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THE DEVELOPMENT AND EVALUATION OF TWO COMPASSIONATE CITIES

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PART 1: GENERAL INTRODUCTION

Introduction

The number of people who need support because they suffer from chronic illnesses is rapidly growing.[1] Traditionally, a service-focused response has been pursued in attempts to alleviate this population of their health-related burden. However, this alleviation has primarily addressed the physical aspects of improving health and paid little attention to people's overall quality of life.[2] As health services focus primarily on harm reduction, preventing illnesses from manifesting and intervening early once they do has not been given the same attention. Meeting the needs of all who are in some way affected by serious illness, dying and bereavement (including families, friends, colleagues, etc.) cannot be addressed with the same approach due to health services limited capacity. Additionally, such needs reside with our social environment and are then best addressed by our naturally occurring sources of support.[3] Community-focused responses are part of a relatively new discourse in public health that are being explored with the aim of improving populations' end-of-life experiences. They look beyond individuals' responsibility and emphasise the effects of social, economic and political environments over our health.[2]

This dissertation considers the Compassionate City model which aims to instigate structural changes in the environments that influence our health with the goal of increasing people's control over their own health and eventually improve their end-of-life experiences.[4] To better understand the existing knowledge base on these models, the aim is to describe existing initiatives contextual characteristics, processes of development and evaluations. As public health approaches to the end of life are still in their relative infancy, our next aims revolve around informing future initiatives about population characteristics which relate to their susceptibility to such interventions. I describe people's discomfort with others' suffering and dying, as well as their willingness to support neighbours in need of help practically or emotionally. As this dissertation revolved around a research project in two Compassionate City interventions in Flanders, our next aim is to describe a study protocol of a process and outcome evaluation of these interventions. Lastly, the process of development of these Compassionate Cities will be reported.

In this introductory chapter, I discuss the relevant background pertaining to public health and how it stands in relation to the end of life, the medicalisation of healthcare and the end of life, the social determinants of health, health promotion, and new public health approaches to end-of-life care, all of which are related to the development of the Compassionate City concept. As attention to these concepts has emerged or increased in response to prior events, I believe it is important to include historical information where appropriate.

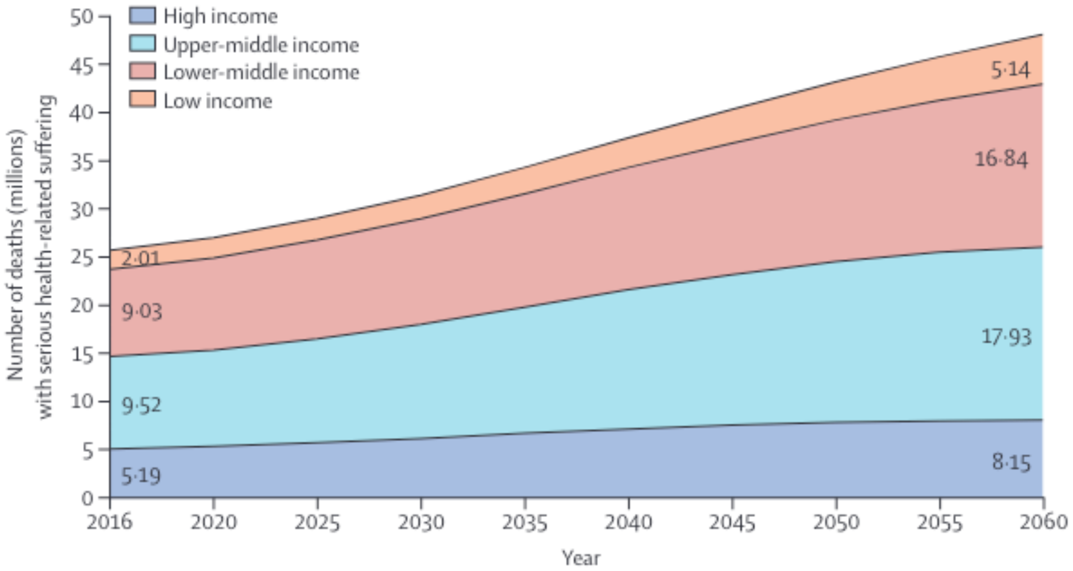
Background

The number of people who need support because they suffer from chronic illnesses is rapidly growing. Traditionally, a service-focused response has been pursued in attempts to alleviate this population of their health-related burden. However, this alleviation has primarily addressed the physical aspects of suffering and paid little attention to people's spiritual and psychosocial needs. Additionally, as their focus has primarily been aimed at harm reduction, preventing illnesses from manifesting and intervening early once they do has not been given the same attention. Meeting the needs not only of people who face illness, but of all who are in some way affected by serious illness, dying, and bereavement (including families, friends, colleagues, etc.) cannot be addressed with the same approach due to health services' limited capacity. Additionally, such needs reside within our social environment and are then best addressed by our naturally occurring sources of support. Community-focused responses are part of a new discourse in public health that is being explored with the aim of improving populations' end-of-life experiences. They look beyond individuals' responsibility over their own health and emphasise the effects of social, economic, and political environments. Compassionate Cities are an operationalization of a new public health approach to the end of life which aims for structural changes in such environments with the goal of increasing people's control over their own health and eventually improving their end-of-life experiences.

Serious illness, death, dying and loss as public health challenges

For the vast majority of human history, populations were on average young and plagued by high mortality rates which limited the average human life span. Ever since the industrial revolution, which saw an exponential increase in the number of people living in cities, social reforms and improved living conditions led to rapid increases in population numbers and life expectancy.[2] In the year 1900, the European average life expectancy was 43 years which increased to 79 years by the year 2019.[3] Acute illnesses such as diabetes, cardiovascular diseases or respiratory diseases have evolved into chronic, life-limiting conditions which permit life to stretch longer than ever before. Combined with dwindling birth rates in many high- and middle-income countries, populations are quickly ageing which results in increasing numbers of people who suffer from health-related physical and mental conditions, requiring specific care support for the long-term illness trajectories they typically face.[4,5] Noncommunicable diseases already make up 74% of all deaths globally and projections predict that the number of people dying from health-related suffering will increase with 87% between 2016 and 2060 *(Figure 1)*.[6,7] Dying has evolved from an imminent event to a gradual process, characterised by steady decreases in overall health status.[8] Healthcare systems currently struggle to provide for this increasing need of support.[9] Globally, only 14% of people in need of essential end-of-life support are actually receiving it, with large differences between countries.[9]

*Figure 1: Projected evolution of burden of serious health-related suffering in World Bank income regions until 2060 as presented by Sleeman et al (2019).[7]**



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The total proportion of people in Europe who provide informal care to others with long-term care needs is estimated to lie between 10% and 25%. Although informal care is a cost-effective cornerstone of healthcare systems globally and the demand for informal care is expected to keep increasing, societies face reducing proportions of people able to provide informal care.[10,11] This trend can be explained by a number of factors such as decreasing nuclear family sizes, the influence on governmental policies by neoliberal paradigms which prioritise economic growth and individualism over population health governance,[12,13] migration waves fuelled by wars, political instabilities and the pursuit of economic improvements,[14] and social changes such as the increased access of women to higher education and the labour market.[10,15] Additionally, people involved in care provision are known to be at health risks, which makes them susceptible to public health interventions as well.[16] As the European Union currently counts about 65 individuals per 100 under the age of 65, a number that is expected to decrease to 44 by the year 2050, it becomes evident that the reliance on this group to sustain a service-focused delivery of care is unsustainable.[5] Whilst population care needs are expected to keep increasing while the proportion of potential (care) providers decreases, governments around the world are challenged to rethink their current policies and approaches to care delivery.

Prevention, early intervention and harm reduction in relation to serious illness, death, dying and loss

In contradiction to traditional primary healthcare delivery, public health specifically does not apply a reactive approach which addresses health symptoms once they appear. Preventive measures, early interventions and harm reducing efforts are fundamental pillars of public health interventions.[17] Preventive measures are initiated with the goal of thwarting health adversities from manifesting themselves. Advance care planning, accessible information about available health services and mandatory seatbelt use while in a car are all examples of preventive measures. The next logical step is to intervene early in the trajectory of the adverse health situation through early detection to prevent progressive worsening. Cancer screening programmes, facilitating access to emergency services or reducing bereaved colleagues' work load all help prevent conditions from worsening. Maximally reducing the physical, social and economic harm adverse health situations cause is then the next focal point. Volunteers that support people at the end of life, death cafés where individuals meet and talk about their grief or health insurance systems that reduce the economic impact of medical interventions all aim to reduce harm on different levels. Although dying is inevitable, the trajectories preceding and superseding death are susceptible to public health interventions. Such interventions can then play an important role in supporting bereaved people (e.g., assisting colleagues who experienced a loss with the goal of not overburdening them), in aiding dying people (e.g., by making pain relief options available) or in supporting carers (e.g., through financial compensation schemes for lost workdays).

Medicalisation of healthcare

In high-income countries, the delivery of care has seen a rapid social and professional evolution. In the beginning of the 20th century, care still used to be primarily delivered by and within the community and family domain. Over time, the jurisdiction of the healthcare system over our health, and thereby our perceived dependency on it, has steadily grown and the involvement of the community has been increasingly limited.[18,19] This transformation can be explained by a number of historical occurances. Under the influence of the Enlightenment, physicians received increased power and responsibility over the management of health. Additionally, medical advancements, such as the eradication of smallpox through vaccination or vaginal smear tests to screen for cervical cancer, were disproportionately credited with population health improvements. While their efficacy is unquestionable, it is noteworthy that public health interventions such as enhancements in housing and access to clean water played a more vital role in the substantial rise in life expectancy during the 20th century.[20] Furthermore, this shift towards care provided by professional health workers has not been met with a proportional expansion in service provision.[21] This trend to apply a medicated response to improve health at the expense of preventive and community-based health interventions, is sometimes cornered the medicalisation of health. Medicalisation in this context can be understood as biomedical interventions to treat nonmedical problems in domains that primarily reside within the social environment such as alcoholism, obesity or cleptomania.[18,22] By granting healthcare professionals the authority to address intrinsically social problems, the treatment of these problems becomes restricted by the limitations inherent to healthcare systems (e.g., the lack of resources).[18] This increased control over our health has led to disenfranchised communities which no longer actively foster and build knowledge and skills to address certain health challenges, an evolution that is slowly but steadily also taking place in low- and middle income countries which currently still have higher levels of community-provided care.[19]

Medicalisation of the end of life

The medicalisation of our health has also found its way to the end of life which becomes evident, for instance, in the discrepancy between our desired and our actual place of death,[23,24] the extent of overtreatment at the end of life,[25] the disproportionate use of resources for people in the last years of life,[26,27] and the marginalisation of communities in care support for these people.[28] The COVID-19 pandemic made the medicalisation of our end of life clearly visible, with people dying devoid of personal choice or preference, human contact limited to healthcare professionals in protective working gear, and burial rituals for loved ones of the deceased being restricted by the number of people allowed to attend. Dying has long been, and often still is, centred around a biomedical model in which the dying person is perceived as being in paramount need of physical symptom alleviation. This reasoning helps explain why a medical-focused response to the dying process is often pursued, which becomes unfounded once we consider that a person’s health cannot be reduced to its physical manifestation, but is also defined by spiritual, psychological and social needs.[29] Indeed, people who are dying, whether hospitalised or not, only spend a marginal percentage of their time with healthcare professionals.[30–32] The vast majority of their time is spent by interacting with family, friends, neighbours, colleagues, social media, pets and others. Given that approximately nine individuals experience a bereavement process when a person dies, we can infer that their primary source of support is derived from social networks and not from professional care providers.[33,34] Therefore, we may consider dying to be a predominantly social experience that occurs through engagement with a diverse group of interactors, rather than a purely physical one.

This medicalisation of the end of life becomes more apparent once we consider how under this influence, many societies now have an ambiguous relationship with death. While healthcare services took charge of managing our sick and dying, the social experience of these events gradually estranged from our societies. With the growing secularisation of numerous Western societies, faith no longer provides solace to many, and the once-available space for rituals that also offered comfort is now increasingly absent.[35,36] Although death is prevalent in the news, the arts, religion and in our schools' history classes, we generally persevere in avoiding the subject of death in our daily social encounters.[35] Notwithstanding many children experience death in their social environment at a young age, we often refrain from discussing it with them in our attempts to shield them from such exposures.[37,38] Although we can try to avoid the topics of death and dying, nothing can stop the imminent certainty of such events taking place. Likewise, it may very well be that this avoidance is fuelled by our personal fears and discomfort in broaching this topic.[39] Studies have shown that even healthcare staff, who encounter people at the end of life on a daily basis, feel their education does not adequately prepare them for working with dying people.[40–42] This social and cultural death avoidance risks leading to negative attitudes and assumptions about death and dying. This undermines the opportunity to build much-needed knowledge and skills in handling these topics, which everyone encounters on multiple occasions in their lives.[21,43] The lack of attention societies place on death and dying can even produce harmful consequences. Research indicates that negative death attitudes in healthcare professionals result in suboptimal support for people at the end of life,[44] that inadequate planning ahead of preferences for end-of-life care makes it more difficult to act upon these preferences,[45] or that people who are seriously ill risk being discriminated.[46,47] Working towards societies that openly acknowledge death as a component of everyday life, facilitates our possibilities and skills to support others who face serious illness, death and dying.[21]

Social determinants of health

Health improvement has long been pursued by assessing a person's physical appearance and alleviating their physical complaints, where the health status was assessed by its absence of illnesses.[12] Today, healthcare systems are still very much functioning according to this biomedical model, operating in a predominantly reactive fashion once health anomalies manifest themselves. As a reaction to global economic recesses in the 1970s and 1980s, neoliberal policies have been influential in prioritising economic growth over social improvements and population health.[13] This has led to health being promoted through power at the individual level as opposed to the state level, an ideology prominently visible in healthcare systems in countries like the United States. Hence, the notion of personal responsibility for one's health has frequently been reduced to the influence of individual biology and behaviours.[48] Governmental policies have disregarded the effects of environments on our health status and thus, end-of-life experiences.[12] Views on how to achieve health improvement have since evolved to include the influences of individuals' social, economic, and physical environments, as well as their individual behaviours and characteristics.[49] By focusing on these different elements that constitute health, health becomes a resource to live and not just a goal in itself.[50] The World Health Organization has been advocating in favour of improving people's daily living conditions (e.g., by giving people fair pay for their work), tackling the uneven distribution of power, money and resources (e.g., by instigating equitable pay for men and women) and tackling health inequity through an evidence-based approach (e.g., by incorporating the determinants of health in medical training).[51] Facilitating people to die at their preferred location or connecting community-dwelling elderly with local volunteers are just two examples that create environments conducive to improving the quality of life for people suffering from health-related conditions. Studies have also generated a sound evidence base which shows the positive effects of these determinants on population health.[52–54]

Applying a public health approach to serious illness, death, dying and loss

With the aim of increasing support for all people facing and affected by serious illness, death, dying, and loss, recognising that these elements are integral components of everyday community life is an important first step. As national healthcare systems are unable to provide end-of-life support to all people in need, the expectancy to extend this support to all, including the people around the persons in need of support, is entirely unrealistic.[9] A public health approach which relies on the assets available within communities surrounding people in need of support is then warranted. Cohen (2021) provides a comprehensive definition of a public health perspective on the end of life: "*the combination of sciences, skills and beliefs directed towards improving and maintaining wellbeing for the full relevant population affected by serious illness, dying and bereavement".*[55] At the core of public health interventions is the development of people's knowledge, skills, attitudes and eventual behaviours through structural changes, education and information distribution, which then enables them to confront and respond to challenges related to the end of life. Several publications have since shown that these interventions which rely on community assets, indeed seem to indicate that attaining forementioned aims is taking place.[45,56–59] However, these interventions exemplify one of the criticisms directed at public health approaches in general, in that the "public" is often interpreted in a restricted sense, primarily targeting behaviours of communities and individuals within them rather than instigating changes at the political or structural level.[60] As the philosophy of public health approaches also targets the people around those who are affected by serious illness, death, dying and loss, it is noteworthy that few publications have this specific focus.[55,61]

Health promotion at the end of life

End-of-life care addresses the quality of life of people facing life-threatening illnesses and their close social surroundings. The introduction of health promotion at this phase of life seems contradictory at first. Considering health in its multifaceted way (recognising the symbiotic relationship between a person's physical, spiritual and psychosocial health) shows that health gains within this spectrum are still very well possible.[9,28] Pain relief, re-establishing or strengthening social relationships, religious rituals for support or reducing unwanted medical interventions are but several examples of how overall health can be improved at the end of life. However, health promotion for people with serious health related suffering has become deeply rooted within the professional care domain, which hampers the involvement of communities and their resources, and focuses predominantly on harm reduction. With an increasing number of people in need of end-of-life support and rising absolute numbers of people dying, coupled with a diminishing availability of individuals of working age to contribute to the care of those in need, and the persistent reliance on a reactive biomedical healthcare model as the core approach to improving health, the growing strain on our healthcare systems becomes self-evident. If we aim to reduce population suffering by increasing the coverage of support for people at the end of life (as advocated by the World Health Organization) through the continued use of a predominantly service-focused delivery to health improvement, healthcare consumption will drastically rise in congruence.[7,9] If this approach is pursued, a radical shift will need to take place in the proportion of people working in the healthcare sector. This indicates that current healthcare approaches are ill-suited to react to contemporary and near-future population health challenges. If we consider that people who experience health-related suffering are also in need of psychosocial and spiritual support, it becomes clear that professional services cannot provide the needed capacity. These needs typically exist within social relationships, rendering them beyond the reach of professional care services, thereby underscoring the necessity to explore alternative options to supply this demand.[21]

History of health promotion

The idea of using community development approaches to pursue health started to receive traction in the 1970s as the educator Paulo Freire advocated for the involvement of communities in decision making over their own lives.[62] Inspired by this community empowerment model, community development approaches began to look beyond the responsibility of individuals in improving their health and considered the development of social capital (i.e., trust-based relationships between people which allow for mutually accessible capital which comes with benefits which relate, among other things, to health status)[63] to be at the core of improving population health. Since then, community involvement in health delivery has increasingly been advocated for and although the World Health Organization’s Alma-Ata Declaration (1978) was not first in promoting that "*people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare"*, it was one of the first declarations that had a significant impact on future health policies.[29,64] Notwithstanding the Alma-Ata declaration instigated a shift from institutionalised care to community-oriented care, it failed to become widely integrated for its lack of proof of efficacy in large-scale settings, lack of practical guidance and a conservative stance of many healthcare systems, among other reasons.[64]

Although the Alma-Ata declaration advocated in favour of community involvement in health provision, this involvement still resided within the primary healthcare domain. The Ottawa Charter for Health Promotion (1986) made a clear shift away from this health service focus by emphasising that people experience health in their daily life settings (at home, work, school, hobbies, etc.) and that these settings should therefore create conditions that are conducive to improved health. Health promotion, formulated as the processes that enable people to increase control over and improve both their personal and population health, is a cornerstone of the Ottawa Charter.[50] It aims to prepare people for possible future adversities and provides five main action areas which should be addressed in interventions:

1) **Build healthy public policy** within all policy domains. Only the coordination of actions can ensure effective improvements.
2) **Environments should be supportive** towards health improvements, as people reside within these diverse environments which influence their health.
3) **Communities should be empowered to undertake action** so that they can attain control and ownership over their own health.
4) **People's personal skills should be developed** through education, information and skill training so that they can exercise control over their own health.
5) **Healthcare services need to be reoriented** towards health promotion and increase their focus on preventive measures. The power to improve health needs to be shared among everyone and not reside within the healthcare system.

The World Health Organization developed an intersectoral, society-wide operationalisation of the principles outlined in the Ottawa Charter for Health Promotion: the Healthy Cities initiatives. The focus on cities can be explained by the fact that growing numbers of people live in cities and that they are the main places where political decisions, resource allocations and multisectoral collaborations are initiated.[1] The objective of the Healthy Cities was to extend interventions beyond the confines of the healthcare system by advocating for community-oriented initiatives in all spaces where people meet, as their health stands in relation to the social, cultural, political, and physical environment in which they reside (i.e., social ecology).[65] The Healthy Cities have been criticised for their lack of rigorous evaluation methods and frameworks to assess impact.[66] They were initiated in a time when randomised controlled trials were (and often still are) considered the gold standard to assess impact. Furthermore, comprehensive (impact) evaluations within unpredictable and complex environments, such as Healthy Cities, were hindered by lack of methodological guidance.[66,67] The sociologist Allan Kellehear also noted that, although Healthy Cities advocate a holistic approach to health and the environments within which people reside, the experiences of death, dying and loss are largely absent from their policies.[1]

New public health approaches to support people at the end of life

When Kellehear published Health Promoting Palliative Care (1999), he criticised the traditional health promotion discourse with its emphasis on the prevention of illness and people who could be considered “healthy”. This reasoning appears to exclude people with serious health related suffering as if they are, in fact, not in need of or not even able to achieve health improvements.[28] Kellehear believes this view is rooted within a medical consideration of death as a failure by health professionals, as opposed to an unavoidable certainty in life. The reasoning that existing healthcare discourses neglect incorporating elements that improve the health of individuals affected by serious illness, death, dying, or grief seems to confirm this.[28] He aligns his perspective for the integration of health promotion and palliative care with the goals formulated in the Ottawa Charter for Health Promotion.[50] Therefore, Kellehear advocates for the involvement of people who face serious illness, death or dying in educational and informational activities with the aim of giving them the authority over their own health management. He also argues that community networks ought to be involved in supporting others, people should learn new skills for themselves and their social surroundings, and palliative care and policies should integrate health promotion principles.[28]

As many people around the world do not have access to, or don’t even have, functioning palliative care services, it should perhaps not surprise that one of the early initiatives that practiced health promotion principles to the end-of-life domain emerged in Kerala, India in 1993. The Neighbourhood Network in Palliative Care is a community-led and owned service which relies on a large volunteer network to provide palliative care to people in need.[68] This initiative marked a clear departure from prior community-oriented initiatives in which the lead and ownership resided within professional care services.

Compassionate Cities & Communities

In 2005, Allan Kellehear published a practical approach to developing end-of-life support for communities with emphasis on local ownership, which he framed *Compassionate Cities.*[1] They are (collections of) communities that start from the premise that experiences of death and dying are everywhere where people meet. Therefore, care for people that face such hardship should be encouraged and facilitated through all environments surrounding us. Compassionate Cities aim to change the experiences of people facing serious illness, death, dying or grief through interventions in a diverse range of sectors within society. They typically involve local governments, communities, health and social services, schools, workplaces, and other domains. A Compassionate City Charter was published which first provided 12, later 13 social changes to cities' key institutions (Box 1).[69] The authors indicate that it is not intended to be used as a step-by-step guide to achieve health promotion around the end of life, but rather as a systematic way of activating community resources.[70,71] Not all Compassionate Cities rely on the use of the Charter, nor is the term "*Compassionate City*" the sole terminology being used for initiatives that draw inspiration from Kellehear's philosophy.[72]

Box 1: The compassionate City Charter as proposed by Abel & Kellehear (2020).[69]

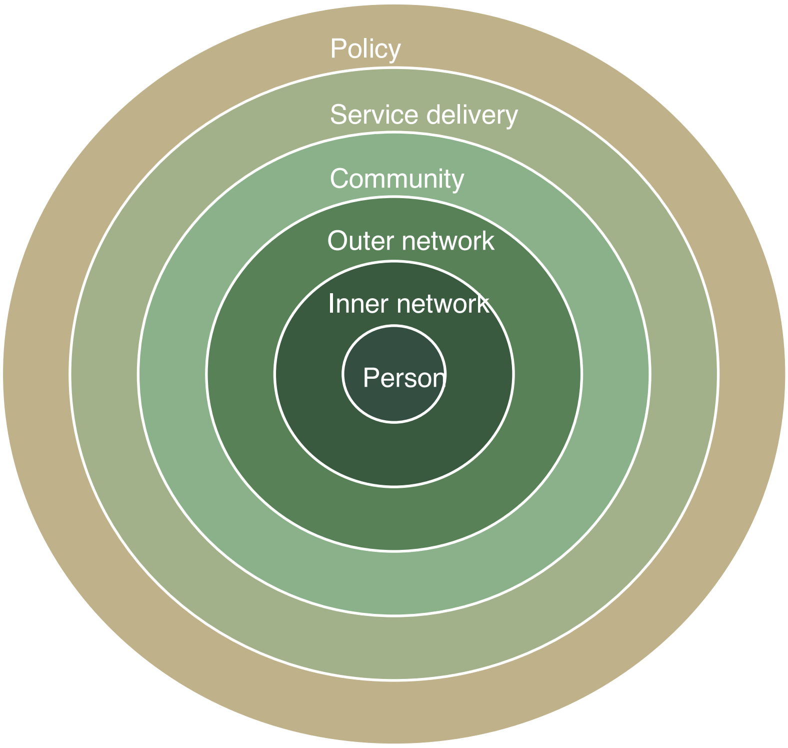
The Compassionate City Charter

1. Our schools will have annually reviewed policies or guidance documents for dying, death, loss and care.
2. Our workplaces will have annually reviewed policies or guidance documents for dying, death, loss and care.
3. Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care.
4. Our places of worship will have at least one dedicated group for end-of-life care support.
5. Our city's hospices and nursing homes will have a community development program involving local area citizens in end-of-life care activities and programmes.
6. Our city's major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care.
7. Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end-of-life care personnel, etc.
8. Our city will promote compassionate community programmes to engage neighbourhoods and local streets in direct care activities for their local residents living with health crisis, ageing, caregiving, and grief.
9. Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organisation, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end-of-life care sector. A 'Mayor's Prize' will recognise individual/s for that year those who most exemplify the city's values of compassionate care.
10. Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address 'our compassionate concerns' with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long-term caring. All end-of-life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organisations.
11. Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.
12. All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.
13. We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end-of-life care and loss and bereavement.

As Compassionate Cities and Compassionate Communities are being developed in many countries, I believe a discussion about the semantic distinction between the two is appropriate to avoid confusion. Compassionate Cities typically start from the network and resources made available by local governments. Their aim is to realise policy changes that affect the environments in which people reside to positively alter their health in relation to the end of life. People are thus considered to exist within a space that is affected by individual behaviours and various environments, also called social ecology.[73] In this context, the term "City" does not restrict initiatives to urban settings but encompasses all areas where people gather for professional, leisure, religious, or other reasons.[74] While the Compassionate City Charter can offer guidance and inspiration for the sectors that can be addressed, its application is not prescriptive and is subject to local needs, possibilities, and preferences.[69] Compassionate Communities on the other hand make use of the available local resources within a community which can be a street, a neighbourhood or any other physical or even digital place that connects people through solidarity.[2] They usually mobilise those living in that community and produce actions to support others facing serious illness, death, dying, caregiving or loss.[73] Although Compassionate Cities and Compassionate Communities are semantically distinct, this distinction is not that clearly applied in practice examples and terms appear to be used interchangeably.[75] Furthermore, as their distinction is primarily theoretically driven, the orientation of an initiative toward a Compassionate City or Compassionate Community does not preclude the application of principles from either.

Every person facing serious illness, death, dying, caregiving or grief is surrounded by multiple potential sources of support (Figure 2). Traditionally, people in need of support rely primarily on policy (e.g., national health insurance systems which refund certain medical expenses), service delivery (e.g., a home visit nurse) and their inner network (mostly a partner or child).[76] Additionally, underused but available sources of support exist within our outer network (e.g., friends from our hobbies) and the community (e.g., neighbours). Abel et al. (2013) argue that lay people's involvement, and thereby their knowledge and skills to act, has been reduced due to the professionalisation of care, among other social changes. Therefore, the authors propose a model that prompts the user to reflect on the available potential sources of support and their relationship to the person in need, asserting that the available potential currently remains largely underutilised.[3] As Compassionate Cities rely on all circles in this model to provide support to people in need, it shows that each profile has a unique potential and expertise around a person with support needs.

*Figure 2: Circles of care with different potential support resources as presented by Abel et al. (2013).[3]**



**The main author gave permission to use this figure.*

The state of knowledge around Compassionate Cities

When my research project commenced, the state of knowledge on Compassionate Cities as public health interventions around people facing serious illness, death, dying and loss was still very limited. Although a number of publications did report on Compassionate Cities and Communities,[57,77,78] and two literature reviews had been published which incorporated a number of such initiatives,[79,80] a comparative literature review exclusively focusing on Compassionate Cities and Communities' contextual

characteristics, their development processes and the nature and content of their evaluations was lacking.
A handful of research protocols were already published on research projects in Compassionate City interventions, yet the results of these research projects were not yet made public.[81–83] Publishing research protocols aids in increasing transparency as they hold researchers accountable to publish the results of the commenced research project, even when results are less favourable than perhaps desired.[84] It is noteworthy that no research protocols had yet been published which planned on evaluating a Compassionate City's process of development and outcomes. This can perhaps be explained by the challenges that evaluations on interventions in complex adaptive systems typically face. First of all, the effect of confounding variables on the intervention cannot be annulled as one would attempt to do in laboratory settings.[85] A complex system operates through the interaction of various components out of which it is composed. As these interactions are unpredictable at the onset of the research project, predicting the outcomes they produce becomes impossible. Furthermore, as the relationship between the input, the output and eventual outcomes is characterised by non-linearity, attributing their existing relationship may be challenging as they may, for example, only become apparent over prolonged periods of time (e.g., ripple effects).[86]

As publications on Compassionate Cities and Communities often voice the contention that death is a cultural and social taboo, a topic evoking certain fears and discomfort when exposed to, exploring to what extent people actually feel such discomfort around others who face death and dying can help orient the community-based reliance of such initiatives.[3,80,87–90] As perceptions about death and dying are not static but subject to change over time, topics and situations that were once taboo may not carry the same sociocultural weight they had once before. Kastenbaum (2000) already remarked that a growing interest in death and dying is noticeable through the increase in scientific publications on these topics, their integration into professional healthcare practice and their heightened representation in peer support groups, among other informative programmes.[91] Furthermore, as the experience of death and dying is embedded within its sociocultural context, we can expect people's discomfort to differ between different regions and cultures. As Kellehear advocates that Compassionate Cities should address marginalised groups like the imprisoned or the homeless, groups that have needs that may be distinct from general population needs, it is likely that their feelings of comfortability may be distinct as well.[4,69] Therefore the assessment of different populations' levels of discomfort around certain situations can inform future action development within Compassionate Cities and Communities.

Compassionate Cities and Communities largely rely upon a community-based response to build supportive networks around people with serious health related suffering and other people affected by that. While publications on initiatives show that building such networks is possible,[57,92] and the large number of informal carers shows that immense numbers of people take up supportive tasks,[12] it remains unexplored how willing people are to practically or emotionally help others within their neighbourhood who are in need of support. People who take up small supportive tasks pertaining to people's practical and emotional needs such as mowing their lawn or keeping the person company, can prove immensely valuable in supporting both the person with support needs and their carers.[93] While caring for a person with support needs is often described in relation to its negative implications (e.g., carer burden), this overlooks the positive aspects of caring such as the acquisition of knowledge and skills transferable to other situations.[44,94]

As Kellehear highlighted that public health discourse does not integrate aspects related to the end of life, Compassionate Cities are presented as a practical solution to fill this healthcare gap.[51] Therefore, it is important to evaluate if they indeed work towards filling that gap. Although some peer reviewed publications do report on certain outcomes from Compassionate City initiatives, their heterogeneity and lack of transparency on how they were realised hampers substantiating the much-needed knowledge base.[57,90,95,96] In this sense, process evaluations are useful additions to outcome reports in determining to what extent the intended intervention was delivered as planned and how much of the intended intervention was executed.[67] They can help explain why and how a programme works or doesn't work in a given context, thus creating transparency which informs both policy makers and other Compassionate

City initiatives. Nonetheless, as Compassionate Cities have the same general focus (i.e., to increase the health of people with serious health-related suffering and their social environments), it is likely that they use similar development approaches targeting different societal domains as is proposed in the Compassionate City Charter.[69] Because frameworks on how a Compassionate City could be developed are lacking, learning from the approaches applied by different initiatives increases much-needed transparency and knowledge. Furthermore, it provides insight in the level of heterogeneity between the developments of Compassionate Cities and Communities. As of yet, no peer reviewed publications have transparently reported on the development process followed to develop a Compassionate City.

Aims and study objectives

Aim 1: To inform the development of Compassionate Cities by identifying existing scientific knowledge and describing attitudes and experiences of citizens in the general population regarding aspects related to serious illness, dying, caregiving and providing support.

1) To identify the existing knowledge base on international Compassionate City and Community initiatives: their contextual characteristics, processes of development and evaluations (CHAPTER I).
2) To describe the general population's discomfort with the suffering and dying of others and whether these feelings are associated with specific personal characteristics or experiences (CHAPTER II).
3) To describe the general population's willingness to emotionally or practically support their neighbours who are facing situations of serious illness, caregiving and loss and whether these feelings are associated with specific personal characteristics or experiences (CHAPTER III).

Aim 2: To evaluate the process of development of the Compassionate Cities.

4) To describe the study protocol of a process and outcome evaluation study of two Compassionate Cities in Flanders, Belgium (CHAPTER IV).
5) To describe the development process of the Compassionate Cities: their development structures and how they revised, involved or participating stakeholders and their roles, the role of facilitation and coordination, the implementation characteristics that facilitated or hindered development and the contextual factors that influenced the development process (CHAPTER V).

Methods

Study design

I used a mixed-methods study design to inform the development of two Compassionate Cities in Flanders, Belgium by identifying the existing scientific knowledge on this topic, and describing attitudes of citizens in the general population regarding aspects related to serious illness, dying, caregiving and providing support (research aim 1) and to evaluate the process of development of the Compassionate Cities (research aim 2).

Methods to answer research aim 1

Systematic integrative review

To meet objective 1 of aim 1, I conducted a systematic integrative review of the peer-reviewed literature.[75] Prior to conducting this review, I registered the review in Prospero (CRD42020173406). I followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines to report the results and the methodological considerations recommended by Toronto and Remington (2020).[97]
I conducted a thorough literature search on the databases Web of Science, Pubmed, PsycInfo, Embase and Scopus on the 6th of October 2021, using a search string developed in collaboration with a librarian. As stated in the introduction of this dissertation, the semantic distinction between Compassionate Cities and Communities is not always clearly delineated in initiatives which explains why I decided not to exclude any initiatives based solely on their applied terminology. However, initiatives did need to be geographically defined, constructed in or after 1999 (the publication of Health Promoting Palliative Care),[29] applied a minimum of one of the action areas of the Ottawa Charter for Health promotion,[51] focused on themes related to serious illnesses, dying, death and/or bereavement, and was published in

an English language article. I included additional articles by reviewing the reference lists of the articles found through the database search (i.e., the snowball method).[98] The selection of the articles was done by the first three authors (BQ, LDEE and TS). A critical appraisal of the included studies was not performed as it was deemed irrelevant given that all studies were to be included regardless. I gathered additional information on the initiatives described in the articles by searching their websites and by contacting the corresponding author with a request for additional information.

I specifically searched for Compassionate Cities and Communities' contextual characteristics, reports on their development processes and on their evaluations. This information was extracted into data extraction tables which were later imported into the qualitative data analysis software NVIVO. The second author, LDEE, repeated the data extraction for 20% of the included articles. Subsequently, I thematically analysed the data. I followed PRISMA guidelines to structure this review.[99] The further description of the methodology is described in CHAPTER I.

Cross-sectional survey

I conducted a combined online and postal cross-sectional survey in a random sample of the general population of people aged 16 and over in four different municipalities in Flanders, Belgium. The municipalities were Bruges (118,000 inhabitants), Sint-Niklaas (80,000 inhabitants), Herzele (18,500 inhabitants) and Gavere (12,000) inhabitants. Bruges and Herzele were selected as the future Compassionate Cities, while Sint-Niklaas and Gavere functioned as control cities and did not undergo the same Compassionate City intervention. This way, the survey can later be repeated in the same municipalities, thereby taking temporal influences on the outcome measures into consideration. The entire questionnaire can be consulted in Appendix A1 of this dissertation and was composed out of different measures which were either literally translated from the original scale using forward backward translation,[100] based on an original scale but adapted or self-developed. To compose the sample, access to the population registers was guaranteed via a civil servant working in the municipalities. The questionnaire was distributed in the first semester of 2021 to a total of 4,400 people. I relied upon Dillman's total design method which involves multiple repeated mailings to non-responders to maximise response rates.[101] Respondents were asked to reflect on their community participation, neighbourhood connections (including willingness to support those neighbours), palliative care knowledge, awareness about palliative care (including prior cultural exposure), skills on palliative care related topics, attitudes towards the suffering and dying of others, self-efficacy in supporting others, intention to look for support and demographic characteristics. Where appropriate, I requested respondents to consider their situation prior to the COVID-19 pandemic, as social distancing measures may have affected their habitual behaviour (e.g., in relation to the provision of family care). A total of 2,135 questionnaires were returned. After removing unusable questionnaires, a total of 2,008 questionnaires were included for data analysis, resulting in a response rate of 45.6%. Two research papers from this survey study were published which considered different outcome measures. A third research paper considering people's palliative care knowledge has been published and was part of the same survey study but is not part of this dissertation.[102] The Based Checklist for Reporting of Survey Studies (CROSS) was followed to structure both survey papers.[103] Further details on the applied methodology can be consulted in CHAPTERS II & III.

1) *First research paper: The discomfort people feel towards the suffering and dying of others*

To meet the second objective, I developed a nonvalidated new scale, based on the Collett Lester Fear of Death scale, which assessed people's discomfort with the suffering and dying of others.[104] By using directed acyclic graphs, I integrated causal thinking to study specific association interests and select the most appropriate deconfounding strategy. The scale consists of eight items which were scored on a five-point Likert scale ranging from (1) not uncomfortable to (5) very uncomfortable. Scores then ranged between 8 and 40. The final score was divided again by 8 to facilitate interpretation. Respondents who filled out fewer than six items of the scale were excluded from analysis (N = 118). This left 1,890 questionnaires for further analysis (43.0%).

2) *Second research paper: People's willingness to support their neighbours practically or emotionally*

For the third objective, I developed an outcome measure which asked people to reflect on their willingness to help others within their neighbourhood practically or emotionally. Respondents were asked to reflect on two different cases which both different situations of persons in need of practical and/or emotional help. The respondents' willingness to then aid these individuals was scored on a five-point Likert scale ranging from (1) definitely not to (5) definitely. Scores then ranged between 8 and 40. Scores were again divided by 8 to facilitate interpretation. Respondents who filled out fewer than six items of the scale were excluded from analysis (N = 157). This left 1,851 questionnaires for analysis (42.1%).

Methods to answer research aim 2

Evaluation of the process of the development of the Compassionate Cities

To meet the objectives of the second aim, I first published a study protocol to make my evaluation intentions explicit. At the outset of this research project, a number of municipalities located in Flanders, Belgium were proactively contacted by the End-of-Life Care Research group to become the setting of the Compassionate City programmes. The municipalities showed their interest in becoming candidate Compassionate Cities and preliminary meetings were held with local politicians to discuss the Compassionate City concept and the prerequisites expected from intervention cities (Appendix A2 of this dissertation). As previously mentioned, the municipalities of Bruges and Herzele were selected for the Compassionate City programmes. Bruges is a city with an urban city centre of about 118,000 inhabitants and Herzele is a much smaller semi-urbanised municipality with an urban city centre of about 18,500 inhabitants. Both intervention cities appointed a project coordinator who takes the lead in bringing together the stakeholders and facilitate the development process. A project facilitator with expertise in change processes and group dynamics was appointed by the research group to facilitate this process. The municipalities were requested to form a leading coalition with local stakeholders who would develop the Compassionate Cities in cocreation. As the Compassionate City development continued after this research project, not all research aims mentioned in the published study protocol have yet been addressed. Evaluating initiatives that apply a public health perspective to the end of life is complex. However, Vanderstichelen and Deliens (2022) advocate that observational research designs should be integral to such evaluations as they help in capturing what happens outside of the controlled environment.[85] Proposed research frameworks for evaluating Compassionate Cities have been suggested, but their applicability remains unproven.[105] I performed a process evaluation of both Compassionate Cities. I followed the stepwise approach as proposed by Parkinson et al. (2016) to develop a framework to analyse the collected qualitative data.[106] The framework method is a deductive approach to analyse qualitative data and leaves room for inductively adding additional categories. The framework was developed based on the research questions, categories from the Consolidated Framework for Implementation Research (CFIR), interests coming from the familiarisation stage of the framework method and an earlier research project.[106–108] The developed framework can be consulted in Appendix A2 of CHAPTER V. For the data analysis, I used the conducted semi-structured interviews, group discussions, semi-structured observations and field notes. The observation template was developed based on ethnographic recommendations.[109] Emails, stakeholder output, documents and photos were collected and consulted to supplement the findings from the primary data sources. All these data were uploaded into the data analysis software NVIVO. The observation template can be consulted in Appendix A1 of CHAPTER IV & V. I adhered to the COnsolidated criteria for REporting Qualitative research (COREQ) checklist to report on this research.[110]

Ethical considerations

The Medical Ethics Committee of the University Hospital Brussels approved this study with reference B1432020000186 on 16 September 2020. The survey sent to the population sample contained a corresponding letter which can be consulted in Appendix A3 of this dissertation. This letter informed the reader on the study objectives, topics, funding, anonymity assurance and provided contact information of the main researcher BQ. An example of one of the reminder cover letters sent to the sample can be found in Appendix A4 of this dissertation. The reader had the option not to participate and could inform the main researcher on this decision or simply ignore the mailings. Filling out the questionnaire was considered consenting to participate. Non-participation did not bear any negative consequences for the contacted individuals. The researcher received the filled out, pseudonymised questionnaires and communicated the respondent numbers to a data collector, thereby guaranteeing the anonymity of the research participants and avoiding sending any reminder mailings. All interviewed participants gave informed consent prior to being interviewed. When possible, individuals needed to give approval to being observed before observations started.

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PART 2: TO INFORM THE DEVELOPMENT OF COMPASSIONATE CITIES BY IDENTIFYING EXISTING SCIENTIFIC KNOWLEDGE AND DESCRIBING ATTITUDES AND EXPERIENCES OF CITIZENS IN THE GENERAL POPULATION REGARDING ASPECTS RELATED TO SERIOUS ILLNESS, DYING, CAREGIVING AND PROVIDING SUPPORT

CHAPTER I

AREA-BASED COMPASSIONATE COMMUNITIES: A SYSTEMATIC INTEGRATIVE REVIEW OF EXISTING INITIATIVES WORLDWIDE.

This chapter is based on:

Quintiens B[1,2], D'Eer L[1,2], Deliens L[1,2], Van den Block L[1], Chambaere K[1,2], De Donder L[2,3], Cohen J*[1,2], Smets T*[1]. Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide. Palliat Med. 2022 Mar;36(3):422–42.

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Abstract

Background: Area-Based compassionate community initiatives are community public health interventions which focus on the role of the community in palliative care provision. They apply a set of actions based on the Ottawa Charter for Health Promotion which aims to increase people's control over their health.

Aim: To review and compare area-based compassionate community initiatives with respect to their contextual characteristics, development processes and evaluations.

Design: A systematic integrative with narrative synthesis. Registered in Prospero: CRD42020173406.

Data sources: Five databases (Pubmed, Web of Science, PsycInfo, Embase and Scopus) were consulted, consisting of publications from 1999 onwards. This was supplemented with grey literature and author-provided documentation.

Results: Twenty articles were drawn from the peer reviewed search, three from grey literature and two from author-provided documentation. Notwithstanding the substantial variation in what is reported, all area-based compassionate community initiatives focus on multiple action areas of the Ottawa Charter for Health Promotion. Variability in their contextual and developmental characteristics is high. Only a minority of initiatives have been evaluated and although conclusions are generally positive, what is evaluated often does not match their aims. Attaining support from policy makers can help in obtaining funding early in the project. Strengthening people's social networks was a recurring community engagement strategy.

Conclusions: While the concept of area-based compassionate community initiatives is gaining momentum as a new paradigm for the creation of palliative care capacity across society, only a handful of initiatives have been described. The lack of formal

evaluations of their proclaimed health benefits indicates a pressing need for rigorous research about ongoing and future initiatives.

Background

There is increasing recognition that the challenges of health and wellbeing around serious illness, dying and bereavement go substantially beyond the scope of professional healthcare services.[1–3] The more protracted part of care in serious illness at the end of life and subsequent bereavement involves periods of time spent not with professionals but with family, friends, co-workers and other social connections. Therefore it has been suggested that promoting the health and wellbeing of people with serious illnesses, their carers, relatives, friends and neighbours, entails a civic response in co-existence with health service responses. These efforts, organised by society to optimise the circumstances of the dying and all those involved through collective or social actions, have by some been coined a 'public health approach to palliative care'.[1,3–5]

Allan Kellehear, a sociologist, published Health Promoting Palliative care in 1999 which adapted the Ottawa Charter principles to palliative care and which laid the foundations for the concepts of compassionate communities and cities.[3,6] Put forward as one possible model of a civic response to palliative care, compassionate communities and cities are social ecology approaches, based on principles of participation, empowerment, inclusion, respect and dignity, which consider serious illness, dying, caregiving and grief as everyone's business.[6] Our focus is on compassionate communities around serious illness, death, dying and loss that target geographic areas delineated by physical or administrative boundaries at the scale of municipalities or larger and are multi-sectoral, inclusive and participatory in nature. Their development is often characterised by the involvement of various stakeholders, including the local government, health and wellbeing organisations, workplaces, schools, churches and neighbourhoods who collaborate to work out actions aimed at prevention, harm reduction and early intervention around serious illness, death, dying, loss and caregiving.[7] The actions can include awareness-raising, education, policy development and creation of new or strengthening of existing social networks in co-creation. These initiatives have sometimes been referred to as compassionate cities but the concept of compassionate communities is equally used and a clear conceptual demarcation between both is lacking. To avoid the existing conceptual confusion, we choose to use the descriptive term “Area-Based Compassionate Communities”. The set of actions or activities are based on the five action areas of the Ottawa Charter for Health Promotion: (1) building healthy public policy around serious illness, death, dying, loss and caregiving, (2) creating supportive environments, (3) strengthening community action, (4) developing personal skills through education and information and (5) re-orienting of healthcare services toward these changes.[8]

While the concepts of compassionate communities and cities seem to be gaining momentum as a new paradigm for the creation of palliative care capacity across society in various countries, there is little systematic knowledge about their characteristics, how they were developed, whether the process and impact of the existing initiatives have been formally evaluated and what the results are of these evaluations.[4,9] Studying these topics is important since it provides future developers with invaluable information on what characteristics are important, what development processes lead to success and what results can be expected when developing a compassionate community or city. We argue that that knowledge is important to add an evidence base to the growing enthusiasm for compassionate communities and cities by, for instance, indicating what can be learned from previous initiatives or where more evidence is needed.

A review by Sallnow et al. (2016) included different examples of new public health approaches to palliative care and concluded that involving communities can result in decreased fatigue and social isolation for those caring for people at the end of life and an increase in the size of caring networks, and that it can influence place of death and the involvement of palliative care services.[4] A recent literature review by Librada et al. (2020) on compassionate communities and cities concluded that there is very little evidence about their development and that assessment models are lacking because no models have been thoroughly evaluated.[10] The authors chose not to apply specific definitions for compassionate communities or cities and thereby included initiatives with a less specific focus. The published review provides hardly any insight into contextual characteristics, the different elements of the process development, the main domains of activity in terms of the action areas of the Ottawa Charter or on results from the evaluations of the programmes. Nevertheless, insight into these aspects seems essential if a review is to motivate and inform further development and evaluation of compassionate community and city programmes. In order to encompass all compassionate community and city initiatives that cover a demarcated area we will use the term “Area-Based Compassionate Communities”. We aimed to conduct a systematic integrative review to address the following research questions:

1. What are the contextual characteristics (i.e. geographical demarcation, number of inhabitants, funding) of Area-Based Compassionate Communities?
2. What is reported regarding the development processes of Area-Based Compassionate Communities?
3. How have Area-Based Compassionate Communities been evaluated and what are the reported results of this evaluation?

Methods

Protocol registration, review design, reporting guidelines

We performed a systematic integrative review which permits the processing of diverse types of data sources, in this case peer reviewed articles and grey literature (i.e. websites of included initiatives, documents and a book) to build a holistic understanding of a specific phenomenon: Area-Based Compassionate Communities. Furthermore, this type of review allows for the inclusion of theoretical literature (i.e. framework presenting or opinion articles).[11] We followed the six steps of the integrative review process as proposed by de Souza et al. (2010): Souza et al. (2010): (1) formulate purpose and/or review question(s), (2) systematically search and select literature, (4) analysis and synthesis, (5) discussion and conclusion, (6) dissemination of findings. We explain further why we did not perform step (3) quality appraisal.[12] Due to the complexity of combining diverse study designs in a review, we decided to apply a rigorous methodology typical of systematic reviews to a heterogeneity of studies. This review can be regarded as a systematic integrative review because we make use of different data sources and apply a synthesis which is drawn up in a table and narratively described.[11] This review has been registered in Prospero (CRD42020173406). We used Prisma guidelines for reporting of results as advised by Toronto and Remington (2020).[11]

Search methodology

We produced a list of synonyms for the most commonly used terms for *Area-Based Compassionate Communities.* We did this to make sure no articles would be missed. ‘Kellehear’ was added as a search term because many, though not all, articles on compassionate communities and cities are based upon the compassionate city model as described by Kellehear and thereby refer to the author in their text. The applied search string was consulted on with a librarian, tested in Pubmed and translated to the other databases. A search in all databases was performed October 6, 2021. We made an overview of findings per database in tables in Microsoft Excel.

Pubmed applied search string:
((("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 "public health palliative care"[Title/Abstract] OR "community participation"[Title/Abstract] OR "community engagement"[Title/Abstract] OR "health promoting palliative care"[Title/Abstract]) AND (palliative* OR hospice* OR terminal* OR "end-of-life" OR bereave*)) OR Kellehear) AND ("1999/01/01"[PDat] : "3000/12/31"[PDat])

Information sources

The information sources consulted are described by referring to the search methods used to obtain the used articles. We first performed a search of the peer reviewed literature by consulting the following databases until October 6th 2021: Pubmed, Web of Science, PsycInfo, Embase and Scopus. To find more information in peer reviewed literature we then used a snowball method by hand searching the reference lists of the publications found.[13] Finally, we performed a grey literature search to find more information on the Area-Based Compassionate Communities covered by screening their websites and by emailing the corresponding author of every included article (July 2020) and asking them to provide additional information on the compassionate community or city described in the article. If after two weeks no response was obtained, they were contacted again together with the second author. If this did not result in a response, no further steps were taken.

Eligibility criteria

We included the article if the described initiative:

(A) related to a geographically defined community and comprised a city/municipality or a group of cities/municipalities, and

(B) was constructed in or after 1999, the date of publication of the book Health Promoting Palliative Care by Allan Kellehear that introduced the principles, and

(C) applied at least one of the five action areas of the Ottawa Charter for Health Promotion[3,8], and

(D) focussed on themes related to serious illnesses, dying, death and/or bereavement, and

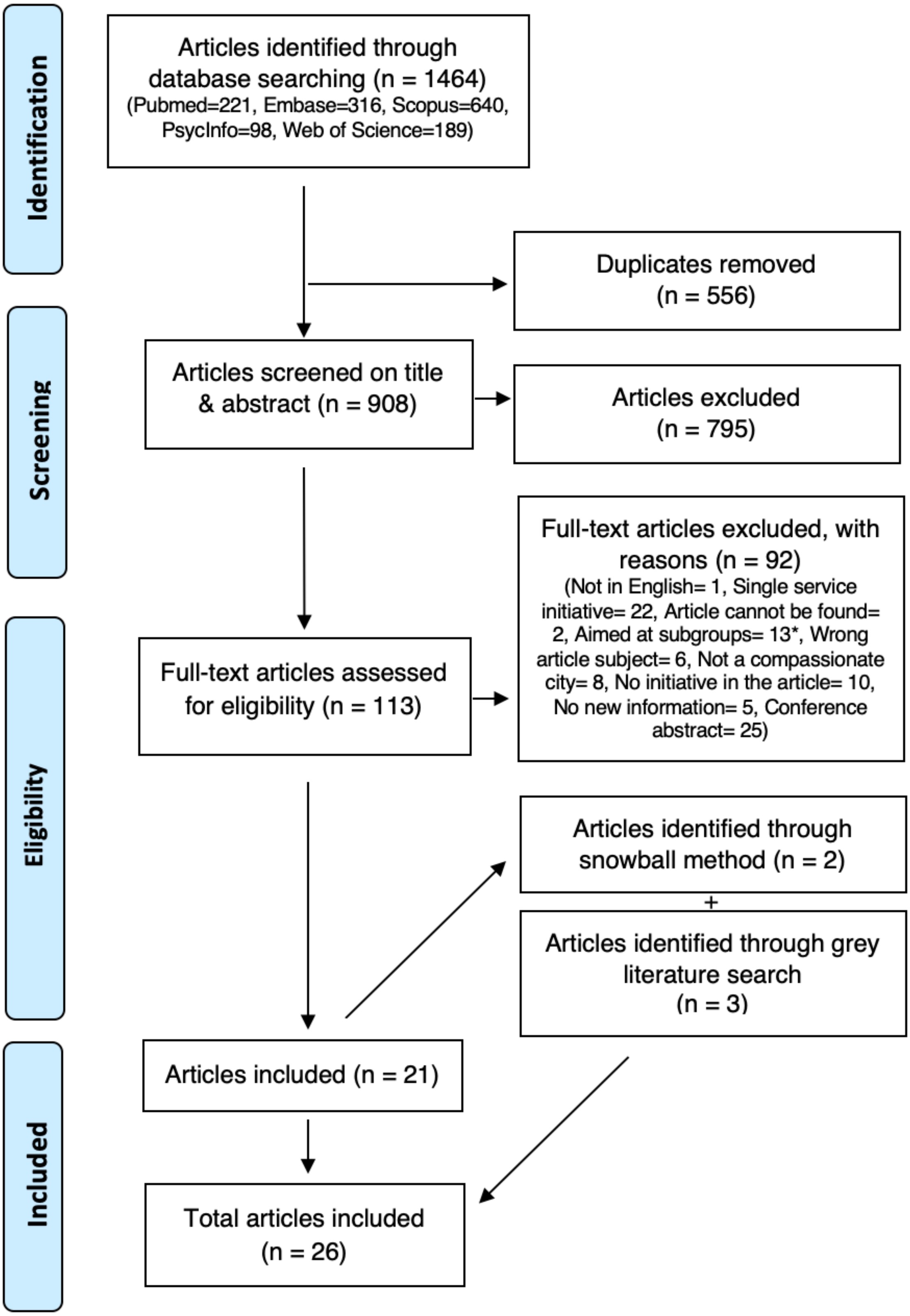
(E) was covered in an article published in English.

We excluded articles that described an Area-Based Compassionate Community that was (A) limited to the functioning of a single service-led initiative or (B) aimed at specific subgroups as opposed to the whole population and (C) if it could not be established, based on the published information, whether the described project was in fact an Area-Based Compassionate Community.

Study selection process

All obtained articles were downloaded from each respective database and then uploaded into Rayyan QCRI, a systematic review application tool which allows for the automatic removal of duplicates.[14] The included articles were imported into Zotero reference manager, together with all other references used in this review. The process of study selection is visualised in a Prisma flow chart (Figure 1). Once the articles were imported into Rayyan QCRI, all duplicate articles were removed. Then they were screened on title and abstract using the in- and exclusion criteria first, after which a full text analysis was performed on all included articles. This process was performed independently for all articles by two authors (BQ and LDEE). If disagreements about the inclusion of an article arose, we attempted to reach an agreement. If no agreement was reached, a third researcher (TS) made the final decision. Reasons for the exclusion of articles were documented.

Figure 1: Prisma flow chart of article selection.



**e.g. persons with dementia, people in the LGBT community*

Data collection process

A data extraction form in the format of the tables in this review was developed prior to data collection and its applicability was tested on one study. The first author extracted data from the articles to answer the research questions on:

(1) contextual characteristics: country, geographical demarcation, number of inhabitants, initiator, funding, reason for initiation, start date and continuation of the Area-Based Compassionate Communities;

(2) characteristics of the development process: aim of the Area-Based Compassionate Communities, development process mentioned, building public policies, creating supportive environments, developing of personal skills, strengthening community action and reorienting healthcare services;

(3) characteristics of the evaluation of the Area-Based Compassionate Communities: whether the initiative was evaluated or not, what was evaluated and reported results.

The data was directly entered into the data extraction form in order to give a clear overview of the answers for each research question. We were as elaborate as possible in order not to miss any information and with the idea of retaining what is most important later in the process. The tables shown in this review are therefore a collection of the most relevant findings from the data extraction. The data extraction was repeated by a second researcher (LDEE) for 20% of the included articles. Discrepancies were discussed and if no agreement was obtained, they were discussed with a third researcher (TS) to make the final decision. Once this was done, all extracted data in the tables were imported into NVIVO, a qualitative data analysis programme which allows performance of a thematic analysis on the data. We started by reading through all the data and constructing initial codes inductively. Next, similarities and differences between the initial codes were sought and grouped together and common codes were formed where possible and inserted into the tables.

