Chapter

Palliative Care Education for Everybody

Georg Bollig

Abstract

This chapter is about palliative care education for everybody including both professional health care workers and all citizens. A six-step approach to life-long palliative care education (as first described by Bollig in 2008 and published as a conference poster in 2009 and a book in German in 2010) will be proposed and discussed. The chapter will summarize the public knowledge approach to palliative care implementation (Bollig 2008) and other strategies to educate the public about palliative care. The concept of Last Aid courses for citizens will be introduced, and international experiences with this concept will be discussed. A possible combination of Last Aid courses and the compassionate community approach might improve palliative care provision in the community.

Keywords: Palliative care, worldwide, education, citizens, public health, compassionate communities, Last Aid course

1. Introduction and background

Our world is in constant change, and today, there is an enormous pressure by the mass media and the Internet to handle a massive amount of information every single day. To keep up with the current knowledge is therefore not an easy task. There is an increasing focus on life-long learning. This applies also to the field of palliative care and end-of-life care. Taking into account the increasing number of frail elderly people and people with demanding care needs in the future, it is obvious that all health care professionals should know how to provide palliative care and end-of-life care. But why should everybody be interested in learning palliative care when there are specialists to handle that? Due to an increased overall life expectancy, the demographic change and a growing awareness of palliative care needs of patients with nonmalignant diseases as, for example, terminal stages of heart-diseases, kidney diseases, neurological diseases, etc., an expected enormous number of people with a need for palliative care cannot be treated by specialized palliative care providers alone. In order to provide good palliative care to all in need, all citizens have to join in to help to provide palliative care for everybody in need. According to Kellehear, everybody has a responsibility of providing end-of-life care for others [1, 2].

Although many people would prefer to die at home, death has moved to happen mostly in institutions like hospitals or nursing homes within the last decades. Thus, communities and health care services have to prepare for an increasing number of people in need of palliative care and end-of-life care at home and in nursing homes [3–5]. The health care systems around the world will not be able to cope with this

enormous task without an increased contribution from the public. In order to meet the needs of as many dying people as possible, the health care system has to cooperate with relatives, friends, and the whole community [1–4]. Based on these facts and thoughts, there is a need that everybody should be educated in palliative care in order to be capable of caring for seriously ill and dying people at home.

2. Learning palliative care throughout life for everybody

As pointed out above, the enormous need for palliative care in the future indicates a need not only to educate health care professionals about palliative care but also to include the whole society and all citizens. First Aid and emergency care can be used as an example for cooperation of the health care system and citizens. Without the help of citizens who provide first aid, many people would die or suffer from more serious damages following a heart attack, cardiac arrest, or trauma. The example of the city of Seattle in the USA has shown that the public can be trained and motivated to participate as bystanders in emergency care [6, 7]. In Seattle, 850,000 people have been trained in cardiopulmonary resuscitation (CPR) since 1971 [6]. The crucial factors to achieve that have been public education classes where people have to attend only once for a short period of approx 1–2 hours and broad information and motivation of the public [6, 7].

2.1 The public knowledge approach

Several models of implementing palliative care have been described in the literature [8, 9]. The most common used approach uses an expert to ensure a good quality of palliative care provision [8, 9]. Based on my experience from working at Harborview Medical Center in Seattle and observations from the work of Medic I and Medic II, I have adapted the approach from emergency medicine applied in Seattle to the field of palliative care. The so-called *public knowledge approach* [7, 10–13] aims to incorporate knowledge about palliative care and end-of-life care in public knowledge that everyone should have. This should in the future become an essential part of public education in schools alongside with biology and first aid education. Palliative care knowledge for the public in palliative care can in analogy with first aid be called *Last Aid*. This expression makes it clear for most people that it includes care at the end-of-life. Many people associate care at the end-of-life and a supplement to first aid with the term *Last Aid* [14]. The public knowledge approach assists implementation of palliative care in the public and may enhance knowledge about palliative care for all health care professionals and the public. It uses lay people to make palliative care available everywhere for all people in need. The *Last Aid course* forms the educational foundation of this approach in order to enable everyone to provide palliative care in the community. It may also form an essential component of the compassionate community approach [15]. The *Last Aid course* will be described in more detail under 3.

