SCREENING FOR MORBIDITY FOLLOWING BREAST CANCER

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Abstract

Background: A screening tool was developed to identify morbidity emerging in the years after breast cancer treatment. *Aims:* This project aimed to investigate patient responses to a newly developed screening tool for lymphoedema, reduced arm function, fatigue and pain. *Methods:* Interviews were conducted following completion of the screening tool by 40 women attending review appointments post-treatment for breast cancer (86% response rate). Questions addressed ease of completion and administration. *Results:* On average, participants were 5.8 years post-treatment (1–28) and 64 years of age (38–79). It took eight to 20 minutes to complete the screening tool, with five participants needing assistance. Ninety-eight per cent of participants generally understood the instructions and 76% were able to answer all questions. There was some confusion about unfamiliar terminology (i.e. 'the axilla') and a question was raised relating to experiences of pain (people had difficulty differentiating pain relating to breast cancer and other conditions). Twenty per cent of respondents would prefer to receive the questionnaire by post, with 41% preferring paper to electronic completion. *Conclusions:* With minor modifications and further pilot testing of validity and reliability, this screening tool has the potential to enable rapid identification of morbidity, enabling appropriate action to be taken as well as facilitating service planning. *Declaration of interest:* None.

Key words

Breast cancer
Morbidity
Lymphoedema
Fatigue
Pain

It is important to identify different types of morbidity that emerge in the years following breast cancer treatment, enabling appropriate referral and prompt management. A screening tool was designed to focus on lymphoedema, reduced arm function, fatigue and pain, and its usability was evaluated in 40 women attending review appointments at the Breast Unit in the Western General Hospital, Edinburgh, Scotland, UK.

Results demonstrated that with minor modifications, the screening tool could be tested further in relation to its validity and reliability. The tool has the potential to provide an indication of both the presence of morbidity, and the extent of its impact on activities and participation.

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Introduction

This report investigates the effectiveness of a screening tool designed to identify morbidity developing in the long term after treatment for breast cancer. Breast cancer is the leading cause of death in women between the ages of 20–59 in high-income countries (World Health Organization [WHO], 2009), accounting for almost 30% of all cancers in Scottish women (Information Services Division [ISD], 2012).

Encouragingly, survival rates are increasing (Hery et al, 2008; ISD, 2012), leading to a focus on the large numbers of women living with a history of breast cancer — 1,528.7 per 100,000 in Scotland — an estimated 1.5% of the Scottish population (ISD, 2012). Emphasis is being placed on minimising morbidity and enhancing quality of life after completing treatment (Purushotham, 2005).

Data collection

In order to provide more personalised management of cancer as a long-term condition (DH, 2004), it is important to have a good understanding of patients' experiences after receiving treatment. There are multiple international and national databases that collate important information relating to:

- Incidence
- Prevalence
- Stage
- Mortality
- Survival.

Some databases also include information on treatment and lifetime risk. These include:

- International Association of Cancer Registries (IACR)
- European Network of Cancer Registries (ENCR)
- US Surveillance Epidemiology and End Results

- Center for Disease Control (CDC)
- National Program of Cancer Registries (IACR, 2010; ENCR, 2010; National Cancer Institute [NCI], 2010a; CDC, 2010)
- Cancer Information Programme (UK-based)
- UK Association of Cancer Registries (ISD, 2009; UKACR, 2004).

A cross-sectional survey of multi-centre clinical databases in the UK found that cancer is the clinical area most commonly addressed, but these vary in size, scope and geographical area (Black et al, 2004). The authors suggest further development. The US *Cancer Trends Progress Report 2009/10* includes a section on life after cancer, identifying data relating to economic impacts, highlighting a lack of data on health-related quality of life (NCI, 2010b). The current focus on mortality and survival leaves a gap in clinicians' knowledge of morbidity and its effects on function, participation and quality of life.

Identifying morbidity

Specific factors have been highlighted as affecting quality of life after treatment of breast cancer, including fatigue, pain, swelling and reduced arm function (Reitman et al, 2004; Ghazinouri et al, 2005; Karki et al, 2005; Meeske et al, 2007; Dawes et al, 2008), not always identified on clinical assessment (Williams et al, 2002).

A tool is needed to identify specific difficulties arising in the years after treatment, facilitating appropriate referral to services.

A literature search using combinations of search terms relating to pain, arm function, lymphoedema or swelling, fatigue, breast cancer, management, assessment and questionnaires was conducted to locate any appropriate tool. Databases searched were:

- Medline
- Cinahl
- Scopus
- Pubmed.

On analysis of existing questionnaires, no single tool covered all of the concerns raised, and completion of numerous questionnaires would have been required to screen for new morbidity. The content of the questionnaires also overlapped substantially. The authors felt that a new screening tool that was quick to complete was needed to identify new issues. It should provide credible information that can inform service development.

Draft screening tool

A draft screening tool was developed through a process of theming existing tools for areas of content and identifying overlap. New short forms were developed for each of four areas:

- Fatigue
- Pain
- Swelling
- Arm function.

The authors aimed to recruit 30–40 patients who were attending the breast clinic onto the pilot study.

