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## **Grandparents facing the illness and death of a child in hospice care**

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### **Introduction**

Being elderly has a number of connotations. Most frequently, it is perceived as a negative and difficult phenomenon, related to numerous risks. It would be hard to oppose such a vision of the elderly; however, at the same time, it is worth noting that there are positive approaches towards this period of human life, where being elderly is portrayed as an opportunity, a stage in human development, as a task [1-7]. The feeling of satisfaction and happiness is not reserved exclusively for young people; it is also possible to attain it at an elderly age. One of the positive events related to elderly age is being a grandfather or a grandmother. It is the source of many valuable stimuli that encourage the activity of the grandparents, provide valuable experience for the grandchildren and reinforce the family system.

Sometimes, such family system is subject to overload because of a disease. Terminal illness and the death of a child are the factors that may disrupt the functioning of the whole family, as well as of its particular members. The specific repercussions resulting from the occurrence of these factors might be observed also in the life of the grandparents. It seems that the effects of the illness and death of a grandchild have not been sufficiently researched and described. The experience of suffering due to an illness of a child is most frequently analysed within the context of the feelings of the parents, less frequently - of elder siblings; the suffering of grandparents is described only accidentally. Such a gap shall be filled in.

The aim of this paper is to focus the reader's attention to the suffering of the grandparents of a child in hospice care. Outlining the problem within the context of such care will allow for determining important features that hospice activity has. In order to improve the precision of the problem in question, it is necessary for us to briefly characterize the role played by the grandparents within the family, in particular their relationship with the grandchildren. Furthermore, it is necessary to indicate the basic areas of disruptions caused by the illness and death of a child and to relate them to the feelings of the eldest members of the

family. This will allow for providing a number of postulates regarding the ways of hospice care directed towards the grandparents.

### **Grandparents and grandchildren**

Although, in the light of available literature, it is difficult to provide a uniform timeframe for the stages of human development that would be acceptable for all authors, it can be assumed that the fact of becoming a grandfather or a grandmother mostly takes place after fifty years of age, when late adulthood and ageing commences [8]. In the period when most of the people experience the so-called mid-life crisis, forcing them to make a summary of the years that have passed, being a grandfather or a grandmother constitutes a factor that reinforces self-esteem [9]. For many elderly people, it is the source of happiness and motivation for being active, since the grandchildren "*are new life, new hope and happiness, are as if a reward for the difficulties of raising children. These difficulties now result in the appearance of a new generation, that seems to prolong the life of the grandparents for the next many years*" [6].

The social role of the grandparents is strictly related to the relationship that commences when, in a multi-generation family, children are born. The parents, as the first people who are the most significant to a newly born child, shape its personality, self-esteem and its type of relationships with the world [5]. The realisation of these tasks is supported and supplemented by the grandparents, and in some cases parents are substituted by the grandparents. This happens when the parents cannot or do not want to take up tasks normally expected from them.

The experience of the everyday life of Polish families shows that the grandparents are not always the foundations of coherence and effectiveness of families. Some of them are reluctant to participate in family life or make a decision as to partial or total separation from younger generations. It is also the case that the grandparents, by engaging in family life, exceed their competences, instigating conflicts related to the bringing up of the youngest generation or to the day-to-day functioning within the family [6].

It should be remembered, however, that the presence of the grandparents in the family can become an irreplaceable element of happy life and an optimal function in the nursing and educational process. Assuming that elderly people have "*the charisma of breaking cross-generation borders before they even appear*" [10], we might say that their creative presence might improve the quality of family life.

Cross-generation family relationship created between the grandparents and grandchildren is characterised by particularly strong emotional ties. "*The phenomenon of*

*grandchildren's ties with their grandparents is, to a large extent, shaped on the basis cognitive and emotional needs that complement each other"* [5]. Grandmothers become a source of love and understanding for their grandchildren, and grandfathers - a source of knowledge, wisdom and experience [9]. Nowadays, when the parents, more and more often, do not have enough time to talk with their children, grandparents can satisfy the children's curiosity about the world expressed by them in questions. For the correct development of a child, it is crucial that such curiosity be satisfied in a wise and responsible manner, therefore the significance of having such conversations is worth stressing.

