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# The Place and Future of Social Work in Palliative Care Services in Turkey: State of the Art

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## ABSTRACT

Palliative care, which is a special type of care including alleviation of physical and psychosocial symptoms of individuals with life-limiting serious diseases, has long been neglected in Turkey. This has also affected the activity of social work and social workers in the presentation of health services. In the present study, the present status of social work in palliative care services in Turkey was analyzed. It has also been attempted to explain the historical place of social work in palliative care services from 2002 on under the guidance of the World Health Organization and Ministry of Health. In the present study, an analysis is carried out of stages social work profession went through in social care services, its strong and weak aspects, and its future perspectives. It is thought that the experience gained and accumulation of knowledge in this process as it has occurred in Turkey may serve as guidance for other countries that have only recently started to implement palliative care services, which are evaluated in the context of human rights at present.

## KEYWORDS

Palliative care; medical social work; end of life care; social worker

## Introduction

The World Health Organization (WHO) recommends that palliative care centers that can serve with a large organization be established and developed in all countries irrespective of their development level (Boyle & Levin, 2008). At present, as the establishment, administration, and management of palliative care, which is evaluated in the context of human rights, has low cost and is preferred by many countries. Hence, being subjected to unnecessary pain and medical interventions in emergency service departments is also prevented.

Patients in the terminal period of their life frequently experience fears of being a burden on their family, losing physical and emotional skills in dying, having unbearable pain, and dying early before they achieve their aims in life. For patients, issues such as receiving an efficient care in terminal period, social support for them and their families, and regulation of the life of remaining family members has lately become increasingly more important. Social work profession assumes important functions in eliminating or relieving these problems of patients. In this framework, the function of social care in end-of-life care of terminal patients is largely involved with offering support for the maintenance of psychological well-being for the patient and his or her family (Allison, Gripton & Rodway, 1983).

For the social worker, who has offered social care support to dying individuals and their families so far, end-of-life care is not a new issue. What is new is that end-of-life care attracts the attention it deserves finally at present. End-of-life care has assumed importance in the last stage of the individual, for himself or herself, family and the society in institutional context (Taylor-Brown & Mary, 2004). To strengthen health and social care services for dying individuals and their families and the contribution of social workers in this area, in 2002 the National Association of Social Workers in the

United States (NASW; 2003) issued *Practice Standards for Social Work Practice in Palliative and End of Life Care*. These standards address the basic stages of social work practice in palliative care and end-of-life care in various groups of diseases (HIV/AIDS, cancer, organ failure etc.). In developed countries, social workers participate actively in services for patients who are dying. For example, in the United States, according to reports of National Cancer Institute, 75% of social support studies for patients receiving care service from cancer centers is conducted by social workers (NASW, 2003). Social workers assume important roles in the interdisciplinary team offering comprehensive medical and psychosocial support services in dying process (Tuncay, 2013).

Social workers contribute to the increase in quality of life by making psychosocial interventions to the patients, who are estimated to have fewer than 6 months of life to live and cannot undergo any curative interventions, and their families. They assume functions such as guiding vital changes, enabling the patients and family to use all their potential force and resources and helping to solve compliance problems. Social workers especially lend support to patients who are terminally ill in recognizing emotions and processes they experience such as loneliness, isolation, depression, anxiety, and in coping with the problems (NASW, 2003).

In the process from diagnosis to death, the needs of family may change and take different shapes. Therefore, family members should use their energy efficiently and should not deplete it that they do not become dysfunctional at the moment they are needed most. In listening to anxieties, desires, and needs of the families, the social worker, who is a member of end-of-life team and emotionally ready for this condition, may help families (Isikhan, 2008).

In many discussions, end-of-life care and palliative care are treated as if they are the same thing, and palliative care is considered a professional expertise field encompassing everything. However, there are differences between them. *Palliative care* is administered in conditions when pain and symptom control exerts physical, social, and psychological impact on person who is dying and his or her family and close acquaintances. Palliative care is derived from services offered to people with cancer or other serious chronic diseases. In addition, it is a short-term service with an important place in medical and nursing care. As to *end-of-life care*, it is care offered to people approaching the end of life. This care is delivered at a period when many people become more powerless day by day and are exposed to many diseases. People in this condition may not need medical and care support requiring detailed expertise. However, families of such people are increasingly in need of health and social work in the society where they live (Payne, 2009).

