

Compassionate communities: How to assess their benefit? A protocol of a collaborative study between different countries

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Abstract

Background: Communities and local governments invest in compassionate communities (CCs) a great deal of time, money, effort, and work. However, it is not known whether the CCs are having the effect they are expected to have, so the value of continuing with these initiatives is unknown, and there is a need for a model for evaluating CCs to solve the question.

Objectives: To identify a set of core outcomes or benefits that should be measured to assess the impact of the CCs.

Design: Multiple-methods study involving three communities, each in a different country (Argentina, Colombia, and Switzerland).

Methods and analysis: To identifying the set of core outcomes, which is the first step in developing the CC evaluation model, five phases will follow: online meetings, literature review, fieldwork, Delphi survey, and social transfer. We will involve members of the local communities of Bern, Buenos Aires, and Medellín at three different levels: (1) citizens (e.g. patients, caregivers, and family members), (2) organizations and institutions involved in the program implementation (e.g. health care organizations, churches, non-governmental organizations, and schools), and (3) political and governmental sectors.

Ethics: The study will be conducted following existing international regulations and guidance such as the Declaration of Helsinki. The ethics committee of Pallium Latin America and the ethics committee of the canton of Bern considered our application exempt from the need for approval. Ethics approval in Bern and Buenos Aires is in the process of being obtained. The ethics committee of the Pontifical Bolivarian University approved this protocol.

Discussion: We expect that this project will help bridge the gap in knowledge regarding the measurable impact of the CCs and enhance more CC development.

Keywords: compassionate communities, palliative care, public health

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Introduction

Death is a sensitive topic. In most cultures, people find it difficult to talk about death and dying,^{1,2} which complicates bereavement and hinders preparation for death for both the persons facing the end of life and their family/caregivers.^{1,2}

The compassionate communities (CCs) movement seeks to normalize conversations about

death and dying and promotes the active participation of society in the end-of-life process.³ In addition, this movement seeks to create resilient cities by empowering members of specific communities to support each other during illness and caregiving.⁴ Moreover, the pandemic and post-pandemic increased the challenge of dealing with social isolation, unwanted loneliness, and bereavement, as well as the need to connect with

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others and develop new ways of support provided by informal social networks.^{5,6}

The concept of CCs comes from the model of 'healthy cities' which began in 1986 with the World Health Organization Ottawa Charter.⁷ In 2005, Dr Alan Kellehear coined the term 'Compassionate Communities'.⁴ By the mid-2000s, the program already existed in the United Kingdom, Australia, and India. Since then, its use has spread to many other countries, particularly in recent years. Despite the initiative seeks to contribute to community welfare, there is little evidence of their benefits for the community. As two recent reviews found, there is little and poor-quality evidence on the evaluation of CC models.^{8,9} In addition to this gap, the researchers highlighted that there are no comparative studies of CCs given the lack of consensus on how to evaluate them.^{8,9} Communities and local governments invest in the CCs a great deal of time, money, effort, and work. However, it is not known whether the CCs are having the effect they are expected to have, so the value of continuing with these initiatives is unknown. There is a need for a model for evaluating CCs to solve the question. Such an evaluation model should be generalizable to different contexts. An evaluation model that emerges from the experience of a CC in a small city in a high-income country may not be transferable to a CC in a large city in a low- or middle-income country. In addition, although compassion may be considered universal, such a model would contribute to increase awareness and knowledge about the extent to which cultural backgrounds moderate the experience of CCs. Therefore, we aim to create an evaluation model involving three CC programs in three particularly different cities (Medellin, Buenos Aires, and Bern) in terms of culture, geography, population size, resources, and so on.

The first step in developing this CC evaluation model will be to identify a set of core outcomes or benefits (hereafter referred to as 'outcomes') to be measured to assess the impact of the CCs. Then, we will identify indicators to measure these outcomes. Finally, we will create a toolkit that details the steps to evaluate CCs. This protocol focuses on the first step: the identification of a set of core outcomes.

Aims

- To develop a set of core outcomes that are relevant, measurable, and feasible to collect, to evaluate CC programs.

