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## EXPERIENCES IN MIDDLE EASTERN POPULATIONS

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### Surprised by Joy: a Journey through Suffering

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#### Abstract

Understanding suffering as possible meaning of cancer for patients and their families is a necessary part of cancer nursing care. Suffering occurs when the intactness or integrity of the individuals is threatened or disrupted (Cassel 1999); the authors believe that exploring cancer patients' suffering is vital to improve patient quality care. This article discusses suffering as a feature for oncology patients at tertiary hospital in Jordan. We are aiming through understanding the three following narratives of cancer patients who experience and witness the suffer during their disease journey to illustrate how the suffering reflect their behavior and day to day life. The first case is a young man of 24 years old who was diagnosed with nasopharyngeal carcinoma five years ago, treated then relapsed and receiving palliative care up to moment, the narrative focus on his suffering from corrupted relations with his wife due to infected face wound and loss of the financial support. The Second case is a 38 years old female who diagnosed with melanoma 15 years ago, she experience psychological suffering due to changes in her body image. She is taking care of motor handicapped husband in addition to her Kids. The Last case is a 54 years old female who had lung cancer. She is still fighting her disease. Consequently, she is suffering from the disease, cause to affect her job. We found out that their spirituality and beliefs system enables them to endure and fight their disease, alleviate suffering, enhance adaptation and redefine hope. The health care team who provide the care for these cases focus interdisciplinary team approach who affirm that the transcendental is there when disease and mute or expressive suffering are recognized together, they do the work of creating a full meaning for patients and families. Nurses play a crucial role in managing such cases. It is the core of nursing care to presence the mean of listening, touching, acknowledging, honoring patient's wishes and working within specialized multidisciplinary team, It is the greatness to be part of a team that being a huge circle surrounding patient with special demand and focusing on them in addition to their families rather than the disease itself aiming to assure best quality of life and to gain patients satisfaction. They recognize, assess and reassess patients' needs reframing of goals by educating, advocating, coordinating and supporting, with the major role in bereavement.

**Keywords:** Cancer - suffering - narratives - multidisciplinary team - spirituality

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#### Background

Suffering: "*I believe suffering to be the distress brought about the actual or perceived impeding threat to the integrity or continued existence of the whole person*" Cassell, 1991. Alleviating of suffering is a fundamental goal of palliative care treatment. This article discusses three narratives experience of cancer patients.

#### Methods and Patients

Three narrative stories for cancer patients treated and receiving palliative care at King Hussein Cancer Center was collected for the aim of understanding patients' suffering. A literature review was made to deepen the concept understanding.

#### Descriptions

Am I alone? A 24 years old male patient, who was

diagnosed with nasopharyngeal carcinoma five years ago, described his suffering after interview with palliative care nurses. His story started after he was diagnosed as a cancer patient who experienced many emotions starting from denial, anger, sadness, isolation, and ends up with acceptance. He wasn't expressing his feelings to others; only after asking him he replied "I feel so sad, lonely and empty". His suffering reached the peak when he developed an infected wound with bad odor after surgical intervention. The wound affects his shape and self image which made him more sad and isolated even from his wife. Consequently, his wife started to reject him and became away from him. His wife didn't accompany him during his admissions to hospital or even visit him. The situation leaved our patient more lonely and fighting cancer alone. The disease complications started up with recurrent aspiration after eating. His suffer continued after discharge in which no body at home would like to share food with him except his two young daughters who's still

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attached to him. As other cancer patient he was feeling pain, fatigue and drowsiness. In many occasions he expressed his feeling of losing control in his life. He had body image deficient; when he remembered his previous image, he started to cry, he is asking people who know him to compare between his current status and the previous image, and he lost his job and had financial problems which lead to more suffering. He was lonely and so many of his feelings were certain and true. "I hope to wake up from this bad and terrible dream I can hardly believe it" he lost some of his friends. The major relief of his suffering exists from surrender and faith in the will of God in addition to his prayers and by reading Holy Quran, addition to the joyful moments he spent with his two young daughters.....

Why me? A 38 years old female patient was diagnosed with melanoma 15 years ago. She described her suffering during the last 15 years by reporting her experience with melanoma to home care nurses. She took care of her motor handicapped husband and three kids. She was treated by chemotherapy and radiotherapy, home care nurses taking care of her by their regular and frequent follow up. She is suffering from pain, cachexia and brown to black pigmentations and dark spots all over her body especially her face which was making her dressing the veil. She did not like to look to the mirror so she removed all the mirrors from her home.

Due to her husband disease she had many financial problems and depends on the financial support from donors and giver institutions in Jordan. She said "I hope to cook to my children but I lost my health and my energy to cook". She feels helpless, powerless as she watched her health slip away from her. Her relief of suffering comes from surrender and commitment to the will of God which revealed in Holy Quran. She expressed her concerns regarding the future of her kids after she passed away, accordingly she started to plan with her sister to be their care giver as she supported her during her suffering. Taking care of her handicapped husband gave her the joyful meaning of giving in life.

The strong woman: A 54 years old female patient was diagnosed with lung cancer with brain metastasis. This women resisting and withstanding her disease and being responsible on her health .In addition to her disease and suffering from pain, dyspnea and seizures especially after brain metastasis, she had bookshop which she couldn't handle after her disease, she faced some of financial problems. Although her weakness, she evinced that she had strong personality and independent during her plan of care and in taking decisions. She was lonely and sad and feels hopelessness; collapsed many times in her room crying lonely and no one hear her or wipe her tears, even she appears to all people that she is strong enough to take care of her self, she redefined her happiness and hope by giving her bookshop to her sons so many can read the books and remember the strong owner for the shop afterward. Her spirituality and consistent prayers in the Church empowered her more to fight her disease and find hope till moment.

## Discussion

After displaying these three narratives which showed that suffering in this sample of Jordanian cancer patients' has physical, emotional, social, financial and spiritual dimensions.

The physical suffering divided into two categories: that caused by disease itself and that caused by treatment which revealed as pain, fatigue, drowsiness, infections, changes in appearance and dyspnea. The psychological and emotional suffering manifested as depression, isolation, loss of control, sadness and loneliness, hopelessness and anger. The social factors which leads to suffering that their social life was restricted by their deteriorating health, infections, became more isolated and their life revolved around the home and the hospital which may leads to separation from their partners.

Finally the spiritual suffering which supported by their religious rituals and faith, beliefs system enable them to endure and fight their disease. Alleviate suffering, enhance adaptation and redefine hope.

## Conclusion

The authors believe that relational intimacy between patient and health care providers is an important component in the partnership experience which strong enough to overcome the patients' feelings toward suffering through openness. The holistic nursing care in especially the psychosocial support is really crucial in oncology practice. Therapeutic listening, touching, acknowledging, honoring patient's wishes and working as multidisciplinary team are occupied great needs of oncology patients, helping them redefining hope and joy in their life's.

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