



*Survey of views
& Perceptions
of Women
who attended
Symptomatic
Breast Clinics*

The Women's Health Council
Comhairle Sbláinte na mBan



**Survey of Views and Perceptions of Women
who attended Symptomatic Breast Clinics**

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Foreword

The Women's Health Council is a statutory body established in 1997 to advise the Minister for Health and Children on all aspects of women's health. Its mission is to inform and influence the development of health policy in order to ensure the maximum health and social gain for women in Ireland.

The Department of Health and Children, through the National Cancer Forum, requested the Women's Health Council to conduct research on the views and perceptions of women who attended symptomatic breast care clinics. The aim of this research was to identify how well the current service meets the needs of women, and whether it could be improved.

Every year significant numbers of women across the country are referred to symptomatic breast clinics for diagnostic purposes. For many of them the service establishes that no active disease is present and no treatment required; for others, however, diagnosis of breast cancer can lead to protracted treatment and concomitant anxiety. Referral for breast screening in itself can raise fears and if delays occur in obtaining an appointment or in being informed of the outcome of the examination these fears and anxieties are greatly increased.

This research has demonstrated that access to clinics, both in terms of time and location, is seen as crucially important both by the women using the service and by the professionals involved. These recommendations with the others, concerning privacy, support, counselling, information, treatment options and continuity of care, offer a model of women centered, holistic care which must be the standard for all women.

Our thanks to all those who participated in this research, particularly the women attending clinics, and to the team of researchers who have completed a thorough and thoughtful study.

The Women's Health Council welcomes the report and its recommendations. We have no doubt that they will be of benefit to health policy makers and practitioners alike, and will have the effect of improving the quality of service to women. We look forward to a programme of implementation so that in the area of symptomatic breast care, women will receive prompt, comprehensive and high quality health care.



Noreen Kearney, Chairwoman

Acknowledgements

The research team would like to thank Geraldine Luddy and the staff in the Women's Health Council for their unstinting support and help throughout this project. As well, we want to thank all the medical and nursing staff who helped us during the fieldwork with background interviews and information. The breast care nurses need special thanks for assisting us with the administration of the questionnaire to women and helping to arrange interview rooms for us. We would also like to thank all of the healthcare staff who took the time from their very crowded working day to answer the staff questionnaire. The Librarian in St. Luke's Hospital, Dublin, Gabrielle Doyle, was very supportive to the team and we thank her for her input. Ellen Coughlan, Miriam Galvin and Passerose Mantoy gave us valuable assistance with aspects of the fieldwork and the database and Martina Reidy ably assisted with layout of the report.

Finally and most importantly, we want to thank and sincerely acknowledge the valuable inputs of the women themselves who volunteered as participants, under circumstances for them which were often highly stressful. We hope that their needs and views will make a substantial contribution to the restructuring of breast care services in Ireland.

Executive Summary

The background to this study is the fact that breast cancer is the most common cancer in women leading to death, although early detection and treatment is steadily improving women's outcomes. One in every fourteen Irish women can expect to contract breast cancer and currently, seventeen hundred new cases are diagnosed every year. It is an issue of great concern to women, and therefore to the government, as outlined in the 1997 document, *A Plan for Women's Health, 1997-1999*.

This current research project arises from the government's intention to develop more comprehensive diagnostic services. The Women's Health Council was asked by the Department of Health and Children, through the National Cancer Forum, to conduct research on women's views and reactions as consumers of existing services for symptomatic breast disease. The research team was asked to document women's views on:

- Diagnostic services;
- Counselling;
- Additional treatment services such as surgery and radiotherapy.

The framework for data collection was as follows:

- Questionnaires administered to one hundred and ninety-one women currently attending the following six breast care clinics:

Eastern Regional Health Authority: St. James Hospital and Beaumont Hospital;

North Eastern Health Board: Drogheda Breast Clinic

North Western Health Board: Sligo General Hospital

South Eastern Health Board: Waterford Regional Hospital

Southern Health Board: South Infirmary Cork

- Focus group interviews conducted with women in Cork, Dublin and Sligo;
- Postal questionnaires sent to staff in the six study sites to ascertain their views on current service provision;
- A literature review of models of best practice for women dealing with breast disease.

