The Impact of the Perception of Chemotherapy-Induced Alopecia on Psychosocial Life

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Abstract

AIM: This study was planned to evaluate the perception of alopecia as a side effect of chemotherapy, and its effect on the psychosocial life of patients.

METHODS: This cross-sectional and descriptive study was carried out at Şişli Hamidiye Etfal Training and Research Hospital, with inpatients in the Radiation Oncology Clinic and outpatients in the Chemotherapy Unit between January 12, 2013 and January 12, 2014. The data for the study were collected by face-to-face interviews using the Patient Identification Form, Disease and Alopecia-Related Features Form, and the Chemotherapy-induced Alopecia Quality of Life Scale, of 213 of the patients who faced chemotherapy-induced alopecia. Descriptive statistics for the statistical evaluation of the data and non-parametric tests such as the Mann–Whitney U-test and the Kruskal–Wallis test for independent group comparisons were used.

RESULTS: The study group consisted mostly of elementary school graduates (71.8%), married (74.2%) and female (73.7%) patients residing in Istanbul. A large number of patients stated that they did not have any complaints when their hair began to fall, while a few patients stated that they felt itching. The Chemotherapy-induced Alopecia Quality of Life Scale average scores (23.9 ± 5.4) were found to be low and quality of life of the patients was negatively affected by their alopecia. Also, the impact of alopecia diminished with increasing level of the patient’s education. It was found that the alopecia-related quality of life scores were lower for the patients who were already wearing a headscarf before illness, compared to the patients who started to wear a headscarf after illness.

CONCLUSION: In conclusion, chemotherapy-induced alopecia is an important problem affecting the psychosocial life of patients.

Keywords: Alopecia, chemotherapy, psychosocial impact

Introduction

Cancer is one of the major health problems of our time. Earlier, it was ranked seventh or eighth among the terminal illnesses, but now it ranks fourth in the world and second after heart disease in Turkey (Ateş & Olgun, 2011; Turkey Health Statistics Yearbook, 2017; World Health Organization, 2018).

Many treatment approaches, such as surgical treatment, radiotherapy, chemotherapy, and hormonal therapy are used against cancer. Chemotherapy, which is one of these treatment approaches, prevents the development and proliferation of cancerous cells. However, it also prevents the development of hematopoietic cells, regeneration of gastrointestinal channel mucosa, and hair growth, and produces numerous side effects such as nausea, vomiting, mouth sores, fatigue, and alopecia (Hintistan et al., 2012). The side effects of the cancer treatment and the perceived discomfort lower patient compliance, and cause them to falter in their expectations and plans for the future (Dedeli et al., 2008). The chemotherapy treatment-related symptoms adversely affect patients’ quality of life, leading to interruptions in the treatment process (Ovaryolu & Ovaryolu, 2013). A diagnosis of cancer brings along with it ambiguity regarding the patient’s future, and chemotherapy adds new fears due its side effects (Duran, 2011).

Alopecia, one of the side effects of the chemotherapeutic antineoplastic agents, is a problem frequently reported by 62.1% of the patients (Hintistan et al., 2012). Depending on the treatment protocol in use,
Chemotherapy-induced alopecia may induce partial to full hair loss (Can et al., 2013; Lemieux et al., 2008). Besides its physical effects, the emotional impact of alopecia is also of great significance for the patients (Dilek, 2010). The alopecia developed 2–3 weeks after the first treatment application may be an important problem affecting physical appearance, self-confidence, family and social environment, and the patient’s battle against cancer (Aktuğ & Gürsoy, 2013). In a study conducted on this issue with the participation of female patients, 47% of the patients identified alopecia as the most traumatic side effect. In addition, in the same study, 8% of patients stated that they declined chemotherapy because of alopecia (Kluger et al., 2012). In another study conducted by Browall et al. (2006), women were afraid that their appearance due to hair loss would change, and some patients reported that chemotherapy-induced hair loss was worse than the breast loss (Lemieux et al., 2008). Since hair loss is like a symbol indicating that a person has cancer, it is expected that it negatively affects both male and female patients (Erol et al., 2012). A study conducted by Can et al. (2013) revealed that the negative impact of alopecia on body image is similar for both male and female participants, and the body image of the patients in both groups who experienced partial or complete hair loss was more negative than in the patients who did not develop hair loss. In the same study, because of the higher incidence of alopecia in females, the psychosocial well-being of females was found to be more affected than males (Erol et al., 2012). This may also be due to the fact that baldness is a socially acceptable phenomenon in men (Dougherty, 2007).

