

Department of Medical and Oncology Nursing, Chair and Department of Oncology
Chair of Community Health Care
Medical University of Lublin

MAŁGORZATA E. KRASUSKA, LUDMIŁA GRZYBOWSKA,
ANDRZEJ STANISŁAWEK

The need of support and care fore the parents after the child's death

Hospitals are reluctant to admit patients with incurable diseases. Despite doctors' reluctance approximately 70% of the total of deaths occur in hospitals. Hospitals are primarily aimed at providing effective treatment and patients' convalescence, consequently incurably ill patients pose a problem. Such patients make doctors reveal their helplessness and limitations of their medical knowledge (5).

It seems that contemporary man, in particular, experiences deep fear of death. In Poland, Public Opinion Research Center surveys show that 80% of the respondents wish to die in their own homes, and only 18% in a hospital. Fear of and a negative attitude towards death have accompanied man for ages, and death is a natural phenomenon in human life resulting from the fact that every life has its beginning and its end (10).

According to a Polish sociologist – Antonina Ostrowska – the causes of abiding alterations in attitudes to death are related to general social processes. These include urbanization, which causes the separation of people from nature and hinders from the observation of the whole cycle of life. People, especially the inhabitants of large agglomerations, have fewer opportunities to participate in the life of primary communities. The shift in the attitudes to death is also affected by the tendency to establish small families. This results in the disappearance of multi-generation families with their "natural" system of support and care for the ill and dying (10).

For hundreds of years death and dying were important events in the life of the whole community that took part in it by means of special prayers and rites. Following social and demographic changes as well as the appearance of large agglomerations, people began to recede emotionally from one another, and social ties gradually weakened. People built cemeteries further and further from their settlements, thus trying to isolate themselves from the dead. Death became a private event, happening in the bosom of a family, only among close relatives. That was the beginning of a further series of changes, which found their ultimate shape in the last decades, and led to further isolation from death. Death and dying were reduced to an individual, personal dimension, and became an intimate process happening discreetly and not witnessed (8, 9).

Following the development of a consumer lifestyle there appeared cultural tanatophobia. This created its own defense mechanism, one very complex and different from those already existing. e.g. avoiding anything that could be associated with death. Dying became an embarrassing phenomenon that was even improper to talk about, and which should occur in a hospital, possibly behind the screen. Simultaneously, there was a clear disappearance of mourning rites and ceremonies as well as a tendency to conceal tragic facts from children and adolescents. Instead, there developed a fascination for and cult of youth as well as an antipathy towards the weak, the sick or the helpless (5, 10, 14).

The death of a child is a disaster for the whole family. In the culture in which youth is particularly valued, such an event is considered an absolute tragedy. Bereaved parents do not think it possible to return to their daily lives, and are beset by the obsessive question "why?". Their relatives and friends do not know what to say or how to help them. (1, 3). The ones who could hearten the parents prefer not to interfere. If it were possible to evaluate whose death causes the strongest reactions, an appropriate strategy could be developed to bring help to the ones who need it most. In her project, Catherine M. Sanders surveyed 120 bereaved people. In the majority of cases she maintained contact with them for two more years after the death. Out of all of the bereavements, the death of a child proved to be the most significant tragic experience (12). Initially, the aim of C. M. Sanders' work was to discover the cause of this extreme agony. Finally understood that the gist of the matter was that pain could not be deceived, it has to be experienced in its entire intensity with full consciousness (12). E. Kübler-Ross says that only those who have enough strength and love to stay up at the close distance with the dying person in silence, which is more meaningful than words, know that this moment is neither frightening nor painful, but a smooth cessation of life functions (5).

Experiencing the approaching death of a close person may occur both because of long-lasting disease with a poor prognosis, and as the result of some violent factors which, however, did not cause a sudden death (e.g. an accident which does not result in a sudden death, but the death happens after several days). The family then faces a twofold problem. On the one hand, they have to live with the consciousness of imminent separation, and on the other, they have to participate in suffering and dying (11). Enduring the consciousness of imminent, eternal separation is different when a close person dies after a long period of suffering versus when the death comes instantaneously and unexpectedly (4).

