Pergamon

European Journal of Cancer, Vol. 35, No. 12, pp. 1667–1675, 1999
© 1999 Elsevier Science Ltd. All rights reserved.
Printed in Great Britain
0959-8049/99/$ - see front matter

PII: S0959-8049(99)00170-7

Original Paper

Caring About Women and Cancer (CAWAC): A European Survey of the Perspectives and Experiences of Women with Female Cancers

U. Veronesi,[1] S. von Kleist,[2] K. Redmond,[3] A. Costa,[4] N. Delvaux,[5]
G. Freilich,[6] A. Glaus,[7] T. Hudson,[8] J.G. McVie,[9] C. Macnamara,[10]
F. Meunier,[11] S. Pecorelli,[12] D. Serin[13] and the CAWAC Study Group*

[1]European Institute of Oncology, Milan, Italy; [2]University of Freiburg, Institute of Immunobiology, Freiburg, Germany; [3]European Oncology Nursing Society, Brussels, Belgium; [4]European School of Oncology, Viale Beatrice d'Este 37, 20122 Milan, Italy; [5]Service de Psychologie, Hopital Universitaire Erasme, Bruxelles, Belgium; [6]Europa Donna, The Cancerkin Centre, Royal Free Hospital, London, U.K.; [7]Zentrum für Tumordiagnostik und Prävention, St Gallen, Switzerland; [8]UICC, COPES Programme, Geneva, Switzerland; [9]The Cancer Research Campaign, London, U.K.; [10]European Union of General Practitioners, Dublin, Ireland; [11]European Organisation for Research and Treatment of Cancer, Brussels, Belgium; [12]European Institute of Oncology, Milan, Italy; and [13]Clinique Sainte-Catherine, Avignon, France

---

This paper reports on the findings of the largest ever European survey of female patients' perceptions of their cancer treatment. It has provided clarification of what women consider important in relation to their management and has identified several areas where more research is needed. It has shown that women's knowledge about cancer before diagnosis is poor and the number undergoing regular screening could be improved. Women are not being adequately prepared and educated about what to expect from treatment and steps should be taken as a matter of urgency to redress this shortcoming. It was revealed that whilst families were the primary source of support to female cancer patients, women also derive considerable support from healthcare professionals, particularly senior doctors; more attention should be paid by specialists and nurses to developing psychological skills to cope with this. In this context, further research is needed into how support groups may best meet patient needs.

Key words: female cancers, cancer services, patient survey, patient attitudes, patient support
Eur J Cancer, Vol. 35, No. 12, pp. 1667–1675, 1999

INTRODUCTION

PROFESSIONAL ATTITUDES to providing cancer care have undergone major changes over the past few decades, and the belief that standards of care should be monitored, evaluated and constantly improved has gained wide acceptance. It is increasingly acknowledged that successful care for cancer comprises more than just the clinical outcome. Parameters such as quality of life and patient satisfaction are now established as valid outcome measures, alongside efficacy, for any new drug or treatment regimen [1]. They are also gaining in importance when decisions are made about provision of healthcare, and used as criteria of quality of care at both local and national levels [2–5]. Improving overall quality of care also reflects recognition of the psychological impact that the diagnosis and treatment of cancer has on the individual, and the need for emotional support and information for the cancer patient has also been well recognised [6–10].

Correspondence to A. Costa.

Received 9 Mar. 1999; revised 5 Jul. 1999; accepted 10 Jul. 1999.

*The CAWAC Study Group: K. Bertelsen, M. Castiglione, M. Codd, H. Cortés-Funes, I. De Wever, J. Diaz-Faes, B. Ernst, J. Fennelly, A. Gentil Martins, M. Giannakou-Koutsikou, T. Hatschek, P. Hietanen, R. Kåresen, M. Kaufmann, K. Kopp, F. Langmark, K. Menoni, M. Micksche, J. Mossman, T. Osório, G. Rigatos, E. Robinson, L. Santi, K. Sikora, M. Sorsa, R. Wodak and M. Ziv.

People are increasingly accepting some responsibility for their own healthcare and becoming better informed about healthcare issues. A greater focus on health education and preventative healthcare has encouraged women to adopt healthier lifestyles and to undergo screening or regular health checks. Moreover, when disease does occur, patients are given more opportunities to participate in decisions about their own treatment, which for many, can lessen the trauma of the whole cancer experience [11–14]. A crucial factor that underpins the ability of a patient to be involved in healthcare is information. Thus, information and psychological support have assumed important roles in the care process for cancer.

This survey was carried out to assess how well educational initiatives are reaching women, whether they are taking up screening opportunities, and how they perceive the current status of cancer care. This is the largest ever survey carried out in Western Europe and included over 13 000 women with cancer from 15 countries. It follows a similar survey conducted on a smaller scale in France [15].