In international policies developed by WHO, palliative care is considered an important part of medical care, for cancer patients suffering chronic pain, especially children (WHO, 2008a). The definition of *palliative care* made by an expert team of WHO in 1990 became the driving force behind policies developed in this context (WHO, 2008b). According to this definition, palliative care is care aiming to detect physical, psychosocial, and psychological problems early and to improve quality of life for patients and their families encountering life-threatening problems by their proper evaluation and treatment (WHO, 2008b).

In countries where services have not been completely developed in healthcare, WHO points to the importance of palliative care in coping with advanced diseases and chronic pain as part of social development (WHO, 2008b). However, recently the perspective of social work has been left aside due to efforts to medicalize palliative care and to lack of experience and resources on the part of social workers. For example; in transition states arising in Middle and East Europe with the dissolution of Soviet Union, many investigations have established that palliative care is in development in many places. However, the contribution and intervention of palliative care was found to be negligible in this development (Clark & Wright, 2003).

Palliative care has sometimes been considered an international phenomenon and attracted attention in many countries, but only in a few countries have notable advances been made. International developments recorded by WHO have exerted quite limited effects on countries (Wright et al., 2006). The European Council, which has played an important role in the recognition of palliative care at international scale, has determined the grounds of consideration of human rights as an important

human right. In the statement, explaining the rationale of human rights approach, the following points have been addressed:

Protection of the dignity and honour of a dying person with a fatal disease and necessity of respect for the person stems from the inviolability of human dignity at all stages of life. This respect and protection requires the establishment of an environment enabling an honorable death. Past and current experience indicates that this duty should be carried out especially for the benefit of most vulnerable members of the society. Human beings starting life weak and dependent need support and protection while dying as well. (European Council, 1999)

In Article 7 of the same document, it was also stressed that not taking psychological, social, and psychological needs of patients into consideration and not providing enough palliative care services in this respect is a violation of human rights (European Council, 1999). This approach clearly indicates that palliative care is an important human right and should be offered to many more people demanding it and social care should be an important component of this care. It should also be stated that this approach is also consistent with the principle that “suffering and pain of humans can not be allowed. If it is inevitable, at least, it should be alleviated.”

### ***Palliative care and social work***

In his comprehensive review on social workers and palliative care, Small (2001) stressed that in the implementation process focusing on social change, social workers make three important contributions to palliative care:

- In clinical practice, social work is usually involved with loss and hence death is an important component in the practice of social work.
- Social work brings a holistic approach to death. This approach naturally shows that family, community, and society perspectives have an impact on health systems of countries
- Social work is involved with healing aspect of practical and social effects of change.

Although death is a great event for individuals, this is also a social experience for them and the family and close relatives (Reith & Payne, 2009). Everybody except the person who is dying is ready for death. As friends and relatives have an intimate emotional bond with the person about to die or professionals are ready when death occurs, the relations and social webs of others with the person who is dying are disrupted with death. In hospitals, special social events are experienced such as visiting the person who is dying, burial, commeration activities, and social processes. The event of death influences may social institutions such as school, social organizations, workplace, care institutions, and rituals associated with people who are dead or dying and their families.

At present, death is usually hidden in social life, but in health institutions it has become medicalized. Hence, many people are not even able to mention the subject of death waiting for them. Preparing the relatives and families of person who is dying and helping old people is much more difficult in this process. As the elderly population increases in developed countries, this issue will become more important (Payne, 2009).

Religious institutions, police and local institutions, and public or private services may be involved with death or the dying process. This means these issues concerning death may attract political attention in overcoming difficulties experienced in planning services offered to people with serious diseases or those who are dying. Euthanasia or help by physician or family for death may lead to many legal debates. Therefore, in the West and developing countries, developing services and policies for people who are dying seems to be a serious problem.

