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## PATIENT CARE AND EDUCATIONAL ACTIVITY OF THE PODKARPACKIE HOSPICE FOR CHILDREN FOUNDATION IN 2006-2021 ON SELECTED EXAMPLES\*

Introduction: The first hospice was established in 1967 by Cicely Saunders. Another important event was the establishment of a day centre for terminally ill patients in Sheffield at St Luke's Hospice. In Poland, hospice care was developed on the initiative of Hanna Chrzanowska. A special type of this institution are children's hospices. One of them is the Podkarpackie Hospice for Children Foundation, established in 2006.

Research Aim: The aim of the research was to present the history of the establishment and development of the Podkarpackie Hospice for Children Foundation, as well as analyse examples of patient care and educational activities undertaken by the management, employees and teachers cooperating with the Foundation in the period 2006–2021. The methodology used involved a critical analysis of documents and source materials and a review of the literature on hospice care.

Evidence-based Facts: Two periods can be identified in the history of the Podkarpackie Hospice for Children Foundation between 2006 and 2021. From 2006 to 2011, patient care was provided under the at-home hospice care system. Simultaneously, efforts were undertaken to organise a separate location to expand the assistance provided, which resulted in the establishment of an in-patient hospice in 2011, which implements a broader range of tasks of the Foundation, including Perinatal Hospice, which was created in response to public demand.

Summary: Patient care and educational activity of the Foundation is carried out through its individual units, including the at-home, in-patient and perinatal hospice, as well as the regional care and therapy centre "Teczowy Domek", which implement the goals and tasks of the Foundation. In addition, the educational activity of the Volunteer Centre helps to breaking down stereotypes related to hospices.

Keywords: hospice, children's hospice, care, education, Podkarpackie Hospice for Children Foundation.

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#### INTRODUCTION

The origin of hospice care dates back to the establishment and development of first institutions supporting terminally ill adults and children (Kromolicka, 2000; Bartoszewska, 2005; Barnaś-Baran, 2008; Rafalski, 2017; Serdyńska, 2021). Since the late 1960s, a number of facilities of this kind has been established, which differ from one another in certain respects but share the underlying assumption that death is a natural part of everyone's life. One of the fundamental rules of care in hospices is no consent to premature termination of life; on the other hand, the patient's life is not artificially prolonged, either (Zawiła, 2008). Palliative and hospice care has been addressed by researchers representing various academic disciplines. One of the examined issues, available in the literature on the subject, is hospice volunteering as a specific type of volunteering activity (Kostek, 2010; Seredyńska, 2019). The activity of the Podkarpackie Hospice for Children Foundation between 2006 and 2021 has not been the subject of research as yet.

### RESEARCH PROBLEM AND AIM

The research problem covers the history of the Podkarpackie Hospice for Children, with a focus on the patient care and educational activity affecting the functioning of the patients of the institution located at 132 Lwowska Street in Rzeszów. The aim of the research was to show the assumptions and forms of implementation of the aforementioned tasks based on selected examples. The chronological scope of the research covers the period 2006–2021, from the establishment of the Podkarpackie Hospice for Children Foundation, through its development over the subsequent 15 years. The paper attempts to answer the question what kind of patient care and educational activities were undertaken by Podkarpackie Hospice for Children in the period 2006-2021. A qualitative analysis was carried out based on the documents of Podkarpackie Hospice for Children, i.e. its statutes, the annual reports on activities from 2006 to 2021, detailed reports on activities and other source materials, such as the data of the Statistical Office in Rzeszów, as well as selected reports of other hospices in Poland included in the database of reports of public benefit organisations. A valuable reference were the materials developed and published by the Hospice to popularise hospice care for children, mainly 13 issues of "Biuletyn",1 a magazine available free of charge. Review also covered literature on hospice care, based on which a need was identified to address the issue of minor patient care in the Podkarpackie Hospice for Children. The presented study can contribute to

<sup>&</sup>lt;sup>1</sup> The issue number of "Biuletyn" was given in the footnotes; the date of issue was not provided due to the lack of this information in the magazine. Also in the Bibliography section, the number of issue is given along with n.d. (no date) indication. For some issues, it was possible to determine the year of issue. "Biuletyn" is available at https://www.hospicjum-podkarpackie.pl/biuletyny/

further in-depth research, for example, on the activities of the at-home hospice or the analysis of other forms of support, especially the patient care and therapeutic activity of the facility run by the Foundation "Tęczowy Domek".

