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Eur J Cancer, Vol. 27, No. 7, pp. 913–917, 1991.
Printed in Great Britain

0277–5379/91 $3.00 + 0.00

What Healthy Women Think, Feel and Do about Cancer, Prevention and Breast Cancer Screening in Italy

Deborah R. Gordon, Antonella Venturini, Marco Rosselli Del Turco, Domenico Palli and Eugenio Paci

In preparation for a major campaign to encourage participation in a breast screening programme for all women between 50–70 years old in Florence, Italy, an in-depth study of 200 women's attitudes and practices regarding cancer and its prevention was undertaken. 72% participated in semistructured interviews, and inclination to participate was analysed in terms of Yes (39%), Uncertain (36%), and No (20%) (5% were unspecified). Age ($P = 0.03$), area of birth ($P = 0.01$), education level of husband ($P = 0.04$) and prior Pap smear ($P = 0.00$) or mammography ($P = 0.00$) were among the variables statistically associated with inclination to participate. While the women shared more or less common images of cancer, concern for health, and belief in the importance of God and destiny, those less inclined to participate felt less personally vulnerable, had less faith in medicine's ability to cure or prevent cancer, were more distant from the medical system and culture in general and regarded information about health or illness more as unnecessary or dangerous than beneficial. Understanding and consideration of both "popular" and "medical" cultures need to be encouraged.
Eur J Cancer, Vol. 27, No. 7, pp. 913–917, 1991

INTRODUCTION

IN PREPARATION for a major campaign to encourage participation in a free breast cancer screening programme beginning in 1990 for about 60 000 women between 50–70 years old in Florence, Italy, an in-depth study of women's attitudes and behaviour related to cancer—specifically breast cancer—was undertaken.

The first aim of the study was to describe how Italian women experience, understand and approach cancer and its prevention in their daily lives. It was assumed that women's perceptions of and reactions to a proposed screening test—including not participating—would be culturally grounded in popular, lay logic(s) that would likely differ from medical logic.

A second aim was to identify attitudes, beliefs and behaviours of potential participants and refusers of the programme to help plan campaign messages to reach women with different inclination to participate.

We describe how cancer is perceived among this healthy population in general as well as the differential characteristics of groups of women with varying inclination to participate in the screening programme.

METHODS

The study was based on a random sample of 200 women 50–70 years old selected from the demographic registry of two representative districts of the municipality of Florence. Women were first contacted by letter and then by telephone.

A semistructured interview questionnaire elaborated from a pilot study of 36 women was used. The interviews were carried out by 3 skilled interviewers at the site chosen by the woman: either at home or at the Center for the Study and Prevention of Cancer (CSPO), or when absolutely necessary, by telephone. Direct interviews were tape-recorded. All the interview questions, barring four, were open-ended yet predominantly precoded and a number of answers were recorded with up to three lines of quotation from the women. Inter-rater reliability was

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Revised and accepted 16 Apr. 1991.

checked and found to be satisfactory during the preliminary phase and after the completion of the study; necessary adjustments in the coding were made.

The areas studied included sociodemographic characteristics (education level reached by a woman or by her husband were used as the best indicators of social class); description of life, health status and values; experiences with, perceptions of and understandings of cancer and breast cancer; sense of personal vulnerability; health-related behaviour; faith in medicine and preventive measures; knowledge of cancer and prevention; and orientation towards information and coping with health problems.

The data were analysed in terms of common themes as well as how women indicated their intention to participate in the screening program: Yes, Uncertain and No.

All coded interviews were computerised and the statistical analysis was carried out using SAS [1]. Unless otherwise specified, χ^2 and P values are estimates of the general association of each variate and inclination to participate.

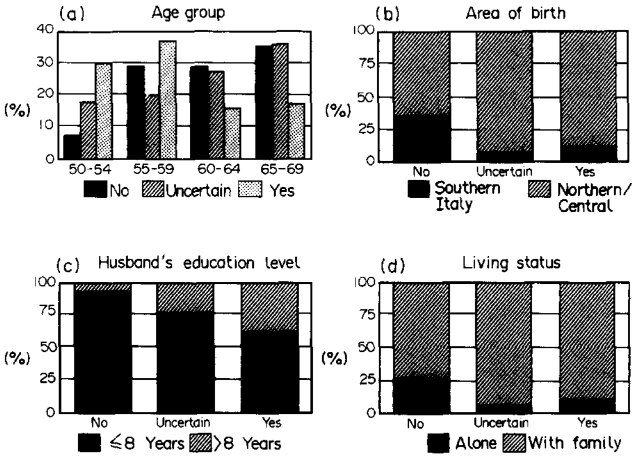

Fig. 1. Sociodemographic characteristics and participation. (a) $P = 0.03$, (b) $P = 0.01$, (c) $P = 0.04$ and (d) $P = 0.03$.

