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A Morbidity Screening Tool for identifying fatigue, pain, upper limb dysfunction and lymphedema after breast cancer treatment: A validity study

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A B S T R A C T

Purpose: This study aimed to investigate validity of a newly developed Morbidity Screening Tool (MST) to screen for fatigue, pain, swelling (lymphedema) and arm function after breast cancer treatment.
Methods: A cross-sectional study included women attending reviews after completing treatment (surgery, chemotherapy and radiotherapy), without recurrence, who could read English. They completed the MST and comparator questionnaires: Disability of the Arm, Shoulder and Hand questionnaire (DASH), Chronic Pain Grade Questionnaire (CPGQ), Lymphedema and Breast Cancer Questionnaire (LBCQ) and Functional Assessment of Cancer Therapy questionnaire with subscales for fatigue (FACT F) and breast cancer (FACT B + 4). Bilateral combined shoulder ranges of motion were compared (upward reach; hand behind back) and percentage upper limb volume difference (%LVD =/>10% diagnosed as lymphedema) measured with the vertical perometer (400T).
Results: 613 of 617 participants completed questionnaires (mean age 62.3 years, SD 10.0; mean time since treatment 63.0 months, SD 46.6) and 417 completed objective testing. Morbidity prevalence was estimated as 35.8%, 21.9%, 19.8% and 34.4% for fatigue, impaired upper limb function, lymphedema and pain respectively. Comparing those self-reporting the presence or absence of each type of morbidity, statistically significant differences in comparator variables supported validity of the MST. Statistically significant correlations resulted between MST scores focussing on impact of morbidity, and comparator variables that reflect function and quality of life.
Conclusion: Analysis supports the validity of all four short-forms of the MST as providing indications of both presence of morbidity and impacts on participants' lives. This may facilitate early and appropriate referral for intervention.

Introduction

With increased survival rates after breast cancer treatment there is greater emphasis on enhancing quality of life after treatment (Armer et al., 2003). The necessary rigour of treatment, potentially involving surgery, chemotherapy, radiotherapy and hormone therapy (Harris et al., 2004), can lead to ongoing morbidity and impacts on quality of life (Markes et al., 2006). About a third of survivors can experience fatigue beyond completion of treatment and evidence exists for chronic pain and upper limb morbidity, including lymphedema. Timely detection of morbidity can frequently enable therapeutic management (Armer, 2005; Bosompra et al., 2002; Byar et al., 2006; Truong et al., 2004).

Recent cancer-specific health priorities include improving the patient journey (Scottish Executive, 2003), more personalised management of cancer as a long-term condition and collection of relevant information (Department of Health: DoH, 2004). Monitoring of patient experiences after treatment, including morbidity and effects on function, participation and quality of life, would add to current databases which focus on incidence and prevalence, survival, mortality, and lifetime risk (DoH, 2004; UK Association of Cancer Registries, 2004). A cross-sectional survey of multicentre clinical databases in the United Kingdom identified cancer as an area with more developed databases, but suggested further

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development, involving nurses and allied health professionals, managers and lay people (Black et al., 2004).

In response to this need, a multidisciplinary research team sought a tool that would quickly and effectively screen for morbidity, with indication of impact. A search of Medline, Cinahl, Scopus and Pubmed used terms relating to fatigue, pain, arm function, lymphedema, swelling, breast cancer, management, assessment, and questionnaires; no single tool was identified as appropriate in screening for all the identified issues and substantial overlap between tools existed.

Therefore, a Morbidity Screening Tool (MST) was developed in a three-stage process to include four self-report short-forms that identify perceived fatigue, impaired upper limb function, lymphedema and pain. Stages one and two focused on content validity, which requires more descriptive processes. Initially, thematic analysis was conducted of questionnaires identified through the literature search to identify relevant topics. This enabled the team to build on the literature base relating to morbidity after treatment for breast cancer. Topics were then included within questions that first aimed to enable rapid screening for an area of morbidity, such as lymphedema. Secondly, questions screened for the degree of impact on activities and participation, as recommended by the International Classification of Functioning, Disability and Health (World Health Organisation: WHO, 2001). The initial question in each short-form enables the respondent to state that they do, or do not, have a concern in the area. If they do not, they can move on to the next short-form, to reduce respondent burden. Subsequent questions relating to activities were highly informed by literature specific to each area of morbidity, as, for example, fatigue and lymphedema differ in their impacts on what a person can do in daily life. Lastly, questions relating to a person's ability to participate in daily life were more similar between sections. In order to ensure face validity of the tool, the first draft was reviewed by medical, nursing and allied health professional staff in the Edinburgh Breast Unit, and feedback enabled modification.

