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Acknowledgement—We thank Mrs Karen Slama for English translation assistance.

Eur J Cancer, Vol. 29A, No. 2, pp. 276–281, 1993.
Printed in Great Britain

0964-1947/93 \$5.00 + 0.00
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The Assessment of Body Image in Cancer Patients

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It is well recognised that cancer treatment can have a negative impact on body image, and this has proved to be an important outcome variable in treatment comparisons, such as surgery for breast cancer. However, there has been a good deal of variation in the way in which dissatisfaction with body image has been assessed, making comparison of results difficult. Some scales or subscales appear promising but lack the rigorous testing required to confirm their accuracy and reliability. This paper reviews the techniques and questionnaires that have been used for the evaluation of body image and highlights their strengths and weaknesses with respect to their use with cancer patients. At the present time, no single scale stands out as the ideal measure, but a pool of items can be generated from recent research, which merit future evaluation.

Eur J Cancer, Vol. 29A, No. 2, pp. 276–281, 1993.

INTRODUCTION

IN THE last decade, a body of knowledge has evolved concerning the psychological effects of cancer and its treatment. In parallel there has been considerable innovation in the design and development of instruments to measure the quality of life of patients both during and following cancer treatment. The need to measure specific effects, such as the impact on body image and sexuality, has become increasingly apparent as the sequelae of cancer treatments have been researched [1–6]. This is particularly important when body integrity is breached or body function altered as a result of medical intervention. In the field of breast cancer surgery, for example, the negative impact of breast loss from mastectomy has contributed to the adoption of a more conservative surgical approach, in order to maintain body integrity and the patient's satisfaction with her appearance. A series of research studies comparing the two surgical approaches has endorsed the view that conservative surgery is associated with the preservation of body image in comparison with mastectomy. However, the evaluation of body image in these studies varied considerably, making accurate comparison difficult [7].

EORTC quality of life study group

The impetus to review the assessment of body image has come from this group, where there is an initiative to develop disease and treatment-related modules to use with the group's core questionnaire. This scale has been designed and developed to

measure quality of life in clinical trials [8, 9]. Field testing and data analysis to establish the psychometric properties of a modified version (QLQC30) of the original core questionnaire has been completed and the scale will shortly be published and made more widely available. Body image items were not included in the core questionnaire but will be developed as a separate module of questions.

Factors to consider in assessment

Conceptually and methodologically there are difficulties in measurement, because body image is not a distinct dimension, but overlaps with sexuality on the one hand (for instance, "I feel sexually attractive" pertains to both domains) and with the broader construct of "self image" on the other. Overall attractiveness, femininity/masculinity, self-confidence, and having a sense of body integrity may all be important to the concepts of body image, self-image or self-esteem. Whilst the disturbance in body image may be severe and at times seemingly out of proportion to the observed disfigurement, this usually reflects a measure of the distress and not an irrational appraisal of body image as may occur in dysmorphobia. Moreover, there is usually no distortion of body size, or misperception of body weight as is found typically in the body image disturbance of anorexia nervosa or bulimia. However, research is needed in this area, to determine whether a subgroup of patients have an underlying psychopathology to explain the degree of body image disturbance experienced.

Body image has been evaluated mainly with respect to breast cancer surgery, but there are many other treatment situations where it merits assessment, such as following the provision of a

colostomy, after orchidectomy, surgery for genital or head and neck cancer or following amputation. More global treatment effects, for example, alopecia from chemotherapy or weight gain resulting from steroid therapy, may also have an impact on appearance and where such treatment effects have to be balanced against the disease response and benefit to survival, the assessment of body image should contribute to the equation. The evaluation of personal attitudes to body image (and sexuality) clearly warrant care and sensitivity in the way questions are posed, in order to avoid offence. Questionnaire items should be constructed carefully, yet unambiguously, and adapted for male and female patients where appropriate.

In deciding which patients should be assessed, it is important to avoid assumptions about their suitability on the basis of age or marital status. The relationship between body image dissatisfaction and age or marital status has been investigated but with some conflicting results. In a study of women with breast cancer treated by mastectomy, Penman *et al.* [10] did not find a relationship between age and disfigurement. In contrast, Metzger *et al.* [11] found younger women (under 50) to be significantly more likely than older women to be concerned about body image, with unmarried women being at greatest risk. In the over 60s the effect of marital status reversed and married women report more concern about appearance.

