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## RESEARCH COMMUNICATION

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# Perception, Attitudes, Preparedness and Experience of Chemotherapy-Induced Alopecia among Breast Cancer Patients: a Qualitative Study

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### Abstract

**Objectives:** Regardless of its negative impact on quality of life, little is known about the importance of alopecia from the patients' perspective. This study aimed to explore the whole experience of chemotherapy-induced alopecia among Korean breast cancer patients including perception, attitudes, preparedness, and changes after alopecia. **Methods:** Patients expected to experience or had experienced alopecia were recruited at a tertiary hospital in Seoul, Korea. Semi-structured in-depth interviews were performed in 21 patients. Recurrent issues were identified and placed into thematic categories. **Results:** All patients think that appearance is important and they pay attention to how they look like. They had negative perceptions about alopecia. Patients were not well prepared for alopecia, and experienced substantial physical, psychological and social distress. Lack of information and limited social support combined with negative images of cancer made it difficult for patients to overcome the trauma and deterred them from usual daily activities resulting in poor quality of life. **Conclusions:** Patients were not well prepared for alopecia and negative perceptions, lack of preparedness, and limited social support and resources increased alopecia-related distress. Educational programs for preparing patients to cope with alopecia distress and advocate activities to change people's negative perception about alopecia are needed to reduce the burden imposed by alopecia in cancer patients.

**Key words:** Breast neoplasms - chemotherapy - alopecia - psychological adaptation - quality of life

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### Introduction

Most breast cancer patients receive adjuvant chemotherapy to reduce the risk of cancer recurrence after primary surgery (Lopez-Tarruella and Martin, 2009; Kelly and Hortobagyi, 2010). Chemotherapy agents most commonly used in breast cancer, such as doxorubicin, cytoxan, or taxotere, result in a variety of severe side effects including nausea, vomiting, weakness, loss of appetite, and alopecia (Fall-Dickson and Rose, 1999; Carelle et al., 2002; Montazeri et al., 2008). Alopecia is one of the most painful side effects of chemotherapy, and it often ranks among the first three most important side effects for breast cancer patients (Sitzia and Huggins, 1998; Duric et al., 2005; Lemieux et al., 2008). Chemotherapy-induced alopecia has a strong negative impact self-image (Baxley et al., 1984;

Hunt and McHale, 2005), shame feeling (Auvinen et al., 2010), and perception of aging and body image (Baxley et al., 1984; Fobair et al., 2006), resulting in reduced quality of life in breast cancer patients (Rosman, 2004; Cartwright et al., 2009). Furthermore, while significant advances have been made in controlling some side effects of chemotherapy including nausea (e.g. new anti-nauseous drugs) and fatigue (e.g. erythropoietin) (Carelle et al., 2002; Jahn et al., 2009), alopecia is still a major side effect with no successful preventive intervention (Lemieux et al., 2008; Trueb, 2009).

While alopecia has a major impact on cancer patients, relatively little is known about the experience of alopecia from the patients' perspective (Lemieux et al., 2008) and, to the best of our knowledge, there are no studies of the experience of alopecia among Asian breast cancer patients regardless of a rapidly increasing number of

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patients. This study aimed to assess the whole experience of chemotherapy-induced alopecia among Korean breast cancer patients including perception, attitudes, preparedness, and changes after alopecia. We conducted in-depth interviews that allowed participants to identify and describe their experiences in their own words.

## Materials and Methods

### *Participants and methods*

Purposive sampling was used to obtain breast cancer patients across a wide spectrum of age and experience of chemotherapy-induced alopecia. Study participants were breast cancer patients seeing by three surgical oncologists at the Samsung Medical Center in Seoul, Korea. Subjects were considered for inclusion in the study if they were 65 years of age or younger, if they had an established diagnosis of breast cancer, and if they had or were expected to experience chemotherapy-induced alopecia. A total of 24 survivors were invited to the study, and 21 (87.5%) of them consented to participate. All procedures were approved by the Institutional Review Board of the Samsung Medical Center in Seoul, Korea, and all participants provided written informed consent.

