

Aleksandra Korzeniewska-Eksterowicz^{1,2}, Małgorzata Cynker-McCarthy², Bogna Kędzierska^{1,3}, Łukasz Przysło^{1,2}, Małgorzata Stolarska^{2,4}, Grzegorz F. Nowicki², Wojciech Młynarski⁴

¹Pediatric Palliative Care Unit, Department of Pediatrics, Oncology, Haematology and Diabetology, Medical University of Lodz, Poland

²Gajusz Foundation — Home Hospice for Children of Lodz Region, Poland

³Institute of Psychology, University of Lodz, Poland

⁴Department of Pediatrics, Oncology, Haematology and Diabetology, Medical University of Lodz, Poland

Development and implantation of a pilot education program for pediatric palliative care in Poland

Described project had been awarded and 90% funded by the Foundation for the Development of the Education System, Measure V edition — Development of Polish Higher Education Institution (Project number: FSS/2009/III/D5/W/0048). Since August 2009 to June 2011 the project has been completed with the support granted by Iceland, Liechtenstein and Norway by means of co-financing from the European Economic Area Financial Mechanism and the Norwegian Financial Mechanism as part of the Scholarship and Training Fund.

Abstract

In many countries over the last forty years palliative medicine have been recognised as a separate speciality and associated with adult cancer patients. Pediatric palliative medicine is a specific discipline which is very distinct from palliative care of adults. In Poland pediatric palliative care has been provided as a home based model of care. Dynamic development of palliative care of children in Poland in the last sixteen years proves high demand for that service. Despite of the dynamic development of the pediatric palliative care in Poland there are two main challenges in that field: difficulties in staff recruitment and significant deficits in the knowledge of the pediatric palliative care. Those difficulties arise as a result of a lack of training among students In majority of Polish medical universities (both for doctors and nurses) palliative care is a part of the teaching program. However most of programs include only adult palliative care. Pediatric curriculum does not cover palliative care. That paper describes development and implantation of a pilot education program for pediatric palliative care in Poland.

Key words: palliative care, children, education, curriculum

Adv. Pall. Med. 2012; 11, 1: 10–14

Address for correspondence: Aleksandra Korzeniewska-Eksterowicz
Pediatric Palliative Care Unit, Department of Pediatrics, Oncology, Hematology and Diabetology
36/50 Sporna str, 91–738 Łódź, Poland
tel.: +48 42 6177791
fax: +48 42 6177798

e-mail: aleksandra.korzeniewska-eksterowicz@umed.lodz.pl

 Advances in Palliative Medicine 2012, 11, 10–14

Copyright © 2012 Via Medica, ISSN 1898–3863

Pediatric palliative care in Poland

In many countries over the last forty years palliative medicine have been recognised as a separate speciality and associated with adult cancer patients. Pediatric palliative medicine is a specific discipline which is very distinct from palliative care of adults. Its' specific characteristics include: relatively small number of patients due to low mortality of children, wide spectrum of diseases (age specific children's illnesses), unpredictable patterns of illness and death, higher uncertainty in regards to appropriate treatment (when to stop life saving invasive treatment?; when to start symptom management?) [1, 2]. As a result of the advancements in the prenatal methods of diagnosis there is a relatively new area of pediatric palliative medicine: prenatal pediatric palliative medicine. It applies to situations in which prenatal diagnosis suggests serious, untreatable pathology of the foetus. Prenatal palliative care of the whole family starts during the pregnancy and continues through the labour and after the baby is being born. The aim is to provide care for babies and infants with life limiting illness. It provides an alternative for those families who did not take up the option of terminating the pregnancy and want to protect their child from suffering and risky medical procedures. Multidisciplinary care offered by the home hospice team gives the families a chance to experience a calm and intimate ending of their child's life. In the last 20 years in Poland we have been observing dynamic development of palliative care, which was started by the independent hospice movement [3]. Pediatric palliative care is a relatively new area of pediatrics. In Poland pediatric palliative care has been provided as a home based model of care. Dynamic development of palliative care of children in Poland in the last sixteen years proves high demand for that service [4–8]. In 1994 the Warsaw Children's Hospice has been established which was the beginning of a home based pediatric palliative care in Poland [9]. In 2009 there were 16 home hospices for children in Poland [8]. Home environment is the most appropriate for terminally ill children. That model of care should be promoted as most suitable for both children and their families, as well as cheaper than the inpatient care. This opinion accords with the international trends which emphasize the importance of home based medical care, especially with psychological and social input [10, 11]. The largest so far retrospective research conducted in

