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Awareness and utilization of palliative care among terminally ill cancer patients: A systematic review

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ABSTRACT

A number of studies have revealed the productivity of the palliative care in enhancing the cancer end-of-life patients' quality of life, yet the issues of its underuutilization become a challenge. This systematic review shall conform to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA), which is an abbreviation of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis. The literature search will be carried out covering different databases that include PubMed, Scopus, Web of Science, and Google Scholar for articles released before May 2024. In this abstract the author describes targeted educational interventions, better incorporation of the palliative services into the oncology treatment and strong policy measures for increasing the acceptance and accessibility of the palliative care. In a community 6.1 per 1000 population needs some form of palliative care. The overall awareness in a community of a developed country is 71%, yet people still feel, it is for cancers. According to the National Trends Survey, 66% of cancer survivors had no knowledge of palliative care, 18% had a limited understanding, and just 17% could describe palliative care to others. This includes even physicians in whom, 15% lack a comprehensive knowledge on palliative care. About 40% of the physicians felt incompetent in discussing the concept of palliative care with their patients. The inclusion of palliative care can actually be integrated from the beginning of the treatment with benefits in regard to the symptoms and may also contribute to an increased lifespan. On the forefoot, awareness and reduction of the negative perception held by the patients and their families about such services is possible with availability of patient educative materials on palliative care. Secondly, there is a poor concordance between the integration of palliative care into oncology care. Some literature points to the fact that timely referral to palliative care enhances patients' prognosis and decreases the costs to the system. Policy development requires this integration by putting in place policies, supporting structures, and reward systems for the integration of oncology and palliative care. Third, it is crucial to preserve community-based practices and outreach in regard to the early introduction of palliative care services. Strategic alliances between the hospitals and primary health care providers and with other NGOs can provide services such as skills enhancement programs, awareness programs, follow up support and home visits to patients and families affected by the neuro advantage. The final strategy in improving the taking of palliative care services is through the use of technology and telemedicine, especially in the rural and under-served regions. Using telehealth, remote monitoring of the patient, and the offering of support groups facilitating group therapy help fill the gap where patients cannot access palliative care services. Enhancing the awareness and use of palliative care among cancer patients will help not only to improve the patients' quality of life but will also address the needs of families in distress. We need to include a special drive to increase the awareness among cancer survivors, community as a whole, and even physicians with a thrust on developing countries.

Keywords: cancer, tolerated, patients, total pain, palliation, awareness

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INTRODUCTION

Sensitization on cancer palliative care becomes difficult in the face of misconceptions about its purpose, lack of wide-scale education, cultural stigmas, and emotional discomfort associated with discussing end-of-life issues. Targeted education campaigns along with compassionate conversations can dispel these barriers and shed light on such benefits for patients' quality of life. Awareness about common diseases is itself not easy to create [1, 2]. Cancer is among the most life-threatening diseases in man and claims an estimated 19. 312 new cases and about nine million 900 thousand new deaths in the year 2020 [3]. Palliative care is an integrated system in cancer treatment and its main goal is to support the quality of life of patients and their families focusing on physical, emotional, social, and spiritual aspects. In addition to being the focus of people with end-of-life or another terminal condition, the palliative care is valuable for the citizens struggling with chronic cancer. The overall awareness in a community of a developed country is 71%, yet people still feel it is for cancers. According to a Survey, 66% of cancer survivors had no knowledge of palliative care, 18% had a limited understanding, and just 17% could describe palliative care to others. However, as noted earlier, several reviews and researches have described the poor knowledge and utilization of palliative care among cancer patients [4, 5]. Even 15% of physicians lack clear knowledge on palliative care. Therefore, there is a growing importance to determine key factors of decision making that contribute to cancer patients' awareness of palliative care, as well as to define methods of increasing such awareness.

Thus, this systematic review seeks to compile available findings on the degree of knowledge and aspects that determine palliative care among patients diagnosed with cancer. Thus, using the results of an updated search in the databases of international scholarly journals, the analysis of the results of both qualitative and quantitative research carried out in the past decade will be conducted. The results of the present study will help fill the gap in existing knowledge about cancer patient awareness of the existing palliative care services and the related factors therefore will be instrumental to healthcare workers, policy makers and researchers who continue to strive to enhance the experiences and prognosis of cancer affected patients.

METHODOLOGY

This systematic review will be carried out in accordance with the

PRISMA, which stands for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The literature search will be done covering various databases such as PubMed, Scopus, Web of Science and Google Scholar for research articles published between the period of January 2010-December 2023. Some of the key terms used during the research will be 'palliative care', 'awareness', 'terminally ill', 'cancer patients' and 'utilisation'.