The family may have the consciousness of an approaching death long before it actually occurs. In European medical care, and also in Poland, there is a rule of informing the family about a patient's condition, or the poor prognosis, simultaneously concealing such information from the patient (14). It is extremely important that the family of a dying person should know about his/her disease as much as the patient him/herself (12). The consequence of informing the family about a patient's poor prognosis while simultaneously concealing such information from the patient him/herself is not only disclosing sad news to the family, but also burdening the family with the necessity of participation in the game of mendacity – to conceal the classified information of dying. In such a situation the relatives not only have to conceal the information of imminent death, but also suppress their own feelings and emotions evoked by the tragic news (1, 2).

The practical experience and research results show that accepting the classified consciousness of imminent death causes numerous problems in internal communication. It often leads to the loneliness of a patient and pangs of conscience of his relatives. Depending on the general condition of a patient the consciousness of his/her imminent death varies from denial to acceptance (5). A patient's better condition results in denial, long periods of suffering; however, they lead to accepting the inevitability of death (1, 5).

MATERIAL AND METHOD

The study was conducted on a group of 65 sets of parents whose children died in one of the hospital in Southeast part of Poland. A survey questionnaire was chosen to be the research instrument in this study. It was prepared according to the rules formulated by the scientific methodology, and contained both open-ended and close-ended questions.

RESULTS

The study showed that in the period of the child's disease, death and during the mourning, parents were affected by problems of biological nature. The child's disease caused throbbing of the heart in 40% of parents, and palpitation in 16.9% of parents. 46.1% of parents reported dyspnoea, 23% of parents complained of diarrhea, and 27.6% of the respondents had fluctuations in blood pressure. 41.5% of parents had difficulties with falling asleep, and lack of appetite was found in 52.3% of parents. 46.1% of respondents observed loss of body weight. Long-lasting tiredness was found in 49.2% of parents, 12.3% complained of muscular hypertonia. 1.5% parents had convulsive tics.

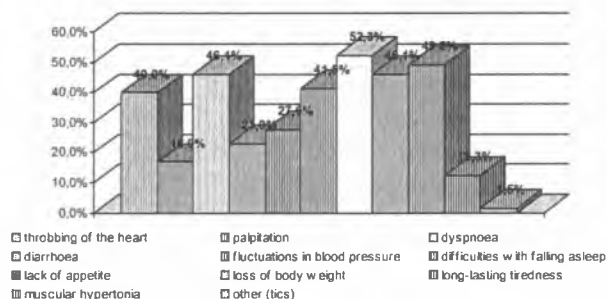


Fig. 1. The symptoms developed by parents during the child's disease

The child's death caused throbbing of the heart in 24.6% of parents, and 24.6% reported palpitation. 23% of parents complained of dyspnoea, diarrhea was found in 3.0% parents, 23% of respondents reported to have fluctuations in blood pressure after the child's death, 15.3% of parents had difficulties with falling asleep, and 15.3% complained of lack of appetite. Loss of body weight was observed in 7.6% of parents, and 9.2% complained of long-lasting tiredness and muscular hypertonia. 1.5% of parents were observed to have convulsive tics.

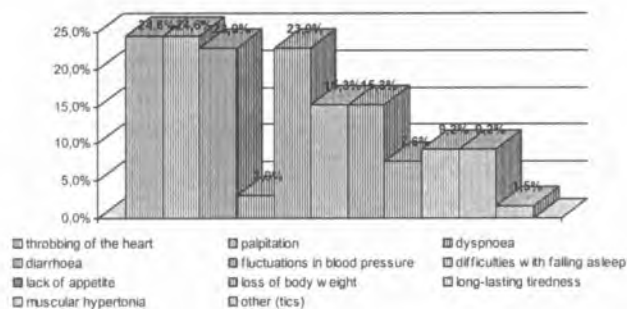


Fig. 2. Symptoms developed by parents during the child's death

The results of the survey concerning the situation after the child's death, expressed in per cent, are significantly lower than those obtained during the disease or death. The reason is that after the child's death (in the period of mourning) medical staff did not maintain such contact with parents as during the disease or dying. 13.8% of parents had throbbing of the heart, dyspnoea and long-lasting tiredness; 10.7% parents had palpitation. 3.0% suffered from diarrhea, and fluctuations in blood pressure were observed in 9.2%. 16.9% of had difficulties with falling asleep and lack of appetite. 15.3% of parents

observed loss of body weight. 6.1% of parents were observed to have muscular hypertonia, and 1.5%, had convulsive tics.

