Przegląd Badań Edukacyjnych
Educational Studies Review

ISSN 1895-4308
nr 29 (2/2019), s. 91–110

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Expectations and Self-Care of Family Members in Palliative Care*. The Analysis of Needs and Workshop Plan

http://dx.doi.org/10.12775/PBE.2019.018

Abstract

The practice has shown that it is the most emotional and difficult situation when family members care for their beloved ones, who suffer from cancer, all the time and without rest. During care of their ill family members they have not only different emotional reactions, but they have special needs in the field of care and support as well. The purpose of this study was to analyze and describe family members' needs and expectations during the process of care, and according to the analysis, to create a training course for family members who look after relatives with cancer. The study involved both qualitative descriptive methods based on face-to-face interview focused on self-care, needs, problems and support to family members as well as expectations addressed at hospice staff. Ten family members of patients who were under palliative care (hospitalized in palliative care in-patient department) were asked to give interviews in the field of their expectations, needs and difficulties as caregivers while caring about their beloved ones with cancer. The results have shown, that among caregivers, 90%

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* This research project was prepared and started during European Palliative Care Course (X.2015-III.2017) and it was finished in December 2017.

reported the need for self-care in the field: being listened to, information, ability to deal with stress, communications skills. Only one person did not think about her/himself while looking after their beloved ones suffering from cancer. All of the 90% family members needed: information about the clinical situation of their beloved ones with cancer, conversations about their experience while caring, and information on what they can do better for their relatives. Overall, caregivers preferred to receive knowledge and information about diet, physical and emotional self-care, communication with relatives about their illness, dying and death. According to that, the curriculum of workshops for family members was created including the course of communication, basic information about the illness and opportunities of care in terms of both physical and emotional health, interpersonal relations, and increasing the feeling of security as well. Conclusion of this study is that caregivers have their own needs and expectations while caring for their family members with cancer. The formal education for the family in the form of workshop may help them in both: caring for the patient and for themselves.

Key words: caregivers, chronic disease, needs, expectations, self-care, curriculum of workshops.

Introduction

It is hardly debatable that a chronic illness is a source of anxiety and fear. It appears that an oncological or long-term disease – requiring focusing attention on a patient for a long time – gives rise to a variety of feelings and emotions more than any other situation. Such a disease as cancer has a direct and tangible impact on the lives of particular members of the family in which the patient is functioning. The life of a family and its members when one of them is suffering from a chronic illness changes completely and taking care of a chronic patient is a difficult and demanding task connected with both physical nursing and psychological support of a patient (Kowalczyk, 2010; Kowalczyk, 2012). "Depending on the overall condition of a patient and their individual life situation, the emotions of their closest relatives range from denial to acceptance" (Ogryzko-Wiewiórkowska, 2002). It happens that they become helpless when confronted with a chronic illness not least because of the reorganization of their lives and roles they used to perform (Walden-Gałuszko, 1992, 2004; Wałęcka-Matyja, 2005). Disease necessitates learning completely new and previously unknown activities that earlier used to be carried out by the patients. This ability – combining care of the patients and self-care – is rarely exhibited by family carers (Koźmińska-Kiniorska, 2005; Łuczak, 2003). The public perception and stereotypes concerning taking care of a close relative seem to stigmatize the people who manage to find time for themselves while looking after their patients. Therefore, that lack of acceptance for self-care activities makes carers feel shame and fear, as well as a number of other negative emotions the moment they start thinking about themselves. Social issues connected with financial support, struggling with bureaucratic regulations and unavailability of professional medical staff become an additional source of suffering (Kowalczyk, 2012; Łuczak, 2003; Walden-Gałuszko, 2000, 2004). Problems concern painful memories and unrealised plans that must be postponed or abandoned entirely. Fears connected with unknown future as well as anxieties concerning the sense of separation arise. The whole range of emotions is supplemented with the overwhelming fear of a potential progress of the disease or death and of what life will be like "later on" (Kowalczyk, 2010; Trylińska – Tekielska, 2009; Heszen-Niejodek, 2000).

