



From diagnosis to accompanying in mourning – support for families with a child with a lethal defect

ABSTRACT: Aneta Jarzębińska, *From diagnosis to accompanying in mourning – support for families with a child with a lethal defect*, Interdisciplinary Contexts of Special Pedagogy, No. 22, Poznań 2018. Pp. 375–391 Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2018.22.21>

This article characterizes the interactions and institutions in which parents can receive support after their child has been diagnosed with a lethal defect. First of all, parents need information and emotional support when making decisions regarding their child. The primary source is the hospital staff and the perinatal hospice – if the parents decide to contact them. If the child is born alive and discharged home parents need support during its treatment (which often means palliative care) and rehabilitation, even social rehabilitation. Home-based hospices for children have a lot to offer in this area. At every stage of the child's illness it is important to contact other parents of children with a lethal defect. They can help to eliminate the feeling of isolation, give practical advice regarding the situation and, above all, provide hope that some children live despite fatal diagnosis.

KEY WORDS: child with a lethal defect, prenatal pedagogy, social support

The article attempts to outline the sources of support for parents of a child with a lethal defect. It describes persons and institutions that already during the period of pregnancy can provide parents with reliable information about various aspects of the disease, help

to plan birth, improve access to health care services and, above all, surround the family with emotional support.

This topic was inspired by blogs run by parents of children with a lethal defect (Edwards, Patau and Miller-Dieker Syndromes). The author of one of the blogs observed that when talking about terminally ill children whose health condition is far from promising any improvement, people tend to use statements such as: “a hopeless case”, “it won’t help him/her anyway”, “it’s a waste of time and money”, “only persistent therapy can help”, “a hospice is the only solution for such children”, “he/she’s just taking the place of children who have a chance to recover”. This leads to a feeling of loneliness, deprives parents of the strength to face the disease and hope for a better future. One such statement can complicate their already dramatic situation. At the same time, the blogs show that parents of children with lethal diseases are not always left to their own devices, because, as they wrote in their virtual diaries, they received support from people and institutions, even if at first they did not realize that such possibilities existed.

The specific situation of parents after the diagnosis of a lethal defect in the child

The term “lethal defect” which appears in the title is used to denote severe developmental abnormalities with uncertain or poor prognosis. A lethal defect can lead to: 1) miscarriage of a dead foetus, 2) premature birth of a dead child, 3) death of a child immediately after birth or in early infancy regardless of the treatment applied. Despite the progress in medicine and the possibility of using the most modern achievements of biotechnology and pharmacology in treatment, there is no possibility of causal treatment of lethal defects¹.

¹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 58.

Every year, more than 600 children with a lethal defect are born in Poland². The number of fetuses with lethal defects is even higher, especially if the mother is older³. Thanks to the development of prenatal diagnostics techniques which are divided into two main groups: invasive (ultrasonography and examination of the pregnant woman's blood serum) and non-invasive, which involve the collection of the prenatal child's cells in order to determine its karyotype and possible DNA analysis (such as genetic amniocentesis, CVS test, cordocentesis and fetoscopy)⁴, some lethal defects can be diagnosed from the end of the first trimester of pregnancy.

It is extremely difficult for parents to learn that an expected child has a disease that will lead to his or her premature death, perhaps still in the prenatal period. As Dorota Kornas-Biela observes, this kind of information evokes panic, sadness, regret, disbelief, denial, emotional lability in parents. A sense of shame, guilt and injustice and many other extremely negative experiences may also appear⁵. As Renata Kleszcz-Szczyrba puts it, the diagnosis of a lethal defect entails a multiple loss. The first one is the irreversible loss of the child's health, the second is the loss of the parents' plans and hopes, which were associated with the child⁶.

² The number of live-born children with a lethal defect was estimated based on the assumption that 3% of live-born children have WRWZAC and 7% of this group are children with a lethal defect; T. Dangel, *Wady letalne u płodów i noworodków: opieka paliatywna jako alternatywa wobec eugenicznej aborcji, eugenicznego dzieciobójstwa i uporczywej terapii*; <http://www.hospicjum.waw.pl/phocadownload/Etyka/WadyLetalneUPlodowINoworodkow.pdf> [access: 2.05.2017].