Meier and Beresford (2008) stated that basic values of social workers in the United States includes subjects such as counselling, understanding family systems, and working with families. In brief, the sensitivity of social workers in social problems of families is a positive asset for palliative care practice, basically. In brief, though the sensitivity of social workers to social problems of families is an asset in

itself, the basic issue that should be addressed is the individual anxiety experienced by people who are dying or their relatives.

Sheldon (2000; Saruç, 2013) defined the roles of social workers in six categories in his study on social workers in palliative care centers, namely:

- Family focus: Focusing on family relations; activation of family communication; parenting lessons; connecting past, present, and future; and making plans for the future.
- Influencing the environment: Giving advice and information, finance planning, preventive studies, establishing relations with colleagues in other institutions and supporting them.
- Being member of a team: Assuming a role in a team, establishing connections with team, addressing disagreements in the team, managing the tension between confidentiality and sharing with team, and being a model for the team.
- Anxiety management: Managing the anxiety of family, managing the anxiety of healthcare professionals, risk management, management of experienced stress, self-awareness, and utilizing past experiences.
- Values and evaluation: Not being judgmental, approving the patient asking for help, encouraging self-determination, confidentiality, empathy, normalization, and challenging discrimination.
- Knowledge and working within the framework of limits: Evaluation, focusing on intervention, withdrawal, adjusting limits, working out anger, securing safety for client, and encouraging open discussion.

### ***The place of social work in palliative care in Turkey***

Studies on palliative care and supportive treatments in cancer started with the initiative of Ministry of Health Fight Against Cancer Directorate on November, 3, 2003. Before this date, subcommittees were established regarding this issue, for example, alternative and supplementary medicine, epidemiology and records, treatment in cancer, preventive oncology subcommittees. Academic personnel and other personnel contributed to the activities of these committees. Issues such as psychosocial support in cancer attracted the attention of management of cancer affairs and hence psychosocial support subcommittee was established as a precondition of holistic approach (National Cancer Advisory Board of Turkey [NCABT], 2002). The Social Support Training and Psychosocial Subcommittee defined the duty and functions of its members in this framework and following subjects that were on the agenda and considered important at that period were discussed (Ministry of Health, 2003).

### ***Activities of Social Support, Training and Psychosocial Subcommittee in 2003***

The duties of the above subcommittee in which specialists come together and discuss the issue of psychosocial support in cancer, are defined as follows:

- Planning and implementing preventive and protective studies for decreasing cancer incidence in the community and making necessary organization.
- Starting studies on smoking and nutrition, which are among most important causes of cancer in Turkey, determining risk groups, and carrying out necessary training and organizations in this area.
- Economic, social, and psychological problems experienced by cancer patients and their relatives are unfortunately neglected. In addition to psychological, economic, and social problems, various problems may be experienced in patient–doctor relationship, communication, treatment process, cancer-specific issues (pain control, etc.), transportation, drug supply, patient referral, burial and mourning period. Carrying out necessary studies on social support resources for solving these problems, and on informing cancer patients, their relatives, and healthcare personnel and organizing necessary activities.

- At the stage of controlling problems experienced patients and supplying necessary help, planning, and presenting necessary awareness training for healthcare personnel.
- Carrying out activities that healthcare personnel working with cancer patients function as a biopsychosocial team and making the necessary organizations to that end.
- Carrying out commissioning and encouraging studies on problems experienced by cancer patients and their relatives.
- Providing help, cooperation, and consultation services to real and legal bodies and volunteer institutions serving in this area to encourage cooperation and collaboration between cancer patient and his and her relatives.
- As it is seen, in this committee, it has been established that it is important to offer preventive services that are important in the struggle against cancer to groups under risk and that social workers assume important roles in the planning and organization of preventive services prior to and at all stages of cancer disease, especially in training studies.

### ***Activities of Social Support and Training Committee in 2009***

In the framework of the 2-year collaboration agreement signed between Ministry of Health and Europe Regional Office of WHO (2008–2009) three meetings were organized to prepare the action plan for the development of “national cancer control program.” One of the programs developed in these meetings was designing an action plan for the development of palliative care services in Turkey.

