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Impact of chemotherapy-induced alopecia distress on body image, psychosocial well-being, and depression in breast cancer patients

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Abstract

***Purpose*: This study aims to evaluate the impact of chemotherapy-induced alopecia (CIA) distress on body image, psychosocial well-being, and depression among breast cancer patients.**

***Methods*: A cross-sectional survey was conducted at the breast cancer advocacy events held at 16 hospitals in Korea. Alopecia distress was assessed using the 'Chemotherapy-Induced Alopecia Distress Scale', body image and psychosocial well-being were measured by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 and breast specific module (BR23), and depression was measured using the Center for Epidemiological Studies Depression scale. Means of outcomes were compared between low and high CIA distress groups. Univariable and multivariable linear regression models were used to analyze the relationship between the CIA distress and body image, psychosocial well-being, and depression.**

***Results*: One hundred sixty-eight breast cancer patients participated in the study; the mean age was 48.4 (SD = 8.4) years, and 55.3% of the patients experienced higher distress from alopecia. In fully adjusted models, the high distress group was more likely to have a poorer body image than the low distress group (35.2 vs. 62.0; $p < 0.001$). Distressed patients were also more likely to report lower emotional (55.3 vs. 76.9; $p < 0.001$), role (58.6 vs. 72.0; $p < 0.001$), and social functioning (51.3 vs. 70.9; $p < 0.001$). The high distress group was also more likely to have depression compared with the low distress group (19.6 vs. 14.8; $p < 0.001$).**

***Conclusions*: Chemotherapy-induced alopecia distress was negatively associated with body image, psychosocial well-being, and depression in women with breast cancer. It is necessary to develop specific interventions to minimize distress due to alopecia for women with breast cancer.**

Introduction

Most breast cancer patients receive adjuvant chemotherapy to reduce the risk of cancer recurrence after primary surgery [1,2]. Chemotherapy involves extensive periods of treatment, repeated hospitalization, and a variety of severe side effects including nausea, vomiting, weakness, loss of appetite, and alopecia [3–6]. Among side effects, alopecia is considered one of the most traumatizing and distressing experiences for women with breast cancer [7–14]. Often, losing hair has been described as a harder experience than losing breasts [13,15], and some patients refuse chemotherapy because of the expected hair loss [16]. Breast cancer patients experience physical, emotional, and psychosocial discomforts due to chemotherapy-induced alopecia (CIA) that may hinder patients' quality of life and their ability to cope effectively with cancer and its treatment [17,18]. Specifically, patients experienced headache and pain on scalp when they are having CIA, and they lost self-confidence while they mirrored themselves. Moreover, patients felt uncomfortable being in public areas because they were worried that people might recognize them as cancer patients with the CIA and limited their daily activities such as grocery shopping or jogging [18].

According to the objectification theory, women are typically acculturated to internalize an observer's perspective as a primary view of their physical selves that can lead

to habitual body monitoring and increase opportunities for shame and anxiety [19,20]. Considering that hair is an important indicator of femininity, sexuality, attractiveness, and personality for women, loss of hair would cause changes in feeling of femininity, sexuality, and attractiveness that can lead to body dissatisfaction and poor post-treatment adjustment [21,22]. Moorey *et al.* [23] reported that depression, shame, and loss of confidence were related to alopecia for women with breast cancer. According to a recent qualitative study with Korean breast cancer patients, they lost self-esteem and felt sad and miserable when they look at the mirror with CIA [18].

Moreover, Korean women with breast cancer seem to experience more difficulties with CIA than patients in Western countries because of negative attitudes toward cancer. In spite of highly developed medical science and increased survivorship in Korea [24,25], the public still has negative attitudes toward cancer and holds stigmatizing views toward cancer patients: 35.2% of participants in a study agreed or strongly agreed that cancer patients could be easily recognized by looking at them and 42.3% of participants agreed or strongly agreed that they felt uncomfortable when they were with cancer patients [25]. Tiggemann and Green theorized that these unfavorable peer and social environments would worsen people's body image [22,26]. Korean breast cancer patients seem to have distress due to CIA and poor body image because of unsupportive social environment for cancer patients. Patients reported loss of privacy and limitation of daily activities, and they tried to conceal alopecia from co-workers and neighbors because of the negative images and stigma toward cancer patients [18]. Patients also reported getting anxious about a wig or scarf falling off, and difficulty in focusing on activities such as shopping or exercising [18]. Yet, there is limited number of studies that investigated issues related to CIA distress among Korean breast cancer patients who would experience more CIA distress depending on social environments.