Inclusion criteria will include investigation of the factors influencing terminally ill cancer patients' knowledge and use of palliative care which should be published in English only those studies that include quantitative or qualitative data will be included. Both the titles, abstracts as well as the published full texts will first be scanned by 2 persons for both relevance and quality standings. Any discrepancies that may occur will be settled through recommendations.

On studies identified, data will be retrieved on features such as study type, sample characteristics, patients' knowledge regarding palliative care and possible barriers to use palliative care. Risk of bias will be conducted by the Cochrane risk-of-bias tool. Information sources will be merged narratively and, if possible, quantitatively using meta-synthesis (Figure 1).

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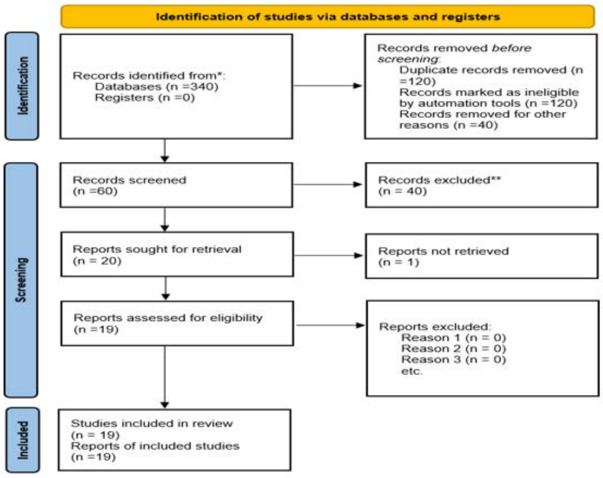

Fig. 1. With Prisma flow chart

Economic status and awareness

In this case, palliative care is another crucial part of cancer care focused on enhancing the patient 's and the family's quality of life concerning their physical, emotional, social, and spiritual needs. But studies reveal that abstract knowledge of palliative care among terminal cancer patients is not very high. Although dealing with cancer, controlling symptoms, offering consolation, and enhancing the patients' quality of life are all essential aspects of palliative care, many patients and their families regard the palliative care as a type of care provided to the patients in their terminal phase.

The surveys have found that the majority of patients still link the term palliative care with a hopeless prognosis and not as the approach to lessening symptoms and supporting patients during all the stages of their illness [6, 7]. These misconceptions can result in late referral, missed chances to effectively manage symptoms and thereby worsen quality of life of the patients and their careers.

A recent systematic review on distribution of palliative across the globe also showed the different but huge gaps in here and there and low and middle-income countries [5]. In the high-income countries, where the access to the palliative care is relatively higher, there are the low levels of awareness about this kind of service depending on the different misconceptions on the type of services that it offers and the positive impact that can be derived from its utilization. However, people's awareness in LMICs where access to such services is significantly limited is even lower, which shows the necessity of education and raising awareness in these countries.

Various factors explain why the knowledge of palliative care is scarce among cancer patients. These include patient and physician factors such as absence of access to communication on the opportunities and uses of palliative care, cultural beliefs and perceptions and lastly the patient's' loss of hope or [7].

Altogether, this kind of study and its results are problematic due to patients' general lack of awareness, misconceptions about, and the social stigma associated with palliative care since patients who are provided with such care have lower symptom, better quality of psychological well-being, and higher quality of life than those who do not [8]. It is thus critical to raise people's consciousness about the existence of palliative care and combat myths about this type of treatment by involving patients, their families, and healthcare workers in information campaigns.

Several factors contribute to low awareness levels. Cultural factors play a crucial role, as various cultures have differing attitudes towards death, illness, and healthcare. Misconceptions that accepting palliative care means giving up active treatment also persist. According to the study by many patients and families believe that opting for palliative care means that the healthcare system has given up on the patient, which discourages them from seeking these services [9].

Barriers to utilization

Healthcare provider factors:

One of the main problems which were identified is the absence of qualification training of the healthcare providers and proper experience in the discussion and recommendations of the questions connected with the palliative care; this can be discussed due to the weak emphasis on the questions connected with palliative care in the medical curricula. Overall, with regards to communication, survey revealed that about 40% of the physicians felt incompetent in discussing the concept of palliative care with their patients [10]. This shortcoming can lead to the loss of the opportunity to increase the quality of terminal or serious patients' treatment. Palliative care management is the primary and continual focus of training and education of healthcare practitioners in communicating the care options for the terminal treatments, pain relief and other physical and psychological symptoms, and assisting patients and families in the difficulties of serious illnesses.