Stage two of the development process involved investigation of the tool for its usability in March 2009 (Bulley et al., 2012) through a pilot study of 40 participants (86% response rate; 1–28 years post-treatment, mean 5.8; mean age 64 years, range 38–79). They completed the screening tool and a short interview regarding clarity, format and administration. The tool was acceptable and understandable; specific feedback led to minor modifications. The final MST (Appendix A) is available as an online supplementary file, with details of scoring.

Stage three of the tool's development is reported here, and aimed to develop evidence for the tool's construct validity. This can be defined as "the extent to which an assessment can be said to measure a theoretical construct or constructs" and requires the accumulation of evidence (Laver Fawcett, 2007, p. 173). Types of evidence include criterion validity, including concurrent and predictive validity. The former can be defined as "correlating an instrument with some criterion that is administered at about the same time" (Thomas et al., 2005, p. 194), often using a measure of the same variable that has previously been validated as the criterion. Predictive validity involves collection of criterion measures at a later date. Convergent and discriminant validity can be defined as: demonstrating that similar constructs correspond with one another, and that dissimilar constructs do not, respectively (Trochim, 2006). Establishing reliability is also important. When conducting research with people who are undergoing treatment for a disease such as breast cancer, however, it is important not to present too great a respondent burden, and therefore a staged approach to investigation is appropriate. This study aimed to investigate aspects of construct validity of the MST in screening for problems with fatigue, pain, swelling (lymphedema) and arm function after breast cancer treatment. This focused on concurrent validity where a suitable criterion measure of the same variable (e.g. lymphedema) was available, and convergent validity where measurement of a similar construct was required to be used as a criterion.

Materials and methods

Study design

This study investigated aspects of construct validity of the MST. It used cross-sectional data that were collected in a single session for each participant between November 2009 and May 2010. Ethical review was conducted within the Higher Education Institution; the local NHS Research Ethics Committee deemed the study a service evaluation.

The MST screens for multiple concerns, such as lymphedema and fatigue, which meant that multiple comparison measures were required. Responses to each question were compared with responses to established subjective and objective measurements to explore concurrent or convergent validity, depending on whether an established measurement of the same variable could be used (e.g. fatigue), or of a construct that one would theoretically expect to alter in tandem (e.g. upper limb function with range of motion) (Trochim, 2006; Thomas et al., 2005).

Participants

Women who had completed treatment (surgery, chemotherapy and radiotherapy), and who were attending review appointments at the Breast Clinic, were included. Women were excluded if they had recurrence, or were unable to complete non-translated questionnaires. After reading information provided in the waiting room, women were given the opportunity to ask the research assistant questions and consider the responses before deciding whether to participate. Those willing to participate completed a written consent form, the MST, and comparator questionnaires in the waiting room (taking approximately 15 min), and participated in objective tests in a private clinic room (taking approximately 10 min).

Procedure and measurement

Comparator measures were sought that addressed each type of morbidity represented in the MST short-forms, i.e. fatigue, impaired upper limb function, lymphedema and pain. Each short-form included questions relating to 'participation in life', which can be conceptually linked with 'quality of life'; therefore a comparator measure was also sought that addressed this. Appropriate objective comparator measures were sought first, and if unfeasible, established subjective comparators were selected. For example, as a subjectively experienced phenomenon, quality of life is assessed using a subjective questionnaire. Medical records were reviewed for treatment characteristics.

Fatigue

The Functional Assessment of Cancer Therapy – Fatigue subscale (FACT F) was selected; a single page of fatigue questions, this was added to a general quality of life questionnaire called the FACT G. It was developed to assess fatigue and anaemia-related concerns in cancer patients and has been found to be reliable, valid and internally consistent (Cella et al., 2002; Jones et al., 2011; Pouchot et al., 2008; Yellen et al., 1997). The scoring system has been well documented (Webster et al., 2003).

Arm function

Limitations in shoulder range of motion would be expected to affect arm function, therefore bilateral comparison of combined