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## The application of grounded theory to research on the educational dimension of paediatric palliative care

Paediatric palliative care addresses a wide range of needs of an ill child and the persons close to them (Friedrichsdorf, Bruera 2018: 7). One of the support areas is the personality development of the child and their family members. Thereby, palliative care becomes part of the process of educating the family environment. The use of grounded theory as an appropriate approach to explore educational issues is justified to research this area (Chong, Yeo 2015: 266). This article presents the results of the author's own research using grounded theory in Kathy Charmaz's constructivist approach. The results have been presented using a model of education in the family of a child encompassed by paediatric palliative care. The model shows the basic educational assumptions, principles, and methods as well as the determinants and implementation perspectives of this process. The support provided by the hospice has a tanatopedagogical dimension.

Keywords: ill child, education, paediatric palliative care, grounded theory, hospice

## Zastosowanie teorii ugruntowanej w badaniu edukacyjnego wymiaru pediatrycznej opieki paliatywnej

Pediatryczna opieka paliatywna odpowiada na szeroki zakres potrzeb chorego dziecka i jego bliskich (Friedrichsdorf, Bruera 2018: 7). Jednym z obszarów wsparcia jest rozwój osobowościowy dziecka i członków rodziny. W ten sposób opieka paliatywna włącza się w proces edukacji środowiska rodzinnego. Dla zbadania tego obszaru zasadne jest zastosowanie teorii ugruntowanej, będącej adekwatnym podejściem do eksploracji zagadnień edukacyjnych (Chong, Yeo 2015: 266). W artykule zaprezentowano wyniki autorskich badań przeprowadzonych z wykorzystaniem teorii ugruntowanej w konstruktywistycznym ujęciu K. Charmaz. Wyniki badań zostały zaprezentowane za pomocą modelu edukacji realizowanej w rodzinie objętej opieką hospicjum domowego dla dzieci. Model pokazuje podstawowe założenia, zasady i metody edukacyjne, a także uwarunkowania i perspektywy realizacji tego procesu. Wsparcie udzielone przez hospicjum posiada tanatopedagogiczny wymiar.

Słowa kluczowe: chore dziecko, edukacja, pediatryczna opieka paliatywna, teoria ugruntowana, hospicjum

## Introduction

Fascination with youth accompanied by the tabooisation of the problem of suffering and death is one of the characteristic traits of modern Western society (Tucker 2009: 1105). However, the separation of youth from suffering and death is artificial and does not stand a chance when confronted with reality. Incurable diseases affect not only the oldest members of society, but also young people and children, being a significant cause of their mortality (United Nations Inter-agency Group for Child Mortality Estimation, 2019: 6). Diseases have particular implications in children, leading to the deprivation of needs, disrupting their development, and also burdening the family environment. It is important for the issue of illnesses and suffering of children to be noticed. It is no less important to show the possibilities of counteracting the destructive impact of suffering, where paediatric palliative care proves helpful.

Once causal treatment is completed, the child and their family can be covered by this care. Its aim is to ensure an optimal level of the quality of life of the child, their family, and caregivers (Klick, Hauer 2010: 120). This care is largely oriented towards the patient's various needs (Smallman 2007: 41) and endeavours to also meet the educational needs of the child and their close others. In order to gain a deeper understanding of the determinants and course of paediatric palliative care, empirical studies are undertaken, fitting the nature of the studied environment. One of the research approaches is using qualitative research involving grounded theory. However, there are no publications describing the use of grounded theory to enhance the understanding of the educational dimension of paediatric palliative care. The aim of this article is to show the validity of applying grounded theory in research on the educational process taking place in a family environment encompassed by paediatric palliative care. It is also important to present the results of the author's own research on this environment, which was carried out in a home hospice for children.

