



**REVIEW: PALLIATIVE CARE EXPERIENCE OF GASTRIC CANCER PATIENTS IN  
AN ACUTE CARE SETTING IN JORDAN**

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**ABSTRACT**

Palliative care is an essential healthcare services and ethical responsibility towards patients suffering from serious life threatening diseases such as cancer. The main goal of palliative care is to prevent or reduce the symptoms or side effect of treatment as early as possible to improve patients' life quality and their families, including psychological, social, and spiritual approaches. Recently, palliative care in developing countries is evolving rapidly, but has far to go compared to Western countries. Palliative cancer care in Jordan has witnessed remarkable improvement during the last two decades but still inadequate. However, many limitations and barriers encounter implementation of palliative care in Jordan.

**KEYWORDS:** Palliative care, Cancer care, Jordan, Nursing, Gastric cancer.

**INTRODUCTION**

Recently, palliative care is progressively established in developing countries, and its significant role is recognized dramatically by healthcare providers. World Health Organization (WHO) considers palliative care as one of essential healthcare services and ethical responsibility, that improves the life' quality of patients and their families who are suffering from threatening diseases and illness. The approaches aim to assist patients and prevent associated suffering from pain and other distressing symptoms by early identification, accurate assessment, treatment, and management of pain through physical, psychosocial and spiritual aspects.<sup>[1]</sup>

Every year, it is estimated more than 56.8 million patients are require palliative care around the world. Unfortunately, the number suggested to increase due to population aging, and the great risk of noncommunicable diseases and chronic illnesses. The statistic showed that 55% of patients require prior palliative care, compared with 45% require near the end-of-life palliative care. Whereas 67.1% of patients are adult over 50 years old, and 7% are children. Unfortunately, the majority of adult (76%) patients who need palliative care live in low and middle-income countries LMICs, leading to significant need to establish and improve palliative care.<sup>[2]</sup>

In 1948, the British doctor Dame Cicely Saunders established the first official hospice dedicated to the care of patients with terminal illness. The achieved outputs

showed a progressive improvement of patients' quality of life. Leading to recognize the importance of hospice care and introduced the concept by other physicians. In 1990, the World Health Organization (WHO) confirmed that palliative care is a distinct specialty in relieving suffering for patients with life limiting illnesses.<sup>[3]</sup> Furthermore, the WHO declared that palliative care requires a multidisciplinary approach in order to improve the quality of life and alleviate suffering for patients and their families. Significantly, team approach with specialist's team playing a fundamental role to manage different symptoms associated with illness and enable them to deal with various stages of their diseases.<sup>[4]</sup>

Globally, units of palliative care are increasingly established especially in Western Europe and North America. Where palliative care has prompted attention and included in the education of medical and nursing colleges, and it is also a part of the approach accepted in the physicians' specialization program.<sup>[5]</sup>

On the other hand, the great majority of world population lives in low and middle-income countries LMICs. Where palliative care is underdeveloped due to difficult economic situation and poorly equipped healthcare facilities. In addition to that, LMICs are more frequently suffer from chronic and noncommunicable diseases such as AIDS, heart failure, cancer, multi drug resistance and chronic respiratory diseases.<sup>[1]</sup>

### About Jordan

The Hashemite Kingdom of Jordan located in Southwest Asia, specifically in the Middle of the Arab Orient in the southern part of the Levant and the northern part of the Arabian Peninsula. Administratively divided into 12 governorates and occupies an area of 89,287 km<sup>2</sup>.

Religion and the family are the most important factors in Jordanians' beliefs. Islam represents the basic religion in Jordan, and Jordanians believe that health, wellness and disease are the will of God. In general, Muslims in Jordan rely on religious practices to alleviate their pain. Cooperation among Jordanian individuals and supporting each other in the illness trajectory is a key characteristic of the Jordanian people, as all family members and friends share the support of the injured individual.

