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Application of a novel transdisciplinary communication technique to develop an Internet-based psychoeducational program: CaringGuidance™ After Breast Cancer Diagnosis

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ABSTRACT

Aim: The aim of this work was is to create CaringGuidance™ After Breast Cancer Diagnosis, an Internet-based, self-guided psychoeducational program to facilitate adjustment among women in the first months after breast cancer diagnosis.
Background: Use of Internet technology addresses a gap in the delivery of psychoeducational clinical interventions immediately after breast cancer diagnosis; providing rapid access to information and guidance during a highly distressing and vital period of adjustment.
Methods: A multi-step transdisciplinary communication process of Personae Creation, Layered Project Mapping©, and Rapid Iterative Prototyping (RIP) was applied to facilitate communication between researcher, technology team and content reviewers during clinical program development.
Results: Through three rounds of content review and two focus groups guided by this process, the reviewers, researcher and technology team communicated effectively; completing the project on-time and within budget.
Conclusions: Application of a multi-step transdisciplinary communication process is feasible and essential to development of an Internet-based psychoeducational program.

1. Introduction

Approximately 30% of women diagnosed with breast cancer experience significant distress (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Initial distress after cancer diagnosis may progress to disorders such as major depression (NCI, 2012) and affect the quality of life (Fann et al., 2008) of thousands of breast cancer survivors. A critical opportunity exists to intervene and support women's psychological adjustment soon after breast cancer diagnosis (Northouse, Templin, & Mood, 2001). This early opportunity is often missed as considerable time may elapse between diagnosis and treatment consultation, infrequent clinical attention is given to psychosocial needs (Taylor et al., 2011) and few referrals are made to psychosocial care (Holland et al., 2010). Furthermore, existing psychosocial interventions primarily address women's needs during the treatment or post-treatment periods rather than in the initial days following diagnosis (Hegel et al., 2006) and focus on Caucasian women as opposed to other cultural groups (Lechner et al., 2013).

To address these gaps, a nurse–researcher (first author) led transdisciplinary team developed an Internet-based, self-guided, tailored psychoeducational program, *CaringGuidance™ After Breast Cancer Diagnosis* (*CaringGuidance™*), to provide information and guidance to women on psychosocial issues throughout the first months after a new breast cancer diagnosis. The goals of *CaringGuidance™* are to address, prevent and reduce distress, anxiety and depression and support psychological adjustment. *CaringGuidance™* consists of 5 self-guided learning modules, survivor video vignettes, information/support resources and tools and cognitive–behavioral based exercises in an Internet format. The program is intended to meet the psychosocial needs (e.g. coping strategies, meaning exploration, social interactions) of newly diagnosed women throughout the continuum from diagnosis and awaiting first consultation to the initial months of clinical assessments and treatment. *CaringGuidance™* may be used alone or in addition to psychosocial care that might be available. Finally, the program is intended to address psychosocial issues relevant to African American women, the second largest group of women diagnosed with breast cancer in the United States, for whom limited resources exist.

Conflict of interest: The authors report no conflict of interest pertaining to this work. Dr. McNees is a Managing Partner of the Kirchner Private Capital Group.

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An Internet-based format was chosen for this clinical intervention for: (1) global reach; (2) availability at any time; (3) easy and private accessibility and the (4) potential to deliver a consistent evidence-based message. Additionally, 85% of U.S. women use the Internet and 80% of Internet users look for health information online (Pew Research Center, 2012a,b). However, developing and transferring psychoeducational content from a researcher's knowledge base to a secure, electronic, user-friendly, intervention environment is complex and involves many individuals from multiple disciplines (e.g. Web design, programmers, lawyers, clinicians, potential users) who often do not know the field of clinical research or patients for whom the content is intended. This paper is a report of the multi-step transdisciplinary communication process applied to develop *CaringGuidance™ After Breast Cancer Diagnosis* in an Internet-based environment prior to feasibility and efficacy testing of the program in a pilot clinical trial. It is intended that clinical nurses and researchers developing Internet-based patient-care intervention programs will benefit from description of the process used to develop *CaringGuidance*™.

2. Methods

Development of *CaringGuidance*™ was guided by the application of a multi-step transdisciplinary communication process for Internet-based psychoeducational intervention development proposed by Meneses and McNees (2007). The process consists of three steps: Personae Creation, Layered Project Mapping©, and Rapid Iterative Prototyping.

