

## RESEARCH ARTICLE

### Palliative Care: Changing Paradigms to Face New Challenges

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#### Abstract

Recent studies conducted in the world's most industrialized nations reveal that access to palliative care is both inadequate and unequal. The problem is exacerbated by the exponentially growing need for this type of care due to the world's rapidly aging population. These findings have prompted governments to address the problem, most often with new legislation and the allocation of more resources. Despite these efforts and a definite improvement in access to palliative care, important inadequacies and inequalities in access to these services persist. A paradigm shift in the way palliative care is seen and implemented, inspired by new research and pioneered by the work of Allan Kellehear, could better serve the world's aging and vulnerable populations: rather than continue to separate the sick and the dying from their communities in order to treat them in costly, depersonalizing institutions, these patients would become a central component around which community services and professional care services would be organically interwoven. This new model, called the "Compassionate Community" model, is inspired by public health approaches of health promotion. Initial experimentation with such communities has yielded promising results, suggesting that the Compassionate Communities model could prove to be a viable alternative to the current approach to palliative care and to the overstrained system borne from it.

**Keywords:** Palliative care, public health, population aging, compassionate, caring communities, end of life, health promotion, death education.

## **1 Palliative and end-of-life care: advances and barriers**

Palliative care (PC) encompasses all care that takes into account the patient's scrupulously assessed needs and delivers care aiming to relieve the physical, psychological, social and spiritual pain of people suffering from a disease with a limited prognosis.<sup>1</sup> In other words, PC does not aim to remedy the patients' ailments but to ease his or her suffering – whether the person is engaged in the last stage of life or not (in the case of a person thus engaged, the care given is designated by the term “end-of-life care”). PC is often administered by professional multidisciplinary teams composed of physicians, nurses, psychologists, pharmacists, social workers, and the like. PC teams also provide professional support to families, often in the form of psychosocial counselling of bereaved loved ones. For the past 50 years, this modern, patient-centred model of PC has made it possible to provide relief and support to millions of people around the world.<sup>2</sup>

The relationship between PC and public health policy (PHP) has not always been obvious. While it has generally been recognized as useful, it is not always regarded as worthy of being integrated into PHP<sup>1,3</sup> even though the World Health Organization (WHO) strongly recommends it<sup>1</sup> and that in 2014, the WHO accepted to act upon the World Health Assembly resolution WHA67.19 aiming to improve access to PC and recognizing PC as a public health problem.<sup>4</sup> Furthermore, where PC is integrated into PHP, it is all too often a neglected dimension of national health policy.<sup>5</sup> The 2017 Lancet Commission on palliative care and pain relief exposed some of the principal reasons for its subordinate position in national health policy, namely

the fact that PC is seen as one of the “luxuries for health-care systems” and that there is often “vigorous and passionate disagreement about the role of palliative care in end-of-life settings”.<sup>5(p1339)</sup> The Commission also concluded that PC and pain relief constitute a crisis that deserves governments' immediate attention.

Whether integrated or not, access to PC is limited<sup>1</sup> and unequal<sup>3</sup>. Each year, in the world, approximately 40 million people need PC, but only 14% of them receive it, and the need to receive this care is sure to increase as the world's population ages.<sup>4</sup> It is presently estimated that, in the U.S.A., 60% of patients who could benefit from PC end-of-life services do not receive them.<sup>3</sup> In addition, certain portions of the American population have significantly more access than others, clearly underserved, for example immigrants, rural communities and certain ethnic groups.<sup>6</sup>

