Researching Compassionate Communities from an interdisciplinary perspective: the case of the Compassionate Communities Centre of Expertise (COCO)

Authors

Steven Vanderstichelen, MSc, PhD\textsuperscript{1,2,7}, https://orcid.org/0000-0002-7214-704X
Sarah Dury, MSc, PhD\textsuperscript{1,3} https://orcid.org/0000-0003-0743-0364
Sara De Gieter, MSc, PhD\textsuperscript{1,4} https://orcid.org/0000-0002-5596-9076
Filip Van Droogenbroeck, MSc, PhD\textsuperscript{1,5} https://orcid.org/0000-0003-1133-3495
Deborah De Moortel, MSc, PhD\textsuperscript{1,6} https://orcid.org/0000-0002-8542-128X
Lisa Van Hove, MSc\textsuperscript{1,7} https://orcid.org/0000-0003-3809-0892
Julie Rodeyns, MSc\textsuperscript{1,8} https://orcid.org/0000-0002-1640-446X
Nele Aernouts, MSc, PhD\textsuperscript{1,9} https://orcid.org/0000-0001-9127-0871
Hanne Bakelants, MSc\textsuperscript{1,2} https://orcid.org/0000-0002-4509-7649
Joachim Cohen, MSc, PhD\textsuperscript{1,7} https://orcid.org/0000-0002-7224-9476
Kenneth Chambaere, MSc, PhD\textsuperscript{1,10} https://orcid.org/0000-0001-6277-072X
Bram Spruyt, MSc, PhD\textsuperscript{1,5} https://orcid.org/0000-0003-0573-724X
Gabriel Zohar, MSc\textsuperscript{1,8} https://orcid.org/0000-0003-3056-6518
Luc Deliens, MSc, PhD\textsuperscript{1,2,7} https://orcid.org/0000-0002-8158-2422
Liesbeth De Donder, MSc, PhD\textsuperscript{1,3,7} https://orcid.org/0000-0003-4999-5902

for the Compassionate Communities Centre of Expertise (COCO) Consortium

\textsuperscript{1} Compassionate Communities Centre of Expertise, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{2} End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Brussels, Belgium
\textsuperscript{3} Belgian Ageing Studies, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{4} Work & Organisational Psychology, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{5} Tempus Omnia Revelat, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{6} Interface Demography, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{7} Brussels University Consultation Centre, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{8} Brussels Research Centre on Innovation in Learning & Diversity, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{9} Cosmopolis Centre for Urban Research, Vrije Universiteit Brussel (VUB), Brussels, Belgium
\textsuperscript{10} End-of-Life Care Research Group, Ghent University, Ghent, Belgium
†Deliens and De Donder served as co-last authors for this study.

*Address correspondence to: Steven Vanderstichelen, MSc, PhD, Vrije Universiteit Brussel, Compassionate Communities Centre of Expertise, Laarbeeklaan 103 Building K, End-of-life Care Research Group. 1090 Brussels, Belgium. E-mail: Steven.vanderstichelen@vub.be
Abstract

Compassionate Communities are places and environments in which people, networks and institutions actively work together and are empowered to improve the circumstances, health, and well-being of those facing serious illness, death, dying and loss. The study of their development, implementation and evaluation requires an interdisciplinary research approach that has hitherto been lacking. In 2020, eight research groups from four faculties at Vrije Universiteit Brussel (VUB) united in the interdisciplinary Compassionate Communities Centre of Expertise (COCO) to investigate Compassionate Communities. This paper describes the first results of COCO; (1) an interdisciplinary mode of collaboration, (2) a shared conceptual understanding and definition of Compassionate Communities, and (3) a shared research agenda on Compassionate Communities.

