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How can a community be successfully empowered to deal with death, dying, and bereavement?—formative evaluation of the Caring Community Cologne using focus groups

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Background: Compassionate communities aim to empower people to deal with death, dying, and bereavement. They also intend to facilitate access to care and support at the end of life. However, there is a need for systematic knowledge on how to achieve the desired outcomes for citizens and for insights regarding the development, implementation, and evaluation. The aim of this study was to assess the views of members of a German Compassionate City, the "Caring Community Cologne" (CCC), and to report on its practical implementation.

Methods: The CCC consists of a citywide Round Table, a Steering Group, a Coordination Office and four Working Groups in areas where activities are already in place. We conducted two qualitative focus groups with nine members of three Working Groups. The transcripts were analysed with qualitative content analysis, using MAXQDA version 2022, and results were transferred into the logic model "Throughput Model".

Results: At the time of evaluation, participants felt that the structures of the CCC were adequate, but criticised the cooperation and transparency between them. A key aspect of this was the requirement for a coordinating body. They stressed the support of federal institutions as a key factor, while at the same time describing insufficient citizen involvement. The transfer of the results into the Throughput Model highlighted four areas that the CCC should address: (I) neighbourhood networks need to be established to strengthen civic support; (II) people need to be made aware of the issues by making them accessible in their everyday lives; (III) the many existing support initiatives need to be better linked and made more accessible; (IV) adequate healthcare service structures have to be guaranteed.

Conclusions: The top-down approach described, supported by the city's engagement and involving existing initiatives can facilitate the development of a bottom-up civic engagement model in a large city. However, active citizen involvement appeared to be a challenge. The Throughput Model was a suitable basis

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for mapping work processes and developing evaluation plans.

Keywords: Compassionate communities; public health palliative care; participatory action research; death literacy; Throughput Model

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Introduction

In many countries, there have been major improvements in medical care and quality of life for individuals with life-limiting diseases (1). However, the medicalization of death and dying and the high number of hospital deaths have led to a neglect of the social and emotional dimensions of the end-of-life experience (1-5). Dealing with death and dying has shifted from being a family and societal matter to becoming primarily the responsibility of the healthcare system. The coronavirus disease 2019 (COVID-19) pandemic exacerbated already existing challenges and needs that have resulted from medicalisation and social denial. Therefore, it is necessary to reframe the approach to end-of-life care (1-3).

The evolution of "Palliative Care and Public Health" has embraced a more holistic perspective, recognizing the need for comprehensive end-of-life care (2,3,6,7). In response to these developments, the concept of compassionate communities has emerged as a model for community-based palliative care. Compassionate communities act as a link between professional care providers and citizens, fostering a supportive environment. They enable individuals to access the care and support they need at the end of life by building supportive networks surrounding the people affected (6,8). The networks can provide hands-on care and support and build up stronger partnerships with the healthcare professionals (8). A Caring Community does not see itself as an alternative to state-public infrastructures, but as a change in the relationship between the welfare state, the individual and the community, leading to a citizen-professional mix (9). Moreover, compassionate communities aim to support people to engage with the end-of-life experience in meaningful ways (6,8). More recently, the term 'death literacy' has been used to address this multidimensional complex concept of competences for engaging with end-of-life issues (10). Enhancing this competence is one important facet of compassionate communities. This involves promoting community engagement and participation, developing community resources and services, as well as cultivating cultural and social practices that acknowledge death and dying as a natural part of life (6,8,11,12).

The diverse cultural and social norms surrounding death and dying necessitate tailored strategies for end-of-life care in different communities (13). Thus, the development of compassionate communities does not have a standardized blueprint, leading to a wide range of approaches and terms worldwide. These initiatives range from grassroots efforts led by local communities to formal programs and policies implemented by governments and healthcare organizations (14-18).

Compassionate Community initiatives have shown a positive impact on health and well-being (19-21). However,

Highlight box

Key findings

- To enable individuals to access the care and support they need at the end-of-life and to engage with the end-of-life experience in meaningful ways, four areas need to be addressed: (I) civic support, (II) visibility of death, dying and bereavement, (III) linkage of and accessibility to care and support structures, and (IV) adequate professional healthcare service structures.

What is known and what is new?

- Compassionate community initiatives have shown a positive impact on health and well-being. However, there is a lack of consensus on how to achieve the desired outcomes.
- We provide a detailed description of the development and implementation of a German Compassionate City with a population of over one million, including structures, work processes, as well as goals, objectives, and tasks, arranged in a logic model.