### *Interview Guide and Data Collection*

A semi-structured interview guide was developed and refined by the research team in a series of meetings prior to the study. To ensure a uniform approach, the interviewer began the interview with common questions, asking patients to describe their perception, attitudes and preparedness about alopecia. The interviewer then enquired about distressing factors which patients were experiencing during the alopecia. Each interview lasted for approximately 60 to 90 minutes.

### *Data Analysis*

All sessions were audio taped and transcribed. Two of the investigators (IK and JC) separately coded the transcripts. Results from content analyses were then compared and discrepancies were discussed. Recurrent issues within each content area were identified and responses were placed into the thematic categories. Quotes from the interviews were highlighted to illustrate each category.

## Results

The mean age of study participants was 45.5 years (range 29 to 64 years; Table 1). Seventeen participants (81.0%) were married or separated, 12 (57.1%) had children <18 years of age, nine (42.9%) had more than college education, 12 (57.1%) were house wives and seven (33.3%) were employed but on leave of absence at the time of the interview. In terms of clinical characteristics, 11 participants (52.3%) were diagnosed with stage II cancer, six (28.6%) with stage III cancer, and two (9.5%) had recurrence of the disease (Table

1). Five patients (23.8%) just had surgery waiting for chemotherapy, and 8 (38.1%) and 5 (23.8%) patients, respectively, were having chemotherapy and radiation therapy at the time of interview. Thirteen patients (61.9%) had lumpectomy, 7 (33.3%) had mastectomy prior to chemotherapy, and two (9.5%) had reconstruction surgery along with mastectomy. All patients either scheduled or had chemotherapy with doxorubicin and taxotere of which a major side effect is total alopecia.

### *Perception and attitudes towards alopecia*

When we asked study participants what perception they had about alopecia before they were diagnosed with breast cancer, more than half of them had negative images such as 'sick person' or 'cancer patient'. Some patients said that 'alopecia' was the way they assumed that somebody had cancer. Other participants did not have a specific perception as they never thought about it. None of the study participants hesitated to receive chemotherapy because of alopecia and they said that they would do anything if they could gain even a small life expectancy.

The attitudes of the patients toward alopecia, however, changed after experiencing it. They said that alopecia was the most traumatizing and painful experience, that it was beyond their imagination, and that they would avoid it if they knew about it. One patient who had additional chemotherapy because of recurrence said that she hesitated to receive the 2nd course of chemotherapy because of alopecia.

"I never thought about alopecia ... It was not a big deal. I focused on getting chemotherapy if it gained me any small life expectancy. However, if I had to receive it again, I will not do it again."

### *Preparedness and coping strategy for alopecia*

Although patients had heard the term "alopecia" when clinicians explained about chemotherapy, they did not receive detailed information about it. Patients said that they were told that they would experience hair loss two to three weeks after the start of chemotherapy, but no one told them how to prepare for or manage it. Patients reported that they obtained information about alopecia primarily from other patients or from mass media outlets like the Internet.

No patient had any prior plans about alopecia when they developed it. Most patients looked for information and purchased wigs or hats once hair started falling out instead of planning ahead. Some patients said that they bought inappropriate wigs recommended by shop owners as they did not have enough knowledge about scalp condition with alopecia. All patients used a camouflage strategy to hide alopecia such as wigs, hats, and scarves. Patients reported that wigs were the most effective way to hide baldness, but often preferred to wear hats or bandanas because of price and convenience. Patients indicated that they wore wigs for work and

**Table 1. Characteristics of Participants of Qualitative Interview (N=21)**

Characteristic	No. (%)	
Age (yr)*	45.5 (29-64)	
Marital status	Married	15 (71.4)
	Separate	2 (9.5)
	Single	4 (19.0)
Have a children (N=17)	<18	12 (57.1)
	≥18	5 (23.8)
Education level	≤High school	12 (57.1)
	≥College	9 (42.9)
Working status	Housewife	12 (57.1)
	Leave of absence	7 (33.3)
	Retired	2 (9.5)
Disease stage at diagnosis	Stage1	4 (19.0)
	Stage2	11 (52.4)
	Stage3	6 (28.6)
Current treatment	Surgery	5 (23.8)
	Chemotherapy	8 (38.1)
	Radiotherapy	5 (23.8)
	Hormone therapy	3 (14.3)
Experience of alopecia	No	5 (23.8)
	Yes - having	12 (57.1)
	Yes - had	4 (19.0)
Type of surgery	Lumpectomy	13 (61.9)
	Mastectomy	7 (33.3)
	Reconstruction	2 (9.5)
Chemotherapy regimen**	AC+T (8 cycles)	12 (57.1)
	FAC (6 cycles)	4 (19.0)
	AC (4 cycles)	4 (19.0)
Recurrence	Yes	2 (9.5)