What's more, the need for PC is growing, whether in the United States or in the rest of the world.<sup>7</sup> In 2014, approximately 6 million Americans needed PC.<sup>8</sup> Seeking to respond to this need, over a ten-year period (2004 to 2014), 1000 new hospital-based palliative care programs were established.<sup>7</sup> In 2000, only 25% of hospitals with more than 50 beds had a palliative care team, whereas in 2010, two-thirds of hospitals had one.<sup>7</sup> As a result, access to palliative care has increased in some states from 20% to 100%, with more than 50% of states having palliative care programs in more than 60% of hospitals.<sup>7</sup> However, in 2019, while 72% of hospitals with more than 50 beds had a palliative care team, only 17% of rural hospitals that had one.<sup>8</sup> Access to PC therefore is still a problem, and the growing need for palliative care is accompanied by a growing number of people living with serious or chronic illness. Approximately 90

million Americans live with serious illnesses and, according to estimates made in 2014, this number will double over the next 25 years.<sup>9</sup>

It is also estimated that by 2034, seniors will outnumber children for the first time in U.S. history and by 2060 roughly 23,4% of the population will be aged 65 and over whereas 19,8% of the nation population will be children 18 and under.<sup>10</sup> The fact that the fastest growing demographic slice of population is in the 85-94 age group, which grew by 30% between 2000 and 2010,<sup>7</sup> gives credence to such prognostics. In addition to the aging of the US population, more Americans are living with chronic disease: in 2005, 133 million Americans had at least one chronic disease and 70% of deaths each year were due to chronic diseases.<sup>7</sup> The United States constitutes by no means an isolated case of an aging population (which, in turn, would be accompanied by a proportional rise in the number of people suffering from chronic diseases). According to the United Nations, it is predicted that by 2050, nearly 25% of the world's population will be aged 60 and over.<sup>11</sup>

Recognizing the aging American population trend and the need to better address future health care, in October 2019 Congress passed the Palliative Care and Hospice Education and Training Act (Bill 647 H.R. 647) in order to increase access to PC and to promote education and research in that field.<sup>10</sup> This legislation means to correct a severe deficit in PC research, which in 2014 represented less than 1% of the National Institute of Health's annual budget, a proportion already significantly greater than that of preceding years.<sup>7</sup>

Furthermore, despite the many advantages to integrated PC, namely the

reduced cost as well as patient and clinician satisfaction<sup>3</sup>, the barriers to proper implementation of PC are many. Common challenges to current national PC programs include: the great number of countries whose PC is not well integrated into national health care systems (214 of 234 countries according to a WHO study on the status of palliative care), equitable access regarding geographic range, the limited possibility of offering PC in the home by a multidisciplinary team, inadequate access to PC medication as well as a persistent lack of knowledge about PC among the general population, patients, their families and friends, and even among certain health professionals.<sup>1,12,13</sup> A partial or erroneous understanding of PC would delay or even restrict access to PC for some patients who could benefit from it. It has also been argued that limited access to PC or poor information regarding existing PC services can lead people to turn to euthanasia or medical assistance in dying in states or countries where it is legal.<sup>14</sup> The fact that, in the afore mentioned states, the criteria for access to euthanasia or medical aid to die tend to expand over time is, in this view, worrisome to say the least.<sup>14</sup>

The idea that PC is reserved for cancer patients and relevant only in the very last moments of life continues to dominate. Yet many patients with neurodegenerative diseases, dementia, and chronic non-oncological conditions such as lung or heart failure could benefit from PC.<sup>15</sup> In addition, although many studies document the benefits of early integration of PC into the disease trajectory,<sup>16</sup> early identification of patients who may benefit from PC remains problematic. In a word, the lack of training for some health care workers, the lack of qualified professionals, as well as the underfunding of PC and the health care system in general - whose needs exceed

resources - are identified as factors that continue to hinder good care for all.