## STATE OF KNOWLEDGE

The activities undertaken by the Podkarpackie Hospice for Children are in line with the definition of care formulated by Kelm. They are implemented, in accordance with the aforementioned definition, for the benefit of persons whose existence has been found to be threatened, and who cannot deal with their difficulties by themselves (Kelm, 2000). They are also in line with the definition of care proposed by Dąbrowski, who perceived it as an activity that consists primarily in the continuous satisfaction of the needs of supra-subjective subjects of care (Dąbrowski, 2002). One of the types of care distinguished by Dąbrowski is curative care, which meets the subjective needs of the sick and is aimed at assisting them in their recovery. Hospice care is classified within this category of care.

The basic task in hospice care is to diagnose the needs of the patient. Taking into account various biological, social, psychosocial and spiritual factors, measures are then taken to address the well-being of the patient. The objectives and tasks of the Podkarpackie Hospice for Children Foundation, formulated in its core document, the *Statute of the Podkarpackie Hospice for Children Foundation* (hereinafter: Statute), are implemented by the management of the Foundation, employees of the Hospice, as well as teachers and volunteers who cooperate with the Foundation.

# OBJECTIVES AND TASKS OF PODKARPACKIE HOSPICE FOR CHILDREN AND THEIR IMPLEMENTATION

The Podkarpackie Hospice for Children Foundation was established and entered into the National Court Register on 4 October 2006. In January 2007, it obtained the status of a public benefit organisation. One month later, on 15 February, a contract was signed with the National Health Fund for providing care for the first nine children. In the same year, on 15 May, the Warsaw Hospice for Children Foundation declared its intention to provide support to the Foundation in Rzeszów. The Founder of the Podkarpackie Hospice for Children Foundation is Janina Jaroń, who for many years worked as a nurse and had contact with the sick and those in need. Rafał Ciupiński has been the chairman of the Foundation's board since its establishment. The Foundation has launched the at-home hospice care programme, which covers the entire Podkarpackie Province, the in-patient hospice facility and the care and therapy centre "Tęczowy Domek" (*Sprawozdanie...*, 2018; "Biuletyn 1, 6-9"; "Biuletyn 11"). Other forms of support include the activities of the Bereaved Parents and Siblings Support Group (since 7 December 2007), the Perinatal Hospice since 2007, as well as the Specialist Outpatient Clinics (Pulmonology, Dentistry and Surgical Clinic, as well as Children's Rehabilitation Centre) ("Biuletyn 2"; "Biuletyn 3"; "Biuletyn 11").

The objectives and activities of the Podkarpackie Hospice for Children Foundation, detailed in 23 points of the Statute, can be summed up as the need to accompany a sick child in illness, suffering and death. An analysis of the individual tasks shows that care is taken not only of the sick child, but also of his or her family. The Foundation plans and provides support, accompanying the bereaved for as long as the family needs it. The most important aim of the Podkarpackie Hospice for Children is to enable a sick child to stay at home, which is considered to be most beneficial for him or her (Sprawozdanie..., 2021). When a child cannot be taken care of at home with the support of the at-home hospice programme, the child stays in the in-patient facility.