Women with breast cancer experience significantly lower body image at the time of alopecia. Moreover, alopecia is associated with serious psychological consequences such as depression and anxiety [27]. However, previous studies have evaluated the general association between alopecia and quality of life [17]. Considering that patients may experience different levels of distress and body image depending on their internalization process and on the influence from peer and social environments,[19,28] it is necessary to evaluate specific alopecia distress and its psychological burden. In addition, body image, which is a complex and multi-faceted construct encompassing perceptual, cognitive, affective, and behavioral aspects of the entire body experience [22], also should be examined in a more comprehensive manner in relation to CIA distress, as it is a key construct that impacts breast cancer patients' psychosocial health such as depression and sexuality.

This study aimed to assess CIA distress and its impact on body image, psychosocial well-being, and depression in patients with breast cancer. Our main hypothesis was that patients with high distress due to CIA would experience poorer body image, poorer psychosocial well-being, and more depression compared with patients with lower distress.

Methods

Study participants

Study participants were recruited between May 1 and August 30, 2009, at breast cancer advocacy events held at 16 different hospitals in Korea. The events were called 'Make up Your Life' for giving breast cancer patients self-confidence and for helping them overcome psychosocial distress due to cancer and its treatment. Anyone could participate in the events, and they were free of change. Subjects were eligible to participate if they were 18 years of age or older, had a histologically confirmed diagnosis of breast cancer (stages I to III), had no evidence of recurrence or metastasis, and had no psychological problems at the time of the survey. We excluded cancer survivors who were unable to read Korean. We approached 457 breast cancer survivors; 353 (77.2%) agreed to participate in the study. Among them, women who had a psychological problem ($n = 10$), recurrence of the disease ($n = 37$), or were stage 4 ($n = 1$) were excluded from the study, resulting in 305 people.

To evaluate actual distress rather than recall of patients that could bias the study, we used the data of only the 138 patients who were diagnosed with breast cancer within 24 months and who were experiencing CIA at the time of survey. This study was approved by the institutional review board of the Samsung Medical Center, and all study participants provided written informed consent.

Measurement

We questioned participants about their alopecia status by giving them specific description of each degree of alopecia: (1) not at all—similar hair to that before experiencing alopecia or hair grew back completely without hair deficits, (2) partial—hair falling now or growing after alopecia, and (3) total—complete hair loss and no hair at all. Alopecia distress was assessed using the brief, self-reporting 'Chemotherapy-Induced Alopecia Distress Scale' (CADS). The 25 items of the initial CADS were developed based on an extensive literature review and qualitative study [18] and tested with a cross-sectional survey of 305 Korean women with breast cancer. Exploratory factor analysis and confirmatory factor analysis yielded

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17 items in four domains (Appendix A) with good model fit (Confirmatory Factor Index = 0.925). The CADS is composed of a 4-point Likert scale and four multi-item distress domains that include physical (two questions), emotional (six questions), daily activity (six questions), and relationship (three questions) domains. The CADS' total score ranges from 0 to 51; higher score indicates higher distress. Alpha coefficients ranged from 0.77 to 0.95 for sub-domains and 0.95 for the total score. Its external validity was also tested using data from another prospective study of 428 breast cancer patients reporting the similar alphas. Detailed methods for the CADS development and validation are described elsewhere.[29] The internal consistency of the items in our questionnaire was satisfactory in our study sample. Coefficient alpha was calculated for the total alopecia distress scale (0.95) and the four subscales (0.77 for physical, 0.95 for emotional, 0.90 for daily activity, and 0.86 for relationship). We dichotomized patients' severity of CIA distress (measured by CADS) by median values, as high distress (score of 14 or above) or low distress (0–13 score). Using CADS as a continuous variable in the analysis resulted in similar conclusions (data not shown).

We used a combined form of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire Core 30 (QLQ-C30) and the breast cancer specific module (BR23), which has been translated into Korean and validated [30]. Body image was measured using the four questions of BR23. The BR23 has 23 items to assess the impact of common breast cancer treatment modalities (surgery, chemotherapy, radiotherapy, or hormonal treatment). It includes questions about body image, sexual functioning, sexual enjoyment, and future perspective for functions and questions about systemic therapy side effects, breast symptoms, arm symptoms, and upset hair loss for symptoms [31].

