



The Social Employee in Interaction with Terminally Ill Patient

ABSTRACT

RESEARCH OBJECTIVE: The aim of the study is to show the interaction between a social worker and a terminally ill patient, his family and the environment.

THE RESEARCH PROBLEM AND METHODS: The situation of palliative and hospice care patients requires the work of many people who are involved in providing comprehensive assistance. Among those providing support are also social employees. They solve many problems of the patient, his environment, both in home palliative and hospice care for adults and children, and in institutional forms of support. They support their involvement with the hospice psychologist, volunteers and other team members. Their role is noticed by many people from various social circles. A competent social worker may contribute to better work of the medical team, doctors and nurses.

THE PROCESS OF ARGUMENTATION: The considerations were based on the chosen subject literature. The relationship between the participation and accompaniment of a social employee in the subsequent stages of the terminally ill patients' lives and the increase of their quality of life was presented. The role of interdisciplinary care and unconventional approach to satisfying the patient's needs was also presented. The multi-faceted dimension of the suffering of the client and his/ her relatives.

RESEARCH RESULTS: There is a large relationship between the activities undertaken by a social employee and increasing the quality of life of people who are terminally ill. It is irreplaceable in the case of lonely and elderly people, because it becomes a kind of coordinator of available medical and social assistance. With the development of the palliative and hospice movement, an increasing share of social workers in interdisciplinary hospice care is observed.

CONCLUSIONS, INNOVATIONS, AND RECOMMENDATIONS: An important conclusion can be drawn that social employees fulfill an extremely important role in the palliative and hospice movement. Their participation in this process is certainly an expression of the humanization of medicine.

→ **KEYWORDS:** **PALLIATIVE AND HOSPICE CARE, PALLIATIVE HOSPICE CARE CLIENT, CLIENT' S FAMILY, HOSPICE SERVICE, SOCIAL EMPLOYEE IN THE HOSPICE SERVICE**

STRESZCZENIE

Pracownik socjalny współdziałający z terminalnie chorym pacjentem

CEL NAUKOWY: Celem opracowania jest ukazanie interakcji pomiędzy pracownikiem socjalnym a pacjentem terminalnie chorym, jego rodziną i otoczeniem.

PROBLEM I METODY BADAWCZE: Sytuacja pacjentów opieki paliatywno-hospicyjnej wymaga pracy wielu osób, które zaangażowane są w udzielanie wszechstronnej pomocy. Pośród udzielających wsparcia są także pracownicy socjalni. Rozwiązują oni wiele problemów chorego, jego otoczenia, zarówno w domowej opiece paliatywno-hospicyjnej nad dorosłymi i dziećmi, jak i w instytucjonalnych formach wsparcia. Swoim zaangażowaniem wspomagają psychologa hospicyjnego, wolontariuszy i pozostałych członków zespołu. Ich rolę dostrzega wielu ludzi z różnych kręgów społecznych. Kompetentny pracownik socjalny może się przyczynić do lepszej pracy zespołu medycznego, lekarzy i pielęgniarek.

PROCES WYWODU: Rozważania przeprowadzono na podstawie wybranej literatury przedmiotu. Zaprezentowano zależność pomiędzy uczestnictwem i towarzyszeniem pracownika socjalnego w kolejnych etapach życia chorych nieuleczalnie a podniesieniem ich jakości życia. Przedstawiono również rolę interdyscyplinarnej opieki i nieszablonowe podejście do zaspokojenia potrzeb chorego. Podkreślono wieloaspektowy wymiar cierpień klienta i jego bliskich.

WYNIKI ANALIZY NAUKOWEJ: Występuje bardzo duża zależność pomiędzy podejmowanymi aktywnościami przez pracownika socjalnego a podniesieniem jakości życia osób nieuleczalnie chorych. Pracownik ten jest niezastąpiony w przypadku ludzi samotnych i starszych, gdyż staje się niejako koordynatorem dostępnej pomocy medycznej i socjalnej. Wraz z rozwojem ruchu paliatywno-hospicyjnego obserwuje się wzrastający udział pracowników socjalnych w interdyscyplinarnej opiece hospicyjnej.

WNIOSKI, INNOWACJE, REKOMENDACJE: Nasuwa się istotny wniosek, iż pracownicy socjalni odgrywają niezwykle istotną rolę w ruchu paliatywno-hospicyjnym. Ich uczestnictwo w tym procesie jest z pewnością wyrazem humanizacji medycyny.

