schemes, the researcher is able to translate narratives into useful and coherent knowledge through an inductive analytic approach that facilitates the understanding of the phenomena under investigation and that allows the development of practical applications of the findings and the providing of suggestions for further investigations (Hunt, 2009; Thorne, 2016). The research question guiding the present study was: "How do medical students describe their

# QRE - Qualitative Research in Education, X(X)

clinical experience with life-threatening patients, focusing on possible risk and protective factors?"

# **Participants**

The participants were individuals enrolled in a medical school in southern Europe selected through a convenience sampling technique. The participation was on a voluntary basis, without any form of reimbursement. The only inclusion requirement was having had clinical experiences with patients suffering from life-threatening diseases during clinical placements. A satisfying proficiency level in the use of English language was guaranteed because it is a prerequisite to access to the course (minimum IELTS - International English Language Testing System - score of 7.0 overall).

# Procedure

After the approval of Ethics Committee and general arrangements with the University, a call for participation was sent via e-mail to the medical students of the two medical programmes (4-year graduate entry and 6-year direct entry), regardless of the stage of their studies. The project and aim of the interview were briefly explained within the email communication, and interested individuals were asked to contact MM or JH for further details. Two follow-up email reminders were sent; the first after one week following the initial email and the second one a day before the commencement of the interview period. Students interested in participating in the study were sent a link where they could choose a time slot for their interview.

# **Ethical Considerations**

Individuals received oral and written information about the aims of the project and were asked to sign a consent form if they were interested in taking part in the study. Signing this form, students consented to the use of any written material anonymously for research purposes. A copy of the consent form was given to each participant, and they were told that they could withdraw without explanations in any moment if they wished. Maffoni et al. - Medical students' risk and protective factors

# Data collection and analysis

Interviews were collected in March 2019 and lasted approximately 30 minutes. MM conducted the face-to-face interviews, following a topic guide (Table 1). Each interview was audio-recorded and transcribed verbatim by trainee psychologists.

# Table 1.

Topics discussed during the interview

1) Reasons behind the choice of studying medicine

- 2) (Emotional and moral) difficulties experienced during the clinical placements when providing care for a patient with a life-threatening illness
- 3) The most difficult aspects to manage patients suffering with a lifethreatening illness
- 4) The helping factors in managing patients suffering with a lifethreatening illness
- 5) Supportiveness, communication and relations in the managing of lifethreatening illness
  - With colleagues
  - With superiors
- 6) Disagreements about treatments or caring plans for patients with lifethreatening illness
  - With colleagues
  - With superiors
  - With patients/caregivers

The interviews were analysed after data collection by MM and KO, following the Interpretive Description approach(Thorne, 2016). The transcriptions were read to gain first impressions. After that, the transcripts were read again to ascertain the main ideas related to the research question in each interview and were compared with each other. Memos about common ideas and supporting quotes from the interviews were identified and discussed by members of the research team. Moreover, periodical briefing sessions via skype were scheduled between the research team in order to discuss analysis and finalize

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results. Next, the results were reviewed in light of previous literature. Finally, the findings were discussed with a senior nurse in order to have an external supervision. The analysis was instrumentally supported by a free qualitative analysis software program called RQDA(Ronggui, 2016).

### Results

Ten students accepted to take part in this study (mean age  $27.7\pm8.3$  years; females/males 5/5; Table 2).

Main charact	eristics of the	he intervie	wees	
Student	Sex	Age	Current year course	Degree course
Student 1	Male	18	1	MD
Student 2	Female	20	2	MD
Student 3	Male	25	2	MBBS
Student 4	Female	30	3	MBBS
Student 5	Male	26	2	MBBS
Student 6	Female	47	2	MBBS
Student 7	Female	23	2	MD
Student 8	Male	25	4	MBBS
Student 9	Female	27	4	MBBS
Student 10	Male	37	1	MD

Main characteristics of the interviewees

Table 2.

MD = Doctor of Medicine, 6-Year Degree in Medicine

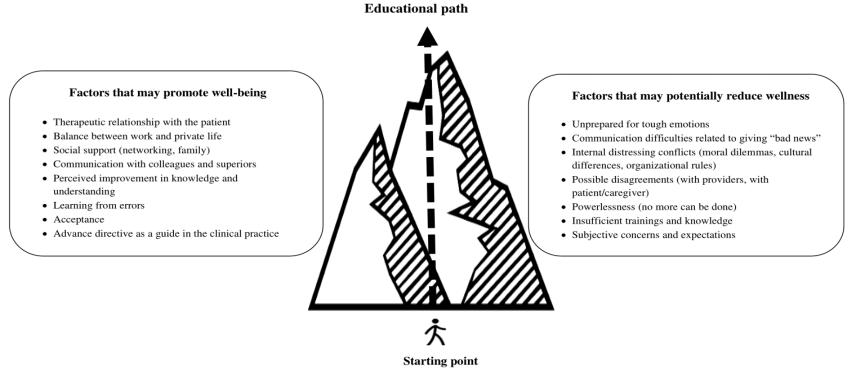
MBBS= Bachelor of Medicine, Bachelor of Surgery, 4-Year Graduate Entry Medicine Degree

The medical students' clinical experience may be described as a journey sideby-side with patients, with a starting point that corresponds to the decision to enrol in Medicine. During their educational path, they experience multiple interconnected factors both positive and negative, that may promote wellness as well as decrease it, fostering distress and unpleasant emotions (Figure 1).

Becoming a physician is a journey with the patient as they're busy dying, the whole thing is that it takes a lot out of you emotionally (Student 6)

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Figure 1. The scaffolding that shows how the students experience their educational path caring for lifethreatening disease



Enrolling in medicine because of:

- Desire of helping others
- Interest in human body and sciences

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# **Starting point**

The enrolment in university to study medicine was the starting point of the educational path of medical students. The triggers that result in this choice were linked to interest in the human body and science, as well as to the desire, as future doctors, to help others.

I find it interesting, I find the human body fascinating, and there are so many different aspects of it that you can do, so there's always something for someone (Student 4)

I just enjoying being able to help people (Student 7)

# Factors that may promote wellbeing

**Therapeutic relationship with the patient.** The first protective factor identified by medical students was the development of a therapeutic relationship with the patient. This therapeutic relationship opened up the possibility to empathise with patients and to think and act in an altruistic way. This approach implied an awareness of professional boundaries, too.

If you've got a therapeutic relationship you can say things [mmm] which 'cause it's a specific kind of relationship between a doctor and a patient so you can, it does help if you got that relationship and you gotta speak about difficult matters so that's helpful (Student 6)

It's putting a line between being there for them and helping them emotionally but at the same time being like having a clear head or clear enough to take the right decision and maybe not the right decision that you think for yourself, like really taking a shared decision with the patient (Student 7)

**Balance between work and private life.** The capacity to maintain a balance between private life and work was also perceived as a helping factor for wellbeing. It permitted students to stay focused on the present, avoiding recursive thoughts that may otherwise consume energies and drain emotions.

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You've got to compartmentalise and say that's totally that is what it is. (Student 3)

I think it's about forgetting. So when you leave work, when you close your office you have to forget about what happened in the morning and then (silence) go back home, go out and live your life as if nothing happened and next in the morning come back and continue (Student 8)

**Social support (networking, family).** Relationships and communication with others also provided students support when they were required to witness or cope with difficult situations experienced in clinical practice. The presence of supportive people, such as family and friends, was perceived as a soothing element and helped the student preserve their own wellbeing.

Having around the right kind of people really helps me (Student 2)

I spoke to my mom [clinician too] about it (feelings, not patient details) (Student 4)

My wife is a GP who is very, very supportive [mmm] in terms of everything (Student 10)

**Communication with colleagues and superiors.** Another helpful element was the possibility to speak with clinical supervisors about patients and treatments. Discussing the clinical experience is supportive when facing difficulties and tough moments.

What helps me in difficult moments are colleagues and superiors, definitively, someone to talk to about these things (Student 9)

**Perceived improvement in knowledge and understanding.** Medical students in this study underlined the importance of perceiving improvements in terms of training, practice and knowledge in order to become a capable healthcare professional. The learning process was perceived as implicit in clinical practice and as never stopping know.

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*I think personally... what helps me is to make me better in what I wanna do and pushes me to continue (Student 7)* 

I think training. Knowledge helps you the more. I do believe that the more you are facing with this situation the more you are learning... When you are going to practical field, the practical field itself teaches you a lot of stuff, which can't be just learned from theory (Student 10)

**Learning from errors.** Medical students noted that being aware of errors and then accepting them as a way to learn more, helped to promote their wellness, too. This experienced interpretation refuelled the students and pushed them to do better in the future, improving their own knowledge and skills.

You should always take that case and say "Ok, what can I do better next time?" and then relive yourself of that guilt of whatever you didn't do or you did wrong [silence] [...] learning more... learn more about it so the next time it doesn't happen (Student 9)

Acceptance. The ability to "let it go" was described as a way to accept situations, avoiding waste of time and energy. Acceptance is described as a sort of respect for the situations and for people, too.

So, respecting the situation, respecting the decision of people depending on the way that their life ends was also a massive [silence] a massive way of like getting over the issue (Student 2)

Advance directive as a guide in the clinical practice. Students reported support for the use of advance directives in clinical practice. Indeed, the presence of advance directives may reduce negative emotions when students provided care. The students perceived to have a "guidance", that is they know what to do on the base of the patient's wills.

I think that an advance directive [mmm] you know letting the family know what the patient wants and letting the doctors know what the patients wants would ease that conflict between the families and the medical professionals (Student 1)

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Makes life easy because if physician has got clear guidance, then there is no... at that point, when you are rushed and when you have to make a quick decision, if you have guidance from patient regarding what they want, makes life easy for the patient and for the doctor (Student 10)

#### Factors that may potentially reduce wellness

Unprepared for tough emotions that come at end of life. The medical students in this study noted that witnessing suffering and sudden death was "tough", "shaking", "shocking" and "sad," and they felt unprepared to manage the emotions experienced in those contexts. They were aware, of course, that they would be likely to witness these types of events, but awareness alone was not enough to overcome the emotional responses.

The difficult thing is... death is always difficult, no matter how prepared you think you are or how much you accept it. At the end of the day it's final and it is difficult to deal with even if you don't know the person personally [...] I was shaken... and I couldn't stop crying for a few days afterwards (Student 4)

It stacked in me because it had happened so quickly, like I wasn't.... when he first came in I wasn't... we all weren't expecting it [...] I also started crying ... (Student 9)

**Communication difficulties related to giving "bad news".** Another issue that had the potential to reduce wellbeing was difficulty related to "bad news." Students noted that it was hard to find the right words and the right approach to deliver unpleasant messages. They often felt unprepared to manage this kind of communication. Situations requiring the sharing of "bad news" typically gave rise to questions from patients that were hard to answer.

I didn't know what to say and I felt bad not saying anything to reassure herbut I didn't (have) the words to say! That's what I struggled with, I didn't know what to say to reassure her. (Student 4)

How telling them that they have to lose someone... or a part of their... an amputation, an arm, a leg or something. So, the management of

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breaking bad news would be the worst. And sometimes not having an answer to their questions. (Student 8)

Internally distressing conflicts (moral dilemmas, cultural differences, organizational rules). The students in this study experienced internal conflicts when they were required to fall into line with difficult decisions with which they disagreed regarding patient care. Students experienced internal distress when dealing with external constraints, such as clinical protocols and organisational rules that pushed them to act against their values.

[The student was taking care of an old woman who suddenly fell down. Although the patient sought help to stand up, the hospital procedures prescribed to ask for the help of a superior and to not move the person in order to avoid secondary damages] It was a problem where I had to follow the protocol or... to follow the situation [...] It takes, I think, a lot of courage to not do something which is naturally required from you and still follow the procedure [...]So... I think [mmm] that affected me the fact that she was crying and she was in pain (Student 10)

Cultural differences were perceived as challenging issues to accept and manage.

Both of them have not been informed by the medical team and often the family will say "we don't want them to know" which I think it's damaging the patient's autonomy it's, you know, stealing from the patient, really, the patient's choices and decisions [...] So it's a bit of an ethical dilemma that I sit with because yeah[...] In this particular context it's cultural but it's not ethical [...] this is not compatible with my values and culture, this is not compatible with my beliefs" or then it puts a situation where I have a conflict of, you know, in a way I'm also involuntary deceiving this patient because I'm part of the team, I'm part of the health team, even though I'm just a student.. So what do you do, you know? (Student 6)

**Possible disagreements (with providers, with patient/caregiver).** Possible disagreements with medical staff or caregivers about care provided

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may also be a risk factor for wellbeing. Some students thought other approaches or treatment choices were more appropriate but were reluctant to voice their views.

I'm like arguing with my colleagues about how they say "No, we should give them this treatment" and I'm like "No, they literally said they don't want it" (Student 9)

So in that case when a patient wants to go with the treatment and I don't think it's medically viable and you want them to ehm [silence] to be better. Yes I guess that that's the most major disagreement between the clinician and the patient (Student 3)

In most cases, the medical students in this study did not openly express disagreement with their superiors because they thought it was not appropriate for individuals still in training.

I was just observing, so obviously I have to bite my tongue, I can't say I don't agree with this, it's not my place to do so, but I thought that was, I did not like that at all, I thought that was [silence] wrong to a certain degree (Student 1)

*I disagreed but kept it to myself because ultimately it is not my place* (*Student 5*)

**Powerlessness (no more can be done).** Powerlessness was perceived as a distressing factor, too. Students described this experience as "loss of control" and regretted they could not do more to make a difference for the patients.

Watching them in so much pain and not being able to do nothing ... now you're seeing them at their worst so I think that was something that was probably quite difficult and it really drains them out (Student 2)

The difficult thing is.... I guess seeing inability, not being able to help someone that needs [mmm] not being able to do [...] So troubling, I would say, the thought of a lack of control over what could happen (Student 3) Maffoni et al. - Medical students' risk and protective factors

"I wish I did more for the patient" but like yeah, I didn't know or, you know, who knows what it was best to do like there were two options and like there were pros and cons to both (Student 9)

Insufficient trainings and knowledge. The experience of not knowing enough to adequately manage demanding situations was another contributor to reduced wellbeing. Although the students recognised that they were at the

outset of their medical education, they complained and felt themselves unprepared for difficult situations.

I don't have enough medical knowledge as well (Student 7)

I think it's important, maybe preparation for the students would be much better before they start, like an icebreaker or something or... just an orientation, how to cope, how not to be affected (Student 8)

Not having the knowledge to do better, definitively, yeah, at that time you wish or specifically for that patient [...] that's the hardest part, looking back and thinking that I haven't enough information (Student 9)

Subjective concerns and expectations. Past experiences and personal characteristics of each student appeared to influence how they interpreted situations that were part of their clinical experience, potentially reducing their wellness. The practical experience gained during their placements was described as a means to adjust previous and potentially incorrect expectations.

