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Distress and impacts on daily life from appearance changes due to cancer treatment: A survey of 1,034 patients in Japan

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Abstract: This study aimed to clarify the psychosocial difficulties and impacts that cancer patients face from appearance changes, in order to develop a patient support program. An online survey was administered to patients registered with an online survey company who met the eligibility criteria. The study population was randomly selected from gender and cancer types to create a sample that reflected the proportion of cancer incidence rates in Japan as much as possible. Out of a total of 1034 respondents, 601patients (58.1%) experienced appearance change. Symptoms that were reported to have a high distress level and prevalence rate, and that widely required provision of information were such as alopecia (22.2%), edema (19.8%) and eczema (17.8%). Distress levels and personal assistance requirements were high particularly for patients who experienced stoma placement and mastectomy. More than 40% of patients who experienced appearance change had quit or were absent from work or school, and reported that their social activities were negatively affected by the visually notable changes in their appearance. Concerns about "receiving pity from others" or about "the exposure of cancer" due to their appearance change also led patients to reduce outings ($\beta = 0.32$ and $\beta = 0.31$ respectively, p < 0.001) and social interactions with others ($\beta = 0.34$ and $\beta = 0.36$ respectively, p < 0.001) and increased the discord in human relationships ($\beta = 0.21$ and $\beta = 0.19$ respectively, p < 0.001). Results from this study indicate the areas in which more support is required from healthcare professionals, as well as the need for interventions for patient cognition to avoid maladaptive behaviors in cancer patients who experience appearance changes.

Keywords: appearance change, alopecia/hair loss, coping behavior, quality of life, appearance care

Introduction

The number of cancer patients is on the rise (1). The top five most common types of cancer in Japan (2019) are colorectal cancer (155,625) lung cancer (126,548) stomach cancer (124,319) breast cancer (97,812) and prostate cancer (94,749) (2). But longterm survival is possible for some types of cancer (3). At the same time, in Japan, duration of hospital stays was 17.1 days (2017), a reduction of one-third from 20 years prior (4), and outpatients account for 41-68% of people receiving chemotherapy (5). As these numbers indicate, contemporary cancer patients live and interact with society while undergoing treatment. However, such social interactions also become an opportunity for patients to be highly aware and sensitive towards appearance changes due to cancer treatments such as surgeries, radiation, and chemotherapy. This may result in hesitation towards treatment as well as decreased quality of life. Therefore, it is necessary for medical professionals to provide appropriate support to patients regarding their appearance concerns.

Previous studies have reported that 84.9% of male patients experience appearance change from cancer treatment (6), and that 80.3% of patients in outpatient chemotherapy centers are concerned about physical changes in various parts of their body (7). The most prevalent topic of study is hair loss (8), as it decreases body image and level of psychosocial happiness, and carries a high likelihood for depression (9). It has also been identified that patients have difficult experiences because of negative reactions from others that noticed their change in appearance (10,11), and they spend a lot of energy concealing their symptoms (12,13) because they are concerned about being treated differently by others and because some appearance changes are a physical indication of cancer (14,15).

However, Previous studies have been conducted at specialized cancer hospitals in urban areas (6) or outpatient treatments centers (7), and the results are specific to the study region or department, or are limited to breast cancer (9-11,14) or male patients (6). The last study on all cancer types was conducted in 2009 (7), making the results outdated by over 10 years. There is a lack of recent studies to understand the current realities of appearance change in cancer patients. Therefore, this study was conducted with a sample that reflects the actual proportions of cancer incidence rates by gender and site as much possible.

This study has the following two purposes: *i*) To obtain a clear understanding of the appearance changes that cancer patients experience due to treatment, and their respective distress levels, to examine the symptoms that require prioritized support and care; and *ii*) To obtain a clear understanding of the psychosocial difficulties and the related factors that patients face, such as the impact on their daily lives, to identify the essential perspective for when healthcare professionals should support patients. Based on the above, this study examined the hypothesis that patient concerns about changes in physical appearance directly lead to behavioral inhibition in daily life.

