


# How does community engagement evolve in different compassionate community contexts? A longitudinal comparative ethnographic research protocol

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## Abstract

**Background:** Compassionate communities build on health promoting palliative care that aims to address gaps in access, quality, and continuity of care in the context of dying, death, loss, and grief. While community engagement is a core principle of public health palliative care, it has received little attention in empirical studies of compassionate communities.

**Objectives:** The objectives of this research are to describe the process of community engagement initiated by two compassionate communities projects, to understand the influence of contextual factors on community engagement over time, and assess the contribution of community engagement on proximal outcomes and the potential for sustaining compassionate communities.

**Research Approach and Design:** We use a community-based participatory action-research approach to study two compassionate communities initiatives in Montreal (Canada). We develop a longitudinal comparative ethnographic design to study how community engagement evolves in different compassionate communities contexts.

**Methods and Analysis:** Data collection includes focus groups, review of key documents and project logbooks, participant observation, semi-structured interviews with key informants, and questionnaires with a focus on community engagement. Grounded in the ecology of engagement theory and the Canadian compassionate communities evaluation framework, data analysis is structured around longitudinal and comparative axes to assess the evolution of community engagement over time and to explore the contextual factors influencing the process of community engagement and its impacts according to local context.

**Ethic:** This research is approved by the research ethics board of the Centre hospitalier de l'Université de Montréal (approval certificate #18.353).

**Discussion:** Understanding the process of community engagement in two compassionate communities will contribute to a deeper understanding of the relationships between local context, community engagement processes, and their effect on compassionate communities outcomes.

**Keywords:** community engagement, compassionate communities, ethnography, implementation, palliative and end-of-life care, public health palliative care, research protocol

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## Background

Palliative and end-of-life care aims to improve quality of life and well-being of people facing serious illness, end-of-life, dying, and death, including caregivers', grief and bereavement support.<sup>1</sup> Unequal access to palliative care is reported worldwide, as only 14% of those eligible for palliative care will access it.<sup>2</sup> In Canada, it is estimated that only 15% of Canadians have early access to palliative and end-of-life care in the community, while 99% of palliative home care is provided by family and friends.<sup>3</sup> Canada is one of the countries most affected by population aging,<sup>4</sup> resulting in an increased prevalence of chronic and degenerative diseases that challenge the health care system, adding to caregivers' burden and leading to a greater social isolation that has important impacts on population health and mortality risks.<sup>5,6</sup> As a result, new models of palliative and end-of-life care have been developed to meet these growing needs.

### *Community engagement in serious illness, end-of-life, loss, and grief: the compassionate community model*

Among these new approaches to end-of-life care, the compassionate communities model – which is rooted in health promotion approaches – seems promising. Impact evaluation of compassionate communities shows an increase in the size of social networks, an increase in the acceptance of support and palliative care, and reduction in hospital admission and caregivers burden.<sup>7,8</sup> Developed in the mid-2000s by the medical and public health sociologist Kellehear,<sup>9</sup> compassionate communities are inspired by the 'Healthy Cities' movement, which is based on the five pillars of the Ottawa Charter for health promotion: (1) build healthy public policy, (2) create supportive environments for health, (3) strengthen community action for health, (4) develop personal skills, and (5) reorient health services.<sup>10</sup> Compassionate communities emerged from the need for cultural changes in palliative and end-of-life care, moving from a biomedical model of institutional care to broader community support. This model is part of a new public health approach to palliative care,<sup>8,11</sup> premised on the idea that caring for people facing dying, death, loss, and grief is everyone's responsibility.<sup>12</sup> It is anchored in a social model of palliative and end-of-life care to address gaps in access, quality, and continuity of care.

Compassionate communities embrace a holistic definition of health that goes beyond the mere treatment of symptoms to include psychological, spiritual, and social well-being, through strengthening social cohesion, increasing capacities for mutual support, and raising the level of end-of-life and death literacy to support the development of a community response to aging, dying, death, loss, and grief.<sup>9,13</sup> The goal of compassionate communities is to promote the empowerment of citizens to care for one another through capacity building and community development. In doing so, a variety of community actors outside the professional health care system (e.g. schools, municipalities, workplaces, community organizations, spiritual and faith groups) are engaged in dynamic relationships oriented toward joint health and social care-related actions.<sup>14</sup>

Community and engagement are complex concepts that entail a variety of definitions, both in the academic literature and among practitioners.<sup>15–19</sup> Communities are defined here as 'groups of people that may or may not be spatially connected, but who share common interests, concerns or identities',<sup>20</sup> and we define engagement as 'dynamic relationships oriented toward joint actions related to health' (e.g. promoting health together, providing support together, developing programs together, caring together).<sup>14</sup> Our focus in this study is on community engagement, which is understood as engagement with individual community members (e.g. patients, informal caregivers, citizens) and groups (e.g. community organizations, civic institutions, municipalities).