### **1.1 The viability of palliative care programs**

Because the world's population is aging and that life expectancy is continually on the rise, it follows that a significant increase in deaths among very advanced age groups is to be expected.<sup>17</sup> In addition, an increase in the number of progressive and chronic diseases as well as the chronicization of serious illnesses such as cancer should also be anticipated. In short, in many Western countries, increasingly more people will be living long lives with deteriorating health conditions and very complex needs.<sup>18,19</sup> This is likely to put more pressure on the health care system, which is already struggling to meet current needs. As well, the very elderly and individuals suffering from one or more serious or chronic diseases also face many other social or psychological difficulties resulting from their health condition: isolation, stigma, depression, anxiety, socio-economic difficulties, etc.<sup>20</sup> A great deal of pressure is placed on the families and natural caregivers of these individuals, which also represents sources of economic, physical, social and psychological stress for a large part of the healthy population who find themselves in a caregiving situation.<sup>21</sup>

Given the social and demographic shifts going forward, it would appear that the current model of specialized PC is insufficient to meet the growing needs of the population.<sup>22</sup> Seemingly, the fate and comfort of sick and dying people and their loved ones can no longer rely solely on the provision of institutional and professional care.<sup>21</sup> Furthermore, the specialization and professionalization of PC – the tendency to relegate the care of sick and/or dying people

to health professionals – has led to a loss of knowledge, comfort and skills on the part of families and communities to care for those who are sick, vulnerable or dying.<sup>21,23</sup> The dispersion of families, smaller households and the greater proportion of people living alone are all social changes that go hand in hand with the professionalization and medicalization of the vulnerable, aging, sick or dying, and even the bereaved. Yet historically, long before the advent of modern PC, communities have always cared for their vulnerable, dying and bereaved members.<sup>23</sup> Instead of becoming the object of professionalization and medicalization, death and bereavement were considered part of the natural cycle of life and of the everyday life of individuals, in much the same way as love or the ability to live and even work with a reserved prognosis disease. Would it not stand to reason that, as much as humanly possible, these important life events take place in the community rather than in an institution?

### **1.2 A tempting paradigm shift in palliative care**

Because the professionalization of dying has significant economic, individual and social costs; because access to quality PH care is something of a right; and because demographic changes will change our health care system, PC is now a real public health issue and a pressing societal need.<sup>22</sup> Indeed, in recent years, there have been many advocates for a paradigm shift in the delivery of PC,<sup>20,22</sup> among which many that propose a shift away from the traditional medical model to a community-based approach. For these advocates, future sustainability and growth of PC depends on the association of professional health care services and community-based services.<sup>1,7</sup> Such a perspective implies that dying, loss, grief and care become the responsibility of

everyone, not just that of individuals or health professionals. In this view, community involvement in PC is built into the health care system, making the community a full partner in the provision of the necessary care and support to patients at the end of life and their loved ones. Such a community is called a compassionate community (CC).<sup>23</sup>

Developed by Allan Kellehear, an Australian researcher, in the early 2000s in his ground-breaking work *Compassionate Cities*, this approach builds on some of the more recent views on PH, namely that health does not necessarily mean the absence of disease and that quality of life does not mean the absence of problems.<sup>23</sup> Thus, the end of life would not be seen only as an experience to be avoided at all costs, but as a natural life event that can, with the support of the community, be lived as a sane and even enriching experience.<sup>23</sup> In this way, death can be dealt with sensitively and constructively in order to foster growth for the individual and the community. Specifically, Kellehear emphasizes that CC fully recognize the value of the natural cycles of life, illness and health, birth and death, love and loss, vital life events that transpire daily, all too often within the walls of institutions. In a CC, it is the responsibility of every member to care for the other in times of crisis and loss. Because the CC model implies that clinical care and community support be complementary, professionals, informal caregivers and community members are all integrated into a continuum of care. Community members help to create a safety net and support network around patients and families dealing with a disease with a limited prognosis from the time of diagnosis.<sup>15,24</sup> Apart from seeking to avoid discrimination based on diagnosis by providing support and PC to people who are aging, have

degenerative diseases or chronic conditions, the CC approach broadens the circle of support to the vulnerable, those who are alone, the bereaved, and caregivers, among others.<sup>23</sup>

