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RESEARCH

Developing a breast cancer screening decision aid in Spanish for average-risk women: a mixed methods study

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ABSTRACT

INTRODUCTION We aimed to develop a decision aid to support shared-decision making between physicians and women with average breast cancer risk when deciding whether to participate in breast cancer screening.

METHODS We included women at average risk of breast cancer and physicians involved in supporting the decision of breast cancer screening from an Academic Hospital in Buenos Aires, Argentina. We followed the International Patient Decision Aid Standards to develop our decision aid. Guided by a steering group and a multidisciplinary consultancy group including a patient advocate, we reviewed the evidence about breast cancer screening and previous decision aids, explored the patients' information needs on this topic from the patients' and physicians' perspective using semi-structured interviews, and we alpha-tested the prototype to determine its usability, comprehensibility and applicability.

RESULTS We developed the first prototype of a web-based decision aid to use during the clinical encounter with women aged 40 to 69 with average breast cancer risk. After a meeting with our consultancy group, we developed a second prototype that underwent alpha-testing. Physicians and patients agreed that the tool was clear, useful and applicable during a clinical encounter. We refined our final prototype according to their feedback.

CONCLUSION We developed the first decision aid in our region and language on this topic, developed with end-users' input and informed by the best available evidence. We expect this decision aid to help women and physicians make shared decisions during the clinical encounter when talking about breast cancer screening.

KEYWORDS Decision Making, Shared, Breast Neoplasms, Early Detection of Cancer, Decision Support Techniques

INTRODUCTION

Breast cancer is the leading cause of death from cancer in women[1]. Breast cancer screening with mammography has proven effective to reduce breast cancer mortality[2]. The risks of participating in screening are falses positives (an error inherent to all diagnostic test indicating that a person has a disease when they don't have it), that could lead to unnecessary biopsies, and overdiagnosis (a cancer diagnosis that would have never caused harm if it was undetected by screening)[3]. The balance between benefits and disadvantages of mammographic screening has been a disputed topic in the medical community in the past decade. Recently, many evidence-based guidelines changed their recommendations limiting the age of recommended screening in average-risk women (women over 45 to 50 years rather than 40), reducing its frequency (biennially rather than annually), and emphasising individualised decisions by engaging women in shared decision making [3–8].

Shared decision making is an approach to inform and help patients make decisions tailored to their preferences and needs[9]. This approach is useful when facing "preference-sensitive" decisions, such as a delicate balance between benefits and harms like screening for health care conditions [10]. For example, women's values and preferences about breast cancer screening can vary if presented with complete information

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MAIN MESSAGES

- This is the first decision aid in Spanish for this topic developed using international patient decision aid guidelines and the first decision aid in Argentina.
- We used a qualitative approach involving the end users of the tool and we pilot tested the comprehensibility, acceptability and usability of the tool.
- We included a small sample of middle-class women and did not test its effect in making shared decisions. Further studies are needed to establish the effectiveness and the transferability of the tool to other populations.

about both benefits and harms of screening [11]. Women value information about the harms of screening. The number of cases of overdiagnosis and falses positives that they would be willing to accept to avoid one death related to breast cancer can vary substantially[12–15]. Decision aids are tools developed to support shared decision making[16]. They do not replace the role of health care professionals. Still, they provide structured guidance to communicate balanced information based on scientific evidence and to incorporate what is most important for patients. Previous studies have shown that decision aids are useful tools that improve knowledge and informed choice in breast cancer screening decisions [17,18]. We are currently conducting a Cochrane review on shared decision making for breast cancer screening which indicates that this intervention may also increase knowledge but the impact on other outcomes, including mental health is more uncertain (the full review is under editorial consideration, the protocol is published in the Cochrane Library 10.1002/14651858.CD013822).