Results

Study selection

The peer reviewed search resulted in 1464 articles. Out of these, 556 duplicates were removed. This resulted in 908 articles of which 113 met the eligibility criteria and were included for full text screening. Ninety-two articles were excluded and 21 were included. There was an initial disagreement about 24 articles between BQ and LDEE; after discussion 20 disagreements were resolved. The four remaining disagreements were discussed with a third reviewer (TS) to reach a final decision (all were excluded). The most common reasons for exclusion were that the article focused on a single service initiative, was a conference abstract or the Area-Based Compassionate Communities aimed at subgroups (e.g. people with dementia, people in the LGBT community). The 21 included articles discuss a total of 22 individual Area-Based Compassionate Communities. By screening the references of the included articles, we included two additional articles on already-included Area-Based Compassionate Communities. The grey literature search resulted in an additional three articles, all on already-included initiatives. Fourteen authors were contacted for additional documentation of whom eight replied. For one article, we could not identify any authors' contact details.[15] This process resulted in a total of 26 included articles on 22 Area-Based Compassionate Communities (Table 1). A short summary of results is shown in the Prisma flow chart (Figure 1). We did not perform a critical appraisal of the included articles for the following reasons: (A) only a minority of the included articles has some empirical evidence and since evidence was only a partial focus of this review, all were included and equally analysed, (B) we included articles based on their relevance to the research questions, not their critical appraisal scores and (C) information was sometimes extracted from parts of the article such as the result or introduction section, a critical appraisal about the article as a whole was less relevant.

Table 1: List of included articles.

Initiative	*Articles*
Vic	**1.** Compassionate communities: design and preliminary results of the experience of Vic (Barcelona, Spain) caring city.[17]
TC Sevilla	**2.** All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18] **3.** Development and Management of Networks of Care at the End of Life (the REDCUIDA Intervention): Protocol for a Nonrandomized Controlled Trial.[43]
TC Badajoz	**2.** All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18]
TC Getxo	
TC Pamplona	
Landeck	**4.** Caring communities as collective learning process: findings and lessons learned from a participatory research project in Austria.[19] **5.** 'Ingredients' of a supportive web of caring relationships at the end of life: findings from a community research project in Austria.[44]
Döbra	**6.** Going public: reflections on developing the DöBra research program for health-promoting palliative care in Sweden.[20] **7.** Navigating power dynamics in engaging communities in end-of-life issues – Lessons learned from developing community-based intergenerational arts initiatives about death and loss.[37] **8.** Developing and using a structured, conversation-based intervention for clarifying values and preferences for end-of-life in the advance care planning-naïve Swedish context: Action research within the DöBra research program.[46] **9.** Death, loss and community—Perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden.[34]
Frome	**10.** Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities.[21]
Merseyside and Cheshire	**11.** End-of-life conversations and care: an asset-based model for community engagement.[22]
GLGDGG	**12.** Health-promoting palliative care: a Scottish perspective.[35] **13.** Scotland's public health palliative care alliance.[23] **14.** To Absent Friends, a people's festival of storytelling and remembrance.[32]
Inverclyde	**15.** Compassionate communities and collective memory: a conceptual framework to address the epidemic of loneliness.[24]
Hume	**16.** From concept to care: Enabling community care through a health promoting palliative care approach.[25] **17.** Bereavement care for the non-bereaved: A health promotion challenge.[47]
The Hills	**18.** Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia.[42] **19.** Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life.[26]
NNPC	**20.** Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care.[29] **21.** Kerala, India: A Regional Community-Based Palliative Care Model.[31] **22.** Neighborhood network in palliative care.[39]
TC Medellin	**2.** All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18]
TC Cali	

TC Fusagasuga	
TC Bogota	
TC Buenos Aires	
Estar ao Seu Lado	**23.** Palliative care for all? How can Brazil develop a palliative care service founded on principles of equity and access for all?[28] **24.** Brazil: time for palliative care in the community![30]
WECCC	**25.** Unpacking ‘the cloud’: a framework for implementing public health approaches to palliative care.[27]
Soweto	**26.** The Soweto care givers network: Facilitating community participation in palliative care in South Africa.[15]

Context

Fourteen of the 22 included Area-Based Compassionate Communities were located in high income countries.[16–27] The other eight were located in upper middle-income[15,18,28] or lower middle-income countries.[29] Of the included initiatives, eleven are in Europe,[17–24] six in South America,[18,28] two in Oceania (Australia),[25,26] one in Asia (India),[29] one in North America (Canada)[27] and one in Africa (South Africa) (Figure 2).[15] Fifteen of the Area-Based Compassionate Communities can be regarded as an individual town or city,[15,17–19,21,25,28] six as a larger administrative demarcated area such as a country or state[20,22–24,27,29] and one as a group of towns or cities.[26] The number of citizens living in the Area-Based Compassionate Communities varied between 3,000-100,000,[17–19,21,24,26,28,30] 100,000-500,000[18,25,27] and >500,000.[15,18,20,22,23,29]

*Figure 2: Location of Area-Based Compassionate Communities**

**Figure made through a freely available online software tool*

Reasons mentioned for developing an Area-Based Compassionate Community programme were diverse but often fell under one or both of the following two major categories: 1) gaps in current healthcare system (e.g. the need for an integrated healthcare system,[17,18,22,27,30] limited resources,[18,25,27] general mentioning of gaps,[18,27] people's complex care needs,[17,21,25,27] having a limited populational palliative care coverage[15,20,28–31] and to unburden the healthcare system[25–27]) or 2) societal challenges (e.g. to strengthen community action,[7,18,19,23,26,27,29,32,33] having an ageing population,[18,25–27,34,35] to normalise palliative care in society[7,20,23] and to address loneliness).[24,32] With the exception of three Area-Based Compassionate Communities,[15,25,29] all were created in or after 2011 (Table 2).

Table 2: Contextual characteristics of the Area-Based Compassionate Communities.

Initiative ***Characteristic***			**Vic**	**TC Sevilla**	**TC Badajoz**	**TC Getxo**	**TC Pamplona**	**Landeck**	**Döbra**	**Frome**	**Merseyside Cheshire**	**GLGDGG**	**Inverclyde**	**Hume**	**The Hills**	**NNPC**	**TC Medellin**	**TC Cali**	**TC Fusagasuga**	**TC Bogota**	**TC Buenos Aires**	**Estar ao Seu Lado**	**WECCC**	**Soweto**	**Total**
Country			**Spain**	**Spain**	**Spain**	**Spain**	**Spain**	**Austria**	**Sweden**	**England**	**England**	**Scotland**	**Scotland**	**Australia**	**Australia**	**India**	**Colombia**	**Colombia**	**Colombia**	**Colombia**	**Argentina**	**Brazil**	**Canada**	**South Africa**	
Geographical demarcation	Town or city		X	X	X	X	X	X		X				X			X	X	X	X	X	X		X	15 *68%*
	Larger administrative demarcated area								X		X	X	X			X							X		6 *27%*
	Group of towns or cities														X										1 5%
Number of inhabitants	3,000-100,000		X			X		X		X			X		X							X			7 *32%*
	100,000-500,000				X		X							X					X	X			X		6 *27%*
	>500,000			X					X		X	X				X	X	X			X			X	9 *41%*
Used inputs	Initiator	Healthcare oriented organisations (both governmental and non-govern-mental)		X		X	X	X		X	X	X	X	X		X	X	X	X	X	X	X	X	X	18 *82%*
		Academic researchers	X					X	X	X					X									X	6 *27%*
		Policy makers			X			X																	2 *9%*

	Funding	Crowd	X	X	X	X	X				X		X			X	X	X	X	X	X			X	14 *64%*
		Non-profit organisation		X	X	X	X	X				X					X	X	X	X	X				11 *50%*
		Government	X							X		X		X	X	X						X	X		8 *36%*
		Healthcare institution								X	X		X												3 *14%*
		Research	X						X																2 *9%*
	Involving external partners	Organi-sations	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 *100 %*
		Lay people	X	X	X			X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	20 *91%*
		Volunteers	X	X			X			X	X	X	X	X	X	X	X	X		X	X		X	X	16 *73%*
		Policy makers	X	X	X	X		X	X			X	X	X	X	X			X			X	X		14 *64%*
		Healthcare institutions	X		X		X	X		X	X	X		X		X						X			10 *45%*
Reason for initiation	Gaps in current health-care system	The need for an integrated healthcare system	X	X	X	X	X				X						X	X	X	X	X	X	X		12 *59%*
		Limited resources		X	X	X	X							X			X	X	X	X	X		X		11 *50%*
		General gaps		X	X	X	X										X	X	X	X	X		X		10 *45%*
		People's complex care needs	X							X				X									X		4 *18%*
		Having a limited populational							X							X						X		X	4 *18%*

		palliative care coverage																						
		Unburden the healthcare system												X	X								X		3 *14%*
	Societal challenges	Strengthen community action		X	X	X	X	X				X			X	X	X	X	X	X	X		X		15 *68%*
		Having an ageing population		X	X	X	X		X			X		X	X		X	X	X	X	X		X		14 *64%*
		Normalise palliative care in society						X	X			X													3 *14%*
		Address loneliness										X	X												2 *9%*
	To lower unplanned hospital admissions									X															1 *5%*
Start date			2016	2015	2015	2017	2017	2013	2013	2014	2011	2011	2017	2003	2018	2001	2015	2015	2016	2017	2016	2014	2014	2001	
Continuation of the compassionate city	Ongoing		X	X	X	X	X		X			X	X		X	X	X	X	X	X	X	X	X		17 *77%*
	Ended (because of ending of the Area-Based Compassionate Community pilot project)							X		X	X			X											4 *18%*

Aims and ambitions

Most Area-Based Compassionate Communities had multiple aims (Table 3). The overarching aims (explicated or inferred) were to improve public health in all the included initiatives, to achieve better end-of-life care at population level in most cities[17–20,22–24,26–29,36] which was sometimes attempted by increasing access to palliative care,[17–19,26–30] to change cultural attitudes,[17–19,23,24,26,37] to build community capacity[19,20,23,25,26,29,38] or to educate the population on the end of life (e.g. by informing people on legal, medical or financial issues associated with the end of life).[22,23,37] Another aim was to promote community action by providing end-of-life care by the community[17,18,20,22,24,26,29,38] and the development of a volunteer programme.[18,25,29,31,39] Other mentioned aims were to create an integrated healthcare system[7,17–21,28] or to change policies.[23,40]

Table 3: Characteristics of the development processes of the Area-Based Compassionate Communities.

Initiative / **Characteristic**			**Vic**	**TC Sevilla**	**TC Badajoz**	**TC Getxo**	**TC Pamplona**	**Landeck**	**Döbra**	**Frome**	**Merseyside Cheshire**	**GLGDGG**	**Inverclyde**	**Hume**	**The Hills**	**NNPC**	**TC Medellin**	**TC Cali**	**TC Fusagasuga**	**TC Bogota**	**TC Buenos Aires**	**Estar ao seu Lado**	**WECCC**	**Soweto**	**Total**
Aim of the Area-Based Compassionate Community	To improve public health		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 *100%*
	Better population end-of-life care	General mentioning	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	X	X		20 *91%*
		Increase access to palliative care	X		X	X		X	X						X							X	X		8 *36%*
		Reduce avoidable suffering							X																1 5%
	To change cultural attitudes		X	X				X	X			X	X		X		X								8 *36%*
	To build community capacity	General mentioning						X	X			X		X	X	X									6 *27%*
		Population end-of-life education							X		X	X													3 *14%*
	To promote community action	End-of-life care provided by the community	X	X					X		X		X		X	X									7 *32%*
		Volunteer programme												X		X	X								3 *14%*
	To create an integrated healthcare system		X	X				X	X	X												X			6 *27%*
	To change policies								X			X													2 *9%*

Development process mentioned	Something mentioned	X	X	X	X	X	X		X	X		X	X			X	X	X	X	X				15 *68%*
	Nothing mentioned							X			X			X	X						X	X	X	7 *32%*
	Extensively mentioned																							0
Outputs categorised according to the Ottawa Charter for Health Promotion action areas																								
Building healthy public policies	Public endorsement of the project by policy makers	X	X		X		X				X		X	X	X						X			9 *41%*
	Policy adaptations										X		X	X	X			X			X	X		7 *23%*
	Nothing mentioned					X			X	X						X	X		X	X			X	8 *36%*
Creating supportive environments	To strengthen social networks		X			X	X	X	X		X		X	X	X	X	X			X	X			13 *59%*
	To create an integrated healthcare system								X	X	X	X										X	X	6 *27%*
	To influence people's social determinants of health								X		X				X							X		4 *18%*
	To focus on underserved groups							X		X	X													3 *14%*
Developing personal skills	By engaging the community	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 *100%*
	By centralising resources						X		X		X	X	X											5 *23%*
Strengthening community action	By supporting the community to undertake action	X				X	X				X	X	X	X	X	X	X	X			X		X	13 *59%*
	By giving ownership to the community				X		X	X	X	X	X	X	X	X	X								X	11 *50%*
	By connecting organisations			X				X	X		X		X		X							X		7 *32%*

	Nothing mentioned			X	X	X											X							4 *18%*
Re-orienting healthcare services	By training healthcare workers		X	X	X		X	X		X	X	X	X		X	X	X	X	X	X	X			16 *73%*
	By applying preventive instead of reactive actions		X					X	X				X	X										5 *23%*
	Nothing mentioned																					X	X	2 *9%*

[1] *The aims mentioned for the Todos Contigo movement were interpreted as common aims for every individual Area-Based Compassionate Community that is part of this movement.*

Development process

Inputs

For some of the Area-Based Compassionate Communities, information was provided about their development process[7,17–19,21,22,24,25,36,41] albeit never extensively. The development of the Area-Based Compassionate Communities was initiated by three main groups (Table 2): healthcare oriented governmental and/or non-governmental organisations,[7,15,18,19,21–25,27,29–32,35,36,41] academic researchers[7,15,17,19–21,26,34,38,40] or policy makers.[18,19,41] Funding for Area-Based Compassionate Communities came from five major sources, where different sources for funding are sometimes combined: crowd,[15,17,18,22,24,26,29,31,39] non-profit organisation,[18,19,23] government,[17,21,23,25–29,35,39] healthcare institution[21,22,24] or research.[17,20] All Area-Based Compassionate Communities involved other organisations in their development where sometimes these organisations were healthcare institutions.[17–19,21–23,25,28–30,33,41] Other external partners were policy makers[17–20,23–29,31,35] and all Area-Based Compassionate Communities, with the exception of two initiatives from *Todos Contigo,*[18] explicitly mentioned the involvement of lay people. In some cases volunteers were involved in the project.[15,17,18,21–27,29,31,35,39,41] At the time of data collection, four of the initiatives had terminated, all because they were initiated as part of a pilot project which had ended.[19,21,22,25] For one initiative, we could not determine whether it was still ongoing or not.[15]

Outputs

The development activities could be classified according to the five action areas of the Ottawa Charter for Health Promotion (Table 3). In terms of the action area *'building healthy public policies'*, Area-Based Compassionate Communities mentioned the public endorsement of the project by policy makers (e.g. mayor presents the project)[17–19,23,25,28,29,41,42] and policy adaptations.[18,23,25,27–29,41,42] For the action area *creating supportive environments*, some Area-Based Compassionate Communities organised activities to strengthen a person's social networks (e.g. training family members in basic personal care),[18,19,21,23,25,26,28,29,32,34,41,43,44] to create an integrated healthcare system (e.g. making an overview of existing healthcare providers and signposting patients to designated services),[15,21–24,27] and to influence people's social determinants of health (e.g. interventions to improve patients' financial problems)[21,23,29,45] and to focus on underserved groups (e.g. events with prisoners).[20,22,23,34,40,46] The action area *developing personal skills* was realised by activities to engage the community around end-of-life related themes which was mentioned for all Area-Based Compassionate Communities (e.g. palliative care information seminar or talking café where people could be signposted to designated services), or by centralising resources (i.e. by increasing access to resources and information people gain more control over the choices they make).[19,21,23–25] The action area *strengthening community action* is achieved by giving ownership to the community (e.g. local initiatives organised by the community so that the Area-Based Compassionate Community becomes self-sustainable).[15,19–26,29,31,36,39] Other strategies mentioned were supporting the community to undertake action[15,17,19,23–26,28,29,31,32,39,41] or connecting organisations.[18,20,21,23,25–27,32,35,37,39,47] The last action area, *reorienting healthcare services*, was sometimes accomplished by training healthcare workers[18–20,22–25,29–31,35] or by applying preventive instead of reactive measures (e.g. healthcare workers stimulating people to make use of their social networks instead of fully relying on professional services).[18,20,21,25,26,46] For the Soweto and the WECCC initiatives, nothing was mentioned with regard to this action area.[15,27]

Evaluation and outcomes

For ten of the 22 Area-Based Compassionate Communities, some form of evaluation was mentioned (Table 4). Sometimes the initiative was evaluated using a combination of quantitative and qualitative methods (Vic, GLGDGG, Hume and The Hills),[17,23,25,26] such as the realist evaluation of The Hills using mixed methods,[42] or using quantitative methods only (TC Sevilla, Frome, NNPC, and WECCC)[21,27,29,43,49] such as the retrospective cohort study of unplanned hospital admission data used to evaluate Frome.[21] Two Area-Based Compassionate Communities (Döbra and Inverclyde) were evaluated using qualitative methods only.[24,34] For some cases, the project's outcomes were evaluated.[18,21,24,25,27,29] For seven Area-Based Compassionate Communities, the generated outputs (i.e. activities) within the Area-Based Compassionate

Community[17,21,23–25,31,34] and/or the process of development were evaluated.[17,24,25] For only two (Inverclyde and Hume), the outcomes of the initiative as well as the process of development were evaluated.[24,25] For another two Area-Based Compassionate Communities, the studies reported on whether their aims were actually achieved.[21,25] For The Hills and WECCC, no results from the evaluation were reported.[26,27] Sometimes reported results were not specific or without adequate explanation, such as “the compassionate city has many strengths in areas which will lead to a positive social return on investment”,[50] or “some areas (media, schools) are not reached by the project”,[17] or one case where an increase in social media activity was reported while at the same time arguing for more social media activity.[51] Examples of what has been evaluated can be seen in Table 5.

Table 4: Characteristics of the evaluation of the Area-Based Compassionate Communities.

Characteristic \ ***Initiative***			**Vic**	**TC Sevilla**	**TC Badajoz**	**TC Getxo**	**TC Pamplona**	**Landeck**	**Döbra**	**Frome**	**Merseyside Cheshire**	**GLGDGG**	**Inverclyde**	**Hume**	**The Hills**	**NNPC**	**TC Medellin**	**TC Cali**	**TC Fusagasuga**	**TC Bogota**	**TC Buenos Aires**	**Estar ao seu Lado**	**WECCC**	**Soweto**	**Total**
Evaluated?	**Yes**	**Quantitative**	X	X						X		X		X	X	X							X		7 *32%*
		Qualitative	X						X			X	X	X	X										6 *27%*
	Not mentioned				X	X	X	X			X						X	X	X	X	X	X		X	12 *55%*
What was evaluated?	**Project outcomes**			X						X			X	X		X							X		5 *23%*
	Generated outputs		X						X	X		X	X	X		X									7 *32%*
	Process of development		X										X	X											3 *14%*
If evaluated, are any results reported?	**Yes**		X	X					X	X		X	X	X		X									8 *36%*
	No														X								X		2 *9%*

Table 5: Evaluated Area-Based Compassionate Communities and their reported results.

Initiative	***Reported results***
Vic	The project's first year of implementation was evaluated (including one output): -High participation by organisations, diverse activities developed by organisations. -Some areas are not activated (media, schools, trade unions,…) by the project. -Some organisations don't develop internal activities (variety in participation grade). -Multicultural visions need to be taken into consideration. -Plan for sustainability is needed. -Trainings scored positively by attendants. A semi-structured survey was distributed and 51 responses were obtained: The topics were considered relevant (3.67/4), the exposition was clear (3.75/4), the training was dynamic and participative (3.24/4), and time and dates were evaluated (3.51/4).
TC Sevilla	The project has planned an outcome evaluation but only preliminary results are reported:[18,43,49] -An increase in care and support networks of citizens participating in the project (from one person to an average of ten people involved in care). -A decrease in the emotional and physical overload of the main caregiver thanks to the creation of care and support networks, and improvement in the satisfaction of family members regarding the care provided in the programme. -An improvement in the quality of life, especially in the areas of anxiety, loneliness and depression in citizens. -It is possible to cover up to 70% of the total identified needs, reduce the loneliness of the beneficiaries of the process, decrease the overload of the caregivers involved in the care network, improve the quality of life of the beneficiaries (especially regarding pain, anxiety, and depression), and increase the degree of family satisfaction, by contributing together to the care of these people in this final stage of life.
Döbra	The project evaluated participants' and parents' reflections on intergenerational workshops:[34] -Participants motivations to participate in Studio Döbra -Participants' experiences of participating -Ways in which participation affected children, older adults and parents The results from this evaluation were divided into three themes with main reported findings: Findings indicate that participants acted as individuals with agency in connecting across generations and in creating spaces for engaging with End of Life-topics, not only in Studio DöBra but also in their social networks. Participants reflected on a changing sense of community through new intergenerational connections and social activities, and expressed a desire to maintain these. However, participants indicated sustainability challenges related to lacking agency in maintaining these spaces and sense of intergenerational community, as they rely on support from community organisations.
Frome	The project performed an outcome evaluation:[21] -Before the project, a not statistically significant trend showed an increase in unplanned hospital admissions in the intervention city and in its surrounding area over a five-quarter period, after the project, an increase in the number of unplanned hospital admissions in the area of the intervention city was recorded (+28.5%) while at the same time the intervention city recorded a significant decrease in unplanned hospital admissions (-14%). -Comparing data from 2013-2014 with data from 2016-2017, the intervention city recorded a reduction of 20.8% in cost for unplanned hospital admissions.

	The project focused on some generated outputs:[72] -Through *The Warwick-Edinburgh Mental Well-being scale* (a tool for monitoring mental well-being at a population level) it was assessed that 81% of the citizens making use of the service to strengthen their social networks had measurable improvements of their wellbeing. Through a patient feedback form distributed to citizens reached by the health connectors, it was assessed that 94% felt more able to manage their health and 95.6% said that they felt more able to access support in the community. -Through *The Patient Activation Measure* (an assessment tool of an individual's self-management competency) it was assessed that citizens making use of the service to strengthen their social networks on average increased on their knowledge, skill, and confidence for managing one's health and healthcare.
GLGDGG	The project focused on the outputs from different editions of an end-of-life themed festival:[32,51,73,74] -Increase in website use and social media activity. -All respondents to an online survey after the festival felt their activity promoted openness about death, dying and bereavement. -A large majority of event organisers felt they were helping people to find ways of dealing with their own experience of death, dying and bereavement and helping individuals or communities to support people through difficult times. -Fewer events were seen as helping NHS/social care/volunteers or helping people to make practical preparations although there were some events. -Most participants return to take part in subsequent years. -Feedback on experiences of the festival was overwhelmingly positive. -Community came through strongly when people were asked what aspects of the festival they found valuable. 62% said that "being part of a community" was one of the things they valued about the festival. In fact, there were a number of aspects of the festival that were rated valuable by a majority of the respondents. These included hearing the experiences of others (63%), having events to get involved with (53%), finding new ways to remember people (51%) and helping others (50%). 49% appreciated having a dedicated time to remember someone. Fewer people valued the festival as a way to meet others who'd experienced loss (19%) or to access bereavement resources (11%). Data obtained through an online survey. -Events that were best attended or particularly well-received were, in general, conceived and organised by one or two enthusiastic individuals, for a community of which they were part. The project also focused on some parts of the process of realising the end-of-life themed festival: -Though there is plenty of creativity and enthusiasm about participating in To Absent Friends, a barrier to participation can be money. In the current financial climate of extremely limited resources, providing just a small amount of money can provide the support an organisation needs to undertake something amazing within their local community. -People appreciate and use ideas and resources produced by the Scottish Partnership for Palliative Care and they acted as a catalyst for participation in the festival. -Dedicated staff time is valuable. Extra staff has increased social media activity and secured more publicity. -Local ownership is the key ingredient for success.

Inverclyde	The project expresses the desire to focus on outcomes:[75] -Reporting has affirmed the countless contributions of local people but has not attempted to attribute direct impact or estimate cost effectiveness. -The data gathered through the evaluation process to date highlights that it has many strengths in areas which will lead to a positive social return on investment (no further information provided). -Hospitalisation data (e.g. readmission to hospital within 28 days, delayed discharge) show a positive trend for Inverclyde, but proving causality is not (yet) possible. -The project reports increased skills and confidence in people, increased volunteering, greater satisfaction with quality of life in the neighbourhood amongst project helpers and those receiving acts of kindness and compassion (citizens). Some outputs are evaluated: -A programme to generate improved wellbeing was developed where participants had to self-assess their wellbeing. A pilot project with a group of carers where participants reported improved wellbeing scores, new friendships and feeling more confident. -Generally positive feedback on the self-assessment of wellbeing in pilot projects in different settings. The project mentions key aspects of their applied leadership (development process): -The type of leadership used: leadership that enhances the intrinsic motivation of people and reinforces their fundamental altruism. It helps promote a culture of learning where risk taking is accepted within safe boundaries, and where there's an acceptance that not all innovation will be successful. Diametrically opposite to cultures of blame and fear and bullying. -The functioning of the board (people who develop compassionate Inverclyde): Representation of volunteers is key; strong and decisive chairmanship which enables healthy debate and shared decision-making; establishing sub groups to execute made decisions, etc.
Hume	The project mentions some evaluated outputs:[76] -Practical skills for working with end-of-life issues were developed for many of the community members. -Sustainability of the community capacity in community members participating in the project has yet to be demonstrated long term; but the reflective thinking, equitable participation and shared knowledge emerging through the local projects are themselves marks of a sustainable community. -Many activities have developed skills in community members that contribute substantially to their local community's capacity to care for those in their midst living with loss and grief, or life-threatening illness. The project mentions some evaluated outcomes:[76,77] -Palliative care volunteer services in the Hume Region provided 14.8% of all patient contacts and 19.5% of all direct client contacts which is higher than the state average. -The leading team had 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 (not mentioned how this was evaluated). -Understanding of end-of-life issues in general and palliative care in particular was enhanced for community members who might otherwise not have come into contact with these resources. The project mentions lessons learned from their development process:[76] -Palliative care volunteer training can be delivered in local areas by local health professionals if a supportive structure is provided.

	-It takes time, effort and skill to effectively lead, manage and coordinate a palliative care volunteer service at the local, sub-regional and regional level and this should be financially recognised. -Education and training information on a public health approach to palliative care needs to be presented to health professionals and staff in an accessible way. -Community based projects sometimes asked for seed funding that otherwise would not have been readily accessible at the local level. Access to other traditional funding sources could then be supported by the identified needs and partnerships formed from this starting point. -Projects seeking smaller funding amounts were achievable for the applicant and community partnerships. The larger the project the more time consuming and unwieldy it became to manage. -The simplification of funding guidelines enabled community groups to be motivated to engage in an activity as they achieved the criteria with a minimum of red-tape. -The Big 7 Checklist was a significant and simple tool used to mentor and guide the development of health promoting palliative care activities, educate around a public health approach and promote a diversity of partnerships between community groups and the local specialist palliative care service and palliative care volunteer service. -How the objectives of the project are achieved is described in detail through 10 different strategies.
The Hills	Nothing mentioned.
NNPC	The projects mentions one evaluated output:[31] -The project expands into 'non-traditional' areas in palliative care (e.g., palliative care for patients with non-malignant conditions, including chronic psychiatric disorders). The project mentions one evaluated outcome:[31,39] -In Malappuram (district in Kerala), coverage of palliative and long-term care rose to 70% in 2 years' time. Within less than five years, the NNPC initiatives have resulted in the establishment of 68 community-based palliative care initiatives in northern and mid-Kerala, covering a population of more than twelve million; an estimated coverage of more than 70% in palliative care and long-term care in the region compared to a national average of around 1%. -Wayanad, Kozhikode and Thrissur (districts in Kerala) show the same steep upward trend in coverage.
WECCC	Nothing mentioned.

Discussion

Main findings

This systematic integrative review identified 22 Area-Based Compassionate Communities initiatives and found considerable variability in their contextual and developmental characteristics and a lack of information on their evaluations. Area-Based Compassionate Communities are located in all continents, but most are in Europe and South America. There were differences, among others, in geographical demarcation, number of inhabitants targeted, sources of funding and in the specific social actions that they developed. However, all Area-Based Compassionate Communities were initiated to address similar gaps in the healthcare system or challenges in society and all aimed to improve public health. All Area-Based Compassionate Communities focused on multiple action areas of the Ottawa Charter. Some form of evaluation was reported for only a few initiatives and studies rarely evaluated on whether the original aims were actually met.

Commonalities and differences

Our study shows that there is substantial variability in the contextual characteristics of Area-Based Compassionate Communities, but that they also share some important similarities. Although we found Area-Based Compassionate Communities existing all around the world, they were generally developed in the last decade, and are thus a very recent form of social innovation in healthcare and palliative care. The main reason for initiating an Area-Based Compassionate Community was to address existing gaps in the healthcare system or societal challenges such as challenges related to an ageing population. They also all aimed to improve public health and more specifically to achieve better population end-of-life care. This is not surprising since healthcare systems around the world are facing similar challenges in the provision of palliative care to their populations.[52–55] Literature and studies have demonstrated that health provision through community engagement together with professional healthcare services can be successful in alleviating stressed healthcare systems.[1,2,4,56–58] The majority of Area-Based Compassionate Communities were initiated by healthcare oriented governmental or non-governmental organisations (e.g. palliative care service, hospital, local health and wellbeing service), which is not surprising because of the movement's focus on palliative care. All Area-Based Compassionate Communities focused on multiple pillars of the Ottawa Charter and although similarities were found (e.g. involvement of schools, local organisations, the media, politicians), the specificities of local actions differed greatly between initiatives. Given the variability in the characteristics of Area-Based Compassionate Communities and the movement's relatively embryonic existence, it is unclear which specific characteristics pave the way to successful Area-Based Compassionate Communities.

For most, but not all, Area-Based Compassionate Communities, some information about the development process was provided, but never extensively. However, a commonality in the development process seems to be that the initiators seek support for the project from policy makers who publicly endorse the project and whose influence can be used to allocate funding. Furthermore, attaining political support is likely to facilitate the creation of networks i.e. political, professional, social or cultural, which would otherwise be more difficult to establish. This finding does not come as a surprise as many of the aims formulated by Area-Based Compassionate Communities (e.g. better end-of-life care for the population, the creation of an integrated healthcare system) imply the need for political support, something community development projects can hardly do without.[59,60] The fact that most Area-Based Compassionate Communities have been initiated only in the last decade may also explain why we found the involvement of policy makers to be a recurrent element: the first years of development are generally characterised by searching for support and funding, establishing a leading coalition for the project and defining its long-term aims.

We found strengthening social networks to be a recurring community engagement strategy in multiple Area-Based Compassionate Communities. Studies have shown that having adequate social networks is strongly related to an increase in quality of life, that the use of these networks may have more positive outcomes than the use of professional services,[61] and that having adequate social networks may lead to a reduction in health service costs.[62] Since Kellehear (2005) highlighted that the potential for improved health provision should be sought in the community, it is not surprising to see Area-Based Compassionate Community developers putting this into practice.[6] The current COVID-19 pandemic challenges activating and expanding such social networks due to many countries applying social restrictions. Finding a balance between adhering to local pandemic regulations, which often limit social contacts, while at the same time broadening these networks is a difficult task but examples in literature exist (e.g. remote befriending using technology).[63–65]

Thorough evaluations are lacking

This review shows that there is a lack of scientific evaluation of Area-Based Compassionate Communities. Only a minority of existing Area-Based Compassionate Communities have been formally evaluated, possibly because initiators may not always have an interest in research but focus mainly on the process of development of the initiative. For those that have undergone some form of evaluation, the conclusions about their impacts have mainly been positive, but the domains and outcomes evaluated often did not match the original individual aims. Evaluators often seem to opt for an evaluation of the short-term effects of specific social actions rather than the long-term impacts of the Area-Based Compassionate Communities as a whole. It may also be that the aims of the initiative were not formulated specifically enough, which complicates the evaluation of whether desired outcomes have been achieved. Furthermore, the methodological background provided on how evaluations were performed is insufficient. The absence of rigorous evaluation methods for these types of new public health interventions further hampers evaluation studies and the assessment of the success of the individual initiative. Our findings confirm the gaps that exist in proving the efficiency of specific community engagement programmes in realising better health outcomes or behaviours.[10,56,58]

Regarding future evaluations, we argue that there is a strong need for transparent process and outcome evaluations in order to better understand which elements are crucial in the development of Area-Based Compassionate Communities in order to realise better health outcomes or behaviours and to demonstrate whether they achieve the impacts to which they aspire. We would promote the use of mixed-method study designs in compassionate city/community evaluations in which a survey is used in combination with qualitative data collection techniques to capture societal and/or cultural changes over a period of time. Interviews, observations and focus groups may be useful for future process evaluations but researchers should consider non-traditional qualitative data collection techniques (e.g. photovoice or the Most Significant Change technique) which may provide rich and diverse data on such a complex intervention.[66,67] The researchers of this review are currently working on a research protocol for the evaluation of an Area-Based Compassionate Community which they aim to publish in the future.

Implications of findings for policy and practice

Although progress in end-of-life care provision differs greatly between and within countries and regions, we have shown that every initiative stemmed from individual priorities and needs and could therefore benefit from the expansion or initiation of palliative care delivery. This conclusion, together with the finding that some actions in Area-Based Compassionate Communities were positively evaluated, can motivate policy makers to invest in Area-Based Compassionate Communities. Emphasis should be put on training healthcare workers in the adequate provision of palliative care who then operate together with an informed community which acknowledges its own potential to decrease the burden on local healthcare systems.

Strengths and limitations

This review was the first to compare Area-Based Compassionate Communities in terms of their characteristics, development and evaluation. By applying a combination of peer reviewed studies, grey literature and the snowball method we were able to provide in-depth information about the initiatives. However, this review also has some limitations. No projects and publications on Area-Based Compassionate Communities were found in low-income countries, where palliative and other healthcare services are often un- or under-developed and health inequality is high.[68–70] This finding however may also be attributed to language and publication biases.[71] This review was limited to publications in English while many more Area-Based Compassionate Communities may exist of which no information has ever been published in peer reviewed journals in English. Furthermore, several authors of included articles could not be contacted, making it likely that we missed some of the existing grey literature. Although we applied a systematic methodology, the presence of data collection bias as well as interpretation bias can not be ignored.

A recently published review by Librada et al. (2020) also described a number of Area-Based Compassionate Communities but had a clear focus on their implementation models. Our review, through its use of an operational definition of an Area-Based Compassionate Community, is more complete and more specifically focused on Area-Based Compassionate Communities and their characteristics.[10] Because we made use of grey literature we were able to add additional information which proved useful especially in finding examples focusing on the pillars of the Ottawa Charter. Lastly, we provided in-depth information on the evaluations by looking at what is evaluated in specific Area-Based Compassionate Communities.

What this review adds/conclusion

While the concept of Area-Based Compassionate Communities is gaining momentum as a new paradigm for the creation of palliative care capacity across society, this review showed that only a handful of initiatives have been described in the last decade and only a minority underwent some form of evaluation. Because of the scarce description of existing initiatives in the literature, it remains unclear which elements are essential to success and which, if any, model yields the best results. The lack of formal evaluations of the proclaimed health benefits of Area-Based Compassionate Communities indicates a pressing need for rigorous research about ongoing and future initiatives to assess whether these benefits are realised. These evaluations can be used to inform and convince various actors and organisations to support the development of Area-Based Compassionate Communities.

Declarations

Authorship

All authors contributed to the concept of this article, the study design and the analysis and interpretation of the data. BQ, LDEE and TS performed study selection. BQ and LDEE performed data extraction. BQ and TS drafted this article with the other authors revised and eventually approved the final version.

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Conflict of interest

The authors declare that there is no conflict of interest.

Ethics and consent

Not applicable.

Data management sharing

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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CHAPTER II

DISCOMFORT WITH SUFFERING AND DYING, A CROSS-SECTIONAL SURVEY OF THE GENERAL PUBLIC.

This chapter is based on:

Quintiens B[1,2], Smets T[1], Chambaere K[1,2], Van Den Block L[1], Deliens L[1,2], Sallnow L[1,3,4], Cohen J[1,2]. Discomfort With Suffering and Dying, a Cross-Sectional Survey of the General Public. Journal of Pain and Symptom Management. 2023 Nov;66(5):529-540.e6.

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Abstract

Background: Death and the process of dying have become increasingly medicalised and professionalised. The associated cultural estrangement from death may affect how comfortable we feel about death and dying. This study examines the general public's discomfort with another person's suffering and dying, and whether these feelings are associated with specific personal characteristics or experiences.

Methods: Cross-sectional survey in a random sample of people aged 16 or older in four municipalities in Flanders, Belgium (N=4,400). We used the self-developed construct *Discomfort with someone's suffering and dying*. A directed acyclic graph guided the development of a multivariable regression model which explored the effect of different variables on the main outcome measure.

Results: 2,008 completed questionnaires were returned (response rate: 45.6%). Average discomfort with someone's suffering and dying was 3.74 (SD = 0.89). Being female or currently mourning a loss was associated with more discomfort. Not being religious, having better knowledge about palliative care, having worked in healthcare, having been with someone else at the time of their death and having been culturally exposed to death and dying were associated with less discomfort.

Conclusions: A considerable level of discomfort is present within the general public about the suffering and dying of others and this may increase social stigma and a tendency to avoid seriously ill people and their social surroundings. Our findings suggest that interventions may help shift this societal discomfort if they incorporate a focus on cultural and experiential exposure and increasing knowledge about palliative care.

Background

Death and the process of dying have become increasingly medicalised and professionalised over recent decades, as is evidenced by the intensified use of healthcare resources and the reliance on professional care services prior to death.[1–5] As a result, societies around the world are becoming largely estranged from death as a social event, to the extent that it is often considered unfamiliar and a failure of healthcare systems, as opposed to the last inevitable step in our life cycle.[5–7] In high-income or urban settings, many older people are cared for in nursing or care homes, people are hospitalised when unwell and the majority of deaths occur in institutions.[8,9] This professionally integrated social management of illness, care and death often takes place hidden from public view, further contributing to our cultural attitudes towards these topics and, therefore, to shaping how comfortable populations feel about death and dying. Considering that a person's health is influenced and shaped by cultural and social norms, the contemporary care delivery model — centralised around professionalised care —needs to align care delivery with societal health evolutions.[10] New public health approaches to palliative care aim to address this by accepting death as a natural part of life, health and wellbeing and integral to the community in which it takes place.[11] Addressing how comfortable populations feel about suffering and dying could be part of the action domains of public health policies aiming to change how we approach serious illness, caring and dying as a society.

When people feel uncomfortable about death and dying, feelings of fear and anxiety may be evoked.[7,12] Becker (1973) stated that a person's self-awareness about their mortality prompts a desire to live which in turn can trigger fear and anxiety.[13] Fear of dying in itself is not abnormal and serves as self-preservation, preventing us from crossing a busy highway, for instance. How uncomfortable we feel about suffering and death is not only expressed with regard to our own mortality though but can also be reflected in feelings about the dying of others. These feelings may become detrimental when people feel uncomfortable around seriously ill or dying people as this may lead to an increase in social stigma and the avoidance of these people or their close social surroundings.[6,14–20] However, when people feel more comfortable about the dying of others, seriously ill people may feel more socially connected, which can positively effect their wellbeing.[21] Moreover, being around seriously ill and dying people or being exposed to these topics through other means (e.g., by watching someone giving testimony about their illness), could open the door towards building new knowledge, developing skills for caregiving, or changing attitudes towards these topics.[22–26] A number of initiatives have been described in the literature which aim to foster the potential of communities through the establishment of community-based mutual support models around serious illness, death, dying and loss. However, the impact of these initiatives remains largely understudied.[27,28] Nonetheless, communities that feel more comfortable about death and dying could leverage more community engagement in health provision, which has shown potential in unburdening healthcare professionals and cutting healthcare expenditure.[29–34]

Although death anxiety has been studied in varying populations with differing results, existing studies largely focus on feelings of fear about one's own death and conclude that this is generally low to moderate.[6,35–39] Until now, very few studies have considered people's discomfort with the suffering or dying of others and those that did exclusively focus on healthcare professionals' perceptions when caring for a dying person.[40–42] No population-based studies have been performed on this topic nor has it been explored if factors such as personal characteristics or experiences with care, illness and death are associated with people's discomfort with the suffering and dying of others.

This study aims to examine the discomfort of the general public with the suffering and dying of others and whether these feelings are associated with personal characteristics or experiences such as having worked in healthcare or having had a family care experience. Specific research questions are:

(1) how uncomfortable do people feel about the suffering and dying of others?

(2) are personal experiences with care, illness and death, and demographic characteristics and religiousness, associated with how uncomfortable people feel?

Methods

Design, participants and setting

We conducted a cross-sectional survey in a random sample of people aged 16 or older in four municipalities in Flanders, Belgium: Bruges (urban centre city of 118,000 inhabitants), Herzele (semi-urbanised municipality of 18,500 inhabitants), Sint-Niklaas (urban centre city of 80,000 inhabitants) and Gavere (semi-urbanised municipality of 12,000 inhabitants). The surveys were part of a baseline measurement (i.e. pre-intervention) in which the municipalities of Bruges and Herzele are undergoing a public health intervention around the topics of serious illness, death, dying and bereavement. The impact of these interventions on people's discomfort with the suffering and dying of others is being explored in separate papers, and is not the aim of this study. To be able to evaluate the interventions in a later stadium and to minimise bias when attributing the observed changes to the interventions, it was decided to also distribute the survey in two control municipalities of which each is comparable to one of the intervention cities concerning their urbanisation grade.[43] Since people in Flanders mostly live in semi-urbanised municipalities or urban cities, the selected municipalities are representative for the majority of the Flemish population. Results from this baseline measurement give insight into the assets and needs of the local population which then help to create a bespoke approach. More information on this intervention can be found in the published study protocol.[44] CROSS guidelines were followed to report on this survey study.[45]

Sampling

In every municipality, a civil servant who had access to the population register drew a random sample of the general population using simple random sampling. In Bruges, we disproportionately oversampled family carers by a factor of six because we expected that the public health intervention, with its focus on serious illness, death, dying and bereavement, might specifically target them as a group. Hence, we aimed at better statistical power for this subgroup in view of improved generalisability of findings. In Bruges (and not in the other municipalities), family carers , defined as anyone caring for someone who is heavily care dependent, are registered for them to receive a municipal financial compensation. Analysing the sample from Bruges, we found a deviation from the population's age distribution and therefore weighted to correct this imbalance. Weighting factors ranging between 0.58 and 2.42 were calculated using the a priori available demographic data to correct for sampling error, the oversampling of family carers and for nonresponse by age.[46] Within each municipality we aimed for a 95% confidence interval with a width of +/-5%, with alpha set at 0.05 to estimate proportions (with the most conservative estimation for heterogeneity at 50%). Based on literature and by applying a conservative approach, a response rate of 35% was anticipated.[47] This led to an estimated required initial sample size of 1,100 potential participants in each municipality (4,400 across all four).

Data collection procedure

A civil servant in each of the municipalities, supported by a data collector from the research team, sent out the questionnaire and accompanying introduction letters to all individuals in the sample in the first semester of 2021. Measures to improve the response rate as suggested in Dillman's total design method were implemented.[48] This included a follow-up mailing procedure with up to three reminder mailings. Respondents had the option to fill out the questionnaire on paper and mail it using an included pre-paid envelope or online using Limesurvey, a secure open-source survey tool. Participants were not offered incentives to participate. Completed questionnaires were sent directly to the researcher who communicated the respondent's unique, pseudonymised number to the data collector, so as to prevent these respondents erroneously receiving a reminder. Through this mailing procedure, responses to the questionnaires could at no point be linked to the individual. All answers on paper were entered into Limesurvey.

Questionnaire and measures

All measures studied in this questionnaire relate to serious illness, care, death, loss or grief and can be found in the published study protocol.[44] Some of the measures used in this survey study are based on background questions from the now validated Death Literacy Index which had not been published when we designed this survey. Through contact with researchers from the Death Literacy Index, we obtained input into the development of several of our used measures. For some measures in the questionnaire, we asked respondents to reflect on their situation prior to the COVID-19 pandemic. Reflecting on their then current situation would have influenced results pertaining to measures about social networks or community participation.

Main outcome measure

We developed a non-validated Dutch adaptation based on the subconcept *Dying of others* from the Revised Collett-Lester Fear of Death Scale.[50] It is a well-known scale with which to assess people's fear of death and dying, where dying is regarded as the degenerative process preceding a predictable death. We changed the original question *"How disturbed or made anxious are you by the following aspects"* to *"How uncomfortable would you feel in the following situations"* after discussion with a literacy service which argued that the inclusion of two concepts within one question could lead to confusion. Additionally, we changed the direction of the response categories as per recommendation in Likert scale development and to create consistency among all other scales used in this questionnaire.[51] We altered the sixth item in this scale from *"Not knowing what to do about your grief at losing the person when you are with him/her"* to *"You are with someone who is dying and this person is grieving"*. We did this since its original phrasing concerns the respondent's emotional suffering rather than the suffering and dying of someone else. The *Dying of others* scale comprises eight items which are scored on a five point Likert scale ranging from (1) not uncomfortable to (5) very uncomfortable, hence higher scores indicate higher levels of discomfort. Total scores range between a minimum of 8 and a maximum of 40. Our alterations to the original *Dying of others* scale have led to a new scale which we named *Discomfort with someone's suffering and dying*, hence the original scale's proofs of validity are not applicable to the operationalisation of our scale.

Personal experience measures

Personal experiences were measured via different constructs. The measure *Cultural exposure to death and dying* was composed of eight items coming from two questionnaires. As a response to the cultural estrangement many societies experience with death and dying, public health initiatives aim to create visibility through cultural activities and integrate the end-of-life into everyday life. This can be achieved through various means, such as visiting an art exhibition on death or witnessing a testimony. Additionally, we registered whether respondents had a family care experience with care, illness and death, had worked in healthcare, had experience as a volunteer around serious illness, death, dying or grief in the year preceding the COVID-19 pandemic initiation and whether they had been with someone at the time of their death. The exact composition of these measures can be found in Appendix 1.

Demographic characteristics, religiousness and other measures

The following personal characteristics were surveyed: Age, sex, highest degree of education, working situation, whether respondents were volunteers, their religious orientation, whether they live in a long-term care residence (nursing home, service flat, institution), whether they have a chronic illness, and whether they considered themselves to be mourning someone who had died. A number of variables, considered as mediators or moderators for this study, were additionally measured: knowledge of palliative care using a validated Dutch translation of the *Palliative Care Knowledge Scale*;[53] subjective estimation of palliative care knowledge (*self-estimated palliative care knowledge)* using a self-developed item. The exact composition of both palliative care knowledge scales can be found in Appendix 1. Lastly, we asked whether they had already undertaken any actions around their own end of life such as having discussed end-of-life preferences or having filled out advance directives.[34]

Translation and testing of the questionnaire

The constructs *Cultural exposure to death and dying* and *Palliative Care Knowledge Scale* were translated following EORTC guidelines.[54] A cognitive testing approach was followed to assess content (face) validity, language and understandability.

Data preparation and data analyses

Missing scores for individual items of the main outcome measure were imputed with the mean score. We calculated both factor scores and average sum scores for the dependent variable *Discomfort with someone's suffering and dying* but, after consultation with a statistician, decided to only use the factor score for the multivariable analysis since that gave a more normal distribution. Prior to performing the factor analysis, we confirmed the subject-to-item ratio which was 247.5.[55] These analyses can be found in Tables 1-3 in Appendix 1. Internal consistency was assessed and showed a reliable factor structure. The independent variables *Cultural exposure to death and dying, Family care experience with care, illness and death, Having worked in healthcare, Experience as a volunteer around serious illness, death, dying or mourning,* and *Being with someone else at the time of their death* are all different types of experiences with care, illness and death. A factor analysis — used to explore if any of the variables could be combined into an underlying variable — identified two different components. We examined the internal consistency of the one component which contained the required minimum of three variables. This showed an unreliable factor structure. Therefore all independent variables are regarded seperately. Variable *Family care experience with care, illness and death* did not have a significant effect on the outcome variable. The analyses can be found in Tables 4-7 and Figures 1-5 in Appendix 1.

Respondents who filled out fewer than six out of eight questions from the main outcome measure *Discomfort with someone's suffering and dying* were withheld from further analysis. This led to the exclusion of 118 cases, leaving 1,890. Figure 1 provides an overview of how the number of questionnaires used for data analysis was obtained. Weighting factors were activated prior to data analyses.

To examine how personal experience measures and the additional measures are associated with people's discomfort with a person's suffering and dying, we performed a bivariate correlation analysis with the factor score of this dependent variable. To inform the construction of the multivariable statistical model and appropriate deconfounding (i.e clearly distinguishing between confounders and mediators) we used a directed acyclic graph to make our assumptions explicit — based on previous findings about death anxiety[6,7,12,37] and plausibility — about the causal relationship between the different variables (Figure 2).[56] Pearson correlation coefficients ($P < 0.05$, one tailed) were then calculated to determine the actual correlations of the relationships specified in the model, which can be found in Appendix 1. Next, we expanded our multivariable regression model by controlling for the effect of confounding variables (step 1), entering the variables that were significantly associated with the dependent variable (step 2) and entering variables identified as possible mediators (step 3).

Ethics

Approval for this study was obtained from the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020

Figure 1: Flowchart of how final number of questionnaires for data analysis was obtained.

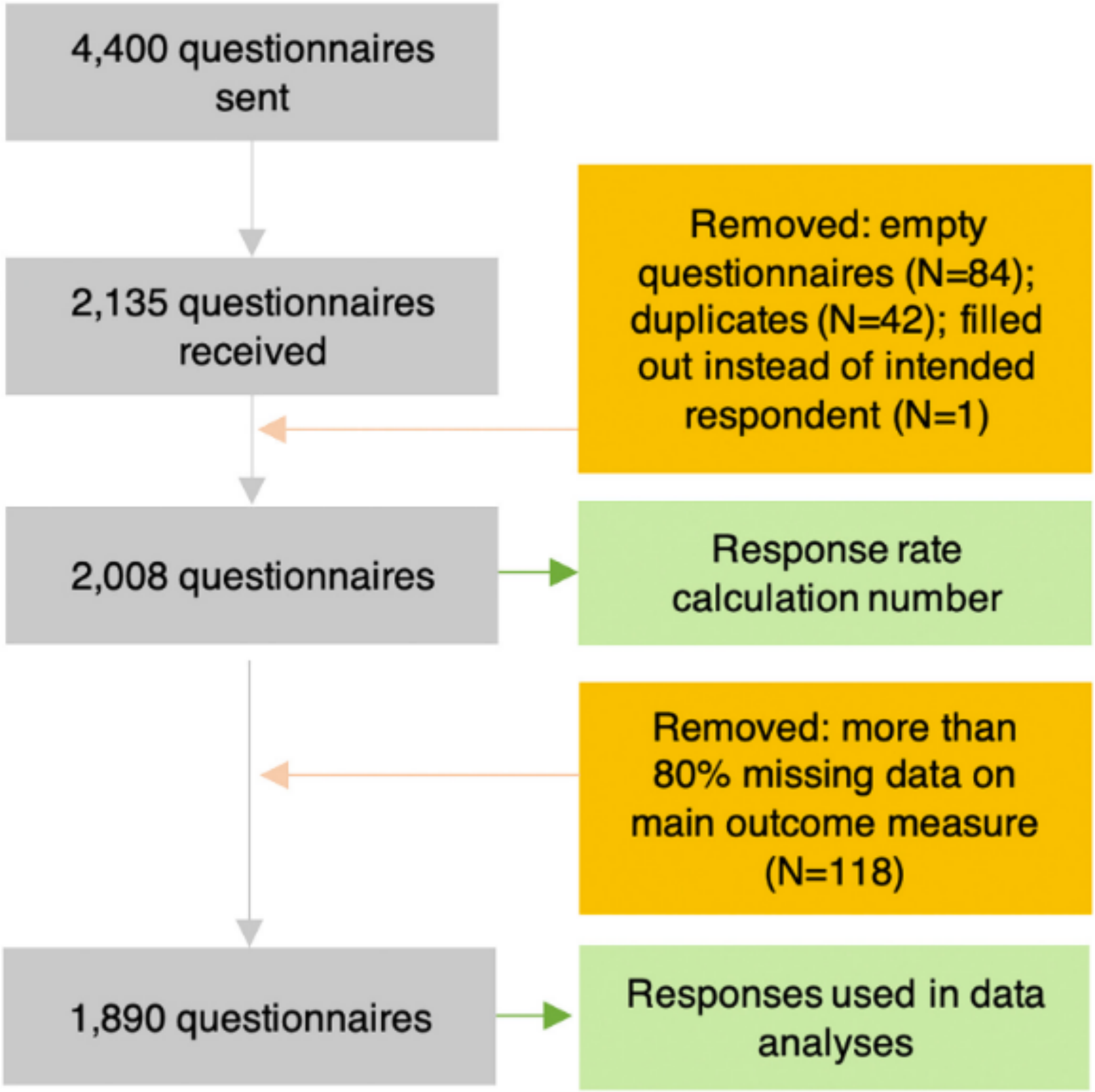
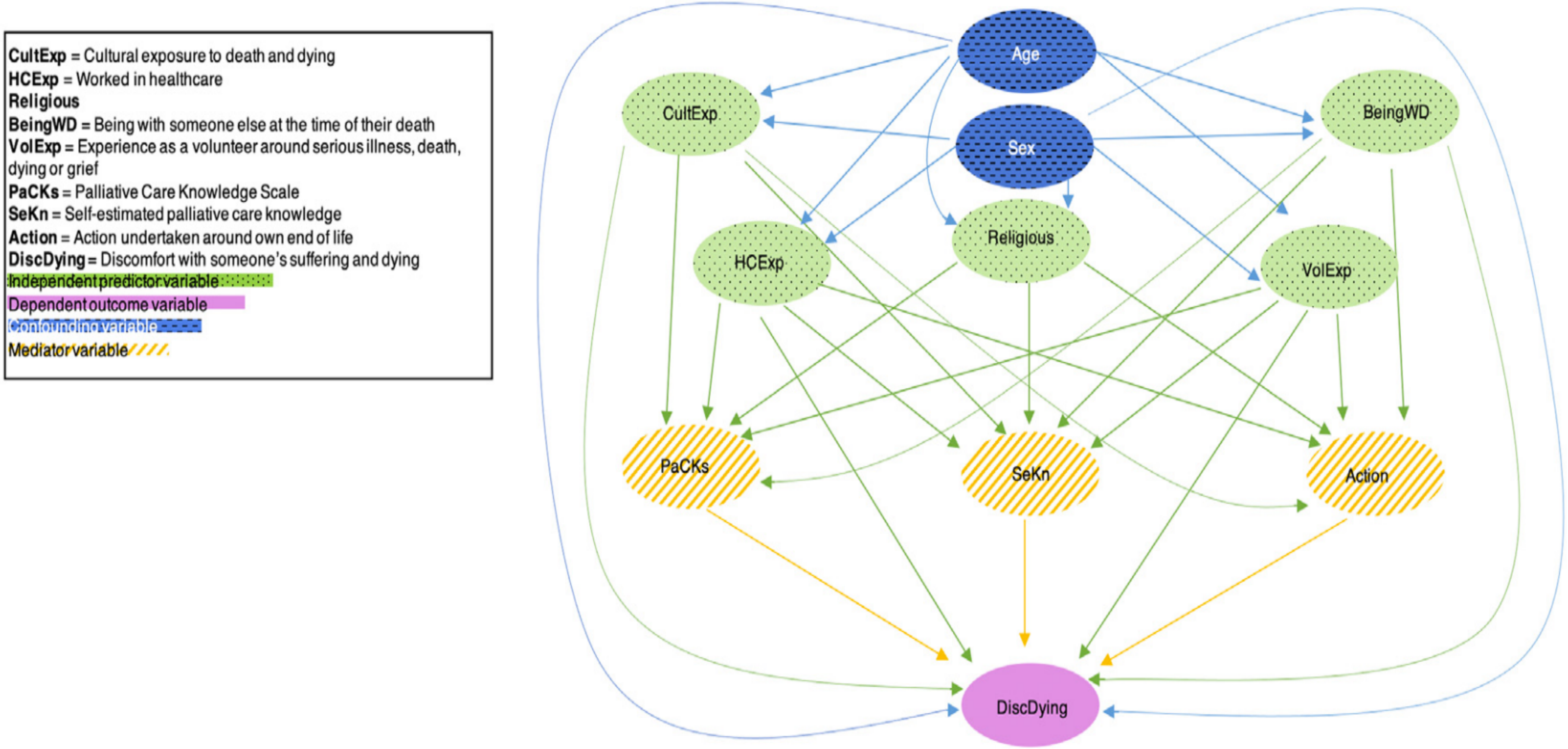


Figure 2: Directed acyclic graph of the hypothesized causal relationships between the predictor . variables and dependent variable "discomfort with someone's suffering and dying."



Results

From the 4,400 questionnaires sent, 2,135 were returned. After removing duplicate questionnaires and questionnaires with more than 80% missing data on the main outcome measure, 2,008 questionnaires were considered as valid responses (response rates were 49.7% for Bruges, 44.1% for Sint-Niklaas, 38.3% for Herzele and 42.5% for Gavere).[57]

Characteristics of the study population

38.2% of respondents had a higher education degree, 52.1% were female, 49.3% were employed and 57.6% identified as Catholic; 34.9% had had a family care experience and 65.8% had been exposed to cultural events around death and dying (Table 1).

Table 1: Characteristics of the study population.

