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Provision of breast cancer risk information to women at lower end of the familial risk
spectrum

Gozde Ozakinci, Ph.D.

Gerry Humphris, Ph.D.

Michael Steel, Ph.D.

University of St Andrews

Corresponding author: Gozde Ozakinci, Ph.D.

Bute Medical School

University of St Andrews

Westburn Lane

St Andrews, Fife, Scotland KY16 9TS

Phone: ++ 44 (0) 1334 463 521

Fax: ++ 44 (0) 1334 467 470

E-mail: go10@st-andrews.ac.uk

1 Abstract

2

3 Background: Breast cancer family clinics provide risk information as one of their key
4 functions. Many referrals to these clinics are 'low risk' women. Objective: To report on
5 the generic risk status letters and printed materials (in the form of leaflets) provided to
6 this category of counselees by UK cancer genetics centres. Methods: Postal survey
7 requesting information materials from genetic centres. Results: Personalised risk letters
8 and/or printed materials were received from sixteen of 22 familial cancer centres in the
9 UK. Personalised risk letters and printed materials currently provided to these
10 counselees display inconsistencies and over-simplification that may lead to
11 misunderstanding. Conclusion: There is a need for collaboration among cancer genetics
12 centres to design more helpful and consistent literature.

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14 *Keywords.* Communication, Risk Perception, Breast Cancer, Familial, Low-risk.

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1 Provision of breast cancer risk information to women at lower end of the familial risk
2 spectrum

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4 Introduction

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6 Breast cancer is the most common form of cancer in women in the UK, accounting for
7 30% of all new cases [1]. Women with a family history of breast cancer are at an
8 increased risk of developing this disease. Recent scientific breakthroughs in medical
9 genetics and growing public awareness have led to greater demand for advice and
10 increased referrals to familial cancer clinics [2]. In addition to risk assessment, women
11 want information about ways to prevent or minimise the chance of developing breast
12 cancer [3]. While many are indeed at significantly increased risk of developing breast
13 cancer, 23-40% of all women referred to breast cancer family clinics are considered (on
14 the basis of their family history) to be at relatively low genetic risk [4-7]. These women
15 are not generally offered access to special surveillance services. The aim of this paper is
16 to report on a survey of generic risk status letters and printed materials (in the form of
17 leaflets) provided to this category of counselees by UK cancer genetics centres.

18

19 Materials and Methods

20

21 Twenty-two familial cancer centres in the UK were invited to provide us with the
22 generic letter written to “low-risk” women as well as any printed material provided. An
23 initial e-mail call via the British Society of Human Genetics was followed up by a letter
24 sent directly by the authors. Overall, twenty centres replied, and from 16 of these,

1 generic letters and/or printed materials were received. Four centres stated that they
2 rarely or never receive “low risk” referrals. We also consulted UK NICE guidelines [5],
3 SIGN Guidelines [6], the American Cancer Society [8], and the Australian National
4 Health and Medical Research Council [9] and National Breast Cancer Centre [10] on
5 population incidence of breast cancer. All leaflets and letters were read and content
6 analysed by the first author. Specifically, the quoted levels of risk were collated and
7 contextual details noted. Ambiguous features of the written information were discussed
8 by all authors to derive consensus.

9

10 Results

11

12 Two sets of observations (see Table) on the printed material and generic letters were
13 recorded:

14

15 1. Breast cancer incidence information: The overall (population) breast cancer
16 cumulative incidence cited in the risk status letters and leaflets ranged from ‘1 in 9’
17 women to ‘1 in 12’ women (see Figure). In the case of one centre, although the letter
18 stated the population risk level as ‘1 in 9’, the Cancer BACUP leaflet that they provide
19 as an accompaniment quoted ‘1 in 10’. Of the thirteen centres which provided
20 cumulative incidence information, 8 stated it as a ‘lifetime risk’, 2 stated the risk as
21 either ‘by the time the women is 80’ or for ‘women under 80’, while 3 did not specify
22 any age range.

23

[Table and Figure about here]

1 NICE guidelines state the cumulative incidence as '1 in 10' by the age of 80, SIGN as
2 8% by age 74; The American Cancer Society reports the lifetime incidence in the
3 United States as about '1 in 7' [8] whereas Australian National Health and Medical
4 Research Council [9] gives '1 in 11' and National Breast Cancer Centre in Australia
5 [10] '1 in 12' before the age of 75.