The implementation of the statutory objectives and tasks is possible thanks to a properly equipped infrastructure, improved and expanded over the years. The Podkarpackie Hospice for Children Foundation started its operations with a single small room in Rzeszów, on Szopena Street, with one leased car ("Biuletyn 12"). In January 2007, three rooms were leased in the Health Clinic on Hetmańska Street. To keep up with growing needs, as an increasing number of people started to apply for support, it was necessary to expand the medical team, as well as establish cooperation with a psychologist, social worker and administrative staff. In 2008, the decision was taken to establish the Foundation's own premises. For that purpose, a plot of land with a house on Lwowska Street in Rzeszów was purchased in November. The plan was to create children's wards and a counselling centre. The project was implemented with EU funds, as well as support and donations from the Foundation's benefactors. The new building was opened in 2010, while in the following year, the in-patient hospice for children at 132 Lwowska Street in Rzeszów was launched with 20 beds available ("Biuletyn 8"; "Biuletyn 9"). In December 2014, the Foundation signed an agreement with the Ministry of Health for the implementation of a project subsidised by the Norwegian and European Economic Area Funds. The amount of the grant was PLN 10,140,000, while own contribution (including donations and charitable contribution deductions) amounted to PLN 3,000,000 ("Biuletyn 9"). In the following year, the amount was much higher. The funds raised from benefactors make supplement the amount that the National Health Fund allocates per day of care for the patients (in 2014, it was PLN 200, while the actual cost of care amounts to PLN 400). The project covered not only the extension and purchase of equipment for the new part of the building, but also the provision of training and specialised courses for those working with and caring for children with disabilities.

In 2011, the in-patient hospice for children started operating as the first facility of its kind in the country ("Biuletyn 11"; "Biuletyn 12"). Subsequent ones were established in Gdańsk, Łódź and Lublin ("Biuletyn 12"). The in-patient hospice in Rzeszów provides care for chronically and terminally ill children requiring hospital treatment, during periods of disease exacerbation or periods of parental burnout, when parents need to take care of their healthy children or when they are sick. Children suffering from chronic illness who have no caregivers are also taken care of. According to doctor Kazimierz Czerwonka, head of the in-patient hospice for children at the time, the facility was established in response to the needs of the patients. A child's illness is also a significant financial burden for the parents and an expense that many people simply cannot afford. The Foundation help to relieve

the suffering experienced by impoverished families due to the lack of access to appropriate resources and assistance, including medicines, hygiene products and diapers ("Biuletyn 11").

Janina Jaroń, founder of the Foundation, who for 30 years visited as a nurse sick and elderly patients supporting them in their final moments always emphasises that: "The hospice is not referred to as a »place of dying«, but as a place that is needed, a place where there is life" ("Biuletyn 10"; "Biuletyn 12", p. 25). She also stresses that: "The hospice also admits children abandoned by their parents. They [the staff – E.B.-B.] try to make it here a substitute of home for them. When you have a look into the small room where the rehabilitation therapist exercises with the toddlers, you can see the closeness in these contacts" ("Biuletyn", 2016, p. 11). In the extended part of the building, a common room for meetings and games, as well as a guest room for the parents of the patients were created. In the founder's opinion, it is important that the children have more space in the facility to play, learn to crawl and walk around. As she says: "They also want to roll around on mattresses, play in the ball pool and laugh. There are no proper conditions for that on the wards" ("Biuletyn", 2016, pp. 11–12). Both the statements of the board members and the staff caring for the children, as well as direct observations of daily activities of the in-patient hospice confirm the compliance with the statutory objectives of the Foundation and the needs of the patients.

## PATIENTS OF THE IN-PATIENT HOSPICE

The statutory objectives of the Foundation are implemented by taking under its care patients from different parts of Poland. Most of them live in the Podkarpackie Province. Among them are children who, for various reasons, cannot stay at their own homes; those children are admitted to the in-patient hospice. The age of the patients ranges from newborns to children under the age of 18, although some patients over the age of 18 are also allowed to stay in the in-patient hospice for

children, as their illness developed in childhood. There is also a group of patients who have been abandoned by their parents or who have had their parental rights terminated or restricted by court order. Another group consists of children transferred from at-home hospice care to in-patient hospice care for a certain period of time due to deterioration of their health or when the child simply cannot stay at home for some time (respite care) (*Sprawozdanie...*, 2021). The largest group of in-patient hospice patients are children with multiple congenital abnormalities, metabolic syndromes, cerebral palsy, hydrocephalus and *spina bifida*, inoperable heart defects and cancer. Such patients need to be provided with specialised equipment and staff ("Biuletyn 12").