PATIENTS AND METHODS

Design and sample

A descriptive survey was undertaken by the Caring About Women and Cancer (CAWAC) programme, with the voluntary support and scientific assistance of a number of European cancer organisations and specialists. The aim of CAWAC is to support female cancer patients and their carers. This survey was conducted to explore the perceptions and experiences of women diagnosed with female cancers at all stages of the cancer experience, in order to identify areas in which patient care and cancer services can be improved. The survey was designed under the supervision of a European Core Advisory Board (ECAB) and carried out by an international market research company (Wirthlin Worldwide) during the period June 1997–April 1998 in 15 countries: Austria, Belgium, Denmark, Finland, Germany, Greece, Ireland, Israel, Italy, Norway, Portugal, Spain, Sweden, Switzerland and the U.K. For the purposes of this survey, in line with the World Health Organisation (WHO), Israel was classified as part of Europe. A similar survey had already been carried out in France. National Advisory Boards (NABs) were responsible for the survey's implementation in their respective countries (see Appendix).

Random sampling of women with cancer was not feasible because a sampling frame could not be constructed. Therefore, it was decided that a randomised hospital selection procedure would be used, but because of the considerable international variations in the structure of healthcare services some flexibility had to be allowed. The standard procedure was to obtain a list of all hospitals that would see cancer patients, either from the Ministry of Health or from a national cancer association. Countries were divided into regions and the number of hospitals to be recruited per region assessed on the basis of population density, thus ensuring a fair sampling across populous and non-populous areas. Hospitals were then selected at random. Major exceptions to this procedure occurred in Denmark, Norway, Ireland, Israel, Spain, and Sweden where named hospitals were selected for inclusion, usually under the direction of the local NAB. Such selection was necessary, since in these countries cancer care is very focused to particular hospitals and random selection would include too many hospitals that saw low numbers of cancer patients. If a hospital refused to take part in the study, it was replaced by another hospital of similar size and/or geographical location. Once hospitals had agreed to participate, they were sent questionnaires to be distributed by doctors and nurses, and asked to return all unused forms. Geographical weighting based on the total population was used to correct for population disproportions in returned questionnaires. The assumption in using total population statistics for weighting was that the distribution of female cancer patients would reflect the distribution of the population as a whole. Ethics committee approval was obtained where necessary, in accordance with local regulations. Patients gave oral consent to being included in the survey and were assured that all questionnaires were anonymous.

Inclusion criteria were: women aged ≥ 18 years, who had been diagnosed with breast or gynaecological cancer (ovarian, cervical, uterine or vulval cancers), who were aware that they had cancer, were scheduled to have or had embarked upon therapy (surgery, radio-, chemo- or hormone therapy or breast implantation or reconstruction), who were literate, and were regarded by the medical staff as physically and psychologically capable of completing the questionnaire.

We accept that there are some limitations to this sampling approach. The aim of CAWAC was to survey opinions across as large a sample population as possible. The involvement of healthcare staff, therefore, had to be minimal to avoid impinging on their time, and there were no incentives to participate beyond the contribution to the body of knowledge in this area. For this reason simple entry criteria were chosen in that the women had to be aware of their diagnosis (which does not always occur in some parts of Europe, but it was considered that anyone unaware of their diagnosis would either produce answers not relevant to the survey or would discover their diagnosis by implication from the survey, which was totally unacceptable). The next criteria were being physically and mentally capable of completing the questionnaire. The form had 70 separate items to be completed and it was felt that frail or very poorly individuals should not be approached and those without a basic level of literacy should not be included, as they would have difficulty in completing the questionnaire.

Questionnaire

Initially focus group interviews were carried out in member countries to identify the issues of concern to women with cancer. These were used for developing the pilot questionnaire by the NAB members, that was used in trials in the U.K., Greece and Germany. The questionnaire underwent redrafts following testing in Italy, Switzerland, Portugal, Austria and the U.K. At each stage patient feedback, medical and sociological considerations were incorporated into the draft, with the NABs ensuring that the questions were relevant and reflected local practice. The final stage included translation, and the other language versions were then translated back into English to ensure accuracy and veracity of translation. The final questionnaire was pilot tested across all participating countries. The resultant questionnaire included 70 closed questions covering five domains (Table 1).

A minimum 30-day period was allowed for distribution; doctors and nurses were asked to give questionnaires to all patients fulfilling the entry criteria who were seen during this period. Patients were asked to complete the questionnaire themselves and return it in a prepaid envelope to the market research company.

Table 1. *Content of the questionnaire*

Domain	Topics covered
Prediagnosis knowledge	Perceptions of cancer; patients level of knowledge; participation in healthcare checks and screening.
Diagnosis	Length of time between first symptoms and diagnosis; level of satisfaction with delivery of the diagnosis; availability of support at time of diagnosis.
Treatment	Length of time between diagnosis and treatment; level of satisfaction with treatment; attitudes towards participation in clinical trials if the option was available.
Emotional and practical support	Support received from, and relationships with, general practitioners, specialists, nurses, cancer support groups and employers; identification of people from whom more support would have been appreciated.
Relationships and lifestyle	Impact of the disease on lifestyle; sexual relationships; interfamily relationships and those amongst friends; how the disease has affected everyday activities.

Data were collected and analysed using SPSS (Statistical Package for Social Sciences) for Windows, version 7.5 (SPSS, Illinois, U.S.A.). Analyses involved weighting the data to account for different sample sizes in different countries. The proportions are expressed as the percentage of those who responded to the particular question.