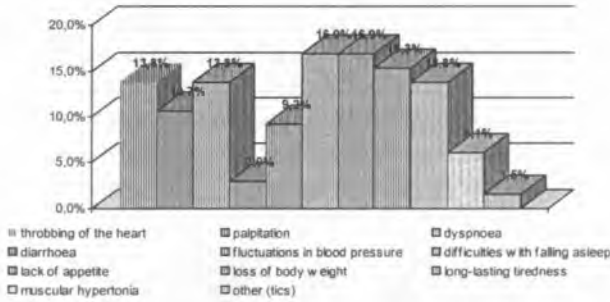


Fig. 3. Symptoms developed by parents after child's death

The question “What difficulties were encountered by parents in the period of the disease of their child?” was answered as follows: 60% parents had problems with communication with their spouses, and 18.4%, with communication between parents and the other children. 27.6% parents had communication problems with their in-laws. 53.8% parents experienced difficulties in communication with medical staff. Problems with concentration affected 41.5% parents, and 38.4% parents had difficulties with decision-making. Financial problems were faced by 1.5%.

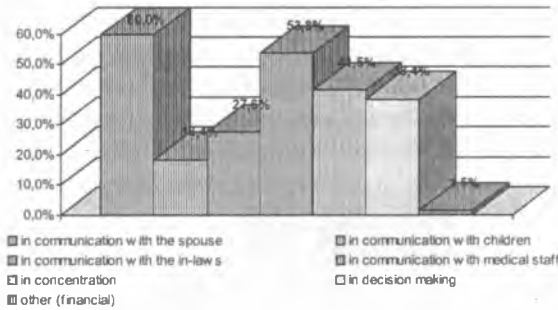


Fig. 4. Problems experienced by parents in period of child's disease

During the death 16.9% parents had difficulties with communication with their spouses, 7.6% – with children, and 15.3% parents with the in-laws. 30.7% parents encountered problems with communication with medical staff. Difficulties with concentration appeared in 26.1% parents. 23.0% parents had problems with decision-making.

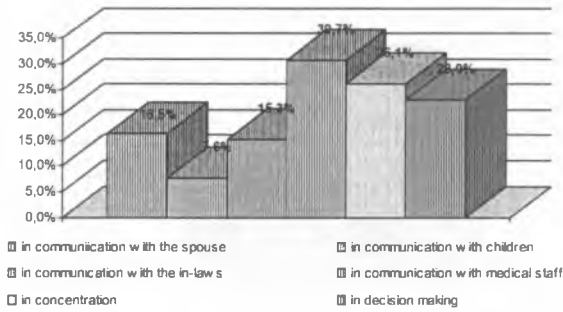


Fig. 5. Problems encountered by parents during child's death

The period after the child's death showed that difficulties in communication with the spouse occurred in 12.3% parents. 10.7% parents had problems with communication with other children, and 12.3% – with the in-laws. 21.5% parents experienced problems with communication with medical staff. 26.1% parents encountered difficulties with concentration, and 15.3% parents had decision-making problems. 1.5% faced financial problems.

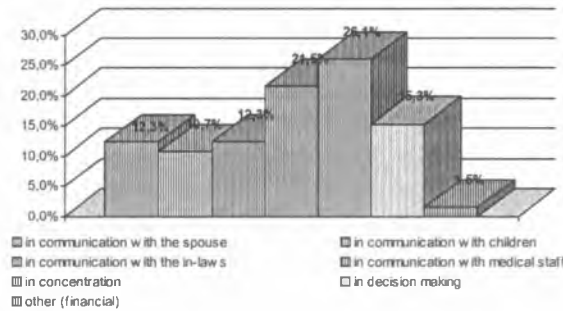


Fig. 6. Problems experienced by parents after child's death

32.3% parents stayed with their children in the hospital for the whole period of the disease. 30.7% parents visited their children very often, 23.0% often, 9.4% did that occasionally, and 4.6% very rarely.