2.2 The chain of palliative care

In analogy to the chain of survival used in emergency medicine (**Figure 1**), a *chain of palliative care* (**Figure 2**) was introduced to illustrate palliative care provision in the community. The first step is that the patient himself or others (e.g. relatives, friends, and neighbors) recognize a need for palliative care. The approach is patient-centered. As in emergency care, one contact (the emergency call) should be enough to get the level of care which corresponds to the patients' needs. If a

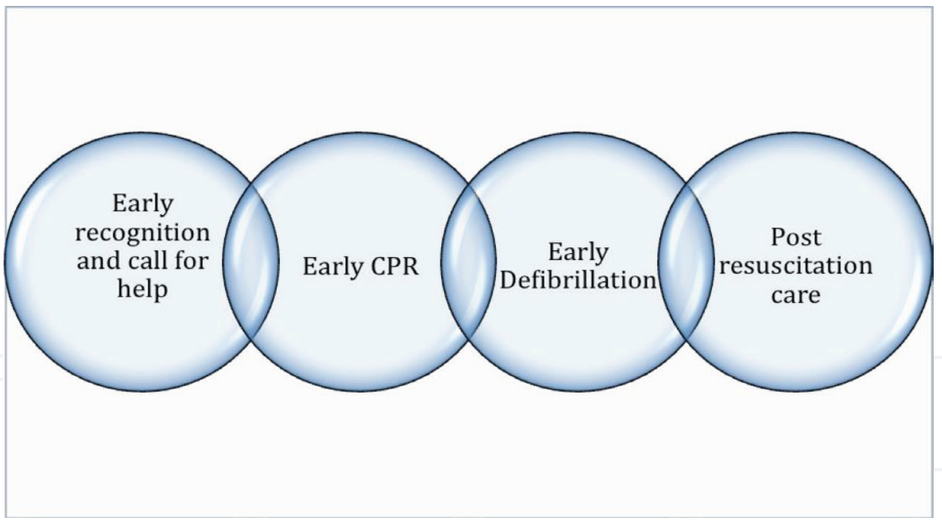

Figure 1.
The chain of survival (from emergency care).

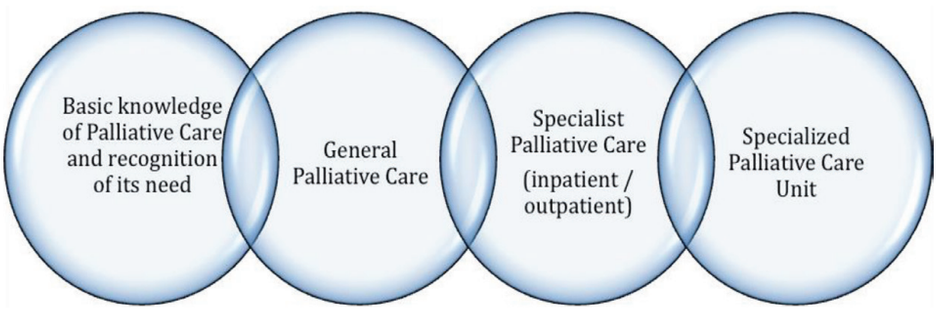

Figure 2.
The chain of palliative care.

general practitioner or a community nurse need help to treat a patient, a palliative care specialist or a specialized palliative care team should be contacted. The patient might be admitted to a specialized palliative care ward if it is not possible to provide satisfactory care within the home.

2.3 The six-step approach to education in palliative care for all

This approach (**Figure 3**) includes education for the public as initial step. One important feature is the demand for multidisciplinary education for all professionals involved in palliative care. Multidisciplinary education can be used to include a team-based approach not only in palliative care provision but also already in learning palliative care. This may increase the understanding of the different views of the different stakeholders involved in palliative care provision. Unfortunately, most education programs in palliative care for health care professionals are monodisciplinary [7]. The European Association for Palliative Care has described three levels of palliative care knowledge (A, B, and C), and educational programs have been designed for professionals (nurses, physicians, etc.) in the field of palliative care according to [16]. In order to include the public, as well as leaders and researches, the six-step approach has been modified to include six different levels. These are six steps on the ladder to education and acquisition of competence in palliative care. It is important to aim for a multidisciplinary education in order to bring the members of the future multidisciplinary teams together already during the learning phase. This will help to understand the different tasks and views of the different professions and can help a team-based approach.

