

Living with Malignant Wound in Cancer Patients and Adolescents with Non- Cancer Diagnosis: a Meta-Synthesis of Qualitative Studies

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Abstract

Background

Malignant wound causes a devastating physical and psychological condition in cancer patients. This study presents a review which can provide better insights into the life of cancer patients living with malignant wound. The aim of this meta-synthesis was to analyze and synthesize findings from qualitative studies of the lived experiences of patients with malignant wound.

Materials and Methods

This meta-synthesis followed the Sandelowski and Barroso's guideline and was designed to synthesize findings from previous qualitative studies. Variety of biomedical archives were searched, including PubMed, Web of Science, PsycINFO, Cochrane library, and ProQuest and Persian data bases such as Magiran, SID, Iran.doc, IranMedex, and recently published articles and books on the lived experience of persons living with malignant wound were reviewed. In this article, the literature searches covering from January,1, 1990 to march,15, 2016 resulted in eight relevant studies which fulfilled the inclusion criteria for the review.

Results

Findings from all these studies were categorized into three main themes: "distortion of lived body", "symptomatic suffering", and "compatible living with wound". Our findings showed that the meanings of patients' experiences living with malignant wound are important for the construction of multidisciplinary palliative care in these individuals.

Conclusion: Gaining insights from analysis of qualitative studies is integral issue for developing new palliative care services for patients with malignant wound.

Key Words: Cancer patients, Children, Lived experiences, Malignant wound, Meta-synthesis.

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1- INTRODUCTION

Cancer related incidence increases with aging population. Some cancers grow in the shape of a cauliflower, like malignant wound such as primary skin cancer of breast, lung, gastrointestinal and malignant melanoma or distant skin metastasis of ovary, head and neck, genitourinary system, and tumors with unknown origins (1). In Canadian study, malignant wounds contained several morphological types: nodular, indurated, ulcerative, zosteriform, and mixed patterns (2). The prevalence rate is reported 6.6% and 5-10% in Switzerland (3) and Cochrane review studies (4), respectively.

Some of these malignant wound may be appear in children. One of these benign tumors is cutaneous warts, benign epithelial tumors, induced preferentially by several cutaneous Human papillomavirus (HPV) types with highest prevalence in children and adolescents at age of 11-16, usually undergoing spontaneous resolution within two to three years (5).

Malignant wounds appear as growing exudative masses with profound malodorous discharge, severe pain, and profuse bleeding. These wounds commonly have devastating impacts on different aspects of patient's life; therefore, multi-faceted interventions need to be addressed. Obtaining non- diagnostic nursing knowledge (6) from this research would provide foundation for development of spiritual caring strategies for malignant fungating wounds in Iranian cancer community. Accordingly, nurses and allied health professional need to understand the lived experiences of patients with malignant wound in order to properly respond to the lived body, psycho-spiritual, and emotional changes.

In this meta-synthesis, the results of qualitative studies which are related to the lived experiences of cancer patients with malignant wound were explored to deepen

the understanding and used for initiating reduction step in phenomenological study of the lived experiences of Iranian malignant wound population.

2- MATERIALS AND METHODS

2-1. Method

This qualitative research describes the phenomenon from participants' perspective by reconstructing processes. Conducting a meta-synthesis across a range of disciplines can help bridge the gap between research and practice, due to the body of knowledge in this field (7, 8). The lived experiences of patients with malignant wounds were selected as the area of interest in this research. Searches were undertaken across online bibliographic databases, including Web of Science, PubMed, PsycINFO, Cochrane library, and ProQuest to retrieve qualitative research articles published from January 1, 1990 to march 15, 2016 on the lived experiences of patients with malignant wound. Malignant wound related terms were combined with terms of "qualitative methods", "living with malignant wound", "lived experience", and supplemented by searches of Google scholar and reference list of related thesis.

Firstly, titles and abstracts were explored for relevance and papers not meeting the inclusion criteria (**Table.1**) were excluded from the study. Secondly, the selected papers were evaluated using the Sandelowski guideline (**Table.2**) (9). The data was thus, organized into the following classifications: research problem, study goal, literature review, orientation about phenomenon of interest, method, sampling, data collection and data analysis (**Figure.1**).