The care for chronic patients constitutes one of the toughest trials to which human life can expose us. Apart from positive emotions: greater intimacy, better understanding, greater concern and desire to be together, empathy and company – emotions, which cause anxiety and remorse, can appear among other members of the family who look after chronic patients (Fopka-Kowalczyk, 2016; Kowalczyk, 2012). Convictions of impropriety of such emotions give rise to dissonance, disharmony and even greater anxiety in carers as well as lack of motivation to take better care of their own physical and emotional health. "The healthy who have been looking after their relatives feel a variety of emotions, both those widely accepted as positive, and those deeply concealed. (…) They are inclined to castigate themselves for unjustified crying, annoyance, because they expect from themselves constant cheerfulness, composure and calmness. They do not accept their own needs and repress the thoughts concerning the possibility of their own fulfilment. Consequently, this situation of self-exclusion results in exhaustion, nervousness, anger, and lack of communication. Such reactions are clear signals that the carer is considerably overburdened. Diverse emotions can legitimately appear, but it is important to express them and not hesitate to ask for help" (Rogiewicz, Paczkowska, 2010).

Academic literature indicates multiple factors that can contribute to such difficult relations. One of the main reasons is connected with long-term nursing and the necessity of resigning from your own life for the sake of better well-being of a sick family member. It is directly linked with self-imposed restrictions of family members concerning meeting their own needs; for example, resignation from further education, travels or other life goals. The long-term consequence of continual resignation from one's own life plans can take the form of concealed dissatisfaction, anger or tension (Walden-Gałuszko, 2004;

Wałęcka-Matyja, 2005). Emotions are concealed and not revealed as “it is improper”, “one should not” behave like that in the presence of a terminally ill relative, and when they are accumulated, they lead to frustration and outbursts of anger. “It happens that carers who are exhausted and discouraged “break down” and lose their temper or experience inner negative emotions towards the patients – and then feeling guilty, they try to make amends to the patients by means of overprotection.” (Walden-Gałuszko, 2000). The inability to take care of one’s own life and continual disregard of one’s own needs can in turn lead to different bodily reactions in the form of chronic tiredness, somatic pain, recurrent colds, or other more serious ailments.

Another factor that is worth mentioning is the sense of being abandoned by other members of the family obliged to keep the patients company as well as lack of permanent assistance from the extended family, friends and others. It must be admitted that family members frequently offer to help to nurse the sufferer. However, it is equally true that illness verifies all acquaintances. There are situations in which a carer is all alone with the patient whose condition or disability is deteriorating and requires more and more attention and care. Loneliness of family members frequently results in increasing exhaustion due to the impossibility of proper rest (Kowalczyk, 2012). Łuczak (2000) draws attention to the occurrence of a certain discrepancy between nursing the sick and self-care. It is often noted that carers have a tendency to neglect themselves: their own needs, health and so forth. When asked about their health, carers answer: “it does not matter, I have no time to think about myself, if only he/she could be helped” (Walden-Gałuszko, 2000).

Due to these reasons, the patient’s family is frequently referred to as “second-line patients,” being at high risk of being overburdened while nursing a sick family member. “In this group more than elsewhere, we observe neurosis and adjustment disorders as well as intense anxiety disorders, mood swings, prolonged breakdown spells, and feeling of depression and hopelessness” (Walden-Gałuszko, 2000). When carers think about themselves, it gives rise to anxiety, whereas exhaustion caused by constant care leads to the feeling of guilt and enhanced irritability. At the same time, any attempt to convince the carer to take better care of himself or herself seems futile and is pushed into the background, to the indefinite “later.” “Taking a breath of fresh air” or “recharging batteries” adds strength and vitality, only to make the carer devote more time and attention to “his or her” sufferer (Kowalczyk, 2012).

Self-care

The aforementioned skills concern self-care. Referring to the analysis by Stanisław Kowalik, these skills can be defined in two ways:

- Concern about others – this behaviour is then defined as caring about others with whom we interact;
- Concern about oneself – can be aimed at the carer himself or herself, and then it is called self-care (Kowalik, 2005).

Similar analyses differentiating between concern about others and self-care are introduced by Anna Ratajska. In her analyses she defines the notion of self-care as "the ability to care about oneself and being capable of creating and consciously controlling events that happen around. It occurs when a person feels responsible for themselves and takes preventive measures in order to improve the quality of his or her life" (Ratajska, 2008).

The phenomenon of self-care describes the acquired ability of concern about oneself as a sense of awareness of and responsibility for one's health and life. We can talk about self-care particularly when it is realised in three different dimensions:

1. Self-care about one's health;
2. Self-care about relations with others;
3. Self-care about one's own safety (Ratajska, 2008).