In Argentina, previous studies conducted in a private hospital (Hospital Italiano of Buenos Aires) indicated that mammography screening was being overused in young women without risk factors for breast cancer screening and that patients' motivation to participate was based on incomplete information about its harms[15,19]. To address this gap and improve how women make decisions about breast cancer screening, we decided to develop a decision aid to support evidence-based conversations between health care professionals and patients. In this study, we describe the stepwise approach we followed for its design and alpha testing. To our knowledge, this is the first decision aid for breast cancer screening in a lower-middle-income country[20].

METHODS

Development

We conducted a mixed-methods study between 2018 and 2020, following the framework suggested by Coulter et al. for developing patient decision aids according to the International Patient Decision Aid Standards (see Figure 1)[21]. Similar to international guidelines, our government recommends biennial breast cancer screening in asymptomatic average-risk women aged 50-69 years and discourages routine screening in asymptomatic average-risk women aged 40 to 49 years[7]. We initially decided to target the population of our screening program, average-risk women aged 50 to 69 years old. But we decided to include both age groups in the decision aid after analysing the interviews (see results). We considered average risk women those with 15% lifetime risk for developing breast cancer or less: without personal or family history of breast, ovary or peritoneal cancer, without genetic mutations that increase breast cancer susceptibility (or women who have been offered genetic testing), without ductal or lobular carcinoma in situ, and that did not receive chest radiotherapy[22]. The project was led by a steering group of family physicians with prior experience in shared decision making research and a consultancy group formed by three family physicians, a gynaecologist, a general internist, a psychologist and a patient advocate. None of the members of the steering and consultancy group had any conflicts of interests.