I was dreading it for a while because I thought it would be really heartbreaking to see people that you know that are about to die [...] it [palliative care] wasn't what I expected, I thought there would be a lot of hysteria and a lot of sadness (Student 4)

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#### Discussion

Ten international medical students were interviewed regarding their clinical experience with patients who were experiencing life-threatening illness. The findings unveiled several relevant aspects that in previous researches were not often considered together.

According to the authors, the metaphor that best describes the findings of this study is a "journey through roses and thorns", that is, the clinical experience a travel characterised by different factors that may promote or inhibit personal wellbeing (Figure 1).

The journey starts with the students' enrolment at the University. The decision to choose a medical degree was linked to their interest in sciences and their desire to help others who are suffering. Since that moment, students began to think about themselves as future doctors, therefore it could be described as a time when the students start to build their professional identity as healthcare professionals (Hatem & Halpin, 2019; Monrouxe, 2010; Wilson et al., 2013).

Along their educational path, the students encountered different positive factors, the so-called roses, which act as potential resources and promoters of wellness. One of the most important helping factors emerged is the ability to "adequately stay with" the patient, avoiding being too emotionally involved and professionally biased. Indeed, it was perceived as necessary to be able to control feelings in order to avoid emotional breakdown and distress (Sasso et al., 2016). Sometimes the relationship with the patient may lead to a loss of boundaries and professional identity. Consequently, the student may be unable to act with a clear mind as a healthcare provider ought. In this regard, it is importance to teach students about how to build a "therapeutic relationship" that allows the students to both empathise with the patient and to provide evidence-based care while maintaining their professional identity (Percy & Richardson, 2018). To this regard, the students of the present study underlined the importance to maintain a balance, that is the necessity to "compartmentalise" private life and work, staying focused in the present time and avoiding thinking about clinical experience at home. The balance between private life and professional activity was described to be a protective factor against burnout

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also in senior healthcare professionals (Maffoni et al., 2020; Pereira et al., 2011; Shanafelt et al., 2015).

Other cornerstones described for potentially preserving students' wellbeing were the importance of an open communication with clinical supervisors and the possibility of receiving support from their social network (family and friends) and medical staff, too. Indeed, spending time with others and having effective communication with them may help to manage tough emotions, as well as to prevent burnout (Gadoud et al., 2013; Pereira et al., 2011; Sutherland, 2019). Social support may act as a buffer, moderating distress (Uchino et al., 2011). For this reason, speaking with colleagues and education supervisors may allow medical students to exchange their points of view and to share demanding situations. The same patterns have been uncovered in other healthcare students (Gallagher et al., 2014). Moreover, the literature addressing healthcare professionals has underlined the importance to foster resilience and supportive environments (Maffoni et al., 2020; Maffoni et al., 2019; Zanatta et al., 2020). This study deepened this knowledge, extending the pivotal role of social support to medical students dealing with life-threatening patients.

The interviewed students reported to perceive a constant improvement of their own knowledge and professional competencies and this perception was described as a helping factor. They appreciated the possibility to gain effective expertise through their practical clinical placements, as well as through their errors, too. Previous authors, going back as far as Aristotle and Aquinas, have confirmed the value of learning from real experience (Gadoud et al., 2013; Head et al., 2012; Hynes, 2016; Ranse et al., 2018; Wechter et al., 2015). Furthermore, it is conceivable that, through this way of learning, the students may also develop their capacity to accept the course of illnesses (Head et al., 2012).

Moreover, all interviewees showed agreement with the implementation of advance directives in clinical practice to safeguard the patients' wishes, and to guide the clinician (Maffoni et al., 2019). In this regard, a previous study reported the medical students' interest in deepening their knowledge regarding advance directives during their educational curricula (Wittenberg-Lyles et al., 2010). Moreover, a review underlined the general health care professionals' positive attitude toward the utilisation of advance directives (Coleman, 2013). Thus, the present study strengthens the relevance of advance directive also from the point of view of medical students.

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The participants to this research described some challenging risk factors, too. These elements may be described as thorns, as they are unpleasant and have the potential to decrease wellbeing. One of the most relevant factors potentially inhibiting wellbeing was the exposure to death and the management of tough and demanding emotions, such as sadness, pain, powerlessness. Students perceived not being ready when their lifethreatening patients died. Some of them were overwhelmed by emotions. Similarly, the experience of nursing students who found themselves unprepared and shocked by the death of their patients has been previously described (Ranse et al., 2018). Moreover, other authors have found that the patients' death is a common experience between medical students and supporting them to manage this occurrence is a need perceived by the learners (Gallagher et al., 2014; Grubb & Arthur, 2016; Heise et al., 2018). So, it is recommended that teachers of medical students provide specific occasions to address this theme. Debriefing discussion groups may be one example of assistance, to deal with issues related to death and dying (Gallagher et al., 2014). Another option might be an invitation to meet with supervisors, who could provide a safe environment for reflection by the students whose clinical exposure includes experiences with dying patients.

Another matter of concern was communication difficulties that future doctors may experience during their clinical placements. Breaking bad news concerning a diagnosis with a poor outcome was reported as a potential risk factor for wellbeing. In our opinion, the presence of supportive superiors is essential in this regard. Indeed, a senior clinician may help the student to move from a "cure" perspective, characterised by a never-ending search of answers, towards a "care" approach, the essence of which resides in the ability to provide emphatic listening. In this way, it is possible to foster the shift from a cure to a care orientation approach in medicine (De Valck et al., 2001). Indeed, the interviewed students were troubled as they perceived themselves lacking in communications and interpersonal skills in this regard. Literature on senior healthcare professionals has already demonstrated this aspect as a critical issue with which individuals face (Ranse et al., 2018; Wittenberg-Lyles et al., 2010). Although a previous research reported that medical students consider communication skills something natural and linked to expertise and practice (Wittenberg-Lyles et al., 2010), in the present studies the students welcomed and fostered

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communication trainings during their educational path, in particular regarding how to manage the breaking of bad news. In a similar way, disagreement and difficulty in communications with colleagues and superiors may also become a matter of distress for students, as already reported by other professionals (Maffoni et al., 2019).

Moreover, the students interviewed reported difficulties in following practices and rules that are not in line with their own values (Bordignon et al., 2019; Sasso et al., 2016). This internal conflict, leading to a decline in wellbeing, is known in literature as moral distress and it affects many healthcare providers, particularly so when dealing with bioethical and moral issues (Hynes et al., 2019; Lamiani et al., 2017; Maffoni et al., 2019; Musto & Rodney, 2018). In this regard, senior clinicians may support the medical students towards the understanding and the adoption of a taking care approach in accordance with local habits and customs, to adequately take care of their patients and caregivers.

Lastly, knowledge, subjective concerns and expectations may affect the students' wellbeing during their practical clinical placements. Indeed, the students interviewed reported difficulties linked to the lack of sufficient know-how and prior negative expectations regarding taking care of patients with life-threatening illnesses. However, improving knowledge and practice with regards to this kind of patients changed expectations and ameliorated their clinical experiences (Ranse et al., 2018). Practising in real contexts may allow students to experience what it really means to work with lifethreatening patients in a scholarly manner, and thus become more aware of the importance of the never-ending learning processes, too (Head et al., 2012).

# **Practical implications**

Although further investigations are needed, these findings may highlight the following points as a take-home message that could be used to develop tailored educational curricula:

- To promote trainings focused on how to build a therapeutic relationship with the patients and how to adopt an effective communication (e.g. how to break bad news) both with the patient and with their caregivers;
- To increase technical knowledge and practical training enhancing and anticipating the clinical placements with life-threatening diseases;

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• To foster occasions and facilities where the students can reflect on their clinical experience and be supported by superiors.

# Strengths and limits

The main strength of this research resides in the focus on manifold risk and protective factors in the same investigation, providing a comprehensive understanding of students' experience in touch with a specific kind of patients, that is individuals suffering from life-threatening illnesses. Moreover, another strength point was the adoption of an approach useful to develop a practice-relevant knowledge valuable to improve educational programs for medical students, bridging the gap between theory and clinical practice. Indeed, using the Interpretive Description approach, the research team was able to detect protective and risk factors characterizing the experience of medical students who dealt with life-threatening patients (Hunt, 2009; Thorne, 2016). In this way, medical students' narratives turn into powerful instruments to improve their training and educational path. Moreover, the flexible but rigorous method enabled the researchers to conduct a coherent preliminary inquiry that may provide a baseline for further studies on the same topic (Hunt, 2009).

Nevertheless, some limits have to be underlined. Firstly, the sample size did not allow safe generalization. These findings provided only suggestions for further studies and fuel deeper reflections on actual educational programs. Secondly, the not considered differences in the length of clinical placements in touch with life-threatening patients may be a bias of the findings. Finally, it has to be underlined that the multi-nationality of the sample may be both a value and a limitation. However, the size of the sample did not allow to do further reflections about possible cultural differences or common traits.

# Conclusion

In this exploratory study, the authors attempted to shed light on students' clinical experience with life-threatening diseases, highlighting the critical issues to be managed, as well as the helping factors to be exploited in support of interventions and educational practice. Indeed, to safeguard the wellbeing and to respond to needs of medical students of today is

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imperative, in order to preserve the wellbeing of our physicians of tomorrow.

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### **Declaration of Conflicting Interests**

No potential conflict of interest to be declared.

### Disclaimer

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XXX = details omitted for blind revision

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Section C: Chapter 10 - Discussion: The integration of quantitative and qualitative findings

# Chapter Ten

# Discussion: The integration of quantitative and qualitative findings

#### 10.1 General discussion

The current observational and multimethod project has provided novel and informative knowledge regarding factors obstructing or promoting wellbeing in healthcare workforce specifically exposed to challenging and demanding issues at work, namely professionals employed in palliative care and neurorehabilitation medicine disciplines. Moreover, the perspective provided by medical students in contact with life-threatening patients was also collected in order to better understand and investigate possible risk and protective factors of the healthcare context from the beginning and along the professional life.

Manifold quantitative and qualitative findings have been unveiled and they will be deepen discussed in the following pages. First, some differences were observed regarding socio-demographic and work aspects stratification. Second, specific risk and protective factors for personal and professional outcomes have been found. The different quantitative and qualitative studies constituting the current research project have focused on the two medical specialties together or only on one of them, according to samples involved and described in chapters five, six, seven, eight, nine. Overall, these findings provided an informative screenshot of risk and protective factors and mechanisms for professionals involved in complex healthcare context, so fueling the scientific literature with deepen information and suggestions to safeguard the wellbeing of these sensitive categories of workers. These results were interpreted through the lens of the COR theory which provides a parsimonious and comprehensive conceptual model emphasizing the individual strive to obtain, retain, foster and protect resources to counterattack stress (Hobfoll, 1989; Hobfoll, Halbesleben, Neveu, Westman, 2018).

#### 10.2. Differences regarding socio-demographic and work aspects

The sample of 315 healthcare professionals taking part in the quantitative part of this project appeared heterogeneous regarding various socio-demographic and work characteristics. This aspect needs to be kept in mind as it might have impacted on some findings unveiled.

As concerns age and tenure, the palliative care subsample is significatively younger and has less years of seniority than colleagues employed in rehabilitation medicine. These characteristics reflect the general "age" of the two investigated medical disciplines in Italy. Indeed, palliative care is a relatively young discipline in the Italian healthcare landscape (Casale & Calvieri, 2014). Palliative care slowly appeared around the 80s thanks to some non-profit organizations which, on a voluntary basis, started to address the unanswered needs of patients on the verge of death and their families, providing care at their home. However, it is only in 1999 that palliative care is recognized by the National Healthcare System (Casale & Calvieri, 2014). Conversely, rehabilitation disciplines are well-established cornerstones of medicine that are in constant evolution during the time according to medical and technological advancements (Santilli, 2007; Tamburin, Smania, Saltuari, Hoemberg, & Sandrini, 2019).

Moreover, palliative care and neurorehabilitation medicine are heterogeneous regarding the professional role. A reason is that the specific work characteristics and the patient population taken in care by these two disciplines require a different work force organization. For instance, physiotherapists are professionals not usually largely employed in palliative care. Conversely, nurses are the largest group of healthcare professionals and, in particular, they play a pivotal role in the palliative care context (Sekse, Hunskår, & Ellingsen, 2018). As far as concerns psychologists, they were underrepresented in the present sample and, for this reason, their responses were considered together with physicians as both have more decision-making autonomy in their areas of competences in respect to nurses, therapists and social healthcare practitioners who usually are demanded to follow physicians' requests. Psychologists and physicians are more numerous in palliative care units probably because this typology of patients usually needs a constant psychological support and medical care from different palliative care specialists (e.g. anesthesiologists, oncologists, psychoncologists).

Furthermore, lower levels of education were generally reported in neurorehabilitation medicine specialty. This data may be linked to the educational pathway requested by the Italian educational system for each kind of profession. Specifically, it has to be noted that social healthcare practitioners are more numerous in the subsample of neurorehabilitation medicine, even if this difference is not statistically significant. This profession is achieved after a 1000-hours professional education course that can be undertaken after the compulsory education whose length has changed and increased during the time (MIUR Site). So, a higher education is not necessary for this healthcare workers.

As concerns shift work, further investigations with more homogeneous samples are needed in order to understand and, perhaps, replicate the differences found in the present sample in which more professionals employed in neurorehabilitation medicine discipline are requested to do work shifts. Whereas, differences regarding types of work contract between palliative and neurorehabilitation medicine specialties seem to reflect the changes of labor market. As palliative care is a younger discipline, the professionals are often younger too. In recent times, the contracts offered to young healthcare professionals are often based on unstable working arrangements (Yeandle, 1999; Bernardi, 2000; Moscone, Tosetti & Vittadini, 2016).

Finally, considering the mean score regarding the different variables investigated, the sample did not report high risk of malaise. Conversely, mechanisms and relations among variables deserved full considerations as they enriched the current knowledge on these aspects, suggesting useful interpretations of phenomena and practical implications described in the following pages.

#### 10.3 Response rates and Cronbach's alpha values

Descriptive statistics showed variances among response rates and internal consistency reliability values (Cronbach's alpha). These differences deserve some considerations.