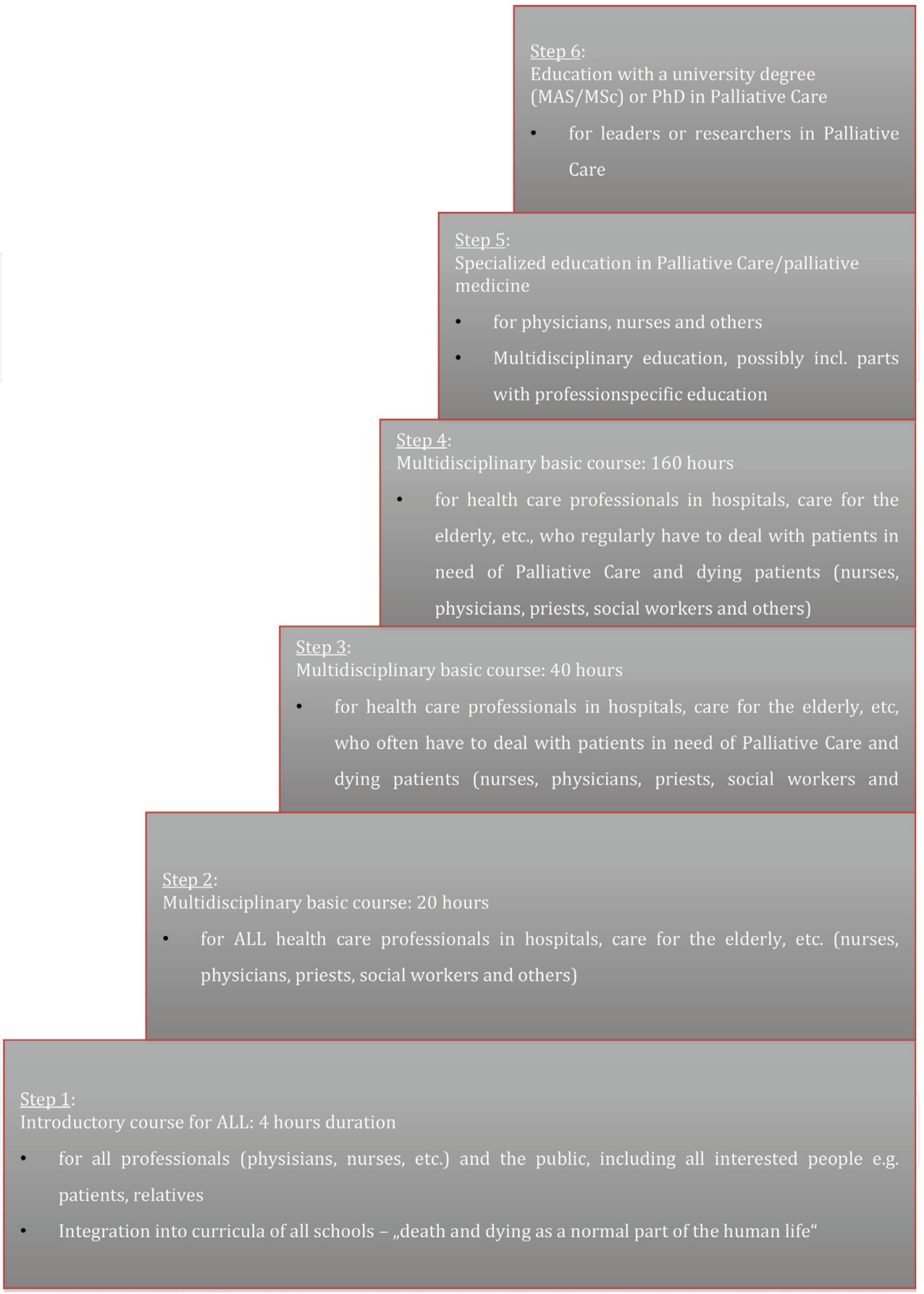

Figure 3.
The six-step approach to education in palliative care for all.