**Keywords:** Public health; Death and Dying; Ageing in place; Serious illness; End-of-life
Communities and societies worldwide are facing one of the largest public health challenges in history – a growing population of older persons and individuals with serious (mental or physical) illness (Cohen & Deliens, 2012). In many countries, increasingly neoliberal policies (Brody, 2014), together with social developments such as individualization, decreasing nuclear family size and the proliferation of two-earner households (Kellehear, 1999; NOUS group, 2018), have led to the outsourcing of caregiving to public or private healthcare services or institutions (Rosenberg et al., 2016). Additionally, this increased medicalization and professionalization of serious illness, death, dying and loss stimulates a decrease in community resilience, capacity and confidence to respond to end-of-life issues (Grindrod & Rumbold, 2016). This evolution is particularly prominent in Western, high-income countries, but is increasingly seen in non-Western and in lower and middle-income countries (Sallnow et al., 2022).
To meet these challenges, “Compassionate Communities” have been suggested as a multidimensional, whole-systems approach to improve community circumstances related to serious illness, death, dying and loss (Abel et al., 2018). We argue that the study of this model, its development, implementation, and evaluation requires an interdisciplinary approach. In this paper we describe the joint effort of eight research teams at Vrije Universiteit Brussel (VUB) who united in the Compassionate Communities Centre of Expertise (COCO) to develop an interdisciplinary understanding of Compassionate Communities and a shared research framework. We will first explain why Compassionate Communities are a valid and relevant answer to pressing societal challenges related to experiences of serious illness, death, dying and loss.

**Compassionate Communities as a multidimensional model for responding to serious illness, death, dying and loss**

Compassionate Communities emerged from public health approaches to palliative care and were first conceptualized by Allan Kellehear (2005). Public health palliative care aims to improve and maintain the health and well-being of people confronted by serious illness, death, dying and loss by focusing on population health rather than individual health (Sallnow et al., 2016). There is a growing awareness that solely engaging more professional caregivers and improving health or social services will be insufficient toward guaranteeing good healthcare or social care for all those in need (Kamal et al., 2017; United Nations General Assembly, 2015). In response, Compassionate Communities strengthen community ties and networks and promote power-sharing, ownership of care, and community support as effective vehicles to achieve significant change and necessary improvements in palliative and end-of-life situations (Kellehear, 2005). They encompass a collection of possible approaches that apply the health-promoting principles of prevention, harm reduction and early intervention to
the challenges of serious illness, death, dying and loss (Karapliagkou & Kellehear, 2014). This may be done via top-down, whole-system approaches (Grindrod, 2020) that reorient settings and institutions through policy interventions or that extend health services to local governments, workplaces and schools. It may also be done via bottom-up, community development approaches (Defilippis & Saegert, 2012) that leverage local assets to answer local needs and mobilize community members and local organizations in the social and cultural sector (e.g., art institutions, popular culture and media).

The need for a concerted, interdisciplinary approach to Compassionate Communities research

The Compassionate Communities approach has seen a rapid uptake worldwide with pioneering initiatives being developed and studied in the United Kingdom, Ireland, India, Canada, Australia, Colombia, Argentina, Brazil, South Africa, Spain, Austria (Librada-Flores et al., 2020; NOUS group, 2018), and most recently Belgium, with two Compassionate Cities and the first European Compassionate University (VUB) (Figure 1). The demand from communities for knowledge and expertise on how to develop, implement and evaluate Compassionate Communities is growing fast, but research on outcomes and how to achieve systematic community-level change remains scarce (Collins et al., 2020; Sallnow et al., 2016).

[Figure 1]

