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A comparison of men and women's experiences of chemotherapy-induced alopecia

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A B S T R A C T

Purpose: The effect of alopecia on men and women has not been fully documented in the literature, especially for Turkish cancer patients. The aim of this study was to determine the incidence of chemotherapy-related alopecia and how it affects the body image and quality of life of Turkish male and female cancer patients, in order to identify variables that may be important in the perception of this problem.

Methods: This descriptive study was carried out between November 2010 and June 2011 at Istanbul University Institute of Oncology; 201 men and 204 women attended. A face-to-face interview was performed during chemotherapy, and the effects of alopecia on cancer patients were assessed using the Patient Information Form, Body Image Scale, and Nightingale Symptom Assessment Scale.

Results: The study group consisted of 55.1% female and 44.9% male patients. Most of the patients experienced partial or total alopecia during chemotherapy. There were no differences between men and women with regard to body image in respect of degree of alopecia, but the body image of the male and female patients who had partial or complete alopecia was lower than that in patients who had no alopecia; psychological well-being of women was lower than that in men, because the incidence of alopecia was higher in women.

Conclusions: This study contributes new knowledge on the cultural characteristics of Turkish patients, which may assist other researchers working with different international populations. Alopecia is a difficult side effect for both men and women. Health professionals should assess and educate patients differently from the current standard.

Introduction

Every individual has a mental picture of his or her own body, which is known as their body image. Body image appears to be determined by interpersonal, environmental and cultural factors. At birth, individuals have no body image, but as they gradually gain awareness of their body throughout life, the individual's body image is constantly developing, depending on their sexual function, occupation, relationship with family or friends, physical appearance, or the loss of or change in any of these components (Cartwright et al., 2008; Dougherty, 2007; Hurk et al., 2010; Hansen, 2007). The initiation of chemotherapy for a diagnosis of cancer sometimes causes severe alopecia, which can cause feelings of stigmatization by changing the individual's identity from that of a healthy person to that of a cancer patient; this affects both the patient and others (Hurk et al., 2010). Chemotherapy-related alopecia, ranging from partial to total hair loss, is a common side effect of some chemotherapy regimens (Hansen, 2007; Randall and Ream, 2005). The likelihood of alopecia is related to the type of drug used and its schedule of administration (Hansen, 2007; Lemieux et al., 2008; Trüeb, 2009). Agents that cause severe alopecia include adriamycin, cyclophosphamide, etoposide, ifosfamide, methotrexate, mitomycin, taxoids, vincristine and vinblastine (McGarvey et al., 2010). The incidence of alopecia is estimated at 65%, and it is considered to be one of the most feared and traumatic factors in cancer patient care (Trüeb, 2009). As hair loss is visible, this problem can serve as a constant visual reminder that "I have cancer", and consequently most cancer patients suffer the stigma of alopecia in social interactions, and behave more discretely when they do not hide their hair loss (Hansen, 2007;

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McGarvey et al., 2010; Randall and Ream, 2005). The visual nature of alopecia can affect the body image, quality of life, social interaction and sexuality of the patient (Randall and Ream, 2005). It may seriously affect body image, which in turn has an impact on self-esteem and self-confidence. Consequently, it may cause emotional suffering, may lead to personal, social and work-related problems, and may have a negative effect on quality of life (Auvien et al., 2010; Cartwright et al., 2008; Christodoulou et al., 2002; Hunt and McHale, 2005; Hurk et al., 2010). It was found that most cancer patients experienced hair loss induced by chemotherapy, and the impact on their individuality, their social relations, and their everyday lives led us to focus on this issue (Hansen, 2007; Randall and Ream, 2005).

Recognition of chemotherapy-induced alopecia and associated psychosocial problems has been noted in the literature for three decades. Alopecia has been cited as the most feared side effect by up to 58% of women preparing for chemotherapy, and some patients may avoid treatment for this reason. Women with cancer who experience alopecia report lower self-esteem, poorer body image, and reduced quality of life (Lemieux et al., 2008; McGarvey et al., 2001). Another study reported that men with alopecia had a worse self-image than women with alopecia. It is also interesting to focus on differences between men's and women's experiences, particularly as hair and the distribution of body hair have been a marker of gender across cultures for centuries (Hilton et al., 2008).

In the light of these results, the aim of this study was to determine the incidence of chemotherapy-related alopecia and how it affects the body image and quality of life of Turkish men and women with cancer, in order to identify variables that may be important in the perception of this problem.

