A current overview of palliative care: Palliative psychiatry

Emel Erdeniz Güreş[1], Azize Atlı Özbaş[2]
[1]Phd Student, Hacettepe University Faculty of Nursing, Department of Psychiatric Nursing, Ankara, Turkey
Res. Asis., Uskudar University Department of Nursing, Umraniye, Turkiye,
https://orcid.org/0000-0003-3949-2770
[2]Assoc. Prof., Hacettepe University Faculty of Nursing, Department Of Psychiatric Nursing, Ankara,Turkey,
https://orcid.org/0000-0001-7614-6354

SUMMARY

Palliative psychiatry is an approach that aims to improve the quality of life of patients and their families by trying to prevent or alleviate suffering through timely evaluation and treatment when faced with physical, mental, social, and spiritual problems associated with serious life-threatening mental illnesses. The fact that individuals with serious mental illness are a disadvantaged group in accessing health services, the rate of physical diseases that are difficult to treat compared to the general population is quite high in this population, their physical diseases are diagnosed later and their compliance with treatment is more difficult, this special group continues to live with a low quality of life and it results in death at an earlier age of 15-20 years. Therefore, considering the burden of serious mental illness on both the family and society, it is clear that palliative care is needed. However, the need for palliative care for individuals with psychiatric illnesses remained in the background, and discussion of the need for palliative care became possible at the beginning of the 21. century. This study was written to raise awareness about where we are in benefiting from palliative care services in our country and in the world and to draw attention to the role of psychiatric nurses, whose role in patient advocacy is at the forefront, in psychiatric palliative care. Psychiatric nurses should realize that there is a serious gap in the field of psychiatric palliative care in our country and should focus on studies in this field.

Key Words: Nursing, palliative care, mental illness

INTRODUCTION

Palliative care emerged in the 1950s as an extension of the hospice concept, which has been in existence since the Middle Ages. By the mid-19th century, hospices primarily operated by religious orders served as care facilities for "incurably" terminally ill patients and shelters for the impoverished (1). They played a pivotal role in facilitating access to modern health services for their beneficiaries. Initially, religious officials and later healthcare professionals worked within hospice settings, interacting with dying patients and amassing considerable knowledge about the process of dying. Over time, awareness increased regarding unmet needs of patients and their families. Pain and symptom management became focal points, with the primary aim of alleviating the individual's suffering and addressing not only the emotional, psychosocial, and spiritual needs of the patient but also of their family. Traditionally, while palliative care mainly catered to individuals diagnosed with cancer, its scope has progressively encompassed those with neurological disorders, primarily AIDS and multiple sclerosis, as well as those with progressive chronic diseases (2). A holistic and humanistic approach has become foundational to palliative care practices (3).

While palliative care providers were initially focused on end-of-life care, over time, they began to prioritize the early detection, accurate assessment, and treatment of physical, psychosocial, or spiritual pain and other issues. Their objective shifted to preventing suffering, ensuring comfort, and enhancing the quality of life for patients and

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their families confronting life-threatening illnesses (2). Today, palliative care has become a standard of care for individuals with advanced and severe conditions, such as cancer or heart failure, and is recognized as a complement to curative treatment. Deviating from traditional perspectives, contemporary palliative care models have emerged, encompassing care from the diagnosis stage through to death, post-mortem, and the family's grieving process. These models include personalized, advanced interventions and run concurrently with curative treatments (4).

The outcomes of comprehensive palliative care services on patients, healthcare professionals, institutions, and the healthcare system are profound. Palliative care facilitates both the family's and the patient's acceptance of the process, enhances the quality of life, well-being, and life expectancy, prepares the patient and family for the grieving process, manages grief, and offers counseling (2,4,5). It increases care satisfaction for the individual, family, and healthcare professional, reduces the need for institutional care, decreases repeated admissions and visits to healthcare facilities, and reduces care costs (4, 6-9).

This review is written with the intention of highlighting the importance and necessity of palliative care services for individuals with serious mental illness, and to initiate discussion on the concept of palliative psychiatry, a relatively new term in the international literature, at a national level as well. It is essential for nurses, who are in a profession fundamentally rooted in caregiving, to show interest in and take responsibility for psychiatric emergency care. It is believed that palliative psychiatric care can help overcome challenges faced by individuals with serious mental illness and their families, who are often considered a disadvantaged population from various perspectives, in accessing holistic and individualized care.

