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Top-down and bottom-up or participation through action? How to build a compassionate community – the experience of Caring Community Cologne

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All living things, as well as human beings, are in a process of development from birth to death. It begins with the first phase of our lives when we (almost) completely depend on others. Approaching the end of life, this dependency usually increases again. Even in the meantime, we are constantly reminded of the fragility and vulnerability of our lives (e.g. by illness, injury, individual and collective crises, grief, and trauma).¹ This is a social reality that constitutes us as living beings and shapes our cultural values and social as well as health policy organization. Death therefore has a great value for our societies.² Consequently, palliative and hospice care – with each other and for each other – also has a political dimension.

Being confronted with death, dying, and bereavement is not an exception at all: currently, about 1.2% of the population in Western societies die each year³ and in each case, about five informal caregivers are directly affected (about 6% of the population).⁴ In addition, some will die with a known severe and progressive disease in the near future. It can be assumed that we die of or with a known disease with a probability of about two-thirds⁵ and the period of living with a foreseeable severe and progressive disease is about 12–24 months before death.^{6,7} This means that in any given year, an additional 4.8% of the population will experience this stage of life as a patient or closed one. Moreover, a further 6% of the population is bereaved by the loss of a loved one who had died in the previous year. Therewith, almost one in five of the population in any given year is

affected directly and acutely by progressive severe disease, death, and bereavement (see Figure 1). This can be seen as a conservative calculation compared with results from a representative online survey in Germany on diverse end-of-life aspects.⁸ Of the 997 participants, 45% stated that in their surroundings, somebody is currently severely ill or has recently passed away. Not surprisingly, we constantly meet people who have some acute experience to share – and this has been even more relevant during the pandemic and in war-torn countries.

The competence in dealing with severe illness, dying, and bereavement is of great societal impact. How can we support this? For decades now, there have been many attempts in this direction: The hospice movement started in the United Kingdom in the 1960s and 1970s as a counter-trend to institutionalized end-of-life care with a strong societal base. It then spread internationally, including Germany and Poland in the 1980s. In 1988, the World Health Organization (WHO) launched the Healthy Cities program building on the Ottawa Charter for Health Promotion, which marked a new approach to public health.⁹ Following this new approach, Allan Kellehear developed the concept of Compassionate Cities in the 1990s.¹⁰ Initially popular in the Anglo-Saxon region, this concept has now spread to many countries, adopting different strategies and terms.^{11–13} In Belgium as a European example (where in Bruges the last Public Health Palliative Care International conference was held), two

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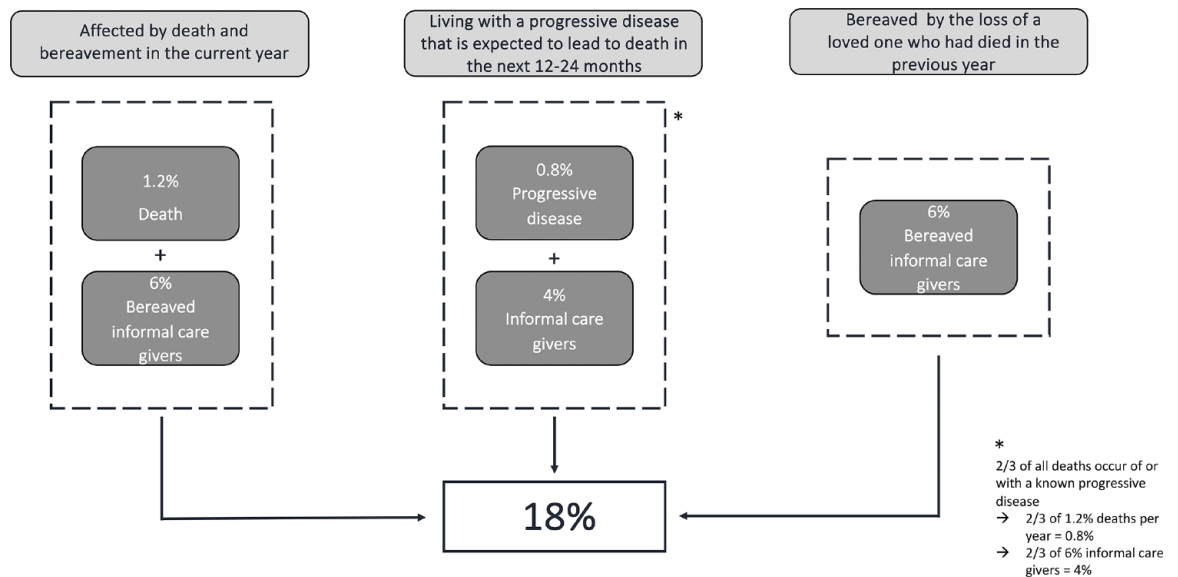


Figure 1. Percentage of the population in high-income countries affected by progressive disease, death, caregiving needs, and bereavement.

