VRIJE UNIVERSITEIT BRUSSEL

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NAVIGATING SERIOUS ILLNESS, DEATH, AND BEREAVEMENT IN HIGHER EDUCATION:

INSIGHTS FROM THE COMPASSIONATE UNIVERSITY PROGRAM AT THE VRIJE UNIVERSITEIT BRUSSEL (VUB)

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General introduction

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Introduction

At some point in our lives, we will all experience illness, death, or bereavement. Yet these experiences too often appear as taboo topics and are almost exclusively embedded in professional healthcare narratives and practices.[1] Suggestions on how to manage the taboos surrounding these topics can be found in the health promoting palliative care literature. Kellehear's[2] notion of 'Compassionate Communities' is relevant in this respect, emphasizing the need to empower communities and build community capacity to support each other in times of serious illness, death, and bereavement. There is a compelling case for higher education institutions to embrace this approach, serving as 'compassionate schools' and 'compassionate workplaces'. They can play a significant role in supporting the well-being of students and staff facing these experiences, and in fostering a culture that acknowledges these issues as an integral part of academic and professional life.[3]

This chapter provides a general introduction to the dissertation. I will first discuss the background and challenges associated with the dominant service model for addressing well-being in the context of serious illness, death, dying, and loss. These challenges highlight the need to reframe and recognize these experiences as public health issues. Next, I introduce the Compassionate Community approach as a new paradigm for this reframing and consider the role of higher education institutions in supporting students and staff facing serious illness, death, and bereavement. Following this, the current state of knowledge regarding Compassionate Communities is outlined, highlighting the existing gaps in understanding how this approach can be implemented in practice, particularly in higher education settings. The chapter ends with the research aims, the dissertation outline, and an overview of the different studies used to address the research questions.

1. Background

Over the past three decades, the world has experienced unprecedented demographic changes, with rapidly aging populations in both industrialized and middle- to low-income countries. With an aging population, the leading causes of death are shifting towards chronic diseases of affluence, such as diabetes, heart disease, and cancer, and diseases of old age, such as dementia.[4] Instead of experiencing a rapid decline of 'getting sick and dying', people now endure prolonged periods of physical and mental deterioration, often requiring dependency on others.[4-6]

Since the 1970s, the palliative care and end-of-life care movement has been a main response to addressing the challenges surrounding serious illness, death, dying, and loss. However, the limitations of the current dominant service model of palliative care provision are becoming increasingly apparent in light of the demographic trends described above and societal changes. Factors such as increased individualization, social fragmentation, and a decrease in nuclear family size have reduced community's capacity to provide care and suggest a growing need for services.[5,7] Moreover, the movement faces criticism that its vision of holistic care is being interpreted too narrowly, focusing predominantly on physical or psychological symptoms at the expense of social concerns.[8] Recent public health palliative care literature has also questioned the predominant focus on health services and healthcare professionals as the primary providers of care.[9,10] While most people may die in hospitals, the majority of care - over 90% - is provided by family and community members outside the professional healthcare system.[11,12] This reality highlights the need for a paradigm shift in how we approach serious illness, death, dying, and loss.[13] Simply increasing the number of professionals or asking for more resources will be insufficient to ensure good healthcare or social care for all.[14]

2. Serious illness, death, and bereavement as public health issues

There is a growing recognition that a social model of health helps to understand how to improve people's experiences of serious illness, death, dying, and loss.[15] This model, also referred to as a 'settings approach' or 'community approach' to care, focuses on empowering individuals, families, and communities to take an active role in the matters affecting them.[16,17] The idea of working in partnership with communities stems from the New Public Health movement, which emerged in the later part of the twentieth century.[17]

New Public Health maintains several aspects of the traditional or classical public health approach from the past century, including the emphasis on policy to improve health and the focus on disease

prevention. However, it also marks a shift away from classical public health by reframing health as 'everyone's responsibility'. This reframing includes recognizing the importance of the social determinants of health (e.g., income, housing, access to healthcare) in addition to biomedical factors.[17] Key institutions such as schools, governments, workplaces, and the media, all became involved in delivering health messages, for example on alcohol, smoking, and sexual health.[16]

A key document that shaped the New Public Health is the World Health Organization's Ottawa Charter for Health Promotion (1986). This document delineates five action areas for a health promotion approach: 1) building healthy public policy, 2) creating supportive environments, 3) strengthening community action, 4) developing personal skills, and 5) reorienting healthcare services towards the prevention of illness and the promotion of health.[18] The World Health Organization subsequently developed an intersectoral, society-wide operationalization of these principles: the Healthy Cities initiatives. The objective of Healthy Cities was to extend interventions beyond the confines of the healthcare system. This was achieved by advocating for community-oriented initiatives in all spaces where people meet, with the aim of understanding the relationship between people's health and the social, cultural, and physical environment in which they reside (i.e., social ecology approach).[19] However, this traditional health promotion discourse, with its emphasis on 'disease prevention' and defining being 'healthy' as the absence of illness, has faced criticism. Allan Kellehear [20] argued that dying and grieving should not be viewed as failures of healthcare or personal resilience but as natural aspects of life itself.

In the late 1990s, Kellehear applied the five action points of the Ottawa Charter to address end-of-life issues and proposed the 'Health Promoting Palliative Care' approach, also known as 'Public Health Palliative Care'. This approach aims to enhance a sense of control and support for those experiencing serious illness, death, and loss, or who are providing care.[21] A central objective is to address the perceived medicalization of end-of-life care by expanding focus beyond the formal healthcare system to encompass the roles, capabilities, and contributions of individuals, social networks, and communities.[22] Public health approaches to palliative care often include the development of personal skills to cope with the challenges of serious illness, caregiving, dying, and loss.[9] The approach acknowledges that, more often than health professionals, it is friends and family who provide the majority of care.[21] Some public health palliative care initiatives are initiated by or based in service delivery, such as palliative care institutions developing their services, and/or involving communities.[23–26] Other initiatives adopt a community-based approach, commonly referred to as Compassionate Communities or Cities.[13,26,27]

3. Compassionate Communities and Cities

Both Compassionate Communities and Cities are an operationalization of a public health approach to palliative care, offering a multidimensional, whole-systems approach to improve community circumstances related to serious illness, caregiving, dying, and loss.[28,29] The approach underscores the integration of health promotion, community development, death awareness, and education to provide a more holistic approach to end-of-life issues.[2] Although there is no universally accepted definition of Compassionate Communities, Vanderstichelen et al.[29] offered the following description:

> Compassionate Communities are communities that invest in and promote individual behavior, group strategies or societal structures or policies that prevent or reduce suffering resulting from experiences of serious (mental or physical) illness, death, dying, and loss; actively promote health and well-being, community support and empowerment of community members affected by such experiences; and actively acknowledge these experiences as natural parts of daily life.

In 2015, Kellehear emphasized the necessity for action at the municipal level, emphasizing the pivotal role of local governments and councils in driving societal change. This perspective, reflected in the Compassionate City Charter, broadens the scope of Compassionate Communities to include civic institutions beyond healthcare bodies and community groups.[30] The Compassionate City Charter outlines action recommendations for key institutions such as schools, workplaces, churches, hospices, care homes, museums, among others. The Charter represents a significant shift within the domain of public health palliative care, transitioning from initiatives solely based in palliative care services to projects that start outside the healthcare system.[31] Moreover, through the concept of 'Compassionate Cities', Kellehear integrated end-of-life care into the World Health Organization's concept of 'Healthy Cities', addressing a previously unaddressed element by recognizing that end of life should be considered as an integral part of health and as a central aspect of the life course.[20,32]

As Compassionate Communities and Compassionate Cities are being developed in many countries, a semantic distinction between the two approaches is appropriate. Compassionate Cities adopt a social ecology approach - employing top-down strategies to reorient settings and institutions through policy interventions or the extension of health services to local governments, workplaces, or schools.[26,29] 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.[33] A community development strategy is typically implemented in conjunction with, but after the initial decisions are taken by the

local government.[20] Compassionate Communities are more bottom-up, community development initiatives that leverage local assets to answer local needs and mobilize community members and organizations in the social and cultural sector, mainly through volunteering.[26] Despite the semantic distinction, this distinction is not that clearly applied in practice examples and the terms are often used interchangeably.[15] Therefore, going forward, I will adopt 'Compassionate Communities' as the overarching term.

4. Serious illness, death, and bereavement in higher education

Higher education institutions are particularly interesting settings for adopting the Compassionate Community approach. They are at the same time intergenerational hubs, employers, and formative actors in the life course of both students and staff. Engaging the university community in dealing better with serious illness, death, and bereavement provides opportunities for individual learning, strengthening community capacity, and personal growth.[22,34] However, some scholars have made specific reference to the idea that higher education institutions may not be naturally conducive settings for providing a supportive atmosphere for these experiences.[35,36] This section discusses the role of higher education institutions in supporting students and staff facing serious illness, death, and bereavement.

4.1 A compassionate school for students

Experiencing the death of someone close to you, such as a family member or a friend, is a disruptive and one of the most distressing events in the lives of students, with a potentially long-lasting impact.[34] Previous studies have shown that students coping with bereavement may experience adverse health outcomes, such as depressive symptoms, sleeplessness, and decreased motivation, all of which can impact their academic performance and increase the risk of developing mental health problems like depression, anxiety, and posttraumatic stress disorder.[37,38] Rather than being places of nurturance, campuses are characterized by competing demands such as maintaining high-performance, meeting deadlines, and participating in social campus activities, which can pose significant challenges for those facing serious illness, death, or bereavement.[3]

Despite a significant proportion of students expressing a willingness to seek help for emotional issues, research indicates that the minority utilize university support services for grief-related or caregiving concerns.[36,39] This low engagement can be attributed to various factors, including stigma associated with seeking support, perception of service ineffectiveness, and barriers to accessing support

services.[40] Regarding the latter, many students appear to be unaware that such services exist or how to reach them.[38,41] Furthermore, appropriate referrals are not always made to students seeking support.[42] Students have often reported that they found support from friends and family to be more helpful than what is offered by the university.[42] Peers express a desire to support their friends but often lack confidence,[42,43] leading to feelings of misunderstanding and alienation among bereaved students.[44–46] Previous studies indicate that students' grief is often disenfranchised due to universities' failure to recognize it, compounded by the unhelpful responses from both staff and peers.[47,48]

This underscores the importance of embedding peer-based programs, education on the grief process, and guidance on offering informal support into university mental health initiatives and support services.[38,42] In addition, Balk[35] suggests several strategies for universities to cultivate a more compassionate environment: i) training non-bereaved students to provide peer support, which may reduce the apprehension many feel in offering social support, ii) providing structured interventions for bereaved college students with specific needs tied to these experiences, iii) raise awareness on university campuses through events like symposia on bereavement and caregiving, exhibitions and other cultural media, and iv) conducting research on the needs of the diverse university population confronted with experiences of serious illness, bereavement, or caregiving responsibilities.

4.2 A Compassionate workplace for employees

While I have made a particular argument for universities to improve their responses to students confronted with serious illness, death, or bereavement, it is vital that this is done as part of a wider institutional shift whereby universities also transform into compassionate workplaces. Existing research underscores the profound impact of death and bereavement on employees' ability to fulfill their work responsibilities.[49] This impact encompasses various aspects, including increased work absences, work and career interruptions, and shifts in career trajectories.[50] Given that most people in the workforce will experience grief at least once during their careers,[51,52] it is crucial to recognize that the workplace environment can significantly influence the level of distress employees experience when faced with death or bereavement.[53]

The actual experience of returning to work after bereavement is often mixed.[54] Research indicates that for some individuals, certain aspects of their work environment can serve as sources of support and restoration following a significant loss.[55] Work itself can offer distraction, stability, structure, familiarity, meaning, and a sense of normalcy, all of which can be beneficial for those grieving.[56–58,61] Conversely, others perceive the workplace as exacerbating negative experiences and emotions, which

can compound their grief and hinder the grieving process.[57] Positive experiences of returning to work after bereavement are found to be influenced by social relationships and colleagues' ability to engage in discussions about bereavement openly.[55] Nevertheless, employees' grief is more frequently 'disenfranchised', as highlighted in studies by Thompson & Bevan[59] and Bauer & Murray.[60] These studies revealed that managers often prioritize workplace productivity over acknowledging individual bereavement.[59,60] Similarly, Fitzpatrick's study focusing on university professors returning to work after the death of a family member found that grief is often disregarded or overlooked in the workplace, with managers and colleagues displaying visible discomfort and uncertainty when interacting with employees who are bereaved.[56]

Enhanced organizational understanding of the grief process, its symptoms, and the importance of compassion could significantly improve the ability of both managers and colleagues to provide appropriate support.[53,57] Moreover, by endorsing shared values, beliefs, and norms centered around caring and bereavement, and adopting practices and policies that encourage helping behaviors, organizations can become more compassionate.[61] A compassionate approach may facilitate closer connections among colleagues, thereby aiding the grieving process.[55] Additionally, individuals may feel more motivated in their subsequent roles if their work environment is perceived as a source of help rather than alienation.[55]

5. The state of knowledge

In recent years, the Compassionate Community approach has gained popularity, with the development of various initiatives in the UK,[24,62] Ireland,[63] India,[64] Canada,[65] Australia,[66] Colombia, Argentina,[67] Brazil,[68] South Africa,[69] and more recently in mainland Europe.[70,71] These initiatives are implemented in diverse settings, including neighborhoods, schools, workplaces, faith communities, and encompass a wide range of practices, such as supporting caregiving networks, engaging the wider society in conversations about death and bereavement, and advocating for supportive policies related to serious illness and bereavement.[27,72] Despite the growing development of these initiatives, rigorous systematic understanding, scientific description, and evaluation of their development, implementation, and underlying mechanisms remain a challenge.[73] This leaves unanswered questions about their practical implementation, contextual nuances, and the factors driving or hindering their success.[27,73] A major difficulty in evaluating Compassionate Community initiatives is that they require a shift from more traditional research designs as they operate in diverse settings and aim to catalyze dynamic change rather than produce controlled effects.[74] Moreover, these initiatives are deeply intertwined with their contexts, involving complex linkages among individuals, organizations, government agencies,

businesses, civil society actors, and funders within communities.[75] Analyzing these multifaceted interactions is a complex undertaking. Additionally, Compassionate Community initiatives do not always yield immediate, measurable outcomes, making it difficult to disentangle linear cause-and-effect linkages;[76] instead, their impact may unfold gradually over time (e.g., through ripple effects).

There have been increasing calls within health research to involve interdisciplinary and social science researchers in studying the development and implementation of new public health initiatives, and to facilitate the use of social theories and methods.[77] Although the explicit use of theoretical frameworks has been advocated, available theories addressing the complexities of practice change related to Compassionate Communities have not yet been identified.[78] Moreover, public health research has been dominated by quantitative research methods, and public health research in palliative care is no exception.[79] To understand the mechanisms driving systematic community-level change, there is a need for greater use of qualitative and participatory methodologies.[80] This can offer valuable insights from the perspectives of stakeholders involved in the development and facilitation of these initiatives, ensuring that subsequent research and practice are grounded in real-life experiences rather than relying on theoretical aspirations.[81]

Additionally, while the existing body of literature underscores the potential for higher education institutions to serve as compassionate schools and workplaces,[82] no initiatives from places of higher education have been described. There is currently a lack of research on how higher education institutions can respond to students and staff confronted with serious illness, death, or bereavement, including what policies and systems are in place and whether there has been any attempt to assess their needs.[35] Most studies on bereavement in education have focused on therapeutic interventions provided by school well-being services,[83,84] primarily in primary and secondary education.[85–87] Despite a few universities, such as the University of Bogotá in Colombia and the University of Loja in Ecuador, have declared their intention to become 'Compassionate Universities,' their efforts are limited to enhancing the knowledge, skills, and attitudes of medical, nursing, and psychology students and staff regarding serious illness, death, and bereavement.[88,89] This approach is limited as it targets only students and staff in health sciences departments, rather than the entire university community. Currently, practical strategies are lacking for implementing a comprehensive Compassionate Communities approach within higher education institutions. Such an approach would foster social capital and confidence across the entire university community in addressing serious illness, death, and bereavement.

A notable intervention gaining attention for fostering a positive regard towards death and bereavement and building community capacity are the death and grief festivals.[90–92] These events aim to engage entire communities, including those who are not dying, caring, or grieving at the time, in open dialogue through workshops, performances, death cafés, and more.[93] Despite their potential relevance to the Compassionate Community approach, evaluations of these initiatives remain scarce and have primarily focused on assessing their reach through post-event questionnaires.[90–92] Furthermore, there is limited information on how these initiatives and other psychoeducation and awareness-raising activities can be adapted for use in educational settings or what additional initiatives are necessary to foster greater compassion within our school and work communities.[3,35]

6. Research aims

This dissertation aims to examine a Compassionate Community initiative within a higher education institution – the Compassionate University program at the Vrije Universiteit Brussel (VUB). The study has three main aims, each comprising specific research objectives.

AIM 1: To provide guidance on designing evaluation research to study Compassionate Communities

a) To identify suitable theoretical frameworks for studying the development, implementation, and underlying mechanisms of Compassionate Communities (Chapter 3)

AIM 2: To describe the process of developing a Compassionate University

b) To gain an understanding of the experiences and support needs of students and staff facing serious illness, death, and bereavement within the university context (Chapter 4)
c) To identify the underlying mechanisms and contextual factors that influence the process of developing a Compassionate University (Chapter 5)

AIM 3: To study the outcomes of the Compassionate University program

d) To examine the experiences of students and staff who participated in the Compassionate Week, a death and grief festival on the university campus (Chapter 6)
e) To map the activities and outcomes resulting from the Compassionate University program (Chapter 7)

7. Outline of the dissertation

Following this general introduction, **Chapter 2** provides an overview of the methodological approach used in the dissertation. It includes a description of the case study, an overview of the methods used in the different studies, and a positionality statement of the researcher. Chapters 3-7 are based on articles which have been published, accepted, or submitted for publication.

The study presented in **Chapter 3** identifies theoretical frameworks to evaluate the complex processes behind Compassionate Community initiatives. Theoretical frameworks were systematically appraised by using a two-step method: i) examining the core characteristics of Compassionate Communities and translating them into assessment criteria, and ii) applying the assessment criteria to a list of widely used and highly cited theoretical frameworks.

Chapter 4 explores the experiences and support needs of students and staff confronted with serious illness, death, or bereavement within the university context. The data are derived from 21 individual interviews with students and 14 individual interviews with staff. Additionally, 3 focus groups with staff were conducted (N=12).

Chapter 5 studies the development process of the Vrije Universiteit Brussel (VUB) towards a Compassionate University, examining both barriers and facilitators encountered by the Compassionate University core team (N=7). This qualitative longitudinal process evaluation employed several data collection methods: field notes, right-now surveys, focus groups, individual interviews, and strategic learning debriefs.

The study presented in **Chapter 6** investigates students' and staff's (N=94) motivations for engaging in the Compassionate Week activities, a death and grief festival on the university campus, and their experiences with the activities they attended.

Chapter 7 explores the activities and outcomes of the Compassionate University program, using Ripple Effects Mapping (REM) as a qualitative impact evaluation tool. The study includes a focus group and individual interviews with members of the Compassionate University core team (N=7).

The dissertation ends with a general discussion in **Chapter 8**. This chapter covers a discussion of the main findings, methodological reflections and limitations, suggestions for further research, and implications for policy and practice.

Table 1 provides an overview of the studies included in the dissertation. As Chapters 3-7 were originally written as stand-alone articles aimed for publication in international scientific journals, there might be some overlap. By the same token, they can also be read independently.

Table 1. Overview of studies included in this dissertation

Chapters	Research Questions	Research Method	Data	Publication Status
Chapter 3. Researching Compassionate Communities: Identifying Theoretical Frameworks to Evaluate the Complex Processes Behind Public Health Palliative Care Initiatives	1) Which theoretical frameworks are suitable to study the development, implementation, and underlying mechanisms of Compassionate Communities?	Two-step method to systematically appraise theoretical frameworks: - Conceptual literature review of core characteristics of Compassionate Communities - Appraisal of theoretical frameworks against the identified core criteria	Literature review	Published in Palliative Medicine
Chapter 4. A Compassionate University for Serious Illness, Death, and Bereavement: A Qualitative Study of Student and Staff Experiences and Support Needs	1) What are the experiences of students and staff confronted with serious illness, death, or bereavement within the university context? 2) What are the support needs of students and staff confronted with serious illness, death, or bereavement within the university context?	Qualitative interviews and focus groups with students and staff of the Vrije Universiteit Brussel (VUB)	1) Individual interviews with students (N=21) 2) Individual interviews with staff (N=14) 3) 3 focus groups with staff (N=12)	Published in Death Studies

Chapter 5. Uncovering Barriers and Facilitators in the Development of a Compassionate University: A Process Evaluation	1) How is the Compassionate University program developed by the Compassionate University core team? a. Which mechanisms bring about change and which mechanisms prevent change? b. What (contextual) factors support the development process and what (contextual) factors undermine the development process?	Qualitative longitudinal process evaluation over a period of two years (2021-2023)	1) Field notes 2) Right-now surveys 3) 3 focus groups with core team members (N=7) 4) 2 rounds of individual interviews with core team members 5) Strategic learning debriefs	Submitted to Death Studies
Chapter 6. The Role of a Death and Grief Festival in Cultivating Awareness of Serious Illness, Death, and Bereavement at University: A Qualitative Study	1) What motivates students and staff to participate in the Compassionate Week activities? 2) How do students and staff experience the activities in which they participated during the Compassionate Week?	Qualitative interviews with students and staff who participated in the Compassionate Week at the Vrije Universiteit Brussel (VUB)	1) Individual interviews with students and staff (N=94)	Submitted to Health & Social Care in the Community
Chapter 7. Mapping the Ripple Effects of a Compassionate University for Serious Illness, Death, and Bereavement	1) What are the activities and outcomes resulting from the Compassionate University program?	Ripple Effects Mapping (REM)	1) Focus group with core team members (N=4) and 3 individual interviews with core team members 2) Administrative project data and field notes	Accepted for publication in Palliative Care and Social Practice

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Chapter 2

Methodological approach

Chapter 2. Methodological approach

This chapter provides an overview of the methodological approach used in the different studies of the dissertation. It begins with a contextualization of the case study, followed by a detailed discussion of the different methods. The chapter concludes with a positionality statement of the researcher.

1. Case description Compassionate University

The Vrije Universiteit Brussel (VUB), located in Brussels, Belgium, served as a case study to examine the development process towards a Compassionate University. The university encompasses nine faculties, namely Languages and Humanities, Social Sciences and Solvay Business School, Law and Criminology, Medicine and Pharmacy, Psychology and Educational Sciences, Sciences and Bio-engineering Sciences, Engineering, Physical Education and Physiotherapy, and Teacher Education. The VUB offers bachelor's, master's, and doctoral degree programs, with a student population of approximately 22.000 students, including approximately 4.700 international students. In addition, the VUB employs about 4.000 staff, including academic staff (teaching and research) and support staff.

In 2019, the VUB declared itself (mainland) Europe's first "Compassionate University", adapting Kellehear's Compassionate City Charter[1] to fit the university environment. The Rectorate signed a declaration of intent, outlining seven action points aimed at fostering a compassionate community, including: enhancing accessibility to professional health services; supporting bottom-up initiatives related to serious illness, caregiving, death, and loss; providing training and coaching on these topics; raising awareness through activities such as exhibitions and debates; establishing dedicated spaces for commemorative moments; recognizing and embracing diversity related to these experiences; and conducting annual evaluations of the Compassionate University's objectives with the university community. A core team comprised of stakeholders from different university departments, including the Rectorate, Student Counseling Center, Human Resources Management, Marketing and Communication, and the VUB's Compassionate Communities Centre of Expertise (COCO), works on translating the action points into tangible practices.

2. Methods

This dissertation used a qualitative case study design to study the development process of the VUB towards a Compassionate University. A case study is a research method that aims to gain a deeper understanding of a particular phenomenon or topic through a detailed investigation of a specific case.[2]

Moreover, qualitative research offers a venue "to learn about the voices of community members, understand the thoughts and processes that people engage with in their everyday lives, and potentially develop theory" (p. 81).[3] Different qualitative research methods were used to answer the research questions of this dissertation. While these methods are detailed within the relevant chapters of this dissertation, a brief description of each method is provided below.

2.1 Appraisal of theoretical frameworks for the study of Compassionate Communities

In Chapter 3, we adopted a systematic approach, as suggested by previous work,[4,5] to identify suitable theoretical frameworks for studying Compassionate Community initiatives. The first step was to conduct a conceptual scoping review to examine the core characteristics of Compassionate Communities by reviewing relevant literature published within the past 20 years up to March 2022. Through this process, three reviews proved particularly useful for the purpose of our analysis.[6–8] A tentative list of Compassionate Communities' characteristics, directly drawn from the selected reviews, was then translated into assessment criteria for the selection of theoretical frameworks. The second step consisted of applying the identified assessment criteria to a list of widely used and highly cited theoretical frameworks.[9]

2.2 Data collection on the Compassionate University core team

A Developmental Evaluation (DE) approach guided the data collection from the Compassionate University core team members. DE entails a long-term, collaborative relationship between evaluators and those engaged in the development initiatives.[10] It is a utilization-focused approach that deploys various data collection activities and methods to inform decision-making on an ongoing basis. In this dissertation, DE was used to inform and support the innovative and adaptive development process of the VUB towards a Compassionate University. Figure 1 outlines the data collection phases of this dissertation, which are discussed further below.

Qualitative process evaluation

Chapter 5 presents the findings of a qualitative study that explores the barriers and facilitators in the development process of a Compassionate University. The Compassionate University core team, consisting of eight members, participated in this longitudinal study spanning from September 2021 to September 2023. During the study period, one member withdrew from the core team after eight months into the study, resulting in their exclusion from subsequent data collection moments. A participatory observation approach was followed, in which I attended the monthly Compassionate

University meetings and documented field notes.[11] Additionally, during the study's initial stages, right-now surveys were sent to core team members from November 2021 to March 2022 to quickly gain insight into the project dynamics as I started as a doctoral researcher one year after the start of Compassionate University. The survey consisted of no more than three questions and consistently addressed variations of: 1) Right now, our greatest opportunities are…; 2) Right now, our biggest challenges are…; 3) Right now, we need guidance on...[12] The survey data was used to pinpoint issues for further exploration during individual interviews and focus groups.

The first focus group (T1 in Fig.1), the orientation and inception workshop, was conducted online to gain insight into the early stages of the Compassionate University program's development (i.e., the start-up). Questions were asked about how the core team members became involved, their initial ideas about the project, and the content of the first meetings. This was followed by individual interviews to explore aspects that had not been shared during the focus group session or were not ready to be disclosed to the entire team. The second focus group (T2 in Fig. 1), the enculturation and prioritization workshop, focused on prioritizing actions based on insights derived from data collected from students and staff regarding their experiences and support needs. By presenting empirical insights from this data collection, I supported the adaptive development process of the Compassionate University program. Follow-up interviews centered on the operational dynamics of the core team and their perspectives on implementing the action points. The third focus group (T3 in Fig.1), the outputs and actions workshop, focused on mapping accomplished actions and outlining future initiatives to provide an overview of progress made and the way forward. Learning debriefs were held with core team members after each data collection moment to summarize the findings from the focus group and individual interviews, and to provide an opportunity for reflection and feedback, aligning with the principles of Developmental Evaluation.[10]

Ripple Effects Mapping

Chapter 7 is based on a qualitative study using Ripple Effects Mapping (REM) as a participatory evaluation tool to map the activities and outcomes of the Compassionate University program (T4 in Fig. 1). A focus group session (N=4) and individual interviews (N=3) were conducted with members of the Compassionate University core team. The focus group followed the "in-depth" rippling approach, which encompasses three stages: (1) partner interviews, (2) group discussion and mapping, and (3) reflection. [13] The partner interviews were guided by specific questions such as: What is a highlight or achievement of Compassionate University? What new or deepened connections with others have emerged as a result of the program? What unexpected things (positive or negative) have happened as

a result of the program? Participants were provided with post-it notes to capture their thoughts during the partner interviews. After the partner interviews, the group engaged in a facilitated discussion, sharing insights gathered from the partner interviews, and mapping the ideas on a whiteboard. Once the post-it notes were documented on the whiteboard, participants connected the post-it notes and brainstormed about possible themes to create a mind map that captured the main actions and outcomes of the Compassionate University program. The focus group session was held in a venue on the university campus. Additionally, three individual interviews were conducted online with core team members who were unable to attend the focus group session, using the same set of interview questions as those employed during the REM focus group session. At the end of the individual interviews, participants were provided with the REM focus group session's mind map so that they could add any missing information and share their reflections. Both the focus group and individual interviews took place in May 2023.

2.3 Data collection on the university community

The data collection on the university community comprised two components: i) data collection on the experiences and support needs of students and staff confronted with serious illness, death, or bereavement within the university context, and ii) data collection on students' and staff's motivations for participating in the Compassionate Week and their experiences with the activities they attended.

Qualitative interviews and focus groups with students and staff

Chapter 4 presents the findings of a qualitative study focusing on the experiences and support needs of students and staff confronted with serious illness, death, and bereavement within the university context. Data were derived from 21 individual interviews with students and 14 individual interviews with staff. Additionally, three focus groups with staff (N=12) were conducted. A semi-structured interview guide, adaptable for individual interviews and focus groups, was used. This guide included questions such as "To what extent have you, yourself or through your environment, encountered experiences of serious illness, death, or bereavement?". Follow-up questions encouraged participants to share their thoughts and feelings about their experiences related to the university environment, while subsequent questions explored their support needs. The interviews and focus groups were conducted in either Dutch or English, depending on the language of the participant, and were held online or in person, as per participant's preference. The data collection took place between March and April 2022.

Qualitative interviews with participants of the Compassionate Week

The study presented in Chapter 6 focuses on the motivations of students and staff (N=94) to participate in the Compassionate Week activities and their experiences with the activities they attended. The Compassionate Week is one of the outcomes of the Compassionate University program, which aims to raise awareness and encourage open dialogue about serious illness, death, and bereavement through a variety of activities on the university campus. A semi-structured interview guide was used to explore participants' motivations for participating in the Compassionate Week activities and their experiences with the activities they attended. Data collection took place immediately following the activities. For those who were willing but unable to participate directly after the activity, arrangements were made for an online interview at a later time. The interviews were conducted in either Dutch or English, depending on the language of the participant. All data collection was completed by the end of November 2023.

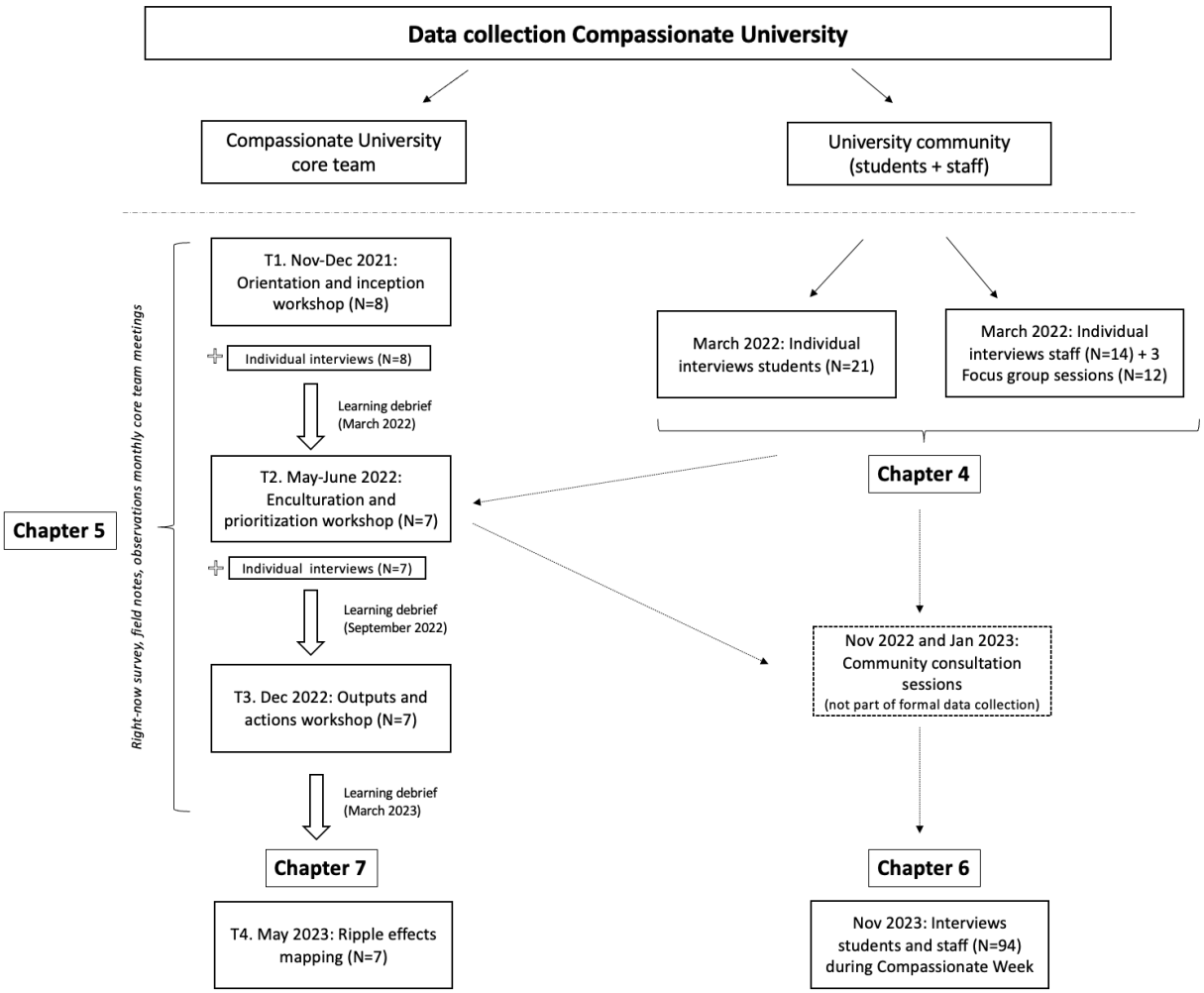

Figure 1. Data collection methodologies and related chapters

3. Positionality statement of the researcher

In Developmental Evaluation, the researcher and the research reality are interconnected, and data gain meaning through interaction with participants and the personal experiences of the researcher.[14] Accordingly, this research was created under the influence of the researcher's individual values and beliefs, which are shaped by factors like education, ethnicity, gender, and social values.[14,15] My background as an individual and as a researcher, as well as the methodologies used, inevitably shaped the research outcomes. To provide context, I am a white female researcher with an academic background in educational sciences and international development. After completing my master's degree at the Catholic University of Leuven (KU Leuven) and the University of Maastricht, I started as a doctoral researcher at the Vrije Universiteit Brussel (VUB) in 2020. Given that my doctoral research focuses on the development process of the VUB towards a Compassionate University, I am part of the community under study as a VUB staff member. In this section, I will reflect on my positionality as a researcher and its potential effects on establishing, conducting, and reporting the research.

During the research trajectory, I used different participatory techniques, which require more and deeper involvement of participants than traditional research methods.[11] The various participatory techniques were part of the Developmental Evaluation (DE) approach used to study the development process towards a Compassionate University. Adopting a participatory evaluation ethos, focusing on the practical "use" of evaluation, I worked closely with the Compassionate University core team throughout the entire evaluation process. My experience was marked by the challenge related to the dual role of being a researcher, evaluator, and integral part of the Compassionate University core team. In balancing these roles, the overarching aim of my work was twofold: i) to actively contribute to and support the refinement and implementation of the Compassionate University program, and ii) to ensure methodological rigor, generating knowledge that could be used beyond the program's scope. Rey et al.[16] distinguish between the 'action-oriented purpose' of DE, which is to continuously inform the development of a complex program by providing real-time feedback based on empirical data, and the 'research purpose' of analyzing the data to generate explanatory insights. Moreover, I was increasingly being recognized by different university stakeholders as a representative of the Compassionate University core team. This placed me in the paradoxical position of being both a judge (evaluator) of the development process and, and as a member of the core team, being judged on the work of Compassionate University. I became aware of my internal desire to ensure the program's success, stemming from my inherent involvement in the core team. Throughout the study period, I tried to adopt a reflective and relative epistemological stance, as advocated by Hartz[17] and Patton[14] to maintain evaluative integrity by making reflective notes after every data collection moment.

When conducting interviews and focus groups with students and staff about their experiences with serious illness, death, and bereavement in the university context, the focus was on capturing their narratives. To preserve their active voice and authenticity in reporting the findings, direct quotes from the interview transcripts were preserved as much as possible. During the interviews, I sought an appropriate approach and tried to maintain an 'empathic distance'.[18] I aimed to achieve this by adopting a non-judgmental approach, listening attentively, and responding in a manner that affirmed my understanding of what was being communicated. The facilitative nature was commented on by participants, who said they appreciated the space it gave them to tell their stories. Yet I could not afford to establish a strict rule of keeping a 'distance'. At times, participants sought advice or asked direct questions about my personal experiences. For instance, I got the question: "What do you think I should do now?" Prior to the start of the study, it was also emphasized that managing participants' expectations was paramount. It was recognized that conducting the study might foster certain expectations about the actions the university would take post-study. The most I could offer was to explain my role as a researcher, as well as the scope and constraints of the study. Additionally, I began to formulate my own reflections and personal stance in relation to my opinions and views. Reflexivity played a crucial role in negotiating the gap between my ideal personal goals and what is practically feasible or appropriate for me as a researcher.