## **2 Compassionate Communities: An overview of founding principles and values**

In *Compassionate Cities*, Kellehear envisions a community in which the leaders and individual members sincerely care for the health and well-being of other members. He is also of the opinion that this compassion, solidarity and empathy could extend specifically to the issue of death, serious illness, loss and bereavement. He imagined that the members of a CC have within them the knowledge and wisdom to support and accompany the most vulnerable in times of crisis, loss, illness and end of life. The founding principles, developed by Kellehear,<sup>23</sup> can be summarized as follows:

In a CC, compassion is an ethical imperative. Members of a CC must be able to debate and discuss the importance of compassion, its meaning, etc., through public forums and discussions on topics as diverse as programs and policies regarding death and dying as well as death education in schools. As some cities run awareness campaigns relating to the environment or road safety, a CC can organize campaigns to remove taboos about death and illness and present the culture of compassionate attitudes as everyone's responsibility.

Access to palliative care and bereavement services should be improved. For example, the promotion of such services in the community could include the mapping of PC and bereavement resources and advertising campaigns. In addition, PC facilities could establish mobile services for

bereavement or crisis situations in schools and workplaces.

A CC addresses the needs of any vulnerable individual, including the elderly, the seriously ill and the bereaved. Volunteer organizations with adequate financial support would intervene with any vulnerable individual, ensuring that homeless, isolated or disadvantaged people receive the same care and services as other members of the community. Campaigns would be launched to raise awareness of the special needs of vulnerable people, including the need for them to take their rightful place in the collective space. These campaigns, by providing an accurate picture (neither embellished nor obscured) of the reality of these people, can bring about the necessary changes in attitude.

Local policies should be developed democratically and include end of life and bereavement specialists. Planning committees should include PC and bereavement workers as well as citizens, such as seniors or caregivers, whose valuable experience can bring a different perspective to local policies and needs.

A CC must ensure access to a variety of supportive experiences related to loss and grief. Citizens at the end of life who wish to remain at home should be able to rely on the support of community organizations and volunteers. Intergenerational exchanges and cultural mediation could also lead to positive experiences and interactions related to death and illness. Thus, a CC works to rehabilitate grief and death, bringing them back into the collective space as meaningful experiences. In this perspective, the different spiritual and religious traditions in the face of death are to be preserved and celebrated, for example through art and cultural exchange. In this way, certain spiritual practices could be put

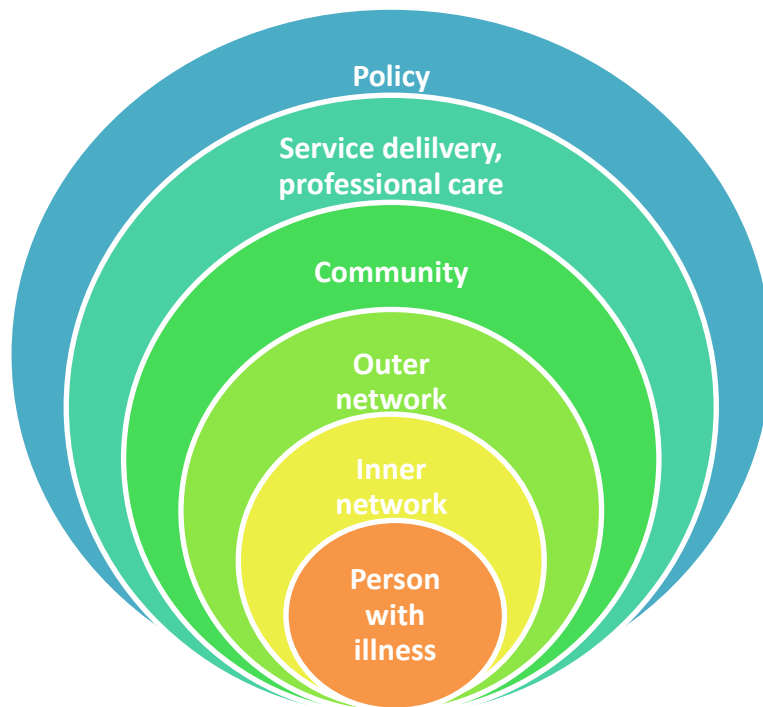
forward in order to demystify them and encourage a dialogue on or between certain beliefs, which are sources of meaning in the face of death.

