

Italian forum of Europa Donna: a survey of breast cancer associations

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Abstract

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Europa Donna is the first European woman's movement against breast cancer. It is a coalition of breast cancer associations and individual women and is active in 20 nations. Europa Donna is not intended to replace existing organizations. Rather, it provides a focus for the exchange of information and experiences between members and serves as a moving force for combined action. It promotes public awareness of breast cancer, advances in research and good clinical practice. In Italy there are more than 200 active breast cancer associations. The Italian forum of Europa Donna was formed in 1996. Between June and September 1996 a postal survey was conducted to research the characteristics and activities of the various breast cancer associations in Italy in order to help, inform and promote future initiatives of the Italian forum of Europa Donna. A total of 213 breast cancer associations were sent a postal questionnaire. Ninety-five of them (44.6%) participated in the survey. The results show that the breast cancer associations in Italy vary markedly in terms of their structure and organization. The associations perceive a variety of deficiencies in the prevention, diagnosis and treatment of breast cancer within the Italian National Health Service and they offer a wide range of services themselves. Their views of the relevance of the 10 goals of Europa Donna vary. In this paper, we discuss the implications of the low rate of participation in the survey and the heterogeneity of the breast cancer associations' structures, activities and views for the future activities of the Italian forum of Europa Donna.

Introduction

Important changes in the last decade have brought consumers – whether patients or not – to the fore in the general debate on health care.¹⁻⁴ Consumers are increasingly encouraged to take more responsibility for their health and to find out more about the treatments available for their health problems.⁵⁻⁷ This has contributed to an increase in the number of voluntary organiza-

tions representing patients' interests. Breast cancer associations feature prominently amongst these.^{8,9}

Europa Donna (ED) is the first European woman's movement against breast cancer. It was inspired by the American National Breast Coalition and is now active in 20 nations: Austria, Belgium, Croatia, Estonia, France, German, Greece, Hungary, Ireland, Israel, Italy, Lithuania, Netherlands, Poland, Portugal,

Russia, Slovene, Spain, Switzerland and the United Kingdom.

As a pan-European coalition, Europa Donna aims to boost the involvement of breast cancer associations and individual women in activities to promote the prevention, diagnosis and treatment of breast cancer. It is not intended to replace existing organizations but rather to provide a focus for the exchange of experiences and information between member countries and a moving force for combined action. Ten goals have been identified. They relate to increasing women's awareness of breast cancer, promoting appropriate screening, campaigning and acting on various fronts to ensure optimum treatment for women with breast cancer and promoting advances in research. The goals were deliberately kept broad in character to allow for national variations within Europe in terms of both cultural, social and economic climates and the state of development of breast cancer care.⁸

In Italy about 31 000 new cases of breast cancer are identified each year and over 11 000 women die from breast cancer each year.¹⁰ About 200 associations work with women with breast cancer. Some associations are locally based (independent associations), some are large national organizations such as ANDOS (Associazione Nazionale Donne Operate al Seno), FADOS (Federazione delle Associazioni Donne Operate al Seno), and Lega Italiana per la Lotta Contro i Tumori, the Italian cancer prevention league. The associations offer a range of services including psychological and physical rehabilitation. Many of the people who are paid or volunteer to work in these associations are themselves women who have experienced breast cancer and have managed nevertheless to build fulfilling and positive lives.¹¹

In 1996 a group of breast cancer associations agreed to organize the Italian forum of Europa Donna (ED-FI). The forum aims to provide an opportunity for the different associations to share information and contacts, to plan strategies for increasing awareness of breast cancer, and to promote good quality care at a national level.¹²

In 1996, the only available list of Italian breast cancer associations did not provide details about their activities.¹³ As one of its first acts, ED-FI carried out a postal survey to obtain information about the characteristics and activities of the various breast cancer associations in Italy. The survey was coordinated by the Mario Negri Institute and had the following aims:

- to collect information about the breast cancer associations' characteristics and activities, and their perceptions of the adequacy of local health service provision relating to the prevention, diagnosis and treatment of breast cancer;
- to stimulate the breast cancer associations to commit themselves to common aims and to share – in Italy and Europe – their historical, social and human experience;
- to assess the relevance of Europa Donna's 10 goals to Italian breast cancer associations and to inform the future programme and activities of ED-FI.