Numerous experts state that the presence of hair contributes to a positive physical appearance and body image, and symbolizes many factors such as charm and personality. Throughout history, hair has become an important part of body image in social, cultural, and political contexts (Erol et al., 2012; Jayde & Boughton, 2013). For each person, his or her illness has a meaning and it affects them psychologically at varying degrees (Koszalinski & Williams, 2012). For many patients receiving chemotherapy, hair loss is the biggest source of sadness. Although hair regrows after treatment, a study reports that even a temporary hair loss may have a major traumatic effect in patients (Irmak et al., 2008). Although being mentally prepared, most patients have reported that they suffer from shock due to the bundles of hair lost in combs and on pillows. Patients who developed alopecia stated that they felt shame and that they try to camouflage it by wearing hats, scarves, and wigs, to hide their cancer (Aktuğ et al., 2013; Erol et al., 2012). A study reported that alopecia is important in social and sexual communication, and it causes patients to experience stress (Batchelor, 2001). A small number of studies have been carried out on the issue. In light of the above, this study was planned to determine the perception on the effect of chemotherapy-induced alopecia on the psychosocial life of the patients.

Research Question
1. Does the perception of chemotherapy-induced alopecia have an effect on psychosocial life?

Method

Study Design
This study was conducted as cross-sectional, descriptive study.

Sample
The research universe consisted of patients who applied to the Şişli Hamidiye Etfal Training and Research Hospital, Radiation Oncology Clinic and Chemotherapy Unit. All of the patients with chemotherapy-induced alopecia who met the inclusion criteria and who agreed to participate in the study constituted our sample. No sampling methodology was used in the study. Required explanations about the research were made verbally to the patients and written consents were obtained. After describing the study, 213 patients with alopecia, out of 510 alopecia patients admitted to oncology, who accepted to participate in the study verbally and in writing were included.

Data Collection
The evaluation forms were filled in with face-to-face interviews with the patients.

Data Collection Tools
Data on the study were collected using the Patient Identification Form, Disease and Alopecia-Related Features Form, and the Chemotherapy-Induced Alopecia Quality of Life Scale (CIAQLS).

Patient Identification Form
The Patient Identification Form was prepared by the investigator based on current literature (Ateş
et al., 2011; Batchelor, 2001; Erol et al., 2012; Lemieux et al., 2012). In this identification form, the sociodemographic characteristics of the patients such as age, gender, marital status, education, occupation, cohabitation, economic status and social security were collected, under eight items.

**Disease and Alopecia-Related Features Form**
The Disease and Alopecia-Related Features Form was prepared using related literature (Ateş et al., 2011; Batchelor, 2001; Erol et al., 2012; Lemieux et al., 2012). In this identification form, the patient’s disease and treatment-related characteristics such as diagnosis, duration of illness, chemotherapy drugs used, number of cures, and cure frequency were evaluated, under 15 items.

**Chemotherapy-Induced Alopecia Quality of Life Scale (CIAQLS)**
The CIAQLS was tested for reliability and validity, and adapted to Turkish by Ateş and Olgun, in 2011. Through this five-point Likert type identification tool, the effect of alopecia on the quality of life is evaluated using 19 statements. Each of the statements is scored as: strongly agree, 1; agree, 2; undecided, 3; disagree, 4; and strongly disagree, 5. The items 2, 15, 16, and 17 of the identification tool are scored inversely. Low scores on the scale indicate deterioration in the quality of life of the patients. The highest score possible from the scale is 95, and the lowest score is 19. The scale consists of three sub-dimensions: “Dimension of Reflections on Life in General,” “Dimension of Negative Reflections on the Inner World,” and “Dimension of Positive Ideas.” The Dimension of Reflections on Life in General includes statements about the negative effects of alopecia in the patient’s life (leisure activities, communication, friendships, etc.). In this sub-dimension, the lowest score is 9 and the highest score is 45. The Dimension of Negative Reflections on the Inner World includes statements about the negative effects of alopecia on the patient’s inner world (such as sadness, morale, anger). The lowest score in this sub-dimension is 6 and the highest score is 30. The Dimension of Positive Ideas, which is scored reversely, includes positive expressions (such as I am satisfied with myself, hair loss doesn’t prevent me from achieving my goals in life). The lowest score in this sub-dimension is 4 and the highest score is 20. Cronbach’s alpha coefficient of the CIAQLS is 0.88.