Concerning the response rate of the quantitative part of the project, some Institutes showed a low participation. In this regard it is worth underlining that this research is in line with a general trend characterized by a significative dropping of response rates over the past several decades, "from rates of more than 90% in the 1950s to those that often struggle to reach 70%, and frequently are much lower." (Morton, Bandara, Robinson, & Carr, 2012; p. 106). Different reasons may be found at the bases of this phenomenon. Generally, the literature posed the attention on two main aspects. On one hand, the decrease in the participation to research studies may be ascribed to a general disillusionment with science and research, an increased frequency of request to partake in studies and experiments, as well as an increasing complexity of life in the 21<sup>st</sup> Century. On the other hand, contemporary research often demands considerable time and efforts from their participants (Morton et al., 2012). The current research project might be perceived quite demanding for healthcare professionals as different variables have been investigated. Moreover, the participants were requested to selfadminister the questionnaire without having a dedicated time during the working schedule and without any kind of reimbursement. In addition, it has to be mentioned the fact that the Institute showing the lowest response rate (i.e. U.O. di Cure Palliative - Pavia (PV), via Boezio, response rate: 40.4%) has been characterized by a very recent reorganization and reallocation of healthcare professionals, thus this event might have impacted on the professionals' motivation to participate to this research. However, despite differences between Institutes, the response rates of this research project may be considered acceptable. Indeed, the previous literature stated that 50% may be considerable a good response rates (Richardson, 2005) and the overall average rate of participation was 55.6% in a revision conducted on 141 published studies and 175 surveys between 1975 and 1995 (Baruch 1999). Furthermore, response rate should not be considered the only index of validity of a study. Although it is an important data and it is desirable to be as higher as possible, the precision and consistency of the methodology, the detailed description of participants and the implication of results unveiled should be considered important elements to evaluate the quality and accuracy of a study (Morton et al., 2012). In this vein, this dissertation attempted to be as accurate and detailed as possible.

As regards Cronbach's Alpha, it is a widely used index of internal consistency reliability, indicating the level of homogeneity of the items within a scale which should all measure a single phenomenon, that is a single latent variable (De Vellis, 2016). In general, acceptable numerical values of this index range from .70 to.95 (Tavakol & Dennick, 2011; Taber, 2018). However, different factors may impact on this index.

Firstly, a relevant aspect is the length of the test. Specifically, if a scale has only few items, this internal consistency index is reduced (Tavakol & Dennick, 2011). This fact may explain the low Cronbach's alpha of the Negative Coping Scale (part of MASI-R instrument) which includes only five items. It has to be underlined that also in the validation paper of this test, the Negative Coping Scale showed a low reliability index compared to the other sub-dimensions ( $\alpha$ =0.65; Massidda et al., 2017). Consequently, the dimension of coping was omitted in the subsequent analysis of the current research project.

Similar considerations deserve the subscales assessing different dimensions of moral distress, including respectively 3 items (Futile Care, Deceptive communication, Poor teamwork) and 5 items (Ethical misconduct). However, in the data analysis of this research only the total index of moral distress was used as the internal reliability scale of the entire scale (14 items) is satisfactory, as already reported in the Italian validation paper ( $\alpha = 0.81$ , with Cronbach  $\alpha$  of the scales ranging from 0.55 to 0.73; Lamiani, Setti, Barlascini, Vegni, Argentero, 2017).

Secondly, the Cronbach's alpha is reduced if the test measures a multifaceted construct. If the unidimensional assumption is in some ways violated, the internal reliability index may be underestimated (Tavakol & Dennick, 2011). This case may regard the SMiLE instrument used in this project to measure the subjective meaning in life experienced by the healthcare professionals. Indeed, this construct is difficult to quantify as strictly connected with subjectivity (Fegg, Kramer, L'hoste, Borasio, 2008). However, the Cronbach's alpha of quite satisfactory for both the SMiLe Index of total Satisfaction and the SMiLE Index of total Weight, being respectively  $\alpha = .76$  and  $\alpha = .69$ .

Finally, it has to be considered that Cronbach's alpha is always related to a specific sample (Tavakol & Dennick, 2011). Despite the use of the Italian validation of these scales, the populations included in the research may impact on the internal reliability of the scales used. To the best of my knowledge, none of these tests has been specifically validated within palliative care and neuro-rehabilitation professionals, thus the specificity of their work was not jet assessed in term of internal

reliability consistency. This may be considered another innovation aspect of the current research project.

#### 10.4. Risk factors

Quantitative and qualitative investigations revealed manifold factors that may contribute to distress and burnout. Regarding this latter, emotional exhaustion was the main facet examined by this project as it was described in the literature to be the core dimension of burnout syndrome (Cox, Kuk, & Leiter, 1993; Maslach, Schaufeli, & Leiter, 2001).

First of all, the present findings corroborated previous evidences describing moral distress to be a relevant predictor of burnout (Meltzer & Huckabay, 2004; Silén, Svantesson, Kjellström, Sidenvall, & Christensson, 2011; Dzeng et al., 2016; Fumis, Amarante, de Fátima Nascimento, & Junior, 2017; Dzeng, & Curtis, 2018; McAndrew, Schiffman, & Leske, 2019). In fact, quantitative analysis showed that moral distress was not only positively correlated with emotional exhaustion, cynicism and negative affectivity, but it also significantly increased emotional exhaustion. These findings are in line with previous researches. For instance, Meltzer & Huckabay (2004) showed that moral distress liked to the provision of futile care explained 10% of the variance in emotional exhaustion in a convenient sample of critical care nurses employed in American ICUs. Similar results were provided also by another research involving physician trainees in internal medicine (Dzeng et al., 2016). Again, a further study involving critical care professionals showed that moral distress was an independent predictor for severe burnout syndrome (Fumis et al., 2017). The current interviews conducted with medical students strengthened these findings as the management of internal distressing conflicts in the taking care of the patient was reported to be a factor threatening wellbeing and possibly causing a relevant malaise. Thus, moral distress should be considered a threat to keep in mind during the entire professional life of these healthcare professionals as it seems to contribute to malaise and burnout since the starting of their career. Dzeng and Curtis (2018) attempted to determine possible systemic and cultural causes of burnout, proposing an interesting model for ICUs professionals where moral distress is considered the "ethical root cause" of clinician burnout. In fact, burnout, and especially emotional exhaustion, was also described as the result of a prolonged and eroding sense of impotence and morally distressing situations related to power structures, ineffective or obstructive policies, communication difficulties and lack of human and material resources (Epstein & Hamric, 2009). Coherently, COR theory interprets the lack of wellbeing as an increasing state of resource loss where moral distress is the beginning of a progressive depletion condition and burnout is the final step. That is, moral distress may trigger an escalating spiral of losses, finally leading to emotional exhaustion (Hobfoll et al., 2018). Indeed, constantly dealing with internal conflicts erodes energies and resources and, over the course of time, the individual is not more able to regain and restore the necessary reservoir of resources to cope with occurring adversities. Thus, COR theory offers a parsimonious functional model to explain burnout posing attention on causes which may consume resources triggering a vicious cycle of impoverishment (Hobfoll et al., 1989; Hobfoll et al., 2018). This interpretation suggests to optimize efforts focusing on the interruption of the excessive loss of resources. Moreover, a point of novelty proposed by this research project is the study of moral distress and burnout in two medical specialties exposed to high-demanding situations at work. Previous studies posed the attention in particular on ICUs context (Meltzer & Huckabay, 2004; Fumis et al., 2017; Lamiani et al. 2017; Dzeng, & Curtis, 2018; McAndrew et al., 2019). Whereas, this research unveiled that moral distress is a significant predictor of burnout also for professionals employed in palliative care and neurorehabilitation medicine specialties. This finding is particularly relevant for the actual and future healthcare landscape because the increasing complexity provided by medical and technological advancements enhances the exposure to ethical and moral dilemmas (Andrews & Crisp, 2017; Castlen et al., 2017; Johnston, 2018; Leuter et al., 2018). This means that there is the urgency to take in consideration not only the causes of distress but also what may be a matter of concern by a moral standpoint as, if not addressed, moral distress become an effective cause of burnout. Furthermore, this project analyzed also a possible mediating role of moral distress. To this regard, it has to be noted that research investigating moral distress as a mediator in the relationship between organizational factors and healthcare professionals is still scant (Lamiani, Dordoni, & Argentero, 2018). The mediation analyses conducted in this project suggested that moral distress partially mediates the relationship between ethical climate (intended as "managerial support in dealing with bioethical issues" and "ethical vision of patient care") and emotional exhaustion such that a positive ethical climate reduces moral distress and, in turn, emotional exhaustion. Thus, this research unveiled both the direct impact of moral distress on emotional exhaustion and its mediating role. This last evidence strengthens and corroborates the previous literature analyzing the relationship between ethical climate and moral distress on one hand (Schluter, Winch, Holzhauser, & Henderson, 2008; Pauly, Varcoe, Storch, & Newton, 2009; Silén et al., 2011; Atabay, Cangarli, & Penbek, 2015; Altaker, Howie-Esquivel, & Cataldo, 2018) and ethical climate and burnout on the other hand (Elçi, Karabay, & Akyüz, 2015; Dzeng & Curtis 2018; McAndrew et al., 2019). The unveiling of the mediating role of moral distress therefore represents another original contribution of this study, linking together these three variables and suggesting a path through which moral distress may impact on burnout in a direct way and as a mediator.

From the qualitative studies conducted, other specific risk factors for wellbeing was reported by professionals employed in palliative care and by medical students taking care of patients in life-threatening conditions. First, the management of unpleasant emotions was described to be extremely demanding and highly distressing. Specifically, respondents highlighted the difficulty in both handling caregivers' and patients' negative emotions and not being overwhelmed by own feelings elicited by their work. These professionals are constantly exposed to patients on the verge of death and suffering from physical and psychological pain. This condition may easily trigger feeling of sadness, sorrow and helplessness in the professionals who perceive to be emotionally drained and depleted by psychological and physical energies. The medical students interviewed reported also a feeling of powerless in certain circumstances. This feeling seems to characterize the medical experience of students who perceive a personal responsibility of providing successful care and have the desire to save every patient (Clay et al., 2015). This finding is in line with previous researches conducted among healthcare professionals (Bruce & Boston, 2008; Pereira, & Fonseca, 2011; Pereira, Fonseca, & Carvalho, 2011; Gélinas, Fillion, Robitaille, & Truchon, 2012; Funk, Waskiewich, & Stajduhar, 2013), as well as among medical students (Gallagher et al., 2014; Grubb & Arthur, 2016; Heise, Wing, & Hullinger, 2018; Ranse, Ranse, & Pelkowitz, 2018; Burr & Beck Dallaghan, 2019). For instance, a systematic review on risk factors for palliative care professionals unveiled that facing patients' death, sufferance and pain contribute to higher levels of burnout, in particular among nurses (Pereira et al., 2011a). Indeed, professionals must not only provide care to the patients, but they also have to face with the emotional stressors given by the containing of patients and caregivers' emotions and reactions (Gélinas et al., 2012). This condition may elicit in the professionals a demanding emotional response as far as existential and ethical concerns such that, over the time, the professionals turn to be emotionally overwhelmed and drained up. In fact, experiencing sufferance triggers a sort of emotional contagion. Differently said, witnessing sufferance and dying on a daily basis creates a "ripple effect", that is "the pain or suffering of a patient spreads out like the ripples in a pond after a stone is thrown in [...] They may not be able to differentiate what is their pain and what is the ripple from the patient's pain" (Bruce & Boston, 2008, p. 52). Thus, experiencing death and managing unpleasant emotions are daily "personal challenges" characterizing the work activity of professionals taking care of palliative and life-threatening patients (Funk et al., 2013). Similarly, medical students reported to perceive the dealing with dying and sufferance as highly demanding and distressing. Specifically, previous researches unveiled that students described themselves as shocked and unprepared to manage patients' death (Gallagher et al., 2014; Ranse et al., 2018; Heise et al., 2018). Again, medical students described themselves as anxious, sad and powerless when facing death (Gallagher et al., 2014) and major matters of concern for students

seemed to be the final hours of death, grief and bereavement, as far as the pain management (Grubb & Arthur, 2016). Considering the findings unveiled by the present project and the previous literature, it is clear that the management of emotion deserves attention as it may be a relevant stressor for healthcare professionals, in particular if daily exposed to death and life-threatening patients. Since the beginning of the career, this aspect results to be pivotal as initial negative and highly distressing experience may lead to feelings of inadequacy and powerlessness and, in turn, to avoiding behaviors (Terry & Carroll, 2008; Anderson, Kent, & Owens, 2015), pushing the individual to experience the unpleasant burnout experience. COR theory explains this outcome stating that outstretched or exhausted people tend to adopt a defensive mode in order to preserve the self and minimize the resource loss (Hobfoll et al., 1989; Hobfoll et al., 2018). Moreover, according to the lens of this theoretical framework, the frequent exposure to sufferance may be a condition triggering a loss of individual's resources since the very beginning of the healthcare professional career, such prompting a long-lasting vicious cycle of resource loss resulting in a state of burnout. Again, as specified by the resource caravan passageways principle (Hobfoll et al., 1989; Hobfoll et al., 2018), facing with loss, sufferance and negative feelings may be considered facets that turn the palliative care setting in an environment obstructing resource creation and sustenance. This consideration underlines the importance of interventions to avoid the onset of a threatening spiral of resource loss in this healthcare workforce. Indeed, the challenging management of emotions is an essential component of this work and a potential risk factor for wellbeing, therefore deserving maximum attention and adequate support.

Second, qualitative findings unveiled that *decision making* is another highly distressing aspect for palliative care professionals. The challenging task is to be able to decide the "right" treatment in the "right" moment, impacting on patients' lives. Differently said, these professionals have to decide for the best care options considering the fluctuating and instable health conditions of patients on the verge of death (Hurst et al., 2007; Flannery, Ramjan, & Peters, 2016; Leuter et al., 2018). The literature has already underlined the burden related to the several ethical decisions that palliative care professionals are asked to constantly take. For instance, they need to make decisions regarding the patient's autonomy and the possibility to fulfil her/his advance directives; they have to choose for euthanasia or assisted suicide (in the countries where these options are legally allowed) and to proceed or not with life-threatening treatments, as well as they need to take the decision not to resuscitate the patient (Worthington, 2005; Pereira et al., 2011a; Pereira, & Fonseca, 2011). Moreover, they may be unsure on the efficacy of a treatment that can be considered as futile (Flannery et al., 2016). These responsibilities may erode the pool of energies and resources of professionals who, as a consequence, may develop distress and burnout (Flannery et al., 2016). Thus, reading this finding through the lens of COR theory (Hobfoll et al., 1989; Hobfoll et al., 2018), the clinical decision-making process may turn to be another distressing element contributing to fuel the spiral of resource loss that may afflict a healthcare professional. Therefore, decision making process has to be considered a relevant stressor in the context of palliative care as clinical choices involve challenging and demanding ethical issues to manage.