RESULTS

Since such large amounts of data were collected it cannot all be included here; this paper focuses on those findings deemed to be of most use to healthcare professionals.

Questionnaire response

A total of 38 387 questionnaires were supplied to hospitals for distribution to patients. Although 'non-response' questionnaires were also supplied to the hospitals in order to obtain demographic data on those women who did not want to, or could not, participate in the study, the number of these returned was too low to be useful. Not every hospital kept accurate records of the number of questionnaires distributed. The response rate calculation therefore used information about the number of questionnaires distributed to patients as the denominator (where this information was available) or (where it was not available) the number of questionnaires given to hospitals for distribution. The resulting 'net' response rate was 43% overall (Table 2). Because the denominator most certainly included questionnaires that were not distributed to patients, this response rate is depressed and should be considered a conservative estimate.

Table 2. *Net response rate by country*

Country	Number of questionnaires distributed to patients	Number of questionnaires completed and returned	Response rate (%)
Austria	1616	594	37
Belgium	1352	459	34
Denmark	2141	1317	62
Finland	3441	1932	56
Germany	1846	799	43
U.K.	3301	1374	42
Greece	628	215	34
Ireland	1815	734	40
Israel	2233	527	24
Italy	2881	951	33
Norway	1574	861	55
Portugal	1267	433	34
Spain	1922	893	46
Sweden	1847	945	51
Switzerland	2547	1102	43
Overall	30 411	13 136	43

The net response rate was calculated by dividing the total number of questionnaires received back and processed, by the total number of questionnaires distributed to patients by hospitals (where this is known) or sent to participating hospitals (where distribution numbers were not known).

Patient demography

Patient demography is summarised in Table 3.

Table 3. *Patient demography (*n = 13 136*)*

	Before illness	During survey
Mean age (± S.D.)		55 ± 12 yrs
Marital status		
Married/with a partner		70%
Other		30%
Education		
No formal education		6%
Up to 18 years		62%
Completed after18 years		26%
University		15%
Employment status		
Homemaker	34%	30%
Working	46%	23%
Unemployed	3%	15%
Volunteer work	11%	19%
Not known	6%	13%
Cancer type		
Breast		77%
Ovarian		10%
Cervical		4%
Uterine		3%
Vulval		1%
Not known		4%
Total with relapse		29%
Breast		28%
Ovarian		37%
Cervical		29%
Treatment		
Inpatients		16%
Outpatients		43%
Treatment complete		35%

S.D., standard deviation.

Table 4. Prediagnosis health checks

Health check	% of patients undergoing this check
Regular breast examination	45
Routine mammography/X-ray	41
Regular PAP/smear test	36
Regular gynaecological check-up	36
Regular medical breast examination	30
Cervical screening	21
Breast awareness programme	3
Don't know/refused	16

Prediagnosis screening and medical examinations

Patient uptake of screening and medical examinations is summarised in Table 4. Over half of the women surveyed were the first person to discover symptoms of their disease and only one-fifth were identified at screening. Most women who discovered their own symptoms or signs responded by visiting their doctor reasonably promptly; 53% saw a doctor within a week. However, 15% waited 2–3 weeks and 26% waited for a month or more. Approximately 50% of women did not suspect that they had cancer, but one-third did.

Diagnosis

Being informed about the diagnosis. The majority of women were told about their diagnosis in a face-to-face interview with a specialist doctor (77%) and 11% face-to-face with a non-specialist. However, over 600 women (5%) were informed by telephone (4%) or mail (1%).

Treatment

Patient satisfaction with treatment. A measure of overall patient satisfaction with treatment was obtained by asking patients how satisfied or dissatisfied they had been during treatment. The percentage of respondents who were extremely satisfied was 68% for surgery, 60% for radiotherapy, 64% for chemotherapy and 45% for hormone treatment. When asked about satisfaction with overall care, 67% were extremely satisfied; 58% felt that the treatment was designed for their individual needs and 54% were extremely satisfied with access to hospital doctors. Areas of less satisfaction were the co-ordination across hospital departments (45% extremely satisfied, 32% satisfied, 11% dissatisfied/extremely dissatisfied) and communication between the hospital and general practitioner (34% extremely satisfied, 26% satisfied, 20% dissatisfied/extremely dissatisfied).

Involvement in treatment decisions. Patient attitudes to involvement with treatment decisions were evenly split; 44% wanted to be involved and thought that they were; 44% preferred to leave the decision to the doctor. Only a small group (7%) of patients wanted to be involved but felt that they were not. The analysis showed that the patients more likely to want to be involved were those who were under 60 years old, those who suffered a relapse, those who were very knowledgeable, or those who had received higher education and were also more likely to be treated in university or private hospitals.

Knowledge and information

Patients' knowledge of cancer before diagnosis. Less than one-fifth of all patients thought that they knew a lot about cancer before diagnosis. A quarter of the patients reported "not knowing very much" and almost one-tenth that they did not know anything at all. The remaining 47% considered that they knew 'a little'. The main sources of information were 'word of mouth', closely followed by television, radio, magazines and newspapers. Information was obtained from cancer societies, healthcare professionals and public health information by less than a quarter of patients.