## Paediatric palliative care

According to the World Health Organisation, palliative care is an active, holistic care of patients with incurable, progressive diseases that are not responsive to causal treatment. Its aim is to improve the quality of life of patients and their families (WHO, 20.11.2018b), which is done by preventing and relieving suffering occurring on various levels of human functioning (Saunders 2000: 9). This requires early diagnosis and an accurate assessment of pain, accompanied by solving any other physical, psychosocial, and spiritual problems (Travers, Mitchell 2012: 2).

Paediatric palliative care has particular characteristics that are related to the determinants of the disease process and treatment of children: "Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family (...). Health providers must evaluate and alleviate a child's physical, psychological, and social distress" (WHO, 20.11.2018a). The aim of paediatric palliative care is "to promote the best possible quality of life and care for every child with a life-limiting or life-threatening condition, and for their family. Giving families real choice is key to this approach; choice of place of care, choice of place of death, choice of emotional and bereavement support; and putting the child and family at the centre of decision-making to produce a plan for care that is right for them" (Chambers 2018: 9).

Palliative care concerns minors with life-limiting or life-threatening conditions in the end-stage of the illness, where health restoration using available methods of treatment or extension of life is impossible (Szczepaniak 2008: 81). The palliative care team consists of the basic team that includes a physician specialising in palliative care, a nurse specialising in this field, and a coordinator of a multidisciplinary team. The presence of other physicians, nurses, and non-medical personnel is essentially complementary to the team (Booth et al. 2010: 10–12).

The care of an incurably ill child and their family is usually provided in a hospital or hospice facility. Sometimes hospice care is distinguished from palliative care in literature on the subject (Crozier, Hancock 2012: 199), but there is no lack of arguments in favour of adopting the assumption that hospice care is a form of palliative care (Connor 2014: 182), which allows the terms "palliative care" and "hospice care" to be used interchangeably. Paediatric palliative care provided in hospice conditions can be performed in stationary or home settings.

Palliative care for a child ensures they are under the care of physicians—thus, the child is given round-the-clock assistance and can benefit from highly specialised medical equipment offered by the facilities. The possibility of having medical consultation, and the availability of nurses and other team members not only facilitates care of the child, but also gives the child's parents a sense of security. The decision to benefit from the home form of hospice care is also dependent on the kind of illness and the medication applied, the degree of complexity of the medical apparatus, and the technologies that are necessary in the last phase of a patient's life (Grinyer 2012: 21). The benefits stemming from care provided at home result from the fact of the child remaining in their family environment. Another key factor is being able to individualise the care programme, adapting it to the family's needs, and thus ensuring a sense of security through twenty-four hour access to the services provided by the hospice team, as well as decreasing the costs of care compared to stationary treatment (Korzeniewska-Eksterowicz 2011a: 28).

## Educational dimension of paediatric palliative care

The occurrence of an incurable disease disrupts the educational and upbringing process of a child, which results in the devaluation of the priority value of education (Lavelle 1994: 87). Needs relating to saving and sustaining life are at the forefront. The limitations that have arisen as a result of the illness are in conflict with the natural desire for development because it goes without saying that young people living with life-threatening illnesses have the same developmental needs as healthy adolescents (Stevens, 2004: 813). Palliative care addresses these needs, according to the assumptions of which each incurably ill child has the right to access education (Chambers 2018: 14). It follows from this that the issue of education of incurably ill children is one of the key assumptions of paediatric palliative care.

The space around the patient's bed can be perceived as the educational environment (Bee 2007: 115–116), which does indeed give it a special status. *Bedside education* is inclusive in nature, expressed in involving the persons accompanying the ill child and any support givers in the education process. Education includes raising the level of knowledge of the patient who wants to obtain information regarding their health, planned treatment, and the manner of their participation in any decision-making concerning further medical interventions. The patient's close others are also engaged in the education. *Bedside education* also encompasses caregivers who are improving their level of knowledge and competences. In this context, a patient and the persons close to them can be perceived as an invaluable source of knowledge that has been acquired through experience (Bee and Hughes 2007: 291–292).