Based on the data presented in the Foundation's reports concerning the number of patients admitted and treated at the in-patient hospice between 2011 and 2021, it can be concluded that every year an increasing number of terminally ill children were receiving care. It is important to stress that the capacity of the hospice depends, to the greatest extent, on the external funding and support provided to the Foundation by state and local government bodies, as well as benefactors. In 2011, 36 patients were provided hospice care. From 2013 onwards, the number of patients in each year exceeded 70 children, with the exception of 2021, when there were 37 patients. This may have been due to the COVID-19 pandemic and the adoption of a different model of medical support. Among the residents of the in-patient hospice, children with cancer constitute only a small percentage of all patients (no more than 4 patients in each year), while the majority are children with other diseases (33 children in 2011, 70 children in 2017, as per data in the report). The register of the in-patient hospice also records discharged patients (20-30 patients on average discharged per year, 53 patients discharged in 2015). An inherent aspect of the functioning of hospices are deaths. The lowest number of deaths was recorded in 2011 (1 case), while the highest number was recorded in 2013 (11 cases) and 2019 (6 cases) (Roczne sprawozdanie merytoryczne za 2011, 2012, 2013, 2014, 2015; Sprawozdanie..., 2016, 2017, 2018, 2019, 2020, 2021). A total of 953 children and their families received hospice support (both under at-home and in-patient hospice care programmes) between 2006 and 2019 ("Biuletyn 13").

The growing number of hospices and care facilities for the chronically ill in the Podkarpackie Province after 2000 indicates the demand of society for this kind of support (Cierpiał-Wolan, 2013). In 2015, there were 1,400 patients in total under the care of 9 hospices in the province, while in 2017, there were 11 hospices and 1,300 patients (Błachut et al., 2017; Korab et al., 2018). In 2019, as many as 13 hospices in the province provided full-time long-term patient care and rehabilitation services, which shows an upward trend compared to 2012 (Cierpiał-Wolan, 2012). In-patient care for terminally ill children was provided only by Podkarpackie Hospice for Children.

## PATIENT CARE AND EDUCATIONAL ACTIVITIES ORGANISED FOR THE CHILDREN

The Foundation organises regular occupational, speech, psychological and rehabilitation therapy sessions for the patients under the at-home and in-patient hospice care, which are conducted by specialists. What also has a therapeutic effect on the patients is playing various musical instruments, singing songs and listening to music together with the nurses and volunteers ("Biuletyn 12"). Cooperation with the UNICEF Special School Complex in Rzeszów is also yielding positive results. Anna Kraczkowska, one of the teachers in charge of educational support at the in-patient hospice, explains that she uses elements of different methods in her work with the children, selected according to their current psychological and physical capabilities. What is important is to provide a relaxing atmosphere, which is ensured by non-verbal means of communication. Elements of the Knill activity programme, polysensory stimulation according to the seasons, the so-called "Morning Circle", neurotactile therapy, sensory integration, hand therapy, NDT Bobath therapy and the Felice Affolter method are used during sessions with the patients. Other beneficial form of activity include music therapy, elements of theatre therapy and storytelling. The healing power of the human voice, sounds and music reduces tension and relieves the suffering of sick children. The activities are adapted to the level of intellectual development and the type of physical disability of the child. Ensuring a variety of occupational therapy forms has a positive impact on the patients' well-being and is conducive to the development of their personality (Zdebska, 2016).

Multifaceted support is also provided by a psychologist cooperating with Podkarpackie Hospice for Children, mainly throughout the dying process and into the final moments of the patient's life. Those who need to be provided with psychological support are also the siblings of the sick child. The consultations offered may also concern the choice of their future educational path, development of abilities, etc. The psychologist helps the families in contacting institutions working for the benefit of children, including psychological and pedagogical counselling centres, various associations and educational facilities. With the help of the psychologist, hospice patients benefit from forms of early development support or rehabilitation ("Biuletyn 11"). The psychologist, in cooperation with a paediatrician and an obstetrician, is also involved in hospice perinatal care in Rzeszów. The aim of the perinatal hospice is to support parents at a time when their dreams of a healthy offspring are threatened. The hospice staff aims to mitigate the negative consequences of the overwhelming stress and tension that follows the diagnose of a severe defect in the foetus ("Biuletyn 3"; "Biuletyn 11"). In 2018, care was provided for 18 families; in 2020, 53 meetings were held for 60 participants; in 2021, support was provided to 38 people expecting a terminally ill child (Sprawozdanie..., 2018,