During the process of data analysis, it occurred to me that I faced a dilemma in relation to my supervisors, the core team, and the wider academic community. How comfortable am I with disclosing my research findings to others, considering the sensitive nature of the material? As I was adopting a Developmental Evaluation approach, the objective was to provide feedback to the Compassionate University core team based on the insights gained from the data collection with students and staff regarding their experiences and support needs. Sometimes these insights were critical of existing support services and initiatives for which core team members were responsible. As a developmental evaluator, it is important to build and maintain a trusting relationship with the key stakeholders involved in the development process. Therefore, I was careful to present the data in a thoughtful manner. I organized workshops where core team members could engage with the data collected from the university community in a structured way. During these sessions, I juxtaposed the findings with ongoing initiatives, highlighting areas of alignment and identifying areas for improvement. This approach facilitated constructive dialogue and fostered a collaborative environment conducive to addressing challenges and refining existing strategies.

One of the recurring themes during the focus group sessions with core team members was the perceived lack of community action. This, coupled with feedback from interviews indicating a strong

interest among students and staff to participate in tangible initiatives, led to my decision to take the lead in developing and implementing the Compassionate Week, a death and grief festival organized on the university campus. This decision was driven by a desire to address the needs identified during the data collection with students and staff and to actively contribute to the goals of the Compassionate University program. However, it also raised methodological questions about my dual role as a researcher and evaluator of the Compassionate University program. Compassionate Week is a notable example of where I, as a researcher, chose to take an active role in shaping the program. I recontacted students and staff who had participated in the individual interviews and focus groups and asked if they would be willing to participate in two follow-up sessions (i.e., community consultation sessions in Fig. 1). The objective of the first session was to reconfirm the narratives arising from the interviews and focus groups (i.e., member-check). The second session aimed to generate ideas for the development of concrete "compassionate initiatives". The collective sessions led to the identification of possible initiatives to be implemented during the Compassionate Week. These sessions were distinct from the formal data collection process of this doctoral research. The Compassionate Week took place in November 2023, after the conclusion of data collection on the Compassionate University core team.

Furthermore, three members of the Compassionate University core team also served as my supervisors, guiding and evaluating my work as a doctoral researcher. This presented a unique dynamic from the outset. Their dual roles allowed for a seamless integration of their expertise and insights into the evaluation process, enriching the quality and depth of my research. However, the blurring of boundaries between supervisors, participants, and authors of academic papers necessitated clear communication and thoughtful reflection to mitigate potential conflicts of interest. Throughout the first two years of my PhD trajectory, I convened with an advisory group every six weeks, transitioning to biannual meetings during the last two years. These meetings provided valuable opportunities to engage with senior researchers who were not involved in the Compassionate University program and to reflect on the research process and potential conflicting views from an outsider's perspective.

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Chapter 3

Researching Compassionate Communities: Identifying Theoretical Frameworks to Evaluate the Complex Processes behind Public Health Palliative Care Initiatives

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Chapter 3. Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives

Abstract

Background: Compassionate Communities have been put forward as a new model for community-based palliative care to positively impact the health and well-being of those experiencing the challenges of serious illness, death, dying, and loss. Despite the growing international movement to develop these public health initiatives to end-of-life care, only a handful of initiatives have undergone some form of evaluation.
Aim: To provide guidance on designing evaluation research by identifying theoretical frameworks to understand the development, implementation, and underlying mechanisms of Compassionate Communities.
Methods: To identify suitable theoretical frameworks for the study of Compassionate Communities, we applied two steps. The first step examined the characteristics of Compassionate Communities and translated them into assessment criteria for the selection of theoretical frameworks. The second step consisted of applying the identified assessment criteria to a list of widely used and highly cited theoretical frameworks.
Results: Three well-established theoretical frameworks were identified as being most suitable to study the development, implementation, and underlying mechanisms of Compassionate Communities: The Consolidated Framework for Implementation Research (CFIR), the integrated-Promoting Action on Research Implementation in Health Services framework (i-PARHIS), and the Extended Normalization Process Theory (ENPT).
Conclusions: The article supports the use of theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives. The complementary use of two determinant frameworks and an implementation theory provides theoretical grounding to gain rich insights into the emergent and shifting interplays between agency, social processes, and contextual factors that shape the development and implementation of Compassionate Communities.

Keywords: Public health, palliative care, Compassionate Communities, implementation science, evaluation methodology

Key statements

What is already known about the topic?

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

What this paper adds

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

Implications for practice, theory, or policy

- More flexible integration of various existing models, approaches, and methods from both palliative care research and other disciplines is needed to support the uptake, scalability, and sustainability of Compassionate Communities and other public health palliative care initiatives.
- Future research can complement traditional research methodologies with approaches that are participatory and directly informed by communities' lived experiences, needs, and aspirations for care.

1. Background

Responses to end-of-life challenges in our society have been medicalized with the development of specialized palliative care and bereavement services in the last 50 years.[1] A growing movement insists that serious illness, death, dying, and loss need to be recognized and reframed as the social experiences they essentially are.[2,3] This includes moving beyond the dominant medical-individualistic approach that focuses on patients or clients defined in terms of health problems or biopsychosocial risk toward a salutogenic approach around serious illness, death, dying, and loss: an approach that aims to normalize and promote healthy attitudes toward these experiences through awareness-raising,[4] increasing death literacy,[5,6] and developing social capital of entire communities.[7,8] This approach is called a "Compassionate Community" model.[9,10] Compassionate Communities are considered a public health approach to palliative care that can encompass a wide range of actions and practices, such as facilitating or supporting enhanced, naturally occurring caregiving networks;[1,11] engaging the wider society in a community discourse through programs in schools,[12,13] universities, workplaces, faith communities, and the arts;[6,14–16] and advocacy activities lobbying jurisdictions to develop healthy public policy to normalize experiences of serious illness, death, dying, and loss.[17] In recent years the model has gained in popularity and has been implemented worldwide through initiatives in the United Kingdom,[18,19] Ireland,[20] India,[21] Canada,[22] Australia,[23] Colombia[24], Argentina,[25] Brazil[26] South Africa,[27] and more recently in mainland Europe.[16,28]

The few studies that have sought to evaluate Compassionate Communities point to some "early suggestion of benefits" as seen in a population-wide reduction of hospital emergency admissions,[29] reduced social isolation,[7] enhanced social wellbeing,[29] increased community capacity and social capital to care,[30] and breaking the taboo around death, dying, and loss.[31] However, little attention has been given to *how* these outcomes are obtained.[32–34] The literature identifies several reasons for the lack of rigorous evaluations. First, developing evaluation tools is difficult given the diversity of targets prioritized by different communities.[33–35] Second, an important part of the initiatives is not-for-profit and volunteer-based, so funding and resources are often lacking to evaluate the practices and programs developed.[33,36] Third, the way people experience events of serious illness, death, dying, and loss is influenced by a wide range of factors (psychological, sociological, economic, cultural, political), which requires an adaptation of conventional (often biomedical) research frameworks predicated on linearity and predictability.[2,31] The characteristics of public health palliative care initiatives suggest that research needs to focus more – as

compared with clinical or health service research approaches – on context and the needs and contributions of a variety of stakeholders involved, and the social and economic determinants of health.[37,38]

Implementation science supports the use of theoretical frameworks to improve our understanding of how, why, and under which circumstances initiatives work or do not work.[36,39] Although there is a growing awareness of the importance of using theories and frameworks for evaluating the complex processes behind new public health initiatives, there are many of them and no obvious way to select the most pertinent for specific situations.[40] This article offers guidance on designing evaluation research by assessing the utility and applicability of theoretical frameworks for the study of Compassionate Communities.

2. Methods

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

2.1 Conceptual literature review

The authors undertook a conceptual scoping review to find reviews written within the past 20 years that reviewed the characteristics of Compassionate Communities A conceptual scoping review is a type of knowledge synthesis that provides new interpretations built from but often extending beyond the original literature or past research.[43] Literature was searched up to March 2022. After considering the reviews independently, the authors agreed on a tentative list of key concepts highlighted across the reviews. Through this process, three reviews proved particularly useful for the purpose of our current analysis, i.e. to identify assessment criteria based on the core characteristics of Compassionate Communities to review the usefulness of theoretical frameworks for the study of Compassionate Communities. A first systematic review on Compassionate Communities was published in 2018 and summarizes development, implementation, and evaluation models.[32] The second review describes and compares “civic engagement

initiatives in palliative care" or "compassionate community initiatives" in terms of context, development, impact, and evaluation.[33] The goal of the third review is to provide a clear overview of similarities and differences between Compassionate Communities on their contextual characteristics and development processes.[34] The tentative list of Compassionate Communities' characteristics, directly drawn from the reviews on Compassionate Communities, was then translated into assessment criteria to appraise theoretical frameworks. Again, the research team discussed any nuances in order to reach consensus on a final list of assessment criteria deemed important for the selection of theoretical frameworks for the study of Compassionate Communities.

2.2 Appraisal of theoretical frameworks

The myriad of existing theoretical frameworks underscores the challenge of selecting the most appropriate framework for a specific intervention or project, particularly when most are used in practice only once or with limited justification.[44] Understanding the options available is made more challenging by unfamiliarity with the language used and the inconsistencies in nomenclature.[40] For clarity, we will refer to frameworks, models, and theories collectively as "theoretical frameworks".

We employed "empirical support" as a criterion for selecting frameworks for appraisal, as suggested by implementation science scholars.[45,46] We used reviews presenting the most used implementation science frameworks cited in academic publications[47] and the theories most used by implementation scientists[48] to guide the selection of theoretical frameworks for appraisal. For pragmatic reasons and relying on the systematic approach taken by the authors of both manuscripts, we considered only those theoretical frameworks within the top-10 on both lists (i.e., both highly cited in the literature, >200 citations, and commonly used in implementation practice).[40] (See Table 1.) We further categorized these frameworks using the taxonomy proposed by Nilsen[49]. The taxonomy demonstrates that the frameworks included those that principally aim to guide the process of translating evidence into practice (i.e., process models),[50–53] those that principally aim to understand and explain what influences implementation outcomes (i.e. determinant frameworks and implementation theories),[54–61] and a single framework explicitly meant to evaluate implementation (i.e., evaluation framework)[62] – however, most frameworks fulfil this role as a secondary function.[50,54,55,57,59,60]

Table 1. Summary of ten commonly used theoretical frameworks

Authors/date	Name of theoretical framework	Nilsen's categorization [49]
Graham et al.[50]	**Knowledge to Action (KTA)** Conceptual model that helps guide and understand how knowledge is created and synthesized. It takes a systems approach and recognizes that knowledge producers and users are situated within a larger social system.	Process model: describes practical steps in translating research into practice
Proctor et al.[51]	**Conceptual model of implementation research** Conceptual model that guides how implementation research can be organized and how it fits/aligns with evidence-based practices.	Process model: describes practical steps in translating research into practice
Klein & Sorra[52]	**Implementation effectiveness model** Conceptual model that provides a list of constructs that can influence implementation effectiveness, based on the premise that implementation effectiveness is a function of an organization's climate for implementing a given innovation and the targeted organizational members' perceptions of the fit of the innovation to their values.	Process model: describes practical steps in translating research into practice
Aarons et al.[53]	**Conceptual model of evidence-based practice implementation in public service sectors** Conceptual model of factors that can influence implementation in the unique context of public sector services at four implementation stages: Exploration, Adoption/Preparation, Implementation and Sustainment (EPIS).	Process model: describes practical steps in translating research into practice
Damschroder et al.[54]	**Consolidated Framework for Implementation Research (CFIR)** Conceptual framework developed to guide systematic assessment of multilevel implementation contexts to identify factors that might influence intervention implementation and effectiveness.	Determinant framework: categorizes implementation barriers/enablers
Wandersman et al.[55]	**Interactive Systems Framework (ISF)** Describes relevant systems to help bridge the gap between science and practice, using three interacting systems: the Innovation Synthesis and Translation System, Innovation Support System, and Innovation Delivery System.	Determinant framework: categorizes implementation barriers/enablers

Michie et al.[56] Cane et al.[57]	**Theoretical Domains Framework (TDF)** Overarching theoretical framework comprised of 14 domains integrating constructs from multiple theories relating to health behaviour change.	Determinant framework: categorizes implementation barriers/enablers
Kitson et al.[58]	**Promoting Action on Research Implementation in Health Services (PARIHS)** Framework positing successful implementation as a function of nature and type of evidence, the qualities of the context of implementation, and the facilitation process.	Determinant framework: categorizes implementation barriers/enablers
Harvey & Kitson[59]	**Revised PARIHS framework (i-PARIHS)** Aims to address the lack of conceptual clarity, specificity, and transparency; the lack of conclusion of relevant elements perceived to be critical to implementation; and the lack of instrumentation and evaluation measures in the original framework.	
May & Finch[60]	**Normalization Process Theory (NPT)** Identifies, characterizes, and explains key mechanisms that promote and inhibit the implementation, embedding, integration and normalization of new practices.	Implementation theory: specifies underlying mechanisms
May[61]	**General Theory of Implementation** or **Extended Normalization Process Theory (ENPT)** Builds on NPT, informed by ideas about agency and its expression within social and cognitive mechanisms and collective action.	
Glasgow et al.[62,63]	**Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework** Helps to plan and evaluate different types of programs, practices, policies, and environmental changes.	Evaluation framework: evaluates implementation

3. Results

3.1 Identifying assessment criteria for theoretical frameworks

The reviews on Compassionate Communities showed substantial variability in the contextual and developmental characteristics of Compassionate Communities.[32–34] First, understanding the uniqueness of each local system, therefore may require constructs to understand, describe, and evaluate the characteristics of initiatives and actions at *different socio-ecological levels*.

Second, developing Compassionate Communities is often characterized by the *active involvement* of various stakeholders, including local government, health and wellbeing organizations, workplaces, schools, churches, and neighbourhoods who *collaborate* to bring about actions aimed at prevention, harm reduction, and early intervention around serious illness, death, dying, and loss. Suitable frameworks should therefore address the *collaboration* between stakeholders and capture their different perspectives. This includes characterizing the collective sense-making and experiential learning process behind the enactment of new practices.

Third, most initiatives also referred to the importance of *facilitation* of activities across different levels and settings. Theoretical frameworks need to guide the understanding and evaluation of implementation strategies used to implement practices across settings. Fourth, Librada-Flores et al.[32] and D'Eer et al.[33] found that sustainability of initiatives is a common challenge for most initiatives. D'Eer et al.[33] emphasize the need for evaluation studies to focus more on the underlying mechanisms that may hamper or facilitate the sustainability of future initiatives. We, therefore, added the criterion of *sustainability* to the list of assessment criteria.

Fifth, given these characteristics, Compassionate Communities can be thought of as complex and adaptive systems. Complex adaptive systems are shaped through the agency of system actors and the interconnectedness and interdependency of system components, which can lead to unpredictability as systems evolved dynamically over time.[64,65] The *complexity* of Compassionate Communities also arises from dealing with issues for which there are no straightforward answers and no general agreements on the strategies to achieve the intended outcomes, the need to recognize multiple perspectives, and the existence of various locally driven interventions that are not easily standardized or replicated.[38] Frameworks must recognize the complexity and dynamic nature of these initiatives.

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

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

Core characteristics of Compassionate Communities	**Assessment criteria**
Change at different socio-ecological levels	- Provide constructs to identify contextual factors (i.e. barriers and enablers) that may influence the development and implementation process at different levels (i.e. intervention, individuals, organization, local environment, system, policy) - Provide structure to identify and evaluate action across different levels (i.e. intervention, individuals, organization, local environment, system, policy)
Active involvement and collaboration	- Recognize the active involvement and agency of community members in creating change - Capture social experiential learning processes arising from collective sense-making processes - Recognize the different perspectives and motives of those affected by the intervention - Capture the relationships between different stakeholder groups and organizations
Facilitation	- Guide capturing the implementation strategies used to address barriers and enablers to implementing the intervention - Capture learning loops and facilitate learning dialogues to support the development of community capacity
Sustainability	- Understand local processes and practices that may influence the dissemination and sustainability of initiatives - Identify systemic issues and challenges that may undermine sustainability of initiatives
Complexity	- Recognize interconnectedness and interdependency of system components - Recognize the nonlinear nature of the development and implementation process
Broader criteria for the selection of theoretical frameworks to inform the evaluation of Compassionate Communities	
Measurement tools	- Provide guidance for measurement of constructs

3.2 Appraising theoretical frameworks against the identified assessment criteria

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

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

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

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

Table 3. Analysis of frameworks for the study of Compassionate Communities

Theoretical framework	**Nilsen's categorization**[49]	**Socio-ecological levels**						**Assessment criteria**				
Title and reference	**Type**	**Intervention**	**Individuals**	**Organization**	**Local environment**	**External system**	**Policy**	**Active involvement and collaboration**	**Facilitation**	**Sustainability**	**Embrace complexity**	**Measurement tools**
Knowledge to Action[50]	Process model	✓	✓	✓				◔	○	◔	○	◔
Conceptual model of implementation research[51]	Process model	✓	✓	✓	✓	✓		○	◔	◔	○	○
Implementation effectiveness model[52]	Process model	✓	✓	✓				○	◔	○	○	○
Conceptual model of evidence-based practice implementation in public service sectors[53]	Process model	✓	✓	✓	✓	✓	✓	○	◔	◔	○	○
Consolidated framework for Implementation Research (CFIR)[54]	Determinant framework	✓	✓	✓	✓	✓	✓	◔	◔	○	◕	●
Interactive Systems Framework[55]	Determinant framework	✓	✓	✓	✓	✓		◔	○	○	◔	○
Theoretical Domains Framework[56,57]	Determinant framework	✓	✓	✓	✓			◔	◔	○	○	◔
integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS)[58,59]	Determinant framework	✓	✓	✓	✓	✓		◑	●	○	◔	◕
General Theory of Implementation or Extended Normalization Process Theory (ENPT)[61]	Implementation theory	✓	✓	✓	✓	✓		◕	◔	◕	◑	◑
RE-AIM framework[62,63]	Evaluation framework	✓	✓	✓	✓			○	○	◔	○	◕

Note: Extend to which assessment criteria is covered; ● - complete coverage; ◕ - extensive coverage; ◑ - moderate coverage; ◔ - slight coverage; ○ - minimal or no coverage. Full details of rationale for decisions can be found in Supplementary file 1. Bolded theories are those selected for the study of Compassionate Communities

Three theoretical frameworks are selected for the study of Compassionate Communities. We will briefly discuss the selected frameworks below.

Understanding context and facilitation process. CFIR is a conceptual meta-framework that provides a common structure for evaluating barriers and facilitators to implementation.[40,66] The framework comprises five domains (intervention characteristics, outer setting, inner setting, characteristics of individuals involved, and the process of implementation) and 39 related constructs. CFIR has a clear dedicated website that provides examples, templates, and tools to assist in developing and evaluating implementation projects and collecting and analysing data.[67] However, CFIR does not consider the active "facilitation process" behind intervention implementation, but it can be combined with i-PARIHS, which positions facilitation as the core ingredient in relation to its other constructs.[59] The i-PARIHS facilitator's toolkit offers pragmatic guidance to support the implementation of initiatives and provides a "Facilitation Checklist" to support structured assessment of the framework's constructs.[68,69]

Understanding the implementation process and underlying mechanisms. While determinant frameworks, such as CFIR and i-PARIHS, are useful as they describe in detail the structural and more static influences on development and implementation, implementation theories have more explanatory power because they characterize the underlying mechanisms of change. ENPT provides a framework that considers the dynamic and social nature of implementation, including individual and collective responses to implementation. The framework consists of four main constructs: capability, capacity, potential, and contribution. [70] The earlier Normalization Process Theory (NPT) has an interactive toolkit that can be used to plan a project or analyse data and helps to think through implementation and integration challenges.[71] Additionally, the NoMAD (Normalisation MeAsure Development) questionnaire, a set of 23 survey items for assessing implementation processes from the perspective of stakeholders, can be used to describe participants' views about how an intervention impacts their work, and their expectations about whether it could become a routine part of their work.[72] The broader Extended Normalization Process Theory has so far only described conceptual measures.[42]

4. Discussion

4.1 Main findings

This article identified three suitable frameworks to study the development, implementation, and underlying mechanisms of Compassionate Communities. Although the purpose of the frameworks differs, they are complementary, as CFIR provides constructs to categorize and describe contextual determinants that influence implementation at different socio-ecological levels, i-PARIHS adds the concept of "facilitation" to the list of contextual determinants, and ENPT helps to understand the underlying mechanisms that shape the way change processes occur.[73] The complementary use of two determinant frameworks and an implementation theory provides theoretical grounding to gain rich insights into the emergent and shifting interplays between contextual conditions and the social and cognitive processes (sense-making) of agents during implementation.

When combining the three frameworks to study Compassionate Communities, we do not suggest using all constructs of each framework. For example, there is a great overlap between the constructs of the CFIR and i-PARIHS framework. This is because CFIR includes constructs based on the original Promoting Action on Research Implementation in Health Services (PARIHS) framework. Although the CFIR is more comprehensive than any single framework for categorizing barriers and enablers because it comprises nineteen other theories and frameworks,[74] it does not include "facilitation" from the revised PARIHS framework. This means that CFIR does not specify mechanisms by which strategies might improve implementation. However, i-PARIHS can support the process of matching identified determinants to implementation strategies by studying the facilitation process as a core ingredient of implementation. We advise using the five key domains proposed by CFIR to assess the implementation context and to use i-PARIHS to inform and assess the internal and external facilitation approach. The online CFIR technical assistance website can assist in selecting and applying suitable constructs and the i-PARIHIS *Facilitator's Toolkit* supports the structured assessment of the facilitation process.

Having identified potential implementation barriers and enablers using CFIR and i-PARIHS, ENPT can further examine process issues potentially hindering implementation and structure challenges needing to be overcome to implement and embed new practices. ENPT gives more insight into the underlying mechanisms of action and the social and cognitive work different stakeholders perform to enact new

practices. The inclusion of the two determinant frameworks (CFIR and i-PARIHS) with the ENPT provides a complementary approach as the ENPT facilitates an understanding of the mechanisms that underlie sustained change. However, it is also worth noting that we did not intend to propose a blueprint for evaluating Compassionate Communities – the menu of potentially usable theories, models, and frameworks is extensive. Future studies need to test the applicability of general constructs to specific projects and identify which modifications are needed to account for particular features in the field.

Research needs to be congruent with the principles of Compassionate Communities – participation, empowerment, collaboration, and social justice,[4] so the importance of using theoretical frameworks in combination with more participatory methods should be emphasized. To foster system change and support community and settings-based initiatives, theory-oriented evaluation approaches, such as realist evaluation[75] and developmental evaluation,[76] can be used combined with the proposed frameworks. Especially developmental evaluation adheres to the principles of co-creation and participation by continuously involving stakeholders to enhance the "use" of evaluation data.

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

4.2 Limitations

Our work builds on systematic reviews that used rigorous methods for identifying Compassionate Community initiatives.[32–34] However, the lack of in-depth descriptions and evaluations of Compassionate Communities made it difficult to define their core characteristics for evaluation purposes. Only a handful of initiatives have been described in the last decade, and only a minority underwent some form of

evaluation. As this often concerns bottom-up initiatives, it is likely that some are not reported or described in the scientific literature, particularly in non-English speaking contexts.[33]

For the selection of frameworks, we consulted the reviews by Skolarus et al.[47] and Birken et al.[48] and considered only those theoretical frameworks within the top 10 on both lists. Other frameworks not on this list might also fit the purpose of studying the complex processes behind Compassionate Communities. Moreover, by only selecting highly cited theoretical frameworks we may have missed out on important innovations from the last few years. However, having a sufficient empirical basis was identified as an important criterion to support the use and uptake of theoretical frameworks by researchers and practitioners in the field.

5. Conclusion

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

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Chapter 3. Supplementary file 1: Detailed comparative analysis of frameworks for the study of Compassionate Communities (Extension of Table 3 in the manuscript)

Theoretical framework	Core constructs	Assessment criteria				
Source reference	**Overview**	**Active involvement and collaboration**	**Facilitation**	**Sustainability**	**Embrace complexity**	**Measurement tools**
Knowledge to Action Graham et al.[50]	Process of knowledge creation: Knowledge Inquiry Knowledge Synthesis Knowledge Tools/Products	The needs of stakeholders as end-users of knowledge creating are integral to the framework. But little mention of the need to engage practitioners and citizens affected by the change or the value of doing so.	Not included.	Although not explicitly mentioned, the model incorporates how knowledge creation through action and reflection can result in sustained changes.	No	No specific measurement tools or guidance on how to do each step of the action cycle but there is some guidance on important elements to consider.
Conceptual model of implementation research Proctor et al.[51]	Intervention strategies Implementation strategies Outcomes	No	Group learning is mentioned, but no explicit focus on the facilitation process.	Sustainability is mentioned as one of the implementation outcomes.	No	No measurement tools available.
Implementation Effectiveness model Klein & Sorra[52]	Climate for implementation Skills Innovation values and fit Commitment Implementation effectiveness	No	Implementation policies and strategies are mentioned, but the need for facilitation is not explicit.	Not included.	No	Only main manuscript available, very wordy (text-based).

Conceptual model of evidence-based practice implementation in public service sectors Aarons et al.[53]	Intervention characteristics Innovation/System fit Innovation/Organization fit Context – Outer setting Context – Inner setting	○ No	◔ Organizational characteristics that support innovation and receptivity are recognized, but no explicit focus on facilitation.	◔ Provides constructs that can influence implementation at each of the 4 implementation stages: Exploration, Adoption/Preparation, Implementation, and Sustainment (EPIS). But no specific reference to sustainability as a construct.	○ No	○ Little clarity on how to operationalize the different constructs and no measurement tools available.
Consolidated framework for Implementation Research (CFIR) Damschroder et al.[54]	Intervention characteristics Context – Outer setting Context – Inner setting Individuals involved Implementation process	◔ Recognition of the role of external change agents and champions to facilitate change, but no further elaboration on how to draw on their knowledge and local insights to inform planning, design, conduct and evaluation of change.	◔ Acknowledgment of generative learning and implementation strategies, but no explicit focus on the role of facilitation.	○ Not included.	◕ Complexity is explicitly considered as a characteristic of the intervention. Recognition of the importance of fit with processes and the need to assess the degree to which the intervention disrupts practices and processes. However, there is no further discussion of how to understand interrelations of system components and emerging, unintended consequences as a result of complex change processes.	● Dedicated website that provides examples, templates and tools to assist developing and evaluating implementation, collecting and analyzing data.

Interactive Systems Framework Wandersman et al.[55]	Delivery system Support system Synthesis and Translation system	Some focus on capacity building for staff to use the intervention and their involvement in local adaptation but restricted to staff and no broader stakeholder engagement.	Not included.	Not included.	Some recognition of the need to understand organizational context, systemic issues and relationships across support and delivery systems.	No clear guidance available regarding how to apply the framework.
Theoretical Domains Framework Michie et al.[56] Cane et al.[57]	Social influences Environmental Context and resources Social/professional role, beliefs, optimism, goals and intentions Reinforcement and emotion Knowledge, skills, memory, behavioural regulation Physical skills	Beliefs about capabilities (including empowerment) and organizational culture and climate are mentioned but not connected to providing supportive learning environments or engaging different stakeholders.	The interpersonal processes that cause change are recognized, but no explicit mention of the need for facilitation.	Not included.	No	Exemplar questions and interview guides provided in main publications.
integrated-Promoting Action on Research Implementation in Health Services (i-PARIHS) Kitson et al.[58]; Harvey & Kitson[59]	Innovation Recipients Context Facilitation	The revised version of the framework added the construct 'recipients' with a specific focus on collaboration and teamwork to create change. There is no explicit recognition of citizens or stakeholders as resource for local problem-solving and decision-making.	Explicit role of facilitation to create change. Leadership defined as important for enabling/empowering those affected by the change.	Not included.	Recognizes that successful implementation is a function of different factors (facilitation, context, recipients, and evidence). However limited information on how different factors influence and interact with each other (i.e., interconnectedness).	Facilitator's Toolkit for qualitative data collection and measures explicitly outlined.

General Theory of Implementation or Extended Normalization Process Theory (ENPT) May & Finch[60]; May[61]	Capacity Potential Capability Contribution	◕ Agency is recognized as potential facilitator for change and the importance of social negotiation of change is highlighted. A range of elements related to engagement from the perspectives of recipients but no recognition of challenges in bringing individuals, groups together or the broader role of social change processes.	◔ Whilst there is recognition that negotiation with stakeholders is necessary to modify existing systems and practices the broader role of facilitation in understanding different and potentially conflicting perspectives is not mentioned.	◕ Sociological theory that goes beyond implementation and examines 'embedding' (*normalisation*) and 'integration' of practices in their local contexts. Integration is defined as 'the *sustaining* of the embedded practices in their social contexts. However, normalization is the core focus of the framework and sustainment is perceived as the following step.	◑ Recognizes the dynamic elements of context and the non-linear nature of social change processes but no further elaboration on system trajectories, emergent prosperities, and interrelationships.	◑ ENPT measurement tools conceptually explained, only NPT provides an interactive toolkit and questionnaire (NoMAD).
RE-AIM framework Glasgow et al.[62,63]	Reach Effectiveness Adoption Implementation Maintenance	○ No	○ Not included.	◔ Only maintenance mentioned as a construct.	○ No	◕ Dedicated website with online tools and examples, RE-AIM planning tool and checklist available.

Note: Extent to which assessment criteria is covered; ● - complete coverage; ◕ - extensive coverage; ◑ - moderate coverage; ◔ - slight coverage; ○ - minimal or no coverage. Bolded theories are those selected for the study of Compassionate Communities

Chapter 4

A Compassionate University for Serious Illness, Death, and Bereavement: A Qualitative Study of Student and Staff Experiences and Support Needs

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Chapter 4. A Compassionate University for serious illness, death, and bereavement: Qualitative study of student and staff experiences and support needs

Abstract

Serious illness, death, and bereavement are common experiences within the work and study context. This study aims to explore the experiences and support needs of university students and staff confronted with serious illness, death, and bereavement. Semi-structured interviews and focus groups were conducted with 21 students and 26 staff. A thematic analysis resulted in three overarching themes: The university as a high-pressure environment; Navigating the complex university information and support system; and Disenfranchised grief. Four themes were identified in terms of what participants needed from the university: Clear processes and procedures; Flexibility in policy application; Proactive support and recognition; and Activities to enhance awareness and interpersonal communication skills. Findings from this study could enable higher education institutions to become more compassionate schools and workplaces.

Keywords: Bereavement, higher education, workplace, support needs, students

1. Introduction

At different points in our life, regardless of our age, gender, location, or socioeconomic background, we are all confronted with experiences of serious illness, death, and bereavement. And yet these experiences appear too often as taboo topics and are almost exclusively embedded in professional healthcare narratives and practices.[1] Suggestions on how to manage the taboos surrounding these topics can be found in the health-promoting palliative care literature. Kellehear's notion of "Compassionate Communities" is relevant in this respect, emphasizing the need to empower communities and build capacity to support each other during times of serious illness, death, and bereavement. [2] The literature on Compassionate Communities suggests an important role and potential for higher education institutions in actively promoting well-being around serious illness, death, and bereavement, and integrating these experiences into local communities.[3] Higher education institutions are interesting environments because they are communities that are at the same time intergenerational hubs, employers, and formative actors in the life course of students and staff.

Some scholars have made specific reference to the idea that higher education institutions may not be naturally conducive settings to providing a supportive atmosphere for serious illness, death, and bereavement (also referred to as end-of-life (EoL) experiences).[4,5] For students, the university environment expects continuous high-performance delivery, meeting deadlines for assessments and examinations, and participating in social campus activities, all of which might be challenging when being confronted with experiences of serious illness, death, or bereavement.[6,7] Previous studies have found that bereavement is associated with deleterious health outcomes for students, including depressive symptoms, sleeplessness, and decreased motivation, which in turn can affect their academic performance and increase the risk of developing mental health problems, such as depression, anxiety, and posttraumatic stress disorder.[8,9] Although the potential challenges associated with student bereavement were first acknowledged about two decades ago,[4] an increase in research activity on this topic and calls for action are fairly recent.[6,10]

A university not only educates students, it is also the work environment of many academic and administrative staff. The workplace can play a significant role in the amount of distress staff experience when confronted with serious illness, death, or bereavement.[11] The American Hospice Foundation noted

that where loss and grief are acknowledged within the workplace, there are fewer mistakes, reduced sickness, lower staff turnover, and improved productivity.[12] Conversely, studies on workplace bereavement have found that grief may be "disenfranchised" due to it being perceived as inappropriate in a context emphasizing productivity and high morale.[13] Despite increasing calls to "put grief on the HR agenda", [14,15] bereavement at the workplace has received little scholarly attention (see Barclay & Kang[16] for a rare exception).

In Belgium, the Vrije Universiteit Brussel (VUB) declared itself as (mainland) Europe's first "Compassionate University" in November 2019, emphasizing the importance of support and compassion during times of serious illness, death, and bereavement. A leading coalition in which different stakeholders are represented (i.e., the Rectorate, Student Counseling Center, Human Resources Management, Marketing and Communication, and some academics of the Compassionate Communities Centre of Expertise) guides the development toward a more Compassionate University. This development process identified a need to define the types of support higher education institutions can offer to both students and staff. However, there is a paucity of research on how universities as institutions can respond to students and staff confronted with serious illness, death, or bereavement, including what policies and systems are in place and whether there has been any attempt to assess their needs.[6] Without a thorough understanding of students' and staff' experiences and needs, it can be difficult to provide appropriate support. We therefore aim to investigate the lived experiences of students and staff when confronted with serious illness, death, or bereavement within the university context, and the kind of support they expect from their university.

2. Methods

2.1 Study design

An exploratory, qualitative research design was used to understand the lived experiences of students and staff when confronted with serious illness, death, and bereavement within the university context and their support needs. Our study adheres to the Consolidated criteria for Reporting Qualitative Research (COREQ).[17]

2.2 Participants and sampling

The Vrije Universiteit Brussel (VUB), located in Brussels, the capital of Europe, serves as a case study. The university has two campuses: the main campus and the Brussels Health campus. The main campus encompasses a diverse range of faculties, while the Brussels Health campus focuses on medical and health-related disciplines. The university comprises nine faculties, namely Languages and Humanities, Social Sciences and Business school, Law and Criminology, Medicine and Pharmacy, Psychology and Educational Sciences, Sciences and Bio-engineering Sciences, Engineering, Physical Education and Physiotherapy, and Teacher Education. VUB offers bachelor's, master's, and doctoral degree programs. The university has a student population of approximately 20.000 students and hosts around 4.700 international students. Furthermore, VUB employs approximately 4.000 staff, including academic staff (teaching and research) and support staff.

Between December 2021 and February 2022, we recruited a purposive sample of students and staff via study announcements disseminated online. Eligible participants had to be registered as student or staff at VUB. There were no other inclusion or exclusion criteria. Students and staff could indicate their interest in participating in the study by filling in an online registration form. They could choose to participate via an individual interview or a focus group. All participants who completed the online registration form were included in the study, except for one staff member. We received an automatic reply by e-mail that she was on sick leave, so we could no longer reach her. One staff member indicated that she did not want to participate through an interview or focus group but was willing to share her experiences via e-mail. In total, 21 university students (5 men, 16 women) and 26 staff (5 men, 21 women) participated in the study (this includes the written statement of one staff member). See Tables 1 and 2 for information on participant characteristics.

Table 1. Participant information, staff

Participant	Gender	Work area	I/FG	Online/F2F
1	F	Administrative staff: Education and Student Affairs	I	Online
2	M	Academic staff: Sciences and Bioengineering	I	Online
3	F	Administrative staff: Education and Student Affairs	I	Online
4	F	Academic staff: Sciences and Bioengineering	I	F2F
5	F	Administrative staff: Finance	I	F2F
6	F	Administrative staff: Psychology and Educational Sciences	I	F2F
7	F	Administrative staff: Education and Student Affairs	I	F2F
8	F	Academic staff: Psychology and Educational Sciences	I	Online
9	F	Administrative staff: Infrastructure	I	Online
10	M	Administrative staff: Innovation and Valorization	I	Online
11	F	Academic staff: Psychology and Educational Sciences	I	Online
12	F	Academic staff: Psychology and Educational Sciences	I	Online
13	F	Administrative staff: Education and Student Affairs	I	Online
14	M	Academic staff: Psychology and Educational Sciences	FG1	F2F
15	F	Administrative staff: Education and Student Affairs	FG1	F2F
16	F	Academic staff: Psychology and Educational Sciences	FG1	F2F
17	F	Administrative staff: Innovation and Valorization	FG1	F2F
18	F	Academic staff: Psychology and Educational Sciences	FG2	Online
19	F	Academic staff: Psychology and Educational Sciences	FG2	Online
20	F	Academic staff: Psychology and Educational Sciences	FG2	Online
21	F	Academic staff: Languages and Humanities	FG3	Online
22	F	Academic staff: Psychology and Educational Sciences	FG3	Online
23	F	Administrative staff: Internationalization	FG3	Online
24	M	Administrative staff: Marketing and Communication	FG3	Online
25	M	Administrative staff: Human Resources Management	FG3	Online
26	F	Academic staff: Psychology and Educational Sciences	E-mail	Written

Note: I= Interview; FG = Focus Group; F2F = face-to-face or in-person.