→ **SŁOWA KLUCZOWE:** **OPIEKA PALIATYWNO-HOSPICYJNA, KLIENT OPIEKI PALIATYWNO-HOSPICYJNEJ, RODZINA KLIENTA, USŁUGI HOSPICYJNE, PRACOWNIK SOCJALNY W RUCHU HOSPICYJNYM**

Introduction

According to the WHO definition, palliative care is a procedure aimed at improving the quality of life of patients and their families when faced with an incurable disease. The prevention and alleviation of suffering is achieved through the early detection, assessment and treatment of pain and other physical symptoms, as well as the resolution of

psycho-social and spiritual problems. Palliative care is a young field of medicine but has its roots in the centuries-old tradition of the hospice service and is based on compassion and understanding of the patient's needs. The role of palliative care is now accepted as an area with a lot to offer. An extremely important role in palliative care play social employee. Their participation in the hospice service is certainly an expression of the humanisation of medicine. Social employees in palliative and hospice care have many opportunities for interdisciplinary cooperation in the integrated care of the patient and his or her environment.

1. The role of social employees in the hospice service

The situation of palliative-hospice care patients requires the involvement of many people who are committed to provide comprehensive assistance. Social employees are also among those who provide support. They solve many of the patient's and his or her environment's problems both in home palliative and hospice care for adults and children, as well as in inpatient care. They support the hospice psychologist, volunteers and other team members with their commitment. "Their role is recognised by many researchers of the problem. For social workers there are many opportunities for interdisciplinary cooperation in the integrated care of the patient and his or her environment. The competence of the social employee releases the energy of the medical team (doctors, nurses) involved in the formal, legal and social and living issues faced by patients and their families" (Krakowiak, p. 27).

Such interdisciplinary care and an unconventional approach to meeting the needs of the patient are necessary due to the multifaceted dimension of suffering of both the patient and his or her family. In the situation of progressive and incurable disease, apart from the patient's pain, troublesome are the thoughts expressing the concern and fear for the future of his children, his spouse and loved ones. As an enormous mental suffering, there is a justified concern for the future of the family, especially for those who had previously supported the family and secured it financially. Many families with dying ill people are afraid of the future, the burden of further life. They often remain helpless in the financial aspect and the requirements of the authorities. Here, a social employee brings invaluable help. The social employee is also irreplaceable in case of lonely and old people, because he is their only support in coordinating the available assistance with palliative and hospice care.

Social employees therefore play an extremely important role. Their participation in the hospice service is certainly an expression of the humanisation of medicine. By definition, every social employee works for the families, groups and social environment to which he or she is sent. The person doing this work should have knowledge of various fields, e.g. sociology, psychology, pedagogy, as well as the basics of law and medicine. The social employee should therefore have basic knowledge of the specific emotional and social problems of patients at the end of life and their families, during the patient's

life and after his death, in the process of mourning. It should also have the ability to provide basic psychopedagogical and social assistance to seriously ill people and their families. It is important for him/her to be familiar with basic issues concerning terminal diseases and palliative-hospice care. He must recognize not only the social needs of patients and their families, but also emotional needs, especially after loss. In addition to social support, orphans need help in the emotional and psychological matter. That is why it is so important to know the process of grief after loss, the course of mourning and the mechanisms of support in this difficult time. The tasks of a social employee also include social education about the end of life as “domesticating” the dying, death and mourning. He also plays an important role as coordinator of hospice volunteering in team care at the end of life. “Social employees in palliative/hospice care often act as integrators of various institutions and organisations in order to provide appropriate assistance to people who need this” (Wesołowska & Makowska, 2000). The involvement of social employees in care enables medical staff to provide professional care and treatment. They no longer have to deal with formal, legal and social issues.

Among the most important procedures implemented by social employees in the field of assistance to patients in various forms of palliative and hospice care includes:

1. Supporting patient in achieving the fullest possible social activity;
2. Providing assistance tailored to the current needs of the patient and his family (e.g. preparing letters, applications, filling in forms, etc.);
3. Wide advice and consulting in the field of patient's rights, authorizations resulting from the provisions on social insurance, social assistance, labour law, family and guardianship law, pension law, civil law (e.g. will, inheritance rules), cooperative law, tax law (deductions rules, etc.);
4. Providing information on benefits and forms of assistance;
5. Support in obtaining benefits from social assistance;
6. Searching for various possibilities of obtaining assistance and institutional support from non-governmental organisations and cooperation with them;
7. Creating, in cooperation with families, individual support programmes and assisting in their implementation;
8. Supporting orphaned persons: conversations, organising meetings of self-help groups, etc. (Daszykowska, 2008, p. 323).

In the hospice work, a social employee should place particular emphasis, among other things, on developing the ability to distinguish the correct process of mourning from the pathological one, in order to effectively help orphaned persons. He should also become familiar with the hospice volunteering as a way of active involvement in helping people at the end of their lives, as well as a practical tool for social support in care at the end of their lives. It is important for a social employee to discover in hospice volunteering a way to counteract social exclusion through involvement in assistance activities for patients and their families.

