Thesis submitted in fulfillment of the requirements for the Doctoral degree of
Doctor in social health sciences

THE DEVELOPMENT AND EVALUATION OF CIVIC ENGAGEMENT IN NEIGHBOURHOODS CONCERNING SERIOUS ILLNESS, DEATH AND LOSS

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In time of trouble, I had been trained since childhood, read, learn, work it up, go to the literature. Information was control.

[……]

Dolphins, I learned from J. William Worden of the Harvard Child Bereavement Study at Massachusetts General Hospital, had been observed refusing to eat after the death of a mate. Geese had been observed reacting to such death by flying and calling, searching until they themselves became disoriented and lost. Human beings, I read but did not need to learn, showed similar patterns of response.They searched.

- Joan Didion, The Year of Magical Thinking

TABLE OF CONTENTS

CHAPTERS II-VII ARE BASED ON THE FOLLOWING PUBLICATIONS

CHAPTER II

D'Eer L, Quintiens B, Van den Block L, Dury S, Deliens L, Chambaere K, Smets T, Cohen J. Civic engagement in serious illness, death, and loss: A systematic mixed-methods review. Palliat Med. 2022, 36: 625-651. [2020 IF 4.762; Ranking Q1; ranking 18/108 in Health Care Sciences & Services in SCIE edition]

CHAPTER III

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Smets T*, Cohen J*. How compassionate is your neighborhood? Results of a cross-sectional survey on neighborhood participation regarding serious illness, death, and loss. Death Stud. 2023 :1-10. [2022 IF 3.8; Ranking Q1; ranking 34/147 PSYCHOLOGY, MULTIDISCIPLINARY in SSCI edition]

CHAPTER IV

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Cohen J*, Smets T*. Citizens with a caregiving experience in the past year are more likely to participate in neighbourhood activities regarding serious illness, death or loss: A cross-sectional survey study. [Submitted -minor revisions]

CHAPTER V

D'Eer L, Chambaere K, Van den Block L, Dury S, Deliens L, Cohen J*, Smets T*. Civic Engagement in Neighbourhoods regarding serious illness, death and loss (CEIN): a study protocol for a convergent-parallel mixed-methods process and outcome evaluation that balances control and flexibility. Palliat Care Soc Pract. 2023, 17: 1-11. [2024 IF 2.7; Ranking Q2; ranking 60/174 in Health Care Sciences & Services in SCIE edition]

CHAPTER VI

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Quintiens, B. Smets T*, Cohen J*. Process evaluation of civic engagement initiatives around serious illness, caregiving, dying and loss: a multimethod study in two neighbourhoods. [Ready to submit]

CHAPTER VII

D'Eer L, Sallnow L. Compassionate Communities: contemporary tensions and challenges. Ann Palliat Med. 2023, 13: 5-9. [2021 IF 1.925; Ranking Q4; ranking 90/109 HEALTH CARE SCIENCES & SERVICES in SCIE edition]

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PART I

Chapter I

GENERAL INTRODUCTION

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1. Introduction

Annually, there are approximately 111,000 deaths in Belgium.[1] Projections indicate that this number will increase in the coming years, reaching 131,000 per year by 2050.[1] A large portion of these deaths can be attributed to non-communicable diseases such as cancer, which is responsible for 25% of all deaths and cardiovascular disease, responsible for 24% of all deaths.[2] Congruently with the rising number of deaths from non-communicable diseases, there is also an increasing proportion of people who require care and support.[3] In Western societies, professional healthcare plays a dominant role in care for individuals with serious illness, dying or bereaved. However, many of the challenges associated with serious illness, death or loss are situated within the social realm, including feelings of isolation, loneliness, social exclusion and depression.[4] Subsequently, there is a growing recognition that the everyday social context in which people find themselves is well-suited to address the various practical, social and emotional aspects that come with death and dying, in addition to professional care if needed.[4] This public health approach, wherein communities play a crucial role in the care of those experiencing serious illness, death and loss through various forms of health promotion, community development and civic engagement, is also referred to as Compassionate Communities.[4-6] In this dissertation we focus on neighbourhood civic engagement initiatives as a particular manifestation of Compassionate Communities.

This dissertation is the product of a PhD study conducted as part of the broader CAPACITY project, which aims to enhance community capacity around the topics of serious illness, death and loss.[7] The primary objective is to describe the development of civic engagement initiatives around serious illness, death and loss in two neighbourhoods in Flanders, and to evaluate these initiatives in terms of their development process. The two neighbourhoods, located in the cities of Bruges and Herzele, were also in the process of becoming Compassionate Cities as part of another PhD project within the CAPACITY project.[7] While the Compassionate Communities movement was already gaining global traction, at the time this study started in 2019, the concept was still novel in Belgium. Although numerous initiatives around the topics of serious illness, death and loss already existed, they had never been unified at the local neighbourhood level with the intention of empowering neighbourhoods in their approach to these topics.

In this introduction, I will first clarify the background and context in which the two neighbourhood civic engagement initiatives regarding serious illness, death and loss are developed. Following this, I will clarify the concept of civic engagement, its definition in this dissertation, and its history specifically around the topics of serious illness, death and loss. Subsequently, I will explain the concept of 'Compassionate Communities' and how the neighbourhood civic engagement initiatives relate to this approach. I will then highlight the gaps in knowledge concerning the development and research on neighbourhood civic engagement initiatives regarding serious illness, death and loss, leading to the formulation of the aims and research questions addressed in this dissertation. Finally, I will outline the research design and methods used to answer these aims and research questions.

2. Background

In most countries, there is an increasing number of deaths per year.[8] This trend is also found in Belgium, where projections indicate that the current annual number of deaths will rise from approximately 111,000 to 131,00 by 2050.[1] Alongside the rising number of deaths, there is also an increasing number of deaths resulting from health-related suffering.[3] By 2060, an estimated 48 million people (47% of all deaths globally) will die experiencing health-related suffering, primarily due to the non-communicable diseases such as cancer and dementia.[3] These projections align with current data in Belgium where 47.8% of all deaths can be attributed to non-communicable diseases such as cancer and cardiovascular diseases.[9] This amount is likely higher when including deaths where a non-communicable disease was the underlying cause of death.

Congruently with the rising number of deaths from non-communicable diseases, there is an increasing proportion of people who require care and support, primarily in the form of generalist palliative care.[3] However, despite projections indicating a rising number of healthcare workers globally, many countries are expected to face shortages, exacerbating existing healthcare workforce crises.[10, 11] Factors contributing to low interest and retention rates among healthcare professionals include inadequate wages and fees, in addition to many professionals in this field feeling undervalued and overburdened.[11] These shortages also impact the quality of care for people with serious illness and their families, for instance, by prolonged waiting times for appointments at palliative care services, posing difficulties to individuals who are in urgent need of palliative care.[12]

In concurrence with the increasing need for professional care and support, informal care has become a more prominent aspect of care for people who are seriously ill.[13] In Europe, caregiving comprises up to 80% of the long-term care for people who are seriously ill, with estimates suggesting that 10% to 25% of the total population in Europe serve as informal caregivers.[13] However, this number is likely an underrepresentation as not all people who care for a person with serious illness, identify with the term informal caregiving.[14] Indeed, a survey study in the Belgian context showed that 58.7% of the responding adult population (n=2,581) provides informal care for a person with serious illness.[15] However, although informal care is considered a cost-effective solution to the growing demands on professional healthcare, it is often forgotten there are also personal and state-related costs to caregiving; including the impact on caregivers' employment, health, and well-being.[13, 16, 17] Furthermore, it is expected that the number of informal caregivers will only decrease over the following years, driven by increasing labour participation and the rising retirement age.[18] Also in Belgium, where 10.8% of the caregivers balance work with their caregiving responsibilities- one of the highest percentages in Europe-the pressure on caregivers is increasing.[13] Studies show that this pressure can lead to negative outcomes such as depression and social isolation.[19, 20]

Furthermore, literature suggests that even with sufficient staffing in the healthcare sector, professional care may not always present the optimal solution for individuals in need of support around serious illness, death or loss.[21, 22] This is exemplified by a population-based survey study of bereaved adults in Australia, which revealed that professional services were perceived as the least preferred and beneficial form of support.[21] In contrast, informal care provided by family members, friends and funeral providers emerged as both the preferred and most beneficial sources of support for bereaved adults.[21] These findings contribute to the increasing recognition that our current palliative care model, which relies primarily on professional caregiving, is insufficient in addressing the diverse care needs of people who are seriously ill, dying or bereaved, and underscore the necessity of exploring alternative forms of care embedded within the context of everyday life.[23]

Subsequently, in recent years, there has been a shift in thinking concerning how to approach care for people who are seriously ill, caregiving or bereaved, with a growing recognition of the importance of public health initiatives that move beyond the role of healthcare services.[23] One manifestation of this shift, is the concept of so-called Compassionate Communities; initiatives aimed at supporting individuals confronted with serious illness, caregiving or bereavement through various forms of health promotion, community development, and civic engagement.[6, 24]

3. Civic engagement

Civic engagement plays a central role in reframing responses to the challenges of serious illness, death and loss within public health approaches.[23] While in Western societies, professional services are considered the primary care providers for individuals with serious illnesses, research has shown that people spend only about 5% of their time with healthcare professionals; the remaining 95% is spent within their daily social contexts.[25] Consequently, the civic society context in which we navigate our daily lives is crucial for addressing serious illness, death and loss, not only in the private spheres of homes but also in some of the key institutions like schools and workplaces.[23] These institutions have enormous potential in familiarising and supporting people around the topics of serious illness, death and loss.[23, 26, 27] For instance, they can implement policies for work leave for those experiencing the death of someone or normalise discussions about these topics by integrating them in the school curricula.[19, 20] Additionally, neighbourhoods, as integral parts of our civic society, can play an essential role by signposting the needs of residents and providing various forms of assistance, including companionship and other forms of practical, social and emotional support.[23, 28] By engaging civic society as a whole, we can substantially contribute to the well-being of individuals with serious illness, caregivers, and people with a loss experience.[23]

3.1. Defining civic engagement

The challenge of defining civic engagement has long been a topic of debate in the literature, often due to a lack of comprehensive definitions.[29] For example, in Putnam's broad interpretation, civic engagement is linked to social capital, encompassing nearly all aspects of societal interaction.[30] In contrast, narrower definitions emerged, focusing on specific activities such as collective action, community service, or political involvement.[29, 31] However, in congruence with the interpretation of civic engagement provided by Adler and Gogging[31], we advocate for viewing civic engagement as a spectrum that spans from personal to public involvement. Subsequently, by combining the definitions of civic engagement provided by Adler et al.[31], Diller et al.[32] and Crowley et al.[33], I define civic engagement as all collective action undertaken to help improve connections between, or conditions for, people in the community. To clarify this definition, I will zoom in on each of the three forms of civic engagement activities—collective action, community service, and political involvement—and demonstrate how they fit within my broader understanding of civic engagement.

3.1.1. Civic engagement as collective action

Collective action is commonly understood as collaborative efforts within a group aimed at achieving a specific goal.[29] However, my conceptualisation expands this definition to include both the process of joint action and its outcomes. Following this interpretation, civic engagement encompasses not only group endeavours but also individual participation aimed at achieving a collective benefit; for instance, fostering a community where discussions about serious illness, caregiving, and bereavement are openly held and normalised. Following this interpretation, my definition excludes informal caregiving for family members as a form of civic engagement, since it is a personal action aimed at supporting a specific individual, rather than contributing to the collective benefit of the communities.

3.1.2. Civic engagement as political involvement

Civic engagement in terms of political involvement is defined as *"actions undertaken by private citizens aimed at influencing the selection of governmental personnel and/or their actions"* (p.46).[29] However, civic engagement in my vision focuses primarily on the intent to enact beneficial change, rather than whether these intentions are linked to a specific political ideology or position. Nonetheless, civic engagement operates within a certain social and political context that cannot be completely separated from it. Thus, I consider societal and political circumstances as the backdrop against which civic engagement operates, shaping its tactics, goals, and results.

3.1.3. Civic engagement as a community service

Civic engagement is often limited to volunteering, defined by Article 3 of the Belgian Volunteer Law of July 3 2005 as individuals who "*selflessly contribute their time and effort for the benefit of organizations or projects without monetary compensation*"[34] (Art. 3). However, where volunteering specifically refers to involvement within organised services associations, organizations, and groups[34], civic engagement in my definition, encompasses all forms of participation aimed at enhancing communities' wellbeing. Thereby its engagement includes a wide range of participatory activities, from volunteering to informal types of engagement, such as helping neighbours.

3.2. Promising results of civic engagement

Civic engagement has been extensively studied, showing promising effects on physical health[35, 36], mental health[36, 37], and overall wellbeing[38, 39] of participants. Notably, these benefits extend beyond individual realms, with civic engagement demonstrating a positive effect on the community level as well, by driving institutional and policy changes[40] or addressing structural inequalities in healthcare[41-43]. Furthermore, specifically on the topics of serious illness, dying and loss, civic engagement is proven to have an impact on increasing access to palliative care services[44,45] and strengthening social connectedness through support networks for people who are seriously ill, caregiving or bereaved[46]. The latter shows the potential of individually performed civic engagement attributing to the collective benefit of communities.

3.3. History of civic engagement around serious illness, death and loss

While civic engagement concerning serious illness, death, and loss has been documented primarily in recent literature[47], it is not a novel approach. Rather, it has evolved and is intertwined with historical trends in caring for individuals facing serious illness, death or loss.

1950s-1960s: In the 1950s, three survey studies shed light on the challenges faced by older individuals and cancer patients at the end of their lives, revealing situations of suffering and neglect in their homes or care facilities.[48-50] These distressing conditions spurred the emergence of modern hospice care and palliative care, which is largely influenced by Dame Cicely Saunders' pioneering work in the United Kingdom.[51] She established St. Christopher's Hospice in London in 1967, known for its holistic approach to caring for people with serious illness, which initially focused on alleviating physical symptoms and enhancing quality of life.[52] Volunteers have played a crucial role in shaping the history and development of hospices and, thus, of palliative care.[53] Initially, they held leadership positions, as many hospices relied entirely on volunteers to carry out essential tasks such as lobbying, service provision, and fundraising efforts.[53] With the gradual introduction of paid staff, volunteers transitioned into more supportive roles. However, their role remained important as they continued to contribute to care for people with serious illness and were thereby seen as integral members of the care team.[53]

1970s-1980s: During the 1970s, the United Kingdom expanded its palliative care provision beyond the hospice setting, introducing home care services, outpatient clinics, day-care centres and support teams.[51] Other countries in the United States and Europe were influenced by the British hospice model, leading to the development of either hospices, as was the case in Germany[54] in 1983 or Poland[55] in 1981, or similar services such as hospital-based palliative care units, as was the case in Canada[56] in 1974. The first palliative care services in Belgium became operational in 1985, however, a precursor for these initiatives was already established in 1981 by community nurse Lisette Custermans and palliative care advocate Joan Jordan.[57] Also in other European countries, the initiation of palliative care services was often the result of efforts by a few dedicated advocates.[57] Thus, although Europe did not have an extensive basis of volunteers for initiating palliative care services as was the case in the UK, civic engagement still played a foundational role. When in 1986, the World Health Organization issued the Ottawa Charter on Health Promotion[58], palliative care was recognized as a distinct discipline essential for providing quality healthcare which facilitated further expansion and establishment of palliative care provision worldwide.[51]

1990s: During the 1990s, there was a growing recognition of the importance of palliative care as a specialised field within medicine.[51] This trend was also evident in Belgium, where the government allocated resources to establish specialised palliative care units and teams.[57] Additionally, this period was marked in Belgium by the emergence of umbrella organizations and networks, leading to the formation of the Flemish Federation for Palliative Care and regionally organized palliative networks aimed at facilitating multidisciplinary collaboration.[57] As palliative care became more professionalised, there was a corresponding emphasis on the training and regulation of volunteers; In the UK this resulted in regulations impacting volunteer requirements, including mandatory criminal record checks.[53]

2000s: The emergence of the health promotion in palliative care approach marked a first departure from the traditional biomedical or biopsychosocial model towards a more holistic approach, placing a greater emphasis on the individual with a serious illness, advocating for palliative care tailored to their specific needs and promoting their empowerment.[59] Recognizing that healthcare professionals alone may not suffice, this approach encouraged broader community engagement.[23] Within this decade of modernisation, civic engagement transformed from its prime association with volunteering for a specific organisation, to civic engagement aligned with more with more individual preferences and goals.[60, 61]

2010s-today: New public health approaches to palliative care emerged, that advocated for integration of the topics of serious illness, dying and loss into communities.[23, 62] A practice example of such an approach is Compassionate Communities, aiming to empower communities in shaping their responses regarding serious illness, death and loss, stimulating civic engagement around these topics in various settings, such as neighbourhoods, schools, workplaces, and cultural organizations.[4] Although Compassionate Communities were already a recognised approach in the Australian context, it was not until the 2010s that this concept began to gain wider traction worldwide.[63] Congruently, there was also an evolution in formal volunteering, as seen in initiatives like the Compassionate Neighbours program established at St. Joseph's Hospice in London in 2013.[64] This initiative departed from traditional service-oriented volunteering, encouraging civic engagement activities akin to those one would undertake for a friend or neighbour, rather than having a pre-scribed volunteering role.[64]

4. Compassionate Communities

The term Compassionate Communities was first coined by Allan Kellehear in 2005.[65] A recent publication from the Compassionate Communities Centre of Expertise, defines Compassionate Communities as *"communities that invest in and promote individual behaviour, 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"* (p. 1397).[66] The underlying ethos of Compassionate Communities is embodied within the broader context of new public health approaches within palliative care, aiming to empower communities in organising support for individuals facing serious illness, death or bereavement, complementing professional care.[23] As Compassionate Communities revolve around collective care and support networks for seriously ill, caregiving and bereaved people, civic engagement is intrinsically linked to it.

Although Compassionate Communities and Compassionate Cities are often used intertwined, there is a nuanced difference between the two terms. Compassionate Cities represent a broader implementation of the Compassionate Communities concept, extending its principles to encompass entire urban areas rather than localised communities.[67] Operating on a larger scale, Compassionate Cities typically involve collaboration with various entities such as local government agencies, businesses, cultural organizations, and educational institutions.[65] However, while Compassionate Cities are often equated with a top-down approach[65, 67, 68], this characterization isn't always accurate. Initiatives within Compassionate Cities can also be driven by grassroots efforts within communities, even within the context of a city-wide program.[65, 67, 68] However, the aspect of bottom-up approaches is more pronounced for Compassionate Communities since they focus on initiatives that originate from within the community itself, driven by the efforts of local residents, organizations, and community groups rather than being imposed from higher levels of authority.[4]

4.1. Compassionate Communities and knowledge gaps

4.1.1 Lacking a systematic description of Compassionate Communities

At the start of my PhD, we found two reports that offered an overview of existing Compassionate Communities.[63, 69] These reports illustrated the rapid expansion of the Compassionate Community movement in the UK, Australian or New Zealand context and the varying forms in which these initiatives were implemented, in terms of funding resources, engagement strategies, resulting activities and impact. However, a systematic description of these elements was lacking, as well as knowledge about Compassionate Communities outside the UK, Australia or New Zealand.

4.1.2. Lacking a more profound insight into development strategies

Furthermore, there was a limited insight into the processes and strategies for developing Compassionate Communities. A UK study revealed a lack of professional health carer's familiarity with the concept and uncertainty about its practical implementation.[70] This uncertainty extended to other populations as well, including researchers, to which in response a few toolkits were developed, aimed at guiding the initiation and implementation of Compassionate Communities.[69, 71] These toolkits were very valuable in providing some generalising steps for implementation (e.g. identifying needs of individuals and local communities), however, specific strategies on how to apply these principles and steps in practice, were lacking. Additionally, while the existing qualitative studies offered some insights into the benefits, successes, barriers, sustainability and lessons learned from existing Compassionate

Communities, a comprehensive description of their development, and the factors that facilitated or hindered this development, were lacking.[72]

4.1.3. Lacking a thorough methodological approach for evaluating Compassionate Communities

Regarding the evaluation of Compassionate Communities, there were already some progressive insights about Compassionate Communities being complex interventions, requiring evaluation designs to match this complexity.[72] A longitudinal mixed-method evaluation was considered ideal for evaluating Compassionate Communities with qualitative methods offering depth and contextual richness and quantitative methods reporting on population-level impacts and outcomes. [72] However, key questions regarding the methodology to evaluate Compassionate Communities remained unanswered, such as determining the most suitable data collection methods and how to adapt them to the unique context of Compassionate Communities where not all outcomes can be anticipated in advance.[73]

4.1.4. knowledge gaps about existing strengths, needs and possibilities for neighbourhood civic engagement initiatives

Furthermore, there are notable knowledge gaps regarding the strengths within neighbourhoods that can be leveraged to develop civic engagement initiatives. Specifically, we lack comprehensive data on the extent to which individuals currently participate in their neighbourhoods on the topics of serious illness, death and loss, the type of activity they engage in (e.g. volunteering, peer support groups, helping neighbours) and the intensity of this engagement. Additionally, while literature provides some insights into facilitating factors for civic engagement in general, and specifically around the topics of serious illness, death and loss, these insights have not been thoroughly investigated. Previous studies have for instance identified neighbourhood social cohesion as a facilitating factor for neighbourhood participation.[74-76] Additionally, specifically around the topics of serious illness, death and loss, literature identified the fear of people's perceptions when they ask for or offer support around these topics[77], leading to the assumption that social cohesion may be important when aiming to stimulate neighbourhood civic engagement. Furthermore, literature indicates that personal experiences with serious illness, caregiving, death and loss can enhance people's knowledge and skills around these topics.[78-80] It is however not known yet, whether neighbourhood social cohesion, previous experiences with serious illness, death and loss and the capacities and skills people derive from them, are indeed a facilitating factor for neighbourhood participation around these topics. Consequently, there is a need for a survey study measuring the extent, types and intensity of neighbourhood participation regarding serious illness, death and loss, as well as the factors that are associated with this participation, such as neighbourhood social cohesion and previous experiences with serious illness, death and loss.

Figure 1. Overview of the knowledge gaps in Compassionate Communities

- We lack a systematic description of Compassionate Communities in a variety of contexts with regard to how they are developed in terms of context, funding resources and engagement strategies, and what their resulting activities and their impact are.
- We lack a comprehensive process evaluation of Compassionate Communities, more specifically, we lack a comprehensive description of the development processes as well as insight in the facilitators and barriers to this development process.
- We lack a thorough methodological approach on how to comprehensively evaluate Compassionate Communities in terms of their process and outcomes, and how to fit this into a research protocol that on the one hand provides enough control and guidance and on the other hand also flexibility in its use.
- We lack a survey study on the extent, type and intensity of neighbourhood participation regarding serious illness, death and loss and the factors that are associated with it.

5. Study objectives and research questions

The overall objective of this PhD is to describe and evaluate two neighbourhood civic engagement initiatives regarding serious illness, death and loss in terms of their development processes.

PART II aims to systematically describe existing neighbourhood civic engagement initiatives regarding serious illness, death and loss worldwide in terms of their context, activities, engagement strategies, impact and evaluation designs and methods.

- Research question 1: In what context, why and for whom are civic engagement initiatives around serious illness, death and loss initiated?
- Research question 2: How are they developed and how are they sustained?
- Research question 3: How have they been evaluated and what is their impact?

PART III aims to identify development strategies for neighbourhood civic engagement initiatives regarding serious illness, death and loss, in terms of the extent, type and intensity of this neighbourhood participation, and the factors that are associated with it.

- Research question 4: To what extent do citizens participate in actions around serious illness, death and loss in their neighbourhood?
- Research question 5: Are citizens more likely to participate in actions around serious illness, death and loss in their neighbourhood when they perceive a higher level of social cohesion in their neighbourhood?
- Research question 6: Are citizens who had a personal experience with serious illness, death or loss in the last year more likely to participate in actions in their neighbourhood around these topics?
- Research question 7: Do the capacity, skills and self-efficacy citizens believe they gained from their previous experiences with serious illness, caregiving, death and loss strengthen this association?

PART IV seeks to evaluate the development process of the two neighbourhood civic engagement initiatives regarding serious illness, death and loss in the context of two Compassionate Cities.

- Research question 8: How do we evaluate neighbourhood civic engagement initiatives, given their unpredictable and dynamic character?
- Research question 9: What are the aspects and contextual factors that facilitated and hindered the development of the neighbourhood civic engagement initiatives in the context of two Compassionate Cities?

PART V aims to reflect on the contemporary challenges, tensions and commonalities of the Compassionate Communities movement and to propose directions for future practice and research.

- Research question 10: What are contemporary tensions and challenges within the Compassionate Communities movement?
- Research question 11: What are the insights we can gain from them to propose directions for future practice and research?

6. Methods

6.1. Research approach

The development of Compassionate Neighbourhoods was guided by an Asset-Based Community Development (ABCD) approach[81], beginning with a stakeholder-mapping exercise to identify existing assets and key individuals involved in activities related to serious illness, caregiving, death, or bereavement. Subsequently, a co-creative approach was adopted involving all interested partners in the development process. However, we make a distinction between participation in the development process which was far-reaching and participation in the research and data collection, which was limited to providing input on the concepts that were measured in the survey study.[82,83] Given that Compassionate Communities are complex adaptive processes, traditional measurement methods designed for linearity and predictability may prove inadequate.[73] Therefore, we adopted a methodological approach that offers clear guidance regarding research design, objectives, data collection methods, and analysis, while also allowing flexibility to adapt the evaluation to the development process. Although we aimed to employ a mixed-methods study design[84] encompassing qualitative data to gain insight into the entire process of development, including participants' experiences and perspectives and quantitative data offering insight into the extent, type and intensity of civic engagement around serious illness, death and loss, this was not entirely the case since we only conducted a quantitative pre-measurement and no post-measurement. Subsequently, we evaluated the neighbourhood civic engagement initiatives from a multimethod research design.[85]

6.2. A review of relevant literature

We conducted a systematic review of civic engagement initiatives regarding serious illness, death and loss worldwide. Initiatives were excluded if they reported on public engagement that was service-driven, with the main aim of enhancing the quality or reach of a service. Six databases, PubMed, Scopus, Sociological Abstracts, WOS, Embase, and PsycINFO, were searched for peer-reviewed literature in English. Additional grey literature was obtained by contacting the first authors and by hand-searching the reference list of the included articles. The review aimed to systematically describe and compare the reported initiatives of civic engagement in serious illness, death, and loss in terms of the context in which they were initiated, their development and sustainability, whether and how they were evaluated, and their impact. By describing these characteristics, we aimed to provide inspiration for current or developing initiatives, for the activities they can undertake, and for ways to sustain and evaluate them. We performed a quality appraisal of the included studies using a self-developed tool that was based on the Mixed Method appraisal tool.[86]

6.3. Quantitative method

6.3.1. A cross-sectional survey-study

We conducted a cross-sectional survey study in two selected neighbourhoods in Herzele and Sint-Kruis, between February and April 2021. Both Herzele, and Bruges, the city in which Sint-Kruis is a sub-municipality, are Compassionate Cities and were chosen based on criteria that are more detailed described in a Compassionate City research protocol.[87] Neighbourhoods were defined based on addresses, as decided by the city representatives. In Bruges, the delineation encompassed the sub-municipality of Sint-Kruis, in Herzele, the neighbourhood was delineated as the streets within a 1.5 km radius around the local service centre, a community-based facility that aims to improve the quality of life of residents across various domains such as loneliness, healthcare, caregiving, leisure activity, etc.[88].

Each neighbourhood comprised around 4,000 inhabitants. Surveys were sent to a random sample of 2,324 adult inhabitants via post, using the Total Design method[89] with up to three reminders. Respondents were asked to complete the questionnaire within two weeks of receiving it and to return it prepaid via post or online. The survey measured seven concepts: perceived neighbourhood social cohesion, perceived help from neighbours, neighbourhood participation, neighbourhood participation regarding serious illness, caregiving, death and loss in the neighbourhood, previous experiences with these topics and perceived capacity, skills and self-efficacy resulting from previous experiences with serious illness, caregiving death or loss. The questionnaire can be found in Appendix 2. The aim of the survey was twofold. Firstly, it aimed to provide knowledge on the assets and priorities within the neighbourhoods around the topics of serious illness, death and loss, as well as the factors that are associated with neighbourhood participation around these topics. Secondly, it aimed to serve as input for the co-development process with relevant parties in the neighbourhoods, and the strategies that can be used by neighbourhoods and cities to enhance their engagement. Descriptive and correlation data on civic participation regarding serious illness, death, and loss in the two neighbourhoods were reported, with detailed findings in **chapters III** and **IV**.

City representatives randomly selected adult residents from the neighbourhoods for participation in the survey study. A compiled file with the names and contact details was sent to the data collector who provided each name with a unique respondent number and subsequently organised the distribution of the questionnaires. After completion, the questionnaires and their respective respondent numbers were sent back to the researcher who communicated the respondent numbers to the data collector. The data collector used this information to send a reminder letter to people who had not filled in the survey yet. Following this procedure, the data collector was the only person who had insight into the names and addresses of the respondents, and the researcher was the only person who had insight into the data. Neither of them could connect the filled-out questionnaires to the identity of the respondent. A cover letter was provided with each questionnaire stating the context and aim of the study, the contact information of the researcher, information about the voluntary nature of participation and the anonymity procedure (Appendix 2). Respondents explicitly provided consent by completing and returning the questionnaire. This study was approved by the Ethics Commission of the University Hospital in Brussels (ref. B.U.N. 1432020000185), on the 2nd of September 2020.

6.4. Qualitative methods

6.4.1. Semi-structured interviews and group discussions

Semi-structured interviews were conducted with the two-fold aim of a stakeholder-mapping of neighbourhood key figures and capturing the development process of the two Compassionate Neighbourhoods. Participants were the relevant parties (i.e. representatives from civic society organisations, other neighbourhood key figures and neighbourhood residents) and all the coordinators in the project (i.e. the project leaders, the project managers and the change manager).

The relevant parties:

- Civic society representatives are people who are professionally active in the health and wellbeing sector and are formally part of the project's steering group to develop the project's vision, and the working groups to translate this vision into actions.
- Neighbourhood key figures are individuals that have a central role in the neighbourhood either by their profession (e.g. neighbourhood police) or by their informal activities (e.g.

neighbourhood committees). They were identified through a stakeholder-mapping, based on their community-building abilities.

- Neighbourhood residents were all people in the neighbourhood who were not social partners nor neighbourhood key figures and were involved in the citizen participation tables or in the activities that were developed in the project.

The project coordinators:

- Project leaders are people appointed by the two cities to oversee the planning, and development process of the neighbourhood civic engagement initiatives in collaboration with the interested parties.
- Project managers_are supervisors who support the project leaders. Project managers include city aldermen, and in one city, the coordinators from the local service centre.
- The change manager is a university-appointed person who facilitates the development process, by aligning the interests of the cities, relevant parties and the researcher.

The semi-structured interviews and group discussions were audio-recorded; the recordings were deleted after their transcription. Topic guides were prepared in advance for each subgroup within the project coordinators and the relevant parties in the neighbourhood. These guides could be adjusted according to the particular phase of the development process. Furthermore, distinct interview schedules were established for each subgroup: project managers were interviewed annually, project leaders every six months, the change manager every six months, and civic society representatives three months after the establishment of the steering group.

6.4.2. Semi-structured observations

Semi-structured observations[90] were systematically conducted during all pertinent meetings throughout the development process. These meetings encompassed informal progress updates by project leaders to the change manager and researcher, as well as formal meetings involving project managers or social partners. Furthermore, observations were extended to activities or events stemming from the development process. The semi-structured observations were conducted using a self-developed template for fieldnotes featuring sections on time and date, participants, the reason for the meeting or activity, and observed events and interactions.

6.4.2. Document analysis

Document analysis encompassed reviewing all meeting minutes drafted by project leaders during meetings with project managers and/or social partners. Additionally, it involved an analysis of all relevant email exchanges with the change manager, which was the chosen communication channel to update the researcher on all communication with the project leaders or managers where the researcher was not present.

6.5. Ethical considerations

Before the study's initiation, written informed consent was obtained from all project managers, leaders, and social partners. Participants were informed that the interviews and group discussions would be audio-recorded solely for transcription purposes and that recordings would be deleted afterwards. Furthermore, it informed them of the option to stop recording at any time. Confidentiality was assured, with data securely stored on a server accessible only to the research team, and coded and reported anonymously. The informed consent process was personally explained by the researcher, allowing for questions or clarifications. Interviews were conducted online or in person at a participant-chosen location which allowed for private discussion; group discussions were held exclusively in-person. The study received approval from the Ethics Commission of the University Hospital in Brussels on September 2nd, 2020 (ref. B.U.N. 1432020000185).

7. Structure of this dissertation

Chapter I entailed a general introduction to neighbourhood civic engagement initiatives on the topics of serious illness, death and loss and described the rationale for this dissertation as well as its objectives and methodology. Chapters II to VII of this dissertation are based on articles which have either been published or submitted for publication.

PART II systematically describes existing neighbourhood civic engagement initiatives regarding serious illness, death and loss worldwide in terms of their context, activities, engagement strategies, impact and evaluation designs and methods. This part covers research questions 1 to 3 in this dissertation.

PART III identifies development strategies for neighbourhood civic engagement initiatives regarding serious illness, death and loss, in terms of the extent, type and intensity of this neighbourhood participation, and the factors that are associated with it. This part covers research questions 4 to 7 in this dissertation.

PART IV evaluates the development processes of the two neighbourhood civic engagement initiatives. This part covers research questions 8 to 9 in this dissertation.

PART V reflects on the current challenges, tensions, and commonalities and proposes future directions within the Compassionate Communities movement. This part covers research questions 10 and 11 in this dissertation.

PART VI, the general discussion, provides a summary of the main findings per chapter, provides the strengths and limitations of the studies we conducted and then goes on to discuss our findings in light of the existing international literature. This general discussion ends with recommendations for policy-makers, community-builders and for future research.

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PART II

TO SYSTEMATICALLY DESCRIBE EXISTING NEIGHBOURHOOD CIVIC ENGAGEMENT INITIATIVES REGARDING SERIOUS ILLNESS, DEATH AND LOSS WORLDWIDE IN TERMS OF THEIR CONTEXT, ACTIVITIES, ENGAGEMENT STRATEGIES, IMPACT AND EVALUATION DESIGNS AND METHODS. THIS PART COVERS RESEARCH QUESTIONS 1 TO 3 IN THIS DISSERTATION.

Chapter II

CIVIC ENGAGEMENT IN SERIOUS ILLNESS, DEATH AND LOSS: A SYSTEMATIC MIXED-METHODS REVIEW

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Abstract

Background: New public health approaches to palliative care such as compassionate communities aim to increase capacity in serious illness, death and loss by involving civic society. Civic engagement has been described in many domains of health; a description of the characteristics, processes and impact of the initiatives in palliative care is lacking.

Aim: To systematically describe and compare civic engagement initiatives in palliative care in terms of context, development, impact, and evaluation methods.

Design: Systematic, mixed-methods review using a narrative synthesis. Registered in Prospero: CRD42020180688.

Data sources: Six databases (PubMed, Scopus, Sociological Abstracts, WOS, Embase, PsycINFO) were searched up to November 2021 for publications in English describing civic engagement in serious illness, death and loss. Additional grey literature was obtained by contacting the first authors. We performed a quality appraisal of the included studies.

Results: We included twenty-three peer-reviewed and eleven grey literature publications, reporting on nineteen unique civic engagement initiatives, mostly in countries with English as one of the official languages. Initiatives involved the community in their development, often through a community-academic partnership. Activities aimed to connect people with palliative care needs to individuals or other resources in the community for support. There was a variety of evaluation aims, methods, outcomes, and strength of evidence. Information on whether or how to sustain the initiatives was generally lacking.

Conclusions: This is the first review to systematically describe and compare reported civic engagement initiatives in the domain of palliative care. Future studies would benefit from improved evaluation of impact and sustainability.

Keywords

Civic engagement, volunteers, community participation, community development, compassionate communities, public health, palliative care, systematic review[1]

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[1] All the concepts are MeSH headings in PubMed, except for ‘civic engagement’ and ‘compassionate communities’, for which no MeSH heading exists.

Key statements

What is already known?

- Public health perspectives on palliative care transcend an individual, service-centred interpretation of palliative care, and value community responses such as civic engagement.
- Previous studies in different domains of health and wellbeing have described the positive impact of civic engagement initiatives, but a systematic description of civic engagement initiatives in palliative care is lacking.

What this paper adds

- All initiatives were initiated after the year 2000, except for one that was initiated in 1995. The year of initiation ranges from 2000 to 2020. Given the fact that we searched for publications in English, a majority of the initiatives are located in countries with English as one of the official languages.
- All initiatives in this review engaged with the community in their development, most often through a community-academic partnership. Initiatives offered a variety of civic engagement activities generally aiming to provide a link between seriously ill people and their caregivers and other resources in the community.
- Although we found that all the evaluation studies showed a positive impact; most conducted either a process or an outcome evaluation without including sustainability as one of the evaluation outcomes.

Implications for practice, theory or policy

- Considering the variation in quality of the evaluation studies, there is a need to conduct in-depth evaluations measuring both the impact of the civic engagement initiatives and the mechanisms that lead to this impact.
- Future research should evaluate factors that influence the sustainability of a civic engagement initiative, and should evaluate the influence of embedding the initiative in a compassionate city context on its continuation.

1. Background

Demographic and epidemiologic trends increasingly confront individuals with the challenges of serious illness, caregiving, dying, loss and bereavement, whether as the person with serious illness, a caregiver, or just as a relative, friend, neighbour, etc.[1, 2] Palliative care can offer added value in this regard by increasing the quality of life of both the person with serious illness and their informal carers. However, as is discernible from recent discussions in the literature about the definition and branding of palliative care[3-5], the term comes with different interpretations. A common interpretation of palliative care is one that sees it as a formal healthcare service approach aimed at optimising individual care relationships and improving distressing symptoms for patients and those close to them.[3, 4] Others point to the informal dimension and affirm that palliative care is also provided by friends, family members and the wider community. [3, 4] In turn, public health perspectives on palliative care insist on the social ecological dimension where palliative care is framed as more than a response to the individual problems and challenges of serious illness by healthcare services or informal caregivers, but includes societal actions designed to improve or promote health and wellbeing around illness, death, dying, loss and bereavement.[5-7] Kellehear, for instance, has formulated this in the notion of caring for one another during times of confrontation with serious illness, death, dying, loss or bereavement as a responsibility for everyone.[8]

Compassionate communities have grown out of this public health approach and entail "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. Members of a Compassionate Community take an active role in supporting people affected by these experiences. This can be done through connecting people to helpful resources, raising awareness about life and end of life issues, and building supportive networks in the community (p.1)".[9] However, engaging community members on topics such as serious illness, death and loss can be a challenge. Civic engagement is an important way of engaging people in civil society [8, 10, 11], and can be interpreted as collective action undertaken to help improve connections between, or conditions for, people in the community .[12-14] We interpret civic engagement as an umbrella term for both volunteering and informal caregiving as the context is the community, as it can be both performed from a personal connection with the person receiving support, as is the case in caregiving, or from a broader social interest position, as is often the case in volunteering. [12-15]

Previous studies have described the positive impact of such civic engagement initiatives in other domains of health and wellbeing[16-21], e.g. serving as a bridge between older people and youth[17, 18]. However, the context, processes, evaluation and impact of civic engagement initiatives in palliative care have not yet been systematically described. Consequently, the aim of the review is to systematically describe and compare the reported initiatives of civic engagement in serious illness, death and loss in terms of the context in which they were initiated, their development and sustainability, whether and how they were evaluated, and their impact. By describing these characteristics, we aim to provide inspiration for current or developing initiatives, for the activities they can undertake, and for ways to sustain and evaluate them. Specific research questions are:

1) In what context, why and for whom are civic engagement initiatives around serious illness, death and loss initiated?
2) How are they developed and how are they sustained?
3) How have they been evaluated, and what is their impact?

2. Methods

2.1. Protocol and registration

A protocol of the review was prospectively registered in Prospero July 5th, 2020. Registration number: CRD42020180688 (https://www.crd.york.ac.uk/prospero/#recordDetails). The protocol was edited on March 29th 2021, in order to clarify our focus on civic engagement, instead of the narrower term ‘volunteering’.

2.2. Review design

We conducted a systematic, mixed-methods review of civic engagement initiatives in palliative care reported in peer reviewed literature, following the ‘Methodological guidance for the conduct of mixed-methods systematic reviews’.[22] Results were reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA).[23]

2.3. Search strategy

Due to the dearth of knowledge on the domain of civic engagement in serious illness, dying and loss, we argue it is a good first step to start from peer reviewed literature to gain a first insight into initiatives that are being researched. Peer reviewed literature in English language publications was searched through six databases: PubMed, Scopus, Sociological Abstracts, Web of Science, Embase and PsycINFO, by using set eligibility criteria. In Scopus, Sociological Abstracts, Web of Science, Embase and PsycINFO a limit was applied to acquire peer reviewed literature only. A search string was developed by the research team in cooperation with a librarian from the VUB library consisting of three main elements and their synonyms: compassionate communities, palliative care and civic engagement. The search string does not include “care” because this term is a too general description of compassionate communities, or a public health palliative care approach. Instead we used the term “caring communities” because it is more specific, and sometimes used as a synonym for compassionate communities. The search string was validated in PubMed (Table 1) and translated to the other databases (Table 2). No limited timespan for literature was applied in the databases. Literature was searched up to November 2021. We searched the reference list of the included articles for peer reviewed literature on other initiatives. Next, additional grey literature publications (including websites of initiatives) were searched by contacting the first authors of the included articles. We contacted fifteen authors of whom eleven replied after sending a reminder e-mail. For those initiatives we did not have the contact details from the authors or for which the author did not reply, we performed a limited google search in order to include the official website of initiatives. We performed a limited google search for five of the initiatives.

Table 1. Search string PubMed

("compassionate community"[Title/Abstract] OR "compassionate communities"[Title/Abstract] OR "caring community"[Title/Abstract] OR “compassionate city” OR “compassionate cities” OR "caring communities"[Title/Abstract] OR "new public health approach"[Title/Abstract] OR "public health palliative care"[Title/Abstract] OR "community based"[Title/Abstract] OR "health promoting palliative care"[Title/Abstract] OR “social network approach”) AND (volunteer OR volunteers OR volunteering OR voluntary OR "civic engagement" OR "civic society" OR "civil society” OR "neighbor" OR "neighbors"' OR "neighbour" OR "neighbours" OR "community connector" OR "community connectors" OR "community initiative" OR "community initiatives" OR “community network” OR “community networks” OR “community group” OR “community groups” OR “community organisation” OR “community organisations” OR “community organization” OR “community organizations" OR “self-help groups" OR “support group” OR “support groups” OR "community participation" OR "community engagement") AND (palliative* OR hospice* OR terminal* OR "end of life" OR bereave*)

Table 2. **Full search string electronic data base**

Pubmed			**Scopus**		
ID#	**Searches**	**Results**	**ID#**	**Searches**	**Results**
1	(“compassionate communities”[Title/Abstract] OR “compassionate community”[Title/Abstract] OR “compassionate cities”[Title/Abstract] OR “caring communities”[Title/Abstract] OR “caring community”[Title/Abstract] OR “new public health approach”[Title/Abstract] OR “social network approach”[Title/Abstract] OR “community based”[Title/Abstract] OR “health promoting palliative care”[Title/Abstract])		**1**	TITLE-ABS-KEY (“compassionate communities” OR “compassionate community” OR “compassionate cities” OR “compassionate city” OR “caring communities” OR “caring community” OR “new public health approach” OR “social network approach” “ OR “health promoting palliative care” OR “community based palliative care”)	
2	(“volunteer”[All fields] OR “volunteers”[All fields] OR “voluntary”[All fields] OR “civil society”[All fields] OR “community”[All fields] OR “neighbors”[All fields] OR “neighbour”[All fields] OR “neighbours”[All fields] OR “community connector”[All fields] OR “community connectors”[All fields] OR “community initiative”[All fields] OR “community initiatives”[All fields] OR “community group”[All fields] OR “community groups”[All fields] OR “community network”[All fields] OR “community networks”[All fields] OR “community organisation” [All fields] OR “community organisations”[All fields] OR “community organization”[All fields] OR “community organizations”[All fields] OR “support group”[All fields] OR “support groups” OR “community participation” OR “community engagement” [All fields] **)**		**2**	ALL(volunteer OR volunteers OR voluntary OR “civic engagement” OR “civic society” OR "civil society" OR neighbor OR neighbors OR neighbour OR neighbours OR "community connector" OR "community connectors" OR "community group" OR "community groups" OR "community initiative" OR "community initiatives" OR "community network" OR "community networks" OR "community organisation" OR "community organisations" OR "community organization" OR "community organizations" OR "support group" OR "support groups" OR "community participation" OR "community engagement”)	
	#1 AND #2	**6,796**		**#1 AND #2**	**256**
3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*		**3**	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*	
	Filter: English			Filter	
	#1 AND #2 AND #3	**166**		**#1 AND #2 AND #3**	**453**
Embase			**PsychInfo**		
ID#	**Searches**	**Results**	**ID#**	**Searches**	**Results**
1	(('compassionate community' OR 'compassionate communities' OR 'compassionate city' OR 'compassionate cities' OR 'caring community' OR 'caring communities' OR 'new public health approach' OR 'public health palliative care' OR OR 'community based' OR 'community-based participatory research' OR 'health promoting palliative care' OR 'social network approach')		**1**	ab("compassionate community" OR “compassionate city” OR "caring community" OR "new public health approach" OR "public health palliative care" OR "community participation" OR "community engagement" OR "community based" OR "community based participatory research" OR "health promoting palliative care" OR "social network approach"	
2	(volunteer OR volunteers OR volunteering OR voluntary OR 'civic engagement' OR 'civic society' OR 'civil society' OR neighbor OR neighbors OR neighbour OR neighbours OR 'community connector' OR 'community connectors' OR 'community initiative' OR 'community initiatives' OR 'community network' OR 'community networks' OR 'community group' OR 'community groups' OR 'community organisation' OR 'community organisations' OR 'community organization' OR 'community organizations' OR 'self-help group' OR ‘self-help groups’ OR 'support group' OR 'support groups' OR 'community participation' OR 'community engagement')		**2**	(volunteer OR voluntary OR volunteering OR "civic engagement" OR "civic society" OR "civil society" OR neighbour OR "community connector" OR "community initiative" OR "community network" OR "community group" OR "community organisation" OR "self-help group" OR "support group" OR "community participation" OR "community engagement)	
	#1 AND #2	**30,911**		**#1 AND #2**	5183
3	palliative* OR hospice* OR terminal* OR 'end of life' OR bereave*		**3**	(palliative* OR hospice* OR terminal* OR "end of life" OR bereave*)	

Table 2. **Full search string electronic data base**

Pubmed			**Scopus**		
	Filter: AND [article]/lim AND [embase] AND [english]/lim			Filter: Peer reviewed, English	
	#1 AND #2 AND #3	**395**		**#1 AND #2 AND #3**	**115**
Sociological Abstracts			**Web of Science**		
ID#	**Searches**	**Results**	**ID#**	**Searches**	**Results**
1	ab("compassionate community" OR "compassionate city" OR "caring community" OR "new public health approach" OR "public health palliative care" OR OR "community based" OR "community based participatory research" OR "health promoting palliative care" OR "social network approach")		**1**	TI=((compassionate community) OR (compassionate city) OR (caring community) OR (new public health approach) OR (public health palliative care) OR (community based) OR (community-based participatory research) OR (health promoting palliative care) OR (social network approach))	
2	volunteer OR voluntary OR volunteering OR "civic engagement" OR "civic society" OR "civil society" OR neighbour OR "community connector" OR "community initiative" OR "community network" OR "community group" OR "community organisation" OR "self-help group" OR "support group" "community participation" OR "community engagement")		**2**	ALL=(volunteer OR voluntary OR volunteering OR (civic engagement) OR (civic society) OR (civil society) OR neighbor OR neighbour OR (community connector) OR (community initiative) OR (community network) OR (community group) OR (community organisation) OR (community organization) OR (self-help group) OR (support group) OR (community participation) OR (community engagement))	
	#1 AND #2	**2,289**		**#1 AND #2**	**21.702**
3	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*		**3**	palliative* OR hospice* OR terminal* OR "end of life" OR bereave*	
	Filter: Peer reviewed			Filter: AND LANGUAGE: (English) AND DOCUMENT TYPES: (Article)	
	#1 AND #2 AND #3	**125**		**#1 AND #2 AND #3**	**439**

2.4. Eligibility criteria

Publications were eligible for inclusion if:

(A) they were written in English, and

(B) described one or more civic engagement initiative in which community members identify certain challenges in their community concerning serious illness, death and loss, and

(C) decide to mobilise collectively in order to address these issues.

Publications were excluded if:

(D) they reported on public engagement that is essentially service-centred, meaning that the engagement work has the main aim of enhancing the quality or reach of a professional service, and the engagement is described as a formal part of this service.

2.5. Study selection

The articles from the database searches were imported into the electronic systematic review program Rayyan. Duplicates were removed by the program. The imported peer reviewed literature was first screened on title and abstract. Articles were either given the label 'included', 'excluded' or 'maybe'. Articles that were labelled as 'included' or 'maybe' in the first screening were subjected to a full text screening. In order to be eligible, articles had to meet the three inclusion criteria and not fall within the exclusion criterion. The screening and study selection were independently performed by two researchers (LDEE and BQ). There was an initial disagreement about nineteen articles between the researchers, sixteen of which were resolved. The three remaining disagreements were resolved by an independent screening by a third reviewer (TS). The study selection resulted in twenty-three included publications, reporting on nineteen unique civic engagement initiatives.

2.6. Data extraction

Data were extracted from the included peer reviewed and grey literature publications to answer the research questions on their context, development and evaluation. A data extraction form was pilot tested for the identified studies found in PubMed. This resulted in the following variables for which data were extracted from the included publications:

- Regarding the context of the initiatives : (1) name of the initiative, (2) year of initiation (3) country and continent, (4) reason for initiation, (5) target group.
- Regarding development of the initiatives: (1) nature of community engagement in the development (i.e. did the community develop the initiative themselves? Or if not, were they informed, consulted or did they collaborate with others partners in the development?), (2) activities of civic engagement, (3) training and support for people participating in civic engagement, (4) continuation (i.e. is the initiative still ongoing at the moment of this publication and if not, what are the reasons for termination), and (5) sustainability recommendations (i.e. recommendations from studies to other initiatives to increase or ensure the continuation of their civic engagement activities).
- Regarding evaluation of the initiatives: (1) the aim of the evaluation, (2) evaluation design (3), data collection methods, and (4) Impact of the initiative.

For each variable, exhaustive data from the article was put directly in the data extraction form (Table 3, Table 4, Table 5 and Table 6). This data was supplemented by the data from the reference list search and from the grey literature search. Data extraction was independently performed by LDEE (entirely) and by BQ for 25% of the publications (five articles).

2.7. Data synthesis & analysis

We conducted a convergent integrated approach to synthesise data from qualitative, quantitative and mixed-method studies.[22] We produced a descriptive paragraph on each of the included studies, thereby providing textual descriptions not only of the qualitative data but of the quantitative and mixed-method studies as well (Table 3). Consequently, the author (LDEE) examined the assembled data and grouped this data into categories, based on their similarity in meaning. These categories were reviewed by and discussed together with author B.Q. in order to come to a consensus.

2.8. Quality appraisal

We performed a quality appraisal of those civic engagement initiatives that were evaluated in a study. The quality appraisal was conducted using a self-developed tool based on the Mixed Method Appraisal Tool (MMAT)[24] (Table 7). We adapted two screening questions from the MMAT: (1) are there clear research questions or is the aim of the evaluation clear? and (2) does the collected data allow us to answer the research questions or aim?. If one or both of these screening questions was answered negatively, the appraisal was stopped and a score of 0 out of 4 was assigned. If both screening questions could be answered 'yes' the following two self-developed screening questions were answered: (1) are the results adequately derived from the data? (2) is the conclusion sufficiently substantiated by data?, for each question answered 'yes', one point was given. Next, we calculated a total quality score by summing the scores of the individual questions, ranging from 0 to 4, with higher scores indicating better quality. Quality appraisal was entirely performed by LDEE, and by BQ for 25% of the included articles (five articles).

3. Results

3.1. Study selection

The process of study selection is depicted in a PRISMA flow chart[23] (Figure 1). From the twenty-three included publications, we searched the reference lists and found two additional peer reviewed publications that met the eligibility criteria. These two additional articles were not identified through the database search because they focused on one specific serious illness (dementia or cancer) and could therefore not be identified using the general terms (palliative* OR hospice* OR terminal* OR "end of life" OR bereavement*) included in the search string. In the next phase, we included eleven additional grey literature publications by contacting the first authors of each of the articles.

3.2. Results on civic engagement initiatives

The twenty-three peer-reviewed and eleven grey literature publications reported on nineteen unique civic engagement initiatives, included in table 3, a descriptive overview of the included civic engagement initiatives.

