



Compassion in palliative care: a review

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Purpose of review

Compassion has been recognized as a key aspect of high-quality healthcare, particularly in palliative care. This article provides a general review of the current understanding of compassion in palliative care and summarizes emergent compassionate initiatives in palliative care at three interdependent levels: compassion for patients, compassion in healthcare professionals, and compassionate communities at the end of life.

Recent findings

Compassion is a constructive response to suffering that enhances treatment outcomes, fosters the dignity of the recipient, and provides self-care for the giver. Patients and healthcare professionals value compassion and perceive a general lack of compassion in healthcare systems. Compassion for patients and for professionals' self-care can be trained and implemented top-down (institutional policies) and bottom-up (compassion training). 'Compassionate communities' is an important emerging movement that complements regular healthcare and social services with a community-level approach to offer compassionate care for people at the end of life.

Summary

Compassion can be enhanced through diverse methodologies at the organizational, professional, and community levels. This enhancement of compassion has the potential to improve quality of palliative care treatments, enhance healthcare providers' satisfaction, and reduce healthcare costs.

Keywords

compassion, compassionate communities, empathy, palliative care

INTRODUCTION

Compassion has been regarded as an important human value for millennia; however, only in the last few decades, compassion has become a focus of interest in scientific research, [1,2,3[■],4,5]. More recently, the field of medicine has seen a growth in interest in compassion as a key aspect of person-centered healthcare, partially as a response to a perceived decrease in compassion in healthcare systems across countries, which affects patients, family members, and healthcare professionals [6–8]. Compassion is at the heart of palliative care [9] but scientific research on compassion in palliative care is still at its infancy [10]. This article provides a review of the science of compassion in palliative care, and presents applications of compassion in treating patients, training professionals, and engaging communities.

WHAT IS COMPASSION?

Compassion can be defined as a sensitivity to the suffering of self and others with a commitment to prevent it and relieve it [11–14]. As a complex and multifaceted response to suffering, compassion

involves sensitivity, recognition, understanding, emotional resonance, empathic concern, and distress tolerance for another's pain or suffering, coupled with motivation, and relational action to ameliorate it [15,16].

Two recent grounded theory studies aimed at identifying how compassion is defined by palliative care patients and palliative care providers. Palliative care patients understand compassion as a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action [17[■]]. For these patients, compassion is an inherent quality in some healthcare professionals but it could also be trained [18[■]]. In the study with healthcare professionals, the theory that emerged posited that compassion is a virtuous and intentional response to know a person, to discern their

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KEY POINTS

- Compassion, sensitivity to suffering, and the motivation to relieve it or prevent it in oneself and others, is a key aspect of high-quality palliative care, and is perceived as a need by patients, families, and healthcare professionals.
- There are several factors that could block compassion in palliative, including moral distress, economic pressures, work overload, toxic organizational cultures, lack of adequate communication and compassion training, and lack of self-care.
- Uncompassionate care, in addition to its negative effects in patients and families, may result in detrimental economic, legal, and public image consequences for healthcare providers.
- There are several evidence-based top-down (institutional policies) and bottom-up (compassion training) that can be implemented to enhance compassion in the healthcare system and palliative care.
- Compassionate communities are a worldwide fast-growing movement that involves community in caring for people at the end of life.

needs, and ameliorate their suffering through relational understanding and action [19].

Compassion differs from empathy, sympathy, and pity. While empathy is the affective and cognitive capacity to resonate and understand the other person's inner state, sympathy involves being emotionally drawn into the suffering of the other but, in this response, the empathic accuracy may be loose, therefore, emotions ignited by sympathy may not match those of the object of sympathy [10,20,21]. While compassion involves perceiving the other person from the perspective of 'shared common humanity' [11] (i.e. the receiver of compassion is perceived as a vulnerable and resourceful human being just like the giver), pity implies feeling sorry for another person that is perceived as being weak and inferior. Compassion includes and transcends emotional and cognitive empathy by adding the motivation to do something to relieve or prevent suffering [11]. In a recent qualitative study with palliative care patients in Canada [10], it was found that patients clearly distinguished empathy, compassion, and sympathy in their healthcare providers, and unequivocally rejected sympathy (which they understood as a pity-based response) while valuing empathy and compassion as desired qualities in their healthcare team. Compassion is a helpful response to suffering that preserves and nurtures the dignity of the recipient [17,22,23].