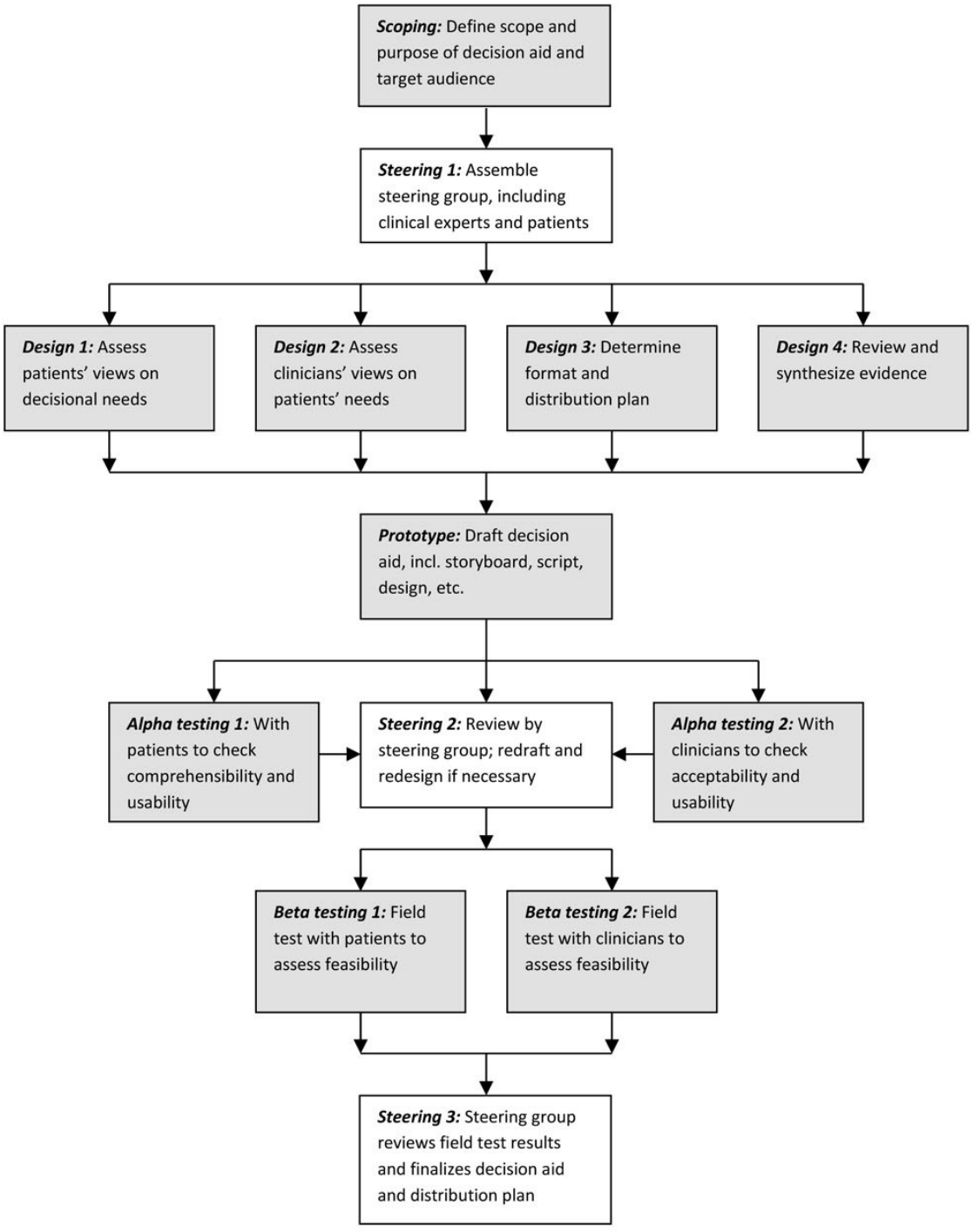
Exploring patients' decisional needs

We used an interpretivist approach and selected a convenience sample of patients and physicians to elicit their views on patients' information and decision support needs for participating in breast cancer screening. Patients were women aged 50 to 69 years old, literate, affiliated to our institution's private health insurance. We selected physicians that usually have preventive health care conversations with women, such as family doctors, gynaecologists and general internists, working at the Hospital Italiano of Buenos Aires. We conducted semi-structured interviews using an interview guide (included in the supplementary materials) based on the work of the University of Ottawa for assessing decisional needs[23]. The interviews were recorded for posterior analysis. The sample size was determined by theoretical saturation. Two independent authors (PR and VRY) analysed the interviews inductively using thematic analysis, identifying codes and grouping them into sub-themes and themes[24]. The investigators used the ATLAS-ti software to develop an initial coding separately and then met to compare findings and reach a consensus on the final codes and categories. A third author (JVAF) that did not participate in the coding phase offered guidance to reconcile differences. All three authors reviewed the final content and agreed on the main themes.

Content and format

Guided by our steering and consultancy groups, we performed a literature review of previous breast cancer decision aids and the evidence about the options, patients values, preferences and information needs regarding this decision to

Figure 1. Model Development Process for Decision Aids by Coulter et al.



Source: Prepared by the authors.

define the preliminary aspects of the tool [2,7,17,18,25–30]. Then, we developed a draft and revised its format and content with the consultancy group in an iterative process.

Alpha testing

Patients and physicians revised the decision aid to determine its usability, acceptability, and comprehensibility. We selected a convenience sample of 20 patients and physicians, and we collected data through an online anonymous survey (included in the supplementary materials) [31,32]. We evaluated nine

Table 1. Participants' characteristics by stage in the decision aid development process

	Patient's decisional needs		Alpha testing	
	Patients	Physicians	Patients	Physicians
Number, N	7	12	11	11
Age, mean	59	37	58	49
Gender, N (%)				
Female	7 (100)	10 (83)	11 (100)	7 (64)
Male	-	2 (17)	-	4 (36)
Education, N (%)				
Primary	1 (14)	-	5 (45.5)	-
Secondary	2 (29)	-	1 (9)	-
Post-secondary	4 (57)	-	5 (45.5)	-
Medical specialty, N (%)				
Family medicine	-	5 (42)	-	8 (73)
Gynaecology	-	3 (25)	-	2 (18)
Internal medicine	-	4 (33)	-	1 (9)

Source: Prepared by the authors from the study data.

items for patients and ten items for physicians using a Likert scale. The major categories were content, design, application, motivation and interaction. We emailed the survey to physicians. Two members of the research team held teleconferences with patients who agreed to participate to show them the tool as a physician would do in a clinical encounter and guide them in completing the survey.