Compassionate Cities emerged from a collaboration of two universities and the cities.¹⁴ A closer look at the German-speaking countries shows that in Austria, the ‘Caring Communities’ project grew out of the local culture of caring for older people and people with dementia (<https://www.sorgenetzwerke.at/>). In Switzerland, there is a national foundation with a nationwide network of Caring Communities (<https://caringcommunities.ch/>). The Round Table of the Charter for the Care of the Critically Ill and the Dying in Germany has recently made the Caring Community a main topic (<https://www.charta-zur-betreuung-sterbender.de>) – as has the World Hospice and Palliative Care Day 2023.^{15,16}

Whatever approach or name you choose for your efforts, we all want to achieve the same goal: to increase the competence of society to better deal with severe illness, dying, and bereavement. However, the question remains open, how to achieve the necessary cultural change in a sustainable and long-term way?¹⁷ At the conference in Bruges, many discussions raised the question of whether a ‘top-down’ (initiative taken by institutionalized strategic level) or a ‘bottom-up’ (initiative taken by citizens’ projects) approach would be best. Purely top-down approaches depend on political agendas, may be of no relevance to the affected people, and can create mistrust.¹⁸ Bottom-up approaches empower individuals and communities by including and valuing the diverse

voices of the community.¹⁹ Identifying problems, developing solutions, and implementing them depend on the active participation of individuals. This makes purely bottom-up approaches challenging to start and coordinate.¹⁸ So, is a political initiative most promising or should we start with concrete projects?

In Cologne, a city of 1 million inhabitants, we try to set impulses and initiatives with a double strategic logic. On the one hand, ‘bottom-up’ initiatives have been developing model projects in the city for years, such as school programs.²⁰ On the other hand, ‘top-down’ initiatives have also been built up, such as the establishment of a palliative and hospice network (<https://palliativnetz-koeln.de/>). Therefore, especially after the COVID experience,²¹ it was the right time to combine these two developments in the creation of the Caring Community Cologne (<https://caringcommunity.koeln/>), a combination of both ‘bottom-up’ and ‘top-down’: We have established a city-wide Round Table initiated and lead by the City of Cologne and the Palliative and Hospice Network Cologne (supported by a Steering Group) – a clear ‘top-down’ approach. This steering group then approached local organizations that represented various aspects of society, calling in further participants if this was felt helpful. At this Round Table currently, representatives of about 35 further organizations are present, such as health insurance companies or the Cologne Chamber of

Crafts. It is meant as a permanent institution to exchange experiences, discuss new approaches, and make all relevant decisions. We believe that this ‘top-down’ structure, also involving the city of Cologne, is necessary to establish a sustainable change, especially for large cities. To integrate this ‘top-down’ approach with ‘bottom-up’, we decided to set up ‘Working Groups’ (WGs) on topics where there was already activity going on in our city. All groups are currently working very productively taking up smaller projects to address the whole city population independent of age and possible diagnoses, which individuals had started. The WG ‘Children and Youth’ expands help for bereaved children and existing school projects. The latter includes project days at primary and secondary schools to provide space for guided discussions on the topics of dying, death, and grief. The WG ‘Bereavement at the Work Place’ started around a large Cologne company which had – upon the initiative of an individual – acted in areas based on the results of a company-wide survey: The WG ‘Care City Map’ had based their further actions on an established database of palliative and hospice institutions. Finally, the WG ‘Care Structures’ coordinates actions that are based on the results of a large research project, ‘last year of life – Cologne’.^{22,23} Of course, challenges of cooperation, transparency, and involvement of citizens remain and constantly have to be reflected (Meesters *et al.*, under revision).²⁴

Despite this combination of a top-down and bottom-up approach, we feel that there is still a long way to go to really see changes for the level of every citizen. However, we notice that things start to change concretely when action is initiated jointly, the understanding of dying to be a relational process is strengthened and all relevant parties are involved resource-oriented.² For instance, we have attracted funding for 3 years from the German TV lottery for an innovative ‘buddy’ support for patients with severe illness who at this stage would however refrain from palliative or hospice support. This ‘buddy’ – the idea of which is again based on research²⁵ – will offer both low-level psychosocial support through a volunteer ‘buddy’ and institutional support through a professional ‘buddy’ – the ‘buddy’ as a Caring Community in person coming to you when you are in need. In setting up this project, we can already see that a participatory approach to this action project resonates very well both in participating institutions and on the social media level, where

we are planning a crowdfunding and participatory concept change campaign. Therefore, participation through action is probably the best way to reach our common goal.

In conclusion, increasing death literacy in your community is indeed possible. However, it takes time. Working on concrete projects in a combined top-down–bottom-up setting is a realistic way to achieve this goal. And it is an endeavor that is fun, as it brings the community together on topics that are so human and close to everyone. It is worth the energy!

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

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Author contributions

Raymond Voltz: Conceptualization; Funding acquisition; Project administration; Resources; Supervision; Writing – review & editing.

Sophie Meesters: Methodology; Writing – original draft; Writing – review & editing.

Karin Ohler: Conceptualization; Project administration; Writing – original draft.

Birgit Weihrauch: Conceptualization; Funding acquisition; Resources; Supervision; Writing – original draft.

Anne Kreische: Conceptualization; Methodology; Resources; Writing – original draft.

Johannes Niessen: Conceptualization; Methodology; Writing – original draft; Writing – review & editing.

Andreas Heller: Conceptualization; Supervision; Writing – original draft.

Julia Strupp: Data curation; Funding acquisition; Methodology; Supervision; Writing – original draft.

Kerstin Kremeike: Conceptualization; Methodology; Supervision; Writing – original draft; Writing – review & editing.

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Competing interests

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