Palliative & end-of-life care research has long focused primarily on clinical health services (e.g., hospitals, nursing homes, and specialized palliative care units) (Cohen & Deliens, 2012), with a particular emphasis on professional physical, psychological and social care. However, in recent years, interest in the role of the community in palliative & end-of-life care has grown and evidence on community contributions is slowly building (Sallnow et al., 2016). In addition, much of the current
research on community initiatives aimed at aging in place (e.g., caring neighborhoods, age-friendly initiatives, healthy cities) does not include the topics of serious illness, death, dying and loss – indeed a recent scientometric review of the Age-Friendly Communities & Cities literature does not mention these topics (Xiang et al., 2021). This may be because these topics have traditionally been considered to be clinical and professional matters (Kellehear, 2020). Nevertheless, ageing in place also requires thinking about dying in place. While there is some important literature on dying in place (Lau, 2021), the role of the community in achieving this outcome has not been fully explored. Compassionate Communities is an innovative concept that brings both strands of research (i.e., palliative & end-of-life care and aging and dying in place) together. It emphasizes the need to view and study communities as places in which serious illness, death, dying and loss are embedded and take place. It considers the community as the unifying level where different spheres of influence (e.g., intrapersonal, interpersonal, social, organizational, societal, physical, and cultural) interact and mediate the influence of experiences of serious (mental or physical) illness, death, dying and loss on individual and population health and well-being outcomes (Bronfenbrenner, 1981; Holt-Lunstad, 2018; Holt-Lunstad et al., 2010).

The literature on Compassionate Community approaches is still developing, scattered, and largely monodisciplinary, driven by health sciences (Sallnow et al., 2016; Sallnow & Paul, 2018). Because Compassionate Communities are organic entities, whose functioning and internal dynamics cut across several domains of life and scales of society, monodisciplinary approaches to studying them are inevitably reductive. Additionally, there are increasing calls for interdisciplinary efforts in research and practice regarding community-based approaches to serious illness, death, dying and loss (Brassalotto et al., 2021). Several disciplines have explored aspects related to serious illness, death, dying and loss in their own fields (e.g., the role of spatial design and physical environments in creating better environments for end-of-life care (Davern et al., 2017; Donovan, 2017), compassion and self-compassion as responses to end-of-life related suffering (Raab, 2014; Rushton et al., 2009), the influence of employment status on mortality risk and health (Benach et al., 2014; De Moortel et
al., 2018). However, a concerted and integrated effort, and an interdisciplinary perspective that employs a diverse range of scientific theories and methods (Van Belle et al., 2017) are lacking and interaction between the literatures remains rare.

The potential benefits of such an undertaking are great, however. By connecting and integrating, as we will suggest, insights from health sciences, sociology, psychology, educational sciences, and critical geography, we can better understand how different personal, social, physical, cultural, and organizational environments influence lived experiences, conditions, and outcomes of serious illness, death, dying and loss at different scales and how compassion may be stimulated within them.

We therefore argue that, going forward, the study of Compassionate Communities and their dynamics must be interdisciplinary.

We argue that to facilitate interdisciplinary research in this field, three things will be required: (1) an interdisciplinary mode of collaboration that allows for frequent interaction, (2) shared conceptual understanding of Compassionate Communities and its core concepts, and (3) a shared research framework with interdisciplinary avenues for inquiry. In this paper we detail the example of COCO and how it achieved these three things in its work. We hope this approach and framework may serve others aiming to study the interdisciplinary field of Compassionate Communities and expand our understanding of it.

**Developing an Interdisciplinary Mode of Collaboration**

**Bringing Together Various Scientific Disciplines**

In 2019, eight research groups at VUB (Table 1) joined together to form the Compassionate Communities Centre of Expertise (COCO). The centre was funded by a seeding grant from VUB’s Interdisciplinary Research Program framework with the goal of integrating each group’s unique perspectives on Compassionate Communities. Five academic disciplines are currently represented in COCO, each contributing unique insights to the study of Compassionate Communities.
The experience that Health Sciences have with social and clinical epidemiology and public health palliative care helps understand the social and environmental dimensions of health and well-being (in addition to the biopsychological dimension) (Cohen & Deliens, 2012). Its insights into social ecology and community-development in palliative care help us understand how settings and social networks can influence circumstances at the end of life (Holt-Lunstad, 2018).

Sociology has an extensive grasp of intergroup relationships and stratification, which helps understand how social position and identity shape our decisions and emotions. Sociology of education and contemplative sciences explores compassion as a social emotion in the face of the suffering of others, linked to social cooperation, which can be trained (Galante et al., 2014; Luberto et al., 2018). Labor sociology explores how work and employment environments might influence the outcomes and processes of initiatives that aim to reduce the social impact of serious illness, death, dying and loss at a societal level (Benach et al., 2014; Vanroelen, 2019).

