

This symposium wants to explore the role of educational institutions in fostering compassion and brings together different educational institutions that are at various stages of developing compassionate initiatives within an educational context. The symposium will share experiences about the development process, the challenges and successes and promote further advances.

Sally Paul will start by discussing the role of education communities in public health palliative care. Drawing on her research with school communities she will present a conceptual model for compassionate schools and how this links with public health palliative care education. Marieke Groot follows with their specific living lab in the Netherlands and focuses on the methods, current situation and first results of the route towards a Compassionate University College. Veerle Coupez en Greetje Desnerck explain how an informal group of ‘believers’ of Howest (UAS Flanders) developed a Compassionate school. They give an insight in the learning network with the VUB and the services of student support. Hanne Bakelants closes the symposium with her research on the development of a Compassionate University in Belgium – Vrije Universiteit Brussel. The goal is to understand how different stakeholders build a shared understanding of the aims and objectives of the Compassionate University and how community members experience the development process.

Abstract ID: 229

Abstract Type: Poster - Family caregivers

Experiences of parenthood when a parent has been diagnosed with ALS

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Background: Amyotrophic lateral sclerosis (ALS) is a neuromuscular progressive disease that attacks the nerve cells in the brain and the spinal cord that control movements of the muscles. This leads to muscle wasting and paralysis of, among other things, extremities, speech, swallowing and

breathing muscles. The average survival is 2-5 years from the first symptoms. The disease means that the person increasingly needs help, and the family is often involved in that support. Research focusing on the parent perspective based on the experiences of both the ill and the healthy parent is limited. Therefore, the aim of this study is to explore the meanings of parenthood when one of the parents has been diagnosed with ALS.

Methods: Parents who have been diagnosed with ALS and their partner, or former partner, with whom they have children in common were interviewed separately. To date, 13 interviews with ill parents and 12 interviews with healthy parents have been conducted. 13 participants were women, and 12 were men. The interviews lasted about an hour, were audio recorded and transcribed. Phenomenological hermeneutic approach to the analysis is ongoing.

Results: The preliminary results show that both the ill and the healthy parents are very worried about the children’s situation. They are aware that the children take a great responsibility, and they are afraid that it prevents the children from living their own lives and spending time with friends as they otherwise would have done. They related about difficulties to talk to each other in the family, which create a culture of silence and the parents sometimes “protect” the children by excluding them from knowledge and support from the healthcare.

Conclusion: The results will lead to an increased knowledge of both the ill and the healthy parents’ situation. It will provide information that will be clinically useful in conversations with the whole family as well as in future supportive actions aimed at this target group.

Abstract ID: 230

Abstract Type: Free Communication - Community engagement and development

Designing human-centred palliative environments

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Background: The palliative environment (PE) can influence various users’ experiences of palliative care. Hence, architects could incorporate

human-centred recommendations into their designs of PE to support such users (i.e., patient, family, caregiver, volunteer) in multiple dimensions of their wellbeing (i.e., physical, emotional, social, and spiritual). However, the impact of research in this field on architectural practices seems little so far. Architects seem to be hampered in using evidence-based knowledge to design PE because the research is usually considered difficult to access, rarely targeted at architects, and challenging to integrate into design. In such cases, architects usually use their intuitive knowledge. However, since PE are generally not commonplace buildings, a possible discrepancy between architectural practice and users' needs and wishes can occur. To increase the impact in practice, it is necessary to consider which and how 'spatial aspects' affect users' experiences and wellbeing with(in) PE.

Method: A scoping review on users' experiences and wellbeing with(in) PE was performed to define spatial aspects; but, from an architectural perspective, some aspects were still missing. Performing fieldwork as a volunteer in two PE enabled data collection through qualitative methods (i.e., participant observation, case study analysis, and photo-elicitation interviews).

Results/conclusion: Users' experiences in PE can differ quite extensively, yet research in this field rarely takes a multi-user perspective. In our project, we explore the impact and interconnections of spatial aspects on users' experiences and wellbeing in PE while integrating multiple users' voices. Knowledge of these various users' experiences was linked to spatial aspects and then categorised into five main themes. These results provide insights, ideas, and support for (re) designing and researching human-centred palliative environments.

Abstract ID: 231

Abstract Type: Free Communication - Arts and end of life

Imaginative Communication Across the Borders of Death. End-of-Life Narratives in Palliative and Bereavement Care

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Background: In 2021, dying mother Lara Switten left a book with stories and pictures to her children. Lara's so-called end-of-life (EOL) narrative, created with the support of biographer Ine Nijs, attests to a growing trend of storytelling practices in Western-European palliative EOL care that prompt us to rethink the modified ways in which the dying anticipate death. More and more people facing severe illness are supported by caregivers and external biographers (e.g., Amfora, Flanders; Passeurs de mots, France) to review their lives and to pass down these stories to loved ones. Research has emphasized the therapeutic benefits of narrative life-review for the dying, relatives, and caregivers in EOL stages. Little is known about the implications of EOL narratives for the bereaved.

Methods: Previewing my literary-sociological study on EOL narratives as textual results of these cultural practices, I address this challenge from the perspective of literary studies and assume an imaginary communicative loop, in which the dying and the bereaved are engaged as authors-narrators and readers-recipients. By comparing Lara's EOL narrative with Ley's fictional 'For when I'm gone' (2020), I argue that literary techniques, such as imaginative narration, structure the ways in which the dying want to be remembered and how they anticipate a future of which they will no longer be part. I hypothesize that the dying and the bereaved not only attribute meaning to EOL narratives in terms of a continuation of parental and intimate roles in absentia. EOL narratives likewise elicit disrupting experiences and intergenerational incomprehension.

Conclusion: Insights into how literary techniques and narrative scripts modify the communicational character of EOL narratives will enhance our understanding of how these texts help the bereaved imagine the deceased and how their relationship could have looked like, and will lead to evidence-based guidance for those involved in narrative practices in EOL care.

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Abstract Type: Poster – COVID

Impact of Covid Pandemic on ambulatory palliative care

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