The importance of community engagement is grounded in two main rationales: (1) the need to empower and strengthen communities' capacity to care for one another and (2) the importance of building on local needs and assets identified and developed with(*in*) the community.<sup>14</sup> Public health palliative care assumes that support networks can contribute to demedicalizing death and dying, as

by drawing on the resources of the community, it is possible, not only to meet a person's social and/or practical needs, but also more broadly to build capacity and resilience in the community and naturalize the process of care, dying, death and bereavement.<sup>21</sup>

By linking support from clinical settings to the community and back, continuity of care should

be improved for people at the end-of-life and their caregivers. Moreover, continuity of care reduces unnecessary suffering and health systems' burden, while learning about end-of-life and grief is created with (*in*) the community.<sup>12</sup> Some community organizations and programs naturally align with compassionate communities principles, although they may not self-identify by compassionate communities labels. In fact, public health palliative care assumes that community members are experts in identifying the needs, issues, and solutions to support people facing dying, death, loss, and grief. As such, community engagement is a core principle and mechanism of action of compassionate communities' approaches.

#### *What is known about community engagement in health promoting palliative care*

While community engagement has a central place in theory, it seems to have received little attention in empirical studies of compassionate communities. Results from a recent scoping review show that, while several hundred compassionate community initiatives have been implemented and evaluated worldwide, the engagement of community members is rarely reported and evaluated.<sup>22</sup> Overall, they are mostly engaged as 'target users' of compassionate communities, with evaluations being largely focused on individual outcomes rather than on their collective engagement in the strategic and early stages of compassionate community development (e.g. priority-setting, need assessment, and governance).

Also, D'Eer *et al.*<sup>23</sup> recently published the first systematic review focused on civic engagement in the context of serious illness, end-of-life, and loss (including compassionate communities). Civic engagement is broader than community engagement, as it includes any institutions outside of the health system, while community engagement refers more specifically to the community organizations, groups, and members. Using a mixed-method approach, these authors were able to systematically describe 19 initiatives with a focus on civic and community engagement, by comparing the contexts, development, impacts, and evaluation methods. These authors found that civic engagement was mostly reported descriptively, and none of the included studies focused on its evaluation. In their systematic review of area-based Compassionate Communities, Quintiens *et al.*<sup>24</sup> also report that the description of compassionate communities development is scarce,

impeding knowledge on how to successfully engage and empower community members in its development, leadership, and sustainability. Formal evaluation and transparent presentation of associated methodologies are also lacking.<sup>23,24</sup> Furthermore, community engagement in compassionate communities initiatives are almost exclusively associated with community-led approaches, while the conjunction of professionally-led and community-led approaches is rarely taken into account.<sup>23</sup> Taken together, the current state of research points toward a common message that highlights a paradox. While community engagement is given a central place in compassionate communities' theory, it also accounts for an important gap in compassionate community evaluation. This has significant implications for practitioners who lack evidence-informed guidance on how to effectively engage and partner with community members and leaders.

Another knowledge gap identified by most evaluation studies and systematic reviews in the field of compassionate communities is the lack of information on how local context shapes the process of community engagement and influences the impact of compassionate communities.<sup>8,22–25</sup> In fact, studies rarely explore how local contexts shape the impacts on individuals, communities, organizations, populations, and health care services. Compassionate communities and cities are complex social innovations taking years to develop and to bring about results. Most initiatives started a few years ago, with rare opportunities to longitudinally study how community engagement processes evolve over time and how it is linked to potential impacts.

A number of compassionate communities' projects are initiated by academic–community partnerships or palliative care institutions.<sup>13,23,24</sup> Leadership transition from research-initiated to community-led usually takes years to achieve, and consequently, results are often not published once researchers withdraw.<sup>22</sup> Thus, it requires long-term planning from the beginning to assess, throughout the trajectories, how the context of compassionate communities' implementation influences the relationship between community engagement, health outcomes, and their surrounding environment (local context). The end of research funding; the lack of resources and sustainability planning; the complex, diverse, and unique nature of this particular community intervention are identified as major

barriers in assessing and evaluating impacts.<sup>22</sup> In addition, the diversity of compassionate communities models, purposes, and design are hard to generalize. In fact, the financial pressure to document short-term impacts may urge project leaders to implement professionally-led programs that by-pass longer, more open and intensive processes of community engagement. However, community-led initiatives may lack research resources to document long-term impacts.<sup>1,26</sup> D'Eer *et al.*<sup>23</sup> thus mention the need for a framework that could support the evaluation of community engagement in compassionate community initiatives.