³ For example, the risk of the fetal Edwards Syndrome is 1:2484 for a 20-year-old woman, 1:1456 for a 30-year-old and 1:157 for a 40-year-old.; H. Kypros, P. Nicolaides, P. Węgrzyn, *Badanie ultrasonograficzne między 11+0–13+6 tygodniem ciąży*, Fetal Medicine Foundation, London 2004, p. 22.

⁴ J. Skrzypczak, J. Kornacki, *Ciąża o przebiegu niepowikłanym*, [in:] *Położnictwo. Podręcznik dla położnych i pielęgniarek*, red. G.H. Bębrowicz, Warsaw 2005, pp. 72–74.

⁵ D. Kornas-Biela, *Niepomyślna diagnoza prenatalna: dylemat rodziców, wyzwanie dla profesjonalistów*, http://www.mp.pl/etyka/poczatki_zycia/39622,niepomyslana-diagnoza-prenatalna-dylemat-rodzicow-wyzwanie-dla-profesjonalistow [access: 2.05.2017].

⁶ R. Kleszcz-Szczyrba, *Witraże w ciemności czyli o przedwczesnej śmierci dziecka. Książka niosąca światło*, Księgarnia św. Jacka, Katowice 2015, p. 78.

If parents receive the diagnosis during the prenatal period, this will involve an additional burden for them as they will have to decide between the following options: termination of pregnancy, which is permitted by law in this situation vs. continuation of pregnancy. If the child is born alive, parents will be confronted with decisions such as: 1) resuscitation of the child vs. no resuscitation; 2) intensive therapy vs. palliative care provided at home, in a hospital ward or in a residential facility; 3) surgical correction of the defect vs. no surgical treatment; 4) death in hospital vs. death at home⁷.

When confronted with a multitude of problems, parents need comprehensive support. During pregnancy, the main focus is on multi-faceted information about the disease, showing understanding to the parents and preparing them to make decisions related to the child. If the child is born alive and discharged home, there is also the need to support parents in their care, treatment, rehabilitation and taking measures to prevent social exclusion of the family.

Support provided by the staff of health care institutions

A pregnant woman, regardless of whether she is insured or not, has the right to health care during pregnancy, childbirth and confinement, which is regulated by relevant regulations, in particular the Regulation of the Minister of Health of 20 September 2012 *on the status of medical procedures for the provision of health care services in the field of perinatal care provided to a woman during physiological pregnancy, physiological birth, confinement and care of a new-born child*. On the other hand, under the Regulation of the Minister of Health of 6 November 2013 *on guaranteed services from the scope of health programmes*, a pregnant woman may also benefit from the “Prenatal tests programme” provided that she meets at least one of the criteria set out

⁷ T. Dangel, *Decyzje dotyczące dzieci z nieuleczalnymi chorobami prowadzącymi do przedwczesnej śmierci w perinatologii*, pp. 3–6, http://www.ptb.org.pl/pdf/dangel_neonatalna.pdf [access: 20.09.2015].

in the programme⁸. When the pregnancy and childbirth are complicated or when there is a obstetric failure, the procedure regarding the woman is specified in the Regulation of the Minister of Health of 9 November 2015 *on standards of medical procedure in the provision of health services in the field of obstetrics and gynaecology in the field of perinatal obstetrics and gynaecology care provided to a woman during pregnancy, childbirth, confinement, in cases of specific complications and care for a woman in the situation of obstetric failures*.

Under optimal conditions, a wide range of medical specialists are involved in the diagnosis of a child's lethal defect and decision-making processes after diagnosis: obstetricians dealing with the pregnancy and prenatal diagnosis, clinical geneticists, foetal echocardiography specialists, paediatric surgeons, neonatologists and palliative medicine specialists who are involved in the care of the child after its birth.⁹ The task of these people is to diagnose the disease properly and to provide parents with as complete information as possible. This should include knowledge about the symptoms of the disease, prognosis, perspectives of treatment and rehabilitation of the child. In addition, parents should be consulted about their procreation plans¹⁰.