We conducted this study to obtain foundational data for the development of a patient support program. This article reports the data gathered as part of this project, which indicate the psychosocial difficulties patients face as a result of changes in physical appearance from cancer treatment.

Methods

Participants

More than 1,000 male and female patients between the ages of 20 and 75 who were either currently undergoing cancer treatment or under post-treatment observation were included. All participants agreed to participate and had the technical abilities to respond to the online surveys.

Procedure

Anonymous self-administered surveys were provided online to conduct a cross-sectional study. First, the researchers investigated Internet-based research companies that are members of the Japan Marketing Research Association (JMA) with the aim of minimizing significant bias in the registered attributes and the frequency of updating the registered information by referring to publicly available information. This resulted in Macromill, Inc. being selected to conduct the survey. Next, we conducted a screening survey of the monitors who had registered to participate in surveys with the Internet survey company and selected eligible patients.

Then, we randomly selected candidates for the survey in proportion to the incidence rate of cancer by sex and site (17), and conducted an Internet survey until more than 1000 valid responses were obtained. In the Japanese estimates of cancer incidence by site (2017), the stomach was the most common site for males, followed by the lung, prostate, colon/rectum, and liver. The most common cancer site for females was the breast, followed by the colon/rectum, stomach, lung, and uterus. In addition, ages (20s, 30s, 40s, 50s, and 60s or older) were also automatically allocated so that differences in attitudes by age could be examined.

This study was approved by the Research Ethics Review Committee of the National Cancer Research Centre (File No. 2017-417) and was conducted from March 2, 2018 to March 22, 2018.

Measures

The survey collected information on patient demographics, appearance change and the associated distress level from cancer treatment, and impacts on daily and social life. Survey items and questions were developed based on preexisting studies (5, 6) and preliminary research by a team of one doctor, two nurses, two clinical psychologists, two cosmetic and makeup specialists, and four patient representatives.

For patient demographics, participants were asked to identify their age, gender, occupation, highest level of education, and the type of cancer for which they are undergoing, or have undergone treatment.

For appearance change due to treatment and related distress participants were first asked if they experienced any appearance changes due to treatment. Those who answered yes were then asked if they (a) were currently experiencing, (b) had experienced in the past, or (c) had never experienced, each item of appearance change on the survey (29 questions). Finally, those who were experiencing or had experienced an item scored 0 to 3 were asked to identify their distress level when the experience was most severe. 0 points indicated that they experienced appearance change but no distress, 1 point indicated a low level of distress (indicated a bit of distress), 2 points indicated a medium level of distress (indicated distress), and 3 points indicated a high level of distress (indicated severe distress). The method of scoring the distress level was based on previous studies (6).

Regarding the impacts of appearance changes on daily and social life, 12 experiences related to how the appearance changes impact daily life and social relationships were listed. Participants were asked to answer if they (1) experienced the impact, (2) experienced the impact to an extent, (3) not applicable, (4) did not really experience the impact, or (5) did not experience the impact at all.

Furthermore, the specifics of this patient's coping behaviors and information and support needs are presented in a separate paper (16). As patients' coping behaviors, we investigated information gathering behavior and daily grooming behavior. In order to clarify the actual situation of information collection on appearance changes, we asked the participants whether they obtain information from medical professionals and their satisfaction level, and whether they use 20 sources of information on appearance changes (family members, patient groups, product retailers, Internet information, *etc.*) and their trust level. Satisfaction and trust were rated on a 4-point scale ranging from "very much so" (4 points) to "not at all" (1 point). They were also asked about 24 daily grooming behaviors (wigs, moisturizers, *etc.*) and their costs (purchase price of wigs, *etc.*).

Descriptive statistics were calculated from participants' sociodemographic statistical variables and their experiences of appearance change. To determine the most highly distressing experiences, the average level of distress was calculated for each physical change. A chi-square test was conducted on the data collected on the impacts on daily and social life in order to examine the difference between genders or ages. A covariance structured analysis was also conducted to examine how patient concerns about changes in appearance affect behavioral inhibition. Statistical analyses were conducted using IBM[®] SPSS[®] Amos 16.0. The multiplicity of the tests was not adjusted for because this was an exploratory study.

