

# The psychosocial morbidity of breast cancer patients with lymphoedema

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*Lymphoedema is a problem for many women after treatment for breast cancer, leading to physical, psychosocial, and psychological problems, which have been acknowledged but are poorly understood. This article discusses the findings of two studies that used the Psychosocial Adjustment to Illness Scale to examine the psychosocial morbidity of patients with breast cancer with lymphoedema. Women with lymphoedema were found to experience increased psychosocial maladjustment and psychological morbidity to their disease and lymphoedema when compared with a group of patients with breast cancer who did not have lymphoedema. These difficulties were not related to the degree of swelling present and persisted after 6 months of specialised treatment to the swollen arm. The findings indicate that the development of lymphoedema in patients with breast cancer carries psy-*

*chosocial and psychological implications that should be acknowledged and addressed at an early stage by a trained health-care professional.*

**Key Words:** Lymphoedema—Breast cancer—Psychosocial morbidity.

After treatment for breast cancer, many women are at risk of developing the unpleasant and distressing complication of arm swelling. Although treatment modalities for breast cancer have become more conservative over recent years, any axillary intervention of a surgical or radiotherapeutic nature may result in the appearance of arm swelling months or even years after treatment.

The incidence of lymphoedema is unclear, but a study by Kissen et al. (1) in 1986 of 200 patients with breast cancer suggested that as many as 38% of the women studied developed arm swelling, depending on the treatment they had received. The number of women throughout the United Kingdom that have lymphoedema is unknown, but a recent study by Bates (2) examined the prevalence of lymphoedema in women who had been treated for breast cancer in one geographical area. Results of the study suggest that 28% of all women receiving treatment for breast

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cancer develop arm swelling at some time after their treatment.

Many problems are associated with the condition of lymphoedema. These include a predisposition to systemic and local infections and, rarely, to the development of secondary malignancies (3). The swollen arm may feel heavy and uncomfortable with increasing disability, which interferes with everyday activities. The distortion in the size of one area of the body also may reduce self-esteem and present problems with body image and social acceptability.

Women with breast cancer are thought to experience a complexity of emotions and reactions during and after treatment for their disease (4). Research describes the psychosocial and psychological morbidity of breast cancer and acknowledges the intense disturbance in feminine identity that can occur (5,6). Surprisingly, the implications of lymphoedema as a result of treatment for breast cancer remain poorly documented, with little acknowledgement made of the psychosocial and psychological problems that a swollen arm may induce for the woman who has already undergone treatment and is living with the diagnosis of breast cancer.

Women frequently describe the considerable misery imposed on them by a swollen arm. Conservative treatment methods using a combination of elements are increasingly being used to gain maximum improvement in the condition followed by long-term control. However, clinical experience and observation have illustrated that adaptation to the swelling varies and does not appear to be related to the size of the limb. Similarly, motivation to reduce and control the swelling, although usually high, appears to vary in intensity.

In order to gain insight into the psychological and psychosocial problems of breast cancer-related lymphoedema, two independent studies by Tobin (7) and Woods (8) were completed. These studies and their findings and implications will be compared and discussed in this article.

### STUDY PARTICIPANTS

All study participants had received primary treatment for breast cancer at least 1 year previously and were free from active disease at the time of recruitment to the studies under discussion.

A study group of 50 women with breast cancer-related arm swelling were matched by Tobin with a control group of 50 women in whom arm swelling was not present. Matching included the type of

treatment that the patient had received, duration of time since treatment, and age. The absence of swelling in the control group was defined by summing circumference measurements of the arm taken 10 cm below and 15 cm above the lateral epicondyle and using a difference of <4 cm as a cut-off point (1). Data collection among the participants of the study took place on one occasion only.

Forty women with breast cancer-related arm swelling were invited (upon referral for specialised treatment for their arm swelling) to participate in the study conducted by Woods. In order to establish and record any change in the patients' perceptions of their lymphoedema, data collection took place at referral for treatment of the swelling and after 6 months of treatment.

### METHODS

The Psychosocial Adjustment to Illness Scale (PAIS) self-report questionnaire was used to assess the quality of the patients' adjustment to their disease and its residual effects (9). In Tobin's study the questionnaire was completed by all study participants on one occasion only, and in Woods's study it was completed on two occasions, 6 months apart.

### ANALYSIS

Paired *t* tests were used in both studies to analyze the differences between the responses acquired in the completed questionnaires.