Information at diagnosis. Whilst approximately half of the patients were extremely satisfied with the openness of their doctors and the time spent with them at diagnosis, there were shortcomings in the usefulness and amount of information imparted. Only 33% of the total respondents were extremely satisfied with the usefulness of the information given and 31% with the amount of information. The main source of dissatisfaction was too little information, which was reported by 88% of the dissatisfied group.

Information on potential side-effects. Adequate preparation helps a patient to cope well with subsequent treatment. This was examined by assessing patient satisfaction with the information about what to expect and the information on side-effects, and also by looking at how expectations compared with the actual treatment experience.

For information about what to expect, extreme satisfaction was expressed by 58% of surgery patients, 54% of chemotherapy patients, 52% of radiotherapy patients and 40% of those receiving hormonal therapy. For information about side-effects, the results were 40, 51, 45 and 35%, of patients, respectively. Dissatisfaction with information about side-effects was expressed by 16% of surgery patients, 15% of chemotherapy patients, 18% of the radiotherapy patients and 25% of those receiving hormonal treatment.

These responses showed that information concerning side-effects was insufficient, especially for those patients undergoing surgery or receiving hormonal therapy. Those receiving hormone therapy were also inadequately informed about what to expect during their treatment. This paucity of information was highlighted by comparing experiences with expectations; only 35–51% of patients found the treatment to be what they were expecting and a high proportion of the patients answered 'don't know' or refused this question, suggesting that overall patients were not well prepared for their experiences (Table 5).

However, by the end of the treatment period patients' level of knowledge had increased; 51% felt that they knew a lot

Table 5. Comparison of expectation of treatment with experience

	Surgery	Chemotherapy	Radiotherapy	Hormone therapy*
% Finding treatment was what they had expected	42%	35%	42%	51%
% Who did not answer or answered 'don't know' about what to expect†	12%	9%	6%	24%

*Excludes Italy (data not available). †Database includes all patients who had received that particular treatment.

Table 6. *Sources of emotional support*

	Person who provided support			Person from whom support was wanted		
Person	Before treatment (%)	During treatment (%)	After treatment (%)	Before treatment (%)	During treatment (%)	After treatment (%)
Husband/partner	62	52	45	34	26	25
Children	52	43	37	25	20	20
Friends	43	39	35	19	16	16
Other family	35	31	27	18	15	15
Specialist	28	27	16	21	17	13
GP	26	19	19	18	12	14
Nurse	19	23	11	10	11	7
Cancer support organisation	5	5	5	6	5	5
Psychologist	3	4	4	8	7	7
Patient support group	2	3	3	3	3	3
Social worker	2	3	2	2	2	2

about their disease; 34% felt that they knew ‘a little’, but there were still 10% of patients who rated their knowledge as ‘not very much’.

Clinical trial participation. Only 17% of patients had been asked to take part in a clinical trial. Most of those patients who were approached agreed to participate (77%) and the most common reasons were that they felt it might improve their treatment and that they would have nothing to lose. The main reason for not wanting to participate was because they only wanted to be given a well-tried treatment.

Practical and emotional support

Women were asked to identify the people who had provided practical and emotional support at the time of diagnosis, during treatment and after hospitalisation. At each period by far the most cited source of support was the patient's husband or partner, followed by children, friends and other family members. Social workers, patient support groups and psychologists were the least cited as sources of support at each time period (Table 6).

Interestingly, the number of patients who did not know or did not respond to this question at the time of diagnosis was 9%, but 23% did not identify sources at the time of treatment and 34% could not identify a source for the period after hospitalisation. When asked if any support was available through the hospital only 34% replied “yes”, 23% reported “no”, but 43% didn't know or didn't reply.

Patients were asked to indicate, regardless of the support actually received, from whom they would most liked to have had support during diagnosis and treatment. Again the main source was firstly the husband/partner, followed by children, but the third individual was now the specialist who came before friends and family (Table 6). As with the previous question, the number of women not answering or who did not know was quite high; 35% of patients for support wanted during diagnosis; 51% for support wanted at the time of treatment, and 53% for support wanted after hospitalisation. Although some patients were in-patients, and would perhaps not find the ‘after hospitalisation’ category of these two questions relevant, this was a small group (16% of the total) and would not account for the 43% who did not know/did not answer who gave most support after hospitalisation or the 53% who did not answer/did not know from whom they wanted support.

The women's ability to cope emotionally seemed to increase as they progressed along the care pathway. Thus, 44% of patients wanted support whilst waiting for the diagnosis, but only 33% whilst learning that they had a relapse and just 19% at follow-up.

When asked what else they would like in terms of support, the most popular item was written material (23%) and less than one-fifth of women wanted personal counselling with a psychologist. Only 16% wanted psychologist-led groups and 15% a cancer patient-led group.

Relationships and lifestyle

Employment status. Half the women working at the time of diagnosis were unemployed at the time of survey (Table 3). Women were asked how relationships with friends, family, employers and colleagues had been affected. Relationships were affected negatively more often with employers than with any other group of non-family, such as colleagues, friends and neighbours.