Table 2. Participant information, students

Participant	Gender	Study program	Online/F2F
1	M	Master Sociology	Online
2	F	Master Psychology	Online
3	F	Master Adult Educational Sciences	Online
4	F	Bachelor Adult Educational Sciences	Online
5	F	Master Adult Educational Sciences	Online
6	F	Master Adult Educational Sciences	Online
7	F	Master Psychology	Online
8	F	Master Adult Educational Sciences	Online
9	F	Master Journalism	Online
10	M	Master Adult Educational Sciences	F2F
11	F	Bachelor Linguistics and Literature	Online
12	F	Master Adult Educational Sciences	Online
13	F	Bachelor Psychology	Online
14	F	Master Adult Educational Sciences	Online
15	F	Bachelor Adult Educational Sciences	Online
16	M	Bachelor Industrial Engineering	Online
17	M	Master Adult Educational Sciences	Online
18	M	Master Business Administration	Online
19	F	Master Psychology	Online
20	F	Master Economics	Online
21	F	Master Psychology	Online

Note: F2F = face-to-face or in-person.

2.3 Data collection

The study used a semi-structured interview guide, adaptable for individual interviews and focus groups (See Interview and Topic Guide in Supplementary files 1-3). After a short introduction and getting to know each other, we started with the question "To what extent have you, yourself or through your environment, encountered experiences of serious illness, death, or bereavement?". Follow-up questions were asked to encourage participants to narrate thoughts and feelings about their experiences related to the university environment. The subsequent questions explored participants' support needs.

Interviews and focus groups took place online or in person, depending on the participant's preference. The in-person interviews and focus groups took place in a quiet room at the university. The lead researcher (HB) conducted all interviews and focus groups with staff. A student researcher (IVB) made field notes during the focus groups to document nonverbal and paraverbal observations, such as smiling, concerned wrinkling, eye contact, and tone of voice. A second student researcher (ES) assisted the lead researcher (HB) in conducting the interviews with students. Individual interviews with students varied in duration from 43 to 78 minutes (median = 61) and interviews with staff lasted between 46 to 75 minutes (median = 58). Focus groups varied in duration from 76 to 94 minutes (median = 81). The interviews and focus groups were conducted in March-April 2022, and were audio-recorded and transcribed verbatim by the two student researchers (IVB, ES). To ensure participant confidentiality, only pseudonymized data was used throughout the study.

2.4 Data analysis

Data were analyzed using the processes of reflexive thematic analysis outlined by Braun and Clarke,[18] which involves familiarization with data, generating initial codes, constructing themes, reviewing potential themes, defining and labeling themes, and writing up analysis. The lead researcher (HB) established initial codes and subthemes to develop the initial coding scheme. The coding scheme was discussed with senior researchers of the research team (SD, JC, FVD) to ensure comprehension of the coding scheme iteratively. No new codes or themes were identified from the 12th interview with students and the 13th interview with staff, suggesting that we had reached the saturation point, defined as "information redundancy" in thematic analysis research.[19] MAXQDA was used for coding and data management.

In terms of positionality, the first author (HB) is a doctoral researcher who has a background in educational sciences and is experienced in qualitative research. The senior researchers and supervisors (SD, JC, FVD) are experts in the fields of education, public health and palliative care, and sociology, respectively. The two student researchers who assisted with the data collection (IVB, ES) are master's students in adult educational sciences. The team met regularly to ensure consistency throughout the study.

2.5 Ethical considerations

The study received ethics approval from VUB (approval number: ECHW_300). All participants were given written and oral information about the study, informing them that participation was voluntary, that they had the right to withdraw from the study, and that they were guaranteed confidentiality.

3. Results

We organized our results in two main thematic sections: 1) student and staff experiences with serious illness, death, and bereavement, and the challenges they encountered; 2) their support needs regarding the university. A numeric participant code is provided with each data extract. For students we use the codes S1 to S21, for staff P1 to P26.

3.1 Experiences

Three broad themes were constructed from the question surrounding experiences with serious illness, death, and bereavement: The university as a high-pressure environment; Navigating the complex university information and support system; and Disenfranchised grief.

3.1.1 The university as a high-pressure environment

The university was often referred to as a demanding, high-pressure environment where there is little room for experiences of serious illness, death, and bereavement. One student said:

> My ex-boyfriend committed suicide. And you're in that rat race, you have to do your internship, you have to complete tasks, you have to take exams. You're on that academic rollercoaster, and then in-between, there are e-mails to arrange practical matters. There is very little room for grief. (S7)

This was echoed by staff, who described the university as an "always-on" environment. A post-doctoral researcher reported:

> The university is a stressful work environment because you need to be available to your students and continue with your research and other responsibilities. You may have to cancel classes or need to find a colleague who can take over, but you're always worried about burdening others. What I wanted to say, is that I'm worried about my potential absence. There is very, very little margin to be missed. (P12)

The fear of not being able to work was also a recurrent theme expressed in the interviews with students. The majority described concerns about their grief compromising their studies and did not see it as possible

to put their studies “on hold” after experiencing a loss, as the comment below illustrates:

> I lost a friend during exams, and what I thought was ‘the only thing I don’t want to lose too are my studies’. That also costs a lot of money. My parents pay for it. I can’t waste a year. I just have to take my exams. (S10)

The university’s performance-oriented environment meant for participants that time taken off for bereavement was seen as “needing to catch up later”, adding to the sense of pressure for both students and staff.

3.1.2 Navigating the complex university information and support system

The theme “Navigating the complex university information and support system” comprises three subthemes: 1) Lack of knowledge about procedures and limited flexibility in bereavement leave, 2) Inadequate HR support and burdensome administration, and 3) Invisible and unavailable support services.

Subtheme 1 describes the perception that the university system is sometimes too hard to navigate due to a lack of knowledge about policies and procedures. Several participants argued that their supervisors were often unaware of the policies and procedures related to bereavement leave, and appeared not to know what types of support could be offered. For example, one staff member did not take the bereavement leave she was entitled to because “no one told her she could do so”:

> I would have taken two months off. Because it’s overwhelming, the loss of a parent. (…) But I have to finalize my PhD, I’m in my final year. I really can’t afford to take time off. I just have to keep working, which I couldn’t do at that moment. And no one told me to take time off, not my supervisor, not my colleagues. So I didn’t even think about taking time off or the possibility of it. (P11)

This quote also interconnects with the previous theme (i.e., the high-pressure university environment), as she couldn’t even conceive taking a leave so close to the end of her doctorate. Additionally, most staff indicated disagreeing with the number of regulated days for bereavement leave:

> That you have to say, in your case four days and in your case one day. That’s very difficult because there is no such thing as a scale of grief. Someone could be your uncle on paper, but

> maybe he was someone you were so close to, or who meant so much to you, that one day is peanuts. And even if it is your mother or your father, what are you entitled to, four days? Let's be realistic. In four days, you cannot even get a funeral organized. (P3)

Other participants echoed the importance of reconsidering how 'close' family is defined when it comes to assessing the time an individual needs before returning to work. For example, P22 stated:

> My grandfather was a father figure to me, but he was not seen as a father figure by the bereavement regulation. I was only allowed to stay away for one day, which was totally insufficient for me. That was far too little for the impact it had on me as a person. (P22)

Individual supervisors' willingness to be flexible in applying or bending official policies was mentioned as an important positive experience. P2 explained: "After my mom died, my supervisor made my job a non-factor. I had no worries about obligations. He just said, 'take as much time as you need', no questions asked. That really saved me". The ability to take paid time off and not have to think about filling in or uploading required documentation was reported as a significant gesture made by supervisors. However, while some participants benefited from the flexible application of bereavement policies, some emphasized how this creates an "unfair" work environment. The lack of a standard approach means that institutional responses are likely to depend on how grief and bereavement are understood by individual supervisors or senior management.

Similarly to staff, the extent of support for students following bereavement depends on the understanding and empathy of individual teaching staff when it comes to (for example) deviating from assignment regulations. These regulations also vary per faculty, such as when exams may or may not be postponed due to bereavement. Because requesting assignment extensions is often perceived as time-consuming, confusing, and difficult to obtain, students avoid seeking support. For example, one student said: "I just submitted the assignment because that was easier than searching for the right information about postponing it" (S9). Students who did apply for deadline extensions explained that there was no clear procedure in relation to bereavement. Participants received different responses from faculty members. One student faced a death before the exams and contacted several staff to get information about the rules for retakes, she explained:

> I was so tired because I was being pushed from pillar to post. So I thought, I'll just do the exams and see what happens, if I pass I pass, if I don't pass I don't pass. That was a real shame. And in the end, I got an e-mail that I was not even able to apply for a retake because the death did not take place within the exam period itself. (S19)

Although the study period before the exams is as important as the exam period itself, it was not seen as such by the regulation. The option of postponing an exam was tied to the period following the death of a loved one and could not be applied days before or several weeks later, when the student actually needed it to enable her to retake her exams.

The lack of clarity about who to approach and to get the "runaround" when asking for support interconnects with subtheme 2, *Inadequate HR support and burdensome administration*. The overwhelming majority of staff were dissatisfied with the impersonal and "harsh" HR system, which is based on a "ticketing system" (i.e., a centralized online system that is the only way to ask HR-related questions, by filling in an online form). As one staff member put it: "I felt very much like a number. I had to put my questions in an online form, and I got a ticket. There wasn't even a person I could contact" (P15). Another staff member shared a similar experience:

> I wanted information about the leave that I needed due to my son's illness. I got a ticket from the online portal and an e-mail with web links. It was a standard e-mail with "yours sincerely" and a signature. But I was too weary to go through all that information online. At such a time, someone from HR should send an e-mail to ask whether it would be okay to call to explain everything you need. (P17)

Participants also shared the difficulty of having to upload supporting documentation. For example, one participant said: "I had to provide a medical certificate to extend my bereavement leave, so I had to see my GP and then put it into the online system. It took so much energy from me. It should be possible to do this another way" (P9). Being asked to provide medical certificates or proof of a funeral was perceived as time-consuming and insensitive at a time when they needed to cope with the death of a loved one.

Subtheme 3, *Invisible and unavailable support services,* describes the barriers to accessing services at the university. Both students and staff often indicated not knowing which services exist, or how to access them. One student said: "There is no signposting at all, and I didn't really know where to go to or where

to start. So I didn't get or asked for any extra help from the university." (S10). Moreover, some students did not know they could access bereavement-related support from the university. For example, "I thought the student counselor is only for when you're having difficulties with your studies" (S16). Participants who did access the university support service reported that it was difficult to access, due to the "tiresome process" (i.e., having to fill out an online form about the reason for approaching them) and the waiting times to see a counselor. This was also mentioned by a staff member who approached the university's psychological support center after a loss:

> I contacted the support center, and received an automatic reply that they will 'review' my case properly. I haven't heard from them since. I got the feeling that my 'case' did not meet the requirements to receive support from the university. (P4)

3.1.3 Disenfranchised grief

The grief of students and staff is often "disenfranchised" due to its being unacknowledged or unrecognized by peers or co-workers. Two interconnected subthemes were identified: 1) Unsupportive peers and co-workers; 2) Discomfort with navigating conversations and offering support.

Subtheme 1 describes the support participants received from peers or co-workers, or more correctly, the support they did not receive but wished to receive. Participants found it painful when peers or colleagues did not acknowledge their loss, avoided the topic, or did not ask how they were doing when they returned to the university. P26 stated:

> Apart from digital condolences from my supervisor, I have felt very little compassion. My request for a consultation at the psychology center was only answered after many months with the question of whether my question was still relevant. And yes, I received a three-month extension for my PhD. I am certainly not ungrateful, but it felt bad that I was urged by my supervisors to look for 'professional' reasons for the delay, and so my almost burn-out due to the combination of a very heavy professional agenda, Covid, and the many experiences of loss in my life was not a valid, acceptable reason. And next to that, only one colleague, besides my supervisor, sent me a warm message during that whole period. I was devastated.

This feeling of being "unseen" and "unrecognized" in one's grief was shared by other participants, for example, P24 stated:

> The rudeness of my manager had a much bigger impact on me than my mother, who was 84 years old, sick, and passed away. I could cope with that. But the cold reaction of my manager, that is something I will never forget.

An international doctoral student, who had to travel back to her home country because her mother passed away, continued working from abroad while arranging all the practical matters for the funeral. She was given additional tasks during online meetings because her supervisor had not informed her colleagues about the loss. She explained:

> And I got another task, and then I explicitly said, 'I'm not the right person to do that at the moment'. But they insisted. And then there was even a joke, I was wearing headphones because my internet connection was very bad, and someone said, 'I think she's just listening to some music and not following'. My supervisor did not support me in that situation. I was really shaking, my hands were trembling. There was no understanding, not even from my supervisor. (P8)

A second subtheme was identified that relates to participants' perceived ability to discuss these topics in a sensitive manner. The results show that although participants were willing to offer support to peers or colleagues, this was often hindered by uncertainty about the appropriateness of offering assistance. Students and staff mentioned limited skills and more specifically limited conversation skills, which they experience both in themselves and in others. As S12 described it: "What should you ask, should you just listen, should you do that? At such a moment I don't want to do anything wrong or say anything to make it worse". The lack of confidence to initiate conversations about death and bereavement often resulted in inaction. One's cultural background may also be an important element in the ability to openly discuss these topics. One staff member from South America explained: "In my country, we're very open. We also celebrate death, that's our culture. Here in Belgium, sorry, I find it much more difficult" (P20).

On the other hand, sometimes when colleagues or peers offered support, it was declined. This was described as an instinctive response, made without considering the value of the intended support, and irrespective of whether assistance was needed. This could be explained by the fact that these topics were often referred to as "private matters". One staff member explained:

> I don't want everyone to know it at work yet. I don't want people to approach me differently or perhaps be softer toward me. I'm still trying to separate that a bit. I see it more as a private matter. But maybe at a certain point, when things get tough, when I have to start taking care of my mom, I might mention it. (P14)

Other participants expressed their desire to talk about their loss but had the feeling that explicit permission was needed to communicate their emotions and that grief was only allowed at the workplace if explicitly invited by colleagues. Participants also worried that expressing feelings and emotions of loss could cause discomfort to others. One staff member said: "I've been trying to share it with my colleagues. But at the same time nobody wants to get in a bad mood, or I don't want to upset anyone" (P2). A student likewise reported: "Well, people can react a bit awkwardly and that's not the conversation I wanted to have at the time. When people seem at a loss for words, I quickly want to make them feel comfortable and minimize it" (S9). Another student referred to not sharing her experiences because she felt it was not legitimate in comparison with others' bereavement, as she said: "My grandmother is already old, and it's 'only' cancer, she didn't die. I had the feeling that it wasn't heavy enough to share it with other students who have their own problems" (S21). The desire "not to be a burden" coexists with underlying wishes that support could take place at times of need.

3.2 Support needs

Four subthemes were identified when reflecting with participants on what they felt they needed from the university when confronted with serious illness, death, or bereavement: 1) Clear processes and procedures; 2) Flexibility in policy application; 3) Proactive support and recognition; 4) Activities that (prophylactically) enhance awareness and interpersonal communication skills.

3.2.1 Clear processes and procedures

Transparent processes and procedures were identified as something that could help students and staff when confronted with serious illness, death, or bereavement. Most students emphasized the importance of clear procedures to receive practical support, such as postponing deadlines and assignment extensions over other forms of support:

> That you have the practicality to postpone an exam, reschedule a task, that they give the documents that are needed. That's the main form of support a university could offer. That you don't have to start looking for 10 documents on 5 sites to be able to postpone 1 deadline. (S5)

Moreover, staff reported that they, but also their managers, have very little knowledge of the administrative procedures for bereavement policies. Participants mentioned that there should be adequate training and support for supervisors, such as "compassionate leadership training" in association with workplace fairness in bereavement leave and other accommodations.

3.2.2 Flexibility in policy application

While it is important for bereavement policies to be in place, it is also important that they can be applied more flexibly, considering individual needs. P4 stated: "I am still grieving, my dad died 5 years ago. I could not work for three months. I really needed that time". Getting adequate time away from work was indicated as important to participants' grieving process. For others, returning to work shortly after a death provided them with distraction from their pain. The university was for them a way to "escape":

> Three days after the funeral, I was back at work and I'm sure I was pulling a long face, but I was happy that I could think of something else. That I could deal with files and focus on other people, not myself. (P5)

Similarly, one student said: "When my father died, the university was the only place where I could go and not have to deal with it. I wouldn't want it any other way" (S1). It is important that the university acknowledges the varying waves of grief and individual needs regarding bereavement leave. During a focus group, one participant also emphasized the need for more "care days", referring to the additional time she needs to go to the hospital with her son who has a disability. Another participant responded: "Perhaps like a top sport statute, there could be a statute for family caregivers. That you don't have to bring in proof from a doctor every time you have to go to the hospital" (P15).

3.2.3 Proactive support and recognition

It was argued that managers should be more proactive in their approach to supporting staff confronted with serious illness or bereavement, rather than waiting for them to ask for support. It was suggested that

a person within each department or research group could be made available to help arrange the required administration and the reorganization of tasks. Participants referred to the need for "HR support on a lower level" or having a "compassionate ambassador". Students also argued the importance of "being able to put a face on it [the support services]" (S17). Moreover, acknowledgment of participants' losses was a recurrent theme in the interviews and focus groups. Recognition included asking about the loss, attending the funeral, and sending cards or flowers. For example, one student said: "One of my professors last year was lovely, she sent me an e-mail with a poem after the loss of my grandmother. I felt so supported by this small gesture" (S4).

It is important to note that a small number of students reported that they do not expect or desire anything from the university. As one student put it: "School is school, and it's a bit strange to suddenly get emotionally involved there. So I'm not really a person who cares about that aspect of the university, but rather about getting my degree" (S18). Most students described family and friends outside the university context as more valuable for support when confronted with serious illness, death, or bereavement.

3.2.4 Skills-training and awareness-raising

Participants believed that increased interpersonal support and communication skills training could increase individuals' capacity to facilitate conversations about serious illness, death, and bereavement. Participants also described how it is necessary to help people understand why talking about these topics is important. Staff and students referred to conversation cafés, support groups, and other (artistic) events as being useful facilitators for a positive attitude toward these themes. One student shared her ideas to 'normalize' these experiences within the university context: "Let's do a theme week about death with arts, music, or dance so we can share things, things we cannot yet comprehend or put into words, like the overwhelming pain of grief" (S3).

4. Discussion

This research aimed to understand the experiences of university students and staff and to explore their support needs when faced with serious illness, death, or bereavement within the university context. The results from this study show similar experiences among students and staff regarding worries about taking time off from studies or work, not knowing what support services exist, or not knowing how to access

specific accommodations. The data revealed that the experience of support depends heavily on the empathy and understanding of direct colleagues or individual staff. In terms of support needs, our findings highlight a difference between the university as a day-to-day work context and as a study context. Below we discuss each of these findings in more detail.

Facing difficulties in navigating the university information and support system is a common experience for both students and staff faced with serious illness, death, or bereavement. Many students reported not accessing the university support services because they didn't know they existed, and some believed that university services were only for study-related issues. Those participants who did approach the on-campus counseling service found it difficult to access due to long waiting lists and difficulty finding the right information. This may be because the counseling services do not include grief as central to their remit.[20,21] Taub and Servaty-Seib[22] suggested that 'grief workshops' and 'grief groups' could be appealing alternatives for students who may be reluctant to seek counseling. In accordance with the present results, recent studies have demonstrated that students tend to describe family and friends as more helpful than formal support, which may also be a reason for not approaching university support services.[8,23]

The difficulty in navigating the university information system also includes not knowing how to access specific accommodation options, having little understanding of the administration of bereavement policies, and a lack of knowledge of these policies and procedures among direct supervisors. Students also experienced the procedures and policies as being unclear and varying between faculties and individual staff. As a result, some students were not able to access the resources that they needed to cope with the loss of a loved one. These results align with previous work indicating that transparent processes and procedures may enhance communication around bereavement leave and accommodation options, and result in more compassionate responses from employers and staff toward bereaved employees and students.[24,25]

However, even clear policies do not necessarily pay attention to individual variations in bereavement experience and needs.[14] Our results show that different people need different responses at different times. These results corroborate those of Hall et al.,[26] who found that some people find aspects of their work – and in this case also their studies – to be supportive and restorative after a death, while others find the workplace or the university environment as adding negative experiences and feelings, which can impede the grieving process. These results reflect how people have different and dynamic coping

strategies, as articulated in the Dual Process Model,[27] which posits that grieving individuals *oscillate* between loss and restoration (i.e., immersion in other tasks) strategies. Although bereavement leave may allow one to address the logistics of death (e.g., making arrangements, attending a funeral), it does not take into account the actual process of grieving.[14] Managers, as well as university staff working with students, must be aware of and responsive to the varying rhythms and timelines of grief. A Compassionate University could provide greater flexibility in accommodations so that employees and students can oscillate between work/study and grief at their own pace. Employers could offer a longer bereavement leave but also provide flexibility in when and how bereaved employees use the leave. In this regard, the university can actually be a welcome respite from grief.

Most universities have bereavement policies for employees (albeit often considered inadequate by participants), but many lack such policies for students. The absence of such policies puts bereaved students in the position of needing to negotiate class absences, missed assignments, and deadline extensions with individual faculty on a course-by-course basis.[4] Our findings support research on the utility of a student bereavement leave policy.[28] The lesson we learn from this study is that the challenge often lies in communicating to students that these policies exist. When students or staff are confronted with experiences of bereavement, they can be so overwhelmed that they lack the energy to search for the right information about policies and procedures.[7] Our findings confirm the importance of having a "compassionate officer" who proactively approaches students and staff and provides information and guidance so that they are aware of the options available and can make informed decisions at a time of bereavement.[6,29]

We also identified acknowledgment of grief as a key concern of participants. Our finding that the university environment was often perceived as a high-demanding context with limited space for bereavement is consistent with previous work that found that students experiencing bereavement find campus life unsupportive of their grief.[30,31] It was revealed that returning to the university following a major loss could result in a challenging and difficult experience, providing some support to the notion of "disenfranchised grief".[32,33] Participants reported that their peers or co-workers often lack the knowledge and/or skills to comfort them or start a conversation about their loss. To avoid unhelpful reactions, several participants started to conceal their feelings, further disenfranchising their own grief.[22] This aligns with previous research in which students expressed their desire for peer support but, at the same time, reported feeling

abandoned by their friends on campus while grieving.[5] Prior studies have noted the importance of addressing this fundamental issue of appropriately supporting grieving individuals through public awareness and psychoeducation.[34,35] Universities may provide psychoeducation to students, supervisors, and administrative staff on how to appropriately support peers and colleagues and raise awareness about death and bereavement by inviting guest lecturers, organizing debates with key figures, and publishing articles and information in the university newspaper and on the website.

This study highlights the difference between the university as a work context and as a study context. While staff may be required to take formal sick leave and have to account for their absence to supervisors and colleagues, students do not always have the same responsibilities and obligations, which may allow them to take time off from classes or attend classes remotely. This may imply that students have greater flexibility in navigating their grieving process. However, as a result, students' grief remains more often under the radar, making it difficult to provide adequate support in times of need (e.g., during exams). The disparity in experiences may be further exacerbated by the fact that staff tend to have longer-term commitments to the university and are responsible for maintaining relationships with colleagues and supervisors over an extended period (sometimes decades), while students' relationships may be more transient and not as deeply ingrained in the university community. The different social reality of students and staff points to the different needs of those two target groups and calls for an adapted policy.

Based on feedback from students and staff, a "Compassionate University" can be described as a higher education institution that is committed to developing and facilitating the practice of (1) building clear and transparent compassionate policies and procedures, (2) re-orienting support services toward experiences of serious illness, death, and bereavement, (3) normalizing these topics through awareness-raising and community engagement, and (4) promoting healthy attitudes toward end-of-life experiences by increasing community cultural literacy. These findings are consistent with the literature on Compassionate Communities, which advocates for a whole-systems or "whole-school" approach to improving community circumstances related to serious illness, death, and bereavement.[36]

The findings from our research should be interpreted within the context of its limitations. First, it should be noted that while our study included a diversity of perspectives, there is an overrepresentation of white participants and female students and staff; similar limitations are observed in previous studies.[4,8,37,38] Additionally, the majority of students in our study are from the humanities or social sciences. Second, the

self-selection process used for participation in the study may have yielded a biased selection toward more negative narratives and experiences but also experiences from students and staff who were coping well to share their stories. Previous research has highlighted the challenge of engaging those students who struggle most with grief during their studies.[9] Last, only a small number of participants shared experiences related to long-term care or illness. We noticed that potential participants may have excluded themselves from the study because they were not sure if they were "eligible" to participate. Future research should take note of these findings and pay attention to these issues, such as "self-exclusion", in follow-up studies.

While many strategies have been suggested for how to support the university community,[39] research on whether these strategies are effective remains scant as most of them remain unimplemented or unevaluated. More work is needed on the design of support programs and interventions for experiences of serious illness, death, and bereavement. Examining the implementation of bereavement leave policies for students across different educational institutions would be valuable to identify good practices, challenges, and potential areas of improvement. In this regard, an illustrative example is the study conducted by Liew and Servaty-Seib,[40] which examined how grieving students perceived the effectiveness of a student bereavement leave policy, the Grief Absence Policy for Students (GAPS). Further research may also focus on how to encourage informal (peer) support to bereaved students, as this is the highest-rated form of support for students in higher education.[10]

Moreover, many universities have a sizeable international population. Not being able to travel home after the death of a loved one can truly encumber grief expression and academic duties while studying or working abroad.[8] Unfortunately, there is little empirical evidence available with regard to international education.[39] Additionally, previous studies have focused on a predominantly white student body.[8] Although students and staff of diverse backgrounds participated in the present study, we did not adopt an intersectional lens. As campuses become increasingly diverse, it is imperative to conduct further research that explores the variations in needs associated with different cultures when it comes to these experiences.[41,42] For instance, the Jewish tradition requires that the funeral and burial take place as soon as possible following a death, preferably in the first twenty-four hours.[43] Therefore, a Jewish student may have little time to contact faculty prior to leaving campus in response to a death. Grassau et al.[44] also highlighted the importance of incorporating the voices of diverse sexual and gender identities when conducting research on dying, caregiving, and grief. In designing policies and developing training and

educational materials, it is important to acknowledge and address the unique needs of diverse communities.[45]

5. Conclusion

This study contributes to the evolving literature on Compassionate Communities, and more specifically on compassionate workplaces and schools. By critically reviewing procedures and policies, increasing personal skills, engaging the community through awareness-raising activities, and re-orienting well-being services toward serious illness, death, and bereavement, educational institutions can become supportive environments for these universal experiences.

6. References

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Chapter 4. Supplementary file 1: Interview Guide - Staff

Introduction interview

We would like to thank you for participating in our study. Before we begin, we will introduce ourselves. I am X, a doctoral researcher, and X is a master's student in Adult Educational Sciences. Through this interview, we aim to hear about your experiences and insights regarding the extent to which VUB provides and can provide support when confronted with experiences of serious illness, death, dying, or loss. We understand that discussing these topics may not always be easy. Therefore, please feel free to interrupt if you have any questions, uncertainties, or if you want to take a break.

The input of these study will be presented to the “Compassionate University” core team, and they will use the data to further develop and adapt actions and initiatives based on the stated needs during the interviews. I will ask open-ended questions and sometimes follow up for further clarification. It's important to note that there are no right or wrong answers. Before we begin, please let us know if you have any questions about the 'consent form' or any other inquiries.

We will now start with the interview. I want to inform you that the interview will be recorded (if permission has been granted in the consent form). It is crucial to emphasize that all information from the interview will be treated with absolute discretion. This means that your data will be processed in a pseudonymous and confidential manner.

Background information participant

Can you tell me a little bit more about yourself?

- What is your position within VUB?
- How long have you been working for VUB?
- How did you hear about the study?

Experiences and support needs

As mentioned earlier, this study focuses on the concept of a 'Compassionate VUB' and aims to understand your needs and how the university community or workplace can provide support when confronted with experiences of serious illness, death, dying, or loss. In essence, we are exploring what a 'Compassionate University' can do to support the university community when confronted with these difficult experiences.

Have you heard of 'Compassionate University' or 'Compassionate VUB' before?	a) **Yes,** what did you think when you first heard about Compassionate University? b) **No,** *(roughly explain Compassionate University),* what do you think of this idea/concept?
How 'compassionate' do you experience VUB now?	a) Can you easily address your supervisor when you encounter serious illness, death, grief, or loss? b) Do you know where to go/with whom to contact within the VUB if you were to encounter serious illness, death, grief or loss? c) Do you sometimes talk to colleagues about these topics? d) To what extent do you feel it is important to be able to turn to someone at VUB?
Have you encountered experienced of serious illness, death, grief, or loss?	**Would you be comfortable if I ask you a few more questions about this experience? Don't hesitate to interrupt when you want to stop or take a break.** a) What gave you strength during this difficult period? b) Who gave you strength during this difficult period? c) What was the most difficult thing during this period? d) Did you seek or get any external support at the time? e) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences? **Were you already working at VUB at the time?** **If yes,** to what extent did you feel supported by your <u>colleagues?</u> a) How were you approached by colleagues? b) How did your supervisor handle it? c) Did you have the feeling that there was (enough) space for your feelings? d) To what extent was it possible to openly discuss these topics? e) What would you have preferred differently?

	To what extent did you feel supported by <u>VUB-services?</u> a) Have you reached out to the support services of the university? b) If you received support, how did you experience this? c) If you didn't approach external services, why not? d) Do you think it is important to receive additional support from university services? What kind of support is important? **If you weren't working at VUB at the time,** where were you working (or studying) at this time? a) How did your environment deal with your (loss) experience at the time? b) Did you feel supported by your colleagues or peers? c) What would you have preferred differently? d) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences?
Have you encountered situations where a fellow colleague has been confronted with serious illness, death, loss?	a) Have you talked about this experience with your colleague? b) How did your team encounter this? c) What was difficult at the time?
How can VUB become more 'Compassionate'?	a) Are there any specific insights or lessons you have gained from own experiences that you believe could be valuable in a professional setting? b) What actions/initiatives can you think of that VUB could take to become more 'compassionate'? c) If you could decide, what would be the first thing you would tackle to make VUB more 'compassionate'?

Check-out	We have now come to the end of the interview. Anything you'd like to add yourself? - How did you experience the interview? - How do you feel now? If anything comes to mind later, don't hesitate to get in touch! Refer to university psychological center (they provide free sessions).

Chapter 4. Supplementary file 2: Topic Guide Focus Group - Staff

Introduction

Purpose of the focus group

- This focus group is part of my doctoral research, in which I try to map the development process towards a more 'compassionate' university and see which role educational institutions can take in framing life experiences of serious illness, death, mourning and loss.
- Based on this session, we would like to gain insight into what is going on within the university community, what the needs are, how to make serious illness, death, grief and loss discussable within our university community. We would like to gather input that we can feed back to the Compassionate VUB core group that is working on setting up social actions.

Reviewing information and Informed consent form

- You all received the information letter and the informed consent form by e-mail on beforehand. This briefly explained the purpose of the study and the expectations. This form indicates that you agree to participate, would you like any further clarification on this or was everything clear?

Introduction

- It is important to state up front that there are no right or wrong answers, and if you prefer not to talk about personal experiences that is certainly not necessary.
- Indicate that confidentiality is requested and that everything stays within the group; absolute discretion is exercised when dealing with data (also stated in the informed consent form); the reason we are with such a small group is to create as safe an environment as possible.

Getting to know each other

- I would like to do a brief introduction (table round):
- Who are you, what do you do at VUB, and whether you had heard of Compassionate VUB before this research? If so, what have you already heard about it?

Experiences with serious illness, death, and bereavement

To what extent have you yourself already encounter serious illness, death, or loss? This may be personally or indirectly through friends, colleagues.

Prompts

- What gave you strength during this difficult period?
- Who gave you strength during this difficult period?
- What was the most difficult thing during this period?
- Did you receive external support at that time?
- How did your work/study environment deal with that loss at the time?
- Were you already working at VUB at the time? (Where were you working then?)
- Did you contact VUB services at the time?

How 'Compassionate' is the university?

- How 'compassionate' do you experience VUB at the moment and what could be different?
- To what extent do you feel that the VUB (services and colleagues) (can) offer you support during these periods?
- To what extent are these topics discussed openly on the work floor?
- To what extent did you feel 'supported' by your colleagues?
- What did you experience as difficult within your work environment?
- Would you have preferred things to be or handled different?
- Do you feel that you could talk to a colleague who has lost someone/is experiencing loss about this experience?
- What makes it difficult to offer support? What are hindering factors?

Future actions

- How can VUB become more 'compassionate'?
- Are there any specific insights or lessons you have gained from own experiences that you believe could be valuable in a professional setting?
- What is still needed for the VUB to become a more 'compassionate' environment?
- What actions/initiatives can you think of that VUB could take to become more 'compassionate'?

Check-out

We have now come to the end of the interview. Anything you'd like to add?

- How did you experience this session?
- How do you feel?

If anything comes to mind later, don't hesitate to get in touch!

Chapter 4. Supplementary file 3: Interview Guide - Students

Introduction

We would like to thank you for participating in our study. Before we begin, we will introduce ourselves. I am X, a doctoral researcher, and X is a master's student in Adult Educational Sciences. Through this interview, we aim to hear about your experiences and insights regarding the extent to which the Vrije Universiteit Brussel provides and can provide support when confronted with experiences of serious illness, death, dying, or loss. We understand that discussing these topics may not always be easy. Therefore, please feel free to interrupt the interview if you have any questions, uncertainties, or if you wish to take a break.

The input of these study will be presented to the “Compassionate University” core team, and they will use the data to further develop and adapt actions and initiatives based on the stated needs during the interviews. I will ask open-ended questions and sometimes follow up for further clarification. It's important to note that there are no right or wrong answers. Before we begin, please let us know if you have any questions about the 'consent form' or any other inquiries.

We will now start with the interview. I want to inform you that the interview will be recorded (if permission has been granted in the consent form). It is crucial to emphasize that all information from the interview will be treated with absolute discretion. This means that your data will be processed in a pseudonymous and confidential manner.

Background information participant

Can you tell me a little bit more about yourself?

- How long have you been studying at the VUB?
- What course are you following?
- What year are you in?

Experiences and support needs

As mentioned earlier, this study focuses on the concept of a 'Compassionate VUB' and aims to understand your needs and how the university community can provide support during experiences of serious illness, death, dying, or loss. In essence, we are exploring what a 'Compassionate University' can do to support the university community when confronted with these difficult experiences.

Before this research, had you heard of 'Compassionate University' or 'Compassionate VUB'?	a) **Yes,** what did you think when you first heard about Compassionate University? b) **No,** *(roughly explain Compassionate University),* what do you think of this idea/concept?
How 'compassionate' do you experience the university at the moment?	a) Do you sometimes talk to fellow students about these topics? b) Can you easily address professors/teachers, teaching assistants and/or other VUB staff when you encounter serious illness, death, grief or loss? c) Do you know where to go/with whom to contact within the VUB if you were to encounter serious illness, death, grief or loss? d) To what extent do you feel it is important to be able to turn to someone at VUB?
To what extent have you already encountered serious illness, death, grief, or loss?	Could I go a bit deeper into this? a) What gave you strength during this difficult period? b) Who gave you strength during this difficult period? c) What was the most difficult thing during this period? d) Did you seek or get any external support at the time? e) Did you talk about this with fellow students at the time? Friends? Family? Partner/love? f) How do you believe these experiences, whether personal or indirect, have influenced your understanding towards others who are going through similar experiences? Were you studying at VUB at the time? **Yes,** a) Did you contact anyone at the VUB at the time? b) Did you know where to go? i) If you received support from university support services, how did you experience this? c) What difficulties did you experience at that time related to the university environment?

	No, a) How did your environment deal with your (loss) experience at the time? b) How was this at your previous school (e.g. university, college)? (Is the VUB different or not) c) Did you feel supported by your peers or institution? d) What would you have preferred differently?
Do you feel you can support fellow students/friends/loved ones when they are dealing with serious illness, death, grief or loss?	a) Yes, what kind of support did you offer? Can you give some examples? b) No, why didn't you offer support? What was difficult? What held you back?
How can VUB become more 'Compassionate' towards the future?	a) Can you think of actions/initiatives the VUB could take to become more 'compassionate'? b) If you were rector, what would be the first thing you would tackle to make VUB a truly Compassionate VUB?
Check-out	We are now at the end of the interview. Would you like to add anything? - What did you think of the interview? - How do you feel now? If anything comes to mind later, don't hesitate to get in touch! Refer to student psychologists (they provide free sessions).

Chapter 5

Uncovering Barriers and Facilitators in the Development of a Compassionate University: A Process Evaluation

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Submitted to Death Studies

Chapter 5. Uncovering Barriers and Facilitators in the Development of a Compassionate University: A Process Evaluation

Abstract

Compassionate Communities are gaining momentum as a new public health approach emphasizing community support during times of serious illness, death, and bereavement. However, evidence on their development, particularly in higher education, is limited. This study investigates the development of a Compassionate University, examining the underlying processes and contextual factors shaping its development. A longitudinal process evaluation was conducted, using field notes right-now surveys, individual interviews, focus groups, and strategic learning debriefs. Factors that facilitated the development process included leadership support, the establishment of the Compassionate Schools Learning Network, and alignment with existing university programs. Barriers were the lack of guiding examples, the fragmented university environment, resource constraints, and limited prioritization. Cognitive and social processes that supported the work involved recognizing the value of the Compassionate University program and adapting implementation strategies based on empirical feedback. However, challenges such as building coherence, engaging stakeholders, and assessing the work hampered the development process.