\*Mean (range) \*\*AC=doxorubicin+cyclophosphamide;FAC=5-FU+doxorubicin+cyclophosphamide; T=docetaxel formal occasions as they looked like natural hair, but that wearing wigs represented an extra financial and physical burden. They said wigs were not only expensive but also required a lot of care such as washing and drying.

“I will get chemo next week, so far; I did not get any information about alopecia at the hospital. It would be helpful if clinicians tell me how to prepare and manage it.”

“I knew that my hair would be falling but I was not prepared psychologically or physically – I went to purchase wig and hats on that day my hair started falling out. I was so embarrassed not because my hair was falling but I was not prepared.”

#### *Physical, psychological and social distress due to the alopecia*

Most of participants described alopecia as a traumatizing and disturbing experience which they never wanted to experience again. Patients reported a broad range of distress including physical pain, loss of privacy, and limitation of daily activities. Alopecia induced physical symptoms and distress not only related to the head but also to all body parts with hair. Patients had irritation, soreness, and pain on the scalp along with severe headache before alopecia. They also experienced

nose pain caused by dried mucus due to loss of nostril hair and problems with eye opening due to loss of eyelashes. Some patients also reported difficulties with urinating due to the loss of pubic hair.

When we asked the participants about their emotions and psychological responses to alopecia, 11 out of 15 patients (73.3%) broke in tears while they were expressing their feelings. They said it was frightening and depressing to see all hair fall out in the morning. They lost self-esteem, had guilty feelings about their past, and felt sad and miserable. Patients said that it was more difficult to look at the mirror due to the negative perception they had about alopecia. For many them, it was the moment that they had to admit that they had cancer.

Patients seemed to experience many problems in daily life caused by alopecia. Negative perception and feelings of making other people uncomfortable made them minimize social activities. Specifically, people's reactions such as avoidance or sympathy made patients feel down and prevented them from enjoying social life. Patients also referred that alopecia induced them to stay at home and to minimize outside activities to hide it. In our study, all participants wore make up and wigs, scarves, or hats when they were outside of their homes. Yet, alopecia limited their daily activities as patients were always anxious about a wig or scarf falling off. They could not focus on activities such as shopping or exercising. They said that they were unconsciously intimidated and paranoid about how people would treat them when they found out that they had alopecia. Specifically, patients tried to conceal alopecia from co-workers and neighbors because of the negative images and stigma towards cancer patients. Some patients whose children were elementary school students wore wigs even at home in case their children's friends visited their house. They worried that their children might be teased by their friends because of their look.

“Although I wear a wig or a bandana, I still feel anxious when I walk on the street, go to the grocery store, or pick up my kids from school ... I am afraid that somebody might find out that I am a cancer patient ... I do not want other people know about my disease.”

#### *Factors Associated With the Distress Related to Alopecia*

Patients experienced different levels of alopecia distress depending on individual, social and environmental factors. Patients with emotional support from family members, especially from their spouses, had substantially less stress, although they could be easily hurt by what family members said about alopecia. Patients with small children were very sensitive about what the children told them. Patients who were financially stable also had less distress as they managed alopecia without financial burdens. In addition, the attitude of the hair dresser who cut their hair influenced the level of distress. Participants said that it made them felt miserable when hair dressers

gave them a bad look or asked about cancer. Patients said that it would be good if there were places where they could manage hair and scalp with alopecia.

“It was a bit too much for me to buy wigs ... The expensive ones looked like real hair but I had to give them up because of the price ... To me, it was another financial burden.”