Timing of assessments

Considerable adjustment and adaptation occurs during the months following surgery for cancer, for example, after mastectomy some women cope better than they had expected, even if they had predicted a need for breast reconstruction pre-operatively. Others continue to be profoundly disturbed by changes in body image and warrant intervention. Polivy [4] observed a deterioration in body image in mastectomy patients 6–10 months after surgery, and it is, therefore, important to plan assessment points carefully and where possible, to repeat assessments 1 year or more following treatment. Furthermore, changes to the skin following radiation, or the continued healing of scars, may influence the impact on body image negatively or positively in the months or even years after treatment. Penman *et al.* [10] suggested that resilience of body self-concept after mastectomy may be attributed to a period of denial about body image and feminine self-image which serves as a necessary defence during recovery, so that reactions to cancer surgery and breast loss may be delayed several months or longer. Ideally, therefore, studies should be longitudinal in design to accurately reflect changes in satisfaction with body image.

The aim of this paper is to review the literature for approaches that have been used to measure body image in cancer patients, and to highlight deficiencies. Directions for further work will be suggested, so that the measurement of body image might be facilitated in the future.

METHODS USED SO FAR

The subjective impact of cancer treatment was first described 30–40 years ago in respect of hysterectomy, mastectomy and the provision of a colostomy. However, these reports were founded on individual case histories and small descriptive studies, or based on projective techniques such as Rorschach protocols, reportory grid techniques and body image projective tests. These assessment methods were highly subjective and therefore difficult to evaluate or interpret.

INTERVIEW-BASED STUDIES

Semi-structured interviews have been used extensively as part of a more global psychosocial assessment of cancer patients, and although body image has been covered in some of these assessments, details of questions used are often not included. The advantage of this approach is that in-depth questions can be asked and data sensitively obtained. Using more acceptable research design and methodology than the early accounts, more recent studies have used designated time points for assessment, but even so there are considerable differences in approach. For instance, interviews have been conducted at the patient's home, in hospital or by telephone. Even in the context of a specific cancer, the range of coverage is very variable. This is illustrated by breast cancer studies in which assessment covered satisfaction with the scar [12], the impact of lymphoedema [12], the extent to which married women concealed their scar from their husband and avoided dressing in their husband's presence [13] and attitude to and self-consciousness about appearance [11, 13]. In telephone interviews, Metzger [11] assessed distress about disfigurement based on a three item index measuring feelings of ugliness, shame and worry about sexuality (no concern = 0; extreme concern = 3). Beckman [14] evaluated alteration in body image after breast surgery as part of a semi-structured interview covering body image in relation to appearing naked, sexual attractiveness and change in the importance of the breast to the woman.

Several authors, such as Maguire [12], have reported descriptively the comments made by women about the impact of breast surgery, such as "feeling a freak", "feeling half a woman", "feeling mutilated". However, questions used to elicit these responses are not detailed.

In an early study of the impact of surgery for anorectal cancer, Devlin [15] reported changed body concept, feeling freakish, and the experience of phantom rectum. Sometimes, only an indirect measure of body image has been specified in an interview-based study, such as the need for, or satisfaction with a prosthesis following orchidectomy for testicular cancer [16], anxiety about resuming sexual activity [17], or a patient's response to the possibility of having a breast reconstruction [17].

These studies have helped to create an awareness of the impact of cancer treatment on body image, but have not aimed to systematically evaluate this as a principal outcome. Their value has been in identifying key areas amenable to assessment by self-report questionnaires.

BODY IMAGE ASSESSMENT BY QUESTIONNAIRE

In 1953, two American psychologists, Secord and Jourard, published one of the first questionnaires to measure individuals' satisfaction or dissatisfaction with various body parts, or processes of the body, so called "body-cathexis" [18]. The scale was designed principally for use by psychologists, and as yet there are no psychometric data relating to its use in a physically ill group. The first part of the questionnaire contains 46 body parts and functions and assesses the patients' degree of satisfaction or wish to change these. The second lists 55 items relating to self-concept, and combined, these two parts make up the Body Cathexis–Self Cathexis (BC–SC) Scale. A companion scale (the H test or Homonym test of body cathexis) is designed to measure undue concern or anxiety about the body, its function or disease. The scale has been used with cancer patients in two breast cancer studies. Ray used items to rate physical attractiveness with respect to 15 body parts in a group of mastectomy patients [19]. Surprisingly, the breasts were not

included in her brief version, and details of item selection were not given. No differences in body cathexis were found in mastectomy patients compared with cholecystectomy patients, but this may be due to deficiencies in this version of the scale, since over half the mastectomy patients reported distress from disfigurement in a taped interview.