Self-care about one's health means trying to maintain or improve one's physical or mental condition (Ratajska, 2008). This, in turn, means taking such action that allows for keeping psychosomatic balance and creating somatic comfort by eliminating physical pain or burdensome medical condition. Self-care in this dimension concerns learning how to improve your general well-being by applying a proper diet, physiotherapy or taking medicine prescribed by doctors. The carer, realising that his or her behaviour and attitude to health can be crucial in the process of well-being, undertakes such efforts that improve the quality of his or her somatic functioning. Acutely aware of their own possibilities, the carer knows that lack of self-care can result in losing desired physical fitness and health.

Self-care about relations with others means, above all, getting on well with other people. Such self-care, shaped as a result of support and education, consists in improving the ability to establish good relations with other people. Self-care in this dimension means also the awareness of who the most important person is, the source of direct assistance and support. It also means forming such behaviours that allow to forge intimate bonds with another person, and what is inextricably connected with it, to develop the ability to have a constructive conversation in every experienced situation.

The dimension described above seems to have particular significance in the case of a chronic illness and informal carers. The ability to conduct a conversation, express one's own needs, but also to show emphatic understanding is indispensable in social relations. It allows for deepening the relationship, increasing mutual trust between partners and building positive relations. This ability seems necessary in the case of an illness when good and sincere communication facilitates acceptance and coping with hardship that emerges due to the illness. Simple conversations about mutual needs and anxieties disperse fears and can offer the desired emotional support. Self-care about interpersonal relations means also caring about relations with other members of the social circle: family and friends. It can be directly connected with different functions performed within the family, daily obligations, and respect shown to one another. An equally important consequence of good communication and positive interpersonal relations is the fact that they appear to reduce the levels of anxiety and stress that inevitably emerge in such difficult situations. The communication of one's own expectations and needs, as well as constructive feedback, offer a chance for more peaceful coexistence with other members of the group and taking better care of oneself (Kowalczyk, 2011).

Self-care about one's safety involves all the activities aiming at meeting one's social needs, the sense of prosperity and adequate life standard. It sometimes happens that a person experiencing a difficult situation cannot rely on support of close family, and at times must become a source of support for others. It is particularly evident in the case of a chronic illness, where communication or expressing one's own emotions becomes more difficult. In such situations it is vital that the person concerned should be able to meet his or her own needs. In practice, it means meeting all the needs that allow for maintaining emotional balance, ensuring peace and quiet or protecting the person from fears and sense of insecurity. The ability to recognise, identify and express needs and the knowledge how to meet them certainly reduces anxiety and does not disturb psychological comfort. Self-care about one's safety also means taking proper care of material prosperity: continuing professional career, accumulating savings and considerate spending (Ratajska, 2008; Kustra, Kowalczyk, 2011).

Material and methods

Study design and participants

The research was approved by Bioethical Commitment number KB 519/2016.

The study referred to the research into the level of self-care, needs, difficulties and expectations among informal carers looking after chronically ill relatives at the final stage of their lives. It involved the assessment of informal carers' level of awareness of the responsibility for their life and health. The focus of the research was on the analysis of informal carers' situation in the context of their care for advanced cancer patients with the aim to create the training which would address the carers needs. For the purpose of this study, the authors invited 10 caregivers who looked after their beloved ones with cancer, hospitalized in a stationary hospice. The study group consisted of women caring for chronically ill family members. The caregivers were aged between 30 and 65 years. The study asked respondents about the duration of care and the answers varied to a large extent from under 5 years (5 respondents) to 2 years (3 respondents), half a year (one respondent) and over 5 years (one respondent).

The main research objective was to analyse the informal carers' behaviour in the context of self-care while they were taking care of a chronically ill close relative. In this case the respondents had to meet a criterion of having taken care of a close relative for a considerable period of time. In the case of qualitative research, the strategies of sample selection are determined by specific objectives concerning empirical units, which should be included in the research (Flick 2011). In the process of selection of the study group, it had been decided to adopt a strategy of sample selection by choosing a criterion easily met by all the case studies (Miles, Huberman 2000). In the planned research a theoretical sample selection had been adopted (Miles, Huberman 2000). The main criterion of theoretical sample selection was performing the function of an informal carer of a chronically ill patient, whereas the specific criterion involved participation in workshops.