- To establish a network of international collaborators for the joint creation of the core set of outcomes and the next steps to create the evaluation model.
- To disseminate the results of the project to the community and to stakeholders involved in the three main CCs of this project.

Methods and analysis

Study design

This multiple-methods study based on the methodology developed by The Core Outcome Measures in Effectiveness Trial (COMET) initiative involves three communities, each in a different country. The COMET initiative advocates standardization of outcomes through the development of core outcomes sets.^{10,11} A core outcomes set (COS) is the minimum agreed outcomes that should be measured and reported in clinical studies for a specific topic. The COMET approach recommends four stages for the creation of the COS: a systematic review of the literature to identifying outcomes that have already been evaluated, gathering information to identify outcomes from the point of view of different experts, a Delphi process to rank the outcomes, and a consensus meeting to propose and agree on the final set of core outcomes.¹²

This study was approved by the ethics committee of the Pontifical Bolivarian University (Act #24 of 2022). The ethics committee of Pallium Latin America (Act of 28 December 2022) and the ethics committee of the canton of Bern (Req-2022-10152) considered our application exempt from the need for approval.

Setting and context

Medellin. In Medellin, the CC program started in 2015 and, since then, has been led by the Pontifical Bolivarian University.^{13,14} In its beginnings, it was called 'Medellin Compasiva, Todos Contigo' (in English, 'Compassionate Medellin, All with you'), following the New Health Foundation model.¹⁵ Later, the program became independent, adjusting to the needs of the local community and was renamed 'Red Compasiva' (In English, 'Compassionate network'). Since 2015, more than 450 health professionals, 300 informal caregivers, 44 community youth, and 150 volunteers have been trained in Medellin as part of the CC program,¹⁴ and about 3250 people have

benefited from the program.¹⁴ In addition, during the COVID-19 pandemic, the CC program broadened its scope of action to accommodate the population needs at this specific time, providing information on polymerase chain reaction (PCR) testing, access to healthcare, and community resources in times of COVID.

Buenos Aires. The CC program started in Buenos Aires in 2015 as a collaboration agreement with New Health Foundation.¹⁵ Since then, Buenos Aires Compassionate City Program ‘Todos Contigo’ (in English, ‘All with you’) has been led by Pallium Latin America,^{13,16} with the participation of an interdisciplinary team of healthcare professionals and volunteers. In 2016, the Inauguration of the first compassionate in-hospital ward at Dr. Carlos Bonorino Udaondo hospital (oncology and palliative care sector) took place. Collaborative work has been developed articulating different activities, including community action and training. During the pandemic, the ‘All with you’ team developed a protocol to guide healthcare teams and community members affected by COVID-19 or other pathologies. In 2022, an agreement was made to develop a CC program in excluded communities with a high percentage of migrants located in the southern area of the Autonomous City of Buenos Aires.

Bern. In Bern, the CC program started in 2018 under the initiative and direction of a Professor in Palliative Care together with the City Council of Bern (Stadt Bern) through different activities, such as public talks and film showings for fostering public and political attention and awareness toward the challenges of providing end-of-life care. In 2019, the University of Bern and the Age Institute from the Bern University of Applied Sciences received funding from Gesundheitsförderung Schweiz for a project about CCs in Bern and Frutigland, a rural area close to the city of Bern.¹⁷ In 2020, the continuing collaboration with the City Council of Bern led to the signing of the CC Charter, making Bern an official Compassionate City.

Population

The focus of the design of this study is the community. Different sectors of the community will be involved in multiple phases of this study. We will involve members of the communities of the three cities at three different levels: (1) citizens (e.g. patients, caregivers, and family members),

(2) organizations and institutions involved in the program implementation (e.g. health care organizations, churches, non-governmental organizations, and schools), and (3) political and governmental sectors. In the latter, we will identify leaders from the local government’s administrative sections, such as education, health, and volunteer programs, and we will identify key individuals from the political sector and opinion leaders from various groups of the city councils.