Figure 1. PRISMA flowchart of the study identification, screening, eligibility and inclusion process

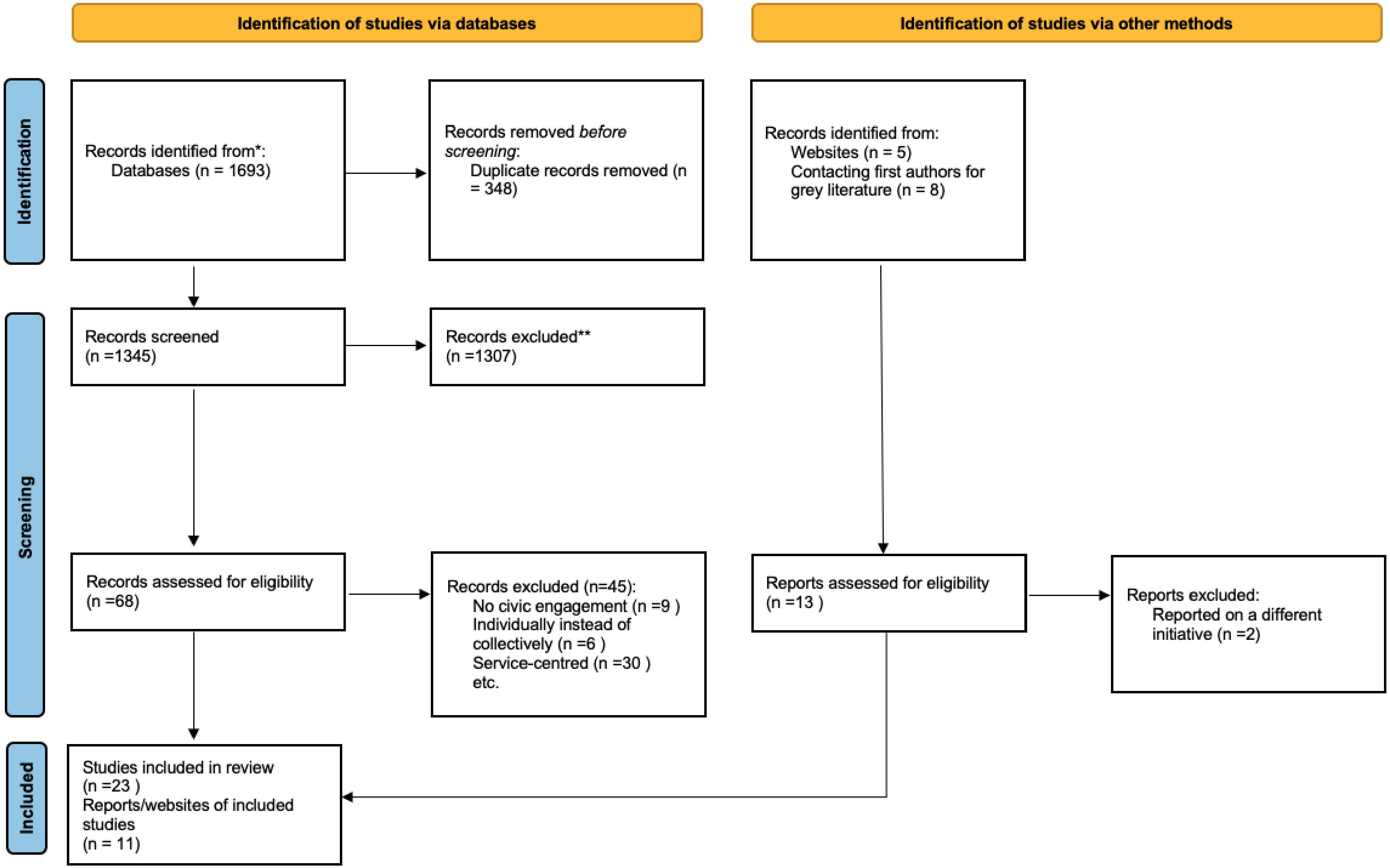

Table 3: Descriptive overview of the included civic engagement initiatives

	Name of the initiative	Narrative description of the initiative
I-1	The Good Neighbour Partnership[25 26]	The Good Neighbour Partnership (GNP), is a volunteer-led model of social and practical care/support for community dwelling adults living with advanced life limiting illness in Limerick, Ireland. The role of a Compassionate Community Volunteer is to make the link between a person/family living with palliative care needs at home, and those in their circle of community who are able to offer support. Thereby aiming to enhance "Good Neighbour" capacity within the local community.
I-2	Health Promoting Resource Team in the Hume Region's Caring Communities Project[27-29]	The Hume Regional Palliative Care Service in Victoria, Australia sought to implement a health-promotion in palliative care approach through partnerships formed with a range of community groups and service agencies in their region. Following the education phase ten people – nurses, social workers and volunteers formed a regional palliative care health promotion resource team. Over a period of two years they mentored and supported community services and groups, as well as palliative care services, in developing, providing and evaluating local projects that utilised a health promotion approach.
I-3	Walk Each Other Home[30]	In 2015, the Okines Community Garden (Okines) in southern Tasmania, Australia, collaborated with the University of Tasmania's Centre for Rural Health (CRH) to explore how the garden community might provide better support for people at the end-of-life and in bereavement. The garden coordinators and volunteers prompted this partnership
I-4	Bereavement support intervention[31]	Ten orphaned adolescents living with HIV (ALHIV) aged 18–21 years volunteered to work with a bereavement consultant to develop a bereavement intervention. After receiving training they facilitated a six-session bereavement intervention as peer counsellors, in ten existing ALHIV support groups.
I-5	Home-and Community-Based Care (HCBC) program[32]	Family Health International (FHI), in collaboration with government, local nongovernmental organizations (NGOs), and community organizations, jointly implemented home- and community-based care (HCBC). HCBC includes provision of basic nursing care by trained volunteer caregivers from the community.
I-6	Community Home Based Care CHBC in Mufudzi[33]	Mufudzi, a Christian organisation, adapted a community home-based care (CHBC) approach modelled on pastoral visits of local churches, involving visiting all chronically ill individuals in a neighbourhood to educate them and their families about HIV, offering comfort-oriented basic care as well as emotional and spiritual support, and referral to appropriate health and social services.
I-7	Neighbourhood network in palliative care (NNPC)[34, 35]	The first palliative care experiment with community support in Kerala (India) was initiated in 1993 by a nongovernmental organisation. Involvement of the community in the decision making was minimal. In the attempts of overcoming the defects of the earlier model that resulted in the formal initiation of a project known as the Neighbourhood Network in Palliative Care (NNPC). In this program, volunteers from the local community are trained to identify problems of the chronically ill in their area and to intervene effectively, with active support from a network of trained professionals
I-8	Sanjeevani[36, 37]	Sanjeevani is a community-based palliative care organization in Nadia district, West Bengal (India), that is modelled on the Kerala approach. Sanjeevani was spearheaded by the District Magistrate of Nadia, in collaboration with physicians from the local chapter of the Indian Medical Association, and the Institute of Palliative Medicine (IPM), Kerala. More than 150 volunteers participated in an elaborate train-the-trainer programme. These trainers then spread out to the villages and conducted satellite training, yielding a total of 1000 volunteers to provide community-based palliative care.
I-9	Four-phase capacity-building program[38, 39]	The Four-phase capacity-building program is part of the JCECC (Jockey Club End-of-Life Community Care Project), a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. The program entails a holistic capacity-building program for volunteers in community-based EoLC, entailing four steps: motivational screening, core competence training, internships, and supervision.

I-10	Gilda's Club Toronto[40, 41]	Gilda's Club of Toronto is a not-for-profit venue in Ontario, Canada, that serves as a communal meeting place where people living with cancer, as well as their families and friends, can join with others to build physical, social, and emotional support as a supplement to their medical treatment. Gilda's Club include yoga classes, art therapy, writing classes, and lectures from health care professionals.
I-11	The Hudson and District Hospice Society[42, 43]	The study occurred when a group of committed citizens from Hudson began to meet informally to talk about how to improve its hospice care in their community. After a meeting between the small community group and the researcher, a request was made to develop a study while they continued through their community development process. The need for, and interest in hospice care grew, resulting in training volunteers to offer care to those with a life limiting illness which also supported family members.
I-12	N-Care/Nav-Care[44-47]	Nav-CARE is a volunteer-led intervention designed to build upon strategic directions in palliative care: a palliative approach to care, a public health/compassionate community approach to care, and enhancing the capacity of volunteerism. Nav-CARE uses specially trained volunteers to provide lay navigation for older persons and family living at home with advanced chronic illness.
I-13	Circles of Care[48-50]	Investigators initially recruited and trained 24 lay health advisors who shared information or support with 210 individuals. New volunteers, separate from those who trained as lay health advisors, were recruited from community organizations or the social network of an individual with cancer. Volunteers were trained to do "what they like to do, when they can do it, in a coordinated way". Support activities were offered by the volunteers based on their time and willingness to provide specific types of support, and the needs that were expressed on the patient checklist.
I-14	Volunteer Information Provider Program (VIPP)[51]	A Volunteer Information Provider Program (VIPP) was initiated in five rural Missouri counties to help families deal with the strain of caregiving. Starting from two major community-based organizations in rural areas, Cooperative Extension Services and Extension Homemaker Clubs, 63 volunteers shared information with over 1100 caregivers in a 14-month period.
I-15	Chinese-American Coalition for Compassionate Care (CACCC) [52, 53]	A group of Chinese-American community activists formed an exploratory group in December of 2005 to establish the CACCC. The coalition identified two projects for the beginning phase of the organization: 1) to provide EOL care training for volunteers and caregivers; and 2) to create an enhanced resource database for the Chinese-speaking population. Overall goal is to improve the quality of end of- life care for Chinese Americans.
I-16	Advance Care Planning Community Guides Program[54]	A community–academic partnership developed an Advance Care Planning Community Guides Program that trained individuals to have community-based advance care planning (ACP) conversations. The ACP Community Guides Program seeks to provide concrete communication skills to train ACP Guides to initiate and facilitate peer-to-peer conversations in the community around ACP.
I-17	Support Teams for Caregivers[55]	The Support Teams for Caregivers is a is a dementia caregiver model program that merges an evidence-based intervention, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), with a proven volunteer program, The Support Team Network. The resulting implementation research program is called Support Teams for Caregivers. The support team members are community volunteers who provide practical, emotional, and spiritual support to anyone who is open to receiving help with their situation.
I-18	Care Teams from the Compassionate Project[56, 57]	The Support Team model enhances community support for practical, emotional, and spiritual caregiving. Project Compassion's network of community-based Care Teams enhancing community support for patients and families dealing with illness and death, caregiving. A Care Team is a coordinated group of 6-12 volunteers working together to help meet practical, emotional, and spiritual needs. Project Compassion provides education, support, and guidance for Care Teams sponsored by faith communities, organizations and other groups.
I-19	Compassionate Communities Connectors[58]	Compassionate Communities Connectors is a model of community volunteers who support people living with advanced life limiting illnesses/palliative care needs. Up to 10 Connectors are trained to work with at least 30 families selected by the palliative care service as requiring support. The approach seeks to map and mobilise people's personal networks of care through the Connectors enlisting helpers in the community (Caring Helpers).

3.2.1. Characteristics of the context of the initiatives

All initiatives were initiated after the year 2000, except for one that was initiated in 1995[33]. The year of initiation ranges from 2000 to 2020, with an equal distribution of initiatives being initiated in the first and second decade. Given the fact that we searched for publications in English, a majority of the initiatives are located in countries with English as one of the official languages, except from the initiative in Ethiopia[32]. We found initiatives in North America[40-58](in Canada or in the USA) , Oceania[27-30] (Australia and in Europe[25, 26] (Ireland). Other initiatives are located in Asia[34-39] (India, Hong Kong) and Africa[31-33] (Zimbabwe, Ethiopia, and Mozambique). The geographic distribution of the initiatives is depicted on a map (Figure 2).

Reasons for initiation vary. Most cited reasons were to address the complex needs of people in the community with serious illness and/or their caregivers and families[30, 32, 42, 43, 48-50, 56, 57], to reduce inequality in access to quality palliative care[32, 34-37, 48-51, 58] , and for research purposes[30, 36, 37, 48-50, 58] such as to examine a model of peer support[48-50] or to study ways to empower and build capacity for civic engagement in end-of-life care[38, 39].

Target populations of the initiatives included healthcare providers[27-29, 52, 53] , all people in the community regardless of their health status[42, 43, 54], or people in the community with a serious illness, their family or caregivers[25, 26, 30-41, 44-53, 55-58,]. Some of the initiatives partially focused on people with a specific condition such as HIV and AIDS[31, 32] or cancer[36, 37, 40, 41, 48-50]. Others partially focused on adolescents[31], older people[44-47], African-Americans[48-50], Chinese-Americans[52, 53], bedridden people[36, 37] or cancer survivors[40, 41].

3.2.2. Characteristics of the development of the initiatives

In all the initiatives, the community was involved in the development process. Twelve out of nineteen were developed from a community-academic partnership[25-31, 38, 39, 42-51, 54, 55]. In eight of these initiatives, the community led the development and consulted or collaborated with a research team[25-31, 42-47, 54, 56, 57]. In the other four, the community was involved to a limited extent; researchers developed the initiative in consultation or collaboration with community members [30, 38, 39, 51, 55]. The other seven initiatives were entirely community-owned and were driven and developed by community organisations and/or governments without any input from research[32, 33, 36, 37, 58], or by individual community members[34, 35, 40, 41, 53].

The actions of the initiatives were generally aimed at linking people with care needs to those in the community who could provide help, to professional health care or to other community resources[32-37, 44-47, 58]. Additionally, activities included identifying the problems of the chronically ill people in their area[25, 26, 32, 34-37], providing social and emotional, physical, spiritual, practical, or financial support for ill people in the community or those affected[32, 34-37, 40-42, 44-50, 55-57].

Almost all the initiatives included training for those participating in civic engagement[25, 26, 30, 32-36, 38, 39, 44-51, 54-58]. The intensity and content of the training varied per initiative. The content included training on navigation to community resources and how to access them[44-50, 54, 56-58], and competencies in providing palliative care and end-of-life care[25, 26, 31-35, 38, 39]. As well as training, a minority of the initiatives provided ongoing support to those participating in civic engagement[25-29, 34-39, 44-50, 54, 57, 58], such as individual feedback opportunities with a mentor or peer-support group meetings[36, 37, 44-50, 58].

Eight out of nineteen initiatives mentioned continuing their civic engagement activities[33-35, 40-43, 48-50, 52, 53, 56, 57]. These eight were either entirely developed by the community[31, 34, 35, 40, 41, 52, 53] or by a community-academic partnership in which the community had made a far-reaching contribution in the development process[42-47, 56, 57]. Of the remaining initiatives, a majority did not report whether they still existed. The three that explicitly mentioned they had stopped[25-29, 38, 39], reported that funding ceased, or the research had been time-limited from the beginning. For the other ten, information was lacking on their intentions regarding sustainability[30-32, 36, 37, 51, 54, 55, 58]. A majority of studies did make recommendations to other initiatives to increase the sustainability of their civic engagement activities[27-29, 32, 34, 35, 42, 43, 50-55]. The sustainability recommendations varied, and included ongoing education and mentoring of people participating in civic engagement[38, 39, 51], and creating a culture of civic engagement in the community[44-47, 52, 53].

3.2.3. Characteristics of the evaluation of the initiatives

An evaluation study was conducted for eighteen[25, 27, 29-34, 36, 38, 40, 42, 44, 45, 48-50, 55, 58] of the nineteen initiatives. Most of these studies involved a process evaluation[25,30, 31, 33, 36, 40, 45, 48, 49, 51, 54]; a minority evaluated outcomes[27,32, 38, 50,] or conducted both a process and outcome evaluation[44, 55]. The majority of the initiatives were evaluated using qualitative[27, 30, 31, 33, 36, 40, 42, 46, 49, 54] or mixed method[25, 32, 44, 45, 48, 51, 52, 58] data collection including interviews, focus groups, observations and surveys. The quality of the evaluation differed between the initiatives. Three received a score of 0 (out of 4)[34, 44, 51], as a result of not being able to answer the two screening questions positively. One initiative received a low score of 1[52] as a result of answering negatively to the three follow up questions. Furthermore, most of the initiatives received a score of 2 or 3[27, 29, 31, 33, 48, 49, 54]. A minority had an evaluation of a very high quality and received a score of 4[25, 30, 36, 38, 42, 45, 46].

Most of the evaluation studies focused on one particular aspect of the initiative, such the role in healthcare or the voluntary organisations in the development process[36]. Also the feasibility, acceptance and reach of initiatives[25, 31, 44, 48, 58] was measured and their preliminary effectiveness on certain outcomes[27, 29, 32, 40, 50, 55] (e.g. empowered people to provide end-of-life care for older persons in their communities[38]); there were studies on how an initiative contributes to the health of cancer survivors[40], on how a community garden might function as a place of end-of-life and bereavement support[30], and the contextual factors that helped (e.g. community-based champions) and hindered (e.g. the lack of direction for rural-focussed, community-based planning for hospice care by government) people in their civic engagement activities[45]. Almost all the initiatives demonstrated positive benefits as a result of civic engagement[27, 29-32, 34, 38, 40, 42, 44-46, 48-52, 54, 55], including increased understanding and knowledge of dying, loss and of palliative care in the community[27, 29]. A minority of the studies included the sustainability of the initiative in their results, e.g. if the future is to be one that is sustainable, caution is required as these community groups are working voluntarily, often in addition to their own paid jobs and family responsibilities[42].

Figure 2: Geographic distribution of the included initiatives

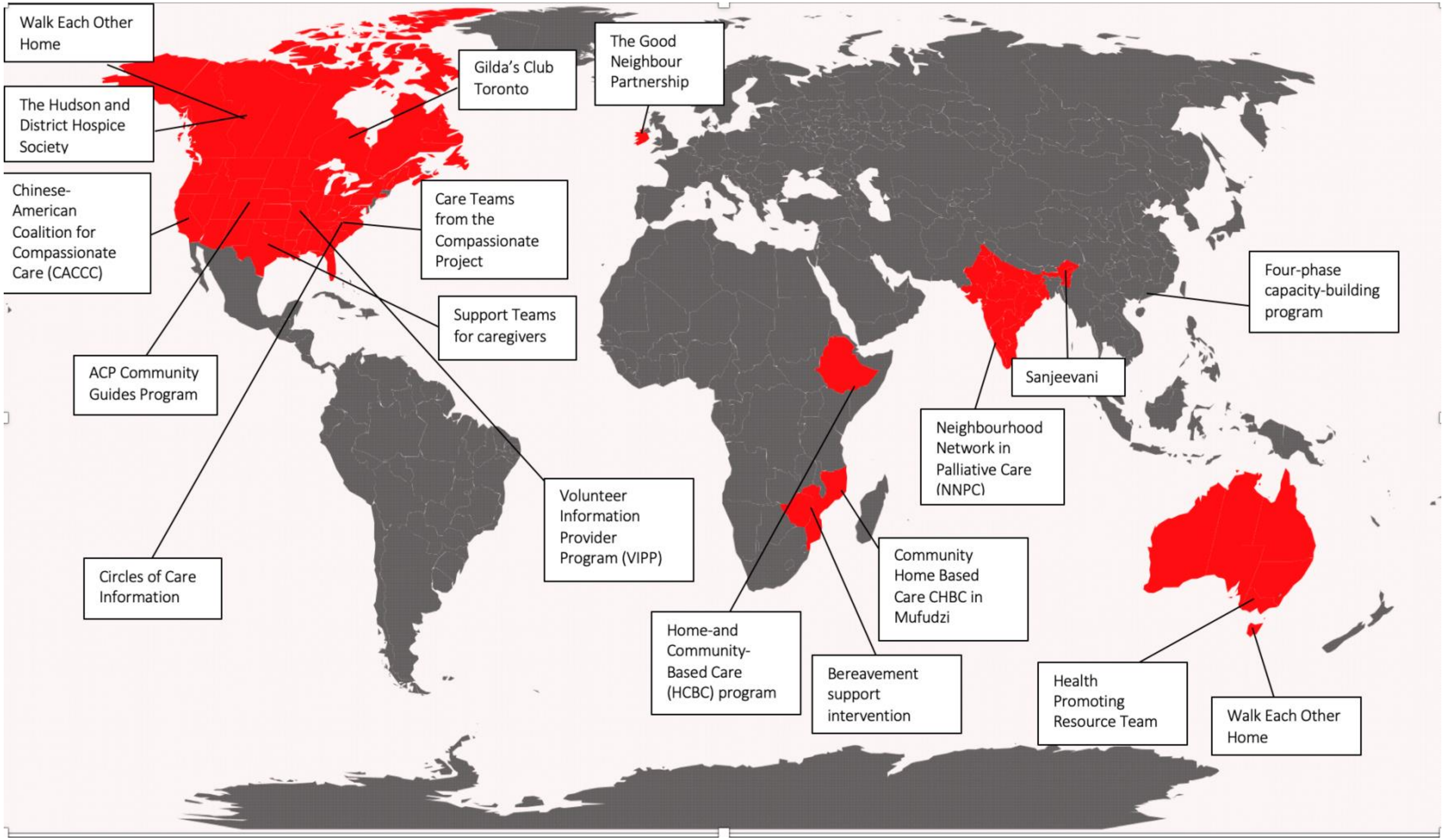

Table 4: Characteristics of the context of the reported civic engagement initiatives: RQ 1= In what context (i.e. year of initiation, country & continent), why (i.e. reason for initiation & target group) and for who are the reported initiatives initiated?

	Name of the initiative	Year of initiation	Country & continent	Reason for initiation	Target group
I-1	The Good Neighbour Partnership[25 26]	2015	Ireland (Europe)	To navigate people with serious illness to community resources & the other way around	People with serious illness, their caregivers & families
I-2	Health Promoting Resource Team in the Hume Region's Caring Communities Project[27-29]	2003	Australia (Oceania)	To reduce the growing demands on local (specialist) PC services	Local (specialist) PC services
I-3	Walk Each Other Home[30]	2015	Australia (Oceania)	- To address the complex needs of bereaved people -To examine the therapeutic landscapes of community gardens (research purpose)	bereaved people
I-4	Bereavement support intervention[31]	Not reported	Zimbabwe (Africa)	To address the complex needs of people with serious illness	Bereaved adolescents living with HIV
I-5	Home-and Community-Based Care (HCBC) program[32]	Not reported	Ethiopia (Africa)	- To address the complex needs of people with serious illness - To reduce inequality in access to palliative care services	People living with HIV and their family members
I-6	Community Home Based Care CHBC in Mufudzi[33]	1995	Mozambique (Africa)	Not reported	People with serious illness
I-7	Neighbourhood network in palliative care (NNPC)[34, 35]	2000	India (Asia)	- The need for culturally and socioeconomically appropriate PC - To reduce inequality in access to palliative care services	People with serious illness
I-8	Sanjeevani[36, 37]	2014	India (Asia)	- To reduce inequality in access to palliative care services - To examine if and how the community form of palliative care in Kerala can be replicated into a new geographic and institutional context (= research purpose)	People with serious illness (partial focus on people with advanced cancer, chronic renal conditions, and people who are chronically bedridden)
I-9	Four-phase capacity-building program[38, 39]	2018	Hong Kong (Asia)	To research ways to empower and build capacity for volunteers in end of life care (research purpose)	People with serious illness
I-10	Gilda's Club Toronto[40, 41]	2001	Canada (North-America)	Not reported	People with cancer, caregivers, families & friends, cancer survivors

	Name of the initiative	Year of initiation	Country & continent	Reason for initiation	Target group
I-11	The Hudson and District Hospice Society[42, 43]	Not reported	Canada (North-America)	-To reduce the growing demands on local PC services -To address the complex needs of caregivers of people with serious illness	Everyone in need of hospice services in the community
I-12	N-Care/Nav-Care[44-47]	2015	Canada (North-America)	To navigate people with serious illness to community resources & the other way around	People with serious illness (partial focus on elderly people)
I-13	Circles of Care[48-50]	2005	USA (North-America)	- To reduce inequality in access to qualitative palliative care - To address the complex needs of people with serious illness -To examine the model of peer support (= research purpose)	African-Americans with serious illness (partial focus on advanced cancer)
I-14	Volunteer Information Provider Program (VIPP)[51]	Not reported	USA (North-America)	-To address the complex needs of caregivers of people with serious illness - To reduce inequality in access to palliative care services	Caregivers of elderly people with serious illness
I-15	Chinese-American Coalition for Compassionate Care (CACCC) [52, 53]	2005	USA (North-America)	To address the lack of linguistically and culturally appropriate PC (information & training)	-Chinese-Americans community regardless of their health status -Health care providers who care for Chinese-American people with serious illness
I-16	Advance Care Planning Community Guides Program[54]	2017	USA (North-America)	To address the need for individuals being able to initiate quality advance care planning conversations in their communities	All people in the community regardless of their health status
I-17	Support Teams for Caregivers[55]	Not reported	USA (North-America)	To provide an evidence-based intervention outside the current models of formal healthcare services (research purpose)	Caregivers of people with Alzheimer's disease or other forms of dementia
I-18	Care Teams from the Compassionate Project[56, 57]	2000	USA (North-America)	To address the complex needs of people with serious illness, their families and caregivers	People with serious illness, their caregivers & families
I-19	Compassionate Communities Connectors[58]	2020	Australia (Oceania)	-To reduce inequality in access to palliative care -To 36address a lack of understanding of palliative care services; -To address the quality of palliative care: poor uptake of Advanced Care Plans; issues with communication, information sharing and poor linkages between agencies; a lack of support for people with a non-cancer diagnosis; and lack of support services for carers and families -To address a scarcity of evaluations of Australian community–led initiatives of practical and social support resulting in improved social connectedness.	People with serious illness and their caregivers & families

Table 5: Characteristics of the development of the reported civic engagement initiatives: RQ 2= How are the reported initiatives developed (i.e. nature of community engagement in the development, activities of civic engagement, training & support for people participating in civic engagement), and sustained (i.e. is the initiative continuing, and if not, what is the reason for termination and what are sustainability recommendations)?

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-1	Developed from a community-academic partnership: developed from a specialist palliative care service (hospice); supported by research & local community organisations	People participating in civic engagement form groups of 10-15, identify the problems of the chronically ill people in their area and organize appropriate interventions (including medical, social and financial support).	Training: Volunteers receive a 15-hour training programme (on knowledge and skills necessary to provide the Good Neighbour Intervention) after screening and prior to the start of the intervention Support: Support provided by a facilitator	No, research was limited in time	Not reported
I-2	Developed from a community-academic partnership: developed by a palliative care service through partnerships formed with a range of community groups, service agencies, and the university	People participating in civic engagement (selected from a pool of trained service providers and volunteers) mentor and support local communities, community services and palliative care services, in developing, providing and evaluating local projects of health promotion in palliative care	Training: As part of the education phase of the project generalist health professionals (including community health workers), palliative care staff and volunteers are offered education and training on health promoting palliative care (Workshop of 1 day) before starting in the Health Promoting Resource Team . Support: Not reported	No, only funding for 2 years	Capacity building without imposing burdens on the people engaging in the initiative
I-3	Developed from a community-academic partnership: development by a group of community members in collaboration with the University	People participating in civic engagement organised three community events: an information evening for service providers and community members; four conversation sessions; and a one-day workshop	Not reported	Not reported	Not reported
I-4	Developed from a community-academic partnership: developed by researchers together with adolescents living with HIV	People participating in civic engagement (10 adolescents with HIV) are trained as peer grief counsellors and facilitate a bereavement intervention for other adolescents with HIV in 10 pre-existing community-based support groups.	Training: Initiative is developed together with the peer volunteers who are already part of a support group. I 4-day training of 5 hours is provided in these pre-existing groups to engage peer volunteers in their own grief and build their understanding of grief processes Support: not reported	Not reported	Not reported

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-5	Developed together by the local government, community-based organisation (NGOs & community groups) and an international human development organisation	People participating in civic engagement provide holistic palliative care in the homes and communities of people with HIV and their family members: including provision of basic nursing care, facilitation of access to clinical services, and transfer of basic nursing skills to family members, needs assessments, and financial support through loan groups	Training: A train-the-trainer module focused on comprehensive palliative care, including sexual reproductive health, was given to more than 120 nurse supervisors. They in turn rolled out the training to 60 para-social community workers and more than 2,100 voluntary caregivers. Support: Not reported	Not reported	Not reported
I-6	Developed from two community-based organisations (NGO's)	People participating in civic engagement visit chronically ill individuals in a neighbourhood to educate them and their families about HIV, offering comfort-oriented basic care, emotional and spiritual support, and referral to appropriate health and social services.	Training: Volunteers attended a two-week workshop on CHBC focused on HIV transmission, the signs of AIDS, and how to care for an HIV-positive person at home, often bed bound, before being assigned to 5 to 6 patients. Support: Not reported	Yes	Not reported
I-7	Entirely developed by local communities. The community or group sets up a process to control its own development). Volunteers are recruited from the community.	People participating in civic engagement identify the problems of the chronically ill people in their area and organise appropriate interventions (including medical, social and financial support). And they act as the link between the patient in the community and the professional health care provider	Training: People who can spare at least two hours per week to care for the sick in their area are enrolled in a structured training program (16 hours of interactive theory sessions plus four clinical days under supervision) before they start giving support. Support: Support is provided by a network of trained doctors & nurses)	Yes	Creation of good-quality palliative care' in a context of poverty and ill health should also be in line with efforts at poverty reduction and provision of essential services such as clean drinking water, sanitation, and primary education.
I-8	Developed by the local government (the District Magistrate of Nadia) in collaboration with physicians from local medical association & institute & other stakeholders & NGO's	People participating in civic engagement survey neighbourhoods for chronically ill patients, identify needs & map home-care schedules & maintain regular contact with families), provide support and provide updates to home care teams	Training: After the kick-off meeting awareness camps and training programmes were held in public auditoriums for students, home-makers, teachers, and local social workers wishing to participate in the project. These 'Master trainers' trained other interested volunteers in their own neighbourhoods Support: Participatory monthly review meetings and general meetings where volunteers deliberated on difficulties	Not reported	Not reported

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-9	Developed from a community-academic partnership: Collaboration between academic institutions & community-based organisations e.g. (healthcare services, NGO's, religious affiliations, community centres)	The four-step capacity-building program selects a group of potential people participating in civic engagement with most suitable qualities for end of life care (motivational screening), trains them (core competence training, internships, and in-service supervision), and evaluates the training	Training: Training is part of the four step-program: motivational screening, core competence training, internships, and in-service supervision. It is a 16-hour training course in core competencies and contextual skills in end of life care in community-based settings Support: Individually mentored or in a group	No, research was limited in time	-More meetings for volunteers for sharing experiences, workshops, and volunteer appreciation events to enhance ongoing support -Instruments for evaluating the effectiveness of capacity building for the people participating in the civic engagement
I-10	Entirely developed by community members	People participating in civic engagement are part of a communal meeting place where people living with cancer, as well as their families and friends, can join with others to build physical, social, and emotional support as a supplement to their medical treatment	Not reported	Yes	Not reported
I-11	Developed from a community-academic partnership: Developed by community members in consultation and collaboration with researchers	People participating in civic engagement provide physical, psychological, emotional, spiritual and educational support in a home-like setting for those in the community facing end-of-life, death or bereavement.	Not reported	Yes	A strong role for governments to be involved in the planning process of the initiatives
I-12	Developed from a community-academic partnership: developed by researchers together with stakeholders from government & community-based health care	People participating in civic engagement partner with a nurse partner to visit older persons living at home with advanced chronic illness, provide social support and facilitate connections to resources in the community	Training: Training is part of the Navigation-Care implementation. After screening, volunteers receive a 3-day workshop on navigation. Support: The nurse navigator meets with individual volunteers on an as-needed basis and through group meetings that take place every six weeks	Yes	–Stronger connections with healthcare services. to ensure that volunteers get the referrals and support they require -Supportive culture for volunteers -incorporating the initiative into existing organisational structures

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-13	Developed from a community-academic partnership: developed by researchers together with community -based organisations and a community advisory board	People participating in civic engagement form support teams (6-10) and work together to provide practical, emotional and spiritual support for African Americans facing advanced cancer	Training: Investigators initially recruited and trained 24 lay health advisors who shared information with volunteers (3-hours training on physical, emotional, and spiritual pain and supportive approaches and region-specific information how to access healthcare services) Support: Volunteers meet monthly (for 1 year) to share experiences, barriers and suggestions to improve support. Community project coordinators check in with the support team to address challenges	Yes	-Broad target population (not limited to one type of illness, e.g. cancer), -Stronger connections with healthcare services -Early awareness of the activities of the initiative -A meaningful community-academic partnership
I-14	Developed from a community-academic partnership: developed by researchers, in consultation with people in the community	People participating in civic engagement share information with caregivers to help them deal with stress, communication problems with elderly persons and doctors, misinformation about aging, identifying and accessing appropriate community resources, medicine use, personal care of the patient	Training: Recruitment and training is provided by State Cooperative Extension Services and entails 3 days (7 hours per day) training Support: Not reported	Not reported	Organising the training for volunteers via the volunteer organisation
I-15	Entirely developed by a group of community members	A community coalition of people participating in civic engagement provide training for caregivers and volunteers, developed a speakers bureau and disseminates written materials about to Chinese cancer survivors.	Training: not reported Support: Operational support from the California Coalition for Compassionate Care (CCCC)	Yes	-Strong leadership -Supportive culture for civic engagement -A feeling of shared purpose among the people participating in the imitative
I-16	Developed from community-academic partnership of community members from a specialist palliative care service (i.e., a chaplain, nurse, volunteer coordinator) and academic members (i.e., a geriatrician, a palliative care physician, and a social scientists).	The program trains people participating in civic engagement to have community-based advance care planning conversations and is developed with an emphasis on communication skills training	Training: The aim of the program is to develop, test, and evaluate a training for lay individuals to engage in relationship-centred advance care planning conversations (16-hour training in advance care planning conversations, knowledge of advance care planning forms, and strategies for linking advance care planning to the health-care system). Support: The advance care planning program coordinator provides ongoing support	Not reported	Not reported

	Nature of community engagement in the development	Activities of civic engagement	Training & support for people participating in civic engagement	Continuation and reason why they stopped (if applicable)	Sustainability recommendations
I-17	Developed from a community-academic partnership: developed by researchers, community only closes gap in human and financial resources	Support Teams for Caregivers is a dementia caregiver model program that merges an evidence-based intervention, Resources for Enhancing Alzheimer's Caregiver Health (REACH II), with a proven volunteer program, The Support Team Network model. People participating in civic engagement provide practical, emotional, and spiritual support. REACH II adds an in-home assessment with target areas	Training Training is part of the program implementation. After recruitment volunteers receive training on building feelings of confidence and self-efficacy for their time spent with caregivers and persons with dementia Support: not reported	Not reported	Incorporating the initiative into existing organisational structures
I-18	Developed from a community-based organisation in collaboration with research	People participating in civic engagement (6-12) work together to help meet practical, emotional, and spiritual needs for all people as they deal with serious illness, death, and grief	Training Training is part of the program implementation. After recruitment volunteers receive training on how to connect to area health resources for cancer care, palliative care, and hospice Support: Project Compassion provides education, support, and guidance	yes	Not reported
I-19	-The South West Compassionate Communities Network (SWCCN) - Initiated from a partnership between the community and the palliative care service in the South West of Western Australia,	Connectors work with patients and families to co-design a plan on how to mobilise their network of Caring Helpers who will be providing the hands-on assistance	Training: Connectors attend a training course of 2-days delivered by content experts. As part of the training, Connectors are provided with a training resource to assist them understand their role and what is expected of them. I Support: The project coordinator will liaise with the Connectors weekly to share their experiences and work through any arising issues.	Pilot project	Not reported

Table 6: Characteristics of the evaluation of the reported civic engagement initiatives: RQ3: How have the reported initiatives been evaluated (aim of the evaluation, evaluation design, data collection), and what is their impact?

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-1	To evaluate the feasibility, acceptability & potential effectiveness of the GNP	Phase III Randomised Controlled Trial (RCT)	Mixed method data from interviews with volunteers & receivers, volunteer record/logs, standardised questionnaires for receivers	It is anticipated that the findings from the various elements will provide important insights into the effectiveness, efficacy, utility and acceptability of a unique model of social and practical care for people with life-limiting illness.
I-2	-An overall descriptive evaluation about the sustainability and effectiveness of the Health Promotion Research Team)	A qualitative study	Qualitative data from focus groups, individual interviews & telephone interviews (coordinators, volunteers & funding applicants)	-Participants indicated that the health promoting resource team has been most effective in its task of promoting and supporting community development activities that have increased understanding and knowledge of dying, loss and grief in general, and palliative care in particular, across the region. -Sustainability of the community capacity thus developed has yet to be demonstrated long term; but the authors argue that the reflective thinking, equitable participation and shared knowledge emerging through the local projects are themselves marks of a sustainable community.
I-3	To investigate how a community garden, largely run by volunteers located in a small rural location, might function as a place of end-of-life and bereavement support	Participatory action research/evaluation	Qualitative data from participant observations, semi-structured in dept interviews (receivers), focus group discussions (the project team)	The community garden provides a physical, social and therapeutic space between home, where family and friends provide care for people as they die and grieve, and between formal care sites where health professionals provide the bulk of care.
I-4	To assess the feasibility and acceptability of the bereavement intervention	Process evaluation	Qualitative data from feedback (volunteers & caregivers), participant observations of the delivery and focus groups (volunteers & receivers)	Implementing high-quality grief interventions is critical when responding to the complex realities of ALHIV in sub-Saharan Africa.
I-5	To assess the results and impact of the HCBC program (primarily to collect information about how the program affects the lives of	Outcome evaluation	Mixed method data from in-depth interviews (stakeholders, coordinators & volunteers), focus group discussions (receivers & coordinators), case studies	The program has been shown to 1) reduce stigma and discrimination of PLHIV and vulnerable children, 2) increase acceptance and use of voluntary testing and counselling for HIV, 3) improve people living with HIV's health and well-being,

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
	people living with HIV, orphans and vulnerable children)		(receivers), limited secondary analysis of existing baseline and service deliveries	4) improve household economic conditions of people living with HIV, orphans and vulnerable children, and other beneficiaries, and 5) increase community support.
I-6	Feasibility study: To consider how it happened that over the course of the scale-up of the initiative, some volunteers felt exploited and ultimately abandoned (and in doing so raising questions about the communities constituted by global health interventions)	Intertwined biography research	Qualitative data from participant observation, semi-structured interviews (interviews)	Mufudzi suffered from a lack of care, as it was granted far more resources than it could successfully utilise in order to carry out national and global priorities. With insufficient training and oversight, the organisation became collateral damage of the scale-up.
I-7	Not reported	Not reported	Not reported	Within less than five years, the NNPC initiatives have resulted in the establishment of 68 community-based PC initiatives in northern and mid-Kerala, covering a population of more than 12 million. Also, expansion into ''non-traditional'' areas in PC (e.g. for non-malignant conditions) and active involvement of the local government in PC. Given these aspects there is a good potential for sustainability.
I-8	To identify the institutional context that influenced the translation of the Kerala community-based palliative care form to Nadia	In depth case study of the initiative	Qualitative data from previous research findings on the Kerala model, other published sources, interviews (stakeholders, volunteers & nurses), field observations & communication between various actors	The findings contribute to translation studies in healthcare, and particularly to conversations about the transfer or 'roll out' of palliative care interventions from one geographic region to another.
I-9	To evaluate the preliminary effectiveness a holistic capacity-building program for volunteers in community-based end of life care (e.g. volunteers' competence in end of life care, awareness of self-care, and death work competence)	A single-group longitudinal design with a pretraining test (T0), post training test (T1), and 6-month follow-up test (T2)	Quantitative data from a questionnaire (volunteers)	The four-phase capacity-building program effectively empowered volunteers to provide end-of-life care for older persons in their communities.

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-10	To explore how Gilda's Club promotes and contributes to healing and health of cancer survivors	Exploratory qualitative evaluation	Qualitative data from semi-structured interviews (receivers)	The findings demonstrate the importance of therapeutic landscapes to cancer survivorship and the contribution of recreation to a holistic understanding of health.
I-11	To describe how a group of citizens in a rural community in Alberta, Canada worked towards meeting their own community's hospice care need; by exploring the factors that both helped (e.g. powerful storytelling) and hindered (e.g. the lack of direction for rural- focussed, community-based planning)	A case study	Qualitative data from focus groups & interviews (stakeholders)	-The results reinforce that communities are not simply 'engaged' but are actually leading the way in the planning, and delivering of social and health supports and services. Their story emphasizes the significant lack and neglect of needed healthcare in rural communities and shows, how rural communities continue to do more with less by building on their own resources and capacities. -If the future is to be one that is sustainable, caution is required as these community groups are working voluntarily, often in addition to their own paid jobs and family responsibilities.
I-12	Study 1 -Piloting a community-based volunteer model, and evaluating feasibility Study 2: To describe the contextual factors that influenced the development of Nav-CARE in eight diverse Canadian contexts. Study 3: To explore the key factors that facilitated the sustainability of Nav-CARE in a rural hospice society.	Study 1: Process & outcome evaluation Study 2: Process evaluation Study 3: A qualitative single case study design	Study 1: Mixed method data from volunteer visit logs, volunteer journals, volunteer mentoring sessions, questionnaires (for volunteers, receivers, coordinator & stakeholders), semi-structured interviews (with volunteers, receivers & coordinator) Study 2: Mixed method data from semi-structured individual & group interviews (stakeholders), email, phone correspondence & teleconferences (coordinators), observations (volunteer mentoring sessions & all interactions), volunteer visit logs Study 3: Qualitative data from individual interviews (community stakeholders, the study volunteer coordinator, hospice society coordinator and Nav-CARE volunteers). Meeting notes of volunteer debriefing sessions and meetings with stakeholders	Study 1 Volunteers providing supportive navigation services during the early phase of palliative care is a feasible way to foster a compassionate community approach to care for an aging population. Study 2: This study highlights the importance of community-based champions for the success of volunteer-led initiatives and the critical need for support and mentorship for both volunteers and those who lead them. -New initiatives such as Nav-CARE, need to be accompanied by adequate resources. -This study illustrated the need to think carefully about the language and role of hospice societies as palliative care moves toward a public health approach to care. Study 3: The role of the facilitator, the facilitation processes and the characteristics of the organizational context were important for the sustainability of Nav-CARE. Future research is needed to understand how to assess and enhance an organization's sustainability capacity and the impact of additional facilitator training and mentoring.

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-13	Study 1: Evidence for the feasibility and acceptance of the intervention (by evaluating the reach, adoption and the implementation of to evaluate reach, adoption, and implementation of peer support using Circles of Care support teams. Study 2: -To understand the potential benefits and barriers of support teams Study 3: To evaluate the support teams' ability to improve support, awareness of services, and quality of life for these patients.	Study 1: Process evaluation Study2: post-intervention qualitative evaluation Study 3: Pre-post outcome evaluation	Study 1: Mixed method data Including surveys (volunteers & receivers), brief interviews (receivers) Study 2:Qualitative data from semi-structured interviews with volunteers, receivers & stakeholders Study 3: Quantitative data from surveys (volunteers & receivers)	Study 1: Support teams are a promising model of peer support for African Americans facing advanced cancer and serious illness, with reach, adoption, and implementation superior to the lay advisor model. This formative initial evaluation provides evidence for feasibility and acceptance. Study 2: There is initial evidence that a support team intervention helps meet the emotional and spiritual needs of African American persons with cancer or other serious illness. Volunteer support teams merit further study as a way to improve quality of life for persons facing serious illness. Study 3: Coordinated volunteer support teams are a promising new model to provide peer support for African Americans facing cancer and other serious illnesses. Further testing in a pragmatic clinical trial is warranted.
I-14	-To review the trainees' experiences of sharing their information with caregivers.	Process evaluation	Mixed method data from debriefing sessions (volunteers), volunteer diaries, volunteer logbooks, daily evaluations, interviews (receivers), feedback & observations (field staff)	VIPP is documented as a successful strategy in reaching and helping rural caregivers.
I-15	-Piloting a training for caregivers and volunteers informal -Gather descriptive feedback of the training for the curriculum committee (i.e. participants' competence in end of life care, their awareness of self-care and their death work competence.	Post-training evaluation	Mixed method data from telephone interviews (coordinators of sponsoring organisations), written evaluations & follow-up questionnaires (receivers)	As a pilot program undertaken entirely by volunteers and with no organisational financial support, the training has provided a vehicle for improving future training and curriculum planning.
I-16	-To understand the quality of the communication between trained advance care planning guides and their conversation partner	Qualitative study	Qualitative data from non-participant observations, individual semi-structured interviews (volunteers & receivers)	Trained advance care planning guides could use the model of communication to support advance care planning conversations.

	Aim of the evaluation	Evaluation design	Data collection	Impact of the initiative
I-17	-To measure the fidelity of the program: the delivery, receipt and enactment of the implementation -To measure the effectiveness of the implementation	Process and outcome evaluation	Quantitative data from questionnaires (volunteers & receivers)	The Support Teams for Caregivers project displays the feasibility of reaching into the community with an evidence-based intervention. Delivering such intervention provides an accessible, needed, and usable tool for family caregivers of dementia patients.
I-18	Not evaluated	/	/	/
I-19	-To Evaluate a training programme for the Compassionate Communities Connectors -To Assess the feasibility, acceptability and preliminary effectiveness of this community model of care.	Non-randomised prospective intervention study with pre/post design	Mixed method data from a questionnaire Baseline (patients and family carers), interviews (patients, family carers and Connectors), a brief questionnaire (Caring Helpers), a focus group (service providers) and social network mapping (patients and family carers)	It is expected that, by the end of the project, the community will have a sustainable pool of trained and experienced people who can work with the palliative care services to attend to the social and practical needs of dying people, improve their social connectedness and reduce the need for unplanned hospital usage.

Table 7: Quality appraisal tool

Instructions: The first two questions are screening questions. If these are answered negatively, further appraisal is not feasible, and automatically answered negatively. If answered positively, appraisal is continued with 4 sequencing questions. A score on 4 is assigned. As there are 4 questions, every question is 1 point.

V Yes X No

	Are there clear RQs or is there a clear evaluation aim?	***Do the collected data allow to answer the RQs or aim?***	**Are the results adequately derived from the data?**	**Is the conclusion sufficiently substantiated by data?**	**Score (on 4)**
Health Promoting Resource Team in the Hume Region's Caring Communities Project[25]	V	V	V	V	4
Walk Each Other Home[30]	V	V	V	V	4
Bereavement support intervention[31]	V	V	X	X	2
Home-and Community-Based Care (HCBC) program program[27, 29]	V	V	V	X	3
Community Home Based Care CHBC in Mufudzi[33]	V	V	V	X	3
Neighbourhood network in palliative care (NNPC)[34]	X	X	X	X	0
Sanjeevani[36]	V	V	V	V	4
Four-phase capacity-building program[38]	V	V	V	V	4
Gilda's Club Toronto[40]	**V**	**V**	**V**	**V**	**4**

	Are there clear RQs or is there a clear evaluation aim?	***Do the collected data allow to answer the RQs or aim?***	**Are the results adequately derived from the data?**	**Is the conclusion sufficiently substantiated by data?**	**Score (on 4)**
The Hudson and District Hospice Society[42]	**V**	**V**	**V**	**V**	**4**
N-Care/ Nav-Care[44]	**X**	**X**	**X**	**X**	**0**
N-Care/ Nav-Care[45]	**V**	**V**	**V**	**V**	**4**
N-Care/Nav-Care[46]	**V**	**V**	**V**	**V**	**4**
Circles of care[48]	**V**	**V**	**V**	**X**	**3**
Circles of care[49]	**V**	**V**	**V**	**X**	**3**
Circles of care[50]	**V**	**V**	**V**	**V**	**4**
Volunteer Information Provider Program (VIPP)[51]	**X**	**X**	**X**	**X**	**0**
Chinese-American Coalition for Compassionate Care (CACCC)[52]	**V**	**X**	**X**	**X**	**1**
Advance Care Planning Community Guides Program[54]	**V**	**V**	**x**	**X**	**2**

4. Discussion

4.1. Main findings

This review identified nineteen unique civic engagement initiatives concerning serious illness, death and loss, often referred to as 'compassionate community initiatives'. The identified initiatives are mostly located in countries with English as one of the official languages. Activities performed by community members participating in them included various forms of support, including identifying the problems of the chronically ill people in their area and organising appropriate interventions. In those initiatives that still existed at the time of this review, the community had the lead in the development process. Although sustainability is a common challenge for all the initiatives, none of the evaluation studies focused on sustainability but consisted mostly of either a process or an outcome evaluation, and were often focused on one particular aspect of the initiative, e.g. researching the institutional context in which an it developed[36].

4.2. Interpretation of the findings

4.2.1. Civic engagement: blind spot in non-English speaking contexts

In 1986 the Charter for Health Promotion was adopted in Ottawa, Canada, in order to give direction to a new public health approach in various domains of health and wellbeing. The translation of this health-promotion approach to the domain of palliative care was first explored by Allan Kellehear in 2000 in an Australian context. Kellehear founded the compassionate city movement, in which geographically defined regions work towards culture change concerning serious illness, death and loss by working together with various stakeholders, including local governments, cultural organisations, health and social care organisations, schools,etc.[59] In the following years, the compassionate city movement found support mainly in Australia and in the UK where the political welfare system considers volunteering and civic engagement as an essential supplement to the mainly service-driven organisation of palliative care.[60-62] We identified nineteen civic engagement initiatives worldwide, almost all in countries with English as one of the official languages. This finding triggers a few critical notes. Firstly, we must note that we only searched for publications in English, thereby excluding those written in other languages. Also, as it often concerns bottom-up initiatives, there is a chance that some are not reported or described in scientific literature – particularly in non-English speaking contexts. Secondly, the civic engagement initiatives we found mainly originated from a bottom-up compassionate community approach instead of a conjuncture of top-down mediations (e.g. creating a supportive policy) and bottom-up approaches (e.g. stimulating community action), as is the case in compassionate cities. This may give the impression that the civic engagement movement is an extension of the Anglo-Saxon compassionate city influence; however, literature shows that some African and Asian regions had already organised themselves into compassionate communities before the concept came into use in Australia and the UK.[63] Future research should therefore investigate the potential blind spot of starting compassionate communities in non-English speaking contexts or not published in English, together with the cultural and political aspects that influence the initiation of civic engagement.

4.2.2. Civic engagement initiatives: commonalities and differences

The initiatives that we identified show great variation in their context, development and evaluation, but there are also important commonalities. These include engaging communities in providing a link between a person with palliative care needs and those in their community who are able to offer help[44-47, 58]. This differs from the common service-centred approach that primarily focuses on clinical contributions and treating illness. Rather, compassionate communities apply a salutogenic approach by trying to increase the overall wellbeing of people through health-promotion.[7] Accordingly, in these initiatives, the community as the core of social interactions provides this social support for people confronted with illness, death and loss. Another important commonality is that most of the initiatives provide training and ongoing support for community members involved in civic engagement. This includes, for instance, individual feedback sessions with a mentor or group sessions with peers[36, 37, 44-50, 58]. Although such training and support is widely provided by the initiatives, many of them recommend that it is a recurrent event throughout the entire course of the initiative, in order to increase the chances of sustainability[38, 39, 44-46].

4.1.3. A lack of information on sustaining civic engagement initiatives

Some the evaluation studies mentioned the structural embedding of the initiative in their results, e.g. the role of the facilitator and the characteristics of the organisational context are important for the sustainability of the initiative[64]. However, although the evaluation studies measured for instance the feasibility and applicability of the civic engagement activities, the results of these feasibility study were often not discussed in the light of whether or not to continue the initiative, or under which conditions the initiative should continue to exist. The three initiatives that explicitly mentioned they ended[25-29, 38, 39], and provided reasons for not continuing, all indicate that funding ceased or research was time-limited from the outset. From this we can tentatively suggest that in community-academic development processes sufficient attention should be paid to empowering the community to continue the initiative when the research ends. Additionally, initiatives should search for alternative funding sources if necessary. As suggested in some of the publications, activities may also be more sustainable if integrated into a context of broader public involvement for encouraging a civic engagement culture in the community[44-47, 52, 53]. Compassionate city programs have been suggested for the purpose of facilitating and stimulating ongoing community action. Through involvement of stakeholders and endorsement by the city council they provide an overarching structure for community engagement, build public health policy, create supportive environments, enhance personal skills, and reorient health services towards the topics of illness, death, dying, loss and bereavement.[8] Future research should investigate the influence of embedding civic engagement initiatives in a compassionate city context on their sustainability.

4.1.4. The need for a thorough evaluation of civic engagement initiatives

Evaluation of civic engagement initiatives remains a challenge. Although all evaluations reported positive outcomes, the results are impossible to compare across the different initiatives as they vary in quality, content and in the way they were studied. Literature suggests that frameworks on how to evaluate civic engagement initiatives in palliative care are needed to build up a robust body of evidence that allows us to increase the overall quality of the evaluation.[65-67] Existing guidelines on such complex interventions recommend evaluating both the process of development and the impact of the initiative by using a mixed-method approach to data collection.[64, 68] Although some of the studies do use mixed method data collection, evaluation is often limited to either the process of development or to specific outcomes. Additionally, the evaluation studies exclusively focus on whether the objectives of the intervention are achieved, rather than providing a clear rationale for the choice of objectives and outcomes. Future research could be ground breaking in sharing experiences not only of measuring the impact of such initiatives but also of better comprehending in which context and through which mechanisms impact can be achieved.