Ethical considerations

Participation in this study was voluntary and confidential. The researchers that recruited participants and conducted the interviews had no relationship with the patients and were not in a position of power (e.g. employer, head of department) with the physicians included in this study. All participants signed an informed consent. The online survey was anonymous and the interview transcripts were anonymized prior analysis to avoid disclosing any personal identifying information. The files were password-protected and saved using unique identifiers.

Patient and public involvement

A patient representative joined our research team in the developing stages of the decision aid, providing input from the analysis phase of the interviews until the alpha testing. MR was also part of the consultancy group that gave feedback on the decision aid prototypes at different stages.

RESULTS

Exploring patients' decisional needs

We interviewed 19 participants in total, seven patients and 12 physicians. Their characteristics are summarised in Table 1.

Based on the transcription of the interviews, we coded the responses and organised them into three main themes: 1) the choice of having a mammogram, 2) information needs, and 3) counselling and communication. Supporting quotations are included in online supplementary table 1 in the supplementary materials.

In general, women had already decided to participate in breast cancer screening as part of their regular check-up. Women saw mammograms as a non-invasive procedure, crucial to women's health and even mandatory, influenced by the input of their families, friends and the media urging them to participate. Some women saw the screening as predominantly beneficial, minimising possible harms. Doctors acknowledged this and found it rare when women challenged the need to do a mammogram or asked about other options. Some of them expressed that women usually think that more is always better when it comes to screening or preventive interventions. Women and doctors mentioned that the ache and pain experienced while doing mammograms impact the patients' experience but do not prevent them from doing the study. They also concur that patients feel fear and anguish while awaiting results or if they had to repeat tests due to false positives.

Physicians thought some women ignored the currently recommended screening tests (mammogram vs ultrasound), the age when to start and the frequency. Mammography was perceived within a "package" of preventive interventions for women, some of which are not currently recommended (e.g., routine transvaginal ultrasound). Furthermore, some did not understand that a mammography is a form of secondary prevention (not intended to reduce the incidence of the disease). They agreed on informing about false positives and overdiagnosis, which are complex terms to grasp for both doctors and patients. Women wanted to know the benefits and harms of screening. They prefered to hear this information from their physician rather than from media campaigns or a brochure. They perceived a favourable balance between the expected benefits and harms of screening. When eliciting views on harms, most of them mentioned the pressure exerted by the mammogram as something that can hurt the breast tissue and the risk of radiation. A woman that had a personal negative experience with a mammogram's false-positive result highlighted the need to inform women about what this entails. But others without this experience did not see false positives as harm but as something necessary and beneficial, something that needed to be checked in detail for their own good.

Patients and physicians identified a good doctor-patient relationship as a common facilitator to improve the patient's understanding of different topics. One woman described the doctor as the most trusted source of information and as the final decision-maker. Physicians highlighted that it is important to have an institutional consensus about recommendations on screening and informative materials supporting what needs to be discussed during the consultation. Both physicians and patients agreed that lack of time during the consultation was a barrier to effective communication. Physicians stated that the changes in recommendations were also a challenge, especially concerning when to start and how often to recommend screening and suggestions regarding breast self-examination. Finally, the physicians identified that some patients have a firm belief about regularly doing mammograms. When they are presented with the option of doing them less frequently or not doing them at all, they are reluctant to engage in a discussion.

Content and format

We conducted targeted literature searches for primary research, other decision aids and systematic reviews based on the input of our expert steering and consultancy groups. We decided that we would gather the evidence on the following categories for the content of the decision aid: a) benefits or advantages of breast cancer screening, b) harms or disadvantages of breast cancer screening, c) information needs and women's values and preferences regarding breast cancer screening, d) format and presentation of the decision aid (see Table 2) [33-39]. Initially, we evaluated the information needs of women aged 50 to 70 years (the screening target population according to our national guidelines). However, we also decided to include women aged 40 to 49 years in our decision aid to address the needs raised by our interviewees and because our previous research has shown women in both age groups have little knowledge about harms [15].