RESULTS

72% (143) of the 200 women randomly selected were successfully contacted and agreed to be interviewed. 34 women refused, 13 women were never found. No differences between the refusers and the participants were found by age ($P = 0.86$) or by health district ($P = 0.66$). Over half (57%) of the interviews were conducted at home, 33% at CSPO and 10% by telephone. The face-to-face interviews lasted approximately 1 hour and those by telephone 20 minutes. In total, 57 women (39%) said they clearly intended to participate, 51 (36%) indicated they were uncertain, 28 (20%) said no and 7 (5%) were not specified. Unless stated otherwise, the percentages cited below are based on 136 women, excluding the 7 women whose inclination is unknown. The "missing" consist primarily of questions not asked in the telephone interviews or of answers classified as "other".

Sociodemographic characteristics are presented in Fig. 1, which shows that younger women or women whose husbands were more highly educated were significantly more likely to say "Yes" to the proposed mammography, while women born in Southern Italy and women living alone were more likely to say "No".

How the women experienced, perceived and explained cancer

Cancer was clearly the illness that most women feared most (80%), primarily for its associations with "suffering" and "an inevitable death" and the way of dying—"slow", "disfiguring", "conscious" and "decaying". Cancer was most often depicted as an aggressive, destructive, malign, external force that attacks the good, healthy, positive part of a person ("an animal that eats, that devours you slowly, slowly") or as cells that are "out of control", "in disharmony", "aggressive, crazy cells that at a certain point begin to work for the devil. . .a factory for the enemy".

Those women who explained the cause of the breast cancer of someone they knew (56 women) cited most frequently a hit or trauma to the breast (20 women; e.g. "the blood can stagnate and become black"). Others referred to a rupture in the normal equilibrium of a woman/mother (such as not having children, having interrupted pregnancies, using birth control pills: 10 women); or to sorrows, stress and worries of everyday life (7 women); or, less frequently, to hereditary factors (3 women).

On the other hand, a good, balanced life, in the sense of eating and living well, was assumed to protect against cancer in general, leaving many women perplexed to explain the cancer of someone they knew. In fact, 40% of all the women named health as the most important thing in their lives, distributed similarly among the three groups (No 39%, Uncertain 37%, Yes 44%).

Nearly half (45%) of the women—essentially equal percentages of those answering Yes, Uncertain or No—believed that God and destiny are very important in matters of health and illness. God, however, was described more as essential in helping one cope with an illness than as primarily responsible for the cause or cure (e.g. "God is important for the support he can give, but not in determining the illness"). Similarly, destiny was often described as subject to the influence of the individual, e.g. "yes, it's destiny, but we write our own destiny".

Experiences with cancer and sense of personal vulnerability

While essentially all women knew someone very close to them who had had cancer, those in the Yes and Uncertain groups tended to have given more direct assistance (No 32%, Uncertain 55%, Yes 51%; $P = 0.14$). Women in all groups said that their fear of cancer increased on the basis of these experiences (No 43%, Uncertain 37%, Yes 53%), but more in the Yes group said they increased their preventive behaviour as a result (No 0%, Uncertain 11%, Yes 39%; $P = 0.00$, missing = 13) and that their faith in medicine and prevention increased (No 14%, Uncertain 27%, Yes 35%; $P = 0.13$).

Furthermore, more women in the Yes group experienced the possibility of having cancer themselves (No 0%, Uncertain 2%, Yes 11%; $P = 0.05$), with 43% having had breast symptoms (No 20%, Uncertain 32%; $P = 0.13$, missing = 16). On the other hand, one quarter of the No group described their health as "bad" or "precarious" (No 26%, Uncertain 12%, Yes 11%; $P = 0.17$, Missing = 4).

Fewer women in the No group named cancer as the illness they most fear (No 64%, Uncertain 82%, Yes 86%; $P = 0.06$). Many women found the question about feeling at particular risk for breast cancer threatening—as if asking or answering it would somehow increase their risk—and thus the question was made optional. 10 of the 13 women responding affirmatively, however, were of the Yes group. The No group had had more fears about contagion when near someone with cancer (No 22%, Uncertain 9%, Yes 2%; $P = 0.02$, missing = 18).

