OVERCOMING BARRIERS TO EDUCATION OF A TERMINALLY ILL CHILD IN THE FAMILY

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Abstract

An ill child and other family members experience numerous consequences of a terminal illness. An ill child experiences total pain in the physical, emotional, social and spiritual sphere of life. The child's development is affected by the illness which significantly reduces the child's educational opportunities, imposes various limitations and decreases the child's cognitive activity. The need for a child to stay in hospital or at home leads to kindergarten or school absenteeism.

It is impossible to completely eliminate an ill child's suffering and the destructive influence of a terminal illness. However, family members may boost the child's development and educational process. Support offered by hospice team may help overcome barriers to education of a terminally ill child.

The research indicated that family members supported by home hospice help the child take part in formal education. It revealed the importance of implementing educational aims in home environment. Its practical dimension strengthens the family. Strategies which the family developed to deal with the child's educational difficulties may be followed by other families facing the child's terminal illness.

The research was conducted in Poland in 2014-2015. 21 families of terminally ill children were studied. Data was collected according to a qualitative paradigm with the use of grounded theory in a constructivist approach.

Keywords: education, ill child, family.

1 INTRODUCTION

The development of a child is determined by numerous factors which either enhance or impair the dynamics of growth. One of the causes restricting the development may be a disease which changes the previous functioning of a child. If such disease is incurable and progressing, it becomes one of the most devastating losses in a human life [1]. By experiencing suffering, a child encounters various difficulties in the process of its development. Incurable diseases cause frustrations in connection with essential needs of a child. They coincide with the needs of a healthy child; but alongside standard desires, there appear specific needs connected with a disease, particularly in the case of cancer [2]. Apart from the source of deprivation of needs, a disease may be perceived as a stressor, a traumatising phenomenon, or a difficult event in the process of development of a child.

Difficulties caused by a disease are adequately described by the total pain concept formulated by C. Saunders, the creator of today's model of hospice care [3]. Shifting her attention to the consequences of physical pain prompted C. Saunders to search for its effects expressed in the emotional, social, and spiritual aspect of a human life [4]. Physical pain distorts normal functioning of a child, it drains its strengths, and impairs its overall functioning [5]. The suffering of an ill child on an emotional level is to a large extent connected with the experience of anxiety. It is triggered by the distortion of the need of safety and is usually connected with a specific threat, i.e. fear of surgeries, isolation, change in appearance, and death [6]. It also involves a kind of anxiety that is not linked to any specific threat — fear of the unknown and resulting sorrow [7]. Spiritual suffering is largely focused around the question "why" regarding the reasons of the origins of the disease and the necessity to suffer its consequences [8]. Suffering on the social level is caused by the strains connected with restricted social contacts and the feeling of loneliness.

Factors mentioned above influence the education of an ill child, making it more difficult to implement its process and devaluating the priority role of education [9]. E. Brown notes that the distortion of school education takes place in four dimensions: limiting the child's presence at school, weakening its mental condition, necessity to continue regular treatment, and missing out on important events connected with educational transfer [10]. One significant deficit experienced by a child is the need to be independent and to develop [11]. The occurrence of a disease in a child does not, however, mean

ISBN: 978-84-697-9480-7

that its development must become unattainable. Constant dynamism is deeply rooted in the very nature of a child, and it can be realised even in the face of a disease. Family and friends of a child may significantly contribute to the strengthening of its development.

Education of a child facing the threat of death is conducted under specific conditions, with the passing of time being an essential factor [12]. Thus, education and upbringing of a child is limited by the suffering and progress of the disease. The problem of the pressure of time and the resulting stress is a significant factor influencing the course of the educational process. Therefore, it is necessary to support the process of child's education on the part of the family, but also school, hospital, or hospice.