Methods

Setting and participants

This descriptive study was carried out between November 2010 and June 2011 in the Outpatient Chemotherapy Unit at Istanbul University Institute of Oncology; 201 men and 204 women were studied. Criteria for the inclusion of patients were as follows: patients who were diagnosed with any type of cancer who were receiving any cycle of adjuvant or metastatic chemotherapy, who were older than 18 years of age, who were able to communicate in Turkish, and who consented to participate in the study. Excluded were those patients with a social or psychological condition that would interfere with their participation in the study, and those who did not want to participate in the study after it was explained to them. Depending on inclusion criteria with power analysis in respect of 95% confidence interval (95%CI), 65% alopecia incidence sample size was statistically computed according to the annual number of patients and the prevalence of alopecia in cancer patients who have received chemotherapy. The minimum sample size was determined as 200 for both sexes. According to the inclusion criteria and the power analysis, 420 patients were invited to participate, and informed consent was obtained. In total, 405 cancer patients completed the study, and 15 forms were excluded because of incomplete data.

Study procedure

A face-to-face interview was performed during chemotherapy, and patients' personal and illness-related characteristics were evaluated using the Patient Information Form. Then patients who were well enough completed the Body Image Scale (Hopwood et al., 2001) and Nightingale Symptom Assessment Scale (Can and Aydıner, 2011) themselves; for those who were unable to do so, a friend or relative of the patient was asked to assist by verbally presenting the questions to the patient and completing scales according to the patient's responses. Each patient interview lasted approximately 30 min.

Measures and instruments

The *Patient Information Form* developed by the researchers contained ten items that addressed both personal characteristics (e.g. age, income level, employment status, the wearing of a head scarf during daily life) and illness-related characteristics (e.g. diagnosis, surgical therapy, radiation therapy) suggested as factors affecting the experience of alopecia.

The *degree of alopecia* was assessed according to the National Cancer Institute Common Terminology Criteria for Adverse Events (NCI-CTCAE) Version 4.0. Grade 1 (partial alopecia) is indicated by hair loss of $<$50% of the normal for that individual which is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage. Grade 2 (complete alopecia) is indicated by hair loss of $\geq$50% of the normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss and its associated psychosocial impact.

The *Body Image Scale* (BIS) is a ten-item measure developed to assess affective (e.g. feeling self-conscious), behavioral (e.g. difficulty looking at the naked body) and cognitive (e.g. satisfaction with appearance) dimensions of body image briefly in cancer patients. Body image changes were quantified using four numeric responses; namely "not at all", 0; "a little", 1; "quite a bit", 2; "very much", 3. The scores for the ten items were then summed to produce an overall score for each patient, ranging from 0 to 30, with zero scores representing no symptoms or distress and higher scores representing increasing symptoms or distress or more body-image concerns (Hopwood et al., 2001). Cronbach's α coefficient of the scale was previously reported as 0.89, and correlation coefficients were between 0.59 and 0.72 (Erol et al., 2011).

The *Nightingale Symptom Assessment Scale* (N-SAS) developed by Can and Aydıner (2011) is a 38-item Likert-type QoL (quality of life) scale that addresses the cancer patients' perceptions related to chemotherapy; the perceived severity of symptoms was quantified using a five-item response scale: 0, not at all; 1, a little bit; 2, somewhat; 3, quite a bit; and 4, very much. These 38 items are used to calculate the Psychological Well-being (PsWB, ten items), Social Well-being (SoWB, eight items) and Physical Well-being (PhWB, 20 items) subscales and a total N-SAS score. Subscale scores represented the average score for the individual items within each subscale. The total N-SAS score represented the average score for all 38 items. These scores are used as an index of treatment-related well-being, with a higher score indicating worse symptoms and poorer well-being. Scores ranging between 0 and 0.50 indicate very good well-being, 0.51 and 1.50 good well-being, 1.51 and 2.50 fair well-being, 2.51 and 3.50 poor well-being, and 3.51 and 4.00 very poor well-being. The original study by Can and Aydıner (2011) tested the comprehensiveness and clarity of the N-SAS. Internal reliability was high, with Cronbach's α values between 0.81 and 0.87 for the subscales, and 0.93 for the overall tool.

Ethical considerations

The study was approved by the administration of Istanbul University Institute of Oncology. All potential participants were informed of the study and verbal consent was obtained.