the States between 1989 and 2003 describes significant shift in terms of the place where children with life limiting illness die [12]. Dying at home becomes more and more possible due to the fast development of the symptom management among terminally ill children, development of medical techniques and procedures (palliative procedures, percutaneous endoscopic gastrostomy, home oxygen therapy) and the advancement of pediatric palliative care [12, 13]. Despite of the dynamic development of the pediatric palliative care in Poland there are two main challenges in that field: difficulties in staff recruitment and significant deficits in the knowledge of the pediatric palliative care (especially rules of children's palliative care, referrals for palliative care and the ways hospices should be run). Those difficulties arise as a result of a lack of training among students (no or very little space for palliative care issues in the medical curriculum).

Graduate and postgraduate training in palliative care

For many years palliative care issues have been part of the medical curriculum in quite a few countries [14–20]. In majority of Polish medical universities (both for doctors and nurses) palliative care is a part of the teaching program [21]. However most of programs include only adult palliative care. Pediatric curriculum does not cover palliative care.

The postgraduate programs allow doctors in Poland to specialise 40 basic disciplines, e.g. pediatrics, surgery, etc. The training takes five to six years. A doctor who became a specialist in a basic discipline can choose a specialised discipline. Palliative medicine in Poland is one of the 28 specialised disciplines and the training takes further two years. The training program applies mainly to adult palliative care; during the two years of training there is only one one-day module on palliative care of children.

In the 6 year course of pediatrics the doctors are supposed to familiarise themselves with specific aspects of palliative care of children but those issues have not been included in any formal training. The doctors are expected to learn about the above issues from the literature.

The doctors who have finished their specialised training are expected to continuously expand their knowledge — in four year periods they are expected to obtain certain number of educational hours. The available forms of training include conferences and seminars.

The nurses in Poland can specialise in 23 basic disciplines or/and expand their knowledge by attending specialised training courses. The palliative care specialisation for nurses consists of 1070 training hours out of which 150 are assigned to pediatric palliative care. The training program allows 35 hours of practice in children's hospice to be exchanged for the same number of hours in the children's oncology unit. Since 2010 the nurses can attend a specialised course of pediatric palliative care.

The professionals already working in children's hospices have opportunities to attend specialised courses and conferences.

Establishment of the educational program

An inspiration to establish a professional training program in pediatric palliative care came from a few years of experience of Home Hospice for Children of Lodz Region, difficulties in co-operation with pediatricians which were a result of lack of information about the rules and organisation of palliative care for children, difficulties in recruiting new members of staff and the gaps in the educational system described above. The first step was to establish in 2009 a Pediatric Palliative Care Unit which is a part of the Department of Pediatrics, Oncology, Haematology and Diabetology of the Medical University of Lodz. This is a first in Poland academic unit which teaches pediatric palliative care. The unit team consist of the hospice staff and the staff from the Department of Pediatrics. That team has developed first in Poland pilot training program, both graduate and post graduate, in the field of pediatric palliative care. The authors of the program emphasised the holistic aspect of the training by including both medical and psychological issues. Passing on difficult information, providing care for terminally ill patients, assisting the patients and their families are burdening experiences which require solid preparation, both medical and psychological. The conclusions of current research and observation underline the importance of preparation of the medical staff for looking after a dying patient and their family. On one hand such a preparation would minimise the risk of re-traumatising the patient and their family. On the other hand it decreases the risk of emotional overloading among doctors, their tendency to keep emotional distance which disturbs their perception of the situation and the risk of a burn-out among the medical staff [22].

Working with dying children can be particularly stressful for doctors; evoking their sense of helplessness and disturbing their rational perception of reality.