In child's education, key role is played by parents, who are its first teachers. Their behaviour, filled with readiness and openness, facilitates the realisation of the process of education and contributes to correct development of a child [13]. It needs to be remembered that this difficult task does influence the parents, too. The profile of a child's development depends to a large extent on the parents' attitude in terms of education and upbringing [14]. When parents and other family members become aware of the threat to the child's life, they start living in fear of its soon death. Education of children in the terminal stage of disease is a challenging task for parents, carers, and teachers. At the same time, due to the significance of the issue, the possibility to provide a child with assistance is a reward in itself and can become a source of development for them [15].

Education of an ill child may be carried out at home thanks to, among others, the support of hospices, because education is one of the fundamental assumptions of palliative care provided to children [11]. The aim of the work of a hospice team is to provide assistance which corresponds to the needs of an ill child and its family. The basic form of activity as part of palliative and hospice care for children in Poland are home hospices, which provide care for children remaining at their family homes. Thanks to such assistance, the upbringing of a child is carried out at a place which is the most favourable to its development [12]. The atmosphere of the family home, which is the natural upbringing surrounding for a child, constitutes an important factor contributing to proper care over the child and to its optimal development. The issue of education in the context of a terminal disease is one of the topics of tanathopedagogy. According to J. Binnebesel, it is a science of upbringing in the awareness of mortality, based on the fundamental principle of respecting the dignity of each human being and the value of human life [16]. These objectives can be best accomplished in a family caring for the development of an ill child.

2 METHODOLOGY

The study was performed through the use of qualitative research. The research is consistent with the grounded theory approach [17] in a constructivist aspect [18]. The research utilises the method of purposeful sampling, analysis simultaneous with the research, and open encoding. The data were collected using the method of an open interview focused on the problem [19] and participating observation. Among various kinds of interview techniques, the research applied the semi-structured interview method [20], which contained the research problem, i.e. the educational dimension of the functioning of families of terminally ill children. A significant part of the project included questions concerning education of ill children within the family.

The research covered members of 21 families with children under the care of "Alma Spei" Home Children Hospice operating in Poland. Data were collected in 2014-2015. The research was carried out in accordance with ethical principles of the research process, which was demonstrated in, among others, obtaining individual consent of each participant of the research, retaining the right to discontinue the research at any time, possibility to obtain support after the interview, changing the data, and remaining anonymous. The research provided research material in the form of recordings, which were then transcribed. Next, the data were encoded and compiled in accordance with the qualitative paradigm with the use of MAXQDA 11 software.

3 RESULTS

The research shows that education of an ill child within a family is an attempt at a practical prevention of barriers hindering the development of the child. A life-threatening situation makes it more difficult but not impossible to take actions for the benefit of the child. To demonstrate them, it appears reasonable to present categories of families distinguished based on an analysis of research material.

3.1 Family categories

A significant variable influencing the process of education within a family of an ill child is the time perspective, which is determined by the expected life span of the child. With this variable taken into account, it was possible to distinguish three categories of families: tanathos-oriented, presence-oriented, and perspective-oriented. The first category includes families which expect soon death of the child, which affects the organisation of life of the family. Presence-oriented families bring up children amid an imminent risk of their death, which, however, is not determined in time. This makes them function under the feeling of instability and a lack of possibility to establish any educational perspectives. In perspective-oriented families, the imminent death of the child is not an expected event; thus, their perspectives of development are much broader [21]. The style of functioning of a family affects the method of realisation of education of ill children.

3.2 Educational activities within the family

Members of researched families take actions which, in their view, contribute to the development of personality of children. These actions result from the assumptions of educational objectives towards children, which encompass all essential areas of its activity.

3.2.1 Arranging experiments in order to "bring the world closer to the child"

One of the objectives of family activity is to enable the child to learn about the world, which is otherwise inaccessible due to disease-related limitations. When a child is bedridden and cannot leave the house, it can learn about the surrounding reality through: reading tales, telling stories, watching TV, using the Internet, direct conversations, or social media. Family and friends of an ill child take initiatives which prove they are creative, as can be demonstrated by the selection of toys adjusted to the child's abilities. The mother of a child who cannot use hands declares: 'I will also strive to customise everything in the house for her. Now, even when I buy toys, I go for the ones which she will be able to operate with her legs only' (mother 11).