What is important is not only the content of the information provided by the medical personnel, but also its form. Parents need someone who will understand their feelings and patiently listen to

⁸ 1) the mother's age over 35; 2) occurrence of chromosomal aberration in previous pregnancy; 3) finding the occurrence of structural chromosome aberrations in a pregnant woman or in the child's father; 4) finding a significantly higher risk of giving birth to a child afflicted with a monogenetically-conditioned or multifactorial disease; 5) confirmation during pregnancy of an abnormal result of ultrasound examination and/or biochemical tests indicating an increased risk of chromosomal aberration or fetal defects (Order No 66/2007 / DSOZ, appendix No 5).

⁹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 57.

¹⁰ A. Libera, *Psychologiczny aspekt poronień*, [in:] *Psychologia w położnictwie i ginekologii*, ed. M. Makara-Studzińska, G. Iwanowicz-Palus, Wyd. Lekarskie PZWL, Warsaw 2009.

them. It is inappropriate to use specific medical terms referring to the child in the presence of the parents, which function in medical nomenclature, but are non-personalistic. When talking with parents whose child is alive, the aspects that constitute the basis for building rational hope (far from presenting an illusion of curing the child) should be highlighted. Finally, as Jadwiga Łuczak-Wawrzyniak emphasizes, providing parents with information about the disease is not, or at least should not be a simple conversation, but an art in itself¹¹.

Once again, we had our daughter examined at the clinic in the University Hospital, scheduled for September. We were received by our wonderful Doctor. The same one who told us about our daughter's disease. Strange, I think of her as wonderful and yet she was the one who told me something which caused the greatest pain in my life. Also this time she was full of empathy and understanding. She examined our daughter with great care. I felt that although she didn't want us to be too optimistic, she let us know that according to her our daughter was doing quite well. She also said a few warm words about us: that we were wonderful parents, which made us to feel a little better¹².

Parents can also count on the support of a psychologist, including the one employed in the hospital. Unfortunately, research shows that most often parents do not know about such a possibility, which leads to the conclusion that the role of the psychologist should not be limited to waiting for parents to come to his/her office themselves, but rather to initiate contact and present the possibilities of psychological care¹³.

¹¹ J. Łuczak-Wawrzyniak, *Leczenie jest sztuką – na podstawie wybranych obszarów działalności szpitala ginekologiczno-położniczego*, „Ginekologia Polska” 2002, No 73(10), pp. 884–887.

¹² The quote, like the subsequent ones, comes from a blog devoted to a child with a lethal defect. In order to protect the identity of the authors of the blogs, the article does not provide their names and internet addresses. For the same purpose, the quoted excerpts of the entries have been slightly edited.

¹³ A. Kopeć et al., *Hospitalizacja dziecka w Oddziale Intensywnej Terapii Noworodka – doświadczenia rodziców*, „Current Problems of Psychiatry” 2016, No 17(1), p. 28.

However, the situation of parents after the child has been diagnosed with a lethal defect, very difficult from the psychological point of view, may prove that support provided by the hospital staff is insufficient. In addition to information, parents need support in the form of appreciative, instrumental and, above all, emotional and spiritual support¹⁴. This is possible provided they use several sources of support simultaneously.

Parents as the source of mutual support

When confronted with information about a child's lethal illness, the first and primary source of support, initially mainly emotional, should be the spouse/partner. However, this may be problematic due to the diversity of experiences and reactions of parents. According to D. Kornas-White, the woman, who is usually more involved in the situation and shows stronger emotional expression, often feels misunderstood by the child's father, abandoned and experiences a sense of underestimation on the part of the father of the gravity of the situation¹⁵. The attitude of the partner, different from one's own, may cause anger in a woman, she may interpret it as a manifestation of the man's small concern for the child or rejection of herself¹⁶.