“Palliative Care Meeting and Training” was held between April 26–28, 2009 with the counseling of experts from WHO European Regional Office to develop palliative care services in Turkey. In this meeting, subjects important for social workers were addressed and the importance of social work in a holistic approach was stressed. It was also stated that the aim of palliative care programs was to increase quality of life for patients and their relatives not only in terminal period but also throughout the process of treatment and that the most important strategy for this was to develop the awareness of palliative care among healthcare workers and the public, to spread palliative care services to whole country and to enable all cancer patients in need of palliative care to receive it (Babek, 2009).

Emphasis was placed on the importance of public training in the spread of palliative care services, and in this framework it was stated that training and conferences should be organized, institutional and regional support groups for patients should be organized (for patients, families and those in bereavement), present ones should be coordinated, palliative care services should be expanded, and that such centers should be numerous enough to deliver palliative care service to all those who need it.

In this approach, determination of the problems experienced by the community and their solution and the method of social work aiming to increase social welfare has a special place. Training of community, consultation, determination of social resources and their utilization for the patient and their families, sensitivity in public health, participation of public, protection and development of health and social organization are important components of these activities.

In palliative care, psychosocial support to the patients and family (family therapies, individual psychotherapies, etc.), social help to family members giving primary care to palliative care patient (financial help, pain, leaves from job etc.), and informing the patients about their rights, supplying support and help on things to do at the last stage of life (testament, place of death, the method of burial, religious demands, etc.) are considered to be important (Babek, 2009).

### ***Activities of Palliative Care Subcommittee of National Cancer Council in 2014***

The Palliative Care Subcommittee of the National Cancer Council convened in 2014 (NCABT, 2014) and issued the following statements:

- Awareness and training studies should be initiated as soon as possible so that palliative care concept can be understood accurately by health workers and the public and these services can be delivered properly.

- As accepted by WHO in January 23, 2014, the reduction of physical, psychosocial, and spiritual complaints of the patient and the family is under moral responsibility of health workers irrespective of whether the patient is curable.
- Coordination should be developed between the components of palliative care and a legal regulation should be made at least at the level of a statute.
- Effort should be exerted to correct the general misperception of palliative care as intensive care.
- To maintain palliative care services, a close cooperation should be made with health services at home, and regulations are necessary for this.
- Given that palliative care is team work, it was stressed that in addition to physician, nurse, psychologist, physiotherapist, social worker, and spiritual care/religious psychology expert should also participate actively in the process.
- Directive put into effect in recent years to supply palliative care services to patients and their relatives, plan their organization, and to offer care service efficiently demonstrated that social work occupies an important place in palliative care services.

### ***Directive on Palliative Care Services***

To restructure palliative care services offered in the framework of inpatient health facilities and to make services more efficient, the Directive of Implementation Method and Principles of Palliative Care Services was put into effect on July 7, 2015). With this directive, the previous directive dated September 10, 2014 and numbered 640 was annulled.

The aim of this directive is to

recognize and evaluate pain and other symptoms early in patients experiencing problems associated with life threatening diseases, to alleviate or prevent their suffering by giving medical, psychological, social and spiritual support to these people and their family members, and to establish palliative care centers acting to develop the quality of life in these people.

In the directive, there are two headings addressing approaches and interventions of social workers. Physical Conditions and Minimum Equipment Standards Article 6 (1):

Centers are opened at easily accessible places. The following areas and physical conditions can be provided: after entrance and reception area, an activity room should be present. In this room, professional therapy, speech therapy, family interviews, treatment and services that will help the patients be relieved physically and psychologically.

This stresses that social workers can carry out their activities in this room to relieve patients psychologically and contribute to the solution of their psychosocial and economic problems.

In the article on the Content Of Services (Article 12), it was stated that, in relation with the services offered in these centers, social workers can carry out psychosocial support and evaluation activities (anxiety, depression, hopelessness, loss, mourning, bereavement, and self-care). The issuing of this directive is important in that it indicates that social workers assume important roles in palliative care in Turkey.