16% of women had also experienced financial difficulties directly as a result of their illness. In half the cases this was related to loss of employment/salary and 11% of these women had difficulty in obtaining a job. Difficulties were also experienced by this group in obtaining life assurance (18%), health insurance (13%), bank loans (7%) and mortgages (2%).

DISCUSSION

Survey methodology

This is the largest ever European survey of women diagnosed with cancer. It used a self-completed questionnaire and over 38 000 were distributed across 15 countries; 13 136 women replied.

Whilst it is widely accepted that patients' opinions are of great importance in assessing the quality of healthcare services, there is no general consensus on the methodology for collecting such information. Two main methods are self-completed questionnaires or interviews [3]. A major difference between these methods is that interviews are very labour intensive, time consuming, costly, and reach only a small number of patients, whilst self-completed questionnaires allow large numbers of patients to be sampled, need less trained staff and consequently incur lower costs for data collection (although possibly higher costs in data analysis). Additionally, self-completed questionnaires allow standardised questions, and avoid interviewer bias. Returning completed forms directly to the survey conductor also relieves patients of the concern that healthcare professionals involved in their treatment will have sight of their particular comments and this anonymity may promote more honest answering of questions.

The scale of the current survey made it necessary to use self-completed questionnaires. However, it is accepted that this will produce an inherent bias, in that only patients who are literate, in sufficiently good health, interested, and motivated will complete and submit the questionnaire; factors that were evident in the patient demography. For example, the survey population was somewhat younger than would be expected from the incidence of female cancers in the general population. However, the proportions of women with different types of cancer were fairly representative of the general population, with perhaps the exception of uterine cancer. Thus, considering the data supplied by the IARC in 1993 [16] breast cancer comprised 66%, ovarian cancer 12%, cervical cancer 10% and uterine cancer 12% of the total female cancers. So although this population are reasonably representative the unavoidable selection bias must be taken into consideration when interpreting the data. The response rates seen in this survey were comparable with those reported for other self-completed surveys [17].

This paper reports on the findings across the countries involved in the survey and as such represents an 'average' response; inevitably, there will be variations in attitudes and services between different countries. Findings for individual countries will be analysed by the NABs.

Prediagnosis screening

Despite the fact that evidence from studies in the U.S.A., Sweden and Scotland have demonstrated that regular mammographic screening of women aged 50–70 years will reduce breast cancer mortality [18] organised mammographic screening is not currently available in all EU countries. The percentage of women who had undergone mammography was only 41% and just under half of the women were examining their own breasts. These findings may reflect a lack of screening services, or the fact that the message about the importance of screening is not reaching a wide enough audience.

There may have been some confusion with the categories of cervical screening/PAP smears/gynaecological check-up, and individual women no doubt gave positive answers to more than one category, but analysis showed that just over half the women (55%) reported at least one of these activities. Screening for cervical cancer reduces the incidence of invasive disease but is not employed nationally throughout the EU [18].

These findings show relatively poor participation in screening programmes and underline the need for effective screening services to be organised on a national basis throughout the EU.

Being informed about the diagnosis

The survey showed that 5% ($n = 600$) of patients were informed about their diagnosis by telephone or by letter. A previous study has reported a similar lack of sensitivity or privacy [19]. In that study 43% of their subjects were informed by phone, letter or in the corridor/on the ward round. The reasons for choosing these methods of communication in the current survey are not clear, but the authors find that this is not an acceptable way of imparting sensitive information (unless, of course it is at the patient's request) and can only endorse the comments of Loge and colleagues that "the findings call for remedial attention ... and improvement in performance".

Patient satisfaction with treatment

High levels of satisfaction with treatment and care have frequently been reported in healthcare surveys [17]. In addition, a survey using postal questionnaires that was followed-up by interviews of responders and the non-responders showed that patients who responded to the postal questionnaire were more likely to be satisfied than those who did not [20]. The high levels of satisfaction seen here may, therefore, reflect this inherent bias of any questionnaire and the fact that postal questionnaires will select those motivated patients who actually return the completed form.

Involvement in treatment decisions

The survey showed that whilst 44% of women wanted to be involved and were, 7% were not invited to participate. Since involvement in treatment decisions has been demonstrated to lessen the trauma of the cancer experience [13, 14] healthcare professionals should perhaps be encouraging patient involvement wherever possible.

Knowledge and information

It is clear from the survey that despite raised awareness of the need for the public to be well informed about cancer, and for patients to be educated about their disease and treatment, there are still shortcomings in the delivery of information. Patients' knowledge of cancer before they were diagnosed was quite poor, both in terms of amount of knowledge and the quality of the sources of information.

Most information was being passed on by 'word of mouth' from family and friends whose understanding is restricted. This may result in misinformation, with unfounded fears and prejudices being promulgated and negative attitudes to cancer reinforced. Other common sources of information were TV, radio, magazines and newspapers. Again, these are sources that have a variable degree of accuracy, and which may be motivated to highlight the more dramatic aspects of cancer and its treatment.