Alpha testing

We collected 22 responses, 11 from doctors and 11 from patients (see Table 1). Overall, patients and doctors agreed that the content and design were appropriate, that it was a useful and applicable tool in their context and that they were motivated to use it. According to patients and physicians, the mean score was 4.1 and 4.2 on a scale from 1 to 5 (5 being "strongly agree"). The majority of patients and doctors agreed that the information in the decision aid reflected important aspects and balanced views about breast cancer screening, that it was clearly presented and that it helped to identify what was most important for patients when making a decision. All physicians agreed the tool was relevant for them and felt confident they could implement it in their practice.

All except one patient agreed that the tool addressed their need to know more about mammography or their health. This person suggested displaying more "aggressive" images about risk factors so people would take them seriously. We decided not to follow this advice because we thought that would confer a biased and judgmental opinion towards an option and modifiable risk factors, and does not embrace a diversity of choice. It does not align with the principles of shared decision making or patient-centred care. Two physicians did not agree that the language was adapted to their patients' knowledge, and we changed the content removing medical jargon. One physician was hesitant (nor agree or disagree), and one did not agree that the decision aid was easy to navigate and that it would be appropriate for use during a consultation. In response to this feedback, we rephrased the navigation instructions and we developed a tutorial showing how to use the decision aid and navigate the website. Also, we summarized the written content and included more interactive features (e.g. flashcards for the risk factors section) to reduce the cognitive load.

Full details about the quantitative results of the survey can be found in the supplementary materials.

International Patient Decision Aid Standards criteria checklist

The quality of the decision aid was tested against the 74-item International Patient Decision Aid Standards checklist [33]. We completed 27 out of 30 criteria for "Content", 25 out of 27 criteria for "Development", and three out of six additional items for internet-based decision aids (two were not included, and one was not applicable).). A detailed checklist of all these criteria can be found in the supplementary materials.

DISCUSSION

Summary of the main results

We describe a systematic approach for developing a web-based decision aid to support physicians and women to make decisions during the clinical encounter about whether to participate in breast cancer screening. To our knowledge, this is the first decision aid developed in Argentina [20].

Results in the context of published literature

When exploring women's information needs concerning this decision, we found similar results as previous research in our setting: mammograms are being overused for screening purposes (women and some physicians mention starting screening earlier or at shorter intervals), there is a common belief that this practice is a mandate more than a choice, and the information about its harms is neglected [15,19,34]. These findings highlight the need to improve the decision-making process. We are currently conducting a follow-up study[35] to explore the effectiveness of the decision aid in promoting shared decisions.

Our decision aid is aimed at women with an average risk of breast cancer, excluding women with major risk factors. However, we can find different baseline breast cancer risk in women of the same age group, i.e., women with no risk factors and women with minor risk factors such as obesity or nulliparity, who could benefit more from the relative reduction in the risk of