What is the implication, and what should change now?

- In a city with a population of over one million, top-down and bottom-up structures, involving government support and existing initiatives, seem to be necessary to create a starting point for an initiative that is sustainably anchored in urban society.
- The next step is to identify new approaches to reach out to and actively involve those affected, in order to evolve into a community-driven Compassionate City.

several challenges persist. There is a lack of consensus on how to achieve the desired outcomes, given the multiple perspectives and locally driven initiatives that are difficult to standardize or replicate (14,17,22). Furthermore, there is limited systematic knowledge regarding the characteristics, development process, and mechanisms influencing the implementation outcomes of compassionate communities. Only a few in-depth descriptions and evaluations of initiatives from the last decade exist (16,17,23).

To develop, implement, and transfer as well as to ensure the sustainability of compassionate communities, there is a need to share knowledge about the theories, frameworks, and methods used in their development. This knowledge sharing provides the basis for evaluating the effectiveness and impact of these initiatives on individuals, families, and communities. Additionally, it helps to identify best practices and strategies for scaling and sustaining different approaches over the long term. For this, logic models are a useful instrument to represent the processes through which an intervention produces outcomes. By describing the link between resources, activities, outputs, and outcomes, logic models can clarify how innovations will work (24-27). The aim of this study was to identify the views of members of a German Compassionate City, the "Caring Community Cologne" (CCC), in order to report on their practical implementation. This includes perspectives on goals and objectives as well as on how to best achieve and ground them. In fact, the term Caring Communities encompasses a wide range of social support networks in general, whereas compassionate communities focus on end-of-life initiatives. However, there is no clear distinction and both terms are often used interchangeably in literature and practice. In this context, we use the term 'Community' as an umbrella term that encompasses both rural and urban initiatives. Accordingly, we define the CCC as a Compassionate City (28). We present this article in accordance with the COREQ reporting checklist (available at https://apm.amegroups.com/article/view/10.21037/apm-23-598/rc) (29).

Methods

Established structure of the CCC

The CCC builds on the long-established hospice movement in Germany, with existing palliative and hospice structures in Cologne for more than 40 years. The CCC was initiated with the aim of strengthening Cologne's society in dealing with death, dying, and bereavement and promoting related skills (30). The planning processes started in 2017 aiming to create sustainable structures in a city of just over a million habitants. At the beginning, the CCC consisted of a citywide Round Table and a Steering Group, initiated and moderated by the Health Department of the City of Cologne and the Palliative and Hospice Network Cologne. The Round Table was established as a decision-making committee and information exchange platform and the Steering Group as a strategic planning committee. At the invitation of the mayor of Cologne, a kick-off meeting was held in January 2020 with the aim of involving citizens in the establishment of the CCC. Thus, the COVID-19 pandemic strongly influenced the initiation and development of the CCC. In the further course, members of the Round Table decided to set up Working Groups (WGs) on issues related to death, dying, and bereavement for which there were already existing activities in Cologne to build up on. The WGs were instructed to outline an overview of all existing offerings in their respective thematic areas and to develop the means to achieve the goals of the CCC. To ensure adequate exchange between the several committees, two members of each WG also act as part of the Round Table. Subsequently, a coordination office was established to create a linkage between all committees (see *Figure 1*). It should be noted that the members of the CCC do not participate as private individuals, but as representatives of their respective institutions. They participate on a voluntary basis, except for the position of the Coordination Office which is mainly funded by charitable foundations. Thus, the CCC represents an independent entity, not subordinate to any other institution.

Design, setting, and participants

For this qualitative focus group study, we invited all members of the WGs via email to participate. At the time of data collection, three WGs existed within the CCC: Care Structures, Care City Map, and Bereavement at the Work Place. We decided to include the WGs because they form the operational part of the CCC, implementing the concept in society. Accordingly, inclusion criteria for participation was to be a member of one of the WGs. To facilitate exchange of experiences, we distributed the participating members in heterogeneous focus groups, each consisting of members of different WGs.