The issue of the position of elderly people within Polish families is related to its axiological aspect. Elderly people being part of a multi-generation family can bring eternally true and objective values into the family, i.e. selfless interest in another person lack of excessive attachment to transitory things, devotion for others, spiritual and religious values. Such models are necessary for the young generation, and their realisation makes the grandparents unquestionable authorities for younger members of the family [4]. These beliefs are supported by research carried out in 2012 by the Public Opinion Research Centre, according to which grandparents are important people in the lives of the majority of Poles [11].

Almost three quarters of adult Poles (72%) feel that they owe something to their grandmother or their grandfather. In comparison with the research carried out in the years 2000 and 2007, now a vast majority of respondents declare that they feel gratitude towards their grandparents. At the same time, there are less respondents whose opinion is different and those who have never known their grandparents. It supports an opinion that was being expressed before, i.e. that in Poland the role of the grandparents is growing. This happens most probably because of their growing participation in bringing up their grandchildren. Nearly general is the conviction among young people aged under 35 that they owe gratitude towards their grandparents. Most frequently, such gratitude encompasses recognising the role played by the grandparents in education and nursing (65%) and in giving their love (64%). Slightly more than a half of the respondents owe their grandparents for a knowledge of the history of their family, teaching them moral principles and faith (54%). Less frequently, the respondents state that they owe to their grandparents such features of character as: sense of duty, diligence, self-discipline or strong will (48%).

In the light of analysed data, two things are worth stressing: an express reference to axiology in connection with the role played by the grandparents in families and their active participation in the educational and nursing function of the family. A key issue is the

engagement of the grandparents in the care over the grandchildren. 83% of the respondents have experienced such care, which allowed them to characterise their relationship with their grandparents as very close [11]. The above mentioned results may constitute one of the reasons why the grandparents may experience the feeling of satisfaction and happiness.

The wellbeing of elderly people may be disrupted by the factors that are inherent to elderly age. Among the most frequent crisis-causing situations we can list the following: the deterioration health and physical fitness, being a widow(er), loneliness, a lower social and economical status, a loss of the feeling of usefulness and prestige, a loss of physical attractiveness, the awareness of approaching death, the necessity of moving into a nursing home [12]. Each of them may cause distress in elderly people, which results in a decrease in the level of their wellbeing and leads to the state of depression.

Difficult life situations related to late adulthood and elderly age might include events that go beyond the private world of the elderly person. The engagement in family life results in the fact that any major disruption of its functioning becomes significant for the grandfather or the grandmother. Particular repercussions in the family are caused by an illness of the grandchild, in particular when the illness becomes terminal and leads to death. Those events influence, in a significant way, the performance of the social role of the grandparents within the family, and at the same time change their life. In order to demonstrate the influence of the illness and the death of a child on the grandparents, it is reasonable to show the context of the appearance of an illness in the family.

### **Family facing illness and death of a child**

Illness and death are among the most difficult experiences ever faced by a human being. They are often incomprehensible, in particular, the event of the death of a child that was born in order to live: *„Although the death of the elderly, disabled, or infirm in our society is often considered a «blessing», the death of children or adolescents is seen as the ultimate tragedy”* [13].

An illness is primarily a personal drama of the patient, experienced to a varying degree, depending on e.g. his or her age, which usually determines the level of consciousness. The suffering related to death goes beyond physical pain: *"A terminally ill person, in particular when nearing death, does not only suffer physically, but he or she also experiences spiritual, existential suffering. There is a growing feeling of loneliness in them (...), a feeling so strong that even those believing in God feel that God has abandoned them in such a moment"* [14].

The model of total pain [15] indicates that the effects of the illness affect not only the patient but also his or her relatives. These can be observed in somatic, psychological, spiritual and social spheres. The model of total pain is related to the systemic approach towards suffering and highlights the very significant influence of a disease on the whole family. This is represented, i.e. in the modification of the conditions of the function of the whole family and the necessity of implementing adaptive action. The disruptions that appear in the family system as a result of the child's illness, consist i.e. in not being able to satisfy the needs related to functioning in extreme conditions: *"The child's illness, in particular cancer, is an event that disrupts the daily rhythm of family's life and produces strong psychological shock. It changes the previously established lifestyle which becomes subject to restoring the child's health"* [16].

