Palliative Care for Palestinian Chronic Cancer Patients in the Community

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Introduction

Millions of people around the world, principally in developing countries, endure great suffering and economic hardship due to life-threatening illnesses such as cancer. According to a WHO global perspective, the key feasible alternative to these urgent needs is to improve quality of life by developing an effective, low-cost approach for palliative care service of good quality and coverage. The best way to do so, in countries with strong family support and poor health infrastructure, is by home-based palliative care [1, 2]. So far in Palestine, palliative care services are not yet integrated within the Palestinian health-care system. Response-based actions are taken by health-care providers to control symptoms of patients with chronic diseases such as cancer, usually inside hospitals. In the community, the conditions are much worse, as still no community-based palliative care services are available.

In most cases, patients go from the hospital back to their homes and rely mainly on their family's help and care. Moreover, in most developing countries there are either very few community-based hospices for cancer patients or none at all, as is the case in Palestine. It is believed that this kind of situation cannot continue for too long a time since the sick patients, along with their families, very often cannot carry the load of both the physical and financial burden, as well as the emotional stress that is associated with chronic diseases such as cancer.

Cancer is one of the leading causes of death both worldwide [3], and in Palestine [4]. Approximately 70% of cancer deaths occur in low- and middle-income countries, and up to 50% of cancer deaths could be prevented by the implementation of evidence-based strategies for cancer prevention, early detection, and management [3]. In Palestine, cancer is the second leading cause of death, accounting for 15.4% (1863) of all deaths. In 2018, there were 3102 new cases reported in the West Bank of Palestine, with an incidence rate of 117.7 per 100,000 [4]. Most cases are diagnosed at the end stage of the disease [5, 6]; this late diagnosis makes it difficult to treat and resource cancer care, and results in poor health-related quality-of-life for cancer patients and a high financial burden on patients, their families, and the health-care system. One study measured the health-related quality-of-life of Palestinian cancer patients at as low as 42 points on a scale of 100 [5]. On the other hand, the cancer incidence in Middle Eastern countries is predicted to increase by 70% in the next 20 years - greater than any other region of the world [7]. Also, the high mortality rate is an indicator of late diagnoses of cancer and highlights the need for palliative care services for this

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population. Literature discusses that the first point for estimating the need for palliative care is the number of deaths [8], especially as the reported overall survival rate in less-developed countries is 30% [9].

Additional resources are necessary in order to deal with advanced diseases, especially in the absence of integrated palliative care services within the health-care system. Costs were highest for those who died in chronic-care facilities and lowest for those who died in the community at home [10]. Home-based end-of-life hospice care has the potential to lessen the demand for acute hospital care, emergency department visits and admissions, as well as to increase patient satisfaction and number of home deaths [11, 12]. In several studies, home-based hospice palliative care was found to be cost-effective and reduced the need for other health services. Those receiving palliative care had health-care costs that were one-third lower [12]. A study in Israel found home hospice care during the last 2 months of life to be less costly than conventional care [13].

Subsequently, there is a significant need for palliative care services in the Middle East, including Palestine [14]. A survey of countries in the region showed that 86% of respondents wished to learn more about palliative care, whereas the question of how to finance such teams was one of the main concerns among the health-care professionals and administrators surveyed [9].

Current Situation

The rising financial burden of cancer care on health-care systems worldwide has led to the increased demand for evidence-based research to find ways to lower medical costs. 95% of stage four cancer patients in Palestine were undergoing expensive chemotherapy treatment, while their quality of life (QoL) was only 31% on a scale of 100 [5]. This shows the extremely deteriorated QoL of patients who are approaching the end of life, while maintaining expensive curative treatment modalities at hospitals, with no community backup, support, or care. A large proportion of the expenditure in Palestinian health care goes to expensive curative care outside the area [6], whereas a number of studies found that PC improves quality of life and lowers the costs of care to cancer patients and families [15, 16].

Nevertheless, most Middle Eastern cancer patients are not treated in the community. Home-based and hospice services must be sustained, as well as encouraging palliative care education [9]. This model of care is associated with additional benefits, such as increased patient and family satisfaction and choice, suggesting that cost alone may not be adequate to judge service delivery models [17].