A prerequisite for the mutual support of parents is a uniform position regarding the future of the pregnancy: whether they want to continue the pregnancy or, as permitted by law, decide to terminate it. There should be no question of an arbitrary suggestion of

¹⁴ Classification of forms of support by S. Kawula, *Wsparcie społeczne– kluczowy wymiar pedagogiki społecznej. Głos w dyskusji, „Problemy Opiekuńczo-Wychowawcze”* 1996, No 1.

¹⁵ D. Kornas-Biela, *Niepomyślna diagnoza prenatalna: dylemat rodziców, wyzwanie dla profesjonalistów*, http://www.mp.pl/etyka/poczatki_zycia/39622,niepomyslana-diagnoza-prenatalna-dylemat-rodzicow-wyzwanie-dla-profesjonalistow [access: 2.05.2017].

¹⁶ J. Makselon, *Typologia i dynamika żałoby*, [in:] *Człowiek nieuleczalnie chory*, ed. B. Block, W. Otrębski, WNS KUL, Lublin 1997.

a solution, detached from emotional argumentation, without respect for the recognised worldview, because this may be the reason for blaming the partner for the decision at a later stage.

After the birth of the child, it is important to share the responsibilities associated with its presence, especially since apart from the duties considered standard in neonatal care, there are also those that are a consequence of the disease, such as feeding with the use of a probe or transcutaneous endoscopic gastrostomy (the so-called peg). There is also a psychological burden resulting from the awareness that the child's condition may deteriorate rapidly at any time and without any warning, because this is the specificity of lethal malformations. If other children are present in the family, they also need attention. Despite the presence of the sick sibling, their needs must be met. In these circumstances, the partner's support cannot be overestimated.

On Saturday our son had fever, diarrhea and nausea. I worked from morning until evening, so Dad stayed at home. He was alone with two sons, one of which required constant changing, dressing, feeding with carrots and rice and hydrating with electrolytes, while the other demanded continuous and active participation in fun and games. Dad was certainly not bored. Fortunately, he is the best Dad in the world and he is doing very well with the boys, so he emerged victorious from this battle.

Parents can support each other in the process of waiting for the child with a lethal defect and its upbringing, especially if they develop certain coping strategies. One of the most interesting things that have been observed when reading the blogs is treating the child's illness metaphorically as a journey, with the conviction that although it is difficult and leads along unknown routes, it will bring about positive changes.

From the first months of their lives we took our children on trips. This time the opposite happened, because it was our son who invited us on an expedition into the unknown. Although not with open arms and without a smile on our lips, we accepted this invitation. And here we

are on our journey together. This time, however, our journey has a much deeper dimension than usual. The non-material sphere that has always been present in our travels has come to the forefront. This time, we don't really know where we're going. At most, we know that this is a difficult road. I am convinced, however, that at the end of the road there is a place which will leave us speechless. Not only because of fatigue, but also due to admiration. I think that something positive has to come out of all this.

The support of the family by a perinatal hospice

A relatively new proposal to support parents of children with lethal defects is the offer of perinatal hospices, which are free of charge from prenatal recognition of the defect to the completion of the 28th day of the child's life¹⁷. The first institution of this type in Poland was established in Warsaw in June 2006, when an ultrasound clinic was opened at the Warsaw Hospice for Children Foundation¹⁸. At present, there are 16 such institutions in Poland, most often organised within the structure of children's hospices or clinical hospitals, offering perinatal hospice care. They are located in: Krakow (three), Wrocław (two), Warsaw, Tychy, Łódź, Białystok, Gdańsk, Poznań, Lublin, Opole, Rzeszów, Katowice and Bydgoszcz (one in each).

Currently there is no uniform model of functioning of perinatal hospices. The most comprehensive seems to be the concept of support developed by the perinatal hospice at the Warsaw Hospice for Children Foundation, which, thanks to the training provided to doctors and psychologists from other centres, is gradually being

¹⁷ More information on perinatal hospices can be found in the author's article *Hospicjum perinatalne – miejsce wsparcia dla rodziny z dzieckiem z wadą letalną*, „Problemy Opiekuńczo-Wychowawcze” 2016, No 8.

