

Unmet Needs of Women Diagnosed with Gynecologic Cancer: An Overview of Literature

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Received date: Jan 18, 2016; Accepted date: Feb 08, 2016; Published date: Feb 12, 2016

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Abstract

The assessment of supportive care and unmet needs is essential in the development of appropriate interventions that may enhance the quality of life of cancer patients. Unmet needs including early diagnosis and treatment process, psychosocial problems alternative approach, fertility, supporting of caregivers and palliative care are common problems in women with gynecologic cancer (GC). It's direct effects on quality of life and evaluations may help improve discussion of quality-of-life issues between patient and health professionals. Studies highlight, as social support and supportive care by the family or health professionals increased, the effective coping ways were detected to be used more frequently. This review describes the unmet supportive care needs of women with GC.

Keywords: Unmet needs; Supportive care; Gynecologic cancer; Women

Introduction

Cancer is becoming a chronic condition that affects physical and psychological health. According to GLOBOCAN 2012, 14.1 million new cancer cases and 8.2 million cancer-related deaths occurred in 2012 [1]. As a major public health challenge, cancer is the second leading cause of deaths in both Turkey and the World [2]. According to the Turkish Cancer Survey results, gynecological cancers, followed by ovarian, endometrial and cervical cancers are the most commonly encountered types of the cancer-leading cause of deaths among women in Turkey [3].

Gynecological cancer is a stressful event that influences interpersonal relationships between women and her family. Because gynecological cancers contains such as femininity, fertility, and sexual life meaning loaded reproductive system structure [4-6]. In addition to the physiological symptoms, it affects routine daily life of women and her families and social relationships, work life and quality of life. The whole family is affected due to appearance of women in the centre families in daily life [5-7]. Caregivers in gynecological cancer experience together with women such as despair, uncertainty, stress-induced agitation, feelings of loneliness, depression and fear. Tiring and during the long acting treatment process the vast majority of roles of women (spouse, mother, family, organization, etc.) are shared by partners, adult children and relatives [8,9]. In this context, providing adequate and comprehensive patient care, determination of supportive care needs and social support will reduce problems of women with gynecological cancer in disease process.

Unmet needs' refers to the gap between a person's experience of services and the actual services desired [10]. Unmet supportive care needs in cancer survivors have been defined as those needs which lack the level of service or support an individual perceives to be necessary to achieve optimal well-being. Unmet needs commonly result from the

discontinuities in treatment due to inadequate resources, inadequate health insurance, or the lack of satisfaction with treatments in the literature [11,12]. In addition, previous research indicates that many patients diagnosed with gynecological cancer express unmet needs in terms of emotional distress, decision-making support, and practical concerns. However, the unmet needs of gynecological cancer patients are widely varied [7-12]. In this regard, we summarize current literature regarding the unmet needs of gynecologic cancer patients, with a specific focus on interventions that address screening and early diagnosis, fertility, self-image and sexuality, psychosocial problems, alternative approach, treatment processes, occupational therapy and supporting of caregivers, post treatment follow-up (survivor) and end of life care.

Risk of unmet need has been related to age, gender, education, income, geographic location, diagnosis, and marital status. Several factors were found in relation to the number and intensity of unmet needs in different studies. In this regard, in the literature prevalence of unmet needs is reported as more than 20-40% of gynecological cancer patients had psychosocial needs including worries and fears [13-16] and 70% expressing unmet needs specifically in the health information domain [17]. Younger age is systematically related to greater unmet needs; particularly sexuality needs and body image concerns, and is compounded when living with a partner [13-15].

Supportive care scale can be used to identify patients' satisfaction and unmet needs related to medical information, communication, psychological wellbeing, social symptom, sexuality, caregiving care and support, spiritual, financial, physical and daily living needs in the gynecological cancer survivors [14,17]. Establishing the definition of being clinically meaningful for unmet needs could be an important focus of future work.

Aim: We present an overview of the literature that has evaluated the unmet needs for individual treatment in gynecological cancer.