Psychology complements these insights with its own understanding of how affective, behavioral and cognitive processes shape our individual responses to various environments and how individuals leverage internal and external resources in response to stressful events like serious illness, death, dying and loss. Clinical psychology explores self-compassion and how it mediates individual mental well-being and adverse outcomes of caregiving and being near suffering, such as traumatic stress or compassion fatigue (Figley, 2002; Raab, 2014). Work and organizational psychology explores how stressful experiences like serious illness, death, dying and loss in an individual’s family domain influence their functioning and needs at work (Hobfoll et al., 2018; ten Brummelhuis & Bakker, 2012).

The expertise of Educational Sciences focuses on 3 major research areas: (1) educational change and innovation, (2) community development, and (3) arts and cultural education. Research within educational change and innovation seeks to identify leverage mechanisms for change in educational settings and subsequent implementation strategies for compassionate learning environments.
Research on community development brings in expertise on participatory processes and research (i.e. peer-research, co-creation) and helps understand ageing, health, well-being and caregiving as social processes and performances rooted in communities. Scholars in this area study Compassionate Communities through life-course and neighborhood-oriented perspectives, through insights from social gerontology (Martinson, 2007), and through the analysis of community resources to adjust learning and living environments to the needs of individuals and communities (Baars et al., 2006). The research area on arts and cultural education explores how art mediates social performances, catalyzing interactions of individuals and communities with experiences of serious illness, death, dying and loss (Anderson et al., 2019; Rodeyns et al., 2021).

Finally, the expertise of Critical Geography in urban studies, spatial planning, urban design and housing helps us understand the connection between physical environments, social interaction and economic processes (Harvey, 2012; Low, 2017). Together with educational sciences, it offers valuable insights into how place and community connect, interact and facilitate social interaction around experiences of serious illness, death, dying and loss (Davern et al., 2017).

The disciplines currently represented in COCO and the collaborations between them are not intended as a final constellation, but as a starting point. Insights from other disciplines will be crucial to further develop this field of interdisciplinary study. These may include urban planning, architecture, design, bioengineering, anthropology, history, and more.

Creating Interdisciplinary Exchange Spaces

To arrive at a mutual understanding between disciplines, interdisciplinary exchange spaces must be created and considered as integral parts of the research process (Kivits et al., 2019). Two central coordinators facilitated the creation of such spaces through (a) bilateral meetings, (b) group discussions, and (c) collaborative seminars.
First, bilateral meetings were crucial to explore shared notions, expectations, and aspirations regarding COCO. The coordinators hold bilateral meetings at least once per year with each member group. Second, regular group discussions are held to integrate these different expectations and views into a shared vision, mission, and operational goals. These group discussions facilitated the gradual development of a conceptual common ground and shared identity for COCO. Finally, COCO members organize collaborative seminars twice per year to expand opportunities for different disciplines and ideas to interact. These seminars have previously explored the role of educational environments in Compassionate Communities, the intersections of participatory art, choreography, urban landscapes and design, loss and caregiving, and bereavement in the workplace. The importance of this time-consuming process for building trust and familiarity cannot be overstated. Frequent and active involvement of all members ensured that everyone felt heard and helped to develop a shared vision.

**Establishing a Shared Conceptual Understanding**

Through these exchanges, the need arose for shared and minimal definitions of three fundamental concepts on which we could build a shared research framework: “community”, “compassion”, and “Compassionate Communities”. Minimal definitions describe the smallest common denominators of a concept, offering a common ground for a wide variety of approaches and perspectives, and flexibility in its application.

**Defining Community**

Despite a fast-growing interest in Compassionate Communities, communities as settings for serious illness, death, dying, and loss remain understudied. With few exceptions, the Compassionate Community literature has mainly focused on geographic communities such as cities, towns and neighborhoods (Abel et al., 2011; Abel et al., 2018; Horsfall, 2018). However, communities can be
defined in various, non-mutually exclusive ways (Bernard et al., 2012; Greenfield et al., 2018) (see Table 2). We therefore propose the following minimal definition:

**Communities** are social units, groups of individuals that share something in common and may vary in scope, size, scale and strength of within-group ties (social relationships).