**Statistical Analysis**
The data were analyzed using the Statistical Package for Social Sciences software version 15 (Chicago, USA). The descriptive statistics were number and percentage in categorical variables, and average, standard deviation, minimum, and maximum value in numerical variables. Non-parametric tests were used in the comparisons of the independent groups, since the numerical variables did not provide a normal distribution condition. The Mann–Whitney U-test was used in the comparison of two independent groups, while the Kruskal–Wallis test was used for comparisons of more than two independent groups. Since a parametric test condition was not provided, the relations between the numerical variables were examined by Spearman’s Correlation Analysis. The statistical significance level of alpha was accepted as $p < .05$.

**Ethical Considerations**
The permission for the study was obtained from Şişli Hamidiye Etfal Training and Research Hospital Ethics Committee on January 14, 2014, with permission number 579; and from the Ministry of Health-Istanbul Province Beyoğlu Public Hospitals Union, numbered 3218 and dated January 29, 2014. The patients were informed verbally about the basic information about the research, and all participating patients provided informed consent and were assured of data confidentiality.

**Results**
The findings obtained from the study were examined under five headings: sociodemographic characteristics, disease-related characteristics, characteristics of alopecia, effects of alopecia on quality of life, and factors affecting alopecia-related quality of life.

**Distribution of Sociodemographic Characteristics**
A total of 213 patients with chemotherapy-induced hair loss, including 157 women and 56 men, with an average age of 51.5 ± 12.9, were included in the study. Most of the patients were married and residing in Istanbul city. Further, 71.8% of them had elementary level education, 70% of the patients had moderate income, and a large portion of them were not employed. Most of the patients had social insurance to cover their healthcare costs (Table 1).
With regard to the diagnostic status of the participants, most of the patients received chemotherapy for a diagnosis of breast cancer (46.9%) or lung cancer (13.6%); 55.9% had been diagnosed with primary and 44.1% with metastatic disease. Half of the patients had undergone surgical treatment and received radiotherapy. The rate of cranial radiotherapy was very low. A small number of patients had been on hormonal therapy for an average of 3.5 ± 1.7 years, and 8% of these patients continued hormone therapy during chemotherapy (Table 2).

### Distribution of Disease-Related Characteristics

| Diagnosis                           | n   | %   |
|-------------------------------------|-----|-----|
| Breast cancer                       | 100 | 46.9|
| Lung cancer                         | 29  | 13.6|
| Gynecological cancers               | 28  | 13.1|
| Lymphoma                            | 15  | 7.0 |
| Gastrointestinal cancers            | 34  | 15.9|
| Other cancers                       | 7   | 3.2 |

| Condition of the disease            |
|-------------------------------------|
| Primary                             | 119 | 55.9|
| Metastatic                          | 94  | 44.1|

| Treatment approach*                |
|------------------------------------|
| Chemotherapy                       | 213 | 100 |
| Surgical treatment                 | 144 | 67.6|
| Radiotherapy                       | 91  | 42.7|
| Cranial radiotherapy               | 15  | 16.5|
| Hormonal therapy                   | 37  | 17.4|

Note: *Multiple options are marked.
1 Prostate cancer (9%), bladder cancer (9%), testis cancer (9%), skin cancer (5%)

### Distribution of the Characteristics of Alopecia and Its Management

The examination of the alopecia-related characteristics of the patients revealed that 65.3% of the patients stated that they had hair loss during the treatment, and 87.3% stated that they had local hair loss prior to chemotherapy treatment. Most of the patients participating in the study were found to have visible alopecia. A small number of patients had been trained in alopecia. Most of the patients reported that they had been wearing headscarves even before they experienced hair loss, and 24.4% of the patients stated that pruritus was the most important complaint during hair loss (Table 3).

### Effects of Alopecia on Quality of Life

Evaluation of the quality of life of the patients affected by alopecia revealed that the average scores were low for both the sub-dimensions and the scale, and the quality of life of the patients...
The gender-related evaluation of the quality of life of patients affected by alopecia revealed that the average scores of women were lower than those of men, in the Dimension of Reflections on Life in General, and their quality of life was affected negatively by alopecia ($p < .001$) (Table 5).

The education-related evaluation of the quality of life of patients affected by alopecia revealed that the average scores of uneducated patients were lower than the patients with undergraduate level education, in the Dimension of Reflections on Life in General, and their quality of life was affected negatively by alopecia ($p < .05$). Compared to the patients with undergraduate level education, the average scores of the patients with elementary and secondary level education were found to be lower, in the Dimension of Negative Reflections on the Inner World, and their quality of life was affected negatively by alopecia ($p < .05$) (Table 5).