Protection, screening and early diagnosis in cervical cancer

In the recent years cancer is on track of becoming the most important public health problem in Turkey, as well as in the rest of the World. Thus screenings or early detection programs are most important in detection of cancer in early stage [3]. Cancer screening views changes in the cells of the cervix that could lead to cancer. Screening includes Pap test and human papilloma virus (HPV) test. According to American College of Obstetrician and Gynecologist, Guidelines 2013; most women don't need cervical screening each year. Routine cervical cancer screening; should start at age 21 years, Pap test and HPV test should be done every 3 or 5 years in women aged 30-65 years, screening after 65 years should stop if there is negative history in a row within the past 10 years. Also women having HPV vaccine should be included in the same screening programme [18]. Turkey ministry of health cervical cancer screening programs are being carried out throughout the country. According to National Cancer Control Program Smear should be taken at least once from every woman between ages 35-40, HPV/Smear should be repeated with five year intervals in women aged 30-65 years. Screening should be ended for 65 year old women with negative results in the most recent two tests [1].

The most important factor regarding cancer in a population is it's diagnose at an early stage [2,18]. In this context, as recommended by the World Health Organization (WHO), a national screening program should be established to reduce mortality and morbidity on cancer in Turkey [1]. However, without raising awareness in the society about the importance of early diagnosis, it is impossible to succeed in early diagnosis and screening programs effectively. There are substantial obstacles in front of implementation of Cancer Control Program and cancer screening [1,4]. To raise awareness on cancer, the most important strategy developed to achieve goals on this issue should be education and advocacy. Insufficient awareness and education levels in the public, inadequate standardization of the education of the public and medical personnel and lack of belief in early diagnosis and screening programs are probable barriers in cancer screening. Therefore, educating and raising awareness of women on cancer is the most important factor. Cancer Registration is the start of "cancer control" activities. Once a database is set up, it becomes possible to study etiological or causal agents and to take appropriate measures to prevent cancers. Obtaining reliable source of data in cancer registration is important. Ineffective operation of centers of cancer registry affects the reliability of the data in Turkey [1,3,4]. Level of health literacy of women is a significant concern in regards to the management of information-based need [7,8,10]. Lindau et al. [14] found that 40% of women who presented for routine cervical cancer screening had a low level of health literacy, and that level of health literacy was related closely with disease-related knowledge. A patient's ability to process information can influence patient participation in care, assessment of risk, understanding of screening and treatment, and even health outcomes [14,19]. Information needs may also increase post treatment survival as patients have less frequent contact with health care providers. Anxiety regarding cancer screenings and cancer treatment is common, but if women understand the risk-benefit information provided by health providers they are more likely to participate in decisions about early gynecologic cancer diagnose or treatment [10,19].

Cancer Data are being collected through active and passive system in Turkey and data entered into the computer program to the Cancer Control Department via electronic medium [1]. In order to reach

correct conclusions on the cancer burden in a given population, accurate and complete cancer registration data is required. Cancer Registries are responsible for the confidentiality of the collected data. This responsibility requires the regulation of legislation on the issue of the confidentiality of cancer registration records [1,4]. A study carried out in the United States showed that the incidence of cervical cancer has decreased by more than 50% in the past 30 years [19]. This result is attributed to the widespread screening of cervical cytology testing.

Fertility, self-image and sexuality

Currently, there has been increasing interest in finding mechanisms to improve cancer patients' and survivors' psychosocial wellbeing. Such efforts require effective measures in order to establish prevalence of unmet needs and to assess the effectiveness of interventions [9,16,20]. Due to the improvements of gynecologic cancer treatment, the survival rate of cancer increased over the last decades. This fact is attributed to the use of more aggressive cytotoxic therapy, leading to a higher risk for the impairment or loss of fertility as one of the detrimental side effects of treatment regimes having a family is one of the important aspects for long-time survivors. Treatment-induced infertility is a major issue for long-time survivors of cancer, especially as many young cancer patients might not have completed their family planning at the time of diagnosis and treatment [21-23].