“As my nurse told me I would better shorten my hair, I went to a hair shop. When I asked the hair dresser to cut my hair, she asked me too many questions. It was too much for me to explain everything then I left the shop without cutting.”

The frequency of outdoor activities and social interactions was also associated with the degree of alopecia distress. Patients said that they had distress when they needed to interact with people in usual daily activities such as grocery shopping or picking up children from school. They said that they felt more comfortable with strangers.

Patients also reported that they had less distress during chemotherapy as they spent more time inside due to a weakened physical condition, but they had increased distress during radiation therapy usually after the chemotherapy when their physical condition and energy level improved and tried to regain their usual daily activities.

“I was O.K. when I received chemotherapy as I did not go out often. However, when I received radiation therapy, I had to go to the hospital every day and returned to my usual activities. Then I cared more about alopecia and got anxious about new hair.”

Alopecia distress was also associated with environmental factors such as weather and season. Patients reported that discomfort with wigs or hats got more intense when it was raining, windy, or hot. Patients experienced more discomfort and distress during the summer than in winter time. Finally, a source of distress was the thought that hair might not grow back.

*Changes after alopecia*

**Table 2 Experience of Chemotherapy-Induced Alopecia in Breast Cancer Patients**

Perception and attitudes towards alopecia	<ul style="list-style-type: none"> <li>- Negative images                             <ul style="list-style-type: none"> <li>· A symbol of sick person or cancer patients</li> </ul> </li> <li>- No specific perception, never thought about it before</li> <li>- Does not affect their decision to receive chemotherapy</li> <li>- Most traumatic and painful experience beyond their imagination</li> <li>- Do not want to experience again</li> </ul>
Preparedness and coping strategy for alopecia	<ul style="list-style-type: none"> <li>- Were not prepared at all</li> <li>- Had limited information about management of alopecia</li> <li>- Did not received appropriate support and attention from medical staff</li> <li>- Try to hide alopecia from other people                             <ul style="list-style-type: none"> <li>· Active strategy - using hats, wigs, scarves etc.</li> <li>· Passive strategy – minimizing social activities or interaction with people</li> </ul> </li> </ul>
Distress due to the alopecia	<ul style="list-style-type: none"> <li>- Physical                             <ul style="list-style-type: none"> <li>· Irritation, soreness, and pain on the scalp</li> <li>· Dryness inside the nose</li> <li>· Difficulty to open up eyes</li> <li>· Difficulties with urinating</li> </ul> </li> <li>- Psychological                             <ul style="list-style-type: none"> <li>· Sad, depressed, frightened</li> <li>· Lowered self-esteem</li> <li>· Guilty feelings about past unhealthy behaviors</li> <li>· Negative and uncomfortable attention from other people</li> </ul> </li> <li>- Social                             <ul style="list-style-type: none"> <li>· Limits of daily activities (shopping, exercise, childcare)</li> <li>· Had to minimize activities require interaction with others</li> <li>· Had to conceal the alopecia at working places and neighborhood</li> </ul> </li> </ul>
Factors associated with the distress	<ul style="list-style-type: none"> <li>- Individual level                             <ul style="list-style-type: none"> <li>· Economic status</li> <li>· Support from family members</li> <li>· Physical condition</li> </ul> </li> <li>- Social and environmental level                             <ul style="list-style-type: none"> <li>· Hair dressers’ attitudes and supports</li> <li>· Frequency of outdoor activities and social interactions</li> </ul> </li> <li>- Weather and season</li> </ul>
Changes after alopecia	<ul style="list-style-type: none"> <li>- Realization importance of having hair</li> <li>- Became more considerate about other people</li> <li>- Appreciate small things in daily life</li> <li>- Became more interested in appearance</li> </ul>

After alopecia, patients realized the importance of having hair and changed their perception about alopecia and about cancer patients. They said that they became more considerate and that they better understood others in similar situations. They became more appreciative of small things in daily life that which they took granted before cancer diagnosis.

If baldness represented being sick, new hair after alopecia represented hope and renewed life. Many participants said that they felt that hardship was over when they saw newly growing hair and that that looking at new hairs made them feel alive and happy. All participants said that they recognized again the importance of their lives. Some patients who never cared about their looks started to pay attention to their appearance after experiencing alopecia. They said that the alopecia experience changed their attitudes towards appearance and now they cared more about it.

