

The importance of holistic assessment in palliative end-of-life care and quality health outcomes

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Abstract

The present increasing numbers in terminal illness and chronic diseases gave rise to the importance of holistic assessment in the Indian clinical settings. Though being in the era of advance modern medicine and its components, people still die in distress as their mental disharmony and psychological suffering is not considered as a symptom to be treating in the Indian clinical setting. Dying should be as normal as birth; however, India turns out to be a country not to die as people died in vulnerable conditions. The absence of the holistic treatment in the Indian palliative end-of-life care resulted in clinicians treating the physical pain symptom alone, leaving the psychosocial and spiritual symptoms untreated, which requires special considerations alongside the physical pain symptom. The holistic assessment is a 'total care' or a 'whole person treatment,' which includes the treatment of physical pain, psychological suffering, mental disharmony, social values, and spiritual symptoms in the palliative end-of-life care. The holistic assessment is based on the unique principle; every human has different worldviews, having their own values, opinions, beliefs, and perspectives that need to be acknowledged and given special treatment until the inevitable death attack. Thus, the holistic assessment not only enhances the quality of life, but also served as a platform for the terminally ill patients can experience genuine choice and quality decision making in the face of inevitable death.

Key words: end-of-life care, holistic assessment, quality of life, terminal illness, suffering

ПАЛЛИАТИВТІК КӨМЕК КӨРСЕТУДЕ ЖӘНЕ САПАЛЫ КЛИНИКАЛЫҚ НӘТИЖЕЛЕРДЕ КЕШЕНДІ БАҒАЛАУ МӘНІ

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ТҰЖЫРЫМДАМА

Бүгінгі күнгі аурудың жәнтәсілім сатысы және созылмалы аурулар санының өсуі Үндістанның клиникалық жағдайларында кешенді бағалау маңыздылығына әкеліп соқтырады. Заманауи озық медицина және оның компоненттерінің ғасырына қарамастан, адамдар әлі күнге дейін қиын жағдайларда өліп жатыр, өйткені олардың рухани келіспеушілігі мен психологиялық қасіреті Үндістанның клиникалық жағдайларында емделуді талап ететін симптом ретінде қарастырылмайды. Өлім өмірге келу секілді қалыпты қабылдануы тиіс, алайда, Үндістанда адамдар нашар жағдайларда өліп жатыр. Үндістанда паллиативті көмек көрсетудегі кешінді емдеудің болмауы дәрігерлердің тек физикалық ауырсынуды ғана емдеуіне алып келеді, ерекше емдеуді қажет ететін психологиялық және рухани симптомдар назарсыз қалып отыр. Кешенді бағалау дегеніміз – бұл «жан-жақты көмек» немесе «тұтас тұлғаны емдеу», ол физикалық ауырсынуды емдеуді, психологиялық қасіретті емдеуді, рухани келіспеушілікті, әлеуметтік құндылықтарды және паллиативтік көмектегі рухани симптомдарды қамтиды. Кешенді бағалау бірегей қағидаға негізделген: әр адамның өзінің дүниеге көзқарасы, өзінің құндылықтары, пікірлері, сенімдері мен әлеуеті бар, олар шарасыз өлімнің келуіне дейін сезінуді және ерекше қатынасты қажет етеді. Осылайша, кешенді бағалау өмір сапасын жақсартып қана қоймай, өткел ретінде де қызмет жасайды, өйткені жәнтәсілім үстінде жатқан науқастар шарасыз өлімге қарамастан шынайы таңдау жасай және сапалы шешім қабылдай алады.

Негізгі сөздер: паллиативтік көмек, кешенді бағалау, өмір сапасы, аурудың жәнтәсілім сатысы, қасірет