Parents who were mountain trekking enthusiasts demonstrated creativity by bringing back a fresh twig of a tree from one of their trips. By touching and smelling a piece of a tree, the young child has an opportunity to learn a new aroma and shape. Such experience stimulates imagination. The twig also takes on a symbolic meaning: the parents wish in some way to include their ill daughter in their adventures. Children who are not bedridden are taken out on trips of varying length: from a short walk to an excursion to the British Legoland.

3.2.2 Supporting intellectual and emotional development

Family and friends of an ill child make efforts to achieve optimal performance in education by adjusting forms of activity to the child's abilities. One of the simplest methods is play or engaging the child in everyday house activities. The path of intellectual and emotional development of a child is connected with the interests of its parents. Intellectual and emotional development of terminally ill children is mostly carried out with participation of educational centres. Parents want their children to go to kindergarten or school; and if it is impossible, they apply for home schooling. For this end, they establish and maintain contact with school, try to motivate the child to study, care for its progress. It is worth highlighting the educational dimension of hospice assistance, which is performed by team members, and particularly by the hospice counsellor. Their cooperation with the family increases the level of pedagogical culture of such family and optimises care over the child.

The nature of actions taken for the sake of intellectual and emotional development of ill children is contained in the statement by one of the mothers, who describes the well-being of her child: 'It seems that Helen is happy. Helen has her own world. And if she has people around and has the opportunity to unfold her interests, she is happy. And I think that may be the most important' (mother 21).

3.2.3 Strengthening child's independence

Each action aimed at the child becoming independent becomes particularly significant in the context of a disease. Independence in self-service actions, in falling asleep, establishing social contacts, striving for emotional autonomy is an added value in the child's life. Becoming independent is necessary for a child to function in the family and out-of-family communities, especially in school. It is also the synonym for the well-being of a child, which in turn is the essential aim of any actions taken in this respect. Methods used for the achievement of independence may be restrictive, in particular in the scope of consistency in performing rehabilitation exercises. This requires a lot of effort on the part of

carers, and triggers conflicting feelings in them; however, the ability to predict real life situations in which their child may find itself motivates them to impose requirements on the child.

3.2.4 Shaping socially-oriented attitudes

Socially-oriented attitudes are shaped based on behaviour models applied within the child's family and acceptable by the society. Their aim is to eliminate egocentric behaviour and to open to the needs of others. What facilitates this process is the inclusion of an ill child, as far as its abilities allow, into house duties, raising its awareness on the needs of its healthy siblings, or teaching respect to older members of the society. In an attempt to socialise their child, parents care for its contact with peers. If a child takes part in school education, it is easier for parents to shape socially-oriented attitudes. Colleagues are invited to the house, but the maintenance of such interactions is significantly limited. An important role is played by volunteers who visit children in their homes. Socially-oriented direction of parents' actions assumes the need to shape the conviction of one's own individuality in the child, which helps accept consequences of a disease. At the same time, upbringing is aimed at finding acceptance in the society: 'We need to raise our daughter so that she is convinced that she is original in her own way, in her own way she has to stand out in the society, and one needs to allow others to like him or her' (father 5).

3.2.5 Strengthening spiritual and religious activity

Carers of an ill child care also for its spiritual development. This requires the ability to confront questions emerging in the minds of children, to find answers or to admit that it is impossible. Questions of ill children concerning the issues of suffering and death are the proof of children's trust towards people around them. Parents are not always capable of living up to this trust; however, as far as possible, they try to prepare the child to face the difficulties of real life and the perspective of death.

