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Medical Decision Making

Towards informed decisions on breast cancer screening: Development and pilot testing of a decision aid for Chinese women

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ABSTRACT

Objective: To pilot-test a novel, self-use breast cancer (BC) screening decision aid (DA) targeting Hong Kong (HK) Chinese women at average risk of BC.
Methods: Women were recruited through a population-based telephone survey using random digit dialling between October 2013 and January 2014. Eligible participants completed our baseline survey and then received the DA by post. Participants (n = 90) completed follow-up telephone interviews one month later.
Results: Most participants thought that all/most DA content was presented clearly (86.7%), and was useful in helping women make screening-related decisions (88.9%). It also achieved its expected impact of improving informed decision-making and increasing shared-participation preference without increasing participants' anxiety levels. Participants showed a modest non-statistical increase in their screening knowledge scores. Older women rated the perceived severity of a BC diagnosis as significantly lower, and more educated women reported significantly lower perceived anxiety about the disease.
Conclusion: Our DA appears acceptable and feasible for self-use by HK Chinese women who need to make an informed decision about BC screening without increasing overall anxiety levels.
Practice implications: This study supports the potential of self-use DAs for cancer screening-related decision support in a Chinese population.

1. Introduction

Decision aids (DAs) are systematically developed interventions that support better informed decision making by enhancing individuals' cognitive attributes and decision-making process related-outcomes, including knowledge and beliefs about a disease and its associated medical interventions, and improving their risk perception accuracy [1]. DAs play an important role in cancer screening with growing evidence indicating that they improve individual decision-making process-related outcomes [1–6] including reducing proportions of undecided patients and related decisional conflicts [5,6]. DAs are particularly useful when there are multiple possible health interventions and when each alternative has its specific benefits and harms that individuals might value differently [7].

There is a need to help women make informed choices about breast cancer (BC) screening based on appraisal of benefits and risks [8,9], in view of unresolved debates on potential benefits versus harms from mammography screening in the US and Europe [8,10–12]. Among various modalities of BC detection, only mammography has been demonstrated to be effective in reducing disease-specific mortality [11,13,14], while the effectiveness of other modalities remain unproven [15–19]. In addition to this uncertainty, false alarms, over-diagnosis and over-treatment have been cited as the major potential harms arising from BC screening [11,19]. A critical examination of the BC screening debate is particularly important in Chinese populations, especially to those living in one of the most westernized and urbanized Chinese cities, Hong Kong (HK), given the fact that its markedly lower BC prevalence might lead to more false positive cases in comparison to the Caucasian counterparts. In 2012, age-standardized incidence rates in the UK and US were 95 and 92.9 per 100,000 women respectively, while the rate in HK was 61/100,000 [20]. With respect to screening uptake, by 2003–2004 approximately 14.7% of women have ever attended mammography screening in Hong Kong [21]. More recently, haphazard opportunistic mammography

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ultrasonography and increasingly MRI screening of women at average risk, have proliferated in recent years.

So public information on BC screening needs appropriate balance [22]. Although HK does not provide population-based systematic BC screening, opportunistic mammography screening services are available in public and private hospital-based units and general outpatient clinics as well as in private laboratories, for a minimal user charge to potential clients. Significant promotion of mammography for HK Chinese women by these service providers, among others is seen as a means to reduce the BC-associated mortality rate [21,23]. However, difficulties in accessing scientifically validated and yet reader-friendly information on early BC detection practices, make it difficult for many Chinese women to weigh the pros and cons of BC screening before making an informed choice. Since individual judgement is a key part of any decision-making process, a tailored decision support tool or decision aid (DA) should help women formulate more realistic expectations of mammography screening and other early BC detection practices.

Most DAs for BC screening were developed and used in Western populations [7]. However, among Chinese women at an average risk of developing BC, a culturally relevant DA that informs Chinese women of available early BC detection strategies has yet to be developed and tested. Our previous research to develop a DA that assisted women making surgical treatment choices for early BC revealed that many HK Chinese women with BC preferred a booklet over alternative formats [24]. That decisional tool was also tested in a randomized controlled trial setting indicating benefit by reducing decisional conflicts and subsequent regret and enhancing clinical services in our BC population [25]. We have therefore developed and pilot-tested a print-based DA tailored for HK Chinese women that focuses on aiding decision-making for early BC detection strategies. We investigated the initial acceptability and utility of this DA and evaluated levels and possible changes in knowledge and perceived risk ('information'), and role in screening decision and decisional conflict ('decision-process') attributes in a sample of HK Chinese women. We also evaluated whether or not there was any systematic variation in the attributes among subgroups.

