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Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives

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Abstract

Background: Compassionate Communities have been put forward as a new model for community-based palliative care to positively impact the health and wellbeing of those experiencing challenges of serious illness, death, dying, and loss. Despite the growing international movement to develop these public health initiatives to end-of-life care, only a handful of initiatives have undergone some form of evaluation.

Aim: To provide guidance on designing evaluation research by identifying theoretical frameworks to understand the development, implementation, and underlying mechanisms of Compassionate Communities.

Methods: To identify suitable theoretical frameworks for the study of Compassionate Communities, we applied two steps. The first step examined the characteristics of Compassionate Communities and translated them into assessment criteria for the selection of theoretical frameworks. The second step consisted of applying the identified assessment criteria to a list of widely used and highly cited theoretical frameworks.

Results: Three well-established theoretical frameworks were identified as being most suitable to study the development, implementation, and underlying mechanisms of Compassionate Communities: The Consolidated Framework for Implementation Research (CFIR), the integrated-Promoting Action on Research Implementation in Health Services framework (i-PARIHS), and the Extended Normalization Process Theory (ENPT).

Conclusions: The article supports and encourages the use of theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives. The complementary use of two determinant frameworks and an implementation theory provides theoretical grounding to gain rich insights into the emergent and shifting interplays between agency, social processes, and contextual factors that shape the development and implementation of Compassionate Communities.

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Keywords
Public health, palliative care, compassionate communities, implementation science, evaluation methodology

What is already known about the topic?
- The Compassionate Communities model has gained momentum as a ‘public health palliative care’ approach that can complement the scope of formal service models of palliative care.
- Previous studies have described the positive impact of public health palliative care initiatives but systematic knowledge about their characteristics, how they were developed, and which mechanisms influence implementation outcomes remains scarce.

What this paper adds
- This article provides guidance on designing evaluation research to understand the development, implementation, and underlying mechanisms of Compassionate Communities.
- Theoretical frameworks provide useful tools to better understand the emergent and shifting interplays between contextual conditions and the social processes shaping the development and implementation of public health palliative care initiatives.

Implications for practice, theory, or policy
- More flexible integration of various existing models, approaches, and methods from both palliative care research and other disciplines is needed to support the uptake, scalability, and sustainability of Compassionate Communities and other public health palliative care initiatives.
- Future research can complement traditional research methodologies with approaches that are participatory and directly informed by communities’ lived experiences, needs, and aspirations for care.
Responses to end-of-life challenges in our society have been medicalized with the development of specialized palliative care and bereavement services in the last 50 years. A growing movement insists that serious illness, death, dying, and loss need to be recognized and reframed as the social experiences they essentially are. This includes moving beyond the dominant medical-individualistic approach that focuses on patients or clients defined in terms of health problems or biopsychosocial risk toward a salutogenic approach around serious illness, death, dying, and loss: an approach that aims to normalize and promote healthy attitudes toward these experiences through awareness-raising, increasing death literacy, and developing social capital of entire communities. This approach is called a “Compassionate Communities“ model. Compassionate Communities are considered a public health approach to palliative care that can encompass a wide range of actions and practices, such as facilitating or supporting enhanced, naturally occurring caregiving networks; engaging the wider society in a community discourse through programs in schools, universities, workplaces, faith communities, and the arts and advocacy activities lobbying jurisdictions to develop healthy public policy to normalize experiences of serious illness, death, dying, and loss. In recent years the model has gained in popularity and has been implemented worldwide through initiatives in the United Kingdom, Ireland, India, Canada, Australia, Colombia, Argentina, Brazil, South Africa, and more recently in mainland Europe.