Principal findings were as follows:

The overwhelming majority of women discover symptoms of breast disease themselves, through self-examination, and thereafter go to their GP.

The next several steps in the referral and diagnostic chain of events can confront women with a series of delays. Respondents reported time delays of three types:

- Delays in having the first clinic appointment;
- Delays during the first clinic appointment because there are too many patients and insufficient clinic time;
- Delays in obtaining all necessary diagnostic tests so that women must return to another clinic session in order to have their complete diagnosis.

Women reported greatly increased anxiety levels as a result of delays. The majority of women reported both that they felt anxious and that they were trying not to think about their situation while they waited for their first clinical appointments. Staff also reported the majority of women, from 50 per cent to 100 per cent in their experience, suffer from anxiety in the course of their first appointment.

Although women were by and large satisfied with their treatment once they were into the clinical system, the principal issues they raised about which they were concerned are as follows:

- Lack of information from the clinic staff;
- Sense of shock if they were given a positive diagnosis of cancer;
- Inability to ask all the questions they needed and wanted to ask about their condition;
- Breast care nurse not able to see every woman, especially after diagnosis;
- Feeling that the staff were under great time pressure;
- Majority of women's reliance on either family member, friend or taxi to get them to their clinic appointments;
- Severe practical and emotional problems for women who had to travel away to access radiotherapy;
- Problems with chemotherapy not being offered on site;
- Lack of formal social support structures.

Women's top five priorities for care were:

- First appointment within one week of referral;
- Having all diagnostic tests in one session, where possible;
- Having any additional tests within one week;
- Unhurried time to talk to consultants after test results;
- Continuity of care – if second visit is required, assurance that woman will see the same breast care nurse and consultant.

Top priorities for the thirteen staff members who replied from four of the six interview sites were:

- First appointment within one week of referral;
- Specialist breast care team;
- Having all diagnostic tests in one session, where possible;
- Having any additional tests within one week;
- Encouragement for the patient to be accompanied by a family member or friend for support.

The literature review looked at the importance of psycho-social care being incorporated into women's treatment in order to improve outcomes and reduce personal problems and reactions of depression. Emerging patterns of formal support services were considered, for the woman and also for her family, including children.

Drawing on this data, the recommendations are set out below.

Timeframes for Initial Clinic Visits and Diagnostic Tests

- Women with symptomatic breast disease must be seen by a specialist breast clinic team within **one week** of a GP referring them for further investigation.
- Women should have all their diagnostic tests completed in their first clinic session. Where current resourcing does not permit this, and until the implementation of changes to make this possible, initial diagnostic tests and any additional tests should be completed within **one week** of a woman's first clinic appointment.

- Women should have specific clinic appointment times that can guarantee they will wait no more than half an hour before beginning their round of consultation and diagnostic testing which will take place in that session.

Communication and Information in the Clinic

- Every effort should be made to ensure sufficient reception staff on duty and sufficient clinic time and spacing for women, so that the woman can be registered, settled in, and have explained to her the clinic routine, and the names of the consultant and breast care nurse on duty that day.
- Well-presented and well-illustrated information on breast disease and the range of diagnostic tests a woman can expect to undergo during her clinic visit should be presented to her in leaflet form by the receptionist as the woman is booked in. This information leaflet should be compiled in a way that respects women with different reading abilities and disabilities such as reduced vision.
- It should be a standard part of clinic routine that once a woman has seen the consultant, had her tests, and been told of her diagnosis that she should then be directed immediately afterwards to the breast care nurse who can spend some time with her, listening to her and helping her deal with her reactions, concerns and her questions.
- Women who have been given a positive diagnosis should be given an information leaflet specifically explaining the range of treatments and presenting them with a checklist of questions they will want to have answered at their next visit, when they return for treatment. The leaflet should also have information on cancer support groups such as ARC and the Irish Cancer Society.