¹⁸ J. Szymkiewicz-Dangel, *Perinatalna opieka paliatywna – czy możliwa jest współpraca położników i neonatologów z hospicjami domowymi dla dzieci?*, „Opieka Paliatywna nad Dziećmi” 2007, Vol. 15, p. 27.

disseminated throughout the country¹⁹. This includes the following stages of support for a family with a child with a lethal defect:

- 1) Consultation with a doctor consultant of the ultrasound clinic at the hospice.
- 2) Further specialist consultations, mainly psychological and genetic; prenatal invasive tests and a meeting with other parents who decided to be supported by a perinatal hospice.
- 3) If the parents decide to terminate the pregnancy, the patient has the opportunity to seek psychological advice and join a support group. If the parents decide to continue the pregnancy, the hospice offers them perinatal palliative care including (depending on the diagnosis):
 - ultrasound scan/echogram control of the foetus at the hospice outpatient clinic,
 - maternity care in the pregnancy pathology clinic,
 - a meeting between the parents and an obstetrician organized by the hospice doctor in order to determine the perinatal procedure,
 - organisation of a meeting between the parents and a neonatologist to discuss the care of the new-born²⁰.

An important aspect of the support provided by a perinatal hospice is the work of the midwife. Her main task is to prepare the parents for childbirth and care at the time of pregnancy. The role of the midwife is also to make parents aware of the possibility of giving birth to a dead or dying child and how to prepare to say goodbye to the child (e.g. by preparing special clothes, filling in rituals according to the religion of the parents, taking pictures during and after the birth)²¹.

¹⁹ *Hospicja perinatalne – placówki poza systemem*, <http://info.wiara.pl/doc/3506371>. Hospicja-perinatalne-placowki-poz-systemem [access: 19.02.2017].

²⁰ D. Maksiewicz, T. Dangel, *II Ogólnopolska Konferencja Hospicjów Perinatalnych*, „Hospicjum” 2015, No 2(72), p. 13, file:///C:/Users/aneta/Downloads/informator-hospicjum-nr72-czerwiec-2015%20(1).pdf [access: 9.05.2017].

²¹ J. Krzeszowiak, R. Śmigiel, *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1, p. 57.

- 4) If the child is born alive, it is placed in a neonatal ward. There he or she receives palliative care aimed at providing comfort and protection against persistent therapy. At the same time, the parents maintain contact with the psychologist of the perinatal hospice.
- 5) If the child survives in the neonatal ward for several consecutive days and his/her condition allows for it, he/she may be referred by a neonatologist to a home hospice²². The family can then count on paediatric palliative care, which includes:
 - healthcare services provided by doctors and nurses;
 - treatment of pain and other somatic symptoms in accordance with current guidelines and medical knowledge;
 - rehabilitation in the event that the hospice physician identifies existing medical indications for this purpose;
 - prevention of complications;
 - examinations commissioned by the family hospice doctor;
 - medication prescription;
 - renting the necessary medical equipment free of charge;
 - psychological care for the patient and his or her family, including support in mourning;
 - social support including, among other things, renovation and adaptation works carried out in the apartment, assistance in organizing and financing holiday trips and spiritual support, the key element of which is building hope, also through reference to religion, as well as assistance in accepting the fact of the illness and most often the death of a child²³.

According to the model propagated by the Warsaw hospice, in the event of a child's death, the hospice staff: a doctor and a nurse

²² Fundacja Warszawskie Hospicjum dla Dzieci, *Hospicjum perinatalne*, Warsaw 2016, p. 8, file:///C:/Users/aneta/Desktop/1037_hospicjum-perinatalne-materialy-informacyjne.pdf [access: 29.04.2017].

²³ A. Korzeniewska-Eksterowicz et al. (compilation), *Standardy prowadzenia pediatrycznej opieki paliatywnej Ogólnopolskiego Forum Pediatrycznej Opieki Paliatywnej*, pp. 2-3, <http://ofpop.pl/wp-content/themes/inove/img/standardy-ofpop-2016.pdf> [access: 29.04.2017].