The challenges of documenting long-term community engagement processes are not unique to health promoting palliative care and have been documented in other health promotion approaches.<sup>27</sup> Many research projects and evaluations to date have focused on testing the impacts of community engagement on health and social outcomes, by conceptualizing engagement as an intervention designed by professionals and public institutions as opposed to a social process deeply influenced by context.<sup>28</sup> This 'black box' approach to research and evaluation tends to evacuate engagement from its local context, resulting in conclusions that are difficult to generalize. Therefore, it explains why it is difficult to have common indicators and measures to assess outcomes and impacts of compassionate communities' initiatives. One way to overcome these challenges is to focus on the parameters that cannot be controlled within this complex intervention, such as contextual factors, individual's perception of community engagement, and how implementation trajectories differ according to local context. In doing so, it should be possible to more accurately interpret the outcomes and later on, the impacts.

In conclusion, compassionate communities position community engagement as a core principle of public health approaches to end-of-life care. Despite its central role in theory, evaluating the process and outcomes of community engagement is an important gap in the research literature. This research protocol capitalizes on the opportunities offered by a long-term compassionate community initiative implemented in two culturally distinct communities over a 5-year period to contribute to the methodological and empirical literature in this emergent area of research.

*Research questions and objectives.* In order to understand the community engagement process in compassionate community initiatives, their contextual factors, and proximal effects on individuals and community organizations, our research questions are:

1. How does community engagement evolve according to different compassionate community contexts?
2. How does community engagement leadership evolve over time?
3. What contextual factors influence community engagement processes and implementation trajectories?
4. How does community engagement influence the perceived proximal impacts of compassionate community initiatives?
5. How does community engagement influence the potential for sustaining compassionate community initiatives?

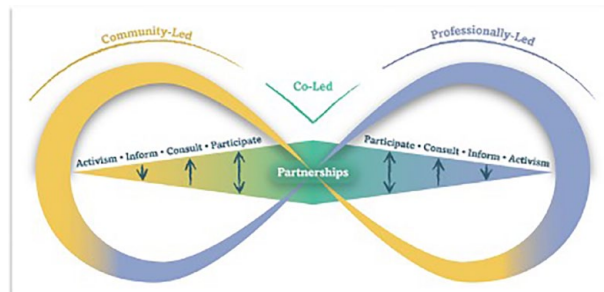
Four research objectives, aligned with these questions, aim to narrow the knowledge gaps previously identified in the literature:

1. To describe the process of community engagement initiated by the compassionate communities projects at all development stages (initiation, mobilization, co-planning, co-creation, and implementation);
2. To understand how contextual factors influence community engagement processes by comparing the engagement trajectories across two contrasted sites;
3. To assess the proximal outcomes of community engagement on community members, citizens, professionals, and organizations;
4. Support knowledge exchange among research and community partners to support community engagement processes and to promote sustainability.

*The ecology of engagement: a theoretical framework to study community engagement in public health palliative care*

We adopt the 'Ecology of Engagement'<sup>14</sup> as a theoretical model to study community engagement in the context of compassionate community initiatives. The ecology of engagement is designed to understand, support, and evaluate engagement relationships at different levels of health ecosystems (micro, meso, and macro), while





**Figure 1.** Engagement: how and under whose leadership.

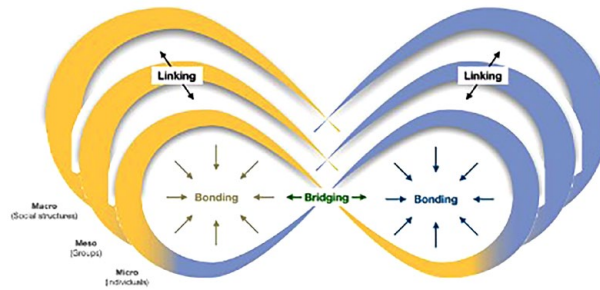
Engagement are dynamic relationships oriented toward joint health-related actions. Engagement can be led by the community (yellow), by professionals (blue), or co-led (green). Engagement is distinguished by knowledge flow (information to, consultation from, participation between) and power (activism to transform power dynamics from the outside, partnering by sharing power from the inside). Engagement relationships evolve over time (“bouncing along the loop”).