Palliative Care in Psychiatric Services

Palliative care practices, which are so significant and beneficial for all stakeholders in healthcare services, are observed to target individuals and their families with chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%), and diabetes (4.6%) (10). However, from a contemporary perspective, it is noticed that discussions have begun regarding the concept of palliative care for individuals with severe mental illnesses, introducing the term "palliative psychiatry" into the discourse (5, 11, 12). In essence, psychiatric care and treatment have accompanied palliative care practices since the very inception of the palliative care concept. Yet, the debate surrounding the need for palliative care for individuals with psychiatric illnesses became feasible only in the early twenty-first century (13).

When considering the burden of serious chronic mental illnesses on the patient, family, and society at large, the need for individualized palliative care becomes evident. Drawing from a philosophy of holistic, humanistic, and personalized care that has become a part of the standard of care in many chronic illnesses, it is clear that individuals and families with chronic mental disorders will also benefit from palliative care practices (5,12). However, it is notable that palliative care applications directed towards individuals with serious chronic mental illnesses are relatively new and limited in scope.

Individuals with severe chronic mental illnesses experience significant functional impairments due to cognitive decline, persistent symptoms, and symptoms arising from the illness and its treatment. This often leads to long-term disruptions in various areas of life, including impairments in social functionality and challenges in education and employment (14, 15). Approximately 10% of this population requires long-term care, which is often provided by family members (16). Reflecting today's community-based mental health services, greater responsibility is thrust upon families and caregivers in the care process, even when they may not be fully prepared (17). Thus, severe mental disorders pose a substantial burden on the patient, family, and society at large (16).

Additionally, due to genetic predispositions,

unhealthy lifestyle behaviors, and the side effects of psychotropic medications, these individuals carry higher risks for serious health issues like cardiovascular diseases, neoplasms, respiratory illnesses, hepatitis, liver cirrhosis, metabolic syndrome, and AIDS (18). When compared to the general population, this patient group, with increased death risks from neoplasms, cardiovascular, respiratory, and gastrointestinal diseases (15, 19, 20), has a mortality rate at least double that of the general population due to comorbid conditions (15). Furthermore, unexplained injuries, suicides, and incidents of homicide also represent health and safety risks this population faces (21). In summary, individuals with severe mental illnesses have a 3.7-fold higher mortality rate for various reasons (22, 23) and tend to live shorter lives due to numerous comorbidities, dying 15-25 years earlier than the general population.

While the specialized health needs of individuals with serious mental illnesses are evident, they remain a disadvantaged group within the intricate health system of the modern age due to cognitive challenges, impaired social skills, loss of capacity, and inadequate support systems. This inequality they face in attending health screenings, seeking help, and accessing treatment and care is also pertinent to accessing palliative care (11, 14).

There are studies that focus on the planning and assessment of palliative care services for individuals with chronic physical diseases (24). However, there is limited research concerning the access to palliative care for individuals with serious mental illnesses. Literature in this domain reveals that individuals with mental disorders; have lesser access to palliative care services in the final months of their lives, have higher needs for emergency service, are more frequently hospitalized in psychiatric wards, and very few receive palliative care consultation (24-29). Stigmatization, negative experiences in service processes, attribution of physical symptoms to psychiatric disorders, and the lack of knowledge and experience among mental health professionals about when and how to refer individuals to other appropriate services pose barriers to the highly vulnerable psychiatric patients' access to palliative care (11).

The aim of palliative psychiatry is to improve the quality of life of individuals with serious mental illnesses, known to be a vulnerable population (5, 24). Individuals with serious mental illnesses are at risk of therapeutic neglect (5,9,24) which overlooks the autonomy of the patient and their families and situations marked by inadequate communication, and/or they face potential challenges like multiple emergency interventions, emergency hospitalizations, clinical admissions, intensive care treatments, and extended hospital stays, denoting overly aggressive care. Consequently, the approach of palliative psychiatry holds the potential to enhance the care quality, autonomy, and self-determination of these patients (5). There are two concepts of recovery in psychiatry: clinical and personal. Clinical recovery targets the reduction in disease symptoms and loss of function, long-term mental stability with little or no relapses, and enhancement of psychosocial functionality (30,31). Personal recovery, on the other hand, focuses on promoting individual processes of personal growth, regaining independence, and deriving meaning from life through peer support, supported employment, housing, and shared decision-making (31,32). Palliative psychiatry inherently embodies both types of recovery, supporting individuals in determining their own fate, autonomy, dignity, and achieving individual life goals through acceptance. Moreover, palliative psychiatry aims to function in connection with other approaches targeted at prevention, improvement, rehabilitation, or recovery throughout the illness process (30,32).