For psychosocial well-being, we used questions in five functioning domains (physical, role, cognitive, emotional, and social), and global health status/quality of life scales of EORTC QLQ C30. Depression was assessed using the patient's complete Center for Epidemiological Studies Depression scale (CES-D) which is a 20-item measure of depressive symptoms [32]. The reliability and validity of this scale has been established in general and clinical psychiatric populations [32,33], as well as with breast cancer patients [34]. The Korean versions of the CES-D have been validated [35]. Higher scores on the CES-D indicate greater levels of depression symptoms. A score of 16 or above (of 60 possible points) suggests clinically significant depression symptoms [36,37]. We used additional measured questions related to sociodemographic and clinical characteristics: age, marital status, education, working status, monthly family income, time since diagnosis, stage, current active treatment, and breast surgery type.

Statistical analysis

We scored the body image and psychosocial function questionnaires according to the EORTC scoring manual [38]. We linearly transformed the QLQ-C30 and BR23 data to yield scores from 0 to 100; a higher score represented a better body image and better level of functioning [39]. For assessing the impact of CIA distress on body image, psychosocial well-being, and depression, we looked for differences between patients depending on severity of alopecia distress, and each item in each of the domains (Table 2) calculated as mean and standard deviation. We used univariate and multivariate linear regression to analyze the relationship between the severity of CIA distress and body image, psychosocial well-being, and depression. In multivariable analysis, we adjusted for age, marital status, education, working status, monthly family income, time since diagnosis, stage, current active treatment, breast surgery type, severity of alopecia, and self-esteem, which would be potential confounders defined a priori. All statistical analysis was performed using STATA 12.0. Statistical significance was defined as $p < 0.05$.

Results

Characteristics of the study population by severity of chemotherapy-induced alopecia distress

The mean age (SD) of the patients was 48.4 (8.4) years. About 85% were married, 75.9% were high school graduates, and 81% were housewives or retired at the time of the survey. Most patients had stage I (33.9%) or stage II (44.6%) breast cancer, and 53% of patients were currently receiving active treatment such as chemotherapy or radiotherapy. In this study, 57.2% of the patients had severe alopecia; 75 (44.6%) of the patients had high distress, and 93 (55.4%) had low alopecia distress (Table 1).

More patients in the current active treatment group suffered from high alopecia distress than in the passive treatment group, and a statistically significant difference was found ($p = 0.04$). In terms of severity of alopecia, 21.1% of patients had no alopecia, 21.7% had moderate alopecia, and 57.2% had severe alopecia. Significant differences were found between severity of alopecia and distress ($p < 0.001$). Although patients who had severe alopecia were more likely to have high CIA distress (72.8%) than patients who had moderate or no alopecia (27.2%), the 37.2% of patients who had severe alopecia reported low CIA distress.

Body image, psychosocial well-being, and depression in patients with high alopecia distress

Body image

The high alopecia distress group was more likely to have poorer body image than the low distress group (35.2 vs. 62.0; $p < 0.001$). Patients with high alopecia distress were

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Table 1. Characteristics of participants by severity of CIA distress

Characteristics	Total (*N* = 168), *n* (%)	Severity of CIA distress[a]		*p*-value
		Low distress (*N* = 75), *n* (%)	High distress (*N* = 93), *n* (%)	
Age				0.44
Mean (SD)	48.4 (8.4)	47.8 (7.4)	48.8 (9.1)	
Marital status				
Married	142 (85.0)	65 (86.7)	77 (83.7)	0.59
Single/divorced/separated or widowed	25 (15.0)	10 (13.3)	15 (16.3)	
Education				0.43
High school graduate	126 (75.9)	54 (73.0)	72 (78.3)	
More than college	40 (24.1)	20 (27.0)	20 (21.7)	
Working status				0.09
Working	32 (19.0)	10 (13.3)	22 (23.7)	
Retired/leave of absence/housewife	136 (81.0)	65 (86.7)	71 (76.3)	
Monthly family income				0.07
Less than $2000	50 (31.5)	17 (23.9)	33 (37.5)	
More than $2000	109 (68.6)	54 (76.1)	55 (62.5)	
Time since diagnosis				0.66
Median (range)	9.5 (2.5–23.8)	10.6 (3.5–22.8)	9.5 (2.5–23.8)	
Less than 12 months	115 (68.5)	50 (66.7)	65 (69.9)	
12 months–24 months	53 (31.6)	25 (33.3)	28 (30.1)	
Disease stage at diagnosis				0.18
Stage 1	57 (33.9)	32 (42.7)	25 (26.9)	
Stage 2	75 (44.6)	28 (37.3)	47 (50.5)	
Stage 3	28 (16.7)	12 (16.0)	16 (17.2)	
Don't know	8 (4.8)	3 (4.0)	5 (5.4)	
Current active treatment[b]				0.04
Yes	89 (53.0)	33 (44.0)	56 (60.2)	
No	79 (47.0)	42 (56.0)	37 (39.8)	
Breast surgery type				0.25
Lumpectomy	77 (48.4)	38 (53.5)	39 (44.3)	
Mastectomy	82 (51.6)	33 (46.5)	49 (55.7)	
Severity of alopecia				<0.001
None	35 (21.1)	28 (37.8)	7 (7.6)	
Moderate	36 (21.7)	18 (24.3)	18 (19.6)	
Severe	95 (57.2)	28 (37.8)	67 (72.8)	