considering the interdependence and bi-directional influence between health systems and communities (both being considered intrinsic components of larger ‘health ecosystems’ that include all members of society). As a reminder, engagement is here defined ‘as dynamic relationships oriented toward joint actions within health ecosystems’.<sup>14</sup> Health ecosystems are broader than professional health systems and include patients, informal caregivers, and other community members. Engagement represents a specific type of relationship between individuals and groups focused on actions taken together (e.g. caring together; promoting health and social care together; developing and implementing compassionate communities together; building end-of-life actions; practices and policies together). Engagement relationships can be developed at the micro-level of individual relationships (e.g. neighbors and family members caring for a dying person), at the meso-level of groups and institutions (e.g. community groups, workplace institutions, or schools collaborating in end-of-life education and support programs), or at the macro-level of the larger social system (e.g. developing end-of-life actions and policies with citizens).

We use a typology of engagement relationships (see Figure 1) which recognizes that compassionate communities activities can be led by community members, by professionals, or both. We distinguish engagement of individual community members at the micro-level (e.g. patients, family members, informal caregivers, neighbors, and citizens), meso-level engagement with groups and institutions (community organizations, health

institutions, municipalities, schools), and larger macro-level social structures (e.g. policies and culture). Engagement relationships are finally distinguished according to knowledge flow (information *to*, consultation *from*, participation *with*) and power (partnership to share power from *within*, and activism to transform power relationship from *outside*). The ecology of engagement further distinguishes community engagement from the engagement of individual health care professionals (e.g. physicians, nurses, social workers) and health system institutions (e.g. palliative care hospices, clinics, hospitals, health authorities).

Engagement relationships are further characterized according to the social capital concepts of bonding, bridging, and linking. Bonding refers to engagement relationships within individuals and groups with shared identities (e.g. among community members and groups). Bridging refers to engagement relationships across community and professional individuals and groups (e.g. partnership between a community organization and a hospice palliative care institution to co-deliver joint educational activities). Linking refers to engagement relationships across ecosystem levels that strengthen connections with individuals and groups across power and authority gradients (e.g. participation of family members in a compassionate community steering committee, linking of community members with an elected representative or manager of a health authority). Within the context of this study, we focus primarily on engagement at the micro- (individual community members) and meso-levels (community organizations and institutions), with macro-level factors being considered largely as contextual influences



**Figure 2.** Engagement with whom and at what level.

Engagement relationships can be distinguished according to who is engaged and at what level. Bonding refers to “inward looking” engagement relationships within community members (yellow) or professionals (blue). Bridging are “outward looking” engagement relationships across community members and professionals (green). Linking are “upward looking” engagement relationships across power authority and levels (black).

(e.g. policies, social attitudes and culture toward death) (Figure 2).

Finally, the Ecology of Engagement points toward broad categories of community engagement impacts. From a process perspective, it assumes a bi-directional influence between community engagement and health ecosystems (community engagement is influenced by the individual, institutional, and social characteristics of health ecosystems; health ecosystems are transformed by community engagement). From an impact perspective, the mutual interdependence between community engagement and health ecosystem is assumed to influence the equilibrium between health, resilience to crisis and changes, overall resources use, and equity.<sup>14</sup>

### Research setting

This protocol describes the community engagement research component, which is embedded in a wider 5-year participatory action research aimed at co-creating, implementing, and evaluating two compassionate communities in Montreal (Canada). As such, the research setting can be characterized as an academic-initiated public health palliative care project, with project funding and coordination being initially led by an academic research team and a hospice palliative care institution. Funded through a philanthropic foundation, the participatory action research has been co-initiated by the Montreal Institute for Palliative Care and Canada Research Chair in Partnership with Patients and Communities. The interdisciplinary action-research team includes clinicians, community members, a patient-partner, and researchers from a diverse

range of expertise in anthropology, community engagement, management, medicine, palliative and end-of-life care, participatory research, psychology, public and population health, social innovation, and sociology. Community development activities are led by three community engager coordinators hired through research as paid employees, who progressively established independent governance structures in each of the participating communities.