The six steps will now be explained in more detail:

- *Step 1:* Public knowledge about palliative care and end-of-life care for all citizens. Learning palliative care should start already in school. Step 1 is at the same time the basic knowledge for all health care professionals and the whole staff working in hospitals, nursing homes, and other facilities that provide medical

care and sometimes palliative care. This includes also staff members working in cleaning, household, mechanics and administration, etc.

- *Step 2:* Palliative care knowledge for all health care professionals including those who do not regularly provide care for seriously ill and dying people. This is meant to ensure an adequate level of care throughout the health care service.

- *Step 3:* Health care professionals who often have to provide care for seriously ill and dying people need a good knowledge about palliative care and symptom treatment.

- *Step 4:* 160 hours of training have been suggested as appropriate for health care professionals who have to care for seriously ill and dying people on a regular basis.

- *Step 5:* A specialized education is needed for health care professionals and others whose main task is care and treatment of seriously ill and dying people. Some countries have for example already introduced a specialization or sub-specialization for physicians and nurses. This helps to ensure a high level of specialized palliative care. Also for these people, education should be as multidisciplinary as possible.

- *Step 6:* Further academic education leading to a Master or PhD degree is important for future leaders and researchers in the field of palliative care. The academic education should aim to support multidisciplinary work in teams, leadership, and research to implement new knowledge and to establish new knowledge in practice.

In Germany, the *Last Aid course* is recognized by the German Association for Palliative Medicine (DGP) and the German Hospice Association (DHPV) as first step of the education in palliative care for both lay people and professionals (personal communication). All health care professionals should have a basic education in palliative care (step 2). According to the grade of daily involvement and professional role in palliative care, the steps 3 to 6 show the educational level suggested for health care workers, leaders, and researchers in the field (**Figure 3**). The Last Aid course is designed as a joint foundation for both lay people and professionals. As for first aid courses, it is recommended to repeat the Last Aid course after a few years to keep updated with the current knowledge and practice. The international *Last Aid* working group revises the curriculum and the course presentation at present every 1 to 2 years.

3. Teaching the public

Different authors have suggested that there is a need to teach the public about palliative care [7, 10–13, 17–19]. Nevertheless, there are just a few existing projects that try to teach the public on a large scale. Approaches that have been used are for example: group teaching of family carers in Australia [20, 21] or the open formats of the so-called death café or death chat [22, 23]. The latter invite people to discuss death and dying on a drop-in basis without any obligation to participate again.

3.1 The *Last Aid course*

A model to teach the public about palliative care is the *Last Aid course*. The *Last Aid course* is a clearly structured approach (like a first aid course) where knowledge

is provided, but in addition, a discussion about death and dying and a reflection of one's attitude is encouraged. An international Last Aid working group with participants from different European countries works during regular meetings every 1–2 years on a consensus about the course curriculum and content. This ensures that the *Last Aid courses* in different areas and countries are based on the same curriculum based on actual scientific knowledge and practice of palliative care. The consensus of experts from different countries ensures evidence-based and updated knowledge to be delivered to the public. An important task of the working group is to ensure that the educational format uses an everyday language in order to address the whole public. **Table 1** shows my first ideas about the topics to teach as first presented in 2008 [7].

Usually the *Last Aid course* includes four modules (each lasting 45 minutes) only. Topics included in the four modules are care at the end of life, Advance Care planning and decision making, symptom management, and cultural aspects of death and bereavement. The course is given during one afternoon or evening with four teaching units (45 minutes each). It usually consists of two parts with 1.5 hours and a 30-minute break. At present, nine European countries participate in the International *Last Aid* working group. These countries include Germany, Denmark, Austria, Switzerland, Slovenia, Scotland, Lithuania, Estonia, Bulgaria and Latvia. At present, talks with more countries about participation in the international Last Aid working group are ongoing. Some countries have already functioning systems

• Dying as a normal part of human life
• Problems around dying, e.g., troublesome symptoms, total pain concept, medical and ethical end of life decisions
• Treatment of troublesome symptoms
• Medical and nonmedical treatment options, fluid and nutrition at the end of life
• Bereavement and grief

Table 1.
Topics Last Aid course.

Figure 4.
Invitation to chancellor Angela Merkel 2015. (Photo: startsocial/Thomas Effinger).

for teaching *Last Aid courses* on a regular basis, while others are still in the starting phase of implementing *Last Aid* education for the public.