4.1.5. Strengths & limitations of this review

A mixed-methods review is the most suitable design to systematically describe a variety of initiatives in different contexts. Since compassionate community volunteer initiatives often rely on public promotion, additional grey literature on the included initiatives was also searched. By searching and retrieving data from both peer reviewed and grey literature, we were able to provide a more comprehensive description of the initiatives, including the characteristics of their context, development, and evaluation. Due to the dearth of knowledge on the domain of civic engagement in serious illness, dying and loss, we argue it is a good first step to start from peer reviewed literature to gain a first insight into initiatives that are being researched. However, having received only additional grey literature for six of the initiatives by the authors, and by performing only a limited google search for websites of the initiatives, we potentially missed other grey literature documents. An independent grey literature search could have provided us with additional data (e.g. reports, secondary websites, blogs) on the included initiatives, or on initiatives that have not been evaluated and therefore are not published in peer reviewed literature. Consequently, we recommend further research to perform a systematic review of grey literature, in addition to this review. However, since we included peer reviewed publications and additional grey literature, it is not surprising that most of those included have already been evaluated in a study. Due to the fact that we included only publications in English, we are likely to have missed initiatives from non-English speaking countries. Furthermore, by using general terms such as "serious illness" and "bereavement" in our search string, we may have missed articles on one specific serious illness or condition. However, focusing on specific serious illness or condition was not an exclusion criterium in this review. Consequently, we did include articles that beside their general description of palliative care or serious illness also mentioned a specific illness or condition, e.g. dementia or cancer.

5. Conclusion

This review identified civic engagement initiatives concerning serious illness, death and loss around the world, initiated in the first and second decades of the 2000s. The initiatives vary considerably but also share some fundamental characteristics. They all draw on community engagement for their development, they aim to connect people with palliative care needs to people or other resources in the community that can address these issues, and have all reported benefits in – albeit often limited – evaluation. The systematic description of the characteristics, strengths and challenges of the initiatives provides a basis for more informed future civic engagement initiatives concerning serious illness, death and loss. Such future initiatives may particularly need to pay attention to their integration into public health policy, the need for a thorough evaluation that provides a rationale for the original choice of objectives and outcomes, and a reflection on sustainability based on the results of their evaluation. Better evaluation of civic engagement initiatives in palliative care could contribute to building a body of evidence, and could allow comparison between initiatives.

6. Declarations

6.1. Declaration of conflicting interests

The authors declare that there is no conflict of interest.

6.2. Funding

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6.3. Research ethics

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

6.4. Data management and sharing

Additional data will be made available on request from the corresponding author (LDEE), including all the data extracted and analysed of the included publications.

6.5. Author contributions

All authors contributed to the concept of the article, the study design, the interpretation of the data and the data analysis. LDEE and BQ performed the study selection and data extraction. LDEE, and TS drafted the article. The draft was revised by all authors. All authors gave approval for the final version.

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PART III

TO IDENTIFY DEVELOPMENT STRATEGIES FOR NEIGHBOURHOOD CIVIC ENGAGEMENT INITIATIVES REGARDING SERIOUS ILLNESS, DEATH AND LOSS, IN TERMS OF THE EXTENT, TYPE AND INTENSITY OF THIS NEIGHBOURHOOD PARTICIPATION, AND THE FACTORS THAT ARE ASSOCIATED WITH IT. THIS PART COVERS RESEARCH QUESTIONS 4 TO 7 IN THIS DISSERTATION.

CHAPTER III

HOW COMPASSIONATE IS YOUR NEIGHBORHOOD? RESULTS OF A CROSS-SECTIONAL SURVEY ON NEIGHBORHOOD PARTICIPATION REGARDING SERIOUS ILLNESS, DEATH AND LOSS

This chapter is based on

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Smets T*, Cohen J*. How compassionate is your neighborhood? Results of a cross-sectional survey on neighborhood participation regarding serious illness, death, and loss. Death Stud. 2023 :1-10. [2022 IF 3.8; Ranking Q1; ranking 34/147 PSYCHOLOGY, MULTIDISCIPLINARY in SSCI edition]

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Abstract

We conducted a cross-sectional survey measuring the extent and nature of neighborhood participation regarding serious illness, death and loss and the factors that are associated with it. We distributed the survey to 2324 adult citizens in two neighborhoods in Flanders, Belgium, to which 714 citizens responded (response rate 30.7%). Of the respondents, 42.4% participated in at least one action in their neighborhood around serious illness, death or loss, for 30.8% of them this participation was sporadic. Most of the respondents participated by helping neighbors (32.4%) or by volunteering (10.3%). We found a positive association between perceived neighborhood social cohesion (β=0.100; CI=0.003-0.040), previous experiences with serious illness, death and loss (β=0.158; CI=0.204-0.586) and neighborhood participation around serious illness, death and loss. Future research should look into strategies on how to move from death literacy developed through illness, caregiving and bereavement experiences to neighborhood participation around these topics.

Keywords

public health, palliative care, compassionate communities, neighborhood participation,
informal participation

1. Background

Communities that 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”, can be termed Compassionate Communities [1]. Compassionate Community networks can be developed through supportive policies, educating citizens about illness, dying, and loss [2] or via civic engagement [3]. We define civic engagement as all collective action that is undertaken to help improve connections between or conditions for people in a community.[4-6] Thereby, we interpret civic engagement as an umbrella term for volunteering, informal caregiving and all other types of collective, community and neighborhood participation. Civic engagement can be performed in different sectors within a Compassionate Communities approach, such as in workplaces, schools or cultural organizations. A systematic review of civic engagement initiatives regarding serious illness, death and loss worldwide illustrated that people are primarily involved in caring for people in their neighborhood, for instance by directing people with palliative care needs to existing neighborhood resources. [3, 7]

Although neighborhood participation around serious illness, death and loss has been shown to build a more extensive support network for the people who participate in it [8] and increases knowledge about palliative care [9], the actual extent and nature of this neighborhood participation around serious illness, death and loss have not been previously described. For instance, survey studies in Flanders, Sweden and the UK measured people’s participation regarding serious illness, death and loss in palliative care settings [10], but did not measure this in a neighborhood setting. Since neighborhood participation around serious illness, death and loss has been suggested as an important means of fostering Compassionate Communities [11], there is a need to develop insights into the current extent and nature of people’s participation and the factors associated with it. Previous studies have identified neighborhood social cohesion as a facilitating factor for neighborhood participation[12-14] but have also illustrated that barriers to helping those who are seriously ill or bereaved may be traced back to changing social relationships, for instance by being afraid to ask for or to offer support [15]. Consequently, we can hypothesize social cohesion to be of particular relevance for supporting people around serious illness, death and loss, and expect to find a positive association between people’s perceived feelings of social cohesion and their neighborhood participation in serious illness, death and loss. Specifically, we posed the following research questions:

1. To what extent do citizens participate in actions around serious illness, dying and loss in their neighborhood?

2. Are citizens more likely to participate in actions around serious illness, dying and loss in their neighborhood when there is a higher level of perceived social cohesion in the neighborhood?

2. Methods

2.1. Study design

We conducted a cross-sectional survey of citizens in two neighborhoods in Flanders, Belgium, pre-implementation of neighborhood civic engagement initiatives around serious illness, death and loss in these two neighborhoods.

2.2. Setting and participants

The survey was distributed in two neighborhoods in two peri-urban municipalities in Flanders, namely Sint-Kruis and Herzele [16]. Sint-Kruis is a sub-municipality of the city of Bruges. Together with the two groups of municipality representatives, we defined a neighborhood in this study as the geographical area matching the city center that contains most of the services, organizations, shops, etc. in that neighborhood. Following this reasoning, the neighborhood in Sint-Kruis (henceforward called neighborhood S) was demarcated as the two geographically defined areas (i.e. Sint-Kruis Kruispoort and Sint-Kruis Centrum) and the neighborhood in Herzele (henceforward called neighborhood H) was chosen as the area that is located in a radius of 1 mile around the local service center. Both neighborhoods are constituted of approximately 4,000 inhabitants.

2.3. Sampling procedure & study size

We chose to take a sample of citizens for each neighborhood. Sample sizes were calculated for a confidence interval of 95%; resulting in a sample of 1,177 inhabitants for neighborhood x and 1,147 inhabitants for neighborhood y. A city official took a random selection of inhabitants in each neighborhood of 18 years or older. A total of 2,324 surveys were sent out.

3. Data collection

Questionnaires were distributed by post between February and April 2021. We used the Total Design method, sending up to three reminders for those not answering.[17] There was a two-week period between each round of sending questionnaires or reminders, in which people could complete the survey and send it back. People were able to return the survey by post via a prepaid envelope or could complete the survey online by using their unique respondent number. A cover letter was provided with each questionnaire stating the context and aim of the research and that people could participate without obligation. The paper questionnaires were processed in compliance with the requirements of the European and Belgian data protection regulations.[18] The data was entered as soon as possible after receipt of each questionnaire in the open-source web-based survey application Lime Survey. The lead researcher (LD) and an independent data collector performed an independent double data entry for 10% of the data. If the number of errors on any given survey exceeded 3%, the entire survey would be re-entered, but this was not the case for any of the surveys. After data entry, the data was exported from LimeSurvey to SPSS. The lead researcher (LD) saved the original, exported file on a secured cloud, after which a second file for data cleaning was created. All data cleaning was conducted via syntaxes to ensure reproducibility by other researchers.

3.1. Confidentiality

To guarantee confidentiality, each participant received a unique respondent code. The lead researcher saved a file with names, addresses and respondent numbers on a secured cloud. This file was password protected and only accessible by the lead researcher (LD).

3.2. Concepts measured

We developed a survey comprised of both validated and novel concepts, of which an overview can be found in Appendix 1. The five main concepts in this survey study with which we perform the regression analysis, are 'perceived neighborhood social cohesion', 'general neighborhood participation', 'neighborhood participation around serious illness, death and loss', 'experiences with illness, caregiving and loss over the past year' and 'perceived help from neighbors'. In Appendix 1, we refer to perceived neighborhood social cohesion as a category 1 variable that is measured with a validated scale. The

Neighborhood Cohesion Instrument consists of eighteen statements (e.g. I feel like I belong in this neighborhood, I would be willing to work together with others on something to improve my neighborhood) on a five-point Likert scale ranging from ‘totally agree’ (5) to ‘totally disagree’ (1).[19]

To general neighborhood participation and neighborhood participation around serious illness, death and loss, we refer to category 2 variables which are measured by an adjusted validated scale. Both concepts were measured with the subscale ‘participation in the local community’ from the Social Capital Measure [20]; respondents could indicate for each item on a Likert scale from 1 to 4 ‘ if they were active in this kind of participation or not with ‘1’ meaning not active and ‘4’ meaning very active. We adjusted the examples of participation to examples that exist in a Belgian context and added the topics of illness, death and loss to the scale. Additionally, we added two items aimed at capturing individuals' participation in assisting their neighbors. These additional items were designed to assess whether participants had engaged in helping neighbors who were ill or in need of assistance. The two items added were:

- "In the six months prior to the start of the COVID-19 crisis, did you help an immediate neighbor (someone living next door) who was ill or in need of help?" Responses ranged from 1 (No, not at all) to 5 (Yes, at least five times).
- "In the six months prior to the COVID-19 crisis, did you help anyone in your neighborhood who was ill or in need of help?" Responses ranged from 1 (No, not at all) to 5 (Yes, at least five times).

After adding these two items, we conducted a Principal Component Analysis (PCA) on the eight items, with an orthogonal rotation (Varimax). The Kaiser-Meyer-Olkin test was used to verify if the sample size was adequate for the analysis. We found a significant KMO value of 0.594 ($p < 0.001$), which exceeds the acceptable threshold of 0.50. Bartlett's test of sphericity, $X^2(10) = 859.782$ ($p < 0.001$), indicated that the correlations between items were sufficiently large to justify performing a PCA. The analysis revealed that there was one component (a single latent factor or scale) with an eigenvalue greater than 1 (Kaiser’s criterion), which explained 28.89% of the variance. The two added items had factor loadings above 0.50. We observed a high internal consistency for the items within the scale (Cronbach’s alpha = 0.621).

All category 1 and 2 concepts were forward-backward translated, to provide a correct translation of the validated instrument, which can be found in Appendix 3. The remaining concepts are category 3 concepts which are self-developed. In the case of perceived help from neighbors the items are self-developed but based on the Medical Outcomes Study Survey (MOS) [21], resulting in 10 items going from (1) totally disagree to (5) totally agree. In the case of experiences with illness, caregiving and loss the items are self-developed, resulting in four items on previous experiences for which respondents could indicate yes or no.

The demographic characteristics of the participants included ‘age’, ‘sex’ (i.e. male or female), ‘highest degree’ (i.e. primary school, lower secondary school, higher secondary school, university college, university) and ‘living situation’ (i.e. living alone, living with a partner, living with children, living with a partner and children, living with parent(s), living with other roommates).

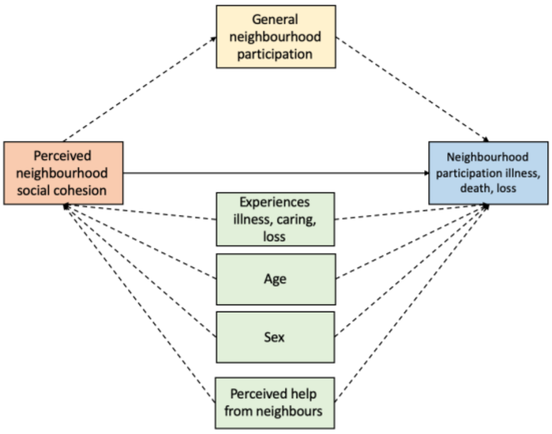
4. Statistical analyses

The demographic characteristics of the respondents and their degree of neighborhood participation in illness, death and loss were analyzed using descriptive statistics. We weighted the data for age and gender for both neighborhoods to generalize the results to the entire population living in the two neighborhoods (Appendix 4). To conduct the regression analyses, we first calculated the sum scores, resulting in a score from 0 to 24 for ‘generic neighborhood participation’ and ‘neighborhood participation regarding IDL’, 18 to 90 for ‘neighborhood social cohesion’, 0 to 40 for ‘perceived help from neighbors’ and 0 to 3 for ‘personal experiences with illness, dying and loss’; with higher values indicating better scores for each of the concepts. If a respondent filled in less than 20% items for a particular scale, these items were reported as missing; if they filled in more than 20% of the items the missing items were replaced by the sample average.

This study is interested in the association between perceived neighborhood social cohesion, general neighborhood participation and neighborhood participation regarding serious illness, death and loss. To inform us how perceived neighborhood social cohesion is associated with neighborhood participation regarding serious illness, death and loss we conducted a one-tailed Pearson correlation analysis ($p<0.05$) (Appendix 6). A study of relevant literature suggests that civic or neighborhood participation potentially plays a mediating role in the association between perceived social cohesion and collective action such as neighborhood participation regarding serious illness, death and loss [22]. Subsequently, our study was based on the assumption that general neighborhood participation has a potentially mediating role in explaining the association effect between perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death and loss. The potential confounding variables age (65+ vs non-retirement age), gender (women versus man), education (higher education vs lower education), living situation (living alone vs living with partner), previous experiences with serious illness, caregiving, and loss in the last year and perceived help from neighbors were identified by consulting previous findings on the subject [23-25]. To inform the multivariable analysis, and more particularly the de-confounding strategies (i.e. the difference between confounders and the mediator), we created a directed acyclic graph visualizing the potential causal interrelation between the different core concepts i.e. perceived neighborhood social cohesion, general neighborhood participation and neighborhood participation regarding serious illness, death and loss, which can be found in Appendix 5. We then calculated Pearson correlation coefficients ($p < 0.05$, one tailed) to determine the correlations of the relationships specified in the model (Appendix 6). Based on these results we constructed a simplified directed acyclic graph, figure 1, guiding our mediation analysis.

We started the mediation analysis by conducting a linear regression with the independent variable being perceived neighborhood social cohesion and the dependent variable neighborhood participation regarding serious illness, death and loss. In the second step we controlled for the confounding variables and in the third step we also added the mediating variable, general neighborhood participation. Variables that were non-significantly associated with neighborhood participation in serious illness, death and loss, were removed from the following step. In all steps we reported on the standardized regression coefficient ($p<0.05$) and the standardized R-squared change, an overview can be found in table 3. The standardized regression coefficients were filled into Figure 1 to give an indication of the direction and strength that each of the variables bring to the association. By multiplying the standardized regression coefficient of the association between perceived neighborhood social cohesion and general neighborhood participation (pathway a, figure 1), and general neighborhood participation and neighborhood participation regarding serious illness, death and loss (pathway b, figure 1) we were able to determine the full mediation effect size. Additionally, we conducted a Sobel test to tell whether our mediation model can be considered significant ($p<0.05$). Our model testing was conducted from the assumption that general neighborhood participation was a mediating variable. To rule out general neighborhood participation as a moderating variable influencing the magnitude of the association between perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death or loss, we calculated its interaction effect with perceived neighborhood social cohesion. A significant interaction effect would suggest moderation, while an insignificant interaction effect would indicate otherwise.

Figure 1. Simplified Directed Acyclic Graph of perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death and loss



5. Results

A total of 714 respondents completed the survey, response rate 30.7% (response rate neighborhood x= 37.81%, response rate neighborhood y= 27.46%). Ten respondents filled in none of the items of neighborhood participation around serious illness, death and loss and were hence removed from further analyses, meaning 704 respondents were retained for further analyses. Of the 704 respondents, 416 (59.1 %; Table 1) lived in neighborhood x and 288 (40.9 %) in neighborhood y. The majority of respondents were female (53.6%) in both neighborhoods, with a mean age of 63.2 years. Of the respondents, 30.9% were highly educated, 36.9% lived with a partner and children, and 28.8% lived alone. Current neighborhood participation around serious illness, death or loss was reported by 42.4% of respondents, with 30.8% of respondents participating ‘seldom or sometimes’ and 11.6% participating ‘more often’ (Table 2). Of those participating, the majority occurred by people helping a close neighbor who was seriously ill or needed help (32.4%) or by participating as a volunteer for seriously ill people, dying people or people with a loss experience (10.3%). To a lesser extent, people participated in community projects such as community care, grief groups or other partnerships related to illness, death or loss(6%), organizing a new service for ill people, dying people or people with a loss experience (6%) or being part of a digital neighborhood group (7.7%).

We found a positive but weak association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death and loss (β= 0.171; CI=0.032-0.083), which was only slightly reduced β= 0.100; CI=0.003-0.040) when adding general neighborhood participation to the analysis (Table 3). The other variables that were significantly positively associated with neighborhood participation around serious illness, death and loss were having had experiences with these topics in the last year (β =0.158; CI=0.204-0.586) and the perception that their neighbors would help them if they were seriously ill, caregiving or lost someone (β =0.134; CI=0.011-0.048). We conducted a Sobel test and found that the mediation model was not significant ($p<0.05$). We performed a moderation analysis in which we calculated the interaction effect between perceived neighborhood social cohesion and general neighborhood participation, which was not significant.

Table 1. Characteristics of the study population per neighborhood

	Neighbourhood S N =416 (59.1%)	**Neighbourhood H N=288 (40.9%)**	**Total N=704**
Age: Mean=63.19, SD=2.02			
18-24	30 (7.2)	11 (3.8)	41 (5.8)
25-49	80 (19.2)	68 (23.8)	148 (21.1)
50-64	109 (26.2)	82 (28.7)	191 (27.2)
65-79	112 (26.9)	81 (28.3)	193 (27.5)
80 (+)	85 (20.4)	44 (15.4)	129 (18.4)
Sex			
Female	210 (50.7)	163 (57.8)	373 (53.6)
Male	204 (49.0)	119 (42.2)	323 (46.4)
Living situation			
Living alone	131 (31.8)	70 (24.6)	201 (28.8)
Living together with my partner	62 (15.0)	59 (20.7)	121 (17.4)
Living together with my child(ren)	31 (7.5)	22 (7.7)	53 (7.6)
Living together with my partner and child(ren)	153 (37.1)	104 (36.5)	257 (36.9)
I live with my parents	30 (7.3)	16 (5.6)	46 (6.6)
I live with other roommates	5 (1.2)	14 (4.9)	19 (2.7)
Highest degree			
Primary school	45 (11.0)	37 (13.3)	82 (11.9)
Lower secondary school	103 (25.2)	50 (17.9)	153 (22.3)
Higher secondary school	136 (33.3)	104 (37.3)	240 (34.9)
University College	86 (21.1)	58 (20.8)	144 (21.0)
University	38 (9.3)	30 (10.8)	68 (9.9)

Missing values= age (0.3%), sex (1.1%), living situation (1.0%), degree (2.4%

Table 2. The degree to which citizens in two neighborhoods in Flanders engage in neighborhood participation regarding serious illness, death or loss

		Neighbourhood S (n= 416)			**Neighbourhood H (n= 288)**			**Total (n=704)**		
		Not active N (%)	**Seldom or Sometimes active N (%)**	**More active N (%)**	**Not active N (%)**	**Seldom or Sometimes active N (%)**	**More active N (%)**	**Not active N (%)**	**Seldom or Sometimes active N (%)**	**More active N (%)**
1.	Do you help in a neighbourhood group as a volunteer to support ill people, caregivers or people who have lost someone?	361 (90.3)	34 (8.4)	5 (1.4)	253 (89.1)	24 (8.5)	7 (2.4)	614 (89.8)	58 (8.5)	12 (1.8)
2.	Have you attended an event in your neighbourhood around illness, caregiving or loss in the six months before corona started (e.g. benefit action to raise money)?	384 (96.6)	12 (3.0)	2 (0.5)	264 (95.8)	11 (4.2)	0 (0)	648 (96.2)	23 (3.5)	2 (0.3)
3.	Are you an active member of an organisation or club in your neighbourhood that did something around illness, caregiving or loss (e.g. memorial for someone who has died)?	391 (98.2)	5 (1.2)	3 (0.7)	226 (98.1)	3 (1.2)	2 (0.7)	616 (98.1)	7 (1.2)	4 (0.7)
4.	In the past 3 years, have you ever been involved in a local-community initiative around illness, caregiving or loss in your neighbourhood (e.g. a bereavement group)?	378 (94.8)	17 (4.4)	3 (0.8)	256 (92.9)	19 (6.9)	1 (0.2)	634 (94.0)	36 (5.4)	4 (0.6)
5.	Have you ever been part of a project to organise a new service in your neighbourhood for ill people, dying people or people with a loss experience?	359 (95.0)	16 (4.2)	3 (0.8)	245 (91.7)	20 (7.6)	2 (0.7)	603 (93.6)	36 (5.6)	5 (0.8)
6.	Are you a member of a digital neighbourhood group on social media that does something for ill people, caregivers or people with loss experience?	350 (90.0)	35 (9.0)	4 (1.0)	261 (95.5)	12 (4.1)	1 (0.4)	611 (92.2)	46 (7.0)	5 (0.7)
7.	Did you help a neighbour (that lives next to you) who was ill or needed help?	274 (68.3)	102 (25.4)	25 (6.3)	182 (66.4)	81 (29.7)	11 (3.9)	456 (67.5)	183 (27.1)	36 (5.3)
8.	Did you help someone in your neighbourhood who was ill or needed help?	281 (69.6)	96 (23.8)	27 (6.6)	167 (64.9)	77 (30.2)	13 (4.9)	448 (67.7)	174 (26.3)	39 (5.9)
	At least one of the above activities	230 (58.2)	116 (29.4)	49 (12.4)	153 (56.7)	89 (33.0)	28 (10.4)	38 (57.6)	205 (30.8)	77 (11.6)

Missing values items 1-8: 2.9%; 4.3%; 10.8%; 4.2%; 8.5%; 5.8%; 4.1%; 6.0%; 5.5%

Table 3. Hierarchical linear regression testing the assumed associations for neighborhood participation around serious illness, death and loss

	Dependent variable: general neighborhood part			**Dependent variable: neighborhood participation regarding serious illness, death and loss**								
				Step 1			**Step 2**			**Step 3**		
	Adjusted R^2= 0.028			**Adjusted R^2= 0.040**			**Adjusted R^2= 0.098**			**Adjusted R^2= 0.131**		
Predictor variables	**β (95% IC)**	**t-value**	**sr^2**	**β (95% IC)**	**t-value**	**sr^2**	**β (95% IC)**	**t-value**	**sr^2**	**β (95% IC)**	**t-value**	**sr^2**
IV=Perceived neighbourhood social cohesion	**0.171*** (0.032-0.083)**	**4.437**	**1.3%**	**0.204*** (0.027-0.061)**	**5.201**	**0.8%**	**0. 128** (0.009-0.047)**	**2.843**	1%	**0.100* (0.003-0.040)**	**2.258**	**1%**
CON=Education (higher education)							**0.161** (0.174-0.518)**	**3.959**	**8.7%**	0.118 (0.088-0.420)	3.009	8.5%
CON=Experiences caring, dying, loss							**0.166*** (0.211-0.611)**	**4.191**	**9.9%**	**0.158*** (0.204-0.586)**	**4.063**	**9.7%**
CON=Perceived help from neighbours							**0.142** (0.012-0.050)**	**3.198**	**1%**	**0.134** (0.011-0.048)**	**3.094**	**0.9%**
CON=Women							-0.020 (-0.483-0.286)	-0.501	19.6%			
MED=General neighbourhood participation										**0.186*** (0.069-0.169)**	**4.706**	**2.5%**
Total mediating effect	**0.171 x 0,186= 0.032**											
Sobel test	**z= 3.228**											

**p<0.05; **p<0.01; ***p<0.001*

IV= Independent variable, CON= confounding variable, MED= mediating variable

6. Discussion

6.1. Main results

This study found that 42% of the respondents participated in their neighborhood around the topics of serious illness, death and loss at least once. This participation consisted primarily of helping close neighbors or being involved in volunteering around these topics. Additionally, we found that people are more likely to participate in their neighborhood in activities around serious illness, death and loss the higher their perception of the neighborhood's social cohesion is, and if they had an experience with illness, caregiving or bereavement in the last year. This association remained after controlling for other variables such as general neighborhood participation.

6.2. Interpretation

Our results show that almost half of the residents of the neighborhoods (42.4%) participated in at least one activity around serious illness, death and loss such as volunteering or helping a close neighbor, with only a smaller proportion participating regularly (11.6%). This finding shows that sporadic participation around illness, death and loss in the neighborhood predominates over frequent involvement. Besides time constraints (e.g. due to demanding work schedules) or changing circumstances (e.g. having children, moving, having health issues) that prevent people from committing to more intense commitments on a weekly or daily basis[26], people may find it emotionally challenging to deal with sensitive issues like illness, death and loss on a more frequent basis [27]. We found a positive association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death and loss, confirming our hypothesis that social cohesion is a potential facilitator for participation around these topics. We can however wonder if a feeling of social cohesion is in itself sufficient enough to remedy emotional challenges that come with frequent informal participation in general and especially around deeply human topics such as serious illness, death and loss. Since this survey showed that people are more likely to help their close neighbor than to participate in general neighborhood activities around serious illness, death and loss where there is no personal connection with someone they know (e.g. involvement in events, clubs, organizations, digital groups), social ties with people in the neighborhood are a likely stimulus for people to see where they are needed and to participate more frequently.

Furthermore, we found that general neighborhood participation only slightly influenced the association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death and loss, suggesting that people who participate around illness, caregiving or loss are specifically triggered by these topics rather than by general neighborhood involvement. In line with this finding, we found a strong positive association between people's experiences with illness, death and loss and their participation in these topics in their neighborhood. A possible explanation could be that exposure to the topics of illness, death and loss either through work experience, educational activities or personal caring or loss experiences, enables people's "knowledge and skills that make it possible to understand and act upon end-of-life and death care options"[28], also known as death literacy [29, 30]. For instance, Leonard et al. found that people with caregiving experiences felt better equipped than others to share knowledge and skills within their network, thereby enabling social action around illness, death and loss.[30] Combining these findings seems to suggest that people with previous illness, caring or bereavement experiences are not only the ones that can benefit from neighborhood participation around these topics, but they are an essential part of this neighborhood participation themselves.

Future research should look into strategies on how to move from death literacy developed through illness, caregiving and bereavement experiences to neighborhood participation around these topics.

6.3. Implications and recommendations for research and practice

The findings of this research resonate with broader research looking into experience-based learning as one of the strategies for developing death literacy and stimulating social actions around serious illness, death and loss. This study provides the first step in mapping the potential of people's previous experiences with serious illness, caregiving and loss with neighborhood participation around these topics. We advise community workers to actively look into how these experiences can be lifted from the individual level to a community-wide level, for instance by organizing group activities. Future research has a role in mapping which specific experiences around serious illness, death and loss are associated with neighborhood participation and if these experiences are sufficient for people to participate in initiatives regarding serious illness, death or loss or whether the development of death literacy is a necessary intermediate step. Additionally, neighborhood participation around serious illness, death and loss is in itself an experience that can develop people's death literacy and can thereby strengthen future participation. This insight challenges us to approach Compassionate Communities from a more circular perspective in which the outcomes of neighborhood participation are also a facilitator for future participation.

6.4. Strengths and limitations

This study is the first to measure the extent of neighborhood participation in serious illness, death and loss in a population of neighborhood citizens, and to provide an insight into the type of neighborhood participation citizens are most involved in. We recognize several limitations in this study. Firstly, our cross-sectional data does not allow us to make causal claims. Secondly, our survey only measured a specific set of activities around serious illness, caregiving, death and loss, thereby counting people who are involved in other potentially relevant activities as non-participating. Thirdly, we did not explore people's motivations for or experiences with neighborhood participation around serious illness, death and loss. Furthermore, although the scale measuring neighborhood participation concerning serious illness, death and loss demonstrated high internal consistency, a potential limitation is the broad phrasing of the item "helping a neighbor in need or who was ill". A yes response to this item may not accurately capture this concept, potentially leading to an overrepresentation which could have been reduced with a more precise formulation focused on serious illness. Finally, when designing the survey study as a pre-post measurement, we chose to measure neighbourhood participation around serious illness, death, and loss by specifically referencing participation before the COVID-19 pandemic in the survey items. This was necessary to avoid measuring participation during the pandemic, which would complicate the possibility of conducting a post-measurement afterwards. As a result, we do not have a clear understanding of whether the pandemic itself acted as a facilitator for participation on these topics within their neighbourhoods. This remains an important aspect to be explored in future research.

7. Conclusion

This survey showed that four out of ten residents in two neighborhoods in Flanders participated in activities in their neighborhood around serious illness, death and loss, though most participated infrequently. Furthermore, we identified that perceived neighborhood social cohesion and experiences with serious illness, caregiving and loss in the last year are both positively associated with neighborhood participation around serious illness, death and loss. We recommend that community workers and policymakers prioritize the fostering of social cohesion and social ties when developing initiatives, and recommend future research to explore how previous experiences around serious illness, death and loss can be used as a means of building these social ties and to stimulate neighborhood participation regarding serious illness, death and loss.

8. Declarations

8.1. Acknowledgements

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8.2. Funding

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8.3. Conflict of interest

The authors declare there is no conflict of interest.

8.4. Research ethics

Ethical approval to conduct the study was obtained from the Ethics Committee of the Vrije Universiteit Brussel (case number B1432020000185).

8.5. Data availability

The data set and data syntax can be provided by contacting the corresponding author.

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CHAPTER IV

CITIZENS WITH A CAREGIVING EXPERIENCE IN THE PAST YEAR ARE MORE LIKELY TO PARTICIPATE IN NEIGHBOURHOOD ACTIVITIES REGARDING SERIOUS ILLNESS, DEATH OR LOSS: A CROSS-SECTIONAL SURVEY STUDY

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Cohen J*, Smets T*. Citizens with a caregiving experience in the past year are more likely to participate in neighbourhood activities regarding serious illness, death or loss: a cross-sectional survey study [Submitted-minor revisions]

Abstract

Experience-based learning is promoted as a strategy for developing death literacy; the knowledge and skills to understand and make informed decisions when confronted with serious illness and death. While death literacy is believed to foster social connections between people around these topics, limited evidence exists on whether it stimulates neighbourhood participation regarding serious illness, death and loss. This study aimed to measure the association between having had personal experiences with serious illness, death or loss in the past year and neighbourhood participation around these topics, and to study whether citizens' self-perceived capacity, skills and self-efficacy developed from previous experiences, strengthens this association. A questionnaire was sent to a random sample of 2,324 citizens aged 18+ in two neighbourhoods in Flanders, Belgium, between February and April 2021; 714 citizens responded (response rate 31%). Hierarchical linear regression analysis showed that people with a caregiving experience in the past year were found to be more likely to participate in neighbourhood activities regarding serious illness, death or loss (ß= 0.161; CI=0.378-1.276) than those who did not have such an experience. The association strengthened (ß= 0.193; CI=0.588-1.393) when adding self-perceived capacity and skills developed from previous experiences to the analysis, indicating that individuals who believed they gained the capacity and skills were even more inclined to participate. Since self-perceived capacity and skills developed from previous experiences are only one aspect of death literacy, we recommend that researchers look into other aspects of death literacy which might be better mediating predictors for neighbourhood participation regarding serious illness, death or loss. Furthermore, we suggest future research should explore the mechanisms behind the associations we measured, with qualitative research seeming a particularly relevant approach.

Keywords

Civic engagement, caregiving, neighbourhood participation, Compassionate Communities, cross-sectional survey,

1. Introduction

Experiencing serious illness, caregiving, dying or loss involves several challenges and needs that cannot be met only with a reliance on palliative care and other healthcare services.[1] There is increasing recognition that social and community approaches that include salutogenic perspectives, focusing on overall well-being of people rather than on the medical aspect of illness, are additionally needed.[2] The development of Compassionate Communities has been proposed as part of such approaches.[3] *"Compassionate Communities are places and environments in which people, networks, and institutions actively work together and are empowered to improve the circumstances, health, and well-being of those facing serious illness, death, dying, or loss"*.[4] One way for community members to be involved in Compassionate Communities is through civic engagement in which people take collective action to help improve connections between, or conditions for, people in the community who experience serious illness, death or loss.[5-7] In Compassionate Communities, civic engagement can be part of different community settings such as neighbourhoods, workplaces, schools, or cultural institutions.[8, 9] However, the neighbourhood is regarded as the setting par excellence for civic engagement in the areas of serious illness, caregiving responsibilities, or loss, henceforth called neighbourhood participation regarding serious illness, death or loss.[10, 11]

Experience-based learning is promoted as one of the strategies for enhancing death literacy, which has been defined as *" the knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options"* [12], and thereby stimulates participation around serious illness, death or loss.[12-14] For example, personal experiences related to serious illness, caregiving, death, or loss can increase people's knowledge and skills and can foster connections between people within neighbourhoods, particularly when individuals with such experiences participate in peer support, caregiving, and bereavement groups.[15] Furthermore, Leonard et al.[14] discovered that people with caregiving experiences in the context of serious illness not only felt better equipped to offer support to people with serious illness but also felt confident in sharing the acquired caregiving knowledge and skills within their social network. These examples illustrate the potential for previous experiences with serious illness, death or loss to increase people's self-perceived capacity and skills and their engagement in social networks regarding these topics. These findings in literature formed the basis of our assumption that there is an association between previous experiences with serious illness, death or loss in the last year and neighbourhood participation relating to these topics and that this association may be mediated by self-perceived capacity, skills and self-efficacy developed from previous experiences with serious illness, death or loss. This aligns with theories on planned behaviour indicating people's belief in their capacity and skills to adopt health-promoting behaviour, influences whether or not they engage in this behaviour.[16-18] Consequently, our study had a twofold aim: (1) to study the association between having had personal experiences with serious illness, death or loss in the last year and neighbourhood participation regarding these topics, and; (2) to study whether the capacity, skills and self-efficacy people believe they gained from their previous experiences strengthens this association.

2. Methods

2.1. Study design

We performed a cross-sectional survey among a random sample of adult citizens (18+) in two neighbourhoods in Flanders, Belgium.

2.2. Setting

This study is part of CAPACITY, Flanders Project to Develop Capacity in Palliative Care Across Society, in which we aim to develop two Compassionate Neighbourhoods in Herzele and Sint-Kruis, the latter being a sub-municipality of Bruges. Both Herzele and Bruges are engaged to become Compassionate Cities. Together with city officials of Herzele, we selected two geographically defined neighbourhoods in a radius of 1.5 km around the local city centre, containing most of the organisations and shops in that area. In Sint-Kruis the neighbourhood coincides with with the already existing geographic areas Sint-Kruis Centrum and Sint-Kruis Kruispoort, in Herzele the selected neighbourhood is demarcated as the area close to the local service centre. Both neighbourhoods are peri-urbanised and constitute around 4,000 inhabitants.[19]

2.3. Sampling procedure

In both Herzele and Sint-Kruis, a city representative with access to the population register took a random sample of residents who were eighteen years or older. In the two neighbourhoods, we aimed for a 95% confidence interval with a width of +/- 5%, with alpha set at 0.05 to estimate the proportions. Following a conservative approach, with the conservative estimation for heterogeneity set at 50%, we anticipated a response rate of 35%. This led to an estimated required initial sample size of 1,177 potential respondents for Sint-Kruis and 1,147 potential respondents for Herzele, 2,324 potential respondents in total.

2.4. Data collection

The survey took place between February and April 2021. We applied the principles of Dillman's Total Design method[20] in the design of the questionnaire, the accompanying letters and the mailing procedures. We sent up to three reminders for non-responders to the questionnaire with two weeks in between each reminder.[20] Each questionnaire was accompanied by a cover letter, providing information on the study and information on how to complete the questionnaire and send it back to the researchers. Respondents could choose to fill in the questionnaire on paper using a prepaid return envelope or they could complete it online via Lime Survey. The researcher (LDEE) entered the data from the paper questionnaires into LimeSurvey as soon as possible after receipt of the questionnaire. An independent double data entry was performed by the researcher (LDEE) and a data collector for 10% of the data. None of the questionnaires required re-entry in its entirety as none of them had an error rate exceeding 3%. After data entry, the data was transported from Lime Survey to SPSS. We used syntaxes to be able to retrace each step in the data-cleaning process.

2.5. Confidentiality

The data was processed in compliance with European and Belgian data protection regulations.[21] Each questionnaire was provided with a unique code which served the double purpose of providing the respondent with a code to fill in the questionnaire online and guaranteeing confidentiality in tracking which questionnaires were sent back and which ones needed a reminder. The researcher (LDEE) and the PI of the project (JC) were the only ones with access to the online survey database and to the SPSS file. The original database is saved on a secured cloud.

2.6. Ethics

Before the start of the study, we received ethical approval from the Ethics Committee of the Vrije Universiteit Brussel (case number B1432020000185).

2.7. Questionnaire and measures

The questionnaire measured seven different themes, either by validated scales, by validated scales which were adapted by adding the topics of serious illness, death or loss to the original items, or by a self-developed scale created by following recommendations in the literature.[22, 23] An overview of the themes and the scales by which these themes were measured, can be found in Appendix 1. Each of the validated scales went through a process of forward-backward translation. This entailed that the original items in English were translated to Dutch by a professional translator, followed by a backward translation to English by another professional translator. The researcher compared the backward translation of the items to the original ones. Inconsistencies were resolved by adjusting the Dutch translation to a more accurate one. The process was repeated until all inconsistencies were resolved (Appendix 3).

Neighbourhood participation around serious illness, death or loss was measured with the Social Capital Measure[24], which we adjusted by adding the topics serious illness, death or loss to the original items, by replacing 'local community' with the neighbourhood, and by adding two items on helping neighbours. This resulted in eight items on involvement in volunteering, in events, community groups, helping neighbours, and initiating new initiatives regarding the topics of serious illness, death or loss. Respondents could indicate for each item on a Likert scale from 1 to 4 whether they were active in this kind of participation; 1 meaning not active, 4 meaning very active. Believed *Capacity, skills and self-efficacy resulting from previous experiences with serious illness, death or loss* were measured by two different scales both containing five items measured on a Likert scale from 1 (totally disagree) to 5 (totally agree). The self-perceived capacity and skills to deal with serious illness, death or loss resulting from previous experiences were measured with the subscale 'experiential knowledge' of the Death Literacy Index, e.g. my previous experiences with serious illness, caring, death or loss provided me with skills and strategies when facing similar challenges in the future.[25] Self-efficacy to deal with serious illness, death or loss resulting from previous experiences was measured by 5 self-constructed items, which we developed by following specific recommendations in the literature on developing items around self-efficacy, e.g. my previous experiences with serious illness, caring, death or loss ensured I can talk to people in my neighbourhood who have lost someone.[22, 23] Furthermore, we developed items on being able to talk to people in the neighbourhood about serious illness, caregiving or loss, talking to professional caregivers, and helping people who are seriously ill, caregivers or bereaved people based on previous experiences with these topics. Lastly, citizens' *previous experiences with serious illness, caregiving, death, or loss in the last year* were measured with four self-developed items: 'I was seriously ill', 'someone I knew very well died', 'a family member was seriously ill', and 'I was caregiver of a family member who was seriously ill', in the last year. Respondents could indicate yes or no for each of these items. Each of these items was employed independently in the analysis.

Demographic characteristics included sex (i.e. female, male, X), age as a continuous variable, highest degree obtained (i.e. primary education, lower secondary education, higher secondary education, university college, university), and living situation (i.e. living alone, living with a partner, living with children, living with a partner or children, living with parent(s), living with other roommates). These variables were coded into fewer categories to conduct the analysis with; 65+ years versus being younger, lower education versus higher education and living alone versus living with other people.

2.7. Statistical analyses

We used descriptive statistics to analyse the demographic data, previous experiences with serious illness, death or loss in the last year and believed capacity, skills, and self-efficacy developed from previous personal experiences with these topics. To generalise the data to the entire population living in the two neighbourhoods together, we weighted the data for age and gender (Appendix 4).

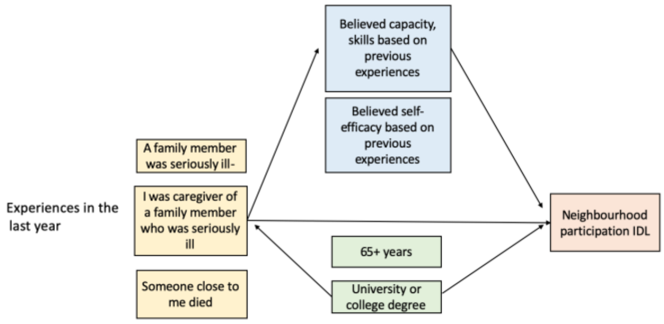
Before looking into the association effects, we calculated the sum score or factor score of the variables involved. Whether we collected a sum score or a factor score of a variable depended on the instructions of the original validated scale. If no instructions were provided, we preferred calculating the factor score because factors consider the shared variance among the variables.[26] Based on the instructions from the Social Capital Measure[24], we calculated a sum score of the eight items on neighbourhood participation regarding serious illness, death or loss, with total scores ranging from 0 to 24. If 2 items or fewer (25% of all items) were missing, we replaced the value for that item with the sample average. When more than two items were missing, that value for that item was reported as missing.

We performed a Principal Component Analysis (PCA) before calculating the factor score of the variable self-perceived capacity, skills and self-efficacy to deal with serious illness, death or loss and found that the factors loaded onto two distinct scales. The first scale represented self-perceived capacity and skills developed from previous experiences with serious illness, death or loss, while the second scale pertained to perceived self-efficacy in coping with these topics developed from previous experiences. Consequently, we computed factor scores for each of these two scales and employed them separately in our subsequent analyses.

This analysis was developed from assumptions, grounded in existing literature[12-14], that there is an association between previous experiences with serious illness, death or loss and neighbourhood participation regarding these topics and that this association may be mediated by self-perceived capacity, skills and self-efficacy developed from previous experiences with serious illness, death or loss. Additionally, we identified retirement age (65+), living together with a partner or children, and having a college or university degree as potential confounding variables affecting the association between previous experiences with serious illness, death, or loss in the last year and neighbourhood participation regarding these topics.[27-29] To inform the multivariable analysis and more specifically the de-confounding strategies, we depicted the assumed causal interrelations in a Directed Acyclic Graph (DAG) model (Appendix 5). We calculated one-tailed Pearson correlation coefficients ($p<0.05$) to determine the correlations of the relationships specified in the model. These correlation coefficients were then filled into the DAG model (Appendix 5). Removing non-significant correlations, resulted in a simplified model, figure 1, that served as a guide for our mediation analysis.

We conducted the mediation analysis via a hierarchical linear regression in which we first examined the association between each of our independent variables ‘I was seriously ill’, ‘a family member was seriously ill’, ‘I was caregiver of a family member who was seriously ill’ and ‘someone I knew very well died’ in the last year, and the dependent variable neighbourhood participation regarding serious illness, death or loss. Then we controlled for confounders by adding age (65+ vs. younger), sex (women vs. men, education (higher education vs. lower education) and living situation (living alone vs. living with other people) to the analysis. Subsequently, we added the mediating variables, perceived capacity and skills and perceived self-efficacy to deal with serious illness, death or loss, developed from previous experiences with these topics to the regression analysis. Non-significant variables were removed in each step. We reported on the standardized regression coefficient ($p<0.05$) the standardized R-squared change and the Confidence Interval (95%) for each step in the regression analysis. Additionally, we calculated the full mediation effect size and conducted a Sobel test to assess the significance ($p<0.05$) of our mediation model.

Figure 1: Simplified model illustrating the assumed association between previous experiences with serious illness, death or loss in the last year and neighbourhood participation regarding these topics



🟨 Independent variables

🟩 Confounders

🟦 Mediators

🟧 Outcomes

3. Results

A total of 714 respondents completed the survey (response rate 30.7%). Of the respondents, 59.4% lived in the neighbourhood in Sint-Kruis and 40.6% in the neighbourhood in Herzele. Overall, there were 53.7% women and 46.3% men who participated. A large proportion of respondents lived alone (29.1%), or lived with a partner and children (36.5%). Responding citizens were generally highly educated with a university or college degree (30.6%) or with a higher secondary school degree (34.9%).

Experiences with being seriously ill, having a family member who was seriously ill, caregiving for a family member who was seriously ill, or having someone close who died in the last year, occurred in both neighbourhoods; 72.1% of citizens had at least one of these experiences in the last year. More than half of the citizens (57.1%) lost someone they knew well, 14.2% reported that they had been caregiver for a family member who was seriously ill and 14.5% reported that they had been seriously ill in the last year. Table 1 shows an overview of the characteristics of the study population per neighbourhood.

In terms of believed capacities and skills to deal with serious illness, death, or loss as a result of previous experiences with these topics (Table 1), 48.3% of the respondents found that their previous experiences gave them capacities and strategies to deal with similar challenges in the future, although this was less often the case for citizens living in the neighbourhood in Sint-Kruis (43.6%) than for the citizens living in the neighbourhood in Herzele (55.4%). Furthermore, 47.0% of the responding citizens indicated that their previous experiences made them emotionally stronger to help others deal with death and dying. In terms of self-efficacy, 59.2% believed their previous experiences made them able to talk with other people in their neighbourhood about loss; 44.1% believed their previous experiences made them able to help people in their neighbourhood who lost someone, 39.3% believed their previous experiences made them able to help someone who is ill or is a caregiver in their neighbourhood; and 33.4% believed their previous experiences made them able to talk a doctor or professional caregiver about what ill people in the neighbourhood need.

We found a significantly positive association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss (ß= 0.161; CI=0.378-1.276), but not for other experiences with serious illness, death or loss (Table 2). Adding the assumed confounding variables to the analysis, we found a positive association between having a college or university degree and neighbourhood participation regarding serious illness, death or loss (ß= 0.115; CI=0.080-0.420). Living situation and sex were not significantly associated. In the third step, by adding the assumed mediators believed capacity, skills, and self-efficacy developed from previous experiences with serious illness, death, or loss to the analysis, the association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss slightly increased (ß =0.193; CI=0.588-1.393). In contradiction to the believed capacity and skills to deal with serious illness, death or loss developed from previous experiences, believed self-efficacy was not significantly associated with neighbourhood participation regarding serious illness, death or loss. The initial model, which included experiences with serious illness, death or loss accounted for an R-squared of 0.049. Upon the addition of the mediator capacity and skills developed from previous experience, the R-squared increased to 0.069. This indicates that the inclusion of the mediator contributes to a 2.0% increase in the variance explained in the dependent variable, suggesting that self-perceived capacity and skills developed from previous experiences contribute to understanding the association between caregiving experiences in the past year and neighbourhood participation regarding serious illness, death and loss.

Table 1: Characteristics of the study population per neighbourhood

	Neighbourhood in Sint-Kruis N =424 (59.4%)	Neighbourhood in Herzle N=290 (40.6%)	Total N=714 (%)
Age: Mean=63.19, SD=2.02			
18-24	31 (7.3)	11(3.8)	42 (5.9)
25-49	83(19.6)	69(23.8)	152(21.3)
50-64	109(25.7)	82 (28.3)	191(26.8)
65-79	114(26.9)	81 (27.9)	195(27.3)
80 (+)	87(20.5)	45(15.5)	132(18.5)
Gender			
Female	216 (51.2)	163(57.4)	379 (53.7)
Male	206(48.8)	121(42.6)	323 (46.3)
Living situation			
Living alone	134 (31.9)	72(25.1)	206(29.1)
Living together with my partner	64(15.2)	59(20.6)	123(17.4)
Living together with my child(ren)	32(7.6)	22(7.7)	54(7.6)
Living together with my partner and child(ren)	154(36.7)	104(36.2)	258(36.5)
I live with my parents	31(7.4)	16(5.6)	47(6.6)
I live with other roommates	5(1.2)	14(4.9)	19 (2.7)
Highest degree			
Primary school	48 (11.6)	37 (13.2)	85 (12.2)
Lower secondary school	104(25.1)	51 (18.1)	155 (22.3)
Higher secondary school	138 (33.3)	105 (37.4)	243 (34.9)
University College	87 (21.0)	58 (20.6)	145 (20.8)
University	38 (9.2)	30 (10.7)	68 (9.8)
Previous experiences with serious illness, caregiving, death or loss			
Someone I knew well, died	227 (56.4)	160 (58.2)	387 (57.1)
A family member was seriously ill	135 (34.6)	119 (43.3)	254 (38.2)
I was caregiver of a family member who was seriously ill	60 (15.4)	34 (12.5)	94 (14.2)
I was seriously ill	59 (14.9)	39 (14.0)	98 (14.5)
At least one of the above experiences	317 (72.1)	216 (72.4)	533 (72.1)

Missing values for the variables in the table are respectively 0.7%; 1.1%; 1.0%; 2.5%; 5.8%; 5.3%; 6.9%; 7.2%

Table 2: Capacity, skills and self-efficacy to handle illness, death or loss resulting from previous experiences

My previous experiences with illness, death or loss …		Neighbourhood in Sint-Kruis (n= 424)			Neighbourhood in Herzele (n=290)			Total (n=714)		
		Disagree N (%)	Agree nor disagree N (%)	Agree N (%)	Disagree N (%)	Agree nor disagree N (%)	Agree N (%)	Disagree N (%)	Agree nor disagree N (%)	Agree N (%)
1.	Increased my emotional strength to help others with death and dying processes	65(17.0)	142(37.1)	176(45.9)	48(18.4)	86(33.0)	126(48.6)	113(17.6)	228(35.5)	302(47.0)
2.	Led me to re-evaluate what is important and not important in life	49(12.4)	98(24.7)	248(62.8)	65(24.9)	114(43.8)	82(31.3)	114(17.4)	212(32.3)	329(50.3)
3.	Developed my wisdom and understanding	42(10.9)	122(31.2)	226(57.9)	43(16.9)	111(43.4)	101(39.6)	86 (13.3)	232(36.0)	327(50.7)
4.	Made me more compassionate toward myself	58(15.1)	164(42.4)	164(42.5)	32(12.3)	100(38.6)	127(49.1)	90(14.0)	264(40.9)	291(45.1)
5.	Provided me with skills and strategies when facing similar challenges in the future	53(13.7)	165(42.8)	169(43.6)	34(13.2)	80(31.3)	141(55.4)	87(13.5)	245(38.2)	310(48.3)
6.	Made that I can talk to people in my neighbourhood about illness, caregiving or dying	87(22.2)	102(25.9)	205(51.9)	44(16.6)	80(30.3)	140(53.1)	131(19.9)	182(27.7)	345(52.4)
7.	Made that I can talk to people in my neighbourhood about loss	74(18.8)	95(24.4)	222(56.8)	33(12.4)	65(24.7)	166(62.9)	106(16.3)	161(24.5)	388(59.2)
8.	Made that I can help people who are ill, or caregiving, in my neighbourhood	103(26.2)	143(36.5)	146(37.3)	52(20.1)	96(37.5)	109(42.4)	154(23.8)	239(36.9)	255(39.3)
9.	Made that I can help people in my neighbourhood who lost someone	95(24.2)	136(34.7)	160(41.0)	45(17.5)	87(33.7)	126(48.8)	140(21.6)	223(34.3)	286(44.1)
10.	Made that I can talk to a doctor or professional caregiver about what people who are ill in my neighbourhood need	116(29.4)	159(40.6)	116(29.6)	52(19.9)	106(41.0)	101(39.1)	168(25.8)	265(40.8)	217(33.4)

Missing values for the variables in the table are respectively: 10.1%; 8.3%; 9.7%; 9.5%; 10.2%; 7.8%; 8.3%; 9.2%; 9.1%; 8.9%

Table 3: Hierarchical linear regression analysis testing the assumed associations with neighbourhood participation around serious illness, death or loss

	DV= neighbourhood participation regarding serious illness, death and loss						MED variable= capacity & skills	
	R^2 change= 0.049		R^2 change= 0.058		R^2 change= 0.069		R^2 change= 0.020	
Predictor variables	β (95% IC)	t-value	β (95% IC)	t-value	β (95% IC)	t-value	β (95% IC)	t-value
ID= A family member was seriously ill	0.065 (-0.032-1.080)	1.850						
ID= I was caregiver of a family member who was seriously ill	0.161*** (0.378-1.276)	3.620	0.197*** (0.615-1.409)	5.045	0.193*** (0.588-1.393)	4.838	0.143*** (0.133-0.436)	3.680
ID= someone I knew well died	0.044 (-0.190-0.638)	1.063						
CON= Highest degree			0.115** (0.080-0.420)	2.881	0.092* (0.034-0.367)	2.362		
CON= age			0.092* (0.001-0.008)	2.291				
MED=Capacity & skills					0.094* (0.046-0.447)	2.414		
MED= Self-efficacy					Redundant for the model			
Total mediating effect	0.143 x 0,193= 0.028							
Sobel test	z= 2.929							

IV= Independent variable, CON= confounding variable, MED= mediating variable, DV= dependent veriable

*p<0.05; **p<0.01; ***p<0.001

4. Discussion

4.1. Main results

Our study found that a large proportion of responding citizens had experienced serious illness, caregiving, or loss in the past year (72.1%) with the most reported experience being someone they knew well who died (57.1% of citizens). We found that citizens who had been a caregiver for a seriously ill family member in the past year were more likely to participate in their neighbourhood around the topics of serious illness, death or loss (ß= 0.161; CI=0.378-1.276). The association between having been a caregiver for a seriously ill family member in the past year and neighbourhood participation regarding serious illness, death or loss strengthened slightly (ß =0.193; CI=0.588-1.393) when adding believed capacity and skills regarding serious illness, death or loss developed from previous experiences to the analysis.

