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Intervention

Helping women make choices about mammography screening: An online randomized trial of a decision aid for 40-year-old women

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ABSTRACT

Objective: To evaluate the effect of a decision aid (DA) on women's knowledge of the benefits and harms of screening and on their ability to make an informed decision.
Methods: An online randomized controlled trial among 321 women aged 38–45 years was conducted. Participants were randomized to either immediate or delayed access to the online DA which (i) explained the benefits and harms, (ii) included a values clarification exercise and a worksheet to support decision making. The primary outcome, knowledge of benefits and harms of screening, and secondary outcomes, informed choice (composite of knowledge, values and intention), anxiety and acceptability of the DA were measured using online questionnaires.
Results: Women in the intervention group were more knowledgeable (mean score out of 10, 7.35 vs 6.27, $p < 0.001$) and were more likely to have made a decision (82% vs 61% $p < 0.001$). Of those who made a decision, women in the intervention group were less likely to start screening now (52% vs 65% $p = 0.05$). There was no significant difference in the proportion of women who made an informed choice (71% intervention group vs 64% control group, $p = 0.24$). The DA was helpful, balanced and clear, and did not make women anxious.
Conclusions: The DA increased knowledge and reduced indecision, without increasing feelings of anxiety.
Practice Implications: This decision aid is easy to access online and could be an inexpensive way of supporting women aged 40 who are considering whether to start screening now, or wait until they are 50. The results of this study demonstrate the potential of DAs to help inform women about both the benefits and risks of screening at this age and to support women and clinicians in this decision making process.

1. Introduction

1.1. Benefits and harms of mammography screening

Mammography screening reduces the risk of breast cancer death but also has risks including intervention for false-positive test results and potential overdiagnosis and overtreatment of clinically inconsequential disease [1,2]. Weighing up the benefits and risks of mammography is particularly problematic for women aged less than 50 years, because of uncertainties in the evidence. The World Health Organization's International Agency for Research on Cancer (IARC) concluded that for women aged 40–49 years, there is only limited evidence of reduction in breast cancer mortality due to mammography screening [3]. However, the recently reported Age trial [4] suggested benefit (relative risk reduction for breast cancer death of 17%, 95% CI 34% reduction to 4% increase) among women who begin screening from the age of 40. The Age trial investigators concluded that women should be provided with full information about the possible benefits and harms of screening. In the US, a meta-analysis by Armstrong et al. [1] concluded that more women aged 40–49 experience harms compared to women over 50 years, implicitly suggesting screening may not be as beneficial in these women. Yet the American Cancer Society recommends annual screening from age 40 [5]. Given these varying assessments of the evidence it is unsurprising that recommendations about screening women aged 40–49 vary between (and within) countries [6].

Thus providing information about the pros and cons of beginning screening at age 40 is a high priority to support women in making an informed choice. Women in this age group want to know about false positives, the benefits of screening and the risk of

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developing breast cancer before making a decision regarding mammography screening [5]. Elmore et al. [7] have provided practical advice about the communication challenges involved in providing information to women to help them make this choice. Despite the need for good quality information there are few decision support tools that provide accurate and balanced information to meet this need [8,9]. Reviews of the information available have found that, in general, such information is biased, encourages uptake of screening, and is insufficient for accepted standards of informed consent, such as those in the General Medical Council's guidelines [10–12]. There is a need for balanced, evidence-based information that enables informed decision making [7,13].

1.2. Decision aids to help people make decisions about cancer screening

Decision aids assist people to make informed decisions by providing information on the options and the outcomes that are relevant to their situation [14]. They perform better than usual care in improving patients' knowledge about the options, reducing decisional conflict and encouraging users to take a more active role in decision making without increasing their anxiety [14,15]. The limited available research provides no evidence that they reduce the uptake of screening [15].

It is suggested that decision aids contain information on the entire screening process—including follow-up tests and treatment and on the chances of having inconsequential disease found and treated [16]. The information regarding the benefits and harms must be balanced. In order to achieve this, the cumulative risks over an appropriate time frame must be presented. Diagrams should be used to enhance the understanding of the probability of each outcome. This should be done using a large denominator (1000 or 10,000) [16,17], to show event rates as whole numbers, and must provide a context to consider the overall effect of screening (such as all cause mortality) [18]. Decision aids must also allow the user to classify the pros and cons of screening as they perceive them [16].

1.3. Decision aids for mammography screening

We have previously evaluated a decision aid for women 70 years old considering whether to continue or stop screening [19] and demonstrated that it is an effective intervention in improving knowledge of mammography screening and increasing informed decision making, without discouraging women from screening participation. Building on this work, we developed an Internet-based decision aid for Australian women aged approximately 40 years, at average (or population risk) considering whether to begin screening. We aimed to evaluate the effect of this decision aid on 1) women's knowledge of the benefits and risks of mammography screening, and 2) aspects of their decision making with respect to screening including whether they were able to reach a decision, whether they made an informed choice and whether they decided to be screened or not. We also examined the usefulness and acceptability of the decision aid to women in this age group.

2. Methods

2.1. Study design and participants

The study was an online randomized controlled trial (Figs. 1 and 2) and was conducted entirely online. People who accessed the site were given information about the study. Women were eligible to participate if they were aged between 38 and 45 years and had not previously been diagnosed with breast cancer. To proceed, women

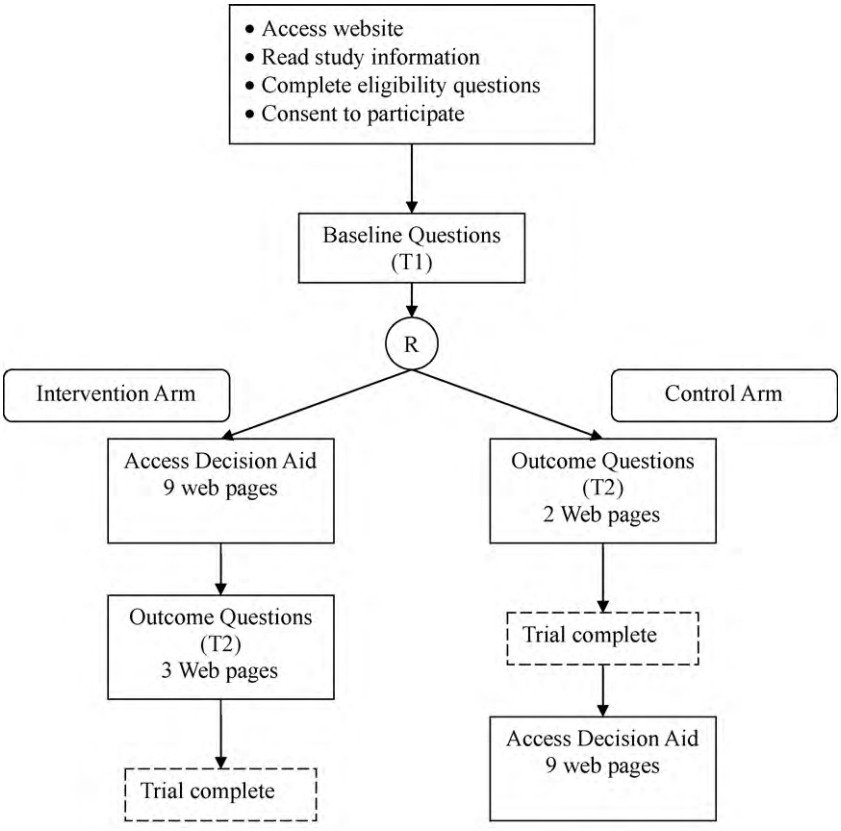

Fig. 1. Study design.