Keywords: Process Evaluation, Compassionate Communities, Compassionate University

1. Introduction

Experiences of serious illness, death, dying, and loss occur within local communities, where people spend their daily lives. Yet these experiences often endure as taboo topics,[1] predominantly confined to professional healthcare narratives and practices.[2] Research underscores the important role of education institutions in creating supportive environments for serious illness, death, and bereavement, not only to enhance the well-being of those directly affected by these experiences but also to provide opportunities for individual learning, strengthen community capacity, and normalize discussions around these topics.[3,4]

The notion of developing a 'compassionate community' or 'compassionate school' is relevant in this respect. Compassionate Communities emphasize the importance of enhancing community capacity to support each other during times of serious illness, death, and bereavement.[5] The Compassionate Community approach draws inspiration from the action domains of the World Health Organization's Ottawa Charter for Health Promotion (1986): 1) building healthy public policy, 2) creating supportive environments, 3) strengthening community action, 4) developing personal skills, and 5) re-orienting health services.[6] In 2015, Kellehear suggested a 'Compassionate City Charter' that applied these action domains to serious illness, death, dying, and loss. The Charter includes action recommendations for schools, workplaces, cultural centers, hospices and care homes, among others.[7]

Despite the growing development of Compassionate Community initiatives,[8,9] there remains a substantial lack of empirical evidence on the principles and mechanisms underlying their development.[10] Questions regarding how the approach works in practice and what factors enable or impede its development remain unanswered.[11] Moreover, while the existing body of literature underscores the significant potential of (higher) education institutions to serve as compassionate schools and workplaces, [12,13] no initiatives from these settings have yet been documented.

To address these knowledge gaps and advance our understanding of how the Compassionate Community approach can be applied within the context of higher education, this paper examines the development process towards a 'Compassionate University'. The aim is to elucidate the processes shaping its development and identify contextual factors that either facilitate or hinder the development process.

2. Methods

2.1 Study design

A longitudinal case study design was applied over a period of two years (September 2021-September 2023).[14] To support the adaptive development toward a Compassionate University, a Developmental Evaluation (DE) approach was adopted by the lead researcher.[15]

2.2 Conceptual frameworks

There is growing recognition of the importance of using theories and frameworks to evaluate the complex processes behind new public health initiatives, such as Compassionate Communities.[16] Theoretical frameworks can help us understand how, why, and under what circumstances initiatives work or do not work.[17] Therefore, to guide the data collection and analysis of this study, we drew on the Consolidated Framework for Implementation Research (CFIR)[18] and the Normalization Process Theory (NPT).[19] CFIR provides a structure for understanding the barriers and facilitators shaping development and implementation, encompassing 39 constructs across five domains: characteristics of the innovation, outer setting, inner setting, characteristics of the individuals involved, and the implementation process. However, determinant frameworks, such as CFIR, do not address *how* change occurs. To complement CFIR's multilevel approach, NPT was used at the micro level to focus on the dynamic process of development. NPT's four mechanisms comprise: coherence (*what is the work?),* cognitive participation (*who does the work?),* collective action (*how does the work get done?),* and reflexive monitoring (*how is the work evaluated?*).

2.3 Context and participants

The Vrije Universiteit Brussel (VUB), located in Brussels, Belgium, served as a case study. The university has an enrollment of approximately 22.000 students and employs about 4.000 staff. In November 2019, the university declared itself Europe's first Compassionate University, emphasizing the importance of support and compassion during times of serious illness, death, and bereavement. The End-of-Life Care Research Group, in collaboration with the Rectorate (i.e., Chancellor's Office), took the initiative to translate Kellehear's Compassionate City Charter to the Brussels University context. The Compassionate University Charter outlines several action points, such as raising awareness and understanding of serious illness, death, and bereavement through campus activities, supporting bottom-up initiatives that complement existing practices, providing training and coaching on the topics, and establishing dedicated moments for remembrance. A core team, comprised of stakeholders from different university departments, including the Rectorate, Student Counseling Center, Human

Resources, Marketing and Communications, and the Compassionate Communities Center of Expertise (COCO), is responsible for implementing the Compassionate University Charter.

The study participants include the eight members of the Compassionate University core team (See Table 1). Notably, one participant (P8) withdrew from the core team eight months into the study, citing an overwhelming workload that hindered his ability to allocate time to the project. Consequently, this resulted in his exclusion from subsequent data collection moments.

Table 1. Participants' characteristics

Participant	Function and Department	Gender	Years of employment at VUB
1	Office Manager (the Rectorate)	Male	21-25 years
2	Professor (Faculty of Psychology and Educational Sciences; COCO)	Female	11-15 years
3	Professor (Faculty of Family Medicine and Chronic Care; COCO)	Male	21-25 years
4	Professor (Faculty of Social Sciences and Solvay Business School; COCO)	Male	11-15 years
5	Office Manager (Human Resources Department)	Male	11-15 years
6	Project Manager (Marketing and Communication Department)	Male	11-15 years
7	Student Psychologist (Student Counseling Center)	Female	16-20 years
8	Postdoctoral Researcher (Faculty of Social Sciences and Solvay Business School)	Male	0-5 years

Note: COCO = Compassionate Communities Center of Expertise

2.4 Data collection

Several data collection modalities were used to examine the development process toward a Compassionate University. Table 2 provides an overview of the different data collection moments.

1) *Field notes*: A participatory observational approach was applied, in which the lead researcher (HB) took part in the monthly core team meetings. The researcher took field notes using a semi-structured observation guide (see Supplementary file 1).

2) *Right-now surveys:* Implemented in the study's initial stages to quickly grasp the project's dynamics. The survey was sent to participants after the monthly core team meetings from November 2021 to March 2022. The survey consisted of no more than three questions and consistently addressed variations of: 1) "Right now, our greatest opportunities are…"; 2) "Right now, our biggest challenges are…"; 3) "Right now, we need guidance on…" (See Supplementary file 2). [20] The survey data was used to pinpoint issues for further exploration during individual interviews.

3) *Focus groups and individual interviews*: Topic guides for both focus groups and individual interviews were developed based on NPT and CFIR constructs. A total of three focus group sessions, structured as workshops, were conducted. All eight core team members participated in the first focus group. In the subsequent two focus group sessions, the participation comprised the remaining seven core team members. Individual interviews complemented the focus groups to reveal concerns or ideas that team members were not sharing in group, or they did not want to disclose to the whole team yet. A total of 15 individual interviews were conducted at two distinct time points. In the first round of interviews, participants were asked to describe their engagement with Compassionate University and share their experiences with the start-up phase. During the second round of interviews, questions were asked about the progress, whether they were adopting the planned approach, and what challenges they encountered (see Supplementary file 3 for semi-structured interview guide with NPT and CFIR cross-referencing). All focus groups and interviews were audio-recorded and transcribed verbatim.

4) *Strategic Learning debriefs:* Following each focus group session, a member-check meeting was held to present the gathered insights and check with the participants for accuracy. Furthermore, the core team was briefed on the empirical data findings regarding the needs of the university community.[12]

Table 2. Timeline of Developmental Evaluation (DE) activities and data collection modalities

DE phase	Timing	Method of data collection
Orientation	September 2021-March 2022	Right-now surveys
	November 2021	Enculturation and inception workshop
	December 2021	Individual interviews round 1
	February 2022	Learning debrief 1
Prioritization	May 2022	Process workshop
	June 2022	Individual interviews round 2
	September 2022	Learning debrief 2
Mapping and adaptation	October 2022	Presentation of empirical data on community needs
	December 2022	Outputs and actions workshop
	March 2023	Learning debrief 3
Throughout the study	September 2021- September 2023	Observation and field notes

2.5 Data analysis and reflexivity

All transcripts were uploaded into MAXQDA, a qualitative data analysis software.[21] The analysis started with a close reading and re-reading of the transcripts to become familiar with the data. Next, operational definitions tailored to the study context were defined for each NPT and CFIR construct, followed by the development of two coding manuals, one for NPT and one for CFIR (see Supplementary files 4 and 5). In the third step, deductive coding based on NPT and CFIR constructs was applied to code transcript data.[22] Multiple coding highlighted where CFIR and NPT complemented each other.[23] In step four, one integrative coding structure was developed by clustering all CFIR codes under the four NPT questions. For example, CFIR constructs such as 'innovation source' and 'compatibility' were related to the question "What is the work?". Additionally, subthemes were developed for each NPT question by examining the interplay of coded data under each NPT question. We also examined the data for deviance to avoid overlooking issues that did not map onto the NPT or CFIR constructs.

In terms of positionality, the lead researcher (HB) is a doctoral researcher with a background in educational sciences, experience in qualitative research and working at the university under study. She was responsible for both data collection and analysis, following the principles of Developmental Evaluation.[15] The lead researcher met two-weekly to monthly with senior researchers (SD, JC, FVD)

who are experts in the fields of adult education, public health and palliative care, and sociology, respectively, to discuss the codes, develop the coding manual, and interpret the findings. Notably, these researchers had a dual role, being members of the Compassionate University core team, and thus also participants of the study. Additionally, bi-monthly debrief sessions took place with four other senior researchers, experts in public health and palliative care, and adult education (LDD, LD, KC, SV). During these meetings questions were asked about decisions made regarding the data analysis and interpretation of findings, enhancing the study's credibility.

2.6 Ethical considerations

The study received ethics approval from the VUB (approval number: ECHW_300). In September 2021, before the start of the data collection, participants received written and verbal information about the different parts of the study, informing them that participation was voluntary, that they had the right to withdraw from the study, and that they were guaranteed confidentiality. All participants provided written consent for partaking in the study.

3. Results

The four NPT questions guided our inquiry and structured the findings: (1) What is the work? (2) Who does the work? (3) How does the work get done? (4) How is the work evaluated? We identified nine subthemes across these questions, each encompassing several types of facilitators and barriers linked to the CFIR and NPT constructs (see Supplementary file 6 for a summary of key facilitators and barriers related to NPT and CFIR constructs). A numeric code is provided with each data extract to refer to the data collection modality, I1 and I2 refer to 'individual interviews' rounds 1 and 2, and FG1-3 refers to 'focus group sessions' 1 to 3, with participants denoted as P1-8.

3.1 What is the work?

3.1.1 The path toward building coherence

In 2019, the End-of-Life Care Research Group, in collaboration with the Rectorate, took the initiative to translate the Compassionate City Charter to the university context. Although the Compassionate City Charter explicitly addresses serious illness, death, and bereavement, questions surrounding the scope of Compassionate University persisted for several months after the inauguration. The central tension was: "Is it about caring when confronted with serious illness and death, or community compassion more broadly?". Moreover, core team members expressed concern that the term "compassionate" might lead to confusion and broader expectations of what it is about. During the first

focus group, a participant highlighted the effort invested in elucidating the concept to colleagues: “A lot of work is just informing people as to what it is because you use the word ‘compassionate’ and it is so wide-ranging” (FG1, P1). Nevertheless, the decision to name it “Compassionate University” is rooted in the global Compassionate Community movement, reflecting participants’ intention to forge a connection with the broader movement. In addition to considering the meaning of ‘compassionate’, there was also a discussion about who the ‘community’ or the ‘target population’ is. Throughout the process, there was a growing consensus that the focus should be on fostering "entire community capacity" rather than directing efforts towards specific groups with needs tied to these experiences. As articulated by one participant:

> An important aspect of Compassionate University is that it does not focus exclusively on those who have experienced loss or illness. It encompasses the entire community. It is about building a supportive community by enhancing skills and cultivating awareness, thereby establishing a foundation of support for those facing these challenging experiences. (FG2, P3)

Although questioning the aim and scope of Compassionate University became less prominent after the second focus group, a core team member associated with the university's well-being services continued to face challenges in determining which initiatives fell under the purview of Compassionate University and which were part of her regular responsibilities. Nonetheless, most participants considered the aspect of "differentiation" from established practices to be of lesser significance. As one participant argued: “I find it a bit an artificial discussion of when it belongs to one and when to the other. We don’t need to become a separate entity. We fit into the university’s broader well-being story” (I1, P2). Core team members agreed that while their work predominantly centers on end-of-life topics, developing a Compassionate University aligns with the broader university’s goal of fostering a “warm environment”.

3.1.2 Grasping the value and relative advantage

The alignment of Compassionate University’s goals with the university’s policy plans (e.g., creating a warm environment) and the fact that it was initiated by the rector contributed to a positive perception of the project’s value among core team members. During the first round of individual interviews, a participant elucidated: “It all began with the rector herself. Her personal dedication played a crucial role” (I1, P6). Furthermore, participants elaborated on the “relative advantage” of Compassionate University, emphasizing its added value over existing programs. As articulated by one participant: "Compassionate University adds a distinct layer that complements ongoing initiatives. It addresses

dimensions that remain uncovered in current programs" (I1, P1). This view was echoed by another participant:

> Our merit is to draw attention to those specific themes that are often forgotten in well-being policies or programs. During the COVID pandemic, there was a lot of attention for the mental well-being of students, but the fact that these students also had to deal with lots of losses and family care situations, there was no attention for that. Recognition of these topics doesn't happen automatically. (I1, P3)

3.2 Who does the work?

3.2.1 Facilitating sustained participation amidst legitimation constraints

The composition of the core team was seen as a core asset to propel the project forward. As one participant said: "Our strength is that we have people from various domains. We have Marketing and Communication, Student Guidance, the Rectorate, HR, ... If you don't have that, it will be more challenging to create something that will be accepted" (I1, P2). However, despite having a student representative on board at the start of the project, the challenge of finding a replacement after her graduation was highlighted as a major constraint during the second focus group.

Each core team member demonstrated a profound personal drive to engage with the project. As one participant stated: "It's not our core task and it comes on top of it. But it's cool that you can be of significance to your own workplace" (I1, P1). For some, the endorsement from the rector also legitimated their role within the core team. One participant expressed: "It's because it's supported by the rector that I dare to push my boundaries and feel supported to commit time to it" (I2, P5). However, there were times when resource constraints made it difficult to stay engaged and attend monthly meetings. A participant put it: "Officially, I don't have any hours, any mandate to be here; I just have to fit it in. I have a significant number of deadlines every week, and each time I have to make the decision" (FG3, P6). The quote may also highlight a lack of recognition or role status when not paid or in a formal position. Ultimately, when the rector passed away and a new senior management took over, core team members expressed a loss of confidence in the project and started to question the effort they put into it next to their busy jobs. During the final focus group, one core team member announced her decision to leave the group, she said:

> I’m done. I'm getting emotional now, but I think I've had enough. There are no resources, and it all accumulates. I believe in the concept, but I don’t have the energy anymore. I’ll choose self-care over fighting for something that isn't supported anyway. (FG3, P7)

Moreover, within the university environment, the “relative priority” of Compassionate University was seen as quite low, as one participant put it: “These are the kind of initiatives that everyone thinks are interesting’, but they’re never a top priority. It’s not the university’s core business, certainly not to allocate resources to” (I1, P1).

3.2.2 A need for community enrolment and internal collaboration

Although participants recognized the value of wider community engagement and expressed a desire to involve different groups, they faced challenges in achieving this. As one participant put it: “In theory, it's a community-based intervention. But how do you do that? How do you engage students and staff in such challenging topics?” (I2, P2). Another participant referred to a lack of guidance in the Compassionate Community literature, arguing:

> In the literature, the emphasis is on ensuring participation and shared ownership. The idea is for community members to participate based on their interests, needs, and strengths, collaboratively shaping the program. However, in practice, you notice that it's much harder to support this, and I don’t find any guidance in the literature. There's often a tendency for a top-down dynamic to emerge, as with the core team. (I2, P3)

In this regard, a participant also underscored that the context of the university is different from the one of cities or neighborhoods, where the Compassionate Community movement originates from. The performance-oriented culture of a university may function as an additional barrier, as articulated: “The context of working and studying is often not one where one wants to think about these issues. These topics are more situated in the private sphere. That’s also a challenge for us” (FG1, P3). However, the core team also faced difficulties in identifying and engaging university partners in their work, which they attributed to the complexity of the university environment. As one participant put it: “The university is more complex than many other professional settings. It's characterized by a multitude of diverse relationships, many of which are unclear. This makes it quite difficult to know who is doing what” (I2, P4). Consequently, participants deemed mapping out internal stakeholders as an important future step to identify where and how the ‘compassionate aspect’ can be added.

3.2.3 The value of external partnerships

Partnerships with other educational institutions played a pivotal role in facilitating the exchange of information and experiences, contributing to the process of sensemaking and legitimation. Over time, the core team members began to recognize their pioneering role as a growing number of educational institutions approached them for information on initiating similar projects. As a result, the "Compassionate Schools Learning Network" was established. The learning network enabled interested educational institutions to convene biannually and discuss their work. Core team members were increasingly seen as experts, instilling confidence in the process and supporting the belief that it was right to be involved. As a participant expressed: “It's quite beneficial to sit down with the people from the learning network. They have the same issues and questions, and that reassures me. Everyone is struggling with the same things” (I1, P1). When queried about potential external partners to engage with, participants expressed a desire for collaboration with the local neighborhood and the university hospital.

3.3 How does the work get done?

3.3.1 Implementing the Compassionate University Charter

Participants voiced uncertainty regarding how to translate the Compassionate University Charter into actionable initiatives. As one participant put it: “We need to work on cultural change, but what does that mean? How do we translate the idea of ‘cultivating awareness’ into concrete actions? It's not a pre-packaged intervention where you can follow a roadmap” (I1, P4). Consequently, some felt that they were doing things without a clear rationale, leading to a perception of working with limited direction. Recognizing their pioneering role was crucial for maintaining trust in the “slow” process.

Moreover, field notes from monthly core team meetings and data obtained from the right-now surveys showed that not all ideas were worked out or put into practice, which appeared to be linked with uncertainty about whose role it was to realize them. Some participants highlighted the initiation of working groups as pivotal for progress and achieving “interactional workability”. However, others were hesitant to implement working groups, fearing that more explicit responsibilities might result in an increased workload.

3.3.2 Working towards an integrated approach

Core team members emphasized the importance of seeking integration with existing programs and practices. As elucidated by one participant: “In essence, a Compassionate University doesn’t mean

starting from scratch. It's about finding connections with other well-being groups and adding grief and serious illness to their work" (I2, P3). This was accomplished, for example, by adding questions to the university's well-being survey, asking students and staff if they had encountered serious illness or experienced the loss of a loved one in the past year, and if they received support from the university. Another example was the establishment of a "grief table" during the university's well-being event. During this event, students could choose to participate in discussion tables, each centering on a particular well-being topic. One participant explained: "We successfully managed to add a "grief table", facilitating discussions in small groups about loss. So, we looked at what's already happening at the university and how we could integrate our topics. We should do that much more" (I2, P2). Additionally, a participant suggested incorporating topics such as serious illness and loss into ongoing training sessions for staff. She explained:

> There is a training coming from HR on customer-oriented work and friendly communication. We could incorporate a compassionate element into that. We have to look for those opportunities. I enjoy organizing things that are purely compassionate, like the yearly remembrance moment. But I also want to stress the importance of an integrated approach, which needs to be there too. (FG2, P7)

3.4 How is the work evaluated?

3.4.1 The difficulty of assessing the work

Worries about what counts as 'evidence', was one of the key themes identified in the data, highlighting the complexity of evaluating these kinds of social change initiatives. Not being able to identify immediate outcomes influenced participants' motivation. As a result, there was an emphasized need to concentrate on achieving "quick wins" to uphold and sustain one's drive. As one participant argued:

> With these complex projects, it's difficult to pat yourself on the back and say, 'look, this is our achievement, and it has led to this specific outcome, which in turn has lessened the problems for these people'. There's a tension between wanting to see change, and at the same time, recognizing that it's a very slow cultural shift. Therefore, as a group, it's important that you tackle some small, visible "low-hanging fruits" to sustain motivation. (I2, P3)

One participant encouraged others to honor the "power of stories" and recognize narratives as evidence too. The difficulty is that within the current climate, resources are given under conditions of surveillance and accountability, this is in relation to narrowly defined outcomes and indicators that are

not very meaningful in these kinds of projects. A participant articulated: “What we have are narratives, but if you want to get the senior management on board and change policies, you need ‘hard’ numbers” (FG2, P1).

In contemplating when participants would consider Compassionate University successful, core team members shared that the ultimate goal would be to render themselves “unnecessary”. One participant explained:

> It should become a part of the university’s identity. The true endpoint is when we are no longer needed, and it’s structurally integrated into all well-being groups. That there’s no longer a need for a Compassionate University working group, and these themes are naturally incorporated without constant emphasis or reminders. (FG3, P3)

3.4.2 Collecting data for process monitoring and journey reflection

Adhering to a Developmental Evaluation approach, insights obtained from the focus group sessions and individual interviews were presented in debrief meetings to the core team. Participants underscored the value of these meetings in fostering reflection and goal setting. Additionally, during the second focus group, the lead researcher shared the findings from interviews with students and staff regarding their support needs. Following this presentation, core team members engaged in prioritizing actionable points, aligning them with the identified needs of students and staff. Participants expressed how this approach significantly propelled their efforts, stating: “I believe this iterative process of receiving feedback and fostering reflection is really unique and helped us to move forward” (I2, P7).

4. Discussion

The aim of this paper was to enhance our understanding of the underlying processes and contextual factors influencing the development of a Compassionate University. The four NPT questions guided our inquiry and structured the findings. The first question pertained to the construct ‘Coherence’ – ‘*What is the work*?’ Coherence was one of the key themes identified from the data, highlighting the importance, but also the difficulty, of building a shared understanding of the scope and objectives of Compassionate University. Barry & Patel’s scoping study,[24] encompassing 28 Compassionate Communities across England, found similar difficulties regarding the process of collective sensemaking. Their study illustrated a diversity of approaches and interpretations across communities, revealing

confusion about the concept of 'Compassionate Communities' itself. This confusion might stem from the narrow conceptualization of 'compassion' within the Compassionate Community movement, primarily focusing on aspects such as death, grief, and palliative care.[3] In the academic and public spheres, compassion is generally understood in a broader sense, encompassing all experiences related to suffering.[25] The more confined interpretation adopted by the Compassionate Community approach can result in misunderstandings and pose challenges in communicating and aligning objectives across different groups and individuals who may have differing expectations based on their experiences and understanding of what compassion encompasses. In our study, the exploration of how Compassionate University differentiated from existing programs, supported communal specification and sensemaking. Core team members were convinced that topics such as serious illness, death, or loss are not adequately covered in existing services and programs, reinforcing the view that their work was both valuable and necessary, ultimately leading to increased internalization of the potential benefits of the Compassionate University program.

The second construct of NPT is 'Cognitive Participation' with the key question '*Who does the work?*' Although core team members were willing to drive the project forward, workload issues, a lack of available resources, and insufficient legitimation were viewed as the main barriers to sustained active participation. As Compassionate University was initiated through strategic meetings with the Rectorate and researchers of the End-of-Life Care Research Group, it embodies a social ecology approach. This signifies a top-down strategy aimed at reshaping the social and physical environment to bring about behavioral and social change.[3] Despite the senior management emphasizing the importance of becoming a Compassionate University, the university did not allocate any resources in return. The passing of the rector, who had been the driving force behind the project and provided legitimacy to the core team members' work, raised concerns among participants about the future of Compassionate University. This underscores the symbolic significance of key individuals who champion the project.[26]

Moreover, achieving meaningful community engagement (i.e., bottom-up change) proved to be difficult. This was partly attributed to the limited guidance available on how to effectively engage community members with these topics. Lessard and colleagues[27] noted that empirical studies of Compassionate Communities have generally given limited attention to the aspect of community engagement. Existing evaluations tend to focus on individual outcomes rather than on collective engagement in the strategic and early stages of Compassionate Community development (e.g., priority-setting, and need assessment). While community engagement stands as a cornerstone in the Compassionate Community movement, this accounts for an important gap in the literature.[11]

Furthermore, participants highlighted the importance of adopting an “integrated approach”, one that incorporates topics related to serious illness, death, and loss into existing well-being practices and programs. This resonates with the findings of Librada Flores et al., [28] who developed the “All with You” method, underlining the significance of finding alliances within the community and building upon existing assets. Nevertheless, encountering collaboration with internal university departments and services posed challenges. This was linked to the complex university environment, characterized by numerous departments and a tendency toward siloed operations. Establishing collaborations with external institutions was more easily attained. The formation of a Compassionate Schools Learning Network fostered a sense of being part of something bigger, a broader Compassionate Community movement. This strengthened participants’ perception that investing time and effort in Compassionate University is both legitimate and worthwhile.

The NPT construct ‘Collective Action’ helped to understand the translation of the Compassionate University Charter into concrete actions, essentially addressing the question: ‘*How does the work get done*?’ One of the central challenges was the absence of well-defined good practices and a lack of prioritization of action points by core team members, both of which acted as significant barriers to collective action. However, recognizing their pioneering role proved pivotal in embracing the gradual process.

Lastly, 'Reflexive Monitoring' involves the ability to adjust practices based on empirical data and assess the work. This prompts the question: ‘*How is the work evaluated*?’. Our analysis unveiled concerns surrounding what constitutes as 'evidence', shedding light on the intricate nature of initiatives aimed at driving social change. While the efficacy of stories as evidence was endorsed by participants, there was a concern that this might not suffice to change policy or pursue organizational-level changes. However, the unpredictable and uncontrolled nature of Compassionate Communities renders the use of quantitative measures to evaluate predefined objectives unsuitable.[29] A risk inherent in this context is that Compassionate Community development may gravitate toward conservatism rather than fostering transformative practices unless new measurement and accountability mechanisms are devised. Therefore, Horsfall et al.[30] advocate for the development of user-friendly documentation processes that enable researchers and workers in the field to provide evidence rooted in lived experiences, predominantly employing stories and narratives as forms of validation. Additionally, previous research underscores the importance of assessing community strengths and needs in order to adapt practices based on real-time feedback.[31] In our study, the lead researcher gathered data about the needs of students and staff, which were subsequently presented to the core team. This data-driven approach facilitated the adaptation and reconfiguration of practices, distinguishing it from the more

conventional process evaluations that typically offer retrospective and explanatory accounts of findings.[32]

4.1 The utility of theoretical frameworks

We argue that combining an implementation theory (i.e., NPT)[19] and a determinant framework (i.e., CFIR)[18] is compelling because it permits a more detailed understanding of the complexity of the entanglement of social processes (i.e., sensemaking) and contextual conditions influencing development and implementation.[23] However, it is important to note that we did not treat these frameworks as restrictive guides, but rather as adaptable tools. Previous studies have demonstrated the necessity of modifying these frameworks to the specific implementation context and the characteristics of the initiative.[33,34] CFIR constructs, such as trialability, adaptability, design quality and packaging were not applicable and were omitted from the coding structure. Moreover, we opted not to incorporate the domains 'characteristics of individuals' and 'process' of CFIR into our analysis, as many of the subconstructs were already covered by NPT. During our analysis, we also observed some overlap among NPT subconstructs (e.g., initiation and enrollment), mirroring findings from previous studies.[35,36]

4.2 Strengths, limitations, and future research

Strengths of this research include the in-depth and longitudinal perspective and use of guiding theoretical frameworks to capture the complexity of the development process towards a Compassionate University. The study focused on one specific case study and therefore the findings may not be easily transferable to other contexts. However, by using NPT and CFIR, we identified system-level barriers and facilitators that are likely to influence the uptake of these initiatives beyond the study setting. We recommend the use of implementation frameworks in further research to enhance our understanding of the dynamics and contextual factors influencing the development of Compassionate Communities.[37]

Furthermore, there is a need for more research on how the Compassionate Community approach can be implemented in diverse settings. Given that the university environment is characterized by a performance-driven culture combining work and education, some scholars state that such settings may not be conducive to fostering a supportive atmosphere for serious illness, death, and bereavement,[12,38] a distinct approach may be required. Unlike 'neighborhoods' where (formal) networks and support services in these areas often already exist, the university setting necessitates

the development of support networks from scratch. Additionally, there is a need to delve into the intricate dynamics of community engagement within the context of dying, death, loss, and grief.[39]

5. Conclusion

Through the application of two implementation frameworks (i.e., CFIR and NPT), this study illuminates the contextual factors and social processes influencing the development of a Compassionate University. The study provides guidance for future endeavors in similar contexts and highlights key elements to consider when planning to work toward a Compassionate University: 1) provide sufficient time to build a shared understanding and common language, 2) look for compatibility with existing initiatives and programs, 3) establish local communities of support with end-users, and 4) start with a few well-supported changes (i.e. “quick, visible wins”), informed by empirical data and aligned with community needs. As we move forward, this study encourages continued exploration and refinement of development and implementation strategies, paving the way for the establishment of more compassionate institutions that positively impact the well-being of students and staff confronted with serious illness, death, or bereavement.

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Chapter 5. Supplementary file 1: Observation guide

Date of meeting	
Participants	

NOTES ON AGENDA

Agenda item 1	Intended outcomes	
	Observed outcomes	
	Notes on process & interactions	
Agenda item 2	Intended outcomes	
	Observed outcomes	
	Notes on process & interactions	
Agenda item 3	Intended outcomes	
	Observed outcomes	
	Notes on process & interactions	
Agenda item 4	Intended outcomes	
	Observed outcomes	
	Notes on process & interactions	

Chapter 5. Supplementary file 2: Right-now survey

Right now, my biggest concerns are…	
Right now, the best opportunities for success are…	
Right now, we most need help with…	

Chapter 5. Supplementary file 3: Semi-structured interview guide with NPT and CFIR cross-referencing (1-on-1 conversation guide)

Semi-structured interview questions	**Corresponding NPT constructs and CFIR domains**
1. How did you first hear about Compassionate University? a. When did you first hear about Compassionate University? b. What did you think of Compassionate University when you first heard about it? c. Who developed, initiated the project? d. How and why did you get involved? e. What is the value/importance of a project as Compassionate University'? f. Was it clear what your role was in the team? g. Do you think the purpose of Compassionate University is clearly conveyed?	**NPT**: Coherence, Cognitive Participation and Reflexive Monitoring **CFIR:** Intervention characteristics and Inner Setting Domains
2. Can you walk me through how Compassionate University was put into practice/place? a. How was the composition of the core team established? b. Was there a plan for development or implementation? Were there goals and objectives clearly communicated? Who was involved in the planning? c. Where did you run into challenges with the work? d. Did you receive any support from the management?	**NPT:** Coherence, Cognitive Participation, Collective Action, and Reflexive Monitoring **CFIR:** Outer and Inner setting and Process domains
3. What are your thoughts about the current status of the project? What's done, what's not done? a. Is there a shared understanding among team members about the purpose and value of Compassionate University? b. At this point in the process, what is your vision for what the project can achieve?	**NPT:** Collective Action, Reflexive Monitoring **CFIR:** Inner setting and Process domains

c. What had the project accomplished so far? Any big wins, little wins? d. What are some of the current barriers or challenges? What ideas do you have for resolving them?	
4. How has Compassionate University impacted your work/practice? a. How is what you do for Compassionate University different from your usual ways of working? b. How did Compassionate University fit with other priorities and daily work? How did you juggle it all? c. Do you see the value of Compassionate University for your work – presently or in the future?	**NPT:** Coherence and Collective Action **CFIR:** Intervention characteristics, Inner setting and Process domains
5. Can you talk a little bit about how you see the project fitting into the broader environment? a. How well is it the support from the university itself? b. Are there any inter-organizational dynamics that are helping or hindering the work? c. Who else needs to be involved?	**NPT:** Collective action **CFIR**: Inner setting
6. Can you describe how you and your colleagues communicate about anything related to Compassionate University? a. When the team meets to de-brief, how often and how did these meetings go? b. How did you communicate to each other's about news, accomplishments, problems, etc.? c. How do you feel about the current way of working and the decision-making process?	**NPT:** Collective Action **CFIR:** Inner setting, Individual characteristics and Process domains
7. What advice would you give future initiatives regarding the development of a Compassionate University?	**NPT**: Reflexive Monitoring **CFIR:** Process domain
8. Is there anything else you would like to add about your experience with Compassionate University?	**Not applicable**

Chapter 5. Supplementary file 4: Operational definitions for CFIR constructs

CFIR	
I. INNOVATION CHARACTERISTICS	
Innovation source	**Construct definition:** Perception of key stakeholders about whether the intervention is externally or internally developed. - Inclusion criteria: statements about the source of the innovation and the extent to which interviewees view the change as internal to the organization (e.g., internally developed program) or external to the organization (e.g., program coming from the outside).
Innovation evidence-base	**Construct definition:** Stakeholders' perceptions of the quality and validity of evidence supporting the belief that the intervention will have desired outcomes. - Inclusion criteria: statements regarding awareness of evidence, as well as the absence of evidence or a desire for different types of evidence.
Relative advantage	**Construct definition:** Stakeholders' perception of the advantage of implementing the intervention versus an alternative solution. - Inclusion criteria: statements that demonstrate the innovation is better (or worse) than existing programs.
Complexity	**Construct definition:** Perceived difficulty of implementation, reflected by duration, scope, radicalness, disruptiveness, centrality, and intricacy and number of steps required to implement. - Inclusion criteria: statements regarding the complexity of the intervention itself; reflected by duration, scope, disruptiveness
II. OUTER SETTING	
Partnerships and connections	**Construct definition:** The degree to which an organization is networked with other external organizations. - Inclusion criteria: descriptions of outside group memberships and networking done outside the organization.
Needs and resources of those involved	**Construct definition:** The extent to which community needs, as well as barriers and facilitators to meet those needs are accurately known and prioritized. - Inclusion criteria: statements demonstrating (lack of) awareness of the needs and resources of those served.
III. INNER SETTING	
Structural characteristics	**Construct definition:** The social architecture, age, maturity, and size of an organization.

	- Inclusion criteria: descriptions of organizational priorities, structure, leadership and senior management support, system and processes, regulation, the social architecture, and size of the organization which makes implementation difficult and complex.
Inner networks and communications	**Construct definition:** The nature and quality of webs of social networks and the nature and quality of formal and informal communications within an organization. - Inclusion criteria: statements about general networking, communication, and relationships in the organization; but also meetings with core team members, such as descriptions of meetings.
Compatibility	**Construct definition:** The degree of tangible fit between meaning and values attached to the intervention by involved individuals, how those align with individuals' own norms, values, and perceived risks and needs, and how the intervention fits with existing workflows and systems. - Inclusion criteria: include statements about the degree of fit with existing programs, processes and workflows within the organization.
Relative priority	**Construct definition:** Individuals' shared perception of the importance of the implementation within the organization - Inclusion criteria: statements that reflect the relative priority of the innovation, e.g., statements related to change fatigue in the organization due to implementation of many other programs.
Leadership engagement	**Construct definition:** Commitment, involvement, and accountability of leaders and managers with the implementation. - Inclusion criteria**:** Include statements regarding the level of engagement of organizational leadership.
Available resources	**Construct definition:** The level of resources dedicated for implementation and on-going operations including money, training, education, physical space, and time. - Inclusion criteria: Include statements related to the presence and absence of resources specific to the project.

Chapter 5. Supplementary file 5: Operational definitions for NPT constructs

NPT	
I. COHERENCE (sense-making work) *Sensemaking work people do to understand individually and collectively what they need to do to enact a new innovation.*	
Differentiation	The sensemaking work people do to understand how a new innovation is different from current practices or usual way of doing things. - Inclusion: references to differences or similarities in practice pre/post the introduction of Compassionate University.
Communal specification	The sensemaking work that people do collectively to create a shared understanding of the benefits of using a new innovation. - Inclusion: references to differences in understanding between team members.
Individual specification	The sensemaking work individuals do to understand what they must do to utilize a new innovation and embed it into existing workflows. - Inclusion: references to individual understanding of Compassionate University.
Internalization	The sensemaking work that people do to come to see value in using a new innovation. - Inclusion: references to aspects of Compassionate University that are valued.
II. COGNITIVE PARTICIPATION (relational work) *The relational work that people do to build and sustain a community of practice around a new technology or complex intervention.*	
Initiation	Ensuring key people are working to move the introduction of a new innovation forward. - Inclusion: references to influential people.
Enrolment	The work people do to organize/reorganize themselves and others to contribute to the work involved in new practices. - Inclusion: references to who should be involved, suitability of involvement.
Legitimation	The work of ensuring that people believe it is right for them to be involved with the innovation and that they can make a valid contribution to it. - Inclusion: references to conflicts in roles, people involved.
Activation	Once the work is underway, people define actions/procedures to sustain a change in practice and to stay involved with a new innovation. - Inclusion: references to methods of embedding the new practices in policies, procedures, processes.

III. COLLECTIVE ACTION (operational work) *Integration of a practice in a specific context, availability of necessary resources to enact the practice***.**	
Interactional workability	The work people do with each other to operationalize a new innovation. - Inclusion: references to the logistics of actually doing the work.
Relational integration	The fit between a new innovation and existing knowledge and confidence surrounding the innovation among groups and professions. - Inclusion**:** references to confidence in other people's .
Skill set workability	Fit between the allocation of work and existing skill sets to carry out the work needed to use a new innovation. - Inclusion: references to allocation of work to people
Contextual integration	Resource work to support the integration of a new innovation – i.e. morale, time, money, leadership. - Inclusion: references to perceptions of organizational support.
IV. REFLEXIVE MONITORING (appraisal work) *The appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them.*	
Systematization	People working together to evaluate the effectiveness of a new innovation – involves the work of collecting information. - Inclusion: references to how people are evaluating the process.
Communal appraisal	People work together to evaluate the value of a set of practices to utilize a new innovation. - Inclusion: references to criteria used for evaluation.
Individual appraisal	Individual appraisal of the work to use a new innovation and how it impacts themselves and the other work they do. - Inclusion: references to reflection about whether the project is worth doing for specific individuals.
Reconfiguration	Evaluation work among individuals or groups may result in changes to the way a new innovation is used. - Inclusion: references to adaptations and changes.