Opinion surveys have long demonstrated the public as having an unrealistic attitude and ignorance about cancer [21], and one of the patients' greatest fears is often that they may not be given sufficient information to cope with their disease and its treatment [22]. The importance of information, explanations and dialogue at every stage of the cancer diagnosis and treatment process has been highlighted by Serin and colleagues [15]. Imparting information can enable cancer patients to adapt to their disease and can do much to relieve anguish and anxiety, facilitating patients and their families to cope with their disease [23] helping in mobilising coping strategies [9], and restoring feelings of being in control [24]. It is quite likely that the availability of information differs in different European countries, and it could be possible that, even where infomation is produced by hospitals or other organisations, it is not reaching its target audience. These factors have not been studied extensively here, but certainly warrant further investigation. However, the overall results from this survey show considerable gaps in patient education and a degree of dissatisfaction with the paucity of information received during the whole process of treatment.

This survey represents a fairly well educated section of the population; it can only be assumed that the picture is even worse when taken across the European population as whole. The results demonstrate a shortcoming in the care that women receive that could be addressed relatively easily.

This survey also clearly showed that it was the women receiving hormonal treatment who had the lowest levels of satisfaction. Leonard and colleagues [25] have shown that clinicians underestimate the degree of distress caused to women by the side-effects of hormonal treatment. It is likely that this failure to appreciate the impact of side-effects is reflected by poor preparation of the patient about what to expect.

Support

Patients identified sources of support more readily for the period 'waiting for the diagnosis' than for the periods 'during treatment' or 'after hospitalisation'. The reasons were not investigated further, but this finding raises the question of whether support for patients actually diminishes as they move through the care pathway, whether the patients themselves find that identifying suitably supportive people becomes harder, or whether they actually stop seeking external support. In a review of survivors of cancer, Welch-McCaffrey and colleagues [26] discuss the fact that supportive relationships do diminish with time and Maher [27] has reported that the intense outpouring of emotional support that cancer patients receive during diagnosis and treatment may not be sustained once they no longer look ill.

The person who provided most support at all times was the patient's partner. It is important, therefore, that healthcare professionals pay attention to women who are alone and who may not be able to identify readily another person to fulfil this role. Single women diagnosed with cancer have been shown to have significantly higher rates of depression than married women and felt alone through initial diagnosis, treatment and recovery [28].

Researchers have increasingly regarded social support as critical to cancer patients' psychological wellbeing [8, 29, 30]. Patients with low social support cope less well with the cancer experience [8] and patients who receive the strongest consistent emotional support are thought to adjust more successfully over time [31]. Social support can be provided by a variety of people, but interestingly in this survey was not wanted by the majority of women from psychologists, or social workers and few women ($<6\%$) gained or wanted support from fellow patients, religious leaders, or cancer support organisations. These findings are similar to those of Slevin and associates [7] where patients' sources of support were firstly family, then senior registrars and consultants; psychologists and social workers were lowest on the list and patients preferred doctor-led or nurse-led support groups to those led by other patients.

Almost half of the patients did not know whether any support was available through the hospital and for one-fifth support was not offered. These findings warrant further investigation for it is important to determine whether patients really do not want access to support groups or whether it is a lack of information about their content, and ignorance of the existence of the range of supportive measures available that underlies patient opinions. Since different sources of support often fulfil different needs [32] patients may be missing out on valuable providers of emotional assistance.

It is interesting to note that patients ranked the specialist higher in the list of people from whom they would have liked support than they did in the list of people actually providing support. The high ranking of senior hospital doctors in the framework of support has also been reported by Slevin and associates [7]. Senior doctors should therefore be aware of the potential they have to help patients through a difficult period. Attitude is probably more important than the time spent since it has been shown that patients overestimate the time spent with them by specialists [33]. A study, tape recording interviews of patients and specialists as the diagnosis was delivered, concluded that whilst patients were well informed about their diagnosis, prognosis and treatment options, their emotional well-being was rarely considered and questions relating to psychological health were few [34]. These findings underline the importance of training in psychological skills for doctors and nurses.

Employment status and financial difficulties

This survey recruited many women in late middle age who perhaps might not be in employment; approximately one-third classed themselves as homemakers. However, nearly half were working before their illness and this had halved by the time of the survey. Discrimination by employers against cancer patients in the U.S.A. has been reviewed by Welch-McCaffrey and colleagues [26] who cited feelings that cancer was contagious and that employers thought that cancer survivors were an unproductive drain on the economy as reasons for unemployment. The reasons for women leaving employment have not been explored further here, but the fact that they classified themselves as 'unemployed' suggests that they may have wished to remain in work, and for some this unemployment had brought financial difficulties. Financial difficulties were compounded by problems in obtaining loans, insurance and mortgages. Although the percentages of women experiencing such difficulties were low, this still represented over 2000 individuals. If all the people with cancer in the participating European countries are considered, this represents a huge number of people who are having to cope with an added financial burden as well as medical problem. These findings warrant further investigation into employer attitudes and other potential prejudices towards cancer patients in Europe.

