Evaluation of the knowledge of women and registered nurses in Japan regarding the benefits and risks of breast cancer screening

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Abstract

Objective: Routine, population-based mammographic screening for breast cancer has been implemented nationally in Japan for the past decade. The objective of this study was to evaluate the knowledge of the general public and of nurses concerning breast screening practices in Japan, especially with regards to the benefits and risks of breast cancer screening.

Methods: In 2014, a questionnaire regarding the benefits and risks of breast cancer screening was administered to women who underwent breast cancer screening and to registered nurses. The questionnaire was distributed to 1,649 women and 1,905 registered nurses. The questionnaire was returned by 1,552 (94.1%) of the screened participants and 1,710 (89.8%) nurses. The majority of the screened participants and registered nurses believed that screening prevented or reduced the risk of developing breast cancer (86% and 62%, respectively); that screening reduced the mortality risk of breast cancer by more than 50% (69% and 60%, respectively); and that 10 years of regular screening for 50-year-old women could prevent ≥ 10 breast cancer deaths per 1,000 women (62% and 61%, respectively).

Conclusions: Women in the target population and registered nurses were aware that earlier diagnosis led to better prognosis, but demonstrated misconceptions regarding other aspects of the benefits and risks of breast cancer screening. In Japan, all women should be educated on both the benefits and risks of breast cancer screening to enable them to make an informed decision on whether to participate in the mammographic breast cancer screening program.

Key words: breast cancer, mammography screening, women’s knowledge, benefits, risks

Introduction

The incidence of and mortality from breast cancer in the Asia-Pacific region, including Japan, has increased over the past two decades⁶. The breast has been the most common cancer site among Japanese women since 1999², ³. Population-based mammography screening was implemented in Japan in 2004 when the Ministry of Health, Labour and Welfare decided that Japanese women should have access to regular breast cancer screening to reduce breast cancer mortality rates. Screening is performed every two years using public funds and includes mammography and clinical breast examination for women ≥ 40-years-old. The implementation of this policy in Japan occurred later than in many Western countries, which is likely one of the reasons why the breast cancer mortality rate is still increasing in Japan, while simultaneously decreasing in many other countries⁶, ³. The Japanese government, medical facilities, healthcare workers, the mass media, and all those involved in breast cancer screening recommend that women be screened for breast cancer by advocating the message that early detection of breast cancer is the best way to reduce mortality rates⁶. Several systematic reviews and meta-analyses have suggested that mammography screening has reduced breast cancer-specific mortality rates, but has also led to overdiagnosis and overtreatment⁷–10. Women for whom
regular screening is recommended should be fully informed of both the benefits and risks\textsuperscript{15}. It is important to inform women not only of the lower mortality rate associated with breast cancer screening, but also of its potential disadvantages, including false positives and overdiagnosis.

The questionnaire-based studies in the field of breast cancer screening are mainly investigations into the reasons for participation in breast cancer screening\textsuperscript{12–14}. Some studies reported on the public perception of breast cancer and screening practices in the US, European countries, and China\textsuperscript{15–17}. In Japan, there are no data regarding Japanese women’s knowledge about the benefits and risks of mammographic breast cancer screening. The knowledge of screening providers is also unclear. This study assessed the knowledge of Japanese women in the general population and registered nurses in breast screening practices regarding the benefits and risks attributable to breast cancer screening.

**Methods**

The aim of this study was to determine the knowledge of the general public and of nurses in breast screening practices in Japan, regarding the benefits and risks of breast cancer screening. A questionnaire was administered to healthy women who were candidates for breast cancer screening and nurses who worked at eight hospitals in the Akita Kouseiren Hospital group.

The data were collected between August and December of 2014, in Akita prefecture, Japan. Akita is located in northern Japan, 600 km from Tokyo. There are 13 cities and the total population is approximately one million. Akita prefecture implemented population-based mammography screening in 2005. The target group was women aged \( \geq 40 \)-years. The Akita Kouseiren Hospital group consists of eight institutions located in eight different cities. This group performs about half of the breast cancer screening in Akita prefecture.

