

SOCIAL WORK IN PAEDIATRIC PALLIATIVE CARE IN SLOVAKIA

^aJANA KUŠNĚRIKOVÁ, ^bMARTINA MOJTOVÁ

Univerzita Konštantína Filozofa v Nitre, Fakulta sociálnych vied a zdravotníctva, Katedra sociálnej práce a sociálnych vied, Kraskova 1, 949 74 Nitra, Slovak Republic, email: ^ajana.kusnierikova@ukf.sk, ^bmmojtova@ukf.sk

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Abstract: Having a child with an incurable disease is a very difficult situation for the family and it interferes with their whole lives. Palliative care is provided by a specially educated multidisciplinary team that works closely with the members so that they can solve all kinds of problems together. In addition to healthcare professionals, social workers are often a part of the multidisciplinary team as well. The paper shows the specifics of paediatric palliative care, its current trends, development and further characteristics of work of social workers. Through ongoing research the authors are mapping the current state of providing palliative care in Slovakia. The paper presents partial results focused on roles of social workers in selected organizations providing specialized paediatric palliative care.

Keywords: paediatric palliative care, social work, social worker

1 Children with life-limiting or life-threatening diseases

According to the world statistics, the incidence of primarily incurable diseases that result in death, i.e. life-threatening or life-limiting diseases, is 1 child per 10,000 children (children aged 0-19 years). The prevalence of these diseases is 10 times higher (10 children out of 10,000) and it has been stated that a half of those children need palliative care. In Europe, according to these data, there are minimally 125,000 children who need some form of palliative care (Goldman, Hain, Liben, 2006; Paliatívni péče v Evropě, 2014; Jasenková, 2007). In Great Britain, according to the recognized British organization Together for Short Lives (former ACT – Association for Children’s Palliative Care), there are up to 49,000 children with life-threatening diseases that could use services of paediatric palliative care (Who we are. Together for Short Lives, 2015). Therefore, an establishment of all forms of palliative care has become a main goal in these countries, which would increase quality of life not only in children but also in their families. In accordance with a designed model of paediatric palliative care, this care does not focus on death but its goal is to help children and their families live as high-quality lives as possible and also face serious diseases (Paediatric and Adolescent Palliative Model of Care, 2009).

Despite the fact that perceiving death as a natural part of life is one of the fundamental principles of palliative care (Sedlárová, 2013), dying and death of children are something unnatural for us. “It is in our subconsciousness that children should have enough time, a possibility to develop their talents, and live longer than their parents. If it is not so and a child’s death enters the family, it shocks all its members from the roots – including parents, grandparents and children (sibling’s survivors)” (Mojtová, Sedlárová, 2011, p. 31) (all citations are translated by the study authors); and thus, the death of a child is perceived as the worst event in one’s life. Because of bad practice and lack of services and information, often there are situations that children with life-threatening diseases spend their last moments in life in isolation, as a result of their diseases or disabilities. And it happens also to their families whose parts they are (Démuthová, 2010). When curative care fails and prolonging life brings the child suffering and pain, palliative care is in the best interest of the child. A precondition, however, is accepting the fact that it is not possible to save the child any more. In this case there are only two options available – to attempt to prolong life, even for the price of certain deterioration of quality of life, or not to influence the length of life and focus on alleviation of symptoms only (Jasenková, Mikesková a kol., 2005). And the latter way of care is referred to as palliative care. Decision making about not continuing in curative care is a long process that involves both child’s physicians and parents, and a result of such decision making includes these factors: a disease is incurable and

necessarily results in death and the child and parents wish to finish life-prolonging treatment that would only significantly worsen quality of life in the child.

1.1 Specifics of paediatric palliative care

Palliative care does not perceive the death of a child as a complete end or failure of medical care and treatment. Although care for children in their last moments in life is particularly demanding and exhausting both for the family and professionals, it attempts to fill these days with life – it does not speed up or prolong the death unnecessarily. “Regardless of the causes, we must accept the fact that it is not granted to every child and not every threatened life can be saved” (Kasanová, 2009a, p. 78).