The process of strengthening the religious development in ill children is also a challenging task. Attempts by some parents to fortify faith and religiousness in their children take on a tanatho-pedagogical dimension and contribute to the development of their children's personalities. Usually, these actions focus on prayer, preparation of the child for the reception of sacraments, teaching about the faith, reading the Bible. It is worth highlighting that care for religious development of a child is a manifestation of parents' faith and is carried out in line with parents' beliefs. Those who do not declare any particular faith provide their children with spiritual care.

3.2.6 Rewarding and punishing in the process of upbringing

Not all carers use punishments and rewards, as they believe these are not necessary means for proper upbringing. However, the majority of carers do use these forms of pedagogical impact. They reward ill children, but research shows that it is not through accomplishments of children that they become more valuable to their parents. The parents' fight for the life of their ill children has convinced them that their children's lives are of intrinsic value. Therefore, rewards are an expression of love for the child, while also providing a pedagogical aspect. Rewards are usually an appreciation of the child's efforts; but in case of ill children, the effects of efforts are measured otherwise. Often, a sufficient motif for rewarding a child is its attempt to perform the simplest of actions, and not the actual result.

Apart from rewards, carers of ill children also use punishments. They are a way to counteract an escalation of pathological behaviour in a child, which is strengthened by improper upbringing attitudes of parents. Such improper attitudes include excessive leniency towards children. This in turn results from difficulties in postponing or refusing to satisfy all needs and especially whims of children. For carers, it is a very challenging task, particularly when they are aware of the limited nature of time they spend with children. Parents perceive the risk of creating an attitude of learned helplessness in the child, and the threat of the child attempting to manipulate or to extort. In all instances, however, the principle of restricted consequence is observed, because ill children are treated more leniently.

4 CONCLUSIONS

The presented methods of educational activities in families under the study show a large level of parents' engagement in the proper development of their children. The research found creativity in the selection and use of upbringing methods, which is necessary as the uniqueness of tanathological situation calls for a specific context of upbringing. The specific nature of these circumstances also means the necessity to be flexible in an approach to the development of children. This is demonstrated in attempts to modify pedagogical methods with which parents are familiar by taking into

account the factor of limited time and threat to life, as well as the possibility to use external support. An important role in education is played by kindergarten, school, and hospice counsellors. Practical solutions applied by parents prove original both in the selection of methods and in the achievement of assumed goals.

The division into three categories of families makes it possible to present the specificity of implementation of the educational process in each of them. It may be assumed that tanathos- and presence-oriented families put a significant stress on maximum elevation of the quality of life. It is connected with the reality of threat to the child's life. Thus, parents make efforts so that the child may obtain as many positive experiences as possible, feel loved, and nurtured with care for its spiritual and religious needs. Parents try to show acceptance to their children, and the tanathos-wise context of upbringing prompts them to use any opportunity to show support.

In perspective-oriented families, the educational stress is tilted towards far-reaching objectives, which results in concentrating on the child achieving the maximum level of independence, intellectual development, shaping socially-oriented behaviour. As a rule, perspective-oriented families have more opportunities to provide support to children, but the long-term care over children poses many difficulties in the scope of upbringing, which the parents and grandparents of ill children try to counter. The upbringing of a terminally ill child entails the risk of its death before expected effects of the educational process show. It is a significant hindrance for carers, which, however, does not put them off, as they are convinced that they need to support the development of their children. The imminent threat of death of a child may sometimes drain their spirits, but at the same time it stimulates them to live every moment of their lives with the child. Thus, their actions take on a tanatho-pedagogical dimension.

REFERENCES

[1] J. McLaren, "The Death of a Child" in *Loss, Change and Bereavement in Palliative Care* (P. Firth, G. Luff and D. Olivier, eds.), pp. 80–95, London: Open University Press, 2005.

[2] P. Poulain, "Treating Pain and Caring for Children at the End of Life", *European Journal of Palliative Care*, vol. 11, no. 5, pp. 198–201, 2004.