An analysis of current situation shows a lack of appropriate training on every level of medical training. At the same time the literature presents some attempts to create such training programs [23].

There is a specific challenge for people who run those trainings: an awareness that it is very important for doctors who decides to look after terminally ill children to minimise the stressors which arise as a result of their own attitudes (personal stressors). It means that apart from deepening one's knowledge and personal competences (communication skills, stress management) it is necessary to work out our attitude towards death by asking ourselves difficult questions (What are my conscious and unconscious thoughts and feelings connected with death?, How do I explain a child's death? In what ways my attitudes and beliefs can be an obstacle in helping a dying child and their family?). That process also includes becoming aware of our emotional reactions and finding creative ways of dealing with it.

Described above program had been awarded and 90% funded by the Foundation for the Development of the Education System, Measure V edition — Development of Polish Higher Education Institution. Since August 2009 the project has been completed with the support granted by Iceland, Liechtenstein and Norway by means of co-financing from the European Economic Area Financial Mechanism and the Norwegian Financial Mechanism as part of the Scholarship and Training Fund.

Implementation of pediatric palliative care education program

Graduate level training

Palliative care of children became a part of the general pediatrics curriculum. It applies to final year medical students and 3rd year nursing students. The module consists of two days of compulsory lectures (5 hours) and workshops (5 hours). During the first day the students are divided into groups of 10–12 people. The issues covered include: rules and organization of pediatric palliative care in Poland, prenatal palliative care, palliative care of cancer patients and related clinical issues. The aim of the first day is to familiarize the students with basic knowledge of home based palliative care, referral's recommendations, and specifics of pediatric palliative care and treatment procedures in most common cases.

The second day takes a form of workshops (in groups of 5–6 students) divided into two parts: clinical and psychological. Clinical workshops focused on detailed case studies of hospice patients. The students were given the script of 18 case studies. Due to the fact that the patients stay at home where the hospice team visits them, their active participation in the training was logistically not possible. The clinical workshops aim to familiarise students with the most common in palliative care children's conditions *and* to understand the elements of a comprehensive end-of-life care assessment. The workshops also provide an opportunity to discuss the most difficult aspects of pediatric palliative care, for example: ending the treatment, euthanasia or the limits of invasive treatment.

The psychological workshops cover the following issues:

- palliative treatment — specifics of the decision making process;
- passing on difficult information:
 - disturbances in doctor-patient communication,
 - the reasons why doctors avoid difficult conversations;
- communication with the parents of terminally ill children:
 - emotional crisis,
 - crisis management;
- child involvement in the decision making process:
 - child development and their ability to understand illness,
 - family patterns and the way children manage their illness;
- child's death and the bereavement process.

Psychological workshops were based on personal experiences of students who were expected to share their reflections on the subject. The aim of psycho-education as a teaching method is to support personal development through increased awareness and wider range of personal and social skills [24]. Due to time and organisational restrictions of the program the workshops focused on exchanging the experiences of students, introducing new experiences and knowledge and the analysis of practical applications.

All the workshops both clinical and psychological were run on individual basis; each trainer aiming to address specific interests and needs of the group. In that way the trainers were hoping to increase student's interest and active involvement. Teaching methods included case study and discussion.

Because of the student's personal reactions: emotions and reflections about their own attitude towards death, the most important was the way

the training was run and the level of competence of the tutor. It seemed more important to develop the student's understanding of the issue and there sense of competence rather than giving them a set of answers so they could talk to the patients. That was achieved though emphasising student's uniqueness, lack of judgement and acceptance of their individual differences.

Postgraduate training for doctors and nurses

Postgraduate training consists of eleven, one-day theoretical courses and two-week clinical placement. The courses are open to students of all specialities; they cover variety of issues like basic pediatric palliative care, prenatal palliative care, pain relief in pediatrics, palliative care for neurologically ill children or psychological aspects of pediatric palliative care. The aim of the courses is to refresh and update the knowledge of the participants as well as to confirm their formal qualification. It enables the participants to apply for work in children's hospices. During the placement the students participate in everyday work of the hospice team like home visits and clinical team meetings. The aim of the placement is to obtain practical experience of a hospice work, its policies and procedures as well as particular clinical issues. Scheme of pilot education program for pediatric palliative care is shown at Figure 1.