Data collection

The interview guide was developed by three researchers

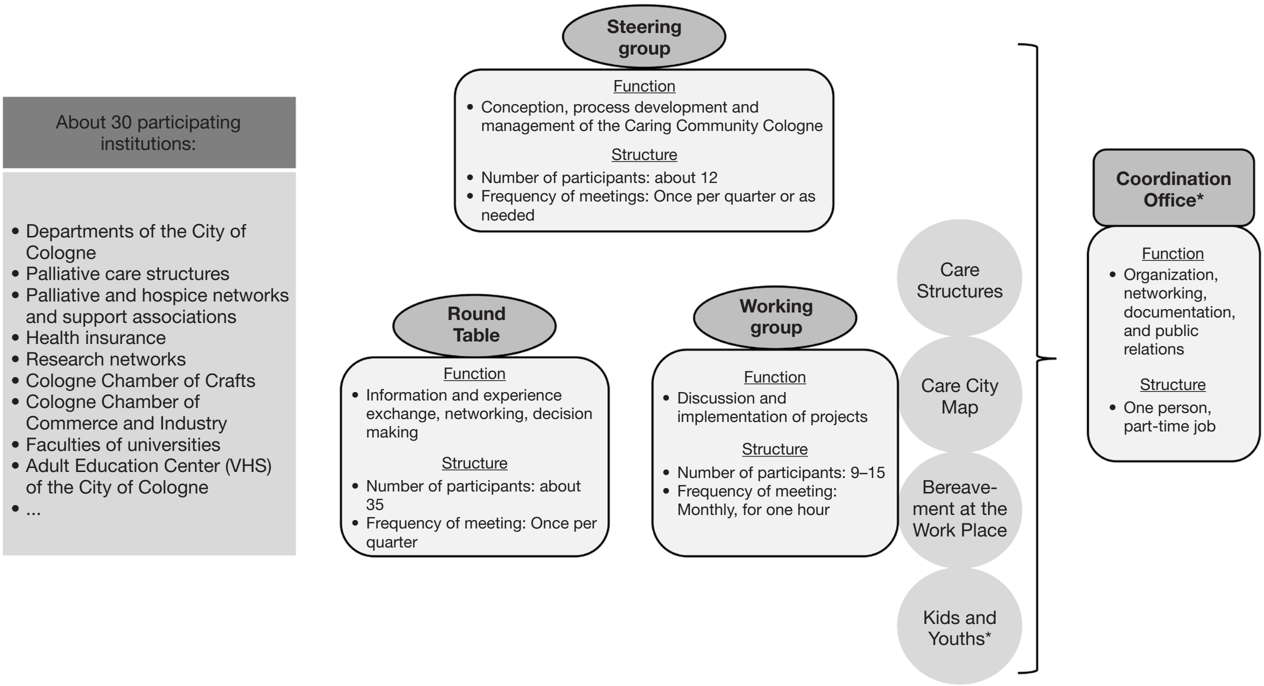

Figure 1 Overview of the bodies of the Caring Community Cologne (CCC). *, Working Group "Kids and Youth": established after the conduction of the focus groups; Coordination Office: restructured following the conduction of the focus groups.

(Lisa Valerius, with support of R.V. and J.S.) and pilot tested in two rounds with four members of a doctoral research college (GROW), respectively. The final interview guide covered four main topics: (I) concept and goals of the CCC, (II) evaluation of the structures, (III) influence of the COVID-19 pandemic, (IV) outlook for the next 5 years. A facilitator (Lisa Valerius) and co-facilitator (doctoral student) led each focus group. As the CCC was scientifically monitored from the beginning, most of the participants already knew the facilitator. The focus groups took place in November 2021 via video call due to the COVID-19 pandemic. To ensure anonymization, we did not collect data on sociodemographic background. Data on professional background were collected within the focus groups.

Statistical analysis

We analysed the focus groups transcripts by qualitative content analysis according to Schreier, using MAXQDA version 2020 (31). Schreier divides qualitative content analysis into several steps. The steps aim to provide researchers with a toolbox for selecting the most appropriate tools for their research question and material when conducting qualitative content analysis (32). To structure and describe the material in relation to the research question, we used a content-structuring approach (31). According to Schreier, it is possible to also quantify the qualitative results, which we did not use. We developed an initial coding frame with categories derived mainly inductively by successively summarizing the transcripts. Therefore, we paraphrased relevant passages, and subsequently summarized similar paraphrases to main and sub categories (S.M.). We discussed and revised the initial coding frame in two rounds (S.M., K.K.) and pilot tested the resulting coding frame on part of the material (S.M.). To ensure consistency, one researcher (S.M.) and one research assistant (Laszlo Hardekopf) independently assigned the units to the final coding frame. Disagreements were discussed until consensus was reached. In addition to thematically describing the focus group material in relation to the research question, we transferred the results into the "Throughput Model", a logic model in the context of health services research (25). This is a central theoretical model of health services research to explain complex interrelationships within the care system (25). The model distinguishes the following areas: Input is described as care needs and resources at the level of patients, professionals, organisations and the system as well as the impact of interventions. Throughput describes the transformation of input factors influenced by complex intervention and context. Output describes the impact at the level of care services and provider behaviour, and at the level of organisations and systems. Finally, outcome is described as patient-perceived results at the population level (25). It should be noted that some of the authors are actively involved in the CCC, which may create an interest in using the results to improve the implementation and outcomes of the CCC.