6

7 2. Delivery of risk assessment: The main theme was the message that the personal risk
8 of developing breast cancer was not significantly raised above that of anyone else in the
9 general population. Statements used included: "*If you are at low risk, your chances of*
10 *getting breast cancer are not much different from that of any other woman in the*
11 *population,*" "*On the basis of your family history you are not at a significantly*
12 *increased risk of developing cancer yourself.,*" "*I would like to reassure you that your*
13 *family history of breast cancer does not significantly increase your own risk of the*
14 *disease. This is a low risk family history.,*" "*This means that your chances of*
15 *developing breast cancer during your lifetime are no different from the chances of any*
16 *other individual in the population.*"

17

18 Discussion

19

20 The effective provision of cancer risk information is important for comprehension and
21 retention of complex information that is important both to the patients and their close
22 relatives. Lack of consensus on how to communicate health risk information effectively
23 [11] presents challenges for health care professionals who are faced with ever increasing
24 numbers of patients seeking advice about personal health risks such as breast cancer.

1 Patients at the lower end of the risk spectrum for hereditary forms of breast cancer
2 comprise a large portion of all referrals to breast cancer family clinics. These patients,
3 after receiving risk information based on their family history, are usually discharged
4 from the services until they reach 50 years of age, when they are entitled to participate
5 in the National Breast Screening Programme, although, in fact, their risks may be
6 appreciably higher than those quoted for the general population [12]. It can be argued
7 that the term “low” (or “lower”) risk, frequently used as “shorthand” by the familial
8 cancer clinics and even in some authoritative literature (though not by the NICE or
9 SIGN guidelines), is misleading and may potentially contribute to inaccurate
10 perceptions of risk of developing breast cancer.

11

12 The observed diversity in the figures quoted can be confusing for patients and their
13 relatives, who may derive cancer related information from different sources and
14 compare notes. Such apparent discrepancies are understandable given that breast cancer
15 risk is highly probabilistic, cumulative incidence of the disease varies from country to
16 country and there are different (valid) methods of calculating risk. Cumulative incidence
17 rates can be calculated on the basis of past cohorts (i.e., historical rates based on those
18 who have completed a full life). Actual lifetime risk of breast cancer was lower for them
19 since breast cancer incidence has increased over the years in all developed countries.
20 Alternatively, the rate may be predicted for women currently in their 30’s by projecting
21 epidemiological trends – probably a more accurate method but dependent on incomplete
22 data. In addition, it is rarely explicit whether the figures cited include any cases of
23 ductal carcinoma in situ (DCIS). Greater numbers of DCIS have been detected since the

1 introduction of large-scale mammographic screening; therefore, incidence rates
2 including them may be inflated [13].

3

4 Delivering information about ways to reduce breast cancer risk is also important for low
5 risk patients, particularly for those who are below the age of 50. This group will not be
6 seen by specialist breast or genetics services unless they present with symptoms to their
7 GPs or their family history of cancer changes. Given that health care provider
8 recommendation is one of the most significant predictors of cancer screening (e.g.,
9 breast, colorectal [14-16], advice and information given to them at the point of personal
10 risk assessment (i.e., via the familial cancer clinics) may be highly salient in initiating
11 behavioural change to reduce breast cancer risk. We observed that several of the centres
12 included advice on risk reduction (e.g., by diet and exercise), ‘breast awareness’, and/or
13 participation in the National Breast Cancer Screening Programme from age 50 but there
14 was no consistent approach adopted.

15

16 Overall, this exercise of examining generic letters and printed material, emphasises the
17 need for agreement on more standardised and comprehensive information provision to
18 “low risk” patients. This may help to reduce misunderstanding and unnecessary anxiety
19 among patients, to improve compliance with risk-reducing measures, and to sustain
20 confidence in genetic and other advice offered by breast cancer family clinics.

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Table. List of centres, type of written information, and provision of cumulative incidence rate

Table.

Centres	Generic Letter	Leaflet	Cumulative Incidence Rate
1	Y	Y	General
2	N	Y	Y
3	N	Y	Y
4	Y	Sheet of information	Y
5	N	Y	General
6	Y	N	Y
7	N	Y	Y
8	Y	N	N
9	Y	Y	Y
10	Y	Y	Y
11	N	Y	Y
12	Y	Y	Y
13	Y	Y	Y
14	Y	N	Y
15	Y	N	Y
16	N	Y	Y

Note. Y = Yes; N = No.