

Experiences of social workers providing palliative care for dying patients in the institutions of palliative care and their ways to overcome stress

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Abstract. Purpose of the research was to reveal experiences of social workers dealing with the death of palliative care patients. Based on scientific literature, the experiences of professionals who encounter the death of patients are showed in the first part of the paper. In the empirical part the qualitative investigation is presented, the purpose of which is to disclose the areas of activity of the social worker in the provision of palliative help. For data collection the semi-structured interview was selected. Five social workers who provide social services in a team of palliative care participated in the individual interviews. The data has been analysed applying the qualitative analysis of the content.

Introduction

In Lithuania the first establishments of social workers in medical institutions appeared only in 1999, after the Regulations on the Activities of Social Workers in Health Care Institutions [1] had been approved. The document states that only the institutions of convalescence, medical rehabilitation, and nursing (maintenance treatment) may have social workers. Nevertheless, the documents regulating the work of medical institutions just recommend and not oblige to have social workers staff [2].

Services of palliative care in Lithuania are organized and provided taking into consideration the Recommendations on Palliative Care of the Committee of Ministers to member states on the organisation of Palliative Care which was approved and adopted on 12 November 2003, in the Council of Europe [3], and the Order of the Minister of Health of the Republic of Lithuania On Approval of the Description of Requirements for Provision of Palliative Care Services for Adults and Children (2007) [4]. The palliative care is defined as a service, the point of which is the improvement of the quality of life of a patient suffering from incurable, life-threatening illness, and of his or her fellow people, by preventing suffering or relieving it, helping to solve other physical, psycho-social and spiritual problems [5]. Providing palliative care the patient is looked at holistically – a set of services including medical, social, psychological is provided [5].

As it is stated in the Description of Requirements for Provision of Palliative Care Services for Adults and Children (2007) the services of palliative support shall be provided by a team of minimum 3 specialists of corresponding competences, consisting of a doctor, a nurse and a social worker [5]. The Document specifies that the functions of the social worker in a palliative team are assessment and monitoring of social needs, planning and provision of social support, mediating in solving the social problems. Those functions shall be organized

and performed by the social worker together with the other members of a palliative care team, by performing various roles in a team of palliative care, which settles different individual cases of a patient and his or her family members.

The social worker within teams of treatment institutions in most cases performs the activities of counselling and informing and the key roles in those activities are those of the former, the implementer, the work-completing person, the coordinator and a team member [6]. According to Lebednykienė (2010), the social worker in a team of palliative care incarnates the following roles: a team member, a mediator, a coordinator and an organizer, a counsellor/ a manager; a dialogue partner [7].

Quite a number of scientists investigate the aspects of palliative care. Foreign scientists investigate the historical development of social work in medicine and palliative care [8], the roles of the social worker in the team of palliative care [9], the steps of social work activity and its specifics in palliative care [10].

In Lithuania the issue of social work in palliative care is new, therefore scientific publications on this subject are very few [7, 11].

The process of patient's dying is emotionally hard experience for each worker. Communication with a dying patient is intimate, subtle and very personal relationship. It is natural that social workers, as well as the other members of a palliative care team, when facing the death of patients and the emotions of their fellow-people experience different emotions. Some of the scientists [12–14] investigated the experiences of nurses facing the death of patients, but the attempts to find explicit research of experiences of social workers working with dying patients failed; this issue has not been explicitly investigated.

The goal of the investigation is to disclose the experiences of social workers working with dying patients in palliative care homes.

Theoretical background – experiences of professionals facing the death of the client (patient)

In health care institutions one faces: pain and suffering of patients, fear, death. The workers experience intense emotions, which are fuelled by the lack of medical and psychological knowledge, perfectionism and the requirements of patients and of the society [15]. The professionals, when facing the death of the patient, themselves experience the fear of death remembering own mortality and identifying themselves with the patient [16]. The fear of death is especially clear when the dead patient reminds to the worker of his close deceased person; this way grief and sorrow are experienced again. According to the scientist, the fear of death is not a specific object, but is referred to as a group of attitudes towards death, expressing itself as fear, threat, apprehension, discomfort and similar negative emotional reactions.