**Defining Compassion**

Compassion can be considered a response to suffering (Strauss et al., 2016) that can originate from various experiences and situations throughout life. COCO applies this concept to suffering – physical, mental, social and existential – that originates from experiences with serious illness, death, dying and loss. Compassion may be formulated and implemented at the micro, meso and macro level.

**Compassion as an Individual Attribute (Micro Level)**

Strauss et al. (2016) define compassion as a cognitive, affective and behavioral process that consists of five elements closely related to human suffering. These five elements include 1) its recognition, 2) its universality in human experience, 3) the need for a feeling of empathy for the suffering person and their distress, 4) tolerating uncomfortable feelings resulting from its recognition (e.g., distress, anger, and fear) in order to remain open and non-judgmental, and 5) the motivation to act to alleviate the suffering. Compassion-based interventions have shown a demonstrable effect on health (Galante et al., 2014), prosocial skills and altruistic helping behavior (Luberto et al., 2018).

**Compassion as a Group Attribute (Meso Level)**

Applied to the context of serious illness, death, dying and loss, compassion as a group attribute is manifested in the mobilization of social networks to support people confronted with serious illness, death, dying and loss, and in linking and aligning the efforts of formal and informal carers (Sallnow et al., 2016). Mobilizing informal networks around persons with palliative care needs has been linked to increases in home deaths and use of palliative care services (Burns et al., 2013), reduced caregiver
fatigue and increased confidence in asking for assistance (Greene et al., 2012), and increased network size and strengthened network ties for bereaved carers (Leonard et al., 2015). Additionally, community-based volunteering initiatives for persons with palliative care needs living at home have been suggested to contribute to social capital (Sallnow, 2018).

**Compassion as a Societal Attribute (Macro Level)**

Compassion implemented at the macro level requires a structural, systematic and sustainable approach to providing long-term answers to the social challenges posed by experiences of serious illness, death, dying, loss and end-of-life care at the population level. This often requires a policy-oriented approach – commonly charter-based (Kellehear, 2016) – to connect different societal sectors in a concerted effort to realize structural changes and macro-level outcomes (e.g., reduced emergency hospital admissions (Abel et al., 2018), increased end-of-life options for vulnerable populations (Grindrod, 2020) and facilitating community-driven action (Grindrod & Rumbold, 2016)).

We propose the following minimal definition of compassion applied to suffering due to serious illness, death, dying and loss:

*Compassion can be an individual behavior or affective state, group strategy, or societal structure or policy that responds to or aims to prevent any suffering originating from experiences with serious (mental or physical) illness, death, dying and loss or that aims to proactively improve the circumstances of people affected by these challenges.*

**Defining Compassionate Communities**

The question remains as to what makes a community compassionate. The literature does not provide a definitive answer. It is often vague (Librada-Flores et al., 2020) or tautological by formulating definitions in terms of outcomes (e.g., Compassionate City charter actions (Kellehear, 2016)) rather than the processes or structures through which such outcomes are
attained. To open Compassionate Communities up as an area for interdisciplinary research, we propose the following minimal definition:

**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.

**Setting Up a Shared Research Framework**

Building on the core concepts described above, we defined a research framework consisting of a shared research agenda and approach.

**A Shared Research Agenda**

The COCO research agenda consists of three overarching objectives:

1. To develop an interdisciplinary, theoretical research framework to study the development, implementation and evaluation of Compassionate Communities.
2. To develop a methodological toolbox: a collection of effective and feasible methods to describe, understand and evaluate Compassionate Communities.
3. To describe and understand the outcomes and processes behind Compassionate Community development and implementation and evaluate the impact of Compassionate Communities.
Three synergetic research themes were identified for the COCO consortium to pursue the objectives. More may be added in the future.

