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A survey of breast cancer awareness and knowledge in a Western population: lots of light but little illumination

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Abstract

There are conflicting data on breast cancer awareness and knowledge in specific population groups. We assessed awareness and knowledge of breast cancer in the general Irish population to identify sources of information on breast cancer and determine factors associated with knowledge and awareness of the disease. Participants (n = 2355, 53% female) completed a multi-part questionnaire. Most (81%) had seen or heard something about breast cancer in the recent past and knowledge of symptoms and treatment was good overall. However, 66% of females overestimated their risk of developing disease, 88% underestimated the age at which it was most likely to develop and 56% underestimated 5-year survival. Knowledge of incidence and survival was higher in males (Odds Ratio (OR) 1.3, 95% Confidence Interval (CI); 1.1–1.5), participants with higher education (1.5; 1.2–1.7) and those who received information from television (1.3; 1.1–1.5). Ignorance regarding incidence, outcome and risk makes it unlikely that the general public or at risk females could currently make informed decisions on a range of breast cancer issues.

Keywords: Breast cancer; Knowledge; Attitudes; Female; Male

1. Introduction

Health-care agencies and the lay media have focused considerable attention on breast cancer since the development of mammographic screening programmes in the 1980s and 1990s [1,2]. Information is usually given to breast cancer patients by their medical and nursing teams, whereas information intended for the general public is frequently delivered through the print and electronic lay media, advocacy groups, governmental institutions and consumer organisations.

The primary purpose of breast cancer educational campaigns should be to provide information so that members of the public can make informed decisions about a range of breast cancer issues, weigh up the risks, assess the harms and benefits of diagnostic and screening tests, compare the effectiveness of different treatment modalities and realistically assess the advantages and disadvantages of various risk modifying lifestyle changes. However, the close association between some educational and screening programmes has resulted in information being presented specifically to promote

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acceptance of mammographic screening and raise awareness about the aims of health-care agencies [3–5]. This is particularly true for advocacy groups and government agencies which systematically present selective and biased information in favour of screening [6]. Thus, both medical and non-medical media are blamed for confusing the public by exaggerating the risks associated with breast cancer and the benefits of screening [7] and by describing risk reduction in relative rather than absolute terms [2].

Although there may be a perceived lack of balance in health information provided, few population data are available on sources of information or on factors associated with knowledge and awareness of breast cancer. A number of reports have studied knowledge of breast cancer and attitudes to this disease in distinct female population groups [8–12]. In addition, studies have investigated knowledge of breast cancer in the general female population in the United Kingdom and Australia [13–15]. However, only a single study has included males [16] and none has systematically surveyed the general population of a country. The purpose of this national survey was to determine awareness and knowledge of breast cancer in the Irish population in order to identify media sources associated with breast cancer education, popular misconceptions about this disease, factors associated with knowledge and population groups who might benefit from education. It was anticipated that the results would be of benefit when developing future health promotion interventions.

2. Participants and methods

2.1. Study sites and participants

The study was approved by the St. Vincent's University Hospital Ethics Committee. Using qualitative research techniques, we chose a purposeful sample of the general well and active population as appropriate respondents for our survey. Based on census-derived quotas we obtained a geographically representative sample by conducting the survey at multiple urban and rural sites within all 26 counties of the Irish Republic in late 2001 and 2002. Trained research assistants approached potential participants in public places and asked them to complete a written questionnaire. Participants were assured that their responses would be confidential and completed the survey without help from the investigators. As in similar studies, no record was kept on those who refused to participate [13,17]. Responses from participants less than 16 years of age were discarded and analysis was performed on a final sample size of 2355 participants. Details of the study population are shown in Table 1. As was expected from our approach, the sample was slightly better educated and younger than the Irish population recently surveyed in the National Survey on Lifestyle, Attitudes and Nutrition [18].

Table 1
Details of 2355 study participants

Variable	Number (%)
Gender	
Female	1250 (53%)
Male	1105 (47%)
Age	
Less than 30 years	1143 (49%)
30–50 years	761 (32%)
Over 50 years	451 (19%)
Education	
No educational qualifications	235 (10%)
Junior certificate (GCSE equivalent)	472 (20%)
Leaving certificate (A level equivalent)	894 (38%)
Third level education	754 (32%)
Smoking status	
Smoker	803 (34%)
Ex-smoker	354 (15%)
Non-smoker	1198 (51%)

2.2. Study questionnaire

A multidisciplinary team of epidemiologists, clinical researchers, breast cancer surgeons, physicians and research nurses developed the questionnaire used in this survey, and the team also took advice from a market research company. The survey was designed to assess awareness of breast cancer and knowledge about risk factors, screening, symptoms and treatments and contained questions relating to the risk of developing and surviving breast cancer. Data on age, gender, educational and smoking status were also collected. Questions were included about colorectal cancer and heart disease that are not reported here.