The nurses working with oncologic patients experience fear of death, which has influence on the attitudes, reactions, and emotional expressions of the workers [14]. The workers experience emotional stress when facing the death. Nurses feel unsafe, emotionally hurt; they may accept the death of the patient as a personal failure, therefore may become angry, nervous. It is disclosed that a nurse when facing dying patients:

- Experiences own disability;
- Reflects the experiences related to the death of the close ones, thinks about own death;
- Eventually gets used to death, death becomes natural;
- With increasing work experience, gains more and more skills, as a result of which the work becomes easier technically, but it does not become easier to bear with the death of the patient;

- Spending a lot of time with the patients gets used to them, becomes close to them, therefore the “traces” of patients’ death sticks for long in the memory of the nurse;
- Suffers inner pain, because knows that the patient will die;
- Experiences emotional strain; inner feelings very often are “terrible”;
- Suppresses feelings, suffering intense feelings inside, but not showing them outside (Žydžiūnaitė, 2007).

According to Dirgėlienė (2013), in the department of intense therapy the nurses face especially hard emotional stress, which may cause serious health problems. Frequent emotional discharge impoverish the organism, psychological consequences are possible: nervousness, feeling of exhaustion, abnormal thinking, abuse of psychotropic substances, etc. Somatic consequences are also possible, such as sleep disturbance, fatigue, allergies, migraine, and chest pain. The investigation performed by the author in the emergency departments of three hospitals in Lithuania showed that the hardest emotional stress to the nurses is caused by the death of a patient [17].

One third of medical staff is distressed because of the disability to provide the patient with the required help. Frequently medical staff feels stress, concern, depression, exhaust and other psychological disturbances [15]. According to Savickas (2012), doctors working with dying patients more often than the others tend to abuse drugs, as well as suffer from depression and suicidal thoughts [18]. This is due to continuous negative emotions and strain. Medical staff does not like to speak about their inner experiences, therefore they try to solve psychological problems in inappropriate and harmful ways.

Scientists [19], analysing the experiences of social workers working with dying patients, recommend, prior to counselling a dying person, to analyse the arising doubts, to realise the vulnerability of own feelings, to name own thoughts about the death for themselves. The social worker should know the literature about the death and dying. Social workers, intensively communicating with patients, experience emotional, physical and psychological overload [19]. Frequent encounters with negative phenomena and low prestige of social work results in negative dynamics in the activity of those specialists; diminishing motivation with the final development of “burnout” syndrome, which, in its turn, facilitates negative changes in the structure of specialists’ personality [2]. The investigation performed in 2010 by Lebednykienė [7] disclosed that the social workers by frequency of experienced stress working in a team of palliative care do not differ very much from doctors and nurses. All social workers who participated in the research indicated that they experience stress, strain when providing palliative services to patients; such work exhausts psychologically and emotionally more than physically [7]. According to Dirgėlienė (2013), the social workers frequently experience stress, which is caused by constant confrontation with complex existential experiences and issues of the human being. This encourages the formation of complex stress, arising from both professional and personal areas [20].

For members of a palliative care team death and dying is a daily routine. Facing the death of a patient the workers may experience fear, hopelessness, and feeling of guilt. This work requires good psychological readiness but even the strongest workers break down, the “burnout” syndrome is possible [11].

According to Pulkas (2000), the “burnout” means disappointment. Disappointment occurs facing the reality which does not correspond to our expectations and beliefs [20]. According to Navaitis (2010), the professional “burnout” can be defined with some specific regularity: the first evidence is weakened empathy, weaker emotions, later on the wish to care for clients and colleagues gets weaker, and an offhanded attitude towards them develops. The workers that manage to avoid the professional “burnout” know how to communicate with themselves, they rarely reproach themselves with mistakes and failures, they do not avoid upraising themselves, tell reasonable conclusions and encouragement to themselves [21].

According to Šeškevičius (2008), people whose profession requires great empathy taking care of others, in the course of time expend their resources of positive emotions, their organism becomes frail and incapable to withstand stress [22]. For prevention of that members of the team should openly communicate with each other, not to be afraid to unburden their minds. It is recommended after the death of a patient to discuss within the team their own feelings and emotions. It is important that workers have a possibility to get a psychologist's consultancy [11].