[3] C. Saunders, "Care of the Dying 3. Control of Pain in Terminal Cancer", *Nursing Times*, October 23rd, pp. 1031–1032, 1959.

[4] C. Saunders, "The Evolution of Palliative Care", *Patient Education and Counseling*, vol. 41, no. 1, pp. 7–13, 2000.

[5] A.Y. Konijnenberg, C.S. Uiterwaal, J.L. Kimpen, J. van der Hoeven, J.K. Buitelaar and E.R. de Graeff-Meeder, "Children with Unexplained Chronic Pain: Substantial Impairment in Everyday Life", *Archives of Disease in Childhood*, vol. 90, no. 7, pp. 680–686, 2005.

[6] B. Ziółkowska, *Dziecko chore w domu, w szkole i u lekarza. Jak wspomagać rozwój dzieci przewlekle chorych*. Gdańsk: Gdańskie Wydawnictwo Psychologiczne, 2010.

[7] G. Godawa, "Hospice Counsellor Facing the Grief of the Terminally Ill Child and Its Family", *The Person and the Challenges*, vol. 2, no. 2, pp. 109–121, 2012.

[8] M. Cobb, "Spiritual Care" in *Psychosocial Issues in Palliative Care* (Mari Lloyd-Williams, ed.), pp. 191–206, New York: Oxford University Press, 2008.

[9] J. Lavelle, "Education and the Sick Child" in *Caring for Dying Children and their Families* (L. Hill, ed.), pp. 87–105, London: Chapman & Hall, 1994.

[10] E. Brown, "The Education of the Life-limited Child" in *Supporting the Child and the Family in Paediatric Palliative Care* (E. Brown and B. Warr, eds.), pp. 207–229, London–Philadelphia: Jessica Kingsley Publishers, 2007.

[11] V. Rowse, "Home-based Palliative Care for Children: The Case for Funding", *Paediatric Nursing*, vol. 18, no. 7, pp. 20–24, 2006.

[12] S. de Graves and J. Hynson, "Family Carers of Children Confronting Life-threatening Illnesses" in *Family Carers in Paliative Care. A Guide for Health and Social Care Professionals* (P. Hudson and S. Payne, eds.), pp. 191-210, Oxford: Oxford University Press, 2009.

[13] D. Niethammer, *Speaking Honestly with Sick and Dying Children and Adolescents. Unlocking the Silence*. Baltimore: The Johns Hopkins University Press, 2012.

[14] M.M. Mahon, “Death in the Lives of Children” in *Children’s Understanding of Death. From Biological to Religious Conception* (V. Talwar, P.L. Harris and M. Schleifer, eds.), pp. 61–97, Cambridge: Cambridge University Press, 2011.

[15] T. Ainsa, “Teaching the Terminally Ill Child”, *Education*, vol. 101, no. 4, pp. 397–401, 2001.

[16] J. Binnebessel, *Tanatopedagogika w doświadczeniu wielowymiarowości człowieka i śmierci*. Toruń: Wydawnictwo Adam Marszałek, 2013.

[17] B. Glaser and A. Strauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine Publishing Company, 1967.

[18] K. Charmaz, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London, Los Angeles, New Delhi, Singapore, Washington. SAGE Publications, 2006.

[19] S. Payne, “Qualitative Research Methods” in *Research Methods in Palliative Care* (J.M. Addington-Hall, E. Bruera, I.J. Higginson and S. Payne, eds.), pp. 139–161, Oxford: Oxford University Press, 2009.

[20] J. Green and N. Thorogood, *Qualitative Methods for Health Research*. London: SAGE Publications, 2009.

[21] G. Godawa, *Funkcjonowanie rodziny dziecka objętego domową opieką hospicyjną. Studium tanatopedagogiczne*. Toruń: Wydawnictwo Edukacyjne Akapit, 2016.

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