The few studies that have sought to evaluate Compassionate Communities point to some “early suggestion of benefits” as seen in a population-wide reduction of hospital emergency admissions, reduced social isolation, enhanced social wellbeing, increased community capacity and social capital to care, and breaking the taboo around death, dying, and loss. However, little attention has been given to how these outcomes are obtained. The literature identifies several reasons for the lack of rigorous evaluations. First, developing evaluation tools is difficult given the diversity of targets prioritized by different communities. Second, an important part of the initiatives is not-for-profit and volunteer-based, so funding and resources are often lacking to evaluate the practices and programs developed. Third, the way people experience events of serious illness, death, dying, and loss is influenced by a wide range of factors (psychological, sociological, economic, cultural, political), which requires an adaptation of conventional (often biomedical) research frameworks predicated on linearity and predictability. The characteristics of public health palliative care initiatives suggest that research needs to focus more – as compared with clinical or health service research approaches – on context and the needs and contributions of a variety of stakeholders involved, and the social and economic determinants of health.
Implementation science supports the use of theoretical frameworks to improve our understanding of how, why, and under which circumstances initiatives work or do not work.\textsuperscript{36,39} Although there is a growing awareness of the importance of using theories and frameworks for evaluating the complex processes behind new public health initiatives, there are many of them and no obvious way to select the most pertinent for specific situations.\textsuperscript{40} This article offers guidance on designing evaluation research by assessing the utility and applicability of theoretical frameworks for the study of Compassionate Communities.

**Methods**

To identify suitable theoretical frameworks for the study of Compassionate Communities, we applied a stepwise approach as suggested by others in previous work.\textsuperscript{41,42} The two-step method helps to systematically appraise theoretical frameworks against the core characteristics of Compassionate Communities and to identify the most pertinent to capture the complex change processes behind these new public health initiatives. First, to determine a set of assessment criteria for the selection of theoretical frameworks, we conducted a conceptual literature review to examine the characteristics of Compassionate Communities. Second, we appraised theoretical frameworks against these assessment criteria.

**Conceptual literature review**

The authors undertook a conceptual scoping review to find reviews written within the past 20 years that reviewed the characteristics of Compassionate Communities. A conceptual scoping review is a type of knowledge synthesis that provides new interpretations built from but often extending beyond the original literature or past research.\textsuperscript{43} Literature was searched up to March 2022. After considering the reviews independently, the authors agreed on a tentative list of key concepts highlighted across the reviews. Through this process, three reviews proved particularly useful for the purpose of our current analysis, i.e. to identify assessment criteria based on the core characteristics of Compassionate Communities to review the usefulness of theoretical frameworks for the study of Compassionate Communities. A first systematic review on Compassionate Communities was published in 2018 and summarizes development, implementation, and evaluation models.\textsuperscript{32} The second review describes and compares “civic engagement initiatives in palliative care” or “compassionate community initiatives” in terms of context, development, impact, and evaluation.\textsuperscript{33} The goal of the third review is to provide a clear overview of similarities and differences between Compassionate Communities on their contextual characteristics and development.
processes. The tentative list of Compassionate Communities’ characteristics, directly drawn from the reviews on Compassionate Communities, was then translated into assessment criteria to appraise theoretical frameworks. Again, the research team discussed any nuances in order to reach consensus on a final list of assessment criteria deemed important for the selection of theoretical frameworks for the study of Compassionate Communities.

Appraisal of theoretical frameworks

The myriad of existing theoretical frameworks underscores the challenge of selecting the most appropriate framework for a specific intervention or project, particularly when most are used in practice only once or with limited justification. Understanding the options available is made more challenging by unfamiliarity with the language used and the inconsistencies in nomenclature. For clarity, we will refer to frameworks, models, and theories collectively as “theoretical frameworks”.

We employed “empirical support” as a criterion for selecting frameworks for appraisal, as suggested by implementation science scholars. We used reviews presenting the most used implementation science frameworks cited in academic publications and the theories most used by implementation scientists to guide the selection of theoretical frameworks for appraisal. For pragmatic reasons, and relying on the systematic approach taken by the authors of both manuscripts, we considered only those theoretical frameworks within the top-10 on both lists (i.e. both highly cited in the literature, >200 citations, and commonly used in implementation practice). (See Table 1.)