At the beginning of work, for new specialists, when communicating to dying patients, sometimes it is difficult to understand their own feelings and emotions, therefore such specialists need support from the working team. According to Žigutienė and Riklikienė (2005), the members of a health care team, who communicate within the team, better trust each other and overcome the occurring obstacles, emotional stress and negative feelings [23].

Coordination of work and inter-relations of the workers predetermine wellbeing of the workers; those factors determine what the worker feels: either stress or satisfaction [17]. Baltrušaitytė, Lapėnienė and Rovas (2012) define four main strategies for stress fighting: social support, problem acceptance analysis, emotional discharge and avoidance, attention swing [24].

Dirgėlienė (2013) [17], when analysing professional stress experienced by social workers, mentions support by supervision, which is applied to regulate professional relations and the atmosphere of work. According to her, supervision may restore harmonious, efficient and positive environment, naming and expressing experienced feelings and emotions, strain and stress.

Summarising, it is possible to assert that professionals facing death of patients experience different negative feelings, such as worry, disappointment, anger, sadness, fear; they also may feel physiological changes – headaches, insomnia, problems with memory and etc. All those feelings cause emotional stress, which can result in the professional “burnout”. For its avoidance organised team work, open and sincere communication among colleagues, a possibility to speak out one's feelings and experiences are important, as well as easily available psychological consultancy, when required.

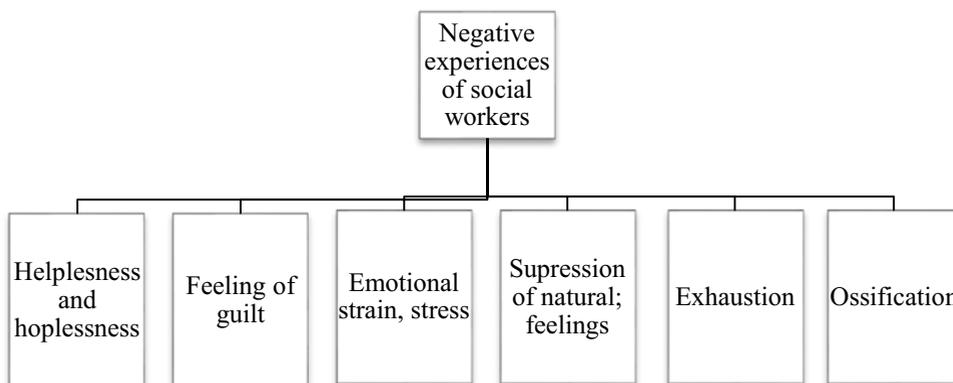
Research methodology

For the research the qualitative type of investigation was selected. The data were accumulated involving the method of semi-structured interview. According to Rupšienė (2007), the interview, as a method for collection of a research data, is based on the assumption that the most important is to know the personal attitude of each informant and the assessment of the phenomenon under investigation [25]. The interviews were recorded. The average duration of an interview was 1.5 h. The content analysis method was used for the results analysis [26]: 1) the texts of the respondents were read through distinguishing the key aspects, reflected by phrases, words, and, based on the highlighted words, categories were established; 2) the identification of meaningful elements was performed: segmentation of the content of the categories, identifying meaningful elements; 3) division of the meaningful elements into subcategories; 4) interpretation of the content data.

Targeted selection of the investigated was selected. The criteria for selection: social workers working in palliative care homes, maintenance treatment and care departments minimum for four years. The number of the informants was determined following the principle of data saturation. Five social workers that provide social services in a team of palliative care team participated in the individual interviews (Table 1).

Table 1. Characterization of the informants.

Respondent no.	Sex	Age	Experience in palliative care
1 r.	Male	45	6
2 r.	Female	36	4
3 r.	Female	39	5
4 r.	Female	51	7
5 r.	Female	45	5

**Figure 1.** Negative experiences of social workers.

The investigation was performed in December 2013–February 2014. The investigation was performed following the key principles of ethics: the free wish of the informants to participate in the research, the security of confidentiality.