### PAIS QUESTIONNAIRE

The questionnaire (9) comprises 46 items within seven principal measurement domains or areas of a patient's life viewed as having a high predictive relevance for psychosocial adjustment to a current medical illness or its residual effects.

In both studies the disease under investigation was breast cancer and lymphoedema, a residual effect of that disease.

The degree of adjustment is evaluated in the following seven domains: health-care orientation, vocational environment, domestic environment, sexual relationships, extended family relationships, social environment, and psychological distress. Each domain is scored individually, and a total score indicative of the patients' adjustment is also calculated. High scores achieved during scoring of the questionnaire indicate poorer psychosocial adjustment. The authors of the

questionnaire suggest a measurable score of 60 as a guideline for what is considered by them to be clinical disturbance in psychosocial adjustment to illness.

The instrument has been validated among patients with cancer, including a small group of patients with breast cancer, and has been recommended as well suited for sequential measurement over time.

RESULTS

The mean or average scores achieved in the PAIS Questionnaire by the study participants are illustrated in Tables 1 and 2. Both tables show that patients with breast cancer-related arm swelling achieved notably higher scores in all domains or areas of their lives than did the control group of patients with no arm swelling, whose mean scores are shown in Table 1.

Tobin observed significant differences between the scores achieved by the patients with arm swelling and those without (Table 1), and Woods observed that in patients with arm swelling there was no significant difference between the scores after 6 months (Table 2). This suggests that patients with breast cancer-related arm swelling experience poorer psychosocial adjustment to their disease and its residual effects than patients with breast cancer who do not have arm swelling. These psychosocial problems appear to span all spheres of the patient's life from the domestic and social environment to sexual and family relationships and appear to continue for as long as 6 months, even if the swelling is being treated.

Within the group of patients with arm swelling, significant differences in the domain of attitudes toward health care were observed by Woods between

TABLE 2. *Pais questionnaire (mean scores achieved): patients with arm swelling*

Domain	At referral (n = 37)	After 6 months (n = 37)	Significance (paired t test)
Health-care orientation	56.3	50.4	p < 0.01
Vocational environment	53.1	52.4	NS
Domestic environment	46.1	47.4	NS
Sexual relationships	46	45.0	NS
Extended family relationships	51.6	51.4	NS
Social environment	42.7	40.6	NS
Psychological distress	50.2	50.7	NS
Total score	49.1	47.0	NS

referral for treatment of arm swelling and 6 months later (p < 0.01). This is illustrated in Table 2.

Because the swelling had been present for an average of 2.8 years among this group, this finding suggests that patients attached blame to themselves for the appearance and continuity of the swelling, resulting in impairment in adjustment to its presence. After 6 months of treatment for their lymphoedema, the observed significant improvement in these patients' attitudes toward health care suggests that receiving information concerning the management of the swelling and care of the swollen arm influenced attitudes in this area.

Using the guideline of a measurable score of 60, outlined by the authors of the questionnaire as indicative of measurable psychosocial maladjustment to illness, the results obtained show that 86% of the patients studied by Woods had measurable psychosocial maladjustment in one or more domains at time of referral for treatment of their lymphoedema and that 81% had maladjustment after 6 months of treatment. Sixteen percent of the patients studied had overall measurable psychosocial maladjustment to illness at referral and after 6 months of treatment.

These results suggest that a considerable number of patients have impairment in adjustment to the experience of breast cancer and lymphoedema resulting in measurable psychosocial maladjustment using the PAIS Questionnaire.

LIMB VOLUME DIFFERENCE AND PAIS SCORES

Among the patients in both studies with breast cancer-related arm swelling, it could be assumed that the problems faced by women with a heavy oedematous arm would lead to poorer psychosocial ad-

TABLE 1. *Pais questionnaire (mean scores achieved): breast cancer patients*

Domain	With arm swelling (n = 49)	Control group (n = 49)	Significance (paired t test)
Health-care orientation	52.84	51.5	NS
Vocational environment	54.14	48.8	p < 0.001
Domestic environment	48.65	39.5	p < 0.001
Sexual relationships	49.2	44.2	p < 0.01
Extended family relationships	51.63	47.8	NS
Social environment	45.6	35.95	p < 0.001
Psychological distress	53.1	47.4	p < 0.05
Total score	51.14	40.2	p < 0.001

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NS, not significant.

justment when compared with women with more minimal arm swelling.