We further categorized these frameworks using the taxonomy proposed by Nilsen. The taxonomy demonstrates that the frameworks included those that principally aim to guide the process of translating evidence into practice (i.e. process models), those that principally aim to understand and explain what influences implementation outcomes (i.e. determinant frameworks and implementation theories), and a single framework explicitly meant to evaluate implementation (i.e. evaluation framework) – however, most frameworks fulfil this role as a secondary function.

Table 1. Summary of ten commonly used theoretical frameworks.

<table>
<thead>
<tr>
<th>Authors/date</th>
<th>Name of theoretical framework</th>
<th>Nilsen’s categorization</th>
</tr>
</thead>
</table>

5
<table>
<thead>
<tr>
<th>Authors</th>
<th>Model Description</th>
<th>Process Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Graham et al.</td>
<td><strong>Knowledge to Action (KTA)</strong>&lt;br&gt;Conceptual model that helps guide and understand how knowledge is created and synthesized. It takes a systems approach and recognizes that knowledge producers and users are situated within a larger social system.</td>
<td>describes practical steps in translating research into practice</td>
</tr>
<tr>
<td>Proctor et al.</td>
<td><strong>Conceptual model of implementation research</strong>&lt;br&gt;Conceptual model that guides how implementation research can be organized and how it fits/aligns with evidence-based practices.</td>
<td>describes practical steps in translating research into practice</td>
</tr>
<tr>
<td>Klein &amp; Sorra</td>
<td><strong>Implementation effectiveness model</strong>&lt;br&gt;Conceptual model that provides a list of constructs that can influence implementation effectiveness, based on the premise that implementation effectiveness is a function of an organization’s climate for implementing a given innovation and the targeted organizational members’ perceptions of the fit of the innovation to their values.</td>
<td>describes practical steps in translating research into practice</td>
</tr>
<tr>
<td>Aarons et al.</td>
<td><strong>Conceptual model of evidence-based practice implementation in public service sectors</strong>&lt;br&gt;Conceptual model of factors that can influence implementation in the unique context of public sector services at four implementation stages: Exploration, Adoption/Preparation, Implementation and Sustainment (EPIS).</td>
<td>describes practical steps in translating research into practice</td>
</tr>
<tr>
<td>Damschroder et al.</td>
<td><strong>Consolidated Framework for Implementation Research (CFIR)</strong>&lt;br&gt;Conceptual framework developed to guide systematic assessment of multilevel implementation contexts to identify factors that might influence intervention implementation and effectiveness.</td>
<td>determinants categorizes implementation barriers/enablers</td>
</tr>
<tr>
<td>Michie et al.</td>
<td><strong>Theoretical Domains Framework (TDF)</strong>&lt;br&gt;Overarching theoretical framework comprised of 14 domains integrating constructs from multiple theories relating to health behaviour change.</td>
<td>determinants categorizes implementation barriers/enablers</td>
</tr>
<tr>
<td>Cane et al.</td>
<td><strong>Promoting Action on Research Implementation in Health Services (PARIHS)</strong>&lt;br&gt;Framework positing successful implementation as a function of nature and type of evidence, the qualities of the context of implementation, and the facilitation process.</td>
<td>determinants categorizes implementation barriers/enablers</td>
</tr>
<tr>
<td>Kitson et al.</td>
<td><strong>Revised PARIHS framework (i-PARIHS)</strong>&lt;br&gt;Aims to address the lack of conceptual clarity, specificity, and transparency; the lack of conclusion of relevant elements perceived to be critical to implementation; and the lack of instrumentation and evaluation measures in the original framework.</td>
<td>determinants categorizes implementation barriers/enablers</td>
</tr>
</tbody>
</table>
### Results

**Identifying assessment criteria for theoretical frameworks**

The reviews on Compassionate Communities showed substantial variability in the contextual and developmental characteristics of Compassionate Communities. First, understanding the uniqueness of each local system, therefore may require constructs to understand, describe, and evaluate the characteristics of initiatives and actions at different socio-ecological levels. Second, developing Compassionate Communities is often characterized by the active involvement of various stakeholders, including local government, health and wellbeing organizations, workplaces, schools, churches, and neighbourhoods who collaborate to bring about actions aimed at prevention, harm reduction, and early intervention around serious illness, death, dying, and loss. Suitable frameworks should therefore address the collaboration between stakeholders and capture their different perspectives. This includes characterizing the collective sense-making and experiential learning process behind the enactment of new practices.