Ethical issues and approvals

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Research Ethics Committee of the Faculty of Medicine at the University of Cologne (reference No. 19-1630). All participants gave written informed consent. The focus groups were audio-recorded and transcribed verbatim, which included anonymization. Transcription was carried out by a research assistant and checked by the facilitator (Lisa Valerius) for accuracy.

Results

Results of the focus groups

We conducted two focus groups with four members of the WG Care Structures, four members of the WG Bereavement at the Work Place, and one member of the WG Care City Map. About half of the participants were professionally involved in the issues death, dying, and bereavement. The remainder were representatives of the City of Cologne, of companies or relatives representing a non-profit organisation. Only few participants were involved in the initiation of the CCC, while most joined at a later stage.

Data analysis revealed three main categories: (I) initial situation: societal discourse about death, dying and bereavement, (II) evaluation of the structure of the CCC and work processes, (III) intended outcome, intermediate outputs and tasks. Questions of the interview guideline to the COVID-19 pandemic did not form a separate main category but complemented the three present main categories.

Initial situation

Openness to death, dying and bereavement

Participants described a loss of normalisation in society, for instance with regard to children who have been excluded from death, dying and bereavement for decades. This has led to fear and a lack of confidence in dealing with these issues. Death, dying, and bereavement are denied and excluded from social life. As a result, people at the end of life and their relatives are left alone. Although the hospice movement in Germany has led to a strong civic engagement, participants described that only a minority seems to be open to dealing with these issues and engaging in the broader society.

The members of the WG "Bereavement at the Work Place" saw many points of linkage in companies for death, dying and bereavement (e.g., emergency plans) and an increasing openness. They explained the increasing openness with the growing need to be an attractive employer and to maintain employees' performance by creating supportive structures. However, reluctance and resistance still prevail.

Participants also mentioned the openness of the federal institutions as a key factor in the successful implementation of the CCC. Several participants commented positively on the City of Cologne's openness to death, dying, and bereavement as well as its engagement from the beginning, while simultaneously stressing the importance of a bottom-up approach.

- ❖ "[...] and there are big differences in politics, which you have to convince with a lot of effort and then in the end nothing really happens, and here is a city that has really supported us very, very much on all levels from the very beginning. And not only that, they are actively involved themselves. [...] because without the political responsibility of such a process we probably won't achieve much." (FG1, B1)
- ❖ "[…] and I agree that this mixture of 'it is politically wanted' and 'it also starts from below' is exactly right. That's the only way it can succeed. I think both sides are important." (FG1, B4)

Existing care and support structures

Participants described the existence of vast quantities of voluntary and professional care and support structures that aim to address a wide range of concerns of those affected (e.g., support associations, self-help groups, city projects, counselling services, or information events). Critically, they pointed to the risk of overload from the variety of options, particularly for the target group facing a life-limiting illness or bereavement.

- ❖ "The problem for the people with life-limiting illness is that they don't know this network at first,

> [...] that they can find the right support structure. Because […], even though the number of offerings is very big, the problem is of course also very big to find the right one.” (FG2, B1)

Participants also criticised discriminatory structures, as existing care and support structures may exclude some people. For example, language barriers might make it difficult to express own concerns, leading to a lack of access to suitable services.

- ❖ “[…] we always have a lot of people who have real difficulties communicating in German and who are also inhibited and ashamed about it. If you can’t express exactly what the person or their relative is missing, that’s just a huge thing and we have to manage to break down those barriers as much as possible. I think there’s a lot of help out there already, but a lot of people don’t get the help they need because of language barriers.” (FG2, B2)

Additionally, the COVID-19 pandemic revealed that services are organised as a “come-structure”. Support is only provided on request. However, there is also a need to reach out to those who are absent to identify their needs in a proactive way.