Methods

The survey was conducted between June and September 1996. An interdisciplinary working group involving the members of breast cancer associations (women with experience of breast cancer), researchers, clinicians and psychologists was set up to contribute to three different phases of the project.

Phase 1 involved the creation of an up-to-date list of breast cancer associations. This was based on the list of associations involved in a Breast Cancer Follow-up Consensus Conference¹⁴ and associations reported in the Yearbook of the Italian Social Voluntary Organizations.¹³

In phase 2 a questionnaire was assembled to gather data about different aspects of the breast cancer associations and their activities. The following areas were considered:

- structure, organization and staffing of the associations;
- the associations' activities, including the services they provide for women with breast cancer;

- the associations' perceptions of deficiencies in local health services in terms of the prevention, diagnosis and treatment of breast cancer (including follow-up care) and their views of the desirability of particular developments;
- the perceived relevance of the 10 goals of Europa Donna.

Most questions had fixed response options. Space was also provided for respondents to provide more details or explanations.

In phase 3 each association was sent a letter describing the research, a copy of the questionnaire together with instructions for completing it, and a stamped return envelope addressed to the co-ordinating centre (Institute Mario Negri). Code numbers were used to identify respondents and associations which did not return the questionnaire (either completed or blank) within 45 days were sent a second questionnaire packet.

The data collected were analysed using the SAS Statistical Package. The results are reported in terms of frequencies. Percentages were calculated using the total number of valid answers to each single question as the denominator. The rate of missing data was low (about 5%) for the questions with fixed response options, but higher for questions with open response formats.

Results

The questionnaire was sent to 213 breast cancer associations and 95 (44.6%) sent it back com-

pleted. The proportions of different types of association that responded varied, ranging from 29% of Lega Italiana branches to 68% of independent associations, as shown in Fig. 1.

Figure 2 shows the geographical distribution of the associations that were contacted. There are more breast cancer associations in the northern and central areas of Italy than in the south. A lower proportion of associations from the south (31%) responded to the questionnaire compared to those from central (40%) and northern (53%) areas.

The main characteristics of the responding breast cancer associations are summarized in Table 1. They have been established for an average of 12 years and are run mainly by volunteers. Relatively few consult with clinical breast cancer specialists on a regular basis and 16% said they were not in contact with other similar associations.

Table 2 shows the percentages of associations that offer particular services or activities on a regular basis. The average number of services offered per association is six, with older associations tending to offer more services. More than 80% of the associations offer psychological assistance and provide printed information materials. About 60% of the associations promote breast self-examination and organize entertainment for their members. Estimates of the number of women with breast cancer who used the services of any one association in 1995 varied from about 10 to several hundred, but

Figure 1 Breast cancer associations contacted (213) and participants (95)
 ANDOS = Associazione Nazionale Donne Operate al Seno, i.e. National Association Women Breast Operated;
 FADOS = Federazione delle Associazioni Donne Operate al Seno, i.e. Federation of Associations Women Breast Operated;
 LEGA = Lega Italiana per la Lotta Contro i Tumori, i.e. Italian Cancer Prevention League.

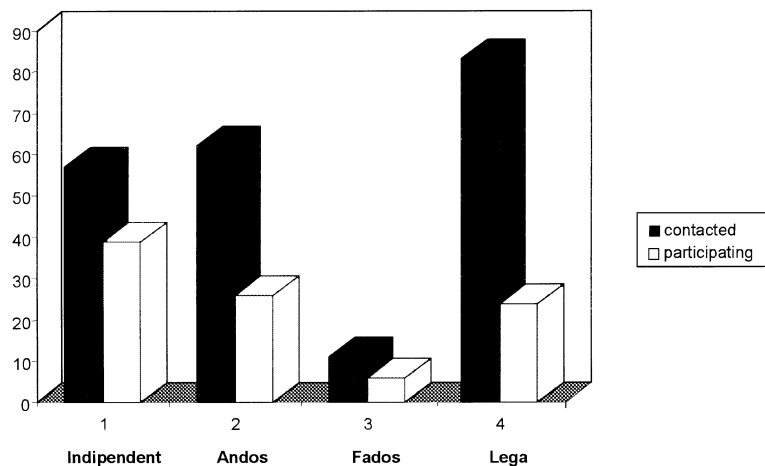




Figure 2 Geographical distribution of breast cancer associations contacted. Grey areas represent regions where more than 50% of contacted associations answer at the postal survey.

quite a few respondents appeared unable to say how many women used their services.