Sanger and Reznikoff [20] also used both the Homonyms Test and the Body Cathexis Scale in a retrospective comparison of mastectomy and conservative surgery for breast cancer, but acknowledged the lack of accuracy of this unstandardised approach. They reported better preservation of overall body satisfaction in the conservatively treated group but commented that the body anxiety measure was influenced more by having cancer than by the nature of the surgery to treat it. Secord and Jourard's scale is too lengthy and too broad in its coverage to be recommended for a clinical trial setting.

The next initiative to develop a specific scale came in 1972, from three American social scientists, Berscheid, Walster and Bohrnstedt, who had worked extensively on the relationships between personality, body and behaviour. The result was a 109-item self-report questionnaire [21] covering satisfaction with body parts and functions as well as attributes such as self-confidence, self-opinion, sexual behaviour, and even demographic data. The number of response categories ranges from two to 10, with an average of six. Despite its apparent length, it has been adopted by a number of researchers in the cancer field. Polivy [4] used a modified version of the scale consisting of 20 body parts and two body qualities rated for appearance along a satisfied to dissatisfied continuum. Her study was one of the first to examine systematically the impact of mastectomy on feminine self-concept and body image. Unfortunately, no psychometric data concerning the shortened scale were included. Bloom and the Psychological Aspects of Breast Cancer Study Group also used the Berscheid Scale in a prospective comparison study of women treated for breast cancer [22], but this study incorporated 18 self-rating questionnaires and details of the Body Image Scale were not reported.

Thirdly, Penman *et al.* (1987) conducted a large collaborative study to evaluate the impact of mastectomy on self-concept and social function [10]. They also measured body image dissatisfaction with Polivy's shortened version of the Berscheid Scale, together with a scale developed by Schain [23] to assess feminine self-image and intimacy. This latter is a scale of items identified by a principal components analysis of the Personal Problem Checklist developed by Schain which addresses concerns particularly voiced by post-mastectomy women but worded without specific reference to breast cancer. The Feminine Self-Image Scale items assess body self-consciousness, sexual attractiveness, feelings of femininity and clothing fit. The intimacy items cover concerns about physical affection, sexual relations and avoidance of close relationships. Unfortunately this scale is unpublished, but is available from the author, Dr Schain. These scales highlighted smaller differences than expected between mastectomy patients and no-surgery controls. The authors suggested that time for adaptation was an explanatory factor, but made no comment on the performance of the scales.

Body image questions are incorporated into a detailed assessment of sexuality in the Derogatis Sexual Functioning Inventory (DSFI) [24], described more fully by Cull [25] in a companion paper. The full scale was used as part of a comprehensive assessment of breast patients to explore psychosexual adaptation to breast cancer surgery [26]. Results for component parts of the DSFI were not reported so performance of the body image

items cannot be judged in this study. The authors commented that patients who elected conservative surgery valued their breast appearance more highly, but limited details of body image were reported. The items in the DSFI are incorporated in two of the seven sections of this lengthy scale, and the scale can only be used when evaluating sexuality, as the body image items have not been designed for separate use.

The scales described above are well documented and the Berscheid Scale has apparently been shown to differentiate between mastectomy and biopsy or non-cancer surgery groups [10]. They are comprehensive but lengthy and are only suited to in-depth studies where body image is a priority outcome measure. They are not applicable to the clinical trial setting, where more concise scales are required. As a result, a number of research groups have designed their own questionnaires or subscales to assess body image. Often these form part of a multidimensional scale, or package of instruments, designed to measure quality of life or to assess the impact of a particular cancer therapy.

MULTIDIMENSIONAL/QUALITY OF LIFE SELF-ASSESSMENT SCALES

For clinical purposes, our main area of interest lies in this group of scales. Quality of life scales are multidimensional by definition but not all of them include body image items. Only those which make specific reference to a body image question or group of questions are included in this review.

Rotterdam Symptom Checklist [27]

This is a 30-item self-report questionnaire designed for use with cancer patients, covering psychological and physical symptoms: one question measures sexual interest but body image items were not included in the original scale. A further eight items assess the patients' activities of daily living. It has been used (in Dutch) by de Haes and van Welvaart [28] in a breast cancer treatment trial with three additional items to assess body image [29].

The items used by the Dutch group are:

- (1) Have you been, since your operation, less satisfied with your appearance?
- (2) Have you felt, since your operation, less feminine?
- (3) To what extent do you feel your body has been damaged as a result of the treatment?

The reliability (Cronbach's alpha) for these three items was given as 0.76 which was considered adequate by the authors and the items were found to discriminate patients treated conservatively from those receiving mastectomy [28].