According Sandelowski guideline, you use interpretively to integrate the results of qualitative studies are as varied as qualitative research itself. Qualitative meta-synthesis entails leaps of imagination

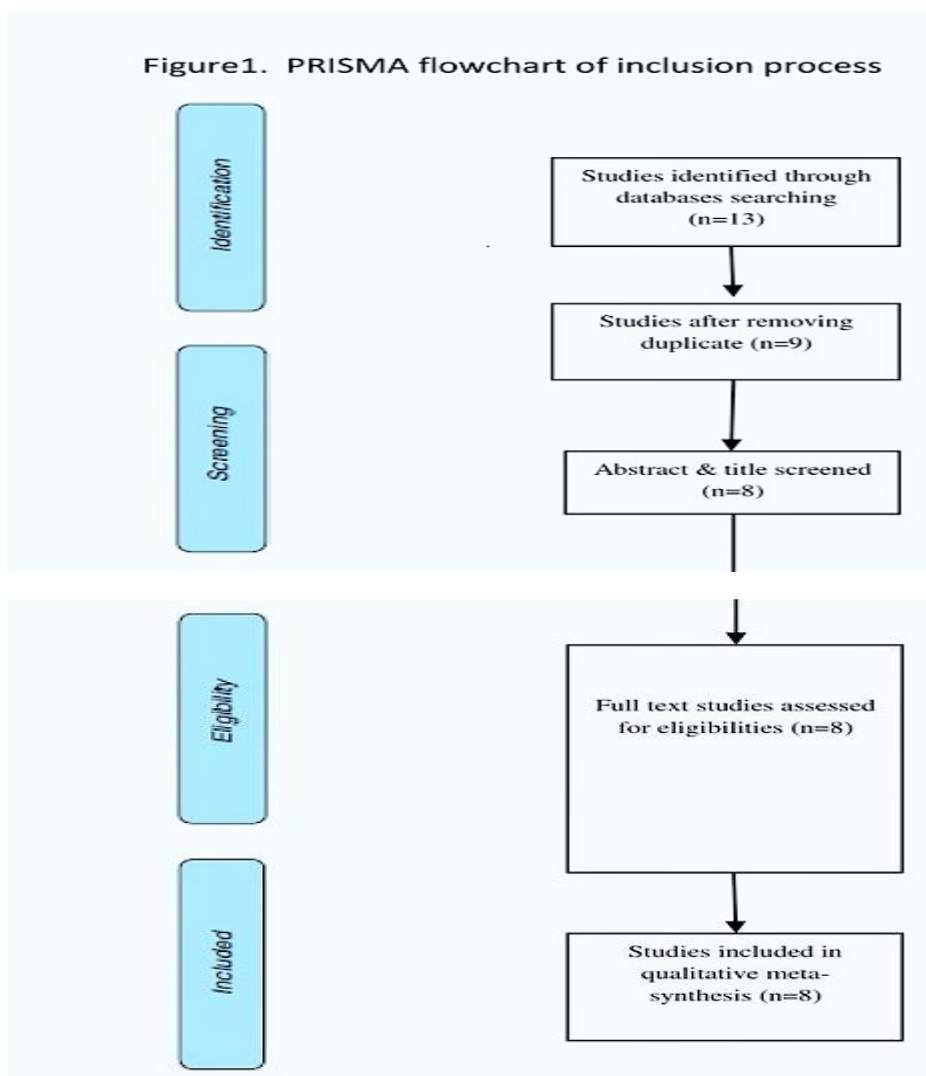
that you try to communicate as best you can. Two qualitative researchers screened the titles and abstracts of selected articles for potential relevance to inclusion criteria and any discrepancy was resolved by consultation with a third lived experience researcher.

2-2. Ethical consideration

The study approved by 36th ethics committee of Baqyatallah University of Medical Sciences, Tehran- Iran, and ethics committee of Cancer Institute of Tehran University in a bi-center research plan(ID number: 8951651004).

Table-1: Inclusion/exclusion criteria

Inclusion	Is a qualitative study which presents substantial qualitative data, e.g., grounded theory, thematic analysis, phenomenology, interpretive phenomenology and life experiences. Explicitly addresses the experience of patients with malignant wound and living with it.
Exclusion	A quantitative study, conference abstract, review or any study lacking qualitative data.



3- RESULTS

Three themes emerged from this meta-synthesis: distortion of lived body, symptomatic suffering, and compatible living with wound.