Preliminary work

First, we had an online meeting to briefly exchange the experience of the three programs and discuss and define preparation and initiation activities. In addition, by way of example, we have extracted some outcomes reported in original research articles or reviews to discuss them on a second online meeting. During that second meeting, we agreed to develop discussion groups in each participating city to prepare us to conduct a workshop at the Public Health Palliative Care International (PHPCI) conference in 2022. Each city held a discussion group with the participation of CC program referents and discussed ideas about the expected benefits of CC programs. Then, on a third online meeting, we shared the experience and prepared the PHPCI workshop. During this workshop, we presented the CC program in each city and the research proposal. Then we asked the attendees to propose and discuss the expected benefits of CC programs. The PHPCI conference is the only international conference that addresses the topic of CCs and is a meeting point for multiple and diverse stakeholders. Conducting a workshop at the PHPCI conference was essential to give visibility to our project, identify partners for the upcoming phases and get feedback on the proposal. The work developed so far can be considered a pilot to evaluate the strategy for identifying outcomes. As a last preliminary step, we had a fourth online meeting to discuss upcoming research study phases and protocol drafting.

Phases

To identify the core set of outcomes, which is the first step for the development of the CC assessment model, we will follow five phases (Figure 1).

Phase I: exchange meetings.

In three meetings, the coordinators of each of the three CCs will thoroughly exchange

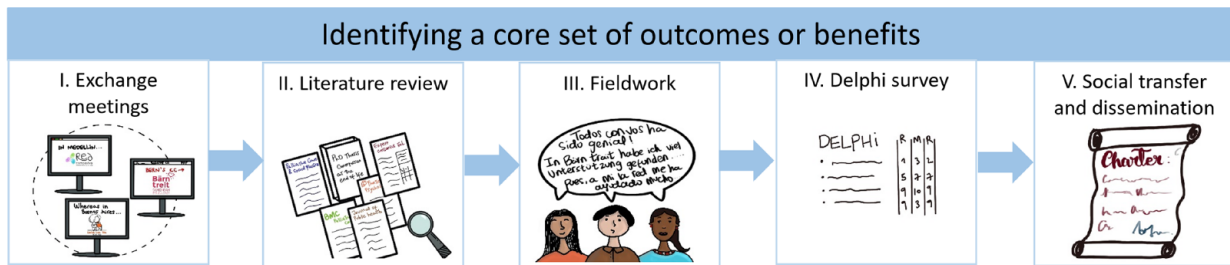


Figure 1. Study phases.

the experience of each program. Each team will document and present the intention of the CC, the community framework, how the CC was established, the partnerships, the scope that the CC has had, and the integration of the broader population of the CC program from their city. We will exchange preexisting documents such as a charter, mission statements, program plans, agreements, or contracts. We will do this exchange to get us in context, as knowing and understanding the peculiarities of each program will be necessary when interpreting and discussing the results.

Phase II: literature review. In 2022, two reviews on CCs and ways to evaluate them were published.^{8,9} We will extract the outcomes reported in these reviews to begin the list of outcomes that will be ranked in the Delphi survey. Since the last search date of both reviews was in 2019, we will search for articles published after this date to complement and update the information.

Phase III: fieldwork. After obtaining the results that have been previously evaluated in the literature, we will proceed to collect outcomes that are of importance to different stakeholders. We will conduct fieldwork in the three participating cities to identify potential outcomes from the viewpoint of key experts. The outcomes collected in this phase will be added to the list of outcomes that will be ranked in the Delphi survey.

We will include participants from the three levels stated above (citizens, organizations, and institutions involved in the programs' implementation, and the political and governmental sector). We will conduct at least three focus groups in each city, one at each level. Depending on the heterogeneity of the resulting groups, we will conduct more than one focus group per level, if necessary. At the beginning of the focus group, we will ask each of the participants to fill out a survey

including demographic characteristics (gender, age, and educational level) and other baseline characteristics to describe the population of the study (their knowledge about the CC initiative, their participation on it, activities they have attended, and their roles in the CC). Then, we will present the overall structure of the local CC so the attendees have a clearer picture of the CC before discussing the expected benefits. After the presentation, we will have a group discussion about the expected benefits/outcomes for each participant, their importance, and for whom are they important. We will record group discussions and transcribe the information collected for analysis. The same person will do the fieldwork in the three cities to avoid heterogeneity in data collection and to facilitate future work in these cities.

