Patient Education and Counseling xxx (2015) xxx–xxx

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Evaluation of risk communication in a mammography patient decision aid

Krystal A. Klein*, Lindsey Watson, Joan S. Ash, Karen B. Eden

Department of Medical Informatics & Clinical Epidemiology, Oregon Health & Science University, Portland, USA

ARTICLE INFO

Article history:
Received 2 June 2015
Received in revised form 18 February 2016
Accepted 23 February 2016

Keywords:
Patient decision aid
Risk communication
Mammography
Women's health

ABSTRACT

Objectives: We characterized patients' comprehension, memory, and impressions of risk communication messages in a patient decision aid (PtDA), Mammopad, and clarified perceived importance of numeric risk information in medical decision making.
Methods: Participants were 75 women in their forties with average risk factors for breast cancer. We used mixed methods, comprising a risk estimation problem administered within a pretest–posttest design, and semi-structured qualitative interviews with a subsample of 21 women.
Results: Participants' positive predictive value estimates of screening mammography improved after using Mammopad. Although risk information was only briefly memorable, through content analysis, we identified themes describing why participants value quantitative risk information, and obstacles to understanding. We describe ways the most complicated graphic was incompletely comprehended.
Conclusions: Comprehension of risk information following Mammopad use could be improved. Patients valued receiving numeric statistical information, particularly in pictograph format. Obstacles to understanding risk information, including potential for confusion between statistics, should be identified and mitigated in PtDA design.
Practice implications: Using simple pictographs accompanied by text, PtDAs may enhance a shared decision-making discussion. PtDA designers and providers should be aware of benefits and limitations of graphical risk presentations. Incorporating comprehension checks could help identify and correct misapprehensions of graphically presented statistics

1. Introduction

Patient decision aids (PtDAs) are evidence-based tools that help patients engage in informed, shared decision making regarding complex health decisions, such as "preference-sensitive"[1] decisions—those where no "best" course of action exists across all patients. PtDAs differ from general educational materials by helping patients understand how their values relate to available options' attributes [2]. One touted benefit is that PtDAs allow more effective, balanced risk communication than typical clinical consultation [3]. Indeed, patients who use PtDAs along with typical care demonstrate knowledge and risk comprehension superior to control patients [4].

The present study partnered with a project evaluating changes in decision quality measures reported by patients after using Mammopad, a mobile device-optimized PtDA designed for patients to use prior to a clinic visit, either at home, or in a waiting room [5]. Mammopad helps average-risk women in their forties understand and consider the costs and benefits of screening mammography options, clarify their values in relation to those options, and empower them to discuss screening mammography with clinicians. Recently, recommendations for routine mammography screening for average-risk women in their forties have been questioned due to equivocal evidence of benefit, *e.g.*, from randomized trials investigating the impact of routine mammography on breast cancer mortality [6–8]. While some organizations maintain these recommendations, the United States Preventive Services Task Force (USPSTF) stated that the decision to begin mammography screening before age fifty "should be an individual one and take into account patient context, including the patient's values regarding specific benefits and harms" [9]—essentially deeming it a *preference-sensitive* decision. This standpoint is

* Corresponding author at: Mail Code BICC,3181SW Sam Jackson Park Road, Portland, OR, 97239, USA.
E-mail addresses: kleinkr@ohsu.edu, krystal@alumni.brandeis.edu (K.A. Klein), watsolin@ohsu.edu (L. Watson), ash@ohsu.edu (J.S. Ash), edenk@ohsu.edu (K.B. Eden).

http://dx.doi.org/10.1016/j.pec.2016.02.013
0738-3991/

supported by researchers with expertise in patient-centered care [10,11].

The details of how to communicate risk to patients within a PtDA must be carefully considered. Currently, risk communication is as much an art as a science, despite a growing literature mapping the effects of numeric formats [12–18], viewer characteristics like statistical numeracy (ability to understand statistical information such as probabilities) [19–23], and chart types [24–27] on perception of risk levels, recall of statistics, and decision outcomes. We recorded reactions of rural-dwelling patients, in their own words, to numeric risk information in Mammopad. We aimed to characterize patients' comprehension, memory, and impressions of risk communication messages in Mammopad, and to clarify the role and perceived importance risk information has in medical decision-making.