Third, most initiatives also referred to the importance of facilitation of activities across different levels and settings. Theoretical frameworks need to guide the understanding and evaluation of implementation strategies used to implement practices across settings. Fourth, Librada-Flores et al. and D’Eer et al. found that sustainability of initiatives is a common challenge for most initiatives. D’Eer et al. emphasize the need for evaluation studies to focus more on the underlying mechanisms that may hamper or facilitate the sustainability of future initiatives. We, therefore, added the criterion of sustainability to the list of assessment criteria.
Fifth, given these characteristics, Compassionate Communities can be thought of as complex and adaptive systems. Complex adaptive systems are shaped through the agency of system actors and the interconnectedness and interdependency of system components, which can lead to unpredictability as systems evolved dynamically over time.\textsuperscript{64,65} The complexity of Compassionate Communities also arises from dealing with issues for which there are no straightforward answers and no general agreements on the strategies to achieve the intended outcomes, the need to recognize multiple perspectives, and the existence of various locally driven interventions that are not easily standardized or replicated.\textsuperscript{38} Frameworks must recognize the complexity and dynamic nature of these initiatives.

Finally, the selected reviews\textsuperscript{32–34} all acknowledged the absence of rigorous evaluation of existing initiatives. One reason for the limited insight into processes and outcomes relates to the scarce availability of funding and time constraints to evaluate such initiatives. Stifler et al.\textsuperscript{45} found that “ease of use”, which refers to the existence of measurement tools and a comprehensive description of constructs, is an important criterion to support the use of theoretical frameworks and subsequently encourage systematic evaluation of initiatives. Hence, we added “measurement tools” as a criterion to the list of assessment criteria. Table 2 summarizes the assessment criteria, derived from the reviews on Compassionate Communities, for the selection of theoretical frameworks.\textsuperscript{32–34}

**Table 2.** Criteria to assess theoretical frameworks for their suitability for the study of Compassionate Communities.

<table>
<thead>
<tr>
<th>Core characteristics of Compassionate Communities</th>
<th>Assessment criteria</th>
</tr>
</thead>
</table>
| **Change at different socio-ecological levels** | - Provide constructs to identify contextual factors (i.e. barriers and enablers) that may influence the development and implementation process at different levels (i.e. intervention, individuals, organization, local environment, system, policy)  
- Provide structure to identify and evaluate action across different levels (i.e. intervention, individuals, organization, local environment, system, policy) |
| **Active involvement and collaboration**         | - Recognize the active involvement and agency of community members in creating change  
- Capture social experiential learning processes arising from collective sense-making processes  
- Recognize the different perspectives and motives of those affected by the intervention |
- Capture the relationships between different stakeholder groups and organizations

**Facilitation**
- Guide capturing the implementation strategies used to address barriers and enablers to implementing the intervention
- Capture learning loops and facilitate learning dialogues to support the development of community capacity

**Sustainability**
- Understand local processes and practices that may influence the dissemination and sustainability of initiatives
- Identify systemic issues and challenges that may undermine sustainability of initiatives

**Complexity**
- Recognize interconnectedness and interdependency of system components
- Recognize the nonlinear nature of the development and implementation process

### Broader criteria for the selection of theoretical frameworks to inform the evaluation of Compassionate Communities

<table>
<thead>
<tr>
<th>Measurement tools</th>
<th>- Provide guidance for measurement of constructs</th>
</tr>
</thead>
</table>

