A Randomized Clinical Trial of a Videotape Intervention for Women With Chemotherapy-Induced Alopecia: A Gynecologic Oncology Group Study

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Purpose/Objectives: To evaluate changes in body image and self-esteem in women with gynecologic malignancies who experience chemotherapy-induced alopecia and to examine the effectiveness of a videotape intervention on body image and self-esteem.

Design: A prospective, randomized study.

Setting: Subjects were accrued from 11 Gynecologic Oncology Group (GOG) member institutions participating in 14 GOG treatment protocols.

Sample: 136 women with chemotherapy-induced alopecia, a mean age of 57.7 years, and advanced disease at study entry.

Methods: Prior to the first course of chemotherapy, all subjects received standard counseling regarding hair loss. Body image and self-esteem scores were obtained prior to course 1 and 3 and after course 4 of chemotherapy. Prior to course 3, women with grade 2 alopecia were allocated randomly to the videotape intervention or no intervention.

Main Research Variables: Total body image and self-esteem as measured by the Body Cathexis/Self-Cathexis Scale (BCSCS).

Findings: A small but statistically significant change ($p = 0.045$) in body image was observed after chemotherapy-induced alopecia, with no change in self-esteem. The videotape did not produce a significant effect on body image score.

Conclusions: The study results support prior studies that have reported changes in body image as a result of chemotherapy-induced alopecia. The intervention employed (a videotape) was not effective. The BCSCS is a simple and quick measurement for use in future studies.

Implications for Nursing: Chemotherapy-induced alopecia has an adverse effect on body image. Novel interventions are needed to assist women in coping with this consequence of treatment.

Key Points . . .

- Alopecia, a common side effect of many chemotherapeutic agents used to treat gynecologic malignancies, may affect patients' body image and self-esteem and influence their treatment decisions.
- Reliable methods exist to measure body image and self-esteem.
- A videotape intervention was not more successful than standard interventions (counseling and prostheses) in improving or preventing changes in body image.

Alopecia is a common and devastating, although temporary, side effect of many antineoplastic agents. The impact of the potential loss is so profound that some patients with cancer consider refusing therapy; indeed, some individuals actually refuse therapy because of the possibility (Fawzy, Secher, Evans, & Giuliano, 1995; Kennedy et al., 1983). Hair reflects personal expression and is associated with beauty, age, and sexuality. Particularly for women, hair loss is a significant concern that is compounded by other physical and emotional events related to cancer therapy. Many women with breast cancer report that dealing with hair loss is more difficult than coping with the loss of a breast because hair loss is visible to others and is a constant reminder of their diagnosis (Pozo-Kaderman, Kaderman, & Toonkel, 1999). In a qualitative study of 15 participants, being constantly reminded of their disease as a result of alopecia emerged as a major aspect of the experience (Williams, Wood, & Cunningham-Warburton, 1999).

Women with cancer have cited alopecia as the most disturbing aspect of the chemotherapy experience (Munstedt,

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Manthey, Sachsse, & Vahrson, 1997; Tierney, Taylor, & Closs, 1992). Altered body image is related to chemotherapy-induced alopecia (Anderson & Johnson, 1994; Baxley, Erdman, Henry, & Roof, 1984; Frank-Stromborg & Wright, 1984). Furthermore, the societal pressure to look "right" reinforces the strong emphasis on the use of wigs during alopecia (Freedman, 1994). In a qualitative study of 35 people with breast or lung cancer, "hide and camouflage" was one strategy to cope with alopecia (Rosman, 2004). Several studies have evaluated the influence of alopecia on body image. In an early study of 77 patients from a private practice treating patients with hematologic and solid tumor malignancies, changes in body image were measured using the Body Cathexis/Self-Cathexis Scale (BCSCS). The sample consisted of 43 patients with and 34 without alopecia. No significant difference in scores was noted between the two groups, although subjects with alopecia decreased their social activities (Wagner & Gorely, 1979). Another study of 40 patients (20 with and 20 without alopecia) treated with various chemotherapy regimens were evaluated for alteration in body image using the BCSCS. In contrast, a statistically significant difference was found between the groups, demonstrating that alopecia negatively affected body image (Baxley et al., 1984).