Chapter 5. Supplementary file 6: Summary of key facilitators and barriers related to NPT and CFIR constructs

NPT question	Subthemes	CFIR and NPT Constructs	Barriers	Facilitators
I. What is the work?	1. The path toward building coherence	**Coherence** Communal specification Individual specification Differentiation	Cultivating a collective understanding of the objectives was time-intensive, given the varied interpretations associated with the term “compassionate”.	Discussing how Compassionate University fits within the broader university structure and who the target population is, supported communal specification and sensemaking.
	2. Grasping the value and relative advantage	**Coherence** Internalization **Innovation characteristics** Innovation source Relative advantage **Inner setting** Compatibility		Factors that contributed to seeing the value of the project were innovation source (initiated by the rector), policy alignment (creating a warm university), and the relative advantage over existing programs.
II. Who does the work?	3. Facilitating sustained participation amidst legitimation constraints	**Cognitive participation** Initiation Legitimation **Inner setting** Leadership engagement Available resources Relative priority	Unable to find a replacement for the student representative. Lack of resources and recognition of professional roles, and lower relative priority compared to other programs, negatively influenced sensemaking and legitimation.	Multidisciplinary team with intrinsically motivated members. Leadership engagement supported legitimation to invest time into it. However, this changed when the rector passed away and a new senior management took over.
	4. A need for community enrolment and internal collaboration	**Cognitive participation** Enrolment **Inner setting** Evidence base	Engaging community members to support bottom-up initiatives proved challenging, compounded by the absence of examples in the literature.	

		Networks and communications	Internal collaborations were seen as crucial to foster an integrated approach, nevertheless, the lack of interdepartmental communication was seen as a significant barrier to achieving this.	
	5. The value of external partnerships	**Outer setting** External partnerships and connections		Regular interactions with other institutions were crucial to regain trust in the process, fostering sensemaking, and establishing legitimacy. The development of a learning network facilitated the exchange of diverse experiences, providing an opportunity to explore ways for moving forward.
III. How does the work get done?	6. Implementing the Compassionate University Charter	**Collective action** Skill set workability Relational integration Interactional workability **Innovation characteristics** Evidence base Complexity	The absence of good practices resulted in uncertainty about how to translate action points into tangible activities. The complexity of the project was recognized, particularly in terms of 'disruptiveness' and the aim of pursuing cultural change. This negatively influenced participants' belief that they can make a valid contribution to it (legitimation). The absence of clear task designations resulted in role ambiguity. Working groups were proposed as a solution, aimed to allocate work to individuals with aligned skills. However, concerns were raised about additional workload.	Acknowledging their pioneering role served as a catalyst in regaining trust in the 'slow' process and the believe that it is right to be involved.

	7. Working towards an integrated approach	**Collective action** Contextual Integration **Inner setting** Leadership engagement		There have been accomplishments in integrating the topics into existing initiatives, such as the university's well-being tables and well-being survey. These small yet impactful efforts are essential in moving towards an "integrated approach".
IV. How is the work evaluated?	8. The difficulty of assessing the work 9.Collecting data for process monitoring and journey reflection	**Reflexive monitoring** Systematization Communal appraisal Individual appraisal **Reflexive monitoring** Reconfiguration **Outer setting and Process** Needs and resources of those involved	Assessing the 'effectiveness' of their work proved challenging, with a prevailing notion that quantifying results is essential for influencing policy changes.	Being part of the core team empowered them to advocate for these topics beyond the group. Feedback shared during team debriefings, derived from data collected by the lead researcher, facilitated process reflection. Moreover, findings from interviews with students and staff, were presented to the core team, supporting adaptation of practices in alignment with community needs.

Chapter 6

The Role of a Death and Grief Festival in Cultivating Awareness of Serious Illness, Death, and Bereavement at University: A Qualitative Study

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Submitted to Health & Social Care in the Community

Chapter 6. The Role of a Death and Grief Festival in Cultivating Awareness of Serious Illness, Death, and Bereavement at University: A Qualitative Study

Abstract

At different points in our lives, regardless of our age, gender, location, or socioeconomic background, we all face experiences of serious illness, death, and bereavement. Yet, these topics are often avoided in communities and are predominantly addressed within professional healthcare narratives and practices. In recent years, death and grief festivals have been planned to offer 'ways in' to these topics via participatory, creative, educational, and cultural activities. In Belgium, the Vrije Universiteit Brussel (VUB) hosted its first death and grief festival, the Compassionate Week, on its university campus. This four-day festival featured a variety of activities aimed at cultivating awareness and encouraging open dialogue about serious illness, death, and bereavement. This study seeks to gain a deeper understanding of students' and staff's motivations for engaging in the Compassionate Week activities and their experiences of the activities they attended. A total of 94 individual semi-structured interviews were conducted. Thematic analysis resulted in three overarching reasons for participation: i) to help with one's own grief, ii) to support friends or colleagues, and iii) to learn about death, bereavement, and the support offered by the university. Additionally, three main types of experience were identified from participants' reflections on the activities. The activities i) created openness to express and share experiences of loss and bereavement, ii) encouraged compassion (i.e., reflecting on and acting upon the suffering of others), and iii) raised awareness of serious illness, death, and bereavement as everyday experiences in school and work life. Our study suggests that death and grief festivals, such as the Compassionate Week, can contribute to greater emotional and practical support for students and staff facing experiences of serious illness, death, or bereavement.

Keywords: Death and grief festivals, Compassionate Communities, Compassionate University, evaluation

1. Introduction

Almost everyone will face serious illness, death, or bereavement at some point in their lives, yet many feel ill-equipped to navigate the emotional landscape of grief and loss.[1] Cultural reluctance to discuss death increased over the past decades, leaving *talk* about death and bereavement as a specialist activity rather than an everyday occurrence.[2] This is particularly notable in the Global North, where the professionalization of death narrates it as an individual event rather than acknowledging it as a collective, shared reality.[3,4] As a result, many people find discussions on these issues upsetting or morbid.[5] As Walter describes, rather than being an absolute 'taboo', conversations can be 'shut down'.[6] The reluctance to talk about these topics exacerbates the already challenging experience of bereavement, as many struggle with socially awkward, and maladapted responses from friends, colleagues, and health professionals who do not know how to offer appropriate support.[7,8] In response, the Compassionate Community model advocates for investing in building community capacity to understand grief, provide support, and reduce the stigma of death and bereavement.[9] To address people's discomfort in thinking and talking about these topics, it is suggested that opportunities to reflect on death and dying need to be created.[4]

In recent years, death and grief festivals have been planned in different places to offer 'ways in' to these topics via participatory, creative, educational, and cultural activities. Examples include the Good Grief Festival,[10] the To Absent Friends festival,[11] the Dying.series,[12] the Compassionate Bruges Nodes City Festival, and the Festivals of the Dead.[2,13] Despite the growing development of these initiatives, evaluations remain scarce and have primarily focused on assessing their reach and impact on attendees' knowledge, attitudes, and practices through self-completed post-event questionnaires.[10–12] Available evaluation evidence suggests that these festivals facilitate spontaneous conversations about death, dying, and bereavement, with participants feeling more confident to talk about these subjects after attending the event.[2,10] Participants also reported a better understanding of how to offer support and an increased awareness of local support services.[10,11] However, there is limited understanding of attendees' *lived* experiences and how these events engage community members, foster openness, and offer solace in the face of death and bereavement.

Furthermore, the existing body of literature on Compassionate Communities highlights the unique role of educational institutions in developing language – *how to talk about death and bereavement* – and enhancing confidence in addressing these topics as an integral part of everyday school and work life.[14,15] However, studies have shown that grief among students and staff is often "disenfranchised" due to it being unacknowledged or perceived as inappropriate in a context emphasizing productivity

and high morale.[16,17] While individuals are willing to offer support to peers or colleagues, this is often hindered by uncertainty about the appropriateness of offering assistance or mentioning the loss.[18]

Prior studies have noted the importance of addressing this issue through public awareness campaigns and psychoeducation, alongside bereavement support in schools.[19,20] Initiatives like death and grief festivals can play an important role in normalizing these topics within school communities and building resilience in both students and staff.[21] Nevertheless, there remains a significant gap in the literature regarding the development and implementation of such events in educational institutions. Limited knowledge exists about whether students and staff would be interested in participating in these events. Schools and workplaces often maintain a culture that emphasizes keeping a boundary between 'work' and personal matters.[16] The abundance of campus activities can also be challenging for students, as participation in initiatives addressing death and grief may seem at odds with the prevailing notion that student life is primarily about 'having fun'.[18,21] However, given that informal (peer) support is the highest-rated form of support among students experiencing bereavement in higher education,[22] it is important to create opportunities for this support to flourish.

Against this background, the Compassionate Week was designed and implemented as a death and grief festival at the Vrije Universiteit Brussel (VUB) in Belgium. The Compassionate Week is one of the outcomes of the Compassionate University program, led by the Compassionate University core team, which is responsible for developing initiatives to promote support and compassion during times of serious illness, death, or bereavement within the university community. The Compassionate Week aimed to cultivate awareness and encourage open dialogue about serious illness, death, and bereavement through a diverse range of activities on the university campus. This study seeks to gain a deeper understanding of students' and staff's motivations for engaging in the Compassionate Week activities and their experiences with the activities they attended.

2. Methods

2.1 Study design

A qualitative descriptive research design was used to understand the motivations and experiences of students and staff who participated in the Compassionate Week activities.[23] To enhance the transparency of the study, O'Brien et al.'s Standards for Reporting Qualitative Research (SRQR) were followed.[24]

2.2 Study context

The Vrije Universiteit Brussel (VUB), located in Brussels, Belgium, served as a case study. The university has an enrollment of approximately 22.000 students and employs about 4.000 staff (not including staff of the University Hospital). In November 2019, VUB declared itself Europe's first "Compassionate University", emphasizing the importance of support and compassion during times of serious illness, death, and bereavement.[18] A leading coalition, comprising key stakeholders such as the Rectorate, Student Counseling Center, Human Resources Management, Marketing and Communication, and the VUB's Compassionate Communities Centre of Expertise (COCO), works on translating this ambition into tangible practices. One of the notable outcomes is the development and implementation of the Compassionate Week in November 2023.

2.3 Design and implementation of the Compassionate Week

The Compassionate Week, held from November 13 to November 16, 2023, featured a total of 10 in-person activities. Additionally, two online activities (webinars) took place which were open to individuals beyond the university community. The four-day festival was free to attend and open to all students and staff of the university. Approximately 230 people were registered as participants in one or more activities of the Compassionate Week, excluding those who accessed the webinars, as these events are not included in the study. The full program is available as a Supplementary file (S1).

The preparatory process was decisive for the design of the Compassionate Week. From February 2022 to April 2022, individual interviews and focus groups were conducted with staff (N=26) and students (N=21) to understand their experiences when confronted with serious illness, death, and bereavement within the university context.[18] In June 2022, all participants were recontacted to gauge their willingness to participate in two follow-up sessions. Seven individuals, including five staff members and two students, agreed to take part in these sessions, taking place in October 2022 and January 2023. The sessions facilitated the identification of potential initiatives to be organized during the Compassionate Week, such as conversation cafés, peer support workshops, and cultural events that use dance, music, and arts to portray the narratives surrounding death and bereavement.

Subsequently, different entities showed their interest in assisting with the development and implementation of activities. A research group from the university's department of Linguistics and Literary Studies orchestrated the Poetry Workshop and Voices of Compassion - a literature night where students and staff could present poems and texts about grief and loss. Two student psychologists took charge of the workshop for student associations on grief support, and a staff member working for the

Human Resources department, who is also part of the Compassionate University core team, worked out the Compassion@Work workshop, together with an academic from the VUB's Compassionate Communities Center of Expertise (COCO). The Grief Studio was organized by KLAD - a student association known for its weekly creative gatherings. Additionally, the Compassionate Café, Compassionate Walk, Compassionate Cards, and Remembrance Tree were executed with the support of three external non-profit organizations (i.e., Missing You, Lost&Co, and Rouwcollectief). The closing event, the Moment of Consolation (i.e., the yearly remembrance moment), was coordinated by VUB's Marketing and Communication department.

2.4 Data collection

The data collection was planned only for face-to-face activities, thus the webinars are not included in the study. The study used a semi-structured interview guide, adaptable for the different activities (see Supplementary file 2). Attendees were approached immediately after the activity and asked if they had time for a short interview lasting approximately 15-20 minutes. For those who were willing but unable to participate directly after the activity, arrangements were made for an online interview at a later time. Following a brief introduction to the study, interviews started with the question "What motivated you to take part in this activity?" Participants were then asked about their experience with the activity, with subsequent questions aimed at encouraging reflection on the aspects they found most meaningful. Four student researchers (FL, RM, AS, LF) from Adult Educational Sciences, assisted the lead researcher (HB) in conducting the interviews. All interviews were audio-recorded and transcribed verbatim.

2.5 Data analysis

Thematic analysis was used to identify, analyze, and report themes informed by the inductive approach of Braun and Clarke.[25] Each interview transcript was carefully reviewed, involving identifying patterns and themes within the data. To ensure rigor, the generated themes were discussed with senior researchers (SD, JC, FVD). Participants' words are quoted in the text to illustrate the themes and subthemes. Each data extract includes a numeric participant code (e.g., P1) along with the name of the activity they participated in (e.g., P1_Poetry Workshop). MAXQDA was utilized for coding and data management.[26]

In terms of positionality, the lead researcher (HB) is a doctoral researcher with a background in educational sciences, experienced in qualitative research, and working at the university under study. She was responsible for both data collection and analysis. It is important to note that she was also

involved in organizing the Compassionate Week, together with the Compassionate University core team. The senior researchers and supervisors (SD, JC, FVD) are experts in the fields of education, public health and palliative care, and sociology, respectively. Notably, these researchers are also part of the Compassionate University core team. Additionally, bi-monthly debrief sessions took place with three other senior researchers, experts in public health and palliative care, and adult education (KC, SV, LD). During these meetings questions were asked about decisions made regarding the data analysis and interpretation of findings, enhancing the study's credibility.

3. Results

In total, 94 interviews were conducted, comprising 36 men and 58 women, with 71 participants being students and 23 being staff members. Of the 94 interviews, 8 interviews were conducted online. The individual interviews with students and staff varied in duration from 6 to 39 minutes (median = 18). Table 1 provides an overview of the total number of attendees (N) and the number of interviews conducted for each activity, alongside the gender ratio of interviewees and the breakdown of student versus staff participants. More detailed information on individual participant characteristics can be found in Supplementary file 3.

Table 1. Information about the participants in relation to the different activities.

	Registered participants	**Interviewed participants**				
Activity	**N**	**N**	**Male**	**Female**	**Student**	**Staff**
Poetry Workshop	10	3	1	2	3	/
Compassion@Work	12	7	3	4	/	7
Compassionate Café	21	8	3	5	7	1
Voices of Compassion	36	12	3	9	9	3
Compassionate Cards	56	23	9	14	20	3
Workshop Student Associations	6	4	2	2	4	/
Remembrance Tree	19	15	2	13	14	1
Grief Studio	36	9	4	5	9	/
Compassionate Walk	8	4	1	3	1	3
Moment of Consolation	27	9	8	1	4	5
Total	231	94	36	58	71	23

3.1 Motivations for participating in the Compassionate Week

Three main reasons for participating in one or more activities of the Compassionate Week were identified: i) To help with one's own grief, ii) To support friends or colleagues, and iii) To learn about death, bereavement, and the support offered by the university.

3.1.1 To help with one's own grief

Several participants expressed their motivation to participate as a means of coming to terms with their own feelings and emotions. One participant shared her intention to find ways to articulate her feelings, especially considering the recent loss of her father: "I lost my father last year, and the title, Voices of Compassion, just spoke to me. I wanted to hear about other people's experiences and perhaps learn how to put my emotions into words" (P20_Voices of Compassion). Another participant echoed this motivation, also connecting it to a recent loss: "I participated because I recently lost a family member. I felt that this could be a way to manage my feelings" (P21_Voices of Compassion).

In a similar vein, participants attended the activities with the aim of supporting their healing journey. One participant expressed: "I came to find hope in listening to these poems and to heal my inner trauma" (P30_Voices of Compassion). Another participant saw the Compassionate Café as an opportunity to break the silence around his loss, remarking: "There was a part of my life that I didn't want to talk about it, or maybe I wasn't able to talk about it. When I heard about the café, I decided to relieve myself from that part" (P16_Compassionate Café). Reflecting on their motivation for attending, a participant shared her reservations before joining Voices of Compassion, however, she decided to attend the event to gauge her emotional resilience:

> I thought about it a lot when I got the final invitation last night. I thought it might be scary to hear people talking about their emotions. But after giving it a lot of thought, and asking myself 'Could I do this? Be exposed to all that?' I thought yes, I could use it. And then it was a really safe place. It was very, very sad but in a good way. (P22_Voices of Compassion)

3.1.2 To support friends or colleagues

Supporting friends or colleagues was also a reason for participating in the activities. One participant emphasized this motive: "I'm here mainly because I wanted to support my friend. The topic is also interesting. But mainly I'm here for her" (P12_Compassionate Café). Similarly, another participant joined the yearly remembrance moment to offer solace to colleagues who have experienced loss:

> I have several colleagues who have been personally affected by loss in the last 12 months. I think it is important for them that I'm here. This is also why I sometimes go to the funerals of people I hardly knew, as I know that their friends and family will find support and comfort in that. (P88_Moment of Consolation)

Moreover, the announcement of the Compassionate Week sparked conversations within social circles, prompting discussions about who signed up for specific events and encouraging dialogue on the topic. For example, a participant recounted how during a conversation about the Compassionate Week, he found out that a classmate had experienced a similar loss, which influenced his decision to attend the Compassionate Café:

> I am here because of a classmate. She said she was coming because she lost her brother in a tragic accident this summer. So, we found out that we share a similar experience, I lost my brother too. And I wanted to support her. But then she cancelled today because she was not feeling well. But I decided to come anyway. (P15_Compassionate Café)

3.1.3 To learn about death and bereavement and find out about university support

Participants were motivated to engage in one of the workshops during the Compassionate Week to learn more about the topic and to explore the types of support offered by the university. For example, one participant said: "Every day, someone faces illness, death, or a difficult situation. So, I wanted to know how we deal with it and what the university offers" (P8_Compassion@work). Another participant recognized the necessity for additional tools to support his team members facing difficult situations. He stated:

> As a manager of 21 people, I frequently encounter situations where one of my team members is facing a challenging situation, not only related to death but also to illness. I felt a strong need to get some extra tips or tools to help me deal with it. It may not be an exact science, but the more information you have about these issues, the better. And I think such activities should be included in some kind of leadership trajectory. (P4_Compassion@work)

Students participating in the workshop for student associations on grief support expressed similar needs, stating: "I came to receive more information about the support available at university and also how to start conversations with peers about these topics" (P57_Workshop Student Associations). Moreover, some participants found the topic compelling and viewed it as an opportunity for personal reflection and growth. A participant explained her motivation for joining the Compassionate Walk: "I came because I find the theme intriguing, despite not having much personal experience with grief.

However, I believe that these moments offer valuable opportunities for reflection and learning" (P82_Compassionate Walk).

3.2 Experiences of the Compassionate Week

Reflecting with participants on their experiences of the activities in which they participated, three main themes were generated: i) Creating openness to express and share experiences of loss and bereavement, ii) Encouraging compassion, and iii) Raising awareness of the universality of these experiences.

3.2.1 Creating openness to express and share experiences of loss and bereavement

The theme "Creating openness to express and share experiences of loss and bereavement" comprises three subthemes: i) Giving voice to experiences of loss and bereavement, ii) Connecting with peers on the topics, iii) Creative approaches as a means of expressing grief, and iv) Enhancing participation through a variety of activities.

(i) Giving voice to experiences of loss and bereavement. Participants emphasized the value of activities that offered a platform for individuals to express their experiences of loss and bereavement. The courage displayed by those who shared their personal stories during events such as Voices of Compassion resonated deeply with participants. One participant remarked:

> I was really struck by how open people can be when you give them the chance. It was great to see people share their most intimate thoughts and feelings in a room with people they don't know, and yet give them the confidence to do so. (P27_Voices of Compassion)

This sentiment was echoed by others who were pleasantly surprised by the enthusiastic participation during the "open mic" part of Voices of Compassion, as one participant said: "I was impressed by how many people were motivated to share their poems. People have a lot to say about the topic. It was also a good opportunity to reflect on my own grief" (P23_Voices of Compassion). The vulnerability exhibited by individuals also left an impression during the Compassionate Café, encouraging others to share their own stories. As a participant shared: "I didn't expect others to open up so much, nor that I would open up to that extent" (P16_Compassionate Café). Moreover, a participant, who shared a poem during Voices of Compassion, written by her brother who had committed suicide, appreciated the opportunity to share her feelings without feeling obliged to respond to sympathy or inquiries from others. She explained:

> I really enjoyed being able to present the poem and give it recognition. At first, it was a bit strange to see other people reading a poem. But when I was standing there myself, it felt so normal. You could just 'dump' your trauma without having to face reactions like: 'oh, that's bad for you' or 'oh, poor thing, I'm sorry for you'. You could simply walk off the stage without having to deal with people who don't know what to say, and without feeling pressured to address or justify your feelings. (P29_Voices of Compassion)

(ii) Connecting with peers on the topics. Creating a safe and supportive environment, where individuals are empowered to voice their experiences of grief and loss, played a pivotal role in helping participants to feel understood and validated in their experiences. Additionally, participants valued the opportunity to connect with peers on these topics. In the poetry workshop, a participant expressed: "I really liked that it was in a group and that you had the chance to talk about it with your peers" (P2_Poetry workshop). Participants also appreciated the opportunity to witness how others navigate similar situations. A participant of the Compassion@work workshop shared: "It was interesting to hear the stories of the rest of the group and you recognize a lot of what you've encountered. It's nice to see how they dealt with it" (P4_Compassion@work).

Participants further expressed how hearing others' stories assisted in understanding their own feelings and forged meaningful connections among attendees. For example, a student remarked: "Their stories helped me, as there were moments when I realized 'oh that's actually how I feel'. And that was really healing" (P20_Voices of Compassion). Another participant echoed this sentiment, stating: "It creates a bond with strangers because you can immediately relate to their experiences. Just knowing that there are other people who have gone through similar processes, is somehow comforting." (P22_Voices of Compassion). Additionally, the conversation cards used in the Compassionate Café were mentioned for fostering positive discussions around these themes and enabling participants to connect with each other on a deeper level. The cards covered questions across three different categories: "Before I Die", "Compassion and Care", and "Loss, grief and death". Reflecting on her experience, one participant who came to the Compassionate Café with a group of friends commented:

> The game helped us to share these deep things that we didn't know about each other. We realized that we all have very different experiences of grief and loss. When one of my friends started to cry, I had to restrain myself. But in a good way, the cards made the conversation easier and more open. It was also nice to see that no one tried to hide. (P12_Compassionte Café)

(iii) Creative approaches as a means of expressing grief. Incorporating creative outlets such as art and writing proved to be important tools for empowering participants to express their feelings. Reflecting on her experience of the Poetry Workshop, one participant said: "It was nice to discover how you can channel your emotions through writing" (P2_Poetry workshop). Another participant described poems as effective "conversation starters" for broaching discussions on death and loss, stating: "These topics are interesting but are often overlooked or considered taboo. Being creative with it serves as a good icebreaker" (P3_Poetry workshop). Participants also conveyed how these activities helped to give a name to the "nameless". For instance, the Grief Studio provided a platform for drawing and painting around the topics. A student who joined the Grief Studio saw it as an opportunity to honor his grandmother. He shared: "I was thinking about my grandmother and her cooking, and I wanted to honor those moments. We don't talk about it much at home because it's still fresh, and it's painful. Drawing makes it easier" (P79_Grief Studio). Another participant expressed how the creative aspect helped to overcome initial reservations to participate in the Grief Studio:

> To be honest, I was not looking forward to this evening. I've had a long day, and now I have to talk and think about death, that's what I thought. But actually it's kind of fun just to do something creative with it. It makes these issues very approachable. (P76_Grief Studio).

Overall, participants suggested that future events should include more drama, music, film, or other performing arts to balance out the sessions based solely on talking and discussion, and to allow time and space to process difficult emotions.

(iv) Enhancing participation through a variety of activities. Participants underscored the value of offering a diverse range of activities so that people can participate at their own level of comfort. Some participants expressed a preference for activities where they do not feel pressured to share personal experiences. For instance, one participant stated: "I find it a bit difficult to participate in activities where I have to expose myself. I find it difficult to talk about these things. So I looked for the activities where I didn't have to share anything" (P5_Remembrance Tree). Another participant who attended the Compassionate Walk emphasized the importance of having the option not to share personal experiences during the activity. She said:

> I liked that there was room to share, but that it was by no means obligatory. The rituals allowed that you could do it in your own bubble, without having to explain it to others. But if you wished to share something, then there was ample space and understanding. I thought that was one of the things that definitely stood out for me. (P85_Compassionate Walk)

Moreover, participants appreciated the inviting atmosphere of diverse activities, which lowered the barriers to participation. For instance, P29 stated: “The good thing is that they are ‘hip’ or they are more ‘modern’. No old-fashioned candle lighting, minutes of silence” (P29_Voices of Compassion). Another participant highlighted the “playful” approach of the Compassionate Café:

> At first, I was worried: 'Oh no, it's going to be a tough evening’, but it was handled very lightly, and in a creative way. I found it pleasant. I really thought it was just going to be a discussion like: 'ah, I felt this way, and this was my experience and ah this is my experience'. But it was much more, I don't want to say more playful, but more light-hearted because there was a balance between music, talking, and listening. (P11_Compassionate Café)

3.2.2 Encouraging compassion

The activities also offered a space for introspection, prompting participants to reflect on their strategies for coping with loss. After participating in the Compassionate Walk, a participant realized that her family rarely discusses her grandmother’s death, motivating her to initiate more open conversations about her grandmother with her family. She explained:

> My grandmother passed away three years ago, and this month our family gathers for a memorial, but at that moment we don’t talk about *mémé*. And that is something I’m taking home with me, that we should mention her more often, because while we share positive memories, we don’t really talk about the loss itself or the mourning. (P82_Compassionate Walk)

Moreover, attendees of the Compassionate Café referred to the core value of the event as pursuing reflection on different perspectives on grief and bereavement and exploring ways to offer support. A participant said:

> It was interesting to see the different perspectives on the topic. I discussed with my friend how your perspective on life and death can influence where you find comfort. For me, my faith offers solace by assuring me that I’ll see the person again when they die. And it’s interesting because someone who doesn’t believe in God might not find comfort in that. We were thinking about how we can offer comfort or how we can be compassionate to different people. Because maybe, it’s not a one-size-fits-all approach. (P14_Compassionate Café)

Other activities, such as the Compassionate Cards, encouraged students and staff to think about who might need support, or who might be going through a difficult time. The activity took place on the main

campus, outside the university buildings, allowing passers-by to write a card to someone. The university facilitated the posting of these cards. A participant reflected on this initiative:

> It's really nice because it gives you a moment to think about other people. My grandfather passed away in August. So I'm writing a card to my father because I know he had a really hard time with that. It's also nice that it is unexpected (P49_Compassionate Cards)

Another participant explained how the activity provided inspiration to offer support to loved ones, as stated: "It's cool because things like this don't happen very often. I wouldn't immediately do it at home. I saw it as an opportunity to show my support to people who are missing someone" (P45_Compassionate Cards). In a similar way, a participant of the Compassion@Work shared how the workshop enhanced his preparedness to support colleagues faced with loss and improved his ability to be more attentive. He shared:

> What do I take with me? I have refined the script that I have as a manager. For example, how can I help arrange bereavement leave, or ask questions like 'do you want us at the funeral?'. And in my diary, noting when a loved one has died. Even if it's just that you know when the person will have a difficult time next year, so that you can say 'that's right, that's the period of the death of that person's father or mother'. And I also shared this information with my colleagues to say, look, you can do this too. (P5_Compassion@work)

3.2.3 Raising awareness of the universality of these experiences

Participants emphasized the significance of the Compassionate Week in raising awareness and normalizing discussions on these topics. One participant said: "The week is something you should continue to do every year. It helps to realize that death and grief are very human" (P86_Moment of Consolation). Moreover, events such as the Remembrance Tree and Compassionate Cards, accessible to all without registration, were particularly highlighted as important in increasing awareness in the wider university community because of their "visibility" across the university campus. As one participant explained: "The fact that you pass by and that you don't have to go to a specific room, that's significant. Also, because people who haven't registered for a specific activity will notice these activities" (P51_Compassionate Cards). This sentiment was shared by another participant who said:

> The biggest value of these kinds of events is that they make things visible. The more this would happen, the more we will talk about it. Because it's not something that's talked about a lot. It's still a taboo, a difficult subject. And this creates space to think and talk about it, because

> when you walk around the campus you see these things happening and it might open up conversations. (P58_Remembrance Tree)

Similarly, the Moment of Consolation (i.e., the yearly remembrance moment), was praised for creating a visible space for vulnerability on the campus. A participant explained: "When everyone stands around the statue, it creates a sense of connection. And the fact that it is outside is a good thing. It makes it a visible spot for vulnerability" (P91_Moment of Consolation). By increasing visibility, the Compassionate Week also helped combat feelings of loneliness and isolation. As one student said: "These initiatives make me feel seen and not alone in my grief. And that is very important when you are grieving" (P40_Compassionate Cards).

4. Discussion

4.1 Summary

This study sought to explore students' and staff's motivations for attending one or more activities of the Compassionate Week, a death and grief festival organized at the Vrije Universiteit Brussel (VUB), and to understand their experiences of the activities. Participants engaged in the various activities for three main reasons: i) to help with one's own grief, ii) to support friends or colleagues, and iii) to learn about death, bereavement and the support offered by the university. Three main types of experience were identified from student's and staff's reflections on the activities. The activities i) created openness to express and share experiences of loss and bereavement, ii) encouraged compassion (i.e., reflecting on and acting upon the suffering of others), and iii) raised awareness of serious illness, death, and bereavement as everyday experiences in school and work life.

4.2 Interpretation of main results

The Compassionate week used several strategies to engage community members: i) providing educational workshops, ii) launching awareness-raising initiatives, iii) providing a platform for the exchange of experiences, and iv) supporting creative expressions of grief. In this way, the festival offered an opportunity for community members to engage in discourse at their own comfort level. Several participants cited this as one of the strengths of the Compassionate Week, as for some the possibility of expressing and sharing personal stories was important, while by contrast, others found this idea uncomfortable and focused on events of silent reflection. Sellen et al.[12] underscored the importance of utilizing a range of resources - including workshops, open discussions, exhibitions, theatre, and film - to accommodate different types of interaction with the topic and to enable

individuals to participate in line with their individual coping styles. Our findings specifically highlighted the potential of creative outlets to overcome hesitancy and encourage engagement in discussions surrounding death and loss. These findings are consistent with previous studies suggesting that incorporating creative modalities in grief support interventions can enhance accessibility by providing a means to process challenging emotions in a less threatening manner.[27,28]

Participants' motivations for attending the different activities of the Compassionate Week partially match findings from Selman et al.'s[10] evaluation of the Good Grief Festival. Their research showed that the most common reasons for attending the festival were to learn about grief and bereavement, to be inspired, and to feel part of a like-minded community. In our study, one of the most frequently cited reasons was to learn about the topics and the support offered by the university. Similarly, the 2018 evaluation report of the To Absent Friends Festival found that participants were primarily driven by the desire to cope with their grief, to honor their loved ones, and to be part of a community.[29] The "desire to cope with their grief" is consistent with our finding that students and staff participated in the activities "to help manage their own grief". While the desire "to be part of a community" was not explicitly mentioned as a reason for participating in the Compassionate Week, participants noted that taking part in the Compassionate Week activities gave them a sense of 'belonging'. We also found that students and staff engaged in Compassionate Week activities to support their peers and colleagues, a motivation not observed in previous studies.[10,29]

Our study makes an important contribution to the published research on grief and death festivals by identifying several key mechanisms of action of such events. The first mechanism relates to how the various activities of the Compassionate Week provided a platform for openly sharing experiences of loss and bereavement. When reflecting with participants on the most significant aspects of the festival, a recurring theme stood out: the power of personal narratives. The enthusiastic participation observed during the "open mic" part of Voices of Compassion demonstrated that people are not only willing but eager to talk about death-related subjects when given the opportunity. This echoes the findings of Islam et al.[30] who found that people are ready to talk about death and dying, but communication is often hindered by the societal taboo around death conversations, the lack of opportunities, and a personal fear of potentially discomforting others. Compassionate Week activities, such as Voices of Compassion and the Compassionate Café, illuminate the transformative potential of witnessing others' stories, prompting individuals to introspectively explore and better comprehend their own experiences and emotions. While our study did not specifically assess the impact of participating in these activities on social connection, interview data indicated a potential development of feelings of "relatedness" among attendees through hearing others' narratives. This observation aligns with Schenker et al.'s[31]

conceptual model, which shows the mental health benefits of storytelling for bereaved family members, aiding in emotional disclosure, thought processing, and social bonding.

The Compassionate Café was inspired by the concept of 'Death Cafés', which are locally organized public events that support discussion on all aspects of death, dying and mortality.[32] It is important to note that Death Cafés, as outlined on their website, are not bereavement counselling or grief support groups.[33] Similarly, the Compassionate Café served as a gathering where people could talk about whatever is on their minds related to death, dying, and bereavement, but no professional counselors were involved. Abel et al.[34] label such initiatives as "network" approaches focused on behavior change, as opposed to "educational" approaches focused on attitudinal change. Furthermore, the Compassionate Café was lauded for fostering a "pleasant" or "light-hearted" atmosphere, shifting the perceptions away from the belief that talking about death is too morbid. In creating these more lightweight interactions, we may have attracted interest from different groups seeking to explore themes of death and dying in a safe and accessible manner. These kinds of initiatives fit within the so-called death-positive movement that aims to reduce the stigma behind death, enhance social support for those experiencing death and loss, and promote dialogue and acceptance of death and grief.[9]

A second mechanism of action of the activities within a grief and death festival such as the Compassionate Week is their ability to prompt participants to reflect on their approaches to supporting others. For instance, participants of the Compassionate Café shared how they gained insights into diverse viewpoints on death, which encouraged them to reflect on how sources of solace can vary depending on one's beliefs. In this sense, it is interesting to further explore the interplay between religion, cultural diversity, coping strategies, and rituals.[35] Moreover, activities such as the Compassionate Cards played a pivotal role in encouraging immediate action to support individuals who are going through a difficult time. The Compassionate Cards allowed individuals to write a message of support, fostering a tangible way to express empathy and solidarity.

A third mechanism of action of the Compassionate Week is to raise awareness of the universality of experiences such as serious illness, death, and bereavement across the university campus. Participants praised the accessibility and visibility of events like the Remembrance Tree and Compassionate Cards, highlighting their capacity to capture the attention of passersby and potentially spark conversations within social circles. Similarly, the Moment of Consolation (i.e., the yearly remembrance moment) was commended for creating a visible space for vulnerability on campus. This visibility not only acknowledges but also validates the experiences of those dealing with loss. Furthermore, there is

potential for broader community impacts, as research suggests that visible reminders of solidarity can act as a catalyst for mitigating feelings of loneliness and isolation.[36]

4.3 Strengths and limitations

The findings of our research should be interpreted within the context of its limitations. Interviews were only conducted with individuals who were approached by one of the researchers immediately following one of the activities. This immediacy was crucial for obtaining authentic and spontaneous responses, which may have been diluted or altered if collected at a later time. While previous studies of death and grief festivals have utilized quantitative methods,[10,11] which offered a broader reach, our decision to employ qualitative semi-structured interviews allowed us to uncover nuances and subtleties of participants' *lived* experiences that would be missed in a purely quantitative design.

It is important to acknowledge that participants may have given more socially desirable responses, assuming that the data collectors were part of the Compassionate Week organizing team. However, in the introduction of the study, the student researchers who assisted with conducting the interviews explained that they were not involved in the organization of the Compassionate Week. Furthermore, it is conceivable that these initiatives primarily engaged people who are already prepared to talk about end-of-life topics, potentially overlooking those who may be less inclined to engage in conversations about serious illness, death, and grief. Although we also focused on activities for which participants did not have to sign up, such as the Compassionate Cards, further research is warranted to explore the perspectives and experiences of people who could not or would not participate in these kinds of events.[37] Follow-up research could also explore the underlying dynamics contributing to staff and students' preferences, as well as the factors influencing their levels of engagement.

5. Conclusion

There is a growing recognition of the importance of reclaiming death and bereavement as social concerns and everyday experiences, emphasizing the need to normalize discussions around these topics and strengthen networks of support. Death and grief festivals offer a promising way to contribute to this goal. Our study identified three key mechanisms of action of such festivals based on the experiences of students and staff who participated in the Compassionate Week. The Compassionate Week created openness to express and share experiences of grief and bereavement, encouraged compassion (i.e., reflection and immediate action), and raised awareness of serious illness and loss as everyday experiences. These mechanisms can enhance emotional and practical support for students and staff confronted with the experiences of serious illness, death, or bereavement.