Results

Participant demographics

By the registration deadline, a total of 1,034 participants, 518 men and 516 women, attended (Table 1). The average age was 58.7 ± 10.6 years with a median age of 60 (26-74) years. The most common cancer types were stomach for men 93 (9.0%) and breast for women 120 (11.6%). The top cancer types in both sexes were the top 5 most common cancers in Japan. Most participants were working, with 347 (33.6%) working full-time and 505 (48.8%) working part-time. The most common final education was a university or graduate degree, 426 (41.2%).

Changes in physical appearance from treatment

Prevalence of appearance change and respective symptoms

A total of 601 patients (58.1%) reported that they experienced appearance change. There were participants who experienced a change in appearance in all 27 items, but the most commonly experienced change was surgical therapy-induced scars on the body surface (49.1%). Other symptoms that were reported by more than 15% of all participants were hair loss (22.2%), change in body from weight loss (22.1%), weak and thin nails (21.2%), dry skin (20.9%), sensitive skin (19.8%), edema on the face and body (including lymphoedema) (19.8%), discoloration of the nails (*e.g.* white lines, hyper pigmentation) (19.6%), injection site scars on arms (19.0%), dermatitis (17.8%), loss of body hair (arms, legs, nose, and pubic) (17.1%), and blemishes (15.1%).

Table 1. Attributes of the study population

Characteristics	<i>n</i> (%), <i>n</i> = 1034						
Gender							
Male	518 (50.0)						
Female	516 (50.0)						
Type of Cancer							
Stomach	93 (9.0)						
Men							
Large Intestine	80 (7.7)						
Lung	79 (7.6)						
Prostate	76 (7.4)						
Liver	29 (2.8)						
Others	161 (15.6)						
Women							
Breast	120 (11.6)						
Large Intestine	82 (7.9)						
Stomach	59 (5.7)						
Lung	36 (3.5)						
Uterine	36 (3.5)						
Others	183 (17.7)						
Age							
20-29	3 (0.3)						
30-39	50 (4.8)						
40-49	170 (16.5)						
50-59	266 (25.7)						
60-74	545 (52.7)						
Occupation							
Full-time	347 (33.6)						
Part-time	505 (48.8)						
Unemployed (housewife included)	127 (12.3)						
Others	55 (5.3)						
Highest level of Education							
Middle School	34 (3.3)						
High School	325 (31.4)						
Vocational School	103 (10.1)						
College degree	146 (14.1)						
Bachelor / Master's degree	426 (41.2)						
Others	0 (0.0)						

It was speculated that most of the changes were due to chemotherapy.

Distress level for each appearance change

Distress level of each symptom experienced for 29 appearance symptoms is shown in Figure 1 and Figure 2. To clarify the frequency of occurrence and distress level, we divided the symptoms into two groups: those with a relatively large number of participants who experienced them (100 or more: Figure 1) and those with a small number of people who experienced them (less than 100: Figure 2). The mean distress level for all 29 symptoms was $1.34 (\pm 0.45)$ points.

The number of participants who experienced symptoms was high, and the distress level for each symptom was higher than average for hair loss, change in body shape from weight gain, edema on the face and body (including lymphoedema), loss of eye lashes, dermatitis and skin sensitivity.