According to Gilbert *et al.* [16], there are three trainable flows or directions of compassion: from self to self, from self to others, and from others to self [24]. This view provides a useful framework to integrate compassion for patients and take better care of healthcare professionals and caregivers. According to this perspective, it is the flow in these three directions what nurtures compassionate cultures, making compassion sustainable, and a buffer against burnout and empathic distress. This resonates with Foucault's view that to take care of others, one must learn to take care of oneself first [25].

DOES COMPASSION CAUSE FATIGUE?

The term compassion fatigue, which has been used interchangeably with the terms secondary traumatic stress and compassion stress, was defined by Figley [26] as 'the natural consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other – the stress resulting from helping or wanting to help a traumatized or suffering person.' The concept has been recently questioned and deemed problematic both in theoretical and practical terms [27,28]. Healthcare providers do suffer from stress, burnout, and secondary traumatization. However, to suggest that their compassion is the main or only cause of these phenomena could undermine the attempts to understand other causes of suffering and generate adequate preventive and coping strategies to work-related stress and burnout. If compassion was the main cause of compassion fatigue, exceptionally compassionate carers would be more susceptible to compassion fatigue, which does not seem to be the case [28].

The most widely used instrument to measure compassion fatigue worldwide, The Professional Quality of Life Questionnaire [29], does not assess any element of compassion and understands compassion fatigue as the composite of burnout and secondary traumatic stress, a negative feeling driven by fear-related and work-related trauma. Recent research has also questioned the psychometric properties of the Compassion Fatigue subscales of the ProQol [30,31]. By labelling burnout and secondary stress as 'compassion fatigue,' researchers are (perhaps unknowingly) pointing to compassion as the cause of fatigue, which reaffirms Figley's view that compassionate caring is costly. This line of reasoning seems to suggest that less compassion would lead to decreased fatigue, which goes against the need expressed by patients, families, and professionals to increase compassion in healthcare [10,18,27]. There is also the risk of misunderstanding the actual causes of healthcare providers' suffering, which may include, but are not limited to,

moral distress [32], economic pressures [33], toxic organizational cultures [34,35], work overload and job insecurity [28³³,34,36].

Recent neurological research has shown that empathy and compassion present differential brain activation patterns. Although empathy for pain activates the anterior midcingulate cortex and anterior insula, compassion activates areas related with positive affect and feelings of wellbeing associated with love and caring, including the ventral striatum, pregenual cingulate cortex, and medial orbitofrontal cortex [37–39]. These differential activation patterns are coherent with the psychological difference between empathy and compassion, suggesting that empathy alone can lead to empathic distress, whereas compassion can serve as a buffer that prevents empathic distress and burnout. In fact, research on the effects of compassion training also show that participants in these trainings enhance psychological wellbeing, empathic concern, compassion for self and others while decreasing empathic distress, depression, stress, and anxiety [40–45].

In short, although there are now dozens of studies reporting the prevalence of compassion fatigue in medical doctors and nurses, this widely used concept does not seem to be psychologically, neurologically, or psychometrically related to compassion and might not be the best way to understand and address the suffering of healthcare providers and caregivers.

COMPASSION FOR PATIENTS

Both patients and healthcare providers value compassion. In a large survey with 800 physicians and 510 patients at the Center for Compassionate Healthcare, researchers found that 85% of patients and 76% of physicians said that compassionate care was ‘very important’ to successful medical treatment. However, only 53% of patients and 58% of physicians said that the healthcare system generally provides compassionate care [46]. Patients’ perception of healthcare providers’ compassion has been correlated with increased immune responsiveness, reduced hospitalizations, decreased intensive care utilization at the end of life, and better psychological adjustment for cancer diagnosis [15,46]. Uncompassionate care, in addition to its negative effects in patients and families, may result in detrimental economic, legal, and public image consequences for healthcare providers [3³³,7,8,20,47,48]. Thus, healthcare institutions are increasingly interested in patients’ perception of their healthcare providers’ compassion or lack thereof. One good example of a new measure developed to evaluate this perception is The Schwartz Center Compassionate Care Scale

[15], which asks patients how successfully their doctor strive to understand their emotional needs and treats them as a whole person.