Among the needs there is a particularly strong necessity of medical support, getting a professional diagnosis, providing the child with adequate care, getting information as to the child's state of health, and their risk of death, which facilitates proper preparation for such death [17]. An important need of the relatives is the possibility of being close to the sick child and helping him or her, realising his or her wishes and caring for such a child. Family members expect support, especially during the moments of increased intensity of the illness and related emotional difficulties. Particularly difficult is the period of child's dying and the period of mourning.

The support provided to the caretakers is reflected in the emotional state of the child and facilitates his or her treatment [18]. Satisfying this kind of needs may become an occasion to eliminate improper behaviour of some members of the family that might appear in relation to the sick patient, making his existence even harder. An important need experienced by many families with a sick child, is social support. Such support is very often a necessary condition for an appropriate care for the child, which, in Polish circumstances, has been laid upon the family and social institutions that support it. Many people caring for a sick child also experience a shortage of spiritual and religious space, which becomes particularly important in the perspective of the child's death. Seeing the necessity to refer to spirituality becomes a more and more widespread conviction of the researchers dealing with the problem of thanatology [19].

### **Grandparents facing the suffering and death of their grandchildren**

A specific group living through the suffering and death of a child are its grandparents. This takes place when said grandparents take an active part in the life of the family of a sick child and are affected by total suffering. Blocking or limiting the possibility of contacting the sick child is a great burden for the grandparents. The awareness that the child is suffering

results in the fact that the happiness of being a grandparent is transformed into a constant state of worrying and sadness.

It happens, however, that at the moment when the illness commences, the grandparents or one of them withdraws from their engagement in the process of caring for the grandchild. This indifference does not necessarily stem from egoism; sometimes it is a way of hiding the feelings of anxiety and pain. An incorrect diagnosis of the grandchild's illness is usually taken by the grandparents with a very strong emotional reaction: *„They often mirror the emotions expressed by the parents such as disbelief and anger, but also often an overwhelming sense of the injustice of the situation”* [20]. Being overwhelmed by the child's illness and the feeling of injustice becomes a very difficult experience for its grandparents. Such situation raises questions about the reasons of the lack of logic in human existence, as exemplified by the death of a young child who should not die when its grandparents, advanced in age, are still alive.

Grandparents' way of reacting to the diagnosis and treatment of the child depends i.e. on the knowledge about the illness, its effects and the principles of palliative care. Often, such knowledge is fragmentary and ignores the current achievements in medicine [20]; therefore the anxiety of the grandparents is even greater. The wellbeing of the grandparents depends, to a large extent, on the level of communication within the family. The decisions regarding the decision-making and taking action are not the competence of the grandparents, but they are the competence of the sick child's parents. The conversations between grandparents and parents about what is happening and about what they feel might be more difficult due to the differences in the emotions experienced, the level of knowledge, and hope [21].

The grandparents *„are not always well-aware of the situation, since an adult child wants to protect them on one hand, and on the other hand does not have enough strength to talk about what is happening. The result is that the grandparents are the last to learn about a chronic disease of their grandchild and feel disregarded. This may lead to the appearance or escalation of tension (...) They are petrified, often ill themselves. They have not imagined their elderly age that way”* [22]. Relieving intra-familial tension, if done in the atmosphere of nervousness and exhaustion, may significantly diminish the potential of the strength inherent in the family, and by that, weaken its regeneration abilities. Such behaviour is a defensive mechanism for each of the parties, since the parents often subconsciously want to protect themselves, they fear that if they inform the grandparents of the condition of the grandchild, then, apart from having to cope with their own feelings they would have to support the grandparents and help them cope with the situation [23].



Because of that, the grandparents become convinced that they should not express their feelings and opinions too often and too openly, since that would have an adverse effect on the parents of a sick child and on the atmosphere at home. However, not satisfying the need of expressing such feelings and opinions might become a source of additional suffering. The grandparents might be treated as invisible members of the family whose needs in comparison with the child's suffering seem to be insignificant. Such a form of marginalization, although accepted by the grandparents, is the source of additional suffering.

