

Mini Review

The last aid course - A Simple and Effective Concept to Teach the Public about Palliative Care and to Enhance the Public Discussion about Death and Dying

Bollig G^{1,2,3*} and Heller A⁴¹Department of Pulmonology and Oncology, Hospital of Southern Jutland, Denmark²Department of Clinical Medicine, University of Bergen, Norway³Sunniva center for Palliative Care, Haraldsplass Deaconess Hospital, Norway⁴Institute of Palliative Care and Organizational Ethics, IFF (Faculty for Interdisciplinary Research and Further Education), University of Klagenfurt, Austria

***Corresponding author:** Georg Bollig, Palliative Care Team, Department of Pulmonology and Oncology, Medical Center, Hospital of Southern Jutland, Sønderborg, Sydvang 1, 6400 Sønderborg, Denmark

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Abstract

At present scientific knowledge about concepts for the education of the public in palliative care is lacking. Based on the experiences of teaching first aid to the public the concept of a *last aid course* was introduced. An international working group has established a curriculum for a *last aid course* with four teaching hours only. Pilot courses have proven the feasibility of the concept in Norway, Denmark, Austria and Germany. At present instructor courses are running and further scientific evaluation of the concept and the courses is ongoing. In addition a review of the literature on palliative care education for the public is provided.

Keywords: Palliative Care; Last Aid Course; Dying; Death at home

Introduction

Several authors have suggested that the demographic change will lead to a worldwide increase of the number of elderly people suffering from dementia, multimorbidity and frailty [1,2]. This implies a growing demand of elderly care and end-of-life care. Many people want to die at home. In Germany 66% would like to die at home, whereas just 20% actually died at home in 2012 [3]. Although 55% of the Danish population wants to die at home, 48% die in hospitals, 26% in nursing homes and only 17% at home [4]. In Norway only 15% of all deaths registered occurred at home in 2012 [5].

As most people want to die at home the need for palliative care and end-of-life care at home will rise and there will not be enough professionals to take care of all severely ill and dying people with the need for palliative care. To meet this increased demand all citizens do need basic knowledge and skills in palliative care in order to find the important and fitting information for different situations in end-of-life care. Public education in basic palliative care can enable everybody to participate in support for their family members, friends, neighbors or others in need. The aim of this article is to give an introduction to the concept of last aid courses and to provide an overview of the current knowledge and publications about palliative care education for the public.

Method

This article is based on our own experiences from the work with the idea of last aid and the “public knowledge approach” as well as the concept of last aid courses including the development of the courses. It summarizes already published articles about last aid. In addition a literature search using the terms “palliative care education” and “public” and “caregivers” was performed in Pubmed and MEDLINE.

An overview of the existing literature on this topic is provided. Challenges of the implementation processes in different countries are addressed.

Results and Discussion**Palliative care education for the public**

In the international scientific literature many publications on education of health care professionals in palliative care can be found. The views and experiences of citizens with death and dying have been included in education for professionals. For example have bereaved family caregivers and cancer survivors been involved in palliative care education for health care providers [6].

In contrast the published knowledge about educational efforts to teach citizens in basic palliative care and end-of-life care is extremely limited. Several authors have stated a need to educate the public about palliative care [7-11]. Singer and Wolfson [10] have described public palliative care education as important challenge for the future:

“Today, the challenge is to develop systematic and comprehensive information on the quality of end of life care at the population level.”

In Australia, a group education program consisting of three weekly sessions has been used to prepare family careers to support dying relatives at home [12,13]. Although there are other innovative concepts and efforts to engage citizens to discuss death and dying as for example the so called “death cafe” [14] and the “death chat” that is offered at St. Christopher’s hospice in London [15], these have not been published in the international scientific literature. The death chat is an offer to citizens who drop in to talk about death and dying without a commitment to join a course or to attend more than once [15].

Table 1: The *last aid course* contents.

Modulo No.	Topic		Course content (examples)
Module 1	Care at the end of life	To care and to accompany	• Caring for dying people • Who cares and supports the career? • Hospice philosophy and Palliative Care • What will be important for me when I have to die?
Module 2	Advance Care planning and decision making	To make plans and decisions on your own	• Basics of communication • How can we reach good decisions? • To make provisions (e.g. Living will) • Social networks
Module 3	Symptom management	To alleviate suffering	• When does dying start? • Living until the end of life • Options to handle and alleviate pain and other distressing symptoms (drugs and non-pharmacological options) • The role of eating and drinking at the end of life (including artificial nutrition and fluid management)
Module 4	Cultural aspects of death and bereavement	To say farewell	• Is there a right place to be? • Grief and bereavement • Rituals around the end of life • Burial - national rules and regulations • Summary

The *last aid course* concept

The current *last aid course* concept uses a course curriculum that has been designed by an international working group from Norway, Denmark and Germany [16,17]. It comprises a short basic *last aid course* with four modules (each lasting 45 minutes) only. The four modules are about: Care at the end of life, Advance Care planning and decision making, symptom management, and cultural aspects of death and bereavement (Table 1). The course is given once during an afternoon or evening with four teaching units (45 minutes each). Usually it consists of two parts with 1.5 hours and a 30-minute break. Pilot courses have been started in Norway, Germany and Denmark from December 2014 [16,17].