The questionnaire that was used in this study included seven questions relating to the participants’ knowledge about breast cancer screening and two additional questions regarding participants’ age and breast cancer screening experience. The questions were multiple choice with 2–6 possible responses, and were developed in our institution. All questions and possible responses were described in Japanese and translated into English correctly for this article. The questions were as follows: Question (Q) 1 (What kind of effect does breast cancer screening have on the prevention of breast cancer development?\textsuperscript{5–10}) intended to determine participant knowledge about the effects of breast cancer screening; Q2 (How many cases of breast cancer are diagnosed among 1,000 people in one screening?\textsuperscript{5–10}) intended to determine the believed sensitivity of breast cancer screening; Q3 (By what percentage does screening reduce breast cancer mortality rates in 50-year-old women who have undergone regular screening for 10 years?\textsuperscript{5–10}) intended to determine believed relative risk reduction; Q4 (How many cases of death due to breast cancer can be prevented among 1,000 women aged 50 years who have undergone regular breast cancer screening for 10 years?\textsuperscript{5–10}) intended to determine believed absolute risk reduction; Q5 (How many women will be recalled for further tests after one screening?\textsuperscript{5–10}) intended to determine believed recall and false positive rates; Q6 (Do you know that there are some slow-growing cancers that do not immediately cause death?\textsuperscript{5–10}); and Q7 (What is the percentage of such slow-growing cancers among screen-detected cancers?\textsuperscript{5–10}) intended to determine participant knowledge of overdiagnosis.

The questionnaire was administered to 1,649 women who underwent mammography and clinical breast examination and 1,905 registered nurses. All participants who were candidates for population-based breast cancer screening underwent breast cancer screening at one of our eight institutions. They completed the questionnaire while waiting for screening and returned it the same day. The registered nurses did not always undergo breast cancer screening and completed the questionnaire during their study period. Responses were totaled at each institution and then sent to Hiraka General Hospital for analysis.

Each question had correct answers based on the Japanese Ministry of Health, Labour and Welfare report, and results from a breast cancer screening trial and meta-analysis\textsuperscript{7–10, 18–21}. The proportion of correct response for each question was calculated and compared between the two groups. Participants were informed that the questionnaire results would be used for research and the data were collected between August and December of 2014, in Akita prefecture, Japan. Akita is located in northern Japan, 600 km from Tokyo. There are 13 cities and the total population is approximately one million. Akita prefecture implemented population-based mammography screening in 2005. The target group was women aged \( \geq 40 \)-years. The Akita Kouseiren Hospital group consists of eight institutions located in eight different cities. This group performs about half of the breast cancer screening in Akita prefecture.

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Statistical analysis

Descriptive statistics were calculated using Statcel 3 (OMS Publishing Inc., Tokorozawa, Saitama, Japan) and Excel (Ver. 14, Microsoft, Japan). Chi-square tests and t-tests were used to test differences between the two groups and \( p \) values of \(<0.05\) were considered statistically significant.

**Results**

The questionnaire was administered to 1,649 women (aged: 29–96 years) and 1,905 registered nurses (aged:
The questionnaire was completed by 1,552 (94.1%) screened women and 1,710 (89.8%) nurses. The screened participants were significantly older than the nurses (mean age: 59.6 ± 11.2 years and 41.6 ± 11.3 years, respectively, \( p < 0.001 \)). Almost all (91.6%) of the screened participants underwent at least one breast cancer screening experience. This was the first breast cancer screening for only 7.6% of this group. However, 39.2% of the registered nurses had never been screened for breast cancer \( (p < 0.001) \).

Tables 2 and 3 show the distribution of responses to each question by screened participants and registered nurses. Only 10.1% of the screened participants correctly indicated that screening had no effect on the risk of breast cancer development, compared with 35.7% of registered nurses \( (p < 0.001) \). The correct response for the cancer detection rate question (Q2) was 0.2–0.3%; the Japanese Ministry of Health, Labour and Welfare reported that the cancer detection rate of Japanese population-based breast cancer screening was 0.32% in 2012 and the Akita Kouseiren Hospital Group reported that it was 0.20% from 2008 to 2013 (no published data)\(^{18}\). Approximately 20% (18.9% of screened participants, 23.0% of registered nurses) correctly answered this question and > 60% (65.0% of screened participants, 63.6% of registered nurses) overestimated the detection rate. According to breast cancer screening trials and meta-analysis, the relative risk reduction related to screening mammography is about 20%\(^{7,9,18}\). Only 25.1% of the screened participants and 35.0% of the registered nurses correctly answered Q3 \( (p < 0.001) \). Many people in both groups believed that relative risk reduction exceeded 50% (68.9% of screened participants, 59.9% of registered nurses). Q4 was intended to measure knowledge of the absolute risk reduction related to breast cancer screening. The number needed to invite (NNI) refers to the number needed to avoid one breast cancer death. Hamashima estimated that the NNI for 50-year-old Japanese women was 864 in mammography-only screening and 1,474 in mammography and clinical breast examinations, so the correct answer to Q4 was set as 1 case per 1,000 women\(^{10}\). Few participants responded correctly (3.0% of screened participants, 4.7% of registered nurses). More than 90% of people in both groups overestimated the absolute risk reduction.