Initially, this 5-year project (2018–2023) aimed at (1) producing a scoping review of the international literature on compassionate communities models, success factors, and barriers to implementation<sup>22</sup>; (2) identifying emerging compassionate communities in Canada in order to inform local implementation; (3) understanding local implementation contexts in two Montreal neighborhoods (West Island and Centre-Sud); (4) supporting the co-development of two pilot compassionate communities in collaboration with local community leaders and organizations; and (5) evaluating compassionate communities, with a focus on understanding and supporting community engagement processes. The latter corresponds to the stage in which the current protocol is situated. It should be noted that a significant part of the initiative took place during the lockdown imposed by the COVID-19 pandemic, with a large number of community development start-up activities being conducted online between March 2020 and March 2022.

### Research approach

We use a community-based participatory research (CBPR) approach to the study. CBPR is defined

as ‘collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity’.<sup>27</sup> CBPR is not a method or a study design but a fundamental orientation to research that seeks to produce knowledge and social change. It distinguishes ‘research that takes place on targeted communities, versus in community settings, versus research with community partners’.<sup>20</sup> CBPR distinguishes itself by the inclusion of community members as partners in different stages of the project (e.g. intervention and research design, data collection and analysis, communication).<sup>29</sup> In the context of this project, community members have been more actively engaged in the compassionate community development activities (e.g. local governance, needs assessment, asset mapping, activity design, and delivery) than in the research design. However, community actors (a community leader, local community engager coordinators, a patient-partner, and hospice manager) have been integrated as part of the research protocol development team.

### Research design

We develop a longitudinal comparative ethnographic design for the study, with an emphasis on qualitative data that are supported to a lesser extent by descriptive quantitative data. This design is relevant to understand the process of community engagement, and how the implementation of compassionate communities varies according to the characteristics of the communities where they are implemented. In fact, the compassionate communities’ sites have their own local contextual characteristics and contrasting cultural backgrounds (e.g. anglophone *versus* francophone, socio-economic and demographic background, urban *versus* suburban setting) that are well suited for comparative ethnographic research. This research design is also well aligned with the recent call for action to use ethnographic research in the field of palliative care to gain a better understanding of the complexities of social practices of palliative care, and to include people most under-represented in palliative care research.<sup>30</sup> For those researchers, ‘ethnographic methods can enable insights not accessible from other data collection methods, including structures, processes, and behaviors the interviewed participants may be unaware of themselves’.<sup>30</sup>

### Data collection and procedures

Data collection extends over a 3-year period (2020–2023). In addition, a retrospective data analysis, including key documents, previous interviews, and focus groups, conducted in the participatory action research (2018–2019) will complete the study of community engagement process in the context of public health palliative care. Several data collection modalities are thus used to capture the process of community engagement:

1. Review of key documents, previous interviews, and focus groups conducted at the onset of the participatory action research;
2. Participant observation of community engagement activities, projects’ development meetings and implemented activities during the project;
3. Annual semi-structured interviews with key informants and partners for each pilot site;
4. Implementation logbooks for each site;
5. Questionnaires and other data collection methods that suit the emergent project development and partners’ needs.

Ethnographic methods will document the community engagement process in real time through logbook analysis, participant observation, semi-structured interviews with key informants, focus groups, and questionnaires to inform project development in an iterative manner. Table 1 links research questions, objectives, data collection, and analysis.

In order to compare community engagement in both pilot sites, our strategy is to use the same data collection modalities for each site throughout the project. Below is a description of the procedure for each data collection method.

1. Key-document review include asset mapping, needs assessment (including interviews and focus groups conducted at the onset of the project), socio-demographic profile, local features and population health data of both neighborhoods, meeting minutes, and annual activities reports;
2. Participatory observation means that the researcher is embedded in the mobilization, engagement, and community development activities. As such, participant observation is at the crossroads of the fieldwork and research, because it allows the researcher to