2. Methods

2.1. Content development of a decision aid

The content of the DA was developed with reference to a thorough literature review using PUBMED database, the latest Cochrane BC screening leaflet [26], existing patient aids materials [27], cross-reference and expert opinion. We adapted the International Patient Decision Aid Standards (IPDAS) framework [28]. Our final DA booklet was written in the traditional Chinese characters commonly used in HK (and also used in Taiwan and Singapore) and consisted of eight components (Table 1).

To formulate the DA content, we established a working group of neutral non-advocates to maintain objectivity, comprising a 7-member panel with backgrounds in statistics, epidemiology, public health, psycho-oncology and oncology. We reviewed common BC detection strategies: mammography, breast ultrasound, clinical breast examination, breast self-examination, and magnetic resonance imaging. These strategies are explained in the DA. A narrative review method was applied to the content development. Two panel members (IW, CNW) conducted the review using the scoping review approach [29,30], which helps to identify appropriate 'parameters' (domains or scope) relating to the potential benefits, harms and uncertainties of BC screening practices (Details in Appendix A). The findings were then adapted to suit the organizational format of our DA.

During this stage, inconsistencies were resolved by iterative discussions in the working group with invited associates. Specifications regarding graphics, layout and typography design were passed on to a graphic design company which produced and printed the DA. Hand-drawn illustrations and graphical representations of proportions were used to facilitate comprehension. An illustrative example is shown in Appendix B.

2.2. Participants and setting

We used a prospective before-and-after survey study design to evaluate the DA effectiveness in helping women make informed decisions about early BC detection practices. Subjects were recruited by a population-based telephone survey, using random-digit dialling to obtain a sample from all fixed, land-based telephone lines, and within-household sampling of an eligible household member. If more than one female member per household met our criterion, she whose birthday was the closest to the date of the interview was selected. For non-response calls, three attempts were made before number replacement. Selected respondents were briefed about our study and invited to participate with verbal informed consent, after which the baseline telephone interview commenced. We also obtained consent to mail the DA, and followed them up through a second telephone survey conducted a month later. Those who completed both baseline and the follow-up surveys were given a HK$100 (~US$13) supermarket coupon as an incentive.

Baseline telephone interviews were administered to obtain information including the information and decision-making process attributes and socio-demographic characteristics. The follow-up survey repeated the baseline telephone survey items and included additional questions on the acceptability and utilization of the DA, decisional conflict and perceived benefits and barriers surrounding BC screening.

The baseline survey (22nd October to 20th November 2013) yielded an overall response rate of 43.9%, while the one-month follow-up survey occurred between 22nd November 2013 and 15th

Table 1
Table of contents of the booklet.

Sections	Content descriptions
(1) Is breast cancer common in Hong Kong?	Provide information on incidence and mortality of breast cancer in Hong Kong.
(2) What is breast cancer screening?	Introduce and describe breast cancer screening modalities including mammography, ultrasound, clinical breast examination, breast self-examination and magnetic resonance imaging.
(3) Assess your risk and consider trade-offs	Include information on structured guidance in reaching a decision, and provide a summary table to review the potential benefits and costs of the available modalities and options for early detection of breast cancer.
(4) What are the benefits of breast cancer screening?	Discuss benefits of the screening modalities, e.g., reduction in mortality and sensitivity.
(5) What are the risks of breast cancer screening?	Discuss risks of the screening modalities, e.g., over-diagnosis, false positives, and psychological consequences such as anxiety.
(6) What are the uncertainties of breast cancer screening?	Discuss uncertainties of the screening modalities, e.g., impact on reducing mortality from breast cancer.
(7) Making informed decisions	Explain the importance of making informed decisions and considerations involved. Highlight the importance of value clarification and provide guidance to reaching decision.
(8) References	Scientific studies and evidence cited.