Every child with a life-threatening or incurable disease, regardless of race, age, religion, gender or place of residence, has a right for access to permanent, holistic and high-quality palliative care and support (A Guide to the Development of Children’s Palliative Care Services, 2009). A strong and respected opinion in society that children should not die, creates one of the barriers how to deal with such a reality and implement paediatric palliative care in the national strategies and standards.

The need of paediatric palliative care appeared also as a result of the increased number of incurable diseases and possibilities of their diagnostics. Due to the medical development with the use of multiple technologies it is possible to reduce child mortality; furthermore, the experts attempt to increase the length of life in children with severe and mortal pathologies that require an entire complex of palliative care. For a long period of time palliative care was not offered to paediatric patients; and also today in Europe, apart from the development of palliative care in some countries, only part of these children can profit from palliative care. Thus, many children die in inadequate conditions – in pain, with multiple unpleasant side effects of treatment, and often in hospitals. Paediatric palliative care has become a serious issue in our society, so far with inadequate solutions (Palliative care for infants, children and young people, 2009); therefore, it is often a discussed issue at many conferences.

Despite certain variations of the terminological definitions of palliative care, most experts agree on its main philosophy. It is an approach or programme that strives to maximize the present quality of life through the implementation of the fundamental principles of palliative care and their adaptation to the target group of children from neonates to adolescents (Davies, Siden, 2010). The central features of palliative care are symptomatic treatment, psychological, social, spiritual and emotional support, assistance to the whole family, and providing assistance, accompanying the decedent’s survivors in the period of grieving. Thus, in accordance with the recommendations of the Council of Europe, organization of palliative care is based on these values: human rights and patient rights, human dignity, social cohesion, democracy, equality, participation, and freedom of choice (Odporúčanie Rady ministrov Rady Európy, 2008).

1.2 Services and forms of assistance in paediatric palliative care in Slovakia

Paediatric palliative care as a complex, active and quality-of-life-centred care provided to children with incurable diseases and their families has, equally to palliative care for adult patients, according to the international standards, at least two levels: general and specialized (Mojtová, 2014). General palliative care is a good clinical practice that is provided by healthcare professionals within their expertise. Its basis includes particularly early detection of an incurable character of a disease and identification of the areas that are significant for the quality of life in the patient. It should be provided by every healthcare professional – general practitioners, hospital departments and clinics, long-term nursing care facilities. Specialized palliative care is active multiprofessional care for patients and their families provided by teams of specialists in palliative care. It is

provided to patients who exceed the possibilities of general palliative care by the complexity of their needs (physical, psychological, social) (Sláma, Špinková, Kabelka, 2013).

The study we conducted focuses on the area of specialized palliative care which specifically focuses on providing palliative care to dying children and their families in optimum forms and in any settings (homes, inpatient hospices, day care centres). The aim of such oriented paediatric palliative and hospice care is palliation – providing comfort and satisfaction and meeting the children's needs. However, it is necessary a child's personality is not deformed by the loss of privacy, social isolation, inadequate medicaments, and inability to express and ventilate their feelings (Gojđová, 2002). Thus, palliative care is not about death but about life that is finished by death. The principal philosophy suggests fulfilment of children's lives by everything that brings joy to them and their families. Services of specialized paediatric palliative care are to be offered and available in all forms of this care. Complex assistance appropriate to age, cognitive and educational ability of the child must be available for the child and family (Craig, 2007). Jasenková, Mikesková a kol. (2005) differentiate between two basic programmes of paediatric palliative care: paediatric inpatient hospices and home hospice programmes. In the world, home hospice care is preferred; it allows dying children to stay in the settings they know, allows the whole family be with such a child, while professional assistance and support are provided all the time. The second form includes paediatric inpatient hospices that are particularly abroad established as independent facilities entirely for paediatric patients and their families. When compared with hospices for adult patients, paediatric hospices are rather used for repeated respite and relaxation stays. The whole family can come to a hospice and is provided with so-called respite care that is provided by the team of professionals (physicians, nurses, psychologists, social workers). The aim of such stays is to allow parents to have a rest and spend time also with healthy siblings who often face the feelings of jealousy and insufficient attention and care from their parents. Entertainment and educational programmes are prepared for these children. "For the whole family, quality respite stays of the child and close family mean multiple stimuli and possibilities to make new friends. According to the experience from abroad, the stays significantly enrich and improve quality of life in affected families" (Jasenková, Mikesková a kol. 2005).