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Chapter 6. Supplementary file 1: Program of the Compassionate Week

1. SEMINARS, WEBINARS, AND WORKSHOPS

NOVEMBER 13TH - WORKSHOP STUDENT ASSOCIATIONS: GRIEF AND RESILIENCE

This workshop on dealing with grief and loss within student circles aims to gain insight into what is on the minds of student circle trustees regarding these topics. The workshop includes sharing experiences, discussing challenges, and identifying support needs. Two student psychologists are facilitating the workshop, providing input on existing services and offering advice on how to provide support to peers confronted with grief and loss.

NOVEMBER 14TH - WEBINAR: WHAT CAN PARTICIPATORY ARTISTS AND NURSES LEARN FROM EACH OTHER? *(not included in the data collection)*

The project 'In The Mirror of Care Work' grew out of the realization that one-on-one performance requires similar physical and social skills as care workers. The project facilitates knowledge exchange between the two disciplines, looks at the history of the professions, and initiates discussions about the politics, mythologies and poetics of both interactive performance and care practices. The webinar presents the project and includes interactive discussions.

NOVEMBER 14TH - COMPASSION@WORK WORKSHOP

What does it take to create a compassionate workplace that provides care and support to employees facing serious illness, death or loss? How can this workplace effectively cope with the challenges that arise from employees facing these difficult experiences? This workshop explores the existing resources and support available within the university and discuss additional tools that can be utilized to support colleagues.

NOVEMBER 15TH - ONLINE MEETING COMPASSIONATE SCHOOLS LEARNING NETWORK *(not included in the data collection)*

The Learning Network Compassionate Schools brings together a diverse group of professionals from Flanders and the Netherlands who exchange experiences, good practices, tools, ideas, and research for integrating themes such as serious illness, mourning, loss and informal care into school communities. During this interactive online meeting, the focus is on developing a guideline that offers practical support and inspiration to schools aiming to cultivate a more compassionate environment.

NOVEMBER 16TH – 6TH COCO SEMINAR: GRIEVING IN PUBLIC PLACES *(not included in the data collection)*

In Flanders, Belgium, a recent wave of movements and organizations that encourage involvement in serious illness, bereavement and mourning is emerging. One example is the creation of public places of mourning that provide physical locations for consolation. What do these places look like? How are

they used? What role do these places play in a neighborhood or community? These questions will be discussed during the 6th webinar of the Compassionate Communities Center of Expertise (COCO).

2. WORDS OF COMFORT, LITERATURE, AND ART

NOVEMBER 13TH - WRITING INTO GRIEF: POETRY AND PROSE WORKSHOP

The workshop "Writing into Grief" aims to cultivate pathways to write about grief, comfort, compassion and related themes. To support the writing process, different prompts are provided - for example, blackout found poetry and emulative 'after' pieces.

NOVEMBER 14TH - GRIEF STUDIO

The student association, KLAD, transforms their weekly open studio into a grief studio. Everyone is invited to express their emotions through art. It is possible to draw, write, paint, create a collage, make music, or even crocheting or knitting.

NOVEMBER 15TH - VOICES OF COMPASSION: AN EVENING OF MOURNING AND HEALING

This evening is dedicated to mourning and healing through texts, poems, stories, songs, in any language. Members of the VUB community and beyond will share their work or the work of others that promotes compassion in the face of loss.

NOVEMBER 16TH - COMPASSIONATE CARDS

Write a thoughtful card to someone you miss or who is in need of encouragement. Cards and inspirational messages will be provided to help you convey your thoughts on paper. These cards will be sent out by the university.

3. REMEMBER AND CONNECT

NOVEMBER 14TH - REMEMBRANCE TREE

With the Remembrance Tree, students and staff are invited to pay a visual tribute to their loved ones. On colorful fabric ribbons, participants can write the names of their loved ones, accompanied by key words and characteristics that characterized the person.

NOVEMBER 14TH - COMPASSIONATE CAFÉ

Talking about illness, grief, and loss can be incredibly challenging, leading many of us to avoid them altogether. However, these conversations can also be deeply meaningful and connecting. The Compassionate Café provides a safe space for discussing these topics. The café starts with an opening by Missing You, followed by personal testimonies, and concludes with live music.

NOVEMBER 15TH - COMPASSIONATE WALK

The Compassionate Walk around the university campuses includes stops at various rituals focusing on grief, solace, and connection. The walk pauses at locations representing the four elements: earth, fire, air, and water, where a ritual is performed at each element.

NOVEMBER 16TH - REMEMBRANCE MOMENT & BEFORE I DIE WALL

Every year, VUB students and staff gather around the Monument of Consolation to commemorate everyone from the VUB community who has passed away in the past year. This moment is accompanied by texts, music and the placement of flowers. The remembrance moment concludes with the inauguration of the permanent Before I Die Wall at our university campus.

Chapter 6. Supplementary file 2: Interview guide

Introduction	• Are you a student or staff member at the VUB? • How were you informed about this activity?

Core questions	• Have you already participated in other activities of Compassionate Week, or do you plan to participate in other activities of the week?
	  ○ If no: *Why not?*
	  ○ If yes: *Which activities?*
	• What was your motivation to attend this activity?
	  ○ *What appealed to you when you heard about this activity?*
	• What did you think of the activity? How did it feel to participate?
	  ○ *Did it meet your expectations, or were there any surprises?*
	  ○ *Did you meet/talk to new people?*
	  ○ *Can you pinpoint specific elements or parts of the activity that stood out to you the most?*
	• When considering future editions, what aspects would you suggest for improvement or modification?
	• Do you have other suggestions/ideas for future activities that can be organized at the university to support engagement with these topics?

Closing questions	• To end, what is the most important thing you take home with you after this event? • Is there anything else you would like to add before we end?

Chapter 6. Supplementary file 3: Participant information

Activity	Participant	Gender	Student/Staff	ENG/NL	Data collection
Poetry Workshop	P1	M	Student	ENG	End of activity
	P2	F	Student	ENG	End of activity
	P3	F	Student	NL	Online
Compassion@Work	P4	M	Staff	NL	End of activity
	P5	M	Staff	NL	Online
	P6	F	Staff	NL	End of activity
	P7	F	Staff	NL	End of activity
	P8	F	Staff	NL	Online
	P9	F	Staff	NL	Online
	P10	M	Staff	NL	End of activity
Compassionate Café	P11	F	Student	NL	End of activity
	P12	F	Student	NL	End of activity
	P13	F	Student	NL	End of activity
	P14	F	Student	NL	End of activity
	P15	F	Student	ENG	End of activity
	P16	M	Staff	ENG	End of activity
	P17	M	Student	ENG	End of activity
	P18	M	Student	NL	End of activity
Voices of Compassion	P19	F	Student	ENG	End of activity
	P20	M	Student	ENG	End of activity
	P21	F	Student	ENG	End of activity
	P22	F	Staff	ENG	End of activity
	P23	F	Staff	ENG	End of activity
	P24	F	Student	ENG	End of activity
	P25	F	Student	ENG	End of activity
	P26	F	Student	NL	End of activity
	P27	F	Student	NL	Online
	P28	M	Staff	ENG	Online
	P29	F	Student	NL	Online
	P30	M	Student	ENG	End of activity
Compassionate Cards	P31	F	Staff	NL	End of activity
	P32	M	Student	NL	End of activity
	P33	F	Student	NL	End of activity
	P34	F	Student	NL	End of activity
	P35	F	Student	NL	End of activity
	P36	F	Student	NL	End of activity
	P37	F	Student	NL	End of activity
	P38	M	Student	NL	End of activity
	P39	M	Student	NL	End of activity
	P40	M	Student	ENG	End of activity
	P41	F	Student	ENG	End of activity
	P42	M	Staff	NL	End of activity

	P43	F	Staff	NL	End of activity
	P44	F	Student	NL	End of activity
	P45	M	Student	NL	End of activity
	P46	M	Student	NL	End of activity
	P47	F	Student	NL	End of activity
	P48	F	Student	NL	End of activity
	P49	F	Student	NL	End of activity
	P50	F	Student	NL	End of activity
	P51	F	Student	NL	End of activity
	P52	M	Student	NL	End of activity
	P53	M	Student	NL	End of activity
Student Associations workshop	P54	M	Student	NL	End of activity
	P55	F	Student	NL	End of activity
	P56	F	Student	NL	End of activity
	P57	M	Student	NL	End of activity
Remembrance Tree	P58	F	Student	NL	End of activity
	P59	F	Student	NL	End of activity
	P60	M	Staff	ENG	End of activity
	P61	M	Student	NL	End of activity
	P62	F	Student	NL	End of activity
	P63	F	Student	NL	End of activity
	P64	F	Student	NL	End of activity
	P65	F	Student	NL	End of activity
	P66	F	Student	NL	End of activity
	P67	F	Student	NL	End of activity
	P68	F	Student	ENG	End of activity
	P69	F	Student	NL	End of activity
	P70	F	Student	NL	End of activity
	P71	F	Student	NL	End of activity
	P72	F	Student	NL	End of activity
Grief Studio	P73	F	Student	NL	End of activity
	P74	F	Student	ENG	End of activity
	P75	M	Student	ENG	End of activity
	P76	M	Student	ENG	End of activity
	P77	M	Student	ENG	End of activity
	P78	F	Student	ENG	End of activity
	P79	M	Student	ENG	End of activity
	P80	F	Student	ENG	End of activity
	P81	F	Student	ENG	End of activity
Compassionate Walk	P82	F	Staff	NL	End of activity
	P83	M	Student	NL	End of activity
	P84	F	Staff	NL	Online
	P85	F	Staff	NL	Online
Moment of Consolation	P86	F	Student	NL	End of activity

P87	M	Staff	NL	End of activity
P88	M	Staff	NL	End of activity
P89	M	Staff	NL	End of activity
P90	M	Staff	NL	End of activity
P91	M	Student	NL	End of activity
P92	M	Student	NL	End of activity
P93	M	Staff	NL	End of activity
P94	M	Student	NL	End of activity

Chapter 7

Mapping the Ripple Effects of a Compassionate University for Serious Illness, Death, and Bereavement

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Chapter 7. Mapping the Ripple Effects of a Compassionate University for Serious Illness, Death, and Bereavement

Abstract

Background: Compassionate Communities have been put forward as a promising community-based approach to enhance support during times of serious illness, death, and bereavement. Educational institutions, in particular, are increasingly acknowledged as interesting settings for adopting this approach, supporting the well-being of both students and staff facing these challenges.

Objectives: This paper investigates the activities and outcomes of a Compassionate Community initiative - the Compassionate University program at the Vrije Universiteit Brussel (VUB) in Belgium.

Design: Ripple Effects Mapping (REM) was used to guide the focus group session and individual interviews conducted with core team members responsible for the development and implementation of the Compassionate University program.

Methods: During the focus group and individual interviews, the core team members reflected on the program contributions, with their narratives visually depicted via a hand-drawn mind map. Qualitative data derived from this mind map was entered into XMIND mapping software and fine-tuned based on the focus group and individual interview transcripts and additional project records.

Results: Thematic analysis identified four outcome areas that encapsulate the key contributions of the Compassionate University program: i) increased acceptance and integration of topics such as serious illness, death, and bereavement into existing practices; ii) broader support for and formalization of compassionate procedures and policies; iii) emergence of informal networks and internal collaboration on the topics; and iv) diffusion of compassionate ideas beyond the university.

Conclusion: The Compassionate University program facilitates a cultural shift within the university environment, fostering greater acceptance of integrating topics such as serious illness, death, and bereavement into existing practices. Additionally, compassionate procedures and policies for students and staff have been formalized, and core team members are increasingly called upon to provide support on these matters. Notably, Compassionate University stands out as one of the pioneering initiatives in Europe, attracting different educational institutions seeking guidance on cultivating a more compassionate environment.

Keywords: Ripple Effects Mapping, Compassionate Communities, Compassionate University

1. Background

There is a growing recognition that serious illness, death, and bereavement need to be reframed as the social experiences they essentially are.[1] This acknowledgement has resulted in the development of social-ecological approaches aimed at addressing the challenges associated with these experiences. Such approaches are, in a large part of the literature, referred to as 'Compassionate Communities'.[2,3] The Compassionate Community approach draws inspiration from the action domains of the World Health Organization's (WHO) Ottawa Charter for Health Promotion (1986): 1) building healthy public policy, 2) creating supportive environments, 3) strengthening community action, 4) developing personal skills, and 5) reorienting health-care services.[4] In 2015, Kellehear suggested a 'Compassionate City Charter' that applied these action domains to serious illness, death, dying, and loss. The charter includes action recommendations for schools, workplaces, cultural centers, hospices and care homes, among others.[5] Educational institutions, in particular, are highlighted in the literature for their significant yet unexplored potential to serve as "compassionate schools" and "compassionate workplaces", promoting the well-being of both students and staff in relation to serious illness, death, and bereavement.[6,7] In Belgium, the Vrije Universiteit Brussel (VUB), declared itself (mainland) Europe's first "Compassionate University", adapting Kellehear's Compassionate City Charter to fit the university environment.[7,8]

Despite the proliferation of Compassionate Community initiatives in diverse contexts, such as schools, workplaces, and neighborhoods, the multifaceted nature of these social change initiatives poses a significant challenge to effectively evaluating their impact.[9,10] D'Eer et al.[11] and Quintiens et al.[12] found in their systematic reviews that only a small minority of Compassionate Community initiatives underwent a thorough outcome evaluation. Most of the identified studies focus on the evaluation of one particular aspect of the initiative, such as the role in healthcare provision or the voluntary involvement of community members.[13,14] The focus on individual-level evaluation results from the pressure on community-based programs to demonstrate impact on individual health outcomes,[15] and reflects the inherent difficulties in operationalizing ecological evaluation models.[16,17] Additionally, classical research approaches aimed at addressing causality questions (i.e., what is the effect of X on Y) are ill-suited for studying Compassionate Community initiatives, which are highly participatory, complex, adaptive, multi-stakeholder, and dependent on community-specific priorities.[9,18] Several scholars have, therefore, argued that studying these initiatives requires a shift away from more traditional research designs predicated on linearity and predictability.[19,20] Moreover, there is a need for more information about the practical implementation of the Compassionate Community's approach and what its operationalization might look like.

In this context, participatory methods prove valuable for incorporating the perspectives of those directly involved in the intervention and evaluating the conceptual outcomes of complex public health interventions.[21] Emerging impact measurement approaches, such as Outcome Mapping,[22] the Most Significant Change (MSC) technique,[23] and Ripple Effects Mapping (REM)[24] aid in understanding the dynamic nature and impact of interventions within complex adaptive systems.[25] Unlike traditional evaluation designs, which primarily focus on attribution and attempt to directly link observed changes to an intervention (e.g., Randomized Controlled Trials), these approaches prioritize understanding contribution. Ripple Effects Mapping (REM), for instance, facilitates the investigation of whether an intervention, project, action, or program has played a role in the observed outcomes and illuminates unanticipated impacts.[24] This method has also proved instrumental in illustrating more dynamic impacts, such as organizational mindset shifts or the cultivation of informal networks.[26]

This paper aims to investigate the activities and outcomes resulting from a Compassionate Community initiative, the Compassionate University program at the Vrije Universiteit Brussel (VUB) in Belgium, using Ripple Effects Mapping (REM) as a participatory evaluation tool.

2. Methods

2.1 Study design

We used Ripple Effects Mapping (REM) to systematically capture and document the wider effects of the Compassionate University program. REM facilitates the examination of contribution-oriented questions by employing a participatory impact evaluation approach, engaging stakeholders in visually mapping the intended and unintended effects resulting from the program.[27] Additionally, a review of project records was carried out to complement the data collected during the REM focus group and individual interviews. The reporting of this study conforms to the Standards for Reporting Qualitative Research (SRQR).[28]

2.2 Context and participants

In November 2019, the Vrije Universiteit Brussel (VUB), located in Brussels, Belgium, declared itself Europe's first "Compassionate University", emphasizing the importance of support and compassion during times of serious illness, death, and bereavement. The university has an enrollment of approximately 22.000 students and employs about 4.000 staff. The End-of-Life Care Research Group, in collaboration with the Rectorate (i.e., Chancellor's Office) took the initiative to translate the Compassionate City Charter to the Brussels University context. The Compassionate University Charter

outlines several action points, such as raising awareness and understanding of serious illness, death, and bereavement through campus activities, supporting bottom-up initiatives that complement existing practices, providing training and coaching on the topics, and establishing dedicated moments for remembrance. A leading coalition, comprising key stakeholders from different university departments such as the Rectorate, Student Counseling Center, Human Resources Management, Marketing and Communication, and the VUB's Compassionate Communities Centre of Expertise (COCO), works on translating the Charter's action points into tangible practices. The study participants include the seven members of the Compassionate University core team (See Table 1).

Table 1. Participants characteristics

Participant	Function and Department	Gender	Years of employment at VUB
1	Office Manager (the Rectorate)	Male	21-25 years
2	Professor (Faculty of Psychology and Educational Sciences; COCO)	Female	11-15 years
3	Professor (Faculty of Family Medicine and Chronic Care; COCO)	Male	21-25 years
4	Professor (Faculty of Social Sciences and Solvay Business School; COCO)	Male	11-15 years
5	Office Manager (Human Resources Department)	Male	11-15 years
6	Project Manager (Marketing and Communication Department)	Male	11-15 years
7	Psychologist for Students (Student Counseling Center)	Female	11-15 years

Note: COCO = Compassionate Communities Center of Expertise

2.3 Data collection

In May 2023, a focus group was conducted on the university campus in Brussels. Facilitated by the lead researcher (HB), the focus group involved the participation of four core team members. The three core team members who were unable to attend the focus group later participated in an online individual interview.

The “in-depth” rippling approach was used to design the focus group session, which encompasses three stages: (1) partner interviews, (2) group discussion and mapping, and (3) reflection.[24,27] After the facilitator introduced the format for the focus group, participants were asked to pair up and interview their partner. A set of guiding questions was provided to the participants, derived from prior REM inquiries by Sero et al.[29] These questions included: What is a highlight or achievement of Compassionate University? What new or deepened connections with others have emerged as part of the program? What unexpected things (positive or negative) have happened as a result of the program? How have initiatives affected the wider community? Participants were provided with post-it notes to capture their thoughts during the partner interviews. After the partner interviews, the group engaged in a facilitated group discussion, sharing insights gathered from the partner interviews, and inviting all participants to provide further detail regarding their narratives. Details of the stories were collected on a whiteboard and further questions from the focus group facilitator encouraged participants to reflect on their experiences. Once the post-it notes had been documented on the whiteboard, participants connected the post-it notes and brainstormed about possible themes, creating a mind map that captured the main actions and outcomes of the Compassionate University program (Fig. 1). The final stage involved reflecting on any “missing” effects or actions that were initially planned but not achieved. This mirrors Chazdon’s[30] approach of augmenting the ripple map to encompass the challenges encountered in moving forward.

In the individual interviews with core team members who were unable to attend the REM focus group, the same set of interview questions as those employed during the REM focus group were used. At the end of the individual interviews, participants were provided with the REM focus group session’s mind map, enabling them to contribute any overlooked information and share reflections. The REM focus group lasted 90 minutes, while the online individual interviews had durations of 43, 48, and 56 minutes. The REM focus group (excl. the partner interviews) and individual interviews were recorded and transcribed for analysis.

To deepen our understanding of the changes resulting from the Compassionate University program, administrative project records were reviewed, including meeting minutes of the monthly core team meetings, policy documents, and the lead researcher’s (HB) logbook with field notes collected throughout the study period (September 2021-September 2023), for more details, see Bakelants et al.[31] These sources facilitated the identification of “ripples” that were not explicitly discussed in the REM focus group session or individual interviews or occurred after the REM data collection.

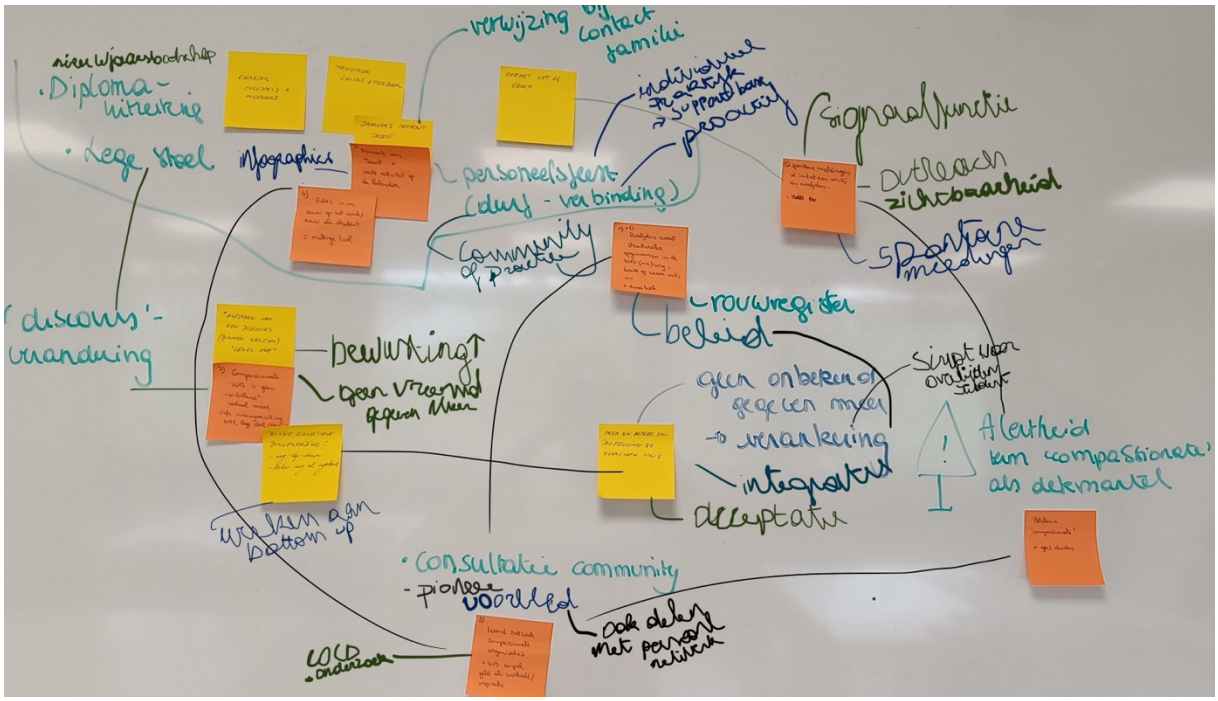

Figure 1. Original Mind Map drawn during REM focus group (in Dutch).

2.4 Data analysis

Following the completion of the REM focus group, the qualitative data from the hand-drawn mind map (Fig. 1) were entered into the recommended mapping software XMIND.[24] This facilitated the conversion of the data into a spreadsheet format, compatible with MAXQDA for subsequent coding and analysis.[32] In addition, both the focus group and individual interview transcripts were imported into MAXQDA. The data (i.e. the mind map and the transcripts from both the focus group and individual interviews) underwent inductive analysis, following the three steps of practical thematic analysis outlined by Saunders et al.[33] Initially, the lead researcher (HB) familiarized herself with the dataset by thoroughly reviewing the transcripts. Subsequently, open coding was conducted, followed by multiple reviews to merge similar codes. Following this, the codes were organized into themes or "outcome areas", supported by the original hand-drawn mind map created during the REM focus group session. These outcome areas (i.e., themes) were discussed with the research team (SD, JC, FVD) until consensus was reached. Using XMIND, a new mind map was generated to visually represent the agreed-upon outcome areas. Each outcome area included mind map nodes from the original hand-drawn mind map, along with insights derived from the transcripts of the focus group and individual interviews. As a final step, the administrative project records (e.g., minutes, logbook) were reviewed to identify any outcomes not yet documented in the mind map. These additional outcomes, enclosed in green circles in the mind map (e.g., the Compassionate Week), were incorporated into the mind

map to create a coherent digitalized mind map encapsulating the main activities and outcomes of the Compassionate University program (Fig. 2).

In terms of positionality, the lead researcher (HB) is a doctoral researcher with a background in educational sciences and experience in qualitative research. She was responsible for both data collection and analysis. As a staff member of the university community under study, her insider position proved beneficial for guiding the focus group sessions and individual interviews, as her familiarity with the university context allowed for the immediate contextualization of participants' reflections. To ensure reflexivity and maintain rigor in our methodology, the lead researcher engaged in reflexive journaling throughout the research process.[34] By documenting personal reflections, she aimed to enhance the transparency and credibility of the study, acknowledging both the benefits and challenges posed by her dual role as a community member and investigator. The lead researcher met monthly with senior researchers (SD, JC, FVD) who are experts in the fields of adult education, public health and palliative care, and sociology, respectively, to discuss the codes and interpret the findings. Notably, these researchers had a dual role, being members of the Compassionate University core team, and thus also participants of the study. This dual role could lead to potential biases, as SD, JC, and FVD may have a personal stake in the program's success, which could influence their interpretation of the data. To mitigate this potential bias, we cross-checked the data by reviewing project records and the lead researcher's field notes. To further enhance the study's credibility, bi-monthly debrief sessions took place with four other senior researchers (LDD, LD, KC, SV) who are experts in public health and palliative care, and adult education. These senior researchers were not part of the Compassionate University core team or involved in the program. During the debrief sessions, questions were asked about decisions made regarding the data analysis and interpretation of findings.

2.5 Ethical considerations

It is important to note that the REM focus group session and individual interviews were part of a larger study led by the lead researcher (HB), evaluating the development and implementation of the Compassionate University program.[31] Data collection for this research project spanned from September 2021 to September 2023. In September 2021, before the start of the study, participants received written and verbal information about the different parts of the study, including REM data collection. They were informed that participation was voluntary, that they had the right to withdraw from the study, and that they were guaranteed confidentiality. The consent form also sought permission for the utilization of project data, such as meeting minutes. All participants provided written consent for partaking in the study and the use of project data for research purposes.

3. Results

We identified four outcome areas that capture the key contributions of the Compassionate University program: 1) Increased acceptance and integration of topics such as serious illness, death, and bereavement into existing practices; 2) Broader support for and formalization of ‘compassionate’ procedures and policies; 3) Emergence of informal networks and internal collaboration on the topics; and 4) Diffusion of ‘compassionate’ ideas beyond the university. Quotes illustrating the themes are included in the text, with identifiers (e.g., P1) to distinguish between participants.

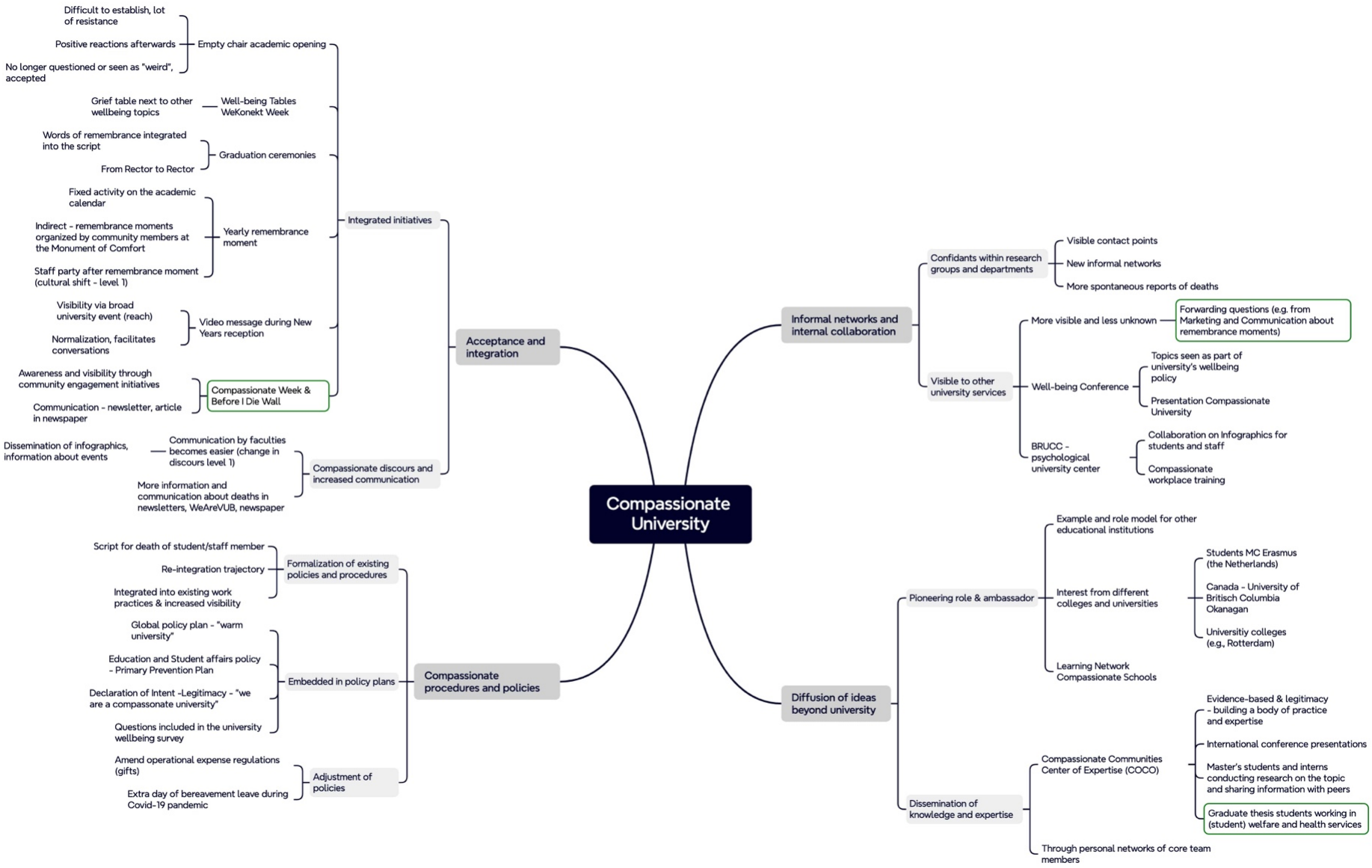

Figure 2. Ripple Effects Mind Map using XMIND software

3.1 Increased acceptance and integration into existing practices

During the focus group session, participants described how small-scale initiatives contributed to heightened visibility surrounding themes such as serious illness, death, and bereavement across the university community. A participant stated:

> We are becoming more visible, and we have small accomplishments that lead to more attention for the theme, such as the empty chair or the infographics with tips on how to deal with grief and loss. They may not have an immediate impact, but they contribute to a cultural shift that encourages gradual change. (P3)

Other initiatives, such as the incorporation of a discussion table on grief into the "well-being tables" of the "WeKonekt Well-being Week", an event that includes various discussion tables on topics such as therapy, sleep, and psychosocial health, have also helped to raise awareness of these issues. However, participants explained that the structural integration of these topics into existing practices was not achieved without its challenges. They elaborated on how university services, such as Marketing and Communication, displayed hesitancy when it came to incorporating these topics into university events. Consequently, a significant amount of time was dedicated to persuading stakeholders of the importance of explicitly mentioning and acknowledging these themes. For example, during the university's annual academic opening, which welcomes all staff and students to celebrate the start of the new academic year, a symbolic "empty chair" was set up on the stage, serving as an initiative to remember those who were missing. A solemn moment followed as everyone stood up while the names of the absent were displayed on a large screen. A participant reflected on the process of achieving this initiative:

> I remember we wanted to include the 'empty chair' in the academic opening. It took a long time to get it accepted. People who were responsible for organizing the event were really scared that such an 'unconventional' act might overshadow the festive nature of the moment. There was a long debate about whether such an initiative would not be too risky. They were afraid that it would bring too much 'darkness' and that we would scare people. (P5)

Another participant responded and explained how the persistent efforts of the core team and their courage to advocate for initiatives such as the empty chair gradually led to their acceptance. As she articulated: "Afterwards, everyone I spoke to said it was a deeply moving moment. And now, a year later, it's something normal, and nobody questions it anymore. That's our achievement" (P2). The

same evolution is evident in the context of graduation ceremonies, wherein a new tradition has taken root. Each year, the rector devotes a moment to remembering those who cannot be present. A participant elaborated on this:

> Now, in memory of our fellow students who are no longer with us, the rector says a few words. This wasn't easily attained, we had to fight for it. But now it's an integral part of the graduation ceremony script. It's formalized. It's something that will happen every year, whether we are here or not. And these things will probably be passed on from one rector to another. (P4)

Participants echoed similar reflections regarding the remembrance moment in November, which has become a recurring event incorporated into the academic calendar. The remembrance moment is open to everyone in the university community, with a special invitation extended to family members of deceased students or staff. The commemoration takes place outside at the Monument of Consolation, a statue unveiled at the start of Compassionate University, with live music, space for personal testimonies, and a speech by the Rector. One participant reflected on organizing this moment: "It was also strange to do it in the beginning. But we see more and more people taking part every year, and it is really embedded because it is now part of the academic calendar" (P4). Additionally, a university department organized a remembrance moment for a deceased staff member at the Monument of Consolation without the core team's initiation. This demonstrates how the Monument has become a space for both the annual remembrance moment and other commemorative events which are driven by community members themselves. Moreover, during the Compassionate Week in November 2023, a variety of events were held on the university campus, including a death café, workshops, and a literature night, to promote openness around serious illness, death, and bereavement. The culmination of the week was marked by the unveiling of a permanent Before I Die Wall on campus. However, the establishment of the Before I Die Wall initially faced resistance due to concerns that students would write inappropriate messages on it. Through the persistence of core team members, the wall was realized.

The instances described above reflect a shift in the organizational culture, where previous initiatives focusing on serious illness, death, or bereavement were considered inconvenient within the university setting, but now, these subjects have become "semi-normalized". Another example of this cultural shift was the presentation of a video message about Compassionate University during the university's New Year's reception, as well as the scheduling of the yearly remembrance moment before the university staff party. A participant summarized:

> Just the fact that these things are happening in an atmosphere of semi-normality. That's a sign that we're making progress. It's becoming part of the university's identity. Last year the university's staff party was scheduled for the same day as the yearly remembrance moment. And I'm sure a few years ago that wouldn't have been possible, we couldn't have done that. But now we agreed that it's okay to combine them, that we can have time for grief, and subsequently, have a party. (P2)

Furthermore, participants noticed an increase in communication about deaths through university newsletters and the online student and staff portals, as well as an improvement in the dissemination of information about events such as the yearly remembrance moment. Moreover, a core team member referenced the distribution of 'infographics' by some faculties, which provide guidance to both students and staff on coping with grief and offer strategies for supporting others. He said:

> It's encouraging to see that even deans are actively disseminating information about the yearly remembrance moment and the infographics we've created with tips for students and staff. It's reached a point where people acknowledge that it's acceptable to organize these initiatives within a university context. In the past, if you had asked them to share this information, some might have raised an eyebrow. (P1)

3.2. Broader support for and formalization of 'compassionate' procedures and policies

Participants also noted that certain practices and procedures were formalized and gained broader university support through the efforts of the Compassionate University core team. One such example is the script used when a staff member returns to work after an extended period of illness. As one participant elaborated: "The impact of this group? The script had already been there for 15 years, but thanks to this group, it has been formalized and widely disseminated" (P5). Another participant who works for the student guidance center echoed this sentiment:

> When I was confronted with the first death of a student in 2012, there was nothing, no guidelines. So, I started formulating a procedure and sat down with other services. It was in 2013 that a document was worked out. And then in 2019, they started with Compassionate University. The core team made sure that the script was presented to all boards and finally approved. The procedure became something official because of Compassionate University. I could never have done that alone. Compassionate university was important to embed it in the larger structure of the university. (P7)

In addition to the formalization of documents, the university's declaration of intent to become a 'Compassionate University' offers support and legitimacy, allowing core team members to leverage ideas and documents under the banner of "We are a Compassionate University". A participant, working for the Human Resources department remarked:

> Compassionate University gives me a sense of grounding and support. For example, a manager may not possess the necessary skills, I can now contextualize it within 'We are a Compassionate University, you need to read the guidelines on return-to-work and educate yourself about the topic'. (P5)

Moreover, Compassionate University, as a project, is included in the Primary Prevention Policy Plan of the Education and Student Affairs Department and the actions of Compassionate University are incorporated into the university's Global Prevention Plan, leading to increased visibility across services. In addition, the core team undertook the task of revising policies that hindered compassionate behavior. One notable instance involved addressing challenges in reimbursing company expenses for gifts to colleagues facing long-term illness or loss. Recognizing this issue, the core team worked to amend expense regulations to include a budget specifically for small gifts to colleagues facing such circumstances. During the COVID-19 lockdown, the university's bereavement leave policy was also extended by one day. Although core team members acknowledged that this adjustment represented just a fraction of the necessary response, they viewed it as a step towards raising awareness about the widespread experience of loss and the need for policy adjustment. While acknowledging the importance of influencing policies on a broader scale, core team members emphasized the need for quantifiable data to underscore the necessity for such changes. Consequently, efforts were made to incorporate relevant questions into the university's well-being survey. These questions sought to gauge the experiences of students and staff who had dealt with serious illness or loss in the past year and whether they received support from the university, intending to inform further enhancements in procedures and policies.