Place	**Total**	**Bruges**	**Sint-Niklaas**	**Herzele**	**Gavere**
N = respondents	**N = 2008**	**N = 561**	**N = 515**	**N = 441**	**N = 491**
1. Demographic characteristics					
Age	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
16-24	178 (9)	65 (11.8)	40 (7.9)	44 (10.1)	29 (6)
25-34	233 (11.7)	77 (13.9)	68 (13.4)	41 (9.4)	47 (9.7)
35-44	257 (13)	72 (13)	68 (13.4)	68 (15.6)	49 (10.1)
45-54	327 (16.5)	84 (15.2)	80 (15.7)	75 (17.2)	88 (18.2)
55-64	378 (19.1)	94 (17.0)	95 (18.7)	79 (18.2)	110 (22.7)
65-74	335 (16.9)	78 (14.1)	81 (15.9)	76 (17.5)	100 (20.7)
>74	273 (13.8)	83 (15)	77 (15.1)	52 (12)	61 (12.6)
Sex					
Female	1034 (52.1)	262 (47.1)	256 (50.3)	235 (53.9)	281 (57.9)
Highest degree of education					
Primary school or lower	200 (10.2)	40 (7.4)	75 (15)	38 (8.8)	47 (9.8)
Secondary school, first 3 years	309 (15.7)	78 (14.1)	83 (16.6)	68 (15.7)	80 (16.6)
Secondary school finished	677 (34.5)	186 (33.9)	168 (33.6)	167 (38.6)	156 (32.4)
College	488 (24.9)	152 (27.7)	108 (21.6)	111 (25.6)	117 (24.3)

University or higher	262 (13.3)	87 (15.8)	56 (11.2)	45 (10.4)	74 (15.4)
Other	27 (1.4)	6 (1.1)	10 (2)	4 (0.9)	7 (1.5)
Working situation					
Student	137 (7)	44 (8.1)	31 (6.1)	35 (8.1)	27 (5.6)
Unemployed	40 (2.1)	17 (3.2)	16 (3.2)	3 (0.7)	4 (0.8)
On (work) disability	88 (4.4)	23 (4.1)	32 (6.3)	22 (5.1)	11 (2.3)
Working	972 (49.3)	276 (50.2)	222 (43.8)	224 (51.7)	250 (51.8)
Retired	658 (33.4)	173 (31.5)	176 (34.7)	138 (31.9)	171 (35.4)
Homemaker	66 (3.4)	14 (2.6)	26 (5.1)	9 (2.1)	17 (3.5)
Other	11 (0.7)	2 (0.3)	4 (0.8)	2 (0.5)	3 (0.6)
Did you move in the last 10 years?					
Yes	693 (36.4)	234 (44.4)	209 (43)	120 (28.3)	130 (28)
I am a volunteer					
Yes	379 (19.1)	117 (21)	83 (16.5)	73 (16.7)	106 (21.7)
2. Religious orientation					
Catholic	1125 (57.6)	262 (48.0)	272 (53.9)	294 (69.0)	297 (62.5)
Islam	92 (4.7)	6 (1.0)	77 (15.2)	5 (1.2)	4 (0.8)
Secular Humanism	83 (4.3)	38 (7.0)	18 (3.6)	12 (2.8)	15 (3.2)
Atheism	598 (30.6)	215 (39.3)	126 (25.0)	106 (24.9)	151 (31.8)
Other religion	40 (2.0)	19 (3.4)	8 (1.6)	6 (1.4)	7 (1.5)
Other non-religious	16 (0.8)	8 (1.4)	4 (0.8)	3 (0.7)	1 (0.2)
3. Personal experiences with care, illness and death					
I take care of a person in need as a family carer	371 (18.5)	108 (19.3)	91 (17.7)	100 (22.7)	72 (14.7)
I took care of a person in need as a family carer in the past	420 (20.9)	106 (18.9)	107 (20.8)	107 (24.3)	100 (20.4)
I have a family care experience	700 (34.9)	185 (33)	182 (35.3)	179 (40.6)	154 (31.4)
I have undertaken volunteer tasks around serious illness, death, dying or grief in the past year before the COVID pandemic	165 (8.3)	58 (10.4)	40 (7.9)	29 (6.6)	38 (7.8)
I have worked in healthcare	278 (13.8)	92 (16.4)	61 (11.8)	55 (12.5)	70 (14.3)
I live in a long-term care residence (nursing home, service flat, institution…)	17 (0.8)	6 (1)	5 (1)	0 (0)	6 (1.2)
I have a chronic illness	220 (11)	72 (12.9)	70 (13.6)	44 (10)	34 (6.9)
I mourn for someone I have lost	441 (22)	135 (24.1)	115 (22.3)	102 (23.1)	89 (18.1)
Culturally exposed to death and dying	1168 (65.8)	358 (70.8)	289 (67.7)	257 (63.1)	264 (60.7)

Discomfort with the suffering and dying of others

Overall, people scored an average of 3.74 (SD = 0.89) on a scale from 1 to 5. People felt most uncomfortable if they had to *watch the person suffer from pain* (4.24; SD =

1.01) and *have to be the one to tell the person that he/she is dying* (4.37; SD = 1.01). They felt least uncomfortable in the situation where they *have the person want to talk about death with them* (2.91, SD = 1.35) (Table 2).

Table 2: Discomfort with someone's suffering and dying.

	Total* **N = 2008**	**Bruges**** **N = 547**	**Sint-Niklaas**** **N = 485**	**Herzele**** **N = 421**	**Gavere**** **N = 468**
	Average sum score (Standard deviation)	Average score*** (Standard deviation)	Average score (Standard deviation)	Average score (Standard deviation)	Average score (Standard deviation)
Discomfort with someone's suffering and dying	3.74 (0.89)	3.68 (0.87)	3.77 (0.90)	3.81 (0.89)	3.73 (0.89)
Being with someone who is dying	3.32 (1.33)	3.25 (1.32)	3.35 (1.35)	3.43 (1.35)	3.26 (1.32)
A dying person wants to talk about death with you	2.91 (1.35)	2.80 (1.31)	2.98 (1.39)	3.00 (1.35)	2.89 (1.36)
Watching a dying person suffer from pain	4.24 (1.01)	4.15 (1.03)	4.29 (0.98)	4.27 (1.03)	4.27 (1.00)
Having to be the one to tell the person that he/she is dying	4.37 (1.01)	4.34 (0.98)	4.38 (1.00)	4.41 (1.04)	4.38 (1.05)
Seeing the physical degeneration of the person's body	3.93 (1.09)	3.85 (1.08)	3.95 (1.09)	3.98 (1.08)	3.96 (1.08)
Being with a person who is dying and grieving	3.92 (1.20)	3.80 (1.21)	3.97 (1.17)	4.00 (1.21)	3.92 (1.21)
Watching the deterioration of the person's mental abilities	3.94 (1.10)	3.91 (1.09)	4.00 (1.08)	4.00 (1.09)	3.88 (1.12)
You realise that you too can someday die in this way	3.53 (1.33)	3.48 (1.32)	3.51 (1.33)	3.61 (1.34)	3.55 (1.32)

*Cases that filled out a minimum of 6 out of 8 items. 5.9% missing values.

**Depending on municipality and item, missing values lay between 5.4% and 10.1%. Missing data are completely at random.

***Values ranging from 1 (not uncomfortable) to 5 (very uncomfortable).

Univariable correlation analysis (Table 3) showed that being female or mourning a loss is associated with feeling more uncomfortable about the dying of others. People felt more comfortable about the suffering and dying of others when they were not religious, when they were volunteers or had volunteered around serious illness, death, dying or grief, had had experience as a family carer or as a healthcare worker, or had already undertaken some action about their own end of life, had been with someone at the time of their death, had been culturally exposed to death and dying, had better knowledge about palliative care or higher self-estimated knowledge of palliative care.

Table 3: Bivariate analysis of variable correlations with discomfort with someone's suffering and dying.

Variable ***(reference category)***	**Discomfort people feel about someone's suffering and dying, 1 tailed* (Pearson correlation**)** *higher R values indicate more discomfort*
Age	R = 0.031 (P = 0.09)
Sex *(Female)*	R = 0.049 (P < 0.05)
Religious *(No)*	R = -0.068 (P < 0.01)
Volunteer *(Yes)*	R = -0.150 (P < 0.001)
Experience as a volunteer around serious illness, death, dying or grief *(Yes)*	R = -0.123 (P < 0.001)
Family care experience with care, illness and death *(Yes)*	R = -0.043 (P < 0.05)
Worked in healthcare *(Yes)*	R = -0.205 (P < 0.001)
Mourning *(Yes)*	R = 0.064 (P < 0.01)
Cultural exposure to death and dying *(Yes)*	R = -0.183 (P < 0.001)
Been with someone at the time of their death *(Yes)*	R = -0.174 (P < 0.001)
Action undertaken around own end of life *(Yes)*	R = -0.121 (P < 0.001)
Palliative Care Knowledge Scale	R = -0.169 (P < 0.001)
Self-estimated palliative care knowledge	R = -0.250 (P < 0.001)

*Significance at P < 0.05 level.

**Pearson correlation coefficient is a parametric test used to measure the degree of correlation between two variables. Values range between 1 and -1, the more a value leans towards 1 or -1, the stronger the correlation.

After controlling for confounders in a hierarchical multivariable linear regression analysis, cultural exposure to death and dying (r = -0.136; P < 0.001), having worked in healthcare (r = -0.162; P < 0.001), having been with someone else at the time of their death (r = -0.107; P < 0.001), having experience as a volunteer around serious illness, death, dying and mourning (r = -0.084; P < 0.001) and not being religious (r = -0.064; P < 0.01) were associated with feeling more comfortable about someone's suffering and dying. When we added the identified mediator variables (i.e.; knowledge of palliative care, self-estimated palliative care knowledge, and having undertaken action around one’s own end of life), the associations became less strong but remained significant for all variables but religiousness (Table 4). Some age groups significantly differed in discomfort when compared using the Mann-Whitney U test, which can be consulted in Appendix 1.

Table 4: Multivariable linear regression analysis of variables associated with people's discomfort with someone's suffering and dying.

	Model 1 **Adjusted $R^2 = 0.002$**		**Model 2*** **Adjusted $R^2 = 0.091$**		**Model 3** **Adjusted $R^2 = 0.116$**	
Independent variable	**Standardised β**	**Significance***	**Standardised β**	**Significance***	**Standardised β**	**Significance***
Age	0.034	P = 0.144	-0.023	P = 0.339	0.001	P = 0.956
Sex *(Female)*	**0.051**	**P < 0.05**	**0.088**	**P < 0.001**	**0.100**	**P < 0.001**
Cultural exposure to death and dying *(Yes)*			**-0.136**	**P < 0.001**	**-0.090**	**P < 0.001**
Worked in healthcare *(Yes)*			**-0.162**	**P < 0.001**	**-0.119**	**P < 0.001**
Being with someone else at the time of their death *(Yes)*			**-0.107**	**P < 0.001**	**-0.093**	**P < 0.001**
Experience as a volunteer around serious illness, death, dying or grief *(Yes)*			**-0.084**	**P < 0.001**	**-0.074**	**P < 0.001**
Religious *(No)*			**-0.065**	**P < 0.01**	-0.037	P = 0.100
Self-estimated palliative care knowledge					**-0.129**	**P < 0.001**
Palliative Care Knowledge Scale					-0.045	P = 0.077
Action undertaken around own end of life *(Yes)*					**-0.070**	**P < 0.01**

*Model 2 presents the total effect size after controlling for confounders but not mediators.

Discussion

This cross-sectional survey study shows that people on average feel somewhat uncomfortable about a person's suffering and dying. People feel most uncomfortable in situations where they have to be the one to tell someone that he or she is dying and where they have to watch the dying person suffer from pain, and least uncomfortable when they need to talk about death with a dying person. People feel more comfortable when they have been culturally exposed to topics around death and dying, worked in healthcare, have been with someone at the time of their death, have had a volunteer experience around serious illness, death, dying or grief, and when they (believe themselves to) have more knowledge about palliative care.

This study has several strengths and limitations. The random samples using full population registers in four purposively selected municipalities makes our findings about people's discomfort with someone's suffering and dying statistically generalisable to the full populations within these municipalities, although possibly not generalisable nationwide or globally due to cultural and social differences in populations. While response rates were satisfactory, some selection bias due to nonresponse cannot be ruled out. The cross-sectional study design, in which outcomes and exposure are investigated coincidently, makes it impossible to examine temporal relations and infer causal associations when studying hypotheses.[58] We used the subscale "dying of others" from the Collett-Lester Fear of Death scale, which has been validated for use in populations. While we had to use a non-validated Dutch adaptation of the instrument, we performed additional cognitive testing of the instrument to ascertain content validity and minimise measurement bias. Based on the insights of our cognitive testing we deliberately chose to refrain from the original formulation of 'anxious and disturbed' because of its negative and directing connotation and opted for the more neutral formulation of 'uncomfortable'. Our obtained results offer valuable insights; however, to enhance the reliability and construct validity of the scale, future research should be conducted. The threatening nature of questions about death and dying may also introduce bias.[6] People may have denied how uncomfortable they really feel or may have refrained from filling out the questionnaire overall due to their high discomfort with death and dying, which would induce bias in our findings.

Our findings on how people feel about the suffering and dying of others deviate somewhat from results in previous research on death anxiety.[6,35–39] We found a larger prevalence of discomfort with someone's suffering and dying in the general public compared with results from death anxiety studies. This may be because of the more neutral formulation of 'uncomfortable' compared to the much stronger formulation of 'anxious or disturbed'. People may feel uncomfortable about death and suffering, but may not necessarily feel anxious or disturbed by it. The concepts of comfortability and anxiety are semantically distinct and not necessarily interconnected; feeling uncomfortable does not unequivocally lead to anxiety. The paucity of literature on discomfort with death explains why we compared our study with literature relating to death anxiety.

A number of personal experiences on cultural, professional and informal levels are associated with lower discomfort with someone's suffering and dying. This corresponds to previous studies which showed that changing attitudes to death and dying through exposure (i.e., experiential learning) is indeed possible.[23,24,59,60] Instilling these feelings of comfort can facilitate the provision of care by lay people, an essential component of good care at the end of life, and can also support overburdened healthcare systems worldwide.[10,61,62] Involving social networks (i.e., family, friends) of people facing an illness early on in the illness trajectory and facilitating their access to information about palliative care may increase awareness about the expected physical or mental decline, thereby decreasing these networks' discomfort with death and dying. Naturally, this can only succeed if realistic information is applied and the inescapabilty of death and the probability of adversity (e.g., increased care dependency) are not avoided.[63] When more social networks take up caring tasks, countries benefit from the economic savings on care expenditure; something difficult to calculate but hard to overestimate.[33,64] For countries to invest in this strategic approach to care delivery may become a necessity due to the growing number of people with complex care needs who live in the community. This may stimulate societies to rethink their traditional service-focused approach to healthcare provision.[2,26]

In addition to personal experiences, we found knowledge about palliative care to be associated with feeling more comfortable about the suffering and dying of others. Increasing people's knowledge about palliative care can be part of a proactive and preventive strategic approach to increasing population health in all societies. Healthcare organisations that provide accessible information can influence people's discomfort about suffering and dying, which contributes to the new public health aim of empowering care in and by the community.[2,65] Additionally, the act of performing informal care has been shown to be an important impetus to the creation of the carer's knowledge, skills and attitudes.[49,66] This approach facilitates people's ability to navigate the local care system and creates opportunities to make informed decisions about their own health and end-of-life care options, thereby minimising preventable harm.

Policy makers and civic administrative institutions, which aim to address current and future societal challenges related to ageing and the increasing presence of people with complex care needs who live in the community, can apply our study findings by making both professional and informal care provision more appealing (e.g., by financially compensating informal carers' lost workdays). Promoting cultural activities around death and dying in collaboration with civic societies is already a valued component in a number of public health interventions which have the explicit or implicit aim to normalise death as part of life.[27,28] Such interventions foster community-based support models which have shown potential in reducing emergency hospital admissions and healthcare expenditure,[32] increasing support networks of those at the end-of-life,[67,68] and increasing death literacy.[34] It can be argued that they provide opportunities for people to access information on death and dying, develop new caregiving skills, or change attitudes and misconceptions on caregiving and illnesses.[22–26] Although religiosity was only moderately associated with people's discomfort, religion has a strong influence on culture and thus cultural activities with a religious component could be considered in religious societies to enhance impact. A retrospective look at discrimination against populations facing Human Immunodeficiency Virus (HIV) or COVID-19 shows that changing people's attitudes about death and dying can have a positive effect on social stigma of seriously ill people and their social surroundings. Concerning future research, we recommend the use of longitudinal studies and quasi-experimental interventions to assess whether decreases in people’s discomfort about the suffering and dying of others can indeed be achieved through increasing experiences, exposure and knowledge building, and whether this ultimately has an effect on patient and care outcomes.

Conclusions

This study shows that people generally feel uncomfortable in situations that revolve around the suffering and dying of others. People feel more comfortable when they have previously been exposed to death and dying (culturally, professionally or in an informal context) or when they have more knowledge about palliative care. A diverse group of stakeholders, both formal and informal, can address people's death and dying avoidance through interventions on cultural, professional and informal levels and thereby change their attitudes towards these topics. This heightened exposure may create more awareness and knowledge about death and dying and lead to decreased social stigma around seriously ill people. Fostering increased comfort about death and dying could eventually aid in normalising support and care delivery by lay people and, as such, increase care by and not exclusively for communities.

Declarations

Ethics approval and consent to participate

Approval for this study was obtained from the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020. A response to the questionnaire was regarded as valid informed consent.

Consent for publication

Not applicable.

Availability of data and materials

All data is backed up and locked with a code on a secured, system encrypted storage server of the Vrije Universiteit Brussel. In accordance with Good Clinical Practice guidelines, electronic data will be stored for 15 years. The questionnaires on paper will be stored for five years. All data are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All listed authors contributed to this paper and gave permission for publication.

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Appendix 1

Calculation of sum and factor scores of main outcome measure: Discomfort with someone's suffering and dying

1.A. Calculation of sum score

- For every case we made a sum score of all eight items out of which the main outcome measure existed. This resulted in a total score ranging between 8 and 40.

1.B Factor analysis of the main outcome variable

- We present the Dutch translation of each item with the corresponding original English formulation in Italic.
- Missing scores were replaced with the mean score and we used Varimax rotation
- Calculation of subject to item ratio: 1980/8 = 247.5

Table 1: KMO and Bartlett's Test of sphericity of the main outcome measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.893
Bartlett's Test of Sphericity	Approx. Chi-Square	7462.67
	Degrees of freedom	28
	Significance	<0.001

- Assessment of internal consistency

Table 2: Internal consistency assessment of the main outcome measure

Cronbach's alpha	**N of items**
0.877	8

- Factor analysis

Table 3: Factor analysis of the items of the main outcome measure

Item	Component 1
U bent bij iemand die gaat sterven en die heeft verdriet. *Being with someone who is dying and who is grieving.*	0.840
U ziet iemand die gaat sterven lichamelijk achteruitgaan. *Seeing the physical degeneration of the person's body.*	0.832
U ziet iemand die gaat sterven mentaal achteruitgaan. *Watching the deterioration of the person's mental abilities.*	0.827
U bent bij iemand die aan het sterven is. *Being with someone who is dying.*	0.724
U moet aan iemand vertellen dat die gaat sterven. *Having to be the one to tell the person that he/she is dying.*	0.723
U ziet een stervende persoon pijn lijden. *Watching a dying person suffer from pain.*	0.723
Een persoon die gaat sterven, wil met u praten over de dood. *A dying person wants to talk about death with you.*	0.671
U beseft dat ook u ooit kan sterven op deze manier. *You realise that you too can someday die in this way.*	0.646

Factor analysis of the independent variables which are different types of exposures to sickness, death and dying to see if any overarching concept can be identified

- Independent variables are: Cultural exposure to death and dying, Professional experience with care, illness and death, Being with someone else at the time of their death and Family care experience with care, illness and death, Experience as a volunteer around serious illness, death, dying or mourning

Table 4: KMO and Bartlett's Test of sphericity of the main outcome measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.573
Bartlett's Test of Sphericity	Approx. Chi-Square	388.440
	Degrees of freedom	10
	Significance	<0.001

Table 5: Component matrix

	Component	
	1	**2**
Cultural exposure to death and dying	0.537	-0.312
Professional experience with care, illness and death	0.590	-0.559
Being with someone else at the time of their death	0.683	0.008
Family care experience with care, illness and death	0.426	0.717
Experience as a volunteer around serious illness, death, dying or mourning	0.511	0.364

- Reliability analysis of variables in Component 1

Table 6: Internal consistency assessment of the main outcome measure

Cronbach's alpha	**N of items**
0.420	4

- Unreliable factor structure, variables regarded independently
- Component 2 does not have the minimum requirement of 3 variables
- Multivariable regression analysis of independent variables' effect on outcome measure

Table 8: Effect of independent variables on main outcome measure

Model		Unstandardised coefficients		Standardised coefficients Beta	t	Significance
		B	Std Error			
1	(Constant)	-.248	.099		-2.516	.012
	Age	.002	.001	.034	1.462	.144
	Sex	.102	.046	.051	2.211	.027
2	(Constant)	.028	.106		.267	.789
	Age	-.001	.001	-.017	-.697	.486
	Sex	.179	.045	.090	3.958	<.001
	Professional experience with care, illness and death	-.465	.067	-.163	-6.918	<.001
	Being with someone else at the time of their death	-.295	.066	-.105	-4.452	<.001
	Cultural exposure to death and dying	-.287	.050	-.135	-5.725	<.001
	Family care experience with care, illness and death	-.035	.050	-.017	-.694	.487
	Religious	.136	.048	.065	2.843	.005
	Experience as a volunteer around serious illness, death, dying or mourning	-.297	.082	-.082	-3.616	<.001

- The variable Family care experience with care, illness and death did not have a significant effect on the outcome measure in a multivariable regression analysis which is why it was not withheld.

Main outcome measure: Discomfort with someone's suffering and dying

The original question "How disturbed or made anxious are you by the following aspects of death and dying" was translated to "How uncomfortable would you feel in the following situations" *(in Dutch: Hoe oncomfortabel zou u zich voelen in de volgende situaties)*.

Personal experience measures

Cultural exposure to death and dying

(1) I have read or discussed a book on death, dying or bereavement; (2) I have read an autobiographical account of a person's dying or bereavement; (3) I have learnt about end of life issues through school (including death, dying and grief); (4) I have participated in community events or activities related to death or dying; (5) I have seen an art exhibition which has featured works about dying, death or bereavement; (6) I have attended a play or film which deeply explored dying, death or bereavement, (7) I have had a conversation with a dying person about their death.[69] The eighth question was derived from a question from the subconcept *Participation in the local community* from the Social Capital survey[70]: How many events/activities have you attended in your city in the year preceding the COVID-crisis which relate to the themes serious illness, death, dying or mourning (e.g., art exhibition, a play, film, a testimony). The answers to all eight questions were combined and binary coded for every respondent to: (0) no cultural exposure to death and dying and (1) cultural exposure to death and dying.

Family care experience with care, illness and death

(1) Do you take up a caring task for a person in need (i.e., family carer); (2) Did you take up a caring task for a person in need (i.e., family carer)

Having worked in healthcare

(1) Did you work in a healthcare domain (now or in the past)

Experience as a volunteer around serious illness, death, dying or mourning

(1) How often did you perform volunteering tasks for an organisation focused around serious illness, death, dying or mourning in the year preceding the COVID-19 pandemic?

Being with someone else at the time of their death

(1) I have kept someone company who is near death; (2) I have witnessed the death of another person; (3) I have spent time with a person after their death; (4) I have helped care for a dead body. Results were recoded to (0) has not been with dead or dying people and (1) has been with dead or dying people.

Palliative care knowledge scales

Palliative Care Knowledge Scale (PaCKS)

- We present the Dutch translation of each item with the corresponding original English formulation in Italic.

Palliatieve zorg heeft onder meer tot doel psychologische problemen aan te pakken die ontstaan bij een ernstige ziekte	One goal of palliative care is to address any psychological issues brought up by serious illness
Stress ten gevolge van een ernstige ziekte kan aangepakt worden door palliatieve zorg	Stress from serious illness can be addressed by palliative care
Palliatieve zorg kan mensen helpen om de bijwerkingen van hun medische behandelingen onder controle te krijgen	Palliative care can help people manage the side effects of their medical treatments
Wanneer mensen palliatieve zorg krijgen, moeten ze hun andere dokters opgeven	When people receive palliative care, they must give up their other doctors
Palliatieve zorg is uitsluitend voor mensen die in de laatste zes maanden van hun leven zijn	Palliative care is exclusively for people who are in the last six months of life
Palliatieve zorg is specifiek voor mensen met kanker	Palliative care is specifically for people with cancer
Mensen moeten in het ziekenhuis zijn om palliatieve zorg te krijgen	People must be in the hospital to receive palliative care
Palliatieve zorg is specifiek bedoeld voor oudere volwassenen	Palliative care is designed specifically for older adults
Palliatieve zorg is een teambenadering van zorg	Palliative care is a team-based approach to care
Palliatieve zorg heeft onder meer tot doel mensen te helpen hun behandelingsopties beter te begrijpen	One goal of palliative care is to help people better understand their treatment options
Palliatieve zorg stimuleert mensen om de behandelingen gericht op de genezing van hun ziekte stop te zetten	Palliative care encourages people to stop treatments aimed at curing their illness

Palliatieve zorg heeft onder meer tot doel mensen beter in staat te stellen om deel te nemen aan dagelijkse activiteiten	One goal of palliative care is to improve a person's ability to participate in daily activities
Palliatieve zorg helpt de hele familie om met een ernstige ziekte om te gaan	Palliative care helps the whole family cope with a serious illness

Self-estimated palliative care knowledge

Hoe goed kent u het begrip 'palliatieve zorg'?	How well do you know the concept 'palliative care'?
Hoeveel denkt u dat u weet over palliatieve zorg?	How much do you think you know about palliative care?
Hoe goed kan u aan iemand uitleggen wat palliatieve zorg is?	How well can you explain to someone what palliative care is?

Directed acyclic graph of independent variables' effect on the main outcome measure

Figure 1: Effect of Cultural exposure to death and dying on Discomfort with someone's suffering and dying

CultExp = Cultural exposure to death and dying
HCExp = Worked in healthcare
Religious
BeingWD = Being with someone else at the time of their death
VolExp = Experience as a volunteer around serious illness, death, dying or grief
PaCKs = Palliative Care Knowledge Scale
SeKn = Self-estimated palliative care knowledge
Action = Action undertaken around own end of life
DiscDying = Discomfort with someone's suffering and dying
🟩 Independent predictor variable
🟪 Dependent outcome variable
🟦 Confounding variable
🟨 Mediator variable

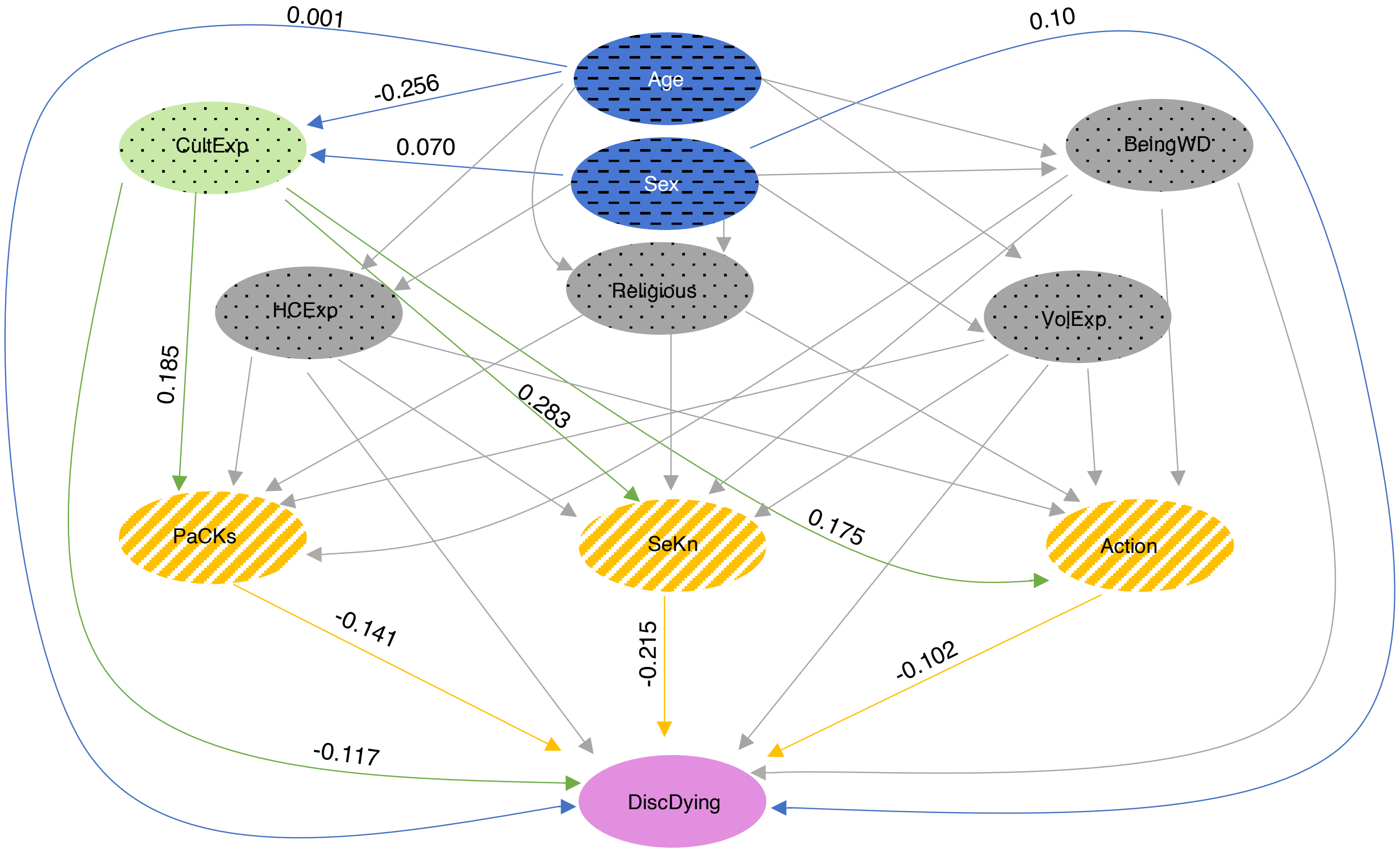


Figure 2: Effect of Having worked in healthcare on Discomfort about someone's suffering and dying

CultExp = Cultural exposure to death and dying
HCExp = Worked in healthcare
Religious
BeingWD = Being with someone else at the time of their death
VolExp = Experience as a volunteer around serious illness, death, dying or grief
PaCKs = Palliative Care Knowledge Scale
SeKn = Self-estimated palliative care knowledge
Action = Action undertaken around own end of life
DiscDying = Discomfort with someone's suffering and dying
Independent predictor variable
Dependent outcome variable
Confounding variable
Mediator variable

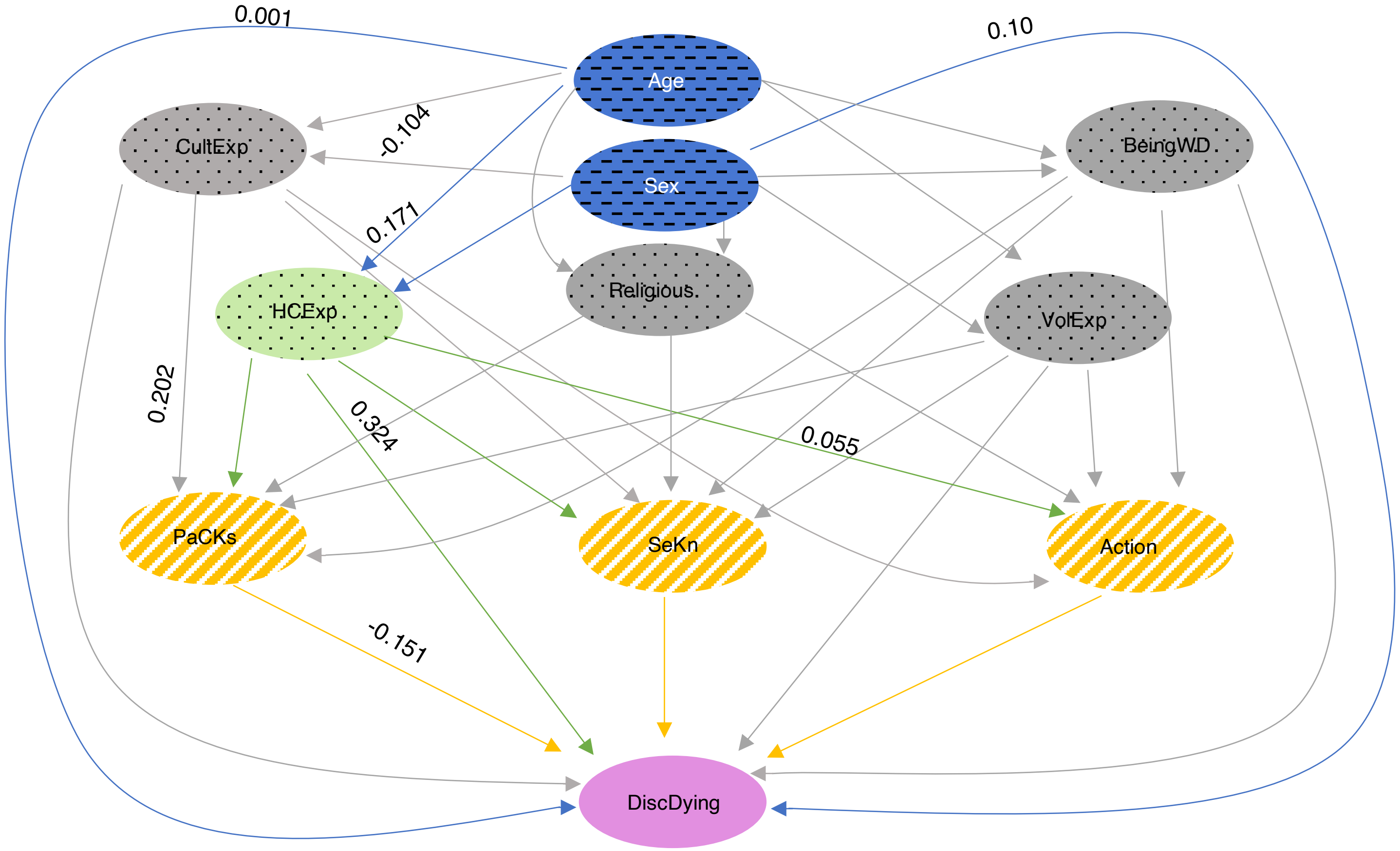


Figure 3: Effect of being Religious on Discomfort with someone's suffering and dying

CultExp = Cultural exposure to death and dying
HCExp = Worked in healthcare
Religious
BeingWD = Being with someone else at the time of their death
VolExp = Experience as a volunteer around serious illness, death, dying or grief
PaCKs = Palliative Care Knowledge Scale
SeKn = Self-estimated palliative care knowledge
Action = Action undertaken around own end of life
DiscDying = Discomfort with someone's suffering and dying
Independent predictor variable
Dependent outcome variable
Confounding variable
Mediator variable

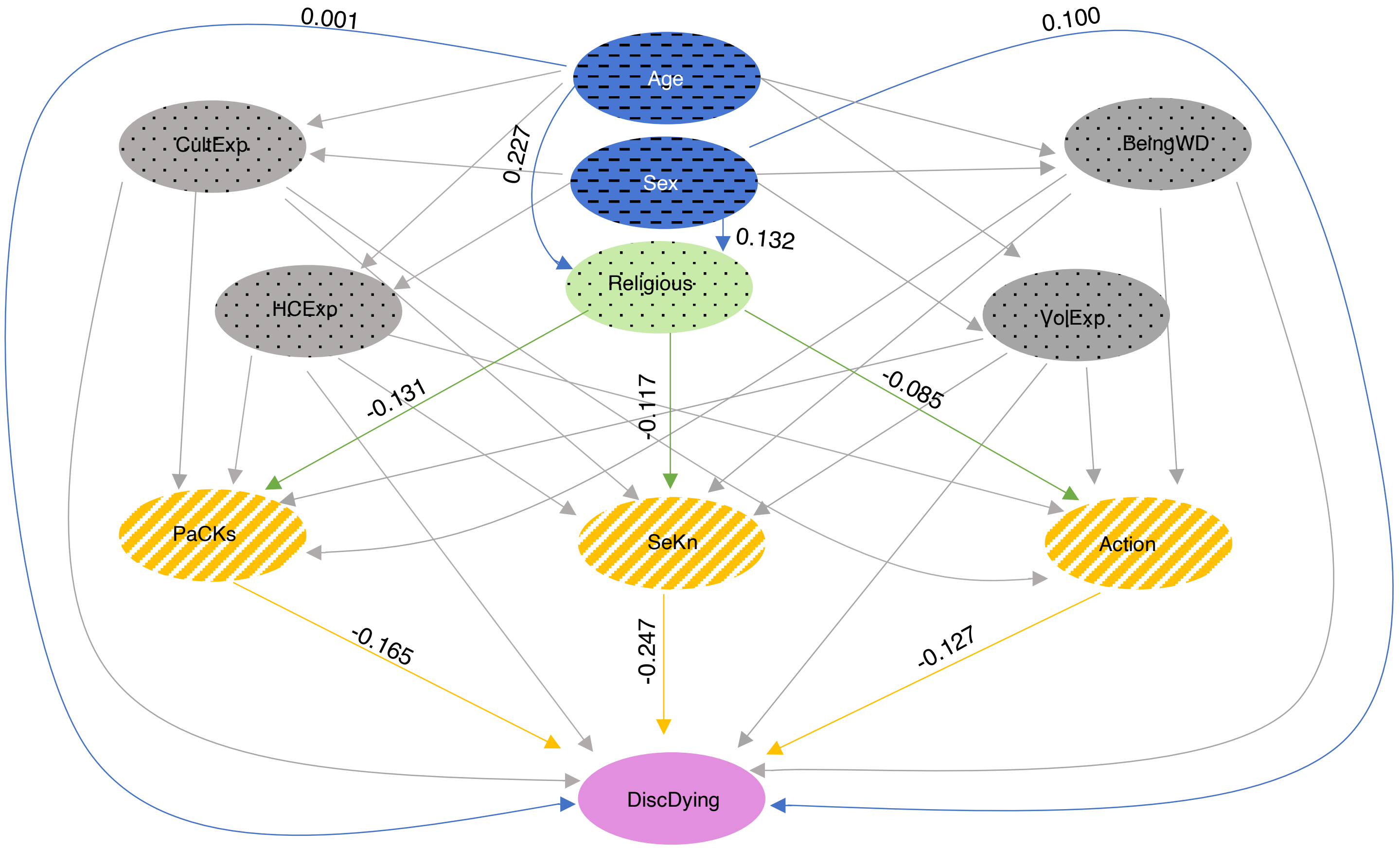


Figure 4: Effect of Being with someone else at the time of their death on Discomfort with someone's suffering and dying

CultExp = Cultural exposure to death and dying
HCExp = Worked in healthcare
Religious
BeingWD = Being with someone else at the time of their death
VolExp = Experience as a volunteer around serious illness, death, dying or grief
PaCKs = Palliative Care Knowledge Scale
SeKn = Self-estimated palliative care knowledge
Action = Action undertaken around own end of life
DiscDying = Discomfort with someone's suffering and dying
Independent predictor variable
Dependent outcome variable
Confounding variable
Mediator variable

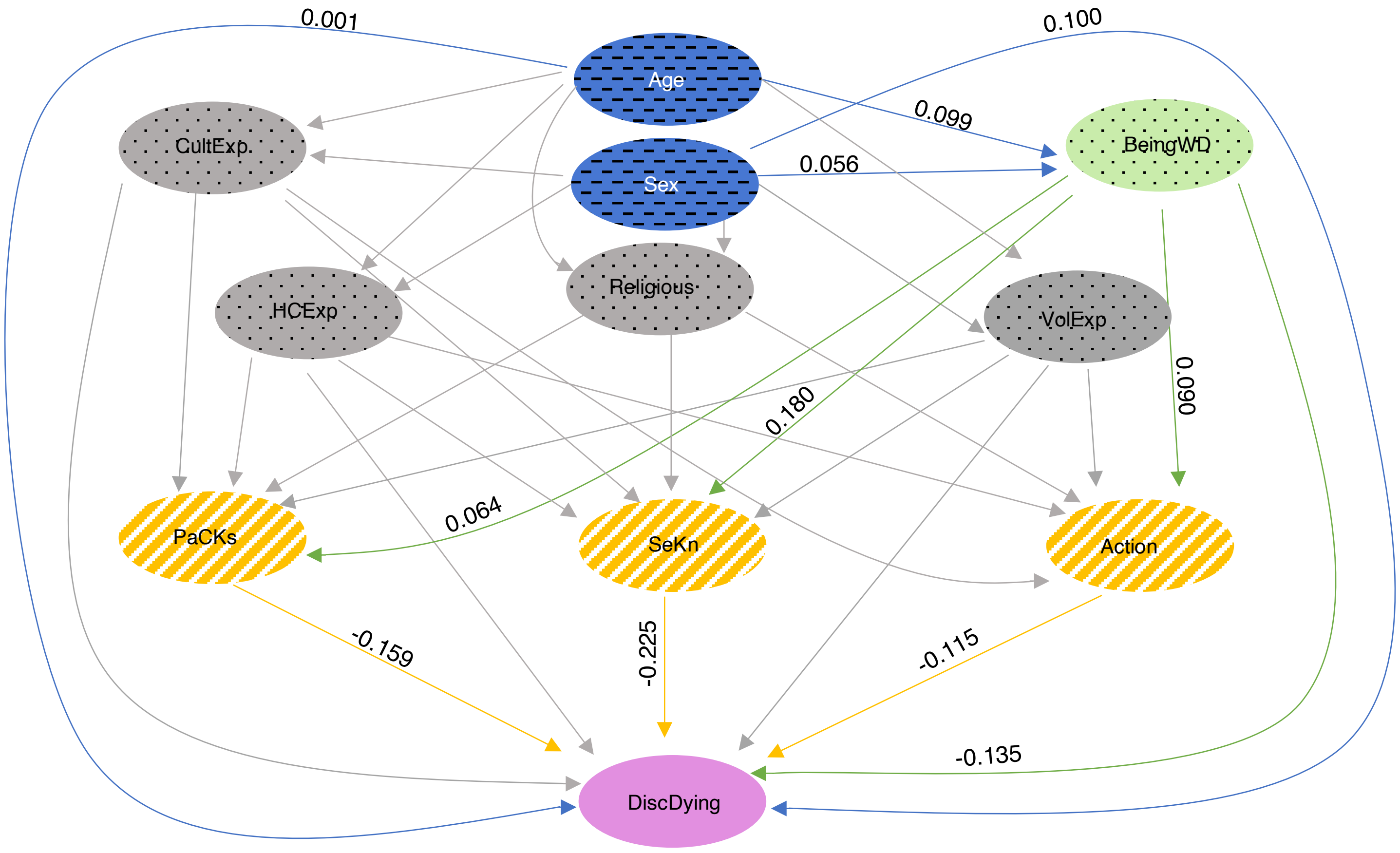
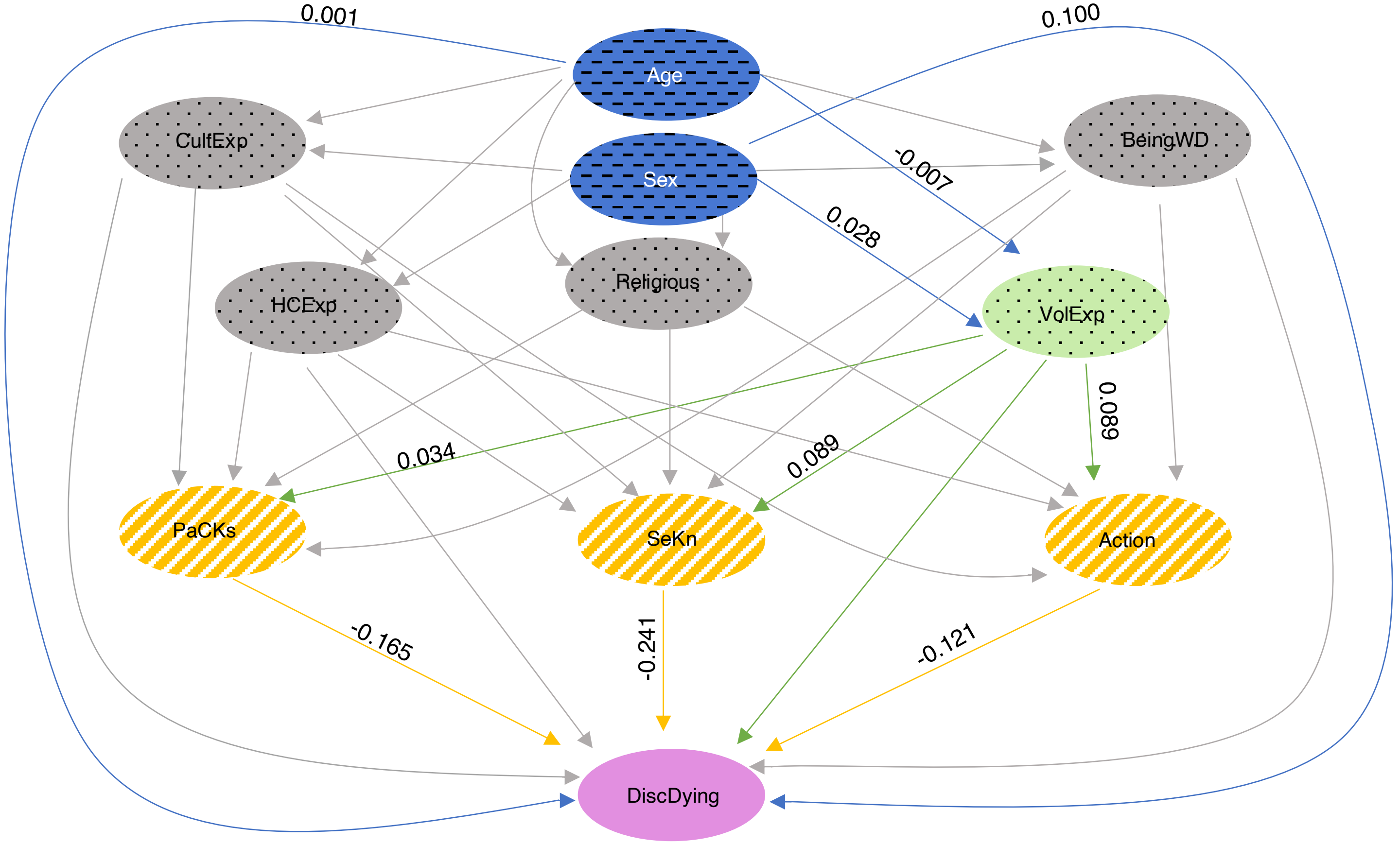


Figure 5: Effect of Having experience as a volunteer around serious illness, death, dying or mourning on Discomfort with someone's suffering and dying

CultExp = Cultural exposure to death and dying
HCExp = Worked in healthcare
Religious
BeingWD = Being with someone else at the time of their death
VolExp = Experience as a volunteer around serious illness, death, dying or grief
PaCKs = Palliative Care Knowledge Scale
SeKn = Self-estimated palliative care knowledge
Action = Action undertaken around own end of life
DiscDying = Discomfort with someone's suffering and dying
Independent predictor variable 🟩
Dependent outcome variable 🟪
Confounding variable 🟦
Mediator variable 🟨



Mann-Whitney U test to test differences in discomfort with someone's suffering and dying when comparing age groups

Age group	16-24 N = 160	25-34 N = 220	35-44 N = 229	45-54 N = 316	55-64 N = 372	65-74 N = 363	74< N = 280
16-24		Z = -3.957 P = < 0.001	Z = -3.540 P < 0.001	Z = -2.317 P < 0.05	Z = -2.777 P < 0.01	Z = -2.615 P < 0.01	Z = -4.217 P < 0.001
25-34	Z = -3.957 P = < 0.001		Z = -0.365 P = 0.715	Z = -1.997 P < 0.05	Z = -1.392 P = 0.164	Z = -1.807 P = 0.071	Z = -0.60 P = 0.953
35-44	Z = -3.540 P < 0.001	Z = -0.365 P = 0.715		Z = -1.519 P = 0.129	Z = -1.043 P = 0.297	Z = -1.363 P = 0.173	Z = -0.459 P = 0.646
45-54	Z = -2.317 P < 0.05	Z = -1.997 P < 0.05	Z = -1.519 P = 0.129		Z = -0.603 P = 0.546	Z = -0.282 P = 0.778	Z = -2.101 P < 0.05
55-64	Z = -2.777 P < 0.01	Z = -1.392 P = 0.164	Z = -1.043 P = 0.297	Z = -0.603 P = 0.546		Z = -0.343 P = 0.731	Z = -1.592 P = 0.111
65-74	Z = -2.615 P < 0.01	Z = -1.807 P = 0.071	Z = -1.363 P = 0.173	Z = -0.282 P = 0.778	Z = -0.343 P = 0.731		Z = -2.001 P < 0.05
74<	Z = -4.217 P < 0.001	Z = -0.60 P = 0.953	Z = -0.459 P = 0.646	Z = -2.101 P < 0.05	Z = -1.592 P = 0.111	Z = -2.001 P < 0.05	

CHAPTER III

WILLINGNESS TO SUPPORT NEIGHBOURS PRACTICALLY OR EMOTIONALLY: A CROSS-SECTIONAL SURVEY AMONG THE GENERAL PUBLIC.

This chapter is based on:

Quintiens B[1], Smets T[1], Chambaere K[1], Van Den Block L[1], Deliens L[1], Cohen J[1]. Willingness to support neighbours practically or emotionally: a cross-sectional survey among the general public. Palliat Care. 2024;18:1–14.

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Abstract

Background: Wider social networks are increasingly recognised in supporting people with care needs. Health promoting initiatives around the end of life aim to foster these social connections but currently provide little insight into how willing people are to help neighbours facing support needs.

Objectives: This study describes how willing people are to help neighbours who need support practically or emotionally, whether there is a difference in willingness depending on the type of support needed, and what determines this willingness.

Design: We applied a cross-sectional survey design.

Methods: We distributed 4,400 questionnaires to a random sample of people aged >15 across four municipalities in Flanders, Belgium. These surveys included attitudinal and experiential questions related to serious illness, caregiving and dying. Respondents rated their willingness (scale 1-5) to provide support to different neighbours in hypothetical scenarios: (1) an older person in need of assistance and (2) a caregiver of a dying partner.

Results: A total of 2,008 questionnaires were returned (45.6%). Average willingness to support neighbours was 3.41 (case 1) and 3.85 (case 2). Helping with groceries scored highest; cooking and keeping company lowest. Factors associated with higher willingness included optimistic outlook about receiving support from others, family caregiving experience, and prior volunteering around serious illness or dying.

Conclusion: People are generally willing to support their neighbours who need help practically or emotionally, especially when they have prior experience around illness, death or dying and when they felt supported by different groups of people. Community-based models that build support around people with care needs could explore to what extent this willingness translates into durable community support. Initiatives promoting

social connection and cohesion around serious illness, caregiving and dying may harness this potential through experiential learning.

Background

There is growing recognition of the importance of involving friends, family members and other social connections to support people living in our communities with care needs.[1] Although most informal care and support for people with care needs is provided by close family members and friends, the wider social networks can be important sources of support as well.[2–5] This support is not limited to providing practical help, but can also be of an emotional, spiritual or social nature.[2,6–8] Care within communities, provided by wider social networks of family, friends, neighbours or volunteers, is increasingly recognised as pivotal to creating sustainable healthcare systems.[9,10]

Several health promoting initiatives around people with life-limiting illnesses and people in need of palliative care have emerged in recent years to respond to the challenges associated with serious illness, caregiving, dying and the decreasing proportion of people able to participate in addressing these support needs.[10–16] These initiatives often rely on the altruism, empathy, sense of communal responsibility and willingness to engage in supporting others within communities who are facing situations of serious illness, caregiving and loss. Community responses that aim to build capacity around people facing such challenges, defined as public health approaches to palliative care, assign valuable roles to neighbours.[17,18] Studying their willingness can explore whether there is indeed a robust foundation from which to build community-based models of support for people confronted with care needs, illness, death or dying.

The literature provides insight into some aspects of people's willingness to support others in need of support. One study in the Netherlands, for instance, suggested that people are generally willing to help persons with care needs but prefer incidental, instrumental tasks such as grocery shopping.[19] The types of help people commonly provide also differ depending on the relationship the helper has with the help-recipient.[4,5,20] Research demonstrated that people are more willing to provide help when they have a close relationship with the person who needs support, when they have a history of (in)formal caregiving, or when they are older.[4,21] People are less willing to provide help when they are employed, and when they have a higher financial income.[21] While the nature of the relationship between the caregiver and care recipient can be indicative of a caregiver's willingness to support, several health promoting initiatives demonstrated interventions which succeed in involving community members outside the support-dependent person's direct social network as well.[22–24]

While several studies have thus suggested that people are usually willing to support others in need of support, these studies have focused on kin carers, are limited by their selective or small population samples, and have not focused on contexts of serious illness or dying.[21,25,26] This focus may influence people's willingness since the role and representation of death and dying in Western cultures has led to social estrangement from these things, as has been amply described.[27,28] Although the involvement and contributions of neighbours in caregiving are recognised in literature,[2,6] research on this population remains scarce.[4,5,29] Notwithstanding that recent health promoting initiatives — which rely substantially on the involvement of non-kin carers —report outcomes which promise the fostering of social connections,[12,24] the willingness of people living in communities to partake in building these mutually-supportive models is still underexplored. In researching this willingness, it is also important to differentiate in the types of support people are willing to provide (i.e., practical or emotional). Moreover, we lack any insight into which personal traits and experiences potentially influence or increase such willingness. Researching people's task preferences to support others contributes to the knowledge base on integrating instrumental and incidental forms of help in the care of individuals with care needs and who are confronted with situations of illness, caregiving and loss.

The research questions of this study are:

(1) How willing are people to provide practical and emotional support to their neighbours in need of support?

(2) Is there a difference in their willingness depending on the type of support tasks?

(3) Are personal characteristics, personal experiences with care, illness and death, religiousness, and perceived social support associated with people's willingness to provide practical and emotional support to their neighbours.

Methods

Design, participants and setting

We applied a cross-sectional survey design and sent a questionnaire to a simple random sample of members of the general public aged 16 years or older in four municipalities in Flanders, Belgium. Two of the municipalities had an urban city centre (Bruges with 118,000 inhabitants and Sint-Niklaas with 80,000 inhabitants) and two were semi-urbanised (Herzele with 18,500 inhabitants and Gavere with 12,000 inhabitants). Bruges and Herzele were selected to be part of a complex public health programme around serious illness, death, dying and bereavement while Sint-Niklaas and Gavere served as control municipalities. The survey was conducted at a baseline moment of the programmes. The protocol of this intervention is published elsewhere and provides more insight into the associated research project.[30] Two other papers of this research studying citizens' discomfort with someone's suffering and dying and their palliative care knowledge, have previously been published.[31,32] CROSS guidelines were followed to structure this paper.[33]

Sampling

A civil servant from each municipality drew a random sample from its population register. We decided to oversample family carers because the overarching research project focused on serious illness, death, dying and bereavement, which we anticipated would impact this population most. In Bruges, in order to increase statistical power for this subgroup, we disproportionately oversampled registered family carers with factor six (i.e. registered in the municipal population to receive a financial municipal compensation for family caregiving). This compensation or register did not exist in the other municipalities. The resulting sample from Bruges had an imbalanced age distribution which, together with the oversampling of family carers, was corrected by applying weighting factors ranging between 0.58 and 2.42.[34] Confidence intervals were set at 95% with accuracy at +/-5% and heterogeneity at

50%. A conservative estimation for a 35% response rate resulted in a total sample of 4,400 individuals from the general public in the four municipalities (1,100 in each).[35]

Data collection procedure

All self-administered questionnaires and accompanying information letters were sent out in the first semester of 2021 via postal mail by the municipality's civil servant and a data collector who was recruited by the research team. We worked with a maximum of three reminder mailings at set time intervals and followed Dillman's total design method to enhance response rates.[36] If no response was obtained after three reminder mailings or if the potential respondent indicated no desire to participate by contacting the researcher, no further steps were taken. To prevent respondents from receiving an unnecessary reminder, the respondent numbers were collected by the data collector each time a questionnaire was received. Respondents could send the questionnaire via mail using an accompanying pre-paid envelope or had the option to fill out the survey online in Limesurvey using their unique respondent number. Since the data collection was performed by the municipalities, the main researcher remained blinded throughout the whole procedure. None of the people involved in this process could link the respondents' responses to their names.

Questionnaire and measures

The entire questionnaire related to the topics of illness, death, dying, care and grief and its measures are outlined in the published study protocol.[30] Here, we describe the measures relevant to this study. For some measures in this survey, we used background questions from the Death Literacy Index which had not yet been published when this questionnaire was designed.[37] Several questions asked participants to reflect on their situation prior to the COVID-19 pandemic (e.g., questions which relate to people being in physical proximity of each other like volunteering which was not possible due to social distance measures) when answering as answers might otherwise not have been representative. Informed by prior research, we chose to focus on specific independent variables which relate to people’s personal experiences with care, illness and death as these experiences can increase their knowledge about these topics, therefore potentially impacting their willingness to help neighbours.[38] We were additionally interested in people's willingness to support others who are not closely related to the caregiver, as a study indicated that the personal relationship between caregiver and -recipient impacts willingness.[4] Lastly, expert input and prior research led us to hypothesise that people who feel socially supported by the people in their neighbourhood may experience an increased willingness to contribute to this supportive culture.