CADS, Chemotherapy-Induced Alopecia Distress Scale; CIA, chemotherapy-induced alopecia; SD, standard deviation.
[a]We dichotomized patients' severity of CIA distress (measured by CADS) as high distress (score of 14 or above) or low distress (0–13 score).
[b]Current active treatment = receiving chemotherapy or radiation at the time of survey.

more likely to have lower overall health status than the low alopecia distress patients (53.8 vs. 64.4; $p < 0.001$).

Psychosocial well-being

Patients who had high alopecia distress reported lower physical, role, emotional, cognitive, and social functioning compared with patients with low distress (Table 2). We considered differences greater than 10 points between the following groups to be clinically important: role functioning (58.6 vs. 72.0; $p < 0.001$), emotional functioning (55.3 vs. 76.9; $p < 0.001$), cognitive functioning (60.7 vs. 74.9; $p < 0.001$), and social functioning (51.3 vs. 70.9; $p < 0.001$).

Depression

We also found that patients in the high distress group were more likely to have depression compared with the low distress group (19.6 vs. 14.8; $p < 0.001$).

Impact of CIA distress on body image, psychosocial well-being, and depression

Table 3 reports the impact of CIA distress on patients' body image, psychosocial well-being, and depression. In the adjusted multivariate analyses for all the sociodemographic and clinical characteristics, body image, overall health status, psychosocial well-being, and depression were still associated with severity of CIA distress. The high distress group was more likely to have a lower body image by 24.6 points than the low distress group ($p < 0.001$). The high distress group was more likely to have lower overall health status by 10.3 points than the low distress group ($p < 0.05$). Most psychosocial well-being scale scores by CIA distress had significant differences. Except for physical functioning, patients with high distress had clinically, meaningfully lower psychosocial well-being status than the low distress group. The

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Table 2. Comparison of body image, psychosocial well-being, and depression between high CIA distress group and low CIA distress group

Domains (range)	Total ($N = 168$), mean (SD)	Severity of CIA distress[a]		p-value[b]
		Low distress ($N = 75$), mean (SD)	High distress ($N = 93$), mean (SD)	
Body image (0–100)	47.3 (27.8)	62.0 (25.7)	35.2 (23.3)[c]	<0.001
Global health status/quality of life (0–100)	58.6 (19.3)	64.4 (18.6)	53.8 (18.7)[c]	<0.001
Psychosocial well-being (0–100)				
Physical functioning	68.4 (16.6)	73.2 (14.1)	64.4 (17.5)	<0.001
Role functioning	64.6 (22.6)	72.0 (20.2)	58.6 (22.7)[c]	<0.001
Emotional functioning	65.0 (23.4)	76.9 (20.7)	55.3 (21.0)[c]	<0.001
Cognitive functioning	67.1 (20.0)	74.9 (18.0)	60.7 (19.4)[c]	<0.001
Social functioning	59.9 (26.8)	70.9 (23.9)	51.3 (25.9)[c]	<0.001
Depression (0–60)	17.4 (7.7)	14.8 (6.9)	19.6 (7.7)	<0.001

CIA, chemotherapy-induced alopecia; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; SD, standard deviation.
[a]Severity of CIA distress measured using a dichotomous (high distress/low distress) response scale.
[b]Low distress versus high distress values within a group.
[c]Difference greater than 10 points on the EORTC QLQ-C30 scale to be clinically important [39].