### Gastric Cancer and Cancer Care in Jordan

Cancer incidence is increasing dramatically around the world, making cancer diseases the second cause of deaths. WHO estimated that 9.6 million deaths in 2018 associated to different types of cancer. Unfortunately, the number is suggested to double at the end of 2030.<sup>[6]</sup> Statistics showed that gastric cancer is the fourth leading cause to deaths globally. According to the Jordan Cancer Registry (JCR) cancer diseases are the second cause of death after cardiovascular diseases with (15%) and (36%) respectively. Cancer increasing rate is significantly increased between 2000 to 2011 to reach 39%.<sup>[7]</sup>

Gastric prevalence often develops from poorly managed gastric ulcers due to mucosal infections.<sup>[8]</sup> This cancer is insidious with most patients ignoring symptoms resulting in a diagnosis at an advanced stage. The risk increases with exposure to the infective bacterium *Helicobacter pylori*, which invades the mucosa of the gastric lining. About one-third of gastric cancer cases result from this infection.<sup>[9]</sup> Another risk factor associated to substances in foods (culturally part of the Middle Eastern diet) such as smoked foods, dried, salted or spicy foods that increase the amount of nitrate in the stomach.<sup>[10]</sup> Conversely, a diet rich in fruits, vegetables or foods stored safely and refrigerated is encouraged to reduce the risk of gastric cancer.<sup>[11]</sup>

In 1997 the first specialized cancer center King Hussein Cancer Center (KHCC) was established to improve the level of care for cancer patients in Jordan. Followed by the first cancer care initiative under the name of (Jordan Palliative Care Initiative) in 2001. The center receives approximately 3500 new cancer patients every year, and providing treatment for about 60% of cancer patients. In addition to that, treatment and surgical services are provided to cancer patients in both public and private hospitals in Jordan, radiotherapy is only available at the King Hussein Cancer Hospital (KHCC) and Al-Basheer Hospital. As for palliative care, this service is not available in all hospitals except at the King Hussein Cancer Hospital and recently at Al-Basheer Hospital.

Omran & Obeidat *et al.* 2015 proposed interest in the palliative care specialization has begun to appear in the Arab countries, and is already progressing in Jordan and Saudi Arabia, and under establishment in Egypt and Kuwait. In the current health climate, there is a need to ensure there is a comprehensive strategy to progress this specialization with the Ministry of Health in Jordan to enable access to all who need it.<sup>[12]</sup> However, there is still much more to be done to determine the effect of palliative care on the experience of gastric cancer patients and the level of its contribution in enabling them to cope with advanced stages of the disease. This potentially may occur through understanding the gastric cancer patient's experience.

Practically, Jordan health care providers have achieved many improvements in palliative care during the last two decades. Prior to the introduction of palliative care in Jordan, the "End of Life Care" service was provided through the Al Malath foundation in the capital Amman. This institution was established in 1993 and aims to provide health care (palliative) services to people with terminal illness whose life is limited. In early 2001, the Palliative Care Initiative for Nurses was launched in Jordan, which focused on training nurses to provide palliative care services in Jordan. In 2004, King Hussein Cancer Center (KHCC) was the first center to provide palliative care by establishing the first palliative care unit in Jordan. The unit was specialized in the provision of palliative care services through a specialized team. The team also provided palliative care services to patients in the home. This service was then introduced at Al-Bashir Hospital.<sup>[13]</sup> However, despite the various steps that Jordan has been able to take in order to enhance the concept of palliative care; Jordan still faces many obstacles and challenges that limit its effectiveness and quality of life for patients.

### METHODOLOGY

A narrative review has been selected in presenting the associated theoretical literature of the study. The electronics databases CINAHL, EMBASE, SCOPUS and the Web of Science were systematically searched through keywords using Boolean operators of; palliative AND care AND cancer AND patients OR people OR Person AND Hospitals OR Acute care OR Surgical patient OR surgical ward OR medical wards OR medical patient OR Inpatients AND Nursing OR Nursing profession AND gastric cancer were conducted.

### Inclusion Criteria

Articles that included primary research OR secondary research (literature reviews) or case studies OR discussion papers OR newspaper articles. Selection has been focused on studies conducted in Arab countries similar to Jordan. Studies and discussion papers relating to palliative care experience in the middle east countries.

**Exclusion Criteria**

Studies that examined the experience of nurses and their families were excluded but were used to support the theoretical framework since the focus of the current study will be on the experiences of the patients themselves.