Trachsel (2019) delineates the scope of palliative psychiatry as follows (13):

• Provide support to individuals in coping with and accepting distressing psychological symptoms,

• Acknowledge the lifelong persistence of serious mental illnesses and focus on enhancing the quality of life,

• Neither hasten nor delay an individual's death,

• Integrate the physical, psychological, social, and spiritual aspects of patient care,

• Offer a team support system to assist patients and family members in co-ping,

• Utilize a team approach to cater to the needs of patients and their families,

• Positively influence the course of a serious mental illness by augmenting the individual's quality of life,

• Make it applicable by supporting prevention, improvement, rehabilitation, or recovery with other therapies.

Most serious mental illnesses follow a chronic course accompanied by relapses. The comorbidities and high mortality rates in individuals with serious mental illnesses are well-acknowledged (19,33). These outcomes suggest that the priority for individuals with serious mental illnesses should not be combating the illness, but optimally managing its symptoms and decreased functionality. Viewed in this light, psychiatric treatments and palliative care appear to share common ground (5). Interventions aiming to enhance the quality of life rather than achieve remission, as seen in instances like long-term psychiatric inpatient care for clozapine-resistant schizophrenia patients (34); decisions to abstain from rehospitalizations involving continual involuntary refeeding cycles for severe enduring anorexia nervosa (35); and the choice of sedation to alleviate anxiety in terminally ill patients (36), can be regarded as practices of palliative care.

Recommendations for psychiatric palliative care practices found in the literature can be enumerated as follows (21,28,33,37-39):

Patient-Centered

• Ensure that patients continue their psychiatric medications as needed in the presence of psychotic symptoms (monitor drug-drug interactions, observe drug effects and side effects) (28,40).

• In the case of cognitive symptoms, individual assessments should be conducted since patients' decision-making capacities may vary (33,37).

• In the presence of negative symptoms, caregivers should be informed to prevent potential misconceptions regarding perceived disinterest (28,33, 38).

Community Services

• Conduct initiatives aimed at overcoming challenges such as housing issues and social isolation that might hinder access to palliative care (21).

• Develop interventions to enhance access of individuals with mental illnesses to centers like community mental health (21).

Health System-Oriented

• Facilitate communication across specialties (39).

• Encourage the tailoring of services based on both psychiatric and medical care needs of the patient (21).

• Address concerns of both psychiatric and medical teams when providing care and treatment to individuals with serious mental illnesses and their families (39).

• Provide cross-training between mental health professionals and medical teams (for example, initiatives to prevent attributing symptoms of physical illness to mental illness) (21).

• Launch initiatives to integrate screening services with units interacting with this population, to detect progressive diseases that might be overlooked due to coexisting diagnoses (24,40).

• Enhance the awareness of the mental health and medical teams about palliative care, establishing a common ground for discussions in this domain (21, 41,42,43).

In psychiatric care and treatment settings, palliative care can be beneficial for a significant portion of individuals with severe mental illness. Given that psychiatric palliative care can be considered a relatively new field, there is limited literature on the subject. Studies in the literature examine palliative psychiatric care in relation to chronic mental disorders such as schizophrenia, eating and feeding disorders, neurocognitive disorders, bipolar disorder, and depression. However, outside of these conditions, there is a lack of evidence-based literature. Therefore, this study focuses exclusively on pallia-

tive psychiatric care in the context of schizophrenia, feeding and eating disorders, and neurocognitive disorders.

Palliative Psychiatric Care in Turkey

Palliative care in Turkey is a relatively novel field of interest. Historically, efforts to develop palliative care began in the late 2000s, and in 2008, the Turkish Ministry of Health's Cancer Control Department implemented the National Palliative Care Program. As the name of the program suggests, palliative care has primarily focused on cancer patients and their families. In terms of legal regulation for palliative care, the "Directive on the Procedures and Principles of Palliative Care Services" was enacted on October 9, 2014, with directive number 640 (44). Palliative care has garnered considerable attention among scientists and nurses, leading to significant national-level research (4,6,9). However, the emphasis in these studies has predominantly been on cancer patients and symptom management (30-35). When we look at the concept of palliative care from a broader perspective, it can be argued that, within a national framework, both academically and clinically, palliative care services should be evaluated in a wider context. This includes considering non-cancer chronic diseases and severe mental illnesses. From the onset of illness, individuals and their families should be addressed not only physically but also mentally and psychosocially.

