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Development and testing of a decision aid for women considering delayed breast reconstruction

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Summary *Background:* The decision to have post-mastectomy breast reconstruction (PMBR) is highly complex and many women feel ill equipped to make this decision. Decision aids have been advocated to promote patient involvement in decision-making by streamlining and standardizing communication between the patient and the health care professional. In this study, we report on the development and testing of a decision aid (DA) for breast cancer survivors considering delayed PMBR.
Methods: The DA was developed and evaluated in three phases. The first phase included the development of the DA with input and review by practitioners and key stakeholders. The second phase involved pilot testing of the feasibility and acceptability of the DA with a convenience sample of women with delayed PMBR. The third phase involved a pretest/post-test evaluation of the DA for women who were making decisions about their PMBR options.
Results: The DA was developed using the Ottawa Decision Support Framework. In the second phase of the study, 21 women completed the acceptability survey, of whom 100% reported that they would recommend the DA to other women. In the third phase, decisional conflict decreased significantly ($p < 0.001$) and knowledge increased significantly ($p < 0.001$) from prior to using the DA to 1–2 weeks after using the DA.
Conclusions: The DA is feasible and acceptable to women considering delayed PMBR. Furthermore, the DA is effective at reducing decisional conflict and increasing knowledge about delayed

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PMBR. The DA is an appropriate tool to be used in addition with standard care in women considering PMBR.

Introduction

The number of women electing for mastectomy for the surgical treatment of breast cancer is increasing.[1,2] These women have the option of post-mastectomy breast reconstruction (PMBR) which aims to enhance a woman's sense of self and femininity.[3–9] However, the uptake of PMBR in Canada is low, where 23.3% of patients have either immediate (11.7%) or delayed PMBR within three years after a mastectomy (11.6%).[10] Recommendations have included education of both the physician and patient to incorporate the use of PMBR in early-stage breast cancer management, which is supported by other studies that have found that up to 29% of women do not receive adequate discussion about PMBR.[11–13] It has been suggested that patients may not feel equipped to participate in decisions due to the lack of information or are intimidated by the decision process.[14] In the ideal scenario, the decision about PMBR should be made by the patient after she has had the opportunity to learn about, discuss, and consider all the possible options.[15] Studies confirm that patient satisfaction is greatest when the patient feels adequately informed and when the level of involvement in the decision making is consistent with her own wishes and expectations.[16]

The choices of PMBR are highly complex and must incorporate the individual's personal values, priorities, previous surgical and medical treatment as well as the anatomy of the patient. At the same time, the patient must also choose between the alternative methods of reconstruction and timing. A decision regarding an elective procedure such as PMBR that does not confer survival benefit can be challenging, and one that will largely rest on a woman's personal values, beliefs, and guidance from her physician.[16,17] To add further complexity to the decision to undergo PMBR, a credible and standard source of information on PMBR for prospective patients does not exist.

Decision aids (DAs) have been advocated to promote patient involvement in the decision-making process for treatment options by streamlining and standardizing communication between the patient and the health care professional.[18–20] These tools are designed with the purpose of helping patients make informed choices by outlining the outcomes of specific health care alternatives. Previous research has demonstrated that DAs are effective for individuals facing health treatment and screening decisions, including cancer outcomes.[20,21] In this study, we report on the development and testing of a DA for breast cancer survivors considering delayed PMBR.

Methodology

Ethics approval was obtained from the University of Healthy Network Research Ethics Board. The decision aid was developed and evaluated in three phases.

Phase #1 – development of decision aid

The DA was developed for women with a mastectomy who were considering delayed PMBR, and was designed to be used prior to plastic surgery consultation. All of the content, efficacy and risk benefits are based on published research findings.

The framework of decision support that guided the development of the DA was the Ottawa Decision Support Framework (ODSF).[22] Driven by the ODSF, the information, content, and format of the DA were developed via a) review of the available evidence on delayed PMBR, b) steering committee input (composed of the investigative team, two PMBR patient representatives, two decision-maker partners, and clinician stakeholder representatives), c) evaluation of needs assessments of individuals with PMBR, and d) input from key informants. The construction of the DA was based on the suggested components outlined by O'Connor and Edwards,[21] and was developed for on-line use, with interactive components to allow for subject input and individualization (see Figure 1). A print-out was generated for each woman based on interactive responses provided during review of the DA (Figure 2). The DA was developed by QoC Health Inc., a patient healthcare focused technology company.

The DA was then assessed by the steering committee for content, as well as clarity, user-friendliness, and visual appeal. Based on the feedback received, revisions were made.

Phase #2 – pilot test: feasibility and acceptability of the DA

The objective of this phase of the study was to ensure that the DA was clearly formatted, acceptable and feasible for women. Eligible participants included women who: a) had previously undergone delayed PMBR, and b) were able to read, speak and understand English.

Participants were contacted to provide study explanation, confirm eligibility and obtain verbal consent. A link to the web-based DA was provided to each participant and 1–2 weeks later the participant was provided with the DA Acceptability survey. Based on feedback, further revisions were made to the DA.

Phase #3 – pre-test post-test evaluation of the DA

The objective of the final phase of the study was to determine the effect size of the DA for the primary (decisional conflict) and secondary (knowledge, choice predisposition, decision self-efficacy) outcomes. Measurement of outcomes was completed at three time-points; 1) prior to using the DA; 2) 1–2 weeks after using the DA; and 3) 2 weeks after consultation with the plastic surgeon.

Each eligible participant had a consultation booked with a plastic surgeon, and was contacted to explain the study