ЗНАЧЕНИЕ КОМПЛЕКСНОЙ ОЦЕНКИ В ПАЛЛИАТИВНОЙ ПОМОЩИ И КАЧЕСТВЕННЫХ КЛИНИЧЕСКИХ РЕЗУЛЬТАТАХ

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РЕЗЮМЕ

Растущее число терминальных стадий заболеваний и хронических болезней на сегодняшний день приводит к важности целостной оценки в клинических условиях Индии. Несмотря на век передовой современной медицины и ее компонентов, люди все еще умирают в тяжелой ситуации, так как их духовное разногласие и психологическое страдание не рассматривается как симптом, требующий лечения в клинических условиях Индии. Смерть должна приниматься так же нормально, как и рождение; однако, Индия оказалась страной, где люди умирают в уязвимых условиях. Отсутствие комплексного лечения в паллиативной помощи Индии приводит к тому, что врачи лечат только физический болевой симптом, оставляя без внимания психологические и духовные симптомы, требующие особого лечения, наряду с физическими болевыми симптомами. Комплексная оценка это «всесторонняя помощь» или «лечение всей личности», которая включает в себя лечение физической боли, психологического страдания, духовного разногласия, социальных ценностей и духовных симптомов в паллиативной помощи. Комплексная оценка основана на уникальном принципе: у каждого человека свое мировоззрение, свои собственные ценности, мнения, веры и перспективы, которые нуждаются в осознании и особом отношении до наступления неизбежной смерти. Таким образом, комплексная оценка не только улучшает качество жизни, но также служит платформой, так как пациенты с терминальной стадией заболевания могут познать подлинный выбор и качественное принятие решения вопреки неизбежной смерти.

Ключевые слова: паллиативная помощь, комплексная оценка, качество жизни, терминальная стадия заболевания, страдание

Introduction

Looking at the current conditions of palliative end-of-life care in India, the primary care concern is on the physical pain symptom alone. The whole person treatment is an unheard therapy as the psychological suffering, mental disharmony, spiritual needs, and the social issues, which purely control the total well-being of a terminal patient were not acknowledges as symptom to be treated. The primary objective of the palliative end-of-life care as described by the World Health Organization (WHO) is not to prolong life, rather to deliver quality of life and good death. However, in the Indian clinical practices the terminal diagnosis is confine within the physical pain symptom alone, resulted in failing to produces quality of life and a good death in patient terminal experience. The exclusion of the terminal patient's psycho-emotional and socio-spiritual suffering in the terminal diagnosis will sometime resulted in worsening the physical health condition of the patient. The terminal experience is the worst experience one has to go through, it is occupy with several ill feelings like isolation, depression, meaninglessness, burdensome, and social stigma, which deliver mental disharmony [1,2]. It requires the interventions of multiple assessments such as physical, psychological, spiritual, and social assessment to deliver quality of life in the clinical practices. Thus, the whole person treatment is the need of the hour in Indian palliative end-of-life care to make death as normal as birth. The whole person treatment provide symptom relief and alleviated suffering by delivering the total care, rather than making oneself as a laboratory for experimenting the modern effectiveness of medicines and its outcomes. However, sadly India terminal patients died every year without receiving the holistic assessment. Thus, the current study is form with an aim to produce quality of life in the face of an inevitable death and to deliver good death in terminal experience in Indian palliative end-of-life care.

Objective

The study is form with an aim to highlight the importance of the holistic assessment in Indian palliative end-of-life care to deliver quality of life in Indian clinical practices.

Method

It is a collective review of the existing documents and literatures on the importance of holistic assessment in terminal diagnosis, followed by a critical analysis on its effectiveness. The study will be focused on four main assessments such as: physical, psychological, spiritual, and social.

Assessment in palliative end-of-life care: meaning and concept

Assessment in the end-of-life is a process of holistic approach of care, which provides an opportunity for those with life limiting terminal illness and their families to explore and identify the best approach of care to meet their needs [1]. It is a process of discovering the limitless possibilities that could be achieved though being with terminal experience and in the face of inevitable death. It is an ongoing person-centered care by acknowledging the total pain in terminal diagnosis that includes the physical pain, the psychological suffering, spiritual need, and the issue of socio-cultural stigma in patient terminal experience until the inevitable death attack. In contradiction to the confusion on who to access, when, where and what; the assessment should be given to every patient suffering from life limiting terminal illness irrespective of their age or setting. The primary focus of the holistic assessment is to discover what patient perceives to be his/her problems, the concern needs, and finding out how the patient could be prioritized in his/her life limiting terminal experience [2,3].