The personality development of an incurably ill child is a special educational area. It occurs in cooperation with the family and educational institutions. Hospice support can also play an important role here. Another area is related to the mechanism of compassion and suffering with the ill child that encompasses their close ones. For parents, siblings, and others close to them, traumatic experiences may become a source of destruction or promote post-traumatic growth. It is notable that, in such circumstances, post-traumatic growth is equated with development, which points to the self-educational dimension of human life. The result is an improvement in a person's functioning (Ogińska-Bulik 2010: 35). Richard G. Tedeschi and Lawrence G. Calhoun (1996: 456–458) identified three fundamental areas within which the positive changes occurring in persons who have experienced trauma can be seen. The changes take place in the scope of self-image, interpersonal relationships, and life philosophy. Spirituality and the religiousness of a person are also factors contributing to personality growth (Ogińska-Bulik 2014: 7).

The educational dimension of palliative care assumes that approaching death does not hinder the possibility of a person's development. This premise is in line with the assumptions of tanatopedagogy, which is a sub-discipline of education that arose from the hospice and volunteering movement. It is the science of nurturing accompanied by an awareness of mortality based on a respect for the dignity of every human being and the inviolability and a priori value of human life (Binnebesel 2013: 251). The basic category of tanatopedagogy is education in the context of suffering and death, which essentially is upbringing to live a conscious personal life, and together with those that are ill. The basis for this sphere of upbringing is the idea of continually caring for life and improving its quality in all circumstances (Grzybowski 2010: 291–292).

### Grounded theory in the paediatric palliative care research area

The palliative care environment is so complex that one method would not suffice to obtain its in-depth diagnosis. Research undertaken in the field of palliative care should factor in a broad range of needs of an ill person and those close to them, including the physical, emotional, social, and spiritual areas of their functioning (Addington-Hall, 2009: 4). The postulate of applying a varied approach to conducting research in palliative care is fulfilled through the application of a quantitative and qualitative empirical research model as well as broadly understood triangulation (Thurmond 2001: 254–256). Due to the very substance of the researched issues and the psychosocial and emotional problems, the application of qualitative research is oftentimes the most adequate research approach. This approach is gaining wider acceptance in the medical sciences (Council of Europe, 2003: 56; DiCicco-Bloom, Crabtree 2006: 314). It is also applied in the methodologies of other disciplines researching the environment of suffering and death in the context of education.

Norman K. Denzin, Yvonna S. Lincoln (2011: 6) define qualitative research as the activity of a researcher that locates the observer in the reality being studied and makes it visible to others. Thanks to its practical direction, it points to actions that can change the world. Qualitative research applied in palliative care reveals the opinions of children and adolescents, parents and clinicians, while preserving their independence in utterances (Chambers 2018: 30). The scope of research relating to paediatric palliative care is broad and also covers issues associated with exploring patients' quality of life, their opinions on the course of treatment, inclusion in decision-making, and expressing their emotions and expectations (Payne 2009: 141).

Grounded theory presented by Anselm Strauss and Barney Glaser (1967; 1968) has a key role among qualitative approaches. Associating grounded theory with

the environment of suffering and death is not coincidental. It is noteworthy that Anselm Strauss and Barney Glaser (1967: 26) undertook research on the experiences of terminally ill patients. Particular attention should be given to the output of Anselm Strauss, whose research served to improve the treatment process and medical care of chronically ill and dying persons (Konecki 2015: 35). Kathy Charmaz's constructivist approach to grounded theory was also applied in studies on the environment of persons afflicted by illness (1991). Constructivist grounded theory arose as a result of the assumption that there is no objective data that can be independent of the researcher, there is only constructed data, an awareness of this, and a description of the context and procedures—hence the strong emphasis on the responsibility of the researcher for the results obtained (Juszczak 2013: 186). The application of constructivist grounded theory allows the researcher to work on a considerable amount of material and to present it conceptually, followed by reordering it into more general, theoretical statements, which enhance the social understanding of a chronic illness and contribute to the advancement of science (Charmaz 1990: 1170).