The questions were not written to allow a total score to be calculated, but rather to allow rapid screening for the presence of an issue, for example lymphoedema, and the degree to which it was impacting on activities and participation. Questions follow the domains indicated by the International Classification of Functioning Disability and Health (WHO, 2001). It was intended that the first question in each section (i.e. for lymphoedema) would allow an individual to indicate the presence or absence of a specific issue. If present, they would be asked to complete further questions — if absent, they would be directed to the next section, reducing the respondent burden.

The first draft of the screening tool was produced and feedback from clinical staff helped the team to modify it. The second draft required testing for usability and validity. The first pilot aimed to investigate the usability of the screening tool, looking at patient responses around clarity, format, and administration.

Key points

- It is important to identify morbidity that emerges in the years following breast cancer treatment in a prompt manner, to enable early management.
- A screening tool has been developed that has four sections, focusing on lymphoedema, upper limb function, fatigue and pain.
- Results of a usability pilot found that with minor modifications, the tool could be studied further in relation to its validity and reliability.
- Although few people wished to complete the questionnaire at home, over half would be happy with electronic completion, which could enable faster decision-making.

Methodology

Market research interviews were conducted following completion of the tool, focusing on usability. Ethical approval was provided by Queen Margaret University, in Edinburgh. Since it was a service evaluation project, NHS approval was not required, however, written informed consent was obtained.

The authors aimed to recruit 30–40 patients who were attending the breast clinic onto the pilot study. These patients were attending a review appointment one or more years after receiving treatment for breast cancer. All were English speakers (later work will include potential for translation) and women with recurrence were excluded to ensure that the focus was on morbidity that had developed since breast cancer treatment.

The research assistant introduced the pilot study and asked if individuals would be willing to participate while waiting for their clinic appointment.

Table 1

Topics covered within the post-breast cancer morbidity screening tool and proposed modifications

Topic within the morbidity screening tool	Pilot study finding	Proposed modification
Section A: Participant characteristics, e.g. age, treatment	▸▸ Some confusion regarding the term 'axilla' ▸▸ Some queries about what constitutes hormone therapy ▸▸ Some concern about symptoms arising from other conditions ▸▸ Suggestions included incorporating a question on occupation	▸▸ Change 'axilla' to 'armpit' ▸▸ Provide an example of hormone therapy medication ▸▸ Include a question relating to other conditions ▸▸ Include a question relating to any changes in occupation, if applicable
Section B: All sections: ▸▸ Fatigue ▸▸ Upper limb/neck function ▸▸ Lymphoedema/ swelling ▸▸ Pain	▸▸ Some overlap with symptoms resulting from other conditions ▸▸ Some queries relating to the time period to which the response refers ▸▸ Regarding pain, suggestion of including a question relating to altered sensations ▸▸ Regarding pain, concern about whether to include pain relating to medications	▸▸ Clarification of questions to indicate the emphasis on breast cancer ▸▸ Inclusion of a time period for consideration, e.g. in the past week ▸▸ Inclusion of an extra question relating to altered sensations ▸▸ Clarification that the question relates to any increased pain relating to treatment for breast cancer

Those who consented were asked to complete the screening tool in a quiet room without the research assistant present and were then asked questions about its usability in an audio-recorded interview. These questions related to:

- Clarity of instructions
- Difficulty in answering questions
- Preferences regarding completion at home or in the clinic
- Preference between completing a paper or electronic survey.

Responses were descriptively analysed by calculating percentage frequencies of responses to open and closed questions within the sample, after first categorising responses to open questions.

Those who consented were asked to complete the screening tool in a quiet room without the research assistant present and were then asked questions about its usability in an audio-recorded interview.

Results

Of the 51 women approached about this study, 44 agreed to participate (86% response rate). Where reasons were given for not participating, these included difficulties in completing the screening tool due to other conditions, for example aphasia or poor eyesight. One person was excluded as she was undergoing treatment for recurrence and three people were unable to complete the study before their clinic appointment, providing 40 participants in total (78%).

Participants were between 11 months and 28 years post-treatment (mean 5.8 years) and between 38 and 79 years of age (mean 64 years). The time taken to complete both the screening tool and the interview ranged between eight and 20 minutes. All participants were English speakers with one patient speaking English as a second language.

Most participants were right handed (34/40) and approximately equal numbers had received treatment to either the left or the right sides of the body. All participants had received surgery (n=40) followed by one or more courses of radiotherapy (n=33), chemotherapy (n=20) and hormone treatment (n=13).

Analysis of screening tool completion

When analysing the number and areas of omitted answers and any possible reasons for non-completion the interview notes were carefully scrutinised. Two participants mentioned co-existing conditions as reasons for not completing some sections. Other participants did not indicate 'yes' or 'no' to the first question in a section, for example, about whether they experienced movement difficulties, which may indicate that the section did not apply to them.

In some cases analysis of interview responses highlighted answers that may be unrelated to their treatment for breast cancer. For example, a participant who had indicated that she had severe neck pain in response to one of the pain-related questions, later on explained to the researcher that she had severe arthritis that affected her neck and knees.