The holistic assessment can be assessed in any physical settings, either at home or in the clinical setting. However, it is important to ensure the comfort and privacy of the patient and its main aim is to minimize or relief the patient from physical pain and psycho-emotional sufferings to deliver quality of life. Palliative end-of-life care is a holistic care focusing on trans-cultural, comprehensive, and patient-centered therapy depending on the need and concerns of the patient and family [2]. In assessing the life limited terminal ill patient, it is important to have a proper Advance Care Planning (ACP) that is giving the freedom for patient to discuss the most appropriate approach of care as per the needs and concern of the patient and family. The discussion on ACP should fulfill the individual's concerns, patient values, or personal goals, and understanding about patient illness and prognosis [4,5]. In providing the quality and meaningful assessment in end-of-life care, it must be on a regular basis and should be delivering at the painful situation when the symptoms are often uncontrolled. However, at some point due to the lack of proper patient caring knowledge and the absence of proper training in end-of-life care among the clinician's, the health care professionals are unwilling to diagnose terminal ill patients who are nearing death and remain helpless [6].

Why holistic assessment is an important domain in palliative end-of-life care?

There is no easy way to deliver a quality of life to those experiencing the most unwanted experience one has to go through in his/her life. Moreover, in caring the distressing physical pain, discomfort, and psychological symptoms like emotional suffering and mental disharmony in the clinical settings, it requires maximum amount of efforts and attentions attained by the multidisciplinary teams, which is not visible in the context of Indian palliative end-of-life care at present. No doubt that in terminal illness or in chronic diseases, physical pain is one of the most common symptoms due to the weak body unable to restore the amount of energy to bear it. Pain becomes the most prominent risk factor for depression, change in behavior and suicide for those with chronic or terminal illness, which need special consideration for quality of life. Sadly, looking at the current Indian clinical setting, the primary aim is on physical pain symptom alone and leaving the bi-products of the physical pain such as psychological suffering, mental disharmony, the spiritual need for healing. However, the WHO on palliative end-of-life care stated that to improve quality of life the illness and all the problems associated with the illness need equal treatment. The psychological assessment can effectively deal with the depression, stress disorder, anxiety, emotional disorder, and mental disharmony for both the patient and the family. Ensuring the psychological well-being of the patient will lead to effective physical pain treatment and deliver quality of life. Moreover, majority of the people coping with cancer or life limiting terminal illness usually experience severe psychological distress, which is a unique discomforting emotional state to a specific stressor or demands that resulted in harm the individual permanently or temporarily [7,8,9].

For those facing or coming near to the end of life, psychological distress mostly manifested in the form of depression, anxiety, and adjustment disorder. In the journey of terminal illness, patient usually experience being alone in the continuum that resulted in experiencing fear, sadness, and grief leading to worsening their ill condition [8]. In the findings of Stiefel, the rate of depression undergone by the palliative end-of-life care patients ranges from 3.7 to 58%, and in Kessler findings the palliative end-of-life care patients experience depression ranging from 3.9 to 6.7 [10]. However, to Jenifer more than 60% of the life limiting terminal ill patients were reported having psychological distress as a result of their illness and 50% of the patients consulted their psychiatric, out of which 45% of the terminal patients were in the stage of committing suicide due to hopelessness, hallucination, exhaustion, and because of experiencing painful chemotherapy [7].

Moreover, unlike any other symptoms, depression is multifaceted and multidimensional in its functioning. In the western world, depression-measuring instruments like CES-D, HADS, and BD-II, are developed mainly to stress out the patient's nature of depression and are positively influencing towards the cognitive, somatic, and behavioral domains of one's life in the face of terminal and chronic illness [8]. Looking at the present condition of palliative end-of-life care in India, symptoms like depression and other psychological related symptoms are considered as the symptoms not to be treated in its clinical practices. Depression as a whole can be successfully taken care in a higher proportion only through the elimination of the distressing symptoms, with emotional support and counseling, which could explore fear and its components more appropriately [9]. Therefore, the psychological assessment in end-of-life care is always an important domain of care to deal

with the neuro-vegetative symptoms of depressions, and the process of treatment. It does not only improve the patient's mental and emotional moods, but also enhances their coping strategy that promotes their conformity with treatments.