A European study also reported significant changes in body image. In a study of 29 patients, most with ovarian cancer, measurement of body image and self-concept was carried out using the Frankford scales of self-concept and body concept at three time points (prior to chemotherapy, prior to course 3, and six to eight months after completion of chemotherapy) (Munstedt et al., 1997). Using either scale, results worsened during chemotherapy and did not return to baseline when patients experienced regrowth of hair.

Two studies evaluated self-esteem. In a descriptive study of subjects' perceptions of physical and psychosocial changes since diagnosis of cancer, 323 ambulatory patients were asked questions regarding their feelings toward themselves. Of the responders, 24% reported that they had experienced changes in body image ("I'm ugly now"), 18% noted lowered self-esteem, and a large percentage (61%) reported negative attitudes toward changes in how they felt about themselves (Frank-Stromborg & Wright, 1984). In a second study of 30 women who experienced alopecia while receiving chemotherapy, the Cantril Self-Anchoring Scale measured self-esteem (Carpenter & Brockopp, 1994). The level of self-esteem was examined retrospectively, prior to diagnosis with cancer, and at the time of chemotherapy-induced alopecia. Self-esteem was significantly lower at the latter time point when compared to prediagnosis.

Research has demonstrated that alopecia is a significant and disturbing side effect of chemotherapy with a detrimental effect on body image, but few studies have examined the role of interventions designed to ameliorate the emotional impact of the experience. Examples of nursing interventions appropriate for self-image changes associated with hair loss have emphasized verbal and written instructions on the use and care of wigs (Ehmann, Sheehan, & Decker, 1991; Keller & Blausey, 1988), the use of head coverings (Schlesselman, 1988; Tierney & Taylor, 1991), and referral to support groups such as "Look Good, Feel Better" (Frank-Stromborg & Wright, 1984; Pozo-Kaderman et al., 1999; Seipp, 2001). Although videotape interventions for alopecia have not been evaluated, an integrative literature review demonstrated the effectiveness of video modeling in facilitating clinical decision making, reducing anxiety and physiologic arousal, and improving self-care practices (Krouse, 2001).

Although changes in body image for women experiencing chemotherapy-induced alopecia have been reported, evidence conflicts regarding the magnitude of the problem. This article reports on a study that aimed to increase understanding of changes in body image for women experiencing alopecia during cancer therapy and to examine the effectiveness of a videotape instruction on body image.

Conceptual Framework

Orem's self-care theory (Hartweg, 1991) was used as a guide to develop a nursing intervention to assist women with chemotherapy-induced alopecia. According to the theory, individuals must meet health-deviation self-care requisites when health is altered. In the context of the current study, deficits included awareness of deleterious effects of medical measures (hair loss), modification of self-concept (body image), and accommodation to the effects of pathologic conditions and treatment measures in a lifestyle that promotes personal development (adjustment to hair loss) (Hartweg).

Based on the self-care theory, women need information about alopecia and self-care strategies to deal effectively with the experience. Although nurses may be responsible for providing such information, individual patients ultimately must respond to it. The interventions employed in the current study included standard counseling and an instructional videotape on hair loss. Both methods used the self-care theory, because activities were personally initiated and performed to maintain well-being.

Purpose

The specific objectives of the study were to (a) prospectively determine whether alopecia affects the body image or self-esteem of women receiving chemotherapy for pelvic malignancies and (b) determine whether the use of a videotape instruction that deals with hair loss improves the status of the women on the two dimensions. The study was conducted and analyzed by the Gynecologic Oncology Group (GOG), a national research cooperative group funded principally by the National Cancer Institute (NCI).