**Table 1.** Research questions, objectives, data collection, and analysis.

Research questions	Research objectives	Data collection	Data analysis
1. How does community engagement evolve according to different compassionate community contexts?	1. To describe in detail the process of community engagement initiated by the Compassionate Communities projects at all stages (initiation, mobilization, co-planning, co-creation, and implementation phases)	<ul style="list-style-type: none"> <li>- Environmental scan</li> <li>- Need assessment (focus groups and meetings minutes)</li> <li>- Key-document review (agenda, meeting minutes, asset mapping)</li> <li>- Asset mapping, socio-demographic and population health data (context)</li> <li>- Logbook</li> <li>- Annual interviews with key informants</li> <li>- Participant observation (from needs assessment activities to early implementation)</li> </ul>	Longitudinal axis (intra-site community engagement process and outcomes): environmental scan, need assessment, key-document review, asset mapping, logbook, interviews, and participant observation will describe the contexts in which community engagement processes take place for both sites. Comparative axis (inter-site comparisons) will compare data on local contexts, community engagement processes, and outcomes (activities implemented) to understand how engagement evolves in different contexts.
2. How does community engagement leadership evolve over time?	1. To describe in detail the process of community engagement initiated by the Compassionate Communities projects at all stages (initiation, mobilization, co-planning, co-creation, and implementation)	<ul style="list-style-type: none"> <li>- Key-document review (agenda, meetings minutes, asset mapping)</li> <li>- Logbook</li> <li>- Annual interviews with key informants</li> <li>- Participant observation (from needs assessment activities to early implementation)</li> </ul>	Longitudinal axis (intra-site community engagement process and outcomes): key-document review, asset mapping, logbook, interviews, and participant observation will describe how community engagement processes evolve over time for both sites. Data will be analyzed using the ecology of engagement framework (i.e. characterizing engagement relationships, evolution of leadership over time). Comparative axis (inter-site comparison) will compare data on local contexts, community engagement processes, and outcomes (activities implemented) for each development stages to understand how engagement evolves over time in different contexts.
3. What contextual factors influence community engagement processes and implementation trajectories?	2. To understand how contextual factors influence community engagement processes by comparing the engagement trajectories across two contrasting pilot sites	<ul style="list-style-type: none"> <li>- Asset mapping, socio-demographic and population health data (context)</li> <li>- Logbook</li> <li>- Annual interviews with key informants</li> <li>- Participant observation</li> </ul>	Comparative axis (inter-site comparison) will compare data on local contexts and community engagement processes for each development stages to understand how contextual factors influence community engagement processes and outcomes (implemented activities)
4. How does community engagement influence the perceived proximal impacts of compassionate community initiatives?	3. To assess the proximal outcomes of community engagement on community members, citizens, professionals, and organizations	<ul style="list-style-type: none"> <li>- Annual interviews with key informants</li> <li>- Participant observation</li> <li>- Google Analytics for online activities</li> </ul>	Longitudinal axis (intra-site community engagement process and outcomes): logbook, interviews, and participant observation will assess the proximal outcomes (implemented activities) and perceived impacts for both sites. Comparative axis (inter-site community engagement processes and outcomes) will compare the proximal outcomes (implemented activities) and perceived impacts of both sites.
5. How does community engagement influence the potential for sustaining compassionate community initiatives?	4. Support knowledge exchange among researchers and community partners to support community engagement processes and to promote sustainability	<ul style="list-style-type: none"> <li>- Logbook</li> <li>- Participant observation</li> <li>- Annual interviews with key informants</li> </ul>	Longitudinal axis (intra-site community engagement process and outcomes): logbook, interviews and participant observation will document facilitators and barriers to sustainability. Comparative axis (inter-site community engagement processes and outcomes) will compare facilitators and barriers to sustainability of both sites. Real-time analysis (logbook, participant observation, and interviews) and regular feedback between community partners and the research team.



contribute to the development of the project, to support the action-research teams (community engagers), and to collect data to produce knowledge. For this reason, the researcher must have an extensive knowledge and expertise in palliative and end-of-life care, including public health palliative care approaches, and must have training and experience with the ethnographic method. Regarding the procedure, the researcher is invited to meetings and activities (on Zoom or in person) by the action-research teams when appropriate, and will be introduced accordingly to the participants. Observations will be noted with a particular focus on engagement relationships and dynamics, but will also pay attention to the needs, concerns, issues, visions, and ideas of the community partners;

3. Based on purposive sampling, semi-structured interviews with community engager coordinators from the action-research team ( $n = 13$ ) and project leaders within community organizations involved in the implementation of the compassionate communities in Centre-Sud ( $n = 20$ ) and West Island ( $n = 10$ ) are done on an annual basis. We define project leaders as dedicated individuals through whom community engagement and partnerships occur. Thus, inclusion criteria for recruitment in both sites are to be a member of the action-research team in charge of community engagement or a project leader representing a community organization involved in the implementation of compassionate communities. This sampling method allows the number of participants to be adjusted according to the evolution of the research project (i.e. staff turnover, arrival of new partners).
4. The completion of the project logbook is done on a bimonthly basis by two members of the action-research team for both sites. All the activities carried out and partners solicited are noted in an Excel sheet, through a conversation between the community engager coordinators and a research professional in which they can identify issues, barriers, and facilitators related to community engagement and project implementation. The logbook is useful for keeping track of the history of the project, the path of the implementation according to who is engaged, in what kind of activities

and with whom, but it is also a reflexive tool for instant feedback on how to overcome issues and barriers and how to improve the scope of actions;