The weaknesses of applying grounded theory in caring for an ill person should also be considered. These weaknesses mainly concern having limited access to the patient and limited possibility of the patient giving an interview, or the risk of them dying before the end of the research, which leads to a potential conflict between the implementation of the postulate to reach research data saturation and the temporary limitation resulting from the tenuous situation (Green and Thorogood 2009: 206).

The most common method in research conducted while providing hospice care services is the in-depth interview and accompanying participant observation (Gray, 2009: 185). An interview allows the ill person to specify their thoughts and reflections and to voice them in the presence of an attentive listener. An interview is absorbing, but does not require the ailing person to concentrate on a questionnaire and is dependent on the interviewing experience of the researchers in clinical settings (Payne 2009:145). Participant observation enables an optimal description of the determinants, events, persons, and meanings to be obtained, particularly when the investigator takes its complex nature into account and is aware of the nuances specific to it (Dicks et al. 2011: 235). Participant observation is particularly useful when gleaning data from persons who, due to their illness, cannot be involved in other research methods. The possibility of observing the functioning of an ill person and the persons close to them allows a great deal of valuable information to be obtained (Payne, 2009:148).

The ethical dimension of research is particularly important in palliative care. The environment of life and suffering expects the research to be treated with the utmost attention and deep thought and consideration as this is what is demanded by the seriousness of the situation and the standards of palliative care principles.

The research areas encompassed by ethical sensitivity include the problem of deriving scientific benefits while at the same time ensuring respondent comfort, the principle of balancing the benefits and risks stemming from undertaking the research, as well as respecting the autonomy of the ill person and the persons close to them (Reyna et al. 2009: 28).

These assumptions also apply to studies on the educational dimension of palliative care. Educational research in principle endeavours to discover a scientific theory describing and interpreting human activities in the area of education (Ary et al. 2010: 19). They usually relate to teaching and learning at school (Research Methods in Education, 2012: 8) and, in this context, are an important tool enhancing the education process (Morrell, Carroll 2010: 3). This research also covers the area of extracurricular education, taking teaching and upbringing within the family setting into account. Although educational research serves mainly to build theory, its practical function cannot be diminished. In undertaking such studies, a researcher tries to enrich it during the course of cognitive explorations, supported by existing knowledge, and to draw conclusions that are useful in the practice of upbringing, education, and self-education (Palka 2018: 52). The practical dimension of educational research is of particular importance to exploring the suffering environment. In this sense, reference is being made to applied research, demonstrating the application of research findings in the practice of caring for ill persons (Green, Thorogood 2009: 232). The therapeutic dimension of these studies is also important (Kubinowski 2011: 150), which inevitably has repercussions on the quality of life of the ill person and those close to them. Contemporary education needs knowledge rooted in empiricism, which is also why grounded theory is mentioned as one of the key approaches to educational research (Bauman 2003: 282–288). This is a promising approach in learning about and describing the experiences of families facing the protracted illness of one of its members (Mazurek 2013: 38).

The application of grounded theory in paediatric palliative care and education creates opportunities to explore areas that are at the interface of the interests of these different scientific disciplines. It opens the opportunity to reach the hidden meanings of educational processes, indicating the directions for solutions to occurring problems (Dworak 2018: 203). The reflection models created in this way point to specific aspects of the deliberations involving analysing, explaining, interpreting and anticipating actions. They also foster reflection, ever so vital in the work of educators (Szymczak 2017: 128), which is particularly important in the field of providing support to an incurably ill child and the persons close to them.

## Method

The assumptions concerning the relevance of taking into account the educational dimension of applying grounded theory in research on paediatric palliative care were realised in the author's own research project titled "Implementation of the educational process in the family of a child in home hospice care". The research project covered studies performed in the years 2014–2015, the results of which were partly published in 2016 (Godawa 2016), and in 2018 (Godawa 2018). The results shown in this article are a conclusion of the whole project.

The studies were conducted in Poland and included 21 families of children who were part of a children's home hospice care service operating in Krakow and its environs during the course of the studies. This hospice provides palliative care to children suffering from incurable illnesses that meet the criteria for palliative treatment (Korzeniewska-Eksterowicz 2011b: 17).