A particularly difficult experience for the grandparents is the agony and death of the child: „*The death of a child is one of the, if not the, most devastating losses that a family can suffer. Everyone is affected – parents, surviving siblings, future siblings, grandparents (...)*” [24]. The life experience of an elderly person includes the experience of the death of close relatives. However, the death of a grandchild is usually a new and extremely traumatic event. It has to be remembered that the mourning of the grandparents has a double dimension: it is caused by the death of the child and by the awareness of the suffering experienced by their adult child [25-26]. With the death of a grandchild, especially if it was the only grandchild, there is a break of a bond that to a large extent determines the identity of an elderly person in the family. There is a widespread conviction of the grandparents that nothing can restore happiness in their life.

The pain of mourning after the loss of a grandchild may be so difficult that the grandparents might feel unable to help the family in living through it. They might feel guilty that they are alive while the grandchild had to die: “*Most grandparents feel a terrible guilt that they will still be alive when their grandchild will be dead. This seems to be totally against the natural order of things and grandparents may feel especially powerless because of this*” [27]. The anxiety felt by the grandparents might be escalated by the feeling of guilt for the fact that the illness was inherited by the child, or for infecting the child, by e.g. using the same cosmetics [28].

Being confronted with the death of a child determines the level of preparation for the grandparent's own death. The approaching perspective of the end of life brings hope for the reencounter with the grandchild. The grandparents who identify themselves with faith and religiousness, during the period of illness and mourning often pray for the child and for its family. The religiosity of an adult person and of an elderly person facilitates providing such type of support. Finding partial relief of their pain in such support, they reinforce their conviction that their prayer is a way of demonstrating love for a deceased child. Mature

religiosity, although not eliminating the pain, helps to face the problem of suffering and death in a positive and creative way [29].

It could seem that abundant life experience and usually an independent place of residence can lower the intensity of mourning. Life demonstrates that things are different, in particular if the grandparents are widows or widowers, since that fact magnifies the suffering experienced. Then, their sadness, brought about by the memories left after the grandchild and the spouse is really enormous.

It is worth highlighting that the illness, despite having a destructive influence on the family system, might become a stimulus for positive changes in its structure, in which the grandparents may play an active part. Their attitude might contribute to the strengthening of familiar bonds and relieve exhausted parents. The grandparents may become an indispensable help for the parents and siblings of a sick child. They can prove to be the best form of relieving care that facilitates the functioning of the family in total suffering. They can also become a safety buffer for the siblings of a sick child who can direct part of their questions and hardly acceptable emotions to their grandparents, especially during the period of mourning [29].

Within a family with a sick child we might observe new subsystems, in which the previously existing relationships acquire a new meaning, e.g. the relationship between the healthy children and their grandmother [30]. The grandparents may, in the new circumstances, take up the tasks of educators, whose advice and support may raise hope and feeling of confidence within the family and the closest relatives. In order for things to be that way, there is a need of support that will allow the grandparents to fulfil the social role designated for them in an optimal way.

### **Hospice-provided support for grandparents**

Child hospice, as an institution of social support, provides help for the sick child and its family, abiding by fixed standards. The model of realising palliative and hospice care might be described by means of a principle: „*Caring for the whole person, and their family, with a multidisciplinary team*” [31]. Hospice care assumes providing support both for the sick child and for its family, understood as a system of mutual interactions. The holistic character of the help is observed, e.g. in the all-encompassing approach towards the patient and his or her relatives, which allows for adapting the action taken to their real needs. This is all made possible by virtue of an inter-disciplinary team, composed both of medical and non-medical workers. Directing the actions of the team towards each of the members of the family system includes also the grandparents of a terminally ill child. On the basis of the analyses that have



been carried out, one might give a number of suggestions, facilitating the help towards the elderly.

An important form of support is the adequate amount of information regarding the illness and the treatment, provided by the doctor. The way of informing should meet the requirements of interpersonal communication [32] and be adjusted to the perceptive abilities of elderly people. By that, one can avoid the misunderstandings related to the lack of information or to the disruption of the manner of providing such information.