The correct answer for the re-call rate question (Q5) was 5–10%; the Japanese Ministry of Health, Labour and Welfare reported that the re-call rate for Japanese population-based breast cancer screening was 8.7% in 2012 and the Akita Kouseiren Hospital Group reported that it was 7.2% from 2008 to 2013 (no published data)\(^{18}\). The proportion of registered nurses who responded correctly was higher than among the screened participants \( (p < 0.001) \). Q6: Almost half of both groups (45.6% of screened participants, 56.8% of registered nurses) knew that there were some slow-growing cancers, and that they did not immediately cause death. The percentage of such slow-growing cancers among screen-detected cancers was 10–30%, based on long-term follow-up data from two randomized control trials\(^{20,21}\). The proportion of correct answers for these two questions was higher among registered nurses compared with the screened participants \( (p < 0.001) \).

### Table 1  Characteristics and response rates of the women screened for breast cancer and registered nurses

|                          | General public | Nurses | \( P \) value |
|--------------------------|----------------|--------|---------------|
| Age (Mean ± SD)          | 59.6 ± 11.2    | 41.6 ± 11.3 | < 0.001 |
| Questionnaire            |                |        |               |
| No. of distribution      | 1649           | 1905   |               |
| No. of response          | 1552           | 1710   |               |
| Response rate (%)        | 94.1           | 89.8   | N.S.          |
| Breast cancer screening experience | |        |               |
| No (%)                   | 118 (7.6)      | 635 (37.1) |           |
| Yes (%)                  | 1421 (91.6)    | 986 (57.7) |           |
| N/A (%)                  | 13 (0.8)       | 89 (5.2)  | < 0.001       |

### Discussion

To the best of our knowledge, this study is the first assessment of Japanese women and nurses’ knowledge of the benefits and risks of breast cancer screening. The results indicated that most women in Akita prefecture overestimated the benefits that can be expected from breast cancer screening and many did not know the absolute number of women who would benefit from screening. These misconceptions were not only present in the general public, but also among the registered nurses.

Many people in both groups thought that screening prevented or reduced the risk of developing breast cancer. There was a big difference between the true effect and wom-
Table 2  Knowledge concerning breast cancer screening among women screened for breast cancer and registered nurses