Most of young women diagnosed with gynecologic cancer can benefit from fertility preservation techniques such as oocyte and embryo cryopreservation. Embryo cryopreservation is the most established technique and has been the standard option for preserving fertility [24,25]. There are limited data on successful pregnancy rates. The greatest benefit from the procedure is expected in children, since they have the highest number of primordial follicles. With ovarian tissue freezing, no ovarian stimulation is needed; therefore, time restrictions for cancer therapy are fewer, and there is no risk of stimulating estrogen-sensitive cancer following ovarian stimulation. Additionally, it avoids ethical concerns regarding ovarian stimulation and oocyte retrieval in children [23-25].

Especially young women have been identified to be most likely to experience psychosocial needs related to sexuality in the literature. Nature of the disease may require invasive treatment procedures to the female reproductive system, for this reason, sexual issues are a major concern for women diagnosed with gynecologic cancer. The literature indicate that a majority of women diagnosed with gynecological cancer have reported sexual dysfunction (SD) in the form of orgasm difficulties, loss of sexual desire, sexual symptoms such as vaginal dryness, dyspareunia, decrease in frequency of sexual intercourse and decreased libido or sex desire [5,6,10,14,21,22]. The literature showed that the changes or loss of their reproductive organs affected women's sexual functions in an adverse manner [5,6,9]. Performed In the Pinar et al. study, Sexual Dysfunction (SD) was observed in 80% of women with gynecologic cancer. In addition, SD rates were higher in women who have undergone surgical intervention [9]. Our society's view is that a woman should have a uterus and should be able to give birth. Therefore, the loss of a woman's uterus is generally considered a loss of her role as a woman.

In addition, reproductive organs are the main identifiers of being a woman and as such, have a paramount role to play in the formation of self-image and self-respect in women, sickness or absence of these organs may lead to the changes in self-image perception of women [5,6,9].

Patient's views about their unmet needs have therefore become increasingly important. Some patients may be unaware of the availability of effective interventions [14]. Fertility preservation requires a multimodality approach. Health providers should take a comprehensive approach in counselling their patients regarding fertility preservation procedures. Despite of the high levels of SD occurrence in Turkey, the percentage of patients who seek professional help tends to be low [9]. In this regard; there is urgent need to improve the communication between patient and health provider in order to enhance the patients' sexual function. Patients should be kept well informed about their illness including any issues that would impact their sexual life.

Psychosocial problems, stigma and spirituality

Despite advances in cancer care, patients continue to experience a substantial level of unmet physical, social, employment, financial, emotional, and especially psychosocial problems and spiritual needs [12,15]. The most common emotional reactions during and after treatment include mood and anxiety disorders such as anxiety, depression, anger and fear. Untreated mood disorders can negatively affect patients' quality of life and response to treatment [11,26-28]. Studies show that psychological and social factors, such as depression and anxiety and inadequate social support, are associated with increased morbidity and mortality and decreased functional status in women with gynecological cancer [6,14-16,20]. In addition, the family support, spirituality, and quality of medical care as important variables for the road to recovery both physiologically and psychologically. In this regard, spirituality as a coping mechanism, and to convey the importance of respecting individual beliefs even if one's own differs fundamentally [29-32].

Spirituality is a distinctive, potentially creative and universal dimension, rising both within the inner subjective awareness of individuals and within communities. In most cultures, many individuals rely on their spirituality and faith when coping with disease [15,23,29,33]. Studies show that women with gynecologic cancer and spirituality may experience positive outcomes, less depression and longer survival, fewer post-surgical complications, and influence of serotonin pathways in the brain regulates mood and possibly pain. In this regard, spiritual care decreases aggressive end-of-life care and improves quality of life [15,29]

Treatment of gynecologic cancer is considered by many to be a financially devastating burden because of the expenses for diagnosis and treatment process. In this situation patient support is completely or partially paid by the family or herself. There is also a perception that a person who has been diagnosed with gynecologic cancer is too ill to be employed. Thus, it will be difficult for women with gynecologic cancer history to return to work after an illness-related absence, or to try to secure new employment. That is why; cancer is often kept as a secret in the workplace [34].