The Rotterdam Symptom Checklist, with five additional items to cover body image, has also been used by Fallowfield *et al.* [30] in a similar comparative study of breast surgery. These items [31] are:

- (i) Feeling self-conscious.
- (ii) Dissatisfied with my appearance.
- (iii) Dissatisfied with my scar.
- (iv) Reluctant to look at myself naked.
- (v) Avoiding people.

The psychometric properties of these items have not yet been reported but further work using some of these questions is being carried out by Fallowfield *et al.* in other cancer types, and it is hoped that more data will follow.

Cancer Rehabilitation Evaluation Systems (CARES) [32]

The CARES is a comprehensive questionnaire aimed to identify patients' rehabilitation needs and concerns. It is self-administered, taking 20–45 min to complete, and is, according to its authors, well-accepted by patients. One of the unique features of this system is that it allows the patient to indicate, using a simple yes/no response, whether or not help is required for any of the concerns listed. It consists of 139 items covering many aspects of quality of life, all rated on a 5-point response scale (0 = not at all; 4 = very much). Five items relate to body image, dealing with clothing, embarrassment to be naked, or to show a scar, and body changes. Two further items concern sexual attractiveness. Despite its length, CARES is being used in clinical studies. The instrument is protected by copyright and its main disadvantage is its cost.

Other scales

The principal source of activity in developing body image items or subscales has been from those research studies comparing surgical techniques in breast cancer management. To date, 14 such studies have been published, and body image has been reported in 11 of them [14, 20, 22, 28, 30, 33–38]. These studies vary considerably in their methodology (e.g. retrospective vs. prospective, patient choice vs. none, time since surgery) and in their assessment of body image (observer-rated vs. self-rated; standardised vs. home-grown scale). Table 1 summarises the published studies in which body image was evaluated, to highlight this point. The need for standardisation of scales of body image is apparent. However, a number of authors give some detail of the items used in their own evaluation. Bartelink *et al.*, for instance, listed the six questions included in the Dutch group's short postal questionnaire. These items, mainly derived from Avery *et al.* [39], cover self-consciousness, shame, sense of feeling changed and sexual inhibition, all rated on a five-point scale (always–never). A separate question enquired about the cosmetic aspect (breast similarity). The items have been used previously in a breast surgery study and factor analysis confirmed that they work as a single scale. In the mastectomy vs. conservation study, a significant difference between the treatment groups was found for each body image question, suggesting that this brief scale is working well.

Kemeny *et al.* [35] also described the use of body image items in a smaller study, using an in-house postal questionnaire. Four items assessed retrospectively the impact of treatment on femininity, attractiveness, significance of the breasts for femininity and satisfaction with clothed appearance, using a four-point response scale. Four other items evaluated current concerns about seeing self nude or dressed, self-consciousness and sexual problems. In addition, seven items were used to assess the emotional reaction to alteration in body image (e.g. feel less attractive) using five emotions as rating responses (e.g. anger, disgust). All the items are listed in the publication, and apparently discriminate between the mastectomy and conservatively treated groups. However, the questionnaire was unstandardised, the sample size was small (52 participants), since compliance was low (62%) and the study must, therefore, be considered with caution.

Lasry and the Canadian group [36] assessed women participating in a randomised trial of mastectomy vs. lumpectomy, with or without breast irradiation, and assessed the impact of disfigurement using a seven-item Body Image Index. The component items, initially a series of 10 questions, were based on work by Polivy and Steinberg [4, 38] but, following a

reliability analysis, three questions were excluded. The remaining items, included in their publication, had a Cronbach's alpha of 0.81, indicating that the scale was reliable. Their index covered satisfaction with appearance and with the breast, attractiveness and concern about sexual attractiveness, and reaction to the scar.

Schain *et al.* [37] reported preliminary findings of a small study in which another postal questionnaire was used. Again the body image items were specified and validation work is in progress. From a brief review of these studies, it is apparent that a number of items are duplicated (e.g. feel negative about yourself nude/dressed, feel self-conscious) and a pool of items has emerged, which would form the basis for testing and constructing a body image scale.

Linear Analogue Self Assessment Measures (LASA scales)

The LASA format has been a popular style for quality of life scales, although there are limitations with this design. Few instruments are described in full, and it is difficult to know how often body image items are included. One example of a British scale is the one developed by Selby *et al.* [40]. This scale includes 31 descriptive categories made up of 16 for general health, seven treatment-related and six disease-related, e.g. appearance of body, attractiveness to opposite sex. The specific items relating to body image were not specified nor psychometric properties of these individual items.