| Question                                                                 | General public | Nurses          |
|--------------------------------------------------------------------------|----------------|-----------------|
|                                                                           | n = 1552       | n = 1710        |
|                                                                           | No. (%)        | No. (%)         |
| 1  What kind of effect does breast cancer screening have on the prevention of breast cancer development? |               |                 |
| - Prevents the risk of breast cancer development                          | 657 (42.3)     | 331 (19.4)      |
| - Reduces the risk of breast cancer development                           | 682 (43.9)     | 730 (42.7)      |
| **- Has no effect on the risk of breast cancer development**              | **156 (10.1)** | **611 (35.7)**  |
| - N/A                                                                    | 57 (3.7)       | 38 (2.2)        |
| 2  How many cases of breast cancer are diagnosed among 1,000 people in one screening? |               |                 |
| - < 1 case per 1,000 people                                              | 67 (4.3)       | 51 (3.0)        |
| - 1 case per 1,000 people                                               | 120 (7.7)      | 162 (9.5)       |
| **- 2–3 cases per 1,000 people**                                         | **293 (18.9)** | **394 (23.0)**  |
| - 5 cases per 1,000 people                                              | 321 (20.7)     | 312 (18.2)      |
| - 10 cases per 1,000 people                                             | 256 (16.5)     | 349 (20.4)      |
| **- > 10 cases per 1,000 people**                                        | **432 (27.8)** | **427 (25.0)**  |
| - N/A                                                                    | 63 (4.1)       | 15 (0.9)        |
| 3  By what percentage does screening reduce breast cancer mortality rates in 50-year-old women who have undergone regular screening for 10 years? |               |                 |
| - Hardly reduces breast cancer mortality                                  | 42 (2.7)       | 70 (4.1)        |
| **- Reduces breast cancer mortality by 20%**                              | **390 (25.1)** | **599 (35.0)**  |
| - Reduces breast cancer mortality by 50%                                  | 599 (38.6)     | 676 (39.5)      |
| - Reduces breast cancer mortality by 75%                                  | 359 (23.1)     | 284 (16.6)      |
| **- Reduces breast cancer mortality by almost 100%**                      | **111 (7.2)**  | **64 (3.7)**    |
| - N/A                                                                    | 51 (3.3)       | 17 (1.0)        |
| 4  How many cases of death due to breast cancer can be prevented among 1,000 women aged 50 years who have undergone regular breast cancer screening for 10 years? |               |                 |
| - None per 1,000 women                                                   | 17 (1.1)       | 22 (1.3)        |
| **- 1 case per 1,000 women**                                             | **47 (3.0)**   | **81 (4.7)**    |
| - 3 cases per 1,000 women                                                | 129 (8.3)      | 219 (12.8)      |
| - 5 cases per 1,000 women                                                | 197 (12.7)     | 297 (17.4)      |
| - 10 cases per 1,000 women                                               | 237 (15.3)     | 325 (19.0)      |
| **- > 10 cases per 1,000 women**                                         | **728 (46.9)** | **717 (41.9)**  |
| - N/A                                                                    | 197 (12.7)     | 49 (2.9)        |
| 5  How many women will be re-called for further tests after one screening? |               |                 |
| - < 1 per 100 women                                                      | 143 (9.2)      | 73 (4.3)        |
| - 1 per 100 women                                                        | 211 (13.6)     | 198 (11.6)      |
| - 3 per 100 women                                                        | 362 (23.3)     | 335 (19.6)      |
| **- 5 per 100 women**                                                    | **299 (19.3)** | **377 (22.0)**  |
| **- 10 per 100 women**                                                   | **174 (11.2)** | **323 (18.9)**  |
| - > 10 per 100 women                                                     | 171 (11.0)     | 360 (21.1)      |
| - N/A                                                                    | 192 (12.4)     | 44 (2.6)        |
| 6  Do you know that there are some slow-growing cancers that do not immediately cause death? |               |                 |
| - Yes                                                                    | 708 (45.6)     | 971 (56.8)      |
| - No                                                                     | 693 (44.7)     | 701 (41.0)      |
| - N/A                                                                    | 151 (9.7)      | 38 (2.2)        |
| 7  What is the percentage of such slow-growing cancers among screen-detected cancers? |               |                 |
| - Very rare                                                              | 149 (9.6)      | 122 (7.1)       |
| - 5%                                                                     | 340 (21.9)     | 371 (21.7)      |
| **- 10%**                                                                | **291 (18.8)** | **384 (22.5)**  |
| **- 20%**                                                                | **212 (13.7)** | **318 (18.6)**  |
| **- 30%**                                                                | **181 (11.7)** | **250 (14.6)**  |
| - > 30%                                                                  | 186 (12.0)     | 213 (12.5)      |
| - N/A                                                                    | 193 (12.4)     | 52 (3.0)        |

* Correct or most appropriate answers to these Japanese breast cancer screening questions were based on the Japanese Ministry of Health, Labour and Welfare report, results of a breast cancer screening trial and meta-analysis and are shown in bold.\(^{7–10, 18–21}\).
en’s understanding of cancer screening. Some women wondered why they developed breast cancer even though they underwent screening. Other women, in whom advanced cancer was detected by screening, asked why they had such advanced cancer, despite regular screening.

Many participants overestimated the cancer detection rate (Q2). This finding might relate to the statistic, “one in eleven Japanese women will have breast cancer in her lifetime,” which may have been misinterpreted as a short-term probability of developing breast cancer rather than a cumulative lifetime probability of developing breast cancer. There was substantial misunderstanding of this point.

Relative risk or relative risk reduction are usually used to demonstrate screening efficacy, not only in scientific articles, but also for public information. However, these concepts are difficult for the general public to understand compared with the concepts of absolute risk and NNI. Furthermore, relative risk may overstate the benefits because it does not consider the morbidity rate; many people are unaware of the actual morbidity rate of breast cancer. The proportion of correct responses for the question on relative risk reduction was 25.1% among screened participants and 35.0% among the registered nurses. Most of the participants who did not answer correctly likely did not understand the numeric value and meaning of relative risk reduction. This is consistent with the finding that > 90% of the people in both groups overestimated the absolute risk reduction. Gigerenzer reported that 92% of women in nine European countries overestimated the absolute risk reduction from mammography screening or indicated that they did not know this value. Black reported that US women (40–50-year-old) overestimated the absolute risk reduction by more than 100-fold. Our result was very similar to these, which indicate that there is a discrepancy between the perceived and actual benefit of breast cancer screening.

The high rate of follow-up testing is one of the major disadvantages of regular cancer screening. More than 30% of both groups correctly identified the actual recall rate for Japanese breast cancer screening; however, many people (46.1% of screened participants, 35.4% of registered nurses) believed the recall rate to be lower.