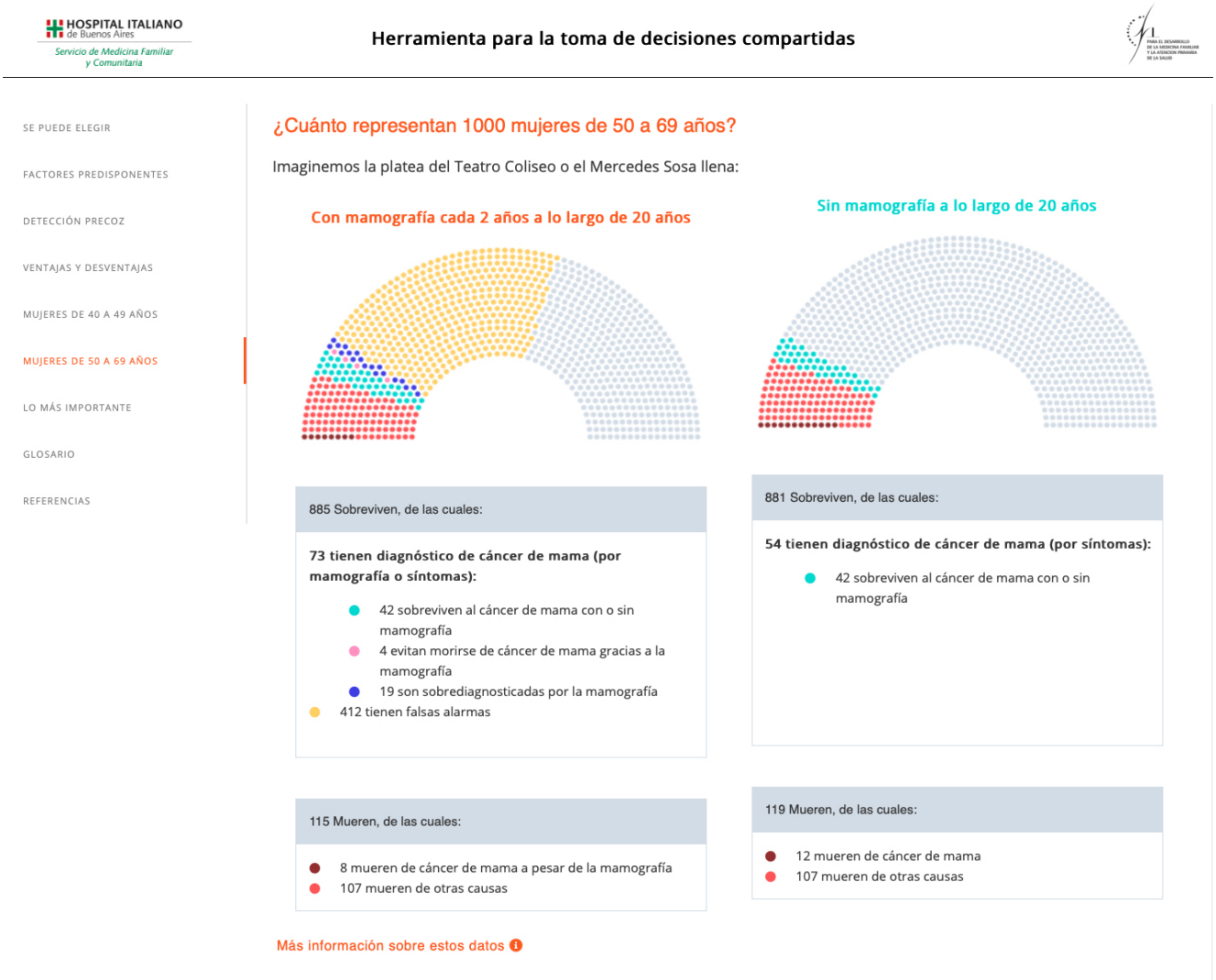
Table 2. Summary of the evidence feeding our decision aid