- ❖ “I’m going to say counselling services or something like that, which are still very, I’m sorry to say, very community-based. So if you come you can get advice there. But the other thing is another way of getting in touch with people and maybe also identifying needs that you wouldn’t otherwise get to because people wouldn’t come.” (FG2, B2)

Different palliative care and hospice structures are available for professional care. They are described as cooperating well, but also as being severely affected by staff shortages. One participant emphasised that it is important to identify the benefits of the CCC, given the large number of care and support structures. This should include an assessment of which topics are already adequately covered and where additional activities are really needed.

Members of the WG “Bereavement at the Work Place” gave a brief description of their work: first, they carried out an initial assessment of the current situation of how companies deal with death, dying, and bereavement. This included an assessment of pre-existing materials and structures of the participating companies as well as determining which of these could be transferred to other companies. Next, the members reported on plans to identify existing needs within the companies to develop needs-based support materials and structures. Participants emphasised the advantage of the network within the CCC, which allows learning from each other and avoids reinventing the wheel. To encourage companies to participate, the benefit for the company needs to be clear and companies need to be actively involved in planning processes.

Evaluation of the structure of the CCC and work processes

Cooperation and transparency between all bodies of the CCC

While participants were generally positive about the working atmosphere within the WGs, the cooperation and transparency between all the bodies of the CCC was criticised. Although efforts were being made to create links between the WGs and the Round Table, participants described insufficient cooperation and collaboration. Firstly, they wished for structures that are more democratic in order to be able to contribute also at the strategic and decision-making level. Secondly, there was a wish for more cooperation between the WGs in order to exploit synergies and create a sense of common identity. Several aspects of lack of transparency were also mentioned. Some participants stated that they did not have a complete overview of all the bodies of the CCC, of the decision-making processes, or the potential means to achieve targets (e.g., financial resources or connections). Others called for the basic agenda and that it should be clarified for all members. However, cooperation and collaboration should not overstretch the capacity of those involved. From the participants’ point of view, an annual face-to-face exchange or a regular newsletter seemed useful and feasible.

- ❖ “Because otherwise you feel like a loner, even in the group. [...] So what exactly does the steering group do, what happens at the municipal level [...] I could use an exchange, but it has to be limited [...]. But then you have the feeling that you are on the road together.” (FG1, B4)

Cooperation with people and institutions that are not formal members of the CCC

In terms of cooperating with people and institutions that are not formal members of the CCC, participants described insufficient citizen involvement. They did not perceive the CCC as a typical bottom-up project and distinguished the CCC from entirely community-based projects. As a citizens’ forum (held online due to the pandemic) failed to generate enough citizen participation, participants stressed the need to find new approaches to reach out to those affected. They expressed the requirement for the CCC to become part of the society in order to fulfil the expectation of the CCC as a countermovement to the professionalization of death, dying, and bereavement. In this regard, it is particularly important not to reach only those who are already dealing with the issue on a professional or voluntary basis. The messages and topics must be aimed at citizens. The CCC was established using a top-down approach, and the integration of the CCC into society necessitates careful consideration in the forthcoming phase.

- "[…] but I think at the end of the day we have to see whether it is enough [...] to take the citizens with us, or whether we have to talk again about the balance in this top-down/bottom-up approach and perhaps develop it further." (FG1, B1)
- "The person spends 95 per cent of the time in the normal personal environment[...] and those 95 per cent of people who are close to the person privately, personally, that's what's really important. They have to be with the person. [...] and that, I think, has to be our particular focus in the next phase of Caring Community." (FG1, B1)

Although they did not yet have concrete answers on how to achieve citizen participation, they formulated several important aspects that have to be considered. Firstly, they perceived companies as an important opportunity to develop into society and noted the importance of establishing links with healthcare services. Secondly, they addressed the importance of choosing appropriate terms and language to facilitate exchanges with citizens. In this context, one participant questioned how inclusive the English term "Caring Community" is for the citizens of Cologne. Finally, the balance between top-down and bottom-up approaches within the CCC was discussed, as the involvement of those affected is obligatory, but too much stakeholder involvement may jeopardise the achievement of setting aims and implementation.

Overall, participants described an optimistic spirit of new beginnings and emphasised that the results of the WGs are suitable starting points with the opportunity to reach more and more people.