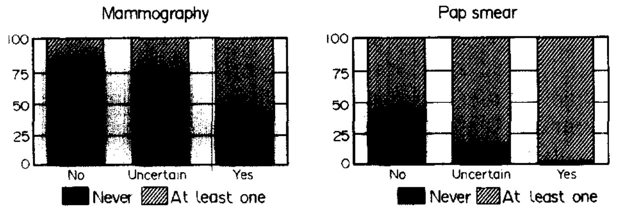

Fig. 2. Health practices and participation (× 100). For both screens, $P = 0.00$.

Health practices vis à vis cancer and illness in general

Women in the No group stood out by the large percentage who had never had a Pap smear (43%) and women in the Yes group by the large percentage who reported having already had a mammography (60%, Fig. 2). In fact, significantly fewer of the Nos had ever frequented CSPO (No 35%, Uncertain 55%, Yes 85%; $P = 0.00$, missing = 9), where public preventive and diagnostic services are offered. Many women in all the groups checked their breasts "a little" (No 61%, Uncertain 69%, Yes 53%); more of the Yes group reported doing it regularly and systematically (No 11%, Uncertain 16%, Yes 30%; $P = 0.07$).

While most women went to the doctor only when they had a specific problem, more of the No and Uncertain groups *avoided* going even with a serious medical problem (No 29%, Uncertain 18%, Yes 9%; $P = 0.05$, missing = 13). Fewer Nos had a regular gynaecologist (No 21%, Uncertain 35%, Yes 52%; $P = 0.03$).

The groups differed little however in attending to potential carcinogens in the foods they eat (No 59%, Uncertain 41%, Yes 45%), in frequency of smoking (No 25%, Uncertain 22%, Yes 23%), or in controlling their intake of animal fats and salt (No 75%, Uncertain 89%, Yes 68%).

Faith in medicine's prevention and treatment of cancer

The No group was more negative about the possibility of really preventing cancer (No 50%, Uncertain 56%, Yes 77%; $P = 0.04$, missing = 23), or of really curing breast cancer (No 46%, Uncertain 65%, Yes 81%; $P = 0.01$). The Yes group associated "prevention" more often with the possibility of early diagnosis (No 14%, Uncertain 22%, Yes 32%), while the Nos cited "controlling what we eat" as the main way they try to prevent cancer in their daily lives (essentially equally with the other groups: No 32%, Uncertain 24%, Yes 30%).

Much more than the others, the No group explained their non-participation in preventive examinations in terms of there being "no need" (50% of those who had never had a Pap smear, 43% of those who had never had a mammography and 32% of those who said they would not participate in the proposed screening programme). "Need" was usually defined as having symptoms. The Uncertain group explained their never having had a mammography mostly by it never having been recommended to them (25%) and by there being no need (24%). A quarter of the No group cited fear as the probable reason for not attending the proposed mammography (No 26%, Uncertain 22%, Yes 16%). On the other hand, the Yes group sought a mammography more on their own initiative and for preventive reasons (No 4%, Uncertain 4%, Yes 32%; $P = 0.00$), and explained their inclination to participate both in terms of belief in the utility of mammography and early diagnosis and in their wanting to remain "tranquil".

Knowledge of medical terminology and attitudes toward being informed

Women in the No group were significantly less familiar with medical terms and facts relating to cancer and its prevention than the others: a fifth (21%) did not know what a Pap smear was ($P = 0.01$, missing = 13); 61% did not know what a mastectomy was ($P = 0.05$); over half (56%) did not know what "breast self-exam" was ($P = 0.03$, missing = 4); and nearly a third (32%) did not know what a mammography was ($P = 0.04$). The Uncertain group was regularly more informed than the No, the Yes group more than the Uncertain. The Yes group referred to cancer as "cancer" more than the others (No 7%, Uncertain 14%, Yes 25%; $P = 0.10$).

Women's inclination to participate was correlated with two characteristic approaches to information as a means of coping with a potentially serious health problem: 43% of the No group identified themselves in the "the less I know the better I am" approach (Uncertain 25%, Yes 16%; $P = 0.01$, missing = 27), while 36% of the No identified with "the more I know and the earlier I know, the better I am" tendency. In fact, fewer Nos were clearly interested in receiving more information about breast cancer and its prevention (No 40%, Uncertain 58%, Yes 75%; $P = 0.02$, missing = 21).

DISCUSSION

Cancer is a known, feared and symbolic illness for very many of these women. It is both grounded in actual lived experiences—often painful and fearful—with someone who has had cancer, while being reified through images of animals and beasts or even cells that embody the bad, the other, the malign or the devil [2, 3]. Undoubtedly it is this wedding of cultural with personal meanings of cancer [4] that makes it so strong and tenacious. Co-existing with these terrifying and pessimistic images, however, are more positive expectations, specifically for breast cancer.