p. 4; *Sprawozdanie...*, 2020, p. 4; *Sprawozdanie...*, 2021, p. 4). Disease diagnoses include malformations, deformities and chromosomal aberrations, acrania, anencephaly, absence of abdominal wall and gastroschisis (*Sprawozdanie...*, 2018). The importance of hospice support is evidenced by statistics concerning the causes of death among infants, according to which, in 2021, 51.1% of infant deaths in the Podkarpackie Province were caused by congenital abnormalities, deformations and chromosome aberrations, 43.8% of deaths were the result of diseases and conditions developed during the pregnancy and the first six days of the newborn's life. In 2022, 16.8 thousand live births were recorded in the province, 14.1% less than in 2015. It is important to note that there was a systematic decline in the population of the province between 2015 and 2022, with a negative population growth rate recorded in 2022 (Ziomek-Niedzielska, 2023).

The Podkarpackie Hospice for Children Foundation also runs the regional care and therapy centre "Teczowy Domek", located at 132a Lwowska Street, which offers institutional foster care. Pursuant to the Resolution of the government of the Podkarpackie Province in Rzeszów of 8 February 2016, the Foundation was commissioned to run a regional care and therapy facility. On 1 February 2017, the Governor approved the proposed name of the facility, "Teczowy Domek" (Roczne sprawozdanie..., 2017). The specialist staff consists of tutors, child carers, a psychologist, an educator, a neurologist, a physiotherapist and a nurse. In 2018, 15 children from 3 m.o. to 18 years of age were provided with care at "Teczowy Domek"; in 2020, that number rose to 20 patients and in the next year, 21 patients. The age of the patients ranges from newborns to children under 18 years of age who suffer from somatoform disorders (as well as associated conditions in some cases). Due to their health condition, the patients require care and rehabilitation, which prevents putting them in foster care or in an institution. In 2018, as a result of the work with the family, one child was returned under the care of parents, while one patient was assisted into independent living (Sprawozdanie..., 2018). The patients of the facility benefit from psychological and pedagogical support provided by an interdisciplinary team. Modern forms of therapy can be implemented thanks to properly equipped therapy rooms (e.g. light experience room), bedrooms (for 2-3 patients) and other rooms (living room, kitchen, bathroom) adapted to the needs of the patients.

Another example of patient care and educational activities carried out in the in-patient hospice is providing training to parents of severely ill newborn babies on proper care. One of the parents, usually the mother, stays in the hospice with the baby, sleeps in the same bed with the baby and learns how to operate a phlegm suction pump, connect oxygen, turn or feed the baby etc. This is very important not only due to the opportunity to learn valuable skills required to care for the child, but also in terms of the parents' perception of their situation, since they can see they are not alone and there are more families with such children. Talking to a

psychologist or chaplain can also provide invaluable support. After they are properly prepared and equipped with the necessary medical equipment, parents return home can remain under the care of the at-home hospice programme. They are also assured that they can always return the child under the care of the in-patient hospice. The training provided involves not only aspects of child care or recognising

abnormal symptoms, but also an appropriate attitude and acceptance of the child's condition ("Biuletyn 11"). The Foundation funds and operates a support programme for children and bereaved families (Bereaved Parents Support Groups and Bereaved Siblings Support Groups). The programme is open to families of the hospice patients, as well as to families of individuals (children or adults) who have died in other circumstances, such as a car accident. Support is provided by psychologists, educators, doctors, lawyers and other specialists. An important aspect is teaching family members effective ways of planning their time and leisure after the death of the child. It can

be said that, in a way, it is about learning to get used to a different daily rhythm after the child's passing. In order to support that process, short excursions and longer trips are organised for the parents ("Biuletyn 4"; *Roczne sprawozdanie...*, 2015, p. 9).