Intended outcome, intermediate outputs and tasks

Participants described the intended outcome of the CCC as well as intermediate outputs. They also identified tasks to be worked on in order to achieve these objectives. We identified four areas in which they defined tasks and intermediate outputs: (I) civic support, (II) visibility of death, dying, and bereavement, (III) linkage of and accessibility to support structures, and (IV) adequate healthcare service structures (see *Table 1*; *Figure 2*). Participants emphasised the need of the CCC to address and involve all parts of the society, especially children and minority groups, in setting and achieving its outcomes. From the participants' perspective, the different thematic areas of the WGs allow for an impact on society from their respective areas, thus reaching more people.

Description of the processes through which the CCC produces the defined outcomes: transfer of the results into the Throughput Model

In order to clarify how the CCC is intended to work, we transferred our results into the Throughput Model (see method section "Statistical snalysis"). To describe the Input, we applied participants' statements on the initial situation (chapter 1) as well as the evaluation of structures and work processes of the CCC (chapter 2). In chapter 3, participants described the intended outcome of the CCC (correspond to "outcome" within the model), intermediate outputs (correspond to "output" within the model), and tasks for attainment (correspond to "throughput" within the model). The model is shown in *Figure 2*.

Discussion

In this study, we aimed to assess the perspectives of CCC members in order to report on the practical implementation of a German Compassionate City. We found four areas in which the CCC has to set objectives and tasks in order to strengthen the society's capacity to deal with death, dying and bereavement: civic support, visibility of death, dying, and bereavement, linkage of and accessibility to support structures, and adequate healthcare services. The evaluation of the structures and work processes of the CCC revealed a need for more participative and transparent cooperation between CCC bodies. Moreover, participants discussed the balance between top-down and bottom-up strategies, emphasising the support of federal institutions while at the same time describing insufficient involvement of citizens who are not formal members of the CCC. Enabling participation of citizens also involves reducing discrimination in existing care and support structures. It is worth noting that the COVID-19 pandemic may have significantly influenced the participants' views on implementing the CCC, making people suddenly broadly aware of the topic of death and

Table 1 Quotes for the areas in which participants defined intermediate outputs and tasks

Civic support
“95 per cent of the [patients’] time is spent in the normal personal environment [...] and that 95 per cent [...] is what really matters. They have to accompany them.” (B1, FG 1)
“In such a big city, we really want to get down to smaller levels. That means in terms of neighbourhood, [...] where I live, a neighbour who notices or reacts when I say: “I need some support here”. [...] that such networks, such neighbourhood networks are made possible.” (B2, FG 2)
Visibility of the issues
“And only by talking about the topic can barriers be reduced and people feel competent to stand by those affected in the situation. And that is why I think a lot of public relations work is needed.” (B3, FG 1)
“[...] and today we are in this war for attention. [...] Death and bereavement is, of course, a subject that is sometimes out of focus until you are affected by it.” (B2, FG 1)
Linkage of and accessibility to support structures
“[...] that this CCC can be a kind of “Bring-together Organisation”, where all kinds of stakeholders [...] can exchange information and also point out problems to each other, work out solutions to problems [...].” (B1, FG 2)
“In my opinion, the CCC should provide help that can be used by those affected [...] to find their way in this network. [...] a fixed point of contact that everyone can access quickly, that they can find quickly and where they can get help.” (B1, FG 2)
Adequate healthcare service structures
“[…] and that in Cologne, too, care is actually guaranteed by the city of Cologne [...] and that we don't have to transfer to other cities.” (B3, FG 1) [Context: specialised outpatient paediatric palliative care teams].
“[...] on a voluntary basis, but also from a professional point of view, of course I would like to see much more social work and spiritual guides. So all in all, to put this whole area on a bigger and broader basis.” (B4, FG 1)