The first results from a German pilot-study [10] from 2015 were very positive which lead to several awards including an invitation to the chancellor Angela Merkel (**Figure 4**) [24, 25]. The scientific evaluation of the *Last Aid course* is at present ongoing in different countries and includes both teaching of the public and the use of *Last Aid courses* to teach nonmedical staff in hospitals [26]. In Germany, work with courses for children starting at the age of 8 years is in the testing phase. First results will be published on the congress of the European Association for Palliative Care [27]. In 2019, the European Association for Palliative Care has established a taskforce on Last Aid [28]. **Table 2** shows the timeline of the development of the Last Aid course project and the International Last Aid working group.

2008	First presentation of the Last Aid concept in the Master Thesis of Georg Bollig
2009	Posterpresentation 11th Congress of the European Association for Palliative Care, Vienna
2010	Master thesis published as a book
2009–2011	Development of a Last Aid Course with 16 teaching hours in cooperation with the Austrian Red Cross and the IFF Vienna, University Klagenfurt/Graz
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
2013–2014	Development of a Last Aid Course with 4 teaching hours in cooperation of the Norwegian and Danish Associations for Palliative Care with Letzte Hilfe Deutschland
2014–2015	First pilot courses in Norway, Germany and Denmark
2015	Participation in the project startsocial–Invitation to chancellor Angela Merkel
2015	Honorable mention for the posterpresentation "Teaching Palliative Care to the Public: The Last Aid Course—An International Multicentre project from Norway, Denmark and Germany" International Palliative Care Network conference
2015	Reception of an award for Palliative Care from the German Association for Palliative Medicine and the pharmaceutical company Grünenthal
2016	Symposium of the Paula-Kubitschek-Vogel Stiftung München on Last Aid
2016	Publication of a German handbook for Last Aid Course participants
2016	Lecture on Last Aid on the International Palliative Care congress in Montreal, Canada
2017	1. German Symposium on Last Aid in Hamburg
2017	Lecture on Last Aid on the Scottish Palliative Care congress in Edinburgh, Scotland
2017–2019	Last Aid International as EUPCA project
2018	Last Aid courses recognized and recommended by German Hospice Association (Deutscher Hospiz und Palliativvverband-DHPV) and the German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin-DGP)
2018	Meeting of the International *Last Aid* working group in May in Frankfurt
2018	Relaunch of the German and English homepage www.lastaid.info
2018	Lecture on Last Aid on the 1. Baltic Palliative Care Conference in Liepaja, Latvia
2018	2. German Symposium on Last Aid in Kassel
2018	Publication of a Danish handbook for Last Aid Course participants

Table 2.
Timetable of the milestones and awards of the Last Aid Course project.

4. Turning knowledge into practice

Knowledge alone is not sufficient enough to change practice. This important statement from Ferris [29] should inform all efforts to spread palliative care in the community. In order to turn knowledge into practice, we do need education, reflection of own attitudes toward death and dying, and a public discussion on the topic. Without a palliative care attitude of the public informed by hospice philosophy and humanitarian thinking, it may not be possible to provide palliative care to all people who need it. From my point of view, it is therefore important to educate people and to encourage public discussion about death and dying. Knowledge alone may be insufficient to change practice but education and discussion could be the first steps toward better palliative care provision for all in need.

5. Conclusions and implication for the future

In the future, the need for palliative care in the community will increase. Education about palliative care by *Last Aid courses* or other initiatives in combination with a compassionate community approach may serve to improve public discussion about death and dying, as well as palliative care provision in the community . There is a need for more research about *Last Aid courses* and other measures to empower the public to engage in palliative care provision in the community.

Possible conflict of interest

GB may have a potential conflict of interest as he receives financial compensation for teaching Last Aid Instructor courses. GB owns the trademarks “Last Aid” and “Letzte Hilfe”.

Author details

Georg Bollig

1 Palliative Care Team, Medical Department Sønderborg/Tønder, South Jutland Hospital, Sønderborg, Denmark

2 Research Unit for Medicine and Palliative Care, Institute of Regional Health Research, University of Southern Denmark, Odense, Denmark

3 Last Aid International, Schleswig, Germany

*Address all correspondence to: georg.bollig@rsyd.dk

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