Methods

Design

A repeated-measures, randomized, analytic design was used to examine the body image and self-esteem of women who experienced chemotherapy-induced alopecia and to evaluate the impact of a videotape intervention.

Subjects

All patients were enrolled concurrently in a GOG treatment study for gynecologic malignancy. To be eligible for the trial, patients had to have a diagnosis of pelvic malignancy; have a GOG performance status of 0, 1, or 2; and be able to read the English language. Women were ineligible if they had past or concomitant malignancy other than skin cancer (excluding melanoma); a history of previous disfiguring surgery such as colostomy, amputation, mastectomy, or insertion of nephrostomy tubes; a history of any disfigurement from drugs, diseases, or radiotherapy; or previous hair loss.

Instruments

Body image and self-esteem were measured using the BCSCS (Secord & Jourard, 1953). The term body cathexis is synonymous with body image, and self-cathexis may be defined as self-esteem. Written at a sixth-grade level, the BCSCS is easy to use and can be completed in 10–20 minutes. The instrument has two components. The first consists of items related to 46 body parts and functions, in which subjects are asked to rate their feelings on a five-point scale. A single score for body cathexis is obtained based on the mean score of the 46 body-item scores. The second part of the scale concerns self-cathexis and lists 55 items that represent a sampling of the various conceptual aspects of self, phrased in nontechnical, popular terms such as morals, conscience, and personality, to approximate the terms in which individuals actually think of themselves. Subjects are asked to rate their feelings on a five-point scale. A single self-cathexis score is obtained, based on the mean score of the 55 self-scores. The scale has an established split-half reliability coefficient of 0.83 for females (Secord & Jourard). The BCSCS was chosen to measure body image because of its ease of administration, established reliability, and use in previous research on body image and cancer-induced alopecia (Baxley et al., 1984; Wagner & Gorely, 1979).

Prior to receiving chemotherapy, patients provided demographic information using a self-administered questionnaire developed by one of the authors. Variables included age, race, religion, level of education, family income, and marital status.

Subsequently, a hair-loss questionnaire, also developed by one of the authors, was completed by a nurse at designated times. The grade of hair loss for various body parts, including scalp, eyebrows, eyelashes, axilla, pubis, legs, and arms, was determined using standard NCI Common Toxicity Criteria (grade 0 = no hair loss; grade 1 = mild hair loss; grade 2 = pronounced or total hair loss). Information also was obtained on the use of prostheses (e.g., wigs, turbans, eyelashes).

Subjects randomized to receive the intervention (a videotape on hair loss) completed a questionnaire designed to provide qualitative data on the usefulness of the videotape. Subjects were asked whether they found the videotape helpful in adjusting to hair loss (yes or no); to rate the component of the videotape that was most helpful (e.g., makeup techniques, wig techniques, hair covering techniques); to comment and explain whether any parts of the videotape were not helpful; and whether they would recommend the videotape to other women (yes or no). Table 1 describes the schedule of testing.

Table 1. Schedule of Assessments

Assessment	Prior to the Treatment	Prior to the Third Course	After the Fourth Course
Degree of hair loss	X	X	X
Demographic questionnaire	X	–	–
Body Cathexis Scale	X	X	X
Videotape questionnaire (to be completed by patients randomized to the videotape intervention arm)	–	–	X

Videotape

Best Look Forward is a 45-minute video that presents makeup techniques and suggestions regarding hair and headpieces to women with chemotherapy-induced alopecia. The videotape, developed by a professional production company in collaboration with one of the authors, uses authentic patients with cancer and presents the information in a positive and uplifting but realistic manner. An expert panel of 20 oncology nurses (nurses who comprised the GOG Nursing Committee) reviewed the videotape and provided positive verbal feedback regarding the appropriateness of the content.

Procedure

Following study approval by the institutional review boards of participating institutions, nurses and physicians identified patients meeting the study eligibility criteria. Patients provided written informed consent consistent with all federal, state, and local requirements prior to study entry.