Main outcome measure

We assessed people’s willingness to provide practical or emotional support to neighbours through two self-developed cases (Box 1). We opted for hypothetical cases to enhance the situation’s recognisability among respondents. Case 1 depicts a person with minimal social support who needs practical and emotional support. Case 2 depicts a neighbour who is a carer for his care-dependent and terminal spouse. These cases allow to study the possibility of enhancing community involvement coming from the outer social network of people in need of support.[1] Each case proposes four hypothetical types of support. Respondents are asked to indicate how willing they would be to provide each kind of support on a scale ranging from (1) definitely not, to (5) definitely.

Box 1: Two cases to assess people's willingness to provide practical or emotional support to neighbours

<u>Case 1 (older person in need of help):</u> In your street lives an older woman. Her husband died a couple of years ago. She is in touch with her son but he lives abroad. You have never spoken to her before. One day your neighbour tells you the woman fell down the stairs. She needs to rest for a couple of weeks. Would you help her with the following tasks if you could? (mow the lawn; go to the shop; cook; keep her company)

<u>Case 2 (caregiver of dying partner):</u> Your neighbour who lives a couple of houses away from you takes care of his wife who will probably not live much longer. He tells you that he is having a hard time. A nurse supports him but he prefers not to leave his wife alone when he goes to the shop or the pharmacy. Would you help your neighbours with the following tasks if you could? (go to the shop; visit them; keep the wife company; talk with the man about his wife's condition)

Demographic characteristics, religiousness, and other measures

We asked respondents their sex, age, working situation, highest degree of education and religious orientation. Since providing care can have important financial consequences for carers, their working situation and highest degree of education may be relevant measures (since financial income may impact people's willingness to exchange paid labour for informal care).[39]

We also asked whether they volunteer, have a chronic illness, are currently mourning the loss of someone or live in a long-term care residence (nursing home, service flat, institution). Lastly, we asked whether people had already undertaken certain actions around their own end of life such as having discussed end-of-life preferences with friends or family, or having prepared a will.

We used a validated Dutch translation of the *Palliative Care Knowledge Scale (PaCKS)* to objectively assess people's palliative care knowledge.[40] We assessed people's subjective palliative care knowledge through three self-developed questions. The composition of the palliative care knowledge scales can be found in Appendix 1. We measured how comfortable people feel about the suffering and dying of others.[31] This feeling might impede people's willingness to help their neighbours when they are confronted with suffering or the end of life. This scale was a non-validated Dutch adaptation of the subscale *Dying of others* from the Collett-Lester Fear of Death scale.[41]

Personal experiences with care, illness and death

We reasoned that certain personal experiences around the topics of serious illness, death, dying and caregiving could affect people's willingness to support their neighbours.[38,42] Prior experiences with care increase the likelihood people will care again and change their attitudes on death.[5,21] A substantial proportion of people with a professional healthcare background take up an additional informal caring task.[43] We additionally asked whether respondents had had experience as a family carer, a volunteer around serious illness, death, dying or grief in the year preceding the COVID-19 pandemic's onset or as a healthcare worker and we asked whether they had ever been with someone else at the time of their death. The variable *Cultural exposure to death and dying* was composed from two existing questionnaires.[37,44] The composition of these variables can be found in Appendix 1.

Perceived social support

This self-developed measure assessed whether respondents believed they themselves would receive help from others if they fell ill and needed to go to the hospital. The exact composition of this scale can be found in Appendix 1.

Translation and testing of the questionnaire

The validated measures *Cultural Exposure to Death and Dying* and *Palliative Care Knowledge Scale* were translated using EORTC guidelines.[45] Our research team with expertise in end-of-life care and survey development reviewed the entire questionnaire and an external language service checked its language and understandability for sixth grade level literacy. The questionnaire was cognitively tested once among 15 individuals from the general public to verify its language and its conceptual and face validity.

Data preparation and data analyses

The main outcome measure *Willingness to provide practical and emotional support to neighbours* has total scores ranging between 8 and 40. These were divided again by eight to facilitate interpretation, resulting in scores ranging from 1 to 5, where higher scores indicate a higher willingness. After consultation with a statistician, we opted to use the factor scores of the main outcome measure for the multivariable analyses examining predictors of willingness since it gave a more satisfactory distribution.[46] Prior to this, we assessed the main outcome measure's factorial validity. Because of our large sample, a satisfactory subject-to-item ratio of 231.4 was guaranteed.[47] The factor analysis showed all items fall under a single component. An internal consistency test revealed the factor structure to be reliable. Several independent variables represent different types of experiences with care, illness and death (Cultural exposure to death and dying, Having been with someone else at the time of their death, Experience as a family carer, Experience as a volunteer around serious illness, death, dying or grief, Experience as a healthcare worker). A factor analysis of these variables identified two components but also an unreliable factor structure which is why they are regarded separately. The analyses can be found in Tables 1 to 6 in Appendix 1.

Missing scores of the responses to the eight items of the main outcome measure were imputed with mean scores. Respondents who answered fewer than six out of eight questions from the main outcome measure were excluded from further analysis (157 cases). Figure 1 presents a summary of the process for obtaining the number of questionnaires used in data analyses. Weighting factors were applied to the data prior to data analyses.

To explore if people's willingness differs between tasks, we calculated the average willingness scores for each type of support and performed a one-sample T-test. A bivariate correlation analysis explored the correlation between the main outcome measure and a respondent's personal experiences with care, illness and death, demographics and religiosity and other measures. Pearson correlation coefficients were calculated. We also assessed whether people's discomfort with someone's suffering and dying is associated with their willingness to support their neighbours. To identify the most appropriate de-confounding strategy (and avoid the so-called 'table 2 fallacy')[48] we identified the possible confounders for each of the variables of interest. Next, each of these variables that were statistically significantly ($P < 0.05$) associated with the dependent variable in the bivariable analysis were entered into multivariable linear regression models, controlling for the right set of confounders.

Results

Of 4,400 questionnaires sent out, 2,008 were returned (45.6% response rate). Individual response rates per municipality were: 49.7% for Bruges, 44.1% for Sint-Niklaas, 38.3% for Herzele, and 42.5% for Gavere.

Characteristics of the study population

The age of the respondents ranged from 16 to 97 and the majority were female (51.2%) (Table 1); 39.8% had obtained a higher education degree. There was a minor non-response observed among certain age groups. Our sample did not show a significant difference between the male-female distribution and the population average. Of all respondents, 52.3% were working while 30.5% were retired and 20.5% had been a family carer in the past. The majority identified with a religious denomination (63.5%).

In the hypothetical case that they themselves became ill and needed help, most respondents (96.8%) believed they would be supported by close friends or family, 87.2% believed they would be supported by acquaintances from their local community, 70.8% by acquaintances from outside their local community, and 43.9% believed they would be supported by people they do not know well from their neighbourhood.

Table 1: Characteristics of the study population.

Place **N = respondents**	**Bruges** **N = 529**	**Sint-Niklaas** **N = 465**	**Herzele** **N = 414**	**Gavere** **N = 443**	**Total** **N = 1851**
4. Demographic and personal characteristics					
Age	%	%	%	%	%
16-24	12.5	8.0	10.8	6.6	9.6
25-34	14.2	14.5	9.8	10.7	2.4
35-44	13.5	14.3	16.4	10.9	13.7
45-54	15.3	16.5	17.8	19.5	7.2
55-64	17.2	19.0	18.1	23.0	19.2
65-74	12.9	14.5	17.1	18.9	15.7
>74	14.5	13.2	10.0	10.5	12.2

Sex					
Female	46.1	49.5	54.1	56.1	51.2
Highest degree					
Primary school or lower	6.0	13.3	7.9	8.0	8.8
Secondary school, first 3 years	13.5	15.8	15.0	15.8	14.9
Secondary school finished	34.8	34.8	39.6	32.4	35.3
College	28.2	22.1	26.8	25.8	25.8
University or higher	16.3	12.0	10.3	16.7	14.0
Other	1.0	2.0	0.5	1.4	1.2
Working situation					
Working	52.5	46.2	54.4	55.6	52.3
Retired	29.4	31.8	29.2	31.7	30.5
Student	8.5	6.5	8.6	6.2	7.5
Unfit for work	3.8	5.6	4.9	2.1	4.1
Homemaker	2.3	4.8	2.2	3.0	3.1
Unemployed	3.4	3.2	0.5	0.9	2.1
Other	0.2	0.9	0.2	0.7	0.5
5. Religious orientation					
Catholic	47.3	52.6	69.1	61.0	56.7
Atheism	40.5	25.7	25.7	32.9	31.6
Islam	0.9	15.7	1.0	0.9	4.7
Secular Humanism	6.6	3.7	2.7	3.2	4.2
Other religion	3.6	1.5	1.2	1.6	2.1
Other	1.2	0.9	0.2	0.2	0.7
6. Personal experiences with care and illness					
I take care of a person in need as a family carer	19.3	17.4	23.4	14.7	18.6
I took care of a person in need as a family carer in the past	18.4	20.2	24.4	19.6	20.5
Having had experience as a family carer[1]	32.7	34.4	41.1	30.7	34.5
I have undertaken volunteer tasks around serious illness, death, dying or grief in the past year before the COVID pandemic	11.0	8.0	6.3	8.0	8.5
I work(ed) in a healthcare domain	17.3	12.0	13.3	14.4	14.4
I live in a long-term care residence (nursing home, service flat, institution…)	0.9	0.9	0	0.5	0.6
I have a chronic illness	12.1	12.9	9.7	6.8	10.5
I mourn for someone I have lost	23.2	22.6	23.4	19.2	22.1
Culturally exposed to death and dying[2]	72.7	69.2	63.3	62.0	67.2

Action undertaken around own end of life[2]	48	41.1	41.5	40.4	43.0
7. Perceived social support In case you fall ill and need to go to the hospital, do you believe you will get support with low threshold tasks from:					
friends or family with whom you are in close contact	95.7	95.7	97.5	98.4	96.8
friends or acquaintances within the local community	88.6	84.1	87.1	88.9	87.2
friends or acquaintances outside the local community	76.2	62.3	71.6	72.4	70.8
people in the neighbourhood you do not know well	49.7	36.9	42.8	45.6	43.9

[1] This variable is a combination of people who currently take up a family caring role and people who took on a family caring role in the past.

[2] The scale is self-developed of which the details are described in Appendix 1.

How willing are people to provide practical and emotional support to neighbours?

Table 2 presents people's willingness to help with different types of support in two different cases. The average score on willingness was 3.41 (SD = 1.00) for case 1 (older person in need of help) and 3.85 (SD = 0.95) for case 2 (caregiver of dying partner). For all types of support, with the exception of cooking, over half of the respondents indicated that they would probably or definitely be willing to provide this support for their neighbours. In both cases, respondents' results indicated that willingness was highest for doing groceries (scores of 3.98; SD = 1.11 and 4.12; SD = 1.04). In case 1, cooking for the person in need received the lowest score (3.11; SD = 1.35) while in case 2, the lowest willingness score was obtained in the situation where respondents would have to keep the dying person company (3.59; SD = 1.16).

Table 2: Willingness of people to provide practical and emotional support to neighbours

Case 1: In your street lives an older woman. Her husband died a couple of years ago. She is in touch with her son but he lives abroad. You have never spoken to her before. One day your neighbour tells you the woman fell down the stairs. She needs to rest for a couple of weeks. Would you help her with the following tasks if you could?						
	Definitely not (%)	**Probably not (%)**	**Not certain (%)**	**Probably yes (%)**	**Definitely (%)**	**Average score* (SD)**
Mow the lawn	254 (14.1)	275 (15.3)	206 (11.5)	660 (36.7)	402 (22.4)	3.38 (1.36)
Do groceries	103 (5.6)	131 (7.1)	157 (8.5)	772 (41.8)	684 (37.0)	3.98 (1.11)
Cook	284 (15.6)	378 (20.8)	344 (18.9)	486 (26.7)	330 (18.1)	3.11 (1.35)
Keep her company	149 (8.1)	307 (16.8)	427 (23.3)	603 (32.9)	348 (19.0)	3.40 (1.20)
Total						3.41 (1.00)
Case 2: Your neighbour who lives a couple of houses away from you takes care of his wife who will probably not live much longer. He tells you that he is having a hard time. A nurse supports him but he prefers not to leave his wife alone when he goes to the shop or the pharmacy. Would you help your neighbours with the following tasks if you could?						
	Definitely not (%)	**Probably not (%)**	**Not certain (%)**	**Probably yes (%)**	**Definitely (%)**	**Average score* (SD)**
Do groceries	89 (4.8)	82 (4.4)	113 (6.2)	783 (42.6)	769 (41.9)	4.12 (1.04)
Visit them	80 (4.4)	172 (9.3)	324 (17.6)	725 (39.4)	539 (29.3)	3.81 (1.09)
Keep the wife company	107 (5.8)	253 (13.8)	399 (21.7)	635 (34.5)	446 (24.2)	3.59 (1.16)
Talk with your neighbour about his wife's condition	82 (4.4)	105 (5.7)	216 (11.7)	755 (41.0)	685 (37.2)	4.01 (1.06)
Total						3.85 (0.95)

‡Depending on the item, missing values lay between 0.4% and 2.9%. Missing data are completely at random.
*Respondents that filled out a minimum of 6 out of 8 items. 7.8% missing values. Values ranging from 1 (definitely not) to 5 (definitely) with higher scores indicating a higher willingness to provide help.

Differences in willingness to provide practical and emotional support to neighbours, depending on the type of support

For both cases, doing groceries was the preferred task ($P < 0.001$). For case 1, people were more willing to mow the lawn than cook ($P < 0.001$), more willing to keep company than cook ($P < 0.001$). No significant difference was found between mowing the lawn and keeping company. For case 2, people were more willing to go to the shop than to visit them, keep the wife company or talk with the neighbour about his wife's condition ($P < 0.001$). People were more willing to talk with the neighbour about his wife's condition than to visit them or keep the wife company ($P < 0.001$), more willing to visit them than to keep the wife company ($P < 0.001$). These analyses can be found in Table 7 in Appendix 1.

Factors associated with people's willingness to provide practical and emotional support to neighbours

Being female, religious, having had personal experiences with care and illness (i.e. being culturally exposed to death and dying, having or having had experience as a family carer, or as a volunteer around serious illness, death or dying, having been with someone else at the time of their death), mourning a loss, having experience as a volunteer, having better (self-estimated) knowledge of palliative care, and believing they would receive support from others themselves if they fell ill, were all associated with scoring higher on willingness. Being older was minimally associated with scoring lower on willingness to support neighbours.

After controlling each variable for their defined set of potential confounders, the multivariable linear regression shows that all significant relationships found in the bivariate correlation analysis remained (Table 3).

Table 3: Multivariable linear regression analysis of variables associated with people's willingness to provide practical and emotional support to neighbours.

Independent variable	**Standardised β**	**95% CI**
Age (continuous)	-0.005	-0.008 — -0.003
Sex *(female)*	0.288	0.195 — 0.381
Cultural exposure to death and dying *(Yes)*[1]	0.341	0.240 — 0.441
Having had experience as a family carer *(Yes)*[1]	0.364	0.262 — 0.466
Being religious *(Religious)*[2]	0.158	0.058 — 0.259
Healthcare worker *(Yes)*[1]	0.195	0.062 — 0.327
Volunteer *(Yes)*[3]	0.211	0.093 —0.329
Volunteering around serious illness, death, dying or grief *(Yes)*[4]	0.464	0.297 — 0.632
Mourning a loss *(Yes)*[5]	0.177	0.057 — 0.278
Action undertaken around own end-of-life *(Yes)*[1]	0.116	0.023 — 0.209
Been with someone else at the time of their death *(Yes)*[6]	0.177	0.045 — 0.310
Palliative Care Knowledge Scale[7]	0.025	0.011 — 0.039
Self-estimated palliative care knowledge[7]	0.085	0.057 — 0.112
Perceived social support from friends or acquaintances within the local community *(Yes)*[8]	0.586	0.443 — 0.729
Perceived social support from friends or acquaintances outside of the local community *(Yes)*[8]	0.435	0.323 — 0.548
Perceived social support from people in your neighbourhood you do not know very well *(Yes)*[8]	0.520	0.408 — 0.632

‡ The following variables which did not have a significant relationship with the main outcome measure in the bivariate correlation analysis were not entered into the multivariable linear regression analysis: Working situation, Highest degree, Discomfort with someone's suffering and dying and Perceived social support from family or others with whom you are in close contact.

Controlled for confounding variables: [1]Age, Sex (Female), Chronic illness (Yes), Living in long-term care residence (Yes); [2]Age, Sex (Female); [3]Age, Sex (Female), Chronic illness (Yes), Living in long-term care residence (Yes), Volunteering around serious illness, death, dying or grief (Yes); [4]Age, Sex (Female), Chronic illness (Yes), Living in long-term care residence (Yes), Volunteer (Yes); [5]Age, Sex (Female), Volunteering around serious illness, death, dying or grief (Yes), Been with someone else at the time of their death (Yes); [6]Age, Sex (Female), Volunteering around serious illness, death, dying or grief (Yes), Mourning a loss (Yes); [7]Age, Sex (Female), Volunteering around serious illness, death, dying or grief (Yes), Healthcare worker (Yes), Been with someone else at the time of their death (Yes); [8]Age, Sex (Female), Living in long-term care residence (Yes)

Discussion

This population-based survey study showed that people are on average willing to support their neighbours in need of help, with different measures being associated with higher willingness. The scores on willingness ranged between 3.11 and 4.12 on a scale from 1 to 5. A higher willingness was associated with being a woman, being religious, having been culturally exposed to death and dying, having had experience as a family carer, working or having worked as a healthcare worker, volunteering in general or volunteering specifically around serious illness, death, dying or grief, having undertaken action around their own end of life, having been with someone else at the time of their death, having higher (self-estimated) palliative care knowledge and believing they would receive support from different groups of people if they were in need of help. People's working situation, highest educational degree, level of discomfort with someone's suffering and dying, and whether they felt supported by family or others with whom they are in close contact was not associated with willingness to support.

Some strengths and limitations of this study ought to be considered. The utilisation of random samples derived from full population registers in four municipalities allows for statistical generalisability of our findings to these municipalities. However, caution should be exercised when extrapolating these results further to other municipalities or countries, due to diversity in their social and cultural characteristics. Although we achieved relatively high response rates, we cannot exclude the possibility of selection bias as we observed minor discrepancies within different age groups when comparing the age distribution of the responders with that of the population. People who are more socially invested may have been more willing to respond to our questionnaire which also indicates that selection bias may be present. Notwithstanding that both cases and the questions for the main outcome measure are developed by a group of researchers with expertise in community development, public health approaches to palliative care, and ageing, we cannot fully ensure the measure *Willingness to provide practical and emotional support to neighbours* is validated for content. We also cannot exclude measurement bias, caused by social desirability bias for example, however we can reasonably assume that this bias is less strong for neighbours than it would be for family members or close friends in similar research.[4,49] Although the main outcome measure *Willingness to provide practical and emotional support to neighbours* was self-developed, we assessed its factorial validity and conducted supplementary cognitive testing to enhance content validity and mitigate possible measurement bias. In contrast to many studies on family care, we did specify the types of help that constitute this care.[4,50] The cross-sectional study design applied in this research allows exploration of which measures influence people's willingness but longitudinal designs would be better suited to providing more insight into temporal influences and residual confounding.

The scores on willingness to help neighbours seemed relatively high in the four studied municipalities. Both our cases depict people who live in the neighbourhood of the respondent and are in need of relatively straightforward types of help. Literature indicates that people's willingness is higher when tasks are short-lasting, less demanding and taking place nearby.[25,26,49] Hoefman et al. (2017) also suggest that practical support may be considered a public responsibility as opposed to nursing help which is more often seen as a shared responsibility between formal care providers and the care recipient's inner social network.[19] Research on family care does not always stipulate how this 'care' is operationalised, leaving it open to the respondent's interpretation.[50] This constitutes the already-known phenomenon of carers who do not regard their tasks as divergent from social norms, thereby undervaluing their work and possibly missing out on potential support (i.e., not applying for financial compensation for family carers or preferring to shoulder the burden alone).[2,49–51] Additionally, connecting individuals willing to provide support with those in need of care can be challenging when there is uncertainty about the specific support required and the ways in which this support needs to be delivered.[51] For communities to make use of the willingness of people to support, we would need to appreciate practical, emotional, spiritual and social support as an integral part of care within and by communities and recognise the added value this creates in the holistic view of both care recipients' and carers' health. Indeed, studies have shown that carers experience less caregiving burden when supported by their social network,[52,53] which is already a valued strategy in several existing public health interventions.[24,53,54]

People who had an optimistic outlook about the support they would receive themselves when in need of help were more willing to support their neighbours. This may indicate a perceived reciprocal relationship between community members: if people believe they are supported by their community, their willingness to support their fellow community members increases in return. This determinant could be further explored using longitudinal models to uncover its specific effect in Compassionate Cities over time. Our finding that people who believed they would receive support from people outside of their community when in need of help were more willing to help others seems to strengthen this reasoning. The fact that people appear to be willing to support others with support needs adds strength to the community-based strategy applied in health-promoting initiatives around people confronted with illness, death or dying.[10–12] The finding that people with experiential exposure related to illness, death or dying exhibited greater willingness to support their neighbours, endorses the broader objective of normalising the end-of-life stage, as formulated by many health promoting initiatives within this domain.[12]

Population care needs continue to evolve in congruence with chronic care demands and ageing populations, thereby increasing the strain on our healthcare systems. Recognising and establishing community-based care and support as an integral and valued part of our healthcare systems, and an essential approach towards sustainability, may become an imperative strategy. As our research showed that people who were culturally exposed to death and dying or who had volunteered around serious illness, death, dying or grief reported higher willingness, interventions pertaining to these topics may help increase community-based care. Such interventions can help decrease preconceptions and change attitudes about the end of life, thereby reducing barriers that exist for people to support their neighbours.[5,55]

Conclusion

People are generally willing to provide practical and emotional support to neighbours who need care or support, with their willingness varying between types of support. Women, people with volunteering experience around serious illness, death, dying or grief, with experience as a family carer, and people who expected to be socially supported when in need of help themselves were more willing to help their neighbours. Hence, there may be a large supportive network in neighbourhoods that can be fostered for people who need support. This shows sound potential for the empowerment of people to engage in community-based support models in health promoting initiatives. Interventions aiming to increase people's exposure to illness, death and dying, inducing experiential learning, may help build community-based support networks.

Declarations

Ethics approval

Approval for this study was obtained from the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020.

Consent to participate

Respondents consented to participate by filling out the questionnaire.

Consent for publication

Not applicable.

Author contributions

All authors contributed to this paper and gave consent for publication.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

The data is securely backed up and encrypted on a storage server of the Vrije Universiteit Brussel. Following the guidelines of Good Clinical Practice, electronic data will be retained for a period of 15 years, while paper questionnaires will be stored for five years. Requests for access to the data can be directed to the corresponding author on reasonable request.

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Appendix 1

Composition of the palliative care knowledge scales

Palliative Care Knowledge Scale (PaCKS)

- We present the Dutch translation of each item with the corresponding (original) English formulation in Italic.

Palliatieve zorg heeft onder meer tot doel psychologische problemen aan te pakken die ontstaan bij een ernstige ziekte	*One goal of palliative care is to address any psychological issues brought up by serious illness*
Stress ten gevolge van een ernstige ziekte kan aangepakt worden door palliatieve zorg	*Stress from serious illness can be addressed by palliative care*
Palliatieve zorg kan mensen helpen om de bijwerkingen van hun medische behandelingen onder controle te krijgen	*Palliative care can help people manage the side effects of their medical treatments*
Wanneer mensen palliatieve zorg krijgen, moeten ze hun andere dokters opgeven	*When people receive palliative care, they must give up their other doctors*
Palliatieve zorg is uitsluitend voor mensen die in de laatste zes maanden van hun leven zijn	*Palliative care is exclusively for people who are in the last six months of life*
Palliatieve zorg is specifiek voor mensen met kanker	*Palliative care is specifically for people with cancer*
Mensen moeten in het ziekenhuis zijn om palliatieve zorg te krijgen	*People must be in the hospital to receive palliative care*
Palliatieve zorg is specifiek bedoeld voor oudere volwassenen	*Palliative care is designed specifically for older adults*
Palliatieve zorg is een teambenadering van zorg	*Palliative care is a team-based approach to care*
Palliatieve zorg heeft onder meer tot doel mensen te helpen hun behandelingsopties beter te begrijpen	*One goal of palliative care is to help people better understand their treatment options*
Palliatieve zorg stimuleert mensen om de behandelingen gericht op de genezing van hun ziekte stop te zetten	*Palliative care encourages people to stop treatments aimed at curing their illness*
Palliatieve zorg heeft onder meer tot doel mensen beter in staat te stellen om deel te nemen aan dagelijkse activiteiten	*One goal of palliative care is to improve a person's ability to participate in daily activities*
Palliatieve zorg helpt de hele familie om met een ernstige ziekte om te gaan	*Palliative care helps the whole family cope with a serious illness*

Self-estimated palliative care knowledge

Hoe goed kent u het begrip 'palliatieve zorg'?	*How well do you know the concept 'palliative care'?*
Hoeveel denkt u dat u weet over palliatieve zorg?	*How much do you think you know about palliative care?*
Hoe goed kan u aan iemand uitleggen wat palliatieve zorg is?	*How well can you explain to someone what palliative care is?*

Personal experience measures with care, illness and death

Cultural exposure to death and dying

(2) I have read or discussed a book on death, dying or bereavement; (2) I have read an autobiographical account of a person's dying or bereavement; (3) I have learnt about end of life issues through school (including death, dying and grief); (4) I have participated in community events or activities related to death or dying; (5) I have seen an art exhibition which has featured works about dying, death or bereavement; (6) I have attended a play or film which deeply explored dying, death or bereavement, (7) I have had a conversation with a dying person about their death.[69] The eighth question was derived from a question from the subconcept *Participation in the local community* from the Social Capital survey[70]: How many events/activities have you attended in your city in the year preceding the COVID-crisis which relate to the themes serious illness, death, dying or mourning (e.g., art exhibition, a play, film, a testimony). The answers to all eight questions were combined and binary coded for every respondent to: (0) no cultural exposure to death and dying and (1) cultural exposure to death and dying.

Family care experience with care, illness and death

(2) Do you take up a caring task for a person in need (i.e., family carer); (2) Did you take up a caring task for a person in need (i.e., family carer)?

Having worked in healthcare

(2) Did you work in a healthcare domain (now or in the past)?

Experience as a volunteer around serious illness, death, dying or mourning

(2) How often did you perform volunteering tasks for an organisation focused around serious illness, death, dying or mourning in the year preceding the COVID-19 pandemic?

Being with someone else at the time of their death

(2) I have kept someone company who is near death; (2) I have witnessed the death of another person; (3) I have spent time with a person after their death; (4) I have helped care for a dead body. Results were recoded to (0) has not been with dead or dying people and (1) has been with dead or dying people.

Other measures

Undertaking actions around own end of life

(1) Which of these actions did you undertake around your own end of life: A will drawn up; A declaration made that you want to donate your organs; A negative advance directive made: specifying which medical treatments you do not wish to receive if you are unable to express your preferences, for example, because you are in a coma; A positive advance directive made: specifying which medical treatments you do wish to receive if you are unable to express your preferences; A disposition of remains made: specifying what should happen to your body upon your death, such as burial, cremation, or donation to science; Created a written euthanasia advance directive; Designated a representative in a document who can make decisions about your health when you are no longer able to; Discussed with a professional healthcare provider what you wish for at the end of your life; Discussed with friends, family, or other people you are in regular contact with what you wish for at the end of your life; I have not done these things yet because; I did other matters related to the end of life.

Perceived social support

(1) In case you fall ill and need to go to the hospital, do you believe you will get support with low threshold tasks from: friends or family with whom you are in close contact; friends or acquaintances within the local community; friends or acquaintances outside the local community; people in the neighbourhood you do not know well? Results were recoded to (0) no social support and (1) some level of social support.

Calculation of sum and factor scores of main outcome measure: Willingness to provide practical and emotional support to neighbours

1.A Calculation of subject-to-item ratio

- 1851/8 = 231.4

1.B Factor analysis of the main outcome variable

- Missing scores were replaced with the mean score and we used Varimax rotation

Table 1: KMO and Bartlett's Test of sphericity of the main outcome measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.862
Bartlett's Test of Sphericity	Approx. Chi-Square	9439.7
	Degrees of freedom	28
	Significance	<0.001

- Assessment of internal consistency

Table 2: Internal consistency assessment of the main outcome measure

Cronbach's alpha	N of items
0.900	8

- Factor analysis

Table 3: Factor analysis of the items of the main outcome measure

Item	Component 1
Case 1	
Mow the lawn	0.572
Go to the shop	0.810
Cook	0.725
Keep her company	0.811
Case 2	
Go to the shop	0.814
Visit them	0.865
Keep the wife company	0.843
Talk with the man about his wife's condition	0.726

Factor analysis of the independent variables which are different types of exposures to sickness, death and dying to see if any overarching concept can be identified

- Independent variables are: Cultural exposure to death and dying, Having worked in healthcare, Being with someone else at the time of their death and Family care experience with care, illness and death, Experience as a volunteer around serious illness, death, dying or mourning

Table 4: KMO and Bartlett's Test of sphericity of the main outcome measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.569
Bartlett's Test of Sphericity	Approx. Chi-Square	296.2
	Degrees of freedom	10
	Significance	< 0.001

Table 5: Component matrix

	Component
	1
Having worked in healthcare	0.656
Being with someone else at the time of their death	0.650
Cultural exposure to death and dying	0.576
Experience as a volunteer around serious illness, death, dying or mourning	0.509
Family care experience with care, illness and death	0.192

- Reliability analysis of variables in Component 1

Table 6: Internal consistency assessment of the main outcome measure

Cronbach's alpha	**N of items**
0.364	5

- Unreliable factor structure, variables regarded independently

Differences in willingness to provide practical and emotional support to neighbours, depending on the type of support

Table 7: Comparison between people's willingness to provide practical and emotional support to neighbours depending on the type of support

		Mow the lawn	Go to the shop	Cook	Keep her company
Case 1	**Mow the lawn**		t = -18.78 P < 0.001	t = 8.43 P < 0.001	t = -0.638 P = 0.524
	Doing groceries	t = 22.99 P < 0.001		t = 33.41 P < 0.001	t = 22.23 P < 0.001
	Cook	t = -8.579 P < 0.001	t = -27.61 P < 0.001		t = -9.21 P < 0.001
	Keep her company	t = -0.047 P = 0.962	t = -21.48 P < 0.001	t = 9.60 P < 0.001	
Case 2		**Go to the shop**	**Visit them**	**Keep the wife company**	**Talk with your neighbour about his wife's condition**
	Doing groceries		t = 12.93 P < 0.001	t = 22.01 P < 0.001	t = 4.69 P < 0.001
	Visit them	t = -12.57 P < 0.001		t = 8.22 P < 0.001	t = -8.26 P < 0.001
	Keep the wife company	t = -20.05 P < 0.001	t = -8.62 P < 0.001		t = -16.00 P < 0.001
	Talk with your neighbour about his wife's condition	t = -4.58 P < 0.001	t = 8.02 P < 0.001	t = 16.96 P < 0.001	

PART 3: TO EVALUATE THE PROCESS OF DEVELOPMENT OF THE COMPASSIONATE CITIES

CHAPTER IV

RESEARCHING TWO COMPASSIONATE CITIES: STUDY PROTOCOL FOR A MIXED-METHODS PROCESS AND OUTCOME EVALUATION.

This chapter is based on:

Quintiens B[1,2], Smets T[1], Chambaere K[1,2], Van Den Block L[1], Deliens L[1,2], Cohen J[1,2]. Researching two Compassionate Cities: study protocol for a mixed-methods process and outcome evaluation. Palliat Care. 2022 Nov;16.

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Abstract

Background/objectives: Compassionate Cities are social ecology approaches that apply a set of actions, targeting a broad range of stakeholders, with the intention of renormalising caring, dying, loss and grieving in everyday life. While several initiatives have been described in the literature, a rigorous evaluation of their processes and outcomes is lacking. This paper describes the protocol for a mixed-methods study to evaluate the development process and the outcomes of two Compassionate Cities in Flanders, Belgium.

Methods and analysis: We will use a convergent multi-phase mixed-methods design, in which a combination of qualitative and quantitative data collection methods will be triangulated in the data analysis stage to capture both development processes and outcomes. Our design includes a quasi-experimental component of a quantitative outcome evaluation in both Compassionate Cities and two comparable control cities with no formal Compassionate City programme. Both Compassionate Cities will be co-created in collaboration with local stakeholders. A critical realism lens will be applied to understand how and why certain processes manifest themselves.

Discussion: The creation of Compassionate Cities implies high levels of complexity, adaptivity, unpredictability and uncertainty. This requires various data collection methods that can be applied flexibly. A researcher taking on the role of active participant in the project's development has several advantages, such as access to scholarly information. Reflexivity in this role is paramount to questioning where the ownership of the project lies. By applying a critical realism lens, we remain cautious about our interpretations, and we test the homogeneity of our findings through other forms of data collection.

Conclusion: This is the first published study protocol to describe both a process and outcome evaluation of a Compassionate City project. By transparently describing our aims and data collection methods, we try to maximise information exchange among

researchers and to inform others who desire to implement and evaluate their own initiatives.

Background

During the last century, healthcare delivery in the developed world evolved from being primarily community-provided to highly professionalised and institutionalised.[1,2] The same trend can be observed with regard to people facing serious illness and dying.[3,4] However, due to a rapidly growing proportion of people with complex care needs, the existing specialised and generalist palliative care might quickly reach its limits. Therefore, novel social-embedded approaches to the challenges of serious illness, dying, loss and grieving are needed to complement current professional services.[2,4,5] By empowering community members to perform caring and supporting tasks for their fellow citizens facing these challenges (e.g., by doing their shopping, keeping them company, or helping them participate in everyday community life), professional services can more effectively focus on their core responsibilities.[6,7] Moreover, there is growing understanding that dying is predominantly a social experience with a medical component, as opposed to the other way around.[8,9] Hence, support by family, friends and others during these social experiences may substantially impact the quality of life as well as the quality of dying.[10,11]

Public health programmes have the potential of enhancing or enlarging these social networks, which direct some responsibilities away from professional healthcare services. Compassionate Cities have been suggested as such public health responses to serious illness, death, dying and bereavement. By focusing on prevention, harm reduction and early intervention, they aim to reintegrate and normalise the end-of-life in everyday life.[5,12] Compassionate Cities are social ecology programmes that focus on creating a supportive environment around people performing caring tasks or experiencing illness, dying, loss and grieving. By facilitating the involvement of citizens in care delivery, Compassionate Cities typically target all sectors of society. They typically start by engaging city or town officials and using their influence to implement changes society-wide. Through the involvement of citizens in defining the actions needed to minimise harm and improve end-of-life care, a sustainable model of community-controlled palliative care is pursued.[8]

To do so, a series of activities is worked out that aim at educating, raising awareness, changing policy, or strengthening networks (among other results) in the local society. This is generally realised through the involvement of a variety of groups coming from workplaces, schools, civil society organisations, and others. From this follows that the development of Compassionate Cities depends highly on the chosen development approach as well as the unique social and cultural background of the involved people, organisations and communities. Since they are designed and realised in co-creation – where outcomes depend on local stakeholders' input – Compassionate Cities might face high levels of unpredictability and adaptivity. Because of their aim to increase the citizens' agency over their own health, certain outcomes pertaining to increases in knowledge, attitudes, awareness, or skills regarding serious illness, caring, dying and grieving can be expected.[5]

Furthermore, the founding principles of Compassionate Cities can be traced back to the Ottawa Charter for Health Promotion which proposes five main domains of focus in order to realise health promotion: building healthy public policies, creating supportive environments, strengthening community action, developing personal skills, and re-orienting healthcare services.[13] The Healthy City movement set an example of operationalising this approach but neglected applying the same principles to illness, dying, loss and grieving.[14] Consequently, outputs related to these domains are an important focus in this research project.

A recent systematic review has shown that several Compassionate Cities and Communities have been described in literature.[11] However, the review also demonstrated that most of the reported initiatives have not been thoroughly evaluated, and that only a few of the evaluation studies include both a process and an outcome evaluation. Since Compassionate Cities aim at bringing about societal change, it is important to perform both process and outcome evaluations in order to provide insight into how Compassionate Cities are developed, to measure the actual impact that has occurred as a result of the implementation, and to uncover the mechanisms that have led to the desired outcomes. Furthermore, the review showed that some evaluation studies reported positive results, but the methods of the studies were never described in enough detail for them to be replicated. Until now, only a handful of study protocols for the evaluation of Compassionate Cities or Communities have been published –

and those that have been published all focus on the evaluation of a single activity or outcome within the initiative (e.g. changes in the patients' quality of life when involving volunteers; evaluation of a model to develop networks of care around people) instead of on the project as a whole.[15–18] Publishing study protocols of studies, including both process and outcome evaluations, helps in better understanding the development, implementation and outcomes of Compassionate Cities.

A collaboration between two universities, two cities, and various local stakeholders within those cities, has recently resulted in the development of two Compassionate Cities in Flanders, Belgium. One is located in the semi-rural municipality Herzele (18,500 inhabitants), and the other in the highly urbanised city of Bruges (118,000 inhabitants). In this paper we describe the protocol for a mixed-methods study that will be performed to evaluate the process of development and the impact of these two Compassionate Cities in Flanders, Belgium.

Methods and analysis

Study design

This study follows a convergent multi-phase mixed-methods design including a quasi-experimental component of a quantitative outcome evaluation performed over a period of time in both intervention cities and two control cities, as well as a process evaluation in both intervention cities.[19] We apply a convergent multiphase mixed method design in which we perform qualitative data collections throughout the whole project, perform quantitative data collections (survey) once pre and once post-implementation and merge the information at the post-implementation stage to be able to describe and compare both compassionate cities (Figure 1). Contesting findings will be tested against literature to confirm or challenge findings or to build new knowledge on the study subject. For the analysis of all gathered data, we are guided by the Consolidated Framework for Implementation Research to regard the elements that were essential in the implementation of the Compassionate City initiatives.[20] This framework provides a structured arrangement of everything that contributed to the implementation and helps in explaining why something works in a certain situation. The development of the Compassionate Cities can be divided into four phases: case search, pre-implementation, implementation and post-implementation. Data collection runs continuously with quantitative and qualitative data collections running parallel at times (Figure 1).[15] At the post-implementation stage, a cross-case comparison is done: results from both intervention cities will be compared as well as the results from the intervention cities with the control cities. Data coming from interviews, document analyses, focus groups, group discussions, observations, diaries, a network analysis and surveys will be collected independently and triangulated at the data analysis stage to formulate uniform answers to the research questions (Table 1).[22] Both Compassionate Cities will be compared and emphasis will be put on *how* and *why* differences manifest themselves and on the mechanisms that have contributed to the results. Where applicable, SPIRIT guidelines were followed when constructing the protocol for this study.[23]

Figure 1: Convergent multiphase mixed-methods design. Green refers to data from the intervention cities, blue from control cities. Dotted lines indicate the progress of time, arrows indicate the data collection or analysis is performed based on the prior event. Data are collected throughout the four project phases and triangulated at post-implementation.

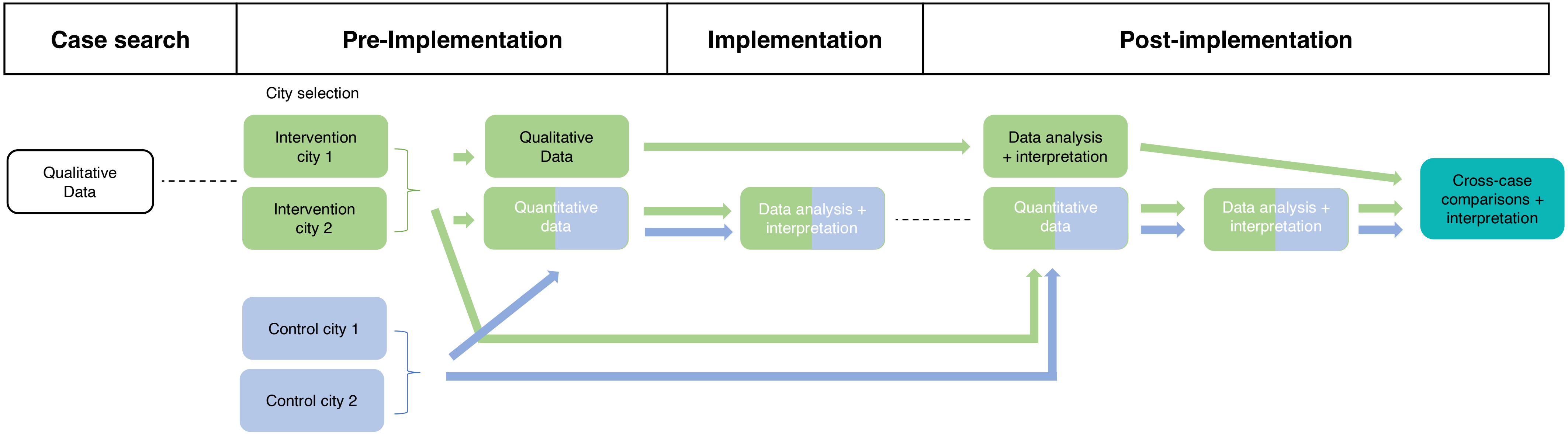


Table 1: Study objectives and research questions with corresponding data collection methods

Objective 1: To describe how both Compassionate Cities are co-created and what they entail. ***(process evaluation)***							
Research questions	Corresponding data collection methods						
	Structured weekly diaries	Semi-structured observations	Semi structured interviews	Focus groups and group discussions	Document analysis	Most Significant Change technique	Pre-post structured survey
- How are the Compassionate Cities co-created with stakeholders in the two cities (describing the process of development)?	X	X	X	X	X	X	X
- What do the Compassionate City programmes entail, and what is their reach?		X			X		
- What proportion of the citizens of the (future) Compassionate City knows their city has become a Compassionate City by the end of the research project? How did they discover this?							X
- What are the barriers and facilitators experienced by the stakeholders and by the community facilitator in developing and implementing a Compassionate City programme? How do they differ between the two cities?	X		X	X	X	X	
- What explains the differences between the two cities when comparing the process of development and the experienced barriers and facilitators (by both stakeholders and the community facilitator)?	X		X	X	X		
- Which stakeholders co-created the Compassionate Cities?		X					

Objective 2: To evaluate the impact of the Compassionate City programmes on the citizens of the Compassionate Cities, on the stakeholders and on the organisations' social networks on the organisational level. ***(outcome evaluation)***

Research questions	Corresponding data collection methods			
	Pre-post structured survey*	Organisational network analysis	Most Significant Change technique*	Health insurance data
- What is the impact of the Compassionate City programme on the citizens' knowledge, attitudes, awareness, self-efficacy, intention to look for support and skills concerning life-limiting illness, death, dying, loss and bereavement?	X			
- What is the impact of the Compassionate City programme on the citizens' local community participation and their neighbourhood connections?	X			
- Is the impact of the Compassionate City programme different between the two cities? What are these differences and how can they be explained?	X			
- What is the impact of the Compassionate City programme on the organisations' social networks related to end-of-life topics on an organisational level?				
- What are the most significant changes experienced by the stakeholders in each Compassionate City, and to what extent are these changes alike or different in the two cities?		X	X	
- What is the impact of the Compassionate City programme on the end-of-life health experiences of family carers and on the healthcare use of patients?				X

*The pre-post structured survey and the Most Significant Change technique are primarily used as data collection tools for the outcome evaluation which explains why their description can be found under the section Data collection methods for outcome evaluation.

Applied research paradigm

This research applies a critical realist paradigm. Considering the aspect of ontology, critical realists attempt to capture anything that is perceived to be *real*, relating to anything that produces observable effects. From an epistemological perspective, critical realism emphasises that an objective world exists independently of the observed reality which is inherently shaped and coloured by our subjective interpretation, imagination and language and is thereby perceived differently by different people. It thus follows that a final, objective truth and knowledge do not exist. Nonetheless, this reasoning argues that it is possible to work towards a closer understanding of the nature of reality. Therefore, critical realism does not rely solely on quantitative or qualitative data collection methods to describe the world, but instead balances between an objectivist approach, which captures the truth in numbers and facts, and a subjective approach, in which all knowledge is relatively debatable and differently interpreted. Thus, one does not simply determine the occurrence of changes, but tries to describe how and why (i.e., the context in which) these changes take place.[24]

Researcher positioning

The main researcher takes on the role of active participant observer.[25] This means that he collects data and actively interacts with the stakeholders involved in the development of the Compassionate Cities, which leads to him being known by the projects' developers. His participation consists of reporting research data to the stakeholders as well as actively participating in meetings. However, he does not provide direct input into the design and development of the two Compassionate Cities

Study setting

As part of the project to Develop Capacity in Palliative Care Across Society (CAPACITY) in Flanders, Belgium, two cities were selected to become

Compassionate Cities. Candidate cities provided a written motivation for their potential participation. Table 2 provides an overview of the criteria used, which resulted in the selection of a smaller municipality of approximately 18,500 inhabitants, Herzele, and one larger city of approximately 117,000 inhabitants, Bruges. Both cities contain an ageing population. For each Compassionate City, a control city was selected that is comparable in size and level of urbanisation – Sint-Niklaas (80,000 inhabitants) and Gavere (12,000 inhabitants) – for the quantitative impact evaluation component.

Table 2: Selection criteria for the potential Compassionate City.

Selection criteria	
1. Number of inhabitants	< 20,000
	75,000 – 125,000
2. Support and involvement of mayor and/or aldermen	
3. Presence of a civil servant to support the researchers and a community facilitator	
4. Confirmed willingness to provide (financial) means for relevant social actions	
5. Willingness to develop a long-term policy related to the end-of-life	
6. Prior experience with social change projects (e.g., dementia-friendly city, fairtrade city, etc.)	
7. Providing access to existing stakeholder coalitions from previous social change projects	
8. Existing advice boards (e.g., youth parliament, cultural board, etc.)	
9. The city area falls within one and the same primary care zone	
10. The city/municipality is a member of a Flemish volunteer network	

Development of the Compassionate Cities in co-creation with local stakeholders

Under the impulse of the End-of-Life Care Research Group of the Vrije Universiteit Brussel and Ghent University, each intervention city was invited to participate and form a leading coalition consisting of local professionals and politicians. A project manager will be appointed to coordinate the project and lead the meetings of the coalition. The leading coalition will select multiple topics of focus through which the Compassionate Cities will be developed. The Compassionate Cities will be developed in co-creation with local professionals, the city council and citizens.[26] The research group will appoint a community facilitator, with expertise in change processes, to facilitate the development of the two Compassionate Cities.

Participants

Five groups of participants who participate in the development of the Compassionate Cities can be distinguished: Researcher, Community facilitator, Local project leads, Local stakeholders and Citizens. Which participants are targeted for which data collection method is presented in Figure 2.

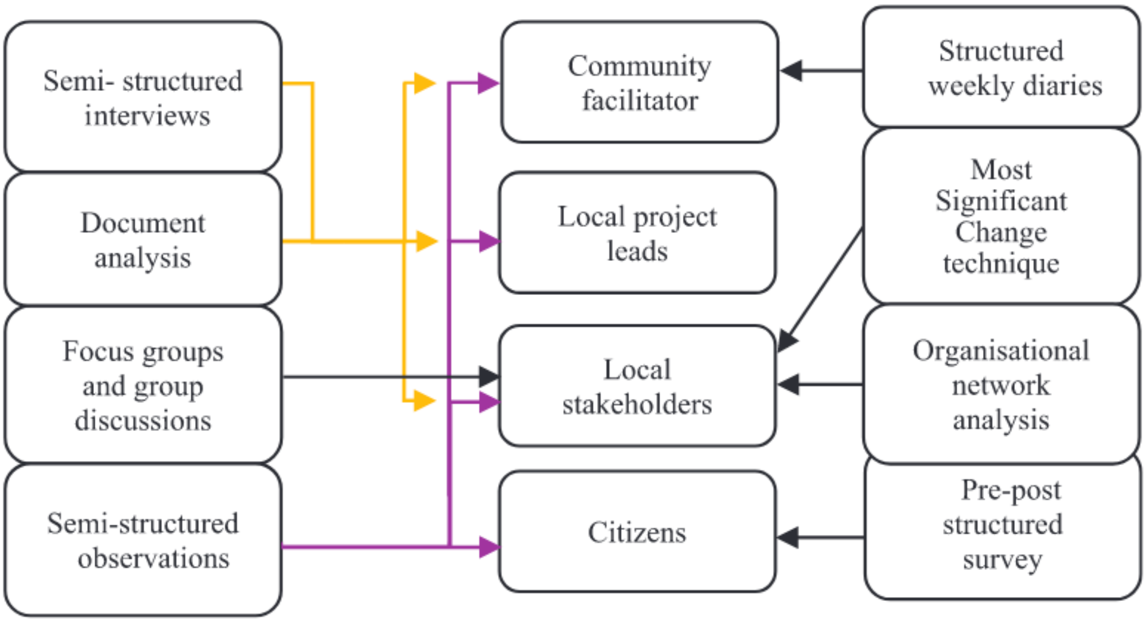
A) Researchers: the researchers will not provide direct input for the project's development, but they may exercise an indirect influence by, for example, communicating scholarly information and research results to involved stakeholders.

B) Community facilitator: the community facilitator is a person appointed by the university with expertise in change processes, change management and group dynamics.

C) Local project leads: each Compassionate City will have a local project lead appointed by the city or municipality. This person has a mandate to lead the project.

D) Local stakeholders: local stakeholders can be anyone involved in the design and/or development of the Compassionate Cities. Stakeholders include representatives of the city council (e.g., aldermen and local politicians), life-stance organisations, healthcare services (including, but not limited to, palliative care), volunteer organisations, family carer organisations, civil society organisations, educational institutions, workplaces, citizens, etc. Due to the unpredictable and co-creative nature of Compassionate Cities, the types of potential stakeholders involved in the development is unlimited.

Figure 2: Data collection methods and corresponding targeted populations. The different arrow colours are to facilitate interpretation and have no other significance.



Data collection methods for process evaluation

<u>Structured weekly diaries</u>

The community facilitator will work with weekly diaries throughout the project to register *how much* time and *on which activities* she spent time. Diaries help in logging reflections shortly after the occurrence of events, which facilitates remembering momentary data such as feelings, emotions, or social contexts. Thus, diaries are well suited for capturing details of time- and context-sensitive data, such as one-on-one meetings or specific actions.[27]

<u>Semi-structured observations</u>

The semi-structured observations will be performed by the main researchers. The observations will be used to register qualitative information (e.g., what is said, which emotions are observed, non-verbal interactions) and quantitative information during any meaningful event in the development of the Compassionate Cities (e.g., how many people are present at the event, duration of the event). Anyone involved in the design of the Compassionate Cities, as well as the design or execution of social actions, can be the subject of an observation. Observations run continuously throughout the project. We will make use of a semi-structured template that will be filled out by the researcher and that contains the following variables: (1) information about the setting, (2) enumeration and description of the participants, (3) chronological event description, (4) description of physical setting and materials, (5) description of behaviours and interactions, (6) conversations, (7) self-reflections.[28] If possible, the participants will be asked for consent prior to the observation. The observation template can be consulted in Appendix 1.

Semi-structured interviews, focus groups and group discussions

We will perform semi-structured interviews with the community facilitator, the cities' project leads, and local stakeholders. During the interviews, we will cross-check hypotheses, explore topics in depth, investigate the reach of the projects, inspect barriers and facilitators in the creation of the initiatives, and gain insight into the strategy and reasoning behind developmental decisions. Interviews with the community facilitator and the projects leads will be held every three months and will be face-to-face or online.

Prior to the interview, the interviewee's consent is requested. All interviews are audio recorded and transcribed non-verbatim. There is no specific timing for the focus groups or group discussions, because at first it is necessary to ensure a functional and trusted operational atmosphere to maximise the likelihood that the participants will voice their true opinions.

Document analysis

We aim to register policy changes on relevant themes and the effect of the Compassionate Cities on participating organisations. To do so, we will collect documentation drawn up or changed by stakeholders or organisations as a consequence of their participation in the Compassionate City project. We decided not to discriminate between types of documentation but instead to focus on all documentation with relevance to the research topics. These documents will be collected throughout the project.

Data collection methods for outcome evaluation

Pre-post structured survey

We will administer a structured survey to a random sample of the general population of both Compassionate Cities and both control cities – once before the development of the Compassionate Cities and once post-implementation. The aim of the survey is twofold: to evaluate the impact of the Compassionate Cities, and to inform the leading coalitions about possible areas of focus (e.g., low scores on palliative care knowledge could warrant palliative care education). The concepts to be studied are: (1) Knowledge of palliative care; (2) Attitudes towards the dying of others; (3) Awareness about the existence of palliative care and how this awareness was obtained; (4) Self-efficacy regarding individual emotional competence and competence in supporting others; (5) Intention to look for support; (6) Skills regarding advanced care planning, in supporting a carer and in finding information; (7) Local community participation for general and palliative care related themes; (8) Neighbourhood connections regarding palliative care related themes.

We will apply a simple random sampling of citizens older than 15 years of age in both intervention and control cities. In each city, 1,100 citizens will be selected with a total of 4,400 citizens. Family carers, if registered in their city of residence, will be oversampled. The survey will be sent out on paper with the possibility to fill it out online. The total design method will be applied to increase our response rate in which a maximum of three reminder mailings are sent to non-responders.[29] The names and addresses of citizens from the sampling frames are accessed only by civil servants of the city who are responsible for the random sampling and the mailing, with remote assistance from the research team. This assures that the researcher remains blinded and cannot link the collected participant information to the individual.

The survey is sent out once pre-intervention and once post-intervention. A difference-in-differences approach will be used to this purpose. The approach is applied in geographically distinct areas with comparable populations, for which, in our case, two out of four populations undergo an intervention and the others do not.[19] Because of the assumption of trends running parallel between similar populations (i.e., societal changes that transcend their locality such as cultural trends or political changes), any changes observed in the Compassionate Cities that are not observed in the control cities can, with a certain level of probability, be attributed to the intervention. Furthermore, by considering societal changes that happen outside the Compassionate City programme, the method limits history bias.

Organisational network analysis

In our research project, the organisational network analysis shows professional connections related to serious illness, death, dying and bereavement made by organisations involved in the Compassionate Cities' development. We will map the connections by using a stakeholder grid, which every stakeholder involved in the development of the Compassionate Cities and representing an organisation will be asked to fill out. The focus is on organisational connections relating to sickness, death, dying, mourning and care. The stakeholders will be asked to reflect on their current organisation's connections and the connections before the project commenced. We will further explore the direction, content, and importance of this connection. This will be repeated during the post-implementation phase to show any network changes as a consequence of participating in the project. These findings will be discussed per stakeholder to verify possible findings.

Most Significant Change technique

Through this technique, we aim to describe the most meaningful and important changes experienced by stakeholders involved in the creation of the Compassionate Cities.[30] It is important to look beyond the predefined outcomes, since the unpredictable nature of Compassionate Cities leads to unpredictable outcomes. Furthermore, since this is a co-creational project, the meaningful outcomes realised by the stakeholders' input can be different from, and bear different significance than, the ones described and pre-constructed by researchers. All stakeholders will be asked to participate. They will be requested to write down the most significant changes they experienced as a result of their participation in the development of the Compassionate

Cities. These changes will pertain to a maximum of five domains of change, which will have been predefined by the city council. An *open domain* and a *negative change domain* will be added, which allow stakeholders to add stories that do not fit the pre-constructed domains, and that allow the researcher to collect negative experiences or weaknesses in the development process.

During group discussions, stakeholders will discuss their story and explain why this story is significant to them. The group discussions will be held without predefined questions and will be audio recorded, with one researcher acting as moderator and a second researcher as observer who fills out the observation template. The moderator may read a story out loud if the participant prefers to keep their story anonymous. During the discussions, participants can voice their opinions on the shared stories (e.g., how many people recognise this story, does anyone wish to react to the story). People higher in hierarchy – possibly local policy makers – will receive the anonymised stories and will be asked to select the most significant change story, along with a written motivation for their selection.

Routinely collected administrative data

Data collected by the Belgian InterMutualistic Agency will be used to compare the healthcare claims data from patients in the intervention cities against those in the control cities. To add strength to the assumption that trends run parallel between both intervention cities and their control cities, it will be possible, by making use of a controlled interrupted time series design over a period of multiple years, with multiple measuring points in time, to compare the number of home deaths, hospital deaths, emergency hospital admissions in the last month of life, intensive care unit admissions in the last month of life, and official palliative care status.[31,32]

Data analysis

Data from the structured weekly diaries will be analysed independently, but we choose to triangulate it with other data (for example, by cross-checking registrations through interviews).[27] We will make use of the qualitative data analysis software NVIVO for thematic analysis and will follow the six analysing steps as proposed by Braun and

Clarke (2006).[33] This procedure is also followed for the semi-structured interviews, focus groups and group discussions. Recurring responses from interviewees will receive special attention.

The semi-structured observations will undergo a thematic data analysis using the NVIVO software, and themes will be constructed inductively. Findings will be tested against existing theoretical literature – leading to confirmation, or warranting additional research when the expected is not confirmed. Important findings will be cross-checked through interviews to prevent misinterpretation.[28] Quantitative data will be analysed for specific actions to study the reach of each Compassionate City.

Documents will be analysed according to content, type and number of documents, and they will be imported into NVIVO for qualitative data analysis.

For the organisational network analysis, data will be analysed both quantitatively (by looking at the number of connections) and qualitatively (by looking at the type of connections that were formed). We will make use of social network analysis software (e.g., Gephi) and present the results in a graph.

Every story coming from the Most Significant Change technique and every additional conversation will be transcribed using verbatim transcription. Then, the transcripts will be imported into NVIVO and analysed using a thematic approach.

Data from the routinely collected administrative data will be collected and analysed for both Compassionate Cities, after which different phases (including pre- and post-implementation) can be compared.