Third, another matter of concern unveiled by the qualitative investigations carried on in this project are conflicts and divergences that can occur at different levels. For instance, the interviewed palliative care professionals described the management of internal conflicts among the healthcare team as something highly distressing. Similarly, medical students reported divergencies with colleagues or superiors as a risk-factor threatening their wellbeing. The reasons of these conflicts were mainly related to how approach the patient and which treatments and care need to be provided. A recent review has already stated that ethical and clinical dilemmas characterizing complex situations lead to conflicts among healthcare professionals because there are different standpoints regarding the assessment and the constant redefinition of patient treatment plans (Rainer, Schneider, Lorenz, 2018). Thus, internal conflicts seem to be the result of divergences among personal values and what is requested to be done, similarly to what was already stated by researches (Gelinas et al., 2012; Cheon, Coyle, Wiegand, & Welsh, 2015; Lokker et al., 2018). Previously, Canadian nurses described as frustrating and uncomfortable to provide care considered as potentially futile and/or aggressive for a certain patient (Gelinas et al., 2012). Similar unpleasant feelings were also reported by Dutch nurses regarding providing palliative sedation (Lokker et al., 2018). Again, goal setting and discharge planning may be other sources of conflicts between colleagues (Kirschner, Stocking, Wagner, Foye, & Siegler, 2001; Mukherjee, Brashler, Savage, & Kirschner, 2009). To this regard, it has to be underlined that the different perspectives are also linked to the interdisciplinarity nature of the palliative care team. Although the first goal is to provide care which are in the best interest of the patient, each medical discipline has its own interpretive lens about what is better for the patient such that a treatment considered effective by a professional may be considered non optimal by another (Bruce & Boston, 2008). Despite the possible reasons, team conflicts are a matter of concern, considering that they may contribute to emotional exhaustion and depersonalization symptoms (Pereira et al., 2011a). This project contributed to strengthen the relevance of this issue for the wellbeing of healthcare professionals. Moreover, interviewees described also divergences between patients' and caregivers' wills. In accordance with this finding, the literature has already described incongruences between patients and their family members as demanding issue that healthcare professionals have to manage (Hudson, Aranda, & Kristjanson, 2004; Lichtenthal, & Kissane, 2008; Gelinas et al., 2012; Rainer et al., 2018). For instance, the caregiver might avoid sedation in order to be able to interact until the last moments with the patient who, at the contrary, needs only to reach pain relief. Again, according to a recent review "some families may want aggressive treatment when the healthcare team recommends hospice; other families refuse intubation for a patient who should easily wean from mechanical ventilation once the acute issue is resolved' (Rainer et al., 2018, p. 3456). Moreover, conflicts among the families members may exist due to different reasons and risk factors: divergent perspective on care and treatments to be provided, different coping styles and levels of emotional expressiveness, as well as the presence of mental illness suffered from one or more members of the family (Lichtenthal & Kissane, 2008). In this context, the healthcare professionals have the challenging task to be a "bridge", enabling the encounter and the reconciliation of the patient's clinical need with the caregiver's desires (Gelinas et al., 2012). It is not difficult to imagine that this activity is emotionally demanding and resources consuming as professionals have to handle with demanding and anxious people. Indeed, it has to consider that in clinical complex and life-threatening situations, caregivers may be unrealistic regarding the diagnosis and prognosis or they may deny their loved one's poor health status as a personal strategy to endure these tough circumstances (Kinoshita, 2007; Rainer et al., 2018). Overall, these manifold types of conflicts may be read as an important risk factor for the professionals as they may trigger and revamp a vicious spiral of resource loss (Hobfoll et al., 1989; Hobfoll et al., 2018). According to COR theory, this constant depletion of resources prevents the individual to be able to restore the necessary resources to cope with difficulties and demands occurring at work, paving the way to distress and, finally, to burnout (Hobfoll et al., 1989; Hobfoll et al., 2018). Differently said, it is conceivable that the distressed healthcare professionals have less and less resources to invest for restoring the own reservoir of resources and, in the meantime, these conflicts may create a negative relational environment that works as an obstacle to the resource caravan passageway, therefore fueling the spiral of resource loss. Conflicts and divergences regarding treatments and patient's approaches may be explained considering also the culture in which the healthcare professionals and the patients/caregivers live in. Specifically, the medical students interviewed for this project clearly described as they perceive internal conflicts derived from differences between own culture and the environment where they were working and studying. Some of them underlined the contrast between the own culture in which the patient deserves open and complete information and decision-making power and the south-Mediterranean culture where the families' desires may prevail. To this regard, it has to be stated that recent literature reviews unveiled that culture and ethnicity may affect how palliative care are provided as there are differences in preferences and approaches to care at the end of life among the different population (Cain, Surbone, Elk, & Kagawa-Singer, 2018; Rainer et al., 2018). This is a thorny issue that may

arise numerous ethical concerns and create a relevant amount of distress in the professionals. Thus, it is pivotal that the healthcare professionals carefully listen the patient's and their family's needs, in an attempt to understand and become aware of their culture for integrating attitudes and preferences in an appropriate care plan (Cain et al., 2018). The current findings contributed to highlight this urgency.

Additionally, *communication difficulties* are unveiled by qualitative analyses as one of the most challenging issue to manage (Barclay, Blackhall, & Tulsky, 2007; Malloy, Virani, Kelly, & Munévar, 2010). In particular, breaking bad news, such as the communication of a poor diagnosis, and prognosis is described as tough and high-emotional demanding by both palliative care professionals and medical students. Even for healthcare professionals who routinely deliver bad news, the difficulty is related to handle with sensitive issues like uncertainty, death, loss and attempts of responding to patient and caregivers' needs in the best way possible (Barclay et al., 2007). The literature has already underlined that breaking bad news, in particular linked to the failure of treatments, is a risk factor for developing burnout and fatigue in healthcare professionals (Brown et al., 2009; Pereira et al., 2011a). Conversely, professionals who feel themselves more confident in their communication skills reported less burnout and distress, as well as higher personal accomplishment (Barclay et al., 2007). A recent systematic review labelled the communication of poor diagnosis as an ethical dilemma because it may raise quandaries about the futility of treatments and the adequacy of care provided until that moment (Rainer et al., 2018). Focusing on medical student, previous researches have already stated that the communication of bad news and the management of patients and caregivers reactions is a thorny and sensitive issues for students (Wittenberg-Lyles, Goldsmith, Ragan, & Sanchez-Reilly, 2010; Gadoud, Adcock, Jones, Koon, & Johnson, 2013; Wechter, O'Gorman, Singh, Spanos, & Daly, 2015; Grubb & Arthur, 2016). To this regard, the literature has reported the necessity and the efficacy of communication skills trainings both for medical students (Rosenbaum, Ferguson, & Lobas, 2004; Back et al., 2007) and healthcare professionals too (Chung, Oczkowski, Hanvey, Mbuagbaw, & You, 2016; Moore, Rivera, Bravo-Soto, Olivares, & Lawrie, 2018). Indeed, training this kind of skills provide the healthcare professionals with a feeling of more confidence in own capacity to adequately address the patient's and caregivers' needs, therefore sustaining healthcare professional's wellbeing (Barclay et al., 2007; Chung et al., 2016). Moreover, it has to be said that the complexity of communication is also related to the fact that "telling the truth" about diagnosis is strictly linked to the culture as different countries have different preferences regarding the complete or partial disclosure of endof-life information and treatments to patients (Barclay et al., 2007; Rainer et al., 2018; Cain et al., 2018). As already stated, this condition created a relevant amount of distress in medical students

interviewed in this project such that they experienced an internal dissonance between what they would do and what has to be done according to the culture they are living and studying in. Considering all these aspects, it is not difficult to imagine that the burden of the communication of bad news is a resource-draining factor. Thus, it deserves attention as, drawing from COR theory, a people impoverished of resources is also more vulnerable and less equipped to cope with stressors (Hobfoll et al., 1989; Hobfoll et al., 2018). Thus, this project reinforces previous knowledge on communication difficulties in the healthcare context and it interprets this issue as another element that may push the professionals into an escalating spiral of resource losses.

All the aforementioned risk factors have been similarly reported by both healthcare professionals and medical students interviewed within this project, suggesting that these factors may threaten the entire career path from the start to the end. Furthermore, healthcare professionals underlined also that, sometimes, private experiences may "color the lens" though which reading what happens at work. For example, the care of a patient may be particularly demanding for some professionals who lived a similar disease experience in their own private life. This situation may lead to empathize and identify themselves with the patient such that the emotional demand is higher than usual. This finding may be in some way connected to the issue of work-private life unbalance or conflict, namely all kinds of possible interferences between work and private life; this aspect has been already described in the literature as another possible stressor (Chittenden & Ritchie, 2011; West, Dyrbye, & Shanafelt, 2018). According to a recent review, the presence of work-family conflicts doubled the risk of burnout (West et al., 2018). Usually, the literature referred to this theme as the individual capacity or inability to maintain harmony and a functional balance between the simultaneous temporal, emotional and behavioral demands risen by work and private life (Chittenden & Ritchie, 2011). However, the specific and novel nuance stressed by the interviewees of this project is related to the possible interference of private experience into work, pushing the professionals to approach and emphasize the care in a different way depending from private memories and emotions evoked by a certain patient. In these circumstances, the professional involvement and engagement are too much such that the boundary line between work and private life is lost or unclear. This issue may be linked also to the difficult and challenging management of tough and unpleasant emotions and sufferance characterizing the palliative care profession (Pereira & Fonseca, 2011; Pereira, et al., 2011a; Gélinas et al., 2012). What is important to underline is that the unbalance and interference between work and private life requests a higher consume of resources by the professional. Therefore, this project puts further attention on this sensitive issue as, drawing from the already mentioned COR theory, a massive loss of resources

may be dangerous because it may pave the way to a state of increasing resources depletion that makes the individual more vulnerable to distress (Hobfoll et al., 1989; Hobfoll et al., 2018).

#### 10.5. Protective factors

Besides the aforementioned risk factors, this project shed light also on various protective factors for healthcare professionals' wellbeing through quantitative and qualitative investigations.

First of all, positive ethical climate was unveiled to be a pivotal element for contrasting malaise. For instance, the previous literature described its role in mitigating moral distress and burnout (Corley, Minick, Elswick, & Jacobs, 2005; Pauly et al., 2009; Silén et al., 2011; Burston & Tuckett, 2013; Herberston, Hamric, Epstein, Fischer 2014; West et al., 2018). Specifically, ethical climate predicted moral distress intensity among American nurses (Corley et al., 2005). Similarly, in another group of Canadian nurses, moral distress intensity and frequency were inversely correlated with ethical climate (Pauly et al., 2009). Again, other studies involving Sweden and American nurses unveiled a significant negative correlation between moral distress and ethical climate (Silén et al., 2011; Whitehead et al., 2014). Drawing from COR theory (Hobfoll et al., 1989; Hobfoll et al., 2018), ethical climate may be considered a relevant resource caravan passageway (i.e., "environmental conditions that support, foster, enrich, and protect the resources of individuals"; Hobfoll, 2012; p. 229). The passageways are to be intended as ecological condition supporting the individual (Hobfoll et al., 1989; Hobfoll et al., 2018). Specifically, ethical climate identifies a resourceful fair work context enabling individuals to access resources as far as protecting them against resource loss and promoting the resource storage. Indeed, healthcare professionals do not act in a vacuum, are instead embedded in a context which may influence their actions. The quality of this context may be the fertile ground for the onset of moral distress and burnout or being a promoter of positive outcomes (Dzeng & Curtis, 2018). A positive climate may be therefore an important environmental protective factor for healthcare professionals helping them to maintain adequate resources for counterattacking distress. It is possible to consider ethical climate a sort of "catalyst" of fair and trust relationship at work, promoting commitment to the organization and better relationship among workers (Chouaib & Zaddem, 2013). In this project, ethical climate was intended in two specific nuances: "ethical vision of patient care" and "managerial support in dealing with bioethical issues". The first one refers to a shared mission of providing ethical and high-quality care in the best interest of the patient, while the second facet denotes the support offered by the superior for facing ethical issues that can occur in the daily clinical practice. Mediations and moderated mediations models involving professionals employed in neurorehabilitation medicine showed that both these climate dimensions were negatively related to emotional exhaustion, directly and

through moral distress. The previously literature already reported that taking care of patients adopting a fair and respectful approach provides the healthcare professional with a feeling of fulfilment, and personal and professional satisfaction (Peery, 2010; McClendon, 2017; Shanafelt & Noseworthy, 2017). When the philosophy of taking in care someone is in line with own personal values, the work is experienced as extremely meaningful and rewarding, so reducing distress and burnout (Bruce & Boston, 2008; Pereira et al., 2011a; McClendon, 2017). The novelty of this study is the possibility to functionally explain this finding through the lens of COR theory (Hobfoll et al., 1989; Hobfoll et al., 2018). In particular, the climate dimension of "ethical vision of patient care" may be interpreted as a resource caravan passageway, that is an environmental milieu which sustains the professional in maintain, retain, and protect resources to cope with difficulties (Hobfoll et al., 1989; Hobfoll et al., 2018). That is, the approach to care turns to be a facilitator fostering wellbeing. Similarly, also the other dimension of ethical climate called "managerial support in dealing with bioethical issue" may be intended as a passageway promoting the resource gain and the reinvestment of resources (Hobfoll et al., 1989; Hobfoll et al., 2018). Indeed, the previous literature has already pointed the crucial role of support received by colleagues and superiors in terms of social, emotional and practical sustain for coping with adversities (Shanafelt & Noseworthy, 2017; Velando-Soriano et al., 2020). However, little is known about the role of superiors in supporting workers facing ethical dilemmas (Rasoal, Skovdahl, Gifford, & Kihlgren, 2017; Poikkeus, Suhonen, Katajisto, & Leino-Kilpi, 2018; McAndrew et al., 2019). Thus, this project shed light on this specific aspect, showing for the first time that managerial support provided in dealing with bioethical issues results to be an important environmental protective facet as it may directly and indirectly- through moral distress - reduce emotional exhaustion experienced by professionals working in neurorehabilitation medicine. In fact, the superior may provide examples and guide for navigating among ethical and demanding dilemmas, so transmitting resources to the other professionals. To this regard, COR theory postulates also the existence of crossover mechanisms that enables the transmission of resources from an individual to another (Hobfoll et al., 2018). The managerial support is therefore both a resource caravan passageway as it is an ecological context that predisposes a favorable environmental for working and a means for promoting the crossover of resources, in order to obstruct resource loss and, in turn, maintain wellbeing.

Moreover, these two dimensions of ethical climate ("ethical vision of patient care" and "managerial support in dealing with bioethical issues") not only seem to reduce the perception of emotional exhaustion, but also play a role in the relationship between resilience and wellbeing and professional efficacy. Specifically, further mediation and moderated mediation analysis conducted in the whole

sample of palliative care and neurorehabilitation medicine professionals showed that resilience improved professionals' wellbeing and self-efficacy, directly and indirectly, as mediated by ethical vision of patient care. In addition, managerial support in dealing with bioethical issues worked as an effective moderator such that highly resilient individuals benefit more from the positive effect of ethical vision of patient care on wellbeing in presence of high managerial support. Therefore, these further findings strengthen the interpretation of ethical vision of patient care as an effective resource caravan passageway (Hobfoll et al., 1989; Hobfoll et al., 2018) which may be fostered by resilience. The managerial support in dealing with bioethical issues enhanced the positive effect of the ethical vision of patient care on wellbeing probably because more resources are made available. Indeed, COR theory assumes that the crossover mechanism enabling the transmission of resources are always present (Hobfoll et al., 1989; Hobfoll et al., 2018). This means that resilient people may transmit positive resources to colleagues, so creating a fair ethical climate in the healthcare context. Thus, more resilient and supported by their superior are professionals, more resources they have. These resources are enough for allowing individuals to invest a certain amount of resources for gaining other resources to strain in times of trial. Indeed, the decision to invest resources is taken depending on the personal resource level possessed: individuals sufficiently equipped with resources are less vulnerable to loss, rather they are more able to strategically invest resources to sustain and maintain their own reservoir of resources (Hobfoll et al., 1989; Halbesleben, Neveu, Paustian-Underdahl, & Westman 2014; Hobfoll et al., 2018).