**Appraising theoretical frameworks against the identified assessment criteria**

The development and implementation of Compassionate Communities is an ongoing, nonlinear, socio-cultural change process that cannot be captured with a linear model. Therefore process models\(^{50-53}\) are not the best fit to study the different aspects of Compassionate Communities. The Implementation Effectiveness Model\(^{52}\) focuses explicitly on improving effectiveness during the development and implementation process. The Conceptual Model of Implementation Research\(^{51}\) and the Knowledge to Action model\(^{50}\) both specify steps or phases to be executed for accomplishing specific implementation goals. The Conceptual Model of Evidence-Based Practice Implementation in Public Service Sectors\(^{53}\), describes different stages of implementation, specifically focusing on the public service sector. These models insufficiently recognize the complex and adaptive nature of Compassionate Communities as they present implementation as a process that proceeds in a stepwise, linear fashion.\(^{49}\)

Determinant frameworks provide constructs to categorize and describe contextual determinants that may influence implementation.\(^{49}\) Two frameworks cover all socio-ecological levels: the Consolidated Framework for Implementation Research (CFIR) and the Conceptual Model of Evidence-Based Practice Implementation in Public Service Sectors.\(^{53}\) The existence of constructs at different socio-ecological levels and the extent to which the constructs are conceptualized and described differ across frameworks. Only CFIR and the integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework provide in-depth descriptions of the constructs and have measurement tools to guide the
operationalization and evaluation of constructs. Moreover, i-PARIHS is the only framework that highlights
the role of the facilitator as a core construct. The other two determinant frameworks, the Interactive
Systems Framework\textsuperscript{55} and Theoretical Domains framework\textsuperscript{56}, are more suitable to understand specific
organizational changes within a well-defined unit and are mostly used in single-setting changes.

The Extended Normalisation Process Theory (ENPT)\textsuperscript{61} is the only “implementation theory” in the list of
theoretical frameworks. ENPT helps to understand the active sense-making process (i.e. the cognitive and
social processes people engage in to integrate and sustain new practices) of actors involved in the
development and implementation process, and recognizes that new initiatives are mediated by wider
organizational structures and contexts.\textsuperscript{60} Moreover, ENPT, is the only framework that considers the
assessment criterion “sustainability” as a core construct.

Last, RE-AIM\textsuperscript{62} is an evaluation framework that emphasizes quantitative implementation metrics to
capture whether anticipated or planned changes took place. Given the co-creative nature of
Compassionate Communities and the focus on reorienting settings, these initiatives cannot be optimized
before implementation but rather experience ongoing change and adaptation. This means that widely
used evidence-based evaluation frameworks, such as RE-AIM, are not suitable to evaluate the complex
processes behind Compassionate Communities. Table 3 provides an overview of the assessment of
theoretical frameworks against the identified criteria. For an in-depth comparative analysis of the
frameworks against the assessment criteria, see Appendix 1.
Table 3. Analysis of frameworks for the study of Compassionate Communities.

<table>
<thead>
<tr>
<th>Theoretical framework</th>
<th>Nilsen's categorization(^60)</th>
<th>Socio-ecological levels</th>
<th>Assessment criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title and reference</td>
<td>Type</td>
<td>Intervention</td>
<td>Individuals</td>
</tr>
<tr>
<td>Knowledge to Action(^50)</td>
<td>Process model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Conceptual model of implementation research(^51)</td>
<td>Process model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Implementation effectiveness model(^52)</td>
<td>Process model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Conceptual model of evidence-based practice implementation in public service sectors(^53)</td>
<td>Process model</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Consolidated framework for Implementation Research (CFIR)(^54)</td>
<td>Determinant framework</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Interactive Systems Framework(^55)</td>
<td>Determinant framework</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Theoretical Domains Framework(^56,57)</td>
<td>Determinant framework</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS)(^58,59)</td>
<td>Determinant framework</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>General Theory of Implementation or Extended Normalization Process Theory (ENPT)(^61)</td>
<td>Implementation theory</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>RE-AIM framework(^62,63)</td>
<td>Evaluation framework</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Note: Extent to which assessment criteria is covered;  ● - complete coverage;  ○ - extensive coverage;  ◀ - moderate coverage;  ◁ - slight coverage;  ◊ - minimal or no coverage. Full details of rationale for decisions can be found in Appendix 1. Bolded theories are those selected for the study of Compassionate Communities.
We selected three theoretical frameworks (CFIR, i-PARIHS, ENPT) because together they cover all socio-ecological levels and assessment criteria necessary for the study of Compassionate Communities. As described above, the other frameworks miss core elements making them less suitable. The three selected frameworks are briefly discussed below.