Data management

All data collected that could lead to identification of the involved persons will be pseudonymised in external communications, including publications. Where possible, the researcher will request participant consent prior to collecting qualitative data. If large numbers of participants are subject to qualitative data collection (e.g., during a festival), the collection of consent is not necessary, because no information will be collected that can lead to the individual's identification. All collected data will be securely stored on an encrypted server of the Vrije Universiteit Brussel, which is only accessible to members of the research team. All paper surveys are stored in a locked cabinet. In accordance with the Good Clinical Practice guidelines, the electronic (raw) data (privacy sensitive information or any other information that could lead to the identification of individual people) will be stored for 15 years. Audio files will be deleted as soon as they have been transcribed.

Discussion

This protocol describes a mixed-methods process and outcome evaluation of two Compassionate Cities in Flanders, Belgium. Published study protocols that include both process and outcome evaluations of Compassionate Cities are, to our knowledge, non-existent. However, such protocols are very much needed to better understand the development, implementation, and outcomes of Compassionate Cities and Communities. Such protocols increase transparency and inform other researchers in their choice of research methods, which can prove useful when studying the relatively recent and poorly understood phenomenon of Compassionate Cities.[11,34]

Mixed-methods research designs combine the strengths of both quantitative and qualitative methods.[22] Focusing solely on quantitative methods would undervalue the importance of contextual factors, would provide little insight into the applied processes and would ignore important process factors such as the extent of self-organisation, sustainability, participation, agency or reach. On the other hand, applying only qualitative methods may fail to encompass population-level changes or to generate representative results. Most importantly, a single evaluation method would be unsuitable for capturing the complex and adaptive nature of Compassionate City or Community interventions.

Typically, the outcomes of complex interventions are unpredictable in an environment where the response to an intervention can be difficult to predefine. This is largely due to synergies between different situational aspects, such as the types and backgrounds of the stakeholders involved, their intrinsic and extrinsic motivations, and the availability of resources such as funding, time and manpower. Because co-creating Compassionate Cities depends on the input of the local stakeholders involved, and since these projects intervene in different complex levels of society (such as civil society organisations, places of worship, and workplaces or schools), outputs and outcomes are highly unpredictable.[35,36] Therefore, we can assume that Compassionate Cities, just like any complex intervention, are predominantly self-regulatory as opposed to centrally planned, which enhances their capriciousness.[36]

This points to the necessity of developing a mixed-methods design, which encompasses a wide range of adaptable data collection methods where the one may be more fitting than the other to grasp the changing environments and therefore data.[37–39] However, when choosing data collection methods prior to an intervention that is characterised by unpredictable outcomes, the limitations of the methods can appear when the outcomes are not (or not satisfactorily) captured. For example, a survey intervention can indeed produce outcomes other than those that the study initially hoped for, which is inevitable when selecting outcomes prior to an intervention. Therefore, complex interventions warrant a mixed-methods data collection approach, so that the chosen method matches the emerging outcomes (and not the predicted, envisioned or assumed outcomes).

A researcher taking on the role of active participant in Compassionate City development projects (and in co-creation projects in general) has several advantages. First, researchers have access to scholarly information from other initiatives that local developers do not have access to. This can inspire them to facilitate bilateral information exchange. Second, at times it is preferred to share information: for example, when input from researchers is requested, or when a situation demands an intervention that can positively influence the project (e.g., examples of specific compassionate actions). Third, the researcher can communicate preliminary results from data collections to designated stakeholders which can positively influence the development process. Fourth, active participation leads to the researcher being known to the developers which facilitates access to research data.[21] However, being an active participant does not necessarily imply the researcher's active involvement in, and decision-making about, the process of development. The focus of the researchers can predominantly remain on capturing the voices of the people involved in, and affected by, the project – which can lead to changes in the development process when the research results are presented to the project developers. Even when the researchers decide not to take on a more participative role, their mere presence in the development of the Compassionate Cities might influence people's behaviour and thereby, the data collected. Therefore, it is paramount for researchers to stay reflective about their positioning and to consider where the ownership of the project lies and the possible influences they are willing to exercise on the development process.[40]

By applying critical realism to this research project, we will remain reflective about our personal (and therefore subjective) interpretations, and we will cross-check what we observe to be real through other forms of data collection in order to confirm or contest the findings.[24,28] Furthermore, what is shared by people in groups is often likely to reflect desirable group behaviour, which calls for us to critically review our perceptions and interpretations. Remaining reflective is a challenging process and thus it is important to log personal reflections during observations and to be quick on the draw by, for example, using informal conversations to discuss recent findings. Apart from focusing on what causes the observed effect, the underlying mechanisms that may have contributed warrant equal consideration. This is where qualitative interviews, in which information is shared in a private environment, play a vital role in capturing the interviewees' individual opinions and possible deviations from our individual interpretations.

Conclusion

In this protocol paper we described the first protocol for evaluating both the process and the outcomes of the development of Compassionate Cities using a set of mixed-methods data collection methods. With this study protocol, we aim to enhance transparency, which is important when studying phenomena that are as yet poorly understood and studied. At the same time, we present examples of the methods that can be used by other researchers and developers of prospective Compassionate Cities to evaluate their initiatives. Finally, we highlight the importance of researchers remaining reflexive about their role in, and possible influence on, the development and outcome of such initiatives, especially when the researcher is an active participant in the project.

Declarations

Ethics approval and consent to participate

Approval for this study was obtained from the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020. The consent to participate is not applicable for this paper.

Consent for publication

Not applicable.

Author contributions

All listed authors contributed to this paper and gave permission for publication.

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Conflict of statements

The authors declare that there is no conflict of interest.

Availability of data and materials

Not applicable.

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Appendix 1

A1: Observation template.

BASIC INFORMATION

Location		
Date		
Observer		
Is the activity taking place once or recurring?		
Objective of the observation		
Timeframe	Starting hour	
	Finishing hour	
	Total duration	
Permission from everyone to perform the observation?		

OBSERVATION

1. REASON FOR THE ACTIVITY Why is this activity being organised? What are the goals of the activity?	
2. WHO IS PARTICIPATING? How many people are participating? What is their relevant background? Which and how many organisations participate? What role do people take up as part of this activity?	
3. HOW DID THIS ACTIVITY COME TO BE? Which stakeholders developed this activity? Which stakeholders execute the activity?	
4. OCCURENCES AND INTERACTIONS What is happening (verbal and non-verbal)? How do participants react on the activity? How does each person behave during the activity?	
5. RESULTS Was what was hoped to be achieved accomplished? If not, why not?	

6. EXTRA OBSERVATIONS Have things that were supposed to happen not happened? Why did this occur? Was there something that disrupted the activity	
7. GENERAL REFLECTION How did the activity proceed? What emotions were present? How did I feel after this activity?	

CHAPTER V

DEVELOPING CITIES THAT PROMOTE WELLBEING AROUND SERIOUS ILLNESS, CAREGIVING, DYING AND LOSS: A QUALITATIVE PROCESS EVALUATION OF TWO COMPASSIONATE CITY PROGRAMMES.

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Abstract

Introduction: Compassionate Cities offer a socio-ecological approach to promoting wellbeing in serious illness, dying and loss through community engagement and support. Published evaluations of such programmes lack comprehensiveness and fail to address their complex, adaptive nature. Significant knowledge gaps remain regarding stakeholder involvement, facilitation roles, and contextual factors. This study aimed to describe the development process of two Compassionate Cities.

Methods: We performed a qualitative process evaluation of two Compassionate Cities' development process in Flanders, Belgium. Interviews, observations, field notes and group discussions were collected from different participant groups who were involved in or affected by the development of the Compassionate Cities. We developed a framework to analyse the data.

Results: Various activities were developed by different stakeholder groups. We identified important themes related to facilitation and coordination such as coaching project coordinators, expediting strategic decisions, and engaging stakeholders and keeping them engaged. Aspects such as including cities leading the programme, creating conceptual coherence and understanding, focusing on long-term and short-term changes, or defining involved stakeholders' mandates facilitated or hindered development. Important contextual factors such as partners' prior experiences and perceptions about death and loss influenced development.

Conclusions: Engaging communities to address real-life needs is essential although external factors and power dynamics can affect adherence to community engagement principles. External facilitation is important to coach project coordinators and empower participants. Identifying motivated stakeholders and focusing on low-cost activities can be a useful approach when faced with limited resources. Integrating Compassionate Cities into local government policy plans seems essential for upscaling and sustainability.

Introduction

The improvement of wellbeing in situations of serious illness, caregiving, dying and loss remains predominantly framed within the realm of professional health services, which typically emphasise reactive approaches to health issues.[1] This contributes to several misalignments. For instance, such situations are primarily social, cultural and spiritual experiences with medical components rather than the other way around, but a health service approach focuses almost exclusively on the latter.[2] Moreover, concentrating disproportionately on reactive approaches to health outcomes misses the potential gains that can be made through prevention and health promotion strategies.[3] The nearly exclusive focus on health service responses is increasingly challenged by scenarios of unsustainability as well as staff and resource shortages in contexts of rising demand.[4,5]

Compassionate Communities have been proposed as a paradigm shift in this respect. They are socio-ecological approaches applying principles of harm reduction, early intervention and prevention to reintegrate end-of-life aspects into everyday life.[6,7] They aim to create the environments where community members collectively notice and respond to the uncertainties and suffering of those impacted by serious illness, dying or loss.[6] Compassionate Cities are specific area-based Compassionate Communities that involve, and are often coordinated by, local administrative or governmental representatives.[2,8] These programmes rely and build on community assets, apply collaborations with diverse organisations and stakeholders and strive to empower the civic society in responding to end-of-life situations. Compassionate Cities are intended to be developed in cocreation and not via pre-specified programmes implemented by external agents. They typically launch activities aimed at raising awareness, increasing skills, developing policies, strengthening social networks, building partnerships, providing care and stimulating community initiatives.[9,10]

While the concept of Compassionate Cities has been described in the literature since the early 2000s and an increasing number of Compassionate City development programmes have been reported,[9–13] important knowledge gaps about their development processes remain. Bakelants et al (2022) point at the lack of process evaluations of Compassionate Communities, which warrant a scrutinous methodological approach as they are complex adaptive systems, with non-linear and unpredictable activities and changes. Stakeholders collaborate at different socio-ecological levels with a strong focus on self-organisation.[14] Activities often arise from spontaneous local interactions rather than from a preconceived plan. Therefore, the processes generating outcomes are unpredictable at the outset as is characteristic for complex interventions.[15] The few published Compassionate City development evaluations do not reflect this complex systems perspective. They often describe or evaluate individual components (e.g., a volunteer model), or focus on observed outputs and outcomes.[10,16–20] Existing evaluations have been criticised for lacking transparency and limitedly use of programme theory.[17–19] Consequently, many questions about the development of Compassionate Cities are badly understood, such as how and which stakeholders are involved, the role of facilitation and coordination, developmental barriers and facilitators and the influence of contextual factors. Such evaluations can provide essential insights for the increasing number of cities worldwide that wish to develop their own Compassionate City programme.

Two cities in Flanders, Belgium started to develop a Compassionate City programme and participated in an extensive evaluation of their development process and outcomes. This context provided a unique opportunity to address several knowledge gaps regarding the development of Compassionate Cities. The aim of this study was to describe the development process of these two Compassionate Cities. Specific research questions were:

1) What development structures were created by the cities for the Compassionate City programmes and how were these revised?
2) Which stakeholders were involved or participated and what were their roles?
3) What was the role of facilitation and coordination in development?
4) What characteristics of the implementation strategies facilitated or hindered development?
5) What contextual factors influenced the development process?

Methods

Study design

We performed a qualitative evaluation of the development process of two Compassionate Cities led by a constructivist epistemology.[21] We adhered to the COREQ (COnsolidated criteria for REporting Qualitative research) checklist to structure reporting on this research. The planned evaluation of the Compassionate Cities has previously been announced in its published study protocol.[22]

Setting of the Compassionate Cities

The Compassionate City programmes were developed in two municipalities in Flanders, Belgium: Bruges, a highly urbanised city with about 120,000 inhabitants, and Herzele, a semi-urbanised municipality with approximately 18,500 inhabitants. Although both cities are socio-culturally comparable (sharing the same language and being part of the same country), they are distinct on a number of characteristics such as their local political governance, level of urbanisation, number of inhabitants and sociocultural significance (Bruges being an important tourist hub). The development and evaluation of the Compassionate Cities occurred as part of a research project running from 2019 to 2023.[22] The project was conceived by the End-of-Life Care Research Group from Vrije Universiteit Brussel and Ghent University.

The intervention: the Compassionate City programme

The programme was primarily designed to respect key principles of Compassionate City development: participatory (working with rather than on city structures and organisations), based on collaboration and trust, striving towards citizen and civic society empowerment, and aimed at sustainability (the ability to continue and develop after the research project concludes).[8] Hence, the programme was not intended to have a structured implementation plan but to facilitate development with an important role for coordination.

In keeping with these principles, the activities or interventions implemented by the municipalities were emergent/unpredictable and not prescribed but generated through the core components of the Compassionate City programmes. These core components were presented a priori to the municipalities as features of the programme and included:

1) A leading coalition (core development group) was to be established with the municipalities identifying their participants. This minimally needed to include: a civil servant project coordinator with an initial mandate from the city council, representative(s) of that city council, organisation representatives, a project facilitator (see point 2) and two researchers. Additional members could be appointed.
2) Facilitated development process. The End-of-Life Care Research group recruited a project facilitator with expertise in group dynamics, change processes and the end-of-life sector. Their main role was to support and coach the project coordinators, including stakeholder mapping, fostering group cohesion, facilitating co-creative development, drafting development plans and facilitating co-created activities. The facilitator was supported by two researchers who participated in meetings to observe, provide feedback based on intermediary evaluations and share inspirational examples from other Compassionate Cities.
3) Asset and needs mapping. The leading coalition was expected to invest in assets and needs mapping, such as stakeholder and asset-based mapping of the municipality environment and a large-scale survey of inhabitants to describe existing capacities and needs. These identified stakeholders, strengths and needs would lay the foundations for the further development of activities.
4) Collaborating with diverse stakeholders within the city to develop activities and stimulate spontaneous community action. The leading coalition members were expected to consult their network to involve different city sectors and focus on enhancing cohesion among community members to promote community action.

Participants, data collection methods and procedures

While all residents of the participating cities were theoretical participants of the Compassionate Cities, data for this study were collected from four different groups of participants: (1) those involved in facilitating the development (project coordinators, project facilitator, city council representatives and researchers); (2) stakeholders with relevant backgrounds involved in the leading coalitions; (3) individuals directly involved in developing activities or specific initiatives within the Compassionate Cities but not part of the leading coalitions (e.g., school teachers); (4) individuals judged by the researchers to be (in)directly affected by the implementation of activities (e.g pupils).

Data collection methods included semi-structured interviews, observations, field notes and group discussions. Semi-structured interviews were conducted with the four research participant groups, exploring their experiences in the development process, acquired social capital, insights, and competencies and reflections. Prior to each interview, semi-structured topic guides were developed by BQ. Interviews addressed the project's overarching research questions,[22] but were tailored based on current development activities and what had been noted from previous data collections. After completing a written informed consent, the online and in-person interviews were always recorded and pseudonymisation guaranteed anonymity. Semi-structured observations occurred during all kinds of meetings and activities organised by different stakeholders involved in activity development. BQ and LDEE completed semi-structured observation templates during these meetings or activities, recording data like the objective, duration, reason for the meeting/activity, participants, occurrences and interaction or general reflections (Appendix 1 A1). BQ also collected documents, stakeholder outputs, emails, and photos. Field notes documented informal conversations with stakeholders and personal reflections. They were either integrated into observations or added as reflections to transcribed interviews.

Data consists of 86 interviews, 121 observations and 7 group discussions with stakeholders from both municipalities. Four group discussions included 18 pupils in total, two included four politicians and three civil servants in total, and one included 21 professional stakeholders. The interview data were generated by four project coordinators, four politicians, the project facilitator, 14 professional stakeholders, 18 pupils, 19 citizens and 12 (head)teachers. Observations mainly occurred between 2020 and 2022, when most meetings took place.

Researchers' positioning

Researcher roles evolved throughout the development process. Initially, they maintained a distance from the participants, interacting primarily to collect data.[23] However, recognising the value of researcher involvement in community-development projects, their role shifted over time. Project coordinators' work-related burden necessitated interventions that ensured project progress and, hence, the creation of research data. This involvement fostered rapport with study participants which facilitated access to research data and the communication of research results which contributed to the programme's development.[22] The researchers remained advisory and operational and did not participate in the decision-making or development process.

Data analysis

We used framework analysis (Appendix 1 A2) to analyse our research data. Our main interest was in the lived experiences of those affected by or involved in developing the Compassionate Cities and the significance and meaning they attributed to that process and project creations. Due to our large and highly diverse dataset, we needed an analysis approach that balanced analysis depth without delving excessively into each individual data source. The framework method allows the integration of a priori foci, while leaving room for identified themes of interest.[24] This combined deductive-inductive approach permitted the integration of constructs from the Consolidated Framework for Implementation Research (CFIR) which is recommended for Compassionate City evaluations.[14] Although this study's published research protocol stated that a critical realism lens would be applied, this study was ultimately not a realist evaluation in the strictest sense, although it was inspired by critical realism in several key choices.[22] First, the emphasis of critical realist evaluations on the context and mechanisms of change aligns with the CFIR, which was an important inspiration in drawing up the eventual framework used to analyse our data. Second, critical realism inspired us to explain the development of the Compassionate Cities. We gathered information on the objective reality which was further given shape by people's interpretations of, for example, the social environment. Third, our focus on the experiences of the individual study participants aligns with critical realism's stance on agency. Finally, a mixed-methods evaluation approach, as recommended by critical realists, was employed to uncover the reality of the intervention.

Interviews were recorded and transcribed in intelligent verbatim. Qualitative data sources were uploaded to the data analysis software NVIVO which allows for the integrated use of framework matrices.

The framework method typically involves five stages. First, the researcher familiarised with the data. Second, a framework was identified based on interests coming from the familiarisation stage, the research questions, the CFIR model and an earlier research project.[25,26] The framework permitted the data to be organised, with interpretations happening later. Researchers BQ, TS, KC and JC tested iteratively the framework on a selection of interviews. Coding discrepancies were discussed and the framework was refined again and again after a number of interviews. Third, sections of the data were indexed into the final framework categories. Fourth, the indexed data were summarised. Last, BQ interpreted the data by looking for links and contesting views to interpretations. As we had a large quantity of data, we made mind maps of the framework categories. This visual representation facilitated interpretation in the following stages and helped in identifying the most important elements.

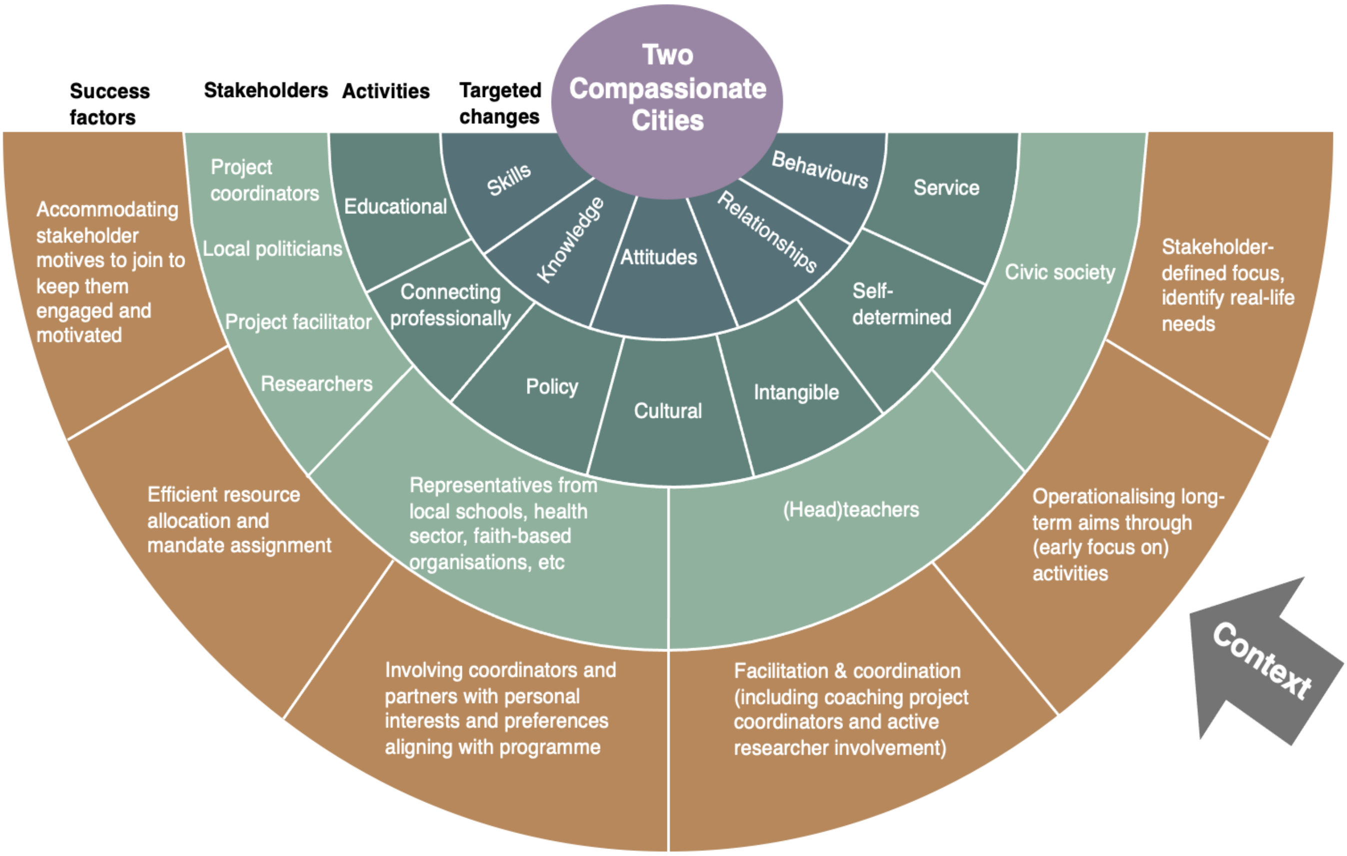
Ethics

The Medical Ethics Committee of the University Hospital Brussels approved this study with reference B1432020000186 on 16 September 2020.

Results

Both Compassionate City programmes exhibited both similarities and differences in their choices regarding development structures and the backgrounds of involved stakeholders. While their development, timing (Appendix 1 A3) and activities varied, similar implementation strategy characteristics either facilitated or hindered the Compassionate City programme (Figure 1). While the theoretical starting point of the Compassionate Cities was in late 2019, they followed a distinct timeline.

Figure 1: The two Compassionate City programmes with their targeted changes, the categories of their developed activities, stakeholders involved in or affected by the development and success factors identified in the data analysis.



Development structures formed and reformed

While both Compassionate Cities started with a leading coalition, there were marked differences over time in the structures formed and reformed. These are summarised in Figure 2. Both municipalities appointed a civil servant as the main project coordinator and appointed two responsible aldermen to join the leading coalition.

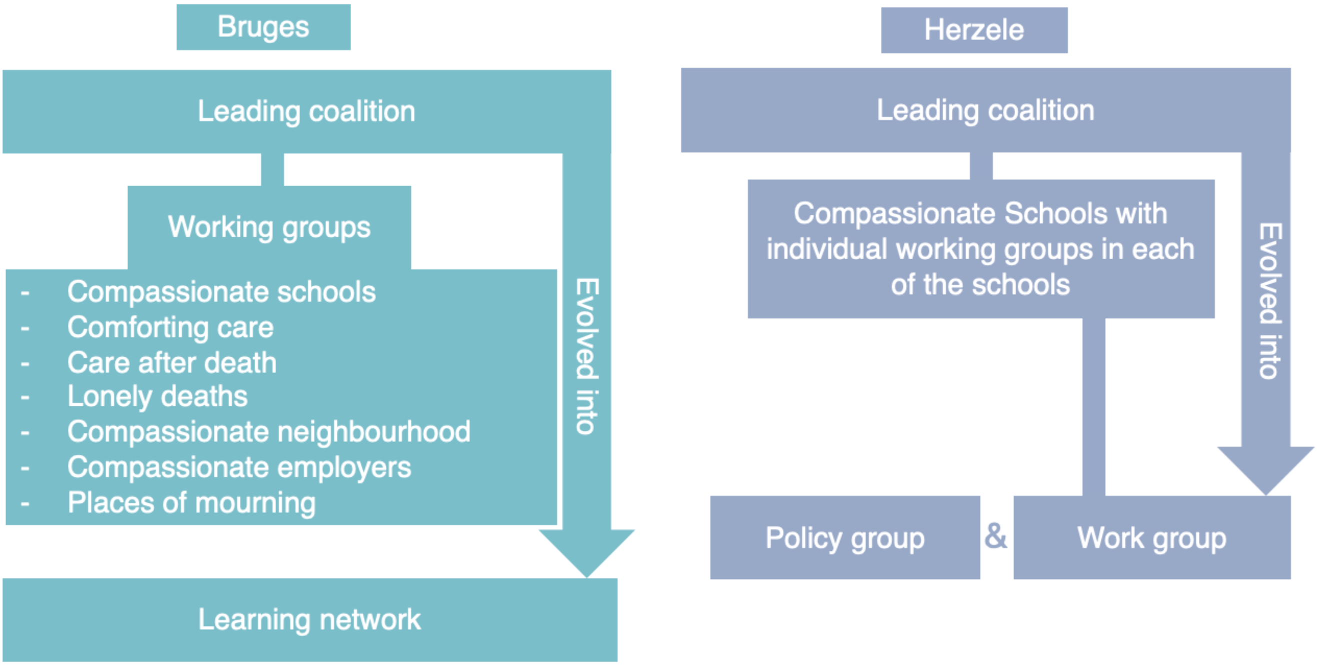
In Bruges, the project facilitator initiated a stakeholder mapping in 2019 which resulted in a leading coalition comprising stakeholders from healthcare, faith-based, education and other sectors. The leading coalition defined priority action areas which they deemed important to address, leading to the formation of seven working groups. These working groups would develop action plans and activities in those specific areas. By June 2021, only one working group (Comforting care) was actively developing actions; others were either planning actions or had become inactive. Participating stakeholders found leading coalition meetings too time-intensive, prompting the project coordinator to reduce their frequency, and focusing more on the individual working groups. This led to a short-lived change where the leading coalition would meet twice a year to make policy decisions and the working groups received individual support. Shortly thereafter, the leading coalition was disbanded and transformed into a learning network which, according to the project coordinator, better met the stakeholders' needs for information exchange.

> *When I see what the learning network does and the response it receives, it's actually tremendously significant. That's something that resonates well with many people, and that horizontal structure is there, it's not vertically organised, and I think we should continue on that path, the enthusiasm, that dynamism to join a learning network.*

This learning network, including both existing and new stakeholders, better responded to stakeholders' desires for increased connection and information exchange, and reduced pressure on the actual Compassionate City development.

In Herzele, an attempt was made to form a leading coalition with community members, which failed, after which aldermen prioritised developing Compassionate Schools before expanding to other city sectors. A leading coalition comprising aldermen, project coordinators and other civil servants coordinated the development. The coordinator developed a project plan, forming working groups within each Compassionate School to drive their practical development. Initially eight, then nine schools participated. Some working groups proactively developed activities while others responded mainly to input provided or requested by the project coordinator. Regular communication between the project coordinator and working groups provided them with support and input and ensured monitoring the development progress. Because of blurred boundaries between policy decisions and operational development, the leading coalition was transformed into a policy group containing the members from the original leading coalition, while the work group comprised only the project coordinator, facilitator and researchers.

Figure 2: The development structures in the Compassionate Cities and their evolution into their final form.



Stakeholder-developed activities

Various activities were developed as part of the Compassionate City programmes and diverse stakeholders were involved in or participated in these (Table 1). In Bruges, the working group Comforting Care was particularly active in collaborating with representatives of faith-based institutions, healthcare organisations, healthcare insurance organisations and civil servants from different city departments to develop actions. The decision to organise a thematic one-week city festival in 2022 on serious illness, caregiving, dying and loss (called '*Nodes festival*') led to engagement with a substantially broad coalition of stakeholders as illustrated by the project coordinator's reflection that this was an unprecedented diverse coalition.

> *That's the only time we've ever worked with so many partners in the city across different locations on one theme. Art, research, info fairs. The diversity we achieved in one week, no other project has ever matched that. It's unparalleled in our city.*

The stakeholders involved in activities through the city festival included both those established members of the different working groups as well as those from outside the existing programme structures. They represented cultural organisations/institutes (e.g., literary production organisation, museums), socio-cultural organisations (e.g., senior citizen advocacy organisation), schools, self-employed individuals (e.g., undertakers) or civil servants from other city departments (e.g., diversity). Some of the activities targeted specific stakeholder subgroups such as children, family caregivers or people with psychosocial vulnerabilities, but most sought engagement with all interested citizens.

In Herzele, due to the initial emphasis on Compassionate Schools, the stakeholders involved in developing school activities included school personnel, representatives from cultural institutes (e.g., public library), self-employed individuals (e.g., psychotherapists) and civil servants from various city departments (e.g., culture). The city project coordinator was extensively involved in all activities, reflecting the operational role they took in the Compassionate City programme. Also, a decision was made to organise a thematic programme on serious illness, caregiving, dying and loss, with activities spread over a one-month period. This led to the involvement of a wide diversity of stakeholders from various socio-cultural organisations (e.g., facilitating letter-writing to deceased loved ones), non-profit organisations (e.g., supporting parents who lost a child), primary healthcare organisations and self-employed professionals.

Table 1: All activities registered during the development of the Compassionate Cities which related to the end of life.

What activity	For whom	With whom developed	Category of end-of-life activity[27]
Bruges			
10 tips for consolation campaign: poster + bookmarks	Anyone but especially targeted at work environment	Secular humanists representative, coordinator Catholic organisation, death café organiser, coordinator palliative day-care centre	Educational Intangible
Red letterbox on market square: people could share their grief on a piece of paper during COVID-19, letters were later burned in a ritual	Anyone	Secular humanists representative, coordinator at Catholic organisation, death café organiser, coordinator palliative day-care centre	Cultural
Death café	Anyone grieving	Secular humanists representative, coordinator at Catholic organisation, death café organiser, coordinator palliative day-care centre	Educational Cultural Intangible
Developing consolation cards	Anyone but mostly children	Secular humanists representative, coordinator at Catholic organisation, death café organiser, coordinator palliative day-care centre, coordinator family care organisation	Cultural Intangible
The hour blue: writer talks about book he wrote on the loss of his father during COVID-19	Anyone	Secular humanists representative, coordinator at Catholic organisation, death café organiser, coordinator palliative day-care centre	Educational Cultural
Symbolic funeral of harmful words people use in trying to console grieving persons	Anyone	Secular humanists representative, coordinator at Catholic organisation, coordinator death café, coordinator palliative day-care centre	Cultural Connecting professionally

Poem recitals for lonely funerals	People who died in social isolation	Secular humanists representative, coordinator project against loneliness, coordinators literary production organisation, civil servants	Policy Cultural Educational Connecting professionally
“Do book” mourning and loss	Family caregivers	Coordinator family care organisation	Educational Self-determined Intangible
Opening place of solace	Anyone, but targeted at people living in neighbourhood of place of solace	Coordinators non-profit organisation providing family and community support services	Policy Cultural Intangible
Project to support those who lost someone close to them	Anyone grieving the loss of someone close to them	Civil servants, coordinator family care organisation, coordinator healthcare insurance	Policy Service
Butterfly card: a card hung on the door of the room of a terminal patient in a local hospital to inform others about the terminal situation	Professional care providers	Healthcare workers in hospital	Service
I SMiSs you: sending a text message to a person you miss, which was then shown on screens throughout the city	Anyone	Secular humanists representative, coordinator at Catholic organisation, coordinator death café, healthcare worker in hospital, coordinator healthcare insurance, coordinator palliative day-care centre, coordinator regional palliative care service	Cultural Intangible

End-of-life themed city festival activities			
Ceramics workshop: a workshop in which people bring broken ceramics and repair it in group	Anyone with a psychosocial vulnerability	Coordinator at socio-cultural organisation for artists with a psychosocial vulnerability	Cultural Intangible
Drawing workshop: drawing daily emotions and feelings	Anyone with a psychosocial vulnerability	Coordinator at socio-cultural organisation for artists with a psychosocial vulnerability	Cultural Intangible
Lifelong caregiver: lecture from expert by experience on caring for a child	For parents who have a child with care needs and for students	Coordinators 2 different family care organisations, coordinator volunteer organisation, coordinator socio-cultural organisation for senior citizens, coordinator organisation for people with a handicap, coordinator healthcare insurance	Educational
“Time for goodbye”: conversations with different representatives from different religions about loss	Anyone	Secular humanists representative, coordinators 2 different regional socio-cultural organisations, civil servant diversity department, civil servant cultural heritage department	Educational Intangible
Poem walk about loss	Anyone	Coordinator family care organisation, 2 art schools, coordinator university	Cultural Intangible
Art exhibition from artist who says goodbye to life	Anyone	Coordinator art school, coordinator university	Cultural
Time to say goodbye: posters about loss in different religions in local beguinage	Anyone	Civil servant cultural department, coordinator university	Cultural
Mourning ritual in church	Anyone	Coordinator Catholic organisation	Cultural Intangible

Workshop weaving your story in a god's eye	Anyone	Coordinator Catholic home care organisation	Cultural Intangible
Information lecture about informal care	Anyone	Coordinator Catholic care organisation	Educational
Stage play about grief and its universality	Anyone	Coordinator mental healthcare organisation	Cultural Educational Intangible
Talk before you go: experts talk about death and loss in our society	Anyone	Coordinator college	Educational
Photography exhibition about loss	Anyone	Regional socio-cultural organisation, photographer	Cultural
I'm compassionate about you: art exhibition	Anyone	Coordinator mental healthcare organisation	Cultural Intangible
Embrace your sorrow: workshop about what each individual needs to express their grief	Anyone	Coordinator mental healthcare organisation	Educational Intangible
Expert lectures about loss and grief	Anyone	Undertaker, healthcare worker in hospital, Coordinator Catholic organisation	Educational
Expert lecture about how people can support each other during situations of loss	Anyone	Coordinator library, mental healthcare expert	Educational Intangible
Information session about lonely funerals and financial support options for funerals	Anyone	Coordinator socio-cultural organisation against loneliness	Educational Service
Creative mourning	Children 6-12 years old	Coordinator organisation for children who lost a sibling	Cultural
Sharing is caring: peer support group	Young adults aged 16-30	Coordinator organisation for children who lost a sibling	Service Intangible

Information fair about loss and grief: support services	Anyone	Undertaker, Secular humanists representative, coordinator end-of-life information organisation, socio-cultural organisations, others	Educational Service Connecting professionally
Various information sessions: caring for someone at the end of life, talking about saying goodbye, palliative sedation and euthanasia, advance care planning, healthcare proxies	Anyone	Coordinator socio-cultural organisation that captures people's end-of-life stories, self-employed person who supports people at the end of life, coordinator healthcare insurance, Secular humanists representative, coordinators end-of-life information organisation, lawyer	Educational Connecting professionally
Death café about grief	Anyone	Coordinator death café	Educational Cultural
The Healing Museum: how a museum can support people around loss	Anyone	Museums, coordinator university	Cultural
The great crossing: public expression of grief	Anyone	Coordinator university	Cultural Intangible
Soul repair café: commemorate a loved one while having a drink	Anyone	Museums, coordinator socio-cultural organisation aimed at changing our grief culture, coordinator university	Cultural Intangible
Lecture grief at work	Professionals who have a mandate to support grieving colleagues	Various stakeholders from working group compassionate employers, coordinator college, coordinator palliative care unit, coordinator mental healthcare organisation, coordinator social welfare organisation, coordinator healthcare insurance	Educational Intangible

Experts by experience talk about the grief associated with their loss of health	Anyone	Coordinator organisation for people who experienced loss of health	Educational Intangible
Musical concert which explores our societal stance towards loss	Anyone who lost a loved one during COVID-19	Concert hall	Cultural Intangible
Comforting walk	Anyone	Coordinator Catholic care organisation	Cultural Intangible
Workshop advance care planning	Anyone	Coordinator healthcare insurance organisation	Educational Service
Singing while connecting to provide comfort	Anyone	Primary healthcare organisation	Cultural Intangible
Concert in which you can lay on the floor to connect with others	Anyone	Coordinator Catholic care organisation	Cultural Intangible
Open house in the local palliative care day centre	Anyone	Coordinator palliative day-care centre	Educational Service
Doctalks: compassionate documentaries.	Anyone	Coordinator socio-cultural organisation	Educational
Herzele			
Opening place of solace	Anyone, but targeted at people living in the neighbourhood	Project coordinator Compassionate City, civil servants from different city departments	Policy Cultural Intangible
Mailbox in schools in which pupils can post letters to talk about their problems	Young pupils	Project coordinator Compassionate City	Cultural
Development of a guide to support teachers with loss in schools	(Head)teachers	Project coordinator Compassionate City, researcher	Educational Intangible

Magic drops: art project in which children fill bottles with their sorrows	Young pupils	(Head)teachers	Cultural
Use of books for children to facilitate talking about loss	Young pupils	Project coordinator Compassionate City, (Head)teachers	Service
Visit to nursing home	Teachers and young pupils	(Head)teachers, coordinators nursing home	Educational
End-of-life art exhibition	Anyone	Project coordinator Compassionate City, artists	Cultural
Expert lecture on death and loss	Anyone	Project coordinator Compassionate City, librarian	Educational
Grieving bench	Young pupils	(Head)teachers, project coordinator Compassionate City	Cultural Intangible
Loss calendar	School personnel	Headteacher	Self-determined Cultural
Expert lecture on loss and grief in children	(Head)teachers	Project coordinator Compassionate City, psychotherapist	Educational
Compassionate training for teachers	(Head)teachers	Project coordinator Compassionate City, teacher trainer	Educational
Compassionate training for pupils	Young pupils	Project coordinator Compassionate City, psychologist	Educational Intangible
Month-long programme in the municipality: "Connection Comforts"			
Fair about the end of life	Anyone	Project coordinator Compassionate City, various coordinators from socio-cultural organisations, primary healthcare organisations, organisations aimed at specific subgroups such as parents who lost a child, psychiatrist, psychologist	Educational Connecting professionally Intangible

Poetry at the graveyard	Anyone	Project coordinator Compassionate City, artists, civil servants from other city departments	Cultural
Comfort library: library offers books on loss and grief	Anyone	Project coordinator Compassionate City, librarian	Educational Cultural
Comfort concert and poetry	Anyone	Project coordinator Compassionate City, artists	Cultural
Poetry about saying goodbye and grieving a loss	Anyone	Project coordinator Compassionate City, artists	Cultural
Informal caregiver café: writing about loss and grief	Family caregivers	Project coordinator Compassionate City, civil servants from other city departments	Educational Cultural Intangible
World lights day to commemorate deceased children	Anyone	Project coordinator Compassionate City, coordinator from organisation for parents who lost a child	Cultural Intangible

As some activities developed spontaneously, this list is incomplete. We only mentioned the partners who we were able to identify, likely more partners participated who are not mentioned. We based the categorisation on the structure proposed by Clark et al. (2017).[27] *Educational = Development of knowledge, skills, good judgment and character required for the delivery of appropriate end-of-life care; Intangible = Actions to promote the recognition and significance of aspects of human existence that have intrinsic value at the end of life; Cultural = Initiatives taken to influence patterns of shared knowledge and symbolic meanings in particular communities, through which people perceive, interpret, express and respond to end of life issues; Connecting professionally = activities with the implicit/explicit focus of connecting stakeholders; Self-determined = Actions, decisions or choices made by individuals to engage in or refrain from something that has implications for them at the end of their life or the life of another; Service = Medical, nursing and other services for the prevention, alleviation and/or reduction of suffering at the end of life through inpatient, outpatient, home care or other forms of services.*

Facilitation and coordination

We identified six main themes from the data related to how facilitation and coordination played a role in the development process.

The project facilitator dedicated a significant amount of time each week to **coaching both project coordinators** to develop their skills in co-creation, communication, organising meetings and overall project coordination. The project coordinators highly valued the project facilitator's coaching efforts.

> *I think the gift I received from the research group were you [researchers] and X [project facilitator] as sounding boards. Without you, I might have taken four years, but you always forced me to think or to think about certain things, and sometimes that was with resentment, but you pushed and forced me to think critically as a policy officer, that was a huge gift.*

Timely and transparent communication was essential in view of co-creation and stakeholder engagement. A teacher emphasised this importance.

> *I found the communication very difficult. On the one hand, there were emails sometimes months in advance that you would lose track of, on the other hand, there were last-minute emails to do things. Come on guys send that earlier, we need to organise that!*

A stakeholder from the working group compassionate employers remarked that **the project facilitator expedited the strategic decisions** of the Compassionate Cities. This was consequently observed and appreciated by stakeholders when asked to evaluate the project facilitator's role.

> *If X [project facilitator] hadn't been there, especially in the beginning, we would still be debating what to do. They were very decisive and could very well summarise or articulate the ideas that were growing around the table so that*

> *we could move forward. I think the project coordinator also benefited a lot from their presence. I saw them grow during that process.*

Both project coordinators encountered **challenges in engaging stakeholders**, leading them to independently design, develop, or execute actions. For example, we observed how one project coordinator personally informed pupils and teachers about the compassionate training and developed a guide on coping with loss in schools.

Stakeholders coordinating working groups encountered similar challenges which sometimes stemmed from the difficulty in incorporating participants' diverse opinions.

> *Maybe I also wanted to take too much account of everyone's opinions because I also know that my expertise is limited. No decisions were made, so I continued with the things I could work on myself, but separate from the working group.*

During interviews, stakeholders mentioned that their participation is motivated by a desire to benefit the organisation they represent. Such motivations included building professional connections, acquiring new information, and enhancing end-of-life experiences in specific populations. **Ensuring stakeholder commitment depended on accommodating their motivations**, as noted by a participating stakeholder.

> *When you engage in such projects, you don't just look at them from a societal perspective but also consider what my organisation and its stakeholders will gain from it. What will be the added value for them if I invest my time in this?*

The fact that the Compassionate City development took place in the **context of a research project** played a role for the project coordinators. On the one hand because they felt pressured to deliver results for the project, work with the project timeline, and build on existing academic literature and guidance,[28] as is expressed by a project coordinator about the ending of the research project context and the Compassionate City's subsequent continuation.

> *I am very grateful for the journey we have taken, but I am also grateful that it is over. Now I feel like I can start playing with that theme at the pace of the city, and I don't have to follow Kellehear's model anymore…Now, we will do what we want in the city.*

On the other hand, the involvement of researchers played a role in the coordination and facilitation. Throughout the development process, the researchers assumed a more facilitative role. For example, in one city they shared stakeholders' feedback on the meeting content of the leading coalition, which resulted in increased attention given to inspiring stakeholders with potential actions.

Underestimated development requirements was another theme related to facilitation and coordination. Particularly in the initial project phase, substantial effort and resources were needed to engage diverse stakeholders and create coherence. As a result, the project coordinators experienced a significant work-related burden. Their direct superior recommended that future Compassionate Cities ensure adequate resources for development.

> *Looking back, I think X [project coordinator] had too much on their plate to take this on as well. That may be another answer to the question of how another city should approach this; assume that human resources and time need to be invested, especially at the outset. Ensure the coordinator is somewhat freed up, that there is space to do it well. That was ultimately the biggest problem, too much all at once. That may have been unclear at the start…we underestimated how much work there would still be.*

Implementation characteristics that facilitated or hindered the Compassionate Cities' development

Regarding the implementation strategies, we identified five main themes that facilitated or hindered the development.

Stakeholders reported both **barriers and facilitators stemming from Compassionate Cities being led by city administrations**, as reflected upon by one stakeholder.

> *The advantage [of partnering with a city] is that you have a nice logo that fits well into a policy, and you have an alderman who cares, which can give it a push if your municipality supports it, which is great. But when you look at the disadvantages, it has brought a lot of resistance with it, certain partners who felt like, oh no, here comes the city with another nice logo and we have to follow along behind.*

A clear facilitator was that cities have access to resources, some of which are difficult or even impossible to find elsewhere, such as financial means, meeting locations or access to city communication channels and partners. However, stakeholders involved in the development mentioned that city administrations are often perceived as slow and bureaucratic.

> *The risk of political interference, sometimes the rigidity associated with administration, the bureaucratic system you have to work within. In a bureaucracy, there's less flexibility, but that's the same for large organisations, they're also bound by rules. We have to learn to live with that.*

Researcher observations and stakeholder interviews revealed that some city characteristics were perceived as barriers to the development. A lack of cooperation among different administrative city departments hindered participating stakeholders' access to and collaboration with these departments.

Multiple stakeholders reflected on how the city (or its politicians) tended to claim credit for output developed by others. While involved politicians' desire to be associated with the project demonstrated their commitment, it strengthened some stakeholders' impression that garnering attention is politicians' primary interest. This also pressured project coordinators to create visibility through activities, even when this did not align with the development plan.

> *They [politicians] all like being in the spotlight so much that even something unfinished or minor ends up on Facebook, leaving you thinking, "that's not what was planned," and if another alderman then puts it on Facebook, the original alderman misses out on the chance. So, it's a sensitive matter.*

As politicians' futures depend on re-election, they may exert pressure to deliver results. In one instance, the aldermen made promises to stakeholders that were ultimately not kept, causing frustration, as was repeatedly reported by (head)teachers.

> *We were promised various things; the local government would definitely assist and do things. I find that difficult because I quickly felt this is not going to work; they just can't handle it, it hasn't been thought through, it's just lobbying, promises made that were not inherent to the project*

We observed how an alderman who was not responsible for the Compassionate Cities showed minimal interest in supporting the programme's development. One project coordinator reflected on such political sensitivities.

> *Department X which falls under alderman Y is handled with kid gloves. First some preparatory work and then presenting the concept to others, ensuring that speeches are well-coordinated, that everyone gets equal time to convey messages. Collaborating like this isn't easy, but if you persist...*

Although multiple societal areas were targeted through working groups in one city, these working groups did not always address real-life needs, as mentioned by the project facilitator.

> *We should have approached this entirely differently, with a survey to determine where the need lies. Now you find yourself doing things that don't meet a need, causing them to stall.*

A project coordinator noted that civil servants’ commitment to their assigned projects is influenced by how well the content aligns with their personal interests and preferences, requiring some luck. As both project coordinators were highly interested in the Compassionate City topic, this served as a clear facilitator for development, as reflected upon by one project coordinator.

> *Your government personnel are civil servants, and you have to be fortunate with their involvement. In the private sector, you choose the company you work for, whereas as a civil servant, you are assigned a task. I'm fortunate that this suits me, but if I had to work on a topic that doesn't interest me for 3 years...*

Although the Compassionate Cities were portrayed as a co-creation development project, involved stakeholders perceived the reality differently sometimes.

> *Especially one working group had quite a few very good ideas or plans that ultimately were not realised because there was resistance in the city.*

Stakeholders commented that they perceived **the Compassionate City concept as vague and abstract, lacking conceptual coherence and understanding**. Without guidance on development, we relied on the Compassionate City Charter which does not provide an operationalisation.[28] A project coordinator noted stakeholders’ difficulties in understanding the concept.

> *The partners jumped into those working groups, and if I could do it again, I would spend much more time explaining the Compassionate City. I only gave one PowerPoint presentation on that. I never gave the professors a chance to speak to provide international good examples. We didn't do that for our partners. And when I call them, I notice they still find it vague.*

Although stakeholders understood the long-term aims of Compassionate Cities, they struggled in operationalising them. This prompted the main researcher to present examples of different activities from other Compassionate Cities (see *Facilitation and coordination*).

We frequently observed a strong willingness among stakeholders to broaden the Compassionate City focus beyond end-of-life aspects. Some emphasised that experiences of loss can also relate to health, friendships, or divorce.

> *I also hear from various people that it's very much about the end of life. Whereas we wanted to take that broader perspective and not just focus on the final phase.*

During development, we noted a **tension between Compassionate Cities' aims for culture change and stakeholder desires for immediate action**. The project facilitator consistently stressed this focus for culture change and resisted stakeholders' desires to develop tangible activities. This strategy stemmed from a concern that while individual activities might be valuable, they should contribute to the overarching cultural shift with associated long-term goals. During an observation, the project facilitator articulated this strategy.

> *We need to focus on the cultural change. If we offer them those actions, they won't pay attention to that cultural change. Actions alone don't create cultural change. They already do actions but without innovating.*

However, this approach did not resonate well with participating stakeholders and contributed to the vagueness and abstraction mentioned earlier. By the end of the Compassionate City programmes, the project facilitator acknowledged the value of concrete actions.

> *About those small actions, I had a judgment about them, that they don't lead to a vision. And I underestimated that they can lead to something. I've learned*

> *that. What I increasingly see myself doing is placing small actions in the context of cultural change.*

Some stakeholders naturally preferred to focus on activities. At times, discussions about defining long-term changes then felt counterintuitive and akin to slowing progress, as mentioned by a teacher.

> *It was a bit confusing, in education, we are doers, we want to do something and grasp it and see immediate results, and that's been the difficulty in my eyes in the beginning because you keep treading water and want to map out a lot, and we are doers and want immediate results, to have something finished, and that was my initial struggle, is something concrete coming now?*

Developing activities created a dynamic among stakeholders and fostered a shared sense of involvement, as mentioned by one of them.

> *We organised this lecture, and I felt that by working on something concrete, we were able to align our efforts and there was also a sense of involvement. I heard that from a number of people, by collaborating on something tangible, we came closer together.*

The adherence to the Compassionate City Charter for development and the ambitious focus on long-term cultural changes resulted in overambitious goal setting, according to a project coordinator.

> *Were we overly ambitious when we started? Absolutely. If another university or external partner were to propose such a concept again, I would say, "No, thank you, we won't do that. It just doesn't work. It's not the right approach." But you can only come to that conclusion by experimenting and experiencing it yourself because it sounded incredibly promising.*

Presenting a project in this way can intimidate stakeholders, especially if they feel such goals exceed their skills and capabilities. In Herzele, the formation of a leading coalition comprising community members failed because people felt they were not suited for such an ambitious project. During an observation, the researcher noted a civil servant's reflections.

> *X [civil servant] remarks that numerous individuals from the potential leading coalition have withdrawn due to the perception that the subject matter is too burdensome and challenging. There is a difficulty in connecting theoretical concepts to real-life applications, leading to high expectations that instil fear and a lack of confidence.*

In Bruges, the end-of-life themed festival left a lasting impact on the engagement of the city's civil servants. Such a festival created a unique environment that enabled various stakeholders to collaborate and inform the public. Such collaborations across administrative city departments were innovative and a first step toward integrating end-of-life issues in domains beyond the healthcare domain (e.g., culture). The project coordinator commented on this in an interview.

> *Before the Compassionate City project, I would never have been able to push such a festival through. Now there's a lot of enthusiasm to bring it back for a second time, and I think that's really great. Having such a social festival for our city is new…That's the only time in the city when we've worked with so many partners at different locations on one theme. Art, research, information fairs. The diversity we achieved in one week, no other project has done that before. It's unparalleled in our city.*

Stakeholders mentioned **the importance of having a clear mandate** defining their operational boundaries. For example, they mentioned confusion about the project coordinator's mandate.

> *Their role... I'm not sure about it, we've often been disappointed in it, not in the person but in the mandate they receive, or the limited hours. If you ask a question and progress is so slow that you can't get your thing done anymore. We have already asked ourselves a lot of questions about it.*

Even after receiving their mandate, project coordinators sometimes still struggled to execute it due to political interference in the actual project development, as mentioned by one project coordinator.

> *I struggle with that, and it concerns the mandate. I was hired as a project coordinator, and although I have experience, every project is new. You can leverage my experience, but it's always a challenge to reach a successful conclusion. I felt I had that mandate at the beginning until I started asking questions. They [aldermen] want to move forward and see results, but that's not the process. I then said, "whatever, let them do it," but I also told myself that it's not right because I don't agree, and actually, that disrupts the process we're in.*

Stakeholders were sometimes confused about the mandate they received by the city.

> *It's sometimes a bit strange this leading coalition, and I'm not quite sure, what is our mandate actually, and why are we here exactly, is this some kind of meeting to get us on board?*

During interviews, we found that not all leaders of the working groups desired this position, as reflected upon by a teacher.

> *[researcher] How did you end up being the leader of that working group?*
> *- Because they asked me to.*
> *[researcher] Were you yourself also eager to join the project?*
> *- I wasn't eager to join [laughs].*

Leading a working group was a vulnerable position when only one individual assumed that mandate. If that individual became unavailable for any reason, a replacement was necessary to prevent operational stalling. One stakeholder reflected on this.

> *For example, X's partner passes away and they drop out, and then the whole working group collapses, and that actually shouldn't happen. I always tell my people, make sure there are two of you in there, so that if someone drops out, there's a backup, then you can guarantee continuity.*

Some stakeholders could only participate in the development once they received a mandate from their employer as mentioned in an interview.

> *I also have my assignments and can't afford to invest a lot of my time in extra activities. That's why I think it's crucial, when I was approached to take on the lead role, I myself said that the question should be directed to my employer, who determines whether or not I will do it. If I got the green light, I had the mandate to do it within certain limits, and that makes it comfortable for me.*

The project facilitator often reflected on their struggles with their own mandate, which was to support the project coordinators and safeguard the research team's interests. This meant that even if they desired different development approaches, they lacked the mandate to implement such decisions.

> *But what mandate do I have to advocate such drastic decisions? As a consultant I would not hesitate to approach management and say, "Look, with this employee and this approach, it's not going to work, and we need this and that." But then I have a mandate to interfere because I'm paid as a consultant to realise a project…I have no mandate as a project facilitator to tell someone that their employee is not capable of doing it...I'm struggling with that.*

We noted that stakeholders' intrinsic motivations significantly impacted their involvement and proactivity. For example, we observed how a highly motivated headteacher consulted a grief expert on their own initiative. Conversely, we saw how stakeholders who were appointed to the project showed less proactivity.

In the Compassionate Schools, (head)teachers underwent a training on enhancing compassion towards pupils and colleagues. The trainer remained available after the training to provide advice on specific end-of-life situations. **Bringing in expertise** was highly valued by (head)teachers.

> *It's really important for us to have someone we can turn to. Someone who truly has the experience, vision to guide us in that, who can direct us to the right resources. Otherwise, you have to reinvent the wheel yourself, but now we're being handed it, and that's a real advantage.*

Contextual factors influencing the development process

Regarding the contextual factors that influenced the development process, we identified six main themes.

The **COVID-19 pandemic** hindered creating a shared vision, cohesion and ownership among leading coalition stakeholders, as reflected upon by the project facilitator.

> *If you simply assess that against change theory, it also rings true for me. In such meetings, strategic thinking and vision are necessary. Due to the impact of COVID-19, I feel like we couldn't work on that vision as we should have, which makes me think that we're already missing a significant part of that change theory.*

The project coordinator remarked the challenges of online meetings, especially during the early project phase when coalition building was crucial.

> *The initial setup we had was all digital. That was a loss in terms of building those personal relationships. Now, when I meet with my partners, I meet in person again. I take the time to say, "Are you coming here, or should I come to you?" It's*

> *a double time investment, but the gain you get from physically seeing someone, that makes such a huge difference compared to a digital chat, especially in building trust.*

The research team temporarily lost contact with Herzele due to the pandemic radically shifting the city's priorities. For example, we were briefed on how a project coordinator became involved in vaccination programmes and organising sanitation interventions at the local welfare centre.

The pandemic also greatly impacted the involvement of participating stakeholders. One teacher described the impact on their work.

> *At one point, we were dealing with COVID, plain and simple, not with developing cards and all those things. We were just organising who would be teaching tomorrow, who would supervise here, and whether there would be hot meals. We did nothing else, and then that was put aside, and the project coordinator probably didn't like that, but well... when there's a fire, you put it out first.*

Conversely, online meetings permitted greater participation from some stakeholders, which subsided once physical distancing measures were lifted as mentioned by several stakeholders.

> *During corona, we initiated larger projects because digital meetings made it easier to start bigger projects. However, this now means that with the combination of everything, we are reaching our limits. And personally, I feel that the commitments I made are difficult to combine.*

When starting a Compassionate City project, some stakeholders inevitably had **experiences from prior interactions**. Whether they were positive or negative, this influenced their continued cooperation as mentioned by a stakeholder.

> *During the lockdown, we organised a discussion café [outside of the Compassionate City programme] partnered with the city. But their communication about this event was so slow…I think we learned that we need to approach some things differently and do them ourselves. We did another discussion café again, and there were many more people, I think that has become the way of working.*

To initiate the leading coalition, the project coordinators contacted stakeholders they were already acquainted with. As a result, some felt that this hindered the involvement of non-typical actors.

> *I feel like we've focused too much on the typical actors. The secular humanist representatives have taken on a very active role, which is great, but that's their core business, so we assume they'll participate. But that broadening to other individuals and organisations hasn't happened for me. We made a broad stakeholder analysis, but were they then involved? No idea.*

Sometimes these experiences were based on particular reputations. Whether these were justified or not, it impacted the willingness to cooperate as remarked by stakeholders.

> *There is definitely a negative perception about organisation X. Of not having such a participatory climate and them being rather dominating. I don't have that experience myself, but I do notice that everyone says that, either it's true or it's a perception and that makes it true.*

Prior experiences with and perceptions about death and loss were important contextual factors in the development. Such experiences could lead to two outcomes: people became more or became less inclined to participate. For example, pupils in a group discussion shared how their teacher's personal experiences influenced their willingness to discuss death and loss.