Participation in clinical trials

Very few patients had been asked to participate in clinical trials, but the vast majority of patients who were asked were willing to participate. Since the survey sampled women from a range of hospitals, it may be that some of the smaller hospitals would not be participating in clinical trials. It could also be possible that patients did not understand that they were actually enrolled in a clinical trial, as it has been shown that clinicians do not always give complete information to patients, especially those in the control arm of studies [35]. A lack of willingness to participate in trials has also been ascribed to the fact that randomisation takes away treatment choice. However, patients in clinical trials are certainly followed more closely and consequently are likely to be better looked after, better informed and more aware about their illness and therapeutic choices [36]. Furthermore, it has been shown that women who agree to participate in randomised clinical trials for breast cancer do not experience any different psychological, sexual or social problems from those who are treated outside trials [37]. Clearly the public, patients and their families need to be better informed about the value of clinical trials.

In conclusion, this survey has assessed several aspects of the care given to women undergoing treatment for cancer. A majority of women were extremely satisfied with treatment (with the exception of those undergoing hormone treatment), overall care and access to hospital doctors. However, the survey revealed several shortcomings in the provision of information and education for cancer patients and gaps in the provision of support; all factors crucial to patients' wellbeing. It has also shown, in common with other studies, that physicians especially should appreciate the potential they have for providing support to their patients [7, 34]. What is also most interesting is that patients' use of support groups, and their desire to obtain support from such groups was very low. This finding should be investigated further to establish whether the structure of support groups is not fulfilling patient needs or whether the availability of the groups is not adequately publicised. This survey highlighted the relatively poor participation by women in screening programmes. This may reflect a need for more national screening programmes or greater publicity to be given to their availability. The number of patients required for clinical trials often exceeds the numbers entered. A discouraging result in this survey was that so few women were asked to participate in trials, and opportunities to recruit individuals were missed, especially as their responses showed that the vast majority of women would be prepared to do so.

An acknowledged aim of healthcare systems is to provide a seamless service of care as the patient passes from GP to hospital and back into community care. This survey revealed low levels of satisfaction with co-ordination across hospital departments and poor communication between hospital and GPs. Clearly more attention needs to be focused on integrating healthcare services, including screening. Healthcare professionals should be pro-active in improving all aspects of care for patients undergoing treatment for cancer. This may be achieved by identifying and showing a greater appreciation of patient needs and contributing to decision making about the deployment of healthcare budgets.