“I still have to take Herceptin treatment and hormone pills but I feel that I am done with the treatment as my hair is growing.”

## Discussion

In our study, alopecia represented a rite of passage for breast cancer treatment for which patients were not well prepared. Lack of information, limited social support, and negative perceptions about alopecia and cancer made it more difficult for patients to overcome cancer burden and increased physical, psychological, and social distress. Alopecia distress not only lowered patients' self-esteem, but also deterred them from daily activities and social life resulting in a worse quality of life.

In previous studies, alopecia was also identified as one of the most distressing events during cancer treatment, and there is data indicating that some patients refused chemotherapy because of alopecia (Tierney and Taylor, 1991; Trueb, 2009). However, none of the participants in our study hesitated to receive chemotherapy because of alopecia and indicated that the fear of the recurrence was greater than the pain expected from alopecia. Patients expected little trouble from hair loss and accept chemotherapy for some gains in life expectancy (Duric et al., 2005). These expectations, however, may be based on insufficient information. Most participants in our study had not received adequate information about alopecia, and they all had difficulties imagining how it would be like.

Patients reported severe trauma and distress with alopecia and all said that they had more troubles than they expected. Previous studies have reported that patients who were well informed about alopecia adjusted and coped with it better than those who were not (Frith et al., 2007). McGarvey et al conducted a pilot study with a computer-imaging program to prepare women for alopecia and found that patients who saw images of baldness and wigs on a computer screen in advance had

significant lower alopecia distress than patients who did not (McGarvey et al., 2001). Although little is known about coping related to alopecia, preparing breast cancer patients for alopecia is important for reducing emotional burden, distress or possible depressive symptoms.

Studies in Western countries found that patients were very likely to wear wigs or bandanas to hide alopecia, but some patients chose not to wear them and show their baldness to other people (Rosman, 2004). In our study, all participants used camouflage strategies and tried to conceal hair loss as much as possible as they worried that if people found about their cancer, they would have negative perceptions and stigma towards them. Indeed, the main concern of the patients was hiding alopecia from other people. Similarly, in a study done in France, cancer patients hid alopecia because they wanted to protect their children and families from other people's attention (Rosman, 2004). These findings imply that negative attitudes, stereotypes, and discrimination towards cancer patients still exist in our society despite of clinical progress and improved survivorship.

We found that breast cancer patients experienced a variety of psychosocial problems related to alopecia, and the resulting distress interfered with social activities and interactions, including their willingness to continue working or returning to work. In addition, the range of physical problems due to alopecia reported in our study was broader than the problems reported in the literature and were not limited to the head or scalp but also to the nose, eyes, and other body hair. Clinicians need to pay attention to these physical problems and provide appropriate care and psychological support.

While alopecia resulted in substantial distress in breast cancer patients, there were also positive changes consequences. Patients reported that they became more considerate and mindful, and more appreciative of little things in their life. Further research is needed to fully characterize coping strategies for alopecia and the potential effects of alopecia on patient's life.

Limitations to be acknowledged in the present study include the small sample size and the fact that all participants were drawn from a single cancer center and may not be representative of other breast cancer patients. However, this is the first study to explore the perception, preparedness, experience, and changes due to alopecia in Asia. Moreover, the study included patients with different status of alopecia and it allowed us to explore changes in attitudes and behaviors related to alopecia. Further quantitative research with larger and unbiased samples will be important to assess the generalizability of our findings.

In conclusion, breast cancer patients were not prepared for chemotherapy-induced alopecia and had very negative experiences with it. Lack of preparedness and social support were the major factors associated with alopecia-related distress. A variety of distressing factors including physical discomfort, financial burden and cancer stigma resulted in lowered self-esteem

and restriction of social activities and interactions. It is important to develop educational interventions to prepare breast cancer patients for coping with alopecia. In addition, more general approaches such as public education and advocate activities may be necessary to change public perception about alopecia and cancer to reduce alopecia-related burden in cancer patients.

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