Another important domain of the holistic care is the spiritual needs of the dying patients, as end-of-life care being a holistic approach of care does not limited its approaches within the physical, cultural, psychological, and economic needs, but also to the spiritual needs of the dying individual's. Mostly, the terminally ill patients acknowledge greater spiritual perspective and orientation than those with healthy and non-terminally ill hospitalize patients. It is not necessarily important to link spirituality always with the religious beliefs and sacred practices, like the current common concept of spirituality in Indian society and culture's as a whole, which relate and bound spirituality only within the religious beliefs realm. Recently, the WHO has declared spirituality as an important dimension for quality of life in the end-of-life care, and a tenet of palliative care. In broader term spirituality is a mechanism that operates one's thought and feelings in regards to ones wellbeing and purpose, basing merely to the individual's philosophies of life, rather than the established faith and religion. Thus, spirituality in palliative end-of-life care is more onto finding meaning, hope, comfort, and inner peace in one's life to deliver quality of life. The primary concern is to deliver the patient sense of purpose in life in any given environment [11, 4, 12].

Moreover, majority of the existing documents and literature's has recognized and described spirituality as the dominant factor in contributing patient's positive health. It is also an effective coping mechanism against depression, suicidal feeling, pain and suffering for the terminally ill patients, especially those nearing death. The spiritual psychotherapeutic is a subjective experienced that exists both within and outside the traditional religious systems [13]. The followings are the important principles that need to be assessed in delivering spiritual psychotherapeutic for those who are facing their end-of-life [14,15,16]:

- Principles of spiritual assessment includes, examining the importance of organized religion in person's life, his/her private religious or spiritual practices, along with those non-traditional spiritual practices. It is also important to acknowledge the intrinsic or extrinsic orientation of patient's spirituality and its practices.
- Investigation of individual spiritual identity refers to one sense of divine worth and its potentiality, as it is particularly important for the palliative care populations in the clinical setting.
- The spirituality psychotherapeutic involves the examination of the patient's inner resources on how the spiritual/religious beliefs, attitudes, and practices influence one's reaction to and with death and dying.
- The importance of examining the patient spiritual problem solving style such as: Self-Directing, Deferring, and Collaborative, to know whether the patient is fully independent and entirely rely to God for remedy and healing or the patient being in partnership with God to arrive at particular solution.
- It is important to acknowledge the functions of spiritual measurement scale and sub-scales, such as the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale, along with the Meaning and Faith Sub-Scale. These spiritual measurement scale and sub-scales addresses the overarching dimension of spirituality, the inner serenity, and peace within oneself. It also measures the extent to which individual find comfort and strength in their beliefs.

- There are three important aspects of patient needs: Situational, Moral/Biographical, and Religiosity. The situational need relates to finding purpose, hope and meaning. Reconciliation in relationships, prayer, moral, social analysis, divine forgiveness, and closure, support, religious rites/sacraments, visit by clergy, meditating on religious literature, discussion about God, eternal life and purpose, are the moral/biographical and religious needs.

- The last principle is the appraisals of one's own spirituality and its components, and the acknowledgement of the karma, and the chances/luck of healing from higher power, God or spirit in the face of medical helplessness.

On the other hand, spiritual assessment is not a mere talk or a simple recording process, it rather is a process of investigation that search for what the patient is feeling and thinking through verbal and non-verbal process for quality of life to deliver meaning and purpose in one's suffering [3]. Moreover, before the spiritual therapeutic assessment in any clinical setting, the assessor competencies in this area's need to be aware of the appropriate exploration on some aspects of Advance Care Planning (ACP) like Preferred Priorities for Care (PPC), Advance Decisions to Refuse Treatment (ADRT) and some other related issues [1].

It is also important for the clinician to acknowledge the risk in relation to terminal ill patient autonomy and social functioning. Social care plays an important role in supporting the ill patient by enabling him/her to connect with his or her own community and remove the feeling of being a social stigma. It helps the terminally ill patient to live the life they wanted and grant them the freedom to have the death of their choice. In the terminal experience, the social assessment is important as it aims to identify the patient's family background and to deliver emotional and social support, which usually improves the patients' conditions. Fulfilling the basic social assessment enhances the patient quality of life until the inevitable death attack. The assessor should be aware of the types of social assessments: the Statutory (legal/constitutional) and the Specialist Social Care. The statutory cares are mostly in practical and physical form that includes the support for the caretakers and families, even to the smallest task. On the other hand, the Specialist Social Care provides advance care planning, palliative care social support, debt/income maintenance advice, housing and advocacy support, and most importantly, the pre- and post-bereavement services [17,12].