Overall, the manifold findings unveiled by this project regarding ethical climate and its nuances ("ethical vision of patient care" and "managerial support in dealing with bioethical issues") strengthen the crucial role that ethical climate may have for fostering wellbeing and professional efficacy, as well as for reducing moral distress. The strength of the COR theory framework is to provide an effective interpretative key for reading the findings. Specifically, as far as my knowledge, the current investigations described for the first time some mechanisms disclosing how certain protective factors may be related and may work together within highly demanding clinical workplace, such as palliative care and rehabilitation medicine settings. These findings not only enrich and deepen the theoretic knowledge on these issues, rather they fuel suggestions for the practice, guiding the implementation of future supportive or preventive interventions.

Moreover, the mediation and moderated mediation analyses shed light on some personal characteristics which may play a relevant role for the healthcare professionals' wellbeing. To this regard, it is necessary to underline that COR theory stated that personal characteristics represent *"resources to the extent that they generally aid stress resistance"* (Hobfoll, 1989, p.517), suggesting that certain characteristics can be treated as personal coping resources. Indeed, being well-equipped with

resources means to be less vulnerable to stressors, as resources may be invested to cope with adversities and to regain new resources, too. Among personal characteristics, resilience is a crucial resource which has been extensively investigated in this project. The previous literature has already reported the protective role of resilience for who is employed in healthcare settings (Zwack & Schweitzer, 2013; Rushton, Batcheller, Schroeder, & Donohue, 2015; Back, Steinhauser, Kamal, & Jackson, 2016; Guo et al., 2018; McKinley et al., 2020). For instance, greater resilience levels were reported to be able to protect American nurses from emotional exhaustion and to contribute to their personal accomplishment (Rushton et al., 2015). Similarly, Guo and colleagues (2018) demonstrated that resilience is negatively correlated with burnout and it is one of the factors that predict burnout in a sample of Chinese nurses. Indeed, resilient healthcare professionals have effective strategies and positive attitudes to develop and maintain mental, physical, and social pool of resources which are essential for a successful clinical decision-making and for coping with adversities encountered during the clinical activities (Zwack & Schweitzer, 2013). Specifically, Back and colleagues (2016) proposed a paradigm in which palliative care professionals should be trained and educated in order to develop eight personal resilience skills (working from strengths, tracking activation, healthy boundaries, recognizing distortions, findings meaning, commitment to long term) that are useful for coping with common challenges faced during their clinical practice and for maintaining wellbeing. In line with these pieces of literature, the current findings showed that, in a sample of professionals working at palliative care and neurorehabilitation medicine disciplines, resilience improves wellbeing and professional self-efficacy, directly and indirectly, as mediated by the ethical climate dimension called ethical vision of patient care. This finding may be explained through the lens of COR theory which interprets resilience as personal resource enabling the professionals to face with distressing situations (Hobfoll, 1989; Hobfoll, Stevens, & Zalta, 2015; Hobfoll et al., 2018). Resilience is not a static characteristic, rather a process changing during the time and that may fuel the resource gain and renewal, thanks to the fact that resourceful people are more prone to invest and gain other resources (Hobfoll, 1989; Hobfoll, Stevens, & Zalta, 2015; Hobfoll et al., 2018). Moreover, resources are not monads, rather they move together, such that resilience may promote other resources too. Thus, it is conceivable that high resilient healthcare professionals are more able to cope with difficulties and to find creative solutions, such that they experience wellbeing and a sense of professional efficacy. Furthermore, they may be also more likely to experience a more positive ethical climate as they have the resources to consider demanding clinical situations as challenges to be addressed with shared high-quality and ethically standards for taking care of the patients. Consequently, resilience deserves special attention as it may positively impact on ethical climate and, in turn, on personal and professional outcomes.

Moreover, considering only professionals employed in neurorehabilitation medicine specialty, quantitative analyses unveiled that individuals high in resilience were able to benefit more from the protective effect of managerial support in dealing with bioethical issues on emotional exhaustion through moral distress. Drawing from COR theory (Hobfoll, 1989; Hobfoll et al., 2015; Hobfoll et al., 2018), we can read this finding considering that resilient healthcare professionals are wellequipped with adequate resources to cope with difficulties and to perceive difficult tasks as challenging occasions of growth and learning, rather than as threats. Thus, they are also more prone to take advantage and enhance resources which are present in the environment, such as managerial support, in order to struggle for reaching and maintaining wellbeing and professional achievement. Indeed, people possessing more resources are more likely to invest them for facing adversities and gaining other resources to preserve a sufficient reservoir of resources for future tough times. Overall, to the best of my knowledge, it is the first time that resilience is investigated in a population of palliative care and neurorehabilitation medicine professionals in relation to personal and professional outcomes, as far as to ethical climate dimensions. These findings deepen the understanding of possible mechanisms and factors at the root of the relationship between resilience, ethical climate, wellbeing and professional efficacy, suggesting a parsimonious and functional explanation of real-life challenging healthcare contexts. Future interventions and investigations should therefore take in considerations these variables and mechanisms as they seem to be crucial elements for fostering wellbeing and counterattacking distress and burnout in workers involved in palliative care and neurorehabilitation medicine contexts.

Another personal characteristic found to be effective for wellbeing is *positive affectivity*. In particular, moderated mediation analyses conducted with professionals working at neurorehabilitation medicine context, showed that individuals with high positive affectivity benefited more from managerial support in dealing with bioethical issues. Differently said, high positive affectivity enhanced the beneficial effect of managerial support on moral distress. Drawing from COR theory, it is conceivable that professionals with high positive affectivity can easily take advantage of positive environmental condition like managerial support (Hobfoll, 1989; Hobfoll et al., 2018). Indeed, individuals with high positive affectivity are characterized by a rosier overlook on life and a more pronounced tendency to use adaptive coping strategies and to perceive a better psychological functioning (Watson, Clark, & Tellegen, 1988; Folkman & Moskowitz, 2000; Greenglassmn & Fiksenbaum, 2009). These predispositions lead to experience ethical issues as challenges and not as dangerous threats. Indeed, they perceive adequate resources in their environment, such as managerial support, in order to resolve problems. Thus, this positive approach results in less moral distress and, in turn, less emotional exhaustion. This finding is

coherent with the previous literature showing the protective role of positive affectivity for healthcare professionals' wellbeing (Folkman & Moskowitz, 2000; Thian, Kannusamy, & Klainin-Yobas, 2015; Mazzetti, Biolcati, Guglielmi, Vallesi, & Schaufeli, 2016). For instance, positive affectivity was described to have a significant negative relationship with distress in a sample of Japanese nurses (Thian et al., 2015). Also, positive affectivity was described to be an effective moderator as it buffered the relationship between emotional exhaustion and job performance (Janssen, Lam, & Huang, 2010). To the best of my knowledge, the moderating effect of positive affectivity on the relationship between managerial support and moral distress in neurorehabilitation medicine professionals has been investigated for the first time by the present research project. Therefore, the unveiling of this specific buffering effect contributes to the literature on the adaptational significance of positive affect, strengthening the understanding of positive affectivity as a key personal resource toward aiding stress resistance.

Qualitative investigation unveiled other possible protective factors, too. One of the main elements is the presence of social support. To this regard, palliative care interviewees described this kind of support as an anchor to take shared decisions regarding patient's care, as well as "to sustain who falls". That is, the team becomes a network for supporting each member in overcoming difficulties. This finding is in line with the previous literature reporting the fundamental presence of social support between colleagues to share the burden of challenging clinical cases which may occur in palliative care (Pereira & Fonseca, 2011; Pereira, et al., 2011a; Hamama, 2019). Indeed, sharing experiences and emotions with peers is a vital behavior to face with the negative emotional impact that healthcare professionals may experience after adverse medical events (van Pelt, 2008). Moreover, healthcare professionals of this project perceived also appreciation received from patients and caregivers as a form of relevant social support. To this regard, it is worthwhile to underline that supportive interactions within the own social system - comprising both the work setting and elsewhere context - was described as prompts to rethink critical events and to provide them with a meaning (Măirean, 2016) such that social support may turn in a crucial buffer, moderating distress (Uchino, Carlisle, Birmingham, & Vaughn, 2011). Thus, using the lens of COR theory, social support can be read as a positive characteristic of the environment which may scaffold the individual in the strive to maintain and regain resources for wellbeing (Hobfoll, 1989; Hobfoll et al., 2018). Similarly to managerial support, social support intended in broad sense may be considered a resource caravan passageway as it is an ecological facet characterizing a favorable work environmental in which invest and regain resources (Hobfoll, 1989; Hobfoll et al., 2018). Specifically, social support was unveiled to protect against burnout symptoms and secondary traumatic stress which may affect healthcare professionals at work (Măirean, 2016; Hamama, 2019).

The medical students interviewed reported the same perspective as they strengthened the fact that social support, including that from family and friends, was a soothing element to cope with challenges encountered during their clinical placement in touch with life-threatening patients. Indeed, supportive interactions and communications with colleagues and superiors enable medical students to metabolize challenging experiences, sharing together the burden and exchanging perspectives and meanings (Gallagher et al., 2014; Farquhar, Kamei, & Vidyarthi, 2018).

Another relevant protective factor revealed by the interviews conducted with palliative care professionals and medical students is the work-family balance. This term refers in broad sense to the capacity to keep the private and work dimensions separated, maintaining an overall sense of harmony (Chittenden & Ritchie, 2011). The reaching of this balance was described as an essential strategy to stay focused on the present, avoiding the emotional drain provoked by recursive thoughts. Being in constant and prolonged contact with individuals suffering from serious and lifethreatening conditions is indeed emotionally charged and it may trigger recursive thoughts such that, along the time, this condition may erode the personal-professional boundaries (Chittenden & Ritchie, 2011). Thus, to compartmentalize these two dimensions was described by interviewees as a sound help to avoid the emotional erosion. Moreover, for medical students, this balance is propaedeutic for creating a therapeutic alliance with the patient, that is to "adequately stay with the patient" without being overwhelmed by emotions and creating a solid professional identity (Percy & Richardson, 2018). To this regard, it has to be said that the protective role of work-family balance has been already unveiled by the previous literature stating that this condition may avoid to be overwhelmed by tough emotions and challenges characterizing the daily work activity in healthcare context (Pereira et al., 2011a; Chittenden & Ritchie, 2011). Moreover, a positive balance between work and private life was associated to psychological wellbeing (Munir, Nielsen, Garde, Albertsen, & Carneiro, 2012). Drawing from COR theory, work-family balance may be considered a relevant resource for supporting the healthcare professionals to cope with difficulties maintaining adequate resources and, in turn, wellbeing (Hobfoll, 1989; Hobfoll et al., 2018). Indeed, professionals, who can keep the private and work dimensions separated, contain a possible spillover of resource loss starting from work to private life or vice versa. In this way, they can avoid a resource loss spiral and preserve as much as possible resources.

Another relevant element is the construct of *meaning*. Specifically, the capacity to find a sense regarding work and life experience seems to be very supportive for healthcare professionals involved in this project. Specifically, palliative care interviewed described their effort to reach the meaning of their work because being conscious of the value and significance of their own profession was a strategy not to be overwhelmed by sufferance and distress. To maintain wellbeing,

the palliative care philosophy has to be aligned with own values and beliefs such that a professional may experience the work to be deeply meaningful and worth (Bruce & Boston, 2008). This finding provided a further confirmation to previous study posing attention to the protective role of meaning of work in the palliative care setting (Bruce & Boston, 2008; Shanafelt, 2009; Pereira et al., 2011a; Moreno-Milan, Cano-Vindel, Lopez-Dóriga, Medrano, & Breitbart, 2019). For instance, meaning of work was unveiled to be pivotal for healthcare professionals' wellbeing as it is negatively correlated with self-perceived stress and it mediated the effect of stress on subjective vitality, personal growth and life satisfaction among palliative care professionals (Moreno-Milan et al., 2019). Moreover, it was stated that enhancing meaning in work may prevent physician burnout as far as may foster a patient-centered approach (Shanafelt, 2009). Indeed, providing a sense to what is done at work seems to protect from the three main symptoms of burnout that may impact on both professionals' wellbeing and quality of care. In particular, meaning of work safeguards professionals from losing enthusiasm and being emotionally drained, prevents the tendency to depersonalize patients, as well as it provides a feeling of professional accomplishment and efficacy (Shanafelt, 2009). Besides meaning of work, the study analyzed the meaning in life of healthcare professionals involved in the present multi-method investigation, too. To this regard, it has to be underlined that the literature has already showed that meaning in life is a pivotal element for supporting health, psychological wellbeing and functioning in general population (Hicks & King, 2009; McKnight, & Kashdan, 2009; Glaw, Kable, Hazelton, & Inder, 2017), as well as in healthcare professionals (Taubman-Ben-Ari, & Weintroub, 2008; Pereira et al., 2011a, Fegg, L'hoste, Brandstätter, & Borasio, 2014). Thorough the SMiLE questionnaire, we revealed no significant differences between palliative care and neurorehabilitation medicine disciplines regarding the number of meaning in life areas listed. However, palliative care professionals were more likely to mention the categories "partnership", "satisfaction", and "social commitment" than neurorehabilitation colleagues. This finding is in line with the previous literature showing that the aforementioned variables may be protective factors for palliative care professionals (Pereira et al., 2011a). Moreover, a further confirmation was provided by the interviews collected from palliative care professionals who subjectively highlighted the protective role of job satisfaction and social support provided by colleagues and family members. Relationships were also referred as one of the most relevant sources of meaning in people's existences by a recent systematic review (Glaw et al., 2017). In addition, interviewees provided a further nuance and understanding of meaning in life, posing attention on the importance of a positive approach to life and past experience. Specifically, the past was intended as an important instrument to learn from and gain new perspectives and meanings regarding life. Similarly, the interviewed medical students described learning from errors

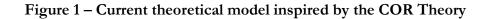
and acquiring increasing acknowledge and knowledge as fundamental supportive elements enriching the meaning of their work and existence, too. Indeed, perceiving improvement of knowledge may help medical students to cope with fears, false expectations and tough emotions that can be experienced when providing care (Gadoud et al., 2013).