An important part of the Foundation's educational activities is the promotion of the concept of hospice care, under both in-patient and at-home care programmes. During meetings with teachers, students of universities and representatives of public institutions, the assumptions of holistic and comprehensive care of terminally ill children and their families are presented, and the objectives of the children's hospice, forms of support available, and the possibility of involvement in volunteering (both short-term and long-term) are communicated (Roczne sprawozdanie..., 2016). An example is the project entitled "Wolontariat - społeczne zaangażowanie dla dobra innych" ("Volunteering - Social Engagement for the Good of Others"), completed in June 2009, as part of which 20 volunteer coordinators managing a network of volunteers in several towns in the Podkarpackie Province were trained ("Biuletyn 11", p. 7). The hospice also implements additional tasks commissioned by local government bodies, such as the promotion of physical activity in 2019. Grants were received from the Municipal Office of the City of Rzeszów for the implementation of the "Lepsza jakość życia" ("Better Quality of Life") programme, the objective of which was to educate parents on the importance of physical activity in the development of children, promote active leisure, and alleviate the consequences of the lack of physical activity and the resulting postural defects (through rehabilitation). Another undertaking was the "Nie jesteś sam" ("You Are Not Alone") project, aimed at improving the social functioning of children and families, as well as reducing the negative effects of developmental disorders. What is also worth mentioning is the "Świadomi bezpieczni" ("Safety Conscious") project, under which educational classes were provided in addiction

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prevention for children with disabilities (Sprawozdanie..., 2019). Analysing the information provided in the Foundation's reports, it can be concluded that the aim of the educational interventions outlined above is to help to better understand the situation of terminally ill children, to awaken the need to help them and their families, to support the activities of the Foundation and, above all, to change the perception of the in-patient hospice. During interviews, the Foundation's staff stressed that the hospice offers a better life for the patients. One of the Foundation's tasks is also the preparation and distribution of educational, informative as well as training materials (Roczne sprawozdanie..., 2015). In November 2017 and 2018, a conference entitled "Wolontariat -społeczne zaangażowanie na rzecz dzieci" ("Volunteering - Social Engagement for Children") was held. It was attended by 120 and 80 students from secondary schools in Rzeszów, respectively. The conference was financed by the Regional Centre for Social Policy in Rzeszów. During the school year, meetings and lectures were organised in primary schools to promote the idea of hospice care, aimed at attracting new volunteers (Roczne sprawozdanie..., 2017; Sprawozdanie..., 2018). Specialised courses and trainings are held at the in-patient hospice. They cover key issues and skills broadening the knowledge and experience of people caring for and working with hospice residents. Examples of topics covered in the courses include: psychomotorics of empowerment, neuro-developmental therapy for children with nervous system dysfunctions, counteracting the effects of stress, course and internship in parenteral nutrition for hospice staff, prevention of professional burnout, etc. ("Biuletyn 12"). In November 2017, the seventh edition of the course for medical volunteers and the fourth edition of the course for volunteers involved in patient care at the in-patient hospice were held. A total of 20 people were provided with training. 14 people completed the course, out of whom eight are active volunteers at the in-patient hospice (Roczne sprawozdanie..., 2017). The Foundation organises a Christmas Eve in the in-patient hospice building for families of the patients, families of the Foundation's staff and volunteers. Children's Day panic held outside the hospice building since 2011 is also becoming increasingly popular. It is organised not only for the Foundation's patients, but also for their siblings, families and all children who want to participate. Playing together is a great educational experience for all those who take part in the picnic. The pandemic has forced a shift of many of the charity's activities into the virtual space, but has not negatively affected the involvement of the benefactors. Carol concerts, craft fairs before Easter and Christmas and picture auctions were organised online. It should be noted that thanks to the Foundation's educational efforts, donations collected for the hospice during weddings are becoming increasingly popular. Instead of buying flowers for the bride and groom, guests make donations for the hospice, buy personal hygiene products, toys and stationery which are later handed over to the in-patient hospice ("Biuletyn 6").