The confidentiality of the participants in the investigation was ensured by *sine nomine* and restricting the information on them. Verbal consent regarding recording of the interviews on the recorder was obtained from the informants.

Results and findings

According to Dirgėlienė (2013), social work is attributed to the group of professions with increased risks, since working with socially vulnerable and support requiring persons social workers frequently experience stress [17].

During the performed empiric investigation the informants were asked about the experiences when working with palliative patients and their relatives. The analysis of the investigation data showed that assessing the experience of work with palliative patients the social workers distinguished positive and negative aspects of this work. In the analysis of the data of the investigation two categories were distinguished: “Negative experiences of social workers” and “Positive experiences of social workers”. The first category, “Negative experiences of social workers”, consists of six subcategories: helplessness and hopelessness, feeling of guilt, emotional strain, stress, suppression of natural feelings, loss of energy, “ossification” (Fig. 1).

Analysing the experiences of social workers it was noticed that social workers often experience helplessness and hopelessness: “<...>. *In the beginning it was very difficult to realise that you cannot save the people present here, they will die anyway. And you see those people, they die, and I would feel so helpless (2r)*, “<...> *the most difficult, probably,*

it is in the beginning, later on you get used to that. But in the beginning very often you get overwhelmed by the feeling that you can help in no way, that any help you provide does not relieve the very death situation. So you feel so helpless (4r)", "*<...> it is not difficult emotionally for me to work here, but sometimes you really want to help more but you cannot, because it is simply impossible. You see one suffering, but cannot help in any way. That is, probably, the most difficult – to be unable to help (5r)*". From the answers of the informants we can see that the most difficult is the very beginning of work with palliative patients. The worker, the purpose of whose work is to help the patient, feels helpless when realises that he is not able to satisfy the essential wish of the client.

Another distinguished sub-category is the feeling of guilt. The informants asserted that, when working with dying patients, they experience the feeling of guilt: "*<...> as for me, the most difficult thing which I fail to control in any way is the feeling of guilt that I sometimes feel, chagrin, when a patient dies. Then I almost always start thinking that I failed to say something, or told something in a wrong way, that I didn't do something that I had to. This is the most difficult for me in this work, the feeling of guilt (3r)*", "*<...> sometimes you feel guilty that you have not done everything, what you could do and had to do (1r)*", "*<...> it so happens that you even feel guilty (4r)*".

The negative emotions experienced at work precondition the occurrence of emotional strain, stress: the informants stated that, when providing services in palliative care, they experience emotional strain, stress. Two of the five indicated that they experience emotional stress very often: "*<...> death of patients every time cause painful experiences, and that stimulates emotional strain both at work and, unfortunately, in private life as well (1r)*", "*<...> as for me, very often the death, the suffering cause big stress, sometimes unstable emotions, stress (3r)*". Other informants said that they do feel emotional strain and stress, but not continuously: "*<...> it happens that clients are hard emotionally. Then you yourself become nervy, feel psychological strain, but it happens rarely to me (2r)*", "*<...> somehow you get used to the whole system of work and do not get overexcited, of course, stress happens, but that is normal (4r)*", "*<...> when I started to work here the emotional load was heavier; now it's much calmer, though it happens that I experience stress (5r)*". Žydzūnaitė (2007) investigating experiences of nurses communicating with dying persons, discloses "double" experiences of feelings, when, in the course of time, the work gets simpler technically, but it does not become easier to accept the death of a human being.

The investigated recognized that in their professional activity they often have to suppress feelings: "*<...> emotions swing a lot. Because in this work you cannot show what you really feel, you are one person, but must show a different one. (2r)*". Frequently a professional has to experience one emotion, and to show another one: "*<...> you have to behave in a professional way, sometimes it is difficult, even very difficult to hide your own feelings (3r)*", "*<...> I often have to hide own feelings, exhaust, irritation, but this is the place where you cannot show such emotions, you have your work to do (4r)*".