3.3 Emergence of informal networks and internal collaboration on the topics

Core team members noted that they are becoming increasingly recognized by community members as the driving force behind Compassionate University. Consequently, community members are more inclined to approach them for information or assistance when confronted with serious illness, death, or bereavement. One participant provided an example:

> I have noticed that colleagues in my department are reaching out to me more often. For instance, last month a professor approached me about a student who had a death in her family, and he was uncertain about what to do with her assignments, what was possible. And also, colleagues come to me more often when they know that a family member of a colleague or someone close to them passed away. (P3)

This illustrates how core team members evolved into ambassadors within their departments or research groups. Without explicitly taking up this role, colleagues started to perceive them as 'experts'. Another participant noted: "People are aware of my involvement in the core team, and that in itself has an impact. People reach the right individuals more quickly through us, resulting in the emergence of a new and visible network" (P4). Moreover, a participant observed an increase in spontaneous reports of deaths to the rectorate. In contrast to the past, when there was often a delay in the rectorate receiving such news, it seems that information is now reaching the relevant individuals more promptly through informal channels. As one participant stated: "We can't be certain about causation, but the fact that there are more spontaneous reports of deaths… People have more of a reflex to come to us and share such news. Perhaps more information about deaths leads to more reports" (P1).

Although inquiries are not always directly addressed to the Compassionate University core team, other services such as Human Resources and Marketing and Communication are becoming more acquainted with Compassionate University and are reaching out for their support. For instance, Marketing and Communication received a query from a research group that had lost a postdoctoral researcher. They sought guidance on organizing a remembrance moment with the department and the family. A representative of Marketing and Communication, who got to know the lead researcher (HB) during the Compassionate Week, reached out to her with this question. Additionally, the psychological center sought the expertise of the Compassionate University core team to conduct a workshop on "compassion in the workplace", while the university's well-being coordinator invited them to showcase their work at the university's Well-being Conference. These instances illustrate a growing recognition of the need for internal collaboration and the importance of integrating these topics into the broader well-being framework.

3.4 Diffusion of compassionate ideas beyond the university

Compassionate University stands out as one of the pioneering initiatives in Europe, attracting different organizations seeking insight and guidance on the topic. Participants emphasized the impact they have through their pioneering role. One participant highlighted this by saying:

> In Rotterdam they also want to work towards a 'Compassionate University College' and the VUB is prominently cited as an example, a source of inspiration, even literally in their documents. We see a lot of ripple effects stemming from our role as an ambassador, demonstrating how we inspire other institutions. (P5)

Another participant echoed this sentiment: "One of our achievements is our ambassadorial role. Colleagues come to us for information, like the professor from the Netherlands and the meeting with a university from Canada. They contact us and want to know how we do this" (P2). Core team members expressed a desire to enhance knowledge and share experiences with other institutions regarding compassionate initiatives on a regular basis. This aspiration led to the establishment of the "Learning Network Compassionate Schools" by VUB's Compassionate Communities Center of Expertise (COCO). The collected empirical data and the publications of the research team on Compassionate University granted those in other universities and colleges more legitimacy to present the case to their university's Human Resources department. Additionally, numerous master's students in Adult Educational Sciences dedicated their thesis to Compassionate University. Notably, one of them is currently employed at the Center for Student Guidance in Brussels, specializing in psychosocial well-being, and incorporating these themes into comprehensive well-being plans. Participants also shared how they disseminate the insights acquired through Compassionate University to their personal networks. For instance, one core team member explained:

> At my daughter's school, a child had lost a parent. So, I contacted the headteacher about the concept of compassionate schools and sent her information about policies and resources to implement a proactive approach. She later messaged me that it really helped. Just systematically identifying the areas where you can offer some kind of support, that's important. (P3)

4. Discussion

This paper aimed to investigate the activities and outcomes resulting from a compassionate community initiative - the Compassionate University program at Vrije Universiteit Brussel (VUB), using Ripple Effects Mapping (REM) as an evaluation tool.

One of the main contributions of the Compassionate University program has been fostering a cultural shift within the university towards greater acceptance and integration of topics such as serious illness, death, and bereavement into existing events. An illustrative example is the inclusion of a dedicated

discussion table on grief in a broader well-being event on the university campus. Other initiatives, such as the empty chair, which gave grief and loss an integral place in the academic opening ceremony, validate the acceptability of these experiences within the university community. In addition, the yearly remembrance moment held on campus supports the act of 'continuing bonds' with the deceased.[35] Regular opportunities for collective remembrance, as advocated by Kellehear,[36] encourage open dialogue among community members. These activities not only normalize the act of remembering meaningful others but also affirm the importance of communal support in times of grief and loss. Grindrod & Rumbold[37] further underscore how such events can challenge social norms and perceptions about offering, accepting, and asking support, prompting to rethink the need for "independence" and fostering greater community capacity to support each other during challenging times.

However, our study also revealed initial resistance from university stakeholders to integrating these topics into existing university practices. This resistance may stem from the perception that students' and employees' grief is inappropriate in a context that emphasizes productivity and prestige.[7,38] Our study highlights the need to embrace the discomfort that comes with initiating 'compassionate' initiatives that focus on serious illness, death, and bereavement. When educational institutions encourage the concealment of these topics, they contribute to their marginalization in public discourse, which can lead to less social support, mental health problems, and poorer academic achievement.[39,40]

Additionally, policies play a crucial role in shaping the culture of communities, as they can either facilitate or constrain compassionate behavior. In our study, the Compassionate University core team took steps to address policy impediments, such as revising expense regulations to include budgets for gifts to colleagues facing illness or loss. The core team also had a significant role in formalizing and disseminating existing documents and protocols for dealing with the death of a student or staff member. Nevertheless, challenges stemming from administrative processes and inconsistencies in policies across faculties, particularly regarding bereavement leave and examination deferrals, coupled with issues relating to inflexible central systems, as identified in a prior study,[7] have largely remained unaddressed by the Compassionate University core team. It is important for future research to explore strategies to navigate these complexities with empathy whilst upholding 'operational efficiency', as part of the challenge in dealing with bereavement is the "empathy-efficiency paradox" – the perception that organizational goals often conflict with the needs of bereaved individuals.[41]

Another ripple effect stemming from the Compassionate University program has been the emergence of informal networks, with core team members noting an increased inclination of colleagues to

approach them for information or assistance in relation to serious illness, death, or bereavement. Previous research has indeed shown that students and staff often struggle to identify whom to approach with questions related to illness or bereavement, underscoring the need for visible contact points.[42,43] Additionally, our study found that university services such as Human Resources and Marketing and Communication are increasingly seeking core team members' support and expertise in handling related matters. This finding aligns with the conclusions of Grindrod & Rumbold,[37] underscoring the crucial role of visible key stakeholders as bridge builders who initiate discussions on the topic within existing community structures. Moreover, participants in our study observed ripples stemming from their pioneering role, as Compassionate University attracts interest from various educational institutions seeking guidance and inspiration on how to cultivate a more compassionate environment.

Achieving ripples through community action, i.e. the process of actively engaging with the community to inspire action,[44] was an effect that was less pronounced in our study, except for the Compassionate Week organized on the university campus. This is in line with the scoping review on Compassionate Communities of Dumont et al.[17] that categorized outcomes of Compassionate Community initiatives according to the five Ottawa Charter action strategies for Health Promotion and found that the one aspect that received relatively less attention was the strengthening of community actions. Patients, families, and community members were found to be most often engaged as the target audience of Compassionate Community initiatives, rather than as full partners of community-led programs. This is despite the emphasis on socio-ecological approaches to community development in the theoretical writings about Compassionate Communities.[2,3]

The findings of our research should be interpreted in the context of its limitations. In the study, we only captured the perspectives of the "implementers" of the Compassionate University program (i.e., the core team members). While REM is typically employed to query community members who are involved in and affected by a particular program or intervention,[45,46] Compassionate University is a prime example of a complex intervention that aims for a systems approach, making it challenging to map its effects through community members interviews due to its numerous interacting parts and initiatives (many of which are small and difficult to track) and its aim of targeting different organizational levels. Moreover, ripples such as the "semi-normalization" of initiatives can significantly influence the potential success of later endeavors, underscoring their role within a complex adaptive system and their inseparability from the project itself. Additionally, REM has proven to be a valuable tool in illuminating areas where demonstrating impact proves difficult, or where ripples lead to "dead ends", making them difficult to track or validate. For example, while the infographics with tips on

dealing with grief and loss were developed and distributed by the core team, their eventual use remains unknown. It is also important to note that it may take a long time before a "ripple effect" can be observed or registered, as public health initiatives often require long timeframes to develop, implement, and evaluate.[26]

Further evaluations are necessary to explore community members' perspectives regarding the ripples identified by core team members and how they are affected by them. Conducting interviews with stakeholders along the chain could also offer a deeper understanding of the further dissemination of ripples. Moreover, there is a need for more case studies that can act as concrete, context-dependent exemplars to gain insights into how complex public health interventions contribute to a broader systems approach aimed at enhancing the well-being of individuals confronted with experiences of serious illness, death, and bereavement. To understand the contextual factors and underlying processes influencing the development of the Compassionate University program, we also conducted a longitudinal process evaluation to provide insights into how the program evolved over time.[31]

5. Conclusion

The study delved into the activities and outcomes generated by the Compassionate University program at the Vrije Universiteit Brussel (VUB). Four outcome areas were identified: i) increased acceptance and integration of topics such as serious illness, death, and bereavement into existing practices, ii) broader support for and formalization of compassionate procedures and policies, iii) emergence of informal networks and internal collaboration on the topics, and iv) diffusion of compassionate ideas beyond the university. Moving forward, continued research will be essential to further examine the impact of Compassionate Community initiatives in the context of educational institutions and to elucidate how these settings can encourage open dialogue about serious illness, death, and bereavement, build community capacity, and potentially enhance the well-being of students and staff facing these challenging experiences.

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Chapter 8

General discussion

Chapter 8. General discussion

Introduction

In November 2019, the Vrije Universiteit Brussel (VUB) declared itself as (mainland) Europe's first "Compassionate University", emphasizing the importance of support and compassion during times of serious illness, death, and bereavement. The overall aim of this dissertation was to examine the development process of the VUB towards a Compassionate University. To address this aim, five studies have been undertaken, each accompanied by its own data collection process. Through these studies, this dissertation offered insights into the experiences and support needs of students and staff, discussed the challenges and opportunities associated with creating a more Compassionate University environment, and explored the activities and outcomes of the Compassionate University program.

This general discussion is structured in different parts. First, the dissertation's main findings are briefly summarized. Next, the strengths and limitations of the chosen methodologies are discussed. Following this, an interpretation of the findings is provided. Subsequently, overall critical reflections and suggestions for further research are formulated. Finally, implications and recommendations for practice and policy are presented.

1. Summary of the main findings

Before studying the development process towards a Compassionate University, it was essential to identify appropriate evaluation approaches for understanding the complex processes behind Compassionate Community initiatives. I, therefore, started with identifying suitable theoretical frameworks for the study of Compassionate Communities (Chapter 3). To do so, two steps were followed. First, a conceptual literature review was conducted to examine the core characteristics of Compassionate Community initiatives. A tentative list of characteristics was translated into assessment criteria. The second step consisted of applying the identified assessment criteria to a list of widely used and highly cited theoretical frameworks. As a result, three theoretical frameworks were identified as suitable for the study of Compassionate Communities: the Consolidated Framework for Implementation Research (CFIR), the integrated-Promoting Action on Research Implementation in Health Services framework (i-PARIHS), and the Extended Normalization Process Theory (ENPT). Although the purpose of the frameworks differs, they are complementary. CFIR provides constructs to categorize and describe contextual determinants that influence implementation at different socio-ecological levels. i-PARIHS adds the concept of "facilitation" to the list of contextual determinants. ENPT helps to understand the underlying mechanisms that shape the way change processes occur.

To understand the needs of the university community, a qualitative study was conducted to explore the experiences and support needs of students and staff confronted with serious illness, death, and bereavement within the university context (Chapter 4). Semi-structured interviews and focus groups were conducted with 21 students and 26 staff. Three broad themes were constructed from the question about their experiences. The first theme, "The university as a high-pressure environment", highlights that the university is often perceived as a high-demanding environment with little room for experiences of serious illness, death, and bereavement. The second theme, "Navigating the complex university information and support system", comprises three subthemes: i) a lack of knowledge of procedures and limited flexibility in bereavement leave, ii) inadequate HR support and burdensome administration, and iii) invisible or unavailable support services. The third theme, "Disenfranchised grief", refers to the feeling that students' and staff's grief is often unacknowledged or unrecognized. Additionally, four themes were generated in terms of what participants needed from the university. The first theme, "Clear processes and procedures", emphasizes the importance of transparent procedures for postponing deadlines and extending assignments. Staff also reported the need for compassionate leadership training to enhance organizational knowledge of bereavement leave policies and procedures. The second theme, "Flexibility in policy application", highlights the importance of considering individual differences in bereavement and caregiving experiences when

providing accommodations. The third theme, “Proactive support and recognition”, suggests that managers should be proactive in supporting staff facing serious illnesses or bereavement rather than waiting for them to ask for support. The last theme, “Activities to enhance awareness and interpersonal communication skills”, underlines the need for training to increase individuals’ capacity to facilitate conversations about these topics. Participants also suggested organizing conversation cafés, support groups, and other (artistic) events to promote positive attitudes toward these issues on university campuses.

The data collected from the university community regarding their experiences and support needs guided the development process towards a Compassionate University. To understand how the Compassionate University program evolved from its initial stages, a longitudinal process evaluation was conducted over a period of two years (Chapter 5). Throughout this period, the Compassionate University core team members participated in the data collection process. The two frameworks identified in Chapter 3, CFIR and NPT, guided the process of data collection and analysis. Several data collection modalities were used: i) field notes; ii) right-now surveys; iii) individual interviews and focus groups; and iv) strategic learning debriefs. The four NPT questions structured the findings. The first question, “What is the work?”, revealed that establishing a shared understanding of the scope and objectives of the Compassionate University program was challenging because of the different interpretations of the term “compassionate”. However, recognizing the relative advantage of the Compassionate University program and discussing its compatibility with existing practices and programs supported collective sensemaking among core team members. The second question, “Who does the work?”, underscored the value of the core team’s multidisciplinary composition and highlighted the intrinsic motivation of its members as an asset in driving the program forward. However, core team members indicated that their demanding schedules hindered their ability to fully commit to the program, ultimately resulting in one member leaving the team. Additionally, fostering community engagement and internal collaboration was seen as crucial for moving towards an ‘integrated approach’. Yet this proved difficult due to the fragmented university environment. The third question, “How does the work get done?”, pointed to a lack of good practices for translating the Compassionate University Charter into tangible actions, leading to uncertainty among the core team members. Interaction with other institutions was crucial to regaining trust in the process. The final question, “How is the work evaluated?”, highlighted that core team members encountered challenges in assessing their efforts. There was a prevailing belief that quantifying outcomes is essential for driving policy change and securing broader support from senior management.

In response to the core team's commitment to demonstrate the impact of the Compassionate University program, the activities and outcomes resulting from the program were evaluated using Ripple Effects Mapping (REM) as a participatory evaluation approach (Chapter 7). Core team members reflected on the program contributions during a focus group session or individual interviews. One of the main contributions of the Compassionate University program has been fostering a cultural shift within the university towards greater acceptance and integration of topics such as serious illness, death, and bereavement into existing events and practices. An illustrative example is the inclusion of a dedicated discussion table on grief in a broader well-being event on the university campus. Additionally, the Compassionate University core team took steps to address policy impediments, such as revising expense regulations to include budgets for gifts to colleagues facing illness or loss. They also played a significant role in formalizing and disseminating existing documents and protocols for dealing with the death of a student or staff member. Another ripple effect stemming from the Compassionate University program has been the emergence of informal networks. Core team members noted an increased inclination of colleagues to approach them for information or assistance in relation to serious illness, death, or bereavement. Furthermore, their pioneering efforts have attracted the interest of various educational institutions seeking guidance and inspiration on how to cultivate a more compassionate environment.

In line with the question "What is the work?" (Chapter 5), one of the outcomes of the Compassionate University program is the establishment of a one-week thematic festival, called the Compassionate Week. Students' and staff members' motivations for engaging in the Compassionate Week activities, as well as their experiences with the activities, were explored (Chapter 6). A qualitative approach was used, conducting 94 semi-structured interviews. Students' and staff's motivations for attending the activities of the Compassionate Week included: i) to help with one's own grief, ii) to support friends or colleagues, and iii) to learn about death and bereavement and find out about university support. Additionally, three main types of experience were identified based on their reflections on the activities. The activities i) created openness to express and share experiences of loss and bereavement, ii) encouraged compassion (i.e., reflecting on and acting upon the suffering of others), and iii) raised awareness of serious illness, death, and bereavement as everyday experiences in school and work life. The study suggests that death and grief festivals, such as the Compassionate Week, can contribute to greater emotional and practical support for students and staff facing experiences of serious illness, death, or bereavement.

2. Methodological considerations

To comprehensively explore the development process of the Vrije Universiteit Brussel (VUB) towards a Compassionate University, I employed different research methods. This section outlines the strengths and limitations of the research methods used.

2.1 Appraisal of theoretical frameworks for the study of Compassionate Communities

The strength of the study presented in Chapter 3 lies in its contribution to guiding evaluation research by identifying theoretical frameworks for the study of Compassionate Communities. The core characteristics of Compassionate Communities were examined, building on systematic reviews that employed rigorous methods for identifying Compassionate Community initiatives.[1–3] Despite the thoroughness of these reviews, we must acknowledge that only a handful of initiatives have been described in the literature and even fewer have undergone formal evaluation. Since many Compassionate Community initiatives are grassroots efforts, it is likely that some have not been reported or described in the scientific literature, especially those in non-English speaking contexts. For the selection of theoretical frameworks, we consulted reviews presenting the most used implementation science frameworks cited in academic publications[4] and the theories most used by implementation scientists.[5] We only considered frameworks ranked within the top 10 on both lists. This approach might overlook recent innovations or less widely used but suitable frameworks. However, having a sufficient empirical basis was identified as an important criterion to support the use and uptake of theoretical frameworks.

2.2 Qualitative interviews and focus groups with students and staff

One of the strengths of the study presented in Chapter 4 is the use of both individual interviews and focus groups as data collection methods. Each data collection method has its own advantages. The individual semi-structured interviews captured the lived experiences of students and staff confronted with serious illness, death, and bereavement within the university context, and allowed for an in-depth exploration of the personal and nuanced experiences of participants. The focus groups facilitated interaction and encouraged participants to build on each other's responses, potentially uncovering insights that might not have emerged in the individual interviews. The group setting stimulated memories and ideas, and I observed that participants felt validated by hearing others' experiences. Notably, in one focus group, participants expressed an intent to meet outside the focus group session, suggesting the potential for network building among participants.

Besides the study's strengths, its limitations must also be considered. While our study included a diversity of perspectives, there was an overrepresentation of white and female participants; a limitation also observed in previous studies.[6–9] Additionally, most students were from the humanities or social sciences. Moreover, the self-selection process used for participation in the study may have yielded a biased selection toward more negative narratives and experiences, but also experiences from students and staff who were coping well to share their stories. Furthermore, only a small number of participants shared experiences related to long-term care(giving) or illness. Potential participants may have excluded themselves from the study because they were not sure if they were "eligible" to participate.

Another limitation of the study was the reliance on online recruitment, necessitated by COVID-19 restrictions that mandated staff to work from home and students to attend classes online. Many participants said that they noticed the news about the study by coincidence, and when they discussed it with their colleagues, they found that their colleagues had not noticed the information about the study. This suggests that we may have missed potential participants with the restricted online recruitment efforts. Moreover, if it had been possible to combine online recruitment with face-to-face efforts, allowing us to provide a more detailed explanation of the study and emphasize that participation was open to everyone, this could potentially have reduced instances of self-exclusion. The data collection process was also disrupted by the COVID-19 pandemic. Initially scheduled for December 2021, the interviews had to be postponed due to a new COVID-19 wave. We hoped that restrictions would ease for conducting in-person interviews, but unfortunately, this did not happen. Interviews and focus groups were eventually rescheduled for February-March 2022. Government regulations permitted physical meetings from January 2022; however, many participants expressed discomfort with in-person interviews or focus groups. Consequently, only 4 out of the 33 interviews were conducted in person, with the remaining conducted online. Additionally, several interviews and focus groups had to be switched from face-to-face to online at the last minute because individuals tested positive for COVID-19. The shift in interview dates due to changing COVID-19 regulations also led to 4 participants dropping out. During the in-person data collection moments, participants highly appreciated the opportunity to create a "safe" atmosphere. I found that establishing a trusting relationship was much more challenging through online Teams meetings, as there were fewer opportunities for informal conversations before and after the interviews or focus groups.

2.3 Longitudinal process evaluation of the Compassionate University development process

A key strength of the study presented in Chapter 5 is its use of an in-depth and longitudinal case study design, spanning two years (September 2021 – September 2023). Through methodological triangulation, the study employed multiple data collection methods (i.e., field notes, right-now surveys, individual interviews, and focus groups) to gain a comprehensive understanding of the development process towards a Compassionate University. The inclusion of learning debrief sessions further enhanced the study's credibility, allowing findings from individual interviews and focus group sessions to be discussed and validated with core team members. Additionally, the application of theoretical frameworks, specifically the Consolidated Framework for Implementation Research (CFIR) and Normalization Process Theory (NPT), provided a structured approach to data collection and analysis. These frameworks offered a robust theoretical foundation for understanding the underlying processes and contextual factors influencing the development process.

The study focused on one specific case study and therefore the findings may not be easily transferable to other contexts. However, we believe that our findings hold a certain degree of transferability. By using NPT and CFIR, we identified system-level barriers and facilitators that are likely to influence the uptake of these initiatives beyond the study setting. An additional critical reflection pertains to my role as a researcher embedded within the core team and as an evaluator of the development process. On one hand, being part of the core team and participating in monthly meetings allowed me to build trust and establish confident relationships with the participants. This involvement also enabled me to easily contextualize participants' responses during individual interviews and focus groups. On the other hand, there is a potential risk that participants may have provided responses they believed were expected or favorable due to my dual role and the involvement of my supervisors - who are also members of the core team. This is also discussed in Chapter 2, in the researcher's positionality statement.

2.4 Qualitative interviews with participants of the Compassionate Week

One of the strengths of the study presented in Chapter 6 is the use of qualitative interviews to examine the experiences of students and staff participating in the Compassionate Week activities. While previous studies of death and grief festivals have predominantly employed quantitative methods,[10,11] which offer a broader reach, our choice to use qualitative semi-structured interviews allowed us to uncover a nuanced understanding of how individuals interacted with and were affected by the Compassionate Week activities.

A limitation of the study is the potential for desirability bias. This bias tends to occur more frequently in qualitative research than in quantitative research because of the direct interaction with the researchers.[12] Students and staff might have provided us with socially desirable responses, possibly perceiving the researchers as part of the Compassionate Week organizing team and not wanting to appear ungrateful. Furthermore, it is conceivable that these initiatives primarily engaged people who are already prepared to talk about end-of-life topics, potentially overlooking those who may be less inclined to engage in these conversations.

2.5 Mapping the ripple effects of the Compassionate University program

One of the strengths of the study presented in Chapter 7 is its use of an innovative participatory evaluation approach, Ripple Effects Mapping (REM),[13] to capture the broader impact and indirect outcomes of the Compassionate University program. The detailed explanation of the steps followed in using REM adds significant value to the field, as there are currently limited studies that thoroughly document the application of this method. To enhance the credibility of the study and deepen our understanding of the changes resulting from the Compassionate University program, administrative project records were reviewed, including meeting minutes of the monthly core team meetings, policy documents, and the lead researcher's logbook with field notes collected throughout the study period.

A limitation is that the study only captured the perspectives of the "implementers" (i.e., the core team members) of the Compassionate University program. While REM is typically employed to query community members who are involved in and affected by a particular program or intervention, Compassionate University is a prime example of a complex intervention that aims for a systems approach. This makes it challenging to map its effects through community member interviews due to its numerous interacting parts and initiatives (many of which are small and difficult to track). As a result, the 'ripples' identified by the core team were not validated by community members.

3. Interpretations of the main findings

In this section, I provide an in-depth discussion and interpretation of the main findings of this dissertation.

3.1 Finding a suitable research approach for studying Compassionate Communities

Given that the overarching aim of this dissertation was to comprehend the development process towards a Compassionate University, an initial step involved exploring suitable methodologies for

studying this phenomenon. Vanderstichelen & Deliens[14] proposed the use of 'change-oriented designs' to study public health palliative care initiatives, involving the use of participatory methods to bring in perspectives of those involved in the intervention and to evaluate the conceptual outcomes.[15] In this dissertation, Developmental Evaluation (DE) was used as a change-oriented design to study and guide the development process towards a Compassionate University.[16] To manage the large amount of data collected during Developmental Evaluation, theoretical frameworks were identified to provide a structure for describing, guiding, analyzing, and evaluating the implementation efforts (Chapter 3). These frameworks include the Consolidated Framework for Implementation Research (CFIR),[17] the integrated-Promoting Action on Research Implementation in Health Services framework (i-PARIHS) framework,[18] and the Extended Normalization Process Theory (ENPT).[19]

The Normalization Process Theory (NPT) and the Consolidated Framework for Implementation Research (CFIR) were subsequently used to study the development process towards a Compassionate University (Chapter 5). It is important to note that I utilized the original Normalization Process Theory (NPT) rather than the Extended Normalization Process Theory (ENPT). ENPT was introduced by May in 2013 in response to critiques of the original NPT.[19] These critiques pointed out that while NPT recognizes the dynamic interplay between its generative mechanisms (i.e., coherence, cognitive participation, collective action, and reflexive monitoring) and local contexts, it tends to overemphasize individual and collective agency without adequately acknowledging contextual factors impacting this agency.[20,21] To address these concerns, the NPT was extended to include additional constructs representing the social-structural resources available to agents (i.e., material resources, cognitive resources, and social roles). Notwithstanding some exceptions, such as studies by Van Zelm et al.[22] and Bacchus et al.,[23] most recent studies continue to employ NPT without incorporating ENPT constructs.[24–26] Given the limited empirical examples and the lack of dedicated resources for ENPT, including the omission of new constructs on the NPT website, we also decided to use NPT rather than ENPT. This decision was further supported by the significant overlap between ENPT constructs observed during the development of interview guides, a challenge also highlighted by Drew et al.,[27] who noted the potential for coding ambiguities when using ENPT.

Alongside NPT and CFIR, I recommended (in Chapter 3) integrating the "facilitation" construct from the i-PARIHS framework into the CFIR framework to guide and evaluate the facilitation process behind Compassionate Community development. In i-PARIHS, "facilitation" focuses on the facilitator's role, including their purpose, expectations, and skills.[18] i-PARIHS provides valuable tools such as the Facilitation Checklist and the Facilitation Guide which offer detailed strategies and practical advice for facilitators to effectively lead and support implementation processes.[28] However, I eventually did not

use i-PARIHS in our study, as our objective was not to actively intervene in the facilitation process itself. Instead, following a Developmental Evaluation approach, I indirectly supported the development process by providing feedback to the core team based on our empirical data collection.

In addition to examining the underlying mechanisms and contextual factors shaping the development process, one of the objectives of this dissertation was to study the outcomes of the Compassionate University program (Chapter 7). As a prime example of a complex intervention employing a systems approach, the Compassionate University program presents challenges in mapping its effects due to its numerous interacting parts. The difficulty in identifying immediate outcomes influenced core team members' motivation. It was discussed that quantification is needed to pursue policy change and gain broader support from senior management (Chapter 5). A significant risk in this context is that Compassionate Community development may gravitate toward conservatism rather than fostering transformative practices unless new measurement and accountability mechanisms are devised.[29] This perspective resonates with the NIHR School for Public Health Research, a partnership between nine leading academic centers with excellence in applied public health research in the UK, making a plea for exploring new and innovative evaluation approaches.[30,31] Similarly, the UK Medical Research Council (MRC) emphasizes the importance of evaluating complex interventions within complex adaptive systems and advocates for a shift to a systems perspective that embraces 'non-linear causality'.[32]

In response, Ripple Effects Mapping (REM) was used as an innovative participatory evaluation approach for documenting the narratives of core team members, thereby validating their efforts.[33] REM served not only as an evaluation technique but also as an intervention to pause and critically reflect on the core team's progress. This reflection subsequently informed the future directions of their work – aligning with the ethos of Developmental Evaluation.[34] Unlike traditional evaluation designs, which primarily focus on attribution (i.e., what is the effect of X on Y) and attempt to directly link observed changes to an intervention, REM prioritizes understanding 'contribution'. It enables stakeholders to document the impact of their efforts and understand how they have contributed or are contributing to a systems approach.[34]

3.2 Community engagement in Compassionate Community development

The Compassionate University program was initiated through strategic meetings with the Rectorate and researchers of the End-of-Life Care Research Group, embracing a social ecology approach.[35] An important starting point was the formation of a core team with representatives of different departments, such as Marketing and Communication, Human Resources Management, the Rectorate,

Student Guidance Center, and some academics from the Compassionate Communities Center of Expertise (COCO). After the core team was formed, a stakeholder workshop was organized in February 2019, inviting staff to share their perspectives on how the university could improve its approach to serious illness, death, and bereavement. The insights and suggestions from the workshop were instrumental in developing the Compassionate University Charter. From March to April 2022, students and staff were consulted again to map their experiences and support needs when confronted with serious illness, death, and bereavement within the university context (Chapter 3). The findings from the interviews and focus groups provided a clear rationale for why Compassionate University programs may need to be developed and offered important insights for the program's adaptation. By asking students and staff about their experience of losing a loved one, universities can proactively prepare for the associated ramifications and identify necessary resources to support their community members.[36] The results of our qualitative study also address a gap in our understanding of grief experiences among university-aged individuals, particularly given that much more is known about the grief experiences of, and interventions for, older adults[37,38] and children.[39,40]

Engaging community members beyond the level of "consultation" proved challenging. The ripple effects mapping session with core team members indicated that outcomes in the community action domain were either missing or less pronounced (Chapter 7). Moreover, Dumont et al.[41] found in their scoping review of the literature on Compassionate Communities that patients, families, and community members are often engaged as the target audience of Compassionate Community initiatives rather than as active partners. Consistent with previous studies,[42,43] core team members described a prevailing taboo, denial, and lack of prioritization of these topics, which may discourage individuals from becoming actively involved.[42] However, community engagement is noted as a key factor for sustainable Compassionate Community development, based on two main rationales: 1) empowering and strengthening communities' capacity to care for one another, and 2) building on local needs and assets identified and developed with(in) the community.[44,45] Core team members pointed out a significant gap in guidance within the Compassionate Communities literature on how to pursue such bottom-up change (Chapter 5). Lessard and colleagues [45] also noted that empirical studies of Compassionate Communities have generally given limited attention to the aspect of community engagement.

To enhance our understanding of community engagement, Sallnow and Paul[46] developed a spectrum of community engagement in end-of-life care. The spectrum extends from informing, consulting, co-production, collaboration, and finally empowerment. As each stage is reached, the levels of power sharing between the organization and the community increase until communities take ownership of

the aspects of care and support.[46] However, it is important to consider whether full 'collaboration' is always necessary or desired. Community consultation is an essential step during which community members need to be asked about their needs and desires for collaboration. For example, during the interviews and focus groups with students and staff about their experiences and support needs (Chapter 4), some participants indicated a desire to be more involved. These participants were contacted to participate in consultation sessions aimed at generating ideas for the Compassionate Week activities. While participants were eager to provide feedback and share ideas, they were not interested in organizing activities themselves. One exception was a staff member from the Department of Linguistics and Literary Studies who, together with her research group, took the initiative to organize a literature night during the Compassionate Week. The group organized the event themselves, with the core team providing only administrative and technical support. This exemplifies mere collaboration, as described by Sallnow and Paul.[46] It is important that opportunities for more active involvement are offered so that community members can decide for themselves at which level they want to get involved. There should be no hierarchy regarding which level of involvement is better; rather, each level should be valued according to the community's preferences and capacity.

3.3 Compassionate policies and procedures

In our qualitative study, students and staff indicated a need for clear and transparent policies and procedures concerning serious illness, death, and bereavement (Chapter 4). Many reported difficulties in accessing specific accommodation options and a lack of understanding regarding the administration of bereavement policies among supervisors. Students also noted that navigating the logistics of obtaining extensions and/or leave is both time- and resource-intensive, as well as emotionally challenging. Furthermore, the existing policies often fail to account for individual variations in bereavement experiences and needs, which has also been highlighted in previous studies.[47,48]

While the Compassionate City Charter,[49] which inspired the Compassionate University program, mentions the importance of having policies or a guidance document for dying, death, loss, and care in schools and workplaces, the policy-building agenda remains largely unaddressed in the literature on Compassionate Communities. Dumont et al.'s [41] scoping review found that building a 'healthy public policy' regarding serious illness, death, and bereavement was one of the least common health promotion strategies observed in Compassionate Community initiatives. This might be explained by the fact that the Compassionate Community approach is often implemented within neighborhoods and not within institutional settings.

The Compassionate University core team took steps to address some policy impediments, such as revising expense regulations to include budgets for gifts to colleagues facing illness or loss and formalizing existing protocols for dealing with the death of a student or staff member. During the COVID-19 lockdown, the university's bereavement policy was also extended by one day. Although core team members acknowledged that this adjustment represented just a fraction of the necessary response, they viewed it as a step towards raising awareness about the widespread experience of loss and the need for policy adjustment.

Despite the expectation that the COVID-19 pandemic and its associated deaths would prompt universities to more thoroughly re-examine their responses to grieving students, Ridgway et al.[50] noted in their report on Revitalising Universities in (Post-)COVID Times symposium that student bereavement continues to be an under-prioritized issue in university policy. Instead, during the pandemic, universities focused on matters such as infection control, the transition to online teaching and learning, and back-to-campus policies. Similarly, Compassionate University core team members observed that while considerable attention was given to students' mental well-being during the pandemic, the additional challenges of dealing with losses were largely overlooked (Chapter 5). This underscores the fact that recognition of these issues does not happen automatically and highlights the importance or 'relative advantage' of an initiative like Compassionate University.

Moreover, it is important to acknowledge that some of the challenges identified by students and staff (in Chapter 4) remained unaddressed by the Compassionate University core team. These include issues related to administrative processes and inconsistencies in policies across faculties, particularly regarding bereavement leave and examination deferrals, compounded by inflexible central systems. As large organizations, universities must navigate the delicate balance between providing flexible responses to individual needs and ensuring timely resource allocation, so that students and staff do not have to wait for support at critical times. Achieving this requires balancing empathy with efficiency, where some processes are managed through central systems while others necessitate a more personalized approach.[51]

3.4 Initiatives to raise awareness of serious illness, death, and bereavement

Through interviews with staff and students, it was found that students' and staff's grief is often "disenfranchised", as it goes unacknowledged by peers or co-workers or is perceived as inappropriate in a context emphasizing productivity (Chapter 4). Our findings revealed that while participants were willing to offer support to peers or colleagues, this was often hindered by uncertainty about the

appropriateness of offering assistance or mentioning the loss. Prior studies have noted the importance of addressing this issue through public awareness-raising activities and psychoeducation, alongside formal bereavement support in schools.[52,53] In line with this, participants in our study (Chapter 4) suggested organizing conversation cafés, support groups, and other (artistic) events to promote positive attitudes toward these issues and encourage open discussions about these topics.

In response, the Compassionate University core team organized the Compassionate Week on the university campus, aiming to raise awareness and support dialogue around serious illness, death, and bereavement. This initiative was inspired by other death and grief awareness days or weeks.[10,11,54] By engaging a broad audience, many of whom may not be directly affected by loss at the moment, these events aim to address the discomfort often associated with discussing these issues within social circles.[55] Participants noted that one of the key strengths of the Compassionate Week was its ability to provide a platform for openly sharing experiences of loss and bereavement (Chapter 6), indicating a willingness among individuals to engage in such discussions. A previous study by Selman et al.[10] evaluating the Good Grief Festival also found that participants in their post-festival sample were less likely to be in a higher category of agreement with the statements 'I would be scared of saying the wrong thing to someone who was recently bereaved' and 'I would avoid talking to someone who was recently bereaved about their bereavement because I wouldn't know how to help' than those in the pre-festival sample. These findings suggest festivals of this nature can play a role in building confidence in addressing these topics within communities.

Additional awareness-raising outcomes, or ripple effects, of the Compassionate University program were identified through the core team's efforts to integrate topics such as serious illness, death, and bereavement into existing university events (Chapter 7). Examples include the symbolic empty chair during the academic opening to honor those who are absent and the rector's acknowledgment of missing students during graduation ceremonies. Furthermore, in response to students' and staff's need for guidance on initiating conversations about these topics (Chapter 4), the Compassionate University core team collaborated with the university's psychological center (BRUCC) to develop infographics with practical tips on supporting colleagues or peers facing serious illness, death, or bereavement. These activities normalize the act of remembering meaningful others and affirm the importance of community support in times of grief and loss.[56]

4. Critical reflections and suggestions for further research

In interpreting the findings of this dissertation, some overall critical reflections should be acknowledged. These reflections will be discussed along with suggestions for further research.

4.1 Need for attention to the experiences and needs of specific groups

We acknowledge that limited data has been collected on i) the needs of students and staff who are taking on responsibilities as informal carers or who are or have been seriously ill; ii) the variation in needs associated with different cultures or related to the international status of students and staff.

Students and staff facing serious illness or informal caregiving responsibilities

In our qualitative study on the experiences and support needs of students and staff (Chapter 4), only a small number of participants shared experiences related to serious illness. This limited response may be due to the potential ambiguity of the term "serious illness" used on the recruitment posters, which could have caused uncertainty about what constitutes 'serious' and led to self-exclusion among potential participants. Furthermore, individuals with serious illnesses may have been less able to participate due to their health conditions. Additionally, limited information has been gathered about the experiences of students and staff who take on informal caregiving responsibilities. The recruitment posters did not explicitly mention caregiving experiences, but instead referred more generally to "experiences and needs of students and staff confronted with serious illness, death, or bereavement, directly or indirectly via friends or family". Previous studies indicate that students often do not recognize their caregiving role as such, viewing these tasks as 'normal' because they have been doing them for a long time.[57] There is a notable gap in research regarding the impact of caregiving on students' participation, engagement, and success in higher education. Little is also known about the support available to employees who balance their work with caregiving tasks at home,[58] despite the acknowledgment that the number of employees needing to provide palliative and end-of-life care is expected to increase.[59] Future research must address the experiences and support needs of students and staff in informal caregiving roles or who are seriously ill themselves to ensure they receive appropriate recognition and the needed accommodations.