## **2.1 Compassionate Communities: Initiating the movement**

The CC approach offers an inspiring vision of multilateral cooperation, whether you are a citizen, a patient, a family member or a PC caregiver. This does not mean that CC are a myth or a utopia: well over a hundred have been established around the world, including Australia and the United Kingdom. Of course, starting a CC requires time, will, activism and conviction. Most communities start with a single initiative and then integrate other policies as the population becomes more aware and involved. For example, improving access to PC and bereavement services may be a realistic and achievable first goal in initiating a CC movement. Often, PC houses are in a privileged position to follow suit by further developing community-based PC, with the help of volunteers. Different models of care and exchange can then be considered to build a CC that can better meet the needs of people with a life-limiting illness.

For example, the Circle of Care model, developed in collaboration with the HOME Hospice in Sydney in 2013, is the product of researchers and caregivers working together to create a CC in South-Eastern Australia.<sup>25</sup> Because the patient is situated in the centre of the graph (Figure 1), it is understood that the needs of the specific person seeking care act as the foundation on which are built filial and community ties leading to support adapted for this person.<sup>21</sup>

**Figure 1:** Circles of Care. Adapted from: Abel J, Walter T, Carey LB et al. Circles of care: should community development redefine the practice of palliative care? *BMJ Support Palliat Care* 2013; bmjspcare-2012-000359.



The family and close friends who surround the patient daily make up his or her inner network and are also likely to benefit from certain services as natural caregivers and/or as bereaved persons. The outer network is made up of members of the patient's extended family, acquaintances and neighbours, who may directly help the person himself or herself in various ways, but also support the inner network in order to avoid the exhaustion of natural caregivers. The community then offers itself as a buffer zone between professional services and the person's inner and outer networks. In a CC for example, one can expect various support programs and volunteer organizations to meet the needs of the patient and his or her family and friends. Among other things, we can imagine a volunteer service that helps in carrying out

daily activities such as meals, housekeeping, and transportation.

If necessary, volunteer services can turn to professional services if the family's needs prove numerous and/or complex. The inner network and the individual can also call upon these professional services directly, if necessary. Finally, all these elements must be supported by policies that encourage and allow for the seamless integration of health services, community services and support networks to meet the needs of people who are ill. Each community can adopt one or more of the policies of CC as it develops. An openness to collaboration on the part of professional bodies is also necessary, as well as government policies that recognize and value the role of community services in supporting people at the end of life.<sup>21</sup>

## 2.2 An inspiring example of Compassionate Community

The Circle of Care model is a concrete example of how PC can be integrated into communities. Nevertheless, CC can and should go beyond community integration of PC. Indeed, one of the major challenges to accessing PC remains the social taboo surrounding death, which is perpetuated by a culture of denial, fear, and avoidance. Thus, to bring about real social change, to develop a true culture of compassion and to encourage citizens to take responsibility for the dying, education and awareness about death are essential.<sup>26</sup> This requires the concrete involvement of schools, workplaces, the media and local businesses. For example, some businesses are referred to as “compassionate companies”. These companies recognize their role and responsibility in supporting employees affected by illness or bereavement. This recognition and the concrete support that comes with it in turn helps to normalize these life situations and thus remove the stigma and taboos associated with them.<sup>19</sup>

Childhood education is another essential way to contribute to the development of compassionate attitudes towards death, illness and loss. However, it is also one of the most difficult avenues to initiate; both parents and teachers are extremely reluctant to expose children to the reality of death. Yet, although most schools have sex education programs whose content is recognized as normal and important, very few schools dare to integrate death into their curriculum. Compassionate Communities are therefore mandated to encourage the formation of “compassionate schools” in municipalities. Death education courses adapted to the age and development of children can equip them personally and

assist in the development of compassionate attitudes towards vulnerable people. At the same time, compassionate schools that include death education in their curriculum and policies are likely to create communities of children, parents, and teachers who can offer support and compassion in difficult times.<sup>19</sup>