It is worth quoting the statement of T. Grądalski from one of the conferences, where he notes that:

A social employee in a team goes far beyond the usual responsibilities of social employees in hospitals or primary health care. Taking a more eccentric position around the patient than other caregivers, he acts as a kind of buffer between the patient's closest environment and his or her far environment, in a way adjusting the shape of this environment to the patient's needs. He facilitates and often even enables communication between patients and their families. Working with the patient's family, he or she identifies those who are the most endangered by the pathological orphanage. It alleviates conflicts within the team resulting from different priorities of patient care. He identifies and shifts social barriers caused by the disease, enabling a fully active life. He is an attorney for the most socially sensitive people in the environment of the sick person – children. Standing aside, the social employee cares for the right relationship between the sick person and the team, thus preventing the burn-out (Grądański, 2002).

It should be added that, according to the report on social work in Poland, it takes place in difficult conditions and is very poorly paid. The remunerations of social employees are among the lowest in the country, despite the fact that this work can be both stressful and very exhausting. Despite being underestimated, it is an extremely valuable work for society as a whole, because it helps people to solve social problems. It stimulates civic and social attitudes and combats social exclusion. Without a modern, well-equipped system of professional Social Labour it is impossible to improve the quality of life of all citizens in the country (Blok, 2001). All the more so in the area of assistance provided in palliative and hospice institutions, where the most needy people are covered by care. A social employee plays an extremely important role there, because he or she often undertakes all actions concerning everyday life for the patient or his or her family. He or she is not only an advisor, but in practice deals with various matters not only related to living matters, but also the official matters, etc. He appears to the patient and his environment as a representative of the community. He is a sign of bond between those who are badly experienced by fate and those who are able to help. He gives encouragement and a sense of security. He makes hospice patients feel that they are still valuable members of society. All those who experience serious suffering want signs of interest and care from others.

2. Social employee in interaction with the terminally ill and his family

Cooperation in treatment centres, of which a social employee is also a part, is still unsatisfactory. In addition to the organizers, some of the blame lies with the health service and doctors. In the past, social employees were also involved to work as nurses or secretaries. This gave the false impression that social work in a hospital is not necessary. As a result, doctors also have doubts about the functionality of the social employee. Even psychologists sometimes consider the social employee as a competitor and refuse to cooperate in the field of psychotherapy.

The help of a social worker can be invaluable if he or she does not seek to replace a psychologist (Vorlíček, ADAM, POSPÍŠILOVÁ ET AL., 2004).

According to Jelínková (2002), two types of services provided by social employees can be distinguished:

- social-legal expert – provides information and handle social and legal problems, ensures contact with relevant authorities and at the same time with the patient's relatives within the framework of social-legal consulting;
- social therapist – cooperates with family and emotionally close people, cooperates with people accompanying the patient and medical personnel, supervises the activity of volunteers.

Five basic areas of intervention of a social employee

Přidalová, who worked as a social employee at the House for the Treatment of Suffering at the Hospital of St. Joseph in Rajhrad, distinguishes five basic areas in which to intervene.

1. To create a plan of life with an incurable disease:

The incurable patient should know his possibilities in his present physical condition and the prognosis of the disease. An important element of the plan is the creation of activities that the sick person could carry out on his or her own. The social employee can draw the attention of the carers of the dying person to leave him/her as much space as possible for independent activity.

2. Helping the sick and their families to define their feelings:

The dying are most afraid that at the moment of dying they will remain alone, nobody will be nearby, nobody will talk to them. The dying are confronted with the multitude of feelings that they want to tell someone about.

A social employee is a person who listens, helps to define his or her feelings, to show his or her participation and helps to find possible forms of help.

3. Helping the dying and the family to communicate in an atmosphere of death:

It is desirable or even necessary for the sick person and his/her relatives to be able to communicate not only with any member of a multidisciplinary team, but also among themselves. The social employee can help to clarify the rules of communication between the sick person and his family. In this process, however, he should avoid imposing his solutions on clients as the only right ones just because experts present them.

4. Preparation for death:

The dying person can express his or her wish for inheritance or funeral. In such a situation, the social employee can deal with all the necessary matters related to the wish.

The social employee can also help the family to carry out all necessary activities after the patient's death.

5. Help for the people related with the deceased:

Death is the saddest experience for the survivors, which is why all care focuses on them during this period. Here you can take advantage of group therapy, or at least self-help group therapy. In the care of terminally ill people and their families, social employees have new opportunities for self-fulfilment.