Table 3 shows the percentages of breast cancer associations nationally and by area that

perceive deficiencies in the prevention, diagnosis and treatment of breast cancer in the local health care system. The associations reported a variety

Table 1 Characteristics of breast cancer associations participating in the postal survey

Average life to date 12 years
On average more than 20 volunteers work for each association
84% of associations are in contact with other associations
73% of associations have their own centre
59% of associations have daily opening hours
61% of associations have volunteers working in hospitals
38% of associations have volunteers providing home assistance
32% of associations are in regular contact with medically qualified clinical breast cancer specialists

Table 2 Number of breast cancer associations providing particular services on a regular basis

Psychological assistance	81.1%
Distribution of information and printed material	80.0%
Promotion of breast self-examination	64.2%
Entertainment (concerts, excursions)	60.0%
Training courses for volunteers	56.8%
Assistance with administrative procedures for obtaining prostheses or invalidity papers	54.7%
Rehabilitation exercises	49.5%
Dietary education	43.2%
Lymph draining services	42.1%
Organization of courses: exercises, yoga, swimming	34.7%
Library	30.5%
Prosthesis fittings	12.6%

Table 3 Percentages of associations reporting structural and organizational inadequacy in local health services relating to the prevention, diagnosis, cure and follow-up of breast cancer

	Nationwide	North	Centre	South
Prevention	67%	59%	76%	81%
Diagnosis	43%	29%	58%	69%
Cure	29%	19%	42%	44%
Follow-up	29%	23%	32%	44%

of plans for tackling problems in their own areas. These included: dissemination of up-to-date information; greater involvement of general practitioners; increasing their contributions to prevention programmes; and investment in the National Health Service.

Finally, Table 4 lists the 10 goals of ED in the order of decreasing relevance to the breast cancer associations that participated in the survey. Highest priority was given to promoting the early detection of breast cancer and information exchange.

Discussion

The Italian Forum of Europa Donna is a coalition. It seeks to develop a consensus amongst all associations involved in the fight against breast cancer in Italy and to plan co-ordinated interventions with their support. An understanding of the characteristics of the existing associations and of the problems they perceive with local health services was seen as a necessary first step to help identify the types of initiative that are likely to interest them. Our survey suggests that campaigns for improving the early diagnosis of breast cancer and quality of care for women with breast cancer will be important.

A large proportion of local breast cancer associations did not answer the questionnaire although it was simple and brief. There are several possible reasons for this. Some of the associations might have had practical difficulties in completing the questionnaire either because they do not routinely document all their activities and/or because they are run largely by volunteers and do not have enough staff or resources to allow them to participate in surveys

Table 4 The goals of Europa Donna in order of decreasing relevance as rated by the breast cancer associations participating in the postal survey

To emphasize the need for appropriate screening and early detection
To promote breast awareness
To promote the dissemination and exchange of factual, up-to-date information on breast cancer throughout Europe
To campaign for the provision of optimum treatment
To advocate appropriate training for health professionals
To promote the advancement of breast cancer research
To ensure that all women understand fully any proposed treatment options, including entry into clinical trials and their right to a second opinion
To ensure the provision of quality supportive care throughout and after treatment
To demand regular quality assessment of medical equipment
To acknowledge good practice and promote its development

without detracting from their priority activities. Members of Lega Italiana, the cancer prevention league which works mainly for early diagnosis (screening programmes), might not have perceived the questionnaire as relevant to themselves. Other breast cancer associations concentrate on providing support to local women with breast cancer. They are possibly less interested in research or political activities. Many local associations, particularly the independent ones, work in relative isolation. They are not in contact with each other and are not well connected to the National Health Service.

The fact that some local associations might not be particularly keen or well prepared to work in coalition with others has important implications and might limit the effectiveness of ED-IF. The ED-IF is currently organizing various initiatives to promote the involvement of breast cancer associations and individual women in coordinated campaigning activities. These include training courses for breast cancer activists, circulation of information on particular topics, a newsletter and a national meeting. In addition, ED-IF is seeking to improve the information that is available about the needs of Italian women with breast cancer and the way they are served by the breast cancer associations.