Table 3. Association between CIA distress and body image, psychosocial well-being, and depression

Domains (range)	Univariate coef. (SE)	Multivariate coef. (SE)[a]
Body image (0–100)	−26.9 (3.83)**[b]	−24.6 (4.74)**[b]
Global health status/quality of life (0–100)	−10.5 (2.97)*[b]	−10.3 (3.50)*[b]
Psychosocial well-being (0–100)		
Physical functioning	−8.8 (2.54)*	−7.8 (2.96)*
Role functioning	−13.4 (3.36)**[b]	−15.8 (4.02)**[b]
Emotional functioning	−21.5 (3.31)**[b]	−24.3 (3.46)**[b]
Cognitive functioning	−14.2 (3.00)**[b]	−13.0 (3.67)*[b]
Social functioning	−19.6 (3.97)**[b]	−15.8 (4.82)*[b]
Depression (0–60)	4.8 (1.14)**	4.4 (1.24)**

CIA, chemotherapy-induced alopecia; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; SE, standard error.
[a]Adjusted for age, marital status, education, working status, monthly family income, time since diagnosis, stage, current active treatment, breast surgery type, severity of alopecia, and self-esteem.
[b]Difference greater than 10 points on the EORTC QLQ-C30 scale to be clinically important [39].
*$p < 0.05$; **$p < 0.001$.

high distress group was more likely to have lower emotional functioning by 24.3 points than the low distress group ($p < 0.001$). Patients with high CIA distress had higher depression than the low CIA distress group; it was statistically significant ($p < 0.001$).

Discussion

In our study, we found that CIA distress was strongly associated with lower body image, overall health status, and psychosocial well-being. CIA distress was also associated with depression, and patients who had higher distress were more likely to have depression compared with the low CIA distress group.

About 55.3% of patients in our study had 'quite a bit' or 'very much' distress from their alopecia, and, like previous studies [17], the degree of alopecia was associated with psychological distress: patients who had severe alopecia reported higher CIA distress than patients who had moderate or no alopecia. Nevertheless, not everyone who had severe alopecia experienced high CIA distress, and even people who did not experience alopecia reported the highest level of CIA distress. This may be due to individual differences in the level of changes in the feeling of femininity, body image, or internalized ideals with patients experiencing different levels of distress and body dissatisfaction [19]. In addition, patients may experience high levels of CIA distress before they experience alopecia because of negative perceptions or norms in the peer or social environment [18,24,28].

Patients who were more concerned about their appearance and hair would be likely to experience distress due to alopecia compared with people who were not so concerned, and patients who had high CIA distress experienced two times poorer body image than patients who had low CIA distress. In our study, participants reported about two times worse body image than that reported in studies of breast cancer patients in the USA or Europe [39,40]. This might be due to specific cultural, peer, and social factors in Korea, as Tiggeman conceptualized [26,28]. In Korea, negative attitudes, stereotypes, and discriminating attitudes toward cancer and people affected by the disease were very common [24,25], and Korean breast cancer patients might experience high CIA distress and lower body image because of this. In a qualitative study in Korea, cancer patients with CIA felt uncomfortable being in public areas and had difficulties for daily activities such as grocery shopping or jogging because they were worried that people might recognize them as cancer patients [18]. Similarly, in France [8], cancer patients hid their alopecia because they wanted to protect their children and family members from people's attention. African American breast cancer patients in a rural area in the USA are also concerned about negative impacts of the CIA on their social and family relationships [41]. Although Korean breast cancer patients might experience more CIA distress because of its specific cultural factors, it seems to be common that

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cancer patients experience more CIA distress when there are negative attitudes toward cancer patients. In addition, Korean society may have unrealistic standards of beauty. In Korea, between 1980 and 2000, there were enormous changes in the social, economic, and political environment [42] with greatly increased power of women, who were able to seek gender equality, improve their level of education, and increase their role in public affairs [43]. However, societal changes for women have been accompanied by an increase in the importance of their physical appearance. When Korean women are in the public spotlight, their appearance tends to be emphasized more than their achievements. Unrealistic standards of beauty have exacerbated the situation, leading to frustration as women they strive to meet these standards [44]. Thus, Korean breast cancer patients may experience more CIA distress and poor body image because of concerns and expectations about their appearance. However, this could be similar in other countries where appearance tends to be emphasized. It would be interesting to compare the CIA distress among breast cancer patients in different countries to evaluate how different cultures and social support impact CIA distress and patients' quality of life.