Patient accrual occurred in two phases. During the first phase, patients were assigned randomly to view the videotape (intervention arm) or not to view it (standard arm). The goal of the first phase was to provide estimates for the actual proportion of women experiencing alopecia and the variances and covariances of the BCSCS score at each course. The estimates from the first phase of the study determined the required sample size to detect a difference of 0.30 units on the BCSCS scale, when comparing patients with alopecia who were randomized to view the videotape and those randomized to not view it.

The sample size then was based on a covariance analysis of the BCSCS scores at course 4. The analysis used the BCSCS score at course 3 as a covariate and estimated the effect of viewing the videotape. The type I and type II errors were set to 0.05 (two-tail test) and 0.20, respectively. Actual sample size based on the interim analysis and power analysis provided that an estimated 68 women were required for each treatment arm.

Prior to the first course of chemotherapy, all patients received standard counseling regarding hair loss (see Figure 1). Counseling training workshops were conducted at semiannual GOG business meetings for nurses from participating institutions. Workshop participants reviewed the guidelines for standard counseling, as well as study procedures, and questions related to the study were discussed and answered.

Randomization was carried out at the GOG Statistical and Data Center such that, prior to the third course of chemotherapy, all patients with grade 2 hair loss were assigned randomly to receive either no intervention or the intervention (videotape on hair loss) (see Figure 2). Patients randomized to the intervention arm were provided with the videotape and viewed the videotape at home or in the clinic.

Results

Demographics

A total of 190 women were entered in the study. At baseline, three women already had experienced moderate or severe alopecia unrelated to cancer or chemotherapy, whereas the remaining 187 women had experienced no hair loss. The three women who had significant hair loss at baseline were excluded from the analysis (N = 187). The mean age of the remaining subjects was 57.7 years (SD = 11.5; range = 27–80). The racial composition of the sample was primarily Caucasian (n = 175, 93%). In terms of disease status, approximately 94% (n = 176) had stage 3 disease or higher at

Incidence
Include some discussion regarding the likelihood of hair loss occurring. For example, patients on doxorubicin should be counseled that complete hair loss is almost universal. Patients receiving other chemotherapeutic agents should be counseled regarding the probable likelihood of hair loss.

Timing
Patients should be counseled that hair loss may start to occur 10–14 days after the first day of chemotherapy. Patients should be advised that it may be a complete loss of hair over a period of several days or may occur as a gradual thinning of hair that may or may not require the use of a wig.

Distribution
Discussion should emphasize that hair loss may encompass loss of scalp hair as well as body hair, including eyebrows, eyelashes, pubic hair, axillary hair, and body hair on the arms and legs.

Regrowth
Patients should be counseled that they might experience some regrowth of hair while on chemotherapy. However, if it occurs, the hair may fall out again. Patients should be advised that hair regrowth after the completion of chemotherapy will start to occur immediately. Hair usually grows at approximately a quarter-inch to a half-inch per month. Patients who choose to wear a wig should be advised that the wig may be necessary for several months after completion of chemotherapy until hair has grown adequately.

Wigs and Other Hair Coverings
Patients should be advised to obtain a wig prior to hair loss if they expect they will want to wear one. They also should receive suggestions regarding other headpieces, such as scarves and turbans, to wear at times when a wig may be uncomfortable or impractical. Patients should be advised that insurance companies often reimburse for wigs, and a prescription for a "cranial prosthesis" should be provided.

Figure 1. Guidelines for Standard Counseling

study entry, and the majority of subjects had ovarian cancer (n = 140) (see Table 2).

Hair loss prior to course 3 was not present in 28 subjects, and 23 subjects did not complete the study because of disease progression or refusal to continue to participate. The final sample for the randomized portion of the study was 136 women (no further intervention, n = 68; intervention videotape, n = 68).