4.2. Strengths and limitations

This study is the first to investigate the association between previous experiences with serious illness, caregiving, death, or loss in the last year, people's self-perceived capacity, skills, and self-efficacy to deal with these topics developed from previous experiences, and neighbourhood participation around serious illness, death or loss. The large random sample provides some generalizability of the findings, and non-response bias is taken into account by weighting the data for age and gender. However, the sample was limited to two purposefully selected neighbourhoods which possibly limits external validity, and thereby generalizability to other peri-urban regions in Flanders and beyond. Also, our cross-sectional design poses important limitations to the causal relationships we are interested in. Longitudinal studies would provide better control over issues of temporality and residual confounding. Lastly, because the study was innovative in its focus on serious illness, death, or loss in neighbourhoods and communities, we could not rely on validated instruments. We reviewed and used many candidate instruments, but these instruments required adaptations for the specific context and focus of our study.

4.3. Interpretations

Our study found that citizens who had been a caregiver for a seriously ill family member in the past year were more likely to participate in neighbourhood activities regarding serious illness, death or loss such as helping close neighbours or volunteering for people in the neighbourhood. We did not find this association for any of the other experiences such as being seriously ill, having lost someone close, or having a family member who was seriously ill in the last year. This can possibly be explained by the active, hands-on care intrinsic to caregiving, which sets it apart from other experiences with serious illness, death, or loss that lack such direct caring experience. Caregiving makes people realise the importance of feeling support and often might motivate them to continue with caregiving tasks for others who need it in their neighbourhood. This has been referred to in the literature as empathetic understanding.[30] Another explanation could be that caregiver burden may be an instigator for social bonding, as care for a family member with a serious illness may lead to a person seeking out support from neighbourhood contacts that are in similar types of situations.[31, 32] Additionally, caring for others might also be about having meaning and being of meaning to someone else.[33] We suspect that the convergence of these three aspects is most prominently among former caregivers compared to current caregivers. Former caregivers may be a particularly interesting group to identify in initiatives to stimulate neighbourhood participation regarding serious illness, death, or loss. Existing literature supports the notion that engaging former caregivers in other caregiving activities related to serious illness, death or loss can help in processing their grief, rebuilding an identity after caregiving, and seeking a new purpose in life after caregiving.[34] It may thus be worthwhile to identify and reach out to both current and former caregivers and find out in what sense neighbourhood participation regarding serious illness, death or loss could be of added value to them. Future research should further examine the mechanisms behind the found association, especially qualitative research could help explore if our assumptions are right.

Furthermore, we found that the likelihood of participating in neighbourhood activities regarding serious illness, caregiving, death or loss of citizens who had been a caregiver for a seriously ill family member in the past year increased if they believed they developed capacity and skills from their previous experiences with these topics. This finding coincides with a tendency towards leveraging learning from previous experiences with serious illness, death or loss as a means to bolster citizens' death literacy.[14] This death literacy is defined as "*a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options*"[12], and provides people with a well-rounded understanding of palliative care and the social context in which it can be provided. Existing literature found that caregivers, since they have first-hand caring experiences, are inclined to share their knowledge and insights within their social network, thereby contributing to the development of death literacy in that network.[14] Based on our findings we suggest that encouraging caregivers to extend knowledge-sharing beyond the personal network and into the community and neighbourhood may foster collective death literacy building and strengthen social action regarding serious illness, death, or loss. However, we also have to note that the mediating effect of capacity and skills developed from their previous experiences with these topics was relatively small. This aligns with our initial expectations, recognising that complex social change processes—such as fostering participation in neighbourhood activities related to these sensitive topics—can only be explained by a myriad of factors, all intricately interwoven within a complex mechanism of change. Consequently, we hypothesise that besides capacity and skills, there may be other aspects of death literacy (e.g. knowledge of community resources, knowledge to provide hands-on support) that co-predict the association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss. Future longitudinal research is needed to further test the hypothesis of increasing the likelihood of neighbourhood participation regarding serious illness, death or loss through developing death literacy, and potentially looking at other mediators for neighbourhood participation regarding serious illness, death, or loss.

5. Conclusions

Our findings suggest that citizens who had a caregiving experience in the last year are more likely to participate in neighbourhood activities regarding serious illness, death or loss, and to an even greater extent if they believe they developed capacity and skills as a result of previous experiences with these topics. We recommend that researchers look into other aspects of death literacy, besides believed capacity and skills, which might be better mediating predictors for neighbourhood participation regarding serious illness, death or loss. Furthermore, we suggest future research should explore the mechanisms behind the associations we measured, with qualitative research seeming a particularly relevant approach. Lastly, we recommend policies and practices to facilitate the social capital of current and former caregivers by for instance organising social activities and support networks in their neighbourhood, that strengthen people's knowledge and understanding of serious illness and end-of-life matters.

6. Data availability

The data set and data syntax can be provided by contacting the corresponding author.

7. Conflicts of interest

The authors declare there are no conflicts of interest.

8. Funding statement

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PART IV

TO EVALUATE THE DEVELOPMENT PROCESS OF THE TWO NEIGHBOURHOOD CIVIC ENGAGEMENT INITIATIVES

Chapter V

CIVIC ENGAGEMENT IN NEIGHBOURHOODS REGARDING SERIOUS ILLNESS, DEATH AND LOSS (CEIN): A STUDY PROTOCOL FOR A CONVERGENT-PARALLEL MIXED-METHODS PROCESS AND OUTCOME EVALUATION THAT BALANCES CONTROL AND FLEXIBILITY

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Abstract

Background: New public health approaches in palliative care attribute an active role to civic society in providing care for those who are seriously ill, caring or bereaved. Accordingly, civic engagement initiatives regarding serious illness, dying and loss (CEIN) are emerging worldwide. However, study protocols that advise on how to evaluate the impact and complex social change processes underlying these civic engagement initiatives are lacking.

Objectives: To describe the study protocol for the evaluation of civic engagement initiatives in serious illness, dying and loss in two neighbourhoods in Flanders, Belgium.

Design: A convergent-parallel mixed-method process and outcome evaluation for the CEIN study.

Methods & analysis: We look at the evaluation of CEIN through a critical realist lens, thereby including the social, political and economic determinants of social change in CEIN, the mechanisms to achieve this social change, the outcomes, and the mutual connection between these three aspects. We will conduct a convergent-parallel mixed-method process and outcome evaluation in which qualitative (i.e. observations, interviews, group discussions, ego network mapping) and quantitative data (i.e. a pre-post survey) are simultaneously but separately collected and analysed, and in the last stage combined by narrative synthesis.

Discussion: This protocol illustrates the difficulty of operationalising the desired long-term impact of social changes regarding serious illness, dying and loss into more manageable outcomes. We recommend a well-cogitated logic model that connects the outcomes of the study to its potential actions. Applying this protocol in practice is a constant exercise between providing sufficient flexibility to meet feasibility, desirability and context-specific needs in the CEIN study, and providing sufficient guidelines to structure and control the evaluation process.

Keywords

Study protocol, civic engagement, community development, Compassionate Communities, new public health, evaluation, mixed-methods research

1. Background

Following a new public health approach in palliative care, citizens have attributed to caring for their fellow human beings in times of serious illness, dying and loss.[1] Communities that embody such societal actions are typically called Compassionate Communities and are defined 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* (p.1)*".*[2] Compassionate Communities, especially on the level of the neighbourhood, are initiated from an asset-based community development approach, that draws on the existing neighbourhood networks and initiatives. This Civic Engagement In Neighbourhoods regarding serious illness, dying and loss (CEIN) study uses the existing societal capital (e.g. volunteer organisations, neighbourhood committees, clubs, organisations and (digital) platforms in the neighbourhoods) to achieve social change and is initiated in the context of Compassionate Cities in which local governments, cultural and care organisations, schools, workplaces and places of worship work together in developing capacity regarding serious illness, dying and loss.[3, 4] The societal actions in CEIN are interpreted as actions of civic engagement, which we define as all collective action undertaken to help improve connections between, or conditions for people in the community around serious illness, death and loss, including all forms of collective formal or informal volunteering.[5-7] Based on this definition, we conducted a systematic review of CEIN initiatives worldwide.[8]

We found nineteen CEIN initiatives, their activities ranging from social, emotional and practical support, to navigation for ill people to community resources.[8] Many of these initiatives showed promising results such as an increased understanding and knowledge of death, loss and of palliative care in the community[9] and increased empowerment of volunteers to provide end-of-life care for older persons in their communities[10]. However, the quality of the evaluation and the strength of evidence varied greatly between the studies as they applied different evaluation aims, designs, data collection methods and outcomes.[8] Additionally, most of the evaluation studies were limited, as they focused either on a process or an outcome evaluation and mostly focused on one particular aspect of the initiative (e.g. training for volunteers). This review showed the potential for CEIN initiatives to achieve social change around illness, death and loss[11], but it also illustrated that Compassionate Communities are complex adaptive processes that are difficult to study with classical methods aimed at linearity and predictability.[8] With the number of Compassionate Communities emerging worldwide, so is the question of how to measure its process of development and its impact adequately.

In this paper, we describe the study protocol for the evaluation of civic engagement initiatives in serious illness, dying and loss in two neighbourhoods in Flanders (Belgium), following the SPIRIT 2013 reporting guidelines.[12] Since this CEIN study transcends a predictable health science model with predefined aims and outcomes, a research protocol is all the more important for avoiding different types of study design and conduct bias (e.g. describing what seems interesting without a predefined model).[13, 14] Consequently, this protocol presents a methodology for a convergent mixed-method process and outcome evaluation that aims to measure how the CEIN initiatives are developed by citizens and other key figures in the neighbourhood, and what the impact of these initiatives is. Furthermore, we reflect on how to apply this methodology in complex, adaptive processes of community development.

2. Methods

2.1. Setting

The study takes place in two neighbourhoods in two semi-urbanised areas in Flanders, Belgium.[15] The first neighbourhood is situated in Sint-Kruis with a total number of 16.225 inhabitants and the second neighbourhood is in Herzele with 18.477 inhabitants. Together with municipality representatives in Herzele and Sint-Kruis, we demarcated the neighbourhoods as the geographical area that is most centrally located and is most likely to entail neighbourhood participation around serious illness, death and loss. In Sint-Kruis this neighbourhood (4.222 inhabitants) coincided with the two geographical areas Sint-Kruis Centrum and Sint-Kruis Kruispoort. In Herzele the neighbourhood (3.210 inhabitants) was chosen in a radius of 1,5 km around this local service centre.

2.2. Design

2.2.1. A critical realist paradigm

Since civic engagement initiatives regarding serious illness, dying and loss go beyond clinical and medical approaches to increase societal capacity in these topics, there is an increasing awareness that their evaluation would surpass a mere health science approach with predefined outcomes; and that their evaluation would acknowledge the complex mechanisms that underlie social change.[16, 17] A critical realist philosophy recognises that in complex change processes, there is both an objective context in which the change takes place and a subjective context that entails people's interpretations, perceptions, language and relationships.[18] Consequently, critical realism recognises that we should not only observe and measure visible change but also the 'causal powers' or the mechanisms that are at play.[18] By looking at the evaluation of CEIN through a critical realist lens, we recognise that the desired social changes around serious illness, death and loss cannot be isolated from the political, social and cultural context in which they occur. Consequently, by identifying the mechanisms of social change in CEIN we look at the broader societal context, as well as the developed actions and initiatives, their desired impact, and the interrelation between these three aspects. Given the theory-driven character of critical realism, we started the CEIN study by conducting a systematic review of civic engagement initiatives around serious illness, death and loss worldwide, to provide us with first assumptions on how social change might occur in CEIN. These assumptions were captured in a logic model which must be considered a dynamic instrument that will be adapted throughout the study.

2.2.2. A logic model

We developed a logic model visualising the mutual connection between the inputs of CEIN, the CEIN initiatives and actions that are developed and their potential outcomes and impact (fig. 1). Although we drew up this initial logic model, it is a dynamic instrument that will be adjusted in the course of the study.

Input

The inputs for developing CEIN initiatives are threefold and entail initiating the study in the context of a Compassionate City, having a Compassionate Community facilitator who enables the process of development and having a neighbourhood worker that enhances connections between the different key figures.

- **A Compassionate City context:** Both neighbourhoods in which the CEIN initiatives are developed, are situated in Compassionate Cities. As a result, CEIN is embedded in a supportive local policy that stimulates participation in actions of civic engagement in different city domains (e.g. schools, workplaces, public spaces and neighbourhoods).

- **A Compassionate Community facilitator:** All CEIN initiatives and actions are developed in collaboration with a community facilitator that enables the process of co-creating CEIN with the different social partners and key figures (e.g. neighbourhood committees, mailmen, volunteers) in the neighbourhood. The community facilitator will consider the different aspirations of these interested parties and will guard whether the CEIN actions that are being developed are in line with the desired social change regarding serious illness, dying and loss.
- **A neighbourhood worker:** In both neighbourhoods, there is the need for someone who initiates and strengthens social networks, and makes the connection between the different key figures. The neighbourhood worker is a very visible and approachable person for people.
- **Stakeholders:** The stakeholders in the neighbourhood are all the social partners and key figures (e.g. volunteers, people from neighbourhood committees, and local merchants) who are motivated to develop CEIN and to engage in the topics of serious illness, death and loss.

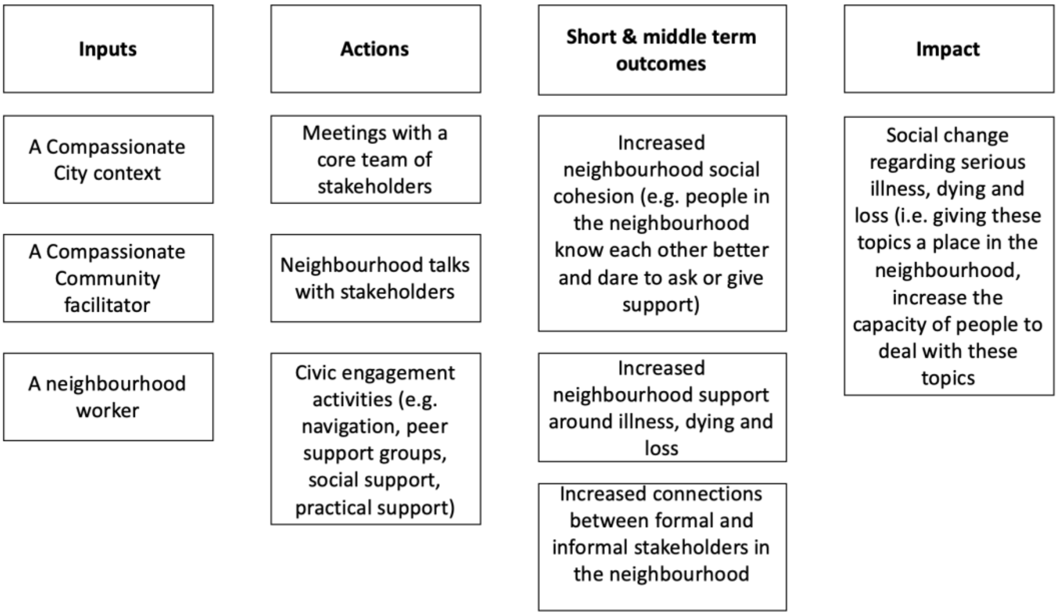
Actions

- ***Meetings with a Compassionate City core team of stakeholders***: The CEIN study will be initiated with the formation of a compassionate city core team of social partners who already work around serious illness, death or loss in the larger city context. Together they address the main direction of the Compassionate City and they brainstorm about the assets from which the CEIN initiatives can be developed.
- **Neighbourhood talks with different stakeholders:** Given the asset-based community development approach of the CEIN study, the initiatives and actions will not be determined by the researcher in advance, but are decided upon by the social partners and key figures in the neighbourhood. Through conversations with the researcher and community facilitator, the social partners and key figures will be made aware of the study and will be enabled in forming networks around serious illness, dying and loss in their neighbourhood.
- **Civic engagement actions:** The CEIN actions can take different forms ranging from neighbourhood networks providing social, practical, medical or spiritual support, to peer support groups, and offering navigation for people with care needs to the appropriate organisations or other community resources. The Compassionate Community Facilitator is responsible for ensuring that all the developed actions are in line with the desired outcomes and impact of the CEIN study.

Outcomes

The desired impact of CEIN, broadly speaking, is a social change regarding serious illness, death and loss in the two neighbourhoods. Based on neighbourhood talks with stakeholders and city representatives in the two chosen neighbourhoods, we translated this long-term impact to middle and short-term outcomes (i.e. increased neighbourhood social cohesion, increased neighbourhood support regarding serious illness, dying and loss, and increased connections between formal and informal stakeholders (i.e. social partners and key figures) in the neighbourhoods).

Figure 1. Logic model for the CEIN study



2.2.3. Participatory action research

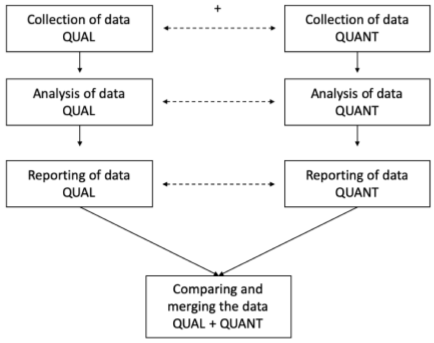
Observational studies have a long tradition of being linked to community research, as it is considered an objective means to capture the complex political and social context of development, as well as the internal group dynamics.[19] However, in the CEIN study, the researcher is not an outsider to the development process, as is the case in purely observational studies, but is a contributor to the development by facilitating the neighbourhood networks and guarding the long-term impact of social change regarding serious illness, dying and loss. Although CEIN is thereby participatory action research, the general public remains the main stakeholder in creating initiatives for issues concerning serious illness, dying and loss in their neighbourhood.

2.2.4. Convergent – parallel mixed-method process and outcome evaluation

Our CEIN study will be evaluated by conducting a convergent-parallel mixed-method process and outcome evaluation in which we will simultaneously collect qualitative (i.e. observation, interviews and focus groups, document analysis) and quantitative data (i.e. pre-post survey, Most Significant Change Technique, ego network mapping).[20] The qualitative and quantitative results will be analysed and reported separately and will then be synthesised into overarching interpretations and insights about the change process in CEIN (figure 2).[20, 21] Data will be synthesised by using a joint display that allows to compare and merge the data based on identified descriptive themes (see also 3.3. Synthesising the data).[22] Our mixed-method research design provides the opportunity to look beyond typical quantitative methods for measuring impact (e.g. a pre-post survey)[23], and allows us to measure impact using qualitative data collection methods as well, e.g. the Most Significant Change technique.[24]

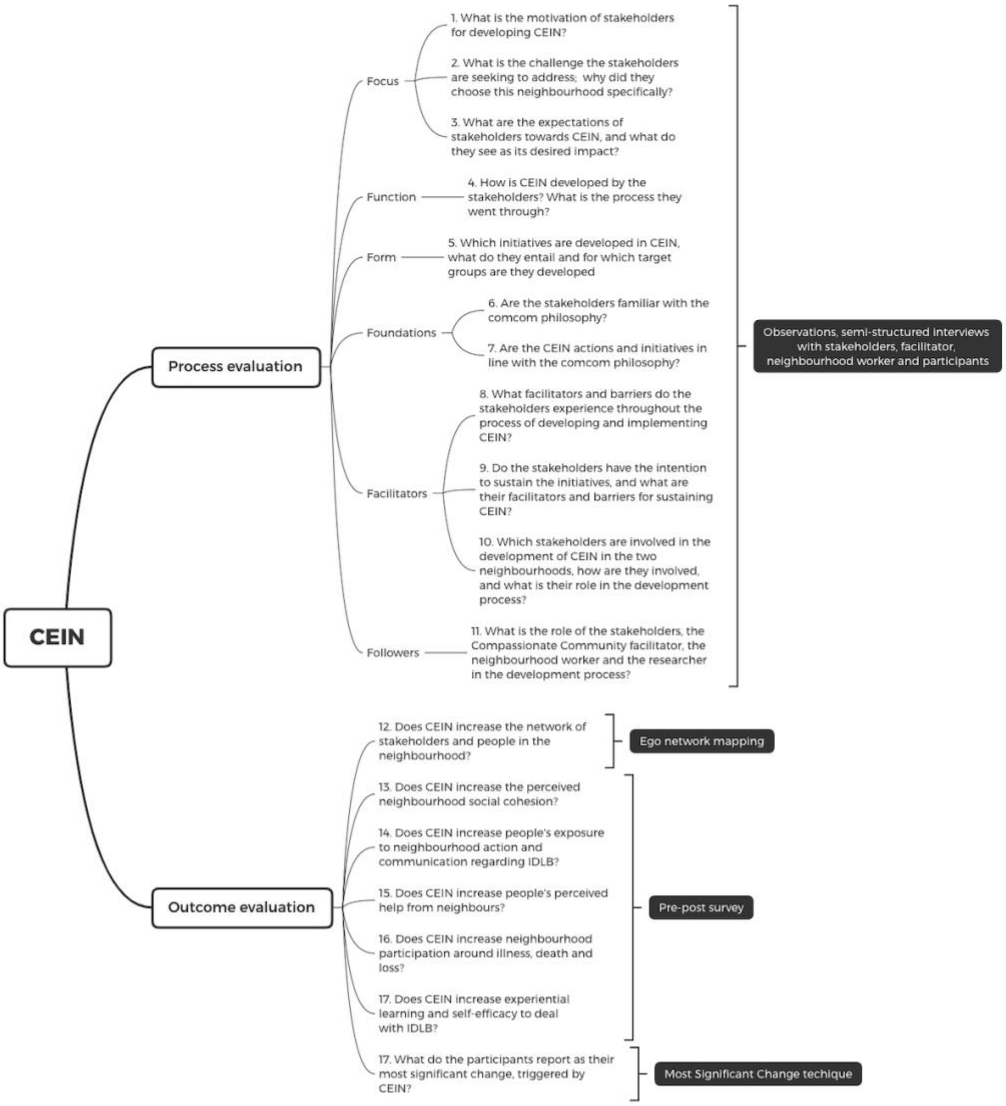
The process evaluation is structured following the 6 F-model, a framework for analysing social innovation actions and initiatives.[25] This framework includes Foundations (the context of CEIN and the compassionate community philosophy behind CEIN), Focus (the challenge CEIN is seeking to address and the desired impact of CEIN), Function (the CEIN actions that are being developed), Form (the development process of CEIN), Facilitators (the enablers or barriers that influenced the development of CEIN), Followers (all interested parties involved in CEIN). The outcome evaluation is based on the outcomes that are formulated in the logic model. An overview of the research questions and data collection methods can be found in **Figure 3**.

Figure 2. Convergent-parallel mixed-methods approach of CEIN



Modified from Cresswell JW (2003)

Figure 3. Overview of research questions and data collection methods



1. What is the motivation of stakeholders for developing CEIN?
2. What is the challenge the stakeholders are seeking to address; why did they choose this neighbourhood specifically?
3. What are the expectations of stakeholders towards CEIN, and what do they see as its desired impact?
4. How is CEIN developed by the stakeholders? What is the process they went through?
5. Which initiatives are developed in CEIN, what do they entail and for which target groups are they developed
6. Are the stakeholders familiar with the comcom philosophy?
7. Are the CEIN actions and initiatives in line with the comcom philosophy?
8. What facilitators and barriers do the stakeholders experience throughout the process of developing and implementing CEIN?
9. Do the stakeholders have the intention to sustain the initiatives, and what are their facilitators and barriers for sustaining CEIN?
10. Which stakeholders are involved in the development of CEIN in the two neighbourhoods, how are they involved, and what is their role in the development process?
11. What is the role of the stakeholders, the Compassionate Community facilitator, the neighbourhood worker and the researcher in the development process?
12. Does CEIN increase the network of stakeholders and people in the neighbourhood?
13. Does CEIN increase the perceived neighbourhood social cohesion?
14. Does CEIN increase people's exposure to neighbourhood action and communication regarding IDLB?
15. Does CEIN increase people's perceived help from neighbours?
16. Does CEIN increase neighbourhood participation around illness, death and loss?
17. Does CEIN increase experiential learning and self-efficacy to deal with IDLB?
17. What do the participants report as their most significant change, triggered by CEIN?

3. Data collection

Since the CEIN study will be co-created with stakeholders (i.e. social partners and key figures) there is a need for flexibility in the choice of data collection methods and for adaptability in using these data collection methods depending on the direction in which CEIN is developing. This means that some of the data collection methods may not be used after all because they are no longer desirable or relevant, and others may be adapted to meet context-specific needs. Keeping this in mind, we describe several possible data collection methods for the process and outcome evaluation of the CEIN initiatives. The described quantitative and qualitative data collection methods will be applied simultaneously following the convergent-parallel mixed-methods approach.[19]

3.1. Data collection methods for the process evaluation

3.1.1. Observations

Aim: Observations are conducted to gain insight into how CEIN initiatives are developed by the stakeholders (social partners, and key figures), which initiatives are being developed, and which barriers and facilitators present themselves in this development process.

Data collection procedure: The researcher (LDEE) will conduct observations during meetings with the core team and during the entire process of developing and implementing CEIN in both neighbourhoods. The observations are conducted following a predefined template that provides flexibility in measuring topics that are not explicitly vocalised by the stakeholders. The observational data will be further explored via interviews or group discussions.

Timing: The observations are conducted in all relevant meetings and actions.

3.1.2. Semi-structured interviews & group discussions

Aim: Semi-structured interviews and group discussions will be conducted to gain insight into the motivations for initiating CEIN, the expectations towards it, the desired impact and the facilitators and barriers in the development process. The interviews and group discussions will be conducted with the stakeholders, the neighbourhood worker and the Compassionate Community facilitator.

Data collection procedure: A topic guide is prepared in advance, based on the research questions in figure 2.

Timing: The interviews with the Community Community facilitator and the neighbourhood worker are conducted every three months. The frequency of the interviews or focus groups with social partners and key figures will depend on what is feasible and acceptable in a specific phase of the research.

3.1.3. Data analysis for observations, semi-structured interviews, and group discussions

Data will be transcribed and thematically analysed in NVivo, following a six-phase approach: familiarising ourselves with the data by transcribing and rereading it, generating initial codes, searching for themes, reviewing potential themes, defining the themes and naming them, and reporting the results.[26] The thematic analysis will be conducted both deductively following the Consolidated Framework for Implementation Research[27] and inductively, comprising new themes that emerge from the data.

3.2. Data collection methods for the outcome evaluation

3.2.1. Pre-post survey

Survey population: We take a random sample of approximately 1.000 inhabitants who are eighteen years or older in each neighbourhood.

Aim & timing: The survey measures seven concepts (i.e. perceived neighbourhood social cohesion, perceived help from neighbours, generic neighbourhood participation, neighbourhood participation around illness, caring, death and loss, self-efficacy around dealing with illness, caring, dying and loss, personal experiences with these topics and experiential learning). The survey will be administered at two points in time: pre-implementation, to have a baseline measurement of what people already do around serious illness, death and loss in their neighbourhood, and post-implementation to measure the impact of CEIN.

Data collection procedure: Respondents can choose to fill in a paper version of the survey and send it back via a pre-paid envelope or fill in the online survey. To guarantee confidentiality; each survey contains a unique respondent number. Distribution of the survey and reminders sent, is based on the Total Design Method.[28] The stakeholders will be asked if they want to add questions to the survey regarding their interests in CEIN.

Analysis: The data will be subjected to descriptive and inferential statistical analyses in SPSS.

3.2.2. Ego network mapping

Aim: Ego network mapping will be conducted to measure if the social support network of people in the two neighbourhoods increased as a result of CEIN.

Data collection: Via a semi-structured interview, participants will be asked about their supportive network of friends and family, but especially of people in their neighbourhood. This network will be illustrated on a map with circles, which represents the closeness of each of these supportive actors. Additionally, data will be collected to gain insight into people's current support needs, satisfaction with their current network and insight into which people have the potential of being included in their network.

Timing: Before and after the implementation of CEIN.

Analysis: The drawn networks will be compared quantitatively on the number of people and their closeness. The qualitative data will be thematically analysed.

3.2.3. Most Significant Change sessions

Aim: Most Significant Change sessions will be conducted to measure the outcomes of the study qualitatively. This method enables us to capture unexpected experiences and outcomes of the CEIN study, and the most salient ones.

Data collection: Most Significant Change stories are collected through group discussions with the stakeholders that are involved in the CEIN study. The story that is most significant is chosen by iterative voting.

Timing: The Most Significant Change session will be conducted at the end of the study.

Analysis: The significant change stories will be transcribed and thematically analysed.[26]

3.3. Synthesising the data

Applying a critical realist lens to the data synthesis, we aim to first identify mechanisms of change that are context-specific of the two CEIN neighbourhoods and then combine this data into generalised insights and interpretations.[18] We use a convergent-parallel mixed-method research design in which we will simultaneously collect qualitative and quantitative data, that we analyse and report upon separately but in the last phase narratively synthesise.[20] We will describe per neighbourhood the context and the development of the CEIN initiatives, resulting in descriptive themes which we will put into the first column of a joint display; a second column will include the qualitative findings on that specific theme, a third column will include the quantitative findings and a fourth column will describe the inferences.[22, 29] When there is a discordance between the qualitative and quantitative findings we will seek for explanations in literature.[22, 29]

4. Discussion

Worldwide, more and more neighbourhood civic engagement initiatives regarding serious illness, dying and loss are emerging. Although most of the published initiatives have been evaluated, the methodological choices are often not described or explained or they have methodological shortcomings (e.g. focusing either on processes or outcomes).[8] This paper presents the design and data collection methods of the CEIN study, a study aiming to evaluate the development and implementation of civic engagement actions in serious illness, death and loss in two neighbourhoods. It includes a methodology to capture complex social change in serious illness, death and loss via a convergent mixed-method process and outcome evaluation. The research is situated within a critical realist paradigm that includes the socio-ecologic factors of the study and uses a logic model as an instrument to guide the evaluation process. Furthermore, the protocol describes different data collection methods (e.g. observations, interviews, ego network mapping) that can be used to evaluate the CEIN initiatives.

Literature shows that in asset-based community development research, social reality is so complex that a thorough process evaluation is necessary to fully understand which mechanisms are at play.[30] Since the development of CEIN is a co-creative process with stakeholders, their collaboration in the development is naturally the first factor to be considered in the process evaluation (e.g. their intrinsic motivation, and their thoughts on developing actions). However, there is an increasing realisation that social change is not only accomplished within the co-creative process itself but that the context of development is an equally important factor.[31] The fact that the CEIN study is initiated in two Compassionate Cities, in which there is also city-wide attention for the topics of serious illness, death and loss, influences the development of CEIN initiatives. Consequently, we started this protocol from a critical realist paradigm with attention to the broader socio-ecological context of the project, e.g. the city policy, the political landscape of the city, the community capacity and readiness to engage in the study. In light of replicating the CEIN study, and Compassionate Communities in general, we believe there is great value in documenting and describing these contextual factors and sharing them internationally.

Compassionate Communities, including CEIN, generally aim to increase people’s capacity to deal with serious illness, death and loss; thereby aspiring for social change in the community.[32] However, since a social change in serious illness, death and loss, is very complex and dependent on the context, it can be operationalised in many different ways.[33, 34] A first implication is that a flexible and adaptive attitude is required from the researcher, who at the start of the study has no full knowledge of the outcomes that will be formulated by the community and the initiatives that will be developed.[35] A logic model can assist in closing the disparity between community actions and the desired social change, by displaying their interconnectedness. Additionally, the chosen data collection methods should be used flexibly to capture the dynamic aspects of social change and should be adaptable to what we want to measure in a specific phase of the research. We argue there is added value in documenting the adaptations that were made in the data collection process. This study protocol is the first step in documenting this for the CEIN study. Additionally, we consider international discussions on the operationalisation of social change essential to inspire the development of CEIN initiatives and to guide how to evaluate them.

5. Strengths and limitations

This study protocol is the first to describe a convergent mixed-method process and outcome evaluation for evaluating Compassionate Communities, to present a range of possible data collection methods and to provide a reflection on the flexibility with which they should be applied. Additionally, this protocol suggests instruments that offer guidance and control in evaluating complex and dynamic social change programs, i.e. a critical realist paradigm that connects the context of the study to its impact and mechanisms of impact, and a logic model that reinforces this evaluation paradigm by visually demonstrating the interconnectedness of the community actions and their impact. Challenges of evaluating neighbourhood civic engagement initiatives regarding serious illness, death and loss are the flexibility needed to adapt the data collection methods to the specific context of the study, and the flexibility of the researcher in applying these dynamic data collection methods.

6. Conclusion

This study protocol describes a process and outcome evaluation that can serve as inspiration for others who aspire to evaluate similar initiatives. We emphasise the importance of a process to fully understand the contextual factors of the study, the mechanisms that lead to impact and to stimulate a successful replication of Compassionate Communities in different contexts. Furthermore, this protocol shows the difficulty of operationalising the desired long-term impact of social changes regarding serious illness, death and loss into more manageable outcomes, and subsequently into more specific community actions. We recommend a well-cogitated logic model that connects the short-, middle-, and long-term outcomes of the study to the potential actions that are being developed. Additionally, we highlight the need for a flexible attitude of the researcher in adapting data collection to what is feasible or acceptable in a particular context. International discussions on how to operationalise and capture social changes in serious illness, dying and loss are needed to inspire civic engagement initiatives around serious illness, death and loss and their evaluation. Applying such a study protocol in practice is a constant exercise between providing sufficient flexibility to adapt it to a specific context and providing sufficient guidelines to structure and control the evaluation.

7. Declarations

7.1. Ethics approval and consent to participate

7.1.1. Ethics approval

Ethics approval was obtained on the 2nd of September 2020 by the Committee on Medical Ethics of the Vrije Universiteit Brussel, Belgium: case number B1432020000185, reference number 2020/279.

7.1.2. Consent for participation

The participants will be asked to sign an informed consent form in advance which states that the interview or discussion will be audio recorded and anonymously transcribed and reported. Data will be used for research purposes only and will be kept on a secured SharePoint to which only the researcher has access. Participants are informed that they can stop the interview or group discussion at any time. Additionally, we obtained permission from the city to observe all meetings held regarding the CEIN study.

7.2. Consent for publication

We will never publish individual information from which it is possible to identify a person.

7.3. Author contributions

All authors contributed to the conceptualization, the methodology, the writing and the review and editing (See CRediT).

7.4. Acknowledgements

We thank the cities of Bruges and Herzele for their participation in this study.

7.5. Funding

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7.6. Competing interests

The author(s) declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

7.7. Availability of data and materials

The data of all participants, including the informed consent forms, will be stored on a secured VUB storage server (SHARE) at the Vrije Universiteit Brussel (VUB), which is only accessible to members of the research team. Following the Guidelines for Good Clinical Practice[36], the electronic (raw) data (without confidential, privacy sensitive or information that could lead to individual people) will be stored for 15 years. Other documentation such as published papers, relevant e-mail correspondence, etc. is handed over to the project leader (J.C.). Audio files will be deleted as soon as they have been transcribed.

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Chapter VI

PROCESS EVALUATION OF CIVIC ENGAGEMENT INITIATIVES AROUND SERIOUS ILLNESS, CAREGIVING, DYING AND LOSS: A MULTIMETHOD STUDY IN TWO NEIGHBOURHOODS

D'Eer L, Chambaere K, Van den Block L, Dury S, Sallnow L, Deliens L, Quintiens, B. Smets T*, Cohen J*. Process evaluation of civic engagement initiatives around serious illness, caregiving, dying and loss: a multimethod study in two neighbourhoods. [Ready to submit]

* Shared last author

1. Introduction

In recent years, there has been a shift in thinking concerning how to approach care for people who are seriously ill, caregiving or bereaved, with a growing recognition of the importance of public health initiatives that move beyond the role of healthcare services.[1] One manifestation of this shift is the concept of so-called Compassionate Communities; community-based initiatives aimed at supporting individuals confronted with serious illness, caregiving or bereavement through various forms of health promotion, community development, and civic engagement.[2-4] The term civic engagement has been used to refer to all collective action undertaken to help improve connections between, or conditions for, people in communities. [5-7] It can be interpreted as an umbrella term for all formal (e.g. volunteers) and informal engagement (e.g. helping neighbours) in civic society. Civic engagement initiatives regarding serious illness, death and loss can be developed in various settings where serious illness, caregiving and bereavement are a part of daily life, including schools, workplaces, cultural organisations and neighbourhoods.[1, 4] The latter is considered an appropriate context for community capacity-building due to its ability to foster connections among individuals through geographic proximity.[8]

A systematic review of civic engagement initiatives regarding serious illness, death and loss identified nineteen distinct initiatives worldwide.[9] These initiatives generally aimed to improve connections within communities and their resources to support each other when confronted with serious illness, death and loss. Some initiatives specifically targeted the neighbourhood level, such as the Neighbourhood Network in Palliative Care in Kerala, India [10], and the Good Neighbour Partnership [11] in Ireland. Although almost all the identified studies included evaluations, the evaluations typically focused on specific aspects such as feasibility, acceptance, or reach, rather than providing a comprehensive analysis of the developmental process.[9] Additionally, although most of the initiatives were initiated through community-academic partnerships, the development process and the dynamics of this partnership were understudied.[9]

As Bakelants et al.[12] formulated, the development of Compassionate Communities involves complex co-creative processes, that are best documented and understood by conducting a process evaluation. Process evaluations, particularly when using qualitative methods, can capture not only the experiences with and perceptions related to the development process, but also the contextual mechanisms underlying it, enhancing our understanding of both the development process and the broader social processes driving it.[12, 13] Consequently, these insights can inform other Compassionate Communities development processes and implementation strategies, serving as valuable resources for good practices of development.[12] The Consolidated Framework for Implementation Research (CFIR) [14], is identified by Bakelants et al.[12] as one of the most suitable theoretical frameworks for evaluating Compassionate Communities and can serve as a deductive guideline for analysing the process data.

Given the potential of process evaluations to gain insight into development strategies, this study aimed to provide insight into the aspects and contextual factors that facilitated or hindered the development process of neighbourhood civic engagement initiatives in two distinct Compassionate Cities in Belgium.

2. Methods

2.1. Study design

We conducted a multimethod process evaluation [15], collected over a development period of nearly four years from December 2019 to September 2023. The researcher and first author LDEE conducted semi-structured observations, document analysis, semi-structured interviews and group discussions with all relevant parties in the development process of the neighbourhood civic engagement initiatives [LDEE] and the Compassionate City Programme [BQ]. Given that Compassionate Communities are complex adaptive systems, traditional methods aimed at predictability and linearity are inadequate to evaluate them.[12] Therefore, our data collection methods needed to be adjusted accordingly, allowing sufficient flexibility in their gathering, and capturing both observable and non-observable determinants of change. [12] The study design and methods were written down in a detailed study protocol.[16] Researchers were involved in the development process via action research, using the development of knowledge to inform decision-making and strengthen the initiatives.[17] Relevant parties in the neighbourhoods were co-creatively engaged in the development of the civic engagement initiatives but did not actively participate in the data collection.

2.2. Setting

The civic engagement initiatives were developed in two distinct neighbourhoods. The first neighbourhood was located in Sint-Kruis, a sub-municipality of the city of Bruges, an urbanised city comprising approximately 120.000 inhabitants.[18] Sint-Kruis was chosen due to its socio-demographic challenges, e.g. a growing proportion of older adults living alone.[18] The second neighbourhood was located in Herzele, a peri-urbanised city comprising approximately 19.000 inhabitants.[19] As Belgium lacks predefined neighbourhood boundaries, collaborative efforts with city representatives led to the delineation of areas within a 1,5 km radius around the local city centres for the development of civic engagement activities regarding serious illness, death and loss. Both identified neighbourhoods in Sint-Kruis and Herzele are estimated to have around 10.000 inhabitants each.

Upon receiving funding from the Research Foundation – Flanders (FWO), academics from the research group approached various candidate partner cities for a compassionate city program and eventually selected Bruges and Herzele based on criteria outlined in the Compassionate City research protocol.[16] The decision to develop Compassionate City Programmes led to the establishment of a city-level steering group, comprising local aldermen, city officials, and relevant interested parties working around the topics of serious illness, death, and loss in their city. The neighbourhood civic engagement initiatives were planned to be developed within these two cities, Bruges and Herzele, henceforth called 'City B' and 'City H', and their respective neighbourhoods: 'Neighbourhood S' and 'Neighbourhood H'.

2.3. Participants

The participants in this study were representatives of civic society organisations in the neighbourhood (n=10), other neighbourhood key figures (n=30) and neighbourhood residents (n=43). Together we refer to them as the 'relevant parties'. Neighbourhood key figures were individuals in the neighbourhood that were identified through stakeholder mapping and were given their central role in the neighbourhood either by profession (e.g. civic society organisations, local merchants, neighbourhood policy) or by their informal activities (e.g. volunteers and neighbourhood committees) interested to be part of the development process of the neighbourhood civic engagement initiatives. Neighbourhood residents participated either in group discussions or in the developed neighbourhood civic engagement activities regarding serious illness, death or loss.

2.4. The development approach

The development of civic engagement initiatives regarding serious illness, death and loss was guided by an Asset-Based Community Development (ABCD) approach[20, 21], beginning with a stakeholder mapping exercise to identify existing assets and key individuals involved in neighbourhood activities related to serious illness, caregiving, death, or bereavement. Subsequently, a co-creative approach was adopted to involve all relevant parties in the initiative's development, based on Appreciative Inquiry, in which we consciously chose to avoid fixating on shortcomings and challenges, and instead looked at opportunities and assets [22]. Given the emphasis on collaborative development, there was little preconceived notion of how neighbourhood civic engagement initiatives should take shape or what their specific activities and outcomes should entail. This imbued the development process with a considerable degree of unpredictability, where decisions taken varied depending on the context in which the development process took place. Both cities appointed a civil servant to serve as project leader to coordinate and facilitate the development process with all the relevant parties, while the Vrije Universiteit Brussel (VUB) provided two researchers [LDEE] and [BQ] to monitor and evaluate respectively the neighbourhood civic engagement initiatives and the Compassionate City programmes. Additionally, a change manager was appointed by VUB to ensure alignment between the university's goals and the city representatives' interests. Further details on these project coordinators can be found in Table 1.

Table 1: Overview and description of the project coordinators

Project leaders	In both cities, a dedicated project leader was tasked with orchestrating the planning, development, and execution of both the Compassionate Cities and neighbourhood civic engagement initiatives, working collaboratively with all relevant parties. In one city, the project leader served also as a local policy officer, while in the other city, the project leader worked as a project manager around the topics of health and wellbeing.
City representatives	In both cities, the project leaders were guided and supervised by city representatives. These included city aldermen and in one city also the managers of the local service centre. In Belgium, a local service centre is a community-based facility that aims to improve the quality of life of residents across various domains such as loneliness, healthcare, caregiving and leisure activity.[23]
Change manager	VUB designated a change manager to supervise the development of the Compassionate Cities and the neighbourhood civic engagement initiatives, in close collaboration with the project leaders and managers. She ensured that the cities' interests were aligned with the research objectives of the project.
Researchers	Researchers LDEE and BQ were both assigned by VUB and tasked with monitoring and evaluating the development processes of the civic engagement initiatives in the two neighbourhoods [LDEE], and of the Compassionate Cities [BQ].

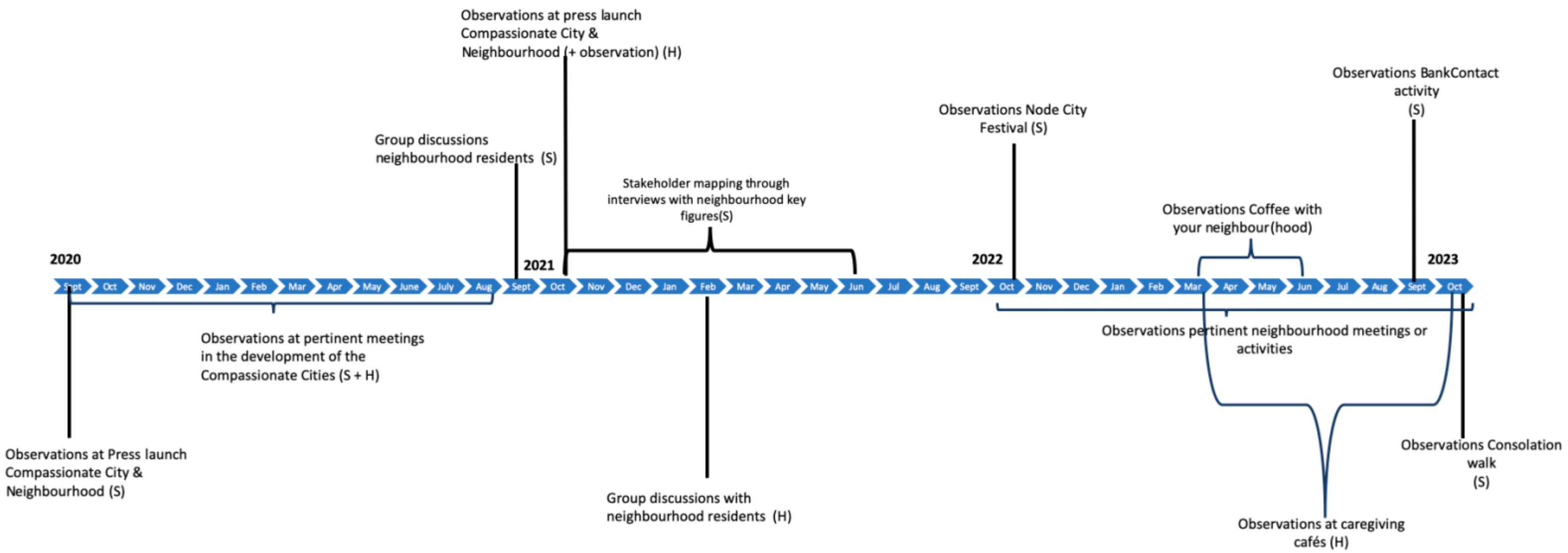
2.4. Data collection

The data collection conducted by the researcher [LDEE] started in December 2019 and ended in September 2023. Several data collection methods were used: a) semi-structured observations, b) document analysis and c) semi-structured interviews and group discussions. Through this diligent data collection, we aimed to cultivate a thorough understanding of the development of the neighbourhood civic engagement initiatives, identifying both facilitators and barriers.

a. Semi-structured observations (n=119 meetings) were conducted during all pertinent meetings with neighbourhood parties and project coordinators as well as during the developed activities in the two neighbourhoods. Using a custom-designed fieldnotes template, observations encompassed the time and date, participants, the purpose of the meeting or activity, observed interactions and achievement of meeting objectives, while also allowing flexibility to capture spontaneous occurrences.
b. Document analysis (n=36) involved examining all written materials generated within the Compassionate Cities and neighbourhood civic engagement initiatives, comprising posters, flyers, the Compassionate City mission statements and minutes of meetings.
a. Semi-structured interviews (n=36) and group discussions (n=8) were conducted utilising various formats, including group discussions with neighbourhood residents, stakeholder mapping exercises, semi-structured interviews with key figures in the neighbourhoods and follow-up interviews with project coordinators. Topic guides were prepared in advance but allowed flexibility based on the development phase. Different subgroups had tailored interview schedules: city representatives were interviewed annually, project leaders and the change manager every six months, and all relevant parties at key development moments.

A timeline of the data collection and activities at which the data collection took place can be found in Figure 1.

Figure 1: Timeline of data collection in Neighbourhood S and Neighbourhood H



2.6. Ethics

Before starting the study, written informed consent was obtained from all participants and project coordinators, assuring them that interviews would be audio-recorded for transcription purposes only, with the option to stop at any time. Confidentiality was secured through data storage on a protected Cloud and by anonymised reporting of the results. The researcher personally facilitated the consent process, addressing any participant questions. The study received approval from the Ethics Commission of the University Hospital Brussels on September 2nd, 2020 [reference numberB1432020000185].

2.7. Data analysis

We chose Thematic Analysis for its ability to create a rich narrative that captures diverse participant experiences and perspectives.[24]The analysis process started with LDEE familiarizing herself with the data – having conducted all of the semi-structured observations, semi-structured interviews and group discussions- and transcribing around 75% of the material. Codes were generated by interpreting data in light of aspects and contextual factors that facilitated or hindered the development process, using a combination of deductive and inductive coding. Inductive coding is particularly valuable for creating new knowledge in emerging areas like Compassionate Communities [24]. CFIR, served as a deductive guide, structuring the codes to cover all relevant development areas: intervention characteristics, outer setting, inner setting, characteristics of individuals, and the implementation process.[14] Adjustments were made to the codes as new insights were developed. LDEE identified recurring patterns within and across codes grouping them into themes based on the CFIR framework and inductively construed sub-themes. A two-stage review process was conducted with TS, first resolving inconsistencies by checking the themes in relation to the coded data and then to the entire data set.[25] This resulted in some data that had not been coded and had been categorised in the code 'miscellaneous', being coded under the constructed themes.

3. Results

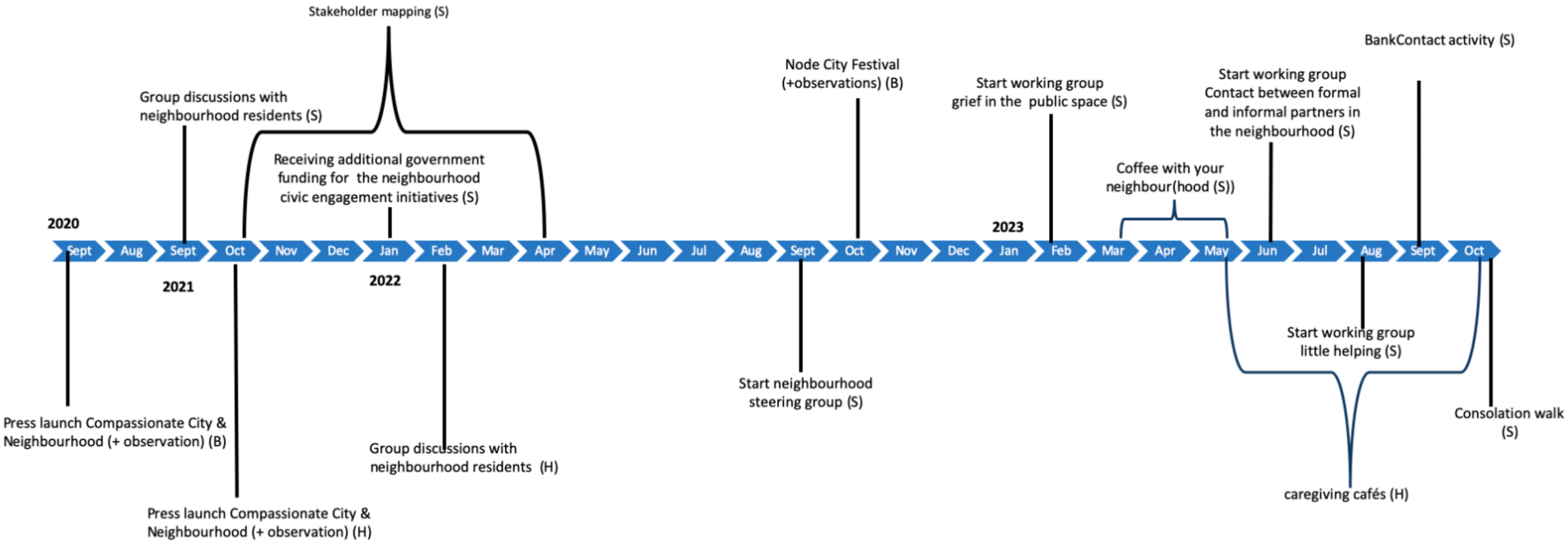
3.1. A short description of the development process

City B and City H launched their Compassionate City Programmes with distinct approaches: City B adopted a city-wide strategy, while City H focused on Compassionate Schools. Despite plans to synchronise the two studies, both cities initially prioritised their Compassionate City programmes before starting with the development of neighbourhood initiatives.

Neighbourhood S in city B, started in September 2021 with a 'Soup with Chats' group discussion, identifying three priority themes: 'grief in the public space', 'little helping' and 'increasing contact between formal and informal actors around serious illness, death and loss in the neighbourhood'. This was followed by a stakeholder mapping exercise (October-April 2021) conducted by LDEE to identify and involve relevant parties and assets in the neighbourhood development process. A neighbourhood steering group was formed comprising civic society representatives, working on the three topics that were identified during the Soup with Chats. Activities that were developed by these working groups included 'coffee with your neighbour(hood)' (March-June 2023) and a consolation walk (October 2023), aiming to raise awareness and strengthen neighbourhood social cohesion around serious illness, death and loss.