The Yes and No groups differ most (the heterogeneity and complexity of the Uncertain group permit only partial conclusions) in their sense of personal vulnerability [5–7], their understanding of disease and early diagnosis and their faith in medicine's ability to prevent and cure cancer [8, 9], their distance from the medical system and culture [6], their pre-existing health behaviour [5, 8–11] and their approach to information [7, 11].

The women saying No seem to have been less affected by cancer and to live it more distantly, albeit more pessimistically. In general they are also more distant from the medical system and culture, even avoiding it when they have a serious problem. Many fewer have adopted the idea of a disease existing without symptoms or the belief and practice of prevention through early diagnosis. In part reflecting their age, social class, personal history and distance from the medical system, they tend to have a more traditional, popular approach to cancer, referring to it more by popular names, having more concern about it being contagious (a likely carryover from knowledge of tuberculosis) and more pessimism about the possibilities for cure. Being less convinced of the curability of breast cancer and cancer in general, many prefer to maintain a tranquil *status quo* rather than look for problems before they arrive. Many in fact perceive information—about one's health status and about breast cancer and prevention in general—as unnecessary if not outright dangerous. Clearly the least informed on medical matters, the No group was also the least interested in learning more. This implies that their lack of medical knowledge is not necessarily due to lack of opportunity and that many are interested in maintaining their distance from the illness.

Of importance, however, is that many in the No group value health highly, but they appear to realise this meaning less through resort to the medical system and more through control of their food and occasional breast self-checking, through living a "balanced life", and through more primary than secondary preventive measures. Similarly, the stereotype of "refusers" as unique in their strong beliefs in destiny or God for matters of health and illness does not hold here, as nearly half of those in the Yes and Uncertain groups held these same beliefs, sometimes more so than the No.

Undoubtedly, many of these characteristics are related to women in the No group being older [12], of a lower social class [10, 12] and coming more from southern Italy [13], but it is unlikely that these factors completely explain the story.

More of the Yes group, on the other hand, have been personally touched by cancer and live with an awareness of the possibility of their having it, which they defend themselves with information and preventive examinations. They tend to regard these examinations as a safeguard for their tranquillity—either as a reassurance that there is no problem, or as a means of preventing or minimising a potential problem [11].

The Uncertain group often stood between the No and Yes groups. They, like the Nos, are older than the Yes group, and while they have more contact with the medical system, are more informed and practise preventive examinations more than the No group, they seem to have adopted medical values and practices less than the Yes. They are more susceptible to support from medical authority.

The health belief model [14, 15] posits four main factors that determine a given individual's preventive behaviour: perceived severity of the illness, perceived susceptibility of the person, perceived benefits of the behaviour and perceived barriers to realising it. This study concords with others that found perceived severity of the illness to be a poor predictor in comparison to perceived susceptibility, benefits and barriers [16]. The prospective nature of this study, however, must be underscored, although other research has found a strong association between stated intention and future participation [5, 16].

We must note that frequently studies of preventive behaviour speak of "psychological factors" or of health beliefs primarily in terms of individuals. The more general cultural context within which these women live and function must also be considered. For example, the wide-spread belief in Italy in the power of thinking, knowing, talking and looking for to bring on the very thing one wishes to avoid [3] is a significant cultural context for any health campaign efforts and action, especially one that addresses the topic of being at risk.

In conclusion, a health screening program in which healthy women are called into a medical establishment to be X-rayed in order to identify a hidden problem represents a very particular approach to prevention and an ideology that is part of the culture of medicine, albeit a minor one. This particular approach to health and illness confronts popular, lay culture(s) of the people it tries to reach. We thus may speak, with due caution, of an encounter between different cultures. In fact, these two cultures are shared by all involved to varying extents: many women have adopted meanings and practices characteristic of official medical culture, and clearly health care practitioners share many popular meanings, emotions and practices [17].

The term "compliance", commonly used regarding screening or treatment programs, implicitly denies the legitimacy of these two cultures and posits instead the rightfulness and the power of the medical approach [10]. Patients comply or not or are obedient or not to the right way to practise health care and prevention. While such a stance is dubious in any case, it is particularly so given the controversy surrounding screening programs within the medical establishment [18, 19].