**Theme 1: Operationalizing and Measuring Compassion**

Compassion as an individual attribute, disposition and behavior is well-documented in sociological and psychological studies (Figley, 2002; Galante et al., 2014), yet more work is needed to develop the concept at the group and societal level and to operationalize these concepts (e.g., outcome and process indicators for measuring compassion at the individual, group and societal level) and evaluate their cross-cultural and social validity.

**Theme 2: Studying Transitions Toward Compassionate Communities and Their Sustainability**

The development and implementation processes underlying transitions toward Compassionate Communities are not yet fully understood (Librada-Flores et al., 2020). We want to explore the policies, structures, processes, and practices that stimulate compassion, and how compassion manifested at one level can influence it at others. For instance, how do community members internalize, sustain, and reconfigure new practices over time? How can communities be reoriented to provide space for serious illness, death, dying and loss, and how can different media (policy, art, space) shape this process? How can compassion be trained at different scales?

**Theme 3: Compassionate Community-building in Specific Contexts**

Individuals may belong to several overlapping and nested communities. We wish to explore how different physical, social, organizational, and living environments can manifest and stimulate compassion.

**Compassionate Workplaces.** Serious illness, death, dying and loss can be stressors that uniquely impact work environments in terms of work-family spillover, labor market opportunities,
employment status and employee well-being (Nielsen et al., 2017; ten Brummelhuis & Bakker, 2012), and can promote accumulation of health-damaging characteristics (e.g., poor-quality employment or housing) (Benach et al., 2014; Vanroelen, 2019). We want to explore how serious illness, death, dying and loss influence job certainty, employment opportunities, and the interaction between work and family life.

**Compassionate Schools and Learning Environments.** Schools and learning environments can create spaces to discuss serious illness, death, dying and loss, help integrate these experiences in local communities (Paul et al., 2016), and help children define their emotional responses to loss and overcome their anxiety when talking about grief (Stylianou & Zembylas, 2018). We want to explore the role of educational and cultural institutions in fostering compassion, supporting community experiences of serious illness, death, dying and loss, and cultivating health, well-being, and healthy attitudes towards them.

**Compassionate Infrastructure and Design.** We want to explore how we can create living environments and infrastructure to support people affected by serious illness, death, dying and loss and to stimulate compassion at various levels. We want to explore the creation and transformation of infrastructure and living environments to host and treat serious illness, death, dying and loss with dignity; how such environments create opportunities for care provision, and build and maintain community ties; and how infrastructure can facilitate social support networks for people affected by serious illness, death, dying and loss (Andreucci et al., 2019; Davern et al., 2017).
A Shared Research Approach

Stakeholder Engagement and Co-creation

Efforts to develop and implement Compassionate Communities should ensure their relevancy, feasibility and acceptability to those that will be affected by them. COCO therefore applies the principles of co-creation and public engagement at all stages – development, implementation and evaluation – of each of its projects. These principles will be explicitly operationalized in study protocols and in agreement with all stakeholders (i.e., communities and their members), ensuring shared ownership by and active representation of all stakeholders. To connect research and practice, COCO emphasizes participatory action research approaches, bringing together action and reflection, theory and practice (Reason & Bradbury, 2008), and involving stakeholders in needs and priority assessments (Bowling, 2014).

Living Labs

COCO will employ Living Labs – user-centered, open innovation ecosystems based on systematic user co-creation (ENOLL, 2021). Living Labs involve communities and citizens in formulating local answers to local needs with sustainability in mind. They are practice-driven, real-life environments that foster innovation, and allow for these innovation processes to be studied. They help us research the application and translation of conceptual models and principles in various practical settings. COCO will partner with cities, institutions and the societal sectors that shape our communities (e.g., schools, workplaces, civil society associations, governments, cultural organizations, advocacy groups) to develop Living Labs. To date, COCO currently has three active living labs: one Compassionate University (VUB), and two Compassionate Cities (Bruges and Herzele).