In neighbourhood H, the development of neighbourhood civic engagement initiatives was tied to an existing support group for caregivers, known as the caregiving cafés. Together with these caregivers, a co-creative process was initiated to determine the focus and content of the meetings. This co-creative process with the caregivers started in March 2023. The resulting activities aimed to provide caregivers with essential information, promote mutual support and reduce barriers to accessing professional help when needed. A timeline of the development process can be found in Figure 2, and an overview of the developed activities and their descriptions can be found in Table 2.

Figure 2: Timeline of the development process



S= Neighbourhood S

H= Neighbourhood H

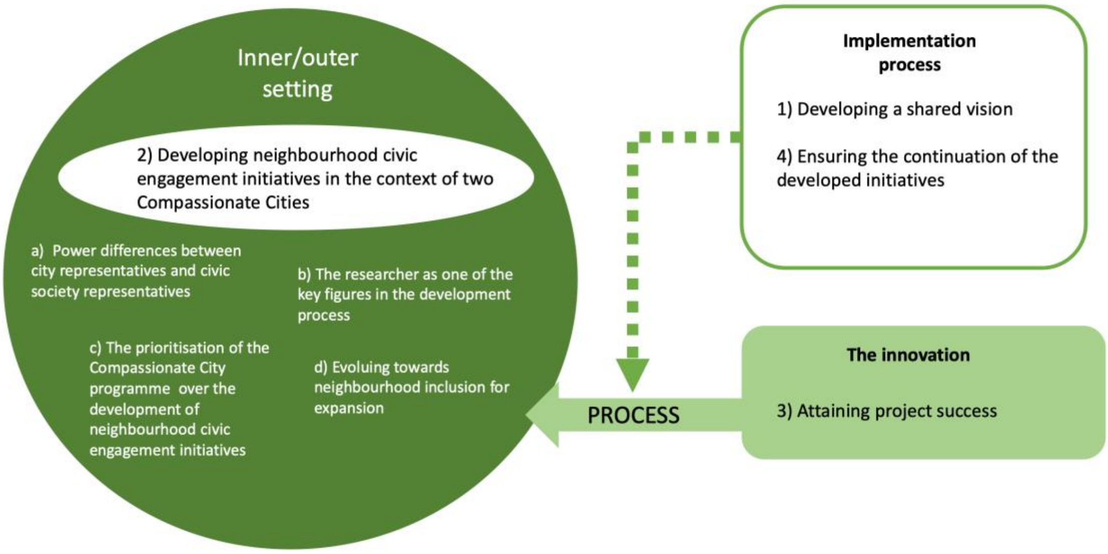
Table 2: Overview and description of the developed activities/initiatives

Name of the activity	Neighbourhood	Participants	Initiator(s)	Aim of the activity	Time	Description of the activity
Soup with Chats	Neighbourhoods S & H	Neighbourhood residents and civic society representatives	Researcher LDEE together with the project leaders in the two cities	-Gathering input -Awareness raising -Neighbourhood social cohesion	Occurrence (Neighbourhood S): one event in Sept 2021 Start (Neighbourhood H) Two events in Feb 2022 Occurrence: One time repeated in Neighbourhood S (Sept 2022)	Soup with Chats events were organised to foster dialogue among neighbourhood residents and civic society representatives to create a vision of the focal points to address within the neighbourhood civic engagement initiatives. In Neighbourhood S, these discussions were also strategically directed towards gathering input for a Flemish funding application called 'Caring Neighbourhoods'.
Coffee with your neighbour(hood)	Neighbourhood S	Neighbourhood residents	Neighbourhood worker	-Awareness raising -Neighbourhood social cohesion	Start: March 2023 End: May 2023 Occurrence: every 3 weeks	Coffee with your neighbour(hood) featured a mobile coffee cart visiting various streets in the neighbourhood over three months. The primary aim was to spark conversations among residents about topics such as loneliness, coping with serious illness, caregiving, and dealing with loss.
Caregiving cafés	Neighbourhood H	Family caregivers and their care recipients	Project leader	-Peer support -Capacity-building	Start: April 2023 End: Ongoing Occurrence: Monthly	A pre-existing caregiver support group in Neighbourhood H was extended with a co-creative approach in which caregivers were actively engaged in shaping the café's priorities. This resulted in informative sessions alternated with collaborative gatherings where caregivers could participate in discussions.
Consolation walk	Neighbourhood S	Neighbourhood residents	Working group 'Grief in the public space'	-Neighbourhood social cohesion -Peer support	Start: November 2023 End: Ongoing	During the COVID-19 pandemic, the organisation Ferm helped establish public spaces of consolation in various Flemish neighbourhoods. In Neighbourhood S, six such spaces were created. The initiators of these spaces collaborated to organise a collective walk connecting the different spaces.
BankContact Initiative	Neighbourhood S	Neighbourhood residents	Working group 'little helping'	-Awareness raising -Neighbourhood social cohesion	Occurrence: 1 time, Sept 2023	The BankContact Initiative involved a performance where an artist relocated benches in the neighbourhood while fostering conversations about loneliness, coping with serious illness, caregiving, and bereavement. The event culminated in a communal gathering, welcoming all participants to partake in dialogue.
Node City Festival	City B (in which neighbourhood S is located)	City and neighbourhood residents	City representatives	-Awareness raising -Neighbourhood social cohesion	Occurrence November 2022. Is repeated every two years. The next festival will be organised in Nov 2024	The Node City Festival, a four-day event in Compassionate City B, invited local organisations to host activities related to serious illness, caregiving, dying, and bereavement. The festival featured exhibitions, informative sessions, theatrical performances, and more.

3.2. The aspects and contextual factors that facilitated or hindered the development process

Aspects that facilitated or hindered the development process of the neighbourhood civic engagement initiatives regarding serious illness, death and loss were constructed in four overarching themes, based on CFIR: i.e. (1) developing a shared vision (in CFIR: mission alignment) (2) developing neighbourhood civic engagement initiatives in the context of two Compassionate Cities (in CFIR: tailoring strategies and engaging), (3) attaining project success (in CFIR: communications and culture, available resources,..) and (4) ensuring the continuation of the developed initiatives (in CFIR: relative advantage, complexity, cost..). The theme of developing neighbourhood civic engagement initiatives in the context of Compassionate Cities is divided into four sub-themes: a) Power differences between city representatives and civic society representatives, b) the researcher as one of the key figures in the development process, c) the prioritisation of the Compassionate City programme over the development of neighbourhood civic engagement initiatives and d) evolving towards neighbourhood inclusion for expansion. Figure 3 gives an overview of the themes within the CFIR framework.[14]

Figure 3: Themes positioned within CFIR



This illustration is adapted from the original CFIR model by Damschroder [14].

3.2.1. Developing a shared vision

In preparation for the development of neighbourhood civic engagement initiatives, group discussions with neighbourhood residents called ‘Soup with chats’, were organised in the two neighbourhoods. The aim was to foster dialogue between neighbourhood residents and to develop a vision for the project. However, in both the Soup with Chats and the meetings with civic society representatives afterwards, challenges arose in creating a shared vision for civic engagement activities in the neighbourhoods.
First of all, there was a difficulty identified among neighbourhood residents who recognised the need to work around the topics of serious illness, death and loss in their neighbourhood, but at the same time perceived a lack of the right skills and capacities to engage themselves fully around these topics. This manifested itself in an anticipated difficulty in providing emotional support. As one of the neighbourhood residents explained: *“Yes, I think that's the most important thing, sharing those problems of grieving and ... And that this is also possible with your neighbour, but I find it difficult that the neighbours have to be ready to provide psychological help... I find that difficult, stressful too.”* (RB21_2021.09.27)

Secondly, there was a difficulty in aligning the interests of the neighbourhood residents with those of the civic society representatives. Neighbourhood residents highlighted 'helping your neighbours,' 'communication between formal and informal neighbourhood partners’, and 'grief in public spaces' as key topics for civic engagement (OB_2021.11.15). However, civic society representatives originally were not that interested in working around these ‘new topics’, outside the scope of their current activities. Instead, they were more interested in building relationships with other partners in the neighbourhood and getting to know their current activities (OB_2022.12.06). As one of the representatives said: *"I mainly want to see the bigger picture... Who are the other partners and what are they already doing. There are many initiatives in the neighbourhood that could be useful to know about."* (RB17_2022.10.05)

3.2.2 Developing neighbourhood civic engagement initiatives in the context of two Compassionate Cities

This theme contains four sub-themes: a) Power differences between city representatives and civic society representatives, b) the researcher as one of the key figures in the development process, c) the prioritisation of the Compassionate City programme over the development of neighbourhood civic engagement initiatives and d) evolving towards neighbourhood inclusion for expansion.

Power differences between city representatives and civic society representatives

The organisation and coordination of the neighbourhood steering group, within a city-led structure, impacted the partnership between city officials and civic society representatives in Neighbourhood S. The city's concentration of decision-making power hindered a sense of ownership among civic representatives. In contrast, implementing an equitable decision-making process that included existing neighbourhood assets increased their ownership.

Initially, civic representatives felt they lacked decision-making power in the development process. For example, they advocated using established mobile neighbourhood teams to build connections, but the city preferred creating a new neighbourhood worker position, which was ultimately implemented (OB_2022.10.18, OB_2022.12.06, OB_2023.03.06). This decision highlighted the power imbalance, as civic representatives were unable to influence key decisions. As one of the representatives in the steering group explained:

> *"I think... in my opinion, we as [name organisation] have been involved, but it was the way how... The city did have in mind they were going to appoint a neighbourhood worker, and then we indicated, that as we are already in the neighbourhood, we can contribute there. We already have those teams in the neighbourhoods, mobile ambulatory teams. But for the city that wasn't a possibility, and neighbourhood work was set up there." (RB12_2023.06.22)*

The city's control in decision-making was further illustrated when the neighbourhood worker initiated 'coffee with your neighbour(hood)' initiatives without consulting the steering group representatives. This action left the representatives feeling excluded and without ownership over the project (OB 2021.10.06, OB 2022.10.14, OB 2022.12.06). Nonetheless, the steering group representatives acknowledged their role in perpetuating a dependent relationship with the neighbourhood worker, where they overly relied on her guidance, thus decreasing their autonomy and agency within the project (OB_2022.12.06). One of the representatives explained it as follows: *"I think [name neighbourhood worker] may have wanted to do too much on her own, which made us feel less involved, and those working groups, well, they never really got off the ground. But on the other hand, maybe we also didn't ask enough about it ourselves, because we all looked to that central figure."* (RB12_2023.06.22)

The resolution of this issue predominantly unfolded with the departure of the neighbourhood worker approximately seven months into the project. This departure facilitated a pivotal change in power dynamics, granting the steering group representatives newfound responsibility and ownership over the project (OB 2023.06.07). This realignment resonated with the original ethos of the steering group and its working groups, aiming to empower civic society representatives around the topics of serious illness, death and loss. Notably, this transformation did not go unnoticed by a city alderman, who expressed satisfaction with the proactive engagement of the steering group representatives.

> *"I've understood that the person leading it [the civic engagement steering group] has dropped out. But what's nice in that group is that someone spontaneously stands up to organize something. This Saturday, September 23rd, there's an action with 'BankContact'. That's something spontaneous that comes from that group, and I think that's quite beautiful. So, there's a kind of self-direction coming from that network, so to speak."* (RB6_2023.09.07)

The researcher as one of the key figures in the development process

The timing and nature of the researcher's engagement were crucial in influencing collaboration with the cities and their acceptance of recommendations. Early engagement would have helped build trust with city representatives, but the researcher only became actively involved later, starting with discussions with neighbourhood residents. This delayed participation hindered trust-building, negatively impacting collaboration and the cities' willingness to adopt the researcher's recommendations.

In City B, researchers LDEE and BQ shifted from primarily observational research to a more active action research approach, allowing them to contribute recommendations based on their data. Despite this transition, LDEE struggled to influence the project leader (OB 2021.11.15, OB 2022.04.13, OB

2022.06.27). The change manager attributed this challenge to LDEE's delayed adoption of a participatory role, which hindered trust-building with the project leader.

> *"If you had been much more active from the beginning and done things differently, perhaps there would have been greater trust to collaborate differently. That's what I did initially, by supporting those working groups. That way, you gain some credit from the partners. But I didn't need that credit from those partners, although I did build up credit with [name of the project leader in city B] [….]. So as a researcher, you could have done that from the beginning." (R1_2022.10.17)*

The limitations of decision-making power and influence in City B became apparent when researcher LDEE identified various key figures with valuable community-building assets who were eager to join the project. Despite LDEE's recommendation to include these key figures in the project, the project leader declined, highlighting that decision-making power ultimately rested with the city (OB 2021.08.20, OB 2022.11.23).

In City H, LDEE's involvement was more extensive from the outset, by collaborating with the project leader in creating an action plan for the project and advocating for co-creative approaches for the caregiving cafés. This proactive engagement stemmed from a direct request for assistance by the project leader. As a result, the researcher gained increased influence in the facilitation process, which was met with greater receptiveness from the project leader. "*But I already mentioned a few times that it is very important to me… You have helped me a lot in managing things a bit and occasionally extracting critical insights. When that support is gone, a lot is lost, and I notice that I am left in a rather solitary position."* (R9_2023.05.17)

The prioritisation of the Compassionate City programme over the development of neighbourhood civic engagement initiatives

Both cities implicitly prioritised developing Compassionate Cities over neighbourhood civic engagement initiatives. A direct consequence of this phased implementation of the two initiatives was a delay in the development of the neighbourhood initiatives. This phased approach complicated the integration of the two initiatives, despite potential benefits. Furthermore, the impact of this prioritisation on the overall development process depended on the city's political priorities and resource allocation.

The decision to develop the Compassionate Cities and neighbourhood civic engagement initiatives sequentially led to the project leader in city B to treat them as two distinct endeavours each with their own strategies and actions. The project leader did not find integrating the two projects for mutual reinforcement to be a desirable approach: *"The neighbourhood project and Compassionate City programme? No, I don't even have to think about it. No, the neighbourhood work will continue with the [name of the neighbourhood worker], and the [name of the Compassionate City steering group],… No, that shouldn't coincide.*" (RB2_2023.04.11)

Nevertheless, the Node City Festival on serious illness, death and loss, organized by City B successfully demonstrated how Compassionate City activities can function as a catalyst for neighbourhood civic engagement regarding these issues. The festival inspired civic society representatives about potential activities in their neighbourhood around these topics in collaboration with others: *"It was a positive experience. There were a lot of people. I found that very good, it was [name project leader] who organised a networking and introductory moment online, and then there were breakout rooms where* *you could get to know each other and find points of connection. For me, it stimulates ideas for the neighbourhood."* (RB17_2022.10.050)

In City H, while the Compassionate Cities and neighbourhood civic engagement initiatives were also developed sequentially, it was initially decided that the two projects should be interconnected over time. However, following the sequential development, the project leader and city representatives encountered difficulties in retrospectively connecting the two approaches. As one of them explained:

> *"My goal is actually to merge all the projects that exist, to try to do that, and bring that within the Compassionate City programme. There is so much, but it should be a bit of a melting pot of everything and it should be possible to do everything in a natural way. You understand? But we have to consider how we should expand to the neighbourhoods and link that to the schools and so on." (*RH8_2023.04.11)

Political motives influenced the project's development, with a clear preference for city-wide initiatives over neighbourhood-specific ones (OB 2020.11.23, OB 2021.03.29, OB 2022.08.18). This prioritisation was reflected in the project leaders' time, which was mainly dedicated to the Compassionate City program, as confirmed by the change manager (R1_2023.05.17). Consequently, the change manager's efforts also focused primarily on city-wide initiatives.

> *"My role in the neighbourhoods? In the neighbourhoods themselves, to be honest, I have the impression, not so much. In the project, I really think it is about the guidance of [names of the project leaders]. […..] Looking back, I think I was quite far away from that [the civic engagement initiatives]. I have the feeling that there has been a lot of pulling, especially from the beginning, to try to get those neighbourhoods on the map."* (R1_2023.05.17)

Evolving towards neighbourhood inclusion for expansion

Despite gathering input from neighbourhood residents, the cities were reluctant to actively involve them in the development of neighbourhood civic engagement initiatives. This hesitation stemmed from concerns about relinquishing control over the project and managing risks associated with granting residents far-reaching decision-making power.

In City H, the representatives feared that resident input might diverge from the city's plans. One representative noted, "*They [the city aldermen] feel uncomfortable about it [involving citizens] because they don't have control over it. For instance, something [in another project] has now emerged in [sub-municipality of City H] that we didn't expect, and they [the city aldermen] feel very uncomfortable about it. But you participate and the result is what comes out, not what you think should come out."* (RH7_2021.11.16).

City B's project leader was concerned about the disparity in working approaches between the city government and neighbourhood residents, fearing inefficiency and lack of knowledge: *"But are we going to have a lot of input from there? No, working with citizens is a different style. In any other conversation with a professional, you can achieve a lot, but with a citizen, you have to double the time to guide them through what can and cannot be done."* (RB2_2022.02.02). However, civic society representatives regretted the lack of resident involvement: *"I think that up until today, we still lack the active participation of citizens in this entire story. There have been discussions here and there, but there hasn't been a concrete request for participation, for providing input into what is currently on the table, and I think that these are definitely missed opportunities."* (RB14_2023.06.20).

3.2.3. Attaining project success

Concerns about achieving project success centred primarily on the workload capacity of project leaders and their ability to fully commit to the project. This highlighted the critical importance of sufficient resources as a prerequisite for a successful project. One of the city representatives in city H described this as a dual struggle, explaining that while the project's ambitions are high, there are also practical limitations regarding time investment. *"City H is a municipality that likes to work on projects, but currently, due to a lack of time, there is not always the time and place to put heart and soul into the project. [....]. We feel a bit of a conflict in the current situation."* (RH8_2020.09.23). This dual struggle was not only experienced on the level of project management, but also at the level of the project leaders, as one of them explained: *"I shouldn't be the only one driving the project; the success or failure of the project shouldn't depend on me, but currently, that's the case."* (RB2_2021.04.01). The Neighbourhood worker offered some relief in this regard, in taking on the workload of the project leader when it comes to the neighbourhood civic engagement project. However, her departure was marked by one of the city representatives as a crisis in terms of staffing (R14_2023.06.21).

Regarding the project's impact, there was a discrepancy between the expected impact, a culture change around serious illness, death and loss, and the actual impact of the neighbourhood civic engagement initiatives, an increased sense of neighbourhood social cohesion. This discrepancy arose from two factors: governmental funding attributed to building systemic neighbourhood support networks, and the research objectives, which initially framed the project as driving cultural change without emphasising the need for incremental progress before achieving such overarching cultural transformations.

Concerning the first aspect, the expectations associated with the government funding allocated in City B, the project leader observed that despite significant efforts invested in the neighbourhood civic engagement project, it did not achieve the intended impact of increasing neighbourhood support, as was outlined by the Flemish government. Instead, the project led to an increased sense of neighbourhood social cohesion regarding serious illness, death and loss. This led to doubts about the feasibility of this objective to begin with.

> *"I think everyone who started that Caring Neighbourhoods story two years ago, it sounded incredibly beautiful how they presented that in Flanders, and how all those projects... They were going to solve it all. But in reality, these projects do not solve the healthcare puzzle. It strengthens neighbourhoods and that's nice, but those are two different things."* (RB2_2023.04.11)

Regarding the second aspect, the initial research objective of creating a cultural shift regarding serious illness, death and loss, the neighbourhood worker in city B realised that such a profound change could not be fully realised within the confines of a four-year research period. Nevertheless, she also acknowledged the importance of fostering neighbourhood social cohesion as a crucial initial step toward achieving the desired culture change.

> *"And I also realised this week that the project will run for another year but in that time we will not have a major cultural change. I don't think we can immediately say that we are a compassionate community for everyone everywhere, but there is also everything we do for associations or other organisations [referring to the neighbourhood civic engagement activities*

> *focused on neighbourhood social cohesion]. And we can take that as a common theme and a way of life."* (RB5_2023.02.16)

3.2.4. Ensuring the continuation of the developed initiatives

Challenges in continuing the Compassionate Cities and neighbourhood civic engagement initiatives stemmed from resource constraints and differences in working approaches. Pursuing a broad spectrum of topics and initiatives was viewed as a greater risk to continuation, compared to focusing on specific initiatives, making them sustainable, and then gradually expanding to other initiatives. The latter was the applied working approach in City H: *"Yeah, I think that's our biggest challenge. Keeping the project alive. And it…I always say that you shouldn't run before you can walk. You first have to take small steps before you can run. How can I explain that? Sometimes people want to achieve very big things within the project. But sometimes it is better to accomplish some small things, maintain them and only then work towards expansion."* (RH8_2023.03.21). On the other hand, in City B, where a broad working approach had been adopted, the project leader expressed concern that over time there would not be sufficient staffing to sustain the project. Therefore, she emphasised the need to make the project self-sustaining: *"The biggest pitfall is that I can't imagine us having the staff to carry out this project within five years. So, we will have to find ways to make the network self-sustaining."* (R2_2021.04.01). However, this idea contradicted subsequent statements expressing hesitance to expand the initiative to neighbourhood residents and other key figures out of fear of losing control over the project (cf. Expanding the neighbourhood civic engagement initiatives to neighbourhood residents).

Furthermore, concerns were raised about the potential loss of paid positions when funding ends. These paid positions encompassed city representatives, the project leaders, the change manager, the civic society representatives in the steering group and the two researchers. Particularly the discontinuation of the position of the change manager was considered a challenge to the sustainability of the Compassionate Cities and neighbourhood civic engagement initiatives since her role was considered crucial in keeping topics of serious illness, death and loss prioritised on the city's agenda. As one of the city aldermen said: *"I think you still have a risk there. Not so much your role, your research role is important and I am also curious about the final report. But I think what is important is that if [name change manager] were to disappear within that process, that would be a risk because the fact that someone externally is also involved ensures that that theme can never be pushed into the background for other priorities."* (RB3_2021.12.01)

4. Discussion

4.1. Summary of findings

This study aimed to gain insight into the aspects and contextual factors that facilitated and hindered the development of civic engagement initiatives regarding serious illness, death and loss in Neighbourhood S and Neighbourhood H. We found that challenges in the development process primarily centred on integrating civic engagement initiatives around serious illness, death and loss into the broader context of Compassionate Cities. This was evident in the unequal power dynamics between the city and representatives from civic society organisations, as well as the difficulties in expanding the project to encompass other neighbourhood key figures and residents. However, we also observed that the context of a Compassionate City could serve as a facilitator. For instance, the organisation of a city-wide festival encouraged neighbourhood participation. Additionally, we found that the development of Compassionate Neighbourhoods was a dynamic process, allowing challenges to be addressed over time. Finally, the timing and nature of the researcher's engagement were pivotal in shaping the collaborative dynamics with the cities, and the cities' acceptance of recommendations.

4.2. Interpretation of findings

Despite previous research demonstrating the potential of civic engagement to empower participants [26, 27], our findings suggest that this was not initially evident among the participants involved in our project. The centralised structure of the steering group, which positioned the city in a top-down decision-making role, created unequal power dynamics between the city and the representatives from civic society organisations, resulting in a perceived lack of influence and ownership among the latter. Existing literature indicates that the effectiveness of power distribution in civic engagement often hinges besides personal characteristics also on the organisational structures in place [28], with centralised structures frequently exacerbating power imbalances [29, 30]. Alternative structures, such as consensus-based decision-making structures, have been shown to effectively address such imbalances by enabling community members to collectively negotiate agreements reflective of broader community needs and to allocate resources accordingly.[26, 27] Stimulated dialogical action, as decribed by Flyvbjerg[31] is not merely a communication method but an entire epistemological approach. It seeks to create more horizontal structures that empower community members to actively engage in identifying their needs, shaping actions and influencing outcomes, ultimately generating power in favour of the communities themselves. In our project, within the civic engagement initiative, we observed a shift from a centralised power structure to a more consensus-based model. This shift occurred following the departure of the neighbourhood worker employed by the city, which prompted civic society representatives to develop a heightened sense of responsibility and ownership in the project. An evaluation of 35 other caring neighbourhoods in Flanders, highlighted the crucial role of the neighbourhood worker's leadership. [32] Rather than organising and controlling the process, it was found that a facilitating and coaching role of the neighbourhood worker was more beneficial to the development process.[32] Combined, these findings show that the neighbourhood worker's role, closely linked to the organisational structure of the development, is essential for fostering ownership and responsibility among the participants.

Since many of the individuals involved in developing civic engagement initiatives held paid positions (e.g. the project leaders, the neighbourhood worker, civic society initiatives, researcher), there was an apprehension that the determination of funding, and subsequently the discontinuation of these paid positions, could endanger the continuity of the project. Sustaining initiatives that arise from community development approaches is a widely recognised challenge in Compassionate communities literature.[33-35] Generally, there are two main strategies mentioned in literature to increase the sustainability of developed initiatives. The first strategy advocates for 'organic' community development, where communities are self-organised and driven by intrinsic motivation to continue their activities.[36] The other strategy focuses on aligning government policies to create a stimulating environment for communities to sustain and expand their initiatives.[36, 37] However, we found that transitioning from local government-initiated initiatives to more self-organised and sustainable initiatives, posed challenges. Community development literature, both in the field of Compassionate Communities and beyond, advocates for the inclusion of Community Champions or Ambassadors in projects. [38-40] These individuals, often holding influential positions in their neighbourhoods due to professional roles or informal activities, can significantly contribute to embedding initiatives in the neighbourhood and garnering support among residents, ultimately increasing the sustainability of the project.[38, 39] However, the strategy of working with Community Champions or Ambassadors raises important questions about the identity and inclusion of the individuals within the project. However, while literature seems to assume that these Champions are readily available and willing to participate, we observed that in reality, their inclusion requires careful observation of who are these Champions and support in their inclusion in the project. We recommend that cities facilitate this process by implementing supportive policies that promote collaboration among city officials, social partners, and other informal stakeholders, while also outlining practical guidelines for effective collaboration.

One particular challenge encountered in expanding civic engagement initiatives to neighbourhoods was the integration of neighbourhood residents into the development process. The primary reason for this difficulty stemmed from the city's desire to maintain control over the process and their concerns regarding unforeseen project outcomes if citizens, outside the realm of the professional health and wellbeing sector, were involved. Wilson et al.[41] affirm this by highlighting power hierarchies within political structures as a key ethical concern in participatory research. Similarly, community development literature reveals a tension between local governments' aspirations between inclusive decision-making and comprehensive community development, and the reality of their existing structures, which often hinder the incorporation of citizen suggestions and initiatives that diverge from their established visions.[42, 43] An additional challenge that is specific to civic engagement around the topics of serious illness, death and loss, is the heightened political sensitivity of these topics, stemming from the fear of addressing these topics unfittingly in the public eye if they are not first well-cogitated on the policy-level.[44] To address this challenge, we suggest that while local governments play a facilitating role in the development of civic engagement initiatives regarding serious illness, death and loss, not every activity needs to fit their qualifications. This approach can grant communities greater autonomy to develop initiatives according to their preferences, without being constrained by political considerations.

A substantial implication of the COVID-19 pandemic emerged at the level of the initiatives' development, as evidenced by delays reflected in the timeline, due to government-imposed protective measures that prohibited group gatherings. However, the delays were not solely a consequence of COVID-19. Other factors, including a shortage of personnel, city-wide initiatives being prioritised over localised neighbourhood initiatives and finding common and tangible areas of interest, were found to have much more of an influence. So, while COVID-19 induced some delays, it mostly amplified structural issues that were already present, such as the lack of time and resources to facilitate two simultaneous co-creative projects. Notably, while the COVID-19 pandemic has been demonstrated in studies by Drury et al.[45], Bowe et al.[46] and Fraser et al.[47] to have a profound societal impact—fostering feelings of shared destiny and solidarity through community support and coordinated action, primarily manifested as intergenerational neighbourhood participation—this aspect was not recognised by the civic engagement representatives as a facilitator for the project. One possible explanation for this oversight could be the project's development being predominantly driven by civic society representatives rather than neighbourhood residents, potentially leading to a missed opportunity to leverage COVID-19 as a springboard for enhancing civic engagement around serious illness, death and loss. Another explanation could be that pandemic-induced opportunities for neighbourhood participation have largely been framed within the concept of "little helping," a term prevalent in the Flemish context that refers to informal neighbourhood support in the form of brief tasks such as grocery shopping, having conversations, or lawn maintenance.[48] Consequently, this narrow focus may obscure other significant opportunities, such as the creation of public spaces for grieving—an initiative associated with the project—that could foster deeper neighbourhood participation concerning serious illness, death, and loss.

The active position of the researcher in the project was an important factor in the development process, particularly in sharing recommendations and suggestions based on acquired knowledge about the development process. However, we also identified a challenge where city representatives, did not always accept these recommendations and suggestions. Literature distinguishes various ways in which researchers can be involved in a development process, including as producers of critical knowledge, dialogue starters, facilitators and contributors of change.[49] However, it is also found that these roles are often perceived as incompatible by coordinators of the development process[49, 50], thus explaining some of the challenges we encountered in sharing the acquired knowledge. This incompatibility arises primarily due to the perceived contradiction between researchers as producers of knowledge, which is associated with distance from the development process, and facilitators and contributors of change, which involves closer engagement with the development process.[50] However, in addressing this challenge, we suggest that the researcher as an 'organiser of space for dialogue' [40] can serve as a bridge by sharing knowledge acquired through research about the development process, with actors involved in the development process. We recommend starting this dialogue early enough in the process, to make people aware of the researcher's role and to build trust. Lastly, we also emphasise that to avoid confusion a clear distinction must be made between the facilitating role of the researcher in the development process, which stems from knowledge about the development and focuses on giving recommendations, and the facilitating role of for instance the neighbourhood worker, which focuses coordination and operational support in the development process.

4.3. Strengths & limitations

The study employed a comprehensive evaluation, including observations, interviews, and group discussions, providing a nuanced understanding of the developmental process and context. Multiple data sources ensured credibility through cross-validation. However, there are also limitations to consider. While we conducted research in two distinct settings—an urbanized neighbourhood and a peri-urbanized area—our findings may be constrained by certain idiosyncratic aspects of the context of the study, limiting generalisability to other settings or populations. Observations, interviews and group discussions are inherently subjective, as was our preferred choice to conduct a thematic analysis. This subjectivity in itself is not per se a limitation but mostly something we must be aware of and be transparent about. However, particularly the observations may cause a bias in presence, since individuals may have adjusted their behaviour under the presence of a researcher.

5. Conclusion

The development of neighbourhood civic engagement initiatives regarding serious illness, death and loss within the context of Compassionate City programs led to several specific activities. Our evaluation of the development process identified challenges regarding power imbalances between the city and civic society representatives, the continuation of the developed initiatives and the broadening of the initiatives to neighbourhood residents. We recommend that Compassionate City programmes can also facilitate the development process in three manners: 1) by establishing consensus-based structures that stimulate equitable decision-making, thus fostering neighbourhood ownership of the project; 2) by fostering a culture that encourages the involvement of neighbourhood residents, including accepting input and supporting initiatives that may diverge from the prescribed working approach in the policy plans and 3) by anchoring these facilitating approaches in policy for sustaining successful initiatives over time.

6. Research data deposit

The data that was collected via semi-structured interviews and focus groups, semi-structured observations and relevant documents cannot be publicly shared due to its confidential content, formally captured in an informed consent form that was signed by all participants and by the researcher LDEE. A study protocol for this data collection is publicly available: DOI 10.1177/26323524231168417.

7. Author contributions

All authors contributed to the conceptualisation of the article and determined the study design and methodology. LDEE was responsible for the data collection and analysis. The data interpretation and analysis were assisted by JC and TS. LDEE and TS provided the first draft of the article, which was revised and edited by all the authors. All authors approved the final version.

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PART V

TO REFLECT ON THE CURRENT CHALLENGES, TENSIONS, AND COMMONALITIES AND PROPOSES FUTURE DIRECTIONS WITHIN THE COMPASSIONATE COMMUNITIES MOVEMENT. THIS PART COVERS RESEARCH QUESTIONS 10 AND 11 IN THIS DISSERTATION.

Chapter VII

COMPASSIONATE COMMUNITIES: CONTEMPORARY TENSIONS AND CHALLENGES

D'Eer L, Sallnow L. Compassionate Communities: contemporary tensions and challenges. Ann Palliat Med. 2023, 13: 5-9. [2021 IF 1.925; Ranking Q4; ranking 90/109 HEALTH CARE SCIENCES & SERVICES in SCIE edition]

Article type: Invited Editorial

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 Communities 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 considers, 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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Ethical Statement

The authors are accountable for all aspects of the work in ensuring that questions related to the accur acy or integrity of any part of the work are appropriately investigated and resolved.

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Part VI

Chapter VIII

GENERAL DISCUSSION

GENERAL DISCUSSION

1. Introduction

The overall objective of this PhD is to describe and evaluate two neighbourhood civic engagement initiatives regarding serious illness, death and loss in terms of their development processes.

The specific research questions were:

Chapter II

- Research question 1: In what context, why and for whom are civic engagement initiatives around serious illness, death and loss initiated?
- Research question 2: How are they developed and how are they sustained?
- Research question 3: How have they been evaluated and what is their impact?

Chapter III

- Research question 4: To what extent do citizens participate in actions around serious illness, death and loss in their neighbourhood?
- Research question 5: Are citizens more likely to participate in actions around serious illness, death and loss in their neighbourhood when they perceive a higher level of social cohesion in their neighbourhood?

Chapter IV

- Research question 6: Are citizens who had a personal experience with serious illness, death or loss in the last year more likely to participate in actions in their neighbourhood around these topics?
- Research question 7: Do the capacity, skills and self-efficacy citizens believe they gained from their previous experiences with serious illness, caregiving, death and loss strengthen this association?

Chapter V

- Research question 8: How do we evaluate neighbourhood civic engagement initiatives, given their unpredictable and dynamic character?

Chapter VI

- Research question 9: What are the aspects and contextual factors that facilitated and hindered the development of the neighbourhood civic engagement initiatives in the context of two Compassionate Cities?

Chapter VII

- Research question 10: What are contemporary tensions and challenges within the Compassionate Communities movement?
- Research question 11: What are the insights we can gain from them to propose directions for future practice and research?

This general discussion provides a summary of the findings of each of the chapters, followed by methodological considerations of each of the methods used in these studies to answer the research questions. This is followed by a general discussion of the main findings. Finally, I will provide recommendations for practice, policy and research based on the research findings.

2. Summary of the findings

In Chapter II I describe a systematic mixed-methods review I conducted of civic engagement initiatives regarding serious illness, death and loss, worldwide. Including initiatives from international peer-reviewed publications in English, we identified nineteen distinct initiatives worldwide. Although these initiatives were dispersed across different countries, nearly all originated in countries where English is an official language (e.g. Australia, the United States, India, Ethiopia and Canada)., We discovered that community members participated in the development of all initiatives, albeit in various forms ranging from community-academic partnerships to entirely grassroots efforts led by community organisations or groups. However, detailed descriptions of their development processes and strategies were lacking. Lastly, we found that most initiatives had been evaluated in studies, showing promising results, such as empowering community members to provide end-of-life care for older people in their community[1]. Nonetheless, the evaluations exhibited considerable variety in their objectives, methodologies, and outcomes, as well as in their overall quality and strength of the evidence. Specifically, we found that process evaluations often focussed only on specific aspects of the civic engagement initiatives such as their acceptance or reach without offering a more comprehensive analysis of the development process. This underscored the need to gain more in-depth insight into how such initiatives are developed through the use of high-quality process evaluations.

Chapter III presents the findings of a cross-sectional survey study that we conducted in the two selected neighbourhoods between February and April 2021. This survey study was part of the needs and assessment mapping conducted before the start of the development process of neighbourhood civic engagement initiatives. Using data from the survey, we aimed to provide a description of the extent and type of neighbourhood civic engagement regarding serious illness, death and loss in the two selected neighbourhoods and study whether citizens were more likely to participate when they perceived a higher level of social cohesion in the neighbourhood. The questionnaires were distributed to a sample of 2.324 adult citizens in the two neighbourhoods. We received 714 questionnaires (response rate 30.7%). We found that 42% of the respondents had participated in at least one neighbourhood activity related to serious illness, caregiving, death or loss. Most respondents participated by either helping a close neighbour (32%) or by volunteering (10%); to a lesser extent, respondents participated in group activities such as bereavement groups (6%) or community initiatives (6%). Additionally, respondents indicated that they participated seldom or sometimes (31%), and only a small minority participated more regularly (12%); the other 47% did not participate or participated only once. Following a hierarchical linear regression analysis, informed by a Directed Acyclic Graph[2] visualising the potential causal interrelations and de-confounding strategies, we found a positive association between perceived neighbourhood social cohesion and civic engagement regarding serious illness, death and loss in the two neighbourhoods. This association remained after adding general neighbourhood participation – beyond the scope of serious illness, death and loss – to the regression analysis. These results suggest that people who perceive a higher social cohesion in the neighbourhood are more likely to participate in civic engagement activities regarding serious illness, death and loss, regardless of whether they participate in general neighbourhood activities outside the scope of serious illness, death and loss.

The findings of the cross-sectional survey study were also reported and discussed in **Chapter IV**, which provides an answer to the research questions of whether citizens are more likely to participate in neighbourhood civic engagement actions if they have had personal experiences with serious illness, death and loss in the last year and whether the capacity, skills and self-efficacy they believe they gained from their previous experiences, strengthened their participation. We found that 72% of the respondents had an experience with serious illness, caregiving or loss in the last year. More than half of the respondents (57%) lost someone they knew well, 14.2% reported that they had been a caregiver for a family member who was seriously ill and 15% reported that they had been seriously ill in the last year. After a hierarchical linear regression analysis, informed by a Directed Acyclic Graph model[2] (a similar approach to Chapter 3), we found a positive association between having been a caregiver in the last year and neighbourhood participation regarding serious illness, death and loss. Notably, this association was not observed for other experiences like being seriously ill oneself or experiencing a recent death in the family in the past year. Furthermore, we found that this association was strengthened when adding perceived capacity and skills gained from their previous experiences with serious illness, death and loss, to the regression analysis. These results suggest that people who have been a caregiver in the last year are more likely to participate in neighbourhood activities regarding serious illness, caregiving, death or loss; and that this is particularly the case if they believe they gained capacities and skills from their previous experiences with these topics.

In **Chapter V**, I present the study protocol that we developed for the evaluation of the civic engagement initiatives concerning serious illness, death, and loss in the two neighbourhoods that we selected, in terms of their development processes and outcomes. Recognising the intricate dynamic and non-linear nature of Compassionate Communities, as well as the limitations of traditional research methods[3], we adopted a methodological approach that offered clear guidance regarding research design, objectives, data collection methods, and analysis, while also allowing flexibility to adapt the evaluation to the development process. We adopted a convergent-parallel mixed-methods evaluation design, encompassing both qualitative and quantitative data collection methods. Given the convergent-parallel nature of our design[4], the different types of data were collected separately, but simultaneously, with a view to integrating and interpreting the combined results. Embracing a critical realist philosophy[5] we acknowledged the presence of both objective and subjective factors underlying the development process of the neighbourhood civic engagement initiatives. Qualitative methods included semi-structured observations of relevant meetings, document analysis of the produced documents and semi-structured interviews and group discussions with all relevant parties, to capture the development process and the social processes underlying it, and a Most Significant Change[6] data collection. The latter was collected but falls outside the scope of this doctorate. Quantitative methods included a cross-sectional survey study. Together, using these methods we were well-equipped to gain a comprehensive insight into the development process of the neighbourhood civic engagement initiatives.

Chapter VI presents the findings from a multimethod process evaluation[7] encompassing semi-structured observations from all relevant meetings, document analyses of the minutes of meetings and produced documents, semi-structured interviews, and group discussions with all relevant parties in the development process. Following a thematic analysis using a combination of inductive and deductive coding[8], our findings revealed that challenges in the development process centred around integrating the neighbourhood civic engagement initiatives into the broader context of Compassionate City programmes. These challenges became apparent in the unequal power dynamics between the cities and civic society representatives, as well as in difficulties in expanding the project to neighbourhood residents and other neighbourhood key figures. Despite these challenges, we identified the potential for Compassionate Cities to act as facilitators. For instance, through the organisation of a city-wide festival that encouraged neighbourhood participation. Additionally, we found that challenges regarding power dynamics could be resolved, by adopting a shared decision-making structure, rather than a centralised one attributing end decision-making power to city representatives. Expanding the initiatives to include neighbourhood residents and other neighbourhood key figures, remained challenging, though it was recognised as a crucial strategy for increasing the sustainability of the developed initiatives. I recommend that cities embed these facilitating mechanisms into their policies to enhance the success and sustainability of these initiatives.

Chapter VII reports the findings of a review of five recent publications on Compassionate Communities[9-13], presented in an editorial format. This review aimed to highlight the existing tensions and challenges within the field of Compassionate Communities and to propose directions for future practice and research. Three primary tensions were identified. The first tension revolved around power dynamics and community engagement in initiatives, questioning whether community-based educational activities, without broader empowerment efforts, could be appropriately labelled as Compassionate Communities. A second tension revolved around whether service-driven or research-driven initiatives, as the majority of the initiatives that were identified in the reviews, conflicted with the interests of communities and populations. A third tension highlighted was the lack of representation of compassionate community initiatives in English-language peer-reviewed literature which mainly focused on Compassionate Communities initiatives in high-income countries, disregarding other contexts. These tensions emphasised the need to broaden, rather than restrict, research on Compassionate Communities to encompass a wider array of contexts, demographics, methodologies, and epistemologies, thereby complementing existing traditional approaches.

3. Methodological considerations: strengths and limitations

I used three types of studies to answer our research questions: a systematic review, a cross-sectional survey study and a multi-methods process evaluation. Together these studies provided us with a comprehensive image of the state-of-the-art literature on Compassionate Communities, the extent and type of neighbourhood civic engagement initiatives in the two selected neighbourhoods and the factors associated with it (prior to the development), and insight into the facilitating and hindering factors in the development processes of these initiatives. For each of these three studies, I will discuss the methodological considerations in the format of strengths and limitations.

3.1. A systematic review of civic engagement initiatives regarding serious illness, death and loss worldwide

Our systematic review was pioneering in its examination of the published, English, peer-reviewed literature on civic engagement initiatives regarding serious illness, death and loss. A key strength of this review was its comprehensive coverage, which included the context of development, the development process and sustainability and their evaluations. This breadth provided us with valuable insights into each of these aspects, thus inspiring us on development and sustainability strategies, possible activities the initiatives could entail and potential evaluation methods and instruments. Additionally, this rich data also heightened the gaps in the current literature on civic engagement around serious illness, death and loss: e.g. the need for a methodologically comprehensive study protocol to evaluate neighbourhood civic engagement initiatives around serious illness, death and loss and the need for insight into contextual factors and social processes underlying the development of these initiatives. Another positive aspect of our review was that by employing the broader term ‘civic engagement initiatives regarding serious illness, death and loss’, and synonyms in the search strategy such as “community development” and “community-based”, we identified initiatives beyond the narrative of Compassionate Communities. The term Compassionate Communities was first introduced in 2005[14]; however, civic engagement initiatives around serious illness, death and loss existed prior to the adoption of this term. Consequently, our review was able to encompass these earlier initiatives as well.

Another positive element of the review was that the search combined English peer-reviewed literature with grey literature. This was achieved by contacting the first authors and by hand-searching the reference lists of the included literature for additional grey literature publications. This approach helped to prevent missing valuable information and perspectives that might not have been captured in peer-reviewed literature.

Our review has some limitations. First, although we found it justified to conduct a review starting from the English peer-reviewed literature because this had not yet been performed, and we were able to include additional grey literature, this choice may be the reason that the initiatives that were included in the review were primarily located in countries where English is the main language, such as the United States, Ireland, Canada and Australia, and countries where English is one of the official languages such as in India and Ethiopia. As a result, we may have overlooked non-English speaking contexts where writing in English could be a potential barrier to publishing initiatives in peer-reviewed journals. Another related potential bias is that the included initiatives are predominantly located in high-income countries. Unsurprisingly, these are also the contexts with the most available research funding, leading to an underrepresentation of low- and middle-income countries in research and hence peer-reviewed literature.

3.2. A cross-sectional survey study to measure the extent and type of civic engagement regarding serious illness, death and loss and the factors associated with it

The main strength of this study lies in its quantitative approach within the field of Compassionate Communities, an area where quantitative research is generally underrepresented, as the majority of studies tend to use qualitative methods[15]. This study, although providing only a baseline measurement, contributes considerably to quantifying trends in participation which would otherwise stay unexplored. In combination with qualitative data on why people prefer to be involved specifically in these types of participation, we can create a rich understanding of the factors influencing neighbourhood civic engagement regarding serious illness, death and loss. Additionally, by looking into the associations between perceived neighbourhood social cohesion and neighbourhood civic engagement around these topics, and between previous experiences with illness, death and loss and civic engagement, we were able to quantitatively substantiate insights for the development of strategies for creating neighbourhood civic engagement initiatives, such as leveraging people’s previous experiences with serious illness, death and loss and the capacities and skills they gained from it into participation possibilities.

The use of a Directed Acyclic Graph (DAG) model[2] can be considered both a strength and a limitation of this study. First of all, we found a DAG model a useful tool to turn our strong assumptions derived from literature into a visualisation of the potential causal interrelations, thus serving as a powerful guide to inform our multivariable regression analysis and to minimize bias by confounding variables. However, we were also aware that applying a DAG model on cross-sectional data has its limitations in terms of internal validity as the design is rather limited in making causal claims. We thereby consciously applied the DAG model as an instrument assisting our analysis, fully aware that the results, although valuable in their aim of elucidating potential causal pathways, need to be translated into hypotheses that can be further tested, through longitudinal data collection which provides better control over issues of temporality and residual confounding.

Following the Dillman Total Design Method[16], we achieved a response rate of 32% (n=714). While 32% is considered a reasonably okay response rate[17], particularly given the focus of the study on the topics of serious illness, death and loss, caution is warranted regarding validity. For instance, in terms of internal validity, we must carefully consider if the results of the study accurately represent the two neighbourhoods where the survey was conducted. Additionally, in terms of external validation, we must exercise caution when extrapolating these results to other per-urbanised regions in Flanders and beyond.

Although we used two validated scales in our study- The Neighbourhood Cohesion Instrument[18] to measure perceived neighbourhood social cohesion and the Death Literacy, subscale experiential knowledge[19], to measure self-perceived capacities and skills derived from previous experiences- validated scales were unavailable for most of the other concepts we measured. To address this issue, we either adapted a validated scale to the topics of serious illness, death and loss or we developed new items for measurement. For 'perceived help from neighbours' and 'self-efficacy to engage around the topics serious illness, death and loss', we developed new items. The items for perceived help from neighbours were based on the Medical Outcome Survey Study (MOS)[20], and the items for self-efficacy were based on guiding literature on how to develop items for self-efficacy.[21, 22] The concept of neighbourhood participation concerning serious illness, death, and loss was adapted from the Social Capital Measure[23], with modifications to incorporate these specific topics. To further expand the scope of the scale, we added two items designed to assess whether participants had engaged in helping neighbours who were ill or in need of assistance. The two items added were:

- "In the six months prior to the start of the COVID-19 crisis, did you help an immediate neighbour (someone living next door) who was ill or in need of help?" Responses ranged from 1 (No, not at all) to 5 (Yes, at least five times).
- "In the six months prior to the COVID-19 crisis, did you help anyone in your neighbourhood who was ill or in need of help?" Responses ranged from 1 (No, not at all) to 5 (Yes, at least five times).

After adding these two items, we conducted a Principal Component Analysis (PCA) on the eight items, with an orthogonal rotation (Varimax). The Kaiser-Meyer-Olkin test was used to verify if the sample size was adequate for the analysis. We found a significant KMO value of 0.594 ($p < 0.001$), which exceeds the acceptable threshold of 0.50. Bartlett's test of sphericity, $X^2(10) = 859.782$ ($p < 0.001$), indicated that the correlations between items were sufficiently large to justify performing a PCA. The analysis revealed that there was one component (a single latent factor or scale) with an eigenvalue greater than 1 (Kaiser's criterion), which explained 28.89% of the variance. The two added items had factor loadings above 0.50. While we observed high internal consistency for the items within the scale (Cronbach's alpha = 0.621), a potential limitation is that the item "helping a neighbour in need or who was ill" may be too broadly formulated. A "yes" response to this item may not adequately represent neighbourhood participation specifically related to serious illness, death, and loss. As a result, our claim that 42% of people have participated in at least one activity concerning serious illness, death, or loss in their neighbourhood might be affected. To address this concern, we performed a sensitivity analysis by excluding the two items related to helping neighbours from the overall score for neighbourhood participation in serious illness, death, and loss. This resulted in a 21-percentage point difference. Although this noteworthy difference suggests a potential overrepresentation bias for neighbourhood participation, we remain cautious about this finding. Helping neighbours may indeed be one of the most common forms of engagement in communities, and including it in the scale might naturally inflate the participation rates. However, we recognise that a more precise formulation focused on serious illness could have reduced this possible overrepresentation.

Finally, acknowledging the complexity of Compassionate Communities as intricate social change processes, we recognise that besides perceived neighbourhood social cohesion and previous caregiving experiences, there are undoubtedly other potential predictors (e.g. the availability of common spaces) for neighbourhood participation regarding serious illness, death, and loss that we did not include and that need consideration. Another limitation is that we did not measure whether positive or negative caregiving experiences increase the likelihood of neighbourhood participation regarding serious illness, death and loss. This can be researched both quantitatively and qualitatively, further unboxing the mechanisms underlying our results, and capturing how people go from having caregiving experiences to developing capacities and skills from these experiences, ultimately leading to neighbourhood participation regarding serious illness, death and loss.

3.3. A process evaluation of the development of the Compassionate Neighbourhoods by conducting observations, semi-structured interviews and group discussions

The overall objective of this PhD is to describe and evaluate two neighbourhood civic engagement initiatives regarding serious illness, death and loss in terms of their development processes. It was an asset-based community development[24] effort, involving relevant parties from the neighbourhoods to shape their initiatives or develop activities based on existing assets, thus encouraging neighbourhood ownership of the process. Within the asset-based community development[24], we employed an appreciative inquiry approach[25], which became a strength of our study. By adhering to the appreciative inquiry technique[25], we consciously chose to avoid fixating on shortcomings and challenges, instead focusing on identifying successes and strategies for further enhancement of the development. By engaging with social partners and incorporating their feedback, we ensured that our data was reflective of the communities' viewpoints and priorities, thus aligning the development process more closely with their needs. However, this co-development also had a few downsides, namely that it led to uncertainty about the outputs it would yield.

To address this limitation, we first developed a comprehensive study protocol that thoroughly considered the methods to manage this unpredictability, capturing both the development process and the mechanisms underlying it **(see Chapter V)**. Additionally, given the longitudinal nature of our data collection, we were able to refine the development process as we assimilated new insights. However, the process remained unpredictable, necessitating flexibility in the timing and specific methods applied, which influenced the consistency and reliability of the study's findings, as well as the ability to draw definitive conclusions. Subsequently, while we extracted some potentially generalisable insights from our findings, the applicability of our findings to other settings was limited due to the unpredictability of the development process and the unique context of the study. Additionally, since the researcher was involved in both the data collection and analysis of the data, there was a possibility of confirmation bias[26], which we tried to limit by using multiple data sources for cross-validation of our findings, thus strengthening the study's credibility.

4. Discussion of the study's findings in light of current challenges and state of affairs

The findings of this study raise some key questions about civic engagement regarding serious illness, death and loss in neighbourhoods, which we want to discuss in the following section. These questions are:

- Can we expect communities to actively contribute around serious illness, death and loss? More specifically, I want to explore the following questions:
    - How to deal with a (mis)alignment of needs, desires and focus in the development process of neighbourhood civic engagement initiatives?
    - Do communities have the necessary capacity and skills to engage around the topics of serious illness, death or loss?
    - Is there a risk of professionalisation of communities through their civic engagement around serious illness, death or loss?

- What are the implications of developing neighbourhood civic engagement initiatives in the context of Compassionate Cities? More specifically, I want to explore the following questions:
    - Do we start with the development of Compassionate Cities or with the development of neighbourhood civic engagement initiatives?
    - Can the Compassionate Cities approach and the Compassionate Communities approach be integrated into the same project?

- What can we learn from other contexts in which Compassionate Communities are developed?
- What are the implications of researching Compassionate Communities in the period of a PhD? Which results can we expect in 4 years?

4.1. Can we expect communities to actively contribute around serious illness, death and loss?

4.1.1. How to deal with a (mis)alignment of needs, desires and focus in the development process of neighbourhood civic engagement initiatives?

The findings from **Chapter VI** showed that the interests of neighbourhood residents did not necessarily align with the interests of civic society representatives and the interests of city representatives. Neighbourhood residents were primarily interested in providing support for their neighbours, which was confirmed in **Chapter III** in which neighbourhood support emerged as the primary form of participation. In contrast, civic society representatives were more concerned with getting to know the other partners in the neighbourhood working around the topics of serious illness, death and loss, and the initiatives and activities they have to offer. However, gradually they found a common ground which helped them to develop activities.