3. Social care for the sick

The social employee takes care of the mental and social needs of the patient – especially those that can be realised by the worker. The social functioning of the client in this case is aggravated by the disease and its character, which is cautiously incurable and limits the life expectancy of the patient. It enters into the social status and role of the sick person and excludes him or her from the activities, relations and activities accepted by society, for example from the work. The patient is in the situation of the begging person, asks for help, is dependent, often in a subordinate role, no matter what status he had in his environment before the disease appeared. Social isolation from everyday life is often a consequence of all these changes (Vorlíček, Adam, Pospíšilová et al., 2004).

4. Social care for the family

As far as family care is concerned, it is irreplaceable and plays a very important but not easy role. The family suddenly finds itself in two roles:

- They are a client of a multidisciplinary team, because it suffers and survives the various stages of reconciliation with the death of a loved one, as well as the dying one, sometimes it suffers even more,
- Creates an essential and irreplaceable element of a multidisciplinary team.

In order to master these roles, it is necessary to ensure, in addition to the highest quality care, a sufficient privacy. A well-managed family can be a huge advantage for the dying, as opposed to an untrained family that can make many mistakes. Much depends on the conditions that should be created. In such extreme situations, sufficient privacy is a very important factor. A single room with the possibility of accommodating a family member cannot be considered as a more than the standard, but as a reasonable standard.

Working with the family can be more difficult and sometimes even longer than working with the patient. It is necessary to analyze the situation of the family as soon as possible, to recognize the type of family and its functioning, whether it takes care of the sick

person, whether they are loving, whether they can be counted on or not. It is necessary to understand and respect the diversity and habits of the family, resulting from cultural, religious or ethical differences. The family, just like the dying one, goes through the stage of reconciliation with death. Some of these stages can be repeated, while some families do not have to go through at all. When a dying person accepts his or her own death, when he or she is reconciled, and the family is only at the stage of denial and negation, this can complicate the dying's departure. It is necessary to cooperate with the family before this phenomenon occurs. When a social worker notices that the patient's family is tired or unable to control the situation, he or she can offer or provide social services or hospice care.

5. Social care for the deceased's survivors

Losing a loved one is a very stressful situation. There is no doubt that excessive and prolonged stress leads to many diseases. Previous and systematic dedication of time to relatives and loved ones for the patient significantly reduces the impact of this factor. After death, roles, functions and priorities in the family change. It must be realised that in such a difficult situation man is neither able to make important decisions nor to change his lifestyle. The peculiarity of hospice care is that it continues as needed even after the patient's death. The employee closing the documentation should decide whether or not to continue working with the family.

In order to maintain the objectivity of this decision, it is necessary to ask oneself a few questions, which Svatošová (2004) considers to be warning signs and risk factors, for example:

- Was anyone emotionally dependent on the deceased?
- Was anyone existentially dependent on the deceased?
- Did anyone lose the roof over head after the patient's death?
- Is anyone extremely depressed, hesitant, clumsy after the patient's death?
- Does anyone feel guilty towards the deceased?
- Was there someone close to him not prepared for death?
- Was there a serious disharmony in the family?
- Will anyone soon be exposed to further stress?
- Is any of your loved ones less independent or dependent (disabled)?
- Was caring for the deceased extremely stressful and exhausting for someone?
- Did any of your loved ones talk about the loss of life sense?
- Did any of your loved ones talk about suicide?
- Is any of your loved ones mentally ill?

Based on these answers, the employee will decide whether it is necessary to maintain contact with the family of the deceased. According to the experience of the Hospice of Saint Agnes from Prague, as many as one third of the loved ones need help. Two-thirds are enough to meet for coffee and talk immediately after the loss of a loved

one. However, the remaining one-third needs long-term care. The hospice also includes a chapel to which people return and take part in funeral services (Svatošová, 2004).

Conclusion

The role of a social employee in palliative hospice care, which has not been noticed by society for a long time, is certainly an expression of the humanisation of medicine. It is his responsibility to help the sick person and his family. A social employee with a great interdisciplinary knowledge accompanies the patient from the very beginning during the period of his diagnosis and treatment. He accompanies him in the most difficult period of his life, at the same time becoming a coordinator of medical and social services. His task is to help in the organization of treatment and rehabilitation at home and in institutional forms of care. This necessitates cooperation, not only with the patient, but also with his family and environment. The main goal of palliative care is to achieve the best possible quality of life for the patient while preparing him or her for death. The high quality of palliative care is possible thanks to the participation in an interdisciplinary team of a social employee. Rejection of reflection on suffering, dying, death and hospice accompaniment in the last moments of life is a rejection of a concrete reality, because the transitoriness of everyday life associated with suffering and the process of leaving is the real turn of human everyday life. Until recently, the stereotype of neglecting issues related to people requiring hospice and palliative care was still dominant. This state of affairs led to negative feelings in social life. The world of marketing, advertising, the Internet and the latest media technologies favors the understanding of suffering and hospice care as an extremely pejorative time.

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