In the world, apart from these forms, they use also palliative day care centres; care for dying patients is provided in the settings of day care centres substituting their home settings during a day. Palliative care departments are another form of care for dying children. In Slovakia, the department is in the National Institute of Oncology in Bratislava where they provide complex oncological palliative medicine for the ill with incurable cancer diseases (multidisciplinary pain therapy and care for the terminally ill) and hospitalizations with administration of palliative chemotherapy and radiotherapy. Other facilities of specialized palliative care include outpatient departments in hospice facilities and hospitals.

In the present in the Slovak Republic, palliative care is provided only by children's mobile hospices; there are not any other forms of care for paediatric patients. Despite that, we can talk about significant steps in the scope of the development of specialized paediatric palliative care (we state some of them):

- Establishment of the Association for Hospice and Palliative Care in Slovakia (1999),
- Development and approval of the Charter of Patients' Rights in the Slovak Republic (2000), article 8 – Care for incurably ill and dying patients,
- Introduction of the term "hospice" into legislation in the Amendment No. 80/2000 which amends the Act of the National Council of the Slovak Republic No. 277/1994 on health care,
- Development and approval of the document the State Policy of Health in the SR (2000) in which one of the priorities is creating the conditions for the development and

improvement of the quality of palliative care, including hospice activity,

- Approval of the Palliative Care Conception in the field of palliative medicine including hospice care in 2006 (the first conception was approved in 2002),
- Defining palliative medicine by the Ministry of Health of the Slovak Republic as a specialized field of medicine in 2006 (Centeno et al., 2013; Kasanová 2009b).

1.3 Social workers as members of multidisciplinary palliative teams

Dying of a child in the family brings multiple unpleasant emotions the family has to cope with – fear that the child will suffer unbearably, feeling guilty that a parent has failed, sadness, and desperation.

Social workers are significant persons in the whole process of work with the dying child and his family because they can provide adequate assistance and often are an interface between a patient and his environment. In the present, according to Sedlářová (2013), it has been repeated through various national and international organizations and institutions, conferences and publications that palliative and hospice care should be one of the priority areas of the development of not only health care but also social care and every person has a right for its availability. In order to improve paediatric hospice and palliative care, the countries design and implement the standards and recommendations for this care, e.g. the Standards for Paediatric Palliative Care in Europe (IMPACT: standards for paediatric palliative care in Europe, 2007). In Slovakia, unfortunately, similar standards or recommendations are lacking.

Social work in palliative care is also in Slovakia labelled as a growing part of social care (Laca, 2011). The main objective of social workers is particularly cooperation with other team members to ensure the best possible quality of life in the dying patients and their families. The uniqueness of social work is a different view of a dying person – a child, because it deals with all current needs – psychological, developmental, social, or spiritual. Social work as a practical science promotes the social change, social functioning of clients-patients and pursues the respect for the fundamental human rights and freedoms. Social workers become supporters of changes in society or life of the individuals or families (Hetteš, 2014).

Social workers work not only with children but also with their families. As Mojtová (2010) states, not only patients but also family members go through different stages of adaptation to the situation. When they overcome a period of anger, they enter a phase of preparatory grief. The role of social workers is to assist not only patients but also their families to overcome individual phases of grief, help them reconcile with the disease and thus increase quality of their lives. Related to the issue of palliative care, social workers have several levels, roles, i.e. they work as clinicians, researchers, advocates, and leaders in communication. Relatives must be encouraged, led to try to understand the ill by trying to feel their situation and imagine how they think and how they experience their situation. Social workers provide the relatives with emotional support and emphasize how necessary help by the relatives in home care is. After death of the child, the role of social workers is to ensure the proper functioning of the family and care for other members. If the family needs it, they help with the funeral and other issues related to the death of the ill.

2 Research

In 2016, the qualitative study was conducted after the implementation of a short survey in which we had identified all providers of specialized palliative care in Slovakia with a target group of children (0-18 years of age). After contacting all the facilities, we specified only these facilities meeting the criteria: Plamienok, a non-profit organization; the Civic Association Svetielko nádeje; Svetielko pomoci, a non-profit organization; and Pod krídlami Dominiky, a non-profit organization (more information in the part Results). In this paper, we state only a

part of the selected results describing the forms of specialized palliative care (mobile hospices) and roles of social workers. The complex study focused on the analysis of the present situation of specialized paediatric palliative care will be published later in 2017.