The history of the idea and course development

The idea of a *last aid course* was first introduced in 2008 in a master thesis on palliative care from the IFF/University of Klagenfurt/Wien of Georg Bollig that was published as a book in 2010 [8,9]. It is grounded on the assumption that knowledge about palliative care should be a part of the public education. The chain of palliative care was introduced to visualize the cooperation between lay people and health care professionals in palliative care (Figure 1). In analogy to the chain of survival used in emergency medicine we need a “Chain of Palliative Care” to illustrate palliative care pathways in the community. Once the patient himself, relatives, friends or neighbours have recognized the need for palliative care one contact should be enough to get the level of care, which corresponds, with the patients needs. When a general practitioner needs help to treat a patient a palliative care specialist should be contacted or the patient might be admitted to a specialized palliative care ward. This opportunity should

be accessible to patients living at home and in nursing homes. The “public knowledge approach” includes educational efforts as a *last aid course* for school pupils and the public to bring a basic knowledge into the whole society [8,9]. The first international presentation of the concept took place in 2009 during the 11th Congress of the European Association for Palliative Care, Vienna in May 2009 [18]. Between 2009 and 2011 a course curriculum of a *last aid course* with 16 teaching hours was created in cooperation with the Austrian Red Cross and the IFF Vienna, University Klagenfurt [19] but no pilot courses have been held so far. In 2012 the concept was presented in a lecture during the International Palliative Care Network Conference 2012 [20].

After a lecture about the concept of last aid during a meeting of the Norwegian and Danish Associations for palliative care in November 2013 a last aid working group was formed and between 2013 and 2014 a *last aid course* with four teaching hours grounded on the concept from Austria was established in cooperation between a German group with the Norwegian and Danish Associations for palliative care. An international working group from Norway, Denmark and Germany with experts in the field of palliative care from different professions designed a short basic *last aid course* with four teaching hours (each lasting 45 minutes) only [16,17,21]. Table 2 shows the timeline of the project development.

Presuppositions to become a *last aid course* instructor are experience within the field of palliative care and instructors may be nurses, physicians, social workers, priests, etc. Usually a *last aid course* is given by two instructors from different professions together to visualize the multi-professional cooperation in palliative care.

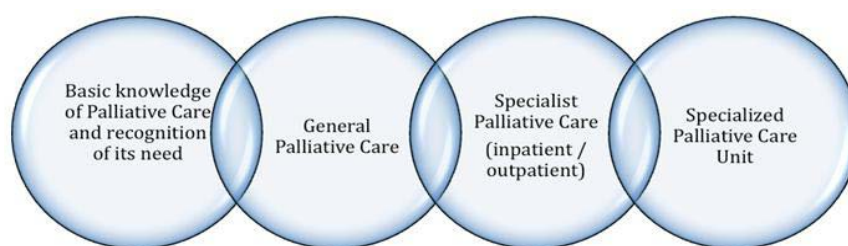
**Figure 1:** The Chain of Palliative Care.

Table 2: Timetable of the milestones and awards of the *last aid course* project.

2008	First presented in the Master thesis of Georg Bollig
2009	Poster presentation 11th Congress of the European Association for Palliative Care, Vienna in May 2009
2010	Master thesis published as a book
2009-2011	Development of a <i>Last Aid Course</i> with 16 teaching hours in cooperation with the Austrian Red Cross and the IFF Vienna, University Klagenfurt,
2012	Honorable mention for the lecture "The public knowledge approach as educational concept for bringing Palliative Care to the public" International Palliative Care Network conference 2012
2013-2014	Development of a <i>Last Aid Course</i> with 4 teaching hours in cooperation with the Norwegian and Danish Associations for Palliative Care
2014-2015	First pilot courses in Norway, Germany and Denmark
2015	Participation in the project start social - Invitation to chancellor Angela Merkel 17.06.2015
2015	Honorable mention for the poster presentation "Teaching Palliative Care to the Public: The <i>Last aid Course</i> – An International Multicentre project from Norway, Denmark and Germany" International Palliative Care Network conference 2015
2015	Reception of an award for Palliative Care from the German Association for Palliative Medicine and the pharmaceutical company Grünenthal 19.09.2015
2016	Publication of a handbook for <i>last aid course</i> participants
2016	The Paula Kubitschek-Vogel Stiftung in Munich, Germany finances a pilot-project to spread the <i>last aid courses</i> in four German regions

The four modules are named according to their content:

1. Care at the end of life,
2. Advance Care planning and decision making,
3. Symptom management,
4. Cultural aspects of death and bereavement.

Details of the contents of the *last aid course* are shown in Table 1.

First pilot courses were held in Norway, Germany, Austria and Denmark in 2014-2016. Pilot courses have been established in all four countries. Evaluation of the pilot courses is ongoing.