Example of Ongoing COCO Research

COCO currently has several ongoing research projects that are guided by the research approach outlined in this paper. One of these is the doctoral study exploring the processes underlying the
development of a Compassionate University at the Vrije Universiteit Brussel (VUB) (2020-2024). The study combines health sciences (EOLC), sociology (TOR) and educational sciences (BAST) and applies insights from Complexity Science and Implementation Science to identify implementation opportunities, barriers, and potential for upscaling of this project. The study fits within research theme 2 (the study of transitions toward Compassionate Communities and their sustainability) and theme 3 (Compassionate Community-building in specific contexts: schools and workplaces). It applies the principles of stakeholder engagement and participatory action research as the university itself functions as a Living Lab and researchers are involved as end-users (university staff, doctoral student) and steering group members of the Compassionate University project group led by the VUB. By working closely with rectorate staff, the human relations department, student representatives and the communication & marketing department, research and practice are intimately connected and new insights are fed back to the stakeholders.

The study aims to answer the following research questions using a variety of qualitative and quantitative approaches:

1. How is the Compassionate University developed/co-created by the leading coalition? (i.e., describing the development process)
2. Which mechanisms bring about change and which mechanisms prevent change during the transition process?
3. Which changes (and outcomes) occur as a result of the transition process?

**Conclusion**

We have argued for the need of an interdisciplinary research approach to the study of Compassionate Communities and have outlined a way forward for this research based on the Compassionate Communities Centre of Expertise’s (COCO) approach. We proposed an interactive mode of collaboration across faculty and disciplinary borders, minimal definitions of the core
concepts of “community”, “compassion”, and “compassionate communities”, and a shared research framework, including a co-creative approach and thematic research agenda to drive scholarship forward. The processes described are time-consuming, require patience, close coordination, and frequent interaction, but have for COCO resulted in a shared foundation, vision, and research framework between researchers, schools, healthcare networks and governments (e.g., Living Labs) that had no previously existing working relationships. Given the growing interest from governments, communities, and institutions, we hope that the COCO approach can serve other researchers aiming to expand our understanding of Compassionate Communities.
Funding

This work was supported by the Vrije Universiteit Brussel (VUB) through its Interdisciplinary Research Program framework [IRP16].

Conflict of Interest

We have no conflict of interest to declare.

Acknowledgment

The COCO consortium is an interdisciplinary research consortium composed of researchers from Vrije Universiteit Brussel (VUB), Belgium (Prof. Dr. Luc Deliens, Prof. Dr. Joachim Cohen, Prof. Dr. Kenneth Chambaere, Prof. Dr. Liesbeth De Donder, Prof. Dr. Sarah Dury, Prof. Dr. Tinne Smets, Prof. Dr. Filip Van Droogenbroeck, Prof. Dr. Bram Spruyt, Prof. Dr. Free De Backer, Prof. Dr. Koen Lombaerts, Prof. Dr. Imke Baetens, Prof. Dr. Peter Theuns, Prof. Dr. Chris Schotte, Prof. Dr. Dominique Verté, Prof. Dr. An-Sofie Smetcoren, Prof. Dr. Sara De Gieter, Prof. Dr. Michael Ryckwaert, Prof. Dr. Christophe Vanroelen, Dr. Steven Vanderstichelen, Dr. Deborah De Moortel,, Dr. Inge Debast, Prof. Dr. Veerle Soyez, Dr. Eva Dierckx, Dr. Karen Puttemans, Lisa Van Hove, Hanne Bakelants, Louise D’Eer, Bert Quintiens, Julie Rodeyns, Gabriel Zohar.)

Data Management and Sharing

Not applicable.

Ethical Considerations

No ethical approvals were required.
References


Librada-Flores, S., Nabal-Vicuña, M., Forero-Vega, D., Muñoz-Mayorga, I., & Guerra-Martín, M. D. (2020). Implementation Models of Compassionate Communities and Compassionate Cities at the End of Life: A Systematic Review. International Journal of Environmental Research and...


