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

Raymond Voltz [iD], Sophie Meesters, Karin Ohler, Birgit Weihrauch, Anne Kreische, Johannes Niessen, Andreas Heller, Julia Strupp and Kerstin Kremeike

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 year[3] 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-thirds[5] 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

Correspondence to:
Raymond Voltz
Department of Palliative Medicine, Faculty of Medicine and University Hospital, University of Cologne, Kerpener Strasse 62, Cologne D-50937, Germany

Center for Integrated Oncology Aachen Bonn Cologne Duesseldorf (CIO ABCD), Faculty of Medicine and University Hospital, University of Cologne, Cologne, Germany

Center for Health Services Research, Faculty of Medicine and University Hospital, University of Cologne, Cologne, Germany

Raymond.voltz@uk-koeln.de

Sophie Meesters
Julia Strupp
Kerstin Kremeike
Department of Palliative Medicine, Faculty of Medicine and University Hospital, University of Cologne, Cologne, Germany

Karin Ohler
Caring Community Cologne, Cologne, Germany

Birgit Weihrauch
´Endlich. Palliativ & Hospiz´ Association, Cologne, Germany

Anne Kreische
Johannes Niessen
Division of Health Planning and Promotion, Public Health Department Cologne, Cologne, Germany

Andreas Heller
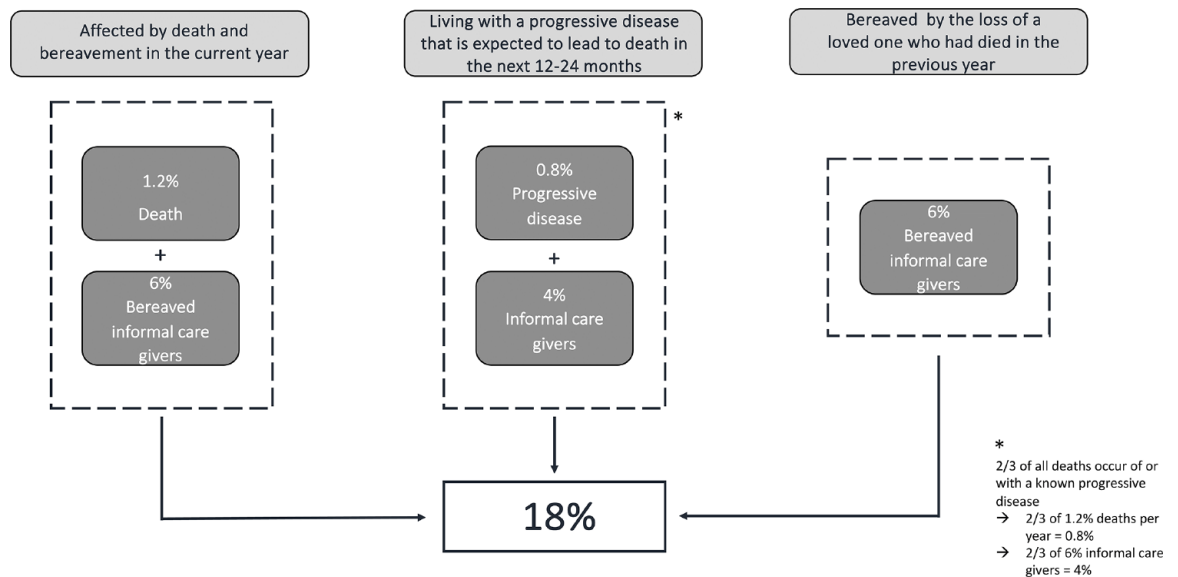Institute of Pastoral Theology and Psychology, University of Graz, Austria

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 research[25] – 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!

ORCID iD
Raymond Voltz https://orcid.org/0000-0002-4761-3395

References

1. Wirth HJ. *Feelings make politics. Populism, resentment and the chances of vulnerability*. Giessen: Psychosozial, 2022.

2. Sallnow L, Smith R, Ahmedzai SH, *et al*. Report of the Lancet Commission on the Value of Death: bringing death back into life. *Lancet* 2022; 399: 837–884.

3. Eurostat. Demographische Veränderung – absoluter und relativer Bevölkerungsstand auf nationaler Ebene [Internet], https://ec.europa.eu/eurostat/databrowser/view/demo_gind/default/table?lang=de (2023, accessed 12 June 2023).

4. Krull E. Grief by the numbers: facts and statistics [Internet]. The Recovery Village Drug and Alcohol Rehab, https://www.therecoveryvillage.com/mental-health/grief/grief-statistics/ (2023, accessed 12 June 2023).