Culturally diverse and international university population

Culture-specific experiences influence how grief is expressed and coped with, underscoring the importance of understanding grief and bereavement within different cultural contexts.[60,61] For instance, the Jewish tradition requires that the funeral and burial take place as soon as possible

following a death, preferably in the first 24 hours. Therefore, a Jewish student may have little time to contact faculty prior to leaving campus in response to a death.[63] This dissertation did not address the needs associated with diverse cultural backgrounds and related rituals. As campuses become increasingly diverse, further research is crucial to explore the variations in needs associated with different cultures when it comes to these experiences.[62,63]

Additionally, little empirical evidence is available regarding international education and accommodation options.[64,65] Understanding the support needs of the international university population navigating grief in a foreign cultural context could significantly inform the development of more inclusive policies and support systems within educational institutions. Moreover, students and staff who are separated from family and friends when confronted with the death of a loved one can be particularly vulnerable to the deleterious consequences of grieving alone during school or work.[50]

4.2 Need for a multi-stakeholder perspective

Creating a compassionate school and work environment requires the active involvement of a diverse range of university stakeholders. Key figures such as student counsellors and Human Resources Management (HRM) personnel are often the first points of contact for students and staff facing these experiences. Studies suggest that there is currently insufficient training for school site administrators on how to support grieving faculty and staff members.[66,67] Other studies have indicated that student psychologists often lack confidence in addressing grief and bereavement and report having no professional development on these topics.[68] Furthermore, HRM scholars have shown limited focus on bereavement in the workplace, which is surprising given its prevalence.[69] To address this issue, further research should explore the perspectives, experiences, and needs of these important university stakeholders concerning these matters. This exploration would help identify the resources necessary to better assist staff and students facing serious illness, death, and bereavement.

Moreover, as noted in Section 2, one limitation of the Ripple Effects Mapping study (Chapter 7) is that the activities and outcomes of the Compassionate University program were assessed solely from the perspectives of the implementers (i.e., the core team members). Future evaluations should incorporate feedback from community members to understand their views on the ripple effects identified by the core team and how they are affected by them. Expanding the ripple effects map could involve gathering data from community members directly engaged in these ripples, such as the research group that organized a remembrance moment at the Monument of Consolation. Furthermore, exploring the progression towards a ripple would be intriguing. For example, examining

how the adjustment in operational expense regulation to include budgets for gifts to colleagues facing illness or loss was actualized, including the sequential steps and individuals involved in achieving this outcome. Such investigations could offer practical insights for institutions aiming to develop compassionate policies or initiatives.

4.3 Reflections on the Compassionate Community approach

It is essential to ensure that the Compassionate Community approach does not become just a "buzzword", or a superficial label added to a university's website. The advantage of adopting the "compassionate schools" or "compassionate workplace" label is that it allows us to identify other compassionate initiatives and learn from each other. However, this also carries the risk of suggesting that becoming a "compassionate place" is a finite goal to be achieved. We must recognize that cultivating a compassionate school or work environment is a never-ending process with no single path. Additionally, some institutions may already exemplify compassion in supporting their community through serious illness, death, or bereavement, without necessarily labeling themselves as 'compassionate'. Conversely, some schools may label themselves as 'compassionate', but do not specifically address themes such as serious illness, death, and bereavement. This issue arises from a narrow interpretation of the term "compassionate" within the Compassionate Community approach, leading to potential misunderstandings and difficulties in aligning objectives across different groups and individuals who may have varying expectations of what compassion encompasses. This confusion is exacerbated when other mental health initiatives within schools use the term "compassionate" to describe their well-being programs. In our study (Chapter 5), core team members also highlighted the effort required to clarify the focus of their work due to the broad understanding of compassion in academic and public spheres, which generally encompasses all experiences related to suffering.[70] Therefore, significant effort is necessary to maintain clarity and precision in defining compassion within the context of Compassionate Community initiatives to avoid dilution or misinterpretation among stakeholders. Hence, it is worth debating whether the adoption of a broadly understood term like 'compassionate' and refining its definition more narrowly is beneficial to the effective development of Compassionate Community initiatives.

Furthermore, I want to discuss the "everyone's responsibility" philosophy of the Compassionate Community approach. We need to acknowledge that informal carers already contribute significantly, as over 90% of care is provided by non-professionals such as family and friends. We need to be cautious of the potential unintended consequence of framing grief and bereavement care as a community responsibility.[71] It is important to advocate for a dual approach, emphasizing the importance of

developing specialist resources while also investing in building community capacity to understand grief, provide support, and reduce the stigma of death and bereavement.[72] Finally, I want to acknowledge that the concept of Compassionate Communities originates from Western cultural traditions. Current research may give the impression that this civic engagement movement is a "new" idea, however, we have to acknowledge that more collectivistic cultures already organized themselves into Compassionate Communities before the concept came into use in Australia and the UK.[2,73]

5. Implications for policy and practice

Based on the overall findings of this dissertation, this section provides implications for policy and practice.

5.1 Following an asset-based community approach

To ensure that intended outcomes align with the needs and values of the community, engaging community members in the priority-setting phases of Compassionate Community development is essential.[42] A pre-community consultation session for participatory planning is recommended early on.[74] Such sessions not only provide valuable insights into community needs and dynamics but also enhance visibility and build trust among community members. The Compassionate University program began with a stakeholder workshop where staff from different university departments shared their perspectives on how the university could improve its approach to serious illness, death, and bereavement. Based on the insights gathered during this workshop, the Compassionate University Charter was developed. However, it is important to note that students were not involved in the initial consultation session of Compassionate University, which represents a significant gap. Our study, presented in Chapter 4, revealed that students and staff have different support needs and thus require tailored accommodation. Future consultations must therefore include students to effectively address these needs. Furthermore, ongoing evaluation of the Compassionate University's objectives with community involvement is crucial. Although outlined in the Compassionate University Charter as a priority, the core team has yet to take action on this front. Recent discussions about participatory evaluation of the social impact of Compassionate Community initiatives emphasize the importance of finding innovative ways to incorporate evaluation feedback from community members.[75,76]

Additionally, adopting an asset-based community approach[77] is encouraged to build on existing resources rather than starting from scratch.[71] Grindrod & Rumbold[78] highlight two ways of thinking about the assets in your community: 1) existing assets – currently contributing to serious illness, death,

and bereavement, 2) potential assets – have the potential to incorporate these issues. Existing assets may include, for example, bereavement leave policies, which can be further examined for their effectiveness and adapted to better meet the community's needs. For potential assets, it is important to find ways to integrate topics such as serious illness, death, and bereavement into existing university practices or services. For instance, the Compassionate University core team has included a question related to serious illness, death, and bereavement in the university's well-being survey. Adding this single question is part of a larger effort to incorporate these topics into the university's well-being policy. Moreover, we found (in Chapter 4) that some students did not access university counselling because they doubted the validity of their need for bereavement-related support. This hesitation may arise because counseling services do not include grief as central to their remit or do not explicitly mention it on their website.[47,79] To leverage 'potential' assets, it should be explored how serious illness and bereavement can be more prominently integrated into the framework and work of university support services.

Asset mapping is instrumental in advancing towards an "integrated approach", a goal highlighted by core team members and previous research as crucial for achieving sustainable outcomes.[80] Internal collaboration with university stakeholders is key to this approach but has proven challenging due to the fragmented university environment. Core team members have stressed the importance of mapping internal stakeholders as an essential future step to create a comprehensive overview of those currently involved in well-being initiatives at the university. The aim of this effort is to enhance internal collaboration and support integration across different university structures, thereby leveraging potential assets more effectively. However, this endeavor remains a work in progress. Potential stakeholders to consider, as suggested by the core team, include 'kotcoaches' (i.e., student accommodation coaches), who are the direct contact points for students living in on-campus housing, and the University Hospital. The latter is interesting as the Compassionate Community approach not only seeks to enhance community resilience in addressing serious illness, death, and bereavement but also focuses on making linkages with specialist or generalist palliative care support services.[81,82]

5.2 Developing clear and transparent 'compassionate' policies and procedures

Open and supportive attitudes towards serious illness, death, and bereavement cannot be cultivated if these experiences are not acknowledged and addressed through appropriate policies and legislation. Therefore, it is crucial to have comprehensive policies and procedures in place regarding serious illness and bereavement for both staff and students.

Policies and procedures for staff

Our qualitative study (Chapter 4) and previous research highlight that one of the most important concerns of employees and a highly valued form of support is receiving (paid) time off from work.[83] However, authors such as Hazen,[84] indicate that current bereavement leave policies do not provide enough time to grieve. Given that most bereavement leave is around three days, employees often return to work while still experiencing significant pain. It is, therefore, common for employees to take additional time off from work, irrespective of the organization's policy, by obtaining a 'sick note' from a GP.[85,86] This practice erroneously classifies grief as a 'disease'. Additionally, previous studies demonstrate ambiguity within organizations surrounding bereavement leave administration, such as eligibility criteria, duration of leave, and work adjustment options.[87,88] This issue was also evident in our study, where participants explained that the level of accommodation depended on the goodwill of their supervisors. In some cases, supervisors managed leave with considerable flexibility, while in other cases, no flexibility or accommodation was provided beyond the regulated bereavement leave period. Consequently, some staff members found themselves unable to access the necessary resources to cope with the loss of a loved one. Participants in our study also criticized bereavement leave policies underpinned by social norms that establish a hierarchy of loss, where only certain (blood) relationships between the employee and the deceased are deemed sufficient to warrant paid leave.

There is thus a clear need for more flexible and comprehensive bereavement policies that acknowledge the diverse and prolonged nature of grief. Workplaces should acknowledge that grieving is a continuous process that often lasts much longer than the time allotted for attending funerals or the brief bereavement leave provided by employers.[89] Employers might consider offering longer bereavement leave (e.g., 20 days, or longer if possible) and providing flexibility in when and how this leave is used. For instance, employees might require time off for appointments with a notary, anniversaries of the death, or moments that trigger memories, such as the first beautiful spring day, even if it is 10 years later. Our qualitative study (Chapter 4) also showed that people need different responses at different times. For some, returning to work after a loss provided the necessary distraction from the sorrow at home, while others needed more time off. A significant misconception is that all individuals mourn in a particular way to adapt to loss.[51,90] The Dual Process Model (DPM),[91] which articulates that grieving individuals oscillate between loss and restoration (immersion in other tasks), could provide a framework for universities to shape their support services and policies.[48] This approach would simultaneously acknowledge staff's grief work and facilitate their ability to focus and reinvest in their work. A bereavement policy that accommodates the varying rhythms and timelines of grief can also help supervisors understand long-term performance issues as being related to the loss

(e.g., inconsistent performance, coming in late or calling in sick, exhaustion).[69] This is important, as the current work context and workplace policies often focus solely on the acute phase of grief, neglecting the long-term impact.[92] Additionally, as a Compassionate University, the next step could be to make a statement by expanding the definition of bereavement leave to include diverse relationships and advocating for policies that recognize the profound impact of losing a friend as well.

Bereavement also relates to cultural and religious beliefs and rituals, which can sometimes conflict with existing HR practices. Many cultural and religious groups have rules about the length of grieving as well as how quickly a burial might occur.[51] In Western secular and Christian communities, funerals are typically held within a few days following the death. In contrast, for example, among the Roma of Eastern Europe, the wake lasts three days, followed by a burial on the fourth day after a procession to the grave site. It is important that policies accommodate these diverse practices. This includes allowing flexibility in leave policies to respect different mourning periods and burial customs, thereby supporting employees in engaging in their bereavement rituals without added stress or conflict with work responsibilities. However, it is important not to assume that an individual's affiliations with a specific belief system mean that they will follow all its principles. Communication is key to finding out what matters to them as an individual. Additionally, our workforce includes a number of international colleagues with family members living abroad. In the event of a family member's death, these colleagues may need to travel significant distances to attend the funeral. Allocating only one day of bereavement leave in such cases is insufficient and not beneficial, as it does not account for the time required for travel and the emotional toll of such a loss.

Our qualitative study (Chapter 4) also noted that supervisors often seem to have limited knowledge of the existing policies and procedures related to serious illness and bereavement and are unsure about how to approach employees facing these experiences. In line with this, McGuiness[85] found that supervisors commonly seek guidance on how to properly support grieving employees' and suggests that an organizational policy should include clear procedures. Having bereavement support protocols in place can assist managers in offering proper support, such as meeting with the employee upon their return to assess their needs and directing them to additional resources.[93] Our study, along with previous research, underscores the importance of encouraging supervisors to adopt a proactive approach.[94] This is supported by research showing that employees often struggle to resume their full workload on return and that many would appreciate more emotional and practical support from colleagues and employers.[93] In line with this, participants of our study (Chapter 4) shared that they would have appreciated having a designated contact person within the organization who would reach out to them and offer support. This could be incorporated in an organization's bereavement support

plan and could help people overcome the common barriers to seeking help, such as reluctance, lack of energy, and insufficient information.[93] Our results also indicate a need for continued support and task-relevant accommodations for grieving employees, such as flexibility in work schedules. Having a bereavement support plan in place that highlights these important accommodations can serve as confirmation that the organization takes 'grief work' seriously.[95] However, it is crucial to remember that such a protocol cannot replace the importance of acknowledging individual differences in the grieving process. Another important point is that documents and procedures are often available, but people do not know where to find them or what already exists.[69] Therefore, it is important that these protocols are easily accessible upon request and well-communicated within the organization.

The workplace must also be proactive in identifying individuals that may need additional support. When we reached out to participants from our qualitative study (Chapter 4) to invite them to follow-up brainstorm sessions for the design of Compassionate Week activities, we received various responses: an automatic reply from one staff member who was on long-term sick leave, another participant who had changed jobs, one participant who called to explain that she was quitting her job at the university, and another participant who declined due to another negative experience with the university, stating that he lacked the energy to participate again. These responses suggest that participants in our study might already be on the verge of disengagement, underscoring the critical need for thorough follow-up to mitigate the costs related to absenteeism and turnover.[51]

Policies and procedures for students

Student bereavement is a pressing concern that is frequently overlooked in university policy development and practice.[96] Few universities offer a dedicated bereavement leave policy for students, irrespective of the fact that many provide this to their staff.[50] Our qualitative study (Chapter 4) described how requesting assignment extensions is often perceived as time-consuming, confusing, and difficult to obtain, leading students to avoid seeking support. Those who did request extensions encountered inconsistent processes that varied widely across departments and faculties.

The general education and examination regulations of the Vrije Universiteit Brussel (VUB) do not mention any exemptions or exam postponements in the event of a death. Each faculty has its own document with additions to the general university education and exam regulations. Among these, four out of eight faculties do not mention anything about bereavement-related exemptions. The other four faculties allow for a "force majeure procedure" in the event of the death of a relative by blood or marriage up to the second degree (grandparents, grandchildren, siblings). Students must contact the

faculty secretariat at the latest on the day of the mandatory class or exam and provide a valid attestation proving their relationship to the deceased person and fill in an online form. Some faculties require written proof within three working days of the absence. If a certificate is not submitted within these deadlines, the absence is considered unexcused. The current system requires students to be proactive at a time when they may be in shock and unable to articulate what has happened.[13] These procedures might explain why students often do not request exemptions and perceive the university system to be unhelpful. It is important to convene with faculty boards and secretaries to discuss how these matters are handled in each faculty. Such conversations alone can raise awareness of the need to reevaluate existing procedures.

There is a need for universities to develop clearer, more inclusive, and easily accessible policies to support grieving students effectively, also for a longer period after the death of a loved one.[97] Overwhelmed by their loss, students often find themselves walking away from their classes, leaving a record of failing grades to contend with upon return.[36] Recognizing this challenge, Servaty-Seib and Liew [98] underscored the importance of colleges and universities developing leave of absence policies for students dealing with loss. A student-focused bereavement policy, like the Grief Absence Policy for Students developed at Purdue University, offers excused absences from classes that require attendance, as well as a set number of opportunities to complete missed coursework.[98] However, students are often unaware of such policies or feel too overwhelmed to take the necessary steps to utilize them.[36] This highlights the need for universities to not only establish comprehensive bereavement policies but also actively educate staff and students about their availability and streamline the process for accessing them, ensuring that support is readily accessible during times of need. Additionally, given that the Vrije Universiteit Brussel (VUB) has students from 152 different nationalities, with 52% of the international student population coming from non-EEA countries, it is crucial to take into account their specific needs in relation to travel and cultural rituals.

Moreover, as indicated before, informal student caregivers are an understudied and unrecognized group. In the literature, they are often referred to as young adult carers (YACs), who are defined as individuals between 18 and 25 who provide informal care, support, or assistance to family members with disability, chronic illness, mental health issues, or substance misuse problems.[99] At the Vrije Universiteit Brussel (VUB), young adult carers can request a “reflex” statute, where reflex stands for reasonable flexibility. This statute involves making necessary adjustments to teaching and examination regulations to ensure an equal chance during evaluations. Although ‘informal caregiving’ is one of the listed possibilities to request such a statute, it is only mentioned on the website under the title ‘other situations’ in a smaller type. In the academic year 2022-2023, 15 students registered as informal

caregivers and applied for a reflex statute. In the first semester of the academic year 2023-2024, there were only six registrations. This will be a great underestimation of the actual number of informal caregivers, as a recent study by Steunpunt Mantelzorg[100] showed that one in five students combine their studies with informal care responsibilities. As indicated in the findings and reported in other studies, not all student caregivers will disclose their carer status on their application.[101] It is important that universities have clear policies in place to identify young adult carers early on to prevent them from dropping out. Student services can play a vital role in ensuring that policies are transparent, understood, and followed by all staff. [101]

5.3 Fostering community engagement and internal collaboration through thematic events

Studies indicate that while most people benefit from social support and information about grief, only a minority require specialized assistance following a loss.[102,103] Moreover, relying solely on professional support may inadvertently frame bereavement as a 'problem to be fixed' rather than an experience to be engaged with. This can potentially lead to the isolation of bereaved students and staff, who may feel that discussions about their grief are confined to private settings or formal university support services. Participants in our study (Chapter 4) suggested that the university could play a role in making these topics more visible and open for discussion.

We observed that death and grief festivals such as the Compassionate Week can significantly enhance visibility and promote open dialogue about serious illness, death, and bereavement. When organizing these thematic weeks, it is crucial to offer a variety of activities that allow participants to choose according to their own comfort levels. For some participants, sharing personal stories was important while others preferred activities focused on silent reflection (Chapter 6). Similarly, Sellen et al.[54] who studied the Dying.Series festival emphasizes the importance of utilizing a range of resources – such as workshops, exhibitions, theatre – to accommodate different types of engagement with the topics. Additionally, given the diverse and international university community, it may be valuable to incorporate activities around different cultural rituals. For example, in Mexico, "the Day of the Dead" is an annual holiday where families and friends come together to pray for and commemorate deceased loved ones. Including activities related to different cultural rituals in the Compassionate Week could provide an opportunity for the university community to learn about and engage with diverse cultural perspectives on death and bereavement. This could foster greater cultural awareness and sensitivity among students and staff, as well as enhance inclusivity by recognizing and honoring different ways of grieving and remembering loved ones.

As previously noted, community engagement and collaboration are key to the Compassionate Community approach, yet there is limited information available on effective community engagement strategies.[41] Our research highlights how events like the Compassionate Week can foster greater community engagement and internal collaboration with university stakeholders. While Compassionate University operates primarily as a top-down initiative, the Compassionate Week spurred the development of bottom-up initiatives, such as the Literature Night organized by a group from the Linguistics and Literary Studies Department. Additionally, colleagues who were initially reluctant to contribute to the first edition later expressed enthusiasm for actively contributing to future editions of the Compassionate Week. In the aftermath of the Compassionate Week, departments such as Human Resources and Marketing and Communication also became more acquainted with Compassionate University and began seeking support for organizing commemoration moments and other related initiatives.

6. Final note

Universities are in a unique position to shape societal responses to serious illness, death, and bereavement. The Vrije Universiteit Brussel (VUB) has taken a pioneering role in this endeavor through its 'Compassionate University' program. In this dissertation, I started with exploring suitable evaluation approaches for studying the complex processes behind such Compassionate Community initiatives. Subsequently, I examined the developmental journey towards establishing a Compassionate University. To ensure that the Compassionate University program evolved in alignment with community needs, I investigated the experiences and support needs of students and staff navigating serious illness, death, and bereavement within the university context. Additionally, I examined the experiences of students and staff who engaged in the Compassionate Week, a death and grief festival held on the university campus. Finally, I documented the activities and outcomes of the Compassionate University program to illustrate its potential impact. While there remains much work ahead, the steps taken mark a significant process towards fostering a compassionate environment for students and staff as they navigate some of life's most common, challenging, and life-changing experiences.

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English summary

1. Rationale and research purpose

At different points in our lives, regardless of our age, gender, location, or socioeconomic status, everyone will face experiences of serious illness, death, and bereavement. Yet these experiences too often appear as taboo topics and are almost exclusively embedded in professional healthcare narratives and practices. In response, the Compassionate Community approach has been introduced as a new public health initiative, emphasizing the need to empower communities and build capacity to support each other in times of serious illness, death, and bereavement. There is a compelling argument that higher education institutions are particularly interesting settings for adopting this approach. They can play a crucial role in supporting the well-being of students and staff while establishing best practices for addressing and accommodating these experiences.

In November 2019, the Vrije Universiteit Brussel (VUB) declared itself Europe's first 'Compassionate University'. The rectorate signed a declaration of intent with action points aimed at fostering a compassionate environment. These action points include: improving access to professional health services; supporting bottom-up initiatives related to serious illness, death, and bereavement; offering training and coaching on these topics; raising awareness through activities such as exhibitions and debates; and organizing commemorative moments. A core team, comprised of stakeholders from different university departments, including the Rectorate, Student Counseling Center, Human Resources, Marketing and Communications, and the Compassionate Communities Center of Expertise (COCO), is responsible for implementing the action points. The overall aim of this dissertation is to examine the development process of the VUB towards a Compassionate University.

2. Discussion of the main findings

Before studying the development process towards a Compassionate University, it was essential to identify appropriate evaluation approaches. Therefore, I started with examining suitable theoretical frameworks for understanding the complex processes behind Compassionate Community initiatives. As a result, three theoretical frameworks were identified: The Consolidated Framework for Implementation Research (CFIR), the integrated-Promoting Action on Research Implementation in Health Services framework (i-PARIHS), and the Extended Normalization Process Theory (ENPT). Consequently, two of these frameworks, namely CFIR and (E)NPT, were used to analyze the development process towards a Compassionate University. This analysis revealed that establishing a

shared understanding of the goals and scope of the Compassionate University program proved challenging due to different interpretations of the term “compassionate”. The multidisciplinary composition of the core team and the intrinsic motivation of its members were highlighted as assets in moving the program forward. However, several barriers complicated the development process, including a lack of good practice examples, the fragmented university environment, and limited prioritization of the topics within the university.

To guide the development process toward a Compassionate University and ensure alignment with community needs, a qualitative study was conducted on the experiences and support needs of students and staff. This study revealed that the university is often perceived as a demanding environment with little space for serious illness and grief. Students and staff emphasized the importance of developing transparent bereavement policies and procedures. Staff also expressed a need for ‘compassionate leadership training’ to increase organizational knowledge of bereavement leave administration. In addition, it was stressed to be mindful of individual differences in grief experiences, which requires personalized accommodations. Finally, students and staff suggested organizing discussion cafes, support groups and other (artistic) events to promote positive attitudes toward these topics on university campuses. Responding to this, the Compassionate Week, a thematic festival around grief and loss, was organized on the university campus as part of the Compassionate University program. Interviews with participants of the Compassionate Week indicated that the activities created openness to express and share experiences of loss and grief, encouraged compassion (i.e., reflecting on and acting upon the suffering of others), and raised awareness of serious illness, death, and bereavement as integral parts of school and work life.

Finally, the activities and outcomes of the Compassionate University program were evaluated using Ripple Effects Mapping (REM) as a participatory evaluation approach. One of the main outcomes of the Compassionate University program has been fostering a cultural shift within the university towards greater acceptance and integration of issues of serious illness, death, and bereavement into existing practices. Additionally, the Compassionate University core team took steps to address policy impediments, such as revising expense regulations to include budgets for gifts to colleagues facing illness or loss. They also had a significant role in formalizing existing documents and protocols for dealing with the death of a student or staff member. Furthermore, their pioneering efforts have attracted interest from various educational institutions seeking guidance and inspiration on how to cultivate a more compassionate environment.

3. Implications for policy, practice, and further research

Based on the findings of this dissertation, several implications for policy, practice, and future research can be formulated. First, developing a Compassionate Community requires a deep understanding of the current values, beliefs, perspectives, and priorities of community members related to end-of-life issues. Therefore, it is recommended that community members are involved in the priority-setting stages of Compassionate Community development. Additionally, adopting an asset-based community approach is encouraged. This approach focuses on leveraging existing resources and assets rather than starting from scratch, fostering a more sustainable and integrated development process.

Second, it is crucial to develop clear and transparent bereavement leave policies that are flexible in their application. Current bereavement leave policies often do not provide employees with sufficient time to grieve, usually only around three days. Requiring a doctor's proof for additional days unfairly classifies grief as a 'disease.' Offering longer periods and allowing flexibility in how and when leave is taken can accommodate the diverse and long-term nature of grief. Further, supervisors may be helped by a bereavement protocol with a set of focal points. Additionally, student bereavement is a pressing concern that is often overlooked in university policy development and practice. Universities need to develop clearer, more inclusive, and easily accessible policies to effectively support grieving students, including long-term support after the death of a loved one.

Third, it is important to create space and recognition for experiences of grief and loss on university campuses. Death and grief festivals, such as the Compassionate Week, can enhance visibility and promote open dialogue about serious illness, death, and bereavement. To optimize the impact of these events, it is essential to offer a variety of activities, from personal storytelling to silent reflection, to accommodate different comfort levels. Furthermore, these events can foster internal collaboration and support the emergence of bottom-up initiatives.

For further research, it is important to focus on the experiences of students and staff who are facing serious illness or who are providing informal care. This group is often overlooked in research, yet a significant proportion of students combine their studies with caregiving responsibilities. Additionally, there is a need to understand the grief experiences and support needs of the culturally diverse and international university population. Further research should also provide insights into the perspectives and experiences of university stakeholders, such as student psychologists and HR personnel, in dealing with these issues since they are often the first point of contact for students and staff facing serious illness or bereavement.

Nederlandstalige samenvatting

1. Rationale en onderzoeksdoel

Op een bepaald moment in ons leven krijgen we allemaal te maken met ziekte, dood, rouw, of verlies. Toch blijven deze thema's vaak taboeonderwerpen en zijn ze bijna uitsluitend ingebed in professionele zorgpraktijken. Als reactie hierop werd de 'Compassionate Community'-benadering geïntroduceerd, gericht op het empoweren van gemeenschappen om elkaar te ondersteunen tijdens deze uitdagende periodes. Er is een sterk argument dat hoger onderwijsinstellingen zich in een unieke positie bevinden om de principes van deze benadering toe te passen en te ontwikkelen naar 'compassionate' scholen en werkplekken.

In 2019 riep de Vrije Universiteit Brussel (VUB) zichzelf uit tot Europa's eerste 'Compassionate University'. Het rectoraat ondertekende een intentieverklaring met actiepunten die gericht zijn op het bevorderen van een compassievolle gemeenschap, waaronder: het verbeteren van de toegankelijkheid van professionele gezondheidsdiensten; het ondersteunen van bottom-up initiatieven met betrekking tot ernstige ziekten, rouw, en verlies; het aanbieden van training en coaching over deze onderwerpen; bewustmaking door middel van activiteiten zoals tentoonstellingen en debatten; en het organiseren van herdenkingsmomenten. Een kernteam, bestaande uit belanghebbenden van verschillende universitaire afdelingen waaronder het rectoraat, Studentenzaken, Mens en Organisatie, Marketing en Communicatie, en het Compassionate Communities Centre of Expertise (COCO) werkt aan de uitvoering van deze actiepunten. De hoofddoelstelling van dit proefschrift is om het ontwikkelingsproces van de VUB naar een Compassionate Univeristy in kaart te brengen.

2. Bespreking van de belangrijkste bevindingen

Om het ontwikkelingsproces naar een Compassionate University te bestuderen, was het van belang om geschikte evaluatiekaders te identificeren voor het begrijpen van de complexe processen achter Compassionate Community-initiatieven. Op basis van een scoping review werden drie geschikte kaders geïdentificeerd: Het Consolidated Framework for Implementation Research (CFIR), het Integrated-Promoting Action on Research Implementation in Health Services framework (i-PARIHS), en de Extended Normalization Process Theory (ENPT). Vervolgens werden twee van deze theoretische kaders, namelijk CFIR en (E)NPT, gebruikt om het ontwikkelingsproces naar een Compassionate University te analyseren. Uit deze analyse bleek dat het een uitdaging was om tot een gedeeld begrip te komen van de doelen van het Compassionate University-programma vanwege verschillende

interpretaties van de term “compassionate”. De multidisciplinaire samenstelling van het kernteam en de intrinsieke motivatie van de leden werden benadrukt als sterke punten om het programma vooruit te helpen. Er werden echter ook obstakels geïdentificeerd die het ontwikkelingsproces bemoeilijkten, waaronder een gebrek aan goede praktijkvoorbeelden, de gefragmenteerde universitaire omgeving, en de beperkte prioritering van deze onderwerpen binnen de universiteit.

Om ervoor te zorgen dat het Compassionate University-programma aansluit bij de behoeften van de gemeenschap, werd een kwalitatieve studie uitgevoerd naar de ervaringen en ondersteuningsnoden van studenten en personeelsleden. Deze studie onthulde dat de universiteit vaak wordt ervaren als een veeleisende omgeving met weinig ruimte voor ernstige ziekte, rouw, en verlies. Studenten en personeelsleden benadrukten het belang van transparante beleidsmaatregelen en procedures omtrent rouwverlof en het uitstellen van examentaken. Personeelsleden gaven ook aan dat er nood is aan ‘compassionate leiderschap training' om de organisatorische kennis over rouwverlof en ondersteuning te vergroten. Daarnaast werd benadrukt dat er rekening gehouden moet worden met individuele verschillen. Ten slotte, stelden studenten en personeelsleden voor om gesprekscafés, steungroepen en andere (artistieke) evenementen te organiseren om een positieve houding ten opzichte van deze onderwerpen op universiteitscampussen te bevorderen. Als antwoord op deze suggestie, werd een thematische week, de Compassionate Week, rond rouw en verlies georganiseerd op de campus. Interviews met deelnemers van de Compassionate Week toonden aan dat de activiteiten tijdens de Compassionate Week openheid creëerde om ervaringen van verlies en rouw te uiten en te delen, compassie stimuleerden (d.w.z. nadenken over en handelen naar het lijden van anderen), en het bewustzijn verhoogden dat men niet alleen staat in deze ervaringen.

Tot slot werden de activiteiten en uitkomsten van het Compassionate University-programma geëvalueerd. Een van de belangrijkst bijdragen van Compassionate University is het aansturen van een verschuiving binnen de universiteit in de richting van acceptatie en integratie van onderwerpen als ernstige ziekte, overlijden en rouw in bestaande praktijken. Daarnaast nam de kerngroep stappen om beleidsbelemmeringen aan te pakken, zoals het herzien van onkostenregelingen om budgetten op te nemen voor giften aan collega's die te maken hebben met ziekte of verlies. Verder speelde de kerngroep een rol in het formaliseren van protocollen voor het omgaan met het overlijden van een student of personeelslid. Een andere uitkomst van het programma is het ontstaan van informele netwerken waarbij collega's meer geneigd zijn om kernleden te benaderen voor informatie of hulp in verband met ernstige ziekte of overlijden. Bovendien werd er de interesse gewekt van onderwijsinstellingen die op zoek zijn naar inspiratie voor het cultiveren van een compassievolle omgeving.

3. Implicaties voor beleid, praktijk, en verder onderzoek

Op basis van de resultaten van dit proefschrift kunnen verschillende implicaties voor beleid, praktijk, en toekomstig onderzoek worden geformuleerd. Ten eerste vereist het ontwikkelen van een Compassionate Community een diepgaand begrip van de huidige overtuigingen, perspectieven en prioriteiten van de gemeenschap. Het omarmen van een 'asset-based community' benadering wordt aangemoedigd. Deze benadering richt zich op het benutten van bestaande middelen en 'assets' of sterktes in de gemeenschap, wat een duurzamer en geïntegreerd ontwikkelingsproces bevordert.

Ten tweede is het cruciaal om een transparant en flexibel beleid te ontwikkelen rond rouw. Het huidige rouwverlofbeleid biedt werknemers vaak onvoldoende tijd om te rouwen, meestal slechts drie dagen. Het vereisen van een doktersbriefje voor extra dagen classificeert rouw onterecht als een 'ziekte'. Door langere periodes aan te bieden en flexibiliteit toe te staan in hoe en wanneer het verlof wordt opgenomen, kan er tegemoet worden gekomen aan de diverse en langdurige aard van rouw. Verder kunnen leidinggevenden geholpen zijn met een rouwprotocol. Een protocol mag er niet toe leiden dat in een situatie van rouw en verlies de regels de bovenhand nemen, maar kan wel gevoeligheid creëren voor de materie. Bovendien moeten universiteiten duidelijkere, meer inclusieve en gemakkelijk toegankelijke maatregelen ontwikkelen om rouwende studenten effectief te ondersteunen, inclusief langdurige ondersteuning na het overlijden van een dierbare.

Ten derde is het belangrijk om ruimte te creëren en erkenning te geven aan ervaringen van rouw en verlies op universiteitscampussen. Rouwfestivals, zoals de Compassionate Week, kunnen de zichtbaarheid aanzienlijk vergroten en een open dialoog bevorderen over ernstige ziekte, dood en verlies. Het is essentieel om een verscheidenheid aan activiteiten aan te bieden tijdens deze evenementen, van persoonlijke verhalen tot stille reflectie. Rouwfestivals kunnen tevens interne samenwerking aanmoedigen en de ontwikkeling van bottom-up initiatieven ondersteunen.

Voor verder onderzoek is het essentieel om te focussen op de ervaringen van studenten en personeelsleden die geconfronteerd worden met ernstige ziekte of mantelzorger zijn. Deze groep wordt vaak over het hoofd gezien, echter combineert een aanzienlijk deel van de studenten hun studie met (mantel)zorgtaken. Daarnaast is er nood om de ondersteuningsnoden van de cultureel diverse en internationale universiteitspopulatie te begrijpen. Verder onderzoek moet zich ook verdiepen in de ervaringen en ondersteuningsnoden van universitaire stakeholders, zoals studentenpsychologen en HR-personeel, omtrent het omgaan met deze thema's aangezien zij vaak de eerste contactpersonen zijn voor studenten en personeel.

List of publications and contributions

PUBLICATIONS IN INTERNATIONAL SCIENTIFIC JOURALS

Bakelants H, Vanderstichelen S, Chambaere K, Van Droogenbroeck F, De Donder L, Deliens L et al. Researching Compassionate Communities: Identifying theoretical frameworks to evaluate the complex processes behind public health palliative care initiatives. Palliative Medicine. 2023, 37(2):291-301. https://doi.org/10.1177/02692163221146589

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Vanderstichelen S, Dury S, De Gieter S, Van Droogenbroeck F, De Moortel D, Van Hove L, Rodeyns J, Aernouts N, **Bakelants H**, Cohen J, Chambaere K, Spruyt B, Zohar G, Deliens L, & De Donder L. Researching Compassionate Communities from an interdisciplinary perspective: the case of the Compassionate Communities Centre of Expertise (COCO). The Gerontologist. 2022, 62(10): 1392-1401. https://doi.org/10.1093/geront/gnac034

COMMUNICATIONS AT INTERNATIONAL CONFERENCES AS SPEAKER

A Compassionate University? A qualitative study of students' and staff's experiences and support needs around serious illness, death, and bereavement. **Bakelants, H** (Speaker), Poster Presentation at 18th European Association for Palliative Care World Congress. 17 Jun 2023. Rotterdam: The Netherlands.

Participatory research in caring communities: Practice what you preach? **Bakelants, H** (Speaker) & Kint, O (Speaker), Workshop at International Conference on Integrated Care (ICIC) 2023. 23 May 2023. Antwerp: Belgium.

Making serious illness, death, dying, and loss 'part of life' in educational institutions. **Bakelants, H** (Speaker), Groot, M (Speaker), Paul, S (Speaker), Desnerck, G (Speaker), Coupez, V (Speaker), Dury, S (Speaker), Oral Presentation as part of a symposium at 7th Public Health Palliative Care International (PHPCI) conference. 23 Sep 2022. Bruges: Belgium.

Caring and Compassionate Communities in Belgium: A focus on their development and evaluation. **Bakelants, H**. (Speaker), Kint, O (Speaker), Dury, S (Speaker) & De Donder, L (Speaker), Oral presentation as part of a symposium at British Society of Gerontology. 8 Jul 2021. Online