Body Image and Self-Esteem

The two primary dependent measures were total score for body image and total self-esteem score. At the first assessment, all subjects provided valid data on the two measurements. Age and race were examined for possible covariation with the dependent variables, but neither was significantly related to either criterion at the baseline assessment. The two dependent measurements were strongly correlated with each other at each of the three assessment points (r = 0.68, 0.69, and 0.75, respectively). The first question to be addressed was how much change in body image and self-esteem was associated with hair loss. The issue was studied by examining the means of the two measurements at baseline and at the subsequent point of total hair loss. At course three, 136 patients had complete hair loss. A small but statistically significant change was observed in body image ($t[135] = 2.01$, $p = 0.045$), but no change occurred in self-esteem (see Table 3). The average change in body image was approximately one-tenth of one scale point. The clinical significance of the difference is debatable.

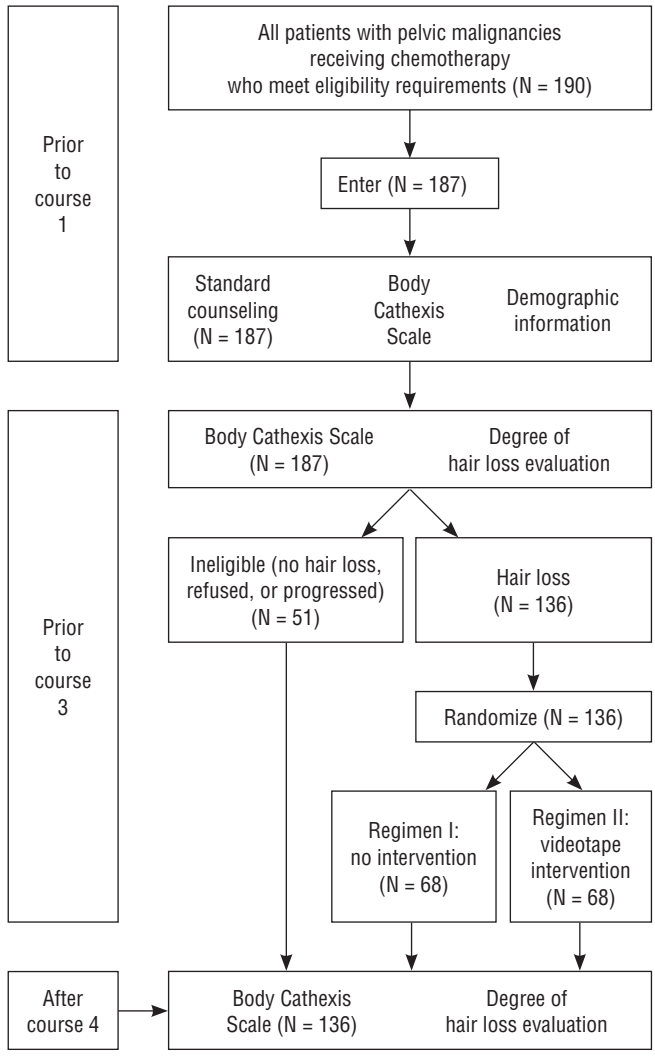

Figure 2. Study Schema

Because of the strong correlation between the measurements at each time point, the researchers considered employment of a total body image and self-esteem index or a doubly multivariate repeated-measures analysis. The analytic options were rejected because the researchers wanted to preserve sensitivity to the distinct content of the scales for body image and self-esteem. The two measurements were examined in separate repeated-measures analysis of covariance tests. In each analysis, the baseline measurement was compared with the assessment after course 4, with the course 3 measurement as a covariate. The course 3 score was used to control variance associated with the standard counseling and to isolate the variance related to the videotape intervention. In both analyses, the course 3 covariate was highly significant (self-esteem: $F[1,133] = 106.38$, $p < 0.001$; body image: $F[1,133] = 8.24$, $p < 0.001$). No intervention effect was found for either measure (self-esteem: $F[1,132] = 0.32$, $p = 0.57$; body image: $F[1,132] = 0.11$, $p = 0.74$).