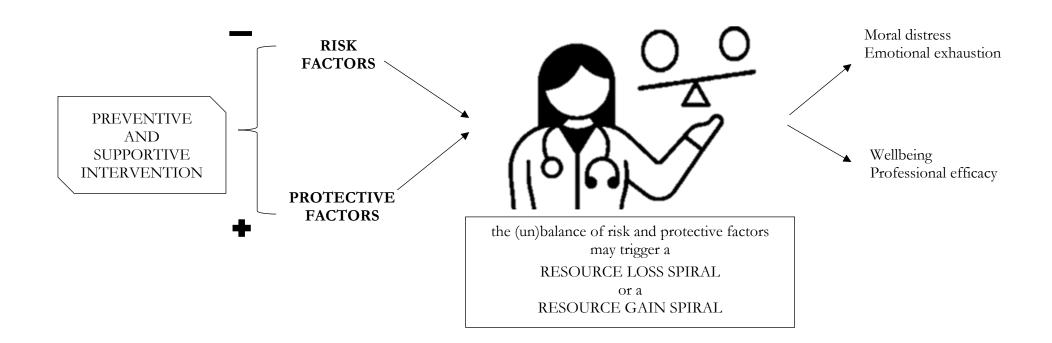
Overall, having a meaning is considered a fundamental element for wellbeing, health and fulfillment of life all over the world (Hicks & King, 2009; McKnight, & Kashdan, 2009; Glaw et al., 2017). In the Japanese culture, the search for a meaning deserves much more attention as it is considered a core resource for a full and health existence. In this culture, meaning and psychological wellbeing are strictly related such that they can be intended as a unique entity. This concept is called with the Japanese term "ikigai" (Kamiya, 1966; Mathews, 1996). Specifically, ikigai refers to a) experiences which provide the individual with a sense of worth and happiness, b) the process of awareness that finds life meaningful thanks to experience, c) the cognitive evaluation of life that result in a sense of fulfillment and joy (Mathews, 1996; Yamamoto-Mitani & Wallhagen, 2002). In Western cultures ikigai may be translated as life worth living and it encompasses the concept of meaning in life as a resource for wellbeing (Frankl, 1963; Martela & Steger, 2016). Thus, through the lens of COR theory (Hobfoll, 1989; Hobfoll et al., 2018), the construct of meaning may be intended as an important personal resource which is used by the individual to strive against difficulties, maintaining a certain amount of resources and avoiding a state of disproportionate depletion of resources. This project strengthened this concept, undelaying the protective role of meaning of work and life as experienced by medical students, as well as healthcare professionals employed in palliative care and neurorehabilitation medicine disciplines. Moreover, another point of strength is the attempt to deepen and better understand what provides meaning in life in these professionals using a well-established instrument as SMiLE which collects subjective standpoints.

Finally, another element promoting wellbeing that was reported by healthcare professionals and medical students was having a regulation concerning *advance directives*. This such of low is seen as a compass to guide the professionals in the decision-making process and clinical practice. For the Italian palliative care professionals, the recent law n° 219/2017 is considered a relevant step forward and a "resource", despite some criticisms still persist. Indeed, the law does not disambiguate all the controversial situations that can occur in the clinical practice nor it is easy to implement in each context. The literature on this theme is multifaceted and reported both pro and cons of these kinds of regulations. On one hand, some Italian authors stated that the law n°219/2017 is not adequate as it makes doctors into little more than executors of their patients' will on the bases of a contract-based commercial relationship which overrides the reciprocal doctor-patient relationship (Di Luca, Del Rio, Bosco, & Di Luca, 2018). On the other hand, some previous literature reported the healthcare professional's awareness of the importance of such regulations for adhering as much as possible to patient's will, despite difficulties in the implementation and the necessity to specific trainings and knowledge of these laws (Pereira, Fradique, Fialho, Cerqueira, Pereira, & Sampaio, 2011; Langer, Stengel, Fleischer, Stuttmann, & Berg, 2016; Juliá-Sanchis, García-Sanjuan, Zaragoza-Martí, & Cabañero-Martínez, 2019). The healthcare professionals' different standpoints deserve a comment. It is necessary to bear in mind that the state of the art regarding living wills and advance care directives is still globally heterogeneous and legally muddled, so each legislation has to be considered as unique and not similar to others. Within the same territory, each context is different, too. For instance, it may be more challenging the retrieval and implementation of advance directives in a rural area in comparison with an urbanistic one where citizenships are usually more informed and made aware on this issue. Thus, the healthcare professionals' perspective mirrored specific experiences occurring in certain contexts and times, such that differences are normal. Despite this, using the key interpretation of COR theory (Hobfoll, 1989; Hobfoll et al., 2018), the law on advance directive may be considered a resource of the environment which may scaffold the professionals in their working activity protecting them from resource loss spirals triggered by bioethical issues at workplace. Indeed, the palliative care interviewed underlined that this regulation is an instrument for navigate in the clinical practice, despite the fact that there is still room for further improvements.

#### 10.6. A global overview through the lens of COR theory and future directions

This research project adopted the COR theory approach (Hobfoll, 1989; Hobfoll et al., 2018) to read in a comprehensive way the findings unveiled as described in the previous pages. The attempt was to find a practical and parsimonious framework able to comprehend both risk and protective factors, putting the attention on their relationships and mechanisms. Overall, the results address a gap between research and clinical practice by advancing a functional explanatory conceptualization of the main risk and protective factors for healthcare professionals employed in high complex healthcare settings as palliative care or neurorehabilitation medicine. Thus, using the lens of this theoretical framework, it is possible to suggest a theoretical model where the positive or negative outcomes have to be intended as the result of a dynamic process of balance or unbalance between risk and protective factors (Figure 1). The variables investigated are elements which may trigger a





Note. The model contains free modified icons offered by The Noun Project (https://thenounproject.com/)

resource loss or resource gain spiral among healthcare professionals. Specifically, when there is an unbalance condition where risk factors are predominant, the healthcare professionals make experience of a dangerous and vulnerable state of resource depletion and a resource loss spiral may begin such that the individual perceives not being able to face adversities. Differently said, workers feel that their resources, particularly after a great deal of resource investment in work, may be no longer sufficient to meet current work demands and this resource impoverishment may result in moral distress and emotional exhaustion (Halbesleben & Bowler, 2007; Halbesleben & Buckley, 2004).

In particular, investigations showed that moral distress contributes to the self-perception of emotional exhaustion. This latter has to be intended as the core dimension of burnout (Cox et al., 1993; Maslach et al., 2001). However, it could be interesting whether future researches will attempt to validate this finding considering the other components of burnout, too. Moreover, the exposure to sufferance and bioethical issues, communication difficulties, possible conflicts, tough decision-making process, as well as work-family unbalance were subjectively described as relevant risk factors for distress and malaise. It is therefore recommended that future quantitative researches should be undertaken in order to further validate these risk factors unveiled by the interviews. In addition, future studies on the current topic are suggested in order to detect other possible riskfactors which may act as trigger for a detrimental resource loss spiral. A multi-method approach may be useful to firstly qualitative detect other variables of influence and secondly investigate their impact on both health and professional outcomes through the quantitative approach.

Conversely, when protective factors counterbalance the impact of risk factors, the professionals experience adequate resources and this condition triggers and fuels a virtuous cycle of resource investment and gain, resulting in wellbeing and professional efficacy. In particular, ethical climate – intended in its nuances of "ethical vision of patient care" and "managerial support in dealing with bioethical issues" – impacted directly and through moral distress on emotional exhaustion, reducing it. Interesting research questions for future research could be whether other facets of ethical climate may contribute to decrease the perception of emotional exhaustion. Furthermore, high positive affectivity and resilience levels enhanced the effect of managerial support on emotional exhaustion through moral distress. Overall, future studies in the current issue are recommended in order to validate the presence of other mediating or moderating factors in the ethical climate-emotional exhaustion relationship. Moreover, the present investigations unveiled also that resilience contributed on wellbeing and professional efficacy both directly and indirectly, as mediated by ethical vision of patient care and moderated by managerial support in dealing with bioethical issues. Again, the search for other possible protective factors playing a mediator or

moderator role might be an important area for future research. Besides this quantitative findings, qualitative investigations shed light on the protective role of social support, work-family balance, meaning of work and in life, as well as advance directives. I must leave to future work the task of investigating these last variables unveiled by qualitative interviews through a quantitative design to detect other possible models explaining mechanisms and relationships underlying the variables investigated.

Overall, malaise or wellbeing may be interpreted as the result of adequate resources or depletion of them given by a dynamic balance or unbalance between risk and protective factors which may act as triggers for virtuous or detrimental resource loss. This interpretation allows room for manoeuvre on preventive and supportive actions. Indeed, each kind of intervention should aim to minimize risk factors and to enhance protective ones. As to my understanding, risk factors - like exposure to death and tough emotions or possible discrepancies - cannot be completely removed, rather the aim should be to minimize or anticipate them. Meanwhile, there are intrinsic protective factors - like positive ethical climate, resilience or meaning in life - that can be fostered and improved. Indeed, the possibility to increase the strength points fuels the healthcare professionals with adequate resources to cope with adversities along their entire professional path, preserving their wellbeing. Thereby, a suggestion for future studies is to test, further validate and ameliorate the current theoretical framework with other samples, possibly employed also in other medical specialties.

#### 10.7. Recommendations for practice

Overall, the present dissertation provides several implications which may inform guidelines for practical interventions aiming to the promotion of wellbeing of who is working in palliative care and neurorehabilitation medicine specialties.

The papers presented in chapters five, six, seven, eight, nine already suggested several courses of action in order to promote wellbeing and professional efficacy in healthcare professionals employed in palliative care and neurorehabilitation medical specialties. The further pages enrich and deepen the discussion on the recommendation for practices.

#### 10.7.1. Promotion of teamwork and multidisciplinary

As a whole, the quantitative and qualitative findings emerged from this multimethod research suggest to the hospital managers the pivotal importance to foster multidisciplinary and teamwork which are facets mainly characterizing the medical specialties investigated. Indeed, the healthcare professional interviewees described as effective protective factors for their wellbeing the possibility

to positively communicate and receive support from their colleagues. The quantitative mediation and moderated mediation models reinforced these findings, confirming the beneficial effect of these kind of support. Moreover, a fair and shared ethical climate was depicted as another relevant factor to counterattack malaise at own workplace. These elements can exist only in context characterized by a strong team spirit in which each professional is welcomed, respected, and proactively involved on the bases of her/his discipline. Previous studies have already underlined the importance of the interprofessional teamwork in medical rehabilitation and other medical specialty in order to improve the professionals' wellbeing and satisfaction, as well as patients' outcomes (Körner, 2010; Epstein, 2014; Mao, & Woolley, 2016; Marsilio, Torbica, & Villa, 2017). Indeed, being a teamwork means acting like "well-oiled machines", thanks to a multidisciplinary staff able to cooperate and effectively communicate, breaking the so-called "silo effect" in which a strict hierarchy creates distances and incapacity to communicate between the members of the team (Epstein, 2014). Being able to cooperate and communicate with colleagues of different disciplines allows also to optimize the "collective intelligence" to promote the wellbeing of professionals, organizations, and patients (Mao, & Woolley, 2016). Thus, healthcare administration should pay attention to propose interventions and management styles which can booster teamwork and multidisciplinary. For instance, the multidisciplinary teamwork can be facilitated by an integrated system-wide perspective based on a sociotechnical approach in which the technical (e.g. devices and procedures) and social (e.g. human resources) dimensions should be managed and considered as an integrated organizational whole to deliver the co-created and shared goals set (Marsilio et al., 2017). It is also pivotal that the healthcare management rewards and valorizes the role of each member of the healthcare staff, creating occasions, opportunities and care procedures connecting people and facilitating communication and exchanges. Differently said, reaching and maintaining the positive and effective outcome on different levels (i.e. patients, sanitary systems and professionals) has to be intended as a "team sport" (Epstein, 2014) as "teams offer the potential to achieve more than any person could achieve working alone" (Mao, & Woolley, 2016; p. 933).

#### 10.7.2. Promotion of positive ethical climate for an ethical provision of care

Chapter seven unveiled the importance of an ethical approach for the provision of patients' care as this positive facet of the ethical climate diminishes moral distress and emotional exhaustion, as well as it contributes to foster wellbeing and professional efficacy. Therefore, interventions and strategies to "color" the ethical climate of hospital words with rosier nuances are strongly suggested. For instance, sharing clearly perspectives and practices may help the healthcare staff to develop a common clinical approach oriented to high-quality care and based on ethical values that are respectful not only to the patient but also to the professionals who perceive a sense of inner gratification and comfort for their profession. In this view, the mission of the healthcare organization should promote among the medical staff and medical students a care-oriented view of medical profession grounded in fair and shared values (De Valck, Bensing, Bruynooghe, & Batenburg, 2001). To this regard, a formal written ethical code of conduct may help healthcare professionals to be aligned regarding the approach to care.

Moreover, it should be increased the involvement of all healthcare professionals, and in particular of nurses, in the taking care of patients, in particular when they are on the verge of death (Hernández-Marrero, Fradique, & Pereira, 2019). Indeed, openly and clearly sharing perspectives, practices and decisions may foster a better cohesion and team spirit and, in turn, a better ethical climate at the workplace. Consequently, this condition may be a resource contributing to maintain and to refuel other resources in the professionals for fostering their wellbeing and counterattacking psychological malaise.

Overall, working as a team and aiming to provide shared high-quality care were described as a promoter of positive ethical climate in acute care wards as this supports the professionals to cope with adversities at work (Silén, Kjellström, Christensson, Sidenvall, & Svantesson, 2012). Similarly, it is conceivable that this approach might improve ethical climate also in other challenging settings such as palliative care and neurorehabilitation medicine.

## 10.7.3. Promotion of managerial support in dealing with bioethical issues

Another important element for sustaining wellbeing is to teach and train managers and superiors to be able to guarantee adequate support to healthcare professionals when dealing with bioethical issues (see chapter seven). Indeed, the exposure to high demanding and challenging situations involving ethical and moral quandaries may request even more support from superiors in respect to other situations occurring at work. For this reason, healthcare organizations should facilitate workplaces which "*support, foster, enrich and protect*" (Hobfoll, 2012; p. 229) healthcare professionals' resources not only by promoting a positive ethical climate but also by fostering managerial support in dealing with ethical dilemmas. This means allowing employees to rely on organizational resources to deal with ethical issues without depleting their own emotional energies, therefore, preventing them from emotional exhaustion (Sommovigo, Setti, & Argentero, 2019). Thus, supervisors should organize periodic sharing and mentoring sessions where healthcare professionals may openly exchange perspectives and share their negative feelings caused by tough

emotions and by the violations of personal morals and values. Moreover, in these occasions, managers should invite professionals to share also experiences of success to make them aware of one's own resources useful to deal with sensitive issues occurred at work. In doing so, a creative solution may be to organize tailored workshops in which it is possible to sharpen coping strategies to face bioethical dilemmas and to discuss clinical cases with supervisors (Thian et al., 2015). It is also recommended to schedule periodic "ethics rounds" - as an additional instrument or as an alternative to traditional ethics committee – where healthcare professionals from different disciplines can reflect on ethically difficult real or fictitious cases in order to increase their awareness for ethical issues, to define a shared approach to care, as well as to teach and training professionals' skills for taking clinical decisions (Schmitz et al., 2018). Such ethics rounds – which aim to strengthen skills required to identify, prevent and solve ethical conflicts – may consist of multidisciplinary case presentations, interviews of patients and/or their families, discussions by the staff on difficult clinical-ethical decisions and overviews by ethicists (Libow et al., 1992).