The research project was executed using grounded theory in Kathy Charmaz's constructivist approach. In-depth interviews and participant observation were used to collect research material. The selection of the participants was purposeful and data saturation was achieved at its end stage. A total of 62 interviews were conducted with family members of incurably ill children. The duration of interviews was from 60 to 90 minutes, and conversations with a child lasted approximately 30 minutes. They were transcribed in line with the transcription rules for qualitative material. Qualitative analysis using MAXQDA commenced once a portion of the interviews were carried out and transcribed. Initial coding of small segments of the material was applied, which was more substantive than theoretical coding. The next stage consisted of creating more general categories, attributing relevant codes to them, and writing notes and reports.

The implementation of grounded theory methodology in a palliative care environment necessitated the application of relevant research standards, which was expressed in procuring the consent of the persons close to the ill children to their inclusion in the research, as well as obtaining a positive opinion from the Ethics Committee at the Pontifical University of John Paul II in Krakow (KE/0/01.2015, 2015). Other ethical requirements were also taken into account like, for instance, the option of withdrawing from the research at each stage of its duration and ensuring anonymity to interlocutors.

## Results

The questions addressed to the interlocutors pointed to research areas relating to education, but the question sequence was not fixed. The research findings were subject to discussion and references were made to hospice practice and educa-



tional theory, with particular focus on references to tanatopedagogy. This led to the creation of the model of education in the family of a child encompassed by paediatric palliative care. The results of the research have been presented in Figure 1 (Source: based on Godawa 2016: 338).

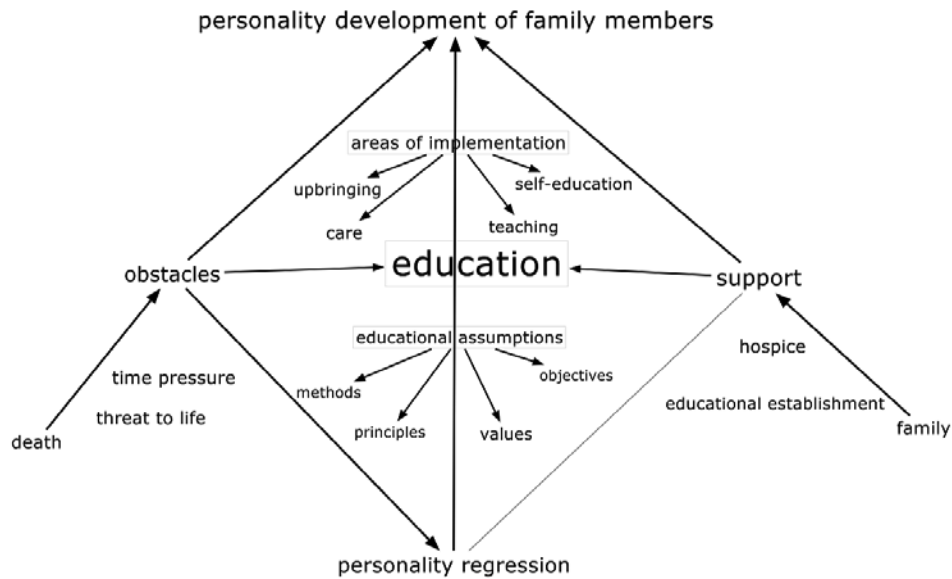


Figure 1. The model of education in the family of a child encompassed by paediatric palliative care

Source: (Godawa 2016: 338).

The model presented in Figure 1 depicts the process of personality development of a seriously ill child and different members of their family. The model also takes into account the possibility of regression of personality. Education, which aims to initiate and enhance positive transformations, plays an important role in the development process. The educational potential of the family determines these changes. Education implemented during the course of providing care to a critically ill child includes teaching and nurturing them and their siblings. Cooperation with the hospice allows the family to benefit from the assistance offer entailing elements of education. Support provided by nurseries, schools, and other educational institutions also contributes to the child’s development, and the extent of their impact depends on the scope in which these services are used, as well as on their quality. Education taking place in a home hospice setting includes the provision of care for the seriously ill child, their siblings, and remaining family members, giving this care an educational meaning.

