



Compassionate Communities: contemporary tensions and challenges

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Roleston and colleagues (1) conducted a scoping review of more than 60 Compassionate Communities interventions, aiming to understand what is currently known about their design, efficacy and impact. This review joins several other scoping and systematic reviews published in recent years, aiming to understand the state of the science relating to Compassionate Communities and new public health approaches to end-of-life care. They each use different inclusion and exclusion criteria and, as a result, present a set of different perspectives and insights into this diverse and growing field. The publication of Roleston *et al.*'s review represents a timely opportunity to appraise this emerging evidence base.

Five reviews have been published since 2022. Roleston *et al.* (1), Dumont *et al.* (2), and Peeler *et al.* (3) carried out scoping reviews, whilst D'Eer *et al.* (4) and Quintiens *et al.* (5) conducted systematic reviews. The review by Roleston *et al.* (1) examined Compassionate Communities interventions, aimed at enhancing community responsibility and building partnerships between communities and services, as a specific application of a public health to palliative care approach. Quintiens *et al.* (5) focused on geographically defined Compassionate Communities, also known as Compassionate Cities, which focus on at least one of the five pillars of health promotion in palliative care: 'strengthening community action', 'creating

supportive environments', 'developing personal skills', 'creating supportive environments' and 'delivering health public policy' (6). Dumont *et al.* (2) and Peeler *et al.* (3) had a similar focus to Quintiens and colleagues (5), by including Compassionate Communities undertaking health promotion activities in palliative care, but without the geographical restrictions of Compassionate Cities. Peeler *et al.* (3) included similar initiatives to Dumont *et al.* (2) and Quintiens *et al.* (5), but focused on two specific pillars of health promotion, namely 'community action' and 'developing personal skills'. Following this approach, they excluded compassionate community initiatives that did not involve any community input or engagement. Lastly, D'Eer *et al.* (4) included exclusively those initiatives that aligned with the concept of community action in palliative care, particularly focusing on civic engagement initiatives regarding serious illness, death, or loss. This editorial aims to highlight contemporary tensions and challenges existing within Compassionate Communities, to understand common insights and to propose directions for future practice and research.

Compassionate Communities are diverse and heterogeneous initiatives, based on the core principle that dying, care in serious illness, and grieving are natural and universal processes, requiring societal responses. In the late 1990s, Kellehear applied the idea of health promotion and healthy cities to

the discipline of palliative care, challenging the increasing dominance of clinical and service-based responses to dying, care and grief. Kellehear asserted that dying, caring and grieving are social challenges with medical components, rather than medical challenges with social components (7). He advocated for communities to reclaim responsibility for death and dying, suggesting that this confidence, knowledge, and capacity were being eroded through the professionalisation of care at the end of life (8).

The varying inclusion and exclusion criteria found in the published reviews may signal underlying challenges related to shared definitions and identity. Such diversity is a common characteristic of emerging and dynamic movements such as Compassionate Communities. A universal definition of Compassionate Communities has been complex to arrive at, owing to the different disciplinary roots informing the movement, and the different interpretations that have developed across the world. A recent interdisciplinary effort was undertaken by the Compassionate Communities Centre of Expertise (CoCo) in which a team of researchers at Vrije Universiteit Brussel from eight different research groups, including labour psychology, architecture and design, end-of-life care and ageing, defined Compassionate Communities as “*communities that invest in and promote individual behavior, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious (mental or physical) illness, death, dying and loss; actively promote health and well-being, community support and empowerment of community members affected by such experiences; and actively acknowledge these experiences as natural parts of daily life*” (9). Another definition is that provided by Pallium Canada, a national non-profit organization focused on building professional and community capacity to help improve the quality and accessibility of palliative care in Canada. They define Compassionate Communities as “*A community of people who are passionate and committed to improving the experiences and well-being of individuals who are dealing with a serious health challenge, and those who are caregiving, dying, or grieving*” (10).

Though definitions may exist for Compassionate Communities, achieving consensus on a complex and multidimensional concept such as Compassionate Communities can be challenging. Despite this, we found shared aspects in the definitions of Compassionate Communities used across the reviews. Four out of five reviews referenced health promotion in palliative care as a theoretical basis for their included Compassionate Communities activities. Additionally, all reviews mentioned

the aspect of involving communities, however, the language used to describe the levels of community engagement differs from review to review: ‘re-orientate care to the community’ (1), ‘involvement of various stakeholders’ (5), ‘members of the community taking an active role’ (4), ‘the ability of citizens to actively participate in the development of their communities’ (2) and ‘the input from members of the target community at every stage of design, implementation, and dissemination’ (3).