2.1. Personae creation

As described by Meneses and McNees (2007) a *persona* is a profile of a composite person(s) for whom the Internet-program intervention is designed. The goal of personae creation is to support design of a user-friendly program that fits patients' characteristics and addresses needs with regard to program navigation, esthetics and health information. The persona of a woman newly diagnosed with breast cancer was created by the first author based on her clinical and research expertise and known breast cancer demographics (American Cancer Society, 2011). From the primary persona, three projected personae of program use patterns were hypothesized based on grounded theory (Lally, 2010; Lally et al., 2012) and stress and coping theory (Folkman & Greer, 2000) (Fig. 1). The personae enabled the first author to communicate to the technology-team (i.e. Web designer, programmers, software engineer, videographer) throughout program development the characteristics of the majority of women diagnosed with breast cancer in the United States as the program's target users and the expected variety in women's program needs and use based on event appraisal and ability to cognitively process the diagnosis experience.

2.2. Layered project mapping©

Meneses and McNees (2007) defined Layered Project Mapping© (LPM) as a method to facilitate researcher–technology team communication. LPM enables the researcher to share with the team a vision for Web-program organization and navigation throughout the many interconnected pages of the program. Each layer of program content outline is drawn by the researcher on a separate page. Although usually done on paper, the result is conceptually similar to the clear pages of an anatomy text in which layers of the outline can be peeled back to reveal additional layers of detail below. For the development of *CaringGuidance*™, the first author mapped an outline for navigation in layers beginning at the users' initial interface with the log-in page and then layer by layer as the future user would progress to the welcome page, tailoring page, individualize homepage (layer 1), through each learning module (layer 2), each module's subparts and links to ancillary resource pages (layer 3). Continued revision of all layer maps documented and communicated the ongoing decisions of the first author and technology team after each round of expert review. For example, the first layer map was changed to document the team's decision that users would navigate through the welcome and tailoring pages at their first log-in, but on subsequent log-ins be directed to their homepage which would hold a link to the tailoring page. Fig. 2 provides an example of a partial LPM with all layers on the same page.

2.3. Rapid iterative prototyping (RIP) process

The rapid iterative prototyping (RIP) process, for development of a clinical, patient intervention in an electronic format, was defined by Meneses and McNees (2007) as involving six steps: (1) development of portions of the intervention, (2) offering these portions electronically for review and feedback from experts, (3) modifying based on feedback, (4) adding components to the program, (5) offering these components for feedback and (6) revising components for review again and so on until a satisfactory product results.

2.3.1. Step 1

The first author outlined and organized the program content into themed learning modules based on her grounded theory (Lally, 2010; Lally et al., 2012). The modules are titled: *Are my reactions normal?,*

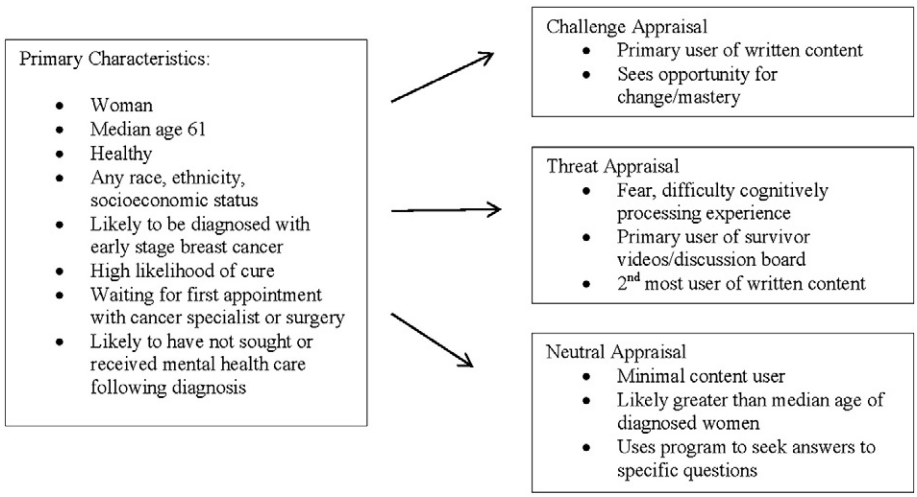

Fig. 1. Personae of potential program users.