Despite the methods used to provide support in cases of ethical issues, it is of paramount importance to empower the team leaders with tailored trainings in order to turn them in guides which may provide examples and instruments to other healthcare professionals in order to cope difficulties and navigate complex moral and ethical landscapes (Shanafelt & Noseworthy, 2017). That is, the team leader should be the spokesperson of the organizational mission, being able to promote and maintain a sound climate, to offer adequate support as well as to assure high standards and ethical approach to care.

### 10.7.4. Promotion of social support (colleagues and families/friends)

Besides managerial support in dealing with bioethical issues, social support intended in broader terms was reported as a pivotal resource to emotionally sustain the healthcare professionals and the medical students in the effort for coping with problems occurring in the clinical practice (see chapters eight, nine). Indeed, the presence of an effective social support from colleagues and superiors to cope adversities was also previously described as a trigger for a more positive perception of ethical climate (Silén et al., 2012; Velando-Soriano et al., 2020) as well as a way to not succumb under the burden of adverse medical events (van Pelt, 2008; Pereira & Fonseca, 2011; Pereira, et al., 2011a; Hamama, 2019).

Thereby, it is suggested to promote leisure time activities or other occasions of conviviality for promoting the connection and mutual acquaintance among colleagues. These activities may contribute to create a team and to strengthen the team spirit, fostering mutual support and collaboration as each one perceives to be a fundamental element of a social network which is vital to buffer the distressing events and to maintain health (Uchino, 2004; Uchino et al., 2011).

Similarly, reaching a balance between time dedicated to work and time for families and private life is also important in order to cultivate relationships outside the workplace which may re-fuel the individual with resources and emotional support to face the challenging demands of the daily clinical practice.

#### 10.7.5. Promotion of resilience

As unveiled in chapter seven, resilience is a personal resource that can make the difference in the attempt to diminish moral distress and emotional exhaustion and, in the meanwhile, to foster wellbeing and professional efficacy.

Thus, healthcare organization should invest resources to promote trainings which aim to develop and strengthen resilience in healthcare professionals dealing with high demanding clinical situations. For instance, Back and colleagues (2016) proposed an acceptable, scalable, and testable multifaceted intervention tailored to palliative care professionals' needs for building resilience. The tenet of this conceptual model is that burnout is a phenomenon happening when work demands outstrip resources, while resilience is the result of a balanced interaction of personal resources with work demands. Thus, they affirmed the necessity to propose early multiple interventions focused both on the professionals and their work environment. On one hand, the authors proposed to develop eight resilience skills through specific trainings: leveraging personal strengths, tracking activation, setting healthy boundaries, regulating emotions, recognizing cognitive distortions, having realistic expectation regarding own performance, finding meaning in life and work, committing to long-term development. On the other hand, the authors recommended to improve the so called "workplace engagement factors" to create a positive environment that can support the professionals. Specifically, the following points are crucial: a) enabling control through the involvement of professionals in shared decisions, b) structuring monetary and social rewards, c) building community and the team spirit, d) fostering a culture where conflicts are openly addressed, e) recognizing fairness, f) fostering inspirational values guiding the clinical practice and balancing as much as possible workload.

Similarly, other healthcare professionals described attitudes and practices to be cultivated by themselves and by the organization for promoting resilience: cultivating contacts with colleagues as well as relations with family and friends, taking time out to dedicate to self-awareness and reflexivity, defining boundaries between themselves and others, developing an approach characterized by acceptance and realism, appreciating the good things, doing leisure-time activities

to reduce stress, fostering a culture where it is possible to openly communicate uncertainties and errors, as well as having time-out periods and a well-calibrated workload (Zwack & Schweitzer, 2013).

Moreover, in another study, palliative care professionals suggested a skill-building approach to build resilience and diminish distress based on mind-body skills interventions (e.g., yoga, meditation), health education sessions on negative effects of stress and teaching of practical strategies to reduce ruminative thoughts (Perez et al., 2015).

As resilience is considered a teachable and modifiable resource, a lot of researches and interventions have been proposed based on high-intensity programs (e.g. weekly sessions over several weeks with or without homework assignments) or low-intensity training (e.g. single session) (Kunzler et al., 2020a). According to a recent systematic review of the Cochrane library, overall these kinds of trainings seem to improve resilience skills and to reduce symptoms of depression and distress (Kunzler et al., 2020a). The same authors conducted a similar review posing attention on healthcare students and findings unveiled that resilience training may improve resilience skills and may reduce symptoms of anxiety and distress immediately (Kunzler et al., 2020b). Thus, although the generalizability of results has to be taken cautiously due to the heterogeneity of the studies conducted until now (Kunzler et al., 2020a; Kunzler et al., 2020b), trainings for building and strengthening individual resilience skills of healthcare professionals are particularly recommended in complex settings such as palliative care and neurorehabilitation medicine disciplines.

## 10.7.6. Trainings for the management of emotions and promotion of positive affectivity

Considering the negative impact of tough emotions and the beneficial effect of positive affectivity depicted in chapter seven, eight, nine, it is recommended to provide trainings for teaching healthcare professionals and medical students how to adequately deal with sufferance and negative emotions, as well as how to valorize and cultivate positive ones. To this regard, educational courses may be useful to help professionals to both take awareness of demanding feelings and to share experiences with colleagues in a dedicated space and time with an expert who can facilitate the self-awareness process and the exchange of perspectives. In addition, periodic debriefing meetings between the medical staff may be an instrument to discuss and elaborate challenging clinical cases occurred and the consequent emotions.

An interesting proposal to cope negative emotions, in particular helplessness, is provided by Back and colleagues (2015) who proposed to shift deliberately from hyper- or hypoengagement/activation toward a more balanced condition, using the so-called approach "RENEW" consisting in recognizing, embracing, nourishing, embodying, and weaving. Specifically, professionals should be helped to recognize their own feelings (mainly through somatic responses) and to embrace the body reactions, taking time to become aware of their somatic and affective responses to suffering. Then, they should nourish themselves, asking for a help from colleagues or other people outside the workplace. As the pick emotional moment is gone, professionals should be ready to experience an embody constructive engagement, that is they are physically ready to engage and emphasize with the patients again. Finally, once the body is stabilized, professionals should be pushed weaving an emotional and cognitive elaboration of what is happened, recognizing the emotional valence and meaning experienced in order to gain insight into one's own response patterns and vulnerabilities. This approach is promising as may teach and help the professionals and the medical students to not be overwhelmed by negative emotions, rather to navigate them with full awareness. Training these skills is essential to avoid an emotional erosion and to preserve resources for facing adversities occurring in the clinical practice with patients on the verge of death or suffering from life-threatening conditions.

Besides this, positive affectivity may be fueled by an organizational culture which considers errors as learning opportunities and by supporting employees when critical events occur. Moreover, it is possible to encourage professionals to experience positive emotions through specific programs. For instance, brief problem-solving training sessions may increase the individual perception of control over their workplace, instilling more problem-solving self-efficacy, greater positive affect and higher job and life satisfaction (Ayres & Malouff, 2007). Furthermore, some "present moment awareness training paradigms" carried on through different techniques of meditation may sustain wellbeing as these activities teach professionals to focus and t full-experience the present moment, containing energy-consuming recursive thoughts and worries for future events (Nasser & Przeworski, 2017).

### 10.7.7. Trainings for effective communication skills and conflicts management

Communication difficulties related to the disclosure of a poor diagnosis and prognosis has been depicted as a relevant matter of concern (see chapters eight, nine). As a consequence, it is of paramount importance to provide medical students and healthcare professionals with adequate communication skills which are pivotal in sensitive and complex disciplines such as palliative care and neurorehabilitation medicine.

The third update of a review published in the Cochrane Library, investigated the different kinds of communication skills courses described in the literature and the findings showed that, despite the fact that further research are needed to determine the most effective training programs, courses on

communication seem to be effective in improving communication skills and self-efficacy of healthcare professionals who may learn to provide information, offering support and without being influenced by the emotional reactions of patients and caregivers (Moore et al., 2018). The most adopted programs are constituted by multifaceted workshop activities ranging from theoretic bases of the communication process and of breaking bad news to role-play scenarios guided by expert facilitators which invite the participants to discuss their concerns and perspectives (Baile et al., 1999; Fukui, Ogawa, Ohtsuka, & Fukui, 2008; Moore et al., 2018). Furthermore, the American Institute for Professionalism and Ethical Practice developed periodic forum based on its Program to Enhance Relational and Communication Skills (PERCS) (Rachwal et al., 2018). Each meeting called PERCS rounds - is a dynamic, monthly educational forum that addresses the educational and support needs of interdisciplinary healthcare teams by providing an occasion for undertaking collective and facilitated discussion about real or fictitious relationally challenging situations occurring at workplace. Although this program has been created for critical care settings, it is conceivable to be a possible effective training also in other challenging healthcare settings such as palliative care and neurorehabilitation medicine. Overall, it is noteworthy that long or intensive trainings, follow-up trainings and formats including role-plays and conversations with simulated or real patients seemed to be the most effective kind of trainings to enhance communication skills (Bos-van den Hoek, Visser, Brown, Smets, & Henselmans, 2019).

In addition, specific protocols for delivering bad news have been developed for guiding healthcare professionals step-by-step to manage this sensitive task. For instance, the protocol called SPIKES suggests to follow some steps for enabling the professionals to successfully disclose bad news: gathering information from the patient, communicating the medical information, providing support to the patient, and prompting the patient's collaboration to take a shared decision regarding a possible treatment plan (Baile et al., 2000; Fujimori et al., 2003).

Educational curricula for healthcare students should include these kinds of trainings focused on the development of communication skills in order to provide the students and the future clinicians with adequate skills, confidence and self-efficacy in communicating clinical information and delivering bad news. Similarly, healthcare professionals may benefit from periodic workshops to tune and ameliorate their communication skills to cope with difficult and sensitive situation occurring in the clinical practice characterized by an increasing complexity (Fallowfield & Jenkins, 1999; Rachwal et al., 2018).

## 10.7.8. Reinforcement of meaning

Interventions aiming to reduce workplace distress in palliative care and demanding clinical settings should not neglect to consider the valance of meaning-making as a crucial factor for maintaining professionals' wellbeing as described in chapters five, eight and nine of the current dissertations. Specifically, healthcare organizations are recommended to consider meaning making as an active coping strategy to cope with unwanted and unchangeable events occurring in the clinical practice. Thereby, interventions training to consciously perceive the significance of what healthcare professionals are doing or experiencing are pivotal for the empowerment and the restoration of resources threatened by the constant exposure to death and sufferance. An interesting example of effective intervention is provided by Fillion and colleagues (2009) who adapted for nurses a meaning-centered group intervention (MCI) grounded in the Viktor Frankl's logotherapy approach (Frankl, 1963). This program was developed over four weekly meetings. The first one aimed to clarify what has to be intended with the concepts of "meaning" and "sources of meaning". The second session had the scope to lead participants to find "own meaning" through a sense of accomplishment at work or elsewhere and through one's own goals and wishes. The third meeting helped nurses to consciously ponder their experiences in touch with suffering patients, paying attention to their reactions. During the last session, the task was the interpretation of emotionfilled experiences as a possible source of meaning helping to safeguard oneself from exaggerate sufferance and tough emotions.

Overall, the healthcare context should sustain professionals to develop personalized self-care strategies within professional and non-professional contexts in order to appreciate the present moment and to find the "meaning" which may trigger wellbeing and professional efficacy at work (Mills, Wand, & Fraser, 2018).

### 10.7.9. Better organization for fostering work-family balance

As reported by healthcare professionals and medical students in chapters eight and nine, maintaining a balance between work and private life is a pivotal element for fostering wellbeing. For this reason, healthcare organizations should welcome actions and strategies to enable professionals to cultivate both the professional career and their own private life.

To this regard, Shanafelt and colleagues (2008) postulated some principles to promote work-life balance in the medical environment. First of all, it is important to minimize clerical work and other administrative chores which are not in line with professionals' vocation and training. In addition, work tasks should provide challenges calibrated with individual skills, interests, and resources in order to do a trigger for growth and not a matter of distress and anxiety. Professionals should have more control and flexibility over their schedule, too. Overall, it is fundamental to guarantee a culture which encourages and gives value to both professionalism and life outside of work, such fostering wellbeing and professional satisfaction of each healthcare professional.

Again, other authors suggested to improve a positive connection between work and life aspects, through minimizing job-related stressors and ameliorating organizational culture, as well as providing support structure and occasions of training and learning (Varma, Kelling, & Goswami, 2016). For instance, a calibrated workload and an adequate number of healthcare professionals in the medical staff may enable the individual to preserve time and energies to invest outside the workplace. Similarly, supportive managers and the possibility to learn new skills and knowledge may empower the professionals who so develop the adequate resources to cope with job demands, without stealing time and attention to private life.

Furthermore, relaxation trainings offered during breaks or shift change may be another strategy to sustain healthcare professionals in the attempt to keep work and private life separated. Indeed, these kinds of courses may teach individuals how to reduce the reverberation of concerns related to work outside the working time (Michel, Bosch, & Rexroth, 2014).

## 10.7.10. Providing guidelines to support clinical practice and decisions

Another suggestion is related to provide healthcare professionals and medical students with written code of conduct and clinical practice, as well as with guidelines. In this way, the individual knows exactly what is expected by the healthcare organization and by the overall healthcare system. This awareness may empower the individual with the adequate information and instruments to properly act, without being distressed by concerns and uncertainties.

Moreover, as described in chapter eight, within sensitive contexts which manage negative prognosis and life-threatening conditions, advance directives may be a valuable tool enabling the professionals to navigate between the complex scenario of living wills and life-sustaining therapies. Indeed, advance directives can help and guide the professionals in the decision-making process according to the patient's wills (Pereira et al., 2011b).

#### 10.7.11. Investment on protective factors and strategies to mitigate distress and burnout

Overall, it is noteworthy to suggest healthcare organizations to invest human and economic resources in enhancing factors which was unveiled by the literature as valuable stress attenuators. Indeed, some risk factors are intrinsic to complex medical profession such as the exposure to death and dying and the necessity to take ethical decisions, so that a certain amount of distress cannot be avoided (Pereira et al, 2011a; West et al., 2018). However, environmental and subjective protective

factors may equip the professionals with the adequate resources and conditions to cope and face with difficulties of their clinical practice, mitigating (moral) distress and burnout, as well as safeguarding their own wellbeing. Regarding this, the previous literature has unveiled manifold protective factors and this research project has contributed to deepen the knowledge, showing some relevant relationships and mechanisms through the lens of a parsimonious and full-explaining conceptual model.