The evaluation of the program

The described above program is a pilot project and requires evaluation in terms of the effectiveness of teaching methods and student's satisfaction. All students are requested to complete a questionnaire testing their knowledge before and after the course. They are also asked to evaluate their satisfaction in terms of the following aspects: organisation of the course, usefulness of the knowledge, quality of teaching and teaching materials.

The questionnaire's analysis will allow to introduce necessary modifications to the program, in terms of it's organisation as well as the curriculum. The results of the analysis will be presented in a separate paper.

The authors of this program hope that the gathered experience and results will help to include the issues of pediatric palliative care into the pediatric curriculum at the Medical University of Lodz. We also hope that our experience will be useful to other medical universities in Poland.

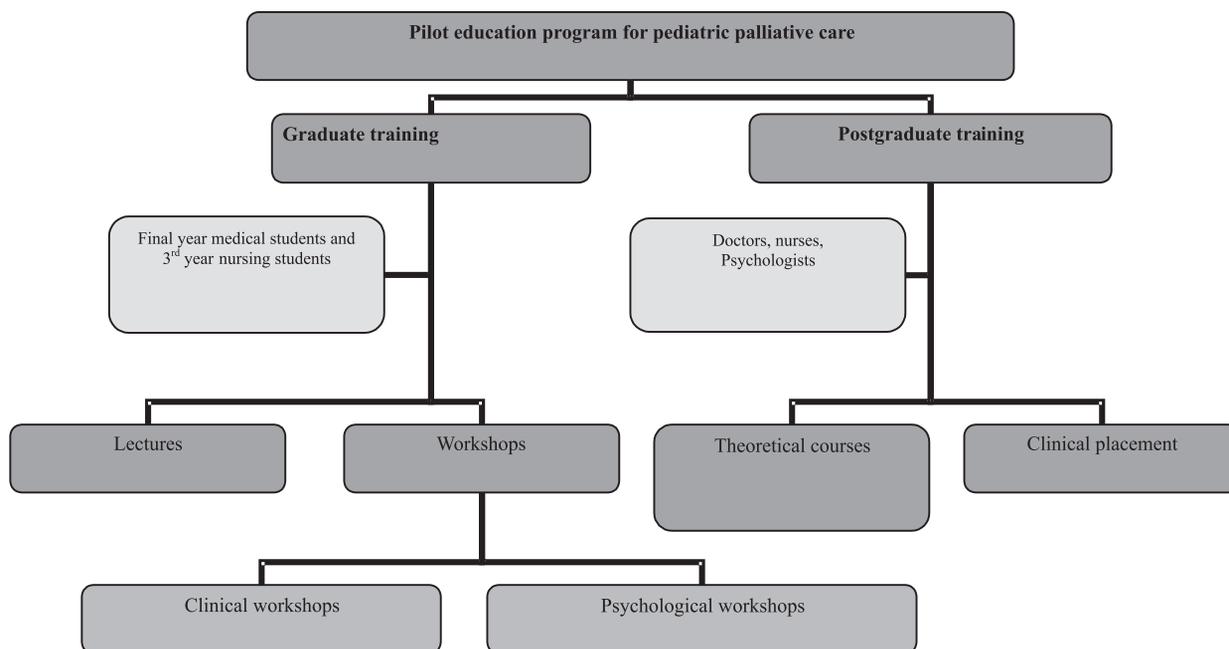


Figure 1. Scheme of pilot education program for pediatric palliative care

References

- Kliegman R.M., Jenson H.B., Behrman R.E., Stanton B.F. Nelson textbook of pediatrics 18th Edition. Saunders Elsevier 2007; 40: 200–208.
- A guide to the development of children’s palliative care services. Second Edition. Association for Children with Life — Threatening or Terminal Conditions and Their Families/Royal College of Pediatrics and Child Health 2003.
- Luczak J. Palliative/hospice care in Poland. Palliat Med. 1993; 7: 67–75.
- Dangel T. The status of pediatric palliative care in Europe. J. Pain Symptom. Manage. 2002; 24: 160–165.
- Dangel T., Fowler-Kerry S., Karwacki M., Bereda J. An evaluation of home palliative care program for children. Ambulatory Child Health 2000; 6: 101–104.
- Korzeniewska A., Przysło Ł., Filipiak E., Grzelewska A., Stolarska M. Demand for palliative home care for children in Lodz Region. Ped. Pol. 2006; 11: 799–805.
- Korzeniewska A., Przysło Ł., Filipiak E., Stolarska M. Home Hospice for Children of Lodz Region — experiences in first year of activity. Ped. Pol. 2006; 11: 806–811.
- http://www.hospicjum.waw.pl/img_in/BIBLIOTEKA/2009_raport_XI_www.pdf.
- Wright M., Clark D. The development of pediatric palliative care in Warsaw, Poland. Eur. J. Pall. Care 2003; 10: 120–123.
- Feudtner C., Hays R.M., Haynes G., Geyer J.R., Neff J.M., Koepsell T.D. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. Pediatrics 2001; 107: 99–e99.