**RESULTS**

Through applying research methodology, the obtained literatures that met the criteria of my review resulted in six studies. These studies have explored palliative care from the view point of specialists, or from the point of view of patients' parents, or from the point of view of

patients. The obtained literatures are (Al Khalaileh & Al Qadire, 2012; Omran, Al Qadire, Ali, & Al Hayek, 2014; Omran & Obeidat, 2015; Shamieh and Hui, 2015; Seow, Dhaliwal, Fassbender, & et al., 2016; Zimmerman et al., 2014). In addition to that, the subject of the study is considered to be new in Jordanian environment, so other studies similar to the subject of my study (Abdel-Razeq 2015, Shamieh and Hui 2015) were utilized to extract information about palliative cancer care in Jordan healthcare facilities. The below table summarizes the articles and studies that mostly serve the subject of my study.

**Table 1: Summary of articles and studies.**

Article Title	Design	Findings
Barriers to cancer pain management: Jordanian nurses' perspectives. <sup>[14]</sup>	Cross-sectional survey using an Arabic translation of Ward.	Many nursing-related barriers to cancer pain management were found, mainly the nurses' negative attitudes toward cancer pain management and the misconceptions about addiction.
Knowledge and Attitudes about Pain Management: A Comparison of Oncology and Non-Oncology Jordanian Nurses. <sup>[15]</sup>	The Nurses' Knowledge and Attitudes Survey Regarding Pain (NKASRP) was used to measure the nurses' pain management knowledge and attitudes.	The study found a difference in the level of knowledge of the nurses in pain management and confirmed the existence of a lack of knowledge of the nurses regarding pain management.
Early palliative care for patients with advanced cancer: a cluster-randomized controlled trial. <sup>[16]</sup>	Quality of life (Functional Assessment of Chronic Illness Therapy--Spiritual Well-Being [FACIT-Sp] scale and Quality of Life at the End of Life [QUAL-E] scale), symptom severity (Edmonton Symptom Assessment System [ESAS]), satisfaction with care (FAMCARE-P16), and problems with medical interactions (Cancer Rehabilitation Evaluation System Medical Interaction Subscale [CARES-MIS]) were measured at baseline and monthly for 4 months.	There was a non-significant difference in change score for FACIT-Sp between intervention and control groups, a significant difference in QUAL-E and FAMCARE-P16, and no difference in ESAS or CARES-MIS.
Palliative Care Nursing in Jordan. <sup>[12]</sup>	Descriptive method (a literature review)	The study emphasized the weakness of the health care providers' skills in providing palliative care services and indicated the need to adopt a sustainable policy that includes providing resources and educational programs for improving the skills of health care providers.
A Comprehensive Palliative Care Program at a Tertiary Cancer Center in Jordan. <sup>[13]</sup>	Narrative review of palliative care program.	The Palliative Care Program provided by King Hussein Cancer Center represents a comprehensive model for providing care to cancer patients in Jordan.
The Effect of Community-Based Specialist Palliative Care Teams on Place of Care. <sup>[17]</sup>	Patients who received care from a specialist palliative care team (exposed) were matched by propensity score to patients who received usual care in the community (unexposed) in Ontario, Canada	The study found that patients who received palliative care at home needed the hospital to a lesser degree than patients who did not receive palliative care.

Al Khalailah & Al Qadire et al. 2012 performed a quantitative cross-sectional study based on translated questionnaire survey through a sample of 96 nurses working in the oncology units of three different hospitals in Jordan. The aim of study was to examine the practical barriers for palliative care and management of patient's cancer. The obtained results showed that the score of overall mean barriers questionnaire was (2.5) with standard deviation (0.8). The questioner's subscale induces; fatalism with lowest mean score (1.6) indicating strong beliefs in the efficiency of medications to reduce pain. Also, the mean score regarding the concern of harmful and physiological effects of pain medications were the highest with mean score (2.7) and (2.6) respectively, showing high risk of addiction and reduce the ability to identification of new pain. Communication subscale indicating significant factor to describe and report pain facilitating pain treatment without wasting time, the mean score was (1.9). Abundant barriers associated with cancer pain management was reported among Jordanian healthcare facilities. Suggested that, continues education and practical courses are necessary to deliver the required knowledge of cancer pain management toward oncology staff, as well as, pain management courses should be integrated extensively in nursing colleges.<sup>[14]</sup>