Table 2

Results relating to administration of the post-breast cancer morbidity screening tool and proposed modifications

Administration of the morbidity screening tool	Pilot study finding	Proposed modification
Preferences regarding postal administration or completion in the waiting room	▸▸ 39% preferred to complete the survey in the clinic ▸▸ 39% had no preference ▸▸ 20% preferred a mail-administered screening tool	▸▸ No change: when analysing reasons given for preferences, completion when attending an appointment may lead to the greatest response rate
Preferences regarding completion on paper or using a touchscreen computer	▸▸ 44% would be comfortable using a computer or paper ▸▸ 41% would only be comfortable with/ would prefer paper	▸▸ Development of computer administration would be useful for some but options or assistance should be provided
Self-administration in the waiting room	▸▸ 10% of participants required assistance for different reasons	▸▸ If the tool is administered in the waiting room prior to a clinic appointment, someone should be available to provide assistance; where problems are musculoskeletal a touchscreen computer might help, but not where the problem is visual/linguistic

Patient opinion on the survey

When analysing participants' opinions on the usability of the screening tool (summarised in *Table 1*), three out of 40 participants (7.5%) were concerned about the time it took to complete and were confused about referring to symptoms that were linked to a different condition. All except one participant (98%) found the instructions clear overall, and the majority of participants felt that they could answer all questions (76%).

However, some people (12.5%) found the questions relating to experiences of pain less clear. Others felt that there were some questions they could not answer for varied reasons, mainly due to the presence of symptoms from co-existing conditions (n=8), or the use of unfamiliar terms such as 'axilla.' In response to a question regarding whether there were any questions the participant did not want to answer, none were identified. Some participants suggested including additional questions regarding pain related to medications (n=4) and altered sensation (n=3).

In general, comments about the screening tool were positive. All participants were happy to complete it and there were no questions they did not want to answer.

Issues that related to administration of the screening tool are summarised in *Table 2*. In general the researcher remained outside the interview room while the screening tool was being completed, and interview questions identified questions that were unclear. However, five participants needed assistance in completing the screening tool due to poor eyesight, difficulty writing (for musculoskeletal or neurological reasons) or English not being their first language.

Equal numbers of participants stated that they would prefer to complete the screening tool in the clinic as those stating that they had no preference (both 39%). Among those who preferred completing this in the clinic, the main reason given was that they might not remember to complete or return a form received through the post. A smaller number of participants (20%) would prefer a screening tool that was posted to them. Almost half of participants (44%) indicated that they would be comfortable completing the monitoring tool using either paper, or through touch-screen responses on a laptop. A similar proportion of participants indicated either that they would be comfortable with 'only paper' or that they would prefer paper (41% for both categories combined). Of the participants that preferred paper it was mainly due to lack of familiarity with computers or having a difficulty in looking at the screen.

Discussion

In general, comments about the screening tool were positive. All participants were happy to complete it and there were no questions they did not want to answer. The majority of participants found the instructions clear and thought the screening tool covered all areas very well. However, the results and comments did highlight a number of areas for revision and consideration prior to undertaking further research. These are summarised in *Tables 1* and *2*.

Four participants needed assistance completing the screening tool due to poor eyesight, multiple sclerosis and a recent hand injury. Although this amounted to a small number of participants, it represented 10% of the sample group. One participant required some help in understanding the language used in the form. In a larger study it would be recommended that a person be available to assist individuals who experience difficulty completing the screening tool.

The main concern for participants was that it was difficult to distinguish between symptoms due to breast cancer treatment and those due to co-morbidities such as arthritis, multiple sclerosis, stroke and Crohn's disease. It is possible that more participants were experiencing pain due to arthritis rather than breast cancer, when considering the specific areas of the body identified as symptomatic, for example 'stiff' or 'painful'. This relates, in particular, to two questions that were not phrased in a way that referred specifically to symptoms experienced since being treated for breast cancer.

Three participants mentioned experiencing 'tingly' sensations around the breast area. While this did not impact on function, it was sufficiently important to these participants that they mentioned the lack of a question relating to altered sensation. Four participants felt that it should be clarified whether pain due to medication could be included.

On consideration of the results of this pilot study, some recommendations were made for the revision and administration of the screening tool, including the availability of assistance with completion; provision of paper copies as well as electronic completion; greater care with terminology; and greater clarity in all questions relating to the focus on breast cancer when responding. The addition of questions relating to co-existing conditions and altered sensations since completing treatment were also recommended.

Conclusions

This study piloted a screening tool to enable rapid identification of morbidity issues arising in the years after treatment for breast cancer, and to facilitate appropriate referral.

The majority of participants felt the screening tool was clear and covered all areas well, however, questions need to be clarified to indicate that they refer to symptoms experienced since having breast cancer treatment.

This pilot has informed a new draft currently undergoing testing for validity of responses when compared with established objective and subjective tools. It is crucial that the tool provides credible information, which would also enable better justification for, and planning of, services.

It is anticipated that this will help to minimise morbidity in the years after treatment for breast cancer, thus increasing quality of life. JL

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Conflict of Interest

The authors did not have any financial relationship with the funding body and had full control of study design, data collection, analysis and interpretation, as well as manuscript preparation.

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