The postulate of improving communication applies also to intra-familiar relationships, upon which the family system is based. The importance of communication is even greater if there is some tension related to the illness of the child and appears in the period of particularly severe attacks of the illness. An open way of communication between family members constitutes a foundation of resolving any problems that might appear [27]. An important thing is to encourage family members to express their emotions and ask any questions that might appear in connection with the illness [20]. It is necessary to create opportunities in which the grandparents will feel safe and will be certain that their sharing of emotions will not increase the pain of the family. This can be achieved by organising family meetings and enabling family members to express their emotions and helping them to develop forms of communication that shall be binding for the duration of the illness and after the death of a child.

An important thing is to keep the balance between an excessive overload of the grandparents or separating them and preventing them from participating in the care over the child. The possibility of engaging the grandparents in family life is perceived by such grandparents as a proof of trust, especially if they can, to a certain extent, participate in the care of the sick child. On the other hand, excessive overload might lead to the appearance of burnout syndrome [33]. The help provided by hospice staff shall balance the level of engagement, in which a conversation with the child's parents and grandparents might help. Taking up such form of support cannot disturb the autonomy of the family, which is why staff members are expected to act with particular delicacy and professionalism in arranging and leading such a conversation.

An important form of support given by the child's grandparents is their spiritual and religious help. It can contribute, to a large extent, to e.g. eliminate unjustified feeling of guilt. It might also provide relief stemming from faith in eternal life and give a spiritual meaning to the suffering that is being experienced. The support of family members, in particular of the child's grandparents - believers, shall also be something that encourages prayer for the whole

family. Spiritual and religious help provided to a dying child and his or her family is one of the most difficult tasks of support teams. Coping with such tasks requires huge subtlety, a deep knowledge of the issue in question, a methodology of helping and cooperation between team members.

The help becomes of utmost importance during the period of dying and mourning. The support given to grandparents during the period of mourning, i.e. a complex of psychological, physical and social experiences, is supposed to be in reference to their grief, sorrow, feeling of emptiness and guilt, and wondering about the meaning of life [30]. Professional support should include help in terminating personal ties with the deceased, help in learning to live without him or her, help in expressing difficult feelings. The spiritual dimension of support may help in reformulating the meaning and objectives of life. Of great help may be the religious support of gaining a new perspective of eternal life, by which the grandparents' confrontation with the death of their grandchild and with the perspective of own death receives a deep meaning.

### **Conclusion**

The presence of grandparents in the process of education carried out in a modern Polish family meets more and more frequently with the approval of the society. Although the grandparents do not always take up nursing and education tasks within their family, if their activity in the family is sufficient, the benefits are shared by all family members. This also happens when the illness and death of a child disrupts family life.

The results of the analyses have demonstrated that the grandparents participate in the suffering of the child to an extent depending on their engagement with family life. The particular character of such participation is seen, i.e. in the feeling of helplessness as to the unfavourable family situation, in the confrontation with their own death and with the feeling of being rejected and not understood. Their suffering is intensified by the awareness of the suffering of their own children. The grandparents of a sick child are deprived of the possibility to fully realise their own nursing and educational tasks, and sometimes they even lose the contact with the child altogether. The death of the child adds to their difficult experience. The range of the different experiences of the grandparents of a terminally ill child is vast and its full description trespasses the scope of this paper. It constitutes the starting point for empirical research, expanding and verifying the understanding of the issue presented above.

The grandparents, in order to be able to function correctly, ought to be provided with the support that is able to satisfy their needs. By virtue of such support, the system of the

family with a sick child is reinforced. Among the actions taken by the support team, there ought to be actions providing support for the eldest members of the family with respect to their emotional, spiritual and religious, social or informative state. An important postulate is improving intra-familial communication. It seems that an adequate realisation of hospice support may effectively strengthen the grandparents and allow them to fulfil their roles, despite the factors that disrupt the functioning of the family system. It may affect the improvement of the quality of life of the sick child, its family, and cause the grandparents to experience their elderly years with more ease.

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