

Report from the Third International Last Aid Conference: cultural diversity in palliative care

Erika Zelko and Georg Bollig

Abstract: The Third International Last Aid Conference was held from October 28 to 29, 2022, as a hybrid event. Altogether, there were 85 participants from 14 different countries. The main topics of the conference were cultural diversity in palliative care, public palliative care education (PPCE), experience with Last Aid courses from different countries, and founding possibilities for courses and research in Last Aid. The speakers from different countries presented their experiences with Last Aid courses for adult and children, as well as the online courses. The contribution of the work of the Last Aid Research Group International (LARGI) for the development of Last Aid was presented. This report provides an overview of the conference and the content of presentations and highlights the most interesting discussions points.

Keywords: community education, compassionate communities, cultural diversity, Last Aid courses, online course, palliative care, public awareness, research

Last Aid courses are already known to the broad international community. The third international conference was, due to the still insecure COVID situation and on request from some of the delegates, conducted as a hybrid event at the Medical Faculty Maribor. Prior to the conference on October 27, the International Last Aid working group met online to discuss changes in the curriculum and the international slide presentation for Last Aid courses. Based on both practical experiences of Last Aid Course instructors and the scientific evidence from studies about Last Aid, the curriculum was adapted. The conference hosted 85 participants from 14 countries, including Austria, Brazil, Czech Republic, Denmark, England, Estonia, Germany, Ireland, Lithuania, Poland, Romania, Slovenia, Sweden, and Switzerland. The program was intensive and divided into a plenary section with multiple renowned keynote speakers and a workshop section with Last Aid Courses for children and teenagers.

The plenary section included lectures from international keynote speakers. Among these was Professor Allan Kellehear, the founder of

Compassionate Communities.^{1,2} This time Professor Kellehear spoke about Compassionate Communities and diversity, which is also an increasing topic in palliative care. Benjamin Langner Von Höveling shared his personal experience of palliative care from when his husband was dying. His report included a discussion about the needs of members of the LGBTQ (lesbian, gay, bisexual, transgender, queer or questioning) community concerning palliative care. He pointed out that human dignity and respect were the most important things he and his husband expected from the palliative care team at that time. They did not ask for special treatment and did not feel any discrimination or difficulties addressing the needs and receiving help from the team. Pandeli Pani introduced an interesting aspect of Palliative Care and Last Aid from a linguistic perspective. He concluded the lecture with the following statement:

Responding to individual needs is an important part of providing person-centred palliative care and the need for awareness and commitment to a culturally appropriate palliative care in societies with ethnically

Palliative Care & Social Practice

2023, Vol. 17: 1–4

DOI: 10.1177/
26323524231166932

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diverse population is especially important. Cultural factors shape patients' preferences around decision making, receiving bad news, and end of life care.

Georg Bollig – the founder of the Last Aid Movement – shared with us the colorfulness of Last Aid, and he compared the diversity of Last Aid with life itself. Last Aid welcomes everybody, and includes and respects people from different countries, beliefs, religions, and ethnicities. The main aims of Last Aid are to empower people to care for each other, to improve end-of-life care for everyone in need, and to make the world a better place. The last key speaker was Erika Zelko who tried to convince the participants about the importance of research in Last Aid. Research means understanding issues and increasing public awareness, and that is an important topic in palliative care and for Last Aid Movement that is a well-known program in 20 different countries. Karin Schmid from Brazil reported about the success of Last Aid in Brazil. She introduced some important facts regarding palliative care in Brazil. For example, there are only few palliative care experts (in the big cities we have some, but otherwise they almost do not exist); most people do think that morphine is used to accelerate death at the end, so people are reluctant to take morphine because it indicates their end of life. Therefore, Palliative Care is often understood as euthanasia. In the ranking of the Quality of Death and Dying 2021 report, Brazil is the 79th out of 81 countries. Karin told us 'that most people prefer to die in the hospital and not at home' (inquiry made some years ago, but we do not know exactly why, maybe because there is little support at home – it's getting a bit better). There is a big difference between the wealthy and the poor. Next speaker addressed a bilateral research. We have the possibility to learn something about the experience of Last Aid courses across the border between Germany and Denmark.³

In the pilot study, the participants found that individual differences are more important than cultural differences in end-of-life care. Some of the participants described the most important differences connected to regulations and organization of service on the different sides of the border. Some interesting suggestions for the future adaptation of the Last Aid Course were made. These suggestions included organization and support across the border, religions, and cultures and supporting people in grief.