For example, in the London area, leaders at St. Christopher's Hospice have initiated a death education program for children aged 9-16 years.<sup>27</sup> The program, planned and developed by both parents and school principals, consisted of four sessions in which the children took part in a visit to a PC facility. Before, during and after the visits, the children were encouraged to share their thoughts and questions. For example, the children were able to ask patients questions such as: “How do you feel about having your breast removed? Why don't you have any hair? What happens to the body after death?” Students and teachers discussed their experiences upon returning to school. Often, the children's reflections were supplemented with artwork or theatrical performances based on what they had learned. The exhibition of the artwork and the public performances of the plays in turn allowed the audience to reflect on and discuss the students' experiences further with them.<sup>20</sup>

The results of numerous evaluations of the St. Christopher's' program suggest significant health promotion benefits for students, parents, teachers and patients. For students, changes in attitude towards death were reported such as uncertainty and anxiety being replaced by a sense of familiarity and trust. Patients have also benefited from this experience by being entrusted with an important mission: as contributors to the awareness and education of these children. In addition, this activity



allows the establishment and maintenance of healthy relationships between people at the end of life and the community around them. Such involvement between students, teachers and parents enables several age groups within the community to develop a better understanding of end of life, death, care, grief and loss and contribute to reducing the children's fear of death. The activity would also have a preventive nature: this kind of early intervention is likely to reduce the negative consequences related to ignorance, fear, isolation and social distancing, stigma and prejudice -an awareness acquired even before the majority of people involved in the program have had to face illness or bereavement in their lives. In short, thanks to this program, children, parents, and teachers are better equipped for the future.<sup>20</sup>

### **2.3 The challenges of research and evaluation**

Research on CC represents a real challenge.<sup>19,23</sup> Since an important part of CC activities are carried out by volunteers, resources are often lacking when the time comes to evaluate the impact of practices and programs on the communities themselves. Moreover, the development of evaluation tools is very difficult given the diversity of targets prioritized by different communities. Nonetheless, CC have given themselves the mandate to evaluate their success and usefulness. This evaluation is necessary to justify the presence of certain programs and the financial resources allocated to them. Documenting the services offered and the number of people benefiting from each program is a necessary first step to eventually develop accurate evaluations of the benefits of CC on people's quality of life.<sup>19</sup> Participatory and qualitative methodologies, such as developmental evaluation, are particularly well suited to

research on CC and such research may well have structuring effects on the communities themselves. Sharing research initiatives in turn supports the development and sustainability of emerging communities.

### **3 Conclusion**

Public health policies have recognized for more than a decade that health is everyone's responsibility. Indeed, individual health depends on the quality of the environment, public policies, available care, etc. It is therefore the responsibility of governments, health care institutions, schools and businesses to provide conditions conducive to the health and well-being of populations. The CC approach conveys the same message but with a focus on the specific issues of end of life and bereavement. The health, well-being and care of people at the end of life is everyone's responsibility. This reality affects us all, as individuals and as a society.<sup>20</sup>

In *Compassionate Cities*, Allan Kellehear presents an example that exemplifies his vision of Compassionate Communities. He recounts a tragic event in which two students were shot and killed on a university campus. When the event was reported in the local media, final comments from reporters indicated that "students and staff at the University are being provided with counselling".<sup>23(pix)</sup> In a compassionate community, explains Kellehear, witnesses to the tragedy could simply have turned to their loved ones for support. Kellehear's belief is that individual citizens would have been able to find appropriate words and comforting attitudes in such a situation of loss.<sup>23</sup> We are still a long way from this goal. Rather, the willingness to address the issues of death and loss head on is, at present, marginal to say the least, but will hopefully change soon.

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