> *Student 1: … when we start talking about it, she says: let's continue with our work, let's continue.*
> *Student 2: I think she has also experienced something herself and that's why she doesn't talk about it.*
> *Student 1: It might also be good for her if she talks about it sometimes.*

This was recognised by another teacher as well.

> *I have to say, I'm an emotional person, when I bring those books into the classroom [laughs], then I also get, well... I find it difficult to work with that, because, well, that emotional aspect, that's also present in me, I lost my dad four years ago, so when it comes to great sorrow, I find it difficult to deal with the children.*

On the other hand, some stakeholders' prior experiences made it easier for them to work with end-of-life themes.

> *Compassionate Cities and I, that was a good match, I've had a personal journey with a lot of experiences of loss, but I've also followed a training as a grief and loss counsellor. That's a common thread running through my life.*

A recurring theme was the **shortage of resources for development**, notably personnel, time, and money. In Bruges, the challenge of finding a second project coordinator impacted the primary project coordinator's responsibilities. Although they preferred policy work, the absence of a colleague required them to engage in practical tasks, as noted by the project facilitator.

> *You can't get the project coordinator on board because I suspect they don't have the time, don't see the big picture and are not interested because they prefer policy. If someone other than them were in charge, maybe it would have worked.*

Financial constraints were evident in both cities. In one instance, we observed the reallocation of dedicated funds for developing the Compassionate City to another social welfare project, which required a bureaucratic approval process for every expenditure. This severely discouraged the project coordinator's willingness to request funding due to the associated uncertainty in receiving it. In the other city, the financial situation was similarly challenging.

It was mentioned on several occasions that organisations are less inclined to participate once a competing organisation is involved, indicating the **competitive professional environment**. They may feel surpassed and thus unappreciated, hindering the goal of making the Compassionate City a city-wide project. A stakeholder remarked how they noticed this.

> *And something else I encountered, is the fact that from the health insurance organisations, I only see one being involved because I know it's sensitive regarding other health insurance organisations. And then I think, we shouldn't get burned by that, it should be approached across health insurance organisations. And I've also been approached by partners who say, "We want to participate but we can't get in, yet we see someone else from another organisation participating." I think you alienate people that way.*

This was also repeatedly mentioned by (head)teachers and although no-one wanted to actively sustain it, all recognised its existence.

> *The competitive rivalry between our schools has grown over the years, and I don't perceive everyone's involvement in it to be equally constructive. As the principal of a school, I believe it's my role to be part of a whole, and education in our city is a whole, regardless of the individual school's vision. I think it's important that we stand together for the children, regardless of the choices each school has made.*

Schools presented a context distinct from other environments. We observed that despite all schools having prior experiences with serious illness, death, dying or loss, and most pupils we interviewed having experienced the loss of someone close to them, (head)teachers lacked training to address such situations. A teacher echoed this deficiency.

> *As teachers, we are not always trained to handle certain things that come our way. But I notice that there is also a demand for further training of teachers, and in that regard, I see that a process has been initiated.*

The recruited teacher trainer observed inadequate support from the national organisation responsible for advising and supporting (head)teachers on this topic, motivating them to fill this gap.

> *I started that because I feel there's a void, but actually the student services should take care of that. The grief kit and everything I've made, that came about because I also felt like, well, the student services are making very good use of it now, and they're allowed to, but that should be part of their service, and then I wouldn't have to do all of that…And I do notice in the schools I've worked with that there's a big difference between student services, you have to be lucky with the professional that gets assigned to you.*

The academic calendar in schools, established before each academic year, presented challenges for initiating spontaneous (larger) activities due to its lack of flexibility. For example, we observed how some teachers could not be present at a workshop as some had an already-planned meeting. The project coordinator's eagerness to develop activities was sometimes met with frustration, as (head)teachers felt that people from outside the school environment lacked an understanding of school operations, as mentioned by a headteacher.

> *What I notice is that if you work in education yourself, you have a strong sense of what's happening in education, and I've heard from several schools that this*

> *is lacking somewhat with the project coordinator. The planning, ideally, should be set in September for the entire year; that's how schools operate. Not communicating things very late and then finding they don't fit.*

Interviewed (head)teachers repeatedly remarked that schools already handle multiple ongoing projects (e.g., on reducing bullying), making it challenging to prioritise the development of Compassionate Schools. With all projects advocating for justified urgency, (head)teachers find themselves burdened with responsibilities that extend beyond the typical cognitive scope of schools.

> *And we recently discussed with the project coordinator, that a lot is coming our way. This project, but many other things as well. Education is involved in everything in society, and everything is important, so it's sometimes difficult to make choices.*

Discussion

This process evaluation of two Compassionate City programmes highlights the important role facilitation and coordination played in development through coaching the city project coordinators, expediting strategic decisions, engaging with stakeholders to develop activities, coinciding with a research project, accommodating stakeholder motivations and considering development requirements. Several aspects of implementation facilitated or hindered development, including city administrations leading the programme, the time needed to develop conceptual coherence and understanding, tensions between distal cultural foci and immediate actions, the importance of mandates and expert guidance.

This research has several strengths. Two researchers conducted all observations and interviews over several years, establishing trust-based relationships with study participants. This facilitated access to research data and increased the likelihood of capturing genuine reflections, both positive and negative.[29,30] The main researcher's involvement in data collection and analysis ensured a high immersion in the data, informing subsequent analyses.[31] The researchers' impartiality, not being a resident or directly involved in developing the Compassionate Cities, mitigated observer and confirmation bias. Semi-structured interviews and observations allowed registering research interests, while also capturing any other relevant information.[30] Efforts were made to reduce social desirability bias. Several limitations should also be acknowledged. Although the development of the data analysis framework and data interpretation involved all authors, the indexing stage of the data analysis was performed by one researcher (BQ). Subjective interpretations (i.e., observer bias) and incomplete registrations can always occur in qualitative research.[32] Additionally, the researcher's personal attributes (e.g., age, professional background) and mere presence (i.e., Hawthorne effect) may have influenced data collection.[30]

Facilitation and coordination are recognised as integral to change projects as evidenced by their integration into process evaluation frameworks.[25,33] Facilitators are *"individuals who influence innovation decisions in a direction deemed desirable by a change agency"*.[34,35] Internal facilitators know and understand organisation culture but are more affected by internal politics. External facilitators typically empower participants more and have a clearer understanding of their roles, but require more time to build rapport.[36] In line with the literature, the facilitator in this research project, especially in the early project phases, was crucial in training leaders and bridging research-practice gaps.[34,37,38] We observed how they indeed focused on relationship building, empowering stakeholders and shared problem-solving.[34,37] This highlights the benefits of a shared vision among stakeholders, an important first step in creating cohesion.[39] We recommend using external facilitators with expertise in change processes and group dynamics to train future internal facilitators. Developing coordinators to communicate effectively and demonstrate democratic leadership is crucial for success.[40,41]

Our identification of important contextual factors and factors directly hindering or facilitating the development process suggests a need to focus on factors that contribute to the successful development of Compassionate City programmes. First, providing clear mandates sets the degrees of freedom within which project coordinators, facilitators, and participating partners are permitted to operate.[38] Rewarding participants by identifying and accommodating their motives is imperative to ensure their involvement and commitment.[42,43] Rewards can be material (e.g., access to meeting locations), social (e.g., meeting new people), or expressive (e.g., contributing to a good cause).[44–46] We observed how some highly-valued activities required minimal resources, such as grief expert guidance or disseminating support information. Project coordinators could facilitate an early focus on such low-cost activities, as they can foster a sense of cohesion and trust and build momentum among involved stakeholders.[39,43,47] Second, Compassionate City programmes warrant the resources needed to set up the structures that permit addressing their aims, goals, and activities. Involving partners with activist and intrinsic motivations from the outset efficiently allocates project coordinators’ time and energy.[48–52] Third, while Compassionate Cities aim for long-term and cultural changes toward environments that are supportive and inclusive of end-of-life situations, our findings indicate that progress is only made when participating stakeholders can focus on short-term actions. Project coordinators can then maintain the causal links between these actions and the desired long-term changes. Additionally, such actions are important for ensuring political engagement and commitment.[53] Fourth, engaging diverse stakeholders and allowing them to define the focus is crucial. While public institutions endorse community engagement,[54] our findings illustrate how external factors such as project coordinators' experience and knowledge or power dynamics between individuals can impact adherence to community engagement principles.[43] This governmental leadership, rather than healthcare institutions leading, sets our evaluated Compassionate Cities apart from previously described initiatives.[9–12] On one hand, this created a context where community engagement is influenced by sectoral divides corresponding to involved aldermen's political responsibilities and by operational terms such as adherence to administrative bureaucracy.[55] Achieving support from all targeted political domains before the project's initiation could accommodate this sectoral division.[52,56] On the other hand, our findings show how city administrations can play a vital role in accessing and mobilizing networks and resources.

Conclusion

Municipalities are theoretically uniquely positioned to develop socio-ecological programmes that promote wellbeing around serious illness, caregiving, dying and loss, bridging the social and medical domains associated with these experiences. Compassionate Cities have been proposed as the operationalisation of this concept. Our qualitative evaluation of the development process of two Compassionate City programmes illustrated how these programmes involved a variety of stakeholder profiles in developing heterogeneous activities. We delineated important aspects related to facilitation and coordination, as well as implementation characteristics that facilitated or hindered development. Additionally, we offered concrete guidance and key points for future Compassionate City programmes: identifying and accommodating stakeholder motivations, providing adequate resources that match the ambitions, involving coordinators and partners interested in the Compassionate City programme, considering facilitation and coordination strategies, optimising research assets, emphasising short-term together with long-term goals, and engaging stakeholders in formulating their needs and desires.

Declarations

Author contributions

All authors contributed to this paper and gave consent for publication.

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Competing interests

No conflict of interest.

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Appendix 1

A1: Observation template.

BASIC INFORMATION

Location		
Date		
Observer		
Is the activity taking place once or recurring?		
Objective of the observation		
Timeframe	Starting hour	
	Finishing hour	
	Total duration	
Permission from everyone to perform the observation?		

	OBSERVATION
8. REASON FOR THE ACTIVITY Why is this activity being organised? What are the goals of the activity?	
9. WHO IS PARTICIPATING? How many people are participating? What is their relevant background? Which and how many organisations participate? What role do people take up as part of this activity?	
10. HOW DID THIS ACTIVITY COME TO BE? Which stakeholders developed this activity? Which stakeholders execute the activity?	
11. OCCURENCES AND INTERACTIONS What is happening (verbal and non-verbal)? How do participants react on the activity? How does each person behave during the activity?	
12. RESULTS Was what was hoped to be achieved accomplished? If not, why not?	

13. EXTRA OBSERVATIONS Have things that were supposed to happen not happened? Why did this occur? Was there something that disrupted the activity	
14. GENERAL REFLECTION How did the activity proceed? What emotions were present? How did I feel after this activity?	

A2: Developed framework.

Main category	Subcategory	Category description
Independent context	Political, economic, technological, practical, cultural context.	Definition: We consider the political, economic, technological, practical, and cultural contextual situation that is clearly independent of the Compassionate City projects. Inclusion criteria: Data regarding the context that either (A) existed before the Compassionate City interventions or (B) occurred during the Compassionate City interventions but manifests independently (e.g., COVID), including the effects of these contextual factors. Exclusion criteria: Data concerning context where it is not clear if they were influenced by the Compassionate Cities; place these under outputs or outcomes. Pay attention to the potential influence of the themes of grief, loss, farewell, death.
	Social structures, networks and relationships	Definition: The nature and quality of social structures, networks, and relationships that exist independently of the Compassionate City projects. Inclusion criteria: Data on the general characteristics and (in)formal relationships between partners within the Compassionate Cities, as well as the description of consultation structures that exist independently of the Compassionate Cities (e.g., a city magazine, Facebook channel). Exclusion criteria: Data concerning the social structures, networks, and relationships that form within the development of the Compassionate Cities.
	Personality traits and characteristics	Definition: The characteristics of individuals involved in the development of Compassionate Cities that exist independently of the Compassionate City projects.

		For example, the lack of self-confidence in a project coordinator.
	Motivations, specific individual experiences, readiness, needs, or desires	The personal contexts of individuals and groups of people that make them more or less susceptible to the Compassionate Cities. Needs or desires refer to changes one would like to see within the organization/society. Exclusion criteria: Exclude data concerning what is being developed within the Compassionate Cities. Desires regarding what one wants to develop should be categorized under 'Reflections, evaluations, aspirations'.
Implementation process	Facilitation	Definition: All forms of governance utilised by project coordinators, project facilitators, champions, researchers or anyone else who participates in leading the development. The applied governance can be positive or negative. Exclusion criteria: Specific developments within the Compassionate Cities fall under 'Actions', such as the execution of an event.
	Intentions and plans	Definition: What intentions are expressed or what plans are made as part of the development of the Compassionate Cities. Inclusion criteria: All intentions and plans preceding an action, without necessarily leading to an action. Exclusion criteria: Do not code reflections or evaluations about these intentions or plans here; code them under 'Reflections, evaluations, aspirations'.
	Actions	Definition: The actions effectively carried out in the Compassionate Cities, which can be both actions set up within the Compassionate City and autonomously by partners. Inclusion criteria: Code all actions here that have a substantive link to the Compassionate Cities, regardless of whether they are a direct product of the Compassionate Cities. Exclusion criteria: Matters that are part of strategic decisions belong under 'Adjustments'.

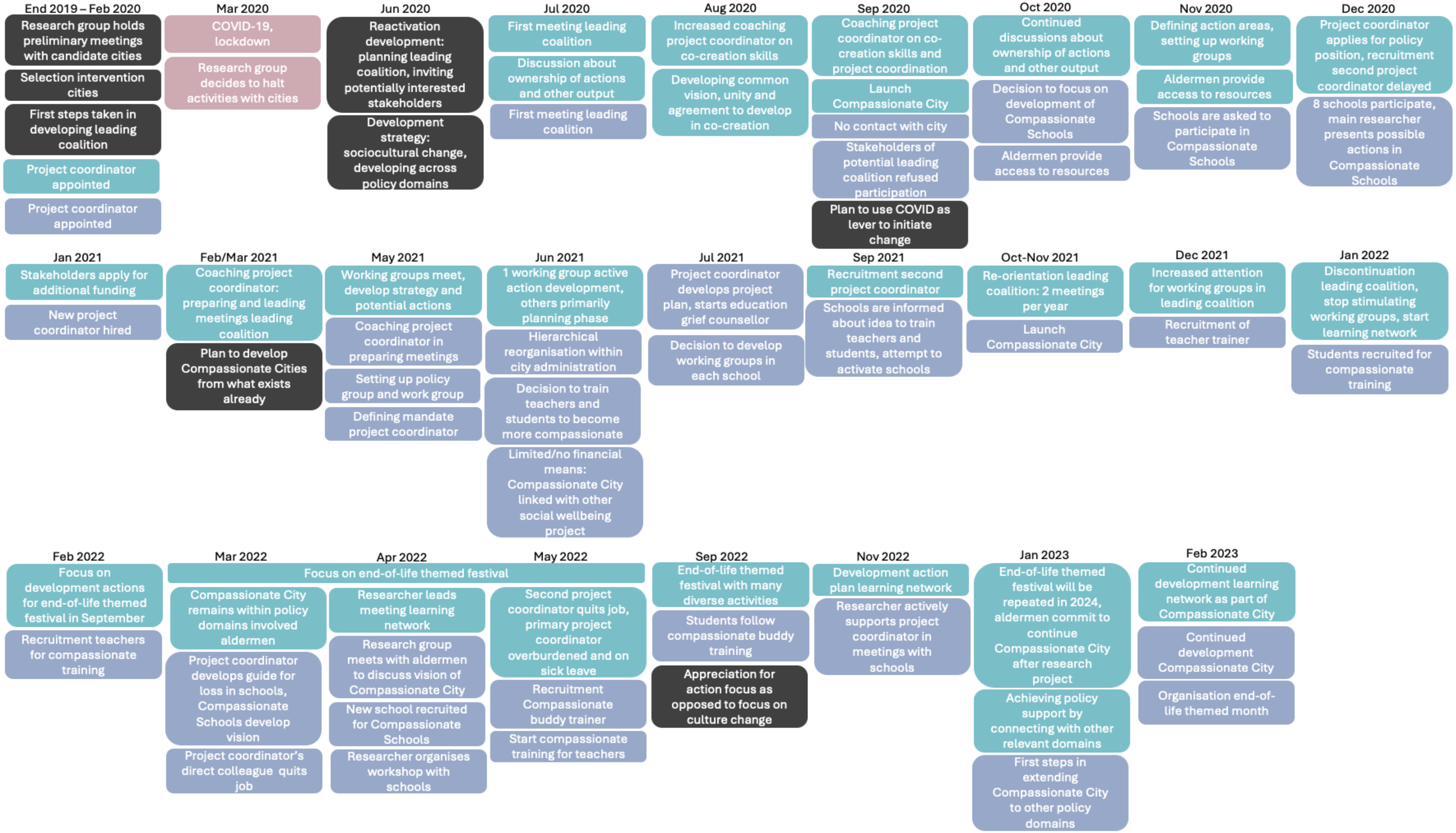
	Reflections, evaluations, aspirations	Definition: Reflections and evaluations on the process as well as the performance of individuals. The aspirations or desires of what one actually wants to undertake or still would like to see within the Compassionate Cities also fall under this category. Inclusion criteria: Assessments of the process. Exclusion criteria: Concrete intentions to carry out an action belong under Intentions & Plans. Evaluating actions belongs under Assessments & perceptions.
	Adjustments	Definition: The concrete adjustments made based on reflections, evaluations, and aspirations. Exclusion criteria: All data concerning adjustments that should happen but are not demonstrably (not happened). Also, everything related to achievements as part of the Compassionate Cities belongs under 'actions'.
	Conceptual application of Compassionate Cities	Definition: All elements related to how the Compassionate City concept is interpreted and understood. For example: data about difficulty understanding what Compassionate Cities are, broadening the initial focus of Compassionate Cities (such as inclusion, bullying behavior, or focus on general well-being).
Mechanisms of change	Outputs	Definition: The direct results or consequences of the actions. For example: 12 children have been trained as compassionate buddies.
	Assessments & perceptions	Definition: The way stakeholders react to specific actions, achievements, and activities of the Compassionate Cities. Exclusion criteria: New insights and skills are coded under 'individual and group developments'.

Outcomes	Individual developments	Definition: All developments at the individual level. Such as the development of new insights, knowledge, skills, attitudes. Changes in thinking or in the relationship the individual has with someone else. For example, the development of self-confidence, interest, skills, or new/changed social interactions. Inclusion criteria: Code all outcomes, regardless of whether they are the result of Compassionate City interventions. Exclusion criteria: The effective consequences resulting from changed group developments are coded under action-oriented or strategy-oriented outcomes.
	Group developments	Definition: All developments at the level of group(s) of people (e.g., organisations, neighbourhoods, or society). Such as the development of new insights, knowledge, skills, attitudes. Changes in thinking or in the relationships or dynamics within and outside the groups of people. For example, a more open communication culture at work. Inclusion criteria: Code all outcomes, regardless of whether they are the result of Compassionate City interventions. Exclusion criteria: The effective consequences resulting from changed group developments are coded under action-oriented or strategy-oriented outcomes
	Action-oriented outcomes	Definition: Changes in what people effectively do spontaneously, both within and outside their organisations, as a result of being exposed to the Compassionate City. Applications of lessons learned. Inclusion criteria: Code all outcomes, regardless of whether they are the result of Compassionate City interventions.
	Strategy-oriented outcomes	Definition: Stakeholders use their experiences of participating in the Compassionate Cities and what they have learned to change the functioning of the practice and/or policy. This can involve embedding it at a higher level within the organization or society. For example, information exchange outside the group of Compassionate Cities stakeholders.

		Inclusion criteria: Code all outcomes, regardless of whether they are the result of Compassionate Cities interventions.
	Negative outcomes/ absence of outcomes	Definition: The negative outcomes or the absence of outcomes that were expected. Inclusion criteria: Code all outcomes, regardless of whether they are the result of Compassionate City interventions.

A3: Development timeline of the Compassionate Cities.

Black = overarching events; Light blue = events in Bruges; Dark blue = events in Herzele; Pink = COVID-19 related events.



End 2019 – Feb 2020
Research group holds preliminary meetings with candidate cities
Selection intervention cities
First steps taken in developing leading coalition
Project coordinator appointed
Project coordinator appointed

Mar 2020
COVID-19, lockdown
Research group decides to halt activities with cities

Jun 2020
Reactivation development: planning leading coalition, inviting potentially interested stakeholders
Development strategy: sociocultural change, developing across policy domains

Jul 2020
First meeting leading coalition
Discussion about ownership of actions and other output
First meeting leading coalition

Aug 2020
Increased coaching project coordinator on co-creation skills
Developing common vision, unity and agreement to develop in co-creation

Sep 2020
Coaching project coordinator on co-creation skills and project coordination
Launch Compassionate City
No contact with city
Stakeholders of potential leading coalition refused participation
Plan to use COVID as lever to initiate change

Oct 2020
Continued discussions about ownership of actions and other output
Decision to focus on development of Compassionate Schools
Aldermen provide access to resources

Nov 2020
Defining action areas, setting up working groups
Aldermen provide access to resources
Schools are asked to participate in Compassionate Schools

Dec 2020
Project coordinator applies for policy position, recruitment second project coordinator delayed
8 schools participate, main researcher presents possible actions in Compassionate Schools

Jan 2021
Stakeholders apply for additional funding
New project coordinator hired

Feb/Mar 2021
Coaching project coordinator: preparing and leading meetings leading coalition
Plan to develop Compassionate Cities from what exists already

May 2021
Working groups meet, develop strategy and potential actions
Coaching project coordinator in preparing meetings
Setting up policy group and work group
Defining mandate project coordinator

Jun 2021
1 working group active action development, others primarily planning phase
Hierarchical reorganisation within city administration
Decision to train teachers and students to become more compassionate
Limited/no financial means: Compassionate City linked with other social wellbeing project

Jul 2021
Project coordinator develops project plan, starts education grief counsellor
Decision to develop working groups in each school

Sep 2021
Recruitment second project coordinator
Schools are informed about idea to train teachers and students, attempt to activate schools

Oct-Nov 2021
Re-orientation leading coalition: 2 meetings per year
Launch Compassionate City

Dec 2021
Increased attention for working groups in leading coalition
Recruitment of teacher trainer

Jan 2022
Discontinuation leading coalition, stop stimulating working groups, start learning network
Students recruited for compassionate training

Feb 2022
Focus on development actions for end-of-life themed festival in September
Recruitment teachers for compassionate training

Mar 2022
Focus on end-of-life themed festival
Compassionate City remains within policy domains involved aldermen
Project coordinator develops guide for loss in schools, Compassionate Schools develop vision
Project coordinator's direct colleague quits job

Apr 2022
Researcher leads meeting learning network
Research group meets with aldermen to discuss vision of Compassionate City
New school recruited for Compassionate Schools
Researcher organises workshop with schools

May 2022
Second project coordinator quits job, primary project coordinator overburdened and on sick leave
Recruitment Compassionate buddy trainer
Start compassionate training for teachers

Sep 2022
End-of-life themed festival with many diverse activities
Students follow compassionate buddy training
Appreciation for action focus as opposed to focus on culture change

Nov 2022
Development action plan learning network
Researcher actively supports project coordinator in meetings with schools

Jan 2023
End-of-life themed festival will be repeated in 2024, aldermen commit to continue Compassionate City after research project
Achieving policy support by connecting with other relevant domains
First steps in extending Compassionate City to other policy domains

Feb 2023
Continued development learning network as part of Compassionate City
Continued development Compassionate City
Organisation end-of-life themed month

PART 4: GENERAL DISCUSSION AND RECOMMENDATIONS

GENERAL DISCUSSION AND RECOMMENDATIONS

The aim of this dissertation was twofold. The first aim was to inform the development of Compassionate Cities by identifying the existing scientific knowledge on Compassionate Cities and Communities, and examining the attitudes and experiences of citizens in the general population regarding aspects related to serious illness, dying, caregiving, and providing support. This aim was addressed by performing a systematic integrative review of international Area-Based Compassionate Communities **(CHAPTER I)** and by conducting a survey in four municipalities in Flanders, Belgium, to study, among other things, the general population's discomfort towards the suffering and dying of others **(CHAPTER II)** and their willingness to support neighbours who are facing situations of serious illness, caregiving, and loss with practical or emotional tasks **(CHAPTER III)**.

The second aim of this dissertation was to evaluate the process of development of two Compassionate Cities in Flanders, Belgium, that were developed as part of my research project. I developed and published a study protocol describing a process and outcome evaluation study of these two Compassionate Cities **(CHAPTER IV)**. The announced outcome evaluation falls beyond the scope of this research project. Finally, I analysed and described the development process of the two Compassionate Cities **(CHAPTER V)**.

The discussion section of this dissertation presents a summary of the main findings of my research. Next, I discuss the strengths and limitations of the methods used in this research project. Then, I discuss the findings and lessons learned. These findings will be further considered in light of the current state of affairs within research around public health approaches to the end of life. Finally, I discuss the implications and offer recommendations for practice, potential future research, and policy.

Summary of main findings

I described the existing knowledge base on international Compassionate City and Community initiatives in terms of their contextual characteristics, processes of development, and evaluations (CHAPTER I).

I conducted a systematic integrative review of worldwide Area-Based Compassionate Community initiatives. My systematic search of the peer-reviewed literature yielded 1,464 articles in total. By excluding duplicates and screening articles' titles and abstracts, 113 articles remained which underwent full-text screening. The screening process was independently performed by two researchers. In cases of disagreement on the inclusion of an article, a third researcher made the final decision. This process led to the exclusion of 92 articles. After using the snowball method and searching the grey literature, an additional 5 articles were identified, resulting in a total of 26 included studies on 22 unique initiatives. The supplementary grey literature search additionally yielded several documents, websites, and books on already-included initiatives.

The identified Area-Based Compassionate Community initiatives were located in high- or middle-income countries in Europe, South America, North America, Australia, India, and South Africa. The majority comprised an individual town or city. Population numbers in these Compassionate Cities and Communities varied widely, ranging from 3,000 to over 500,000 inhabitants. The initiatives were launched for various reasons, which can all be grouped under addressing healthcare system gaps (e.g., shortage of resources) and addressing societal challenges (e.g., loneliness). All had the overarching aim to improve the health of their targeted populations, most specifically in relation to the end of life. We found that initiatives commenced under the impulse of either healthcare-oriented (non-)governmental organisations, academic researchers, policymakers, or a combination thereof. Diverse sources of funding were identified. Initiatives relied on different stakeholder groups for their development such as policymakers, professionals from other organisations, and laypeople who were sometimes volunteers. All activities taking place in these Compassionate Cities and

Communities fell under the action areas of the Ottawa Charter for Health Promotion.[1] Ten initiatives underwent some form of evaluation using either quantitative and/or qualitative methods. These evaluations reported on outputs, outcomes, and/or the process of development but lacked a transparent, holistic vision of the contexts and mechanisms that led to these results, which hampered the interpretation of these findings.

I described the general population's discomfort with the suffering and dying of others and whether these feelings are associated with specific personal characteristics or experiences (CHAPTER II).

Of 4,400 questionnaires sent to a random sample, 2,135 were returned. After removing duplicate questionnaires, questionnaires filled out by others than the intended person, and questionnaires in which the missing data of the main outcome measure exceeded 80%, 1,890 (43.0%) were left for data analysis. On a scale ranging from 1 (not uncomfortable) to 5 (very uncomfortable), people scored an average of 3.74 (SD = 0.89). Watching a person suffer from pain (4.24; SD = 1.01) and having to be the one to tell a person that (s)he is dying (4.37; SD = 1.01) resulted in the highest discomfort, while having a person want to talk about death with the respondent resulted in the lowest discomfort (2.91; SD = 1.35). We found significant associations between lower discomfort around the suffering and dying of others and cultural exposure to death and dying ($r = -0.136$; $P < 0.001$), having worked in healthcare ($r = -0.162$; $P < 0.001$), having been with someone else at the time of their death ($r = -0.107$; $P < 0.001$), having experience as a volunteer around serious illness, death, dying, and mourning ($r = -0.084$; $P < 0.001$), and not being religious ($r = -0.064$; $P < 0.01$). These findings support prior research on experiential learning which indicates that changing people's attitudes through specific topic-related experiences is possible.

I described the general population's willingness to emotionally or practically support their neighbours who are facing situations of serious illness, caregiving, and loss and whether these feelings are associated with specific personal characteristics or experiences (CHAPTER III).

Of the 2,135 returned questionnaires, 1,851 (42.1%) remained after exclusion following the same steps as described for CHAPTER II. Respondents were presented with two cases assessing their willingness to support neighbours practically or emotionally. Case 1 presented an older person who was incapacitated and in need of help. Case 2 presented a person whose partner was seriously ill and nearing the end of life. Responses were registered on a Likert scale ranging from 1 (definitely not) to 5 (definitely). People's average willingness in case 1 was 3.41 (SD = 1.00) and 3.85 (SD = 0.95) in case 2. In both cases, respondents' answers showed that willingness was highest for doing groceries (3.98; SD = 1.11 and 4.12; SD = 1.04). In the first case, cooking for the person in need yielded the lowest willingness (3.11; SD = 1.35), whereas in the second case, the lowest willingness was found in the situation where respondents would have to keep the dying person company (3.59; SD = 1.16). Higher willingness was found in respondents who were female, religious, had personal experiences with care and illness (i.e., were culturally exposed to death and dying, had experience as a family carer, or as a volunteer around serious illness, death, or dying, had been with someone else at the time of their death), mourned a loss, had experience as a volunteer, had better (self-estimated) knowledge of palliative care, and believed they would receive support from others themselves if they fell ill. The findings suggest that community members are generally willing to assist individuals with support needs in their neighbourhood, which is a strong argument supporting the idea of implementing community-based care provision. This approach can be an important component of health policies that aim to respond to challenges associated with the rising proportion of people with health-related suffering who live in the community, and the associated burden healthcare systems face today.

I described the process of development of two Compassionate Cities (CHAPTER V).

I categorised data from 86 semi-structured interviews, 121 semi-structured observations, 7 group discussions, and numerous field notes into a self-developed research framework. Both Compassionate Cities followed distinct development processes. In Bruges, a leading coalition was formed with stakeholders from healthcare, faith-based, education, and other sectors. The leading coalition identified societal needs which they aimed to address through different working groups, each focusing on these specific needs. Eventually, a learning network was constructed to facilitate information exchange and professional connections. In Herzele, the focus was set on the development of Compassionate Schools with an ambition to later extend to the full community. Each school formed working groups to coordinate the development of the programme within their school.

In both Compassionate Cities, numerous activities took place with educational, cultural, policy, self-determined, healthcare service, intangible, or professional connection focuses.[2] We identified different stakeholders who participated in the development of these activities. Most activities were developed for the general population, but some targeted subgroups such as children. I described how the development structures and procedures were revised. I further described the important aspects of facilitation and coordination in developing the Compassionate Cities which related to coaching of the city project coordinators, expediting strategic decisions, engaging with stakeholders to develop activities, the coincidence with a research project, accommodating stakeholder desires and taking development requirements into account. Next, I identified the characteristics of the implementation strategies that facilitated or hindered the development of the Compassionate Cities: cities leading the programme, the importance of developing conceptual coherence and understanding, tensions between working towards distal culture change and immediate actions, and the importance of mandates and expert guidance in working on the programme. Last, six main themes were identified as contextual factors influencing the development process: COVID-19, experiences from prior social or professional interactions, prior death and loss experiences, resource shortages, competitive professional environments and the distinct school context in Herzele.

Methodological considerations: strengths and limitations

To address the research aims, I applied a mixed-methods research design using both quantitative and qualitative data collection methods. By gathering information from stakeholders who were involved in or facilitated the development of the Compassionate Cities, their multifaceted perspectives allowed for a comprehensive understanding of the topic under study. I now discuss the most important strengths and limitations of the applied methodological approaches to provide transparency about how they can impact the conclusions that can be drawn from the findings.

Systematic integrative review

Strengths

In this review, I utilised peer-reviewed literature, websites, books, and documents. Integrative reviews are a suitable method that permits the integration of different data sources to discuss the current state of knowledge on a particular phenomenon, in our case, Compassionate Cities and Communities. Integrative reviews allow for a systematic, holistic understanding of heterogeneous and context-specific programmes and apply a broader perspective than typically found in systematic reviews.[3] When performing an integrative review, the inclusion of studies regardless of their research design is permitted.[4] This review method suited our needs for identifying the contextual characteristics, development processes, and outcome evaluations of Compassionate Cities and Communities. One of the main strengths of our integrative review was its exclusive focus on Compassionate Cities and Communities, achieved through the application of a clear definition and in- and exclusion criteria. Two researchers independently conducted the entire article screening process. Our results provide valuable insights into the increasingly popular but poorly understood operationalisation of new public health approaches to the end of life, complementing two previously published reviews.[5,6] Our systematic approach in collecting data and the adherence to PRISMA guidelines reduced the chance of bias.[7,8] As the focus of this review was on the information from initiatives rather than the scientific rigor in the included studies, we were able to include a greater number of studies and consequently extract more information than if we had based our decision on inclusion solely on a quality appraisal.

Limitations

A limitation of this review is that only English-language data sources were included. Because Compassionate Cities and Communities are being developed in many different countries, it is likely that publications exist in languages other than English. The decision to include geographically defined Compassionate Cities and Communities was based on the choice to exclude initiatives that targeted specific places with specific populations, such as compassionate workplaces, schools, or hospices, as opposed to the general population. This approach likely resulted in the exclusion of Compassionate programmes with relevant information. Although we included grey literature in our search, it was primarily used to supplement information on initiatives already identified through the peer-reviewed search. Given that a significant amount of information about initiatives is available on websites, documents, student theses, and other sources, a systematic review of grey literature is likely to uncover information and initiatives that were not identified through the peer-reviewed search. As most of our included studies reported positively on the impact of initiatives, grey literature may be very useful in identifying contesting impact information since this information is less likely to be published.[9] Additionally, many initiatives may not even be (in)formally described.[10] For practical reasons, a second reviewer performed only 20% of the data extraction process while 100% would have boosted the research’s rigor.

Cross-sectional survey study

General strengths

Both the concepts of discomfort around the suffering and dying of others and willingness to help neighbours practically or emotionally are core concepts in the thinking about Compassionate Cities and the mobilisation of community assets to support people experiencing challenges of serious illness, death, dying, and loss. However, they had never been studied before and as a consequence, also lacked a measurement operationalisation. Because of this, we developed our own measures instead of relying on previously validated instruments. The development of the entire questionnaire was coordinated by several recognised experts in the domains of end-of-life care, ageing, and public health. By refraining from using negatively loaded words like anxiety, fear, or disturbed and opting for the more neutral formulation of uncomfortable, we reduced the likelihood of biasing people's responses in a certain direction. Research indicates that people often interpret care restrictively, focusing primarily on physical assistance needs, thereby neglecting other types of support.[11,12] Despite the fact that care can also include spiritual, emotional, or instrumental support, some respondents might not have perceived the types of support we proposed as "caregiving", which explains my decision to operationalise caregiving.[13] By considering people who lived in the neighbourhood of the respondent and whom the respondent was largely unfamiliar with, this research provided important insights into activating the dormant social capital surrounding people with support needs, which is a primary aim of Compassionate Cities and Communities.[14] This consideration of neighbours likely resulted in reduced social desirability bias, as frequently observed in similar research on family care where individuals well-known to the caregiver are typically considered.[14] An external language service reviewed the language used, and the entire questionnaire underwent cognitive testing among 15 people to ensure face validity. The interpretation of the observed results was facilitated by effectively using tables, as has been recommended.[15] The population-based survey used random sampling of the populations in four municipalities; hence, the results are generalisable to the entire population in those municipalities. Moreover, the purposive selection of both urban and semi-urbanised municipalities increases the external validity of the findings and their potential generalisation to other municipalities. Several evidence-based methods were applied to increase the response rate, including Dillman's total design method, resulting in reasonable response rates for both outcome measures studied (43.0% and 42.1%).[16] The strict procedures to guarantee data protection and pseudonymisation likely contributed to the achieved response rates. The Consensus -Based Checklist for Reporting of Survey Studies (CROSS) reporting guideline was followed for both publications.[17]

General limitations

The instruments used to measure the concepts of discomfort around the suffering and dying of others and willingness to help neighbours practically or emotionally were self-developed and therefore not previously validated. This means that measurement bias (e.g., discrepancies between the concept and what is actually measured) and content validity are thereby not guaranteed. However, we tried to achieve a certain level of content validity through cognitive testing. As our survey was conducted in four municipalities, and findings are likely to be influenced by local socio-cultural factors,[18] It may not be possible to generalise to the full national population or other populations. The survey revolved around the end of life, which could evoke feelings of anxiety and therefore reluctance to participate or increase the chance of answering more positively.[19] This means that the possibility for non-response and response bias need to be acknowledged.[20] While our survey was not aimed at addressing causal questions per se, we were interested in examining associations between our core constructs and sociodemographic categories, experiences, and attitudes. As it is hard to make sense of associations without any causal thinking, we made causal diagrams (Directed Acyclic Graphs) to identify the most appropriate deconfounding strategies.[21] This also avoids the so-called 'Table 2 Fallacy' (i.e., difficulties in interpreting whether the shown values of variables are direct or total effect sizes, which was negated by explicating for which variables the shown variable had been controlled).[15] However, it should be noted that cross-sectional survey designs are notably poor designs for drawing causal inferences between different variables.[22] Not only do they provide limited control over temporality (i.e., the exposure happening before the outcome investigated), but they also offer little control over various sources of (residual) confounding.[21,23,24] Although people's discomfort around death and dying and their willingness to help their neighbours practically or emotionally was studied, the reported results do not provide any insight into people's actual behaviour when they meet someone who faces serious illness, death, dying, or grief and needs some form of assistance.

Process evaluation

Strengths

To evaluate the process of development of the two Compassionate City programmes, we used the framework approach as a data analysis method. In developing our framework, we drew inspiration from the Consolidated Framework for Implementation Research (CFIR), which Bakelants et al. (2022) suggested as a useful framework for Compassionate Community process evaluations.[25,26] As no previous framework existed that could be applied in research projects on Compassionate City or Community initiatives, we believe our developed framework is well-suited to capture the essential information on contextual factors, development processes, mechanisms of change, and outcomes. Compassionate Cities and Communities are complex initiatives tailored by various involved stakeholders with heterogeneous profiles. Additionally, the used data set was substantially large which makes the framework method a suitable method to capture people's lived experiences and the significance they attribute to anything taking place.[27] Furthermore, the developed framework is applicable in subsequent Compassionate City or Community process evaluations, facilitating their comparability. I performed both the data collection and analyses, which has been identified as an asset as it ensures data immersion.[28] Considering that the same individuals took part in multiple interviews, their reflections on the development process were taken into consideration when interpreting the data, incorporating both their earlier and more recent perspectives. The utilisation of various data collection methods to document the evolution of Compassionate Cities ensured diverse perspectives in the eventual data analyses. As the data has been accumulated over several years, it offers valuable insights into the initial phases of Compassionate City development.

Limitations

Having more than one researcher analyse the data would have definitely strengthened the rigor of this research and its reported results.[29] Due to practical constraints, I was unable to identify every individual involved in designing or developing activities within the Compassionate Cities for interviewing. This inevitably resulted in incomplete reflections on the identified themes reported in this research. Exploring the motivations of those who chose not to participate, as well as conducting a deeper investigation into the experiences of individuals not engaged in the development, would have added valuable insights. Exploring in-depth the experiences of people who participated in developed activities, as well as non-involved politicians' opinions about the Compassionate City programmes would have been useful additions. It's important to acknowledge that any selection of data collection methods carries inherent limitations, and alternative approaches such as photovoice, go-along interviews, or the use of journals by participating stakeholders could have provided valuable perspectives. The findings coming from the chosen qualitative data collection methods are subject to observer bias. I personally established contact with the interviewed individuals and developed the interview guides and observation templates. Hence, it is essential to consider selection bias when interpreting the results.[29]

Researcher reflexivity

As a researcher, I served as the primary observer, collector, and analyser of the data. While researchers strive for objectivity, complete assurance is unattainable because inherent biases, influenced by personality traits, preconceptions, physical appearances, and scientific experiences, inevitably influence our work.[30] For researchers to reflect on themselves facilitates interpreting the observed and constructed knowledge.[31] Considering that this reflexivity is especially relevant when performing qualitative research, I attempt to make my own position in this data collection process as explicit as possible.[29] While this discussion is presented from a personal perspective, in which I employ the first person "I" more frequently than I feel comfortable with, it feels appropriate to emphasise that this research project was by no means a sole endeavour. It was achieved through the collaborative efforts of an inspiring team of top-notch researchers who guided and coached me throughout the entire process.

Prior to the start of this research project in 2019, I had worked for several years as a nurse and as a coordinator of clinical pharmaceutical trials. As part of my work, I was in contact with people who suffered from health-related conditions on a daily basis. On multiple occasions, I have been in the company of individuals and provided care for them during and after their passing. Because of these experiences in my young adult life, I had already come to regard serious illness, death, dying, and loss as part of life. The care I witnessed these people receiving led me to regard end-of-life care as the exclusive authority of healthcare professionals. When I applied for the position of doctoral researcher, I voiced my concern that palliative care was always initiated at an extremely late stage, causing avoidable delays and suffering. While I saw palliative care services contacted in the days preceding the individual’s passing, I wholeheartedly believed this should be initiated at least a few days, maybe a week earlier. This reasoning exemplifies my blurred vision between palliative and terminal care, of which I believe I was no exception in the healthcare context. In my defence, this was shaped by how people at the end of life were treated in my professional experience: dying at home was an exception and never actively promoted, and the palliative care unit available in the hospitals I worked in was exclusively reserved for people who would die on very short notice, if they had not died yet before reaching the unit. Additionally, my education did not properly prepare me for end-of-life care as the palliative care course covered a meagre two hours.

Although researcher reflexivity is well integrated into qualitative research, I believe a short discussion about it in relation to the quantitative aspect of this dissertation is relevant. As my systematic review was the first paper I ever wrote, I relied more heavily on the co-authors for its design and writing compared to subsequent papers. Looking back on the discussion section in my review as a more experienced researcher with greater knowledge of Compassionate Cities and Communities, I realise there are other interesting topics which are not highlighted.

Although only one research paper has yet been written from the qualitative data I collected (CHAPTER V), data collections ran throughout the entire duration of the research project. I integrated a section in my semi-structured observation template to report on my personal reflections and interpretations. I also kept short field notes after conducting interviews and group discussions which were added to the transcripts. Not only does this approach facilitate testing my personal interpretations against study findings,[30] it also helped in *reliving* the context in which the data was collected. Listening and transcribing all audio recordings further immersed me in this process and evoked early ideas about data analysis as I noticed recurring or interesting themes. Green et al. (2007) advocate for the integration of data collectors in data analysis, and as I was the sole data collector and also performed the analyses, my personal data immersion is evident.[28] I am not ashamed to admit that my inexperience in qualitative research led me to restart the data analysis process on more than one occasion. Additionally, at one point, I felt so lost in the forest of data analysis methods that I lost considerable time finding my way out. Although this was extremely time-intensive, it made me very familiar with my data, and I consider this bumpy journey a rewarding process that built my experience.

Conducting qualitative research prompts spontaneous inward reflection, especially when encountering situations that cause discomfort. Having been highly immersed in and experiencing firsthand the not-always-smooth development of the Compassionate Cities, I plead guilty to showing a certain level of negativity bias. As the projects did not develop as planned and were met with significant delays, hindrances, worries, and frustrations among participating stakeholders, I tended to have a skewed vision about certain neutral or positive aspects of the development. The research team supporting me throughout my research project pushed me again and again to reflect and explore the positive effects of the Compassionate Cities (i.e., appreciative inquiry).[32] This made me integrate this perspective more prominently into my data collection process. I encountered group discussions with participants who did not respond to my questions, individuals who showed little interest in my presentations, or people whose personality traits evoked some levels of discomfort in me. I managed to view such situations as challenges and opportunities for new learnings. Being a qualitative researcher has taught me to focus on the meaning behind people's behaviours rather than solely on the behaviours themselves. Why are they not engaging in conversation during a group discussion? What factors might contribute to their lack of interest in my presentation? Why do I feel negatively towards this person? Upon reflecting on such experiences, I began to appreciate these behaviours as they clearly tried to convey message to me. Perhaps the group discussion participants did not feel secure in the environment, the presentation was overly scientific, or individuals' personality traits could provide insights into my research findings. I believe that once I started to approach each of these situations with an open mind, akin to how people viewed sushi in the past (unappealing idea, great flavour), it positively influenced both my research project and my personal development.

Discussion of the study findings in light of current research on Compassionate Cities and Communities

General considerations

Comparing different Compassionate Cities and Communities remains difficult

In line with my own review in CHAPTER I, other reviews on Compassionate Cities and Communities identified that the majority of initiatives reported some form of evaluation, but most lacked transparency in their applied methodology, thus hindering the assertion of their methodological rigour. Although some studies reported positive outcomes, their mechanisms of change remain unclear.[33,34] As also mentioned in CHAPTER I, Peeler et al. (2023)'s review reports high levels of heterogeneity in study designs, chosen outcome measurements, mechanisms of action, implementation strategies, and evaluation approaches. The authors further highlighted a lack of transparency in the methodological approaches of included studies, thus emphasising the need for publishing study protocols and strengthening my decision to do so (CHAPTER IV).[34] This lack of transparency makes it difficult to compare study findings from different initiatives, which, in turn, makes it harder to inform other Compassionate City and Community initiatives.[35] Compassionate Cities are situated in socially and culturally distinct environments and encounter contexts that evolve and interact with these environments (CHAPTERS I & V). Regardless of their development theory, the development processes and outcomes within Compassionate Cities are impossible to predict at the outset of the programme.[26,36] This makes comparing outcomes and processes between projects particularly challenging. My own research in CHAPTER V is an important first step towards increasing transparency on Compassionate City and Community programmes. Transparency is especially crucial when the subject under study is still poorly researched and understood, indicating a persistent need for subsequent process evaluations on Compassionate Cities and Communities that reflect the complexity of developing such programmes in emerging contexts. Such evaluations contribute to understanding the processes behind, and the ways in which Compassionate Cities and Communities function.

Susceptibility to change of societal and cultural perspectives on death and dying

Although Western cultures have often been described as death-denying in the past, many scholars suggest that this has slowly been changing since the 1960s and 70s under the influence of the death-positive movement and the hospice movement.[18,37,38] My own dissertation undoubtedly reflects the increasing public and scientific interest in listening, studying, and communicating about the end of life. However, death and dying remain somewhat taboo in some respects. For instance, literature mentions the existence of death cafés as partially stemming from a need to discuss topics related to the end of life, which often struggle to find an entry into day-to-day conversations (this particular activity is also mentioned in CHAPTER V).[39,40] In contemporary medicine, disproportionate resources are spent to postpone death and healthcare workers feel insecure initiating end-of-life discussions with their patients.[41–43] Notwithstanding, my research findings indicate that people felt the least discomfort in the situation where a dying person wanted to discuss death with them, such events can still evoke unease and discomfort, which sometimes stems from individuals' prior experiences with these topics (CHAPTERS II & V). Perhaps the most obvious manifestation of death as a persisting taboo is in our views on how children should be protected from exposure to (talk about) death.[44] However, with Herzele's Compassionate City programme deliberately focusing on schools, I encountered no difficulty in discussing topics of death and dying with children. This prompted some of their headteachers to realise that discomfort around death and dying is not intrinsic to people but rather socio-culturally constructed (CHAPTER V).[18] Paul (2019) indeed found that children are open and willing to discuss death and even desire accessible information about it.[45] Altering our socio-culturally constructed perspectives regarding the position and normality of death and dying in various aspects of daily life is not only a feasible pursuit but has likely occurred continuously throughout human history.[46] Diverse activities taking place in Compassionate Cities and Communities show how developers actively attempt to shape our current end-of-life attitudes (CHAPTERS I & V).[34,47,48] This illustrates that, perhaps for the first time ever, groups of people exhibit attitudes towards death that diverge from the majority of their society and strive to guide end-of-life practices towards those that enhance health and wellbeing. In CHAPTER V, I described how numerous individuals were keen to initiate activities linked to the end of life, indicating that significant human capital exists within societies, willing to aid in changing attitudes and subsequent behaviours.

Involving and reaching the community

Communities rarely lead, while health services do

Compassionate Cities and Communities represent public health initiatives designed to empower communities to effect changes concerning local circumstances of serious illness, death, dying, or grief.[49] Kellehear, for instance, has emphasised that Compassionate Communities are developed through a series of activities that should be owned by the local community.[50] However, in line with other studies, my own findings (CHAPTER V) suggest this may not always be the case, as we saw how other leaders, rather than the community, take the lead in development. Indeed, Compassionate Cities and Communities — and in the broader context, public health approaches to the end of life — face similar challenges in engaging the community: only in a minority of cases the public is engaged in leadership roles which limits the agency it can exert over its (self-)identified needs.[33–35] This has resulted in community engagement programmes being criticised, as these leaders are often representatives of the organisation that takes the initiative rather than community members. This certainly raises doubts about the extent to which Compassionate Cities and Communities can achieve their desired outcomes, as a systematic review by Cyril et al. (2015) identified that for community engagement programmes to achieve improved health behaviours, shared leadership with that community is paramount.[51] The World

Health Organization advocates that health promotion activities in communities not only consult and collaborate with communities, but also be owned by them.[4] However, with very few exceptions, including our own initiatives (CHAPTER V),[53,54] literature reviews on Compassionate Cities and Communities identified that this leadership role almost exclusively resides within the professional care domain.[33–35] My own review indeed pointed to healthcare institutions as the main initiators (CHAPTER I). This may be explained by the fact that healthcare institutions are the historical innovators in care for our dying, with Compassionate Cities and Communities then being an extension of this responsibility. The choice of putting healthcare services in this leadership role may also be a logical one, as grassroots initiatives often lack the resources and skills to scale up and formalise their programmes.[55] However, as a consequence, such initiatives then risk facing shortcomings characteristic of the healthcare sector, such as shortages of resources or difficulties in reaching hard-to-reach populations, which puts their sustainability into question. Additionally, the goals of Compassionate Cities and Communities can and should not be reduced to merely extending the services of healthcare organisations.[1] While it remains difficult to assess whether such initiatives indeed strive to extend their reach beyond their clinical mandate, the fact that this is a substantiated risk was recently underscored in a study investigating the interests of palliative care occupational therapists in Compassionate Communities.[56] Such a high reliance on healthcare services to lead Compassionate City and Community development programmes definitely strengthens the impression that even community-oriented approaches that aim to change experiences of serious illness, death, caregiving, dying and loss — experiences that primarily reside within our social environment — through empowered communities are subject to healthcare systems' authority. The difficulty in engaging community members in both Compassionate Cities certainly questions how realistic it is to make Compassionate Cities true community engagement initiatives. In part this can be explained by the ambiguous position in which I found myself as a researcher: promoting the use of community engagement to leaders who had little to no experience about community engagement principles. Although the impact on Compassionate City sustainability is difficult to assess if the leadership is not shared with the community, sustainability may be under threat as exemplified by the frustrations from stakeholders in our Compassionate Cities who perceived and received a limited agency in their role. This highlights the need for sufficient education about such principles, which may be a stark departure from habitual operations in organisations and local governments, and the identification of leaders willing to change their habitual way of operations. Unlike in this research programme, a more facilitative role could be taken up by involved researchers from the start to help initiate a community engagement programme in which the leading organisation is an equal partner. I believe community engagement is a realistic, and even imperative, approach in the development of Compassionate Cities. However, abiding by community engagement principles may warrant more attention and resources than were anticipated in this research project.

As many initiatives appear to choose for this development structure and approach, developers should be reflective about how their community can be involved and be careful not to develop goals that merely serve the health service’s interests. Although co-development with communities may be a stark departure from habitual organisational operations, efforts should be made to implement such principles as this may increase sustainability and better align with community needs.

Empowering communities comes with challenges

Interestingly, our own Compassionate Cities appear to be an exception in that not a health service took the lead but a local government (CHAPTERS I, IV & V).[33–35] In line with the aforementioned reflections on community involvement, CHAPTERS II & V clearly demonstrate some of the difficulties that arise when trying to grant community members this leadership role. We highlighted project coordinators’ unfamiliarity with engaging the community, community members’ reluctance or impossibility to bear such responsibilities, and people’s discomfort towards topics associated with the end of life. Additionally, as described in CHAPTER V, any community engagement approach is subject to its context, such as participants’ availability, a sudden pandemic restricting social connections, or the costs associated with the chosen approach.[57] Furthermore, literature indicates that community engagement can also cause adverse effects when, for example, community members are empowered to care for their sick, a task traditionally bestowed upon women.[58–60] Integrating community leadership from the outset of subsequent initiatives has been identified to be essential for fostering sustainability, a crucial factor for Compassionate Cities to reach their long-term aims (CHAPTER I).[51] This may involve significant educational activities aimed at informing and potentially changing the attitudes of future Compassionate City and Community leaders, as literature indicates that community leadership contrasts with traditional hierarchy structures (CHAPTER V).[61,62] This became clear during my research when stakeholders expressed how inefficient communication from civil servants was one reason why a sense of false co-leadership was perceived. Therefore, if the Compassionate City aspires to empower the community to (co-)lead the programme, maximal transparency on this structure, the identification of local needs, the allocation of resources, the decision-making process, and activity development are essential to instigating trust and a sense of ownership among involved stakeholders, especially in the early project phases when stakeholders are still assessing the DNA of and their specific roles in the Compassionate City.

Whether all relevant populations are targeted and reached remains questionable

A scoping review by Peeler et al. (2023) reports that communities have needs pertaining to their practical environment (e.g., helping with grocery shopping), personal growth (e.g., increasing knowledge about the end of life) and community capacity (e.g., increasing social capital).[34] My survey study showed that people generally seemed to be willing to support others within their neighbourhood with tasks pertaining to some of these needs (CHAPTER III). Literature indicates that neighbourhood support outside of family-based relationships is indeed already taking place.[63–65] Compassionate Cities and Communities' activities have been classified by categorised into educational (e.g., to increase knowledge or raise awareness about end-of-life care), cultural (e.g., death cafés), service (e.g., using volunteers to extend a service's reach) and clinical (e.g., healthcare workers facilitating advance care planning) activities.[2,33] This classification matches to some extent the activities in our Compassionate Cities (CHAPTER V). In line with other literature, these activities fell under the Ottawa Charter for Health Promotion's domains (CHAPTER I).[35] In

CHAPTERS I & V we confirmed that activities in Compassionate Cities often target subpopulations such as family carers or lonely people.[33] This leads me to infer that targeting specific populations is an important focus in many Compassionate City and Community initiatives. However, such initiatives, even when they relied on the Compassionate City Charter, rarely targeted structurally marginalised populations.[66] I believe one reason behind this conclusion may be the relatively early phases in which most described Compassionate Cities and Communities find themselves, leading them to prefer targeting easier-to-reach populations given the known difficulties of health services in reaching hard-to-reach populations.[67] Furthermore, although Compassionate Cities and Communities train individuals to support specific groups of people,[68–70] it is not known whether such trainings or other activities lead to spontaneous and durable increases in social capital and hence, mutual community support. These findings raise questions about the extent to which Compassionate Cities and Communities currently reach or even target the full relevant population.[35]

Politics and policy in Compassionate Cities

Top-down or bottom-up development?