Stigma, issues of spirituality and myths about cancer are important problems that must be addressed. They present significant challenges to cancer control. Myths and stigma can have a silencing effect, whereby efforts to increase cancer awareness are negatively affected; myths and stigma can affect individual's behaviors, such that they are less likely to adopt cancer-risk-reducing behaviors or seek out the support and services they need when they are diagnosed with the disease. Unfortunately, stigma and myths associated with cancer are not directly addressed or challenged in many countries. Friends or family members can alternatively be a source of stigma [15,33,34].

They try to isolate the women with gynecologic cancer. In this situation, cancer care professionals play a critical role in supporting the women.

In the study of Hodgkinson et al. [16] nearly 49.0% of survivors reported unmet needs and requested help to reduce stress in their lives, %42.3 requested emotional support to be provided for them, %61.5 requested help to manage their concerns about the recurrence of cancer. Wenzel et al. [29] found that gynecological cancer survivors after five or more years post cancer diagnosis reported persistent fears of disease recurrence. In addition, unmet needs levels gynecologic cancer survivors increased with higher levels of symptoms of anxiety, and higher levels of symptoms of depression in the literature.

Complementary and alternative approach

Complementary and Alternative Medicine (CAM) is becoming an increasingly popular and visible component of gynecologic oncology care [35,36]. Women with gynecological cancer often face unmet needs for CAM approach. Reasons given include the unmet needs for a new source of hope, preference for natural therapy and achieving a sense of greater personal involvement. In addition several studies have documented the frequency with which gynecologic oncology patients use CAM methods. CAM using by Women with gynecological cancer improves physical and emotional wellbeing and quality of life, boosts the immune system and reduces side effects, help them gain a feeling of control over the treatment and by this way treat their cancer or improve their quality of life [35-38].

Gynecologic cancer patients frequently desire CAM methods to aid in relief of both cancer-related and treatment-related side effects and find satisfaction in their use. Furthermore, women also seek treatment to aid in superior outcomes and cure rates. Unfortunately, evidence suggests that the use of CAM is underreported or not discussed with health providers [36,38]. In the literature, there is a lack of scientific evidence either supporting or negating CAM. Because of the lack of information available, health care providers do not have adequate information regarding safety and efficacy of CAM [37,38]. This leads to miscommunication or absence of communication between health providers and women with gynecological cancer. Because patients use CAM to improve quality of life during and after treatment, it would be educational for providers to know the specific quality of life deficits among patients who require attention. Thus, with the ultimate goal of improving quality of life for gynecologic cancer patients, health providers should be pushed to investigate CAM and determine an honest support or rejection of CAM methods. In addition, when patient talks about her desire to seek CAM methods, the health providers should listen and avoid being judgmental and potential harm of such methods must be explained. However, there is a lack of scientific literature in gynecologic cancers, which either supports or rejects various CAM modalities [35-38]. Future research should focus on randomized controlled trials of CAM in women with gynecologic cancer with emphasis on quality of life.

CAM use in gynecological cancer patients as a discrete group of patients has received little attention in the literature. In a recent study, Hodgkinson et al. [16] determined that nearly 20% of survivors reported complementary and/or alternative therapy services needs. Molassiotis et al. [35] show that 40.3% women of used CAM after the diagnosis with cancer. This rate is close to reported prevalence rates of CAM use samples of gynecological cancer patients. This is important information for health professionals as it highlights that CAM is used frequently by their patients. In addition, CAM improves the body's

ability to fight cancer or to improve physical and emotional well-being, and a very high level of satisfaction with CAM use was reported.