#### SUMMARY

The hospice carries out a wide range of activities, the scope of which depends on the Foundation's financial situation. The range of patient care and educational activities selected for analysis were those carried out for the benefit of the patients under the care of the facility at 132 and 132a Lwowska Street. While the quality of life of the patients is affected by the illness, it is also influenced by the range of care and educational activities carried out by the hospice, as well as the involvement of its staff and the volunteers. The statutory goals and tasks of the hospice are in line with the concept of care as formulated by Kelm and Dąbrowski, and include the necessary services to support the sick child, his or her parents and caregivers. The educational activities offered have a positive effect on the well-being of the patients and help to strengthen the sense of responsibility for others of those involved in hospice care.

The analysis of the fifteen-year history of the Foundation allowed to identify certain stages and their time frames in the development of the support offered. The first stage was from 2006 to 2011, when the Board of the Foundation, based on the model of the Warsaw Hospice for Children, developed its own strategy. At that time, assistance was provided mainly through at-home hospice programmes. The second stage commenced after the development of the Foundation's own premises. From 2011, a modern complex and infrastructure made it possible to expand the Foundation's range of support services, as well as to open an in-patient hospice, as well as admit a greater number of patients. In 2017, specialist outpatient clinics providing medical assistance not only to the patients of the hospice, but also to other people, were launched, and in 2018 the Foundation launched "Teczowy Domek", a facility for sick children who cannot stay in other full-time care or foster care facilities due to their state of health. The range of patient care and educational activities undertaken in the period 2011-2021 were part of the holistic model of palliative care planned and implemented by the Foundation. What should also be noted is the expansion of the support network for terminally ill children through the development of facilities taking care of their well-being (counselling centres, "Tęczowy Domek", perinatal hospice, as well as the community room and conservatory at the in-patient hospice). A significant achievement in the period in question was the establishment of cooperation with specialists and their integration in the operations of the in-patient hospice. A measure that is indirectly linked to the functioning of the hospice, but has a significant impact on the perception of terminally ill children and their family, is the promotion of hospice care and volunteering. In the period 2011-2021, such measures yielded positive results, as an increasing number of schools and educational institutions engage their students in various activities to support the hospice (e.g. "Fields of Hope" - campaigns promoting the idea of hospice and palliative care, charity auctions, St. Nicholas Day).

The paper does not analyse this form of statutory tasks, but it should be emphasised that the range of charitable activities is the result of a long-term commitment on the part of the volunteer coordinator at the hospice, Monika Barłowska-Kuchar and marketing specialist Justyna Babiracka employed at the institution.

The number of people benefiting from the services provided by the perinatal hospice is growing. The professional staff of the hospice, including the psychologist Agnieszka Jankowska-Rachel, offers diagnosis regarding the state of health of the unborn child, as well as valuable information about the illness and principles of postnatal care. Assistance and support are also extended to women and families of children with lethal defects, which there is no cure for and which can lead to intrauterine death or postnatal death of the child (*Sprawozdanie...*, 2020).

The analysed examples of activities confirm that the patients of the hospice, as well as their families, receive comprehensive care, not only in terms of health, but also psychological, social and educational support. It can be concluded that the establishment of the Podkarpackie Hospice for Children Foundation has had a positive impact on the quality of life of terminally ill children under its care.

#### CONCLUSIONS

The fifteen-year history of the Podkarpackie Hospice Foundation has been positively assessed by the author. Its development has had an impact on the form of care and assistance offered from 2006 to terminally ill children outside hospitals. Modelling the strategy on that of Warsaw Hospice for Children allowed to optimise the organisational and decision-making process with regard to the development of operations. Between 2006 and 2011, care was provided to children and families primarily under the at-home hospice programme. In 2011, following the construction of new premises at 132 Lwowska Street, patients started to be admitted to the in-patient hospice, as well. Funding is still needed to retrofit the premises and to purchase modern medical and rehabilitation equipment.