Alexandra Hieck and Georg Bollig reported about the new course format for People with Disabilities. To enable participation of people with disabilities, an adapted Last Aid Course format was established. A working group from Letzte Hilfe Deutschland with experts from the fields of palliative care, education, pastoral care, parents of children with handicaps, and integration assistance adapted the course curriculum and presentation. The course presentation was assessed and approved by people with disabilities and a German organization for easy language. The results from the pilot courses show that people with disabilities appreciate the Last Aid Course; they want to talk about death and dying. They used an approach with easy language, and short and simple sentences have proven useful.

After the pilot courses, the participants received a Last Aid Box, and this proved to be a real 'ice breaker' to start a conversation about care and practical Last Aid measures at the end of life. The Last Aid Box contains material for palliative oral care: an oral care swab, sweet almond oil, and a spray bottle flower seed. These boxes helped to establish communication about death, dying, and palliative care with others who had not attended the course. This might be an easy option to improve the conversation about death and dying at home or in institutions with others. Another group of Last Aid courses that supported the idea about diversity in Last Aid international are children. Kids and teens are often relatives of seriously ill and dying people. The course is provided for children and teen from the age of 8. The aim is raising awareness on death, dying, and palliative care. The courses have less lectures and presentations, but more activity, play, and fun. Of the 128 children aged 9 to 17 years, 120 Last Aid course participants (response rate of 94%) from the 9 Last Aid courses in Germany have participated in the study. The main findings were that children and teenagers appreciated the possibility to talk about death and dying.⁴ In all, 82% had previous experience with death and dying, 95% found the course useful for everyone, 92% would recommend the course to others, and 89% found the contents of the course easy to understand. A huge interest to discuss the topic Children and Last Aid was visible also in our workshop. Boris Knopf and Georg Bollig led us perfectly through the workshop on this topic. The workshop included an extensive discussion of different aspects of talking about death and dying with children.

Due to the COVID pandemic in some countries, ONLINE Last Aid Courses were the only possibility to conduct Last Aid education. Online teaching experiences were reported from Germany, Brazil, Scotland, Slovenia, and Switzerland. The scientific evaluation from Scotland and Germany demonstrates the feasibility of the online Last Aid course.^{5,6} Special attention is needed to increase both participant-to-participant and instructor-to-participant interaction. Participants suggested continuing online Last Aid Courses after the pandemic to give participants the possibility to choose between classroom and online teaching. Hopefully, with this approach we might increase the number of younger participants and people who stay at home due to their domestic caring duties.^{4,5} On the other hand, the Last Aid facilitators felt the need for further training on how to deliver online, including digital skills and online facilitation skills. They expressed the need to have regular updates and a tangible facilitation guide/handbook.⁵

It is also known that many people are not confident in caring for dying relatives at home, as they often lack the necessary basic knowledge of end-of-life care and palliative care. Last Aid courses offer participants not only the acquisition of knowledge but also the opportunity to reflect on their own experiences with death and dying and to develop a palliative approach. To date, there is a lack of data on the effects of courses for informal caregivers to empower them for care, especially in Germany; because of that, an interesting research project was launched in Germany, which was presented by Chantal Giehl. A special group of professionals who often face dying people are police officers. In Germany and Scotland, colleagues provided several Last Aid courses to this population and came to similar conclusions. Police structures and questions vary from the general population, so there are different needs to be addressed. When the police address the issue of death, they recognize their own vulnerability and that must be addressed in the course.

Stefan Meyer talked about the needs of cultural sensitivity in Last Aid; that was an interesting point for discussion among the participants. Special Courses are in the pilot testing phase in Germany. Eva Niedermann summarized the Last Aid activities in Switzerland. For 5 years, the Evangelical-Reformed Church of the Canton of

Zurich has been a licensee for Last Aid Courses in Switzerland. Meanwhile, various organizations are involved in this project. Churches, hospitals, nursing homes, and foundations from 17 cantons of Switzerland now offer courses in German, French, and Italian. In addition to the international experiences with Last Aid Courses, there was also room for representation of the Slovenian Hospice Association and their activities in palliative care in Slovenia. Hospice Slovenia has also initiated a model for establishment of a Compassionate Community in Slovenian. How Last Aid activities could be included in founding and promoting integration of palliative care between health care institutions and nongovernmental organization was presented by Petra Gornik from Slovenia.

The final part of the conference focused on research on public palliative education and Last Aid. Georg Bollig presented the increasing number of publications that mentioned Last Aid and that can be found in PubMed. Future perspectives for Last Aid research were rehearsed in the final interactive session and discussion that generated some interesting ideas for work in the international society and Last Aid Research Group International (LARGI). With that discussion, the conference ended. The Fourth International Last Aid Conference will be held in Inverness, Scotland in June 2024.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Both authors agree on publishing this manuscript.

Author contributions

Erika Zelko: Conceptualization; Writing – original draft.

Georg Bollig: Conceptualization; Reviewed the last version.

Acknowledgements

None.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Competing interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


Availability of data and materials

Not applicable.

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