5. Finally, questionnaires and tools adapted to the evolution of the research project will be used according to the needs that arise, but will keep a focus on community engagement. For example, a questionnaire on the perception of community engagement or the Death Literacy Index<sup>31</sup> could be used to assess the proximal outcomes of community engagement on community members, citizens, professionals, and organizations. Because participatory action research is cyclic and iterative, it is not possible to control neither what's going to happen next, whether the sample size per implemented activity will be sufficient to be statistically significant, nor what needs to be documented or measured in the future. In fact, the number of participants is usually small at the initial and early implementation stages. We believe that a longitudinal comparative ethnographic design is flexible enough and highly adaptive to contexts to mitigate those uncertainties, as well as documenting facilitators and barriers to sustainability.

#### *Data analysis*

In line with our ethnographic design, our data analysis approach relies primarily on qualitative and descriptive approaches to understand the process of community engagement and its relationship to contexts and perceived outcomes.

Data analysis is structured around two axes with specific purposes: a longitudinal axis and a comparative axis. To assess the evolution of community engagement over time, a longitudinal data analysis will provide a detailed account of the intra-site community engagement process that led to the implementation of compassionate activities. The comparative axis, an inter-site comparison, will be useful to explore the contextual factors influencing the process of community engagement and its proximal impacts according to local context.

As a pilot site for testing the Canadian compassionate communities evaluation framework, developed under the leadership of the BC Centre

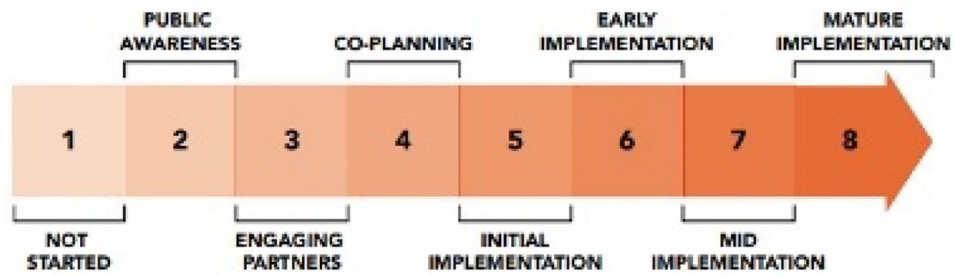
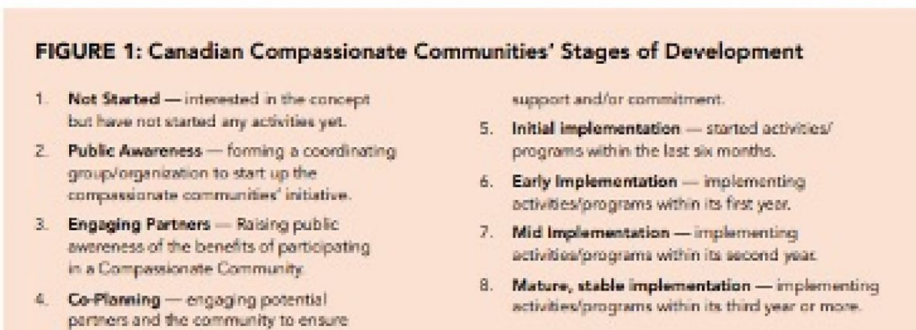


Figure adapted from: Pallium Canada, BC Centre for Palliative Care, Hospice Palliative Care Ontario (2021). Canadian Compassionate Communities' Stages of Development.



**Figure 3.** Canadian Compassionate Communities' Stages of Development.

for Palliative Care, Hospice Palliative Care Ontario, and Pallium Canada,<sup>1</sup> we will use the Canadian Compassionate Communities' eight stages of development to structure data analysis over time around the community engagement process. Stages 1 to 4 correspond to community engagement activities, while Stages 5 to 8 are related to the implementation (see Figure 3).