Negative emotions and stress in a course of time often cause energy exhaust. The informants admitted sometimes feeling exhausted and tired. The informants associated the loss of energy with decrease of inner resources, the feeling of emptiness: "*<...> it so happens that you feel like pumped out, like empty (2r)*", "*<...> you cannot get out of bed, there are no inner forces that would make you stand up. The feeling of some emptiness happens. I noticed that it happens when you get more patients (3r)*".

The informants stated that the most of the negative experiences and stress are experienced at the beginning of work, just starting to provide social services to palliative patients. Later on, the reaction towards the death of a patient is "mechanical", and that facilitates professional "ossification" which can be defined by poor empathy and decreasing work motivation.

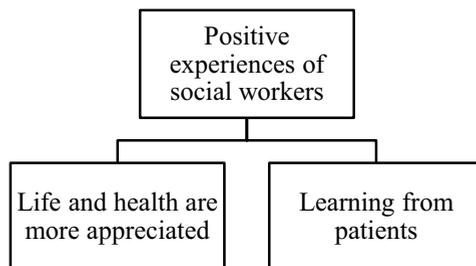


Figure 2. Positive experiences of social workers.

The informants stated that they often feel that death of the patient becomes a common thing to them and it do not cause strong emotions to them: “< . . . > sometimes I do feel that the death of patients is not a shock for me, sometimes I do not over react to it, just as is a daily phenomenon (5r)”, “< . . . > The death sometimes seems a simple elementary thing, sometimes you have no time to react – here is the client, and then he is gone, another one instead. You come to work without any emotions and leave it the same. Become like a robot, but then I recover (2r)”. Žigutienė, Riklikienė (2013), when investigating emotional reactions working with oncologic patients, notices that “ossification” expresses itself with the increasing work time, frequently experienced death of patients become “natural” work routine [28]. Volkavičiūtė (2002) [29] considers “ossification” as one of the evidences of professional burnout. According to the author, it can be defined by cooled feelings, boredom at work, decrease of work motivation, emotional dissociation from clients and colleagues.

Irrespectively of the fact that social workers working with patients experience a lot of negative emotions, the communication with the dying one also gives an opportunity to have a different look at the life and the values. Analysing the data of the investigation the distinguished category “Positive experiences of social workers” discloses the positive experiences of social workers working with dying patients. This category was subdivided into two sub-categories (Fig. 2).

The informants stated that facing the death of patients frequently, they started to more appreciate their lives and health: “< . . . > as banal as it may sound, but somehow you start to appreciate own health and the health of the others in a different way. And you do understand how important is the family, how important it is to forgive and do not get angry, because one can lose those possibilities any time (3r)”, “You start appreciate health, you understand that it is the most important in the life (1r)”, “< . . . > you start look at your health in a different way; I started to be more careful about myself. In this work you really realise that the health is the most important wealth (4r)”. The investigated noted the importance of health, which they started to appreciate working with severely ill patients.

Also the informants stated that, when seeing death, suffering and pain at their work they learned to accept difficulties in their lives easier: “< . . . > I do not cry over minor things any more. When I see people suffering, how their relatives suffer, I have no ideas to cry, complain over small things. I react even to death somehow more quietly, I show less reaction when I learn about the death of some relative. Somehow the attitude towards life and the dying has changed. It is easier to accept that (5r)”, “< . . . > recently we had to burry my father, but I somehow accepted this fact peacefully, though the death was unexpected. It really was sad, painful, but I managed to keep self-control when I learned about it. Probably my work has taught me seriousness, clear thinking in critical situations (4r)”. The investigated stated that, when working in a team of palliative care, they learned to keep self-control in private life in stressful situations.

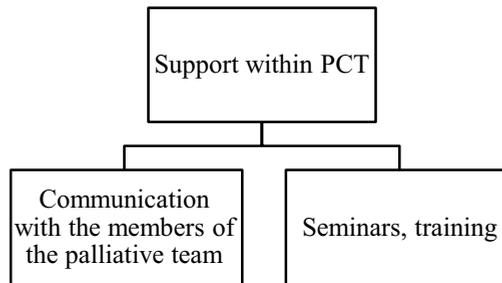


Figure 3. Support within PCT (Palliative Care Team).