According to literature, the idea of an in-depth interview has its origin in the assumptions of hermeneutics which state that "understanding human activity or life, is possible owing to processes of interpretation carried out from the position of analysing the individual's own actions or lives" (Pilch, Bauman, 2001). An interview is defined as a conversation which "has as its basis a predetermined pattern of thematic plots, but where the questions themselves are not standardised, where the interviewer decides on the order and method of asking questions, and where additional questions can be asked" (http://pl.scribd.com/

doc/19155299/Rozdzia-II). The questions focus on the problem, therefore, concern a specific subject matter, though this problem can offer enough flexibility to introduce alterations during the conversation. The main category[1], which was determined in view of the subject matter and research objectives, concerned the reactions experienced by carers after the death of their patient, their needs, difficulties and expectations as well.

Data collection

In qualitative research, the technique of focused interview was applied, which allows the interviewer to conduct an open and free conversation with a carer about their experiences while nursing, needs and expectations. According to Krzysztof Konecki (2000), it could be possible to prepare an explanation of findings.

1. The first step in analysing the results obtained in the interviews was to isolate the part of the theoretical framework emerging from the general concepts, considerations and definitions of self-care existing in the source literature. The preliminary conceptual framework was based on a previous analysis of the literature on carers of chronically ill people, but also their needs, expectations and experienced difficulties during care.
2. Then, the survey areas need to be determined. In the present study the area of interest was the way of functioning of caregivers of chronically ill patients:
    - 2.1. The level of emotional, social, physical and spiritual difficulties
    - 2.2. The reported needs of carers and their expectations from hospice staff and other people while caring for their beloved ones.
    - 2.3. The degree of self-care of caregivers, i.e.:
        - 2.3.1. the ability to take care of themselves and their health
        - 2.3.2. the field of communication with the beloved ones and others
        - 2.3.3. their sense of security.
3. Based on selected research areas, a set of codes adequate to the presented areas was prepared by authors of this article. These codes are presented in the following table:

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[1] The term ”main category” was used by K. Rubacha to describe the issue which is the subject of interest of a researcher using the qualitative strategy. See also: *Metodologia badań nad edukacją,* Warszawa 2008.

Table 1. Codes according to research areas

Research area	Code
Level of difficulties:	
– emotional,	**ED**
– social	**ScD**
– physical	**PD**
– spiritual	**SpD**
Needs of carers:	
– Information	**N-I**
– The possibility to confess problems or pain	**N-PC**
– Rest	**N-R**
– Leisure time	**N-T**
– Stress management skills	**N-SM**
Expectations of caregivers:	
– Proper care for the patient	**E-Pc**
– Teaching to care of a sick person	**E-T**
– Being listened to during difficulties	**E-H**
– Relaxation techniques	**E-RT**

Sources: Authors' research.

4. The obtained data was subjected to qualitative analysis by M.B. Miles and A.M. Huberman (2000). According to the authors, the analysis consists of three concurrent actions: data representation, output, and verification of applications. It should be said that the data reduction is steadily progressing. It refers to the process of selection, concentration, simplification, extraction and transformation of data, either in the form of written field notes or transcription. Miles and Huberman treat data reduction as a part of the analysis, because all decisions of the researchers (e.g. which data should be coded) force us to keep in mind the previously set goals and research questions while maintaining an open mind.

A code is a designator or label used to assign the meaning of a unit to descriptive or inductive analysis during the study. The coding process consists in reviewing it and then selecting those that are connected with each other. Some data will be repeated; then the researchers will name them and mark them with a code. It was assumed, following the authors, that the researchers should prepare a temporary starting list of codes even before the start of the research. This is the result, among other things, of the adopted conceptual framework and research questions indicated in the text.

5. The data representation is the second stage of the activities which form a qualitative analysis. Representation is an organized, compressed collection of information that allows conclusions to be drawn and actions to be taken.

After preparing the research plan, the authors talked to the carers about their experiences, needs and expectations. The questions are in the following table.

Table 2. Questions in the interview

Questions
1. How long have you been caring for your beloved one? 2. What is/was the most difficult problem while caring? 3. Did/ do you have emotional problems during the care? 4. Did/do you have social or medical problems as a caregiver? 5. Did/do you have any spiritual problems while caring for beloved one with cancer? 6. Did/do you have any support from family or the other people? 7. What do you need while caring from hospice staff/from others? 8. What part of caring was/is the hardest for you? 9. Have you got any expectations when you care for your beloved one? 10. If there was a workshop for caregivers about self-care, communication and other issues connected with caring organised, could you participate in this program? 11. What information or skills that you want to learn would be for you the most important?