While in community development literature finding a common ground is generally considered a good development strategy[27-29], some critical voices argue that this approach might overlook the diversity of interests in communities.[28, 30] Research from the Compassionate Communities Centre of Expertise aimed at constructing a shared conceptual understanding and definition of Compassionate

Communities, identified five distinct forms of communities through literature search. They found that *"communities that emerge around a common interest or passion"* (p. 1396)[31], are defined as a specific type of community, referred to as communities of interest, and that there were five different types of communities that increased connections between people, even if they did not have a shared interest. For instance 'communities by place' which aligned with our research's focus on geographically demarcated neighbourhoods, or 'communities by circumstances' which are *"driven by position, circumstances, of life experiences rather than a shared interest"* (p. 1396).[31] However, although these definitions were very informative in their linearity, we found that in practice, different types of communities co-existed in the development process of neighbourhood civic engagement initiatives regarding serious illness, death and loss. This was exemplified when one of the cities focused with their neighbourhood project on a caregiving support group in which all participants shared the common circumstance of caring for a person with a serious illness and seeking the support of peers. By employing a co-creative approach where caregivers determined the café's focal points and activities, they gradually formed a community of shared interests. However, both the researcher and the coordinator of the initiative were aware that this initiative, although connected by shared interest and circumstance, only reached a specific sub-population in the neighbourhood and that for the needs of other neighbourhood residents to be met, other initiatives needed to be developed.

Although our findings show that meeting the distinct interests of different communities living in a neighbourhood remains a real challenge, our results instil a sense of hope illustrating that a shared interest is something that can be cultivated over time based on other commonalities, such as shared circumstances.

4.1.2. Do communities have the necessary capacity and skills to engage around the topics of serious illness, death or loss?

We found in **Chapter VI** that although neighbourhood residents recognised the need to participate around the topics of serious illness, death and loss in their neighbourhood, and specifically regarding helping neighbours, they were concerned about lacking the right skills and capacities to engage themselves fully around these topics. However, our finding in **Chapter IV** showed that exposure to serious illness, death and loss in the form of previous experiences had the potential to increase people's perceived capacities and skills and from there to increase neighbourhood participation around these topics.

In recent years, there has been a shift in thinking about how to approach care for people who are seriously ill, caregiving or bereaved, with a growing recognition of the importance of public health initiatives that move beyond the role of healthcare services.[32] Thereby, the importance of communities in health promotion, community development, and civic engagement around serious illness, death and loss has become widely accepted in public health literature.[31,33, 34] Some authors, such as Kellehear, even go as far as to say that participation in serious illness, death and loss is a collective social responsibility, that pertains to everyone in society.[35] However, we identified that while communities are encouraged to support each other when confronted with serious illness, death and loss, they often perceive a lack of the necessary skills and capacities to do so. Further substantiated by literature on capacity-building around these topics[36-38], and our results in **Chapter IV**, we can consider capacities and skills as a facilitator for neighbourhood participation regarding serious illness, death and loss. However, where I mainly considered it as a prerequisite for neighbourhood participation, best attained before the development process, literature on capacity-building Compassionate Communities models suggests that capacities and skills do not necessarily have to reach their full potential from the start, but that they can be gradually acquired throughout the development process; and that this gradual growth is beneficial in enhancing of community empowerment.[38-40]

While I agree that capacities and skills are important in the development process of neighbourhood civic engagement initiatives, we also questioned in **Chapter VII** whether awareness-raising and training activities, as emphasised by many public health initiatives, actually help individuals build capacities and skills aimed at empowerment. Alternatively, we considered whether more comprehensive exposure to these topics might be more effective. The Lancet Report on the Value of Death has sparked a shift in perspective on this matter, highlighting that gaining capacity and skills is not just an individual endeavour through educational and awareness-raising activities, but rather a collective action that must be integrated within our entire death system to be successful.[41] Therefore, the report advocates for structural changes within our current death system, aiming to expose communities to serious illness, death or loss on the level of civic society, professional health services and governments.[41]

Since civic society encompasses the everyday contexts in which we live and interact, exposure to topics such as serious illness, death and loss can be created in a variety of settings, including schools and workplaces. Bakelants et al. highlighted the potential role of universities as both workplaces and educational environments in normalising the topics of serious illness, death and loss.[42] For example, universities could organise cultural theme weeks about death and dying on the university campus and establish clear procedures for temporary leave, care days and postponing assignments for staff and students.[42] Additionally, there is also a potential for professional services to expose communities to the topics of serious illness, death and loss.[43] Residential care centres, for example, could organise activities that are open to the neighbourhood, as many of them in Belgium already do.[44] Furthermore, Paul et al. found that there is a unique opportunity in linking services with schools, for instance in facilitating classroom conversations about serious illness, death and loss.[45] Paul et al. refer to this type of integration between communities and services as a reorientation of services toward community development.[45] Lastly, governments can develop policies to enhance services engaging with communities around serious illness, death and loss.[41, 46] Not merely to improve service quality or reach, but with the more far-reaching aim of community development.[41, 46] An example of this, is the palliative care policy provided by the government of Kerala which emphasises the importance of participatory palliative care in close connection with communities and enhances collaborations between professional health care units and volunteer units.[47] In Belgium, the residential care decree of February 15th 2019, mandates close engagement between the residential care centres and their neighbourhood surroundings.[48] Thus, while educational and awareness-raising activities are essential for equipping communities with the necessary skills and capacities to engage comfortably around the topics of serious illness, death and loss, I also recommend implementing broad systemic changes on the level of civic society, professional services and government institutions. This recommendation is substantiated by the provided examples on each level.

4.1.3. Is there a risk of professionalisation of communities through their civic engagement around serious illness, death or loss?

The systematic review presented in **Chapter II** and the results of the process evaluation in Chapter 6 revealed that most civic engagement initiatives regarding serious illness, death and loss originated from collaborations between researchers and the community or between various community-based organisations. Only a minority of the initiatives were initiated by community members. These findings underscored the prevalent involvement of professionals, either as researchers or as professional services in initiating civic engagement initiatives regarding serious illness, death and loss. This professional involvement indicated a degree of professional control over the development process of these initiatives, including the focus on activities and collaborations in the development. This finding leads me to wonder whether this professional involvement also leads to a more professional role of community members participating in it, and if so, which risks or opportunities are attributed to this.

Over the years we have seen a shift in the motivations behind civic engagement activities.[49-51] While in the past civic engagement was primarily driven by altruistic motives and a collective sense of responsibility, current trends indicate a decline in this collective ethos, leading to more individualistic motives for civic engagement.[49-51] On an individual level, this change has resulted in more short-term engagements that better fit personal schedules and specific interests.[50, 52] On an organisational level, a broader range of civic engagement opportunities is being offered, often within a project-based format, allowing for shorter-term involvement.[50, 52] However, combined, these approaches risk creating a more professionalised form of civic engagement, increasingly based on achievement rather than a sense of membership and collectiveness.[50, 52]

Although public health initiatives concerning serious illness, death and loss originated from the idea of moving death and dying beyond the confines of the professional sphere and into communities[53], there is, also in these approaches a persistent tension between professional-led initiatives targeting efficiency and effectiveness, and community development approaches.[54] This tension is particularly evident in cities and neighbourhoods, where the intricate relationship between professional services, local governments and community members creates a complex context to develop civic engagement initiatives in.[55, 56] Consequently, professionals are often entrusted with leading the development processes of civic engagement initiatives, due to their ability to navigate these complexities and their capacity to engage with local authorities.[55] This trend was also observed in Chapter 6, where the development process of neighbourhood civic engagement initiatives in our study involved a wide range of professionals, including project leaders, a neighbourhood worker, a change manager, two researchers and representatives from civic society organisations. Community development literature both inside and outside the scope of public health indicates that professional-led initiatives may contribute to the professionalisation of initiatives, by prioritising effectiveness and efficiency, which require specific skills and knowledge that may not be present in the communities.[54, 57, 58] This raises the question of whether our professional-led development of neighbourhood civic engagement initiatives increases the risk of professionalisation, excluding certain populations from the development. Current Compassionate Communities models, e.g. Community Connectors[59] and Compassionate Neighbours[60], emphasise the importance of 'community-led' activities when working together with professional services. Community-led is here interpreted as, even when initiatives are developed in collaboration with professional services, the community has an active role and shaping the initiatives to their needs.[59, 60] Subsequently, I advocate for a more community-led approach to developing neighbourhood civic engagement initiatives, in collaboration with professionals. If initiatives are led by professionals, I recommend that they create space for diverse forms of participation, including low-profile engagement that does not require specific expertise and does not aim solely for efficiency.

4.2. What are the implications of developing neighbourhood civic engagement initiatives in the context of Compassionate Cities?

Chapter VI which reported on the aspects and contextual factors that facilitated or hindered the development process of the neighbourhood civic engagement initiatives regarding serious illness, death and loss, illustrated that many of these factors pertained to the development of these initiatives within the contexts of Compassionate Cities. More specifically, it highlighted the political prioritisation by the cities of the Compassionate City programme over neighbourhood civic engagement initiatives and begs an exploration of the relation between these two approaches in terms of their development approaches.

4.2.1. Do we start with the development of Compassionate Cities or with the development of neighbourhood civic engagement initiatives?

Findings from **Chapter VI** show that the two selected cities considered the Compassionate City, with its city-wide scope, as a higher political priority than the neighbourhood civic engagement initiatives.

In 2021, the Flemish government launched a two-year Caring Neighbourhoods funding call to promote neighbourhood networks of care around health and wellbeing, providing funding to 133 neighbourhoods. One of the cities applied for and received funding for its neighbourhood civic engagement project regarding serious illness, death and loss. However, a divergence in priorities emerged. While the Flemish Government endorses the caring neighbourhood project and intends to further emphasise neighbourhood-oriented work in the future[61], the two cities in which we developed initiatives, preferred city-wide initiatives. Kenny et al. indicate that city-wide initiatives generate greater visibility among citizens, which is important from a political perspective.[58] However, despite the absence of specific guidelines for fostering neighbourhood civic engagement within the framework of Compassionate City programmes and how these two approaches intersect, literature within the scope of urban design highlights a notable disparity in complexity between city-wide and neighbourhood-level initiatives.[62] This complexity arises primarily from a diminished sense of community connectivity at the city level, attributed to a lower geographic proximity.[62] Additionally, the involvement of a diverse array of relevant parties, each with distinct priorities and collaboration preferences, adds layers of complexity to city-wide initiatives.[63] As a result, De Carli and Frediani advocate for initiating development processes at the local level before considering expansion to a city-wide scale to establish stronger foundations for engagement and collaboration.[62] The latter approach was implemented in neighbourhood H, which focused on specific areas of interest within both the Compassionate City and neighbourhood initiatives, with the intention to expand to other initiatives later in the process. This approach not only created a solid foundation for participation, as anticipated in literature[62], but also increased the level of sustainability of the developed initiatives.

Consequently, the endorsement and financial support of neighbourhood-focused care projects by the Flemish government creates an opportunity for making politicians on the local level aware of the importance of neighbourhood-oriented work, for successful and sustainable Compassionate Communities and Compassionate Cities. However, integrating neighbourhood civic engagement initiatives into city contexts is not the sole method for achieving sustainability, nor is it sufficient on its own. It is essential to extend these initiatives to the neighbourhood level and develop a robust support base, ensuring the initiatives become self-sustaining.

4.2.2. Can the Compassionate Cities approach and the Compassionate Communities approach be integrated into the same project?

In **Chapter VI** we found that both cities faced challenges in integrating the neighbourhood civic engagement initiative into the Compassionate Cities program. This challenge stemmed partly from the sequential development process where the Compassionate Cities initiatives took precedence over the neighbourhood civic engagement initiatives.

In both cities, the Compassionate Cities were approached as co-creative development strategies that also incorporated several top-down elements. Regarding the co-creative aspects, initiatives were developed by relevant parties from the health and wellbeing sector and beyond. The top-down elements involved city representatives who played a large role in bringing together relevant parties, selecting the focal topics of the project and coordinating the development of initiatives. Conversely, for the neighbourhood civic engagement initiatives, an a priori decision was made to adopt more of a community development approach by organising group discussions with neighbourhood residents to solicit input and employing co-creative methods to involve civic society representatives in the development process. These different approaches- with Compassionate Cities favouring a more top-down approach and Compassionate Communities a more bottom-up approach- align with the manner in which Kellehear, who strongly inspired the Compassionate Cities movement, has suggested both are developed.[64] However, while his writings have been instrumental in clarifying the difference between the two approaches, they also risk oversimplifying Compassionate Cities as inherently top-down and Compassionate Communities as bottom-up community development initiatives, which was to a certain extent the case in the two cities. Additionally, when discussing Compassionate Cities and Communities with city representatives, I generally based my discourse on the approaches described by Kellehear, which may have further distanced the two approaches.[64] Consequently, I recommend that researchers introduce the two approaches with the nuance they need.

Despite the prevailing perception of city representatives of Compassionate Cities and Communities as two distinct approaches, aspects of the Compassionate Cities' development approach inadvertently influenced the neighbourhood civic engagement development. This became apparent when in one of the neighbourhoods a hierarchical structure akin to that of the Compassionate City's development approach was installed, with a steering group and respective working group developing the neighbourhood civic engagement initiatives. However, the adoption of this top-down approach precipitated a series of challenges. These included a power imbalance between civic society representatives and city representatives, difficulties in mobilising neighbourhood resources and difficulties in extending the development to encompass neighbourhood residents and other relevant key figures. Nevertheless, notwithstanding the challenges posed by including top-down elements in a community development approach, we refrain from advocating for a strictly bottom-up approach, since it is important to recognise that cities can also assume a facilitating role in the development process of neighbourhood civic engagement initiatives.[65] For example, by organising city-wide festivals that foster neighbourhood participation[66], and by providing structural support to the developed initiatives[34]. Hence, rather than reducing Compassionate Cities to a top-down approach and Compassionate Communities to local community development approach, I posit that both contexts can mutually reinforce each other. Based on known Compassionate Communities and experiences in the two neighbourhoods, I recommend a hybrid model where local governments can provide a supportive framework for neighbourhood civic engagement initiatives around serious illness, death and loss to be developed. Conversely, I propose the more top-down initiated Compassionate Cities could benefit from community development approaches to increase ownership over the initiatives that are developed.

4.3. What can we learn from other contexts in which Compassionate Communities are developed?

The systematic review presented in **Chapter II** and the review in **Chapter VII** both highlighted the insufficient knowledge available on civic engagement initiatives around serious illness, death and loss globally, particularly in low and medium-income countries, as these regions are consistently underrepresented in peer-reviewed literature. Fortunately, we were able to identify the Neighbourhood Network in Palliative Care (NNPC) [47] in India, a prominent initiative that is well-documented in peer-reviewed literature, and the Compassionate Neighbours[67] initiative[67] in London, which was influenced by the NNPC initiative in India in its development. These initiatives, along with the respective contexts in which they were initiated, offer significant potential for inspiring and informing the development of neighbourhood civic engagement initiatives regarding serious illness, death and loss within a Flemish and Belgian context. Compassionate Neighbours is inspiring for its far-reaching form of community engagement, and the Neighbourhood Network in Palliative Care for its supportive policy framework that allows for the different actors that are active around serious illness, death and loss, to collaborate.

Historically, palliative care provision in the United Kingdom has been deeply intertwined with volunteerism, as the hospice movement has heavily relied on volunteers since its inception.[68] This historical legacy continues to resonate in the United Kingdom, with an estimated 160,000 volunteers contributing approximately 23 million hours of their time to palliative care.[68] Conversely, while volunteers in Belgium initially played a less prominent role in the development of palliative care compared to the UK, they have become an integral part of the current landscape of palliative care provision.[69] A survey study illustrated that over 80% of specialist palliative care services in Belgium involve volunteers in various activities, such as assisting people who are seriously ill with eating or taking their medication.[69]

However, a notable disparity exists in the levels of community engagement of specialist services between the UK and Belgium, with UK services attributing 80-90% of their engagement to the general public, compared to 31-71% for Belgian services.[70] This difference is largely attributed to variations in funding mechanisms.[70] In the United Kingdom, hospices heavily rely on charitable donations from communities to support their daily operations. Subsequently, they pursue increased efforts to engage with and customise their care services to meet the specific needs of communities.[68] This approach is exemplified by the Compassionate Neighbourhoods initiative in London, which was initiated in response to the identified gaps in the available palliative care services, particularly for people from Black, Asian, and Minority Ethnic (BAME) backgrounds.[67] This initiative departs from traditional service-oriented volunteering, encouraging civic engagement activities akin to those one would undertake for a friend or neighbour, rather than having a pre-scribed volunteering role.[67]

The Compassionate Neighbours initiative drew inspiration from the Neighbourhood Network in Palliative Care (NNPC)[47] in Kerala, India. In India, the uneven geographic distribution of palliative care services makes them predominantly accessible to individuals with sufficient financial means.[47, 71] Kerala, situated in South-West India, exemplifies this disparity as it encompasses two-thirds of the country's palliative care provision, yet remains accessible only to a specific sub-population capable of affording it.[51] Additionally, just like in the UK context, only a minority of palliative care relies on government funding, as most of the provision is centred within community-based and non-governmental organisations.[47, 71] In response to this unequal palliative care provision, the Neighbourhood Network in Palliative Cate (NNPC) was established in 1999.[47] This pioneering initiative aimed to involve communities in palliative care, supported by progressive public health policies in Kerala.[47] These policies enabled communities to play an active role in palliative care, complementary to existing home-based services.

These two initiatives were also shared as inspiring examples with the two cities where we conducted our research. However, in practice, it was challenging to apply these inspiring examples in our context, where the component of community engagement around serious illness, death and loss is much less pronounced than in the British and Indian contexts. Nevertheless, there were several strong examples in our neighbourhoods where civic society representatives from organisations organised activities within the neighbourhood to reach neighbourhood residents. However, since the number of activities that required active participation from the neighbourhood was limited, I suggest that increasing such activities to active participation is a crucial next step in the project. In terms of adapting supportive policies, as seen in Kerala, no changes have been implemented in the cities. One possible explanation is that only a limited number of city aldermen were involved in the project, rather than the entire city council and mayor who are essential for city-wide policy changes. Another explanation could be that policy adaptions are far-reaching forms of change that require ample time for policy-makers to recognise the added value of communities around the topics of serious illness, death and loss.[72]

Furthermore, although both the UK and the Indian initiatives serve as inspirational examples in terms of engaging with communities and adapting supportive policies, we also want to remain mindful of the contexts in which these initiatives were initiated. Both community development approaches were partly instigated by challenges relating to the underfunding of palliative care services, and in the Indian context, challenges regarding the geographical distribution and accessibility of these services.[73, 74] Consequently, although state-funded institutionalised palliative care in Belgium may have constrained far-reaching community development approaches, I do in no case argue for reduced funding for palliative care. Instead, I would like to emphasise the necessity for integrating community development approaches complementary to existing services, as was done in our study, while also further investing in these services. A few active examples in Belgium include Coda vzw, a hospice and day-care centre which is based on the British hospice model and organises various activities, some charitable, to increase connections with neighbourhood residents.[75] Furthermore, the EU Navigate research project, adapted from the Canadian Nav-Care[76], is being studied in six European countries, including Belgium.[77] This model aims to connect people with care needs to the necessary services and resources, by working with trained community volunteers.[77] Lastly, I suggest that we must be mindful that what works in one context, cannot be copied to another context, without the necessary contextual and cultural adaptions.

4.4. Civic engagement, what's in the definition?

In our introduction, we adopted a comprehensive definition of civic engagement, encompassing three core elements: engagement through community services, collective action, and political involvement.[78] Utilising such an expansive definition allowed us to conceptualize civic engagement as a dynamic and multifaceted concept, spanning a spectrum from informal, everyday acts of support through well-structured, community-based initiatives. With the completion of this study, we now have the opportunity to revisit this definition in light of our findings. This reflection will enable us to explore how various forms of civic engagement have manifested throughout our research and which aspects may require further consideration.

One of the first distinctions we made in our exploration of civic engagement was to categorise those forms of engagement carried out through community services. In practice, we observed that in both Sint-Kruis and Herzele, the primary participation indeed stemmed from local civic society representatives involved in community services. A key reason for this substantial involvement may be attributed to the traditional relationship between services and government in Belgium, which operates under a service-politics split.[79] This split refers to the structure wherein political leaders determine the policy direction and funding, but the actual administration and delivery of care are carried out by professional, non-partisan civil entities- including healthcare providers, social insurance funds, and hospitals.[79] This dynamic was also evident in our study, where both local governments prioritized the topics of serious illness, death, and loss within their cities. However, despite their efforts, they remained heavily reliant on external services to implement these policies effectively. As a result, these services took on a central role in the project, shaping much of its direction and execution.

When applying our definition of civic engagement as was set out in the introduction, we made an explicit exclusion in our systematic review of service-oriented initiatives. These initiatives' sole aim is to enhance the quality of their services by leveraging community engagement. However, although this criterion was useful on paper, and guided our systematic review in the direction of including a focus on forms of civic engagement that go beyond mere service improvement, it proved challenging to apply in practice. Specifically, in our process evaluation, we found that while the initial motivations of local partners often revolved around enhancing the quality of their services, they were also genuinely interested in embedding their operations within the community and organising activities that would promote this goal. So, while a narrow definition of civic engagement would offer greater theoretical precision, I suggest I would fail to capture the full scope of community development efforts.

Another important conceptual consideration is the role of collective action as a form of civic engagement. In our interpretation, collective action encompasses not only group activities but also individual participation aimed at achieving collective benefits.[78] Initially, we excluded informal caregiving from this conceptualisation, believing that individual engagement with family members or close friends did not align to foster collective involvement within communities, as emphasized by the principles of Compassionate Communities. However, our observations revealed a blurring of boundaries between assisting neighbours and providing care for family and close friends living in the same area, caregiving often extends to those living in the same neighbourhood[80] which suggests that informal caregiving should not be disregarded as a form of civic engagement within Compassionate Communities. Instead, the focus should be on how this caregiving is integrated into broader community efforts. Additionally, while the classic interpretation of informal caregiving for close family or friends may not, on its own, constitute civic engagement, I suggest it can be transformed into a meaningful form of collective engagement through connection and collaboration within the community.

The literature on volunteering highlights the influence of modernisation, which has introduced more reflexive, consumer-driven forms of engagement.[50, 81] This type of involvement is typically characterized by more individual, episodic, and short-term participation.[4] These reflexive styles of engagement are indeed evident in our study, where citizens expressed a preference for shaping their involvement based on personal interests and time availability. However, while we described collective action in our introduction as one of the three elements of civic engagement, in practice is very much intertwined with how engagement through community services is organised and what is the political stance towards these more autonomous forms of civic engagement.

In line with the existing literature on volunteering, many of the initiatives and services in our study have already been adapted over the years to incorporate more autonomous and reflexive forms of volunteering. For example, several organizations offered a "volunteering menu," providing individuals with various options to suit their interests and availability.[50] However, we found that introducing more profound forms of civic engagement, grounded in community development principles—where communities take the lead in formulating their own responses to serious illness, death, and loss—posed new challenges at both the service and political level. Specifically, for services, there were questions regarding how civic engagement relates to existing volunteer work and how it aligns with risk and reliability policies within those services. Additionally, there was a broader discussion about who is responsible for these types of civic engagement. The struggle to understand the relationship between community services and civic engagement is not unique to the Belgian context. A similar challenge arose in the United Kingdom's Compassionate Neighbours project, organized through a hospice, where there was initial difficulty in reconciling this new form of engagement with the existing volunteer work already in place. Ultimately, the hospice opted to keep the Compassionate Neighbours initiative separate from the established volunteer program. While this decision posed a risk initially, it ultimately led to increased trust and legitimacy for both the hospice and the Compassionate Neighbours.[60]

The third aspect of our definition of civic engagement is political action. In our study, we observed that civic engagement was not primarily driven by political motives; rather, it was influenced by political processes. Hustinx[81] previously discussed how neoliberal processes at the macro level can impose limitations on the autonomous and reflexive styles of volunteering. For example, these processes might manifest in the forms of mandatory volunteering for students seeking extra credits or in rehabilitation programs for incarcerated individuals. Although this is not explicitly the case in Compassionate Communities, there are still expectations set by governments regarding the roles of citizens and neighbourhoods. In this regard, De Donder[29] has argued that the warm engagement arising from neighbourhoods should not be seen as a substitute for the colder forms of solidarity organised by governments, which continue to serve as a foundation for addressing structural inequalities. This highlights that our definition of civic engagement must account for the interplay between civic engagement initiatives and the broader political context, in terms of processes rather than motivations.

4.5. What are the implications of researching Compassionate Communities during the COVID-19 pandemic?

The COVID-19 pandemic induced a societal impact by fostering increased feelings of shared destiny and solidarity, which were expressed through community support and coordinated action.[82, 83] A large portion of this support manifested as intergenerational neighbourhood participation, where people assisted each other with tasks such as doing groceries, picking up prescriptions, and other daily activities.[82] Although this was a spontaneous societal response to a healthcare crisis, many governments, including the Belgian government actively promoted and encouraged these forms of community-based support.[84] Given the significant potential of informal neighbourhood support highlighted during the COVID-19 pandemic, it is not surprising that also in our study, which focuses on serious illness, loss, and grief, local governments emphasised promoting "little helping", which are small acts of helping within neighbourhoods. However, this policy focus should not be viewed solely as a response to the pandemic. In the Flemish context, there has long been an emphasis on this “little helping”, especially within the framework of "caring neighbourhoods" where this concept is promoted as a key component of the socialisation of care, a process aimed at integrating informal support into the broader healthcare system.

Furthermore, the COVID-19 pandemic only led to a limited thematic impact on the neighbourhood initiatives that were developed. The two cities either involved caregivers with pre-existing roles in neighbourhoods or civic society representatives from local organisations who struggled to promote "the little helping” due to the constraints of their professional positions. One notable COVID-related initiative was the “consolation walk,” which connected various public spaces of grief and consolation in the neighbourhood. These spaces emerged during the pandemic and were facilitated and supported by the civic organization Ferm. However, while the creation of these spaces was directly prompted by COVID-19, the focus within our study was rather on using them as a way to foster further neighbourhood connections around themes of serious illness, death, and loss. Subsequently, although there was some thematic influence of COVID-19 it was rather limited and mostly indirect.

A more substantial implication of the COVID-19 pandemic emerged at the level of the initiatives' development, as evidenced by delays reflected in the timeline discussed in **Chapter VI**. The delay was partially attributable to government-imposed protective measures that prohibited group gatherings. Even after these restrictions were lifted, city officials maintained a cautious approach, opting to minimise risks, which further extended the timeline. However, the delays were not solely a consequence of COVID-19. Other factors, described in **Chapter VI** played a more substantial role. These factors included a shortage of personnel, city-wide initiatives being prioritised over localised neighbourhood initiatives and finding common and tangible areas of interest, etc. So, while COVID-19 induced some delays, it mostly amplified structural issues that were already present, such as the lack of time and resources to facilitate two simultaneous co-creative projects. Subsequently, COVID-19 was neither identified as a barrier nor a facilitator by the civic society representatives.

When designing the survey study as a pre-post measurement, we chose to measure neighbourhood participation around serious illness, death, and loss by specifically referencing participation before the COVID-19 pandemic in the survey items. This was necessary to avoid measuring participation during the pandemic, which would complicate the possibility of conducting a post-measurement afterwards. As a result, we do not have a clear understanding of whether the pandemic itself acted as a facilitator for participation on these topics within their neighbourhoods. This remains an important aspect to be explored in future research.

4.6. What are the implications of researching Compassionate Communities in the period of a PhD? Which results can we expect in 4 years?

The findings of our process evaluation, presented in **Chapter VI**, revealed that the anticipated impact of the neighbourhood civic engagement initiatives was not yet reached, but other shorter-term achievements emerged. Although the aim was to foster a cultural shift in the neighbourhoods, encouraging mutual support around the topics of serious illness, death and loss, this objective was not yet reached in this short amount of time. What the initiatives did accomplish, however, was a perceived increase in neighbourhood social cohesion, as experienced by the civic society representatives and city representatives. Nevertheless, this result did not meet their initial expectations, leading to some feelings of disappointment.

Compassionate Communities do not operate in a vacuum but within a context of governance bodies, health and palliative care services and existing civic society initiatives.[53] This complex environment makes achieving culture change in a short period difficult[3], confirming that aiming for such a shift around serious illness, death and dying may have been an unrealistic goal from the outset. Additionally, our results in **Chapter II** confirm that increased neighbourhood social cohesion is in fact not a bad result. We found that people who perceive higher levels of social cohesion are also more likely to participate in neighbourhood activities regarding serious illness, death and loss. This can be attributed to the increased connection among people, which reduces barriers to seeking or providing on sensitive topics of serious illness, death and loss.[85] Thus, while the outcome of heightened neighbourhood social cohesion may initially seem underwhelming, it represents an essential first step towards the desired culture change regarding serious illness, death and loss.

Considering these findings, it is also necessary to reflect on the question of whether the funding and consequently the time that was allocated to the project, truly sufficed for achieving culture change regarding serious illness, death and loss. Indeed, our findings in **Chapter VI** revealed that the development of the two Compassionate Cities and neighbourhood civic engagement initiatives was highly resourced, mainly driving on paid positions of the project leaders, the neighbourhood worker, the change manager and researchers, yet inadequate to ensure long-term results or the self-sufficiency of the initiatives to continue their activities. The latter was substantiated by the results of our systematic review **(Chapter II)**, in which the discontinuation of funding was mentioned as the main risk for continuing the civic engagement initiatives and achieving long-term impact. This was also confirmed in a Compassionate Communities feasibility evaluation report where paid positions were linked with risks regarding sustainability.[86] Therefore, I advocate for long-term funding approaches to anchor the developed neighbourhood civic engagement initiatives and achieve long-term impact. Firstly, follow-up funding from the Flemish government is essential to further support the caring neighbourhood initiatives until they become more self-sufficient. Additionally, at the local level, more long-term funding should be provided for the development of neighbourhood civic engagement initiatives on the topics of serious illness, death and loss. Involving other policy domains in the city, such as culture and education, could be beneficial in this regard. Finally, I advocate for a culture change in research funding, where community development projects are considered as valuable as intervention-oriented projects. Instead of primarily financing new research projects, more funding should be allocated to measuring the long-term impact of initiatives developed with previously acquired funding.

5. Recommendations for policy, practice & research

5.1. Recommendations for local policy-makers

5.1.1. Adopting a community development approach

At the policy level, we advocate for a paradigm shift, transitioning away from traditional top-down development strategies towards embracing community development and empowerment approaches within neighbourhoods. Effectively implementing this strategy shift requires policy-makers to consider neighbourhood initiatives equal to city-wide initiatives, and to recognise that while community development is a time-intensive and resource-demanding endeavour, investing sufficient time and resources into nurturing grassroots initiatives, successfully bolsters their success and longevity.

Furthermore, to cultivate a robust foundation for civic engagement initiatives within neighbourhoods, it is crucial that residents are not merely consulted for their input but are actively involved in the development and implementation process. We urge policymakers to establish a framework that empowers citizens to participate actively in the development process, even if their viewpoints diverge from the original policy plans or if they opt for alternative approaches, which may not prioritise efficiency and effectiveness. I recommend policymakers establish a support network in neighbourhoods offering mentorship stimulating collaboration and sharing best practices for all sorts of neighbourhood civic engagement, not only those that fit within the pre-existing policy plans.

5.1.3. Long-term strategies for increasing sustainability

Recognising that culture change around the topics of serious illness, death and loss cannot be achieved within four years[3], I argue that local policy must play a critical role in developing a long-term strategy to ensure the project's sustainability and prevent its discontinuation after four years. This approach should also ensure the continuity of the theme across different political terms, preventing it from becoming associated with specific politicians, and potentially subsiding thereafter. Additionally, local governments should acknowledge that total self-sufficiency of the project is difficult to attain within four years. Therefore, resource allocation must be adapted accordingly. In the event of discontinuity of resources, strategic considerations should be made for continued investment and facilitation of the project. This may involve seeking additional funding sources or engaging new partners. Additionally, expanding partnerships throughout the project's duration is needed to ensure that the project does not solely rely on individuals in paid positions, implicating the project's discontinuity when these positions are resolved.[86] Furthermore, I suggest that policymakers account for the time required to develop initiatives through a community development approach, allowing these initiatives the necessary time to evolve. More specifically, I recommend a culture shift among policymakers to move away from the expectation of quick wins and instead adopt a long-term vision focused on gradual evolution rather than rapid revolution.

5.2. Recommendations for national policy-makers

5.1.2. Increasing exposure to serious illness, death and dying

Since our current Western palliative care provision primarily operates within the confines of professional palliative care services, policy interventions are essential to connect services with the communities in which they operate. I recommend that policy-makers draw inspiration from frameworks, like the one in Kerala, where policies facilitated the integration of civic engagement initiatives within existing professional practices. However, it is crucial to ensure that this integration does not undermine community empowerment, but rather that both communities and professional services complement and reinforce each other.

In Flanders, a reform of palliative care is in progress, focussing on three main pillars: continuous palliative care, palliative care that addresses the care and support needs of people with serious illness and their families and raising public awareness around palliative care among other things, increasing palliative care literacy and making palliative care accessible.[87] Especially the latter creates interesting opportunities to bring the topics of serious illness, death and loss closer to the public through neighbourhood civic engagement initiatives. We recommend that the Flemish government establish a link between their focus on awareness raising as part of the palliative care reform in Flanders and the caring neighbourhood programmes. Caring neighbourhoods lacking initiatives regarding serious illness, death and loss should be further encouraged and facilitated to integrate these topics into their current activities. Additionally, other neighbourhoods that were not formally part of the Caring Neighbourhoods project, should be allowed to access information and support in developing initiatives around these topics. Instead of initiating new initiatives, emphasis can also be placed on enhancing existing efforts, as demonstrated with the caregiving café in one of the cities. Additionally, ongoing neighbourhood activities, which face a loss of support following the ending of this research project and the caring neighbourhoods initiative, should receive further support within the context of the palliative care reform. This support can be in terms of coaching, coordination and resources.

5.3. Recommendations for community-building practitioners

5.3.1. Facilitating community-ownership

Since we found some challenges regarding the adoption of a far-reaching community development approach within the context of two Compassionate City programmes, one of the key recommendations is to attribute sufficient ownership to communities and neighbourhoods in the development process. This can be achieved through several strategies. Firstly, when employing an asset-based community development approach[24], it is crucial to create opportunities for effectively leveraging existing assets, in a way that resonates most with the interests and aspirations of the communities involved. For instance, if civic society organisations already have existing neighbourhood teams, which they wish to engage in the development process, an opportunity should be created to do so. Additionally, these assets can also be individuals with community-building capacities in the neighbourhood (e.g. local merchants, neighbourhood police) who are eager to contribute but were not previously involved. The latter can be further facilitated by providing various opportunities for participation, ensuring that everyone who wants to join, has the opportunity to do so. Secondly, project leaders must adopt an organising and coordinating role, rather than taking on the responsibility themselves to organise activities. This approach has the potential to foster a greater sense of ownership within the neighbourhoods.[29]

5.2.2. Adopting inclusive approaches

Furthermore, community-building practices need to maintain a continuous focus on adopting inclusive approaches within neighbourhoods. While group discussions with neighbourhood residents are a positive step towards involving residents in the development process, they tend to engage only a specific group of people who are intrinsically motivated and often already have expertise on the topics of serious illness, death and loss. Although starting with the most motivated individuals, aligned with the asset-based community development approach can be a good idea, there’s a risk of overlooking the diversity within the neighbourhood. To foster inclusive approaches, it is worth drawing inspiration from initiatives abroad, like Compassionate Neighbours[67] in London aiming to include people from Black, Asian, and Minority Ethnic (BAME) backgrounds in community development through community outreaching activities (e.g. having a stand at the weekly market inviting people over for a conversation).

5.2.3. Focus on realistic, achievable goals

Finally, we advise community-building practitioners to establish achievable goals within the predefined timeframe. Pursuing an ambitious goal of completely shifting attitudes towards serious illness, death and loss can lead to disappointment among participants. Instead, I would like to recommend beginning with developing small-scale initiatives that facilitate gradual progress towards longer-term objectives, as was the case with the caregiving cafés in one of the cities.

5.4. Recommendations for research

5.4.1. Cross-cultural research

The civic engagement initiatives were developed in the specific context of two neighbourhoods: one in a peri-urbanised city, and the other in an urbanised city. Although we were able to derive some generalisable insights from our findings as facilitating communities' ownership, it is necessary to gather insights from additional contexts to achieve a more comprehensive understanding of effective facilitation strategies, and their mechanisms in order to know what are universal or local aspects of their development. To this end, it is essential to examine other neighbourhoods in Flanders with a similar context, but also with a higher or lower level of urbanisation and with other demographic profiles. Given the Flemish government's aspiration to scale up the Caring Neighbourhood approaches to other neighbourhoods in Flanders[61], there is a significant opportunity for researchers to examine and compare these diverse developmental contexts. An evaluation study on 35 of the caring Neighbourhoods in Flanders and Brussels has already been conducted by De Donder et al. providing valuable insights into the development strategies of these neighbourhoods.[29] However, given that some neighbourhoods also partially focus on the topics of serious illness, death and loss, is particularly interesting to further evaluate the Caring Neighbourhoods, not only in terms of the long-term impact but also to examine which aspects of their development are specific to serious illness, death and loss, and which are common to community development projects outside this scope. Furthermore, in our study, many identified facilitators and barriers to the development process were specifically linked to the fact that the project was city-initiated, particularly within Compassionate City programmes. A comparative study of initiatives not initiated within (Compassionate) Cities could provide deeper insights into the risks and facilitating factors associated with these contexts.

Additionally, I recommend to conduct more cross-cultural international research. Both our systematic review (**Chapter II**) and the review of literature in **Chapter VII** indicate that our current knowledge of Compassionate Communities is primarily concentrated in high-income countries where English is one of the main languages. Consequently, we have a particular understanding of the activities Compassionate Communities focus on, such as navigation through existing resources[76], and the partnerships from which they emerge, including community-academic partnerships and collaborations with community-based organisations. While these often-comparable contexts – where civic engagement initiatives are situated with an institutionalised palliative care framework – are highly valuable for drawing parallels to the Flemish context, it is equally important to gain insights in other, more diverse contexts. Understanding the different political and societal factors from which these initiatives arise and the development strategies applied in those settings can provide valuable perspectives and enhance our overall comprehension of effective Compassionate Communities strategies.

5.4.2. In-depth research into processes and outcomes

Based on the process evaluation we have formulated numerous potential strategies for the development of neighbourhood civic engagement initiatives and made several assumptions regarding possible development strategies, such as expanding initiatives to include other neighbourhood residents and key figures. Further research is needed to effectively implement these strategies and assumptions and to evaluate their progress. Additionally, we found that many challenges arose from the civic society representatives lacking ownership in the project. However, while the Compassionate Communities literature emphasises the need to empower communities, it provides limited guidance on how this power can be effectively attributed to them, as we found in **Chapter VII.** Therefore, more in-depth research is needed to examine these power dynamics within the specific context of Compassionate Communities.

Furthermore, the survey articles **(chapters III and IV)** have yielded several results that require further investigation. We found that individuals who perceive higher neighbourhood social cohesion are more likely to participate in neighbourhood activities regarding serious illness, death and loss. This finding needs to be further tested quantitatively through longitudinal data collection. Additionally, qualitative data is necessary to understand the mechanisms behind this association: specifically, how neighbourhood social cohesion translates into participation around serious illness, death and loss-related activities. Additionally, we found that individuals who had a caregiving experience in the last year were more likely to participate in neighbourhood activities regarding these topics, particularly if they believed they gained capacities and skills from their previous experiences. Similarly, this result requires further testing through longitudinal, quantitative data collection on these concepts, complemented by insights from qualitative literature on how we go from experiences to gaining capacities and skills from them and then to neighbourhood participation around these topics. Additionally, I suggest we need to explore whether there is a difference in participation between people who had a positive or negative caregiving experience.

5.4.3. Making outcomes visible

Furthermore, research plays a crucial role in sustaining the developed neighbourhood civic engagement initiatives, not only by formulating potential sustainability strategies based on a process evaluation but also by gathering visible data about the outcomes (e.g. the number of participants at activities). Such data can support applications for continued funding and help prioritize these initiatives on cities' agendas, to ensure their continuation. Furthermore, it should be noted that the four-year research period was insufficient to measure long-term changes or impacts. Therefore, I recommend that researchers seek funding not only for new initiatives but also to continue the research on the already developed ones. This enables us to measure also long-term impact and build a thorough body of evidence on Compassionate Communities. Additionally, since the active involvement of the researcher in the process may lead to feelings of abandonment among participants when the researcher leaves at the end of the project, it is crucial to avoid such outcomes. This advocacy for continued research requires of course also a shift in thinking for research funding institutions, which should recognise the value of sustaining and embedding existing initiatives as equally important as developing and studying new ones. Subsequently, I recommend the development of a funding scheme that supports longitudinal research.

5.4.4. Embracing unpredictability and uncertainty

An inherent aspect of neighbourhood civic engagement initiatives is their co-development with interested parties in the neighbourhood. Although the flexibility required to adapt data collection to the evolving development process- posed challenges for researchers, I recommend embracing community development approaches along with their unpredictability and uncertainty. While pre-set models offer numerous advantages, such as providing clear opportunities for community members to participate in specific activities, and having pre-defined outcomes[88], I believe also in the benefits of community development approaches that are less pre-defined, resonate with neighbourhoods' interests and empower the people participating. Furthermore, to address unpredictability in data collection, I recommend using methods that can adapt to changing circumstances. For example, semi-structured interviews to which we can add or adapt certain topics to fit within a particular phase of the development process or observations which can capture developmental changes. Additionally, a logic model, which we included in our study protocol in **Chapter V**, can provide a framework to illustrate changes in input and development, which in turn affect activities and outputs. Therefore, we advocate for using a logic model as a dynamic tool to capture these changes effectively. Including this approach in a protocol can serve as a guide for evaluation, despite its inherent unpredictability. Lastly, I believe that researching neighbourhood civic engagement initiatives on the topics of serious illness, death and loss, requires researchers to maintain a degree of relativity when unpredicted events occur, such as delays in development. Unforeseen events can enrich the research process by introducing new dynamics, activities or outcomes that were not initially anticipated. These unexpected developments, I believe, can ultimately contribute to the researcher's growth and the project's success.

6. Researcher reflexivity

Throughout the research, I frequently questioned the extent of my involvement in the development process. Where research in the past decades focused on a clear demarcation of either doing ethnographic research or not, action research or not; current trends more and more embrace the hybridity of research forms, as advocated by among others Parker-Jenkins et al.[89] While I did not conduct an ethnographic study, I did employ ethnographic forms of data collections. I found that, as Blumer noted decades ago, these methods helped me get closer to capturing the complex character of the neighbourhood civic engagement development process.[90] So rather than strictly delineating my participation as a researcher, I experienced being involved in the development process as a sort of continuum ranging from conducting observations to asset-mapping and providing suggestions and recommendations. Although my participation as a researcher was thereby not completely delineated, I experienced navigating this continuum as a freedom that also aligns with the dynamic and unpredictable nature of the research. Furthermore, I made a distinction between my role as a researcher in the development process and the role of the neighbourhood worker. Where my participation was driven by research purposes, such as providing recommendations and suggestions derived from insights out of the data, or by providing methodologies for co-creation in for instance the caregiving cafés, the neighbourhood worker had a much more operational role in the development process.

While social science literature until recently associated risks regarding the objectivity of the researcher with action research and qualitative research, recent years have shown a departure from such positivist standards which allows for a more reflexive understanding of social phenomena.[91] Aligned with the principle of reflexivity, increasingly acknowledged as a valuable attribute in qualitative research[92], I perceive my active involvement as a researcher in the development process of the civic engagement initiatives, as a beneficial aspect. It created the opportunity to iteratively refine both my own role as a researcher and the developmental process itself, informed by evolving insights. From this perspective, withholding these insights until after the development process would not a been a beneficial strategy.

However, one of the challenges was determining to which extent I could engage in the development process through the recommendations and insights I offered. It is, however, crucial to recognise that researchers also occupy a position of power, since they are often perceived as having extensive knowledge about the most beneficial approaches.[93] However, I experienced the development process in the two neighbourhoods and its evaluation very differently, as it was undoubtedly a learning curve for me as a researcher, one I went through jointly with the city representatives, the neighbourhood worker, civic society representatives and the other relevant parties. Consequently, I consciously chose to provide recommendations without insisting on their implementation, allowing the participants to make their own decisions. However, I also observed that as a researcher, it was neither feasible nor desirable to step into the development process and make recommendations without first establishing a relationship of trust. In hindsight, I would have adopted a more active role earlier in the development process, rather than an observational one, to build this trust earlier in the project.

In addition, there is the question to which extent my insights from the data were influenced by my personal background. Before enrolling in the PhD, I studied criminology and international development. These studies share a common focus on not only examining the micro level but also the macro-political and societal factors to explain developments. This perspective certainly influenced my research, as I found it essential to gain insight into the context in which the developments occurred. Before starting my PhD, I worked as a researcher at a university college where my research focused on supporting civic engagement initiatives in their search for housing for recognised refugees; making civic engagement the red thread in my research, but the topics of serious illness, death and loss entirely new. However, the novelty of these topics, in combination with having no prior experiences with the neighbourhoods in which I conducted my research, was in a way also beneficial as it allowed me to explore with a fresh 'birds-eye view' how the topics of serious illness, death and loss could be integrated within neighbourhood civic engagement.[94]

Furthermore, I also recognise the importance of ensuring that the data were not interpreted solely from my perspective. Project group meetings were held, during which the findings about the development process were consistently reviewed by other co-authors. Interviews with the change managers, who were involved in the development process from a facilitating role- primarily within the Compassionate Cities programme- provided an alternative perspective on the development process. This combined approach ensured that alternative explanations were offered for my insights, as well as additions, refinements or considerations I had not previously contemplated.[95] Finally, it is important to note that my position in this doctoral study was not a solitary one. Rather, it was a group effort, with the support and guidance of co-authors, fellow researchers, and the cities and neighbourhoods in which I conducted my research.

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ENGLISH SUMMARY

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1. General introduction

In most countries, there is an increasing number of deaths per year.[1] This trend is also found in Belgium, where projections indicate that the current annual number of deaths will rise from approximately 111,000 to 131,00 by 2050.[2] Alongside the rising number of deaths, there is also an increasing number of deaths resulting from health-related suffering.[3] By 2060, an estimated 48 million people (47% of all deaths globally) will die experiencing health-related suffering, primarily due to the non-communicable diseases such as cancer and dementia.[3] These projections align with current data in Belgium where 47.8% of all deaths can be attributed to non-communicable diseases such as cancer and cardiovascular diseases.[4] This amount is likely higher when including deaths where a non-communicable disease was the underlying cause of death.

Congruently with the rising number of deaths from non-communicable diseases, there is an increasing proportion of people who require care and support, primarily in the form of generalist palliative care.[3] However, despite projections indicating a rising number of healthcare workers globally, many countries are expected to face shortages, exacerbating existing healthcare workforce crises.[5, 6] Factors contributing to low interest and retention rates among healthcare professionals include inadequate wages and fees, in addition to many professionals in this field feeling undervalued and overburdened.[6] These shortages also impact the quality of care for people with serious illness and their families, for instance, by prolonged waiting times for appointments at palliative care services, posing difficulties to individuals who are in urgent need of palliative care.[7]

Furthermore, literature suggests that even with sufficient staffing in the healthcare sector, professional care may not always present the optimal solution for individuals in need of support around serious illness, death or loss.[8, 9] This is exemplified by a population-based survey study of bereaved adults in Australia, which revealed that professional services were perceived as the least preferred and beneficial form of support.[8] In contrast, informal care provided by family members, friends and funeral providers emerged as both the preferred and most beneficial sources of support for bereaved adults.[8] These findings contribute to the increasing recognition that our current palliative care model, which relies primarily on professional caregiving, is insufficient in addressing the diverse care needs of people who are seriously ill, dying or bereaved, and underscore the necessity of exploring alternative forms of care embedded within the context of everyday life.[10]

Subsequently, in recent years, there has been a shift in thinking concerning how to approach care for people who are seriously ill, caregiving or bereaved, with a growing recognition of the importance of public health initiatives that move beyond the role of healthcare services.[10] One manifestation of this shift, is the concept of so-called Compassionate Communities; initiatives aimed at supporting individuals confronted with serious illness, caregiving or bereavement through various forms of health promotion, community development, and civic engagement.[11, 12]

Civic engagement plays a central role in reframing responses to the challenges of serious illness, death and loss within public health approaches.[10] While in Western societies, professional services are considered the primary care providers for individuals with serious illnesses, research has shown that people spend only about 5% of their time with healthcare professionals; the remaining 95% is spent within their daily social contexts.[13] Consequently, the civic society context in which we navigate our daily lives is crucial for addressing serious illness, death and loss, not only in the private spheres of homes but also in some of the key institutions like schools and workplaces.[10] These institutions have enormous potential in familiarising and supporting people around the topics of serious illness, death and loss.[10, 14, 15] For instance, they can implement policies for work leave for those experiencing the death of someone or normalise discussions about these topics by integrating them in the school curricula.[19, 20] Additionally, neighbourhoods, as integral parts of our civic society, can play an essential role by signposting the needs of residents and providing various forms of assistance, including companionship and other forms of practical, social and emotional support.[10, 16] By combining the definitions of civic engagement provided by Adler et al.[17], Diller et al.[18] and Crowley et al.[19], I define civic engagement as all collective action undertaken to help improve connections between, or conditions for, people in the community.

2. Study objectives and research questions

The overall objective of this PhD is to describe and evaluate two neighbourhood civic engagement initiatives regarding serious illness, death and loss in terms of their development processes.

PART II aims to systematically describe existing neighbourhood civic engagement initiatives regarding serious illness, death and loss worldwide in terms of their context, activities, engagement strategies, impact and evaluation designs and methods.

- Research question 1: In what context, why and for whom are civic engagement initiatives around serious illness, death and loss initiated?
- Research question 2: How are they developed and how are they sustained?
- Research question 3: How have they been evaluated and what is their impact?

PART III aims to identify development strategies for neighbourhood civic engagement initiatives regarding serious illness, death and loss, in terms of the extent, type and intensity of this neighbourhood participation, and the factors that are associated with it.

- Research question 4: To what extent do citizens participate in actions around serious illness, death and loss in their neighbourhood?
- Research question 5: Are citizens more likely to participate in actions around serious illness, death and loss in their neighbourhood when they perceive a higher level of social cohesion in their neighbourhood?
- Research question 6: Are citizens who had a personal experience with serious illness, death or loss in the last year more likely to participate in actions in their neighbourhood around these topics?
- Research question 7: Do the capacity, skills and self-efficacy citizens believe they gained from their previous experiences with serious illness, caregiving, death and loss strengthen this association?

PART IV seeks to evaluate the development processes of the two neighbourhood civic engagement initiatives.

- Research question 8: How do we evaluate neighbourhood civic engagement initiatives, given their unpredictable and dynamic character?
- Research question 9: What are the aspects and contextual factors that facilitated and hindered the development of the neighbourhood civic engagement initiatives in the context of two Compassionate Cities?

PART V aims to reflect on the contemporary challenges, tensions and commonalities within the Compassionate Communities movement and to propose directions for future practice and research.

- Research question 10: What are contemporary tensions, challenges and commonalities within the Compassionate Communities movement?
- Research question 11: What are the insights we can gain from them to propose directions for future practice and research?

3. Methods

To answer the research questions of this dissertation, several methods of data collection were employed. First, we conducted a systematic review to describe existing neighbourhood civic engagement initiatives regarding serious illness, death and loss worldwide **(Chapter II)**. Then, we A cross-sectional survey to identify development strategies for neighbourhood civic engagement initiatives regarding serious illness, death and loss, in terms of the extent, type and intensity of this neighbourhood participation, and the factors that are associated with it **(Chapters III and IV)**. We conducted a process evaluation to provide insight into the aspects and contextual factors that facilitated or hindered the development process of neighbourhood civic engagement initiatives in two distinct Compassionate Cities in Belgium **(Chapter VI)**. This evaluation was based on a detailed study protocol we developed **(Chapter V)**.

Study 1: A systematic review to describe existing neighbourhood civic engagement initiatives regarding serious illness, death and loss worldwide in terms of their context, activities, engagement strategies, impact and evaluation designs and methods.

We conducted a systematic review of civic engagement initiatives regarding serious illness, death and loss worldwide. Initiatives were excluded if they reported on public engagement that was service-driven, with the main aim of enhancing the quality or reach of a service. Six databases, PubMed, Scopus, Sociological Abstracts, WOS, Embase, and PsycINFO, were searched for peer-reviewed literature in English. Additional grey literature was obtained by contacting the first authors and by hand-searching the reference list of the included articles. The review aimed to systematically describe and compare the reported initiatives of civic engagement in serious illness, death, and loss in terms of the context in which they were initiated, their development and sustainability, whether and how they were evaluated, and their impact. We performed a quality appraisal of the included studies using a self-developed tool that was based on the Mixed Method appraisal tool.[20]

Study 2: A cross-sectional survey to identify development strategies for neighbourhood civic engagement initiatives regarding serious illness, death and loss, in terms of the extent, type and intensity of this neighbourhood participation, and the factors that are associated with it.