Bearing in mind these knowledges, healthcare systems should propose preventive and supportive interventions tailored on the specific needs of each medical staff. A preliminary analysis of the context, of its characteristics and criticisms are fundamental in order to consciously prioritize some interventions and actions, optimizing investments and positive outcomes. Effective results to counterattack distress and burnout are indeed obtained using holistic approaches which address the issues to different perspectives and through different tools for respond in the best way possible to all risk factors which are present in the workplace (Wiederhold, Cipresso, Pizzioli, Wiederhold, & Riva, 2018).

#### 10.8. Overall limits and strengths

The manifold contributions of the current dissertation need to be interpreted in the light of its limitations.

Firstly, all investigations were based on self-report measures without considering other objective variables of burnout and psychophysical malaise such as clinical and organizational indicators (e.g. medically certified sick-leave absences, absenteeism; turnover rate) (Toppinen-Tanner, Ojajärvi, Väänänen, Kalimo, & Jäppinen, 2005). Future studies should therefore integrate various information sources to provide different perspectives. However, it has to be said that the current research adopted different kinds of self-reported measures, that is questionnaires and interviews. This approach allowed to minimize possible biases linked to a specific data collection method. Thus, interviews allowed to provide quantitative responses with a meaning grounded in the real experience, whereas questionnaires allowed to overcome possible interviewer biases (Salazar, 1990).

Secondly, the sample involved in the quantitative part of the project was heterogeneous in term of numerosity (palliative care vs neurorehabilitation medicine professionals) and sociodemographic characteristics. However, the sample' characteristics were representative of the Italian healthcare workforce (OECD, 2019). Similarly, interviews were conducted only with professionals employed in palliative care discipline. The interviewed students constituted a little sample, too. Future studies should therefore include a less heterogenous and bigger samples in order to validate the current findings.

Thirdly, the non-longitudinal nature of the current research project prevented causality inferences. Future studies should use longitudinal designs and should measure possible variances of the outcomes along the time in order to better tune the model proposed and deepen the understanding of the relationship of variables under investigation. Moreover, future replications are recommended to adopt a research-intervention approach in order to test the theoretical model proposed in real healthcare contexts for verifying its acceptability and efficacy, in an attempt to translate into practice the manifold findings unveiled (Sekhon, Cartwright, & Francis, 2017; O'Cathain et al., 2019). Thereby, the choice of a longitudinal design will enable to quantify the effects of interventions proposed, having more information to rethinking and project further theoretical and practical steps.

Fourthly, the response rates of some Institute were not very satisfactory and future research should find new strategies and motivational triggers to booster the participation (Nulty, 2008). However, having collected the data from different organizations should have minimized as much as possible the biases (e. g. recent personnel reorganization) linked to a single Institute, potentially impacting on the response rate. Moreover, the participation levels registered may be considered acceptable as the previous literature described response rates around 50% as satisfactory (Richardson, 2005). In addition, these response rate should be read through the lens of a general trend within the social science research reporting a decrease of voluntarism to take part in scientific research in the last decades (Morton et al., 2012).

Similarly, some Cronbach's alphas adopted as internal reliability consistency index of the different subscales were quite low. However, it has to be said that only the dimensions with a fully satisfactory internal reliability consistency index (i.e. ranging from .70 to .95) were considered to carry on the analysis presented in the present dissertation. Moreover, the Cronbach's of alphas reported in this research are in line what already showed by the Italian validation papers addressing different populations.

Fifthly, because of various hindrances and delay in the implementation of the research protocol abroad, this dissertation reports data from Italian healthcare professionals only. It would be interesting to compare Italian data with those provided by the other countries initially agreeing to take part into the project. Indeed, as the healthcare systems of countries differ each other, it would be informative to detect similarities and differences to better understand and sustain the career of the healthcare professionals working in high demanding clinical context. Data provided by different nations would increase the generalizability of the findings, too. However, it has to be underlined that the quantitative part of the current research protocol is actually in progress in Portugal. Therefore, comparisons of Italian and Portuguese data will be possible in the near future.

Besides these limits, the current project has manifold strength points.

Firstly, this project offers an original contribution to the existing literature on risk and protective factors for healthcare professionals by adopting a multimethod design which capitalize the strengths of quantitative and qualitative methods, providing a full comprehensive understanding of the complex healthcare context (Andrew & Halcomb, 2009; Östlund, Kidd, Wengström, & Rowa-Dewar, 2011; Strudsholm, Meadows, Robinson Vollman, Thurston, & Henderson; 2016). Specifically, this project is one of the still few researches approaching the study of the healthcare workforce thought different methodological perspectives. Considering that palliative care and neurorehabilitation medicine are multifaceted scenarios, the investigation of the research questions through quantitative and qualitative methods enables to gain a more detailed picture of the real experience (Morse, 2003). Thus, quantitative investigations tested some hypothesized relationships between relevant variables suggested by the previous literature. Concurrently, qualitative studies have been also conducted to add other nuances of meanings to the subjective experiences provided by healthcare professionals. Due to the increasing complexity of the present and future healthcare landscape, it is worldwide recognized the necessity to choose a multimethod approach to deepen the understanding of certain delicate issues.

Secondly, the significance of this dissertation lies in addressing palliative and neurorehabilitation medicine disciplines by investigating organizational and individual variables through the lens of COR theory (Hobfoll, 1989; Hobfoll et al., 2018). It is a well-established parsimonious and full-comprehensive model of stress based on resources, as well as a motivational theory. In doing so, we extended and enriched the existing literature by unveiling possible mechanisms and relationships of the variables investigated within a unique theoretical framework which provides useful suggestions for practical preventive and supportive interventions. To this regard, an overall model inspired by the tenets of COR theory (Hobfoll, 1989; Hobfoll et al., 2018) is provided in an attempt to suggest a useful theoretical framework to better tailor future supportive actions for the wellbeing of healthcare professionals. Specifically, as far as I know, this is the first dissertation to unveil the mediation of moral distress in the relationship between ethical climate (i.e. ethical vision of patient care and managerial support in dealing with bioethical issues) and emotional exhaustion within professionals employed in neurorehabilitation medicine. For the first time it was also examined the buffering role of positive affectivity and resilience in the aforementioned association. Similarly, considerable progress has been made by showing how resilience may be considered a relevant resource for maintaining wellbeing and professional selfefficacy within palliative and neurorehabilitation medicine professionals both directly and indirectly, as mediated by ethical vision of patient care and moderated by managerial support in dealing with bioethical issues.

Thirdly, another strength point is the investigation of both individual (e.g. resilience, positive affectivity) and environmental variables (e.g. ethical climate facets) into the same research project. Specifically, the attention has been put on possible relationships and crossover processes among individual and context, as well as between different resources. To this regard it is worthy to highlight once again the efficacy of COR theory (Hobfoll, 1989; Hobfoll et al., 2018) which provides a theoretical framework able to explain in an ecological way the real experience.

Fourthly, this research project takes an important step forward in providing the Italian researchers with a first psychometric evaluations of the Hospital Ethical Climate Survey (Olson, 1998). This instrument is worldwide the most used tool for the assessment of ethical climate, originally developed for nurses. However, to the best of my knowledge, the Italian version of this instrument was still lacking. Additionally, at an international level, a well-recognized multiprofessional instrument to assess ethical climate is still missing. Thus, this dissertation attempted to bridge these gaps providing a preliminary Italian version of this instrument, rewording some items in order to develop an inter-professional instrument suitable for all healthcare professionals. Its factor structure was checked through exploratory factor analysis (EFA) and the emerged factor structure was confirmed using confirmatory factor analysis (CFA). Future studies are recommended to further validate the Italian version of this instrument. Moreover, it has to be underlined that this version could be adapted and validated in other national contexts, so turning to be a possible gold-standard tool to assess ethical climate on a multi-professional level. Indeed, this issue plays a pivotal role in the healthcare landscape as bioethical and moral quandaries are constantly increasing due to the medical and technological advancements.

Fifthly, the relevance of this contribution lies also in the fact that this project is a multicentric study, namely it involved different institutions in the North and in the Centre of Italy. In doing so, the dissertation overcomes possible biases that can be linked to the characteristics of a single context, promoting the generalizability of these findings to all Italian palliative care and neurorehabilitation settings. Moreover, in the next future, it hopefully will be possible to integrate these conclusions with data collected in Portugal where the project is still in progress. In doing so, the generalizability of the results will be extended.

Sixthly, this dissertation contributes to our knowledge beyond the existing literature on risk and protective factors for healthcare professionals working in palliative and neurorehabilitation medicine disciplines suggesting a life-span interpretation of results. Indeed, the participants of this project comprised also medical students taking care of patient with life-threatening conditions. Although they were involved only into the qualitative part of the research, they described factors similar to those unveiled also by professionals. Thereby, it is conceivable that some issues are sensitive elements deserving maximum attention along all the professional career, since the start of the profession as medical student. In the meantime, only students shed light on specific topics such as the awareness of knowledge increasing and the possibility to learn from errors, suggesting that these factors may be particularly crucial at the beginning of the career.

Finally, the overall novelty and strength point of this project can be found in the fact that the focus is put on moral and bioethical issues which are drawing the worldwide attention. For this reason, professionals employed in challenging and demanding contexts such as palliative care and neurorehabilitation medicine were invited to part take in the research. Bioethical issues are indeed a very sensitive theme as the healthcare landscape is changing and new dilemmas are arising, threatening the wellbeing of healthcare professionals and, in turn, of the entire healthcare system (Andrews & Crisp, 2017; Castlen et al., 2017; Johnston, 2018; Leuter et al., 2018). Therefore, it is of paramount importance to investigate these new aspects and to be able to detect as soon as possible healthcare professionals' problems and needs in order to suggest tailored actions for their safeguard.

#### 10.9. Conclusions

Healthcare professionals' wellbeing is more and more often threatened in the actual sanitary context. This issue is particularly sensitive for who is employed in complex medical disciplines because medical and technological advancements pave the way to new demanding clinical tasks and bioethical quandaries. This dissertation addressed the professionals employed in palliative care and neurorehabilitation medicine, describing a confluence of self-perceived factors which may impact on their wellbeing, such as the contact with sufferance and tough emotions, possible interpersonal conflicts and communication difficulties, challenging decision-making processes and moral distress. Overall, these risk factors may be potential triggers of resource loss spirals.

However, this project has also shed light on manifold protective factors which may support the healthcare professionals to maintain adequate resources to overcome adversities occurring during their work. In particular, ethical climate (ethical vision of patient care and managerial support in dealing with bioethical issues) was negatively related to emotional exhaustion, directly and through moral distress. Moreover, professionals showing high levels of resilience and positive affectivity benefited more from the protective effect of managerial support on emotional exhaustion through moral distress. Besides this, resilience improved wellbeing and professional self-efficacy, directly

and indirectly, as mediated by ethical vision of patient care. In addition, it was unveiled that highly resilient professionals take more advantage from the positive effect of ethical vision of patient care on wellbeing, in presence of high managerial support. Finally, participants pointed social and family support, work-life balance, meaning in life and of work and advance directives as further protective factors contrasting the depletion of resources.

Overall, these findings enrich the knowledge and awareness of risk and protective factors for the professionals working in palliative care and neurorehabilitation medicine. Preventive and supportive interventions should be focused on these elements in order to effectively counterattack the malaise of this healthcare workforce. For instance, educational trainings for promoting adequate communication skills, positive personal resources (e.g. resilience and positive affectivity), and some organizational facets (e.g. ethical climate) are strongly recommended. Similarly, the promotion of occasions for openly discuss and the rediscovery of the meaning of work may be other crucial elements for these professionals. Indeed, providing tailored and effective actions based on the professionals' needs may be the winning card for promoting the individual's wellbeing and, in turn, the wellbeing of the entire healthcare systems.

## 10.10. References

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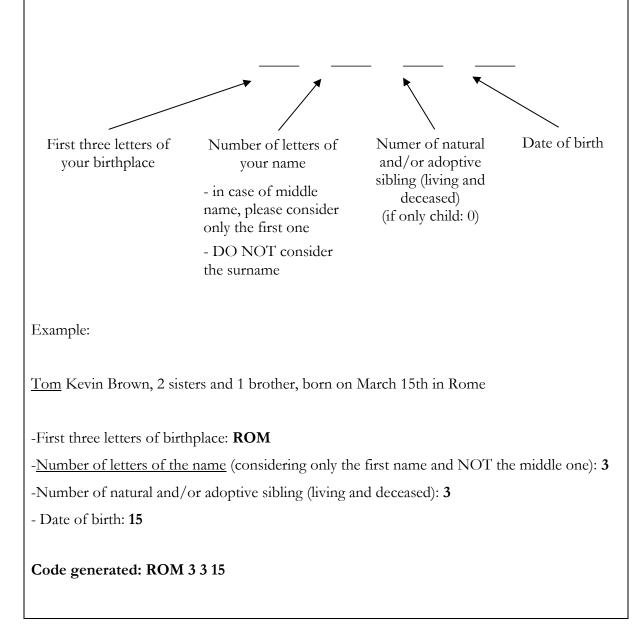
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# APPENDICES

## Annex 1 - Self-generated code

Before starting, we ask you to pay attention on the following questions in order to create a univocal code that collects all your answers. It will NOT be possible to trace your identity. Anonymity of your answers is guaranteed.

Please, generate the code following the indication written in the box:



Note. This box and has been presented to respondents in Italian language.

# Annex 2 - Professional and socio-anagraphic data requested

## Age

- $\circ$  < 40 years old
- o 41-50 years old
- o 51-60 years old
- $\circ$  > 60 years old

# Gender

- 0 Female
- 0 Male

# Education

- o Middle school diploma
- o High school diploma
- o Bachelor's degree
- o Master's degree
- o Post graduation (Phd, other high-specialization)

# Occupation

- o Physician
- 0 Psychologist
- o Nurse
- Therapist (phisiotherapist/occupational therapist/ dietician/speech therapist)
- o Social-healthcare practitioner

# **Overall seniority**

- $\circ$  < 5 years
- o 6-15 years
- o 16-25 years
- o 26-30 years
- $\circ$  > 30 years

# Overall seniority in current occupation

- $\circ$  < 5 years
- o 6-10 years
- $\circ$  > 10 years

# Shift work

- o Yes
- o No

# Work contract

- o Open-ended
- o Fixed-term
- o Temporary/ Co-op/ VAT registration

# Extra-working stressful events in the last year of life

- o No
- 0 Yes

Id yes, specify, if you want:

Note. These questions have been presented to respondents in Italian language.

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