The question about who should inform the child (appropriately to his/her age) about the approaching death was answered by the respondents as follows: 33.8% people thought that it should be done by the parents, 35.3% preferred the doctor, 23.0% people decided it should be the child's favorite person, 21.5% people chose a psychologist, and 7.6% a priest. 1.5% chose a nurse. 20% people said that a child should not be informed about approaching death. 1.5% did not answer that question.

Parents received emotional support from the following sources: conversation – 61.5% respondents, psychological literature on dealing with emotional crisis – 1.5%, presence of and conversation with medical staff during medical and nursing activities – 21.5%. 23.0% respondents chose the answer “other form” not specifying what form it was. 7.6% did not give any answer to that question.



Fig. 7. Forms of emotional support lent to families after child's death

66.1% people thought that family could provide emotional support and consolation in the period of mourning. 32.3% chose a psychologist. 21.5% respondents mentioned a priest, 4.6% a doctor. 15.3% expected emotional support from a friend, 7.6% sought consolation from other bereaved families. 1.5% said that emotional support could be lent by anybody willing to do that. 1.5% chose a nurse. 7.6% did not give any answers.

DISCUSSION

The disease and death of a child as well as the period of mourning substantially disturb all the aspects of human existence in physical, psychological, social, spiritual and emotional sense. Reactions of people burdened with the seal of death of their own child significantly vary from negative feelings associated with perception of the child's death, to the alteration of life values and priorities (1, 5, 15).

This study was an attempt to evaluate the effects that the disease and death of a child as well as the state of mourning exert on biological, emotional and spiritual aspects of human life. Since medical staff is directly involved in the process of treatment and medical care, an attempt was also made to assess the level of doctors' and nurses' knowledge necessary for the successful implementation of the program of support for bereaved families after the death of a child due to the cancer. Helping dying patients and their family members to cope is an integral part of professional nursing practice (7). The study was conducted on a group of 65 sets of parents whose children died during the hospitalization. A survey questionnaire was used as the research instrument in this study. The study revealed that the main problems of biological nature that affected parents in the period of their child's disease were throbbing of the heart, dyspnoea, lack of appetite, long-lasting tiredness. In the time of the child's death the following problems appeared: throbbing of the heart, palpitation, and dyspnoea. After the child's death the main problems are difficulties with falling asleep, lack of appetite and loss of body weight. Parents experience the following difficulties during the child's disease: problems in communication with the spouse and medical staff, significant difficulties in concentration and decision-making. The most severe period of the child's death brings problems in communication with medical staff. After the child's death the most serious difficulty that parents encounter is decline in concentration powers.

Evaluating the levels of nurses' and doctors' knowledge with respect to providing bereavement counseling for families after the child's death, it was concluded that the doctors' and nurses' knowledge in this area is very poor. This is confirmed by the fact that only 7.6% of the surveyed group would try to help a bereaved family, 63.0% say that they are not professionally prepared to provide such support,

and 12.3% say that this does not belong to their duties and responsibilities. The findings are consistent with those described by Merja Kuuppelomaki (2003), where the author conducted research in 32 Finish health centers, "A number of respondents reported that nurses did not always show an understanding attitudes towards family members; sometimes they were even fearful of family members. Other issues that were mentioned included conflicts between family members, difficulties in arranging enough time for patients and family members to spend together, and the patient's reluctance to inform the family of the situation" (7).

It could be concluded that the reason for this alarming situation lies in the present system of professional education of medical staff. Secondary education curriculum does not comprise subjects that would professionally prepare future nurses to realize bereavement support program. University education provides some training in this area, but its extent is insufficient to lend effective support in real-life situations (2, 4, 5). Another significant reason for the lack of bereavement support from doctors and nurses is cultural stereotypes and convictions that are still popular with Polish society. All subjects associated with death are considered difficult, and thus ought not to be asked about, or touched upon in conversation (1, 10).