Benefits or advantages	• According to systematic reviews, the main benefit of mammography screening is to reduce breast cancer mortality[2,3,6,7]. This benefit increases with age. • For every 1000 women aged 40 to 49 who perform mammograms every two years over ten years, one avoids dying from breast cancer. For every 1000 women aged 50 to 69 who perform mammograms every two years over 20 years, 4 avoid dying from breast cancer. [26 ,27]. Another way to express these probabilities: for every 10000 women aged 39 to 49 who perform mammograms every two years over ten years, four avoid dying from breast cancer; for every 10000 women aged 50 to 59 who perform mammograms every two years over ten years, five to eight avoid dying from breast cancer; for every 10000 women aged 60 to 69 who perform mammograms every two years over ten years, 12 to 21 avoid dying from breast cancer[33]. • Detecting breast cancer at earlier stages allows for more conservative surgeries [30]. • Receiving true negative results from mammographic screening brings a sense of reassurance and satisfaction to women[15].
Harms or disadvantages	• False negatives, that can give a false sense of reassurance [34]. • False positives, that can result in additional testing until the abnormal finding is refuted, leading to unnecessary exams and anxiety in some women [25 ,35]. • Overdiagnosis: Breast cancer screening leads to the detection of indolent cancers that would not have caused harm if left undetected [36 ,37]. • For every 1000 women aged 40 to 49 who perform mammograms every two years over ten years, 239 will have a false-positive result and seven an overdiagnosis. For every 1000 women aged 50 to 69 who perform mammograms every two years over 20 years, 412 will have a false-positive result and 19 an overdiagnosis.[26 ,27] Estimates on overdiagnosis vary depending on the type of study, measures and methods used, and there is no consensus about the appropriate approach. Data based on trials with long term follow-up found a 22% overdiagnosis rate for invasive cancer for the combined age groups[33].
Information needs and women's values and preferences	A systematic review[25] found that: • Women had limited awareness about the harms of screening. This information triggered different emotions such as surprise, concern and mistrust. • Some women consider it appropriate to inform women about the harms of screening, but others fear it could deter women from participating in screening. • Women value better the possibility of an early diagnosis over the risk of false positives and overdiagnosis. • Overdiagnosis might discourage younger women instead of older women from participating, but others found the contrary. According to our interviews: • Women and doctors preferred a decision aid used in a clinical encounter, containing information on the benefits and harms of screening. • The content of our interviews yielded similar findings to those in the systematic review.
Format and presentation	According to our interviews: • Women prefer to talk about the harms of screening with their doctors. This allows them to ask questions and clarify concepts that might be misinterpreted. That is why we developed a decision aid to be used during the clinical encounter. • Physicians' recommendations for breast cancer screening were not always consistent with institutional and national guidelines. Furthermore, many of them express that false positive and overdiagnosis are complex terms to explain. Hence, we included more detailed information in the tool to serve as an evidence-based summary in lay terms to support clinicians in having these conversations with their patients. • Many women preferred a digital format, so we decided to develop a digital tool. However, we included the option to print a paper-based summary. Information was divided into sections: introduction to breast cancer, risk factors, definition and purpose of screening, benefits and harms, graphics with probabilities of benefits and harms, values and preferences, a glossary (including false positives and overdiagnosis definitions) and references.

- We decided to present information about the probabilities in absolute risk, using frequencies with a constant denominator, as the evidence shows that they are easier to understand and interpret [38].
- We chose to depict numerical information using graphics that would contextualise the magnitude of the numbers, i.e. using a theatre seating plan representing 1000 women (see Figure 2).
- To help patients match their values, we included patients' narratives regarding motivations and feelings about the decision to undergo breast cancer screening that emerged in the interviews and previous studies [15,39]. They can classify these narratives in three different columns if they agree, disagree, or nor agree nor disagree with each one of them.

Source: Prepared by the authors from the study data and by reviewing the literature.

Figure 2. Risk graphic display used in the decision aid



Source: https://decidirmamografia.com.ar/

dying from breast cancer. An accurate risk assessment is a crucial feature in a decision aid[36]; however, some argue that there is less evidence for including personalised risk estimates in these tools[37]. Including a risk calculator in our tool required more sophisticated software programming. Moreover, the available breast cancer risk calculators were tested in screening programs in different populations[38]. We do not have local data that validated these risk tools in our Latin American population. Thus, we do not know if these risk calculators underestimate or overestimate the impact of screening on our patients' breast cancer risk. Using a pragmatic approach, we decided to include two different pictograms of benefits and harms of screening

according to women's age (40 to 49 and 50 to 69 years old), clarifying that these graphics could underestimate the risk of women with additional minor risk factors.

Strengths and weaknesses

As part of the iterative process in designing our decision aid, we initially explored the information needs of patients that were 50 to 70 years old. Still, later on, we also decided to include 40 to 50-year-old women. Hence, the information needs of women in this age group might be underrepresented in this study. However, our findings were similar to previous studies in our setting, including this group of women[15]. Furthermore, we explored the needs of middle-class women, most of them with secondary education or higher, affiliated with a private academic hospital. We expect that the beta testing of the decision aid will assess the effects and transferability of this decision aid on women of different age groups with different health literacy levels and backgrounds.