Breast Care Nurses, Emotional Support and Continuity of Care

- The breast care nurse must have privacy, time and space in which to carry out her work. Each breast care nurse (or nursing team where there are different shifts or job-sharing) requires a dedicated room to carry out her work within the larger clinic setting.
- The brief of the breast care nurse must be set out clearly so that she is not asked to take on other non-nursing tasks but can devote her time to patient support.

Privacy and Space in the Clinic

- Where possible, breast care clinics should occupy hospital space and a time slot which can ensure a dedicated clinic and waiting area for that purpose only at that time.

Treatment Issues

- There should be expert medical advice available for women at the weekends, especially if they are undergoing treatment like chemotherapy where they are likely to be quite ill afterwards.
- It is critical for women to have radiotherapy and chemotherapy, as well as the full range of diagnostic services, locally available or, at the furthest, regionally available so that they can travel there and back comfortably and safely in the same day.
- Low income women who do not hold a medical card but who require radiotherapy and chemotherapy in centres where public transport is very difficult to access should be able to reclaim travel costs from their Health Board.

Ending Treatment and Aftercare

- Each woman who has reached the end of her treatment should be given the opportunity to avail of a final discharge interview with the breast care nurse in which the woman can review the whole of her treatment, ask questions about her future and about any necessary aftercare. The discharge interview will enable the woman to achieve some sense of completion and closure around this major life readjustment she has undergone.

Counselling and Support Groups

- Breast care nurses should be able to identify women who need specialised counselling and refer them on to a specialised counsellor or social worker.
- There is a role for the social worker as a lead support person in liaising and helping to set up support groups.

Expanding the Multi-Disciplinary Team to Meet Women's Needs

- To deal with the full range of needs and to impact most favourably on outcomes, the multi-disciplinary team must be staffed by the full range of medical staff. But it must also be expanded to include, as a matter of course, fully-trained breast care nurses and social workers or trained counsellors/psychologists.
- Ethnically sensitive awareness will need to be built into breast care teams for the near future in order to offer treatment to women coming from very different cultural backgrounds who may have different psycho-social needs around breast disease.

Additional Information Campaigns

- GPs need to be updated about current protocols on breast cancer treatment so that they target their referrals indicating urgent and less-urgent diagnostic needs.
- A dedicated telephone advice line for breast cancer only, run by a group like the Irish Cancer Society could fulfil an additional support need for women, enabling them to explore and make sense of their symptoms and reactions during treatment and recovery.
- A general public information campaign should be initiated to reinforce the message that breast health is an issue for women at all ages and not just post-menopausal women.

I Background to the Study

- *Breast Cancer in Ireland*
- *The Elements of Quality Care*

Background to the Study

Breast Cancer in Ireland

Latest Irish data on cancer suggests that one woman in fourteen will develop breast cancer with nearly 1,700 new cases being diagnosed each year (National Cancer Registry figures). Although uncommon under the age of 30, thereafter, the chance of developing it increases with age. Most breast cancers are found in women over the age of 50. There is a wide-ranging debate about risk factors associated with the onset of the disease, including lifestyle and genetic factors. But the advice issued by the Irish Cancer Society is that because in most cases there is no known cause, women should be vigilant about self-examination. Women over the age of 50 are advised to have a mammogram on a regular basis. Any lumps, swelling or discharge should be brought to the attention of a GP as soon as possible, and, while it is true that nine out of ten lumps which women discover prove to be non-cancerous, it is crucial to get these checked out very rapidly. In 1994, data from the women's health survey, carried out by the ESRI, indicated that one woman in three never conducts self breast examination, underlining the importance of both a national screening programme and much greater emphasis on health promotion strategies for women in the most vulnerable age groups for this cancer (Wiley and Merriman, 1996).