One of the methods for data collection was document analysis by which we obtained the information about the character of the organizations providing paediatric palliative care (annual reports of the organizations, national strategies, organization registers, reports, and data available on the Internet). In the study, we were interested in these areas: an establishment of an organization and its status (legal form), offered services, a target group, and a professional focus.

Another method for data collection about the roles of social workers was a semi-structured interview. We used audio recording. The interviews were conducted with social workers and directors of the organizations; the total number of the respondents was 5 (n=5), which was sufficient to meet the partial objective (to maintain anonymity, we do not state the workers positions in the specific facilities because of a narrow sphere of professionals and their possible identification).

2.1 Results

Based on the document analysis we state the current character of the organizations providing specialized palliative care in Slovakia. In Slovakia, as we have stated above, apart from mobile hospices, there is a lack of other forms of specialized palliative care. The table below closely describes the current providers of this type of care.

Table 1: Facilities providing specialized palliative care for children in Slovakia

Name	Plamienok	Svetielko pomoci	Svetielko nádeje	Pod kridlami Dominiky
Place	Bratislava	Košice	Banská Bystrica	Nitra
Establishment	2003	2011	2013	2014
Legal form	Non-profit organization	Non-profit organization	Civic association	Non-profit organization
Type	Mobile hospice	Mobile hospice	Mobile hospice	Mobile hospice
Focus	Home hospice care	Home hospice care, clinical oncology	Home hospice care	Home hospice care

According to the study of the European Association for Palliative Care, Slovakia is one of the countries where palliative care is provided at the general level and the process of integration of palliative care in the health care system is only at its beginning (Centeno, 2013). Although the Constitution of the Slovak Republic guarantees a free access to a broad basic package of health care for all the citizens, still we can witness a lack of services and limited capacities of healthcare facilities. In spite of the fact that the attempts to develop palliative and hospice movement in Slovakia have been developing since 1989, there is not a complex of related services and forms of assistance for dying paediatric patients, which is suggested also by the study results. The facilities providing this type of care are either non-profit organizations or civic associations. Thus, support by the state is lacking, for example in the form of system funding of these facilities or paediatric departments of palliative medicine in hospitals.

In Slovakia, the first mobile hospice was established in 2003 (Plamienok), but it started to provide home hospice care services in Slovakia only in 2004. This year (2017), the fourth mobile hospice obtained the licence, which improves the availability of palliative care from the view of the geographic distance.

In the analysis of the facilities, we focused also on the services and forms of assistance provided to paediatric patients and their families by these organizations. We identified main three areas: health care, social assistance, and psychological assistance; the fourth area includes multiple additional services and types of assistance.

Table 2: Provided services

Provided services	Description	Number of facilities providing the service
Health care	Pain relief, symptom and pain management, drug administration, equipment loans	4
Social care	Basic social counselling (assistance in arranging various benefits), social assistance	4
Psychological care	Psychological counselling in coping with crisis situations, accompanying, assistance also after the loss of the child	4
Spiritual care	Mediating the contacts	1
Other	Patient transport (for examinations, home after discharge from hospital)	3
	Cultural and other events (weekend stays, other leisure time activities)	3
	Providing material assistance	2

Apart from home visiting services including health and nursing care, the facilities provide a broad range of services and assistance depending on the personnel structure, funds and focus of each of the organizations. All of the organizations provide care also after the death of the child. The offers of the services correspond with the personnel structures where apart from the clinicians (health, social workers, psychologists, etc.) there are also project managers, fundraisers, economists, and lawyers. Some of the personnel have only part-time contracts (or other types of employment contracts), which requires accumulation of work positions.

We closely focused on the roles of social workers who are significant members of multidisciplinary teams. The field of activities and competences of social workers corresponds with the identified services of social care. A surprising finding, however, was that there were no social workers in one of the organizations in spite of the fact that they declared providing social care in the form of counselling. A key status of physicians as guarantors of provision of palliative care was found in every facility.