The questions were chosen for their simplicity and most had been used in previous publications on breast cancer knowledge and perceptions. Overall, we were specific in our questioning in order to leave no leeway for misunderstanding. However, in relation to the question "have you seen or heard anything about breast cancer recently", we used the word "recently" rather than a precise time by design because of the dual phenomena of "Time telescoping" and "Time expansion" which make it difficult for individuals to remember the timing of social, news and other events with any degree of certainty [19,20]. A pre-test of 20 individuals was performed to determine if the questions were understandable to the lay public and a number of questions were modified slightly as a result of this exercise.

2.3. Statistical analysis

Logistic regression analysis, using the Statistical Package for the Social Sciences (SPSS, Chicago, IL)

was used to determine variables significantly associated with knowledge of risk of developing and surviving breast cancer.

3. Results

Eighty seven percent of females and 74% of males had seen or heard something about breast cancer in the recent past and the majority had received information through the print or electronic media (Table 2). Most participants knew that a positive family history was associated with breast cancer (Table 3). However, knowledge of other risk factors was poor, including the protective effect of early pregnancy, while two thirds of females thought that breast cancer was positively associated with stress. Most participants were aware that screening tests were available, could name at least one symptom and knew that surgery was a useful treatment for breast cancer (Table 4). Knowledge of symptoms, available treatments and screening was better amongst women than men.

Table 5 shows that 66% of females and 50% of males overestimated a woman's risk of developing breast cancer, 88% of females and 76% of males underestimated the age at which it was most likely to develop and 56% of females and 48% of males underestimated 5-year survival following diagnosis. Stepwise logistic regression analysis showed that knowledge relating to breast cancer risk and survival (defined as being able to correctly answer at least one of the three questions in Table 5) was better in males (Odds Ratio (OR), 1.3 (95% Confidence Interval (CI) 1.1–1.5)), those with third level education (OR 1.5 (95% CI 1.2–1.7)) and those who had received information from television or radio (OR 1.3 (95% CI 1.1–1.5)).

Table 2
Awareness of breast cancer in 2355 participants stratified by gender

	Female (n = 1250)	Male (n = 1105)
Number of participants who replied "yes" to the question "Have you seen or heard anything about breast cancer recently?"	1083 (87%)	818 (74%)
Source of information		
Television/radio	606 (48%)	488 (44%)
Magazines/newspapers	536 (43%)	380 (34%)
Family/friends	506 (40%)	288 (26%)
Doctor/nurse	163 (13%)	44 (4%)
Internet	43 (3%)	20 (2%)
Other	111 (9%)	63 (6%)

Note that many participants had gained information from multiple sources.

4. Discussion

The overall lifetime risk of developing breast cancer is approximately 1 in 12, varying with time, across countries and the extent of screening, inflating incidence due to detection of borderline pathologies. The disease is rare in those under 30 years, but age-specific incidence rates rise rapidly between 30 and 60 years, peak in the early 70s, and 5-year survival following diagnosis is over 70% [21,22].

We undertook this study to determine the extent of breast cancer awareness and knowledge in the Irish population so that we could both assess the need for future breast cancer educational programmes and identify audiences that might benefit most from such programmes. Previous studies on this subject have tended to be relatively small, confined to specific racial, age or social groups, have usually been performed by telephone or post or been conducted using a limited questionnaire. Almost all have excluded males. In contrast, this study was designed to be population-based and inclusive, capturing a broad cross-section of the adult general population.

A high proportion of Irish female were aware of breast cancer and appeared to have a fair grasp of facts relating to symptoms, diagnosis and treatment.

Table 3
Knowledge of breast cancer risk factors in 2355 participants stratified by gender

	Females (n = 1250)				Males (n = 1105)			
	Decreases risk	No effect on risk	Increases risk	Don't know	Decreases risk	No effect on risk	Increases risk	Don't know
A family history	6	35 (3%)	1146 (92%)	63 (5%)	18 (2%)	37 (3%)	849 (77%)	201 (18%)
HRT	91 (7%)	98 (8%)	622 (50%)	439 (35%)	52 (5%)	83 (8%)	393 (36%)	577 (52%)
Eating fatty foods	25 (2%)	311 (25%)	585 (47%)	329 (26%)	18 (2%)	190 (17%)	507 (46%)	390 (35%)
Cigarette smoking	13 (1%)	117 (9%)	937 (75%)	183 (15%)	6 (1%)	90 (8%)	759 (69%)	250 (23%)
A stressful life	23 (2%)	179 (14%)	837 (67%)	211 (17%)	15 (1%)	138 (12%)	636 (58%)	316 (29%)
Regular exercise	597 (48%)	406 (32%)	16 (1%)	231 (18%)	471 (43%)	284 (26%)	25 (2%)	325 (29%)
Eating vegetables	542 (43%)	463 (37%)	8 (1%)	237 (19%)	426 (39%)	331 (30%)	10 (1%)	338 (31%)
Early children	191 (15%)	529 (42%)	129 (10%)	401 (32%)	113 (10%)	367 (33%)	113 (10%)	512 (46%)

Note that because of rounding percentages do not always total 100%.
HRT, hormone replacement therapy.