Although palliative care patients see healthcare professionals’ compassion as a quality that is to a degree innate and nurtured by life experiences prior to professional training, they also see it as a skill that can be trained and enhanced experientially through person-centered communication skills, reflective practice, and compassionate role-modeling [18³⁴]. The result of such training, from the patients’ perspective, would include: enhanced skills to build relationships, enhanced capacity to understand the patient as a human being (and not just as a disease’s host), and the capacity to connect emotionally.

Three interesting frameworks that have been developed to care for the whole patient and not just the disease in palliative care are Dignity Therapy, Spiritual Care, and Meaning Making. Dignity Therapy, a brief individualized psychotherapy, aimed at relieving emotional and existential suffering in the face of a life-threatening disease. In this context, patients explore their core values, important life experiences, and what they would like to recall and communicate to loved ones with a Dignity Therapy-trained healthcare professional. A recent systematic review of 28 high-quality Dignity Therapy studies showed that Dignity Therapy was well accepted by patients and had several benefits, including significant decreases in anxiety and depression, improvements in existential and psychosocial, and a better end-of-life experience, according to patients, relatives, and professionals [49].

Another approach to compassionate palliative care, Spiritual Care, involves identifying the spiritual needs of patients and intentionally addressing them. A recent qualitative study with palliative care nurses in New Zealand [50] highlighted the following themes: individuality and respect; connection; love and compassion; meaning, touching and presence; communication; divine-related spiritual care provision and referral; death preparation and post-mortem spiritual care. The nurses in this study highlighted the importance of focusing on the individual patient and developing a relationship that enabled the patient’s unique spiritual needs to be met. This is a common factor across different compassionate interventions: while there must be a structure to implement the specific strategy, the treatment should be fully individualized for the patients to feel seen as an individual person and not as just another patient.

Intimately related to spiritual care is Meaning Making, a process of redefining one life’s meaning in

the face of a life-limiting illness. A recent qualitative study with palliative care patients [51] suggests that patients who are able to redefine their perspective and cope better with existential distress find meaning in family relationships, the connection to friends, and a change in compassion towards others. According to this perspective, meaning is generated when individuals view their lives as significant and purposeful and this is influenced by their relationship with others, including their healthcare providers.

COMPASSION IN HEALTHCARE PROFESSIONALS

Several recent reports and studies have shown that there is a state of unease in the medical and nursing professions. In a recent survey with more than 17 000 medical doctors in the United States, 49% of them often or always experience feelings of burnout, 49% would not recommend medicine as a career to their children, and only 13.9% perceived they had the time they needed to provide the highest quality of care [52]. Similarly, a recent survey of 30 000 nurses revealed that 53% felt 'upset/sad' as they could not deliver the level of care they wanted [53]. Compassion interventions for healthcare professionals involve recognizing their suffering, understanding what blocks the three flows of compassion in them, and the intention to relieve and prevent their suffering.

One common way compassion can be blocked in palliative care professionals is moral distress, which occurs when individuals feel they cannot act in accordance with their deepest beliefs and values because of hierarchical or institutional constraints. Chronic moral distress result in emotional exhaustion and burnout, affecting job satisfaction and generating the belief that their work is futile, which in turns decreases their empathy and enhances dehumanization.