Omran et al. 2014 utilized Nurses' Knowledge and Attitudes Survey Regarding Pain (NKASRP) which was developed by Ferrell et al. 1993.<sup>[18]</sup> Comparing the attitudes of Jordanian nurse's pain management between oncology and non-oncology. The results represented significant relation between continuous education of pain management and score of knowledge. Also, deficiency in knowledge for cancer pain management among undergraduates' level was observed during clinical practice.<sup>[15]</sup>

Furthermore, Zimmerman et al. 2014 evaluated the effects early palliative care for cancer patients at advanced stages. The study included 461 cancer patients, and assess quality of life (Functional Assessment of Chronic Illness Therapy--Spiritual Well-Being (FACIT-Sp) scale and quality of life at the end of life (QUAL-E) scale, symptom severity (Edmonton Symptom Assessment). The findings showed that no significant difference was observed for FACIT-Sp at 3 months. On the other hand, significant differences were reported for all outcomes at 4 months, and favoured the intervention group, supporting that early palliative care for cancer patients improve quality of life and increase stultification with their treatment.<sup>[16]</sup>

Omran & Obeidat et al. 2015 declared a descriptive method to establish national action strategies that improve the implementation of palliative care for cancer patients and overcome the barriers. However, weakness of healthcare provider was emphasized through pain management skills and services. Indicating the significant role of educational programs and clinical

practice to improve skills of health care providers. In parallel to that, integration of higher education accreditation should be taken place into the undergraduate curricula in every nursing.<sup>[12]</sup>

In addition to that, comprehensive palliative care program in King Hussein Cancer Center (KHCC) was described by narrative review study achieved by Shamieh & Hui et al. 2015. Results showed that patients at KHCC have been provided with palliative care and pain management through 400 consultations and 979 referrals and admissions, compared to 1133 visits at outpatient's clinic. Successfully, the program of palliative care in KHCC showed a promising result to deliver palliative care for inpatients cancer and outpatients by multidisciplinary teams of specialists. The program is considered as unique model in Middle East due to achieved integration of education for oncology team and interpreting the clinical results in research.<sup>[13]</sup>

Besides that, the place of providing palliative care at the last month of life was examined by Seow et al. 2016 through retrospective cohort study that categorized place of palliative care into two groups: inpatient hospitalization (exposed) and usual care in the community (unexposed). Statistical analysis of collected data demonstrated that exposed group significantly ( $p < 0.001$ ) utilized more home palliative care services and fewer days in hospital than unexposed group. As well as the place of death (last day of life) showed that exposed group had 18% die in hospital compared to 29% of the second group. Consequently, the study revealed that exposed group who received palliative care from specialist team required less hospitalization and more home care over time compared to patients who received usual care.<sup>[17]</sup>

## DISCUSSION

Palliative care in Jordan has become one of the priorities of the Jordanian Nursing Council. Despite that, research and studies in the field of palliative care are still limited, more studies and investigations should be performed to obtain improvement strategies and solve the constraints that limit the desired application. In addition to that, planning approaches should be taken place to increase the awareness about the importance role of palliative cancer care for patients, families, and community. However, Palliative care is an interdisciplinary approach, ideally includes doctors, nurses, psychologists, social workers, pharmacists, and physiotherapists who are responsible to develop a clear communication approach giving cancer patients the ability to express themselves and ask questions related to various aspects of their lives. Also, palliative care specialists provide moral and psychological support to patients and confirming that they have the right to understand the conditions of their illness. Even though their priority to deliver effective treatment for cancer patients<sup>[17,19]</sup>