Sources: Authors' research.

The interviews were recorded and transcribed. Tables no. 3 and 4 contain the research results . It is also important to mention that the results let the authors prepare a curriculum and a workshop for caregivers.

Results and discussion

The interviews were focused on the experiences of caregivers, their needs, their expectations as well as the level of self-care.

Table no. 3 shows what needs and expectations were taken into consideration.

Table 3. Needs and expectations of caregivers

	Needs/expectations	Codes	Number
1.	**Information about disease of the relative and basic symptoms**	**N-I**	**10**
2.	**Communication skills in contacts with others, especially with patients with cancer**	**N-C**	**7**
3.	**Knowledge of stress management**	**N-SM**	**9**
4.	**Relaxation techniques**	**N-RT**	**5**
5.	**Focus on the beloved one and information about techniques of care**	**N-IC**	**10**
6.	**Being listened to**	**N-H**	**10**

Table 3.

	Needs/expectations	Codes	Number
7.	Proper care for the patient		5
8.	Leisure time	N-T	3

Sources: Authors' research.

The theoretical note and interpretation based on the received data

All caregivers (n=10) had a need to be informed and to have knowledge of the disease of their beloved ones. Each respondent expected from the hospice staff the information about techniques which can help them while taking care of their relatives in such a way as to make this situation painless.

„We have visited different hospitals and different doctors. I have received detailed information about my husband's condition and what it will be like later so rarely… After all, we have the right to know. How am I supposed to look after him if I hardly know anything? On the one hand, we are told not to search for information on the Internet, because there is a lot of gibberish there… On the other hand, we have so little information. It was not until we encountered Doctor X that we found out a little more. And the nurses here explain what to do and how."

"Madam, a while ago the doctor told me that my husband is dying. Please tell me, what does it really mean that he is dying?"

„The staff here are very helpful ... really ... I can always ask them about anything I want and they always explain everything to me very patiently. This is very supportive and helpful."

Seven respondents reported communication problems. They claimed that they had more problems with communication with their beloved ones, talking about needs or asking for help while taking care. During the interviews most of them emphasized that they want to change this situation by means of teaching constructive communication especially with people who they take care for.

„I sometimes feel like shouting that I am also important. I am nearly 50 years old and I am really feeling fatigue. I would like someone to help me with

taking care but then I really say nothing and keep quiet. And the situation is like this: I do everything and the rest of the family at home do nothing, because they don't even know that I need their assistance".

„I just can't speak about my real emotions … because what could I possibly say? That I cannot come to terms with the fact that he is dying? That I do not want this to happen and that I cannot imagine my life without him? You can expect me to say something like that … But I don't say anything, just do what needs to be done. Hhmm … Maybe sometimes I feel like saying something, then maybe it would be easier for me …".

„Actually, since I can remember, it has been difficult for both of us to talk to each other. Now it isn't any better. I wish I knew what to say in every situation, for example when he asks me if he is already dying… Because how to answer such a question, Madam?"

Another need which they talked about was the willingness to know the methods of coping with stress. Nine participants reported the necessity to ascertain how they could deal with stressful situations in their lives and what kind of methods were the best to control stress. Based on the interviews, it was analyzed that the knowledge and application of the methods of controlling stress could contribute to enhancing their quality of life and motivation to self-care.

"Surely, I would love to be shown what to do when I get nervous … I am stressed out, Madam. And then I don't know what I should do … I feel an urge to yell, go away somewhere far, far away, just run away … but it probably won't help, will it?"

„I sometimes can't help it, I tend to worry too much, and everything gets on my nerves. It there were some workshops available based on how to deal with our own problems, of course I would take part, even just to listen. But how to find them and when to find time for them … in this situation."

All of the interviewees wanted to be listened to especially when experiencing difficult situations and when they had problems, they found it hard to deal with them. In the same manner, all the interviewees would like to be listened to, particularly in situations regarded by them as difficult, tiresome, onerous or impossible to be coped with by themselves. While taking care of a sick relative, they would like to be able to confide in someone, to be listened to without being criticised, consoled or judged. They would like to be understood that caring for a chronically ill relative is a strenuous task and be treated with kindness.