As for the symptoms that were experienced by a small number of participants, they had notably high distress levels (1.79 points or higher, which is over 1 standard deviation of the overall average). These include

		Distress	6 10%	6	20%	30%	40%	50%	60%	70%	80%	90%	100
[n=	level											
Hair loss	(230)	1.62	33.9				20).4	19	19.6		26.1	
Change in body shape from weight gain	(143)	1.59	24.5				30.1			25.9		19.6	
Edema on the face and body (including lymphoedema)	(205)	1.58	24.4			26.3			32.2			17.1	
Loss of eye lashes	(134)	1.43	21.6		29.9			18.7		29.9			
Dermatitis	(184)	1.42	17.4 2		26.6	26.6		37.0			19.0		
Skin sensitivity	(205)	1.35	14.6 24.4		24.4			42.0	42.0		19.0		
Loss of eye brows	(149)	1.31	20.	8	2		5.2	16.1		31		36.9	
Injection site scar on arms	(196)	1.29	14.3	.3 24.0		24.0			37.8		24.0		
Surgical therapy induced scars on the body surface	(508)	1.21	17.9		19.7 28.1						34.3		
Eczema	(148)	1.14	10.1 20.9			41.2				27.7			
Dry skin	(216)	1.13	10.6	10.6 19.0				42.6			27.8		
Weak and thin nails	(219)	1.12	5.9 27.4			39.3			27.4		27.4		
Brittle nails	(143)	1.10	10.5 20.3			37.8			31.5				
Blemishes	(156)	1.06	14.1	.1 17.3			28.8			39.7			
Discoloration of the skin (hyperpigmentation)	(186)	1.01	14.0 15.6			27.4			43.0				
Discoloration of the nails (e.g. white line, hyper pigmentation)	(203)	0.84	5.9 16.7			32.5			44.8				
Change in body from weight loss	(229)	0.79	7.9 15.3			24.5		52.4					
Loss of body hair (arms, legs, nose, and pubic)	(177)	0.59	6.8 12.4 13.6 67.2										

High level of distress Medium level of distress Low level of distress Change was noticed but not distressing





High level of distress Medium

Figure 2. Distress level of symptoms experienced by less than 100 people.

stoma, festering of nails, loss of breast from mastectomy, amputation, loss of part of the face and hand-foot syndrome.

For breast cancer patients only, distress level for hair loss (2.16 points) was higher than loss of breast from mastectomy (2.00 points).

Impact on daily life

Participants were asked 12 survey items related to how appearance change impacted their thoughts and activities in daily life. Participants who indicated that they "experienced the impact" or "experienced the impact to an extent" were considered to have experienced the indicated impact (illustrated in Figure 3 and Figure 4).

Overall, over 40% of the participants who experienced appearance change reported becoming passive towards social activities, such as quitting or becoming absent from work or school (42.6%), finding meeting people troublesome (40.2%), and having decreased occasions to leave the house (40.1%). Meanwhile, more than 50% of participants who experienced appearance change also reported maintaining their self-identity even if their appearance changes (55.7%), and having capacity to attend to physical appearance during treatment (55.2%). Results of the chi-square analysis that was performed to examine gender differences indicated the following four items were statistically significant. Females were significantly more distressed than males.

- I did not want to receive pity from others
 - $(\chi^2 = 11.65, df = 1, p < 0.001)$
- · Decreased occasions to leave the house
- $(\chi^2 = 13.98, df = 1, p < 0.001)$
- Finding meeting people troublesome
- $(\chi^2 = 36.12, df = 1, p < 0.001)$
- Relationship issues with partner became awkward ($\chi^2 = 9.79$, df = 1, p < 0.001).

We also conducted a chi-square analysis by dividing into age groups (60 or under and over 60) in order to examine the effect of working age, and significant differences by age were found in nine items.

The following items were significantly higher in those 60 or under than in those over 60.

- I was concerned about my appearance change $(\chi^2 = 7.34, df = 1, p < 0.01)$.
- I did not want to receive pity from others
- $(\chi^2 = 15.31, df = 1, p < 0.001).$
- Decreased occasions to leave the house





□ All patients(594) Males(240) Females(354)

Figure 3. Impact on daily life by gender. *p < 0.05, **p < 0.01, and ***p < 0.001.

Figure 4. Impact on daily life by age. *p < 0.05, **p < 0.01, and ***p < 0.001.



Figure 5. Path analysis with motivation inhibition as the dependent variable. Numbers indicate standardized path analysis coefficients. *p < 0.05, **p < 0.01, and ***p < 0.001.