We conducted a cross-sectional survey study in two selected neighbourhoods in Herzele and Sint-Kruis, between February and April 2021. Both Herzele and Bruges, the city in which Sint-Kruis is a sub-municipality, are Compassionate Cities. Neighbourhoods were defined based on addresses, as decided by the city representatives. In Bruges, the delineation encompassed the sub-municipality of Sint-Kruis, in Herzele, the neighbourhood was delineated as the streets within a 1.5 km radius around the local service centre, a community-based facility that aims to improve the quality of life of residents across various domains such as loneliness, healthcare, caregiving, leisure activity, etc.[21]. Each neighbourhood comprised around 4,000 inhabitants. Surveys were sent to a random sample of 2,324 adult inhabitants via post, using the Total Design method[22] with up to three reminders. Respondents were asked to complete the questionnaire within two weeks of receiving it and to return it prepaid via post or online. The survey measured seven concepts: perceived neighbourhood social cohesion, perceived help from neighbours, neighbourhood participation, neighbourhood participation regarding serious illness, caregiving, death and loss in the neighbourhood, previous experiences with these topics and perceived capacity, skills and self-efficacy resulting from previous experiences with serious illness, caregiving death or loss. The concept of neighbourhood participation regarding serious illness, death and loss was adapted from the Social Capital Measure[23] in which we incorporated these specific topics. For 'perceived help from neighbours' and 'self-efficacy to engage around the topics serious illness, death and loss', we developed new items. The items for perceived help from neighbours were based on the Medical Outcome Survey Study (MOS)[24], and the items for self-efficacy were based on guiding literature on how to develop items for self-efficacy.[25, 26] The questionnaire can be found in Appendix 2.

Study 3: A process evaluation to provide insight into the aspects and contextual factors that facilitated or hindered the development process of neighbourhood civic engagement initiatives in two distinct Compassionate Cities in Belgium.

We conducted a multimethod process evaluation[27], collected over a development period of nearly four years from December 2019 to September 2023. The researcher and first author (LDEE) conducted semi-structured observations, document analysis, semi-structured interviews and group discussions with all relevant parties in the development process. Given that Compassionate Communities are complex adaptive systems, traditional methods aimed at predictability and linearity are inadequate to evaluate them.[28] Therefore, our data collection methods needed to be adjusted accordingly, allowing sufficient flexibility in their gathering, and capturing both observable and non-observable determinants of change.[28] LDEE was involved in the development process via action research[29], using the gain of knowledge through research to inform decision-making and strengthen the developed initiatives. Relevant parties in the neighbourhoods were co-creatively engaged in the development of the civic engagement initiatives but did not actively participate in the data collection. The civic engagement initiatives were developed in two distinct neighbourhoods. The first neighbourhood was located in Sint-Kruis, a sub-municipality of the city of Bruges, an urbanised city comprising approximately 120.000 inhabitants.[30] Sint-Kruis was chosen due to its socio-demographic challenges, e.g. a growing proportion of older adults living alone.[30] The second neighbourhood was located in Herzele, a peri-urbanised city comprising approximately 19.000 inhabitants.[31] The participants in this study were representatives of civic society organisations in the neighbourhood, other neighbourhood key figures and neighbourhood residents.[32]

4. The main findings of this dissertation

In Chapter II I describe a systematic mixed-methods review I conducted of civic engagement initiatives regarding serious illness, death and loss, worldwide. Including initiatives from international peer-reviewed publications in English, we identified nineteen distinct initiatives worldwide. Although these initiatives were dispersed across different countries, nearly all originated in countries where English is an official language (e.g. Australia, the United States, India, Ethiopia and Canada)., We discovered that community members participated in the development of all initiatives, albeit in various forms ranging from community-academic partnerships to entirely grassroots efforts led by community organisations or groups. However, detailed descriptions of their development processes and strategies were lacking. Lastly, we found that most initiatives had been evaluated in studies, showing promising results, such as empowering community members to provide end-of-life care for older people in their community[33]. Nonetheless, the evaluations exhibited considerable variety in their objectives, methodologies, and outcomes, as well as in their overall quality and strength of the evidence. Specifically, we found that process evaluations often focussed only on specific aspects of the civic engagement initiatives such as their acceptance or reach without offering a more comprehensive analysis of the development process. This underscored the need to gain more in-depth insight into how such initiatives are developed through the use of high-quality process evaluations.

Chapter III presents the findings of a cross-sectional survey study that we conducted in the two selected neighbourhoods between February and April 2021. This survey study was part of the needs and assessment mapping conducted before the start of the development process of neighbourhood civic engagement initiatives. Using data from the survey, we aimed to provide a description of the extent and type of neighbourhood civic engagement regarding serious illness, death and loss in the two selected neighbourhoods and study whether citizens were more likely to participate when they perceived a higher level of social cohesion in the neighbourhood. The questionnaires were distributed to a sample of 2.324 adult citizens in the two neighbourhoods. We received 714 questionnaires (response rate 30.7%). We found that 42% of the respondents had participated in at least one neighbourhood activity related to serious illness, caregiving, death or loss. Most respondents participated by either helping a close neighbour (32%) or by volunteering (10%); to a lesser extent, respondents participated in group activities such as bereavement groups (6%) or community initiatives (6%). Additionally, respondents indicated that they participated seldom or sometimes (31%), and only a small minority participated more regularly (12%); the other 47% did not participate. Following a hierarchical linear regression analysis, informed by a Directed Acyclic Graph[34] visualising the potential causal interrelations and de-confounding strategies, we found a positive association between perceived neighbourhood social cohesion and civic engagement regarding serious illness, death and loss in the two neighbourhoods. This association remained after adding general neighbourhood participation – beyond the scope of serious illness, death and loss – to the regression analysis. These results suggest that people who perceive a higher social cohesion in the neighbourhood are more likely to participate in civic engagement activities regarding serious illness, death and loss, regardless of whether they participate in general neighbourhood activities outside the scope of serious illness, death and loss.

The findings of the cross-sectional survey study were also reported and discussed in **Chapter IV**, which provides an answer to the research questions of whether citizens are more likely to participate in neighbourhood civic engagement actions if they have had personal experiences with serious illness, death and loss in the last year and whether the capacity, skills and self-efficacy they believe they gained from their previous experiences, strengthened their participation. We found that 72% of the respondents had an experience with serious illness, caregiving or loss in the last year. More than half of the respondents (57%) lost someone they knew well, 14.2% reported that they had been a caregiver for a family member who was seriously ill and 15% reported that they had been seriously ill in the last year. After a hierarchical linear regression analysis, informed by a Directed Acyclic Graph model[34] (a similar approach to Chapter 3), we found a positive association between having been a caregiver in the last year and neighbourhood participation regarding serious illness, death and loss. Notably, this association was not observed for other experiences like being seriously ill oneself or experiencing a recent death in the family in the past year. Furthermore, we found that this association was strengthened when adding perceived capacity and skills gained from their previous experiences with serious illness, death and loss, to the regression analysis. These results suggest that people who have been a caregiver in the last year are more likely to participate in neighbourhood activities regarding serious illness, caregiving, death or loss; and that this is particularly the case if they believe they gained capacities and skills from their previous experiences with these topics.

In **Chapter V**, I present the study protocol that we developed for the evaluation of the civic engagement initiatives concerning serious illness, death, and loss in the two neighbourhoods that we selected, in terms of their development processes and outcomes. Recognising the intricate dynamic and non-linear nature of Compassionate Communities, as well as the limitations of traditional research methods[28], we adopted a methodological approach that offered clear guidance regarding research design, objectives, data collection methods, and analysis, while also allowing flexibility to adapt the evaluation to the development process. We adopted a convergent-parallel mixed-methods evaluation design, encompassing both qualitative and quantitative data collection methods. Given the convergent-parallel nature of our design[35], the different types of data were collected separately, but simultaneously, to integrate and interpret the combined results. Embracing a critical realist philosophy[36] we acknowledged the presence of both objective and subjective factors underlying the development process of the neighbourhood civic engagement initiatives. Qualitative methods included semi-structured observations of relevant meetings, document analysis of the produced documents and semi-structured interviews and group discussions with all relevant parties, to capture the development process and the social processes underlying it, and a Most Significant Change[37] data collection. The latter was collected but falls outside the scope of this doctorate. Quantitative methods included a cross-sectional survey study. Together, using these methods we were well-equipped to gain a comprehensive insight into the development process of the neighbourhood civic engagement initiatives.

Chapter VI presents the findings from a multimethod process evaluation[27] encompassing semi-structured observations from all relevant meetings, document analyses of the minutes of meetings and produced documents, semi-structured interviews, and group discussions with all relevant parties in the development process. Following a thematic analysis using a combination of inductive and deductive coding[38], our findings revealed that challenges in the development process centred around integrating the neighbourhood civic engagement initiatives into the broader context of Compassionate City programmes. These challenges became apparent in the unequal power dynamics between the cities and civic society representatives, as well as in difficulties in expanding the project to neighbourhood residents and other neighbourhood key figures. Despite these challenges, we identified the potential for Compassionate Cities to act as facilitators. For instance, through the organisation of a city-wide festival that encouraged neighbourhood participation. Additionally, we found that challenges regarding power dynamics could be resolved, by adopting a shared decision-making structure, rather than a centralised one attributing end decision-making power to city representatives. Expanding the initiatives to include neighbourhood residents and other neighbourhood key figures, remained challenging, though it was recognised as a crucial strategy for increasing the sustainability of the developed initiatives. I recommend that cities embed these facilitating mechanisms into their policies to enhance the success and sustainability of these initiatives.

Chapter VII reports the findings of a review of five recent publications on Compassionate Communities[39-43], presented in an editorial format. This review aimed to highlight the existing tensions and challenges within the field of Compassionate Communities and to propose directions for future practice and research. Three primary tensions were identified. The first tension revolved around power dynamics and community engagement in initiatives, questioning whether community-based educational activities, without broader empowerment efforts, could be appropriately labelled as

Compassionate Communities. A second tension revolved around whether service-driven or research-driven initiatives, as the majority of the initiatives that were identified in the reviews, conflicted with the interests of communities and populations. A third tension highlighted was the lack of representation of compassionate community initiatives in English-language peer-reviewed literature which mainly focused on Compassionate Communities initiatives in high-income countries, disregarding other contexts. These tensions emphasised the need to broaden, rather than restrict, research on Compassionate Communities to encompass a wider array of contexts, demographics, methodologies, and epistemologies, thereby complementing existing traditional approaches.

5. Interpretation and discussion of findings

5.1. Can we expect communities to actively contribute to serious illness, death and loss?

5.1.1. How to deal with a (mis)alignment of needs, desires and focus in the development process of neighbourhood civic engagement initiatives?

In **Chapter VI**, it was highlighted that the interests of neighbourhood residents often diverge from those of civic society and city representatives. Neighbourhood resident residents primarily want to focus on supporting their neighbours, as was affirmed in **Chapter III**, where helping neighbours was identified as the main form of participation in the neighbourhood. Conversely, civic society representatives were more invested in networking with local partners and in identifying the existing initiatives and activities regarding serious illness, death and loss. Despite these differing priorities, a common ground was eventually found, which resulted in the development of a mutually shared activity. This aligns with community development literature that advocates for finding common ground as a beneficial strategy for initiating initiatives.[44-46] However, critics argue that this approach might neglect the diverse interests within communities. [45, 47] We found that in addition to communities based on shared interest, different types of communities coexisted within the geographic delineation of a neighbourhood. For example, we found communities based on shared circumstances, as was the case for caregivers, and that evolving into a community of shared interest could be cultivated over time. However, we must be aware that although a shared interest can be cultivated, one single initiative does not address the diverse needs and interests within communities.

5.1.2. Do communities have the necessary capacity and skills to engage around the topics of serious illness, death and loss?

Chapter VI revealed that neighbourhood residents acknowledge the importance of engaging around the topics of serious illness, death and loss, particularly in helping neighbours, yet they felt they lacked the necessary capacities and skills to participate. **Chapter IV** showed prior experiences around serious illness, death and loss in the past year, increased the likeliness of neighbourhood participation on the topics of serious illness, death and loss, especially if people felt they gained the capacities and skills to engage around these topics based on their previous experiences.

Literature on capacity-building around serious illness, death and loss suggests that capacities and skills can be developed gradually over the development process and that this approach can enhance community empowerment.[48-50] Nevertheless, the report of the Lancet Commission on the Value of Death[51], advocates that wider exposure to these topics is needed in communities if we truly want to increase their capacities and skills. This exposure can be created on the level of civic societies, professional services and governments.[51] For instance, universities could host cultural weeks on death and dying and establish supportive policies for staff and students.[14] Professional services, like residential care centres, can facilitate exposure by organising neighbourhood-inclusive activities.[52] Governments can create exposure through policies promoting participation and collaboration between communities and professional services.[51, 53] Thus, while educational and awareness-raising activities are crucial, I advocate that systemic changes at the civic, professional and governmental levels are also necessary if we want to equip communities to participate around the topics of serious illness, death and loss.

5.1.3. Is there a risk of professionalisation of communities through their civic engagement around serious illness, death and loss?

Chapter II's systematic review and **Chapter VI's** process evaluation showed that most civic engagement initiatives around serious illness, death and loss were initiated by professionals, either as researchers or as service providers. This professional involvement suggests a degree of professional control over these initiatives. Over the years, there has been a shift from altruistic motives to more individualistic reasons for civic engagement, leading to more short-term, project-based engagement.[54-56] The same trend is also observed in public health initiatives, where the often professional-led initiatives, tend to focus on efficiency and effectivity. Current Compassionate Communities models, e.g. Community Connectors[57] and Compassionate Neighbours[58], emphasise the importance of 'community-led' activities when working together with professional services. Community-led is here interpreted as, even when initiatives are developed in collaboration with professional services, the community having an active role and shaping the initiatives to their needs.[57, 58] Subsequently, I advocate for a more community-led approach to developing neighbourhood civic engagement initiatives, in addition to creating space for diverse forms of participation, including low-profile engagement that does not require specific expertise and does not aim solely for efficiency.

5.2. What are the implications of developing neighbourhood civic engagement initiatives in the context of Compassionate Cities?

5.2.1. Do we start with the development of Compassionate Cities or with the development of neighbourhood civic engagement initiatives?

Findings from **Chapter VI** indicate that both cities prioritised the Compassionate Cities programme over the development of neighbourhood civic engagement initiatives. This prioritisation suggests a higher political value placed on city-wide initiatives due to their greater visibility among citizens. However, literature indicates that city-wide initiatives, while politically advantageous, are more complex due to a reduced sense of community connectivity and the involvement of diverse stakeholders with varying priorities.[59] In contrast, local initiatives provide a stronger foundation for engagement and collaboration, leading to more sustainable outcomes.[59] The Flemish government's support for neighbourhood-focused projects presents an opportunity to raise local politicians' awareness of the importance of neighbourhood-oriented work for successful and Compassionate Communities.

5.2.2. Can the Compassionate Cities approach and the Compassionate Communities approach be integrated into the same project?

Chapter VI reveals challenges in integrating neighbourhood civic engagement initiatives into the Compassionate Cities programmes. The Compassionate Cities in our study adopted a co-creative development strategy with top-down elements, where city representatives played a large role in coordinating the development and selecting the focus of developed initiatives. Conversely, for the neighbourhood civic engagement initiatives, an a priori decision was made to adopt more of a community development approach by organising group discussions with neighbourhood residents to solicit input and employing co-creative methods to involve civic society representatives in the development process. These different approaches- with Compassionate Cities favouring a more top-down approach and Compassionate Communities a more bottom-up approach- align with the manner in which Kellehear, who strongly inspired the Compassionate Cities movement, has suggested both are developed.[60] However, while his writings have been instrumental in clarifying the difference between the two approaches, they also risk oversimplifying Compassionate Cities as inherently top-down and Compassionate Communities as bottom-up community development initiatives, which was to a certain extent the case in the two cities. I posit that both contexts can mutually reinforce each other. Based on known Compassionate Communities and experiences in the two neighbourhoods, I recommend a hybrid model where local governments can provide a supportive framework for neighbourhood civic engagement initiatives around serious illness, death and loss to be developed. Conversely, I propose the more top-down initiated Compassionate Cities could benefit from community development approaches to increase ownership over the initiatives that are developed.

5.3. What can we learn from other contexts in which Compassionate Communities are developed?

Chapters II and VII highlight a global lack of knowledge on civic engagement initiatives around serious illness, death and loss, especially in low and middle-income countries. Despite this, initiatives like the Neighbourhood Network in Palliative Care (NNPC) in India and the Compassionate Neighbours initiative[61] in London offer valuable examples that can be inspirational for the Belgian context.

A notable disparity exists in the levels of community engagement of specialist services between the UK and Belgium, with UK services attributing 80-90% of their engagement to the general public, compared to 31-71% for Belgian services.[62] This difference is largely attributed to variations in funding mechanisms.[62] In the United Kingdom, hospices heavily rely on charitable donations from communities to support their daily operations. Subsequently, they pursue increased efforts to engage with and customise their care services to meet the specific needs of communities.[63] This approach is exemplified by the Compassionate Neighbourhoods initiative in London, which departs from traditional service-oriented volunteering, encouraging civic engagement activities akin to those one would undertake for a friend or neighbour, rather than prescribing a certain volunteering role.[61] The Compassionate Neighbours initiative drew inspiration from the Neighbourhood Network in Palliative Care (NNPC)[64] in Kerala, India in which policies enabled communities to play an active role in palliative care, complementary to existing home-based services. Applying these models in the Belgian context proved challenging due to less far-reaching community engagement approaches around serious illness, death and loss. Ultimately, while the UK and Indian examples offer valuable examples, implementation must consider local contexts and cultural differences.

5.4. What are the implications of researching Compassionate Communities in the period of a PhD? Which results can we expect in 4 years?

Chapter VI's process evaluation reveals that the neighbourhood civic engagement initiatives did not achieve the anticipated cultural shift around serious illness, death and loss. However, they did increase perceived neighbourhood civic engagement, a positive albeit somewhat disappointing result, for some. Compassionate Communities do not operate in a vacuum but within a context of governance bodies, health and palliative care services and existing civic society initiatives.[65] This complex environment makes achieving culture change in a short period difficult[28]. Our results in **Chapter III** confirm that increased neighbourhood social cohesion is in fact not a bad result. We found that people who perceive higher levels of social cohesion are also more likely to participate in neighbourhood activities regarding serious illness, death and loss. This can be attributed to the increased connection among people, which reduces barriers to seeking or providing on sensitive topics of serious illness, death and loss.[66] Thus, while the outcome of heightened neighbourhood social cohesion may initially seem underwhelming, it represents an essential first step towards the desired culture change regarding serious illness, death and loss. Given these findings, there is also a need to consider whether funding and thus time spent on such projects are truly sufficient to bring about a culture change around serious illness, death and loss and make the initiatives self-sustaining. The latter is supported by the results of our systematic review **(Chapter II),** which identified discontinuation of funding as the most stated risk to the continuation of civic initiatives and the achievement of long-term effects. Consequently, I argue for long-term funding to anchor the developed neighbourhood initiatives and achieve long-term impact.

6. Recommendations for practice, policy and future research

6.1. Recommendations for local policy-makers

6.1.1. Adopting a community-development approach:

To cultivate a robust foundation for civic engagement initiatives within neighbourhoods, it is crucial that residents are not merely consulted for their input but are actively involved in the development and implementation process. We urge policymakers to establish a framework that empowers citizens to participate actively in the development process, even if their viewpoints diverge from the original policy plans, or if they opt for alternative approaches which may not prioritise efficiency and effectiveness.

6.1.2. Long-term strategies for increasing sustainability

Local policy must play a critical role in developing a long-term strategy to ensure the project's sustainability and prevent its discontinuation after four years. This approach should also ensure the continuity of the theme across different political terms, preventing it from becoming associated with specific politicians, and potentially subsiding thereafter. Additionally, local governments should acknowledge that total self-sufficiency of the project is difficult to attain within four years. Therefore, resource allocation must be adapted accordingly. In the event of discontinuity of resources, strategic considerations should be made for continued investment and facilitation of the project. This may involve seeking additional funding sources or engaging new partners

6.2. Recommendations for national policy-makers

Since our current Western palliative care provision primarily operates within the confines of professional palliative care services, policy interventions are essential to connect services with the communities in which they operate. I recommend that policy-makers draw inspiration from frameworks, like the one in Kerala, where policies facilitated the integration of civic engagement initiatives within existing professional practices. However, it is crucial to ensure that this integration does not undermine community empowerment, but rather that both communities and professional services complement and reinforce each other. Additionally, ongoing neighbourhood activities, which face a loss of support following the ending of this research project and the caring neighbourhoods initiative, should receive further support within the context of the Flemish palliative care reform. This support can be in terms of coaching, coordination or resources.

6.3. Recommendations for community-building practice

6.3.1. Facilitating community-ownership

Since we found some challenges regarding the adoption of a far-reaching community development approach within the context of two Compassionate City programmes, one of the key recommendations is to attribute sufficient ownership to communities and neighbourhoods in the development process. This can be achieved through several strategies. For instance, when employing an asset-based community development approach[67], it is crucial to create opportunities for effectively leveraging existing assets in a way that resonates most with the interests and aspirations of the communities involved.

6.3.2. Adopting inclusive approaches

Community-building practices need to maintain a continuous focus on adopting inclusive approaches within neighbourhoods. While group discussions with neighbourhood residents are a positive step towards involving residents in the development process, they tend to engage only a specific group of people who are intrinsically motivated and often already have expertise on the topics of serious illness, death and loss. Although starting with the most motivated individuals can be a good development strategy, there is a risk of overlooking the diversity within neighbourhoods. To foster inclusive approaches, it is worth drawing inspiration from initiatives abroad, like Compassionate Neighbours[61] in London which includes people from Black, Asian, and Minority Ethnic (BAME) backgrounds in community development through community outreaching activities (e.g. having a stand at the weekly market inviting people over for a conversation).

6.3.3. Focus on realistic, achievable goals

Finally, we advise community-building practitioners to establish achievable goals within the predefined timeframe. Pursuing an ambitious goal of completely shifting attitudes towards serious illness, death and loss can lead to disappointment among participants. Instead, I would like to recommend beginning with developing small-scale initiatives that facilitate gradual progress towards longer-term objectives.

6.4. Recommendations for future research

6.4.1. Cross-cultural research

I recommend conducting more cross-cultural international research. Our current knowledge of Compassionate Communities is primarily concentrated in high-income countries where English is one of the main languages. While these often-comparable contexts – where civic engagement initiatives are situated with an institutionalised palliative care framework – are highly valuable for drawing parallels to the Flemish context, it is equally important to gain insights into other contexts. Understanding the different political and societal factors from which these initiatives arise and the development strategies applied in those settings, can provide valuable perspectives and enhance our overall comprehension of effective Compassionate Communities strategies.

6.4.2. In-depth research into processes and outcomes

Based on the process evaluation we have formulated numerous potential strategies for the development of neighbourhood civic engagement initiatives and made several assumptions regarding possible development strategies, such as expanding initiatives to include other neighbourhood residents and key figures. Further research is needed to effectively implement these strategies and assumptions and to evaluate their progress. Additionally, we found that many challenges arose from the civic society representatives lacking ownership in the project. Therefore, more in-depth research is needed to examine these power dynamics within the specific context of Compassionate Communities. Furthermore, we found in Chapter IV that individuals who had a caregiving experience in the last year were more likely to participate in neighbourhood activities regarding these topics, particularly if they believed they gained capacities and skills from their previous experiences. This result requires further testing through longitudinal, quantitative data collection on these concepts, complemented by insights from qualitative literature on how we go from experiences to gaining capacities and skills from them and then to neighbourhood participation around these topics.

6.4.2. Making outcomes visible

Furthermore, research plays a crucial role in sustaining the developed neighbourhood civic engagement initiatives, not only by formulating potential sustainability strategies based on a process evaluation but also by gathering visible data about the outcomes (e.g. the number of participants at activities). Such data can support applications for continued funding and help prioritize these initiatives on cities' agendas to ensure their continuation. Furthermore, it should be noted that the four-year research period is insufficient to measure long-term changes or impacts. Therefore, I recommend that researchers seek funding not only for new initiatives but also to continue the research on the already developed ones. This enables us to measure also long-term impact and build a thorough body of evidence on Compassionate Communities.

6.4.3. Embracing unpredictability and uncertainty

An inherent aspect of neighbourhood civic engagement initiatives is their co-development with interested parties in the neighbourhood. Although the flexibility required to adapt data collection to the evolving development process posed challenges for researchers, I recommend embracing community development approaches along with their unpredictability and uncertainty. While pre-set models offer numerous advantages, such as providing clear opportunities for community members to participate in specific activities, and to evaluate pre-defined outcomes[68], I believe also in the benefits of community development approaches that are less pre-defined, resonating with neighbourhoods' interests. Furthermore, to address unpredictability in data collection, I recommend using methods that can adapt to changing circumstances.

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NEDERLANDSTALIGE SAMENVATTING

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1. Algemene inleiding

In de meeste landen neemt het aantal sterfgevallen per jaar toe.[1] Deze trend zien we ook in België, waar projecties aangeven dat het huidige jaarlijkse aantal sterfgevallen zal stijgen van ongeveer 111.000 naar 131.00 tegen 2050.[2] Naast het stijgende aantal sterfgevallen is er ook een stijgend aantal sterfgevallen als gevolg van gezondheidsgerelateerd lijden.[3] Tegen 2060 zullen naar schatting 48 miljoen mensen (47% van alle sterfgevallen wereldwijd) sterven door gezondheidsgerelateerd lijden, voornamelijk als gevolg van niet-overdraagbare ziekten zoals kanker en dementie.[3] Deze projecties komen overeen met de huidige gegevens in België, waar 47,8% van alle sterfgevallen kan worden toegeschreven aan niet-overdraagbare ziekten zoals kanker en hart- en vaatziekten.[4] Dit cijfer ligt waarschijnlijk hoger wanneer ook rekening wordt gehouden met sterfgevallen waarbij een niet-overdraagbare ziekte de onderliggende doodsoorzaak was.

In overeenstemming met het stijgende aantal sterfgevallen als gevolg van niet-overdraagbare ziekten, is er een toenemend aantal mensen dat zorg en ondersteuning nodig heeft, voornamelijk in de vorm van generalistische palliatieve zorg.[3] Ondanks prognoses die wijzen op een wereldwijd toenemend aantal gezondheidswerkers, zullen veel landen naar verwachting te maken krijgen met tekorten.[5, 6] Factoren die bijdragen aan de lage interesse en retentiegraad van professionele zorgverleners zijn onder andere ontoereikende salarissen en vergoedingen, naast het feit dat veel professionals in deze sector zich ondergewaardeerd en overbelast voelen.[6] Deze tekorten hebben ook gevolgen voor de kwaliteit van de zorg voor mensen met een ernstige ziekte en hun familie, bijvoorbeeld door langere wachttijden voor afspraken bij palliatieve zorgdiensten, wat problemen oplevert voor mensen die dringend palliatieve zorg nodig hebben.[7]

Bovendien suggereert literatuur dat zelfs met voldoende personeel in de gezondheidszorg, professionele zorg niet altijd de optimale oplossing is voor mensen die steun nodig hebben rond ernstige ziekte, sterven of verlies.[8, 9] Dit wordt geïllustreerd door een survey-onderzoek van rouwende volwassenen in Australië, waaruit bleek dat professionele diensten werden gezien als de minst geprefereerde en nuttige vorm van ondersteuning.[8] Daarentegen kwam informele zorg door familieleden, vrienden en begrafenisondernemers naar voren als zowel de favoriete als de meest voordelige bron van steun voor volwassenen in een rouwproces.[8] Deze bevindingen dragen bij aan de toenemende erkenning dat ons huidige palliatieve zorgmodel, dat voornamelijk steunt op professionele zorgverlening, onvoldoende tegemoet komt aan de uiteenlopende zorgbehoeften van mensen die ernstig ziek, stervende of aan het rouwen zijn, en onderstrepen de noodzaak om alternatieve vormen van zorg te onderzoeken die ingebed zijn in de context van het alledaagse leven.[10]

In de afgelopen jaren heeft er een verschuiving plaatsgevonden in het denken over hoe de zorg voor mensen die ernstig ziek zijn, sterven of rouwen moet worden benaderd, met een groeiende erkenning van het belang van initiatieven op het gebied van de volksgezondheid die verder gaan dan de rol van de gezondheidszorg.[10] Een uiting van deze verschuiving is het concept van Compassionate Communities; initiatieven die gericht zijn op het ondersteunen van mensen die geconfronteerd worden met een ernstige ziekte, zorg of rouwverwerking door middel van verschillende vormen van gezondheidsbevordering, gemeenschapsontwikkeling en maatschappelijke betrokkenheid.[11, 12]

Betrokkenheid van de burger speelt een centrale rol bij het opnieuw vormgeven van antwoorden op de uitdagingen van ernstige ziekte, dood en verlies binnen de aanpak van de volksgezondheid.[10] Hoewel in Westerse samenlevingen professionele zorgverleners worden beschouwd als de primaire zorgverleners voor mensen met ernstige ziekten, heeft onderzoek aangetoond dat mensen slechts 5% van hun tijd doorbrengen met zorgverleners; de overige 95% wordt doorgebracht in hun dagelijkse sociale omgeving.[13] Bijgevolg is de maatschappelijke context waarin we ons dagelijks leven leiden cruciaal voor de aanpak van ernstige ziekten, dood en verlies, niet alleen in de privésfeer van thuis, maar ook in een aantal belangrijke instellingen zoals scholen en werkplekken.[10] Deze instellingen hebben een enorm potentieel om mensen vertrouwd te maken met en te ondersteunen rond de thema's ernstige ziekte, dood en verlies.[10, 14, 15] Ze kunnen bijvoorbeeld rouwverlof implementeren voor mensen die iemand verloren of discussies over deze onderwerpen normaliseren door ze in de lesprogramma's van scholen op te nemen.[19, 20] Daarnaast kunnen buurten, als integraal onderdeel van onze maatschappij, een essentiële rol spelen door de behoeften van bewoners te signaleren en verschillende vormen van hulp te bieden, waaronder gezelschap en andere vormen van praktische, sociale en emotionele steun.[10, 16]

2. Studiedoelen en onderzoeksvragen

Het algemene doel van dit doctoraat is het beschrijven en evalueren van twee buurtinitiatieven rond ernstige ziekte, dood en verlies in termen van hun ontwikkelingsprocessen.

DEEL II beschrijft op systematische wijze bestaande buurtinitiatieven rond ernstige ziekte, sterven en verlies wereldwijd in termen van hun context, activiteiten, strategieën voor betrokkenheid, impact en evaluatiedoelen en -methoden.

- Onderzoeksvraag 1: In welke context, waarom en voor wie worden burgerbetrokkenheidsinitiatieven rond ernstige ziekte, dood en verlies geïnitieerd?
- Onderzoeksvraag 2: Hoe worden ze ontwikkeld en hoe worden ze in stand gehouden?
- Onderzoeksvraag 3: Hoe zijn ze geëvalueerd en wat is hun impact?

DEEL III beoogt ontwikkelingsstrategieën te identificeren voor buurtinitiatieven rond ernstige ziekte, dood en verlies, in termen van de omvang, het type en de intensiteit van deze buurtparticipatie en de factoren die ermee samenhangen.

- Onderzoeksvraag 4: In welke mate nemen burgers deel aan acties rond ernstige ziekte, dood en verlies in hun buurt?
- Onderzoeksvraag 5: Zijn burgers meer geneigd om deel te nemen aan acties rond ernstige ziekte, dood en verlies in hun buurt als ze een hoger niveau van sociale cohesie in hun buurt ervaren?
- Onderzoeksvraag 6: Zijn burgers die het afgelopen jaar een persoonlijke ervaring hebben gehad met ernstige ziekte, dood of verlies eerder geneigd om deel te nemen aan acties in hun buurt rond deze onderwerpen?
- Onderzoeksvraag 7: Versterken de capaciteiten, vaardigheden en zelfredzaamheid die burgers denken te hebben opgedaan van hun eerdere ervaringen met ernstige ziekte, zorg, dood en verlies, deze associatie?

DEEL IV heeft als doel de ontwikkelingsprocessen van de twee buurtinitiatieven rond ernstige ziekte, sterven en verlies te evalueren.

- Onderzoeksvraag 8: Hoe evalueren we buurtinitiatieven rond ernstige ziekte, sterven en verlies, gezien hun onvoorspelbare en dynamische karakter?
- Onderzoeksvraag 9: Wat zijn de aspecten en contextuele factoren die de ontwikkeling van deze buurtinitiatieven in de context van twee Compassionate Cities vergemakkelijkten en belemmerden?

DEEL V heeft als doel om op basis van de huidige uitdagingen, spanningen en overeenkomsten in de Compassionate Communities-beweging; richtingen voor toekomstige praktijk en onderzoek voor te stellen.

- Onderzoeksvraag 10: Wat zijn de hedendaagse spanningen en uitdagingen binnen Compassionate Communities?
- Onderzoeksvraag 11: Welke inzichten kunnen we hieruit opdoen om richtingen voor toekomstige praktijk en onderzoek voor te stellen?

3. Methoden

Om de onderzoeksvragen van dit proefschrift te beantwoorden, werden verschillende methoden van dataverzameling gebruikt. Eerst voerden we een systematische review uit om bestaande buurtinitiatieven rond ernstige ziekte, sterven en verlies wereldwijd te beschrijven **(Hoofdstuk II)**. Vervolgens voerden we een cross-sectionele survey uit om ontwikkelingsstrategieën te identificeren voor buurtinitiatieven rond ernstige ziekte, sterven en verlies, in termen van de omvang, het type en de intensiteit van deze buurtparticipatie, en de factoren die ermee samenhangen **(Hoofdstuk III en IV)**. We voerden een procesevaluatie uit om inzicht te verschaffen in de aspecten en contextuele factoren die het ontwikkelingsproces van de buurtinitiatieven in twee verschillende Compassionate Cities in België vergemakkelijkten of belemmerden **(Hoofdstuk VI)**. Deze evaluatie was gebaseerd op een gedetailleerd studieprotocol dat we ontwikkelden en terug te vinden is in **Hoofdstuk V**.

Onderzoek 1: Een systematische review om bestaande buurtinitiatieven voor burgerbetrokkenheid bij ernstige ziekten, sterven en verlies wereldwijd te beschrijven in termen van hun context, activiteiten, betrokkenheidsstrategieën, impact en evaluatiedesigns en -methoden.

We voerden een systematische review uit van buurtinitiatieven rond ernstige ziekte, dood en verlies wereldwijd. Initiatieven werden uitgesloten als ze rapporteerden over publieke betrokkenheid die dienstgedreven was, met als hoofddoel het verbeteren van de kwaliteit of het bereik van een dienst. Zes databases, PubMed, Scopus, Sociological Abstracts, WOS, Embase en PsycINFO, werden doorzocht op Engelstalige peer-reviewed literatuur. Aanvullende grijze literatuur werd verkregen door contact op te nemen met de eerste auteurs en door de referentielijst van de geïncludeerde artikelen met de hand door te nemen. De review was gericht op het systematisch beschrijven en vergelijken van de gerapporteerde initiatieven van maatschappelijke betrokkenheid bij ernstige ziekte, sterven en verlies in termen van de context waarin ze werden geïnitieerd, hun ontwikkeling en duurzaamheid, of en hoe ze werden geëvalueerd, en hun impact. We voerden een kwaliteitsbeoordeling uit van de geïncludeerde studies met behulp van een zelfontwikkelde tool die gebaseerd was op de Mixed Method appraisal tool.[17]

Studie 2: Een cross-sectionele survey om ontwikkelingsstrategieën te identificeren voor buurtinitiatieven rond ernstige ziekte, sterven en verlies, in termen van de omvang, het type en de intensiteit van deze buurtparticipatie en de factoren die ermee samenhangen.

We voerden een cross-sectionele surveystudie uit in twee geselecteerde buurten in Herzele en Sint-Kruis, tussen februari en april 2021. Zowel Herzele als Brugge, de stad waarin Sint-Kruis een deelgemeente is, zijn Compassionate Cities. De wijken werden afgebakend op basis van adressen, zoals bepaald door de vertegenwoordigers van de stad. In Brugge omvatte de afbakening de deelgemeente Sint-Kruis, in Herzele werd de buurt afgebakend als de straten binnen een straal van 1,5 km rond het lokale dienstencentrum, een gemeenschapsgerichte voorziening die tot doel heeft de levenskwaliteit van de bewoners te verbeteren op verschillende domeinen zoals eenzaamheid, gezondheidszorg, zorgverlening, vrijetijdsbesteding, enz.[18]. Elke buurt telde ongeveer 4.000 inwoners. De enquêtes werden per post verstuurd naar een willekeurige steekproef van 2.324 volwassen inwoners via de Total Design-methode met maximaal drie herinneringen.[19] Respondenten werd gevraagd om de vragenlijst binnen twee weken na ontvangst in te vullen en deze voorgefrankeerd per post of online terug te sturen. In de survey werden zeven concepten gemeten: gepercipieerde sociale cohesie in de buurt, gepercipieerde hulp van buren, buurtparticipatie, buurtparticipatie met betrekking tot ernstige ziekte, mantelzorg, sterven en verlies in de buurt, eerdere ervaringen met deze onderwerpen en gepercipieerde capaciteiten, vaardigheden en zelfredzaamheid als gevolg van eerdere ervaringen met ernstige ziekte, mantelzorg, sterven of verlies. De vragenlijst is te vinden in Bijlage 1.

Studie 3: Een procesevaluatie om inzicht te verschaffen in de aspecten en contextuele factoren die het ontwikkelingsproces van burgerinitiatieven in buurten vergemakkelijkten of belemmerden in twee verschillende Compassionate Cities in België.

We hebben een multimethod procesevaluatie uitgevoerd[20], verzameld over een ontwikkelingsperiode van bijna vier jaar, van december 2019 tot september 2023. De onderzoeker en eerste auteur (LDEE) voerde semigestructureerde observaties, documentanalyse, semigestructureerde interviews en groepsdiscussies uit met alle relevante partijen in het ontwikkelingsproces van de buurtinitiatieven. Aangezien Compassionate Communities complexe adaptieve systemen zijn, zijn traditionele methoden die gericht zijn op voorspelbaarheid en lineariteit niet geschikt om ze te evalueren.[21] Daarom moesten onze methoden voor het verzamelen van gegevens daaraan worden aangepast, zodat er voldoende flexibiliteit mogelijk was bij het verzamelen en zowel waarneembare als niet-waarneembare determinanten van verandering konden worden vastgelegd.[21] De onderzoeksopzet en methoden werden vastgelegd in een gedetailleerd studieprotocol (**hoofdstuk V**).[22] LDEE was betrokken bij het ontwikkelingsproces via actieonderzoek[23] en gebruikte het vergaren van kennis via onderzoek om beslissingen te onderbouwen en de initiatieven te versterken. Relevante partijen in de buurten werden op co-creatieve wijze betrokken bij de ontwikkeling van de burgerbetrokkenheidsinitiatieven, maar namen niet actief deel aan de dataverzameling. We kozen voor een thematische analyse[24] met een combinatie van inductief en deductief coderen. Inductief, data-gestuurd coderen, maakt het mogelijk om zowel expliciete als onderliggende betekenissen van het ontwikkelingsproces te construeren.[24]

4. De belangrijkste bevindingen van dit proefschrift

In **hoofdstuk II** beschrijf ik de resultaten van een systematisch review van burgerinitiatieven rond ernstige ziekte, sterven en verlies, wereldwijd. Door initiatieven te includeren uit internationale peer-reviewed publicaties in het Engels, identificeerden we negentien verschillende initiatieven wereldwijd. Hoewel deze initiatieven verspreid waren over verschillende landen, kwamen ze bijna allemaal uit landen waar Engels een officiële taal is (bijv. Australië, de Verenigde Staten, India, Ethiopië en Canada). We vonden dat gemeenschappen deelnamen aan de ontwikkeling van alle initiatieven, zij het in verschillende vormen variërend van samenwerkingsverbanden met academici tot samenwerkingen met organisaties Gedetailleerde beschrijvingen van hun ontwikkelingsprocessen -en strategieën ontbraken echter. Tot slot ontdekten we dat de meeste initiatieven waren geëvalueerd in studies, waaruit veelbelovende resultaten naar voren kwamen.[26] Desalniettemin vertoonden de evaluaties aanzienlijke verschillen in hun doelstellingen, methodologieën en resultaten, evenals in hun algehele kwaliteit en sterkte van het bewijs. Specifiek vonden we dat procesevaluaties zich doorgaans alleen richtten op specifieke aspecten van de burgerinitiatieven, zoals hun bereik, zonder een uitgebreidere analyse van het ontwikkelingsproces te bieden. Dit onderstreepte de noodzaak om meer diepgaand inzicht te krijgen in hoe dergelijke initiatieven worden ontwikkeld door het gebruik van procesevaluaties van hoge kwaliteit.

Hoofdstuk III presenteert de bevindingen van een cross-sectionele survey die we tussen februari en april 2021 uitvoerden in de twee geselecteerde buurten. Dit onderzoek maakte deel uit van het in kaart brengen van ‘assets in de buurt’ met betrekking tot participatie, en het formuleren van ontwikkelingsstrategieën voor buurtinitiatieven rond ernstige ziekte, sterven en verlies. Concreet, wilden we een beschrijving geven van de mate en het type van burgerparticipatie in de geselecteerde buurten met betrekking tot ernstige ziekte, sterven en verlies en bestuderen of burgers meer geneigd waren deel te nemen als ze een hoger niveau van sociale cohesie in de buurt ervoeren. De vragenlijsten werden verspreid onder een steekproef van 2.324 volwassen burgers in de twee buurten. We ontvingen 714 vragenlijsten en vonden dat 42% van de respondenten had deelgenomen aan ten minste één buurtactiviteit in verband met ernstige ziekte, sterven of verlies. De meeste respondenten participeerden door een buur te helpen (32%) of door vrijwilligerswerk te doen (10%); in mindere mate namen respondenten deel aan groepsactiviteiten zoals rouwgroepen (6%). Van de respondenten participeerde 31% zelden soms, een kleine minderheid nam regelmatiger deel (12%); de overige 47% nam niet deel. Na een hiërarchische lineaire regressieanalyse, geïnformeerd door een Directed Acyclic Graph[27] die de mogelijke causale verbanden en ‘deconfoundingstrategieën’ visualiseerde, vonden we een positieve associatie tussen gepercipieerde sociale cohesie in de buurt en participatie rond ernstige ziekte, dood en verlies in de twee buurten. Deze associatie werd niet beïnvloed door toevoeging van algemene buurtparticipatie - buiten de scope van ernstige ziekte, sterven en verlies - aan de regressieanalyse. Deze resultaten suggereren dat mensen die een hogere sociale cohesie in de buurt ervaren, een grotere kans hebben om deel te nemen aan activiteiten van met betrekking tot ernstige ziekte, dood en verlies, ongeacht of ze deelnemen aan algemene buurtactiviteiten buiten de scope van ernstige ziekte, sterven en verlies.

De resultaten van de cross-sectionele survey werden ook gerapporteerd en besproken in **hoofdstuk IV**, dat een antwoord geeft op de onderzoeksvragen of burgers meer geneigd zijn om deel te nemen aan buurtparticipatie rond ernstige ziekte, verlies of rouw als ze in het afgelopen jaar persoonlijke ervaringen hadden deze onderwerpen en of de capaciteit, vaardigheden die ze denken te hebben verworven door hun eerdere ervaringen, hun deelname versterkten. We ontdekten dat 72% van de respondenten het afgelopen jaar een ervaring had met ernstige ziekte, sterven of verlies. Meer dan de helft van de respondenten (57%) verloor iemand die ze goed kenden, 14,2% meldde dat ze mantelzorger waren geweest voor een ernstig ziek familielid en 15% meldde dat ze het afgelopen jaar ernstig ziek waren geweest. Na een hiërarchische lineaire regressieanalyse, ondersteund door een Directed Acyclic Graph-model[27] (een vergelijkbare aanpak als in **hoofdstuk III)** vonden we een positieve associatie tussen het afgelopen jaar mantelzorger zijn geweest en buurtparticipatie met betrekking tot ernstige ziekte, dood en verlies. Deze associatie werd niet gevonden voor andere ervaringen zoals zelf ernstig ziek zijn of een recent sterfgeval in de familie in het afgelopen jaar. Bovendien vonden we dat deze associatie versterkt werd wanneer de regressieanalyse werd uitgebreid met de gepercipieerde capaciteit en vaardigheden die ze hadden verworven op basis van hun eerdere ervaringen met ernstige ziekten, sterven en verlies. Deze resultaten suggereren dat mensen die het afgelopen jaar mantelzorger zijn geweest meer geneigd zijn om deel te nemen aan buurtactiviteiten met betrekking tot ernstige ziekte, mantelzorg, dood of verlies; en dat dit vooral het geval is als ze denken dat ze capaciteiten en vaardigheden hebben verworven door hun eerdere ervaringen met deze onderwerpen.

In **hoofdstuk V** presenteer ik het studieprotocol dat we ontwikkelden voor de evaluatie van de burgerinitiatieven rond ernstige ziekte, dood en verlies in de twee buurten die we selecteerden, in termen van hun ontwikkelingsprocessen en uitkomsten. Gezien de complexe dynamische en niet-lineaire aard van Compassionate Communities[21], kozen we enerzijds voor een methodologische aanpak die duidelijke richtlijnen bood met betrekking tot het onderzoeksdesign, de doelstellingen, de dataverzameling en de analyse, en anderzijds voldoende ruimte bood voor flexibiliteit om de evaluatie aan te passen aan het ontwikkelingsproces. We kozen voor een convergent-parallel 'mixed methods' evaluatieontwerp dat zowel kwalitatieve als kwantitatieve methoden van dataverzameling omvat. Gezien de convergent-parallelle aard van ons design[28], werden de verschillende soorten data afzonderlijk, maar tegelijkertijd verzameld met de idee deze te integreren en te interpreteren in een later stadium. Vanuit een kritisch-realistische filosofie[29] erkenden we de aanwezigheid van zowel objectieve als subjectieve factoren die ten grondslag liggen aan het ontwikkelingsproces van de buurtinitiatieven voor maatschappelijke betrokkenheid. Kwalitatieve methoden bestonden uit semi-gestructureerde observaties van relevante bijeenkomsten, documentanalyse van de geproduceerde documenten en semi-gestructureerde interviews en groepsdiscussies met alle relevante partijen, om het ontwikkelingsproces en de sociale processen die eraan ten grondslag lagen te capteren. Het protocol omvat ook een Most Significant Change[30]; deze werd uitgevoerd maar valt buiten het bereik van dit doctoraat. Tot de kwantitatieve methoden behoorde de cros-sectionele surveystudie, waarvan we enkel een pre-meting uitvoerden. Samen bieden deze methoden een goed inzicht in het ontwikkelingsproces van de buurtinitiatieven rond ernstige ziekte, sterven en verlies.

Hoofdstuk VI presenteert de bevindingen van een multimethod procesevaluatie[20] bestaande uit semigestructureerde observaties van alle relevante bijeenkomsten, documentanalyses van de notulen van bijeenkomsten en geproduceerde documenten, semigestructureerde interviews en groepsdiscussies met alle relevante partijen in het ontwikkelingsproces. Na een thematische analyse waarbij gebruik werd gemaakt van een combinatie van inductieve en deductieve codering[24], vonden we dat de uitdagingen in het ontwikkelingsproces zich concentreerden rond het integreren van de buurtinitiatieven in de bredere context van de Compassionate City-programma's. Deze uitdagingen kwamen duidelijk naar voren in de ongelijke machtsdynamiek tussen de steden en de vertegenwoordigers van organisaties in de buurt, evenals in moeilijkheden bij het uitbreiden van het project naar buurtbewoners en andere sleutelfiguren in de buurt. Ondanks deze uitdagingen ontdekten we het potentieel van Compassionate Cities om als facilitator op te treden. Bijvoorbeeld door de organisatie van een stadsbreed festival dat buurtparticipatie aanmoedigde. Daarnaast ontdekten we dat uitdagingen met betrekking tot machtsdynamiek konden worden opgelost door een gedeelde besluitvormingsstructuur te hanteren, in plaats van een gecentraliseerde structuur die de eindbeslissingsbevoegdheid toekent aan vertegenwoordigers van de stad. Tot slot bleek het uitbreiden van de buurtinitiatieven naar andere sleutelfiguren uit de buurt die niet betrokken waren bij de ontwikkeling een uitdaging. Hoewel deze uitbreiding ook werd erkend als een cruciale strategie om de duurzaamheid van de ontwikkelde initiatieven te vergroten. Ik raad steden aan om de faciliterende mechanismen in hun beleid op te nemen om het succes en de duurzaamheid van deze initiatieven te vergroten, en om de initiatieven uit te breiden naar andere sleutelfiguren in de buurt.

Hoofdstuk VII geeft de resultaten van een ‘review’ van vijf recente publicaties over Compassionate Communities[31-35] , gepresenteerd in de vorm van een ‘editorial’. Het doel van deze review was om de bestaande spanningen en uitdagingen binnen het veld van Compassionate Communities te belichten en om richtingen voor te stellen voor de toekomstige praktijk en onderzoek. Drie spanningen werden geïdentificeerd. De eerste spanning betrof de machtsdynamiek en de betrokkenheid van de gemeenschappen bij de ontwikkeling van dergelijke initiatieven, waarbij de vraag werd gesteld of het aanbieden van educatieve activiteiten aan burgers, zonder bredere inspanningen op het gebied van zelfbeschikking, terecht als Compassionate Communities kunnen worden bestempeld. Een tweede spanningsveld draaide rond de vraag of dienstgerichte of onderzoeks-gerichte initiatieven, zoals de meerderheid van de initiatieven die in de reviews werden geïdentificeerd, in strijd zijn de belangen van burgers en gemeenschappen. Een derde spanning die naar voren kwam, is de Engelstalige peer-reviewed literatuur die zich voornamelijk richt op Compassionate Communities in hoge-inkomenslanden, waardoor weinig is gepubliceerd over Compassionate Communities in andere contexten. Deze spanningen benadrukken de noodzaak om onderzoek naar Compassionate Communities te verbreden in plaats van te beperken, zodat het een breder scala aan contexten, demografische gegevens, methodologieën en epistemologieën omvat, als aanvulling op de bestaande traditionele benaderingen.

5. Interpretatie en bespreking van bevindingen

5.1. Kunnen we van gemeenschappen verwachten dat ze actief bijdragen aan ernstige ziekte, dood en verlies?

5.1.1. Hoe om te gaan met een (verkeerde) afstemming van behoeften, wensen en focus in het ontwikkelingsproces van buurtinitiatieven voor burgerbetrokkenheid?

In **hoofdstuk VI** werd benadrukt dat de belangen van buurtbewoners verschilden van die van vertegenwoordigers van organisaties in de stad. Buurtbewoners hadden voornamelijk interesse in het ondersteunen van hun buren, zoals werd bevestigd in **hoofdstuk III**, waar het helpen van buren werd geïdentificeerd als de belangrijkste vorm van participatie in de buurt. Omgekeerd waren de vertegenwoordigers van organisaties meerder geïnteresseerd in netwerken met lokale partners en in het identificeren van de bestaande initiatieven en activiteiten met betrekking tot ernstige ziekte, sterven en verlies. Ondanks deze verschillende prioriteiten werd er uiteindelijk een gemeenschappelijke interesse gevonden, wat resulteerde in de ontwikkeling van een gezamenlijke activiteit. Dit sluit aan bij de literatuur over gemeenschapsontwikkeling die pleit voor het vinden van een gemeenschappelijke basis als een goede strategie voor het initiëren van initiatieven.[36-38] Critici beweren echter dat deze aanpak voorbij kan gaan aan de verschillende belangen binnen gemeenschappen. [37, 39] Wij ontdekten dat er naast gemeenschappen op basis van een gedeelde interesse, verschillende soorten gemeenschappen naast elkaar bestaan binnen de geografische afbakening van een buurt. We vonden in de buurt bijvoorbeeld ook gemeenschappen op basis van gedeelde omstandigheden, zoals mantelzorger zijn, en dat het evolueren naar een gemeenschap van gedeelde interesse in de loop van de tijd konden worden gecultiveerd. We moeten ons echter bewust zijn dat één enkel initiatief niet tegemoet komt aan de uiteenlopende behoeften binnen gemeenschappen.

5.1.2. Beschikken gemeenschappen over de nodige capaciteit en vaardigheden om zich in te zetten rond de thema's ernstige ziekte, dood en verlies?

Hoofdstuk VI toonde dat hoewel buurtbewoners het belang erkennen van buren helpen, ze een gebrek aan de nodige capaciteiten en vaardigheden ervaarden. Hierbij aansluitend vonden we in **hoofdstuk IV** dat mensen met eerdere ervaringen met ernstige ziekte, sterven en verlies, meer geneigd zijn tot buurtparticipatie rond ernstige ziekten, sterven en verlies, voornamelijk wanneer ze het gevoel hadden dat ze capaciteiten en skills ontwikkelden als gevolg van deze ervaringen. Desalniettemin, daarnaast is, op basis van het rapport van de 'Lancet Commission on the Value of Death'[40] ook een bredere blootstelling aan deze onderwerpen in gemeenschappen nodig is als we hun capaciteiten en vaardigheden willen vergroten. Deze blootstelling kan worden gecreëerd op het niveau van maatschappelijke organisaties, professionele diensten en overheden.[40] Universiteiten kunnen bijvoorbeeld een ondersteunend beleid voor personeel en studenten opstellen.[14] Professionele diensten, zoals woonzorgcentra, door het organiseren van buurtgerichte activiteiten.[41] Overheden kunnen blootstelling creëren door beleid dat participatie en samenwerking tussen gemeenschappen en professionele diensten bevordert.[40, 42] Hoewel educatieve en bewustmakingsactiviteiten dus cruciaal zijn, pleit ik ervoor dat systemische blootstelling op niveau van buurten en gemeenschappen, professionele organisaties en op overheidsniveau noodzakelijk zijn als we gemeenschappen willen versterken om te participeren rond ernstige ziekte, sterven en verlies.

5.1.3. Bestaat er een risico op professionalisering van gemeenschappen door hun burgerbetrokkenheid rond ernstige ziekte, sterven of verlies?