Despite that, we were able to identify several categories – roles of social workers resulting from care for dying children and their families. In defining the basic roles, the authors use various divisions of these activities. Based on the analysis of the selected authors (Mojtová, Dobříková, Student, Vorlíček, Payne, etc.), Sedlářová (2013) suggests four groups of these roles to which we added the study results (specific descriptions of the activities specifically focused on work with children in the selected facilities):

1 Roles focused on patients – dying children: providing crisis/social interventions, social diagnosis, counselling activities, accompanying the dying, documentation, planning the services and work with dying children.

2 Roles focused on families (relatives, survivors): obtaining and recording the information about the family, mapping the family social situation, active search for family members, accompanying the family and survivors, social counselling – informing the family about possible solutions for difficult social situations, assistance in job seeking, help with the funeral, crisis interventions, work with survivors, organization of support groups (parents, siblings).

3 Roles focused on multidisciplinary teams and volunteers: seeking and mediating new information to other co-workers, e.g. legislative changes, coordination of volunteers, management of educational courses and programmes, supervision, possibility to participate in regular meetings.

4 Other roles and requirements: organization of conferences, lectures for educational purposes, introducing the philosophy of palliative care, diminishing the taboo theme of dying of children and significant advocacy and promotion of social work in palliative care; social workers can be initiators of legislative changes.

We would recommend the fifth group of activities: *Roles focused on cooperation with other sections of the system*; Mojtoová (2014) states work with the local community or institutions which the families or dying children are in contact with (authorities, schools, employers, parishes) and action in clients' interest, their representation.

In the centre of specialized palliative care, patients and their families are always in the first place, which shows high quality of this conception of care (Mojtoová, 2014). Thus, they are included among the team members and addressees of the information, supported by other professionals. The composition of the team must be complex and multidisciplinary adapted to the needs of paediatric patients. Inseparable part of health care includes support for patients, dealing with social problems, planning the interventions, or assessment of psychosocial aspects of the situation. Therefore, in the present, also social section of this care is emphasized; but even despite the significant and long-term status of social work in palliative care, roles and competences of social workers are not clearly defined.

3 discussion and conclusion

Specialized palliative care is considered an optimum form of care focused on meeting the needs of families with a dying child that can provide adequate and directed services and forms of assistance. It respects wishes of paediatric patients and their families, maintains an individual approach, and achieves and maintains the quality of life to the highest degree. It is a complex care that includes the areas of physical, psychological, social and spiritual needs of dying children and their families through the specially trained and experienced team of professionals. The above mentioned facts as well as the results of various studies and practical experience of professionals have become the basis for selection of specialized paediatric palliative care as an optimum form of assistance to children with life-limiting or life-threatening diseases. In the ongoing study, we continue in mapping the model of assistance for this target group, and possibilities and limitations of further development of paediatric palliative care.

If there are suitable conditions in society (high prestige of social work, adequate moral and financial appraisal, possibility of specifically focused education, and offer of further education), social work in specialized palliative care has space for its implementation and further development. In the present, we have defined the following problems and limitations important for increasing the effectiveness of social work to improve care for dying children and their families:

- Lack of clearly defined roles of social work in palliative care for dying children and their families (a definition of care),
- Lack of a legislative definition of the scope of social work and standards for its performance,
- The need to improve professional education in social work with dying children (university education, post-gradual education, further education),
- Insufficient/no regulations for funding the performance of social workers.

Social workers play multiple roles related not only to children but also their families and other members of the

multidisciplinary team. Often they are in the position of an interface in the multidisciplinary team of professionals, and help and support other professionals.

Children's complex needs are determined by age, course and status of a disease, family and religious environment, which requires cooperation of all sections of care (Liben, Goldman, 1998), including assistance by social workers but also implementation of paediatric palliative care in all countries and following its basic standards that are recommended by various international institutions and organizations (for example, the Standards for Paediatric Palliative Care in Europe developed by the European Association for Palliative Care; the Recommendation Rec (2003) 24 of the Committee of Ministers of the Council of Europe to member states on the organization of palliative care; the Recommendation of the Council of Europe No. 1418/1999: Protection of the human rights and dignity of the terminally ill and the dying; etc.).

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