"I am really enjoying our conversation ... Thank you so much. It is something I really needed ..."

„Can I speak to someone? Hhmm, you know when his condition was better in the beginning; there were many people willing to talk. Now there are far fewer ... Mother has been ill for such a long time that her acquaintances started to erode because not everybody has time. At the moment I have two people who are really close to me and they are always ready to listen. However, I try not to call them too often as not to scare them (laughter)."

Cognitively interesting findings refer to the need of relaxation. The results obtained allow citing the results of the analyses of Walden-Gałuszko (2000, 2004) or Łuczak (2004) , who clearly indicate that care-givers, as second-line patients, are incapable of caring for themselves and resting properly.

Table 4. Emotional, social, physical and spiritual problems.

1. emotional	Difficulty in communication, frustration, anger combined with love and concern, loneliness, helplessness, remorse	9 persons
2. social	Deterioration of social relations, loss of acquaintances, impossibility of proper relaxation, financial problems	persons
3. physical	Tiredness, exhaustion, somatic ailments, tearfulness	10 persons
4. spiritual	Questions concerning the meaning of suffering and disease, fear of the future	6 persons

Sources: Authors' research.

Interpretation of Obtained Results in Table no. 4

The interviews conducted with the care-givers of chronically ill patients indicate a range of hardships experienced in all dimensions of life. All the respondents pointed to social difficulties – particularly financial problems (for example, as a result of pursuing permanent disability benefits stemming from disease or job loss due to providing 24h care to a sick relative).

“Well, it is not easy life. When Father was at home, we needed bandages, chemotherapy and medicines ... it takes a lot of money, and to make matters worse, after the diagnosis Father practically did not return to work ... the invalidity pension that he received was too low to cover all his expenses and to buy all the things he needed”.

„I resigned from my second job. Because when I was there I couldn’t stop thinking about my parents and I kept worrying. So I used all the time off I had and now I work only in one place and have more time for them.”

„Everyone has their own lives. Of course, they declare help. But, let’s face it Madam, who will sacrifice his or her time and go to B. every time a sick acquaintance requires it?”

„There are fewer and fewer acquaintances around us, far fewer ...”.

Additionally, the interviewees frequently indicated the reduction in the number of acquaintances, which means that they felt rejected, lonely and misunderstood. A considerable number of carers (9 people) revealed also emotional difficulties. The prevailing problems concerned primarily anger and irritation caused by exhaustion, which in turn led to a feeling of guilt and remorse.

“Well, I get angry as if I were mad, but it happens only when my mother can’t see it. When I’m with her, I do my best to remain calm. But it is tough ... Perhaps it is getting tougher every single day. Later I am angry with myself so much that I want to scream, because she is seriously ill after all ...”.

A frequent symptom was helplessness and tearfulness as a consequence of the necessity of constant care, interwoven with feelings of concern, worry and love. However, another important aspect was complaining about somatic ailments, extreme tiredness and physical exhaustion as a result of taking care of a patient, the necessity of lifting, changing diapers, bathing and other activities, which when carried out quickly depleted the organism of the care-giver (10 respondents).

“I am just simply exhausted. It was not until my husband was taken away that I could rest a little ... it’s horrible what I am saying, but it’s true. When we were at home I suffered from chronic backache resulting from lifting him up all the time, I barely slept because I wanted to hear my husband call me ...”.

More than half of the interviewees indicated also that at times (especially at the initial stage of nursing a sick patient), there occurred existential questions relating to the meaning of suffering and disease. The care-givers were not aware of the fact why it had happened to them and what their life would be like both while looking after a sick relative and after his or her death.

"I often ask a question what we have done to deserve what has happened to us …".

„I don't know, I just try not to think what will happen later".

„Why is my husband dying, Madam?"

Project of Workshops for Care-givers to Chronically Ill Patients

On the basis of the interviews concerning the needs and expectations of carers for chronically ill patients, an attempt has been made with regard to the second primary objective of the project, namely the preparation of the series of workshops addressed to families looking after chronically ill patients. The aim of the workshops, the participants of which were supposed to be the previously interviewed respondents, was to meet their needs during the period of care as well as to meet their expectations with regard to the previously expressed needs. The workshop plan included 10 hours of classes on the subjects connected with chronic diseases, communication issues, expression of emotions and selected stress management techniques. The workshops have been planned for a group of 10 to 15 participants so that they would feel comfortable and could share their own ideas and experiences. A preliminary plan of such a workshop has been presented in the Table no. 4 below.