Evaluation and first experiences with the *last aid course*

The first results are promising. So far more than 300 people participated in last aid courses in the three countries. Most participants appreciate the course and talking about death and dying in a comfortable atmosphere. Most of the participants stated that they would recommend the course to others.

Results from the first pilot courses from Germany showed that most participants appreciate the course and talking about death and dying in a comfortable atmosphere. After the course, all participants were invited to fill in a questionnaire about the last aid course. All participants stated that they would recommend the course to others [16]. Examples of statements from the German course participants are [16]:

- If I only had known that before it would have helped me when my aunt died.
- I appreciate the natural way to deal with the topics death and dying.
- Lively and easy, although the topic is complicated.
- I have no suggestion that could improve the course.
- Clear and structured.

Some of the Norwegian course participants told us that they talked about the course topics afterwards at home with their family members

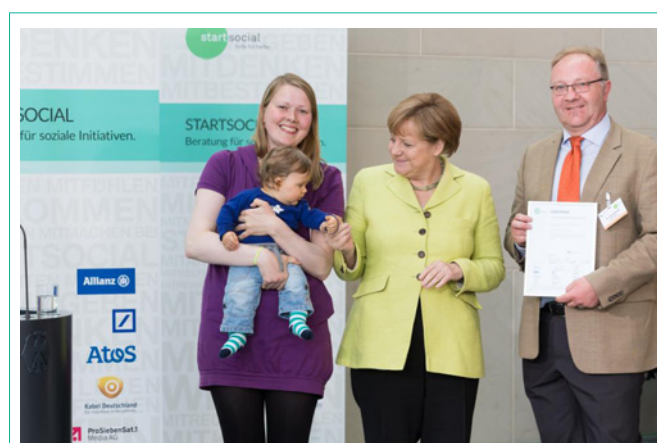


Figure 2: Invitation to Chancellor Angela Merkel.
(Foto: Start social / Thomas Effinger)

or friends. That shows that the course not only provides information about Palliative Care in the public but also leads to discussion of the topics with other people than the course participants. Thus the aim of spreading knowledge in the public is extended to cover other people than *last aid course* participants only.

In Germany a course participant became seriously ill due to cancer some months after the course and called for the palliative care team of the hospital. The patient knew what to expect and what needed to be planned in order to be able to die at home. She had some further questions concerning her care and stated that she was lucky to have attended the *last aid course* that enabled her to make plans for future care despite of being seriously ill.

Since October 2015 instructor courses are ongoing to spread the *last aid course* in Norway, Denmark, Austria and Germany. Within the year 2016 it is estimated that more than 270 instructors will have been educated to teach last aid courses in the three countries.

In July 2016 a small handbook in pocket size-format has been published in German [22]. Translation into other languages is planned.

International recognition and prizes

The project has received a prize from the German Association for Palliative Medicine in September 2015 [23] and has been awarded by start social and chancellor Angela Merkel as one of the best social projects in Germany in 2015 (Figure 2) [24]. The Paula Kubitscheck-Vogel-Stiftung Munich, decided to support the idea as a last aid project of the IFF in four German regions (Schleswig-Holstein, Baden-Württemberg, Bayern und Sachsen). After evaluating this model phase it is intended to spread the courses in the whole country [25].

Challenges in different countries

A major challenge in the participating countries is to find organisations that can distribute the concept in their respective countries. Participating organisations can be associations for palliative care, the church or others.

Major issues discussed at present are the adaptation of the curriculum to local needs as for example the legislation about advance care planning, etc. and possible local variations of the concept. In the future the working group will have to address the amount of standardization needed versus local adaptation.

Future plans

The education of *last aid course* instructors is ongoing. It is planned to continue with the work in an international last aid working group that is coordinated by Georg Bollig and Andreas Heller at the IFF Vienna, University Klagenfurt. More countries are invited to participate and at present Austria, Switzerland, Serbia and Sweden are about to start their participation in the international working group.

As shown above, there is an urgent need to educate the public about palliative care, end-of-life care and advance care planning. So far scientific knowledge about educational programs and their effects on public knowledge about palliative care is very limited. Kellehear has suggested that we need compassionate communities as a public health approach to palliative care [26]. He highlights the responsibility every citizen has for end-of-life care. This approach aims to enable citizens to care for each other and to participate in end-of-life care provision and is similar to the public knowledge approach [8,9,18,20]. At present the INSPIRE study investigates the feasibility and effects of the compassionate communities approach [27].

The death chat, the compassionate communities approach and the public knowledge approach with last aid courses as described in this paper are at present the most promising efforts to teach the public in palliative care. Probably these efforts could be combined in the future. More research on palliative care education of the public is needed.

Conclusion

Palliative care education of the public is needed. The aim of the *last aid course* is to stimulate people to talk about death and dying has been reached. First results from the evaluation of the last aid courses are very promising. More research on the education of the public in palliative care in general is needed. Further research on the implementation of the *last aid course* is needed and is already ongoing. It is planned to spread the course to other countries.

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