### ***Present status of palliative care centers in Turkey***

According to International Palliative Care Monitorization Unit (Wright, Wood, Lynch, & Clark, 2006) advances in palliative care made in 234 countries all over the world are as follows:

- In 33% of these countries ( $n = 78$ ), that is, in 4% of world population, no development occurred in palliative care.
- In 18% of these countries ( $n = 41$ ), that is, in 9% of world population, there are ongoing studies for partial development.

- In 34% of these countries ( $n = 80$ ), that is, in 78% of world population including China and India, this service is provided at some places.
- Only in 15% of countries ( $n = 35$ ), that is, in 18% of world population, palliative care is closely integrated with health system of countries.
- Therefore, it can be said that palliative care has not developed much during this period in spite of some exceptions.

In the study of Gültekin, Özgül, Olcayto, and Tuncer (2010) investigating the present status of palliative care services in Turkey, it was stated that palliative care is the cornerstone of struggle against cancer in Turkey and that in this care medical approach is adopted and palliative care is offered through pain units. In this study, it was stated that as of 2009, there are 10 palliative care centers in Turkey, two of which are affiliated with Ministry of Health, seven with universities, and one with private hospital.

In Turkey, units serve predominantly in palliative care are pain units. There are overall 72 pain centers in 33 provinces, 35 are situated in state hospitals, 31 in university hospitals, and the remaining six in private sector. The overall number of personnel working in these centers is 334; and of these, 254 are physicians. Twenty-eight centers are in Ankara and İstanbul, whereas 56 are in West and Middle Turkey. In palliative care team in Turkey, religious official and in palliative care centers certified nurses and volunteers are not employed (as of 2009). In addition, there is no hospice care in Turkey.

According to the Palliative Care Subcommittee, as of 2015 there were 31 certified palliative care centers with 389 beds in Turkey, as well as 38 centers at the stage of application representing an additional 373 beds, which was expected to bring the total number beds in palliative care centers to 762 by the end of 2015 (NCABT, 2014).

### ***The number of social workers employed in health sectors in Turkey***

At present, there are around 150,000 social workers employed in hospitals in the United States (Cowles, 2003). In Iran, the number of social workers in Ministry of Health is 552, and among these 32 have a graduate license as social worker (psychosocial therapy) and 100 people supply social services (“Healthcare in Iran,” n.d.).

In Turkey, it has been established that there are overall 970 social workers in the health sector. Their distribution is as follows: Ministry of Health: 800, university hospitals: 80, private sector: 70 (Ministry of Health General Directorate of Personnel Affairs, 2015). It is known that there are about 50 social workers working in oncology, and they are employed in social work and patients rights units of oncology hospitals. In hospitals with palliative care centers, upon the demand of physicians and nurses, social workers go to these centers and provide professional support.

### ***Problems experienced in palliative care in Turkey***

In 2014, the Palliative Care Subcommittee of National Cancer Advisory Board expressed the following problems in offering palliative care services:

- Public was not able to talk about death and avoided this.
- Personnel working in this field lacked listening, talking, and asking questions skills (effective communication techniques).
- Being wary of communication with angry relatives of patients.
- Inadequacy in offering high quality care.
- Excessive work load in health workers – lack of personnel.
- Personnel experience such feelings as job stress, tiredness, mobbing, and burnout due to excessive number of patients and too many bureaucratic procedures and correspondence.
- Healthcare personnel do not understand when the patients need palliative care and when they need end-of-life care.
- Patients and their relatives do not have adequate information on disease and its prognosis.

- Treatment aiming to prolong life and supportive treatments are segregated.
- Healthcare personnel do not receive any training on the care of patient who is dying and do not know the subject.
- Feeling of helplessness experienced against death.
- Hierarchy problem produces obstacles in forming a team.

In the same report, the following favorable aspects of care services in Turkey were listed as follows:

- The issuing of Palliative Care Directive by Ministry of Health has contributed to the spread of palliative care services in Turkey.
- The presence of volunteer and experienced health workers experienced in palliative care.
- Traditional family structure.
- Health services at home and family practice system.
- Regulations made by Family and Social Policies Ministry are important (National Cancer Advisory Board of Turkey, Psychosocial Subcommittee, 2015).