Treatment processes, occupational therapy and supporting of caregivers

Another mostly unmet service need in this patient population that also calls for occupational services is the need for management of clinical outcomes of gynecological cancer. Gynecological cancers can most likely be treated by surgery, radiotherapy and chemotherapy. The side effects of these treatments cause significant problems that have a negative effect on physical, psychological, social and spiritual aspects of life [5,6]. Diagnosis and treatment phase affects not only their quality of life, but also their family members. Patients experience many physiological and psychological problems; therefore it is important for the health professionals to have the care skills and to help the patients deal with their challenges and difficulties [7-10].

Although there are more debilitating side effects of aggressive treatment options for women, gynecological cancer survivorship rates are increasing. This situation requires an important shift from quantity of care to quality of care and quality of life to meet needs of women [38,39]. The World Health Organization (WHO) has defined rehabilitation as: 'processes intended to enable people with disabilities to reach and maintain optimal physical, sensory, intellectual, psychological and/or social function [40]. Patients' needs are influenced by different factors for rehabilitation services. Studies show that absence of rehabilitation services might lower expectations and thereby reduce the number reporting unmet needs. Rehabilitation encompasses a wide range of services including rehabilitative medical care, physical, psychological and occupational therapies (OT) and support services [41,42].

Occupational therapy (OT) is an important service to help women with gynecological cancer during and after treatment. Services can provide valuable benefits during the on-going diagnosis and intervention process in women with gynecological cancer, for fewer long-lasting effects of treatment in hospital, home, day care hospices and in patient hospices. In addition, they facilitate and enable to achieve maximum functional performance physically and psychologically and assist in managing the physical psychological emotional limitations caused by illnesses including gynecological cancer [38,39,41,43].

Women can benefit from OT intervention at any stage of an illness from primary diagnosis, through attempts at curative treatment, to palliation and finally terminal illness. There are different OT techniques or equipment to help them manage following gynecologic cancer treatment and improve their quality of life. Some examples can include: management of activities of daily living, lifestyle management, improved fitness, sleep and fatigue management, low-energy tasks that focus on restoring engagement in daily occupations and therapeutic exercise [43].

By this way, it helps in assessing self-care, work, and leisure and home/domestic tasks of patients to manage daily activities, and can play a positive and vital role in equipping patients to achieve their goals and improve their quality of life. Every patient will experience a different form of therapy as the treatment programmes are shaped to meet specific patient and career needs. In this context, the unmet needs were the lowest for occupational therapy in gynecological patients. In contrast, the supportive group session was the service that was most frequently offered but not needed.

Post-treatment follow-up (Survivor)

Due to the improvements of cancer treatment, the survival rate of women with gynecological cancer increased over the last decades. Screening techniques, such as the Pap smear and advances in cancer therapies have led to improved survival rates. Survivors live with the adverse effects of their disease and treatment, which constitute a significant physical and emotional adjustment [7,16,20]. Cancer survivors are known to face many stressors and to experience psychological problems and distress in addition to the physiological symptoms. The literature indicates that health status is significantly impaired among gynecologic cancer survivors, and especially social support affects health status positively and health behaviors of women via the mechanism of social control [21,30,33]. The determination of the effect of social support and related factors is important in coping with stress by gynecologic cancer patients. The level of social support affects quality of life in women with gynecologic cancer.

Studies performed in Turkey showed that [27,31,44-46], as social support from the family increased, the effective coping ways were detected to be used more frequently. In the study of Yılmaz et al. [45] emotional support was reported by patients as the most helpful type of support from spouses. In addition, the same patients reported further emotional adjustment to cope with stress when their partners were highly supportive. Reis et al. [46] shows that parental, familial, and friends' support was at quite a high level as these are characteristics of Turkish social life, thus making an immense contribution to the improvement of social well-being. Fukui et al. [15] determined on Japanese cancer patients' family members, friends, healthcare professionals, and peers that they communicate information, and provide reliable alliance, aid, and esteem (i.e., informational, emotional, instrumental, and affirmational support).