 $(\chi^2 = 6.51, df = 1, p < 0.05).$

- Finding meeting people troublesome $(\chi^2 = 15.80, df = 1, p < 0.001).$
- Quitting or becoming absent from work or school $(\chi^2 = 18.10, df = 1, p < 0.001).$
- Relationships with coworkers became awkward $(\chi^2 = 7.41, df = 1, p < 0.01).$
- Relationship with my partner became awkward $(\chi^2 = 13.25, df = 1, p < 0.001).$
- It is better not to treat the cancer than change my appearance ($\chi^2 = 9.29$, df = 1, p < 0.01).

On the contrary, the following item was significantly higher in those over 60.

• Maintain their self-identity even if their appearance changes ($\chi^2 = 8.57$, df = 1, p < 0.01).

Concerns about changes in physical appearance and its impact on behavior inhibition

A covariance structured analysis using statistical software Amos 16.0 was conducted to examine the impact of concerns about appearance change on behavior inhibition and negative changes in relationships.

The causal model envisaged is that concerns about changes in physical appearance (Q1-3) impact actual life (behavior inhibition in daily life, *etc.*: Q4-9). The final model with the best fit is shown in Figure 5.

For the model fit to the data, Goodness of Fit Index [GFI] =1.000, Adjusted Goodness of Fit Index [AGFI] =1.000 and Root Mean Square Error of Approximation [RMSEA] = 0.000. The standard partial regression

coefficients show a direct positive effect from Q2 or Q3 to Q4, Q5, Q6, Q7, Q8 and Q9. On the other hand, an effect was observed from Q1 to Q4, Q5 and Q8, but a direct effect was not observed from Q1 to Q6 and Q7.

The effects from Q2 and Q3 on Q4 and Q5 were especially significant. Participants that expressed anxieties such as "I did not want to receive pity from others", and "Others noticed I have cancer due to my appearance change" had decreased outings ($\beta = 0.32$, $\beta = 0.31$, respectively), social interactions ($\beta = 0.29$, $\beta = 0.37$, respectively), and attendance at work/school ($\beta = 0.17$, $\beta = 0.19$, respectively), and increased relationship issues ($\beta = 0.26$, $\beta = 0.25$, respectively).

Discussion

Actual conditions of appearance change due to cancer treatments

Experience of appearance change

Upon sampling the data proportioned to gender and cancer type variables, the overall rate of participants who experienced changes in physical appearance was 58.1%, which is less than previous studies (5,6). Additionally, excluding "surgical therapy induced scars", which was experienced by about 50% of participants, all other symptoms were experienced by less than 25% of participants. A study of 1,030 people from the general population showed that 95.2% identified hair loss as the most symbolic side effect of cancer treatment (18), and hair loss has consistently been indicated as one of the most prevalent distressing symptoms in past studies (7). However, in reality, not all cancer patients undergo treatment with hair loss and the prevalence of hair loss is only 22.2%, which is very low in comparison to common belief. It is essential for accurate information to be delivered in the early stages of treatment so that patients who have just been diagnosed with cancer will not be misled by the negative image and panic. Additionally, there is a significant importance in raising awareness in the general public as well.

This study may have provided a complete picture of the appearance problems faced by cancer patients, unlike previous studies, such as a survey of patients undergoing chemotherapy with hair loss (6, 8, 12), which were conducted only on patients with the symptoms in question.

Distress from appearance change and patient support

Symptoms that were reported with high distress levels were long-term changes that were visible to the patients themselves and others, such as surgical removal of body parts including breasts, limbs, and facial features, stoma, and hair loss, as well as symptoms that have a significant negative impact on patients' activities of daily living such as hand-foot syndrome and symptoms related to the nails.