In addition to that, family support plays a significant role to provide psychological and emotional support, raising the morale of their loved one and supporting them through different stages of disease. In parallel to that, families are responsible to take on the role of decision-making on treatment including surgeries and medications. Family support includes preparing food, and complete their basic daily tasks, such as bathing, dressing and mobilizing.<sup>[20]</sup> However, communication subscale of palliative cancer care is an area that still require improvement. Communicating with patients and loved ones, treating pain, giving bad news, spiritual therapy, nutrition, and alternative medicine are among the most prominent palliative care principles. This involves giving enough time for the patient to express his or her feelings, giving the patient the attention if he or she wants to say something, such as shaking his hand and sitting nearby, talking with the patient to express his interest and empathy and start the conversation with an open question. Enabling the patient to cope with their illness means giving the patient autonomy and courage, confidence, and faith in his ability to cope with the various difficulties he is likely to face.<sup>[21,22]</sup>

The spiritual part of palliative care is an important aspect indicating quality of life. Studies have shown that spiritual well-being is positively associated with the spiritual and health outcomes of cancer patients.<sup>[23]</sup> Cancer patients with high levels of spirituality also have high levels of quality of life, lower levels of depression, and lower levels of thinking and anxiety about death.<sup>[24]</sup> Cancer patients stressed that spirituality helped them to overcome their experiences with cancer, and gave them the strength, hope and desire to survive and receive treatment and face pain. In the Middle East in particular, many individuals rely on the spiritual aspects of dealing with the disease, and studies have confirmed that patients who relied on the spiritual aspects when receiving treatment achieved effective positive results, such as longer survival, low level of depression, less post-operative complications, and less pain.<sup>[25,26]</sup> Culturally in Jordan and in the Middle East Spiritual care means trust, a strong belief in God and faith in God's judgment and destiny. This faith becomes very important when confronting cancer. Spiritual care services include encouraging positive thinking influenced by prayer and other religious rituals, reviving hope in cancer patients, emphasizing the importance of patience during their treatment stages, and providing guidance to the parents of the patients regarding the meaning of death and life in the afterlife.<sup>[25]</sup>

Globally, the implementation of palliative care facing many challenges. However, it is widely believed that developed countries already have provided palliative care services to patients and elderly. While palliative care is under developing across developing countries due to limit of financial support, lack of government policy, shortage of trained specialists and not enough equipped healthcare facilities.<sup>[4, 27]</sup> In addition to that, palliative

care training is limited in the Eastern Mediterranean (EM) regions, and the level of knowledge among Jordanian medical staffs of pain management is low compared to other countries.<sup>[27]</sup> The provision of basic resources for the integration of palliative care through educational programs aimed to increase the awareness of the specialized medical team is a challenge with direct effect to clinical care setting.<sup>[22]</sup> On the other hand, palliative cancer care in developed countries is more successful and more effective to overcome complications associated with cancer treatment and diagnosis. Silbermann et al. 2012 pointed out that the level of individuals' awareness about cancer increased, and methods of treatment have improved, which contributed to increase the number of survivors.<sup>[28]</sup> However, this is not the situation in developing countries, especially in the Middle East, where most cases of cancer are diagnosed in advanced stages, which reduces the chances of survival. Therefore, for patients with cancer in the Middle East, finding access to medications to relieve symptoms and receive palliative care is the paramount, especially in the advanced stages.

Most of these challenges include political, legislative, education and research challenges. As well as Jordan has no national policy for palliative care, except the King Hussein Cancer Center is the only healthcare facility that provides home-based and in hospital palliative care services. However, there are many cancer patients who cannot access palliative care.<sup>[12,29]</sup> In practical, palliative care in Jordan focuses on the therapeutic aspects in return for providing acceptable care services to patients who are dying. Recent studies revealed that lack of nurse knowledge in palliative care and in the philosophy, along with the difference settings of acute care and hospice care. Many nurses in Jordan lack sufficient knowledge of pain management, as a large proportion of these nurses have negative attitudes toward the treatment of pain, such as opioids. They believe that giving patients such analgesic drugs contributes to addiction.<sup>[30]</sup> It is found that about 90% of the patients with chronic diseases who need to be treated with palliative treatment do not receive treatment. About 10,000 of the 18,000 people die while they are suffering from pain due to the misconceptions around pain. This may be related to misconceptions associated with taking opioids. Some patients may refuse to take opioids because they believe that when they take them, they will not have the ability to control themselves and increase their sleepiness therefore unable to coherently communicate with family members, along with possibility of addiction.<sup>[27]</sup>