There is a relatively low level of pain control, palliative care, staff training, and health facilities that care for cancer patients in Palestine. To the best of our knowledge, there are only three main centers for cancer care in the West Bank of Palestine, and only one non-governmental organization dedicated to palliative care. Unfortunately, there are no organized palliative care services in Palestine yet. As far as we know, there are no hospitals, community primary health centers, or home-based services available for cancer patients. In addition, there are no hospices or home hospice care available for such patients. Palliative care nursing is still underdeveloped in Palestine.

Even so, there are new initiatives to establish palliative care in the country. A non-governmental organization in Bethlehem, the AL-Sadeel Society for Palliative Care for cancer and chronic diseases, which was established in 2008, is the first palliative care society in the country. It focuses on spreading awareness about the importance of palliative care service and the need to integrate it within the health-care system. Its work includes follow-up on cancer and other chronic diseases at homes in the community on a small scale. This is done mainly by a small team of workers and based mainly on voluntary endeavors. One of their successful initiatives is the lending program of medical devices and equipment, which is trying to bridge the gap of the absence of such equipment provided by the governmental and private services. Some other programs are starting in the academic field either by integrating palliative care education within the curricula or by establishing stand-alone courses and programs on both undergraduate and postgraduate levels. One master program is expected to begin by the end of 2020 in Bethlehem, which will have a major focus on palliative care.

What Are the Difficulties?

Palliative care is not yet integrated within the national health-care system in Palestine [5, 14, 18]. The poorer QoL of cancer and chronic disease patients in the Palestinian community could be due to the deteriorating socio-economic and political situation in the country, as well as the lack of professional and specialized care to support those patients. Challenges include insufficient secured funds for organizations working in the field, weak governmental support, limited prioritization of palliative care by the policy makers, and absence of facilities for community-based palliative care and home care. Literature shows that the main problems in the region are shortage of funding or governmental support and lack of awareness among the public, as well as policy makers and professionals, concerning the need for such services [14].

Moreover, the national economy, strategic planning, health-care policy formulation, and the setting of national priorities are affected by the predominant geopolitical conditions, political, geographical, and administrative fragmentations of Palestine under occupation and barriers to movement; all these have damaging effects on the health-care system [6, 19], mainly in the community and on the most vulnerable people residing in areas remote from urban centers.

Community Involvement

Attitude toward end-of-life care and palliative care is somehow unclear due to the limited number of studies on the attitudes of the Palestinian communiity and population. Issues such as writing a will, choosing a health guardian, and peaceful death are not well-known, even amongst health-care professionals. There is an grave need for public awareness campaigns in the community and throughout the mass media. Topics should include the importance of palliative care for better quality-of-life for cancer and chronic disease patients and end-of-life care needs. Societal and religious figures of the community need to be involved in order to identify any cultural or religious barriers, which may not necessarily be in line with the concept of palliative care itself, but to education in palliative care [20]. However, some cultural thoughts are positive when it comes to death and dying. Death is somehow an acceptable event for many individuals, from a religious view, as it is the path to mortal life and happiness, as is the acceptance of associated pain or discomfort as a means to cleanse one's sins. Inside this debate, many patients would respond that they prefer to die at home, even though when the time comes, they and their families run to hospitals and die there, mainly as no services are available in the community to support these patients and families.

On the other hand, the community's and professionals' attitude toward the patients' perception of pain and their disbelief of the patients' complaint of pain hinders pain management in the community as well as in the hospitals. In many Middle Eastern countries, moderate to severe pain appears to be controlled using multimodal therapy, including the usage of nonsteroidal anti-inflammatory drugs and limited doses of injectable opioids [21]. In the Palestinian community structure, there is a culture of shame in admitting pain, especially in the masculine community, and the belief that bearing pain makes one stronger. The fear of addiction, fear of the limited available options, fear of complications, respiratory depression, fear of losing control, and the will to maintain the ability to communicate and be present with the people surrounding them, are some of the cultural barriers to better end-of-life care and pain management. Similar discussions can be found in literature, specific to the Middle Eastern region, debating the culture of taboo and the stigma of cancer and its pain, and citing that people consider and accept pain as part of the disease [20].