Analysing the positive experiences of a social worker it became clear that the investigated learn from their patients “<...> *it is really possible to learn from some patients optimism, the ability to accept it (3r)*”, “<...> *seeing some of the relatives caring of their patient, how they keep themselves up ... it is really possible to learn optimism from them (4r)*”. Another informant states that he learned to keep hope from the relatives of the dying person: “<...> *I happened to see how they keep hope till the last moment when caring of their close person. Somehow I myself started to have some reserve of hope, as I say (2r)*”.

The results of the investigation showed that social workers working with the dying people and their relatives experience many both negative and positive experiences, such as: guilt, hopelessness, loss of physical and inner energy, emotional strain, stress. They also learn from the patients another attitude towards the life and death; they start to better appreciate health.

Combating and ways to overcome stress experienced by social workers working with dying patients

Working in complicated psychological conditions, when professionals frequently have to face pain, suffering and death of their patients, it is natural that workers experience big emotional stress and experiences, as a result of which depression or professional “burnout” may occur.

According to Ovčinkovienė (2004) [30], stress is a psychic and physical reaction of organism to tense, oppressing situations, when the inner energy of the human being is being mobilised for overcoming of them. According to the author, a person who regularly experiences emotional stress feels strain, insufficient freedom, after completion of the work feels no satisfaction. The person which fails to pay attention to his disordered emotional balance in right time may get sick with severe both physical and mental diseases. Ovinčkovienė notes that for professionals who work under complicated work conditions it is very important to know how to help themselves: to relax after a work day, to engage in favourite activities, when needed, to visit specialists who could help [30].

Kiaunytė (2008) [31] notes that social work is a specific activity; the roles of the representatives of this profession are often problematic, causing inner conflicts of the personality. Social workers experience a complex stress – from both professional and personal area, interacting with different systems experience emotional, psychological and physical overload and that causes stress and concern.

Three categories distinguished during the content analysis reflect the ways of stress combating of social workers working with dying patients: “Support within the team of palliative care”, “Personal support ways”, “Assistance from specialists”. The support of social workers within the team of palliative care is reflected by two distinguished categories: communication with the members of the team, seminars, training (Fig. 3).

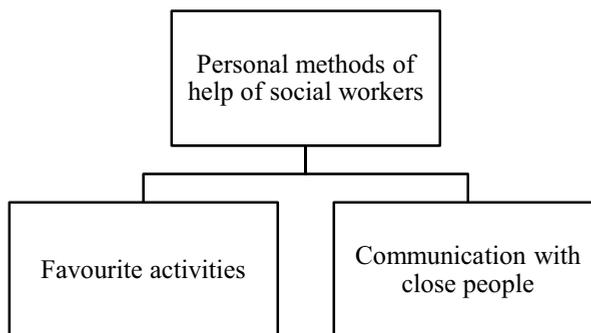


Figure 4. Personal methods of help of the social workers.

The investigated named the communication with the team members as one of the ways to combat stress: “< . . . > when everything seems totally bad, I talk to nurses, because it’s even worse for them. Somehow it becomes better after you talk to some nurse, because their work is hundreds of times more difficult. Finally, we have a psychologist, sometimes like a colleague rather than a patient, we talk together (5r)”. Communication among the staff as one of the main ways for combating of stress experienced at work [12, 20, 28, 29]. It is recommended to speak out own accumulated emotions during conversations with colleagues, to search for compromise together and to change inappropriate work models which interfere with feeling comfortable at work.

The investigated social workers, when speaking about support in fighting with stress at work, mentioned seminars and trainings organised at work, with the purpose to teach the members of a health care team to overcome stress experienced at work: “< . . . > we had some seminars on stress control at work. Of course, the most of it was senseless talking about things that everyone naturally knows. But one of the seminars was really interesting and useful < . . . > even now I make use of the information obtained there, it helps (2r)”. The answer of the informant shows that the seminars organised by the employer not always give particular tangible benefits.

Kiaunytė (2008) notes that every person should have personal protection system, own ways of help, which could help to overcome stress experienced at work [31]. During the content analysis the second category “Personal help resources of social workers” was defined, which discloses self-help methods of PCT social workers overcoming stress experienced at work. This category was sub-divided into two sub-categories: favourite activities and communication with the close people (Fig. 4).