Additional Analyses

Examination of the pattern of means at each course suggested that, at the group level, the body image and

Table 2. Diagnosis and Chemotherapy of Study Subjects

Gynecologic Oncology Group Protocol	Chemotherapy	Disease Site	n	%
172	Paclitaxel and cisplatin	Ovary	1	0.5
162	Cisplatin and paclitaxel	Ovary	15	7.9
157	Carboplatin and paclitaxel	Ovary	11	5.8
152	Cisplatin and paclitaxel	Ovary	22	11.6
115	Bleomycin, etoposide, and cisplatin	Ovary	1	0.5
114	Cisplatin, cyclophosphamide, paclitaxel, and carboplatin	Ovary	24	12.6
132	Cisplatin and paclitaxel	Ovary	10	5.3
158	Cisplatin, carboplatin, and paclitaxel	Ovary	56	29.5
108	Ifosfamide, mesna, and cisplatin	Uterus	4	2.1
122	Doxorubicin and cisplatin	Uterus	9	4.7
139	Doxorubicin and cisplatin	Uterus	14	7.4
150	Ifosfamide, mesna, and cisplatin	Uterus	2	1.1
163	Doxorubicin, cisplatin, and paclitaxel	Uterus	14	7.4
149	Cisplatin, ifosfamide, and mesna with or without bleomycin	Cervix	7	3.7

N = 190

Note. Because of rounding, percentages may not total 100.

self-esteem scores were remarkably stable over time. To examine the pattern more closely, the researchers created the clustered box plot shown in Figure 3. The box plot shows the median, interquartile range, and extreme cases of individual variables for all participants who provided complete data. The overall pattern could be regarded as uninteresting if stability in the body image of patients with cancer was not a relevant parameter with regard to the impact of treatment. However, the graph shows that most of the patients remained close to the center of the scale at each time point and in both conditions. The interquartile range indicates that 75% of the patients in the study at each time point were below a scale value of 3, which reflects moderate satisfaction with the body items. Thus, the majority of the patients in the current study did not experience the decline in body image associated with alopecia that has been found in other studies.

Table 3. Paired Comparison of Body Image and Self-Concept Before and After Alopecia

	Alopecia Grade				
	0 (No Hair Loss)		2 (Total Hair Loss)		
Measurement	$\bar{X}$	SD	$\bar{X}$	SD	t
Body image	2.43	0.60	2.52	0.62	–2.01*
Self-concept	2.17	0.53	2.24	0.61	–1.54

* p = 0.045

The pattern appears to represent the two study groups well, but the group-level stability reflected in the box plot might have masked important individual variability in self-esteem, body image, or response to the videotape. To examine to what extent such individual differences were evident, the researchers conducted a second graphic analysis. In the analysis, the difference scores from the assessment before course 3 to the assessment after course 4 were calculated, converted to z-scores, and plotted. Figure 4 represents every individual in one of four quadrants based on whether increases or decreases were observed in their scores from the point of hair loss until study conclusion. For example, if an individual's difference score was positive on both measurements (reflecting improved status), her score would be located in the upper right quadrant. The largest number of cases (40) fell into the quadrant showing negative changes on both measurements. However, of the 40, only one case changed more than two standard deviations from the mean. Thus, the pattern of general stability observed at the group level is enhanced with the evidence that, although individual differences often were in the negative direction, the degree of difference was quite small.

Qualitative Data

Most subjects randomized to receive the intervention videotape reported that it was helpful in adjusting to hair loss. Only three patients described the videotape as not helpful, and one remarked, "It should be provided earlier." Four patients indicated that the makeup portion of the videotape was not helpful, with one noting "I'm too old for makeup." Despite the negative comments, all who viewed the videotape stated that they would recommend it to other women experiencing hair loss.