(as well as a priest, if the parents wish him to be present), try to reach the patient's home as soon as possible. They show compassion for the parents, and by stressing that they took good care of their child, that they have done everything possible, they also provide appreciative support. There can also be a common prayer, which is an expression of spiritual support. Afterwards, the hospice staff assists the parents in formal matters: the doctor fills in the death certificate and the social worker handles official matters. In addition, the hospice staff accompany the parents in funerals and then invite them to join a support group in mourning²⁴.

I quickly contacted the home hospice. When I asked for help, I was mostly thinking about the essentials – about the equipment I would need to take care of my daughter at home. The response from the hospice was immediate. The next day the doctor and the nurse came to the hospital to get to know us. I must admit that I did not expect that this meeting would help me so much, especially mentally. I felt strong and safe. After the meeting I became convinced that our decision to take my daughter home was the right one. The next day the nurse brought us: an oxygen concentrator and syringes and probes needed for feeding. Our home is now surrounded not only by medical help and professionalism, but also by peace, cordiality and a good word.

Support received from other parents with children with a lethal defect

When a child has a rare disease, it is usually difficult to find people in a similar life situation in our immediate environment. At the same time, contact with such people could reduce the sense of isolation, result in the exchange of information and experience, make us aware of what we have influence on and what cannot be

²⁴ *Szpital to nie jest dobre miejsce dla dzieci. Rozmowa z Tomaszem Dangelem, „Hospicjum” 2011, No 1 (55), p. 26, file:///C:/Users/aneta/Downloads/informator-hospicjum-nr55-marzec-2011.pdf [access: 21.02.2017].*

changed. Research confirms that parents of terminally ill new-borns appreciate the role of people with similar experiences when coping with the difficult situation²⁵.

As part of the hospice support, parents may establish contact with other families with a child with a lethal defect already during pregnancy. Holiday trips, organized and financed by the hospice, are also an opportunity to meet other families with a sick child. Face-to-face contacts are not only a valuable source of knowledge for parents about various aspects of the disease, but above allow to build hope, as parents find out that there are children who live despite fatal prognosis and who have mastered skills that are true milestones.

In June we got in touch with another family with a child with the Edwards Syndrome. Naturally, we decided to meet. Then another “summit meeting” took place. I found out that children with the same disease can develop very differently. The other girl can maintain an upright position and walk, though only on tiptoes, but it’s a huge success for her and her parents. Our Princess also looked at her “sister in disease”. In September we had a long-awaited trip to the Baltic Sea. A lot of iodine, an ideal period for improving the respiratory tract, but it was more important to get to know other sick children. And the most important thing was to get to know Małgosia – the oldest child with the Edwards Syndrome I know. I would like to use this opportunity and say hello to everyone.

The Internet cannot be overlooked when considering the issue of supporting parents of children with a lethal defect. It is a popular source of information about health and disease, including children with a lethal defect. Parents of such children can be contacted through virtual support groups existing on social networking sites (e.g. *Mali Giganci z zespołem Edwardsa*), discussion forums (including associations’ websites, e.g. the *Association for Children with Rare Genetic Diseases and Their Families “Wspólnie”*) or parent blogs.

²⁵ A. Kopeć et al., *Hospitalizacja dziecka w Oddziale Intensywnej Terapii Noworodka – doświadczenia rodziców*, „Current Problems of Psychiatry” 2016, no. 17(1), p. 28.

Internet groups, although they have their disadvantages, offer unique conditions that make it easier for their members to disclose personal experiences and develop supportive relationships. One of the most important are: the ability to communicate across spatial boundaries and at any time, the impression of anonymity and the lack of divisions resulting from age, gender, appearance or education²⁶. The written form, which is the basis of any on-line communication, also has its advantages. The process of writing down thoughts, emotions and experiences is beneficial from a therapeutic point of view, as it improves one's mood and well-being, observes Małgorzata Wysocka-Pleczyk²⁷. It is worth noting that contacts established in the network are sometimes carried out outside the Internet, including telephone calls or even personal meetings²⁸.