5. van der Heide A, Deliens L, Faisst K, *et al*. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003; 362: 345–350.

6. Temel J, Greer JA, Muzikansky A, *et al*. Early palliative care for patients with metastatic non–small-cell lung cancer. *N Engl J Med* 2010; 363: 733–742.

7. Ferrell BR, Temel J, Temin S, *et al*. Integration of palliative care into standard oncology care: ASCO Clinical Practice Guideline update summary. *J Oncol Pract* 2017; 13: 119–121.

8. Strupp J, Köneke V, Rietz C, *et al*. Perceptions of and attitudes toward death, dying, grief, and the finitude of life: a representative survey among the general public in Germany. *Omega (Westport)* 2021; 84: 157–176.

9. World Health Organization and Regional Office for Europe. Ottawa charter for health promotion [Internet]. WHO/EURO, https://apps.who.int/iris/handle/10665/349652 (1986, acessed 12 June 2023).

10. Abel J and Kellehear A. Palliative care reimagined: a needed shift. *BMJ Support Palliat Care* 2016; 6: 21–26.

11. Department of Health. *Final report: compassionate communities feasibility study*. Australia: Nous Group, 2018, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/09/Compassionate-Communities-Final-Report-min.pdf (acessed 12 June 2023).

12. Quintiens B, D'Eer L, Deliens L, *et al*. Area-based compassionate communities: a systematic integrative review of existing initiatives worldwide. *Palliat Med* 2022; 36: 422–442.

13. Keller ML. Developing a compassionate community: a Canadian conceptual model for community capacity development. *Palliat Care Soc Pract* 2023;17: 26323524231193040.

14. Quintiens B, Smets T, Chambaere K, *et al*. Researching two Compassionate Cities: study protocol for a mixed-methods process and outcome evaluation. *Palliat Care Soc Pract* 2022; 16: 26323524221137601.

15. Worldwide Hospice Palliative Care Alliance (WHPCA). World Hospice and Palliative Care Day [Internet], https://thewhpca.org/world-hospice-and-palliative-care-day/about-2/ (2023, accessed 24 October 2023).

16. Mills J, Abel J, Kellehear A, *et al*. The role and contribution of compassionate communities. *Lancet*. Epub ahead of print October 2023. DOI: 10.1016/S0140-6736(23)02269-9.

17. Gonzalez-Jaramillo V, Krikorian A, Tripodoro V, *et al*. Compassionate communities: How to assess their benefit? A protocol of a collaborative study between different countries. *Palliat Care Soc Pract* 2023;17: 26323524231170885.

18. Huber JT, Shapiro RM and Gillaspy ML. Top down versus bottom up: the social construction of the health literacy movement. *Libr Q* 2012; 82: 429–451.

19. Buchmann M. Von Machtpositionen zu Machtpersonen: Machtfaktoren in Caring Communities. In: Sempach R, Steinebach C and Zängl P (ed.) *Care schafft community – community braucht care*. Wiesbaden: Springer, 2017, pp. 175–191.

20. Strupp J, Valerius L, Herrler A, *et al*. 'I see the high level of interpersonal support during the pandemic as proof that the good in people prevails': the COVID-19 pandemic as a catalyst

for building a caring community? *J Public Health*. Epub ahead of print January 2024. DOI: 10.1093/pubmed/fdad283.

21. Nolden N, Fay K, Weihrauch B, *et al. Palliativ & Schule: Sterben, Tod und Trauer im Unterricht mit jugendlichen Schülerinnen und Schülern*. Stuttgart: Kohlhammer Verlag, 2017.

22. Voltz R, Dust G, Schippel N, *et al.* Improving regional care in the last year of life by setting up a pragmatic evidence-based Plan-Do-Study-Act cycle: results from a cross-sectional survey. *BMJ Open* 2020; 10: e035988.

23. Strupp J, Hanke G, Schippel N, *et al.* Last Year of Life Study Cologne (LYOL-C): protocol for a cross-sectional mixed methods study to examine care trajectories and transitions in the last year of life until death. *BMJ Open* 2018; 8: e021211.

24. Meesters S, Ohler K, Voltz R, *et al.* How can a community be successfully empowered to deal with death, dying, and bereavement? Formative evaluation of the Caring Community Köln using focus groups. *Ann Palliat Med*. Epub ahead of print.

25. Kasdorf A, Voltz R and Strupp J. The Buddy intervention: designing an additional support system for the last year of life. Qualitative insights from triangulated interviews and focus group discussions. *J Public Health*. Epub ahead of print June 2023. DOI: 10.1007/s10389-023-01950-0.

Visit Sage journals online journals.sagepub.com/home/pcr

S Sage journals