All patients recruited to the study by Woods received ongoing advice and treatment for their arm swelling. Management of the swelling was planned individually according to the patient's needs, using conservative treatment techniques with the aim of reducing limb volume and gaining control of the swelling. A significant reduction in the percentage difference between normal and swollen arms was observed within the study group after 6 months ( $p < 0.01$ ).

As shown in Table 2, the scores achieved in the PAIS questionnaire among this group of patients with breast cancer with arm swelling studied by Woods remained notably higher at commencement of the study and after 6 months of treatment than did those observed within the control group used in Tobin's study and illustrated in Table 1. However, limb volume differences were observed to vary enormously at referral and after 6 months of treatment, bearing no relationship to the PAIS score achieved. This is illustrated in Table 3. Therefore, disturbance in psychosocial adjustment to breast cancer and lymphoedema does not appear to be related to the size of the patient's swollen limb, with psychosocial maladjustment evident in patients with greater and minimal limb volume differences.

## DISCUSSION

The two studies compared highlight that patients with breast cancer-related arm swelling appear to experience increased psychosocial maladjustment and psychological morbidity to their disease and its residual effects when compared with a group of patients with breast cancer who do not have arm swelling. The difficulties in adjustment were found to persist despite treatment over a period of 6 months and were not found to be related to the size of the swollen limb. However, women without arm swelling appeared to have incorporated the whole experience of breast cancer into their lives and were not experiencing any significant difficulties in adjusting to their diagnosis.

The appearance of arm swelling was usually sudden and often occurred after use of the arm, leading the patient to blame herself for its appearance. Many patients denied receiving even basic advice concerning the risk of the swelling developing after treatment for breast cancer, and its appearance then generated a mixture of reactions. These were often

TABLE 3. *Pais scores and limb volume differences in patients with arm lymphoedema*

Patient study	Pais score at referral	Pais score at 6 months	Limb volume difference at referral (%)	Limb volume difference at 6 months (%)
9	65	65	84	61
13	58	49	14	10
14	60	57	2	4
24	61	65	-1.4	-1.2
27	63	51	53	43
32	70	65	41	35

based on fear that the cancer had returned and that the swelling was permanent.

The results of the PAIS Questionnaire show that these fears and concerns can affect all aspects of the patient's life. As the arm becomes a focus of attention for others, a loss of interest in social activities can result; as the swelling progresses, difficulties in function may influence the home and work environment. Further distress occurs when any adaptation to the altered body image caused by the swelling is hindered by problems with dress, sometimes resulting in a complete change of style of dress or loss of interest in appearance. Loss of self-esteem may then contribute to the difficulties observed with interpersonal and sexual relationships.

Many patients reported the presence of swelling for prolonged periods of time before any treatment became available. Previous literature has suggested that the development of potential complications in a swollen limb can be minimised by prompt and early referral for treatment (10). A clearer definition of lymphoedema and greater availability of and access to health-care professionals experienced in the identification and treatment of lymphoedema would ensure that any swelling perceived by the patient is acknowledged and appropriate treatment initiated at an early stage while the swelling can be more easily treated.

Patients at risk of developing lymphoedema should also be identified and given appropriate advice and education at an early stage, followed by prompt referral for specialised treatment should swelling develop. Access to the skills of a trained counsellor at this early stage may also minimise psychological and psychosocial distress.

Research with counselled mastectomy patients showed that patients were found to experience significantly less depression and anxiety 12-18 months

after surgery than a control group who did not receive formal psychological care (11). Therefore, treatment for lymphoedema over a period of just 6 months may not demonstrate a significant improvement in psychosocial adjustment to the condition. However, a general trend toward overall improvement could be observed in the results acquired by Woods. This trend needs to be explored further to study any possible continuity over a longer period of time.

Although limb volume was reduced during the 6-month period, it is possible that the expectations of the patients in this study group were higher and that nothing less than the complete reversal of the swelling was psychologically acceptable. A full discussion of realistic expectations of the outcome of treatment based on a thorough assessment of the patient at referral should be combined with regular subjective and measurable evaluation of the progress being made. This will ensure that patients are given the opportunity to be fully informed about their swelling and can facilitate the development of psychological coping mechanisms enhanced by the skills of a trained counsellor when necessary.

### CONCLUSION

Further research in this area is essential. The psychosocial issues identified in these studies of patients with lymphoedema cannot possibly be confined

to patients with breast cancer-related arm swelling alone. If the problem is to be fully recognised and acknowledged, it needs to be clarified further in future research involving all patients with lymphoedema. □

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