3-1. Distortion of lived body

In malignant wound, internal body contents spill into the external body via breached boundary like an iceberg phenomenon. The patient's body becomes untrusted and he or she might be uncontrollable about his or her exudative, and malodorous discharge(10). Patients describe their concerns for unexpected signs appearing in their existential body. In one of these qualitative studies, the authors disclosed the influence of uncontrollable nature of malignant wounds on patients' adaptabilities(11).

Livia (12) stated how the wound on her breast was spreading further, distorting her lived body:

"It was growing so fast, the first, it ate away my breast and then it continues to eat further. Then, it went round to my back. It was so embarrassing seeing it. It actually feels like I'm falling apart".

In our lived experience research, we encountered a new immune compromised 11 years old boy with aggressive proliferations of genital wart. Wart necrotizes underlying structure and child overwhelmed with it. Our especial care is not sufficient and professional for the treatment of this type of malignant wound. His fungating wound has been growing for about 4 months. Nurses, surgeons, and other staff have been helping him relieve pain.

"He whispers to me 'I hope I will be free of this pain soon'".

Living with a malignant wound gets patients to experience life with different feelings, such as isolation, sadness, and

embarrassment. Living with unpredictability and uncontrollability of this type of wound as a result of symptoms including pain, easy bleeding, perfuse exudative secretions, and losing the control of body boundaries remain as a great suffering for these individuals (10, 13, 14).

3-2. Symptomatic suffering

Patients with malignant wound suffer from different physical and psychological symptoms such as declining their physical well-being, pain, bleeding, exudative lesions, and despair (15). These symptoms invaded other parts of these patients' lives, including body image, psycho-spiritual, and emotional aspects, resulting increase in the search for medical consultation services (15). In malignant wound, physical and social role performance limitations may become a psychological burden and as such the patients are further isolated from their lived relations (10).

In this type of suffering, the painful, distorted and symptomatic body has become an integral focus for patients' intense and unforgettable daily experiences, leading to a diminished articulation of both self and world. These individuals suffer from loss of self-identity and distorted bodies, where they feel detached from daily habits and cannot reinstate the taken-for-granted of their previous body behavior. Reflecting on a large number of narratives about patients' experiences on malignant wound represents a devastating condition that progressively disturbs their identities and thoughts of the future.

In this bizarre condition, having a wound-related stigma with profound malodorous discharge, fear of offending family and their professional caregivers are very embarrassing for these persons. They are trying to live with offensive smell and different sequela of their wounds (10).

The senses in these individuals change in detecting malodor, in order to better

defend their distorted body (10). As explained by Helen (15), some of these persons become desensitized to this malodor; but a number of them describe a rotten, disgusting, and distressing smell:

"Yes, it came from your breast directly to your nose, well you smelt it yourself. That is awful. You cannot describe this smell. It is awful. Well, it is as if somebody was mouldy; and I had a feeling that other people smelt it too. So, I started to stuff towels and things in it to close it, so that the smell does not appear straightaway. But, dealing with it that way worked for a bit".

Participants in these studies often state how the wound-related stigma influences their social communications. They are detached from their previous social status. The discomfort of bandage pressure, overweight dressing, profound disgusting smell, and safety issues related to excessive wound oozing isolated them from effective social relationship and previous joyful living activities.

3-3. Compatible living with wound

Patients with malignant wound are able to live compatibly with their wounds. Creating lived relation with professional health-care personnel provides essential information for these patients as they learn how to manage and live with their unusual and disgusting wounds' secretions. They are initiating a new being-in-the-world in a lived time transition of abrupt and painful body changing. They understand how to respond to malignant wound demands and seek wound-related information in various ways with success or failure. Compatible living with wound begins with previous cancer invasion and may be promoted by multidisciplinary health care team. This type of positive being was stated in one qualitative study (15):

"After I used this new dressing, the pain is much better, I have good sleep now".

Alexandra explored the experiences of patients, nurses, and caregivers of malignant wound sufferers. She revealed new way of being-in-the-world as an outcome of the malignant wound. Living with malignant wound changes both the patient's and caregiver's life and they care all time for a hard-healing wound in exhaustible manners with unforgettable memories (10).

4- DISCUSSION

In this research, findings from various qualitative studies were analyzed to give an overview of the lived experiences described by patients with malignant wound after invasion of cancer to their body boundaries. In our review, only three articles were found that researched what it was like to experience a malignant wound from patient's perspective (10, 14, 15).