Schizophrenia and Other Disorders Accompanied by Psychosis: Globally, the number of individuals with treatment-resistant schizophrenia is estimated to be around 24 million (13). These figures highlight the significant percentage of individuals with schizophrenia in populations worldwide. Due to the inherent positive, negative, and cognitive symptoms of schizophrenia, coupled with its chronic trajectory, it stands among the mental disorders associated with the most significant functional losses (29). However, the likelihood of receiving palliative care for those with schizophrenia is known to be less compared to individuals with other physical illnesses (28). Barriers to palliative care for patients with schizophrenia include communication difficulties, cognitive deterioration, lack of insight, delusions, health professionals' unfamiliarity with how to administer palliative care to schizophrenic patients, absence of palliative consultation procedures in psychiatric services, amplification of these challenges in advanced stages of the disease, and insufficient social resources (21,36).

Suggestions for the palliative care of patients with schizophrenia include:

• Planning interventions to enhance individual functionality,

• Interventions to prevent the emergence of comorbid diseases in individuals, • Including this population in early screening systems,

• Performing comprehensive assessments specific to the individual to prevent the confusion of physical symptoms with mental ones,

• Encouraging health-seeking behaviors of individuals and combating challenges like stigmatization and internalized stigma,

• Conducting initiatives aimed at enhancing social resources,

• Early detection, assessment, and treatment of pain and other symptoms to improve quality of life, • Psychosocial assessment of the family and necessary interventions (e.g., burnout, stress, emotional challenges, physical illnesses),

• Understanding an individual's end-of-life care preferences during remission,

• End-of-life care,

• Grief counseling (35).

Eating and Feeding Disorders: Globally, it is known that eating disorders (anorexia nervosa, bulimia nervosa, binge eating disorder) affect one in every six women and one in every forty men (35). If not detected and treated in the early stages, eating disorders can lead to fatal physical deteriorations, characterized by a decline in quality of life and social functionality (38). The most common types of eating disorders, Anorexia Nervosa (AN) and Bulimia Nervosa (BN), are chronic conditions where recovery is typically expected within the first 12 years after diagnosis. As the duration of the illness increases, the likelihood of recovery diminishes. A comprehensive, patient-centered palliative

care approach that respects the patient's right to request care not only in the hospital but anywhere, has been adopted for Anorexia Nervosa to reduce potential damage (35).

Suggestions for the palliative care of patients with eating disorders include:

• Management of symptoms,

• Implementation of interventions aimed at enhancing the quality of life,

• Strengthening of family relationships,

• Preservation of dignity and privacy,

• Supporting activities that the individual can participate in within the community, taking into account their level of disability,

• Providing an environment where the individual can make their own decisions,

• Providing emotional or spiritual support when needed,

• Understanding and respecting the individual's end-of-life care preferences (35).

Neurocognitive Disorders: In the literature of palliative care, much like the broader spectrum of neurocognitive diseases, there is a predominant focus on Alzheimer's disease (43). Alzheimer's disease, and the irreversible cognitive decline associated with it, deprives individuals of their ability to live independently, hence exerting a multitude of negative physical, psychological, and social impacts on the individual, family, and society (42, 43). The care and treatment needs of individuals vary greatly between the early and late stages of the disease (43). For individuals with dementia, palliative care aims to prolong life by treating in the early stages of the disease, enhance the quality of life by providing comfort in the later stages, and offer support for a dignified death. The objectives of palliative care in dementia involve maintaining the individual's existing functions, enhancing comfort, and ensuring the continuation of life (42,43).

Suggestions for the palliative care of patients with neurocognitive disorders include:

• Early detection of the disease,

• Endeavors to increase the comfort of the individual,

• Maintaining or striving to improve functionality,

• Enhancement of social resources,

• Inclusion of family and caregivers in the patient's care (42),

• Addressing the psychosocial issues faced by caregivers,

• Reviewing and respecting end-of-life care decisions made by the individual in the early stages of the disease (43).

Conclusion and Recommendations

The high prevalence of treatable comorbidities, which cause pain and reduce life expectancy in individuals with severe mental disorders, highlights the need to incorporate these individuals into comprehensive palliative care services. All mental health professionals must unanimously recognize the palliative care needs of individuals with severe mental disorders. Due to factors such as the holistic and trans-cultural nature of care, its relevance and acceptability in the health system and society, there is a need for national studies in this field.

Psychiatric nurses, who act as advocates for individuals with severe mental disorders, should recognize the significant gap in psychiatric palliative care in our country and prioritize work in this area. Leading the effort to produce methodologically sound studies that help define the current challenges for this disadvantaged population is the responsibility of psychiatric nurses.

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Correspondence address: Phd Stud. Emel Erdeniz Güreş , Saray Mahallesi Siteyolu Cd. No: 10-13 Ümraniye / İstanbul / Türkiye İstanbul - Türkiye, emelerdenizz@gmail.com

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