Examining the relationship between the prevalence of symptoms and distress level from the perspective of patient support, the symptoms can be divided into two separate categories. One category consists of symptoms such as hair loss and edema, which are high in both prevalence and distress level, and support addressing these symptoms is generally a broad category that needs to be prioritized. The other category consists of symptoms of low prevalence but that cause significantly high distress levels such as having a stoma, loss of breast from mastectomy, loss of a body part, hand-foot syndrome, and fingernail detachment. These symptoms require personalized support, which is vital as these symptoms in particular have a direct relationship with decreased body image, self-esteem, and activities of daily living.

One of the interesting findings of this study was the difference in distress levels for similar symptoms. For example, hair loss was reported with a high distress level when it occurred on the head, but not when it was body hair or beard. Similarly for changes in body shape, while weight gain and edema were reported with high distress, weight loss had lower distress levels. This may reflect the value of appearance in contemporary society, i.e., slimming perception that leaner body types are more attractive and obesity has a negative impact on employment (19-21) or body hair removal preference (22,23). Similar to findings in non-cancer related studies that report higher distress levels for changes in the appearance of areas of the body that are more visible (24), surgical scars were often in areas hidden under clothing and were reported with lower distress levels. When examining breast cancer patients only, distress levels were higher for hair loss than mastectomy. It can be assumed that concerns for appearance are not solely based on one's own body image, but deeply interconnected with contemporary societal standards and values, concern for societal acceptance, and as a result of social relationship concerns.

Impact on daily life

When examining the ways appearance change has impacted patients' daily lives, especially activities and ways of thinking, more than 40% of participants had behavioral inhibition such as quitting or being absent from work or school. In particular, women who are more conscious about their physical appearance than men and people of working age (60 or under) who are engaged in social activities were negatively impacted in terms of activities.

Meanwhile, patients were generally able to maintain their self-identity despite changes in their appearance, were able to attend to and take care of their physical appearance, and had high self-worth. This suggests that when healthcare professionals provide patients with support, it would be more effective to support people to feel that they are able to maintain their self-identity and self-worth despite the struggles of treatment instead of focusing on negative behaviors only.

Concerns about changes in physical appearance and its impact on behavioral inhibition

When beginning this study, it was hypothesized that the concerns patients have about changes in appearance directly impact their behavioral inhibition in daily life. In fact, results from this study showed no relationship between concerns and behavioral inhibition. Instead, the results indicated strong concern about others noticing that they have cancer or being pitied by others due to appearance change decrease social interactions and attendance at work and school and increases difficulties in social relationships (Figure 5). This may be a negative behavioral change that occurs because many patients feel that their changed appearance is a "symbol of cancer that others can see" (10,15).

If this is true, when patients report physical symptoms to healthcare professionals there is no resolution if the treatment only focuses on caring for the physical symptoms. There is a need to provide patients with not only treatment of symptoms or coping skills, but also information to change beliefs about cancer and appearance and communication skill education to facilitate relationships with others after appearance changes. This may be in line with the importance of cognitive training, as the degree of appearance change is not necessarily proportional to psychosocial health, as demonstrated in a study of non-cancer disfigurement (25). It may also be related to critiques on the globally popular "Look Good... Feel Better" approach that its coping techniques may be too limited (14).

Limitations

There are limitations to this study as it examined selfreported retrospective data, and the timeframe from the day of diagnosis to when patients answered the survey was not confirmed. It also lacked information on treatment each patient received, so it is not possible to further analyze the details of treatment. Despite these limitations, using an online survey was beneficial to meet the goal of collecting a wide range of information in relation to appearance issues. Moving forward, we hope to further continue this research by collecting additional details with more conventional methods such as interviews and mail-in surveys to achieve a more elaborate interpretation.

Conclusion

This study clarified the specific symptoms that require prioritized support by healthcare professionals, as well as beneficial specific suggestions for the process of www.globalhealthmedicine.com

treatment and beauty techniques for camouflaging appearance changes are all important and essential; however, in order to avoid behavioral inhibition, it is important to mitigate patients' underlying concern. There is a need for educational program structures that support effective cognitive transformations and techniques for coping with appearance change, and developing successful experiences in social communication, to mitigate the social struggles patients face in relation to appearance change.

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