The ecology of engagement will be used as a framework for analyzing the data that document the evolution of the community engagement process. In doing so, we will be able to describe who is mobilized and engaged with whom, to characterize engagement relationships according to social capital concepts of bonding, bridging, and linking (e.g. is bridging happening between professionals and community members, is linking being supported with community leaders and institutions holding symbolic or financial resources ensuring the growth and sustainability of the initiative?), the evolution of leadership according to power and knowledge flow (to what extent do professionally-led engagement activities move toward community-led), and at what level engagement relationships occur (micro-, meso-, and macro-level). Finally, using both the ecology of engagement (theory) and the Canadian

Compassionate Communities Evaluation Framework for an inter-site comparative analysis will highlight the contextual factors influencing the processes of community engagement and its proximal impacts on the implementation trajectories.

### Discussion

Studying the community engagement process will allow us to examine how compassionate community's initiatives operate to produce outcomes according to local context. Therefore, understanding and comparing the process of community engagement in two compassionate communities will provide more generalizable results in the field of public health palliative care. Results could eventually contribute to the development of a framework for evaluating community engagement in compassionate community initiatives. Ultimately, the results of this community engagement research will help explain the outcomes and impacts of compassionate community initiatives derived from the 5-year participatory action research. Ethnographic methods are flexible enough to quickly adapt to different research contexts, such as diverse and emerging needs or concerns of our community partners and research

collaborators. In doing so, it allows us to examine uncontrolled parameters such as individuals' perceptions, contextual factors of community engagement, and implementation trajectories according to local contexts.

### Limitations

Online data collection was the only way to conduct the research during the strict lockdown imposed in Montreal and the province of Quebec between March 2020 and March 2022. While the fieldwork successfully adapted to these challenging conditions, particularly in the context of online community engagement and development, some limitations were identified. The initial stages of compassionate community development (public awareness, engaging partners, co-creation, co-planning, and early implementation) were conducted on Zoom. Consequently, the number of hours to perform participant observation is limited to this particular configuration of the research settings. This prevented spending more time in the fieldwork, limiting opportunities for informal discussions that strengthen relationships between researchers and community members, for example. It is likely that this situation hindered the community engagement process in one site, but not in the other (e.g. it could be a facilitator in one context and a barrier in the other). We will take into account the influence of the pandemic as a contextual factor to ensure that we capture its effect on community engagement and the implementation trajectory of both pilot sites.

Another limitation identified was that fieldwork did not begin at the same time for the two pilot sites, because the Centre-Sud team was constituted almost a year later (2020) than the West Island (2019). This situation may affect the comparative analysis of implementation trajectories, as the data on the first year of development in the West Island excludes participant observation. However, it is possible to reconstruct the process of community engagement from the needs assessment data, the project logbook, minutes of strategic meetings, and interviews with the community engagers and community partners.

### Conclusion

Community engagement is recognized as having an important influence on sustainability for

compassionate communities, as well as other social innovation projects.<sup>1</sup> Studying the process of community engagement in the context of public health palliative care initiatives will narrow the knowledge gaps by explaining the relation between community engagement process, local context, and later on, their effect on health and social outcomes. The ecology of engagement framework provides a theory-informed research for public health palliative care and other community-led initiatives. In addition, the Canadian compassionate community stages of development allow a detailed description of the process of community engagement as well as the implementation trajectories throughout the lifespan of the project. A longitudinal comparative ethnographic design will support a deeper understanding of the complexity of the community engagement in the context of dying, death, loss, and grief. Finally, by deepening our understanding of this process, it will be possible to better assess future outcomes and impacts by understanding how they occur and in what context.

### Declarations

#### *Ethics approval and consent to participate*

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#### *Consent for publication*

Not applicable.

#### *Author contributions*

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**Isabelle Marcoux:** Conceptualization; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing.

**Serge Daneault:** Conceptualization; Investigation; Project administration; Writing – review & editing.

**Andreea-Catalina Panaite:** Conceptualization; Data curation; Investigation; Visualization;

Writing – original draft; Writing – review & editing.

**Lise Jean:** Conceptualization; Investigation; Project administration; Writing – review & editing.

**Mélodie Talbot:** Conceptualization; Investigation; Methodology; Writing – review & editing.

**Dale Weil:** Conceptualization; Funding acquisition; Project administration; Supervision; Writing – review & editing.

**Ghislaine Rouly:** Conceptualization; Methodology; Writing – review & editing.

**Libby Sallnow:** Conceptualization; Methodology; Writing – review & editing.

**Allan Kellehear:** Conceptualization; Methodology; Writing – review & editing.

**Antoine Boivin:** Conceptualization; Funding acquisition; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing.

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