During 1998 it has been carrying out a survey of the types of information that women ask breast cancer associations for.

There is a deep-rooted presence of local breast cancer associations in Italy. Many women with experience of breast cancer work actively as volunteers to help others and many associations try to keep a centre open for women with breast cancer every day. The local associations each have their own history. They came to be involved in the breast cancer situation in a variety of ways. This has led to them relying on different sources of information and developing different types of service. The local associations are likely to differ in their views about particular treatments. They may, for example, tend to favour different techniques of lymph draining or different types of psychological support.

A lack of consensus amongst local breast cancer associations may be a barrier to effective coordinated action. The ED-IF is proposing several projects to attempt to establish a consensus amongst the associations and individual women through research, sharing of information, working groups and discussions.

The associations describe a generally unsatisfactory picture of many aspects of the prevention, diagnosis and treatment of breast cancer within the National Health Service in Italy. Proportionally more breast cancer associations in the central and southern areas of the country reported dissatisfaction with local services than in the north. This reflects the findings of previous surveys of medical staff.^{15,16} The ED-IF can make a difference by lobbying for changes in the health care system. In 1997, for example, it successfully worked to simplify the medical-bureaucratic-administration procedure required by the National Health Service to obtain breast prostheses.¹⁷

There is undoubtedly plenty of room for improvement in the prevention, diagnosis and treatment of breast cancer in Italy. The ED-IF will work to enable existing breast cancer associations and individual women make a more effective contribution to improving the range of services offered, quality of care and the quality

of information given to the patients. In doing so, it will need to continue to be sensitive to the views of Italian women and the characteristics of the local breast cancer associations.

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Appendix 1 List of Association participating in the postal survey

ANDOS

Alba, Arezzo, Aversa, Belluno, Borgomanero, Cortina, Ferrara, Gravelona Toce, Grottaglie, Legnago, Mantova, Milano, Napoli, Padova, Pordenone, Portoferraio, Roma, Rovigo, Roccaspede, Roma, S. Daniele del Friuli, Tolmezzo, Udine, Viadana, Varese, Viterbo.

FADOS

Firenze, Lucca, Padova, Pistoia, Roma, Torino.

Independent Associations

Arona, Forti e Serene; Bari, Donna Piu' di Prima; Belluno, Commissione Intesa Associazioni Volontaristiche; Bergamo, Gruppo Piu' Donna; Biella, Fondo Edo Tempia Lotta Contro i Tumori; Bologna, Comitato Sempre Donna; Bolzano, Assistenza Tumori Alto Adige; Busto Arsizio, Centro Donna-Donna; Cagliari, Asa.Ma Associazione Sarda Assistenza Mastopatiche; Chianciano Terme, Iosempredonna; Firenze, European Association Of Women's Health; Firenze Societa' Italiana Di Medicina Generale; Foggia, Per Essere Sempre Donna; Forli', Istituto Oncologico Romagnolo; Genova, Sempre Donna; Livorno, Sempre Donna; Milano, Attive Come Prima; Monza, Salute Donna; Napoli, Donna Come Prima; Napoli, Alts-Associazione per la Lotta ai Tumori Del Seno; Padova Ceav Cancro E Assistenza Volontaria; Omegna Associazione; Padova, Azienda Ospedaliera; Perugia Associazione Umbra Lotta Contro i Tumori; Perugia, Conoscere Per Vincere; Piacenza, Rosalei; Piacenza, Armonia; Piombino, Sempre Donna; Reggio Emilia, Associazione Per La Salute Femminile 'La Melograna'; Rimini, Adocm-Crisalide; Roma, Commissione Donna & Salute—Movimento Difesa del Cittadino; Salsomaggiore, Insieme Per La Salute; Salsomaggiore, Insieme Per La Salute Ass. Di Volontariato Qdv In Oncologia; Siena, Associazione Studio Qualita' Della Vita In Oncologia; Siena, Associazione Serena; Torino, associazione Nazionale Assistenza Psicologica Malati Cancro; Saronno, Centro Donna-Donna; Trento, Donna Come Prima; Varese Centro Donna- Donna Varese.