As for strengths, our tool was fully developed and customised for our patient population, designed based on the needs of our end-users, and written in Spanish. There are few decision-aids in Spanish and fewer developed in low and middle-income countries (LMICs)[20]. We consulted a wide variety of health-care professionals who provided significant input in our tool and its applicability in a real-world setting. Furthermore, we incorporated a patient advocate in the development process who provided crucial inputs regarding the clarity, relevance and format of the tool. Being also a law professor, she added some technical legal suggestions on how to phrase the tool in the context of our law, differentiating it from traditional informed consent.

Implications for practice and future research

This web-based decision aid (http://decidirmamografia.com.ar/) is expected to help women and physicians to make decisions during the clinical encounter about whether to participate in breast cancer screening in our country and possibly in our region, where the uptake of shared decision making and tool development is low. A description of the developmental process in our setting might encourage others to build up evidence on shared decision making implementation in our region.

CONCLUSIONS

We developed the first decision aid in our region and language to assist women in their conversations with their physicians when deciding on breast cancer screening with the input of the perspective of their end-users and informed by the best available evidence. Future research will assess the effectiveness of improving shared decision making and the transferability to other contexts.

Contributor roles PR: Conceptualisation, methodology, interviewing, data analysis, drafting decision aid prototype, manuscript-writing draft preparation, approval of final draft. MVRY: Conceptualisation, interviewing, data analysis, drafting decision aid prototype, manuscript-writing draft preparation, approval of final draft. JVAF: Conceptualisation, methodology, interviewing, data analysis, drafting decision aid prototype, manuscript-reviewing and editing, approval of final draft. JC: Interviewing, feedback during the development of the study, approval of final draft. MR: Feedback during the development of the study, drafting decision aid prototype, approval of final draft. KK: Conceptualisation, supervision, drafting decision aid prototype, approval of final draft.

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Desarrollo de una herramienta en español para ayudar en la toma de decisiones del cribado de cáncer de mama para mujeres de riesgo promedio: un estudio de métodos mixtos

ABSTRACT

INTRODUCCIÓN Nuestro objetivo era desarrollar una ayuda para la toma de decisiones compartida entre médicos y mujeres con un riesgo medio de cáncer de mama a la hora de decidir si participar o no en el cribado de cáncer de mama.
MÉTODOS Se incluyeron mujeres con riesgo promedio de cáncer de mama y médicos involucrados en apoyar la decisión de tamizaje de cáncer de mama de un Hospital Académico de Buenos Aires, Argentina. Seguimos los Estándares Internacionales de Ayuda a la Decisión del Paciente para desarrollar nuestra ayuda a la decisión. Guiados por un grupo directivo y un grupo consultor multidisciplinario que incluía un defensor del paciente, revisamos la evidencia sobre el cribado del cáncer de mama y las ayudas para la toma de decisiones anteriores, exploramos las necesidades de información de las pacientes sobre este tema desde la perspectiva de las pacientes y de los médicos mediante entrevistas semiestructuradas, y realizamos pruebas alfa del prototipo para determinar su usabilidad, comprensibilidad y aplicabilidad.
RESULTADOS Desarrollamos el primer prototipo de ayuda a la toma de decisiones basada en la web para su uso durante el encuentro clínico con mujeres de entre 40 y 69 años con un riesgo medio de cáncer de mama. Tras una reunión con nuestro grupo consultor, desarrollamos un segundo prototipo que se sometió a una prueba alfa. Médicos y pacientes coincidieron en que la herramienta era clara, útil y aplicable durante el encuentro clínico. En función de sus comentarios, perfeccionamos el prototipo final.
CONCLUSIÓN Hemos desarrollado la primera ayuda para la toma de decisiones en nuestra región y en nuestro idioma sobre este tema, elaborada con las aportaciones de los usuarios finales y basada en las mejores pruebas disponibles. Esperamos que esta ayuda para la toma de decisiones ayude a las mujeres y a los médicos a tomar decisiones compartidas durante el encuentro clínico al hablar sobre el cribado del cáncer de mama.