As it has been presented in the table, the plan of workshops is a response to the needs, expectations and difficulties expressed during the interviews. Prepared as shown above, the workshops include issues allowing the respondents to focus on their own feelings and experiences, teach them to communicate with themselves and others, especially in the context of expressing their own needs. The workshops offer also theoretical knowledge and they acquaint participants with stress management techniques, which are practised under supervision during classes. In addition, care-givers are capable of sharing their experiences and hardships during the long period of care for a chronically ill relative, which provides them with a unique opportunity of being listened to by others as well as getting acquainted with the experiences of other care-givers. Such workshops give care-givers a chance to obtain the desired support and make them consider the possibility of better self-care.

Table 5. Curriculum – workshop „Self-care" for caregivers

	Main topic	Particular theses
1.	Introduction – activating methods	– my strong points (emphasis) – what I like/respect myself for (emphasis) – if I were to change something (expectations, dreams, needs)
2.	What happens to me when a close person falls ill	– difficulties and experiences – theory and possibility to share experiences
3.	Self-care concerning your own health and well-being	– what helped me to feel better physically? – well-known and frequently applied methods of self-care – why those methods fail? what goes wrong? – diet – creating more sophisticated menu which could help us feel better – a healthy body makes a healthy spirit (gymnastics, active relaxation) – our mind wants to be healthy; your own plan of relaxation and visualisation – satisfied care-giver – what does he/she look like? how does he/she behave? – illness of a close relative and sexuality (symptoms, how to express it?)
4.	Care-giver is also most important – expressing your own needs and emotions	– how did I do it before? – basics of good communication – how to formulate feedback, particularly negative one (when we do not like something) – „me" communication type – why is this important?
5.	Stress as „blocker"	– what is stress and what does it cause? – theory – activation methods (drawing stress) – what used to help and does not help any longer – own methods of coping with stress – how to befriend stress and take to it – re-evaluation, what can it help with? how can it be useful during care of a sick relative?

Sources: Authors' research

Conclusions

Taking care of a chronically ill relative seems to be one of the most arduous tasks. The hard work, often done during the whole day and night, is performed at the expense of other activities. It is not uncommon that looking after a sick person hampers the realization of own dreams and ambitions, and sometimes even prevents a devoted care-giver from meeting the most basic needs such as self-care and expressing one's own desires. The conducted research and the presented data clearly indicate that long-term caring for chronically ill family members has a negative impact on virtually every sphere of caregivers' functioning. Based on previously gathered data we can conclude that caregivers for people with chronic illnesses experience a variety of emotional difficulties, especially in the context of negative emotions and difficulties with communication about their problems and emotions. The lack of abilities to express one's needs and negative feelings as well as feeling remorse when such emotions occur seem to be the most common issues. The caregivers often experience frustration and anger while caring, but they also struggle with hopelessness and loneliness associated with permanent care. They frequently experienced spiritual suffering and existential doubts trying to answer the question why they and their families must face such a difficult situation. The study group exhibit immense exhaustion and somatic fatigue resulting from permanent care and physical conditions associated with tiredness. The described fatigue and somatic disorders are often exacerbated by the feeling of loneliness and not being understood by others which result from the fact that fewer and fewer people are engaged in help. In addition, there are economic challenges and financial issues connected with the access to care services and the provision of the most indispensable healthcare articles (adult diapers, medication and wound dressings). The respondents indicate the difficulties they face but they also describe their needs as caregivers. The analysis of these needs led to the creation of a support workshop project for the caregivers presented in the article. The interviews lead to the conclusion that the caregivers' primary need is to have the opportunity to talk, share their experiences and find understanding. The need for easy access to information about the condition of the loved one and his or her illness is equally important. The knowledge is important for them not only as a preparation for a variety of situations which might occur during the care process but also for better understanding of what is happening to the person in their care in order to look after them properly. They would also like to learn how to manage stress in a constructive way and prevent it from negatively influencing the quality of the care they give. The need to be listened to and, as a consequence, to be understood is a crucial aspect of the support.

Subject literature and research findings indicate that appropriate self-care of care-givers can enhance not only the quality of their lives and improve their functioning in everyday reality, but more importantly, can obviously affect the quality of life of an ailing patient.

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