The promotional and educational activities yielded tangible results, increasing the involvement of a growing number of people in supporting the Foundation and changing the perception of the institution of hospice. The information campaign should be continued, especially to underline the financial aspect. Mass media campaigns indicate the increasing professionalisation of education and information activities. The volunteering programmes available at the hospice offer is a valuable lesson in empathy and selfless help to the terminally ill, but also teach how to manage one's own free time, by offering it to those in need. A desirable measure would be a programme for shaping the social competences of young people and awakening sensitivity to the needs of others, especially terminally ill children, which could be implemented, for example, in primary and secondary schools. In addition, teaching students of pedagogy the skills of establishing contact and communicating with the terminally ill, especially children and their parents, is essential to prepare them for their future careers. It is necessary to inspire reflection on suffering and dying, as well as spread medical, psychological and pedagogical knowledge allowing for the proper selection of methods and forms of work with sick people. During the classes aids can be prepared for meetings with hospice patients and their parents.

Another group that could be involved in patient care and educational activities of the hospice are senior citizens, students of Universities of the Third Age in Rzeszów. Invitations should be extended to that group to cooperate and assist in hospice activities as well as to engage in volunteering. Their maturity, conscientiousness, patience and, above all, their knowledge and life experience could be extremely valuable. Patient care and educational activities offered by the in-patient hospice, as well as all professional and non-professional activities of the hospice staff, have a significant impact on the quality of the patients' lives.

The social campaigns implemented and publications distributed by the hospice are aimed at educating the public, conveying knowledge about the functioning of these institutions, the possibilities of obtaining help by families of children with incurable diseases and, above all, overcoming the stereotypes and myths about the hospice as a place of dying. Not only coordinators of volunteering programmes at schools, but also teachers and educators in various other institutions should be actively involved in this process. What is necessary is the involvement of educational authorities and the active participation of their representatives in conferences, trainings or courses prepared by the hospice staff.

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## DZIAŁALNOŚĆ OPIEKUŃCZA I EDUKACYJNO-WYCHOWAWCZA FUNDACJI PODKARPACKIE HOSPICJUM DLA DZIECI W LATACH 2006–2021. WYBRANE PRZYKŁADY

**Wprowadzenie:** W 1967 roku w Londynie Cicely Saunders utworzyła pierwsze hospicjum. Kolejnym ważnym wydarzeniem było powołanie ośrodka dziennego pobytu dla nieuleczalnie chorych w Sheffield przy Hospicjum św. Łukasza. W Polsce ruch hospicyjny rozwinął się z inspiracji Hanny Chrzanowskiej. Szczególną odmianą opieki hospicyjnej jest działalność hospicjów dziecięcych. W 2006 roku utworzono Fundację Podkarpackie Hospicjum dla Dzieci.

**Cel badań:** Celem badań było ukazanie powstania i rozwoju Fundacji Podkarpackie Hospicjum dla Dzieci. Analizowano przykłady działań opiekuńczych i edukacyjno-wychowawczych, jakie podejmował zarząd, pracownicy Fundacji oraz współpracujący z nią nauczyciele w latach 2006–2021. Zastosowano metodę krytycznej analizy dokumentów i materiałów źródłowych oraz dokonano przeglądu literatury poświęconej ruchowi hospicyjnemu.

**Stan wiedzy:** W działalności Fundacji Podkarpackie Hospicjum dla Dzieci w latach 2006–2021 można wyróżnić dwa okresy. W latach 2006–2011 opiekę świadczono w ramach Hospicjum Domowego. Dążono zarazem do rozwoju bazy lokalowej umożliwiającej wzbogacenie oferty pomocy. Od 2011 roku działa Hospicjum Stacjonarne (Dom Hospicyjny), które realizuje kolejne zadania Fundacji. Odpowiedzią na zapotrzebowanie społeczeństwa jest Hospicjum Perinatalne.

**Podsumowanie:** Ustalono, że działalność opiekuńcza i edukacyjno-wychowawcza Fundacji przyjmuje określone formy. Hospicjum Domowe, Stacjonarne, Perinatalne, Regionalna Placówka Opiekuńczo-Terapeutyczna "Tęczowy Domek" zajmują się realizacją celów i zadań opiekuńczych oraz edukacyjnych Fundacji. Działania edukacyjne Centrum Wolontariatu korzystnie wpływają na przełamywanie stereotypów na temat hospicjum.

**Słowa kluczowe:** hospicjum, hospicjum dziecięce, opieka, edukacja, Fundacja Podkarpackie Hospicjum dla Dzieci.