A top-down initiative is usually led by organisations or institutions, while bottom-up initiatives commonly develop through communities who take the lead and/or initiative.[71] In theory, Compassionate Cities employ a top-down approach and then empower communities to design and lead activities.[50] However, literature does not indicate that better health outcomes are achieved by following this approach.[72,73] Top-down initiatives have been criticised for being bureaucratic, not meeting the needs of disadvantaged populations, and causing distrust in participating stakeholders. Our findings in CHAPTER V echo these contentions and show the considerable effect this had on stakeholders' preconceptions about governmental partnerships which, even if they were unfounded, influenced cooperation and consequently the development process. On the other hand, bottom-up initiatives are resource-intensive and often fail to scale up.[55,61,74] The Compassionate Cities and Communities described in peer-reviewed literature show that different degrees of both bottom-up and top-down principles are commonly applied.[33–35] However, if Compassionate Cities target entire societies, this can hardly be achieved without the involvement of local governments, which implies the need for top-down involvement at some point (CHAPTERS IV & V). Developers will eventually have to take the bureaucracy of a top-down approach into consideration, which can be considerably different from their habitual modus operandi.[61] Stressing the opportunities that come with such an approach, as described in CHAPTER V, and anticipating predictable and well-described obstacles in such cooperations may be a worthwhile strategy.[61,75]

Sustainability

I believe that if any Compassionate programme desires to extend its reach and create a sustainable existence, structures will need to be formed in which local governments minimally take on a facilitative role. In correspondence with literature,[35] CHAPTER V shows how governmental bodies provide access to resources and therefore pave the way for new possibilities that community members might not otherwise attain. As Compassionate Cities are developed through community engagement and are therefore susceptible to people's motivations, providing space for involved stakeholders' developmental preferences is paramount to ensure their commitment. I described in CHAPTER V how this was insufficiently applied in our own Compassionate Cities and evoked frustrations in participating stakeholders. In line with previous research, an early focus on activity development creates momentum among participants.[76] Furthermore, I described how many stakeholders voiced their desire to broaden the focus of Compassionate Cities beyond end-of-life topics. Including a project facilitator to guide the development can facilitate creating a sustainable development structure, as discussed further.[77] Sustainability lies in the hands of the people who lead the Compassionate City; shaping the programme to participating stakeholders' preferences may be essential to ensure their commitment. To make such programmes sustainable, frameworks have been suggested, but their effectiveness is yet to be proven.[66,78,79]

Compassionate Cities' potential on economy, population health and social connectedness

As Compassionate Cities are frequently proposed as a means to address overburdened healthcare systems (CHAPTER I), it is important to consider their economic potential in times of resource scarcity. Belgium's budgetary deficit amounts to 4.4% of the Gross Domestic Product (GDP), and the country's debt ratio stands at 105.2%, making it one of the countries in the European Union with the largest budgetary deficit.[80] With a multitude of sectors urging the Belgian government for increased investments, it is unlikely that any sector will receive all they desire. I experienced myself how resource constraints severely impacted development possibilities (CHAPTER V). A higher investment in healthcare also does not necessarily equate to better health outcomes.[81] Between 8.5 and 11.2 percent of yearly healthcare resources in high-income countries are spent on the 1% of the population that dies that year. If we consider the resources spent in the last three years of their lives (i.e., people with chronic health conditions), healthcare spending rises to 24.5%.[82]

Important research has underscored the association between social isolation and increased healthcare usage, as well as between social isolation and mortality risk.[83–85] Although exact numbers are unknown, a significant proportion of emergency hospital admissions are categorised under "social admissions" (i.e., people who present no clear medical or health condition).[86] When people are lonely, healthcare providers are commonly their sole source of support. Our Compassionate Cities, together with several other initiatives described in literature, implicitly aimed to increase social connection (CHAPTER V).[87,88] Community engagement approaches, as those seen in Compassionate Cities, have indeed shown to positively influence social capital.[48,89] In addition to the human and emotional aspects associated with increased social connections, significant health-improving effects can realistically be expected in the long run. Two small-scale Compassionate Community programmes already showed promising results in decreasing the burden on their local healthcare system.[68,69]

Increased social capital also provides opportunities for people to collaborate, build, and exchange knowledge and skills, and gain access to the social networks of these new connections.[90] My research showed the important finding that when people feel socially supported by others within their neighbourhood, they are more willing to support them in return (CHAPTER III). Although literature predominantly focuses on the negative aspects related to caregiving (e.g., caregiver burden), providing family care to others also builds the caregiver's knowledge and skills, which are important assets to be used in subsequent care situations.[11,91]

As Compassionate Cities aim to increase social capital, they bear the potential to reduce healthcare consumption and expenditure. Governmental policies that promote the development of Compassionate Cities choose to invest in preventive measures, which can positively influence social capital, population health, and healthcare expenditure. My own research has not (yet) studied the impact Compassionate Cities can have on these outcomes; therefore, I urge future evaluators to pay attention to such aspects, as they are key in substantiating the importance and potential of Compassionate Cities.

Recommendations for practice, policy and research

Practice recommendations

Engaging communities in Compassionate City development

There are some well-defined aspects of community engagement that make it a worthwhile approach in a Compassionate City project. First, community engagement can be an asset by definition as it increases transparency and public representation.[73] Second, health production is a cooperative endeavour which implies that the public deserves to have a say in decisions that affect their (determinants of) health. The chosen community engagement approach does not need to be carved in stone at the outset of the Compassionate City initiative as it exists on a spectrum defined by the level and intensity of collaboration, indicating that it can be changed and tailored throughout the development.[36,71,92] Third, engaging community members to voice their concerns informs the development of solutions that match a realistic need, something we struggled with in our own Compassionate Cities (CHAPTER V).[93] Fourth, applying a community engagement approach can improve the circumstances of disadvantaged populations such as the impoverished, imprisoned or sick.[73] Any group of people being engaged requires adequate support to foster commitment.[75] Notwithstanding that no single type of community engagement approach has been identified to lead to the best health outcomes, developers need to question how communities can be empowered to increase their agency, as governments too benefit from this approach. Subsequent initiatives could therefore engage community members early in the development process and be explicit about their role. Development leaders may opt to be critical and reflexive about how they uphold the envisioned community engagement format and evaluate whether the stage of development warrants changes in the chosen approach. Furthermore, keeping an ear to the ground by regularly communicating with participating stakeholders and integrating their feedback to shape the further development approach may prove essential in keeping them motivated and engaged.

Although local governments show a clear interest in community engagement, I showed in CHAPTER V how their civil servants sometimes lack the knowledge and skills to adhere to community engagement principles, which highlights the need for education and skill development in Compassionate City leaders. If a Compassionate City project is portrayed as a community engagement project, it is paramount that this does not just serve as a 'false advertisement' to convince people to partake in development. The negative consequences this can have pertaining to participant motivation and trust are clearly highlighted in CHAPTER V. To avoid this from occurring, I recommend the use of external facilitators with expertise in community engagement to take up this role, which is motivated further. I can make no claims as to the effectiveness of community engagement in the development of Compassionate Cities, however its described benefits in relation to durability, the formulation of goals that adhere to real-life needs and the potential to reach hard-to-reach populations justify its approach in Compassionate City development.[51]

Plan activities that build social networks

Compassionate Cities and Communities rely on reciprocal relationships to build capacity around individuals faced with situations of serious illness, death, dying, and loss. The discomfort people feel about situations of death and suffering (CHAPTER II) may impact their reliance on these networks once the need arises. Although we did show that there's no association between this discomfort and people's willingness to support others within their neighbourhood (CHAPTER III), we cannot make any statements about people's actual behaviour in such situations. However, research indicates that people support each other more easily when they have close relationships with the person in need, which is also exemplified by the fact that most family carers are direct family members.[13,60,94] Therefore, Compassionate Cities would do well in preventively building such relationships, ensuring they are readily available when the need arises. Activities that do not have a specific end-of-life focus can then still have value in Compassionate Cities when they focus on strengthening existing or building new relationships (CHAPTER V). We showed the association between people's experiences with end-of-life topics and their discomfort around the suffering and dying of others (CHAPTER II). Such topics can also be integrated in a ‘soft’ manner while still bearing value, for example, through a festival around the end of life, art exhibitions, or the development of a place of solace (CHAPTER V). Therefore, I advocate for future initiatives to integrate the implicit aim of building people’s social capital and social connectedness in all suitable activities. The emphasis on end-of-life topics is important to change socio-cultural perspectives, but building social networks which can eventually be activated in the support around people who face the end of life may also be achieved without integrating this emphasis in every activity. Indirectly building social capital may also be achieved by targeting, for instance, specific social, economic or political environments. Developers may choose to develop healthy policies (e.g., universal health coverage), facilitate access to (end-of-life) education or instigate governmental funding schemes for cultural activities related to the end of life as I showed how such types of exposure may have beneficial effects in CHAPTER III & IV and indirectly impact people’s social capital. In addition to this, the development of Compassionate Cities and Communities involves cooperation between different stakeholders. Cooperation, in itself, bears value as increasing professional connections was an important impetus for stakeholders to participate (CHAPTER V). Through their participation, they hoped to strengthen their organisations’ operations while diminishing the fragmented healthcare landscape. Meeting in person is then extremely important to facilitate this process as online meetings leave little room for informal relationship building which is especially important in the early project phases to enhance mutual trust and ownership.

Developing activities is important to build rapport between developers

In CHAPTER V, we described the project facilitator’s focus on distal sociocultural changes which caused delays in community action as well as confusion and frustration among involved stakeholders. Although literature indicates that community action should be preceded by a development plan or even an extensive programme theory,[73] we experienced how this also risks becoming a lengthy process that does not align well with the diverse interests of stakeholders (CHAPTER V). Based on my experiences, I recommend that if stakeholders’ interests lie in action development itself, this should warrant significant attention early on in any community development programme. Literature shows that action development ensures a correspondence to and a mutual understanding of the needs of the individuals designing the action.[51] A crucial aspect then is the identification of project themes sufficiently relevant to involved developers to keep them motivated.[51,61,95] While there is abundant peer-reviewed literature on community engagement projects, developed activities, and their effect on health outcomes, there appears to be a paucity in peer-reviewed literature on the intrinsic value of developing activities.[73,89,96] CHAPTER V clearly articulates advantages that did not relate to the activity design or aim, but to the effect it had on the cohesion between those who participated. When starting any community engagement project, a number of stakeholders will be unacquainted with each other. Working together then builds rapport and mutual trust, which are important assets in the early project phases.[97] We observed how some stakeholders lacked self-esteem which can also be built through activity development, as echoed by prior research.[59] In conclusion, I advocate for early activity development in Compassionate Cities as working on activities holds intrinsic value, especially in the early project phases. The development of programme theory and development plans has its own value and can also occur more intuitively, with the more abstract process in the background and with those selected stakeholders who show an interest in this process. Developers should pay attention to integrating the end-of-life focus in activities as otherwise this tends to be overlooked, as happened in the Healthy Cities movement.[50]

Facilitation is key

Facilitators are individuals who guide the process of translating an envisioned change into a practical format that stipulates what needs to change and how this should be done.[98] They create a shared understanding and empower local stakeholders to lead the change while typically focusing on relationship building, learning and shared problem-solving.[99] As mentioned in CHAPTER V, and as may be the case in many cities, proposed project coordinators may be unfamiliar with community engagement principles, which prior literature also indicates.[61,62] An external facilitator (i.e., someone with expertise from outside of the organisation) can then be used not only to adhere to such principles, but also to train local project coordinators and promote a learning mindset that may significantly differ from their organisation's habitual work modus.[77] In CHAPTER V, I reported on involved stakeholders' positive reflections on the use of an external project facilitator in developing Compassionate Cities and prior research has underscored the usefulness of facilitators in change programmes.[25,77,98] Certain competencies of the project facilitator have been identified as important, including project management skills, active listening, trust-building skills, clear and timely communication, and rule setting.[99] Some of these competencies clearly touch upon identified barriers and facilitators in our Compassionate City programmes and aspects of facilitation and coordination (CHAPTER V). Therefore, I believe that involving an external facilitator with these skills and competencies can be beneficial, as this individual can eventually help transition the facilitation role to one or more internal facilitators once they possess adequately trained competencies and skills in facilitation, which may differ from traditional skills and competencies needed in other organisations.[61] Khan, Manalili and Moore (2024) recently identified ten steps in which the project facilitator plays an important role:[77]

1) Develop a team
2) Unearth the problem
3) Select the programme (Compassionate City)
4) Assess barriers and facilitators
5) Select and build change strategies
6) Adapt to the local context
7) Plan for implementation and implement
8) Engage in continuous learning for improvement
9) Plan for sustainability and sustain
10) Plan for and enact spread and scale

In any case, when involving a project facilitator, clearly defining this person's mandate (i.e., to develop in co-creation, facilitate rather than decide, and work towards sustainability) is essential to optimising the professional boundaries within which they can operate. Furthermore, I observed how a project facilitator can help guard the interests of both the programme and its corresponding research project.

Long-term aims are realistic endeavours

Compassionate Cities aim to instigate changes at the structural level, targeting any sector where people meet for work, leisure or any other reason.[66] The movement's long-term aim is to alter the sociocultural perception of death and dying across entire populations rather than focusing solely on individuals. We observed how to some, this objective seemed distant, vague, challenging, or even impossible to achieve (CHAPTER V). Prior to the hospice movement in the late 1960s and 70s, the event of death was attributed to natural or supernatural causes over which humans exercised no control.[100] Ever since, the topic of death took on a more prominent place both in medicine and public debate.[101] Today, end-of-life care is recognised as an integral form of support for people with health-related suffering and it is acknowledged as an essential component of healthcare.[102] This heightened awareness towards end-of-life care also permeated our sociocultural environments and thus generated increased public awareness and changed attitudes. For instance, the concept of death cafés has appeared to support and inform individuals (CHAPTER V),[40] physicians in some countries have started to consider assisted suicide which was unthinkable a couple of decennia back,[103,104] our Western cultural funeral rites have evolved with the availability of other than coffin burial options and vloggers openly discuss their end-of-life trajectory.[105] Sociocultural changes regarding serious illness, death, dying, and loss may appear distant or vague but are already slowly taking place, which means they are subject to change through interventions. Therefore, Compassionate City developers need to translate long-term aims into a well-designed operationalisation that makes such aims relatable to the involved community and audience. Both the long-term aims and operationalisation perfectly fit within programme theory which guides further development.

Developing across sectors warrants political involvement across sectors

Compassionate Cities and Communities are logical extensions to the increased attention of democratic governments towards community advocacy in the pursuit of better health outcomes.[106] If Compassionate City developers choose to instigate such changes at the structural level, our findings in CHAPTER V clearly indicate that the will and support from politicians are essential to success. Several of our results illustrate the vulnerability of Compassionate City initiatives, which arises from the limitations inherent to the political structures in which they operate. First, since politicians' future depends on re-election, initiatives risk losing support early if their responsible politicians fail to get re-elected. Second, if initiatives are assigned to specific politicians, expanding beyond their designated policy domains can prove difficult as this requires support from (potentially competing) politicians. I found how activities can enhance political engagement by increasing visibility, which developers believed was valuable because it contributed to electoral opportunities.[75] Third, if politicians who are not responsible for the Compassionate City experience it in some other capacity (e.g., a politician who also works in a domain targeted by the Compassionate City programme), their willingness to interact with the initiative can be influenced by political competition. Therefore, I recommend that if developers indeed aim for sector-wide changes, political support across all these policy domains needs to be secured prior to the project's launch. Creating activities also holds value for the involved politicians and therefore warrants attention. Discussing with involved politicians, as needs to be done with any involved stakeholder, which elements are important to them (and hence, keep them motivated and secure their commitment) is an essential preparatory step in the development.

Considerations in attaining political support

Compassionate Cities are maybe innovative in their end-of-life emphasis, they are by no means unique in their approach.[61] Age-friendly Cities, Healthy Cities, Fairtrade Towns or Caring Neighbourhoods are but some examples which fit in a wider sociopolitical movement aimed at instigating structural changes to improve population health through community advocacy.[61,107–109] "Despite their diverse focuses, such initiatives share the common aim of empowering societies to shape their environment so that it becomes conducive to health. However, advocating for political engagement in Compassionate Cities raises certain considerations that warrant discussion. First, as we experienced in our own research, Compassionate Cities address a topic not all people feel comfortable considering (CHAPTERS II & V). For example, we observed how the execution of an activity was prevented by local politicians as they feared a negative public response (CHAPTER V). Achieving political support can thus be negatively influenced by concerns about broaching such culturally sensitive topics. Second, on multiple occasions we encountered stakeholders sharing the contention that end-of-life topics are not a daily occurrence in contrast to poverty or bullying (CHAPTER V). The fact that Compassionate Cities are often reductionistically interpreted to situations of dying alone as opposed to anything related to the end of life undermines the level people can relate to the topic's relevance. The social epidemiology surrounding the end of life happens primarily hidden which makes recognising its omnipresence more challenging.[110] A strategic communication plan, tailored to its audience, could then be developed that shows the relevance of Compassionate Cities. Third, the backgrounds of the people participating in community-based collaborations are influential in achieving political backing. Many Compassionate Cities coincide with research projects (CHAPTERS I & 4). This may facilitate their initiation as researchers wield significant power, resources, scientific knowledge, and have an esteemed societal job-related status.[111] It is important to recognise that grassroots-initiated community engagement programmes may not have the same political leverage.[75,112] In conclusion, launching Compassionate Cities is subject to the themes it addresses, the chosen development approach and the backgrounds of involved stakeholders. Developers should critically reflect on their advocation strategies in achieving political support.

Research recommendations

Integrating flexibility when studying complex interventions

Compassionate Cities, as well as many of the key locations in Compassionate Cities such as schools, local municipalities, work environments or neighbourhoods, can be considered complex environments. This means that although certain changes can be envisioned, the interaction between the components that constitute the intervention (such as the available funding or the people who participate) create unpredictability. When evaluating such environments when they undergo an intervention, it is essential to identify data collection techniques that suit the evolving environment. This justifies our choice for a variety of data collection techniques which could be used to fit the emerging development process and hence, data. My choice for the framework analysis to analyse the qualitative data provided flexibility in that elements from an existing framework (the CFIR) could be deductively integrated while leaving room for the inductive addition of themes that were uncovered during the initial analysis stages.[25] Choosing for flexible data analysis tools leaves room for the adaptation of tools to the data and research interests, something that may be harder when purely relying on deduction for data analysis. As such, I integrated the constructs from the CFIR which were most relevant to the development of the Compassionate Cities, which was also a pragmatic choice in that I alone was performing the most time-consuming stages of the data analysis. Researchers may consider a more extensive framework (e.g., with the inclusion of more constructs from the CFIR) if permitted by their available resources. Although choices were made in the selection of data collection techniques, I recommend future evaluations of complex interventions to select a more extensive *menu* of data collection techniques, including variability in specific data collection techniques such as regular interviews, go-along interviews or phone interviews.

Continued research on causality attribution and process evaluations

I conducted a single cross-sectional survey study in both Compassionate Cities (CHAPTERS II & III). While these studies provided intriguing insights into people's attitudes towards aspects related to the end of life, such research designs do not offer insights into the temporal impact (i.e., causal attribution) of Compassionate City initiatives. The challenge with researching initiatives that occur outside of a controlled laboratory setting is that they are susceptible to changes over which researchers have no control, and which transcend regional or even national borders (e.g., the legalisation of assisted dying, migration waves). The Compassionate City initiatives took place in real-life settings, which excludes them from experimental research designs (CHAPTERS IV & V). Longitudinal studies, which follow a group of people during a given period and evaluate different outcome measures using repeated quantitative and/or qualitative data collection methods, are one way to attribute impact to the initiative.[113]

The influence of temporal changes can also be addressed through quasi-experimental research designs in which outcomes are compared between an intervention group (the targeted population in the Compassionate Cities) and a control group (the people not in these cities but in a comparable environment). The Difference-in-Differences is one method that studies the outcomes in these populations by collecting data at different points in time. By looking at both populations simultaneously, researchers can control for the effect of temporality on the outcomes.[114] The use of this method was announced in this research project's study protocol but due to the time associated with the manifestation of changes in sociocultural aspects at population levels, this was not (yet) performed (CHAPTER IV). Population databases can be a valuable tool in studying the effects of Compassionate Cities on healthcare usage.[115]

Although the contextual characteristics of Compassionate Cities and Communities are highly unique, it is likely to assume that they can lead to certain health benefits as has been suggested in CHAPTER I and other reviews.[33,34] Although some systematic reviews showed the positive outcomes from community engagement projects related to health outcomes for disadvantaged populations, no Compassionate Cities were included in these reviews, nor have other reviews thus far been able to draw comparable conclusions for Compassionate Cities.[51,73] Certain frameworks for the development of Compassionate Cities have been proposed and although I relied on one to evaluate our own Compassionate Cities (CHAPTER V), their applicability still warrants consideration in future evaluation research.[26] Only the methodologically sound, continued publication of research on Compassionate City outcomes and processes of development can inform future review studies in drawing general and more methodologically reliable claims. The continued use of cross-sectional survey studies is important to inform Compassionate City developers on the assets and deficiencies of targeted populations and areas. Future research could focus on attributing outcomes to Compassionate City programmes. Such reports may facilitate the integration of public health approaches to the end of life in governmental/organisational policies. To respond to the difficulties in comparing outcomes between Compassionate Cities and to the difficulties in implementing development strategies from one initiative with a unique context to another, I advocate for the continued reporting on such outcomes and development processes.

Publishing study protocols

The decision to publish this research project's study protocol was motivated by a number of reasons which I believe ought to be considered by future Compassionate City researchers. First and foremost, it enhanced transparency regarding my research intentions, thereby adding methodological rigour to the subsequent research publications on the planned initiative. Second, as Compassionate Cities are still poorly studied and understood, explicating research intentions informs other scholars who may be interested in replicating or challenging our study findings, or diversifying their own research approach to investigate new topics.[116] Third, it provides important information for developers who choose to be inspired by the described structures, development approaches or evaluation methods. Last, publishing study protocols is important for holding researchers accountable to report on study findings which they may be less inclined to do if findings are less favourable than initially aspired.[117] Publishing study protocols has several identified benefits which further scientific transparency, rigor and knowledge on the relatively novel phenomenon of Compassionate Cities.

Researchers can play an important role in development

The Compassionate Cities in which I was involved led me to reflect on the positive aspects of researchers who actively take part in their development (CHAPTERS IV & V). Researchers' level of interaction with study participants can lie anywhere between complete observation (i.e., collecting data from a distance without interaction with activities or study participants) and complete participation (i.e., the researcher is an equal member taking part in the Compassionate City development).[118] Naturally, the mere presence of a researcher already influences study participants' behaviour.[29] Furthermore, although some of researchers' personal characteristics such as job-related social status, sex or language are considered "fixed", that does not mean they do not interplay with the environment.[119] As researchers bring certain qualities to the table other stakeholders are less likely to possess, I believe their input can be worthwhile in community engagement projects. First, while developing in co-creation is generally valued by organisations,[73] I experienced how project coordinators did not always abide by the associated principles which caused frustration in participating individuals (CHAPTER V). Researchers can more easily access the existing theory on co-creation which can then be applied to aid project coordinators and facilitators in their approach. Second, scientific knowledge is considerably more challenging to access and interpret without a scientific background. I experienced how only I knew how to navigate information in publications, documents, or websites on other Compassionate Cities and translate it into digestible information. Researchers also have greater ease in connecting with other researchers or developers, thus facilitating information exchange. Third, applying qualitative study findings to positively influence the development process appreciates the role of participating stakeholders. Reporting quantitative study findings, such as from survey studies, can facilitate the use of community assets as well as point at potential areas that can benefit from interventions.[62] To conclude, I believe researchers can play valuable roles in community engagement projects and have the moral obligation to consider how they can facilitate development. Their level of involvement should be weighed against both their own and the development programme's goals and chosen approaches.

Policy recommendations

The need for end-of-life support in countries that need it the most

Recent reviews, including my own (CHAPTER I), have uncovered dozens of initiatives aimed at improving people's experiences around serious illness, death, dying and grief through public health initiatives.[33–35,58] With the exception of one initiative, all were located in high-, and to a lesser extent, middle-income countries.[1–4] This stands in stark contrast to the countries that face the highest needs pertaining to end-of-life support and health-related suffering.[120] Populations in low-income countries are the most affected by chronic illnesses and short-term predictions foresee a steep increase in the prevalence of such illnesses in these countries.[121] Additionally, their inhabitants are confronted with structural and functional weaknesses in local health systems (e.g., people not receiving needed curative care may consequently need palliative support) and an overall environment which lacks some of the basic conditions for health gains (e.g., unsanitary living conditions).[122] Because of the difficulty in accessing, or the total absence of, healthcare services in these countries, people's reliance on family care providers may often be the sole form of end-of-life support available. Contrary to popular belief, this form of support is largely provided by the recipient's spouse and children rather than an entire community, in that sense not differing much from the social character of family caregiving in high-income countries.[60,123] Given that virtually all health promotion initiatives surrounding end-of-life care described in literature are initiated and/or led by professional care services, it should perhaps not surprise that, with the exception of one, no initiatives from these countries have yet been described in peer-reviewed literature due to the minimal presence of health services.[124] Additionally, a minority of publications on palliative care comes from these countries as they possess minimal research funds compared to high-income countries and may choose to address topics which they consider more urgent.[125] If the development of health promotion initiatives continues to rely predominantly on professional care services, inhabitants of low-income countries suffer needlessly awaiting these services' structural development. I therefore advocate for the continued exploration of health promotion initiatives led by community activists. Such initiatives should be explored in all income-level countries, but low-income countries may benefit the most from implementing findings due to the absence or dysfunctionality of local health systems.

Recognise community expertise which exists next to health services

Although health promotion initiatives should be co-produced, and if possible co-led, by communities, this does not imply promoting the shift of care from services to communities. This distinction is important to stress as Compassionate Cities and Communities are often proposed as solutions to address societal challenges that affect our healthcare systems today and in the future.[52,120] In the context of public health approaches to the end of life, healthcare systems are often defined by their shortcomings. Literature in that regard promotes cost-effective solutions that can positively affect population health through family care, the use of volunteers, or other strategies (CHAPTER I).[60,68,126,127] One may then draw the conclusion that public health approaches to the end of life are a viable means to address gaps in health services, particularly during times of resource constraint. Preliminary studies on Compassionate Cities and Communities, of which the results are not repeated and should be interpreted with caution, indeed show that aspiring to such outcomes is not entirely out of thin air.[68,69] However, healthcare services have the explicit task of reorienting themselves to promote health and not merely extend their reach through community resources.[1] Communities that join the reactive, bio-medically focused model of health systems will not impact the increasing health-related suffering in populations. Therefore, policy development should recognise communities for their unique expertise which exists alongside that of healthcare services. The development of governmental policies that facilitate building social capital (e.g., financial seed funding for cultural activities) and the activation of that social capital (e.g., providing children who take on family caregiving tasks with an adapted educational programme, as exists in some countries for athletes) could be a paramount strategy.

People’s environments are thus conducive to effectively build and establish social capital which may then support people with end-of-life needs. For example, changing the environments in which people live, by openly talking with children about the end of life, by instigating national policies that support bereaved people or by making cemeteries more accessible, may help in normalising the end of life and strengthen people to support others when confronted by it. Such interventions may contribute to reduce people’s discomfort about the suffering and dying of others or increase their willingness to support others when they are confronted by end-of-life situations. I showed in CHAPTER III the reciprocal relationship between perceived social support and willingness to provide social support, which indicates the importance of building social relationships in Compassionate Cities.

Integration in policy to ensure sustainability

Regardless of which organisation or institution takes the lead in the development of Compassionate Cities, integrating their commitment should be part of long-term policy plans and integral to programme theory. We have observed how the future of Compassionate Cities becomes uncertain when the responsibility for the project is assigned to individual leaders, as opposed to being integrated into long-term policy plans (CHAPTER V). Involving policymakers in Compassionate Cities is therefore paramount to developing and instigating such policy changes.[74] On the other hand, the involvement of communities in the development of those policies that affect them has been identified to be beneficial over centralised, bureaucratic policy development.[61] Such collaborations need to take the possibility of contesting goal formulations into account.[128] Local governments are enthusiastic about the idea of empowering communities, but may appear conservative towards high levels of community involvement. Empowered communities are meant to voice their own needs and solutions, and not to execute governmental policy agendas. To realise relevant policy changes, governmental enthusiasm towards community involvement could be matched with democratic decision-making extending to the level of policy development. Although I acknowledge that this represents a significant departure from the customary approach to governmental policy development, I firmly believe that granting ownership and recognition to the community will prove advantageous if the aim is truly sustainable development towards sociocultural changes surrounding end-of-life matters.

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SUMMARIES

English summary

Background

A healthcare service-focused approach is typically pursued in response to the rising number of people suffering from chronic illnesses. Due to the significant support needs of all those affected by serious illness, death, dying, loss, and grief, this approach inevitably reaches its limits. With the proportion of potential care providers decreasing, governments are challenged to rethink their approach to care delivery. For too long, death has been regarded as a medical failure rather than the last, inevitable step in a human's life. Health policies have traditionally focused predominantly on healthy populations and illness prevention, thus excluding people facing end-of-life situations as if they health improvements are not applicable to this population. By considering population needs not only on a physical but also on a psychosocial and spiritual level, it becomes evident that responding with a service-focused approach is entirely unrealistic. Population needs around the end of life predominantly reside within our social domain, but death and dying have become increasingly estranged from society. Therefore, public engagement programmes around the end of life have been proposed to alleviate people's needs on these levels and counter the medicalisation of our health and the end of life.

The Ottawa Charter for Health Promotion (1986) marked a clear departure from prior health policies by promoting attention to the surroundings in which people reside and how they affect and permit health creation. The Ottawa Charter proposes five main action areas: building healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and reorienting health services. The Healthy Cities movement was an operationalisation of these areas, but as it did not regard end-of-life situations, the sociologist Allan Kellehear applied the same principles to the end of life in 2005 and coined the term "Compassionate Cities." A public health approach to the end of life engages local communities to increase their wellbeing around serious illness, death, dying, and loss by relying on local community assets and resources. Such approaches typically develop people’s knowledge, skills, attitudes, and behaviours which enable them to act on end-of-life situations. Compassionate Cities are an example of a public health approach to the end of life which aims for long-term and structural changes to improve populations’ end-of-life experiences. They acknowledge the omnipresence of death and dying in all environments where people meet and target these environments (i.e., social ecology) as they relate to our health. To facilitate this, the Compassionate City Charter has been proposed with 13 social changes to cities’ key institutions such as schools, workplaces, and the development of policies.

Compassionate Cities are a response to neoliberal paradigms that emphasise individual responsibility in health status. The development of social capital at the community level has been identified as central to improving health, as trust-based relationships between people have been found to be conducive to health. Individuals typically rely on their close family members for support, but important help can also be found in other social connections such as neighbours, friends, or colleagues. Compassionate Cities aim to develop policy and structural changes to target the environments that impact our health.

Compassionate Cities seek to improve population health related to the end of life, but as they are developed in complex environments with diverse stakeholder profiles and face non-linear pathways between inputs, outputs, and outcomes, predicting and attributing outcomes is challenging. Prior to the research performed in this dissertation, only a few publications on Compassionate Cities and Communities had been published, but none extensively report on their contextual characteristics, development processes, and the nature and content of their evaluations. Such evaluations are important, however, to guide and inspire other developers, to substantiate the development of Compassionate Cities by linking outcomes to the programmes, and to further scientific knowledge on this innovative topic. It is noteworthy that prior to this research project, no Compassionate City research protocols have been published which announced the planned evaluation of a programme’s development process and outcomes.

Compassionate Cities are often proposed as a response to the sociocultural taboo surrounding the end of life. However, no prior research has yet explored the discomfort people actually feel when presented with typical end-of-life situations. Such information can help developers target specific end-of-life domains and guide future activity development. Although Compassionate City programmes rely on community assets and engagement, it remains unexplored whether people are indeed willing to help their neighbours with practical or emotional tasks. This is important to know, as this assumption is one of the cornerstones on which Compassionate Cities rely for building and activating communities' social capital.

This dissertation aims to address the following research gaps:

- What are the contextual characteristics, processes of development and reported evaluations on international Compassionate City and Community initiatives?
- What is the general population's discomfort with the suffering and dying of others and are these feelings associated with personal characteristics or experiences?
- What is the general population's willingness to emotionally or practically support their neighbours who are facing situations of serious illness, caregiving and loss and are these feelings associated with specific personal characteristics or experiences?
- What is the process of development of two Compassionate Cities in Flanders, Belgium?

Research aims

I aim to address these knowledge gaps through two main research aims. Aim 1 is to inform the development of Compassionate Cities by identifying existing scientific knowledge and describing the attitudes and experiences of citizens in the general population regarding aspects related to serious illness, dying, caregiving, and providing support. Aim 2 is to evaluate the process of development of two Compassionate Cities in Flanders, Belgium.

Methods

Research aim 1 is addressed using different quantitative methods. A systematic integrative review of peer-reviewed literature on Area-Based Compassionate Communities reported on their contextual characteristics, processes of development, and reported evaluations (CHAPTER I). The found literature was supplemented with other literature using the snowball method and with grey literature by screening the included initiatives' websites and contacting the first author of included articles with a request for additional documentation. The data extraction process was performed by a second researcher for 20% of the included articles. Next, a combined online and postal cross-sectional survey was conducted in four municipalities in Flanders, Belgium, and distributed to a total of 4,400 inhabitants. I used repeated mailings to achieve higher response rates. A linear regression model was used to explore associations between the self-developed measure of people's discomfort with the suffering and dying of others and their personal experiences with care, illness and death, demographic characteristics, and religiousness (CHAPTER II). Directed acyclic graphs made my association interests explicit and guided a deconfounding strategy. A second, self-developed measure reported on people's willingness to support their neighbours practically or emotionally, whether willingness differed depending on the type of support tasks, and whether there were associations between the main outcome measure and people's personal characteristics, personal experiences with care, illness and death, religiousness, and perceived social support (CHAPTER III).

For research aim 2, a study protocol was published which reported on the intentions to evaluate the process of development and outcomes of two Compassionate Cities in Flanders, Belgium (CHAPTER IV). Semi-structured interviews, observations, field notes, and group discussions were used to collect data on the process of development of both Compassionate Cities (CHAPTER V). These data were generated by people involved in facilitating the development, stakeholders with relevant backgrounds who were in the leading coalition who led the development, individuals directly involved in activities or specific interventions, and individuals who were in some way (in)directly affected by these activities or interventions. The framework method was used to analyse the data and structure reporting the main findings regarding the developed structures, the involved stakeholders and their roles, how the development was facilitated, the characteristics of the development that facilitated or hindered it, and important contextual factors.

Main findings

In CHAPTER I, the primary focus was identifying peer-reviewed articles on Area-Based Compassionate Communities. The initial search yielded 1,464 articles which, after removing duplicates and screening titles and abstracts based on inclusion and exclusion criteria, was further narrowed down to 26 articles on 22 unique initiatives. Articles were highly heterogeneous in their contextual and developmental characteristics. Only a minority of Area-Based Compassionate Communities underwent an evaluation that had been published in the peer-reviewed literature. Such evaluations reported on the process of development, outputs, or outcomes, albeit never extensively. Strengthening people's social capital was a recurring strategy in the included initiatives.

As the discomfort people feel about the suffering and dying of others can play an important role in developing Compassionate Cities, this was the main focus of CHAPTER II. A total of 1,890 questionnaires (43.0%) from the initial 4,400 sent were included in the analysis. With an average score on the main outcome measure of 3.74 (SD = 0.89) on a Likert scale ranging from 1 (not uncomfortable) to 5 (uncomfortable), we can conclude that people feel somewhat uncomfortable about the suffering and dying of others. The highest discomfort was reported in the situation where people had to tell a person that they were dying, and the lowest when they would have to talk about death with a dying person. Respondents felt more comfortable when they had prior experiences on cultural, professional, and informal levels with the end of life. They also felt more comfortable when they had better knowledge about palliative care.

As Compassionate Cities rely on community engagement to build their programme, CHAPTER III discusses people's willingness to get involved in supporting other people in their neighbourhood who are confronted with the end of life. From the 4,400 questionnaires sent, 1,851 (42.1%) were included in the analysis. On a Likert scale ranging from 1 (definitely not) to 5 (definitely), respondents scored an average willingness to support their neighbours of 3.41 (SD = 1.00) in case 1 (older person in need of help), and 3.85 (SD = 0.95) in case 2 (caregiver of dying partner). A higher willingness was found among respondents who were female, religious, previously culturally exposed to death and dying, had experience as a family carer, work(ed) as a healthcare worker, volunteered (around serious illness, death, dying or grief), had undertaken action around their end of life, had been with someone else at the time of their death, had higher (self-estimated) palliative care knowledge, and believed they would receive support from different groups of people if they needed help.

CHAPTER IV reports on the planned process and outcome evaluation of two Compassionate Cities in Flanders, Belgium.

The process evaluation of the development of the two Compassionate Cities is reported in CHAPTER V. A total of 86 interviews, 121 observations, and 7 group discussions were used for data analysis. Both Compassionate Cities underwent changes regarding their development structures, with one city focusing on the development of Compassionate Schools. Various activities were developed in the cities with an educational, intangible, cultural, service, policy, professional, or self-determined focus. These activities were developed by different stakeholder profiles and were mostly developed for the general population, but sometimes focused on a subgroup of the population such as teachers. The themes identified under facilitation and coordination included coaching project coordinators, expediting strategic decisions, engaging stakeholders and associated challenges, accommodating stakeholder motivations to participate, utilising the research context, taking development requirements into account. Several themes related to implementation strategy characteristics that facilitated or hindered the development were city administrations taking the lead, conceptual coherence and understanding, tension between culture change and immediate action, the importance of mandates, and bringing in expertise. Finally, the themes related to the contextual factors that influenced the development were COVID-19, experiences from prior interactions, prior death and loss experiences and perceptions, resource shortages, competitive professional environment, and the school context.

General discussion

This dissertation compiles scientific information to inform the development of Compassionate Cities by reviewing the peer-reviewed literature on this topic. I further studied and discussed the general population's attitudes and experiences regarding aspects related to serious illness, dying, caregiving, and providing support. Lastly, I reported and evaluated the development process of two Compassionate Cities in Flanders, Belgium.

Importance of publishing evaluations on Compassionate Cities

I highlighted the difficulty that exists in comparing programmes within complex environments such as Compassionate Cities. The lack of transparency in applied methodology and the lack of comprehensive Compassionate City evaluations hamper comparisons, as has been echoed in several recent reviews on Compassionate Cities and Communities. To address this, I first developed and published a study protocol that transparently reported the evaluation intentions for our two Compassionate Cities. The process evaluation that I then conducted provided important insights that can be considered by subsequent Compassionate City developers. Notwithstanding the importance of the context in such process evaluations, reporting on the development of Compassionate Cities in peer-reviewed literature is an effective way of exchanging information and learnings.

Continued attention to death and dying is needed to achieve sociocultural changes

Death and dying remain topics that struggle to find an entry into aspects of daily life such as schools or day-to-day conversations. I reported how involved stakeholders sometimes desired to broaden the Compassionate City to topics like wellbeing. Although this does not necessarily indicate that death and dying were taboo, it does indicate that they warrant continued attention so as not to be disregarded, as happened in the Healthy Cities movement. Additionally, there are some clear signs in today's society that people face difficulties handling situations related to death and dying. Notwithstanding this, I reported how people felt least uncomfortable when they had to discuss the end of life with a dying person. Furthermore, people were actually willing to support their neighbours who are faced with end-of-life situations. This shows that there is sound potential to change our sociocultural perspectives on death and dying. Such perspectives are not set in stone but subject to change through a series of interventions and activities.

Both top-down and bottom-up developments have advantages and drawbacks

Neither top-down nor bottom-up developments have shown clear evidence of being better than the other in achieving the best health outcomes. Top-down initiatives often face issues related to bureaucracy while bottom-up initiatives often fail to upscale their programme. I reported on how a top-down development is met with criticism and frustration. However, the advantages related to the availability of resources and networks are likely difficult to attain without the support from very large organisations. In any case, an important facilitative role should be taken up by local governments as they possess unique assets in Compassionate Cities. Integrating aspects from both bottom-up and top-down development approaches is likely necessary in the development of sustainable Compassionate Cities. On the other hand, I showed the importance of integrating preferences and ideas from participating stakeholders as this was essential to keep them motivated and hence, continue development.

Compassionate Cities may have a positive impact on the economy, population health and social connectedness

Prior research has indicated that community engagement programmes can positively impact social connection. I showed how people who felt supported by community members were more willing to support others in their community. This possibly indicates implicit feelings of reciprocal relationships between community members regarding community support and strengthens the evidence that there is sufficient willingness to build and activate support networks, a key pillar of Compassionate Cities. Preliminary studies on Compassionate Cities have shown the potential positive economic impact that such initiatives may have on healthcare expenditure, while also providing the opportunity for increasing skills and knowledge on topics like caregiving. What is certain is that increasing social capital is strongly connected to wellbeing and health. Governmental policies that facilitate the development of Compassionate Cities may consequently achieve results that are relevant to domains both in and outside of the healthcare sector. Studying the outcomes of Compassionate Cities should remain an important focus in future research as such results guide and potentially facilitate the support needed for Compassionate Cities.

Practice recommendations

- Engage communities in the development of Compassionate Cities. Listen and integrate opinions from participating stakeholders. Evaluate and reevaluate the chosen community engagement approach.
- Integrate the implicit or explicit aim of building people’s social capital and social connectedness as much as possible. The emphasis on end-of-life topics is important but does not need to be present in every activity.
- Incorporate an early focus on activity development. Develop programme theory and development plans with those stakeholders who show an interest in doing so.

- Consider the use of an (external) facilitator with expertise in change processes and group dynamics to train Compassionate City leaders.
- Translate long-term aims into well-designed short-term aims which involved stakeholders can relate to.
- If developers aim for sector-wide changes, achieving the political support corresponding to these sectors is essential.
- Develop a communication plan that clearly states the need and relevance of Compassionate Cities. Information should be tailored to the interests of the audience.

Research recommendations

- Continue outcome and process evaluations.
- Publish study protocols.
- Make use of the assets of researchers to facilitate development.

Policy recommendations

- Recognise the expertise of, and engage communities in the development of Compassionate Cities.
- Develop governmental policies that facilitate building and activating social capital.
- Consider the involvement of the community in policy development.

Nederlandstalige samenvatting

Situering

Een zorgdienstgerichte benadering wordt doorgaans nagestreefd als reactie op het toenemende aantal mensen dat lijdt aan chronische ziekten. Vanwege de aanzienlijke ondersteuningsbehoeften van allen die getroffen worden door ernstige ziekte, dood, sterven, verlies en rouw, botst deze benadering onvermijdelijk op zijn limieten. Door de proportionele afname in het aantal potentiële zorgverleners worden overheden uitgedaagd om hun benadering van zorgverlening te herzien. De dood werd te lang beschouwd als een medisch falen in plaats van de laatste, onvermijdelijke stap in het leven van de mens. Gezondheidsbeleid heeft zich traditioneel voornamelijk gericht op gezonde populaties en ziektepreventie waardoor mensen aan het eind van hun leven werden uitgesloten alsof gezondheidsverbeteringen niet van toepassing zijn op deze populatie. Door niet alleen naar fysieke, maar ook naar psychosociale en spirituele behoeften van deze populatie te kijken, wordt het duidelijk dat reageren met een dienstgerichte benadering volkomen onrealistisch is. De behoeften van mensen aan het levenseinde liggen voornamelijk binnen het sociale domein. Desalniettemin zijn dood en sterven zijn alsmaar meer vervreemd van de samenleving. Als reactie werden ontwikkelingsprogramma's voorgesteld waarin de samenleving betrokken wordt rond het levenseinde met als doel in de behoeften van mensen op deze niveaus te voorzien en de medicalisering van onze gezondheid en het levenseindetegen te gaan.

Het Ottawa Charter for Health Promotion (1986) bewerkstelligde een duidelijke breuk met eerder gezondheidsbeleid door aandacht te vestigen op de omgeving waarin mensen leven en hoe deze gezondheid beïnvloeden en gezondheidswinst mogelijk maken. Het Ottawa Charter stelt vijf actiedomeinen voor: gezond overheidsbeleid ontwikkelen, ondersteunende omgevingen creëren, gemeenschapsacties versterken, persoonlijke vaardigheden ontwikkelen en gezondheidsdiensten heroriënteren. De Healthy Cities-beweging was een operationalisatie van deze domeinen, maar omdat het geen rekening hield met eindelevenssituaties, paste de socioloog Allan Kellehear in 2005 dezelfde principes toe op het levenseinde en noemde dit de "Compassionate Cities". Een volksgezondheidsbenadering van het levenseinde betrekt lokale gemeenschappen om hun welzijn rond ernstige ziekte, dood, sterven en verlies te vergroten door gebruik te maken van lokale gemeenschapsmiddelen en -bronnen. Dergelijke benaderingen ontwikkelen doorgaans de kennis, vaardigheden, attitudes en gedragingen van mensen, waardoor zij kunnen handelen in situaties rond het levenseinde. Compassionate Cities zijn een voorbeeld van een volksgezondheidsbenadering van het levenseinde die streeft naar langetermijn- en structurele veranderingen om de eindelevenservaringen van populaties te verbeteren. Ze erkennen de alomtegenwoordigheid van dood en sterven in alle omgevingen waar mensen samenkomen en focussen zich op deze omgevingen (sociale ecologie) aangezien deze betrekking hebben op onze gezondheid. Om dit te faciliteren werd het Compassionate City Charter voorgesteld met 13 sociale veranderingen gericht op de belangrijkste stadsinstellingen zoals scholen, werkplekken en de ontwikkeling van beleid.

Compassionate Cities zijn een reactie op neoliberale paradigma's die de nadruk legden op ieders individuele verantwoordelijkheid in zijn of haar gezondheidsstatus. De ontwikkeling van sociaal kapitaal op gemeenschapsniveau wordt erkend als centraal voor het verbeteren van gezondheid, aangezien relaties tussen mensen die gebaseerd zijn op vertrouwen bevorderlijk zijn voor de gezondheid. Mensen vertrouwen doorgaans op hun naaste familieleden voor ondersteuning, maar belangrijke hulp kan ook worden gevonden in andere sociale verbindingen zoals buren, vrienden of collega's. Compassionate Cities streven ernaar beleid en structurele veranderingen te ontwikkelen om de omgevingen te beïnvloeden die dan weer onze gezondheid beïnvloeden.

Compassionate Cities streven ernaar de gezondheid van de populatie rond het levenseinde te verbeteren. Aangezien ze worden ontwikkeld in complexe omgevingen met diverse belanghebbenden met diverse profielen en te maken hebben met niet-lineaire paden tussen inputs, outputs en resultaten, is het voorspellen en toeschrijven van resultaten een uitdaging. Er waren slechts enkele publicaties over Compassionate

Cities en Communities gepubliceerd voorafgaand aan het onderzoek uitgevoerd in dit proefschrift en geen enkele rapporteerde uitgebreid over hun contextuele kenmerken, ontwikkelingsprocessen en de aard en inhoud van hun evaluaties. Dergelijke evaluaties zijn echter belangrijk om andere ontwikkelaars te informeren en te inspireren, om de ontwikkeling van Compassionate Cities te onderbouwen door er uitkomsten aan te kunnen toewijzen en om de wetenschappelijke kennis over dit innovatieve onderwerp te vergroten. Het is opmerkelijk dat er voorafgaand aan dit onderzoeksproject geen onderzoeksprotocollen van Compassionate Cities waren gepubliceerd die de geplande evaluatie van een ontwikkelingsproces en de resultaten van een dergelijk programma aankondigden.

Compassionate Cities worden vaak geponeerd als zijnde een antwoord op het socioculturele taboe rondom het levenseinde. Er is echter nog geen eerder onderzoek gedaan naar het ongemak dat mensen daadwerkelijk voelen wanneer ze worden geconfronteerd met typische situaties rond het levenseinde. Dergelijke informatie kan ontwikkelaars helpen om specifieke domeinen van het levenseinde te identificeren en toekomstige activiteiten te sturen. Hoewel Compassionate City-programma's afhankelijk zijn van lokale middelen en de betrokkenheid van de gemeenschap, is het nog niet onderzocht of mensen daadwerkelijk bereid zijn om hun buren te helpen met praktische of emotionele taken. Dit is belangrijk om na te gaan, aangezien deze aanname een van de hoekstenen is waarop Compassionate Cities vertrouwen om het sociale kapitaal van gemeenschappen op te bouwen en te activeren.

Dit proefschrift heeft als doel de volgende onderzoekshiaten te beschouwen:

- Wat zijn de contextuele kenmerken, ontwikkelingsprocessen en gerapporteerde evaluaties van internationale Compassionate Cities en Communities?
- Wat is het ongemak van de algemene bevolking met het lijden en sterven van anderen en zijn deze gevoelens geassocieerd met persoonlijke kenmerken of ervaringen?
- Wat is de bereidheid van de algemene bevolking om emotioneel of praktisch hun buren te ondersteunen die geconfronteerd worden met ernstige ziekte,

zorgverlening en verlies, en zijn deze gevoelens geassocieerd met specifieke persoonlijke kenmerken of ervaringen?
- Wat is het ontwikkelingsproces van twee Compassionate Cities in Vlaanderen, België?

Onderzoeksdoelstellingen

Ik poog deze onderzoekshiaten aan te pakken door middel van twee hoofddoelstellingen. Doelstelling 1 is om de ontwikkeling van Compassionate Cities te informeren door de bestaande wetenschappelijke kennis te identificeren en de houdingen en ervaringen van burgers in de algemene bevolking met betrekking tot ernstige ziekte, sterven, zorgverlening en het bieden van steun te beschrijven. Doelstelling 2 is om het ontwikkelingsproces van twee Compassionate Cities in Vlaanderen, België te evalueren.

Methoden

Onderzoekdoelstelling 1 wordt beschouwd met behulp van verschillende kwantitatieve methoden. Een systematische integratieve review van peer-reviewed literatuur over gebiedsgebonden Compassionate Communities rapporteerde over hun contextuele kenmerken, ontwikkelingsprocessen en gerapporteerde evaluaties (CHAPTER I). De gevonden literatuur werd aangevuld met andere literatuur via de sneeuwbalmethode en met grijze literatuur door de websites van de geïncludeerde initiatieven te screenen en de eerste auteur van de geïncludeerde artikelen te contacteren met het verzoek tot aanvullende documentatie. Het data-extractieproces werd uitgevoerd door een tweede onderzoeker voor 20% van de geïncludeerde artikelen. Vervolgens werd een cross-sectionele enquête uitgevoerd in vier gemeenten in Vlaanderen, die zowel online als via de post beschikbaar was. De enquête werd verspreid onder in totaal 4.400 inwoners. Ik gebruikte herhaalde mailings om hogere responspercentages te bereiken. Een lineair regressiemodel werd gebruikt om associaties te verkennen tussen het zelfontwikkelde meetinstrument voor het ongemak van mensen met het lijden en sterven van anderen en hun persoonlijke ervaringen met zorg, ziekte en dood, demografische kenmerken en religiositeit (CHAPTER II). Directed Acyclic Graphs maakten mijn associatie-interesses expliciet en maakten deel uit van de deconfoundingstrategie. Een tweede, zelfontwikkelde meetinstrument rapporteerde over de bereidheid van mensen om hun buren praktisch of emotioneel te ondersteunen. Hierin ging ik na of de bereidheid verschilde afhankelijk van het type ondersteunende taken en of er associaties waren tussen de resultaten op dit meetinstrument en de persoonlijke kenmerken van mensen, persoonlijke ervaringen met zorg, ziekte en dood, religiositeit en de ervaren sociale steun (CHAPTER III).

Voor onderzoekdoelstelling 2 werd een studieprotocol gepubliceerd waarin de intenties werden gerapporteerd om het ontwikkelingsproces en de uitkomsten van twee Compassionate Cities in Vlaanderen, België te evalueren (CHAPTER IV).

Semi-gestructureerde interviews, observaties, notities en groepsdiscussies werden gebruikt om gegevens te verzamelen over het ontwikkelingsproces van beide Compassionate Cities (CHAPTER V). Deze data werden gegenereerd door mensen die betrokken waren bij het faciliteren van de ontwikkeling, belanghebbenden met relevante achtergronden die in de leidende coalitie zaten die de ontwikkeling leidde, individuen die direct betrokken waren bij activiteiten of specifieke interventies, en individuen die op een of andere manier (in)direct werden beïnvloed door deze activiteiten of interventies. De framework-methode werd gebruikt om de gegevens te analyseren en de belangrijkste bevindingen te structureren met betrekking tot de ontwikkelde structuren, de betrokken belanghebbenden en hun rollen, hoe de ontwikkeling werd gefaciliteerd, de kenmerken van de ontwikkeling die deze faciliteerden of belemmerden, en belangrijke contextuele factoren.

Belangrijkste bevindingen

In CHAPTER I lag de primaire focus op het identificeren van peer-reviewed artikelen over gebiedsafgebakende Compassionate Communities. De initiële zoekopdracht leverde 1.464 artikelen op die, na het verwijderen van duplicaten en het screenen van titels en samenvattingen op basis van inclusie- en exclusiecriteria, verder werden teruggebracht tot 26 artikelen over 22 unieke initiatieven. Artikelen waren zeer heterogeen in hun contextuele en ontwikkelingskenmerken. Slechts een minderheid van de gebiedsafgebakende Compassionate Communities onderging een evaluatie die was gepubliceerd in de peer-reviewed literatuur. Deze evaluaties rapporteerden over het ontwikkelingsproces, de outputs of de uitkomsten, zij het nooit uitgebreid. Het versterken van mensen hun sociaal kapitaal was een terugkerende strategie in de opgenomen initiatieven.

Omdat het ongemak dat mensen voelen bij het lijden en sterven van anderen een belangrijke rol kan spelen bij de ontwikkeling van Compassionate Cities, was dit de hoofdfocus van CHAPTER II. In totaal werden 1.890 vragenlijsten (43,0%) van de aanvankelijke 4.400 verzonden vragenlijsten opgenomen in de analyse. Met een gemiddelde score op het meetinstrument van 3,74 (SD = 0,89) op een Likertschaal van 1 (niet ongemakkelijk) tot 5 (ongemakkelijk), kunnen we concluderen dat mensen zich enigszins ongemakkelijk voelen bij het lijden en sterven van anderen. Het grootste ongemak werd gerapporteerd in de situatie waarin mensen iemand moesten vertellen dat die persoon aan het sterven was, en het minste wanneer ze over de dood moesten praten met een stervende persoon. Respondenten voelden zich meer op hun gemak wanneer ze eerdere ervaringen hadden op cultureel, professioneel en informeel vlak met het levenseinde. Ze voelden zich ook meer op hun gemak wanneer ze meer kennis hadden omtrent palliatieve zorg.

Omdat Compassionate Cities afhankelijk zijn van de betrokkenheid van de gemeenschap om hun ontwikkelingsprogramma's uit te bouwen, bespreekt CHAPTER III de bereidheid van mensen om betrokken te raken bij het ondersteunen van andere mensen in hun buurt die geconfronteerd worden met het levenseinde. Van de 4.400 verzonden vragenlijsten werden er 1.851 (42,1%) opgenomen in de analyse. Op een Likertschaal gaande van 1 (zeker niet) tot 5 (zeker wel), scoorden respondenten een gemiddelde bereidheid om hun buren te ondersteunen van 3,41 (SD = 1,00) in casus 1 (oudere persoon die hulp nodig heeft), en 3,85 (SD = 0,95) in casus 2 (mantelzorger van stervende partner). Een hogere bereidheid werd geregistreerd onder respondenten die vrouw waren, religieus, eerder cultureel blootgesteld aan dood en sterven, ervaring hadden als mantelzorger, werkten (of hadden gewerkt) als zorgverlener, vrijwilligerswerk deden (rond ernstige ziekte, dood, sterven of rouw), actie hadden ondernomen rond hun eigen levenseinde, bij iemand anders waren geweest op het moment van hun dood, meer (zelf ingeschatte) kennis hadden over palliatieve zorg, en geloofden dat ze steun zouden ontvangen van verschillende groepen mensen als ze zelf hulp nodig zouden hebben.

In CHAPTER IV wordt de aangekondigde proces- en resultatenavaluatie van twee Compassionate Cities in Vlaanderen, België gerapporteerd.

De procesevaluatie van de ontwikkeling van de twee Compassionate Cities wordt gerapporteerd in CHAPTER V. Voor de data-analyse werden in totaal 86 interviews, 121 observaties en 7 focusgroepen gebruikt. Beide Compassionate Cities ondergingen veranderingen in hun ontwikkelingsstructuren, waarbij één stad zich richtte op de ontwikkeling van Compassionate Scholen. Er werden verschillende activiteiten ontwikkeld in de steden dewelke een educatieve, immateriële, culturele, dienstverlenende, beleidsmatige, professionele of zelfbepaalde focus hadden. Deze activiteiten werden ontwikkeld door verschillende belanghebbenden en waren meestal bedoeld voor de algemene bevolking, maar richtten zich soms op een subgroep van de bevolking zoals leraren.

De thema's die geïdentificeerd werden onder facilitatie en coördinatie omvatten het coachen van projectcoördinatoren, het versnellen van strategische beslissingen, het tegemoet komen aan de motivaties van belanghebbenden om deel te nemen, het benutten van de onderzoekscontext, en het rekening houden met ontwikkelingsvereisten. Verschillende thema's met betrekking tot kenmerken van de implementatiestrategie die de ontwikkeling bevorderden of belemmerden, waren stadsbesturen die het voortouw namen, conceptuele samenhang en begrip, spanning tussen cultuurverandering en onmiddellijke actie, het belang van mandaten, en het binnenhalen van expertise. Ten slotte waren de thema's gerelateerd aan de contextuele factoren die de ontwikkeling beïnvloedden COVID-19, ervaringen uit eerdere interacties, eerdere ervaringen en percepties van dood en verlies, tekort aan middelen, de competitieve professionele omgeving, en de schoolomgeving.

Bespreking van de bevindingen

Deze dissertatie verzamelt wetenschappelijke informatie om de ontwikkeling van Compassionate Cities te informeren door de peer-reviewed literatuur over dit onderwerp te onderzoeken. Ik heb verder de houdingen en ervaringen van de algemene bevolking bestudeerd en besproken met betrekking tot aspecten die verband houden met ernstige ziekte, sterven, mantelzorg en het bieden van ondersteuning. Ten slotte heb ik het ontwikkelingsproces gerapporteerd en geëvalueerd van twee Compassionate Cities in Vlaanderen, België.

Belang van het publiceren van evaluaties over Compassionate Cities

Ik heb de moeilijkheid benadrukt die bestaat in het vergelijken van ontwikkelingsprogramma’s binnen complexe omgevingen zoals Compassionate Cities. Het gebrek aan transparantie in de toegepaste methodologie en het gebrek aan uitgebreide evaluaties van Compassionate Cities bemoeilijken vergelijkingen, zoals ook is benadrukt in verschillende recente reviews over Compassionate Cities en Communities. Om dit aan te pakken, heb ik eerst een onderzoeksprotocol ontwikkeld en gepubliceerd dat de evaluatie-intenties voor onze twee Compassionate Cities transparant rapporteerde. De procesevaluatie die ik vervolgens uitvoerde leverde belangrijke inzichten op die kunnen worden overwogen door latere ontwikkelaars van Compassionate Cities. Ondanks het belang van de context in dergelijke procesevaluaties is het rapporteren over de ontwikkeling van Compassionate Cities in peer-reviewed literatuur een effectieve manier om informatie en geleerde lessen bekend te maken.