De systematische review **van hoofdstuk II** en de procesevaluatie van **hoofdstuk VI** toonden aan dat de meeste burgerinitiatieven rond ernstige ziekte, dood en verlies werden geïnitieerd door professionals, hetzij als onderzoekers of als dienstverleners. Deze professionele betrokkenheid suggereert een zekere mate van professionele controle over deze initiatieven. In de loop der jaren is er een verschuiving geweest van altruïstische motieven naar meer individualistische redenen voor burgerparticipatie, wat leidt tot meer korte-termijn, projectmatige betrokkenheid.[43-45] Deze neiging tot professionalisering i ook merkbaar bij Compassionate Communities, waarbij het vaak professionele zorgverleners zijn die de leiding nemen, gezien deze initiatieven vaak worden ontwikkeld in complexe contexten met diverse interesses waarbij een zekere expertise nodig is om dit te navigeren.[46] Hoewel er ook voorbeelden zijn, zoals Community Connectors[47] en Compassionate Neighbours[48] die ook al zijn ze geïnitieerd vanuit de professionele zorg- of onderzoeksector, toch een actieve en zelfbeschikkende rol aan gemeenschappen toekennen. Vervolgens pleit ik voor een dergelijke aanpak bij het ontwikkelen van buurtinitiatieven en raad ik aan om ook ruimte te creëren voor diverse vormen van participatie waarvoor geen specifieke expertise vereist is.

5.2. Wat zijn de implicaties van het ontwikkelen van buurtinitiatieven voor burgerbetrokkenheid in de context van Compassionate Cities?

5.2.1. Beginnen we met de ontwikkeling van Compassionate Cities of met de ontwikkeling van buurtinitiatieven voor burgerbetrokkenheid?

Bevindingen uit **hoofdstuk 6** geven aan dat beide steden prioriteit gaven aan het Compassionate Cities-programma boven de ontwikkeling van buurtinitiatieven voor burgerbetrokkenheid. Deze prioritering suggereert een hogere politieke waarde van stadsbrede initiatieven vanwege hun grotere zichtbaarheid onder burgers. Literatuur geeft echter aan dat stadsbrede initiatieven, hoewel ze politiek voordelig zijn, complexer zijn vanwege een verminderd gevoel van verbondenheid met de gemeenschap en de betrokkenheid van diverse belanghebbenden met verschillende prioriteiten.[49] Lokale initiatieven bieden daarentegen een sterkere basis voor betrokkenheid en samenwerking, wat leidt tot duurzamere resultaten.[49] De steun van de Vlaamse overheid voor buurtgerichte projecten biedt een kans om lokale politici bewust te maken van het belang van buurtgericht werken voor succesvolle en Compassionate Communities.

5.2.2. Kunnen de Compassionate Cities-aanpak en de Compassionate Communities-aanpak in hetzelfde project worden geïntegreerd?

Hoofdstuk VI onthult uitdagingen bij het integreren van buurtinitiatieven rond ernstige ziekte, sterven en verlies in Compassionate Cities programma's. De verschillende benaderingen - waarbij Compassionate Cities eerder top-down en Compassionate Communities meer gemeenschapsgericht worden ontwikkeld- komen overeen met de manier waarop Kellehear, die de Compassionate Cities-beweging startte, heeft voorgesteld om beide te ontwikkelen.[50] Maar hoewel zijn beschrijving nuttig is bij het verduidelijken van de twee verschillende benaderingen, ontstaat er hierbij ook het risico om Compassionate Cities te simplificeren als inherent top-down en Compassionate Communities als bottom-up. Ondanks dat de stadsvertegenwoordigers de Compassionate Cities en Communities als twee verschillende benaderingen ervaarden, zagen we dat de Cities benadering een invloed had op de ontwikkeling van de buurtinitiatieven, hetgeen het ontwikkelingsproces zowel positief als negatief beïnvloedde. Bijgevolg beveel een hybride model aan waarbij lokale overheden een ondersteunend kader kunnen bieden aan buurtinitiatieven rond ernstige ziekte, sterven en verlies. Omgekeerd stel ik voor dat de meer top-down geïnitieerde Compassionate Cities baat zouden kunnen hebben bij benaderingen van gemeenschapsontwikkeling om het eigenaarschap over de ontwikkelde initiatieven te vergroten.

5.3. Wat kunnen we leren van andere contexten waarin Compassionate Communities worden ontwikkeld?

De hoofdstukken II en VII leggen de nadruk op het gebrek aan kennis over burgerinitiatieven rond ernstige ziekte, sterven en verlies in landen met een laag of gemiddeld inkomen. Desondanks bieden initiatieven zoals het Neighbourhood Network in Palliative Care (NNPC) [51] in India en het Compassionate Neighbours initiatief [52] in Londen dat hierop gebaseerd is, inspirerende voorbeelden die ook nuttig kunnen zijn in de Belgische context.

Er bestaat een opmerkelijk verschil tussen het Verenigd Koninkrijk en België in de mate van betrokkenheid van gemeenschappen bij professionele diensten.[53] Dit verschil wordt grotendeels toegeschreven aan verschillen in financieringsmechanismen.[53] In het Verenigd Koninkrijk zijn de 'hospices' voor hun dagelijkse activiteiten sterk afhankelijk van liefdadigheid en schenkingen vanuit gemeenschappen. Bijgevolg zijn er vanuit deze hospices uitgebreide inspanningen om gemeenschappen op een actieve manier te betrekken bij hun dagelijkse werking en de activiteiten en initiatieven die ze organiseren.[54] Deze aanpak wordt geïllustreerd door het Compassionate Neighbours initiatief in Londen, dat afwijkt van het traditionele servicegerichte vrijwilligerswerk en activiteiten stimuleert die men zou ondernemen voor een vriend of buur, in plaats van activiteiten vanuit een voorgeschreven vrijwilligersrol.[52] Het Compassionate Neighbours initiatief is geïnspireerd op het Neighbourhood Network in Palliative Care (NNPC)[51] in Kerala, India, waar het beleid gemeenschappen in staat stelde een actieve rol te spelen in de palliatieve zorg, als aanvulling op de bestaande thuiszorg. Het toepassen van deze modellen in de Belgische context bleek echter een uitdaging vanwege de minder verregaande maatschappelijke betrokkenheid rond ernstige ziekte, dood en verlies. Hoewel de voorbeelden uit het Verenigd Koninkrijk en India zeer waardevol zijn, moet er bij de implementatie dus ook rekening worden gehouden met lokale contexten en culturele verschillen.

5.4. Wat zijn de implicaties van onderzoek naar Compassionate Communities in de periode van een doctoraat? Welke resultaten kunnen we verwachten over 4 jaar?

Uit de procesevaluatie van **hoofdstuk 6** blijkt dat de buurtinitiatieven niet de gehoopte cultuuromslag rond ernstige ziekte, dood en verlies teweegbrachten. Ze verhoogden echter wel de gepercipieerde sociale buurtcohesie, een positief hoewel enigszins teleurstellend resultaat voor sommigen. Desalniettemin tonen onze resultaten in **hoofdstuk III** dat een verhoogde sociale cohesie in de buurt geen slecht resultaat is. We ontdekten dat mensen die een hoger niveau van sociale cohesie ervaren ook meer geneigd zijn om deel te nemen aan buurtactiviteiten rond ernstige ziekte, dood en verlies. Dit kan worden toegeschreven aan de grotere verbondenheid tussen mensen, waardoor de barrières om informatie te zoeken of te geven over gevoelige onderwerpen als ernstige ziekte, dood en verlies worden verminderd.[55] Hoewel het resultaat van een verhoogde sociale cohesie in de buurt in eerste instantie misschien wat mager lijkt, vertegenwoordigt het een essentiële eerste stap in de richting van de gewenste cultuurverandering met betrekking tot ernstige ziekte, dood en verlies. Gezien deze bevindingen is het ook nodig om na te denken over de financiering en dus de tijd die aan dergelijke projecten wordt besteed, werkelijk voldoen om een cultuurverandering rond ernstige ziekte, dood en verlies te bewerkstelligen en de initiatieven zelfvoorzienend te maken. Dit laatste wordt gestaafd door de resultaten van onze systematische review (Hoofdstuk II), waarin het stopzetten van de financiering werd genoemd als het belangrijkste risico voor het voortzetten van de burgerinitiatieven en het bereiken van langetermijneffecten. Bijgevolg pleit ik voor een lange-termijnfinanciering om de ontwikkelde buurtinitiatieven te verankeren en langetermijneffecten te bereiken

6. Aanbevelingen voor praktijk, beleid en toekomstig onderzoek

6.1. Aanbevelingen voor lokale beleidsmakers

6.1.1. Een op gemeenschapsontwikkeling gerichte aanpak:

Om een stevige basis te leggen voor burgerinitiatieven in buurten, is het cruciaal dat bewoners niet alleen geraadpleegd worden om input aan te leveren maar dat ze ook actief betrokken worden bij het ontwikkelings- en implementatieproces. We dringen er bij beleidsmakers op aan om een kader op te zetten dat burgers in staat stelt om actief deel te nemen aan het ontwikkelingsproces, zelfs als hun standpunten afwijken van de oorspronkelijke beleidsplannen of als ze kiezen voor alternatieve benaderingen, waarbij efficiëntie en effectiviteit niet op de eerste plaats komen.

6.1.2. Langetermijnstrategieën voor meer duurzaamheid

Lokaal beleid speelt een cruciale rol bij het ontwikkelen van een langetermijnstrategie om de duurzaamheid van buurtinitiatieven te garanderen en te voorkomen dat ze na vier jaar wordt stopgezet. Deze aanpak moet ook zorgen voor continuïteit van het thema over verschillende politieke termijnen heen, om te voorkomen dat het een project enkel geassocieerd wordt met specifieke politici en daarna mogelijks afzwakt. Daarnaast moeten lokale overheden erkennen dat volledige zelfvoorziening van het project moeilijk te bereiken is binnen vier jaar en moet de toewijzing van middelen hiernaar worden aangepast. In het geval van discontinuïteit van middelen, moeten strategische overwegingen worden gemaakt om het project te blijven faciliteren. Dit kan betekenen dat aanvullende financieringsbronnen worden gezocht of dat nieuwe partners worden aangetrokken die het project kunnen verderzetten.

6.2. Aanbevelingen voor nationale beleidsmakers

Aangezien onze huidige westerse palliatieve zorg voornamelijk wordt verleend binnen de grenzen van professionele palliatieve zorg, zijn beleidsinterventies essentieel om deze diensten te verbinden met de gemeenschappen waarin ze werkzaam zijn. Ik raad beleidsmakers aan inspiratie te putten uit buurtinitiatieven zoals in Kerala, waar beleid de integratie van burgerinitiatieven binnen bestaande professionele praktijken vergemakkelijkte. Het is echter cruciaal om ervoor te zorgen dat deze integratie de zelfbeschikking van gemeenschappen niet ondermijnt, maar dat zowel gemeenschappen als professionele diensten elkaar aanvullen en versterken. In het kader van de continuïteit van lopende initiatieven raad ik aan om lopende buurtinitiatieven, verder te verankeren in de context van de hervorming van de palliatieve zorg in Vlaanderen. Deze steun kan bestaan uit coaching, coördinatie en middelen.

6.3. Aanbevelingen voor gemeenschapsopbouwende praktijken

6.3.1. Vergemakkelijken van gemeenschapsbezit

Aangezien we een aantal uitdagingen hebben gevonden met betrekking tot het integreren van de buurtinitiatieven binnen de context van twee Compassionate Cities programma's, is een van de belangrijkste aanbevelingen om voldoende eigenaarschap toe te kennen aan gemeenschappen en buurten in het ontwikkelingsproces. Dit kan via verschillende strategieën worden bereikt, door gemeenschappen de mogelijkheid te bieden om de bestaande 'assets' waarover ze beschikken in te zetten bij de ontwikkelingen van initiatieven, zoals reeds bestaande ambulante buurtteams.

6.3.2. Een inclusieve aanpak hanteren

Gemeenschapsopbouwende praktijken moeten voortdurend gericht zijn op het toepassen van inclusieve benaderingen binnen buurten. Hoewel groepsdiscussies met buurtbewoners een positieve stap zijn in het betrekken van bewoners bij het ontwikkelingsproces, hebben ze de neiging om alleen een specifieke groep mensen te betrekken die intrinsiek gemotiveerd zijn en vaak al expertise hebben op het gebied van ernstige ziekte, sterven en verlies. Hoewel het een goed idee kan zijn om te beginnen met de meest gemotiveerde individuen, bestaat het risico dat de diversiteit binnen de buurt over het hoofd wordt gezien. Om een inclusieve aanpak te bevorderen, is het de moeite waard inspiratie te putten uit initiatieven in het buitenland, zoals Compassionate Neighbours[52] in Londen die mensen met een Black, Asian, and Minority Ethnic (BAME) achtergrond op een actieve manier betrekken bij buurtgerichte activiteiten (bijvoorbeeld een stand op de wekelijkse markt waar mensen worden uitgenodigd voor een gesprek).

6.3.3. Focus op realistische, haalbare doelen

Tot slot adviseren we mensen die aan community building doen om haalbare doelen te stellen binnen het vooraf gedefinieerde tijdsbestek. Het nastreven van een ambitieus doel om de houding ten opzichte van ernstige ziekten, dood en verlies volledig te veranderen, kan leiden tot teleurstelling bij de deelnemers. In plaats daarvan zou ik willen aanraden om te beginnen met het ontwikkelen van kleinschalige initiatieven die een geleidelijke vooruitgang naar langeretermijndoelen mogelijk maken.

6.4. Aanbevelingen voor toekomstig onderzoek

6.4.1. Context-overschrijdend onderzoek

Aangezien onze huidige kennis over Compassionate Communities is voornamelijk geconcentreerd in hoge-inkomenslanden waar Engels een van de hoofdtalen is, raad ik aan om meer intercultureel internationaal onderzoek te doen. Hoewel deze vaak vergelijkbare contexten - waar burgerinitiatieven gesitueerd zijn in een geïnstitutionaliseerd kader van palliatieve zorg - zeer waardevol zijn om parallellen te trekken met de Vlaamse context, is het even belangrijk om inzichten te verwerven in contexten dit niet zo is. Op deze manier krijgen we inzicht in de verschillende politieke en maatschappelijke factoren waaruit deze initiatieven voortkomen en kunnen de ontwikkelingsstrategieën die in deze contexten worden gebruikt waardevolle perspectieven bieden en ons algemene begrip van effectieve Compassionate Communities strategieën verbeteren.

6.4.2. Diepgaand onderzoek naar processen en resultaten

Op basis van de procesevaluatie hebben we tal van potentiële strategieën geformuleerd voor de ontwikkeling van buurtinitiatieven rond ernstige ziekte, sterven en verlies en hebben we verschillende aannames gedaan over mogelijke ontwikkelingsstrategieën, zoals het uitbreiden van initiatieven naar andere buurtbewoners en sleutelfiguren. Verder onderzoek is nodig om deze strategieën en veronderstellingen effectief te implementeren en de voortgang ervan te evalueren. Daarnaast ontdekten we dat veel uitdagingen voortkwamen uit het gebrek aan eigenaarschap van de vertegenwoordigers van de burgermaatschappij in het project. Daarom is er meer diepgaand onderzoek nodig om deze machtsdynamiek binnen de specifieke context van Compassionate Communities te onderzoeken. Verder ontdekten we in **hoofdstuk IV** dat individuen die het afgelopen jaar een zorgervaring hadden, meer geneigd waren om deel te nemen aan buurtactiviteiten met betrekking tot deze onderwerpen, vooral als ze dachten dat ze capaciteiten en vaardigheden hadden opgedaan door hun eerdere ervaringen. Dit resultaat moet verder worden getest via een longitudinale, kwantitatieve gegevensverzameling over deze concepten, aangevuld met inzichten uit de kwalitatieve literatuur over hoe we van ervaringen naar het opdoen van capaciteiten en vaardigheden gaan en vervolgens naar buurtparticipatie rond deze onderwerpen.

6.4.3. Resultaten zichtbaar maken

Verder speelt onderzoek een cruciale rol bij het in stand houden van de ontwikkelde buurtinitiatieven voor burgerbetrokkenheid, niet alleen door het formuleren van mogelijke duurzaamheidsstrategieën op basis van een procesevaluatie, maar ook door het verzamelen van zichtbare gegevens over de resultaten (bijv. het aantal deelnemers aan activiteiten). Dergelijke gegevens kunnen aanvragen voor voortgezette financiering ondersteunen. Verder moet worden opgemerkt dat de onderzoeksperiode van vier jaar onvoldoende is om veranderingen of effecten op de lange termijn te meten. Daarom raad ik onderzoekers aan om niet alleen financiering te zoeken voor nieuwe initiatieven, maar ook om het onderzoek naar reeds ontwikkelde initiatieven voort te zetten. Dit stelt ons in staat om ook de impact op lange termijn te meten en een grondige hoeveelheid bewijsmateriaal over Compassionate Communities op te bouwen.

6.4.4. Onvoorspelbaarheid en onzekerheid omarmen

Een inherent aspect van buurtinitiatieven is dat ze samen met belanghebbenden in de buurt worden ontwikkeld. Hoewel de flexibiliteit die nodig is om de datacollectie aan te passen aan het evoluerende ontwikkelingsproces een uitdaging vormt voor onderzoekers, raad ik aan om benaderingen van gemeenschapsontwikkeling te omarmen, samen met hun onvoorspelbaarheid en onzekerheid. Hoewel vooraf vastgestelde modellen veel voordelen bieden, zoals het hebben van vooraf gedefinieerde resultaten[56], geloof ik ook in de voordelen van benaderingen die vooraf minder gedefinieerd zijn en die aansluiten bij de belangen van buurten. Om aan de van dit proces tegemoet te komen, raad ik onderzoeker aan om methoden te gebruiken die zich kunnen aanpassen aan veranderende omstandigheden, zoals semi-gestructureerde observaties, interviews en groepsdiscussies.

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CURRICULUM VITAE

Curriculum vitae

Louise D’Eer is a criminologist with a second master’s degree in international development. Before the doctorate she worked as a researcher at the Odisee University College on the topic of civic engagement initiatives in the housing support of recognised refugees. She continued her work on studying civic engagement, this time on the topic of serious illness, death and loss, at the End-of-Life Care Research Group, where she started in 2019 as a PhD student. Her research was about the development and evaluation of neighbourhood civic engagement initiatives regarding serious illness, death and loss and was part of the CAPACITY project (Flanders Programme to Develop Capacity in Palliative Care Across Society), a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. The research project was supported by a grant from the Research Foundation Flanders.

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Oral presentations at international conferences after peer-reviewed abstract selection

6th October 2021
Civic engagement regarding serious illness, death and loss: a systematic mixed-methods review. **EAPC 17th world congress.**

21 September 2022
Community development around serious illness, dying and loss: stories and perspectives from three countries. **7th Public Health Palliative Care International conference.**

1 April 2022
Burgerinitiatieven rond ernstige ziekte, sterven en verlies: een systematische mixed-methods review. **Vlaams-Nederlandse Wetenschapsdagen.**

21 September 2022
Community development around serious illness, dying and loss: stories and perspectives from three countries. **7th Public Health Palliative Care International conference.**

22 May 2023
Neighbourhood civic engagement around serious illness, death and loss: results of the development of initiatives in two neighbourhoods in Flanders. **ICIC: International Conference on Integrated Care.**

16 June 2023
How Compassionate Is your Neighbourhood? A Cross-sectional Survey Study Measuring Neighbourhood Participation Regarding Serious Illness, Death and Loss. **EAPC 19th world congress.**

17th November 2023
Caregiving experiences in the last year are associated with neighbourhood participation regarding serious illness, death and loss: A cross-sectional survey study. **3rd International Seminar on Public Health Research in Palliative Care.**

Oral presentations at national conferences after peer-reviewed abstract selection

25 May 2023
Hoe ‘compassionate’ is jouw buurt ? Resultaten van een dwarsdoorsnede-onderzoek naar buurtparticipatie bij ernstige, overlijden en verlies. **Dag van de Sociologie** (UGent).

Invitation for presentations at international symposiums

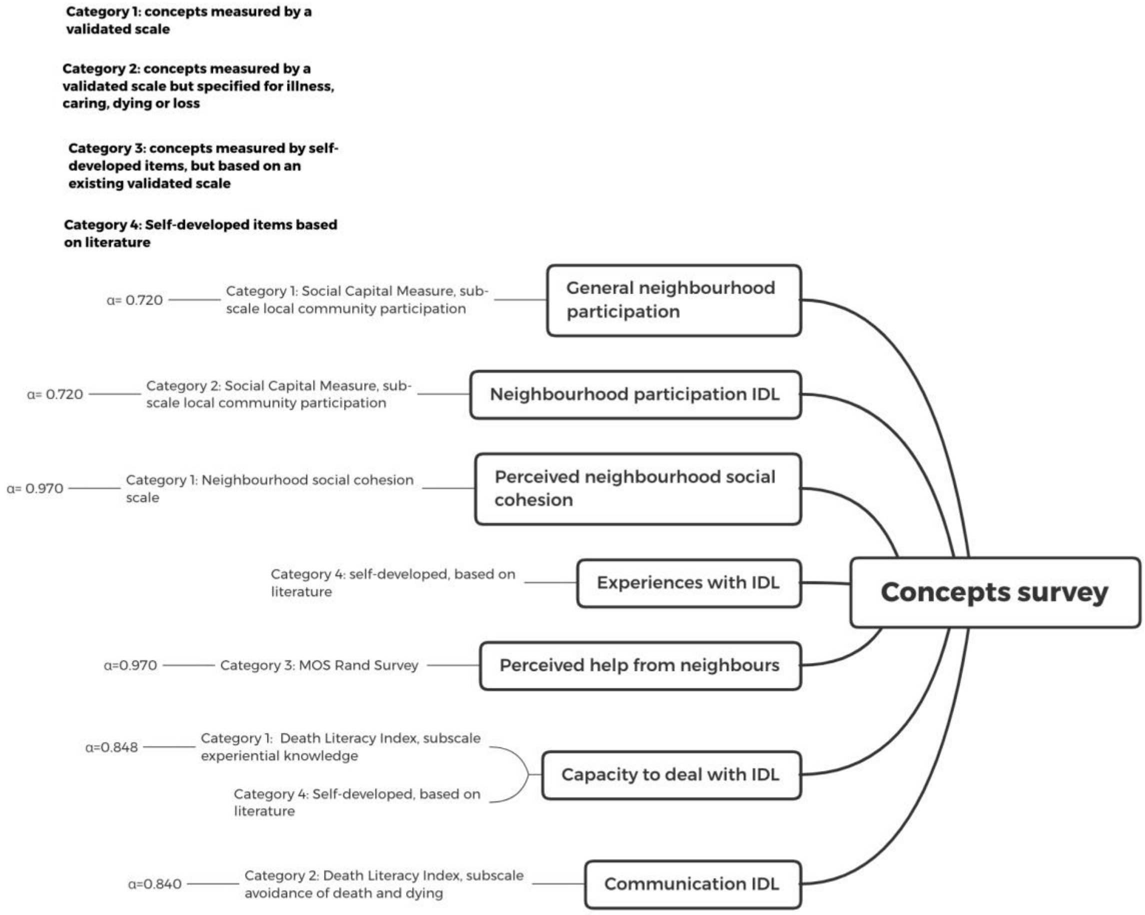
2th November 2021
Developing Compassionate Communities. World Compassionate Communities Symposium. [panel discussion]
1st December 2023
Compassionate communities in Belgium. Good life, good death, good grief. [Plenary presentation]
29 March 2023
Compassionate Neighbours in the United Kingdom and Belgium. Compassionate Neighbours Day London. [Plenary presentation]

Research stay

9th Jan -9th Febr 2023	Compassionate Neighbours research stay at St.Christopher’s Hospice London

Appendices

Appendix 1. Survey concepts and the scales by which they are measured



IDL= serious illness, death and loss

α= reliability of the original, validated scale

Appendix 2. Vragenlijst inwoners Herzele of Sint-Kruis

- Vul bij elke vraag één antwoord in. Als u meerdere antwoorden mag aanduiden dan vermelden we dit bij de vraag.
- De vragenlijst invullen duurt ongeveer 15-20 minuten
- Met '**ziekte**' bedoelen we een ziekte die lang duurt en levensbedreigend kan zijn, zoals kanker, multiple sclerose (MS), dementie, diabetes, hartfalen…
- Met '**mantelzorgers**' bedoelen we personen die op regelmatige basis zelf zorgen voor een zieke persoon die ze goed kennen (bv. een familielid).
- Deze vragenlijst wordt afgenomen in Herzele. Het woord '**buurt**' in deze vragenlijst kan u, indien gewenst, zo ruim interpreteren als heel Herzele.

Het eerste stuk van de vragenlijst gaat over hoe verbonden u zich voelt met de buurt waarin u woont, de mensen die in uw buurt wonen en de mate waarin u deelneemt aan activiteiten in uw buurt

DEEL 1: VERBONDENHEID MET UW BUURT EN BUREN

1. In welke mate bent u het eens met elke stelling? Kruis per stelling het meest

	Helemaal eens	Eens	Niet eens of oneens	Oneens	Helemaal oneens
A. Ik heb het gevoel dat ik thuishoor in deze buurt	☐	☐	☐	☐	☐
B. De vriendschappen en banden die ik heb met andere mensen in mijn buurt betekenen veel voor mij	☐	☐	☐	☐	☐
C. Wanneer de mensen in mijn buurt iets plannen dan zie ik dat eerder als iets dat wij doen, in plaats van iets dat zij doen	☐	☐	☐	☐	☐
D. Ik denk dat ik het met de meeste mensen in mijn buurt eens ben over wat belangrijk is in het leven	☐	☐	☐	☐	☐
E. Ik voel me loyaal aan de mensen in mijn buurt	☐	☐	☐	☐	☐
F. Ik zou bereid zijn met anderen samen te werken aan iets om mijn buurt te verbeteren	☐	☐	☐	☐	☐
G. Ik zie mijzelf graag als gelijkend op de mensen die in deze buurt wonen	☐	☐	☐	☐	☐
H. Er is een hecht gevoel van vriendschap tussen mij en de andere mensen in de buurt	☐	☐	☐	☐	☐
I. In deze buurt wonen geeft mij een gemeenschapsgevoel	☐	☐	☐	☐	☐
J. Over het algemeen spreekt wonen in deze buurt mij aan	☐	☐	☐	☐	☐
K. Als ik de kans krijg, zou ik graag uit deze buurt verhuizen	☐	☐	☐	☐	☐
L. Ik ben van plan een aantal jaren in deze buurt te blijven wonen	☐	☐	☐	☐	☐
M. Ik bezoek mijn buren bij hun thuis	☐	☐	☐	☐	☐
N. Als ik advies over iets nodig zou hebben, kan ik terecht bij iemand in mijn buurt	☐	☐	☐	☐	☐
O. Ik denk dat mijn buren mij zouden helpen in geval van nood	☐	☐	☐	☐	☐
P. Ik leen dingen en verleen wederdiensten aan mensen in mijn buurt	☐	☐	☐	☐	☐
Q. Er komen zelden buren bij mij op bezoek	☐	☐	☐	☐	☐
R. Ik stop geregeld om te praten met mensen in mijn buurt	☐	☐	☐	☐	☐

DEEL 2: PARTICIPATIE IN UW BUURT

We stellen u graag een aantal vragen over uw deelname aan evenementen, verenigingen, en andere initiatieven in uw buurt. Ook indien uw deelname eerder laag is, nodigen wij u graag uit om deze vragen in te vullen. Het geeft ons een beeld van de participatie die er al is in uw buurt, en op welke vlakken deze nog verder kan versterkt worden.
2. Omcirkel bij elke vraag het meest geschikte antwoord: 1, 2, 3 of 4.

A. Helpt u in een groep (vereniging of organisatie) in uw buurt als vrijwilliger?	1 Neen, helemaal niet	2	3	4 Ja, vaak (minstens 1x per week)
B. Heeft u in de afgelopen 6 maanden <u>voor de start van de coronacrisis</u> een evenement in uw buurt bijgewoond? (bv. parochiefeest, schoolconcert, hobbybeurs,….)	1 Neen, helemaal niet	2	3	4 Ja, meerdere (minstens 3)
C. Bent u een actief lid van een vereniging of organisatie in uw buurt? (bv. sportclub, hobbyclub, boekenclub,….)	1 Neen, helemaal niet	2	3	4 Ja, zeer actief
D. Zit u in een beheers- of organisatiecomité voor een vereniging of organisatie in uw buurt?	1 Neen, helemaal niet	2	3	4 Ja, verschillende (minstens 3)
E. Heeft u in de afgelopen 3 jaar ooit meegedaan aan een actie in uw buurt om een noodtoestand op te vangen? (bv. helpen bij een verkeersongeval, een zieke buur naar spoed brengen,…)	1 Neen, helemaal niet	2	3	4 Ja, frequent (minstens 5 keer)
F. Heeft u in de afgelopen 3 jaar ooit deelgenomen aan een gemeenschapsproject of een liefdadigheidsactie in uw buurt? (bv. buurttuin, straatfeest, een festival voorbereiden, geld inzamelen…)	1 Neen, helemaal niet	2	3	4 Ja, zeer veel
G. Heeft u ooit deelgenomen aan een project om een nieuw initiatief in uw buurt te organiseren? (bv. nieuwe jeugdclub, nieuw scoutslokaal, nieuwe recreatie voor mindervaliden,…)	1 Neen, helemaal niet	2	3	4 Ja, verschillende keren (minstens 3)
H. Bent u een actief lid van een digitale buurtgroep? (bv. Whatsappgroep, Facebookgroep,….)	1 Neen, helemaal niet	2	3	4 Ja, zeer actief

Het tweede stuk van de vragenlijst gaat over hoe er in uw buurt wordt omgegaan met ziekte, sterven, verlies of rouw

Wij beseffen dat informatie geven over uw eigen ervaringen met ziekte, sterven, verlies of rouw niet gemakkelijk is. Toch nodigen wij u uit om de volgende vragen in te vullen zodat wij de noden omtrent ziekte, sterven, verlies of rouw in uw buurt in kaart kunnen brengen en informatie kunnen verzamelen over hoe we elkaar hierin kunnen ondersteunen. `

DEEL 3: COMMUNICATIE IN UW BUURT OVER ZIEKTE, STERVEN, VERLIES OF ROUW

3. We stellen u graag enkele vragen over de communicatie in uw buurt over ziekte, sterven,

Omcirkel bij iedere stelling het meest geschikte antwoord: 1, 2, 3, 4 of 5.	**Helemaal oneens**	Oneens	Noch eens, noch oneens	Eens	**Helemaal eens**
A. In mijn buurt praten we over ziekte	1	2	3	4	5
B. In mijn buurt praten we over sterven, verlies of rouw	1	2	3	4	5
C. Ik begin spontaan te praten over ziekte, sterven, verlies of rouw tegen mensen in mijn buurt.	1	2	3	4	5

Koos u bij bovenstaande vragen A tot C ergens voor de optie 'eens' of 'helemaal eens', vul dan onderstaande vraag in. Indien niet, ga naar stelling D. Hoe praat u met de mensen in uw buurt over die onderwerpen?

- ☐ Op straat
- ☐ Op bezoek bij hen thuis
- ☐ Op een buurtfeest- of evenement
- ☐ In een club of vereniging
- ☐ Aan de school
- ☐ In de winkel
- ☐ Via telefoon
- ☐ Via e-mail of sociale media
- ☐ Andere:……………………………………………………………………………………………

Omcirkel bij iedere stelling het meest geschikte antwoord: 1, 2, 3, 4 of 5.	**Helemaal oneens**	Oneens	Noch eens, noch oneens	Eens	**Helemaal eens**
D. Ik ben geneigd om gesprekken over ziekte, sterven, verlies of rouw uit de weg te gaan om mensen niet van streek te maken	1	2	3	4	5
E. Ik ben geneigd om gesprekken over ziekte, sterven, verlies of rouw uit de weg te gaan omdat ik me daar ongemakkelijk bij voel	1	2	3	4	5

DEEL 4: MEEDOEN AAN EVENEMENTEN ROND ZIEKTE, STERVEN, VERLIES OF ROUW

We stellen u graag enkele vragen over uw deelname aan evenementen, verenigingen, en andere initiatieven omtrent ziekte, sterven, verlies of rouw in uw buurt. Ook indien uw deelname omtrent deze onderwerpen in uw buurt eerder laag is, nodigen wij u graag uit om deze vragen in te vullen. Het geeft ons een beeld van de initiatieven in uw buurt die er al zijn, en waar er aanvulling en verbetering mogelijk is.

4. Omcirkel bij iedere vraag het meest geschikte antwoord 1, 2, 3 of 4, en volg de instructies ernaast.

A. Helpt u in een vereniging of organisatie als vrijwilliger voor het ondersteunen van zieke mensen, mantelzorgers of mensen die iemand hebben verloren? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4 en volg de instructies ernaast)	1 Neen, helemaal niet	Koos u voor 1? Ga dan naar vraag B.
	2	Koos u 2, 3 of 4? Vul dan eerst deze vraag in. U mag meer dan één antwoord kiezen. Hoe helpt u zieke mensen, mantelzorgers of mensen die iemand hebben verloren? ☐ Ik organiseer activiteiten, zoals een uitstap. ☐ Ik help met praktische dingen zoals vervoer, naar de winkel gaan… ☐ Ik help bij vragen over het leven of over hoe ze zich voelen ☐ Ik geef door aan hulpverleners wat zij nodig hebben ☐ Ik help op andere manieren: ………………………………………………………………
	3	
	4 Ja, minstens één keer per week	

B. Bent u in uw buurt naar een evenement rond ziekte, mantelzorg, sterven, verlies of rouw geweest in de 6 maanden voor de start van coronacrisis? Bijvoorbeeld: straat- of buurtfeesten, liefdadigheidsacties om geld op te halen…. (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4 en volg de instructies ernaast)	1 Neen, helemaal niet	**Koos u voor 1? Vul eerst deze vraag in en ga dan naar C.** U mag meer dan één antwoord kiezen. **Waarom ging u niet naar die evenementen?** ☐ Mijn buurt organiseert geen evenementen rond die onderwerpen ` ☐ Ik weet niet of mijn buurt zulke evenementen organiseert ☐ Die onderwerpen interesseren mij niet ☐ Die onderwerpen schrikken mij af ☐ Die evenementen zijn moeilijk bereikbaar voor mij ☐ Andere redenen:……………………………………………………………………………
	2	**Koos u voor 2, 3 of 4? Vul eerst deze vraag in en ga dan naar C.** U mag meer dan één antwoord kiezen. **Naar welke evenementen over ziekte, sterven, verlies of rouw ging u?** ☐ Straat- of buurtfeest ☐ (Benefiet)concert, tentoonstelling of theater ☐ Liefdadigheidsactie om geld op te halen ☐ Andere evenementen: …………………………………………………………………
	3	
	4 Ja, minstens één keer per week	
C. Bent u lid van een vereniging of organisatie in uw buurt die al iets gedaan heeft rond ziekte, mantelzorg, sterven, verlies of rouw? (Omcirkel ja of nee en volg de instructies ernaast)	Ja	**Koos u voor ja? Vul dan vraag D, E & F in.**
	Nee	**Koos u voor nee? G dan naar vraag G.**
D. Bent u actief lid van deze club of vereniging? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4)	1 Neen, helemaal niet	
	2	
	3	
	4 Ja, zeer actief	
E. Wat heeft uw vereniging of organisatie al georganiseerd? U mag meer dan één antwoord kiezen		☐ Een herdenking voor iemand die gestorven is ☐ Een liefdadigheidsactie om geld op te halen voor een goed doel rond ziekte, sterven of verlies (bv. een spaghetti-avond, wafels verkopen..) ☐ Een benefietoptreden voor zieke mensen, mantelzorgers of mensen die iemand hebben verloren ☐ Andere activiteiten: ………………………………………………………………………. ☐ Geen van die activiteiten
F. Wat heeft uw vereniging of organisatie al georganiseerd voor zieke mensen, mantelzorgers of mensen die iemand hebben verloren? U mag meer dan één antwoord kiezen.		☐ Een activiteit, zoals een uitstap ☐ Geholpen bij praktische dingen zoals vervoer, naar de winkel gaan.. ☐ Geholpen bij vragen over het leven of over hoe ze zich voelen ☐ Aan hulpverleners doorgegeven wat zij nodig hebben ☐ Andere activiteiten:………………………………………………………………………. ☐ Geen van die activiteiten

G. Hebt u in de afgelopen 3 jaar ooit deelgenomen aan een gemeenschapsproject of initiatief in uw buurt zoals buurtzorg, een rouwgroep of andere samenwerkingen rond ziekte, mantelzorg, sterven, verlies of rouw? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4)	1 Nee, helemaal niet	
	2	
	3	
	4 Ja, verschillende keren	
H. Hebt u ooit deelgenomen aan een project om een nieuw initiatief in uw buurt te organiseren voor zieke mensen, mantelzorgers of mensen die iemand hebben verloren? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4 en volg de instructies ernaast	1 Neen, helemaal niet	Koos u voor 1? Ga dan naar vraag I.
	2	Koos u 2, 3 of 4? Vul eerst deze vraag in en ga dan naar I. U mag meer dan één antwoord kiezen. Wat heeft u toen mee georganiseerd? ☐ Ontspannende activiteiten, zoals een uitstap ☐ Praktische hulp zoals vervoer of naar de winkel gaan ☐ Hulp bij vragen over het leven of over hoe mensen zich voelen ☐ Doorgeven aan hulpverleners wat die mensen wensen en nodig hebben ☐ Andere:……………………………………………………………………………………
	3	
	4 Ja, verschillende keren (minstens 3)	
I. Bent u een actief lid van een whatsapp-buurtgroep, een facebookgroep of een andere groep op sociale media die iets doet voor zieke mensen, mantelzorgers of mensen die iemand hebben verloren? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4)	1 Neen, helemaal niet	
	2	
	3	
	4 Ja, zeer actief	

DEEL 5: MENSEN IN UW BUURT HELPEN

We stellen u graag enkele vragen over de mate waarin u mensen in uw buurt helpt en de mate waarin u zelf door mensen in uw buurt wordt geholpen. Aan de hand van de antwoorden kunnen wij de ondersteuning in uw buurt versterken voor iedereen die op een bepaald moment met ziekte, sterven, verlies of rouw wordt geconfronteerd.

A. Hebt u in de 6 maanden voor de start van de coronacrisis een directe buur (die naast u woont) geholpen die ziek was of hulp nodig had? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4 en volg de instructies ernaast)	1 Neen, helemaal niet	Koos u voor 1? Ga dan naar vraag B.
	2	Koos u voor 2, 3 of 4? Vul eerst deze vraag in en ga dan naar B. U mag meer dan één antwoord kiezen. Wat hebt u voor die buur gedaan? ☐ Een activiteit georganiseerd, zoals een uitstap ☐ Praktisch geholpen, bijvoorbeeld met vervoer of naar de winkel gaan ☐ Geholpen bij vragen over het leven of over hoe ze zich voelden ☐ Doorgegeven aan hulpverleners wat die mensen nodig hadden ☐ Andere: ………………………………………………………
	3	
	4 Ja, minstens 5 keer	
B. Hebt u in de 6 maanden voor de coronacrisis iemand in uw buurt	1 Neen, helemaal niet	Koos u voor 1? Ga dan naar vraag 6.

geholpen die hulp nodig had of ziek was? (Omcirkel het meest geschikte antwoord: 1, 2, 3 of 4 en volg de instructies ernaast)	2	Koos u voor 2, 3 of 4? Vul eerst deze vraag in en ga dan naar 6. U mag meer dan één antwoord kiezen. Wat hebt u voor die persoon in uw buurt gedaan? ☐ Een activiteit georganiseerd, zoals een uitstap ☐ Praktisch geholpen, zoals vervoer of naar de winkel gaan ☐ Geholpen bij vragen over het leven of over hoe ze zich voelden ☐ Doorgegeven aan hulpverleners wat die mensen nodig hadden ☐ Andere:…………………………………………………………………………
	3	
	4 Ja, minstens 5 keer	

6. Kruis per zin het meest geschikte antwoord aan.

Indien u in de situatie zit dat u zelf ziek wordt, mantelzorger wordt van een zieke persoon, of een naaste verliest, is er in uw buurt…….	**Helemaal oneens**	Redelijk oneens	Noch eens noch oneens	Redelijk eens	**Helemaal eens**
A. Iemand waarop u kan rekenen wanneer u nood hebt aan een babbel	☐	☐	☐	☐	☐
B. Iemand die u in vertrouwen kan nemen om te praten over persoonlijke problemen, bezorgdheden en angsten	☐	☐	☐	☐	☐
C. Iemand die u informatie geeft om u een situatie beter te helpen begrijpen	☐	☐	☐	☐	☐
D. Iemand die u goed advies geeft bij een crisis	☐	☐	☐	☐	☐
E. Iemand tot wie u zich kan wenden voor suggesties over hoe u moet omgaan met een persoonlijk probleem	☐	☐	☐	☐	☐
F. Iemand om u te helpen indien u bedlegerig bent	☐	☐	☐	☐	☐
G. Iemand die u naar de dokter brengt indien nodig	☐	☐	☐	☐	☐
H. Iemand om uw maaltijden te bereiden wanneer u dit niet zelf kan	☐	☐	☐	☐	☐
I. Iemand om u te helpen bij uw dagelijkse taken	☐	☐	☐	☐	☐
J. Iemand om mee samen te komen voor ontspanning	☐	☐	☐	☐	☐

DEEL 6: UW ERVARINGEN MET ZIEKTE, STERVEN, VERLIES OF ROUW

Volgende vragen gaan over uw eigen ervaringen met ziekte, sterven, verlies of rouw. Informatie geven over ervaringen met ziekte, sterven, verlies of rouw is niet gemakkelijk. Toch nodigen wij u uit om deze vragen in te vullen om zo de steun voor elkaar te versterken in uw buurt.

A. Ik was zelf zwaar ziek	Ja	Nee	B. Iemand die ik goed kende is overleden	Ja	Nee
C. Een familielid was zwaar ziek	Ja	Nee	D. Ik was mantelzorger van een familielid die zwaar ziek was	Ja	Nee
E. Ik werkte als vrijwilliger rond ziekte, mantelzorg, sterven, verlies of rouw	Ja	Nee	F. Ik deed mee aan evenementen rond ziekte, sterven, verlies of rouw	Ja	Nee
G. Ik zat in een vereniging of organisatie die werkte rond ziekte, sterven, verlies of rouw.	Ja	Nee	H. Ik praatte met mensen in mijn buurt over ziekte, mantelzorg, sterven, verlies of rouw	Ja	Nee
I. Ik hielp in mijn buurt een zieke persoon, een mantelzorger of een persoon die iemand verloren had	Ja	Nee			

8. Kruis per stelling het meest geschikte antwoord aan.

Mijn voorgaande ervaringen met ziekte, mantelzorg, sterven, verlies of rouw hebben:	Helemaal oneens	Redelijk oneens	Noch eens noch oneens	Eens	Helemaal eens
A. me emotioneel sterker gemaakt om anderen te helpen omgaan met de dood en sterven	☐	☐	☐	☐	☐
B me ertoe aangezet opnieuw na te denken wat van belang is en niet van belang is in het leven	☐	☐	☐	☐	☐
C. me wijzer en meer begripvol gemaakt	☐	☐	☐	☐	☐
D. me milder gemaakt tegenover mezelf	☐	☐	☐	☐	☐
E. me vaardigheden en strategieën gegeven om in de toekomst met soortgelijke uitdagingen om te gaan	☐	☐	☐	☐	☐

9. Kruis per stelling het meest geschikte antwoord aan.

Mijn ervaringen met ziekte, sterven, verlies en rouw zorgen ervoor dat ik volgende zaken kan:	Helemaal oneens	Redelijk oneens	Noch eens noch oneens	Eens	Helemaal eens
A. Ik kan praten met mensen in mijn buurt over ziekte, mantelzorg, sterven of dood	☐	☐	☐	☐	☐
B. Ik kan praten met mensen in mijn buurt die iemand hebben verloren	☐	☐	☐	☐	☐
C. Ik kan zieke mensen of mantelzorgers in mijn buurt helpen	☐	☐	☐	☐	☐
D. Ik kan mensen in mijn buurt helpen die iemand hebben verloren	☐	☐	☐	☐	☐
E. Ik kan met een dokter of andere hulpverlener praten over wat zieke mensen in mijn buurt nodig hebben	☐	☐	☐	☐	☐

DEEL 7: NOG ENKELE VRAGEN OVER UZELF

A. Wat is uw geslacht?	☐ Man ☐ Vrouw ☐ X
B. Wat is uw leeftijd?	……………… jaar
C. Wat is uw hoogst behaalde diploma?	☐ Lager onderwijs ☐ Lager secundair onderwijs ☐ Hoger secundair onderwijs ☐ Hogeschool ☐ Universiteit
D. Wat is uw gezinssituatie? Kies de situatie die het beste bij u past.	☐ Ik woon alleen ☐ Ik woon samen met mijn partner ☐ Ik woon samen met mijn kinderen ☐ Ik woon samen met mijn partner en met mijn kinderen ☐ Ik woon samen met mijn ouder(s) ☐ Ik woon samen met andere huisgenoten

Heeft u nog vragen of opmerkingen bij de vragenlijst?

Hartelijk bedankt voor uw medewerking!

Appendix 3. Forward-backward translation of the Social Capital Measure scale

Social Capital Measure, subscale local participation[2]		
Original item	**Adjusted to the neighborhood**	**Adjusted to the topics of illness. caregiving and loss**
Do you help out a local group as a volunteer? *No, not at all – Yes, often (at least 1x a week)*	Do you help in a **neighborhood** group as a volunteer? *No. never – Yes, often (minimum 1x per week)*	Do you help in a neighborhood group as a volunteer **to support ill people. caregivers or people who have lost someone?** *No, never – Yes, often (minimum 1x per week)*
Have you attended a local community event in the past 6 months (e.g. church fete. school concert. craft exhibition)? *No, not at all – Yes, several (at least 3)*	Have you attended an event in your **neighborhood** in the past six months (e.g. parish festival. school concert. hobby fair)? *No. not at all – Yes, several times (at least 3)*	Have you attended an event in your **neighborhood** around illness. caregiving or loss in the past six months **(e.g. benefit action to raise money)?** *No. not at all – Yes, several times (at least 3)*
Are you an active member of a local organization or club (e.g. sport. craft. social club)? *No, not at all – Yes, very active*	Are you an active member of an organization or club in your **neighborhood** (e.g. sports club. hobby club. chat club)? *No, not at all – Yes, very active*	Are you an active member of an organization or club in your **neighborhood that did something around illness. caregiving or loss** (**e.g. memorial for someone who has died)**? *No, not at all – Yes, very active*
In the past 3 years. have you ever taken part in a local community project or working bee? No. not at all – Yes, very much	In the past 3 years. have you ever been involved in any local-community initiative **in your neighborhood**? No, never – Yes, very much,	In the past 3 years. have you ever been involved in a local-community initiative **around illness. caregiving or loss in your neighborhood (e.g. a bereavement group)?** *No, not at all – Yes, very much*
Have you ever been part of a project to organize a new service in your area (e.g. youth club. scout hall. child care. recreation for disabled)? *No, not at all – Yes, several times (at least 3)*	Have you ever been part in a project to organize a new service in your **neighborhood** (e.g. youth club, scouts' premises. childcare. recreational activities for disabled people)? *No, not at all – Yes, several times (at least 3)*	Have you ever been part in a project to organize a new service in your **neighborhood for ill people. caregivers or people who have lost someone?** *No, not at all – Yes, several times (at least 3)*
Do you belong to a formal or informal neighborhood watch? *No, not at all – Yes, very active*	Do you belong to a **digital neighborhood group (e.g. WhatsApp, Facebook)?** *No, not at all – Yes, very active*	Do you belong to a **digital neighborhood group that does something for people who are ill. caregiving or people who have lost someone (e.g. WhatsApp, Facebook)?** *No, not at all – Yes, very active*

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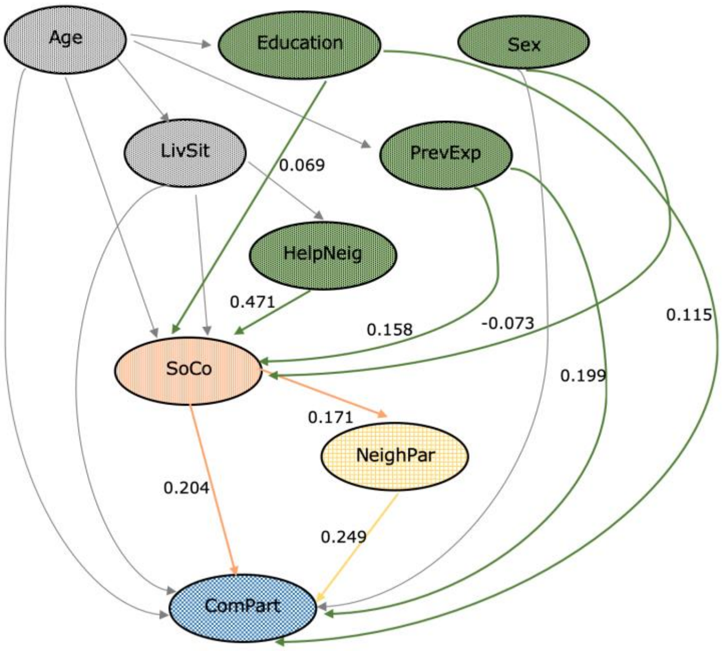
[2] Onyx, J., & Bullen, P. (2000). Measuring social capital in five communities. *The journal of applied behavioral science*, *36*(1), 23-42.

Appendix 4. Weighing of the data by age and sex

	Neighbourhood H						Neighbourhood S					
Age	Population (%)		Sample (%)		Weighing coefficient		Population (%)		Sample (%)		Weighing coefficient	
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women
18-24	8.77	8.77	7.6	1.2	1.15	7.31	9.34	8.03	7.4	7.1	1.26	1.13
25-49	39.81	38.54	18.6	28.2	2.14	1.37	44.12	41.06	16.7	21	2.64	1.96
50-64	28.55	26.0	28.8	29.4	0.99	0.88	23.53	23.28	27.9	24.8	0.84	0.94
65-79	17.59	17.79	33.1	23.9	0.53	0.74	17.39	18.35	30.4	23.8	0.57	0.77
80(+)	5.28	8.90	11.9	17.2	0.44	0.52	5.63	9.29	17.6	23.3	0.32	0.4

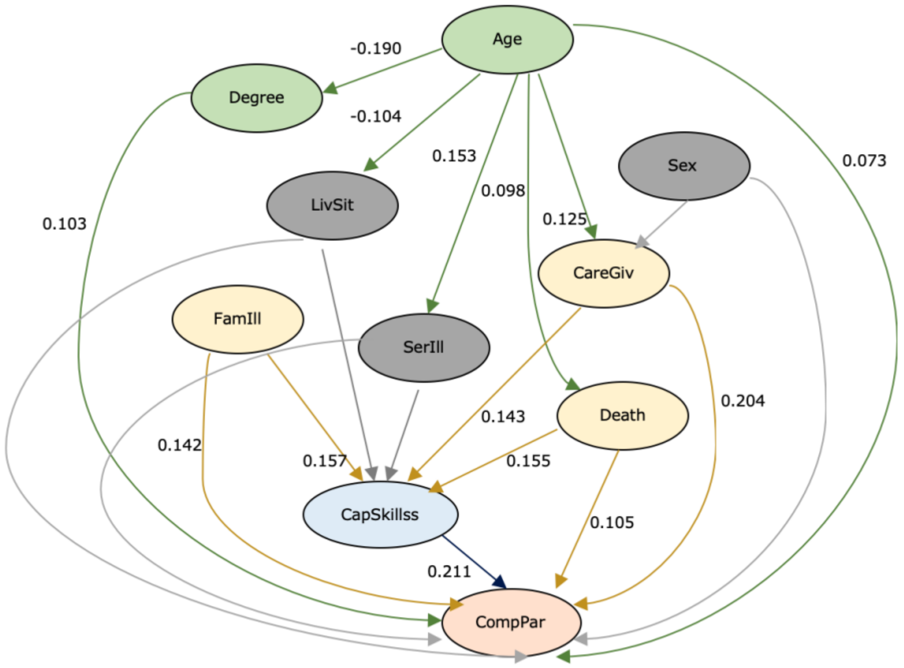
Appendix 5. Directed Acyclic Graph (DAG) model with correlation coefficients (for Chapter III) (Pearson one-tailed, p<0.05)



PrevExp= having had previous experiences with caregiving, serious illness, death or loss in the last year
HelpNeigh= perceived help from neighbours in the case you are seriously ill, caregiving or lose someone
SoCo= perceived neighbourhood social cohesion
NeighPar= general neighbourhoodf participation
CompPart= neighbourhood participation concerning serious illness, death or loss

Yellow= predictors
Green = confounders
Blue= mediator

Appendix 6. Directed Acyclic Graph (DAG) model with correlation coefficients (for Chapter IV) (Pearson one-tailed, $p<0.05$)



LivSituation= living situation (living alone vs. living with other people)
SerIll= I was seriously ill in the last year
FamIll= A family member was seriously ill in the last year
Death= Someone I knew well, died
CareGiv= I was caregiver of a familly member who was seriously ill
CapSkills= Self-perceived capacity and skillls to deal with serious illness, death and loss based on previous experiences
CompPar= neighbourhood participation concerning serious illness, death or loss

Yellow= predictors
Green = confounders
Blue= mediator