Discussion

The results of the current study support previous research findings that alterations in body image may occur as a result of treatment-related alopecia (Anderson & Johnson, 1994; Baxley et al., 1984; Frank-Stromborg & Wright, 1984). However, the videotape intervention, which described makeup techniques and provided suggestions regarding hair loss and headpieces, was not successful in improving or preventing changes in body image. The identification of effective methods to reduce the negative changes in body image and self-esteem caused by chemotherapy-induced alopecia is of importance to the development of future studies, in which quality-of-life changes and related measurements such as body image and self-esteem may be of clinical significance.

Why Was So Little Change Found in Body Image and Self-Esteem?

If the videotape had been associated with a significant difference in scores (either body image and self-esteem improving in the experimental group or declining in the control group), then the randomized design used in the study would have supported a strong causal interpretation of the result. However, the pattern suggested very little change in either measurement over time. Four plausible explanations for the outcome exist.

The first is that standard counseling was sufficient to prevent clinically significant alterations in body image and self-esteem. The second is that the stability in body image and

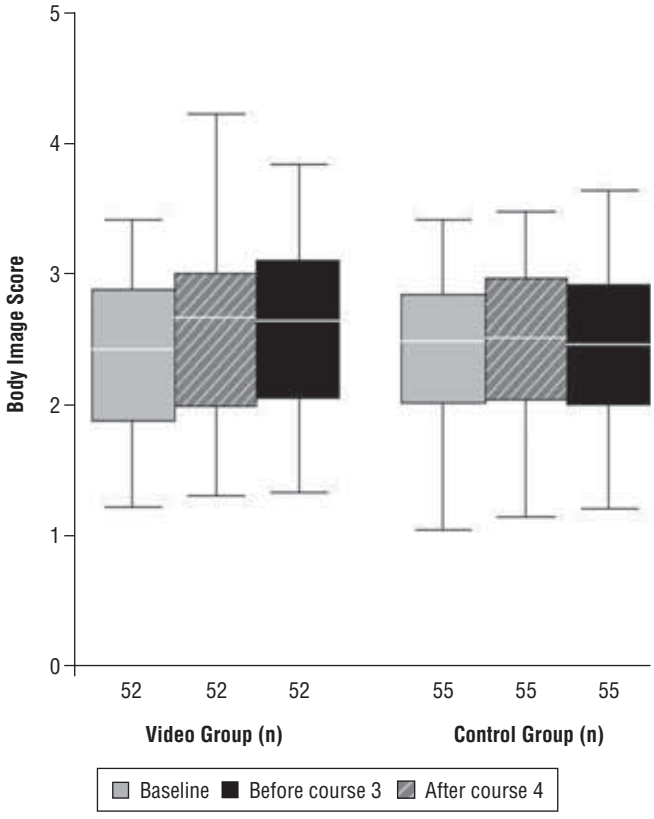

Figure 3. Box Plot of Body Image Scores by Group and Time

self-esteem was preserved by the use of the prostheses that were recommended in the standard counseling, which were used by all but one study participant. The third possibility is that the pattern of stability is an artifact of some aspect of the measurements or the patients' experiences in the trial that is unknown. When individual differences were examined, women commonly changed slightly in the negative direction on one or both measurements, but the changes were small and probably not clinically meaningful in almost all cases. Finally, the timing of the videotape intervention was prior to the third course of chemotherapy. The timing rationale was to identify women who experienced alopecia prior to the randomization procedure. Although all subjects in the current study said they would recommend the videotape on the use of wigs, head coverings, and makeup to other patients with cancer and the majority reported its usefulness, the videotape intervention did not result in significant improvement in scores for body image. Whether providing the videotape prior to actual hair loss might have produced a more positive result is unknown. The most likely explanation is that the standard counseling, which was systematically delivered and included attention to the use of prosthetics, was effective in maintaining stability for the group as a whole.