To approach women who are less inclined to participate as ignorant, fearful and full of misconceptions and superstitions denies the cultural sense and historic grounding of these women's behaviour. Understanding such a sense could lead either to respectful acceptance or to reaching women in terms of the very things they value. In fact, this study suggests that both primary and secondary prevention best be conceived of as personal health habits, rather than medical ones, as part of women's life-style and culture, rather than a response to medical authority and culture. In other words, secondary prevention should be demedicalised to the greatest extent possible, oriented towards healthy women rather than "potential patients" and provided in settings that evoke more a sense of home than of medicine and illness.

Clearly the pattern has been to know little about how people live and understand cancer, its genesis, development, prevention and treatment. Such ignorance on the part of those in the health care system can be as costly as the ignorance of people regarding health matters that affect their lives. Respect and understanding among the two sectors may help to decrease mutual ignorance and provide a common ground for challenging the difficult history that cancer has presented.

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Acknowledgements—We thank Nicoletta Susini and Donatella Tanzini for interviewing and coding; Eva Buiatti and Enzo Merler for their comments on the manuscript; and the Italian Association for Research on Cancer (AIRC) and the Italian League for the Fight Against Cancer, Florence branch, for financial support.

Eur J Cancer, Vol. 27, No. 7, pp. 917–921, 1991.
Printed in Great Britain

0277–5379/91 $3.00 + 0.00

Socioeconomic Status and Cancer Mortality and Incidence in Melbourne

Joanne Williams, Christine Clifford, John Hopper and Graham Giles

Data were obtained for all deaths registered between 1979–1983, and for all new cancers recorded at the Victorian Cancer Registry between 1982–1983, in residents of Melbourne. A socioeconomic status (SES) measure had been produced for each local government area (LGA) by principal components analysis of sociodemographic variables recorded at the 1981 census. A SES score from 1 to 10 was assigned to each death and cancer. Population data from the census were similarly scored. Age standardised rates for all cause mortality, for mortality from all causes other than cancer and for both incidence and mortality of total cancers, cancer of the stomach, colon, rectum, lung, female breast, cervix, uterus, prostate and bladder, and for melanoma, lymphoma and leukaemia were analysed as a function of SES decile using weighted linear regression. Despite the limited number of years of data and the misclassification of the SES score, analyses showed there were inequitable distributions of mortality, and of some major cancers, across social strata in Melbourne during the early 1980s. The incidences of cancer of the breast, colon, prostate and melanoma were all positively associated with SES, while the incidences of cancer of the stomach, lung and cervix demonstrated negative SES gradients. For cancers where incidence showed a significant SES gradient there was a similar SES gradient with mortality. These patterns are consistent with the literature and implicate SES differences in education and access to services. Implications for health policy are discussed.
Eur J Cancer, Vol. 27, No. 7, pp. 917–921, 1991

INTRODUCTION

SINCE THE late nineteenth century, much has been written about the typically negative associations between socioeconomic status (SES) and measures of both health status and mortality [1–5]. This is particularly true of malignant disease, and many associations between specific cancers and SES have been observed in studies from several countries using various measures of SES. The consistency of this evidence has lent credence to the idea that SES has a real association with cancer occurrence and mortality. It is the mechanisms that have remained subject to debate.

A review of 28 studies from 11 countries published prior to 1981 [5] showed that all cause mortality and all cancer mortality decreased with increasing SES and that mortality from cancer of the oesophagus, stomach, liver, lung and cervix also decreased with increasing SES, whereas mortality from cancer of the breast, ovary and brain increased with decreasing SES. In the same review, mortality from cancer of the colon, rectum, skin, uterus, prostate, bladder and kidney, leukaemia and lymphoma varied in its relationship with SES across populations.

Analysis of reports of the Registrar General's Office of England and Wales from 1851 to 1971 on cancer mortality by occupation and social class [5] showed that standard mortality ratios decreased with increasing SES for cancers of the oesophagus, stomach, rectum, lung and skin (other than melanoma) in both men and women, and for prostate cancer in men and for cervical cancer in women. Conversely, standard mortality ratios which increased with increasing SES included cancer of the colon, pancreas, melanoma and brain, leukaemia, lymphoma and myeloma in both men and women and breast and ovary in women.

A relationship between SES and cancer has also been reported in Australian populations. McMichael [6] demonstrated a strong negative correlation between SES and deaths from lung and stomach cancer in Australian males. Siskind *et al.* [7] investigated all cause mortality in Brisbane and found higher overall mortality rates in lower ranking SES strata. Lung cancer, however, was the only malignancy for which this association was evident. Bonnet *et al.* [8] examined cancer survival and SES in South Australia. Significantly lower survival in low SES groups was observed for both cancer of the colon and breast cancer.

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Received 2 Apr. 1991; accepted 3 Apr. 1991.