Patient and family factors:

The society, patients, and their families are often confronted with fear, denial, and ignorance about the advantages of utilizing palliative care services. According to a survey, this non-acceptance of palliative care can be attributed to the Lamp's and his or her family's denial or unawareness of the incurable nature of the disease [11]. Patients get scared when they are told they have only a short time to live and consider hearing about end-of-life care a sign of abandonment hence denying themselves a chance to health palliative care services.

In addition, this may also be due to the fact that people lack information concerning what it is to receive palliative care. Palliative care is not only limited to end-of-life patients but can be provided to all seriously ill patients and focuses on physical, psychosocial, and spiritual dimensions of the individual as well as the coordination of care. Enhancing clients' knowledge on the objectives and advantages of receiving palliative care can also provide assurance and elucidate their reasons for receiving the services, thus overcoming some of the causes of denial.

Patient cultural rights entail using proper communication techniques when discussing options of the palliative care with the patients and their families. Thus, developing trust, as well as mutual cooperation and appreciation, key to successful partnerships for reception of respected individualized care and proved to be efficient for clarity of the idea, the contribution of palliative care for people, who faced serious illnesses. Belief systems, which are cultural and religious, can also be a reason why people refuse care. Sometimes, patients and doctors prefer invasive management, and broaching the topic of palliative care might be considered improper or culturally biassed.

Systemic factors:

A key area is how systematic factors prove instrumental in preventing the institution of optimal palliative care options in cancer care units. One of the main problems is the extent of discontinuity of care given by multiple facets of the healthcare delivery system and delivering proper continuity of care between them. This is usually accompanied by a delay in the referral of patients to the appropriate palliative care service.

In a study done, set trends show that few cancer patients are referred to palliative care at the right time [12]. The reasons for this are symptomatic; they comprise underdiagnosis and assuming that such referrals dictate a terminal input. Besides, the present members of the healthcare service providers may misunderstand the requirements of palliative care or feel awkward in conveying details of terminal care to the patients.

There are also several other gaps of the health system that contribute to the problem; the provision of palliative care services is severely rationed, especially in low-income and rural communities. Problems in this area arise from this restriction in access because the people who live in these areas do not get early and effective medical attention.

Interventions and improvements

Based on the results of researches, there are several interventional and improvement strategies regarding the enhancement of awareness of patients with cancer regarding palliative care. Such efforts are meant to help phase the gap and encouraged people to seek services of palliative care at an early stage.

One strategy is to build capacity for teaching about and practicing palliative care among healthcare professionals commencing on a medical course, nurses, and any other learners in the healthcare field [10]. This will help providers identify the cases that require this kind of care and to be more open with clients regarding such issues as the end-of-life care. The third intervention entails use of patient education for palliative care of cancer patients through use of relevant materials. These resources can be made available through printed brochures, online websites, and patient support groups who have been described to play a critical role in patient support [11]. Through enhancing knowledge and understanding about palliative care services among the patients and families that seek them, more persons will be able to avail for these services without having to face numerous misconceptions and decrease their fears. Awareness programs and community programs may also help in early referral to palliative care services. These interventions may include hospital and primary care collaborations with community organisations to provide workshops, support group sessions and home visits for the patient and his or her family [12]. However, increasing the utilization of technology and telemedicine that offers palliative care services to the underserved rural areas can be considered as a solution. This has created duality in terms of utilizing telehealth, remote monitoring, and virtual support groups to ensure the patients have a way of accessing the palliative care services even if they cannot attend specialized care services physically.

Educational programs:

Courses directed for the officials of educational institutions that are operating can be immensely beneficial to upgrade the dealing skills of the healthcare providers that are concerned with the palliative care. For instance, a pilot program described was helpful in enhancing healthcare providers' knowledge of ways of talking to the patient regarding palliative care [13].

Public awareness campaigns:

Promoting the understanding of the public about palliative care includes creating broader awareness about the advantages of this type of care at every stage of the allowable disease. Such campaigns could include a patient's and or family members' success stories of palliative care as recommended in the campaign model [14].

Policy Initiatives:

Efforts to bring palliative care into mainstream cancer care need to be given through policy. The policies could also recommend that patients receive their first consult for palliative care at the time of cancer diagnoses, while endorsed healthcare institutions should ensure that they allocate enough funding and resources to reach offer these services. The WHO has issued standards regarding the implementation of the palliative care at different levels and countries' health systems recommendations respond to such guidelines (World Health Organization, 2018) [15].

DISCUSSION

Thus, the information gathered in different studies and researches on awareness and use of palliative care in terminally ill cancer patients reveals a notable gap that has been left unaddressed. Undoubtedly it is important to educate people about infertility and its risks, to develop changes at the organizational level, and make certain adjustments in the legislation [16].