Key independent variables shaping the profile of education in the family of a chronically ill child include the threat to life and the passage of time. The proximity of death and an awareness of the limited time left for the family lead to the performance of family functions taking on a tanatic dimension (Godawa 2018: 41). It is, therefore, reasonable to interpret the educational experiences of the family in a tanatopedagogical context. Applying this interpretative key, the significance of the axiological dimension of family functioning and the need to specify the educational objectives were highlighted on the model. Among the values mentioned by the study participants, the most common were: life, health, love, family, time, belief in God, justice, personal development, independence, the ability to share, goodness, the ability to work together, kindness, patience, work, family traditions, and money. In turn, the educational objectives mainly concerned achieving the highest possible independence in life, continually improving quality of life, and the intellectual and emotional development of the ill child and persons close to them, as well as activating spiritual, religious, and cultural sensitivity, shaping prosocial attitudes, organising an environment centred on the satisfaction of the child's needs in terms of nurturing, and preparing the child and the family environment for their approaching death (Godawa 2016: 319–330).

The presence on the model of educational principles and methods allows the general standards of behaviour and specific educational methods to be described. These may include the clearing of communication channels, establishing and maintaining social contacts, organising the cognitive experiences of the child, playing, and rewarding and applying punishment. Particular attention should be paid to the area of self-education which is the most mature stage of education. The subjects of self-education can be adolescent and adult family members (Godawa 2018: 211–213).

## Discussion

The application of grounded theory in researching an environment encompassed by paediatric palliative care seems fully justified. The methodological assumptions of grounded theory meet the requirements for educational research. Conducting research within a hospice environment reveals the main directions in the education process. Through this, it complements the exploration of research carried out in the field of caring for a terminally ill child and contributes to overcoming the stereotypic, negative attitude to hospice care in society (Levin 2001: 286). By calling attention to education and development, the profound importance of caring for an incurably ill child comes to the fore (Bialic 2016: 131-142).

Research conducted in the model of grounded theory aims at overcoming the limitations indicated by quantitative research undertaken in the field of palliative care, which is highlighted by Alicja Przyłuska-Fischer and Agnieszka Wójcik (2009: 119–131). This type of research is partially inadequate to the conditions of the functioning of an incurably ill child, which results in the fact that research applied in grounded theory gains great significance, particularly when it is conducted in home settings where it is possible to capture things and phenomena in their natural environment and try to make sense of them or interpret them. Norman K. Denzin and Yvonna S. Lincoln emphasise an advantage of this type of research. Terms used by the researched people appear in such studies, which deepens the understanding of commonly used concepts (2009: 23). It is of special importance in educational research. The adoption of a bedside education model opens broad research perspectives. Although the bedside teaching model mainly concerns medical education in literature on the subject, it seems that it can be successfully applied to the area of education in its broad sense (Peters and Ten Cate 2014: 77).

## Conclusion

The presented model of education in the family of a child encompassed by paediatric palliative care is an attempt to systematically describe this process. The application of grounded theory in educational research requires the problem to be supplemented by further research projects. It would appear particularly important to extend the scope of empirical research by triangulating research approaches.

Theoretical deliberations on the implementation of grounded theory in the research on education in the family of an incurably ill child stem from everyday life experiences and lead to them. In education, similarly to medical care, good practices elaborated by a child's caregivers are of crucial importance. Recognising them and demonstrating a willingness to enhance them contributes to improving the quality of life of an incurably ill child and the people close to them. Drawing attention to the educational dimension of the functioning of the family of an ill child also enhances the quality of hospice care as well as that of educational institutions. Through this, their activities acquire a special dimension, countering the tendencies towards the over-medicalisation of the care of the sick and suffering.

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