Many differences are between Western and Eastern countries in the role of palliative care of cancer patients. Firstly, religious beliefs and cultural values influences end-of-life care. For Eastern population death is seen as a post-life phase<sup>[28]</sup>, while in Western community suffer from a range of constraints that make it harder to manage end-of-life, which is linked to the strong religious views held by the families of patients regarding the sanctity of

life.<sup>[31]</sup> Leading to conclude that Western communities are less accepted death compared to Eastern communities who are accept death and live within the realization of the inevitability of death. Silbermann & Hassan et al. 2011 clarified that the attitude of Arab societies towards death positively affects the psyche of the patient and his/her family.<sup>[32]</sup> However, these beliefs can influence health practices and may pose challenges for health care providers.<sup>[33]</sup> Furthermore, the inadequate preparedness for death will adversely affect the phases of palliative care. In Eastern societies, the perception of palliative care is that it is the 'end of life', not 'pain relief'. The problem lies with the staff of health care providers who consider their selves as end-of-life caregivers. This problem requires a focus on education and training of medical staff from different countries of the world. Improve staff conviction in the role of palliative care is to relieve patients and motivate them to cope with the disease and not only to prepare them to face deathbed have a better quality of life. This concept of quality of life is consistent with the principle of palliative care.<sup>[28]</sup>

Other differences are associated with patients' families, In Western countries, medicine focuses on the individual's side, respect their independence, privacy and involvement in decision-making, while Eastern countries focus on the family and its direct role in decision-making because of the strong ties that bring together family members. Therefore, family members in Eastern societies meet with each other to support each other, and other families come to support and raise their morale. It is, therefore, important to integrate the family into palliative care programs and to consider them as a main unit of this program.<sup>[34]</sup> Good palliative care requires an understanding of the cultural and social aspects of the environment to meet the needs of patients and their families appropriately, and the family is an essential element in the provision of palliative care services to patients.

The below table represents the main difference in palliative care between Western and Eastern countries.

**Table 2: Summary of differences between Western and Eastern Countries.**

Comparative aspects	Western Countries	Middle Eastern Countries
Viewing palliative care in general	"giving up on life"/" End of life" rather than "providing quality of life"	Providing quality of life
End-of-Life care	Suffer from a range of constraints that make it harder to manage end-of-life, which is linked to the strong religious views held by the families of patients regarding the sanctity of life	They respond to end-of-life care because they accept death
Accepting death	Lack of acceptance of death	Accept death and live within the realization of the inevitability of death
Family involvement	Focus on respecting patient autonomy rather than family involvement	Focus on the role of the family based on strong family ties
Family role	The family does not feel the responsibility to provide care to the patient. Elderly cases are usually directed to nursing homes and shelters	The family is primarily responsible for providing care to the patient
Family ties	Less than Eastern countries	More than Eastern countries
Family response to death	Do not accept it/ Deny death	Accept it
Spiritual care	Health institutions for chronic diseases seek to strengthen the spiritual aspects of patients	Rely on the spiritual aspects of dealing with their disease. Thus, they experience a lower level of depression, live longer, and suffer less
Government policies that consider palliative care	Existed	Lack of government policies that consider palliative care. Turkey is the only country in the Middle East with a national policy of palliative care
Natural, synthetic, and semi-synthetic opiates, such as morphine, oxycodone, fentanyl, and its analogues	It is acceptable to use them for medical purposes	Not available in most Middle Eastern countries. The lack of these drugs is due to regulatory barriers, pricing, and misconceptions of illegal use.

## CONCLUSION

Palliative care is relatively new specialty in Jordan. Despite that, it is progressively growing to improve patients' life quality and their families. Few Jordanian nursing research in the field of palliative care are available, but most of them are associated to pain

management. However, publication associated to Jordan experience in palliative cancer care is limited. Many limitations and obstacles were observed which negatively affect the implementation of palliative cancer care in Jordan. Shortage of financial resources, lack of specialists, inadequate training courses, and low level of

knowledge and about cancer pain management and palliative care. It is suggested to introduce palliative care courses as mandatory subject at undergraduate nursing college. Also, government should perform national strategy to establish and sustain palliative care units, improve the knowledge of medical staffs by continuous training courses and provide adequate funding.

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