Of particular concern is the suggestion in one study that the impact of alopecia persists even six to eight months after completion of therapy, when hair regrowth has occurred (Munstedt et al., 1997). The current study did not evaluate the long-term effect of alopecia. Whether the observed difference in body image is exclusively the result of alopecia or perhaps related to coping processes that were initiated by chemotherapy and possibly enhanced by alopecia is not known.

Implications for Nursing Research

Alopecia has a detrimental effect on body image among women undergoing chemotherapy unless specific counseling is provided. Nurses should be alert to changes in body image and continue to provide relevant information regarding the use of head coverings. The BCSCS is a simple and relatively quick measurement of changes in body image that can be used in future studies. Future studies should employ only the body cathexis portion because of the significant covariance of body cathexis and self-cathexis as noted in the current study, the stability of the self-related items, and the small but significant change observed in the body-related items. Use of the abbreviated instrument saves patients and investigators (primarily research nurses) time without compromising study objectives.

Although changes in body image and self-esteem related to alopecia have been reported previously, the studies were limited by small sample sizes and lack of baseline data. The results reported in the current study represent the largest known prospective, randomized study to evaluate alopecia-related changes in body image over time and, secondarily, to evaluate the effectiveness of a videotape intervention on the construct.

Future research should include the development and investigation of novel intervention techniques to assist women with chemotherapy-induced alopecia. Qualitative and quantitative results from research on women reporting stable body image during chemotherapy could provide information to serve as

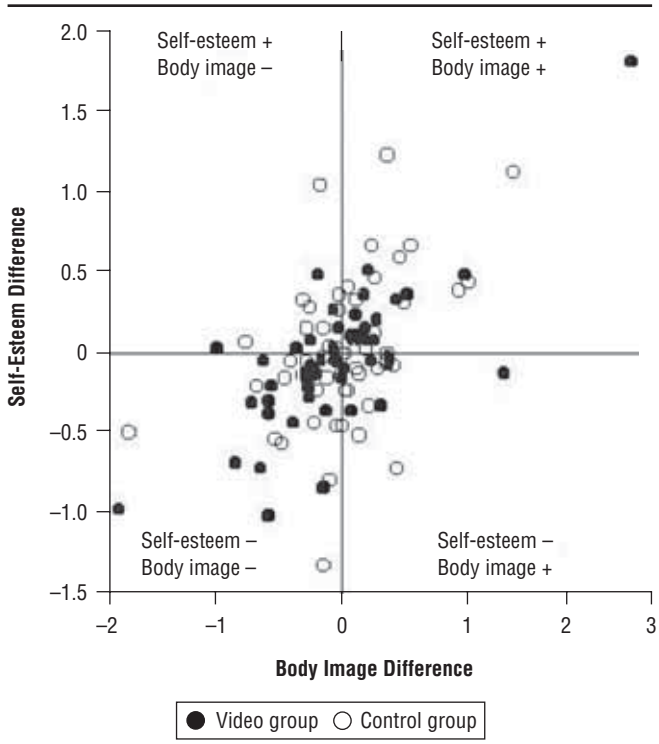

Figure 4. Scatter Plot of Self-Esteem and Body Image Difference Scores

a basis for future intervention studies. Alterations in body image over time, even after hair regrowth occurs, need to be studied further.

The following GOG member institutions participated in this study: Abington Memorial Hospital in Pennsylvania; University of Iowa Hospitals and Clinics in Iowa City; Indiana University Medical Center in Indianapolis; the School of Medicine at Wake Forest University in Winston-Salem, NC; University of California Medical Center–Irvine in Orange; Tufts-New England Medical Center in Boston, MA; Johns Hopkins Oncology Center in Baltimore, MD; Columbus Cancer Council in Ohio; University of Massachusetts Medical School in Worcester; Case Western Reserve University in Cleveland, OH; and Brookview Research Inc. in Nashville, TN.

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