Conclusion

After the child has been diagnosed with a lethal defect, the family enters an extremely difficult psychosocial situation. Parents learn that their child will die prematurely as a result of the lack of treatment of the cause of the disease. Despite the tragic diagnosis, many of them decide to make every effort to ensure that the child's life, even if it is short, is good (in the sense that it is free from pain and persistent therapy, surrounded by loving people). However, parents may feel incompetent and overburdened in achieving this goal.

²⁶ More information on the features of the Internet conducive to communication can be found in the work of M. Grabowska, *Wartość dodana Internetu na przykładzie internetowych grup wsparcia*, [in:] *Wielka sieć. E-seje z socjologii Internetu*, ed. J. Kurczewski, Trio, Warsaw 2006, pp. 270-273.

²⁷ M. Wysocka-Pleczyk, *Grupy wsparcia online jako nowa forma pomocy w zmaganiu się z chorobą*, "Hygeia Public Health" 2012, 47(4), p. 394.

²⁸ The described tendency was observed by the author while researching the participants of the discussion on the forum devoted to children with the Edwards Syndrome; A. Jarzębińska, *Wsparcie społeczne w interakcjach rodziców dzieci z Zespołem Edwardsa – użytkowników forum internetowego*, Wyd. US, Szczecin 2017, pp. 142-144.

They require support in virtually all its forms and from many sources at the same time.

First of all, parents need the support of specialists in the field of medical sciences: obstetricians dealing with the pregnancy and prenatal diagnostics, geneticists, paediatric surgeons, neonatologists. By providing parents with knowledge about various aspects of the disease, they support them in making decisions related to the child. They provide medical care for pregnant women and the child. After the birth, the family can receive help in the form of a home hospice, which provides support in various forms, even after the death of the child. Other families with a sick child complement the sources of support for parents with a child with a lethal defect. Such interactions allow for the exchange of information, guidance, provide appreciative and emotional support and – which is essential – build hope that, despite the fatal prognosis, some children with a lethal defect live and acquire further developmental skills.

Bibliography

- Dangel T., *Decyzje dotyczące dzieci z nieuleczalnymi chorobami prowadzącymi do przedwczesnej śmierci w perinatologii*, http://www.ptb.org.pl/pdf/dangel_neonatalna.pdf
- Dangel T., *Wady letalne u płodów i noworodków: opieka paliatywna jako alternatywa wobec eugenicznej aborcji, eugenicznego dzieciobójstwa i uporczywej terapii* (20.05.2017); <http://www.hospicjum.waw.pl/phocadownload/Etyka/WadyLetalneUPlodowINoworodkow.pdf>
- Fundacja Warszawskie Hospicjum dla Dzieci, *Hospicjum perinatalne*, Warsaw 2016, file:///C:/Users/aneta/Desktop/1037_hospicjum-perinatalne-materialy-informacyjne.pdf
- Grabowska M., *Wartość dodana Internetu na przykładzie internetowych grup wsparcia*, [in:] *Wielka sieć. E-seje z socjologii Internetu*, ed. J. Kurczewski, Trio, Warsaw 2006.
- Hospicja perinatalne- placówki poza systemem*, <http://info.wiara.pl/doc/3506371.Hospicja-perinatalne-placowki-pozasystemem>
- Jarzębińska A., *Hospicjum perinatalne – miejsce wsparcia dla rodziny z dzieckiem z wadą letalną*, „Problemy Opiekuńczo Wychowawcze” 2016, No 8.
- Jarzębińska A., *Wsparcie społeczne w interakcjach rodziców dzieci z Zespołem Edwardsa – użytkownikom forum internetowego*, Wyd. US, Szczecin, 2017.