Data collected during fieldwork will be analyzed using a qualitative approach. We will voice record the focus groups' discussions and will transcribe them verbatim using NVivo software.¹⁸ The focus groups' moderator will review the transcription and edit it if needed. We will use conventional content analysis¹⁹ to identify the specific expected benefits/outcomes and for whom are they important. For this, we will code all instances in the transcripts where participants discuss the above-mentioned areas of importance. We will not employ a predetermined list of categories or sub-categories but will assign codes inductively. To assign the initial codes, V.G.-J., S.C.Z., and a research assistant with experience in qualitative studies will code the first transcript separately and will compare their codes aiming to ensure that the research assistant notices all meaningful instances to be coded. Following this, the research assistant will continue to code all subsequent transcripts independently. During the coding phase and subsequent phases of analyses, V.G.-J. and the research assistant will hold regular discussions about preliminary findings, questions arising

from the coding process, and so on. Once all focus groups transcripts are coded, V.G.-J., S.C.Z., and the research assistant will proceed to identify categories and subcategories around the expected benefits of CCs and for whom they are important, this will be in a process of constant comparison, taking into account participant type and country where the focus group was undertaken. Initial categories and subcategories will be further discussed among all co-authors. At all stages of data collection and analysis, the research assistant will keep an audit trail with memos and observations about the focus groups' discussions, her preconceptions, and research ideas during data analysis. This reflexive approach, including the frequent discussions with other team members, will facilitate transparency. To further ensure rigor, we will report the findings following the consolidated criteria for reporting qualitative research (COREQ) criteria.²⁰

Phase IV: Delphi survey. We will share the list of outcomes collected in phases II and III with representatives from the three community levels, as well as with international experts identified in the PHPCI conference and from the literature. We will use a web platform to build, distribute, and administer the Delphi surveys. We will conduct two rounds of Delphi surveys. In the first one, we will ask participants to rate, from 1 to 10 (with 1 being the least important and 10 being the most important), three aspects: relevance, measurability, and feasibility of measuring the outcome. We will average the three ratings to obtain the single score necessary to continue with the selection process of the COS proposed by the COMET initiative. Therefore, to determine which outcomes should be included for the second round of the Delphi, we will follow these thresholds:¹¹ the consensus to include an outcome will be when more than 70% of the participants score the item between 8 and 10 and less than 15% of the participants rate it from 1 to 3. In addition, to guarantee that the outcomes that will be part of the final list are both relevant, measurable, and feasible to collect, even if they have passed the cut-off point to move on to the next phase, they will only do so if, in each of the three measures, they scored at least 7. The same method will be used to determine which outcomes should be included in the final list after the second Delphi round.

In addition, we will ask participants to provide outcomes that are essential to assess the benefits of CCs and are not in the list. The second round

of the Delphi will include all the outcomes accepted by consensus in the first round as well as all the new ones proposed by the participants. Knowing this predetermined list, the participants will be asked to rate each of the outcomes again in the second round of the Delphi.

Phase V: social transfer and dissemination strategy. Upon project completion, we will invite local government of Buenos Aires and Medellín to sign a charter for a jointly supported end-of-life. The City Council of Bern already signed the charter in 2020. We have planned some strategies to improve the readiness of the governments of Buenos Aires and Medellín to sign the charter. Due to the territorial extension of the Autonomous City of Buenos Aires, which is organized into 15 districts, we decided, as a starting point, to contact District number 2, located in a central area. Pallium Latin America has already signed a Framework Agreement with the Autonomous City of Buenos Aires as a first step of a process aimed at gaining a deeper understanding of the community care needs, prioritizing its rights and resources. In addition, post-pandemic has shown the importance of community-based care. Therefore, the next step is to meet with representatives of the district and design a local strategic partnership agreement inviting them to sign the charter and enhance commitment with its key principles by implementing community action plans. In Medellín, it is important to regularly meet with local government secretaries such as the Health Secretary and the Social Inclusion Secretary, seeking help to escalate the project to the city mayor. In addition, because local government members change frequently, it is essential to develop an awareness-raising strategy aimed at local governments on an ongoing basis. Finally, we plan to present the project to local administrative units and community action units in different municipalities to promote joint efforts and seek resources from participatory budgets.