Voortdurende aandacht voor dood en sterven is nodig om socioculturele veranderingen te bereiken

Dood en sterven blijven onderwerpen die moeite hebben om een ingang te vinden in aspecten van het dagelijks leven zoals scholen of alledaagse gesprekken. Ik heb gerapporteerd hoe betrokken belanghebbenden soms wensten de thema's van de Compassionate Cities uit te breiden naar onderwerpen zoals welzijn. Hoewel dit niet noodzakelijkerwijs aangeeft dat dood en sterven taboe waren, geeft het wel aan dat ze voortdurende aandacht verdienen om niet genegeerd te worden, zoals gebeurde in de Healthy Cities beweging. Bovendien zijn er in de huidige samenleving duidelijke tekenen dat mensen moeite hebben met situaties die verband houden met dood en sterven. Niettemin heb ik gerapporteerd hoe mensen zich het minst ongemakkelijk voelden wanneer ze het einde van het leven van een stervend persoon met deze persoon moesten bespreken. Bovendien waren mensen best bereid om hun buren te ondersteunen die geconfronteerd worden met situaties rond het levenseinde. Dit toont aan dat er een solide potentieel is om onze socioculturele perspectieven op dood en sterven te veranderen. Dergelijke perspectieven zijn vastgeroest maar wel onderhevig aan verandering door middel van interventies en activiteiten.

De rol van de gemeenschap in het ontwikkelingsproces

Mijn eigen ervaringen met het ontwikkelen van Compassionate Cities tonen duidelijk aan dat geen mensen van de gemeenschap maar wel anderen de leiding nemen in de ontwikkeling. Dit is eerder onderwerp van kritiek geweest op gemeenschapsinitiatieven. Hierin zijn de leiders vaak vertegenwoordigers van de organisatie die het initiatief neemt en dus geen mensen van de gemeenschap. Deze leiders maken vaak deel uit van gezondheidsdiensten, wat specifieke uitdagingen met zich meebrengt die verband houden met deze sector, zoals tekorten aan middelen. Bovendien roept dit vragen op met betrekking tot het feit of zij hun activiteiten uitbreiden voorbij hun typische dienstverlening, zoals de Compassionate City-beweging pleit. Hoewel de impact op de duurzaamheid van Compassionate Cities moeilijk te beoordelen is, staat deze onder druk indien het leiderschap niet met de gemeenschap gedeeld wordt. Dit blijkt ook uit de frustraties van belanghebbenden in onze Compassionate Cities, die ervoeren dat hun rol en mandaat eerder beperkt bleef. De literatuur pleit inderdaad voor mede-leiderschap met gemeenschappen om de eigenlijke gemeenschapsbehoeften te identificeren. Aangezien het ontwikkelen van Compassionate Cities via gezondheidsdiensten de voorkeur lijkt te hebben in veel initiatieven, moeten ontwikkelaars actief reflecteren over hoe de gemeenschap betrokken kan worden bij het ontwikkelingsproces. Ik toonde hoe intenties om gemeenschapsleden te versterken kunnen worden belemmerd door praktische beperkingen zoals een gebrek aan tijd om effectief deel te nemen. Dit mag ontwikkelaars echter niet ontmoedigen om gemeenschapsleden te betrekken, aangezien dit een belangrijke factor kan zijn voor een duurzame ontwikkeling. Het betrekken van gemeenschappen kan duidelijk verschillen van de gebruikelijke werkwijze in organisaties, wat wijst op de noodzaak om leiders van Compassionate Cities te trainen in dergelijke principes. Compassionate Cities richten zich vaak op specifieke subpopulaties in plaats van de volledige relevante bevolking. Ze richten zich echter zelden op gemarginaliseerde groepen zoals wel bepleit wordt in het Compassionate City Charter. Hoewel het misschien nog te vroeg is om conclusies te trekken of Compassionate Cities inderdaad de volledige relevante bevolking bereiken, is het misschien belangrijk voor huidige en toekomstige ontwikkelaars om te reflecteren of dit inderdaad een focus binnen hun ontwikkeling is.

Zowel top-down als bottom-up ontwikkelingen hebben voor- en nadelen

Noch top-down noch bottom-up ontwikkelingen hebben duidelijk aangetoond dat ze beter zijn dan de ander in het bereiken van de beste gezondheidsresultaten. Top-down initiatieven worden vaak geconfronteerd met problemen met betrekking tot bureaucratie, terwijl bottom-up initiatieven vaak falen om hun programma op te schalen. Ik heb gerapporteerd hoe een top-down te maken kan krijgen met kritiek en frustratie. Echter, de voordelen die er zijn met betrekking tot de beschikbaarheid van middelen en netwerken zijn waarschijnlijk moeilijk te bereiken zonder de steun van zeer grote organisaties. In ieder geval zou een belangrijke faciliterende rol moeten worden ingenomen door lokale overheden, aangezien zij unieke troeven bezitten in Compassionate Cities. Het integreren van aspecten van zowel bottom-up als top-down ontwikkelingen is waarschijnlijk noodzakelijk bij de ontwikkeling van duurzame Compassionate Cities. Ik heb ook getoond hoe belangrijk het is om voorkeuren en ideeën van deelnemende belanghebbenden te integreren, aangezien dit essentieel was om hen gemotiveerd te houden en dus de ontwikkeling verder te zetten.

Compassionate Cities kunnen een positieve invloed hebben op de economie, de gezondheid van de bevolking en sociale verbondenheid.

Eerder onderzoek heeft aangetoond dat ontwikkelingsprogramma's die de gemeenschap betrekken een positieve invloed kunnen hebben op sociale verbondenheid. Ik heb laten zien hoe mensen die zich gesteund voelen door andere mensen, meer geneigd waren om anderen in hun gemeenschap te steunen. Dit duidt mogelijk op het bestaan van wederkerige relaties tussen buurtbewoners met betrekking tot ondersteuning en versterkt het bewijs dat er voldoende bereidheid is om ondersteuningsnetwerken op te bouwen en te activeren, een belangrijke pijler van Compassionate Cities. Voorlopige studies over Compassionate Cities hebben het potentiële positieve economische effect laten zien dat dergelijke initiatieven kunnen hebben op gezondheidsuitgaven, alsook op individuele vaardigheden en kennis op het gebied van mantelzorg. We weten dat het vergroten van sociaal kapitaal sterk verbonden is met welzijn en gezondheid. Overheidsbeleid dat de ontwikkeling van Compassionate Cities faciliteert kan bijgevolg resultaten behalen die relevant zijn voor domeinen zowel binnen als buiten de gezondheidszorgsector. Het bestuderen van de resultaten van Compassionate Cities moet een belangrijke focus blijven in toekomstig onderzoek, aangezien dergelijke resultaten richting geven en potentieel de ondersteuning vergemakkelijken die nodig is voor het ontwikkelen van Compassionate Cities.

Praktijkaanbevelingen

- Betrek gemeenschappen bij de ontwikkeling van Compassionate Cities. Luister naar en integreer meningen van deelnemende belanghebbenden. Evalueer en heroverweeg de gekozen benadering om de gemeenschap te betrekken.
- Integreer het impliciete of expliciete doel om de sociale netwerken en sociale verbondenheid van mensen zoveel mogelijk op te bouwen. De nadruk op onderwerpen rond het levenseinde is belangrijk, maar hoeft niet aanwezig te zijn bij elke activiteit.
- Focus vroeg op de ontwikkeling van activiteiten. Ontwikkel theorieën en ontwikkelingsplannen met die belanghebbenden die hierin interesse tonen.
- Overweeg het gebruik van een externe facilitator met expertise in veranderingsprocessen en groepsdynamiek om leiders van Compassionate Cities te trainen.
- Vertaal langetermijndoelstellingen naar goed ontworpen kortetermijndoelstellingen waarmee betrokken belanghebbenden zich kunnen identificeren.
- Als ontwikkelaars streven naar veranderingen op het niveau van verschillende beleidsdomeinen, is het essentieel om de politieke steun te verkrijgen die overeenkomt met deze domeinen.
- Ontwikkel een communicatieplan dat duidelijk de noodzaak en relevantie van Compassionate Cities schetst. Informatie moet worden afgestemd op de interesses van het publiek.

Onderzoeksaanbevelingen

- Voer evaluaties uit van het ontwikkelingsproces en de resultaten.
- Publiceer onderzoeksprotocollen.
- Maak gebruik van de sterktes van onderzoekers om ontwikkeling te faciliteren.

Beleidsaanbevelingen

- Erken de expertise van, en betrek gemeenschappen bij de ontwikkeling van Compassionate Cities.
- Ontwikkel overheidsbeleid dat de opbouw en activering van sociaal kapitaal faciliteert.
- Overweeg de betrokkenheid van de gemeenschap bij beleidsontwikkeling.

CURRICULUM VITAE, PUBLICATIONS, PRESENTATIONS & WORKSHOPS

Curriculum Vitae

Bert Quintiens is a registered nurse and holds a Master of Science degree in Healthcare Management and Policy from Ghent University. Bert has worked for several years as a nurse and as a clinical trial coordinator. In May 2019, he started his research project as a doctoral candidate at the End-of-Life Care Research Group (Vrije Universiteit Brussel and Ghent University). His research 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. This research project was supported by a grant from the Research Foundation Flanders. Bert's research revolved around the development and evaluation of two Compassionate Cities in Flanders, Belgium.

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APPENDIX

A1: Questionnaire used in the general population of four municipalities

Vragenlijst inwoners stad X

UW BETROKKENHEID IN DE LOKALE GEMEENSCHAP

We stellen u enkele vragen over uw activiteiten in uw lokale gemeenschap. Indien we spreken over lokale gemeenschap, bedoelen we elke plaats waar u binnen de 20 minuten geraakt. Zowel te voet als met de auto, fiets, bus,…

1 Antwoord op de volgende vragen.

A	Helpt u bij in een lokale groep als vrijwilliger?	**Nee, helemaal niet**			**Ja vaak (minstens 1x per week)**
		1	**2**	**3**	**4**
B	Heeft u in de 6 maanden voor de coronacrisis een evenement in uw lokale gemeenschap bijgewoond? (bv. Parochiefeest, schoolconcert, hobbybeurs).	**Nee, helemaal niet**			**Ja, meerdere (minstens 3)**
		1	**2**	**3**	**4**
C	Bent u een actief lid van een organisatie of club in uw lokale gemeenschap (bv. sportclub, hobbyclub, praatclub)?	**Nee, helemaal niet**			**Ja, erg actief**
		1	**2**	**3**	**4**
D	Zit u in een beheers- of organisatiecomité voor een groep of organisatie in uw lokale gemeenschap?	**Nee, helemaal niet**			**Ja, verschillende (minstens 3)**
		1	**2**	**3**	**4**
E	Heeft u in de afgelopen 3 jaar voor de coronacrisis ooit meegedaan aan een actie in uw lokale gemeenschap om een noodtoestand op te vangen? (helpen bij een verkeersongeval, een zieke buur naar spoed brengen,…).	**Nee, helemaal niet**			**Ja, frequent (minsten 5x)**
		1	**2**	**3**	**4**
F	Heeft u in de afgelopen 3 jaar ooit deelgenomen aan een gemeenschapsproject of liefdadigheidsactie in uw lokale gemeenschap? (buurttuin, straatfeest, een festival voorbereiden,…).	**Nee, helemaal niet**			**Ja, zeer veel**
		1	**2**	**3**	**4**
G	Heeft u ooit deelgenomen aan een project om een nieuwe dienst in uw lokale gemeenschap te organiseren? (bv. nieuwe jeugdclub, bouw scoutslokaal, opstarten kinderopvang, ontwikkelen van recreatie voor mensen met een handicap).	**Nee, helemaal niet**			**Ja, verschillende (minstens 3)**
		1	**2**	**3**	**4**
H	Hoeveel evenementen/activiteiten heeft u in het jaar voor de corona-crisis in uw stad bijgewoond die betrekking hadden op thema's rond ernstige ziekte, overlijden, sterven of rouw (bv. kunsttentoonstelling, theater, toneel, film, een getuigenis bijwonen)?	**Geen enkel**	**Éen of twee**	**Drie of vier**	**5 of meer**
		1	**2**	**3**	**4**

I	Hoe dikwijls heeft u in het jaar voor de corona-crisis vrijwilligerswerk gedaan bij een organisatie die zich inzet rond onder andere ernstige ziekte, overlijden, sterven of rouw?	**Nooit**	**1 keer**	**2 tot 5 keer**	**Meer dan 5 keer**
		1	**2**	**3**	**4**

2 Als u ziek zou worden en naar het ziekenhuis moet, krijgt u dan hulp om naar de winkel te gaan, het gras af te rijden, voor uw huisdieren te zorgen van de mensen hieronder?

		Zeker niet			**Zeker wel**	**Ik weet het niet**
A	Familie of mensen met wie u veel contact hebt	**1**	**2**	**3**	**4**	**0**
B	Vrienden of kennissen uit uw lokale gemeenschap	**1**	**2**	**3**	**4**	**0**
C	Vrienden of kennissen buiten uw lokale gemeenschap	**1**	**2**	**3**	**4**	**0**
D	Mensen uit uw buurt die u niet (zo goed) kent: vrijwilligers uit de buurt, Whatsapp-buurtgroepen, een pastoor …	**1**	**2**	**3**	**4**	**0**

E	Stel: u woont samen met iemand die hulp nodig heeft. U moet even weg. Zou u iemand uit uw lokale gemeenschap vragen om even bij die persoon te blijven?	**Nee, helemaal niet**			**Ja, meerdere personen**
		1	**2**	**3**	**4**
F	Hebt u de voorbije week iemand uit uw lokale gemeenschap bezocht die het moeilijk heeft? Bijvoorbeeld omdat die iemand heeft verloren, voor iemand moet zorgen, een burn-out heeft ….	**Nee, helemaal niet**			**Ja, vaak**
		1	**2**	**3**	**4**
G	Als u gaat winkelen in uw lokale gemeenschap, komt u dan vrienden of kennissen tegen?	**Nee, helemaal niet**			**Ja, bijna altijd**
		1	**2**	**3**	**4**
H	Hebt u iemand uit uw lokale gemeenschap geholpen in het jaar voor de coronacrisis? Bijvoorbeeld: door een bezoek te brengen, eten te maken, te helpen met poetsen, de hond uit te laten,…?	**Nee, nooit**			**5 keer of meer**
		1	**2**	**3**	**4**

3 Hieronder ziet u drie situaties die in uw lokale gemeenschap kunnen voorkomen. Omcirkel telkens wat u denkt dat u zou doen.

			Zeker niet	**Waarschijnlijk niet**	**Niet zeker**	**Waarschijnlijk wel**	**Zeker wel**
A	In uw straat woont een oudere vrouw. Haar echtgenoot is enkele jaren geleden gestorven. Ze heeft een goed contact met haar zoon, maar die woont in het buitenland. U hebt nog nooit met haar gepraat. Op een dag vertelt uw buur dat de	Het gras afrijden	**1**	**2**	**3**	**4**	**5**
		Naar de winkel gaan	**1**	**2**	**3**	**4**	**5**

	dame van de trap is gevallen. Ze moet enkele weken zoveel mogelijk rusten. Zou u haar met deze zaken willen helpen als u kon?	Koken	1	2	3	4	5
		Gezelschap houden	1	2	3	4	5
B	Uw buur van een paar huizen verder zorgt voor zijn vrouw, die waarschijnlijk niet meer lang zal leven. Hij vertelt dat hij het heel zwaar heeft. Een verpleegkundige helpt hem thuis, maar hij wil zijn vrouw liever niet alleen laten als hij naar de winkel of de apotheek moet. Zou u uw buren willen helpen met volgende zaken als u kon?	Naar de winkel gaan	1	2	3	4	5
		Op bezoek gaan	1	2	3	4	5
		Haar gezelschap houden	1	2	3	4	5
		Met uw buurman praten over de toestand van zijn vrouw	1	2	3	4	5
C	In uw straat is pas een eenzaam persoon gestorven. U en de andere mensen in de straat wisten het pas na de begrafenis. Uw buren organiseren een straatfeest om de mensen beter te leren kennen en om eenzaamheid tegen te gaan. Zou u deze zaken doen als u kon?	Naar het straatfeest gaan	1	2	3	4	5
		Mee het straatfeest organiseren	1	2	3	4	5

Bij de volgende vragen willen we graag meer weten over uw kennis over palliatieve zorg. Het is geen probleem indien u er weinig of geen kennis over hebt.

4 Omcirkel het getal dat het best bij u past.

A	Hoe goed kent u het begrip ‘palliatieve zorg’?	**Totaal niet**						**Zeer goed**
		1	**2**	**3**	**4**	**5**	**6**	**7**
B	Hoeveel denkt u dat u weet over palliatieve zorg?	**Ik weet er niets over**						**Ik weet er erg veel over**
		1	**2**	**3**	**4**	**5**	**6**	**7**

C	Hoe goed kan u aan iemand uitleggen wat palliatieve zorg is?	**Ik kan het niet uitleggen**						**Ik kan het zeker correct uitleggen**
		1	**2**	**3**	**4**	**5**	**6**	**7**

5 **Hoe hebt u over palliatieve zorg gehoord?** U mag meer dan één antwoord kiezen.

A	☐ Een kennis of vriend sprak erover	G	☐ Ik hoorde erover in mijn opleiding (verpleegkunde, psychologie, bij het Rode Kruis …) ☐ Via mijn werk als vrijwilliger
B	☐ Een familielid sprak erover		
C	☐ Ik ken het via internet of sociale media (Facebook, Twitter, Instagram …)	H	☐ Via radio of televisie
		I	☐ Via kranten of tijdschriften (ook online)
D	☐ Ik heb er nog nooit over gehoord	J	☐ Ik weet het niet meer
E	☐ Ik heb zelf palliatieve zorg gekregen	K	
F	☐ Een kennis, vriend of familielid heeft palliatieve zorg gekregen	L	☐ Andere:………………………………………..

Hebt u meer dan 1 antwoord aangekruist? Beantwoord deze vraag:
Wat was voor u de belangrijkste manier om informatie over palliatieve zorg te krijgen?

……………………………………………………………

6 **Hoe zou u het liefst informatie willen krijgen over palliatieve zorg?** Duid maximaal 3 antwoorden aan.

A	☐ Via de huisarts of andere hulpverleners	E	☐ Via vrienden, familie of collega's
B	☐ Via sociale media (Facebook, Twitter, Instagram …)	F	☐ Via posters op straat, in bushaltes, in de metro …
C	☐ Via activiteiten in de buurt, georganiseerd door bijvoorbeeld een lokaal dienstencentrum of een regionaal netwerk palliatieve zorg	G	☐ Via radio
		H	☐ Via televisie
D	☐ Via één website waarop u alle info vindt over palliatieve zorg in Vlaanderen	I	☐ Via kranten of tijdschriften (ook online)
		J	☐ Andere:………………………………………..

7 **Wij zijn geïnteresseerd in culturele ervaringen in verband met de dood en sterven.** Kruis ja of nee aan.

		Ja	**Nee**			**Ja**	**Nee**
A	Ik heb een boek over de dood, doodgaan of het verlies van een dierbare gelezen of besproken	☐	☐	E	Ik heb een kunsttentoonstelling gezien met werken over sterven, de dood of rouw	☐	☐
B	Ik heb een autobiografisch verhaal over iemands stervensproces of verlies gelezen	☐	☐	F	Ik ben naar een toneelvoorstelling of film geweest die het doodgaan, de dood of rouw uitvoerig behandelde	☐	☐
C	Ik heb op school geleerd over levenseindekwesties (waaronder de dood, sterven en rouw)	☐	☐	G	Ik heb een gesprek gehad met iemand die op sterven lag over zijn/haar dood	☐	☐

D	Ik heb deelgenomen aan gemeenschapsevenementen of activiteiten die verband houden met de dood of sterven	☐	☐	

8 Duid aan of volgens u de volgende uitspraken juist of fout zijn of dat u het niet weet. Gelieve niet te gokken.

		Juist	**Fout**	**Weet niet**
A	Palliatieve zorg heeft onder meer tot doel psychologische problemen aan te pakken die ontstaan bij een ernstige ziekte	☐	☐	☐
B	Stress ten gevolge van een ernstige ziekte kan aangepakt worden door palliatieve zorg	☐	☐	☐
C	Palliatieve zorg kan mensen helpen om de bijwerkingen van hun medische behandelingen onder controle te krijgen	☐	☐	☐
D	Wanneer mensen palliatieve zorg krijgen, moeten ze hun andere dokters opgeven	☐	☐	☐
E	Palliatieve zorg is uitsluitend voor mensen die in de laatste zes maanden van hun leven zijn	☐	☐	☐
F	Palliatieve zorg is specifiek voor mensen met kanker	☐	☐	☐
G	Mensen moeten in het ziekenhuis zijn om palliatieve zorg te krijgen	☐	☐	☐
H	Palliatieve zorg is specifiek bedoeld voor oudere volwassenen	☐	☐	☐
I	Palliatieve zorg is een teambenadering van zorg	☐	☐	☐
J	Palliatieve zorg heeft onder meer tot doel mensen te helpen hun behandelingsopties beter te begrijpen	☐	☐	☐
K	Palliatieve zorg stimuleert mensen om de behandelingen gericht op de genezing van hun ziekte stop te zetten	☐	☐	☐
L	Palliatieve zorg heeft onder meer tot doel mensen beter in staat te stellen om deel te nemen aan dagelijkse activiteiten	☐	☐	☐
M	Palliatieve zorg helpt de hele familie om met een ernstige ziekte om te gaan	☐	☐	☐

Hier stellen we u enkele vragen over wat u reeds gedaan hebt en of u weet waar u informatie kan vinden over aspecten die te maken hebben met het levenseinde.

9 **Welke zaken hebt u al gedaan rond het einde van uw leven?** U mag meer dan één antwoord kiezen.

A	☐ Een testament opgemaakt	F	☐ Een schriftelijke wilsverklaring voor euthanasie opgemaakt
B	☐ Een verklaring opgemaakt dat u uw organen wil doneren	G	☐ In een document een vertegenwoordiger aangeduid, die persoon kan dan beslissen over uw gezondheid als u dat zelf niet meer kan
C	☐ Een negatieve wilsverklaring opgemaakt: daarin staat welke medische zorgen u **niet** meer wil als u het niet meer kan zeggen, bijvoorbeeld omdat u in coma bent	H	☐ Met een professionele hulpverlener besproken wat u op het einde van uw leven wenst
		I	☐ Met vrienden, familie of andere mensen met wie u vaak contact hebt, besproken wat u op het einde van uw leven wenst
D	☐ Een positieve wilsverklaring opgemaakt: daarin staat welke medische zorgen u **wel** wil als u het niet meer kan zeggen	J	☐ Ik heb deze zaken nog niet gedaan, omdat: …………………………………………………………………
E	☐ Een wilsbeschikking opgemaakt: daarin staat wat er met uw lichaam moet gebeuren als u overlijdt, bijvoorbeeld: begraven, cremeren of doneren aan de wetenschap	K	☐ Andere zaken rond het levenseinde: ………………………………………………………………….

10 **We zijn geïnteresseerd in uw ervaringen met het ondersteunen van een mantelzorger.** Antwoord met ja of nee op de volgende uitspraken.

	Ik heb iemand die een stervende persoon bijstaat (mantelzorger) geholpen door:	**Ja**	**Nee**	
A	Contact op te nemen om te tonen dat ik bezorgd ben	☐	☐	Ik heb andere zaken gedaan voor iemand die zorgt voor een stervende persoon (mantelzorger), namelijk:
B	Emotionele ondersteuning te geven	☐	☐	…………………………………………………………………
C	Hem/haar te ondersteunen bij het verdriet en verlies	☐	☐	…………………………………………………………………
D	Beschikbaar te zijn om te praten	☐	☐	

11 **We zijn geïnteresseerd in uw ervaring van bij iemand te zijn op het moment van zijn/haar overlijden.** Antwoord met ja of nee op de volgende uitspraken.

		Ja	Nee			Ja	Nee
A	Ik heb iemand gezelschap gehouden die dicht bij de dood stond	☐	☐	C	Ik heb tijd doorgebracht met een persoon na zijn/haar overlijden (bijvoorbeeld een groet uitbrengen)	☐	☐
B	Ik ben getuige geweest van het overlijden van een andere persoon	☐	☐	D	Ik heb geholpen bij het verzorgen van het lichaam van een overledene	☐	☐

12 **Hoezeer gaat u akkoord met deze zinnen?** Omcirkel**.**

	Ik weet waar ik informatie of hulp kan vinden over:	**Helemaal niet akkoord**				**Helemaal akkoord**
A	Rouw of de ervaring om iemand te verliezen	**1**	**2**	**3**	**4**	**5**
B	Mantelzorg: zorgen voor iemand die hulp nodig heeft	**1**	**2**	**3**	**4**	**5**
C	Sterven	**1**	**2**	**3**	**4**	**5**

De volgende vragen gaan over hoe u zich zou voelen in bepaalde situaties die te maken hebben met het levenseinde.

13 Hoe ongemakkelijk zou u zich voelen bij deze situaties? Omcirkel**.**

		Niet ongemakkelijk	**Een beetje ongemakkelijk**	**Neutraal**	**Ongemakkelijk**	**Heel erg ongemakkelijk**
A	U bent bij iemand die aan het sterven is.	**1**	**2**	**3**	**4**	**5**
B	Een persoon die gaat sterven, wil met u praten over de dood.	**1**	**2**	**3**	**4**	**5**
C	U ziet een stervende persoon pijn lijden.	**1**	**2**	**3**	**4**	**5**
D	U moet aan iemand vertellen dat die gaat sterven.	**1**	**2**	**3**	**4**	**5**
E	U ziet iemand die gaat sterven lichamelijk achteruitgaan.	**1**	**2**	**3**	**4**	**5**
F	U bent bij iemand die gaat sterven en die heeft verdriet.	**1**	**2**	**3**	**4**	**5**
G	U ziet iemand die gaat sterven mentaal achteruitgaan.	**1**	**2**	**3**	**4**	**5**
H	U beseft dat ook u ooit kan sterven op deze manier.	**1**	**2**	**3**	**4**	**5**

14 Hoezeer gaat u akkoord met deze zinnen? Omcirkel.

	Ik denk dat ik deze zaken kan:	**Helemaal niet akkoord**						**Helemaal akkoord**
A	omgaan met mijn verdriet als een vriend of familielid gaat sterven	**1**	**2**	**3**	**4**	**5**	**6**	**7**
B	bij vrienden of familieleden zijn die gaan sterven	**1**	**2**	**3**	**4**	**5**	**6**	**7**
C	praten over sterven en dood met een stervende vriend of familielid	**1**	**2**	**3**	**4**	**5**	**6**	**7**
D	vrienden of familie steunen bij het overlijden van hun dierbare	**1**	**2**	**3**	**4**	**5**	**6**	**7**
E	een stervende vriend of familielid steunen	**1**	**2**	**3**	**4**	**5**	**6**	**7**

De volgende vragen gaan over de praktische of emotionele steun die u zou kunnen ontvangen in situaties rond het levenseinde.

15 Stel: u rouwt om iemand die overleden is. U hebt praktische hulp nodig, zoals uw kind ophalen van de crèche, de begrafenis voorbereiden … Bij wie zou u die hulp zoeken? U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …
B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

16 Stel: iemand in uw omgeving wordt ernstig ziek of sterft. U hebt praktische hulp nodig, bijvoorbeeld bij de boodschappen, om de hond uit te laten, te koken … Bij wie zou u die hulp zoeken? U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …
B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

17 Stel: iemand in uw omgeving wordt ernstig ziek of sterft. U hebt emotionele steun nodig, bijvoorbeeld om erover te kunnen praten, raad te vragen… Bij wie zou u die hulp zoeken? U mag meer dan één antwoord kiezen.

A	☐ Familie	D	☐ Professionele hulpverleners, zoals een huisarts, verpleegkundige, psycholoog …
B	☐ Vrienden of kennissen	E	☐ Ik zoek geen hulp
C	☐ Mensen uit mijn omgeving die ik niet (goed) ken, zoals vrijwilligers, buren, Whatsapp-buurtgroepen, een pastoor …		

UW DEMOGRAFISCHE GEGEVENS

18 Bent u de afgelopen 10 jaar verhuisd?

Ja	Nee
☐	☐

19 Hoe oud bent u?

………….. **jaar**

20 Welk geslacht heeft u?

Man	Vrouw	X
☐	☐	☐

21 Wat is uw hoogst behaalde diploma?

Lager onderwijs of minder	Lager middelbaar onderwijs (eerste 3 jaren)	Hoger middelbaar onderwijs (middelbaar afgerond)	Hogeschool	Universiteit of hoger	Andere:
☐	☐	☐	☐	☐	……………………

22 Wat is uw professioneel statuut?

Student	Werkzoekend	Arbeids-ongeschikt	Werkend	Gepensioneerd	Huisvrouw/ -man	Andere:
☐	☐	☐	☐	☐	☐	……………………

23 Wat is uw religieuze/ levensbeschouwelijke overtuiging?

Katholiek	Islam	Joods	Vrijzinnig humanisme	Niet gelovig	Andere:
☐	☐	☐	☐	☐	……………………

24 Om een betere interpretatie van de resultaten te verkrijgen willen we van u vernemen of een van de volgende stellingen bij u past. Meerdere antwoorden mogelijk.

A	☐ Ik <u>neem</u> de zorg op mij voor een zorgbehoevend persoon (mantelzorger)	D	☐ Ik heb een chronische ziekte
B	☐ Ik <u>nam</u> vroeger de zorg op mij voor een zorgbehoevend persoon (mantelzorger)	E	☐ Ik rouw om iemand die ik verloren heb
C	☐ Ik verblijf in een verzorgingscentrum (woonzorgcentrum, serviceflat, instelling,…)	F	☐ Ik werk(te) in de gezondheidszorg en mijn beroep is/was: ………………………………………..

Heeft u opmerkingen of bedenkingen na het invullen van deze vragenlijst? Dan kan u dat hier delen.

A2: Information letter preceding Compassionate City programme

MEELEVENDE STAD BRUGGE/HERZELE: VERDUIDELIJKING VAN HET ONDERZOEKSGEDEELTE

1. Verduidelijking van dit document en de gebruikte termen

Het project Meelevende Stad wordt uitgevoerd in twee steden: Brugge en Herzele. Aangezien het project is geïnitieerd door de onderzoeksgroep Zorg rond het Levenseinde (VUB & UGent), is onderzoek een onlosmakelijk onderdeel van het project. Met dit document willen we weergeven wat de rol van het onderzoek in dit project precies is. We willen hiermee uitklaren wat wij als onderzoekers van de stad verwachten, maar vooral ook welke meerwaarde het onderzoek voor het project en voor jullie stad kan betekenen.

Meelevende Stad = we spreken van een Meelevende Stad als vertaling van de Engelstalige benaming voor het project (compassionate city). Deze naam kan aangepast worden naar de persoonlijke voorkeur van de leidende coalitie.

Leidende coalitie = alle belanghebbenden van de stad die samen de ontwikkelingsgroep van de Meelevende Stad vormen. Zij zullen samen het ontwerp van de Meelevende Stad bepalen en ontwikkelen. Hun voornaamste taken bestaan uit het coördineren, faciliteren en enthousiasmeren van het project.

Acties = het geheel aan initiatieven van de verschillende belanghebbenden en burgers binnen de stad die bijdragen aan het doel van de Meelevende Stad.

Het onderzoek = dit omvat alle kennisverzamelingsactiviteiten die de onderzoekers in samenwerking met de belanghebbenden en burgers van Brugge/Herzele verrichten in functie van het informeren, beschrijven, begrijpen en evalueren van acties.

2. Filosofie van het project en de implicaties voor onderzoek

Het onderzoek speelt een geïntegreerde rol in de acties van de Meelevende Stad: het dient niet slechts om de acties te documenteren, te beschrijven en te evalueren maar ook om zinvolle gegevens te verzamelen om de actie te inspireren, informeren en op te volgen. De aanpak van het onderzoek wil ook zo goed mogelijk aansluiten bij de kernideeën van de Meelevende stad.

DE HELE STAD IS BELANGHEBBENDE

Iedereen wordt in zijn of haar leven geconfronteerd met ziekte, sterven, verlies of rouw. Alhoewel dit thema's zijn die maatschappelijk erg gevoelig liggen, moeten we ons er bewust van zijn dat zij integraal deel uitmaken van ieders leven. In een Meelevende Stad erkennen we dat we dat het omgaan met deze thema's niet enkel de verantwoordelijkheid is van professionele diensten, mantelzorgers en vrijwilligers, maar dat we als burgers en maatschappelijke organisaties elkaar hierin ook kunnen ondersteunen. Dit betekent dus dat we aspecten rond ziekte, sterven, verlies en rouw beschouwen als een gedeelde verantwoordelijkheid die iedereen aanbelangt.

Implicatie voor het onderzoek

Het project zal zich bijgevolg niet enkel richten op bepaalde voor de hand liggende doelgroepen (vb. ouderen, mantelzorgers) maar op iedere burger die op welke manier ook met ziekte, sterven, verlies of rouw wordt geconfronteerd. Hieruit volgt dat elke burger van Brugge/Herzele een potentiële belanghebbende van de Meelevende Stad is. Dit houdt in dat het onderzoek gegevens zal verzamelen bij een steekproef van de burgers dewelke een zo goed mogelijke weerspiegeling van de bevolking van de gehele stad is. Bovendien zal het onderzoek waarnemingen doen overheen de verschillende initiatieven waarbij burgers, organisaties en instituties betrokken worden.

VERTREKKEN VANUIT BESTAANDE STERKTES EN NIET (ENKEL) VANUIT PROBLEMEN

In een Meelevende Stad willen we de burgers extra capaciteiten geven om te kunnen omgaan met ziekte, sterven, verlies of rouw. Daarbij willen we vertrekken vanuit de capaciteit bij de burgers die reeds aanwezig is en deze versterken (vb. de sociale cohesie tussen buurtbewoners die er al is door onder andere buurtfeesten of de sociale cohesie binnen organisaties en verenigingen die al rond de thema's werken).

Implicatie voor het onderzoek

Aangezien we in het onderzoek vanuit de sterktes van de burgers willen vertrekken is het onze eerste taak als onderzoekers om de sterkte en mindere punten in kaart te brengen. Dit doen we via een vragenlijst die we onder een steekproef van de inwoners verspreiden (zie 6. Overzicht van meetmethodes). Anderzijds speelt ook de leidende coalitie hier een rol in. Onder begeleiding van facilitator Ruth, voert de stad een stakeholder-mapping uit om de belanghebbenden te identificeren die in verschillende gradaties betrokken kunnen worden bij het project.

CO-CREATIE

Hoewel de Meelevende Stad in dit geval geïnitieerd wordt vanuit het onderzoek, willen we dit project verwezenlijken in co-creatie met de leidende coalitie en de burgers in de stad. Dit houdt in dat de Meelevende Stad gezamenlijk gecreëerd en gedragen wordt en niet ontwikkeld zal worden door de onderzoekers alleen. We erkennen dat de kennis over de stad niet bij het onderzoek ligt, maar aanwezig is bij de burgers van de stad zelf. Dit betekent dus dat iedereen die mee in het project stapt actief betrokken kan worden bij het ontwerp en de implementatie van de acties. Er is dus een actieve rol vanuit de stad zelf in het creatieproces van het project. De stad staat hier niet alleen voor en wordt daarin bijgestaan door onze facilitator Ruth Raes. Ruth is coördinator bij Netwerk Levenseinde en heeft jarenlange ervaring in het begeleiden van veranderingsprojecten. Ruth zal de stad begeleiden in het komen tot een Meelevende Stad. Dit betekent echter niet dat zij de volledige leiding van het project op zich zal nemen. Zij zal het proces faciliteren: ‘de zaadjes planten’ die nodig zijn om het project te doen slagen en de nodige hulpmiddelen aanreiken.

Implicatie voor het onderzoek

De onderzoekers en de deelnemers in het project fungeren als evenwaardige partners. Het onderzoek ligt niet volledig a priori vast en wordt mede beïnvloed door de deelnemers van het project.

INTERSECTORALE AANPAK

In de eerste plaats willen we de Meelevende Stad binnen verschillende sectoren in de stad (bedrijven, scholen, culturele organisaties en geloofsgemeenschappen) realiseren. Zo is er de mogelijkheid om acties op poten te zetten samen met bedrijven en scholen (die een meelevend beleid kunnen ontwikkelen); culturele organisaties die via kunst en cultuur mensen vertrouwd maken met ziekte, sterven, verlies en rouw, kan men ook binnen geloofsgemeenschappen praten en nadenken over zorg aan het levenseinde, etc.

Implicatie voor het onderzoek

Het onderzoek zal er mede op gericht zijn om te beschrijven wat verschillende organisaties ondernemen in functie van de Meelevende Stad en samen met die organisaties bespreken we wat dit betekent voor hen.

AANDACHT VOOR HET BUURTNIVEAU

Daarnaast zullen de acties binnen het project zich niet enkel richten op de hele stad. Ook op zeer lokaal niveau, in een buurt, een wijk of een straat zullen initiatieven gerealiseerd worden rond ziekte, sterven, verlies en rouw zodat er een lokaal buurtnetwerk ontstaat dat het omgaan met ziekte, sterven, verlies of rouw versterkt.

Implicatie voor het onderzoek

Er worden een of meerdere buurten in de stad gekozen waar het ontwikkelen van burgerinitiatieven rond ziekte, sterven, verlies of rouw wordt gefaciliteerd. Deze burgerinitiatieven worden door het onderzoek beschreven en de effecten en implicaties ervan weergegeven

3. Verwachtingen van en aanbod aan de Meelevende Stad

Verwachtingen naar de Meelevende Stad toe	
1. Samenstellen leidende coalitie met belanghebbenden	Ruth zal de stad assisteren bij het uitvoeren van een oefening om deze belanghebbenden te identificeren. Van deze leidende coalitie wordt verwacht dat zij de sterktes en de zwaktes van de stad goed kennen. Een enthousiasmerende rol opnemen tegenover de burgers van de stad die interesse hebben in deelname aan het project is hierbij essentieel. Van deze leidende coalitie wordt ook verwacht dat zij zetelen in een overkoepelende coalitie waarin ook Brugge/Herzele is opgenomen. Vanuit het onderzoek verwachten we dat de stad toegang verleent aan de onderzoekers om bij de leidende coalitie aanwezig te zijn zodat zij de vergaderingen kunnen observeren. Ook verwachten we dat de leidende coalitie deelneemt aan een groepsgesprek in het begin van het project om te peilen naar hun motivatie om mee te stappen in dit project, en een groepsgesprek op het einde van het project in het kader van de Meest Betekenisvolle Verandering (zie verder).

2. Betrekken van verschillende sectoren en actoren in het project	Om een Meelevende Stad te creëren binnen verschillende sectoren (bedrijven, scholen, culturele organisaties en geloofsgemeenschappen) is er een minimum-engagement van de stad vereist om (minimaal) de voorgenoemde sectoren in het project te betrekken
3. Minstens 1 actie gericht op het ontwikkelen van betrokkenheid tussen buurtbewoners	Om ook op buurtniveau acties te krijgen in de Meelevende Stad is er vanuit de stad een minimum-engagement vereist om minstens één meelevende buurt mogelijk te maken. Binnen het project is het ons doel de inwoners van een geselecteerde buurt zelf warm maken om actie te ondernemen. Een vereiste daartoe is de organisatie van minstens één burgerparticipatietafel in de buurt. Deze mag georganiseerd worden op een manier die de stad het meest passend acht.
4. Faciliteren van het onderzoek:	Algemeen kunnen we stellen dat van de Meelevende Stad verwacht wordt dat zij hun medewerking verlenen aan de onderzoekers bij het uitvoeren van hun onderzoekstaken. De specificaties hiervan kunnen onder deel 4 worden teruggevonden.

Aanbod aan de Meelevende Stad	
1. Ondersteuning facilitator vanuit het project voor co-creatieproces	De stad krijgt hiervoor de hulp van Ruth Raes. Ruth plant 'de zaadjes planten' die nodig zijn om het project te doen slagen en reikt de nodige hulpmiddelen aan.
2. Grondige registratie en documentatie van alle acties	Bert Quintiens en Louise D'Eer zijn doctoraatsonderzoekers aan de onderzoeksgroep Zorg rond het Levenseinde (VUB & UGent). Zij nemen als onderzoekers een observerende rol op. Als onderzoekers engageren zij tot het documenteren en beschrijven van het hele proces om tot een Meelevende Stad te komen. Dat zorgt voor duidelijke, transparante en goed gedocumenteerde strategie waar de stad zich mee kan profileren
3. Zeggenschap in het onderzoek	Aangezien dit een project in co-creatie is, is het onmogelijk om op voorhand te gaan voorspellen wat er precies zal gebeuren. De leidende coalitie neemt een prominente rol op in het ontwerpen en ontwikkelen van acties onder begeleiding van de facilitator. Verder heeft de leidende coalitie ook inspraak in hetgeen onderzocht zal worden via de vragenlijst: zij weten immers het best wat belangrijk om te meten is in hun stad.

4. Empirische gegevens over de stad, haar organisaties en haar bevolking die helpen om op korte, middellange en lange termijn acties uit te werken	De onderzoekers brengen de bestaande sterktes, problemen en het potentieel in kaart binnen de stad. Dit gebeurt onder meer in de vorm van metingen via vragenlijsten. Op die manier krijgt de stad een duidelijk zicht op de zaken die reeds goed verlopen en op zaken waarin men verbetering wil zien.
5. Grondige evaluatie van de bereikte resultaten	De impact van het project wordt grondig geëvalueerd. Dit stelt Brugge/Herzele in staat als pionier naar buiten te treden met de concrete resultaten die bereikt zijn. De onderzoekers voeren niet enkel deze metingen uit maar analyseren ook de resultaten zodat de implicaties van de acties naar de buitenwereld toe gerapporteerd kunnen worden.
6. Nationale en internationale uitstraling	De Meest Betekenisvolle Verandering biedt de stad de kans zich te profileren in Vlaanderen. Dit geldt zeker voor Brugge dat zich - met het oog op het internationaal palliatief congres dat er in 2021 zal plaatsvinden (zie verder) – kan profileren als een stad die begaan is met de thema's omtrent ziekte, sterven, verlies en rouw. Bovendien zullen de onderzoeksresultaten gepubliceerd worden in internationale gerenommeerde tijdschriften hetgeen dan weer reflecteert op de creatie die de stad verwezenlijkt heeft.

7. Pioniersfunctie in het valoriseren van Meelevende Steden naar heel Vlaanderen	Brugge/Herzele neemt met dit project een pioniersfunctie op als een van de twee eerste Meelevende Steden in België en een vormt hiermee een voorbeeld voor andere steden die in haar voetsporen wensen te treden.
8. Korte-lijn en snelle feedback van alle (tussentijdse) resultaten ifv monitoring van alle acties (vb op meetings van leidende coalitie)	In het belang van de ontwikkeling van de Meelevende Stad, streven de onderzoekers er naar de tussentijdse resultaten die zij hebben en die van belang kunnen zijn in het bepalen van de strategie of acties te delen met de leidende coalitie. Ook tussentijdse resultaten die door het onderzoek verkregen worden zullen als monitoring meegedeeld worden.
9. Uitgebreid gepersonaliseerd rapport aan het einde van het project	Het onderzoek bezorgt de stad op het einde van het onderzoeksproject een gepersonaliseerd rapport waarin de resultaten die tot dan toegekend zijn worden meegedeeld. Dit zal de stad een goed idee geven van wat de specifieke bevindingen uit het onderzoek zijn.

4. Overzicht van gebruikte observatie- en meetmethodes voor het onderzoek

SURVEY AAN DE HAND VAN EEN VRAGENLIJST (2 MAAL AFGENOMEN)

We wensen een vragenlijst af te nemen bij een steekproef van burgers van de stad bij de start van het project om zo een goed zicht op de thema's gerelateerd aan ziekte, sterven, verlies en rouw in de stad te verkrijgen. Bij afloop van het project nemen we dezelfde vragenlijst opnieuw af bij een steekproef van burgers van de stad zodat we de impact van het project kunnen meten. In de vragenlijst meten we bijvoorbeeld de kennis en attitudes van de burgers omtrent eindelevensthema's maar gaan we evengoed kijken naar zaken als de sociale cohesie tussen burgers in buurten.

Meerwaarde voor de stad

De resultaten uit de vragenlijst verstrekken de stad belangrijke informatie over haar burgers hetgeen zal helpen gerichte acties op te zetten. Het proces van co-creatie laat bovendien voldoende ruimte om vragen die de stad belangrijk vindt toe te voegen aan de vragenlijst

De vragenlijst staat ons toe te evalueren of de uitgevoerde acties effect hebben gehad door de twee meetpunten met elkaar te vergelijken

Minimaliseren van de belasting van personeel van de stad: de organisatie en het afnemen van de survey (oa versturen vragenlijsten) worden door het onderzoeksteam uitgevoerd tenzij de stad of de leidende coalitie dat graag anders wil.

Verwachtingen ten aanzien van de stad

De onderzoeksgroep heeft toegang nodig tot het bevolkingsregister (namen en adressen) om zo een steekproef van de bevolking te kunnen trekken. De onderzoekers zullen zelf nooit toegang hebben tot het bevolkingsregister (omwille van behoud van anonimiteit).

Om de vragenlijst te kunnen afnemen kan het zijn dat bepaalde faciliteiten nodig zijn. Dit zal op een later punt nog met de stad besproken worden. Dit alles is nodig eenmaal voor het project van start gaat en eenmaal naar het einde van het onderzoeksproject toe.

OBSERVATIES DOOR DE ONDERZOEKERS

De onderzoekers zullen observaties uitvoeren tijdens vergaderingen van de leidende coalitie en op vergaderingen die plaatsvinden in de meelevende buurt. De onderzoeker observeert en maakt notities tijdens de vergaderingen, maar neemt zelf niet actief deel aan de vergaderingen. De observaties en notities worden later voor het onderzoek geanalyseerd en dragen bij aan de registratie van het proces van de totstandkoming van de Meelevende Stad.

Meerwaarde voor de stad

De onderzoekers zullen de resultaten van de observaties asap meedelen aan de leidende coalitie in een tussentijds soort rapport dat zij dan kunnen gebruiken om hun toekomstige acties verder vorm te geven of bij te sturen.

Verwachtingen ten aanzien van de stad

De onderzoekers hebben zo maximaal mogelijk toegang nodig tot elke vorm van overleg die kadert binnen de ontwikkeling van het project, zowel op het niveau van de leidende coalitie als op lokaal niveau (binnen lokale sectoren). De onderzoekers hebben toestemming nodig om notities tijdens het overleg te mogen maken. Ten slotte moeten zij aanwezig kunnen zijn bij elke actie die kadert binnen het project.

INTERVIEWS & GROEPSGESPREKKEN

Interviews en groepsgesprekken staan de onderzoekers toe om meer diepgang te verkrijgen over bepaalde gebeurtenissen en acties. Zo kunnen er bijvoorbeeld interviews met leden van de leidende coalitie plaatsvinden om te peilen naar hun motivatie om mee te stappen in dit project. Deze interviews en groepsgesprekken zullen dus gebeuren met verschillende spelers in de stad: Personen in de leidende coalitie om naar hun verwachtingen van de Meelevende Stad te polsen.

Personen in de leidende coalitie & burgers die actief betrokken zijn bij de co-creatie van initiatieven in de stad of buurt, personen in een buurt die zich actief inzetten in het initiatief, personen die gebaat zijn bij de initiatieven in de stad of buurt (vb. patiënten & mantelzorgers).

De frequentie en duur van de interviews of groepsgesprekken kunnen aangepast worden naargelang de nood en de specifieke context.

Meerwaarde voor de stad

De geïnterviewde persoon krijgt de mogelijkheid zijn of haar mening over het onderwerp te schetsen waardoor ook meer diepgaande informatie aan de leidende coalitie teruggekoppeld kan worden. De leidende coalitie kan vervolgens deze informatie gebruiken om hun acties en strategie bij te sturen waar zij dit nodig achten. Dit zal gebeuren via een verslag dat door de onderzoeker wordt opgemaakt.

Verwachtingen ten aanzien van de stad

Deelname van de personen in de leidende coalitie aan een eenmalig groepsgesprek voor de officiële start van de Meelevende Stad omtrent hun verwachtingen ten aanzien van het project. De individueel geïnterviewde personen dienen hier wat tijd voor vrij te maken

ONDERZOEKEN VAN RELEVANTE DOCUMENTATIE

Een van de basisvereisten voor een entiteit (organisatie, onderneming, etc.) om mee te stappen in het project is het opstellen van een beleid gericht naar zijn werknemers/leden. Het raadplegen van (beleids)documentatie staat ons toe inzicht te verkrijgen in welke beleidsregels er reeds bestaan betreffende ziekte, sterven, verlies en rouw en welke er ontwikkeld zijn door deel te nemen aan het project. Deze documenten worden in de verschillende betrokken sectoren opgevraagd en de inhoud ervan zal worden onderzocht. Verder zal ook gebruik gemaakt worden van verslagen die gemaakt worden op vergaderingen.

Meerwaarde voor de stad

Door de beleidsdocumentatie te raadplegen en te vergelijken alvorens en nadat de interventie plaatsvond, krijgen we een goed zicht op welk beleid er bestaat in de verschillende sectoren ten aanzien van de thema's ziekte, sterven, verlies en rouw. Dit staat ons dus toe om de veranderingen van het project te documenteren. Dit zal volledig door de onderzoekers gebeuren.

Verwachtingen ten aanzien van de stad

De onderzoekers hebben zicht nodig op relevante documentatie die de stad en de betrokken entiteiten hebben met betrekking tot thema's rond ziekte, sterven, verlies en rouw (indien dit bestaat). Voor de stad zelf hebben we enerzijds de documentatie van de stad naar haar burgers toe nodig, anderzijds van de stad als werkgever naar haar werknemers toe. Het ter beschikking stellen van stadsrelevante documentatie (beleidsdocumentatie en verslagen van vergaderingen). Het aanstellen van een contactpersoon die de relevante stadsdocumentatie aan de onderzoekers kan bezorgen. Het verzamelen van de documentatie: bij elke vergadering zal het nodig zijn om verslag te nemen. Dit wordt best gedaan door een van de belanghebbenden. Dit zal in beperkte mate een tijdsinvestering zijn. Indien geplande acties uitgevoerd worden kan aan belanghebbenden gevraagd worden over het verloop van de actie een kort verslag op te maken.

DE MEEST BETEKENISVOLLE VERANDERING (MBV)

De MBV methode is een manier om de gecreëerde waarde van een project in kaart te brengen. De techniek polst naar de 'meest betekenisvolle verandering' die burgers ervaren hebben. De onderzoekers zullen interviews afnemen of een groepsdiscussie houden met burgers die nauw betrokken zijn bij initiatieven in de Meelevende Stad en zullen gevraagd worden om een getuigenis met de onderzoeker te delen die hun perceptie weergeeft van de meest betekenisvolle verandering die zij ervaren hebben binnen het kader van het project. Het is dus de bedoeling om verhalen te verzamelen die rechtstreeks van de persoon komen die het verhaal meegemaakt heeft. Niet enkel worden individuele verhalen verzameld, deze verhalen kunnen ook verschillen in waarde: zo kan eenzelfde verhaal dat meerdere keren door verschillende personen wordt verteld als erg waardecreëerend worden beschouwd.

Meerwaarde voor de stad

De MBV zal de stad zeer belangrijke informatie bezorgen die niet via de andere methodes verkregen kan worden. Verhalen die door personen rechtstreeks gedeeld worden, geven niet enkel een goed zicht op de gecreëerde waarde van het project, maar zijn dikwijls veel sterker in het personaliseren van de waarde (denk bijvoorbeeld aan een getuigenis in een krant versus een artikel met enkel cijfermateriaal).

De stad kan ervoor kiezen om deze verhalen naar buiten te brengen om zo eigen burgers en mensen daarbuiten te tonen hoe ze gezamenlijk tot de positieve veranderingen gekomen zijn. Het biedt de stad dus de kans om zich op een bepaalde manier te profileren in Vlaanderen.

Met het oog op het congres Public Health Palliative Care International dat in 2021 in Brugge zal plaatsvinden, krijgt de stad de uitgelezen kans om zich internationaal te profileren als een stad die begaan is met eindelevensthema's. De verhalen die tegen dan reeds verzameld zijn bieden de stad de bijzondere kans om aan een internationaal gerenommeerd publiek op een originele manier al enkele resultaten van haar inzet te kunnen voorleggen.

Verwachtingen ten aanzien van de stad

Toelating en medewerking verlenen aan de onderzoekers om deze groepsdiscussie eenmalig te kunnen uitvoeren binnen de coalitie. Deze groepsdiscussie vindt pas plaats later in het project.

De tijdsinvestering voor de leidende coalitie is beperkt

VERANTWOORDELIJKEN VOOR DEZE STUDIE

Onderzoeksgroep Zorg Rond het Levenseinde VUB & UGent

Professor Joachim Cohen
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Professor Liesbeth de Donder
Professor Sarah Dury

A3: Corresponding letter sent together with the questionnaire

Geachte heer, mevrouw,

Wij leven in een land waarin de gezondheidszorg goed ontwikkeld is maar op sommige vlakken kan er nog veel verbeterd worden. De sociale ondersteuning voor mensen die (zwaar) ziek zijn en mogelijk dichter bij het einde van het leven komen, is vaak nog onvoldoende. Daarom is uw stad een project begonnen dat als doel heeft zijn burgers te motiveren om zorg voor elkaar te dragen in makkelijke maar ook in moeilijkere tijden. Ook beoogt de stad moeilijk bespreekbare thema's zoals ziekte, dood, sterven, verlies en rouw bespreekbaar te maken.

Waarom dit onderzoek?

Met dit onderzoek willen we een licht werpen op aspecten rond het levenseinde. Deze vragenlijst zal gebruikt worden om gerichte acties in de stad op poten te zetten binnen het project Compassionate X dat binnen uw stad loopt. Dit onderzoek wordt mede uitgevoerd door de Vrije Universiteit Brussel, de Universiteit Gent en de Katholieke Universiteit Leuven.

Waarom deelnemen?

Uw antwoorden op de vragenlijst zijn voor de stad van enorm belang; hoe meer mensen de vragenlijst invullen, hoe nauwkeuriger het beeld dat we kunnen schetsen omtrent het levenseinde in stad X. Deze verzamelde kennis staat ons toe bepaalde pijnpunten aan te duiden die ons helpen acties in uw stad op poten te zetten om een sociaal draagvlak te creëren voor de vermelde thema's. U werd willekeurig geselecteerd uit de gehele bevolking van uw stad.

Wat wordt er van u gevraagd?

Het is de bedoeling dat u uw eigen kennis en situatie zo correct mogelijk weergeeft, er bestaan op deze vragenlijst geen foute antwoorden. Meestal dient u bij elke vraag

1 antwoord in te vullen. Indien er meerdere antwoorden gevraagd worden staat dit ook zo aangegeven. Het invullen van de vragenlijst neemt ongeveer 20 minuten in beslag.

Gelieve de vragenlijst terug te sturen door gebruik te maken van de voorgefrankeerde en geadresseerde envelop. U moet hier dus zelf niet voor betalen. Indien u de vragenlijst liever via internet invult, dan kan dit door te surfen naar www.meelevend.be . U dient hiervoor uw uniek nummer in te geven dat rechtsboven op deze pagina staat.

Wat gebeurt er met uw gegevens?

Alle antwoorden op papier worden in een afgesloten ruimte in gebouw K op de VUB-campus Jette bewaard. De digitale antwoorden worden op een beveiligde server bewaard die enkel toegankelijk is voor onderzoekers van deze studie.

Het onderzoek en de vragenlijst werden goedgekeurd door de Commissie Medische Ethiek van het UZ Brussel. De verwerking van de resultaten gebeurt steeds **anoniem**, dat wil zeggen dat uw identiteit niet te achterhalen zal zijn op basis van uw antwoorden. Het invullen van deze vragenlijst gebeurt op **vrijwillige basis** en het niet invullen ervan heeft voor u geen nadelige gevolgen. Door deze vragenlijst ingevuld terug te sturen geeft u aan voldoende geïnformeerd te zijn en stemt u in met de anonieme verwerking van uw antwoorden voor het onderzoek. Dit onderzoek wordt gesteund door het Fonds voor Wetenschappelijk Onderzoek.

Heeft u nog vragen of opmerkingen naar aanleiding van de vragenlijst of het verdere onderzoek, aarzelt u dan niet om contact op te nemen met de uitvoerende onderzoeker:

Bert Quintiens
Vrije Universiteit Brussel, Onderzoeksgroep Zorg rond het Levenseinde VUB & UGent
Laarbeeklaan 103
1090 Jette
Tel: 02/477.49.45
E-mail: bert.quintiens@vub.be

Indien u na het invullen van deze vragenlijst vragen zou hebben omtrent aspecten rond het levenseinde kan u steeds contact opnemen met uw huisarts of surfen naar www.leif.be .

Namens stad X en de onderzoekers danken wij u van harte voor de tijd en moeite die u wilt doen om deze vragenlijst in te vullen en ons terug te bezorgen.

A4: Reminder cover letter

Geachte heer, mevrouw,

U ontvangt deze brief omdat u recent een vragenlijst opgestuurd kreeg. Wij hebben van u nog geen antwoord mogen ontvangen. Indien u de vragenlijst bij het ontvangen van deze brief al opgestuurd zou hebben, gelieve deze brief dan te negeren. Deze brief is de laatste herinnering en indien u de vragenlijst niet invult zal u hierna ook geen herinneringen meer ontvangen.

Wij zouden u vriendelijk willen vragen om de vragenlijst die u recent ontving in te vullen en ons terug te bezorgen met de voorgefrankeerde envelop. U kan de vragenlijst ook online invullen door te surfen naar www.meelevend.be. U dient hiervoor uw uniek nummer in te geven dat rechtsboven op deze pagina staat.

Indien u vragen zou hebben kan u de uitvoerende onderzoeker contacteren: bert.quintiens@vub.be

Namens stad X en de onderzoekers danken wij u van harte voor de tijd en moeite die u wilt doen om deze vragenlijst in te vullen en ons terug te bezorgen.