Comparing the reviews by Roleston *et al.* (1), Dumont *et al.* (2), Peeler *et al.* (3), Quintiens *et al.* (5), and D'Eer *et al.* (4), we identified three key tensions within the Compassionate Communities literature. The first tension revolves around power and the role of the community in initiatives, as passive recipients or active leaders. It specifically asks whether community-based educational activities, when not part of broader community empowerment efforts, can still be labelled as compassionate communities. The second tension relates to the level at which Compassionate Communities work is situated, whether at the level of a service and individuals or the level of a community or population. Service-driven initiatives can prioritize service improvement over community empowerment and similarly, researcher-driven initiatives can influence research agendas and outcomes, potentially conflicting with a community’s goals. The third tension explores the partial view that peer-reviewed published research in English provides on compassionate communities, as compared to the wider work taking part in the field.

The different descriptions of the level of community engagement in the studies included in the reviews provoke the first tension, which relates to who is leading Compassionate Communities initiatives, specifically whether the community is a target or a leader. The majority of the initiatives identified across the reviews were initiated by palliative care teams, organisations, or community services, highlighting a predominance of service-driven approaches. Compassionate Communities are based on the fundamental principle of empowering community members to take action relating to serious illness, death, and loss, addressing the increasing professional control at these times. Core to empowerment is a recognition of power differentials that exist across societies. The term ‘power’ was mentioned only in the reviews by Roleston *et al.* (1) and Quintiens *et al.* (5), and referred to initiatives such as the Döbra project that attributes power to communities through community-based art initiatives regarding serious

illness, death and loss (11). None of these reviews consider, in light of the initiatives they included, the power dynamics within service-centred Compassionate Communities and how these may impact community empowerment.

Many of the initiatives included in the reviews focused on educational activities relating to serious illness, death or loss. This represents a limited form of community engagement, primarily aimed at informing a community, not at building community empowerment (12). Although ‘developing personal skills’ does comprise one of the pillars of the Ottawa Charter, we suggest that labelling purely education-focused activities, delivered by professionals, as Compassionate Community is incorrect, as they primarily aim to improve knowledge about services or conditions, rather than stimulate community action or ownership of the work. These activities, whilst valuable, are more appropriately categorized as community-based educational programs. They can contribute to improving the knowledge base, and ultimately death literacy of a community, enhancing their understanding and ability to act on end-of-life and death care options, an important first step in community empowerment (13). However, general health promotion activities that focus only on educational activities have been criticised for ignoring the wider structures that determine health and health outcomes, placing the focus on individuals to make better choices or take different actions, ignoring the wider structures that prevent this (14). When integrated into a wider series of efforts, these educational programs can be a first step towards strengthening community action in addressing serious illness, death, and loss. When offered in isolation, or to limited groups within a population, they do not address the wider community action aspirations of Compassionate Communities.

The second tension identified builds on the first, by asking about the level at which Compassionate Communities interventions are focused. Studies identified through the reviews often target certain groups within populations, such as patients known to a service or people with a specific condition. Dumont *et al.* highlighted the limitations of focusing on an individual level versus a population level in Compassionate Communities. While individual-level evaluations are more suitable for demonstrating the impact on personal health outcomes, they do not provide us with insights into the social changes occurring within compassionate communities, for which population-level data is more appropriate. Furthermore, concerning the sustainability of Compassionate Communities initiatives, Dumont *et al.* (2) and D’Eer *et al.* (4)

both highlight the importance of capturing insights on how to maintain successful Compassionate Communities. Individual-level evaluations lack the capacity for broader comparisons across diverse contexts, which are essential for enhancing the development of compassionate communities. Additionally, if the majority of initiatives are service-led, then the focus is more likely to be on those currently experiencing serious illness, caregiving and bereavement and receiving support through the service. Whilst these groups within populations are important to focus on, a core premise within Compassionate Communities is that dying, caregiving and grieving are universal events, affecting all in a society. Quintiens *et al.* (5), excluded initiatives aimed at specific subgroups as opposed to populations, arguing that responses must support everyone to find ways and means to deal with serious illness, death and loss. This upstream, population focus is central in Compassionate Communities.

A final point to this tension relates to the need to ‘fix’ the shortcomings of palliative care services versus a need to understand broader narratives and build capacity around death, dying, caregiving and grieving across societies. Initiatives led by services will often aim to improve the quality of or access to the service and not address broader societal needs. This tension is also present in language choices.

Applying the term ‘palliative care’ rather than dying, caring, or grieving can subtly shift the focus from population-level change to service improvement. Four out of five reviews use mainly the term palliative care or end-of-life care (1-3). D’Eer *et al.* (4) opt for a broader linguistic approach, employing the terms ‘serious illness, death, dying, and loss’. By employing broader language and excluding service-oriented initiatives, the shift in focus advocated by D’Eer *et al.* (4) extends Compassionate Communities beyond an emphasis on service provision. It encourages communities to play a more active role, going beyond information dissemination or being mere target groups.