In addition, it was also stressed that nursing homes in Turkey are not suitable to serve as palliative care services, and planning an organization specialized in this area that will offer care to patients who are outside hospitals and do not need hospital care will be more convenient.

It was also stated in the report that patients and their relatives should be informed on interventions that will be made in end-of-life care and interventions that are known not to prolong life and can be evaluated as causing suffering for the patient should be talked over with the patient and relatives privately, and these interventions should be made only with the consent of the patients and their relatives.

## Conclusion and clues for future

In Turkey, whose population constantly becomes older with a consistent increase in cancer and other chronic diseases, unfortunately palliative care services have long been neglected. The country's traditional patriarchal family structure may be stated to be among the causes of this neglect. Not only cancer patients, but also patients who chronic and constantly disabled are not left by themselves and abandoned by their families. Although this cultural characteristics has been eroded due to economic and social adaptation problems caused by urbanization, at present, a large majority of patients are cared for at home with economic support (home care) or receive service from newly established palliative care centers. In Turkey, the most important problem in the future is that there is not enough qualified healthcare personnel in palliative care. Planning and professional organization should be initiated at once in this subject. Social workers who increase their impact in oncology and palliative care centers assume important roles in health in the framework of a holistic approach for increasing quality of life for the patient and the family.

Social workers have important roles and responsibilities in meeting psychological, social, economic, and spiritual needs which arise in oncology patients and their relatives in the process from diagnosis to death and bereavement. In developed countries, service policies for improving quality of life for the individual and family in end-of-life periods become increasingly important politically and socially. The aim of end-of-life care strategies should be to offer services for meeting psychological, social, economic, and spiritual needs of patients approaching death step by step and experiencing more problems day by day. People need social work service to be able to talk openly about the process of death and losing their close ones.

Training of the public; support mechanisms in the workplace, school and nursing homes; showing compassion to reactions against death and loss; and supporting a positive approach to special needs of people who are getting older, dying or losing their relatives, are among the policy recommendations especially addressed by Kellehear (2005) in regard to social workers in palliative care. Macrolevel studies are required aiming the intervention of society in the needs of people approaching the end of

their lives. Administrators in the community and institutions should be sensitive to increasing vulnerability of people who are aware of coming to the end of their lives. Social workers should utilize active communication methods to talk openly about death, death process, and losing their close ones. To increase quality of service offered by staff of palliative care centers, day of information, training on the problems experienced by people who are dying or who are losing their relatives, and group studies for these people may be recommended. In addition, emphasis should be placed on the following issues as regards the future of social work dimension of palliative care:

- The quality and quantity of personnel that will work in palliative care centers should be determined in advance. By making projections to future, the posts for physicians, nurses, social workers, psychologists, and other professionals that will work in these centers should be prepared beforehand.
- Standards and physical equipment of palliative care centers should be determined and regulations should be made considering the next 10 to 15 years.
- According to the latest statute, social workers are supposed to work part-time or full-time in palliative care centers. Resident physician or nurse should demand social worker or refer the patient to social worker that social worker can carry out psychosocial or other professional activities in palliative care centers. However, social workers should be employed continuously that they can have one-to-one contact with patients and their relatives and carry out professional work.
- It can be seen that nongovernmental organizations have a limited impact in the process of increasing quality of life for patients and their relatives, which is the aim of palliative care. Unions and nongovernmental organizations established by patients and their relatives should take the initiative in palliative care and make recommendations to Ministry of Health in this respect.
- In view of these developments, social workers, as a profession involved with coping of community with social problems such as death and bereavement, should make interventions to increase social network and their capacity.

### Limitations of the study

The present study attempted to analyze the place and importance of social workers in palliative care services in Turkey. Qualitative and quantitative studies should be planned to elucidate the activities of social workers in these centers, the problems they encounter in offering service, and problems in intrateam harmony. At present, studies on intervention of social workers on palliative care in clinical practice are quite limited. A larger social work model should be developed that will incorporate clinically focused practices specific to the country in palliative care. Further studies that will determine the problems experienced by patients and their families are required.

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