- Serwint J.R., Nellis M.E. Deaths of pediatric patients: relevance to their medical home, an urban primary care clinic. Pediatrics 2005; 115: 57–63.
- Feudtner C., Feinsein J.A., Satchell M., Zhao H., Kang T.I. Shifting Place of death among children with complex chronic conditions in the United States, 1989–2003. JAMA 2007; 297: 2725–2732.
- Kliegman R.M., Jenson H.B., Behrman R.E., Stanton B.F. Nelson textbook of pediatrics 18th edition. Saunders Elsevier 2007; 40: 200–208.
- Ellman M.S., Rosenbaum J.R., Cherlin E., Bia M. Effectiveness of an Integrated Ward-based Program in preparing medical students to care for patients at the end of life. Am. J. Hosp. Palliat. Care 2009; 26: 18–23.
- Mason S.R., Ellershaw J.E. Undergraduate training in palliative medicine: is more necessarily better? Palliat. Med. 2010; 24: 306–309.
- Mason S.R., Ellershaw J.E. Preparing for palliative medicine; evaluation of an education programme for fourth year medical undergraduates. Palliat. Med. 2008; 22: 687–692.
- Hammel J.F., Sullivan A.M., Block S.D., Twycross R. End-of-Life and Palliative Care Education for final-year medical students: a comparison of Britain and the United States. J. Pall. Med. 2007; 10: 1356–1366.
- Gibbins J., McCoubrie R., Maher J., Wee B., Forbes K. Recognizing that it is part and parcel of what they do: teaching palliative care to medical students in the UK. Palliat. Med. 2010; 24: 299–305.
- Yazdani S., Evan E., Roubinov D., Chung P.J., Zeltzer L. A longitudinal method of teaching pediatric palliative care to interns: preliminary findings regarding changes in interns’ comfort level. Palliat. Support Care 2010; 8: 35–40.
- Roth M., Wang D., Kim M., Moody K. An assessment of the current state of palliative care education in pediatric hematology/oncology fellowship training. Pediatr Blood Cancer 2009; 53: 647–651.
- Luczak J., Okupny M., Wieczorek-Cuske L. The program of palliative medicine and care in the curriculum of sixth-year medical students in Poland. J. Palliat. Care 1992; 8: 39–43.
- Nancy A., Larson J., Scofield S., Sourkers B., Cohen H. Hospital staff and family perspectives regarding quality of pediatric palliative care. Pediatrics 2004; 114: 1248–1252.
- Bagatell R., Meyer R., Herron S., Berger A., Villar R. When children die: a seminar series for pediatric residents. Pediatrics 2002; 110: 348–353.
- Kędzierska B., Znajmiecka-Sikora M. Education and active methods of group working. Innovation in Education. Scientific Journal WSHE In Lodz, 2003; 1: 70–81.