Finally, a third tension relates to the limited perspective these reviews capture, as compared to the reality of compassionate communities working globally, and asks the question of whether these methods and those of the published studies they draw on are appropriate to understand and represent this field. Articles published in peer-reviewed, academic journals are well-recognized as under-representing work from low- and middle-income countries, and from countries or groups writing in languages other than English. The reviews of Compassionate Communities discussed here are no

exception, with a predominance of initiatives from high-income countries and the exclusion of studies published in languages other than English. Most reviewed initiatives are concentrated in North America, the UK, and Europe, with a minority of low-income countries such as India, Ethiopia, and Mozambique included.

Similarly, published articles in the healthcare and health services sectors have historically given preference to large-scale quantitative studies and traditional methods such as randomized controlled trials, along with research aligning with a biomedical paradigm. The field of public health in palliative care is characterized by its dynamic and complex nature, with new challenges and research needs constantly emerging, requiring researchers to adopt innovative methods and paradigms, using mixed methods, participatory and interdisciplinary approaches. As a result, this balance is shifting, with the contribution of different methods and epistemologies being increasingly recognised by publishers, as the complexity of many contemporary health challenges is appreciated.

Insufficient discussion in the literature regarding the power dynamics of researchers involved in Compassionate Communities raises critical questions. These questions pertain to whose agenda is prioritized, who decides which questions matter, and who determines the success of interventions. The mere involvement of researchers can influence the research agenda and choice of outcomes, potentially shaping Compassionate Communities' activities. Only one review involved community members or people with lived experience in the conduct of the review (2), thereby potentially increasing the relevance of the review by aligning it with community members' interests. However, it is not clear how many of the included studies involved wider participation beyond the research team. Additionally, a consistent issue identified by reviewing authors is the focus of included initiatives on describing Compassionate Communities activities and their evaluation, rather than offering a comprehensive account of their development, often involving community-academic partnerships. This lack of emphasis on the development aspect contributes to a limited understanding of power-sharing in the creation of Compassionate Communities through community-academic collaborations.

The five reviews all point to the significant increase in articles published on Compassionate Communities in recent years, attesting to the growth of the field and growth in research on the field. Research is essential within Compassionate Communities, it supports the development

and understanding of the movement, legitimizing its position alongside more traditional approaches to care in serious illness, dying and loss. It can also shape the agenda and direction of the movement. Many of the studies and all the reviews call for more rigorous research and a deeper understanding of the mechanisms of compassionate communities. Whilst these insights can be valuable, we also believe that rigorous research must include and integrate a broader diversity of people, approaches, and epistemologies, complementing the traditional ones already in us (15). We should be striving to broaden not narrow the focus of research in this emerging area. The Compassionate Communities movement has brought a critique and radical challenge to existing, traditional approaches to care when dying, caring, and grieving, let us ensure that the research approaches used are commensurate with that vision.

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References

1. Roleston C, Shaw R, West K. Compassionate communities interventions: a scoping review. *Ann Palliat Med* 2023;12:936-51.
2. Dumont K, Marcoux I, Warren É, et al. How compassionate communities are implemented and evaluated in practice: a scoping review. *BMC Palliat Care* 2022;21:131.
3. Peeler A, Doran A, Winter-Dean L, et al. Public health palliative care interventions that enable communities to support people who are dying and their carers: a scoping review of studies that assess person-centered outcomes. *Front Public Health* 2023;11:1180571.
4. D'Eer L, Quintiens B, Van den Block L, et al. Civic engagement in serious illness, death, and loss: A systematic mixed-methods review. *Palliat Med* 2022;36:625-51.
5. Quintiens B, D'Eer L, Deliens L, et al. Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide. *Palliat Med* 2022;36:422-42.
6. WHO. The 1st International Conference on Health Promotion, Ottawa, 1986.
7. Abel J, Kellehear A. Palliative care reimaged: a needed shift. *BMJ Support Palliat Care* 2016;6:21-6.
8. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. *QJM* 2013;106:1071-5.
9. Vanderstichelen S, Dury S, De Gieter S, et al. Researching Compassionate Communities From an Interdisciplinary Perspective: The Case of the Compassionate Communities Center of Expertise. *Gerontologist* 2022;62:1392-401.
10. BC Centre for Palliative Care, Pallium Canada, Hospice Palliative Care Ontario. Pan-Canadian Compassionate Community Definition 2020. [cited 2023 Sept 02]. Available online: <https://www.pallium.ca/evaluation-toolkit/>
11. Kleijberg M, Ahlberg BM, Macdonald A, et al. Navigating power dynamics in engaging communities in end-of-life issues - Lessons learned from developing community-based intergenerational arts initiatives about death and loss. *Death Stud* 2021;45:651-64.
12. Sallnow L, Paul S. Understanding community engagement in end-of-life care: developing conceptual clarity. *Critical Public Health* 2015;25:231-8.
13. Noonan K, Horsfall D, Leonard R, et al. Developing death literacy. *Prog Palliat Care* 2016;24:31-5.
14. Lupton D. *The imperative of health: Public health and the regulated body*. London: Sage Publications, Inc.; 1995.
15. Bakelants H, Vanderstichelen S, Chambaere K, et al. Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives. *Palliat Med* 2023;37:291-301.

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