A positive aspect in the situation is the fact that some of the respondents think that it is possible to provide emotional support and bring consolation to bereaved families in the period of mourning (1, 10). "Nurses reported deficiencies in their skills and competences with regard to the provision of emotional support to the patients. In this respect, the study raises the issue of training needs among nursing staff, which of course has been raised in many earlier studies. Training courses ought to be arranged by nursing managers in collaboration with training organizations. Several studies have highlighted positive effects of training on the attitudes, actions and preparedness of the nursing staff to help dying patients. Nurses can also improve their skills and competencies in this area by reading the literature: this study clearly demonstrated the association of frequent reading with the provision of emotional support" (7). *As defined and updated by the World Health Organization (2002), "Palliative care provides relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual"* (6, 15).

Palliative care interventions should be considered throughout patient's disease trajectory and not reserved for the imminently dying or performed within a time-defined framework, such as at the end-of-life (12, 18). Undertaking the realization of bereavement support program it must be remembered that its effectiveness entirely depends on medical staff's good relationship and contact with parents, understanding their problems and fears (1, 4). Winning their confidence by the staff is the key to the program's success. Are all nurses or doctors capable of undertaking such responsibilities? Definitely not. A nurse or a doctor undertaking to realize bereavement support program in relation to families after their child's death must not be an inappropriate person. Medical staff involved in the program should posses exceptional communication skills, both verbal and non-verbal, as well as the ability to make conversation on topics of personal feelings and emotions concerning death and mourning. In addition, it is essential that such people should be characterized by the following qualities: candour, warm-heartedness, ability to listen to and understand other people (2, 4, 5, 8, 9, 13).

Professional realization of bereavement counseling to families after a child's death will considerably improve the quality of medical services provided by nurses and doctors, thus contributing to creating a positive image of contemporary nursing and medical services in the eyes of Polish and foreign societies (1,10). The death of a child is a tragedy for the parents, so they need to be a subject for professional care, assistance and support of the medical staff who was caring for their loved one.

REFERENCES

1. Buczyński F.: Rodzina z dzieckiem chorym na białaczkę (Family of the child with leukemia). RW KUL, 7, Lublin 1996.
2. Burke C., Gerraughty S. M.: An oncology unit's initiation of a bereavement support program. *Oncology Nursing Forum*, 2, 1675, 1994.
3. Calabrese J. R. et al.: Alterations in immunocompetence during stress, bereavement, and depression: Focus on neuroendocrine regulation. *American Journal of Psychiatry*, 144, 1123, 1987.
4. Degner L., Gow C.: Preparing nurses for care of the dying. *Cancer Nursing*, 11, 160, 1988.
5. Kübler-Ross E.: *Rozmowy o śmierci i umieraniu (On death and dying)*. Media Rodzina, 7, Poznań 1996.
6. Kuebler K., Esper P.: *Palliative practices from a-z for the bedside clinician*. Oncology Nursing Society, Pittsburgh 2002.
7. Kuuppelomaki M.: Emotional Support for dying patients – the nurses' perspective. *European Journal of Oncology Nursing*, 7, (2), 120, 2003.
8. Lev E. L. et al.: Loss and Bereavement. In: McCorcle R. McCorcle, M. Grant, M. Frank-Stromborg, S. B. Baird (eds.): *Cancer Nursing: a Comprehensive Textbook*. W.B. Saunders Company, Philadelphia 1996.
9. Osterweis M., Solomon F., Green M.: *Bereavement reactions, consequences, and care*. National Academy Press, Washington 1984.
10. Ostrowska A.: *Śmierć w doświadczeniu jednostki i społeczeństwa (Death in the experience of self and the society)*. IFiS PAN, Warszawa 1997.
11. Rando T. A.: Living and learning the reality of a loved one's dying: Traumatic stress and cognitive process in anticipatory grief. In K.J. Doka., J. Davidson (eds), *Living with grief when illness is prolonged*. Hospice Foundation of America, Washington 1997.
12. Sanders C. M., *Powrót nadziei (Comeback of hope)*. Gdańskie Wydawnictwo Psychologiczne, Sopot 1996.
13. Sepulveda C. et al.: The World Health Organization's global perspective. *Journal of Pain and Symptom Management*, 24, 91, 2002.
14. Winch B.: Praca z rodziną w okresie żałoby. In: *Leczenie bólu i opieka paliatywna u dzieci (Working with the bereaved family. Treatment of pain and palliative care)* Warszawskie Hospicjum dla Dzieci, 1997.
15. World Health Organizations.: *National cancer control programs, policies and managerial guidelines*, Geneva, Switzerland, 2002.