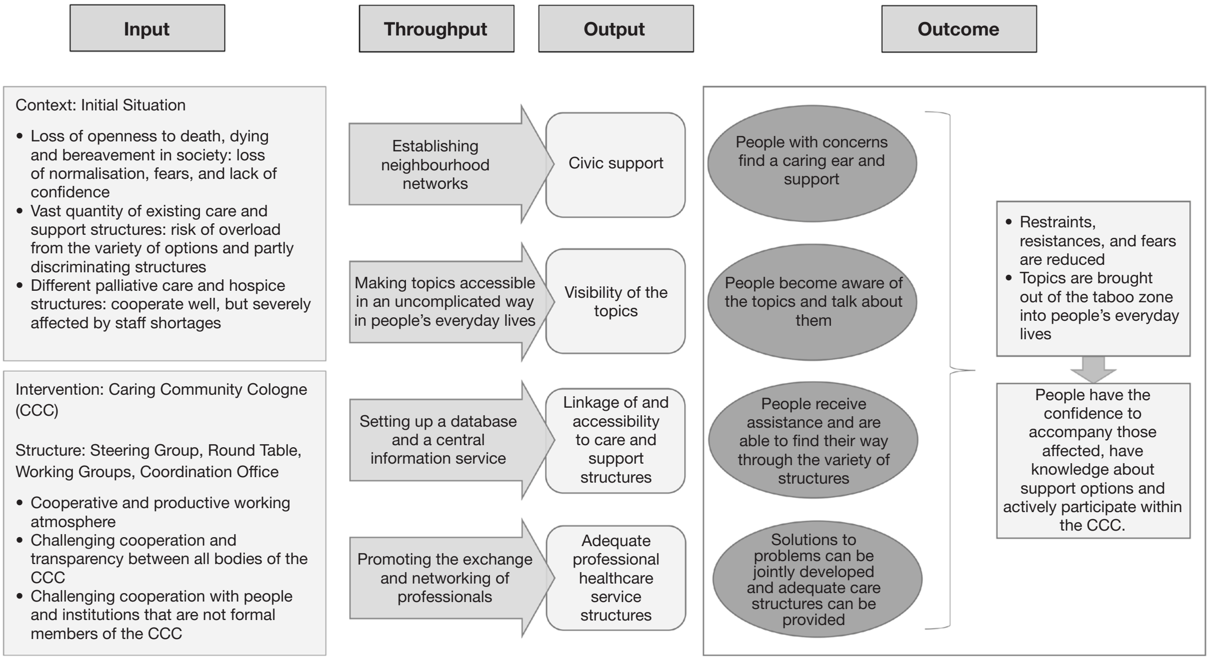

Figure 2 Transfer of the results into the Throughput Model (24).

dying. The presented findings were complemented by implications related to the pandemic. To gain a better understanding of the pandemic's impact on the CCC, we conducted a further qualitative online survey. Therefore, reflections on the influence of the COVID-19 pandemic on the CCC can be found elsewhere (33).

Defining aims and sustainable outcomes of a compassionate community: application of logic models and core outcomes

While there has been considerable interest in compassionate communities, there is still much to learn about their benefits and effective implementation. Various reviews found that there is little and poor-quality evidence on the evaluation of compassionate communities as well as a lack of consensus on how to evaluate them (16,17,34). In recent years, one theoretical framework has been developed to evaluate the complex process behind compassionate communities (23). To understand and measure their benefits, it is important to first identify and define the intended outcomes (35). One of the challenges in this respect is the diverse nature of compassionate communities with context-specific priorities and goals. Gonzalez-Jaramillo and colleagues recently published a protocol on the identification of a set of generalizable core outcomes. They emphasized that the resulting model should also contribute to increase awareness and knowledge about the extent to which cultural backgrounds moderate the experience of compassionate communities (35). To ensure that the intended outcomes align with the needs and values of the community, it is essential to engage its members in the priority-setting stages of the compassionate community development. The four areas formulated by the CCC members (see *Figure 2*) are therefore an important basis for the application of the evaluation models currently being developed. Another important consideration when defining core outcomes of compassionate communities is the focus on sustainability. While short-term improvements are important, the long-term sustainability of compassionate communities is crucial for creating lasting change. Logic models support the arrangement of intended outcomes regarding their chronological implementability and sustainability. Therefore, the Throughput Model helps to define working plans and to understand the steps, which are necessary to reach sustainable outcomes. This is also necessary for funding compassionate communities projects, as the benefits must be clear to sponsors (36).

The role of top-down and bottom-up approaches in creating compassionate communities