Q6 and Q7 were intended to assess general knowledge of overdiagnosis. Overdiagnosis of cancer is defined as follows: 1) The cancer never progresses (or regresses) or 2) the cancer progresses slowly enough that the patient dies of other causes before the cancer becomes symptomatic. It poses a serious problem to cancer screening and occurs among 20–30% of screen-detected breast cancers; however, much information regarding this remains unknown. Jørgensen reported that one in three breast cancers detected in a population offered organized screening were overdiagnosed. About half of both groups were aware of slow-growing cancers. People were more knowledgeable about this concept compared with others on the questionnaire.

A survey in Switzerland in 2001 showed that only 20% of women understood the effects of breast cancer screen-

### Table 3: Correct or appropriate response rate for each question among women being screened and registered nurses

| Question | General public | | | | Nurses | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| | Correct answer | Wrong answer | % (C / C+W) | | Correct answer | Wrong answer | % (C / C+W) | |
| 1 What kind of effect does breast cancer screening have on the prevention of breast cancer development? | 156 | 1396 | 10.1 | | 611 | 1099 | 35.7 | p < 0.001 |
| 2 How many cases of breast cancer are diagnosed among 1,000 people in one screening? | 293 | 1259 | 18.9 | | 394 | 1316 | 23.0 | N.S. |
| 3 By what percentage does screening reduce breast cancer mortality rates in 50-year-old women who have undergone regular screening for 10 years? | 390 | 1162 | 25.1 | | 599 | 1111 | 35.0 | p < 0.001 |
| 4 How many cases of death due to breast cancer can be prevented among 1,000 women aged 50 years who have undergone regular breast cancer screening for 10 years? | 47 | 1505 | 3.0 | | 81 | 1629 | 4.7 | p < 0.05 |
| 5 How many women will be re-called for further tests after one screening? | 473 | 1079 | 30.5 | | 700 | 1010 | 40.9 | p < 0.001 |
| 6 Do you know that there are some slow-growing cancers that do not immediately cause death? | 708 | 844 | 45.6 | | 971 | 739 | 56.8 | p < 0.001 |
| 7 What is the percentage of such slow-growing cancers among screen-detected cancers? | 684 | 868 | 44.1 | | 952 | 758 | 55.7 | p < 0.001 |

N/A was included in wrong answers.
ing16. Another report concerning women’s perception of breast cancer screening in the US, UK, Italy, and Switzerland showed that a high proportion of women over-estimated the benefits of breast cancer screening15. Though more than 10 years have passed since the policy change in Japan and more information about cancer screening is widely available, misconceptions remain among Japanese women concerning the benefits and risks of screening.

One of the reasons why such misunderstandings were widespread is that only advantages, such as “early detection saves lives,” are included with information about breast cancer screening. The quantification of the absolute risk reduction or NNI has not been publicized. Mammography leaflets for the general public by the Nordic Cochrane Centre and by Public Health England (UK Government) describe the benefits and harms clearly and have been translated into 17 and 18 languages, respectively, but there is no Japanese version27, 28. Although it is important that information about the benefits and risks of screening is balanced, the risks associated with screening have not been well communicated to the public9.

To represent the benefits and risks of breast cancer screening, easily understandable tools and statistics that are relevant to Japan are needed. Gigerenzer recommended using a fact box, a useful tool for informed decision-making. It clearly shows that cancer-specific mortality rates are reduced to 1 in 1,000 women, and that this difference is not reflected in the overall cancer deaths or in the overall mortality rates10. Woloshin also reported that we should provide people with the information that they need to make informed decisions10.

This study had some limitations. One is that many of the screened participants had previously been screened, considered screening favorable, and overestimated its effects. Whether these results are generalizable to all of Japan is unclear, because Akita prefecture is a rural area. Even if there is a difference in the general public’s knowledge by locality, registered nurses’ knowledge should not differ. However, the rate of correctly answered questions was not high among the registered nurses. This study does not take into consideration physicians’ knowledge, although there is a possibility that even they might not know the correct answers32, 33.

Thus far, with respect to breast cancer screening, it has always been considered that earlier detection of the cancer is always beneficial. Information about screening should present both the benefits and the risks so that women can make informed choices. Whether the benefits of screening to reduce breast cancer mortality outweigh the harms of over-diagnosis and false positives is an individual decision. It is necessary to disseminate accurate knowledge to the general public and healthcare professionals.

Conclusions

This survey demonstrates that, 10 years after the implementation of routine mammography for breast cancer screening in Japan, women in the screened population and registered nurses believe that earlier diagnosis leads to better prognosis of breast cancer, but are not knowledgeable about other aspects of breast cancer screening. This study demonstrates that, in Japan, all women should be educated on both the benefits and risks of breast cancer screening to enable them to make an informed decision on whether to participate in the mammography breast cancer screening program.

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