## Table 1: The disciplines, research groups and expertise represented in COCO, 2021

<table>
<thead>
<tr>
<th>Research domains</th>
<th>Disciplines</th>
<th>Research Group</th>
<th>Expertise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical Sciences</td>
<td>Health sciences</td>
<td>End-of-Life Care Research Group (EoLC)</td>
<td>Primary care, health services and professional partnerships, care volunteers, death literacy, and palliative and end-of-life care</td>
</tr>
<tr>
<td>Human and Social Sciences</td>
<td>Sociology</td>
<td>Tempus Omnia Revelat (TOR)</td>
<td>Compassionate attitude training programs to improve well-being and prosocial attitudes, and reduce intergroup prejudice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interface Demography (ID)</td>
<td>Psychosocial working conditions and tackling social inequality in health</td>
</tr>
<tr>
<td>Psychology</td>
<td></td>
<td>Brussels University Consultation Centre (BRUCC)</td>
<td>Measurements and tools on dealing with bereavement, self-compassion training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Work &amp; Organisational Psychology (WOPS)</td>
<td>Improving psychosocial well-being and functioning of employees in caring/grieving situations</td>
</tr>
<tr>
<td>Educational sciences</td>
<td></td>
<td>Belgian Ageing Studies (BAS)</td>
<td>Community development and change, social exclusion and inclusion, social gerontology</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Brussels Research Centre for Innovation and Learning Diversity (BILD)</td>
<td>Social, cultural, and educational sector, art, and cultural education</td>
</tr>
<tr>
<td>Basic, Natural and Applied Sciences</td>
<td>Geography</td>
<td>Cosmopolis Centre for Urban Research</td>
<td>Geography, spatial planning, urban design, embedding care solutions in sustainable housing environment, including safe social and physical environments and fostering social inclusion</td>
</tr>
</tbody>
</table>
Table 2: Examples of types of communities with examples from Compassionate Communities

<table>
<thead>
<tr>
<th>Type of community</th>
<th>Definition</th>
<th>General examples</th>
<th>Examples from Compassionate Communities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community of Place</td>
<td>Communities that emerge around a shared identity based on a shared geographical area</td>
<td>Neighborhoods, villages, cities, regions, countries, schools</td>
<td>Compassionate Plymouth (UK), Bruges (BE), Frome (UK), Burlington (CA), Cologne (DE)</td>
</tr>
<tr>
<td>Community of position</td>
<td>Communities that emerge around shared life stages</td>
<td>Teenagers, students, persons entering the job market, married couples, parents, retired adults, persons who have lost a loved one</td>
<td>Coffin Clubs, Compassionate Schools (Herzele (BE), Plymouth (UK))</td>
</tr>
<tr>
<td>Community of Interest</td>
<td>Communities that emerge around the same common interest or passion</td>
<td>Football fans, heavy metal fans, trekkies, theater fans, student associations, hiking groups, festival goers</td>
<td>Coffin Clubs, Death Cafés, Public Health Palliative Care International</td>
</tr>
<tr>
<td>Community of Action</td>
<td>Communities that emerge around common goals that direct the collective action</td>
<td>Social movements, charity movements, political participation</td>
<td>Plantroost (BE), Reveil (BE), Dying to Know Day (AUS), Compassionate Neighbours (UK)</td>
</tr>
<tr>
<td>Community of Practice</td>
<td>Communities that emerge from processes of social learning and idea-sharing through collaboration over extended periods of time</td>
<td>Wikipedia, Healthcare Information for All (HIFA2015)</td>
<td>Compassionate workplaces, Compassionate University VUB (BE), The Resilience Project (UK)</td>
</tr>
<tr>
<td>Community of Circumstance</td>
<td>Similar to communities of practice, except they may be driven by position, circumstance, or life experiences rather than a shared interest.</td>
<td>Festivals, AA (Alcoholics Anonymous) Fight Cancer Global</td>
<td>To Absent Friends festival (UK)</td>
</tr>
</tbody>
</table>

*a Description of community of place adapted from Bernard et al. (2012). Descriptions of communities of position, interest, action, practice and circumstance adapted from Draghici et al. (2008).*