**Understanding context and facilitation process.** CFIR is a conceptual meta-framework that provides a common structure for evaluating barriers and facilitators to implementation. The framework comprises five domains (intervention characteristics, outer setting, inner setting, characteristics of individuals involved, and the process of implementation) and 39 related constructs. CFIR has a clear dedicated website that provides examples, templates, and tools to assist in developing and evaluating implementation projects and collecting and analysing data. However, CFIR does not consider the active “facilitation process” behind intervention implementation, but it can be combined with i-PARIHS, which positions facilitation as the core ingredient in relation to its other constructs. The i-PARIHS facilitator’s toolkit offers pragmatic guidance to support the implementation of initiatives and provides a “Facilitation Checklist” to support structured assessment of the framework’s constructs.

**Understanding the implementation process and underlying mechanisms.** While determinant frameworks, such as CFIR and i-PARIHS, are useful as they describe in detail the structural and more static influences on development and implementation, implementation theories have more explanatory power because they characterize the underlying mechanisms of change. ENPT provides a framework that considers the dynamic and social nature of implementation, including individual and collective responses to implementation. The framework consists of four main constructs: capability, capacity, potential, and contribution. The earlier Normalization Process Theory has an interactive toolkit that can be used to plan a project or analyse data and helps to think through implementation and integration challenges. Additionally, the NoMAD (Normalisation MeAsure Development) questionnaire, a set of 23 survey items for assessing implementation processes from the perspective of stakeholders, can be used to describe participants’ views about how an intervention impacts their work, and their expectations about whether it could become a routine part of their work. The broader Extended Normalization Process Theory has so far only described conceptual measures.

**Discussion**

**Main findings**
This article identified three suitable frameworks to study the development, implementation, and underlying mechanisms of Compassionate Communities. Although the purpose of the frameworks differs, they are complementary, as CFIR provides constructs to categorize and describe contextual determinants that influence implementation at different socio-ecological levels, i-PARIHS adds the concept of “facilitation” to the list of contextual determinants, and ENPT helps to understand the underlying mechanisms that shape the way change processes occur. The complementary use of two determinant frameworks and an implementation theory provides theoretical grounding to gain rich insights into the emergent and shifting interplays between contextual conditions and the social and cognitive processes (sense-making) of agents during implementation.

When combining the three frameworks to study Compassionate Communities, we do not suggest using all constructs of each framework. For example, there is a substantial overlap between the constructs of the CFIR and i-PARIHS framework. This is because CFIR includes constructs based on the original Promoting Action on Research Implementation in Health Services (PARIHS) framework. Although the CFIR is more comprehensive than any single framework for categorizing barriers and enablers because it comprises nineteen other theories and frameworks, it does not include “facilitation” from the revised PARIHS framework. This means that CFIR does not specify mechanisms by which strategies might improve implementation. However, i-PARIHS can support the process of matching identified determinants to implementation strategies by studying the facilitation process as a core ingredient of implementation. Consequently, we advise using the five key domains proposed by CFIR to assess the implementation context and to use i-PARIHS to inform and assess the internal and external facilitation approach. The online CFIR technical assistance website can assist in selecting and applying suitable constructs and the i-PARIHS Facilitator’s Toolkit supports the structured assessment of the facilitation process.