- Kawula S., *Wsparcie społeczne- kluczowy wymiar pedagogiki społecznej. Głos w dyskusji*, „Problemy Opiekuńczo Wychowawcze” 1996, No 1.
- Kleszcz-Szczyrba R., *Witraże w ciemności czyli o przedwczesnej śmierci dziecka. Książka niosąca światło*, Księgarnia św. Jacka, Katowice 2015.
- Kopeć A. i in., *Hospitalizacja dziecka w Oddziale Intensywnej Terapii Noworodka – doświadczenia rodziców*, “Current Problems of Psychiatry” 2016, No 17(1).
- Kornas-Biela D., *Niepomyślna diagnoza prenatalna: dylemat rodziców, wyzwanie dla profesjonalistów*, http://www.mp.pl/etyka/poczatki_zycia/39622,niemomyslna-diagnoza-prenatalna-dylemat-rodzicow-wyzwanie-dla-profesjonalistow.
- Korzeniewska-Eksterowicz A. et al. (compilation), *Standardy prowadzenia pediatrycznej opieki paliatywnej Ogólnopolskiego Forum Pediatrycznej Opieki Paliatywnej*, <http://ofpop.pl/wp-content/themes/inove/img/standardy-ofpop-2016.pdf>.
- Krzyszowiak J., Śmigiel R., *Rola i zadania położnej jako członka zespołu sprawującego opiekę nad ciężarną pacjentką z rozpoznaną wadą letalną u płodu*, „Pielęgniarstwo i Zdrowie Publiczne” 2016, 6, 1.
- Kypros H., Nicolaides P., Węgrzyn P., *Badanie ultrasonograficzne między 11+0–13+6 tygodniem ciąży*, Fetal Medicine Foundation, London 2004.
- Libera A., *Psychologiczny aspekt poronień*, [in:] *Psychologia w położnictwie i ginekologii*, ed. M. Makara-Studzińska, G. Iwanowicz-Palus, Wyd. Lekarskie PZWL, Warszawa 2009.
- Łuczak-Wawrzyniak J., *Leczenie jest sztuką – na podstawie wybranych obszarów działalności szpitala ginekologiczno-położniczego*, „Ginekologia Polska” 2002, No 73(10).
- Makselon J., *Typologia i dynamika żatoby*, [in:] *Człowiek nieuleczalnie chory*, ed. B. Block, W. Otrębski, WNS KUL, Lublin 1997.
- Maksiewicz D., Dangel T., *II Ogólnopolska Konferencja Hospicjów Perinatalnych*, „Hospicjum” 2015, No 2 (72), file:///C:/Users/aneta/Downloads/informator-hospicjum-nr72-czerwiec-2015%20(1).pdf.
- Regulation of the Minister of Health of 9 November 2015 on the standards of medical procedure in the provision of health services in the field of obstetrics and gynaecology in the field of perinatal obstetrics and gynaecological care provided to a woman during pregnancy, childbirth, confinement, in cases of specific complications and care for a woman in the situation of obstetric failures (Journal of Laws, item 2007).
- Regulation of the Minister of Health of 6 November 2013 on the services granted in the scope of health programmes (Journal of Laws 2013, item 1505).
- Regulation of the Minister of Health of 20 September 2012 on the standards of medical procedure in the provision of health services in the field of perinatal care provided for women during physiological pregnancy, physiological childbirth, confinement and care of the new-born child (Journal of Laws 2016, item 1132).
- Skrzypczak J., Kornacki J., *Ciąża o przebiegu niepowikłanym*, [in:] *Położnictwo. Podręcznik dla położnych i pielęgniarek*, ed. G.H. Bębrowicz, PZWL, Warsaw 2005.

Szpital to nie jest dobre miejsce dla dzieci. Rozmowa z Tomaszem Dangelem, „Hospicjum” 2011, No 1(55), file:///C:/Users/aneta/Downloads/informator-hospicjum-nr55-marzec-2011.pdf.

Szymkiewicz-Dangel J., *Perinatalna opieka paliatywna- czy możliwa jest współpraca położników i neonatologów z hospicjami domowymi dla dzieci?*, „Opieka Paliatywna nad Dziećmi” 2007, Vol. 15.

Wysocka-Pleczyk M., *Grupy wsparcia online jako nowa forma pomocy w zmaganiu się z chorobą*, „Hygeia Public Health” 2012, 47(4).

Order No 66/2007/D SOZ of the President of the National Health Fund of 20 September 2007.