Psychometric properties of assessment scales

Regrettably, as yet very few of the scales referred to above have published data supporting their performance in terms of validity and reliability. Establishing psychometric properties of research questionnaires is a time-consuming process and requires substantial patient samples, and it is perhaps not surprising that such data are lacking, since a considerable number of scales have been devised "in house" or for specific projects. This lack of standardisation of scales causes difficulty in the interpretation of results, however, and particularly in comparison between trials. Much the same criticism can be levelled at quality of life scales generally, although some groups such as the EORTC Quality of Life Group, have taken the time to carry out essential field work to establish the psychometric properties of their scale.

CONCLUSION

At the present time a review of the literature reveals that there is no well-researched brief self-report measure of body image suitable for use in clinical trials. Nevertheless, a small number of scales and subscales look promising and there is some overlap in the items covered so that general guidelines can be obtained. The brief scales described normally restrict themselves to general questions relating to the body as a whole, both dressed and undressed. Where questionnaires have been used in a specific disease or treatment setting, e.g. breast cancer, questions may be included relating to the scar or prosthesis. There is an overlap in enquiry about body image and sexuality and this warrants further research to better clarify the boundaries of these subscales.

In addition to these brief scales there is a small number of more detailed questionnaires that may provide valuable reference material to this area of enquiry. At the present stage of consideration, the following items could form the basis of a body image module. Clearly, reduction or expansion of these items would be needed according to the clinical trial in question.

Table 1. Body image assessment in studies comparing mastectomy (MXT) and breast conserving (BC) surgery

Authors	Patient sample	Time of assessment	Body image assessment used	Psychometric data for body image scale
Ashcroft <i>et al.</i> 1985	40	Prospective pre-op, 3 and 12 months postoperatively	Semi-structured i/v plus in-house scale of body satisfaction	Unstandardised
Bartelink <i>et al.</i> 1985	172	Retrospective 1–2 years postoperatively	Postal questionnaire, six body image items and one cosmesis item specified	Not given
Beckman <i>et al.</i> 1983	22	Retrospective 6–12 months postoperatively	Unstructured interview	—
de Haes 1986	34	Retrospective 11 and 18 months postoperatively	RSCL three items	Cronbach's $\alpha = 0.76$
Kemeny <i>et al.</i> 1988	52	Retrospective 6 months postoperatively	Postal questionnaire, four aspects of body image (specified) at four time points Seven items re. emotional reaction to body image (specified) Two current concerns re. body image (specified)	None given
Lasry <i>et al.</i> 1987	123	Retrospective mean interval since surgery: 40 months MXT; 42 months BC	In-house scale. Seven items (based on studies by Polivy and Steinberg) specified	Cronbach's $\alpha = 0.81$
Sanger and Reznikoff 1981	40	Retrospective mean interval since surgery: 15 months MXT, 16 months BC	Secord and Jourard Body Cathexis Scale Homonyms Tests	Reliability in college students given
Schain <i>et al.</i> 1983	38	Median interval since surgery: 333 days (MXT); 345 days (BC)	Rorschach Tests of Body Boundary Postal questionnaire, several examples given	Unstandardised In progress
Wolberg <i>et al.</i> 1989	119	Prospective (i) pre-operatively (ii) interval from surgery: 4 months MXT; 8 months BC	Derogatis Sexual Functioning Index (one item: view of body)	Data available for full scale

RSCL, Rotterdam Symptom Checklist.

- (i) Dissatisfaction with appearance (dressed).
- (ii) Loss of femininity/masculinity.
- (iii) Reluctance/avoidance to look at self naked.
- (iv) Feeling less attractive/sexually attractive.
- (v) Adverse effect of treatment/loss of body integrity.
- (vi) Self-consciousness about appearance.
- (vii) Dissatisfaction with scar/prosthesis.

It is assumed that sexual activity, psychological status and social/interpersonal relationships or activities would be assessed elsewhere in a quality of life questionnaire. Whilst it cannot be assumed that body image problems would be causal in other areas of dysfunction, useful correlations and comparisons could be made. More detailed evaluation of interactions are beyond

the scope of quality of life instruments designed for clinical trials.

The next step is to agree a subscale of items, particularly in conjunction with a sexuality subscale, and to test these in clinical practice.

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Acknowledgements—The author wishes to thank Dr Ann Cull for her helpful collaboration in the preparation of this paper. Thanks are also extended to Dr Hanneke de Haes and Dr Lesley Fallowfield for agreeing to the use of their unpublished work in this review. Finally, grateful thanks are expressed to Mrs M. Donnelly and Miss J. Pennington for preparation of the manuscripts.