Table 4
Knowledge of breast cancer screening, symptoms and treatment in 2355 participants stratified by gender

	Female (n = 1250)	Male (n = 1105)
Using specialised "screening" tests, can breast cancer be found before any symptoms have developed?		
Yes	993 (79%)	753 (68%)
No	77 (6%)	93 (8%)
Don't know	180 (14%)	259 (23%)
Please name any symptoms of breast cancer		
Could name at least 1 symptom	947 (76%)	642 (58%)
Breast lump	928 (74%)	603 (55%)
Pain	169 (14%)	63 (6%)
Nipple bleeding/discharge	74 (6%)	13 (1%)
Other symptoms[a]	84 (7%)	34 (3%)
Which treatments may be useful for patients with breast cancer?		
Surgery	971 (78%)	744 (67%)
Radiotherapy	778 (62%)	492 (45%)
Medicine	421 (34%)	303 (27%)
Don't know/none available	78 (6%)	161 (15%)

Note that because of rounding percentages do not always total 100%.
[a] Other symptoms included anorexia, weight loss, nipple and skin changes, enlarged glands and fatigue.

Table 5
Knowledge of breast cancer incidence and survival in 2355 participants stratified by gender

	Female (n = 1250)	Male (n = 1105)
At some stage during life, what percentage of females will develop breast cancer?		
Less than 5%	16 (1%)	37 (3%)
5–15%	**17 (14%)**	**218 (20%)**
15–30%	334 (27%)	303 (27%)
Over 30%	486 (39%)	249 (23%)
Don't know	237 (19%)	298 (27%)
What is the most common age to develop breast cancer?		
Less than 45 years	481 (38%)	375 (34%)
45–60 years	621 (50%)	466 (42%)
60–75 years	**31 (2%)**	**31 (3%)**
Over 75 years	2	3
Don't know	115 (9%)	230 (21%)
What percentage of people will still be alive 5 years after having a diagnosis of breast cancer?		
Less than 40%	234 (19%)	185 (17%)
40–60%	470 (38%)	346 (31%)
More than 60%	**325 (26%)**	**309 (28%)**
Don't know	221 (18%)	265 (24%)

Note that because of rounding percentages do not always total 100%. Figures in bold indicate the correct answer.

By contrast, they appeared to have little factual knowledge regarding risk factors for disease. Although most knew that a positive family history was an important risk factor, most also thought that smoking and stress were important. Perhaps more importantly, females were even less knowledgeable about age at onset of disease and long-term survival. So much so that Irish men were significantly better informed on the subject than women, who were particularly pessimistic about incidence and survival following diagnosis. Indeed, only 1 in 4 females realised that prognosis following diagnosis was relatively good and only 1 in 50 recognised that the disease affects primarily older women.

It might be argued that there is no particular reason why survey participants should know anything about breast cancer. However, it is alarming that what females think they know is often incorrect. We specifically included "don't know" as a stem to the answer portion of questions so that participants could indicate their lack of knowledge. Although males answered "don't know" more frequently than females to all questions, males also consistently answered questions relating to risk and outcome correctly more often, although one might imagine that women would be better informed. Our findings relating to males are also important from a social and educational perspective. Although breast cancer rarely develops in men, their partner's or relative's disease often substantially affects them. In addition, the opinions of individual women regarding risk factor modification or screening may also be shaped by their partner's attitudes and beliefs. In addition, individuals of both sexes shape public health opinion and policy. For these reasons, it may be inappropriate to investigate women's breast cancer knowledge and attitudes in isolation. Only a single small postal study performed in Switzerland has previously assessed knowledge of breast cancer in males as well as females: this study found that breast cancer knowledge was no better in women than men [16]. Further data from other countries would be valuable to determine if our results are broadly applicable throughout the European Union.

Why should it be that women are so aware and yet have such poor understanding of breast cancer incidence and outcome? It is clear that risk and outcome data are difficult for the public to understand. Indeed, previous research indicates that even doctors may have a poor insight into breast cancer statistics, precisely because data are frequently given in confusing terms such as conditional probabilities rather than natural frequencies [23]. In addition, perhaps because most information comes from the popular media rather than professional sources, correspondents tend to sensationalise the disease and focus anecdotally on young patients [1], thereby presenting an unrealistic and gloomy overall picture. It is also clear from our study that few women hear of the disease from professionals and the poor grasp of information may reflect how little cancer funding (approximately 2%) is spent on prevention in the British Isles [24]. Furthermore, even when information does

come from professional sources, researchers have found its quality to be frequently poor, especially with regard to risk assessment, mortality and screening [2]. These problems might be redressed somewhat if impartial health-care agencies provided accurate information directly through the print and electronic media in a style which is easily understandable and balanced. In its absence, the ignorance regarding risk factors, incidence and outcome highlighted by this study makes it unlikely that the general public or at risk females could currently make sensible or informed decisions on a range of breast cancer issues including population screening, treatment options or risk modifying lifestyle changes.

Conflict of interest statement

None declared.

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