Compassionate communities exist along a spectrum, depending on who is in charge of initiating and leading activities and initiatives (18,37). Opinions vary widely about the ideal level of engagement between the community on the one side and government together with healthcare services on the other side (37). Of course, there is no one-size-fits-all approach and differences must exist due to different care systems and structural preconditions. Experience in the field of health literacy shows the limitations of purely top-down approaches, as they are dependent on political agendas, create mistrust and face implementation challenges (38). Successful programs require collaboration among healthcare providers, policymakers, and the community (3,38). It is widely recognized that the involvement of affected people is essential and different articles described community ownership as key factor for sustainability (3,37-39). However, one recent scoping review revealed that health services organizations and providers are most often engaged as compassionate community leaders instead of community members, which are mainly engaged as target users (16). Our focus group participants also described a lack of citizens' involvement. The CCC was mainly initiated and has been driven by members of health care services and networks with a focus on palliative care, supported by the City of Cologne. We believe that this approach, which was assigned by the FG participants as rather top-down, is necessary to establish a starting point and create structural preconditions in a city of over one million habitants. The participation of companies built a first bridge to citizens and the four WGs cover important areas of life. The next step is to identify new approaches to reach out to and actively involve those affected, in order to evolve into a community-driven Compassionate City. However, in line with previous studies, focus group participants described a taboo, denial and lack of prioritisation of death, dying, and bereavement in the society, which may discourage individuals from becoming actively involved (5,40). Learning from other projects and adopting models and frameworks can help to address this challenge. Examples comprise an asset-based community engagement approach that facilitates community-led awareness initiatives, the implementation of Death Cafés or a conceptual model of community engagement in end-of-life care (15,41,42). Related initiatives need to occur in various settings such as schools, workplaces, care homes, neighbourhoods, and high streets (3,13). Based on these findings, members of the CCC developed new approaches, including the implementation of a Buddy-Project or the cooperation with the Adult Education Centre (VHS) of the City of Cologne (43). Additionally, the coordination office was restructured to comply with the demands of the focus group participant for more participative structures and more transparency.

Enabling equality in citizens participation and reducing discrimination in existing care and support structures

Our focus groups participants emphasised the need for the CCC to take into account all members of the society, especially children and minority groups. Moreover, they criticized discriminating structures of existing offers, as they may exclude for example individuals with language barriers. Compassionate communities claim to encourage empathy, kindness, and social justice, with compassion at their core (6). These communities aim to create a supportive environment for all citizens, regardless of their background or circumstances (6,39). Diversity is essential in compassionate communities, bringing together people from different backgrounds to fully understand the needs of the community and fostering innovation and growth through the inclusion and appreciation of diverse voices (44,45). Empowerment is often cited to promote equity. While empowering individuals and communities is undoubtedly valuable, this alone cannot address systemic inequalities and disparities (38,46). Health and healthcare disparities exist across various dimensions, including race, ethnicity, socioeconomic status, age, geography, language, gender, disability status, citizenship status, and sexual identity and orientation. Not all people have the same opportunities to participate, which is manifested in the fact that active engagement in a society increases with education level and income (38,44-46). While equity and diversity are emphasized in most of the contextual articles on compassionate communities, a recent scoping review found that most of the published programmes aim at the general public, with a minority of the included articles reporting specifically on programmes designed with and for marginalised populations (16). Taking into account existing barriers and biases, intentional efforts and strategies are necessary to create equitable and diverse communities and to avoid perpetuating inequities. This includes also involving underrepresented groups in decision-making, developing cultural sensitivity or addressing biases and stereotypes (45,47,48). Additionally, it may be useful to incorporate checklists on diversity and track progress on health equity goals (49). Only by understanding and addressing health disparities and recognizing the unique needs of marginalized groups, compassionate communities can truly flourish.

Strengths and limitations

By including members of all the WGs in existence at the time of data collection, we were able to capture a variety of perspectives from those responsible for the implementation in society. Participants particularly appreciated the sharing of experiences that resulted from the heterogeneous focus groups. By using a qualitative approach, we were able to gain detailed and comprehensive insights into the CCC. However, the sample size was relatively small and we did not receive any information on reasons for non-participation. As a result, some perspectives may not be fully represented. Although we see the involvement of the WG members as a key strength, the exclusion of other relevant bodies and citizens may not fully capture the different perspectives and experiences of all the stakeholders involved. The findings should therefore be interpreted with caution, recognizing the potential bias and incomplete representation of the wider Compassionate City community.

Conclusions

We argue that the top-down approach taking into account existing initiatives in a city with a population of over a million inhabitants was crucial in paving the way for the subsequent development of a bottom-up approach to civic engagement. The openness and commitment of the City of Cologne played a central role in the development of the CCC. An important lesson for the implementation of future Caring Communities is the need for financial support for an adequate coordinating body to ensure effective cooperation and transparency between the different structures of the CCC. CCC The active involvement of citizens in the CCC appeared to be a challenge. An essential aspect that needed to be addressed was the integration of death, dying, and bereavement into everyday life, rather than treating them as isolated and marginalised events. The implementation of the Throughput Model served as an applicable basis for mapping work processes and developing comprehensive evaluation plans.

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