Firstly, there should be improvements in education being provided to hospital personnel concerning the sphere of palliative care. Inclusion of elements of palliative care in the fundamental curricula of medical schools would possibly provide future professionals with the amount of knowledge and confidence in implementing the services necessary as well as allow to feel comfortable discussing terminal care with the patients [10].

Secondly, it is also important to eliminate the systematic barriers in being able to achieve early referral to the palliative care. This can also be done supported by effective communication of the physicians with the patients and their families, coordinating the timing of the transfer to palliative care services [11]. In regard to these barriers one of the successful strategies is to form the interdisciplinary teams comprising oncologists, primary care physicians, nurses, social workers, and chaplains, among others. They can ensure integrated care focusing on cancer patients involving palliative care in the course of the disease [17].

Another useful strategy is to include patient education materials that focus on palliative care into the patients' treatment regimes. It can also be disseminated through printed forms of advertisements such as the brochure and through information technology in the internet and support groups of patients [11]. To reduce figures of fear and misconceptions about the services provided by palliative care, there is a need for health care practitioners to enhance the knowledge of patients and families that receiving palliative care is an important aspect to receive.

It also means that local programs and awareness-raising activities may be helpful in encouraging the early use of some sorts of palliative care. Such interventions may consist of programmer coalitions with hospitals, primary care, and community agencies to provide workshops, support groups, and home visits for patients' and families [12].

Finally, such service delivery models as technological support and telemedicine facilitate the delivery of palliative care in suburban and other remote regions. Mobile apps, video consultations, home visits, monitor patients' health via technologies, and teleconferencing for support groups can address the problem of inaccessibility of specialized palliative care for some people [10].

Critical comments

Palliative care is one of the components of cancer treatment that aims at preventing, identifying, and treating symptoms and psychological and spiritual distress. Unfortunately, despite the widespread advocacy for it, informing more cancer patients of available palliative care is an issue that has not been overcome.

In its turn, the first problem is the absence of primary education by healthcare professionals about the possibilities and aims of using palliative care services. Patients or caregivers can be ignorant of when or if they should seek palliative care and also, that it is part of the total cancer therapy. In addition, some of the patients and/or their families might see managing of symptoms and improving quality of life before death as a surrender to treatment but not as a choice to receive the best care regardless of the stage of the disease.

Secondly, culture and religion can also affect decisions by patients on matters concerning acceptance of palliative care. However, there are many centres and communities where the meaning connected with the term "palliative care" is associated with negative connotations that may hamper the patient from obtaining needed service. This is especially important as anyone giving care must be sensitive to culture and approach this matter with any issues or perhaps misconceptions about the practice of palliative care.

Thirdly, there might be restrictions concerning the funding and provision of accessible and effective palliative care. This is especially important in delivering palliative care since these are specialized skills and may not be available in some impoverished resource environments. However, the cost of implementing these services is rather high and thus, many patients and families cannot afford the palliative care services. Finally, the programmes for continuing education and training of healthcare providers are needed so that the providers themselves have requisite knowledge and skills in palliative care. However, the development of these programs may not be a common practice, or feasible for all the professional bodies in the health care delivery systems. Besides, it has been suggested that there is a requirement of frequent training and continuing education to update the advancement of the palliative care [18, 19]. In conclusion, the enhancement of the level of knowledge of cancer patients regarding palliative care still poses a significant concern and needs a combined methodological approach. Stakeholders need to increase awareness campaigns to encourage the use of palliative care, work on demystifying culture and religion, to consider the issue of resources lastly, accept to invest on personnel through training and education. As a collaborative effort in addressing these issues, the quality of palliative care that will be provided to all patients with cancer is guaranteed to be complete and sensitive from the moment of diagnosis to the time of death.

Physician awareness

One study found a lack of understanding and insufficient expertise in the management of terminal patients addressing various medical and ethical issues with Palliative Care. Formal education and training are urgently required to improve the overall view and practice of palliative care [20].

Palliative care training and understanding are lacking among doctors across departments [21]. Almost all doctors are interested and willing to receive additional training in pain management, conveying terrible news, communication skills, and terminal care.

CONCLUSION

There is a lack of needed awareness about palliative care among cancer survivors, and also in a community which includes even physicians. There is an urgent need to enhance awareness and utilization of palliative care among terminally ill cancer patients. Targeted educational initiatives, better integration of palliative services into oncology care, and robust policy measures are essential to bridge the existing gaps. Improving palliative care awareness and utilization will not only enhance the quality of life for patients but also provide much-needed support to families during challenging times. We need to include a special drive to increase the awareness even among community, physicians with a thrust on developing countries.

CONFLICTS OF INTEREST

All the authors have contributed significantly to the article. The authors declared no conflicts of interest.

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