The social care services, being the most important, valuable, and sensitive form of care for quality assessment can be provided by a professional care workforce, informal carers like families, friends and volunteers. Moreover, society as a whole does need to come together for the support and in helping to meet the demands of the dying individual and having family that enables someone to die at home with peaceful and more meaningfully. However, in the case of those who are alone and without having carers at home or elsewhere, hospital turns out to be the most likelihood place of dying [12]. Most importantly, good and effective communication between physicians, parents, and patient's plays an important role to avoid confusion and misinterpretations of the situation and issues. Information's and issues relating to dying and death need to be explored appropriately, sensitively, and in a clear manner. This will help the family and dying patient to have an opportunity for quality time and discussions, saying proper goodbye, contact relevant people, to prepare themselves for death and bereavement [18]. It is also important to let parents and community to access maximum number of hours as dying becomes an unpredictable

process with numerous possible trajectories depending on a person circumstances and diagnosis. Thus, death may take years, months, or days from when the condition becomes incurable to end someone's life. Even in the present context of India, people live seven years longer than before, but spends 8 years in bad/ill health resulting in experiencing the most vulnerable stage of their life. Therefore, multiple settings of care require to be delivered in different ways, to meet the patient's needs and helping them achieving their specific aspirations, rather than focusing on the medical illness alone. Moreover, looking at the emerging needs of the dying patient at present, it is true to say that, health and social care services are unlikely to cope with the effects of changing populations unless major changes had being made to the way they are delivered.

Conclusion and challenges

The modern medicines and its technology succeeded in treating and sustaining human life more longer than before, however, it fails to achieve well-being, quality of life, and a good or peaceful death. Especially in India today, when it comes to end-of-life care, due to the absences of holistic assessment in the palliative end-of-life care, it turns out to be a country not to die. The holistic assessment is not only an important approach of care, but also the needs of the hours for the dying patients. It is a pathway moving from the early identification of the dying phase, through changes in person's condition and in the treatments provided to the last days of one's life. It is the assessment that comprises the patient as 'whole person' by promoting an appropriate response to the patient needs in the face of death and dying. The whole person assessment in end of life care includes the factors like physical, social, psychological, and spiritual, which are identified as the important domains of care for the overall health, well-being, and quality of life. It provides the necessary skills that help to fulfill the core principles and objectives of end-of-life care, enabling 'good' and 'meaningful' death. Most importantly, it addresses the underlying issues for the whole person treatment, providing the needs by preserving and respecting the dignity, right for self-determination and the autonomy of the patients and families.

However, due to the confusions over its assessment like, who to assess, how, where, why and when to assess, holistic assessment turns out to be the most difficult task in the clinical environment. The confusions are mainly due to the lack of proper education and training among the health care professionals and other care providers in most of the existing medical colleges, institutes, and hospitals in the country. The unavailability of proper syllabuses like any other popular medicinal medical subjects is also an important reason of why quality of life, well-being, and peaceful and meaningful death cannot be achieved into its fullest in India. The failure of quality end-of-life care in India is also due to the negligence of hiring well-trained psychologists and other social workers in the clinical setting.

Though being the most difficult task in the clinical settings, holistic assessment at the end-of-life care is an important mechanism that comprises the patient as 'whole person' through promoting suitable response to the patient's need in their most vulnerable stage of their existence. Moreover, it is the mechanism or process of care, which brought the palliative end-of-life care into a new level of its existence by providing patients and families with maximum amount of effective and standardize end-of-life care. It also promotes well-being and quality of life in the face of medical helplessness. However, looking at the practical level of current professional medical practices in India, the holistic assessment is still in its infancy. The challenges lie

in implementing the objectives and principles of palliative end-of-life care, which were set up by the WHO and other medical organizations towards end-of-life care assessment. This being the reason, most of the medical hospitals and care centers in India, the ACP cannot effectively promote into its fullness. Failing in the implementations of ACP and other quality assessments like preservation of patient's dignity and autonomy, India remained

as the worst place for dying. The greatest challenges lie in the implementation of holistic care assessment as a subject of studies in the medical and para-medical academic program in the training process of the clinicians such as, the upcoming doctors and nurses as a whole.

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