In the discussion document, *Developing a Plan for Women's Health*, published in 1995, the government flagged its intentions to make early detection a priority and the Minister for Health assigned £600,000 to facilitate the phased expansion of breast cancer screening programmes (Department of Health, 1995: 46-48). A pilot programme by the Mater Foundation on breast screening for those with symptomatic breast disease had already advocated an approach of total management of the breast cancer patient, with diagnostic facilities which were rapid, comprehensive and which reduced the numbers of false positive diagnoses. This model, using clinical palpation, mammography and fine needle aspiration had already been in operation in Sweden at the Karolinska Clinic and had the important spin-off of reducing women's anxieties about the diagnosis, primarily because of the accuracy of this three-stranded approach (*ibid.*).

This approach has now been incorporated into the work of a number of breast care clinics across Ireland. The aim of these clinics was to develop specialised expertise in order to meet women's treatment needs at all levels of symptomatic breast disease.

The establishment of breast care clinics has been seen as a positive step in addressing some of the concerns that had been raised in the course of the consultative process about women's health needs. These concerns were:

- Difficulties for women in gaining access to treatment;
- Deficiencies in communication and counselling for patients with breast cancer;
- Difficulties in other aspects of rehabilitation, including the provision of prostheses.

(ibid.)

More recently, a study on cancer support services (Department of Health and Children, 1999) explored this issue for patients with cancer. Amongst its main findings were:

- Marked anxiety for people waiting for their diagnosis;
- Common psychosocial problems associated with cancer, of anxiety and depression going unrecognised and untreated;
- Inadequate psychosocial support within the health care services for cancer patients;
- Practical problems for cancer patients including difficulties with additional costs, transport, and accommodation.

(ibid.2)

These identified needs and issues constitute ongoing areas of concern for the Department of Health and Children and, to a great extent, are also part of the background to the study findings we present now.

This current project arises out of the circumstances of high rates of breast cancer and the responses to date in developing more comprehensive diagnostic services. The Women's Health Council was asked by the Department of Health and Children, through the National Cancer Forum, to conduct research on women's views and reactions as consumers of existing services for symptomatic breast disease. This includes their views on:

- Diagnostic services;
- Counselling;
- Additional treatment services such as surgery and radiotherapy.

The project team was directed to pay attention to the issue of access, the distance women are travelling to reach specialist diagnostic services, and their views of what, for them, would comprise a specialist multidisciplinary centre of excellence in symptomatic breast care, based on their experiences.

The aim of this current research is to identify where there are gaps in the current services which need to be improved, in addition to identifying what is working well for women. It is hoped that the research findings will be used to draw up guidelines to establish best practices for women experiencing breast disease.

The Elements of Quality Care

Best clinical practice goes hand in hand with multi-dimensional quality care. In a recent review article on the provision of human services (Wilding, 1994), the point is made that assessing quality care cannot be done from a purely technical or clinical standpoint. This is because users and outcomes alike are affected by the manner in which services are provided. Therefore, the objective of establishing quality care must focus on the way the entire care package is put together. Wilding offers four concepts with which to measure quality care. These are:

- Accessibility of service
 - geographical
 - physical
 - psychological
- Acceptability of service
 - how it is provided
 - environment and amenities
 - interaction between staff and users
 - ambience must be acceptable to users, not just agreeable to providers
 - ethos must be supportive rather than critical or patronising
 - empowering rather than disabling
 - personal rather than routinised
- Effectiveness of service
 - appropriate to the objectives sought
 - service must be flexible and reliable
 - comprehensive in its coverage of needs

- Openness of service
 - Organisation must be
 - open about its aims and objectives
 - about what it can and cannot offer
 - about the standards at which it aims
 - about success at achieving them
 - about the way it makes decisions
 - open in communication with users
 - sensitive to complaints in such a way that it can learn about its provision

Ultimately, Wilding argues, what is being stressed about the provision of quality care is that individual relationships are the bedrock of human services.