SUMMARY

The purpose of the study was to find out what kind of support and psychosocial care was needed in the hospital for parents of the dying child. The group included 65 sets of parents whose children died in the Regional Hospital in East region of Poland. The study was conducted using survey questionnaire and retrospective analysis. The parents were asked to describe the most prevalent problems they faced in the periods of advanced disease, dying and at the very moment of death of their children. The study revealed that the main problems that affected parents in the time of the child's death were: throbbing of the heart, dyspnoea, lack of appetite, long-lasting tiredness, palpitation, difficulties with falling asleep and loss of body weight. Doctors and nurses are challenged and encouraged to become more knowledgeable and

sensitive to the issues surrounding the psycho-social, to provide emotional and spiritual support within the hospital care for parents of a dying child as well as to be a source of support and professional help in the period of dying and at the very moment of death. The study also demonstrated that most members of the medical staff are not well prepared in a professional way for caring for parents during the dying process, and only some would try to help a grief-stricken, bereaved family.

Potrzeba wsparcia i opieki nad rodzicami po stracie dziecka

Reakcje osób po śmierci własnego dziecka bywają dość różne, począwszy od negatywnych odczuć wskutek samej śmierci, po zmianę wartości i priorytetów życiowych. Niniejsza praca stanowi próbę oceny, jakie zmiany w sferze biologicznej, emocjonalnej, duchowej wywołuje u rodziców postępująca choroba, śmierć, a także żałoba. Badaniem objęto grupę 65 rodziców, u których hospitalizacja dziecka zakończyła się niepomyślnie. Przeprowadzone badania ujawniły, że do problemów najczęściej obecnych w czasie choroby dziecka należą: szybkie bicie serca, wrażenie duszności, brak apetytu, przewlekłe zmęczenie. W trakcie umierania i śmierci dziecka manifestują się: szybkie bicie serca, kołatanie serca i wrażenie duszności. Po śmierci dziecka najwięcej rodziców cierpi na trudności w zasypianiu, brak apetytu oraz spadek wagi ciała. Ponadto dochodzą problemy w komunikacji ze współmałżonkiem oraz personelem medycznym, wyraźnie zaznaczone są także trudności natury kognitywnej. Dużą trudność sprawia rodzicom również proces podejmowania decyzji. Należy przypuszczać, że istotną przyczynę trudności w komunikowaniu się rodziców z personelem medycznym stanowią kulturowe i obyczajowe stereotypy wokół śmierci, nadal silnie obecne w społeczeństwie polskim. Z rozmów z rodzicami można wnioskować także, że nie otrzymują oni efektywnego wsparcia w trakcie tych tragicznych przeżyć. Dlatego też wydaje się właściwe, aby proces profesjonalnego kształcenia pielęgniarek i lekarzy w większym zakresie uwzględniał w swoim programie nauczanie treści i umiejętności umożliwiających efektywną opiekę i wsparcie dla rodzin przeżywających śmierć dziecka. Pielęgniarka czy lekarz podejmujący się realizacji programu opieki wobec rodzin po śmierci dziecka powinni posiadać umiejętności komunikacji, zarówno werbalnej jak i pozawerbalnej, oraz zdolność podejmowania rozmów na tematy związane z odczuciami dotyczącymi śmierci i żałoby, starać się poznać rodziców oraz ich obawy oraz zdobyć ich zaufanie. Profesjonalna realizacja poradnictwa w zakresie opieki nad rodziną po śmierci dziecka powinna w znaczący sposób wpłynąć na jakość życia jej członków.