The set of core outcomes resulting from this project and the charter will be interconnected. The charter will be the public face of the project toward the community, while the set of outcomes, will be the face of the same project toward researchers and program evaluators. The charter will also specify support for further evaluation to ensure the operation of a quality program within each city. Since CCs are dynamic process, the charter already signed in Bern can be modified to include this last part.

While these are the steps we plan to take to achieve a social transfer of this project, we are aware that there may be some barriers to achieving this. Lack of funding, socioeconomic and political barriers to participation in organized activities, underlying social determinants of health, and unmet healthcare needs are examples of problems we may face.

For further discussion and condensation of the interviews' results, we plan to conduct meetings with a bigger local audience, inviting members of the city councils and the broad public to foster dissemination and public debate, including media reports.

In addition, we will use already existing connections with local and social media to disseminate the CCs and our international collaboration project to the general community. For example, we will use the radio channel of the Pontifical Bolivarian University in Medellin and a Bernese radio channel and newspaper. In addition, we will use already existing cooperation between our academic communities and neighborhood networks, churches, and schools to disseminate our project. In Medellin, 60 organizations collaborate with the CC program, including health care and palliative care services, nursing homes, governmental and non-governmental organizations, universities, and patient associations. In Bern, universities, palliative care organizations, churches, and voluntary actors already collaborate with the CC program. In Buenos Aires, three schools, three public hospitals, two universities, one non-governmental organization, and one hospice already collaborate with the CC program, and a new collaboration will start in 2022 with an organization dependent on the University of Buenos Aires that carries out extension activities with migrants and language-diverse communities. Finally, we will disseminate the CC programs and our project at the Bern Senior Citizens' University and the University of the Patient and the Family in Buenos Aires. The dissemination to the research community will consist of publishing our results in a peer-reviewed journal and presenting the results and the methodology for the next steps at a relevant international conference.

Scale up plan

After developing the set of core outcomes, future steps to create the CCs' evaluation model will

involve the identification of other outcomes that may be relevant to certain specific contexts, the indicators to measure the outcomes, and the creation of a toolkit that details the steps to evaluate CCs.

Declarations

Ethics approval and consent to participate

The research is purely observational and does not contain any intervention. The study will be conducted in accordance with existing international regulations and guidance including the Declaration of Helsinki, the International Conference on Harmonization and Good Clinical Practice, and existing national legislation and guidelines such as the Federal Act on Research involving Human Beings in Switzerland. Before starting the focus groups, we will explain the research proposal to the participants and ask them to fill out the informed consent form, which will include a section on consent to publish the results of the project. Collected person-related data will be encrypted and only anonymized and summarized data will be published in scientific journals and presented at congresses. Encrypted and anonymized data will be stored at the three research sites for at least 10 years after the termination of the study. Anonymized data will be stored in the open data repository of the University of Bern and may be available upon request. The ethics committees involved in each CC will be in Medellin, the ethics committee of the Pontifical Bolivarian University; in Buenos Aires, the ethics committee of Pallium Latin America; in Bern, the cantonal ethics committee. The ethics committee of the Pontifical Bolivarian University approved this protocol (Act #24 of 2022, date: December 12, 2022). The ethics committee of Pallium Latin America (Act of 28 December 2022) and the ethics committee of the canton of Bern (Req-2022-10152) considered our application exempt from the need for approval.

Consent for publication

The informed consent form will include a section on consent to publish the results of the project.

Author contributions

Valentina González-Jaramillo: Conceptualization; Funding acquisition; Methodology; Project administration; Writing – original draft.

Alicia Krikorian: Conceptualization; Methodology; Writing – review & editing.

Vilma Tripodoro: Conceptualization; Methodology; Supervision; Writing – review & editing.

Margarita Jorge: Conceptualization; Investigation; Methodology; Writing – review & editing.

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Silvina Montilla: Investigation; Writing – review & editing.

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Competing interests

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Availability of data and materials

Not applicable.

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