The income-related evaluation of the patients’ quality of life affected by alopecia revealed that the average scores of the patients with lower income level were lower than the patients with moderate income, in the Dimension of Reflections on Life in General and the Dimension of Negative Reflections on the Inner World, and their quality of life was affected negatively by alopecia ($p < .05$) (Table 5).

The patients’ social security-related evaluation of the quality of life affected by alopecia according to the Dimension of Reflections on Life in General revealed that average scores of the patients without social security were lower than the patients with social security, and their quality of life was affected negatively by alopecia ($p < .001$) (Table 5).

In the evaluation related to patients’ hair loss and the level of quality of life affected by alopecia, the average scores and the CIAQLS total scale scores of the patients with visible hair loss were found to be lower in the Dimension of Negative Reflections on the Inner World, than the patients with slight hair loss, and their quality of life was affected negatively by alopecia ($p < .05$) (Table 6).

The evaluation of the level of quality of life affected by alopecia according to the status of the patients’ awareness on alopecia revealed that the average scores of the patients who were not given prior information and made aware of alopecia as a side effect,
were lower than the patients who were informed, in the Dimension of Reflections on Life in General and the Dimension of Negative Reflections on the Inner World, and their quality of life was affected negatively by alopecia ($p < .05$) (Table 6).

When this study evaluated the level of the quality of life affected by alopecia according to the patients’ use of headscarf, it was found this study that the Positive Ideas average scores of the patients who were wearing headscarf before the disease were lower, and their quality of life was affected negatively ($p = .04$) (Table 6).

### Discussion

The findings obtained from the study were examined under five headings: sociodemographic characteristics, disease-related characteristics, the characteristics of alopecia, the effects of alopecia on the quality of life, and the factors associated with alopecia affecting quality of life.

Women comprised the greater proportion of a total of 213 patients with an average age of 51, who had experienced chemotherapy-induced hair loss and who agreed to participate in the study and were included. Most of the participants were married. The vast majority of the patients who participated in the study were elementary school graduates residing in Istanbul. Although most patients were not working, their level of income was moderately good. The majority of the study group comprised female patients. The levels of education of the patients were representative of the general education level, according to data of the Turkish Statistical Institute (2018). Most of the patients in this study received treatment for the diagnosis of breast cancer or lung cancer. Both disease groups are among the common
In a study conducted by Usta Yeşilbalkan et al. (2003), it was reported that 50.5% of the patients had complete hair loss. Since this study included only the patients with chemotherapy-related alopecia, all patients had the complaint of alopecia and most of these patients had visible hair loss.

It is important that the patients are informed about chemotherapy-related alopecia on the first day of the treatment, to reduce distress related to the hair loss. In a study conducted by (Ateş & Olgun, 2011), only 9.3% of the patients were informed about the alopecia beforehand. Most of the patients who participated in the study stated that they were not informed about chemotherapy-induced hair loss. The average scores of the patients who were not informed about alopecia were found to be lower than the patients who were, in the Dimension of Reflections on Life in General and the Dimension of Negative Reflections on the Inner World, and their quality of life was affected negatively by alopecia. For this reason, it is important to make the necessary regulations to reduce the psychological distress of the patients.

In a study conducted by Ateş and Olgun (2011), 82.97% of the patients were using an assistive accessory such as a wig or a headscarf, to hide the chemotherapy-induced hair loss. In a study conducted by Usta Yeşilbalkan et al. (2003), it was reported that 50.5% of the patients had complete hair loss. Since this study included only the patients with chemotherapy-related alopecia, all patients had the complaint of alopecia and most of these patients had visible hair loss.

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conducted by (Erol et al., 2012), half of the patients stated that they started to wear a headscarf to hide the alopecia after chemotherapy. Since most of participants in this study were wearing headscarves before their treatment, only 17.6% said they started using a headscarf to hide the alopecia after treatment. A few patients were using an accessory, such as a wig, a hat, or a bandana. In literature, it has been reported that the use of wigs help to reduce the side effects of chemotherapy, such as anxiety (Batchelor, 2001). For this reason, it is important to inform the patients and support their use of assistive accessories such as hats, scarves, bonnets, wigs, etc. in order to reduce their distress levels.