---

1. Maguire P, Selby P. Assessing quality of life in cancer patients. *Br J Cancer* 1989, **60**, 437–440.
2. Hopkins A. *Measuring the Quality of Medical Care*. London, Royal College of Physicians, 1990.
3. Fitzpatrick R. Surveys of patient satisfaction: I—Important general considerations. *Br Med J* 1991, **302**, 887–889.
4. Mahon PY. An analysis of the concept 'patient satisfaction' as it relates to contemporary nursing care. *J Adv Nurs* 1996, **24**, 1241–1248.
5. Winefield HR, Neuling SJ. Social support, counselling and cancer. *Br J Guidance Counselling* 1987, **15**, 6–16.
6. Broadhead WE, Kaplan BH. Social support and the cancer patient. *Cancer* 1991, **47**(Suppl.), 794–799.
7. Slevin ML, Nichols SE, Downer SM, *et al*. Emotional support for cancer patients: what do patients really want? *Br J Cancer* 1996, **74**, 1275–1279.
8. Grassi L, Rosti G. Psychiatric and psychosocial concomitants of abnormal illness behaviour in patients with cancer. *Psychother Psychosomat* 1996, **65**(5), 246–252.
9. Grahn G. Coping with the cancer experience. I. Developing an education and support programme for cancer patients and their significant others. *Eur J Cancer Care* 1996, **5**, 176–181.
10. Holland J. *Psycho-Oncology*. New York, Oxford University Press, 1998.
11. Hames A, Stirling A. Choice aids recovery. *Nursing Times* 1987, **Feb**, 49–51.
12. Payne DK, Sullivan MD, Massie MJ. Women's psychological reactions to breast cancer. *Semin Oncol* 1996, **23**, 89–97.
13. Luker KA, Beaver K, Leinster SJ, Owens RG. Information needs and sources of information for women with breast cancer: a follow-up study. *J Adv Nurs* 1996, **23**, 487–495.
14. Monson MA, Harwood KV. Helping women select primary breast cancer treatment. *Am J Nursing* April 1998 (Suppl.), 3–7.
15. Serin D, Pujol H, Schraub S, Chevalier H. Parcours de femmes. Enquête d'opinion réalisée après des femmes traitées pour cancers gynécologiques et mammaires et auprès des équipes soignantes qui les ont prises en charge. *Bull Cancer* 1998, **85**, 578–588.
16. Estève J, Kricker A, Ferlay J, Parkin DM. *Facts and Figures of Cancer in the European Community*. IARC, 1993.
17. French K. Methodological considerations in hospital patient surveys. *Int J Nurs Studies* 1981, **18**, 7–32.
18. Boyle P, Veronesi U, Tubiana M, *et al*. European School of Oncology advisory report to the European Commission for the "Europe Against Cancer Programme" European code against cancer. *Eur J Cancer* 1995, **31A**, 1395–1405.
19. Loge JH, Kaasa S, Hytten K. Disclosing the cancer diagnosis; the patients' experiences. *Eur J Cancer* 1997, **33**(6), 878–882.
20. Ley P, Kinsey J, Atherton ST. Increasing patients' satisfaction with communication. *Br J Soc Clin Psychol* 1976, **15**, 403–413.
21. Brooks A. Public and professional attitudes towards cancer: a view from Great Britain. *Cancer Nursing* 1979, **2**, 453–460.
22. Rhodes VA, McDaniel RW, Hanson B, Markway E, Johnson M. Sensory perception of patients on selected antineoplastic chemotherapy protocols. *Cancer Nursing* 1994, **17**, 45–51.
23. Ream E, Richardson A. The role of information in patients' adaptation to chemotherapy and radiotherapy: a review of the literature. *Eur J Cancer Care* 1996, **5**, 132–138.
24. Brockopp DY, Hayko D, Davenport W, Winscott RN. Personal control and needs for hope and information among adults diagnosed with cancer. *Cancer Nursing* 1989, **12**, 112–116.
25. Leonard RCF, Lee L, Harrison ME. Impact of side-effects associated with endocrine treatments for advanced breast cancer: clinicians' and patients' perceptions. *The Breast* 1996, **5**, 259–264.
26. Welch-McCaffrey D, Hoffman B, Leigh SA, Loescher LJ, Meyskens FL. Surviving adult cancers. Part 2: Psychosocial implications. *Ann Int Med* 1989, **111**, 517–524.
27. Maher EL. Anomic aspects of recovery from cancer. *Soc Sci Med* 1982, **16**, 907–912.
28. Lewis FM, Zahlis EH, Shands ME, Sinsheimer JA, Hammond MA. The functioning of single women with breast cancer and their school age children. *Cancer Practice* 1996, **4**, 15–24.
29. Dow KH. A review of the late effects of cancer in women. *Semin Oncol Nurs* 1995, **11**, 128–136.
30. Bottomly A, Jones L. Social support and the cancer patient—a need for clarity. *Eur J Cancer Care* 1997, **6**, 72–77.
31. Dunkel-Schetter C. Social support and cancer: findings based on patient interviews and their implications. *J Social Issues* 1984, **40**, 77–98.
32. Wortman CB. Social support and the cancer patient: conceptual and methodological issues. *Cancer* 1984, **53**, 2349–2363.
33. Blanchard CG, Labreque MS, Ruckdeschel JC, Blanchard EB. Physician behaviours, patient perceptions and patient characteristics as predictors of satisfaction of hospitalised adult cancer patients. *Cancer* 1990, **65**, 186–192.
34. Ford S, Fallowfield L, Lewis S. Doctor–patient interactions in oncology. *Soc Sci Med* 1996, **42**, 1511–1519.
35. Williams CJ, Zwitter M. Informed consent in European multicentre randomised clinical trials—are patients really informed? *Eur J Cancer* 1994, **30A**, 907–910.
36. McVie JG. Why clinical trials? *Eur J Surg Oncol* 1995, **21**, 9–10.
37. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *Br Med J* 1990, **310**, 575–580.

Acknowledgements—C. Bolund (Member of the CAWAC Study Group).

Funding for this survey and the CAWAC Programme was provided by Bristol-Myers Squibb Company.

APPENDIX

The organisations that are members of the ECAB are: Europa Donna, European Institute of Oncology (EIO), European Cancer Leagues (ECL), European Oncology Nursing Society (EONS), European Organisation for Research and Treatment of Cancer (EORTC), European School of Oncology (ESO), European Society for Psychosocial Oncology (ESPO), European Union of General Practitioners (UEMO), Bristol-Myers Squibb Company.

Members of the European Core Board: Mr Lamberto Andreotti, Dr Alberto Costa, Ms Nicole Delvaux, Ms Gloria Freilich, Dr Agnes Glaus, Mr Tom Hudson, Dr Cormac Macnamara, Professor Gordon McVie, the late Ms Maria F. Méndez-Nuñes y Gomez Acebo, Professor Françoise Meunier, Professor Sergio Pecorelli, Ms Kathy Redmond, Dr Daniel Serin, Professor Umberto Veronesi, Professor Sabine von Kleist.

Chairs and co-chairs of the National Advisory Boards: Dr Kamma Bertelsen, Dr Christina Bolund, PD Dr Monica Castiglione, Dr Mary Codd, Dr Hernán Cortés-Funes, Ms Nicole Delvaux, Professor Ivo De Wever, Dr José Diaz-Faes, Dr Brigitte Ernst, Professor James Fennelly, Professor Dr António Gentil Martins, Dr Marietta Giannakou-Koutsikou, Dr Agnes Glaus, Dr Thomas Hatschek, Dr Päivi Hietanen, Dr Rolf Kåresen, Professor Dr Manfred Kaufmann, Ms Kirsten Kopp, Dr Frøydis Langmark, Mrs Kicca Menoni, Professor Michael Micksche, Ms Jean Mossman, Dr Teresa Osório, Professor Gerasimos Rigatos, Professor Eliezer Robinson, Professor Leonardo Santi, Professor Karol Sikora, Dr Marja Sorsa, Professor Ruth Wodak, Ms Miri Ziv.