Successful ways of coping with moral distress include formal and informal conversations with colleagues and superiors about the emotional and ethical challenges of providing care at the end of life [32,48]. The Schwartz Center Rounds (SCR) is one relevant form those compassionate conversations are becoming a reality. The SCR are spaces in which a multidisciplinary forum of caregivers shares social and emotional aspects inherent to patient care. The SCR began in one hospital in 1997 and now are implemented in more than 400 health centers in the United States and in 135 cities in other countries [54,55]. The SCR are usually focused on one case or one topic that involves complex emotional issues, and then a panel of three or four staff who are involved in the topic presented take turn in sharing

their experiences. The participants are then invited and supported to tell and explore their stories, to listen, be curious about and reflect on those of others and to make connections between them. Several systematic evaluations of the SCR have found that they increase openness with colleagues, normalize emotions, reduce isolation, provide support, facilitate more compassionate care with patients, and improve inpatient care, develop a shared purpose, and change hospitals' cultures [56,57,58–61]. Other initiatives aimed at creating spaces that support health-care providers in offering compassionate caring while also providing a space for self-care and emotional support include the Balint groups [62,63] and the Caring Conversations Framework [64].

Along with the importance of peer support groups to elicit meaningful conversations, the use of rituals has a positive effect in palliative care professionals. A recent survey with 390 hospice staff and volunteers showed that those who used personally meaningful rituals had higher compassion satisfaction and lower burnout than those who did not use rituals. Rituals described by participants included attending the funeral of patients, calling the bereaved to offer condolences, writing a poem or journaling, lighting a candle or saying a prayer, walking in a forest or near a beach, or simply picturing the deceased and wishing them well on their 'next journey' [65].

Interventions that train mindfulness and compassion skills are also emerging as a promising strategy to develop self-care in palliative care professionals and to enhance their relational skills. In one recent study [66], palliative care professionals participated in an 8-week mindfulness and compassion program that included meditation practice, communication skills, and value clarification exercises. Prepost measures showed a significant decrease in depressive symptoms, depersonalization, post-traumatic stress disorder (PTSD) re-experiencing, and cognitive fusion. In another pilot study [67] with medical providers who care for children facing life-threatening illness or bereaved children, a nine-session multimodal mindfulness program also reduced depressive and PTSD symptoms. Another intervention that combined mindfulness, metta (a meditation practice to enhance loving-kindness) and tonglen (a meditation that fosters self-confidence, courage, and altruism) in a 10-week training with members of a palliative care team, found that participants improved in anxiety, stress, two dimensions of burnout (emotional exhaustion and personal accomplishment), emotional regulation competencies, and joy at work. Participants also reported enhanced self-care, integration

of mindful pauses in work routine, a reduction in rumination, and patient-related distress and enhancement of communication skills [68]. Although these are pilot interventions with relatively small samples, the promising outcomes and high acceptability of the trainings grant further research in this direction.

COMPASSIONATE COMMUNITIES AT THE END OF LIFE

The emergent Compassionate Communities movement is based on the motivation of communities to take more responsibility in their own healthcare and to take better care of people at the end of life [69¹¹]. This view was articulated in the Ottawa Charter [70], which defines the promotion of health as the way to provide individuals with the necessary means under equal conditions to improve their health and exercise greater control over it. To achieve an adequate state of physical, mental, and social well being, an individual or group must be able to identify and fulfil their aspirations, satisfy their needs and change or adapt to their environment.

Community involvement is core to the model of provision of services aimed at raising awareness and involving society in the care and accompaniment of people with advanced chronic disease or at the end of life. Compassionate communities are motivated by caring for other community members at the end-of-life improving quality life for patients and their family members. The development of compassionate communities and cities is a new focus of public health oriented towards creating or activating internal and external support networks [71¹²], complementing healthcare and social services [72].

The Compassionate Communities movement, driven by the Public Health and Palliative Care International (PHPCI) from the Compassionate City Charter [73] is currently expanding and being implemented in models of care in several countries, including United Kingdom [74], Ireland [75], India [76], Canada [77], Australia [78], Latin America, and Spain [79]. This movement brings together healthcare providers, social workers, volunteers, and the community (including family members, friends, neighbors, and co-workers), to support palliative care patients and their families.

At a broader organizational level, this community-level approach also involves working with schools, universities, companies, healthcare and social services providers, community organizations, third sector organizations, administrations, municipalities, and governments. The organizations committed with a public health approach to palliative care seek to integrate three levels of bio-social support: a population health approach that involves

community development and education; a strong primary care service that implements the initial evaluation, support, and intervention, and; a third level that involves specialized professionals and centers such as hospitals, clinics or, in the case of palliative care, hospice-type centers [69¹¹,80]. This perspective challenges the traditional view in which palliative care is exclusively delivered at the tertiary level. The PHPCI puts the focus of palliative care services on the primary services (i.e. general practitioners, community nurses) that can provide an initial assessment and share responsibilities with specialized services to provide better care and comprehensive interventions for people at the end of life.