All investigated social workers said that the best way to overcome stress experienced at work for them was favourite activities: “I go for sports a lot, spend my leisure time actively (1r)”, “Nature is the best anti-depressant for me. Just some time in a park, or going to a country house and I immediately feel better (3r)”. The rest of the respondents also indicated that the best ways to relax and “unload” are active leisure time, relaxation in the nature. Kondrošovienė and Kupriūnienė (2008) [19] specify engagement in favourite activities as a preventive measure against the professional “burnout” syndrome. According to the authors it is very important to know how to distribute one’s time and energy for satisfaction of own needs, to fill in the used energy resources. It is important to plan the work load correctly, so that there is time for the activities, which are not related to work. The workers must understand that it is their duty to save themselves; they should not be afraid to ask to not be disturbed during their holidays and days off.

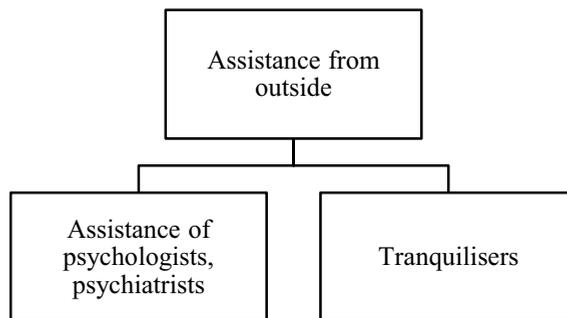


Figure 5. Assistance of specialists.

In the opinion of informants communication with their close people is also a personal way of help in overcoming work stress. The investigated asserted that communication with the close people calms them down and comforts emotionally after emotionally and physically hard work day: “< . . . > as for me, the best is to come home and talk to my husband. Though sometimes this carrying work problems home is treated as a bad thing, but talking out to my husband helps me the best (2r)”. Another woman under research says that she avoids bringing work problems home, but sometimes it cannot be avoided: “< . . . > my husband himself asks me about my work and little by little I talk everything out. For a moment it becomes better. (3r)”.

It is very important that people, who face stress at work, could get emotional, psychological support, which may be direct or indirect, inside and outside the organisation, provided by psychologists, psychiatrists, supervisors and other professionals [31]. The content of the Category “Support from outside” disclosed that social workers select assistance of psychologists, psychiatrists and use of tranquilisers (Fig. 5).

One of the investigated said that he had applied for help from psychologists: “< . . . > just when I started to work here I applied to a psychologist. There were a lot of personal things, a close person had died, and here at work so much death and suffering. That was too much for me, that’s why I applied for a psychologist (4r)”. In the opinion of another informant, the employer should provide psychological consultancy at work: “< . . . > I believe that it would be quite good if everyone employed here could have an opportunity to apply for help from a psychologist any time (3r)”.

Some informants stated that in order to regain inner balance, they take tranquilisers or other medicine stuff: “< . . . > I had to take medicine for half a year to recover from stress, so that I would be able to work normally (4r)”, “< . . . > I remember drinking various herbal teas and valerian pills when I started to work here (3r)”.

Summarising the data of the research analysis it is possible to assert that social workers do not tend to apply for help to specialists or their team colleagues, or other colleagues. Most often the respondents try to overcome the stress experienced at work by their personal efforts: engaging into favourite activities, communicating with their fellow people. In spite of this the investigated said that they have a demand for easily available services of a psychologist at work.

Conclusions

Professionals, working with dying patients, experience the feelings of hopelessness, guilt when they cannot help the patient. The emotional stress experienced by professionals may cause the professional syndrome of “burnout”.

The empiric investigation showed that social workers working with palliative care patients face positive and negative emotional experiences. The negative experiences relate to the feelings of hopelessness, helplessness and guilt, emotional stress, suppression of feelings, exhaust, and ossification. The positive aspects of the work with dying patients: varied attitude towards health, life – workers start to better appreciate own health; they also learn optimism from their patients and their relatives. Social workers overcome stress, negative emotions involving own inner resources and of the palliative team, but sometimes they have to search for help outside.

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