Having identified potential implementation barriers and enablers using CFIR and i-PARIHS, ENPT can further examine process issues potentially hindering implementation and structure challenges needing to be overcome to implement and embed new practices. ENPT gives more insight into the underlying mechanisms of action and the social and cognitive work different stakeholders perform to enact new practices. The inclusion of the two determinant frameworks (CFIR and i-PARIHS) with the ENPT provides a complementary approach as the ENPT facilitates an understanding of the mechanisms that underlie sustained change. However, it is also worth noting that we did not intend to propose a blueprint for evaluating Compassionate Communities – the menu of potentially usable theories, models, and
frameworks is extensive. Future studies need to test the applicability of general constructs to specific projects and identify which modifications are needed to account for particular features in the field.

Research needs to be congruent with the principles of Compassionate Communities – participation, empowerment, collaboration, and social justice, so the importance of using theoretical frameworks in combination with more participatory methods should be emphasized. To foster system change and support community and settings-based initiatives, theory-oriented evaluation approaches, such as realist evaluation and developmental evaluation, can be used combined with the proposed frameworks. Especially developmental evaluation adheres to the principles of co-creation and participation by continuously involving stakeholders to enhance the “use” of evaluation data.

The authors will test and evaluate the theoretical frameworks proposed in this article in a study of the processes and mechanisms at play in the development of a Compassionate University in Flanders (Belgium). The study will identify opportunities and barriers when launching social actions to normalize experiences of serious illness, death, dying, and loss. The principles of stakeholder engagement and participatory action research are applied as the university itself functions as a Living Lab and different stakeholders are involved as end users. By making our commitments and reflections to the selected frameworks explicit, we hope to start a fruitful debate about future evaluation in public health research.

We invite fellow researchers to jointly advance the state of science regarding research about Compassionate Communities by sharing insights about the theories, frameworks, and methods applied and drawing from our collective experiential knowledge.

Limitations

Our work builds on systematic reviews that used rigorous methods for identifying Compassionate Communities initiatives. However, the lack of in-depth descriptions and evaluations of Compassionate Communities made it difficult to define their core characteristics for evaluation purposes. Only a handful of initiatives have been described in the last decade, and only a minority underwent some form of evaluation. As this often concerns bottom-up initiatives, it is likely that some are not reported or described in the scientific literature, particularly in non-English speaking contexts.
For the selection of frameworks, we consulted the reviews by Skolarus et al.\textsuperscript{47} and Birken et al.\textsuperscript{48} and considered only those theoretical frameworks within the top 10 on both lists. Other frameworks not on this list might also fit the purpose of studying the complex processes behind Compassionate Communities. Moreover, by only selecting highly cited theoretical frameworks we may have missed out on important innovations from the last few years. However, having a sufficient empirical basis was identified as an important criterion to support the use and uptake of theoretical frameworks by researchers and practitioners in the field.

**Conclusion**

In this article, we argue that the use of theoretical frameworks and participatory evaluation methods will improve our understanding of how to develop and support community and settings-based initiatives to improve the circumstances of people faced with serious illness, death, dying, and loss. Moreover, we call on interdisciplinary and social science researchers to engage in the field to collectively develop an increasingly sophisticated understanding of Compassionate Communities. Flexibility and integration of various existing and practical conceptual models, ideas, approaches, and methods from various disciplines might help the uptake of Compassionate Communities and promote the scalability and sustainability of the model.
Abbreviations

CFIR: Consolidated Framework for Implementation Research; NPT: Normalization Process Theory; ENPT: Extended Normalization Process Theory; i-PARIHS: integrated-Promoting Action on Research Implementation in Health Services

Declarations

Author contributions
HB: conceptualization and design, data analysis, interpretation of data, led the writing process and drafted the original article. SD and JC: conceptualization and design, interpretation of data, and reviewing for critically important content and editing. SV, KC, FBD, LD and LDD: Reviewing for critically important content and editing. All authors read and approved the final manuscript.

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Declaration of conflicting interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Research ethics
This article does not involve research on human subjects, hence it did not require approval of an Ethics Committee or IRB.

Data management and sharing
No datasets were generated or analysed during the current study.

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