In the context of this new paradigm of people-centered care models, palliative care could become an example of how to integrate excellent healthcare services, social services, and the community. This requires a new kind of dialogue between healthcare organizations and policy makers in the design, development, and evaluation of compassionate communities, a dialogue that could transform health and social services, reducing costs through models of integrated care [79]. The World Health Organization has included the development of compassionate communities in their guide for the planning and implementation of palliative care services [81,82].

According to Zulueta [34], it is necessary to create compassionate leaderships to bring about change in the current paradigm to foster care, humanization, and compassion. For the compassionate community movement to grow and be sustainable, it is necessary to design methods and evaluation procedures, as it has been the case with the 'All with You' method [79], which includes establishing alliances, developing campaigns to enhance public awareness, and offering courses to professionals and volunteers.

Among the elements of integrated care that have shaped the development of compassionate cities in Spain and South America we find: multidisciplinary work; a proactive identification of cases; an integral assessment of needs; the creation of the role of the 'community promoter' (a person that is responsible for mobilizing resources and activating support networks for the palliative patient); the creation of social intervention protocols such as 'REDCUIDA' for the management and development of caring networks [79]; and an integral support to caregivers and family. Initial evaluations of these strategies suggest that the compassion communities program enhance caring networks, reduce isolation in patients and their families, improve life quality, reduce caregiver overload, and increase satisfaction in family and support networks [79].

As Abel [83] expresses in his 'Circle of Care' model, the goal of these programs is to involve family, friends, neighbors, volunteers, and the organizations in the care and accompaniment of the patient. Program evaluations that promote community volunteering to assist with needs of care and accompaniment at home show that patients and family are highly satisfied [77]. The creation of caring networks has also shown to improve life quality while reducing healthcare demands. For example, in the city of Frome (Somerset, England), the implementation of a compassionate community model reduced hospital emergency admissions by 30%, which has led to a 6% reduction in the total cost of the health system [84]. Other community intervention projects have reduced the use of primary care, specialized care, and visits to the emergency room [85]. Community intervention protocols such as ELSA [86], INSPIRE [75], RED-CUIDA [87] also offer guidelines to assess their impacts. The most recent REDCUIDA protocol evaluations have shown an increase in the number of caregivers in patients' network from 1 to 9 [87]. The 'inner' circles of care typically consist of 3–10 people who are closely related to the person with the illness. They usually provide personal (physical) care, as well as companionship, psychological, and emotional support. The 'outer' circles of care consist of 5–50 people or more, with an average number of 16 [88].

CONCLUSION

Compassion is recognized by patients, families, and healthcare providers as a key element of high-quality palliative care. There are several factors that could block compassion in palliative care, including moral distress, economic pressures, work overload, toxic organizational cultures, lack of adequate communication and compassion training, and lack of self-care. There is a need to enhance compassion among palliative healthcare professionals so that they can offer better care for patients and foster self-care among caregivers. To do so, compassion needs to be nurtured by both bottom-up interventions, such as compassion training for healthcare professionals, and top-down interventions, such as designing compassionate institutions and implementing compassionate policies [89].

When palliative care is reoriented towards a view that integrates healthcare, social services and community, there is an improvement in the quality of life of the patient, greater satisfaction of the family, and its caring networks, as well as a greater efficiency because of a reduced use of healthcare

resources that cannot meet certain needs that are social and communal by nature.

Compassionate palliative care models that integrate communal, social, and medical resources could serve as a natural place of entry of a humanizing mindset that takes better care of patients and caregivers for the whole healthcare system. This would not only benefit patients, but could also be part of a creative response to the pervasive malaise among healthcare professions linked with increasing dehumanization and lack of meaning. The science of compassion in healthcare is still young, but recent research mentioned in this article offers evidence-based hope of an important cultural change.

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- of outstanding interest

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