2. Methods

We evaluated risk communication in Mammopad through mixed-methods triangulation using three approaches: (1) a quantitative pretest–posttest design where participants answered a word problem about the positive predictive value (PPV) of screening mammograms for women in their forties before and after using Mammopad; (2) a qualitative content analysis of what participants found valuable about numeric risk information; and (3) a qualitative content analysis of interpretation of risk communication diagrams, including misperceptions.

2.1. Participant recruitment and consent

2.1.1. Risk scenario participants

Participants in the Mammopad parent study–women in their forties at average risk of breast cancer according to the Breast Cancer Genetics Referral Screening Tool; BRST [29–31] (which included women with few or no risk factors) answered the risk scenario question described in Section 2.3.1 immediately before and after using Mammopad. The parent study's participants were recruited through chart review at three clinics identified through the Oregon Rural Practice-based Research Network (ORPRN) and eligibility screening phone calls. Rural clinics (i.e., in non-urbanized, medically underserved areas as defined by the State of Oregon) with low income patients were recruited to address concerns that these women may not be aware of their own breast cancer risk or have considered when to begin getting screening mammograms. Women in rural areas are less likely to have had a mammogram or to have an up-to-date mammogram [28]. Details of recruitment and participant flow into the parent study, including risk screening with the B-RST, were reported previously [5].

2.1.2. Interview participants

Early interview participants were a convenience subsample of Mammopad participants from two of the three clinics that volunteered for this follow-up study. After determining that all initial interviewees had previously had mammograms, we began recruiting participants without a previous mammogram. Because the Mammopad study completed enrollment before this study completed recruitment, we recalled some women who had participated previously. Participants were recruited to participate in a 30- to 40-min interview in exchange for a gift card. Recruitment ended when all women with no previous mammogram had either participated, declined, or were unreachable.

2.1.3. Consent

Participants consented separately for the parent Mammopad study and the semi-structured interview. Both protocols were approved by Oregon Health & Science University's Institutional Review Board.

2.2. Mammopad app and administration

Mammopad included three modules: a breast cancer informational module, a mammography informational module, and an interactive priority-setting module, which allowed users to prioritize harms and benefits of screening and identify questions and concerns to discuss with providers [5]. A summary report was presented to participants, and emailed to them, if requested. The numeric risk and probability graphics in Mammopad closely adhered to recent evidence-based guidelines for risk presentation [2,32]; they were refined through several rounds of discount usability testing of Mammopad.

In the parent study[5], a researcher loaded Mammopad for each participant on an Apple iPad mini 7.9-inch tablet computer. Participation occurred in a private clinic room, lasted about 30 min, and was observed at a distance by the researcher.

2.3. Data collection

2.3.1. Risk scenario phase

A risk scenario question assessed the participants' perception of the PPV of mammography (the breast cancer risk associated with abnormal mammogram results). The question, shown in Box 1 , was posed immediately before and after using Mammopad. Participants responded using iPad mini's on-screen keyboard.

2.3.2. Interview phase

Semi-structured interviews were administered by the first author in private examination rooms at ORPRN-affiliated clinics (Appendix A contains the interview guide). The interviewer probed for recall of risk statistics (focusing on verbal explanations and numeric recall), and elicited participants' evaluations and explanations of what numbers were useful when consuming health information. Participants also reviewed Mammopad screenshots and discussed them with the interviewer. Screenshots explaining statistical information included a pair of breast cancer incidence

Box 1. Risk scenario question.

Jane is a woman in her 40s who is at average risk of developing breast cancer sometime during her life. She decides to have a mammogram to screen for breast cancer. She gets a call from her doctor saying that the result of the mammogram was abnormal and that she needs to have more tests to determine if she has breast cancer.
On a scale of 0–100, what are the chances that Jane has breast cancer, where 0 means she does not have breast cancer and 100 means she does have breast cancer.

Please cite this article in press as: K.A. Klein, et al., Evaluation of risk communication in a mammography patient decision aid, Patient Educ Couns (2016), http://dx.doi.org/10.1016/j.pec.2016.02.013