A number of studies have demonstrated that as age level increases, and educational level and perceived social support decrease, the use of the ineffective coping ways increases; also, the use of the effective coping ways increases, as perceived social support increases [7,20,30]. In this context, an awareness of the factors related to social support and coping ways of stress may be helpful in the determination of features required while giving nursing care, performing researches, or counselling and training.

There is little data on the relationship between social support and quality of life in gynecologic cancer, in spite of a substantial literature describing the long-term benefits of social support in various cancer survivor samples. Many studies have determined the significant sexual problems that commonly occur following diagnosis and treatment of women with gynecological cancer [5,6,9,22,24,25], a few studies describe psychological quality of life outcomes [31,44]. These studies generally focus on the two-year period following treatment, thus health-related quality of life in long-term (≥ 5 years) is known very little. Also, a few studies have been conducted with long-term survivors of gynecologic cancers and examined the quality of life of women who were diagnosed with gynecological cancer and underwent treatment in Turkey. Cancer-related health status is associated with increased levels of psychological distress and traumatic stress symptoms and social support.

After women are diagnosed with cancer and the initiation of treatment, the levels of stress commence to increase. In order to improve the quality of nursing care for women communication skills of nurses should be improved and nurses should be provided more time to spend with them and to address women' concerns. In addition, the

care should be tailored individually in order to meet each patient's needs best.

End of life care-palliative care

Palliative care is a human right and eliminates the problems caused by the cancer itself or treatment methods. It can be applied to newly diagnosed patients or patients undergoing treatment or in the terminal phase. Because life and death are considered as normal processes, it improves the quality of life of women with gynecological cancer and aims to increase the quality of life rather than the length of life in palliative care, by providing pain and symptom relief, spiritual and psychosocial supportive care from diagnosis until the end of life [47,48]. Palliative or end of life care has long been recognized as important and considered to be a part of gynecological cancer treatment. But more recently, it's getting much more attention and more studies are performed.

Hospice care is a type of care provided to terminally ill patients and focuses on enhancing the dying person's quality of life rather than trying to cure the terminal illness. However, in the final days of life many end-of-life decisions have to be made, and these decisions involve many potential ethical concerns. These states, effective between health care professionals and patient communication are the cornerstone of excellence in patient care. Ensuring good communication among the nurses, patients, and family will facilitate care, and avoid ethical problems [47-50].

Performed studies show that the benefits of palliative care and patients who had hospital-based palliative care visits spent less time in intensive care units and were less likely to be re-hospitalized. In addition, women with gynecological cancer who get palliative care have less severe symptoms and better quality of life and their families also feel more satisfied [48-50]. The objective of the palliative care is to improve the quality of life of women with gynecological cancer and their relatives, throughout the whole treatment. And palliative care only is not confined to the patient; it includes attention to the emotional needs of the primary care givers during the patient's illness and subsequently to bereavement.

The numbers of institutions providing palliative care services have increased in Turkey and hospice care services are planned as part of palliative care but these are very limited and are not included in all the regions. In this regard, the legal and regulatory requirement work continues in palliative care [48-50]. In addition, Palliative Care Program Action Plan was prepared by the Ministry of Health to improve quality of care and definition of the palliative care in Turkey [48]. In this context, ensuring certification and in service training for palliative care nurses, increases cadre allocation for nurses who are experienced in oncology (at least 5 years) and development of training certification programmes for specialized nurses in oncology identification of palliative care at every stage in planning cancer treatment were included in program objectives.

Conclusion

In conclusion, we found a significant level of unmet needs for care among individuals with gynecological cancer. The most common needs included psychological needs, information needs, and needs in the physical domain. Unmet needs should be identified as soon as possible by health professionals. Therefore, alternative strategies should be considered to reduce the frequency of unmet needs based on motivational interviewing methods, other cognitive-behavioral

approaches, psychoeducation, medication self-management, and, more recently, environmental support. Further research is required to establish the clinical utility of unmet need interventions so that appropriate urgent interventions can be developed.

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