Furthermore, the community usually tries to help chronic disease patients and their families. The community provides good emotional and social support in the event of illness and loss. The society in Palestine, like other Arab countries, is collaborative in their support to individuals in need - emotionally, by giving them a sense of belonging, and even with financial assistance. Ultimately, these humanitarian endeavors are still limited and based on personal relationships and geographical boundaries; they cannot make up for the lack of community-organized palliative care services.

Community Professional Infrastructure

Palliative care (PC) is still a new theme in Palestine. As such, new palliative teams are advised to begin at the bedside, to show everyone what they can do, to be available, and also to educate other staff members [20]. There are a few palliative care nurses in Palestine who are officially trained and certified, through a combined oncology and palliative care diploma program. These efforts are still in the early stages and need a lot of support on both national and international levels. However, the AL-Sadeel Society for Palliative Care provides a palliative care consultative model through a team of palliative care nurses and two social workers specialized in palliative care. This is done mainly by telephone, as there is very limited access to the patients' homes. Approximately 200 patients were served by this team in 2018, according to the Society's registry. The author would like to add that the Society succeeded in acquiring a scholarship from the American National Cancer Institute for one doctor to be specialized in palliative care for oncology patients in Israel. This doctor is now practicing in East Jerusalem hospitals with limited access to Palestinian patients due to the restrictions on the freedom of movement by the Israeli authorities.

There are still no services such as hospices, geriatric homes, or home-nursing. There are, however, some unorganized and non official home care nursing services scattered throughout the centers of some urban areas, which are based on personal contact with patients undergoing hospitalization. There are two privately owned centers in the West Bank of Palestine that provide private home care nursing services for direct out-of-pocket payment [18].

A local study in the West Bank of Palestine showed that nurses had poor knowledge of palliative care [22]. Moreover, most health-care providers in Palestine who work in cancer units need training and education in providing patients with palliative care [23]. Palliative care requires competent practices which may be achieved through training programs, an essential part of standard cancer care. Of course, investments in human and logistic resources are needed [24].

What Can Be Done?

Based on the findings from a recent study by the author, the quality of life of Palestinian cancer patients is very poor, especially for those in the advanced stages. Palliative care was found to demonstrate improved outcomes of care and save costs for the health-care system. Long-term palliative care service and the persistent work of the palliative care team is essential for success. The adoption of such cost-effective strategies by policy makers would appear to be a wise use of public funds. The study recommends further research on a broader scale and longer follow-up periods to reinforce similar conclusions [25].

On the other hand, the incidence of cancer in the Middle East is predicted to double in the next 10 years, more than in any other region of the world [26]. The Worldwide Palliative Care Alliance recommends that palliative care be integrated into countries' health-care systems [27], as long as it is estimated that 80% of the adults requiring palliative care live in low- and middle-income countries [28]. Nevertheless, socio-cultural, ethical, and religious involvement are crucial to the palliative care initiation in the Middle East, due to the prevalence of religious observance and community structure [9].

Arguably, in order to develop palliative care teams in the Middle East, the most urgent task is to focus on the education of professionals [20]. Health professionals must be trained in palliative care, attend scientific workshops and conferences for professionals who are working in the field of cancer care, and palliative care education should be included within the curriculum of schools for health professions [18, 23, 29]. Cooperation and support from the Ministries of Health and Education, local cancer care centers, education bodies and international support are vital for success, extending to policy makers' involvement and priority-setting on both national and international levels.

Further recommendations include: providing support for patients with cancer and chronic diseases and to have palliative care and symptom-management facilities all over the country. Also, to ensure drug availability, especially adopting an essential drug list based on the international essential drug list for palliative care, to address the stigmatization of patients and, finally, to monitor systems for the proper practice and provision of oncology health services in the community and other health facilities. Regrettably, Middle Eastern countries still need governmental policies that recognize palliative care [30]. The successful example of the Al-Sadeel Society can serve as an inspiration for the initiation and adoption of palliative care models in Palestine.

Conclusion

There is a desperate need for integrating palliative care into the health-care and community-care systems in Palestine. The integration of cost-effective community-based palliative care services will provide a solution to the burden on the health-care system and patients at the same time. Efforts need to begin by integrating palliative care into the national health plans and health education, training providers of palliative care at different levels (including community health workers, nurses, and physicians) providing good home-based care and institutions providing home care, and valuing competent palliative care science and culture within the community and nation.

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