Unlike in other studies, more than a half of participants in this study were wearing headscarves when chemotherapy started. In the study conducted by (Ateş & Olgun, 2011), it was reported that the use of headscarf before chemotherapy was 24.11%. This difference in the use of headscarf is related to the cultural habits of the region in which the patients applied. The other study reported that the alopecia-related distress of the patients remains same for both patient groups, namely the patients who were wearing headscarves before treatment and the ones who started to wear after treatment (Erol et al., 2012). Contrary to their result, this study showed that the average scores of the patients who were wearing headscarves before disease were lower than the patients who were not, in the Positive Ideas sub-dimension, and that their quality of life related to alopecia was affected in the negative direction. This result may also be related to the cultural diversity of the region where the patient lives. On the other hand (Erol et al., 2012), reported that women with headscarves have lower education levels in comparison to women who did not wear headscarves. This issue can be studied further.

The study that Schmidt et al. (2001) conducted on the patients with diffuse alopecia showed that the patients with a clearly visible hair loss have a lower level of quality of life than the patients whose hair loss is not so visible. In this study, using the Hairdex scale, it was found that the scores of the patients with clearly visible hair loss differed significantly in the functional, emotional, self-esteem, and stigma sub-dimensions of the scale. It was reported that the increase in the level of alopecia also increased the level of anxiety (Schmidt et al., 2001). It was found in this study that the average scores of the patients in the Dimension of Negative Reflections on the Inner World were lower than their average scores in the Dimension of Reflections on Life in General and the Dimension of Positive Ideas. Ateş and Olgun (2011) have also obtained similar results. They found that the level of alopecia-related distress in 93.5% of the participants was above the average.

The evaluations of the significance of the variables of individual characteristics and illness-related characteristics in patients’ perception revealed that age, gender, education level, income level, and presence of social security significantly change the patients’ perception of alopecia.

Although studies conducted by Ateş and Olgun (2011) have reported that age is not a significant variable in the perception of alopecia, Hopwood and his colleagues reported that younger women had more body image issues (Hopwood et al., 2001); another study by Avis and his colleagues revealed that younger women diagnosed with breast cancer felt more distress compared to older women with the same diagnosis (Avis et al., 2005). Can et al. (2013) reported that the body image of the younger patients was lower than that of the older patients. It was found in this study that the quality of life of young patients was more affected by alopecia. This study, as other studies, revealed that that young patients give more importance to body image.

Compared to male patients, the average scores of the female patients in the Dimension of Reflections on Life in General were found to be lower, and their quality of life was affected negatively by alopecia. Can and his colleagues also reported that the male patients’ alopecia-related body image was less affected, and that their psychosocial well-being was better than the female patients in a study (Can et al., 2013). In the study conducted by Ateş and Olgun (2011), it was found that female patients had lower average scores in Negative Reflections on the Inner World, and lower general scores in the CIAQLS, compared to male patients. In a literature review conducted by Lemieux et al. (2008), it was reported that within the group of patients with alopecia, males had a lower self-image than females. No other difference between males and females was shown. Carelle et al. (2002) reported that comparing women and men, alopecia ranked second in the list of distressing symptoms for women and tenth in the list of distressing symptoms for men. In a different study
conducted by Dougherty, chemotherapy-induced alopecia in both women and men can be one of the most devastating effects of cancer treatment (Dougherty, 2017). In light of these studies, alopecia is thought to affect men as much as women.

In this study, it was found that the average scores of the low-income and low-education patients were lower in the Dimension of Reflections on Life in General and the Dimension of Negative Reflections; and the average scores of the patients without social security were lower in the Dimension of Reflections on Life in General, and they were more affected by alopecia. The study conducted by Ateş and Olgun (2011) stated that the level of education, marital status, economic status, and social security status are not the variables that affect the alopecia-related quality of life. In a different study carried out by Kanarığ, it was reported that work status is not a significant variable in the quality of life (Kanarığ, 2007). Can et al. (2013) also reported that the body image of patients who had a low level of income was lower than those who had a moderate income.

Conclusion and Recommendations

In this study, conducted to determine the effect of chemotherapy-induced alopecia on psychosocial life of the patients, it was found that some sociodemographic characteristics of the Turkish population have a negative impact on the quality of life of the patient group and that most of the patients are not informed on these issues prior to chemotherapy. To prevent the negative psychosocial impact of the chemotherapy-induced alopecia on the patients, It is important that they are informed about the issue prior to treatment, and that training on coping strategies should be carried out with the involvement of patients and their families, and that the relevant regulations should be made within the clinic. Patients should be informed about camouflage equipment and how to access them. Alopecia patients can be involved in programs organized for guidance and socialization. Symptomatic treatment may be recommended for complaints of hair loss.

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