As expected, CIA distress was significantly associated with negative body image after adjusting for age, marital status, education, working status, monthly family income, time since diagnosis, stage, current active treatment, breast surgery type, severity of alopecia, and self-esteem ($p < 0.001$). Although many studies have dealt with alopecia distress during chemotherapy, its association with body image was infrequently reported [17]. Most of the studies evaluated body image in relation to different types of breast cancer surgery (lumpectomy vs. mastectomy) [45,46]. We found that CIA distress is associated with negative body image after controlling for breast cancer surgery. According to a recent qualitative study, women report more decreased self-esteem and body image with hair loss than loss of breast [18]. Therefore, it is necessary for health professionals to pay attention to alteration of body image of breast cancer patients during chemotherapy as well as alterations from surgical procedures [46]. Health professionals should also provide culturally appropriate education or interventions for self-care strategies related to alopecia and lowered body image as well as psychosocial support.

Our findings suggest that CIA distress has a significant impact on patients' psychosocial well-being. Almost all scores of functional scales among patients with high CIA distress were substantially lower than those of patients with low CIA distress. Especially, the high CIA distress group had much lower emotional and social functioning after adjusting for all other covariates ($p < 0.001$). This supports the view that the experience of alopecia can cause intense emotional suffering, which leads to personal, social, and work-related problems [47]. According to previous studies, women with breast cancer rated alopecia as the most traumatizing, painful, and depressing experience, and the alopecia made had them lose their self-esteem, have guilty feelings, and feel sad and miserable [18]. Furthermore, alopecia limited patients' daily activities and social interactions — even their willingness to continue working or return to work.[18] For example, about 40% of women with alopecia have had marital problems as a consequence of hair loss, and about 63% claim to have had career-related problems [10,48,49].

We also observed that CIA distress was positively associated with depression. Patients with high CIA distress were more likely to have depression adjusting for all socioeconomic status and clinical characteristics. This finding is similar to a previous study that people with alopecia have higher levels of anxiety and depression than controls. They also experience lower self-esteem, poorer quality of life, and poorer body image [50]. Depression was noted by 21% of the women with alopecia in the study by Hirsso *et al.*, and they had significantly lower physical functioning and role limitations compared with the healthy controls [51]. Schmidt *et al.* also reported reduced social and emotional functioning in female cancer patients with depression due to alopecia [52]. Although it is not clear whether CIA distress increased the burden of depression or the depressed mood increased CIA distress, it affected not only patients' psychological health but also their quality of life. Thus, clinicians should also consider possible CIA distress along with routine screening and management of depression when they give chemotherapy to patients.

Our study has several limitations. First, most of the data were self-reported and would be influenced by individual characteristics or social desirability. Second, this was a cross-sectional study; we were not sure in which direction the associations between alopecia distress and body image and psychological outcomes are related. Third, this study was performed at a community event, and people who participated in the event may be different from non-participants. However, the response rate was relatively high, and characteristics of the study population were fairly similar to those of Korean breast cancer patients in general. Fourth, findings may not be generalizable in other countries where people would have different socio-cultural perspectives on cancer, physical appearance, and body image.

In spite of limitations, this study confirms that patients experience moderate to severe distress due to CIA. It was negatively associated with body image and psychosocial well-being, and positively associated depression in women with breast cancer. In future studies, it will be necessary to identify factors that associate the onset and course of alopecia distress and develop interventions to ensure that women with breast cancer have minimal distress due to alopecia.

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Appendix A. Chemotherapy-Induced Alopecia Distress Scale (CADS)

We are interested in knowing how much and what kinds of distress you are having due to hair loss caused by chemotherapy. Please answer that best describe your experience, difficulties, or distress due to the hair loss caused by chemotherapy during the past week.

Domain	Item	Not at all	A little	Quite a bit	Very much
Physical	The area is itching.	1	2	3	4
	The area is burning or prickling resulting pain.	1	2	3	4
Emotional	I feel different from others.	1	2	3	4
	I am dissatisfied with my appearance.	1	2	3	4
	I lose confidence about the future.	1	2	3	4
	I am easily irritated and stressed.	1	2	3	4
	I feel depressed.	1	2	3	4
	I feel lonely.	1	2	3	4
Activity	I have difficulty doing personal care such as bath and make-up.	1	2	3	4
	I experience limitations doing leisure activities.	1	2	3	4
	I feel sicker because of my hair loss.	1	2	3	4
	I do not like it when people find that I have cancer because of my hair loss.	1	2	3	4
	I have problems going out shopping and to restaurants.	1	2	3	4
	I always wear a wig or scarf to hide hair loss.	1	2	3	4
Relationship	I am worried about relationships with family and friends.	1	2	3	4
	I am worried about my relationship with my spouse or partner.	1	2	3	4
	I am worried about my sexual relationship with spouse or partner.	1	2	3	4

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Conflict of interest

All authors have declared no conflicts of interest.

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