This study was limited to a meta-synthesis of different qualitative studies. A meta-synthesis of these research findings concerning patients' lived experiences might provide valuable data and increase our understanding of important dimensions of life with malignant wound. Living with malignant wound is life for small group of sensitive cancer patients with psychological suffering and overly burden of physical symptoms. In most recent studies, the meaning of life with malignant wound has been uncovered from the perspectives of some cancer patients, caregivers, and health-care personnel in combination form (10); but, gaining insight from patients' specific and individual experiences may vary in different qualitative research (10, 15, 16).

4-1. Study limitations

Debate exists among meta-synthesizers about a number of philosophical issues(17). In this research, qualitative studies from all methodological tradition about lived experience of patients with malignant wound was eligible to be

selected and quality was assessed to be sufficient if study was published in peer review journals. This meta-synthesis shows there has been little investigation of lived experience or psychological issues associated with malignant wounds.

5- CONCLUSIONS

Living with malignant wound is a life of sensitive population of cancer or non cancer patients at various ages. We need to know, how to response to their personal caring needs with better insight and in a multidisciplinary caring perspective. This study increases the knowledge base of malignant wound by re analysing cancer patients real experiences in a review of qualitative literature.

6- CONFLICT OF INTEREST: None.

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Table-2: Qualitative articles characteristics

Author & Year	Type of qualitative study	Aim of study	Participants	Data collection & analysis	Finding
(Alexander, 2010)	Hermeneutic phenomenology	Investigating the lived experience of malignant wounds from the perspectives of patients, caregivers and nurses.	One male patient & two female, one female caregiver and ten female nurse	In depth interview & thematic analysis	Study show four themes: (i) malodor; (ii) new mode of being-in-the-world; (iii) still room for hope and (iv) enduring memories.
(Probst et al., 2012)	Heideggerian hermeneutic phenomenology	The study was to explore the experiences of carers who care for a loved one with a fungating breast wound.	Seven women	Semi- structured interview & thematic analysis and categorization of caregivers experiences	Experiences of care giver are subdivided in three category: “Challenge for a lay person managing the wound”, “Wound put stamp of the course on everyday life” and “Caring a great deal for her”.
(Lund-Nielsen, 2011)	Descriptive phenomenology	The purpose of this study was to describe the experience of health care avoidance in women with Advanced breast cancer that has developed malignant wounds.	Seventeen women with advanced breast cancer	In depth individual interview & systematic text condensation analysis was used.	The essence “an avalanche of ignoring” is pointing to the destructive feeling behind health care avoidance.
(Probst et al., 2013)	Heideggerian hermeneutic phenomenology	The aim of this study is to explore how women living at home with a MFW can cope with such wounds.	Nine women with breast cancer	Semi-structured interview Phenomenon categorization analysis	Finding are divided into two categories: “Living with a MFW; and “Feeling different.

(Lo et al., 2008)	Grounded theory	The purpose of this study was to explore the experience of cancer patients living with a malignant fungating wounds.	Ten participants, six women & four men	In depth interview & Thematic analysis	Five key themes demonstrated an emerging model that offers an insight into how patients experience their wound. Firstly, 'Declining physical well-being' refers to the initial impact of the wound, this is linked to two further themes; 'Wound related stigma', the Need for expert help', 'Strategies in wound management' and 'Living positively with the wound'.
(Probst et al., 2013b)	Heideggerian hermeneutic phenomenology	This study focuses on understanding the lived experiences of patients with a malignant fungating breast wound and their informal carers.	Nine women with breast cancer	Semi-structured interview & interpretive phenomenological analysis (IPA)	Two categories emerged from the data: the first category "Having to simply deal with the situation" and the second category "Having this problem is very embarrassing".
(Piggin and Jones, 2007b)	Heideggerian hermeneutic phenomenology	Study that aimed to illuminate the meaning and experience of living with a malignant fungating wound.	Five women	Unstructured interview & content hermeneutic analysis	Four themes were identified: representing the worst part of the patient's cancer; living within a body that cannot be trusted; a changing relationship with the patient's family and friends; and a loss of identity while continuously striving to be normal, yet feeling different.

(Wilkes et al., 2003)	Cross-sectional qualitative study	To explore rural nursing personnel experiences of dealing with patients with malignant, often malodorous, wounds.	26 rural nurse	Semi-structured telephone interviews & content analysis	Nurses working in this setting strove to do the best for patients and their families under circumstances that are emotionally and physically difficult. Some of them suffered personal distress as a consequence. Patient isolation and altered body image are significant challenges for these nurses.
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