Aspects of why these are such critical core values can already be glimpsed in the two reports cited above. For example, the objectives of openness in communication with users have not been achieved if some health care users must report that they have been given diagnoses in an insensitive manner and others report that they want but have not necessarily received full and timely information on their disease and the ramifications of it for them (Department of Health, 1999).

Caring about Women and Cancer (CAWAC), a survey of 700 Irish women with breast cancer, in Northern Ireland and the Republic of Ireland, covered the knowledge, attitudes and perceptions of women both prior to their own diagnosis of having the disease and afterwards; their take-up of screening tests before diagnosis; their levels of satisfaction with the services they received, and their perceptions of the impact the disease had on them and their families (Codd, 1999).

One of the most interesting findings, from the perspective of this current study in progress was that amongst women with breast cancer, 39 per cent received their diagnosis within one week while a further 31 per cent received their diagnosis two to three weeks after they had first presented. Given the findings in the *Review of Cancer Support Services* on the anxiety people experience while waiting for a diagnosis, this is surely not a satisfactory state of affairs. It was however a very important issue to examine in depth in relation to symptomatic breast care services.

The respondents in the CAWAC study with breast cancer expressed satisfaction with time spent with hospital doctors, the degree of openness of doctors and nurses, how the diagnosis was explained and opportunities to ask questions. We

recognised that these issues would also require testing and exploration, for this may not be a simple expression of complete satisfaction.

There is a problem in making sense of survey reports on expressed satisfaction with services. Sociologists working with women on antenatal and obstetric services were the first to note how difficult it is for women to critique the care they receive in respect of the medical treatment itself and what doctors do or do not do. They could criticise conditions, for instance, but not medical decision-making and treatment they receive (see for example, Kirke, 1980; Macintyre, 1984; Porter, 1990). It is argued that in relation to treatment itself acquiescence is in the patient's best interests. Researchers have noted fears that any negative comments about anything beyond the practicalities of waiting times etc, may rebound on them and in the end, they are dependent on medical treatment and thus do the work of sustaining good will with the doctors.

There is also a problem of women not feeling especially qualified to comment on their medical treatment as such. An experience as complex and potentially life-threatening as breast cancer would certainly frequently occasion this sort of response. Satisfaction in this context may be tempered with the relief that technically, the oncology services have brought women through the confrontation with a possible life-threatening illness. This may make their reactions to the problems they encountered such as the waiting times until first clinic appointments and other aspects of how their care was delivered seem less important in the immediate aftermath. However, over a longer period of time, these issues re-emerge as significant. There is also a problem with aggregate data in such surveys, where the experience of a majority of respondents, for example, who can access initial diagnostic and care services fairly rapidly, gets rated as satisfactory, while a minority of women who have to wait longer and who experience far greater anxiety, do not get their voices heard through the quantitative data results. A further problem may relate to what Wilding (1994) is discussing about service effectiveness. Patients may not be able to recognise a comprehensive quality of service delivery until they have experienced it in its fully developed form, where all their needs, including their psycho-social needs, have been assessed in putting together a total care package. The real challenge for a health service is to meet those needs in advance planning, rather than to consider that technical aspects come first before other aspects of service delivery can be improved. The key is to think in terms of an integrated strategy from the outset.

Having presented all the data findings, we will be using Wilding's model (which he is applying to the delivery of all services, not just health services) to help us reach a conclusion about the gaps women with breast disease are reporting to us.

II Research Methodology and Fieldwork Sites

- *Setting Out a Framework for Data
Collection*
- *Fieldwork Sites and Interviewing
Strategies*

Research Methodology and Fieldwork Sites

Setting Out a Framework for Data Collection

The project team proposed the collection of quantitative data, in the form of a questionnaire, and qualitative data, drawn from open-ended questions from the questionnaire, interview notes and focus groups. This data would be sought from women currently attending the following six breast care clinics:

Eastern Health Board: St. James Hospital and Beaumont Hospital;
 North Eastern Health Board: Drogheda Breast Clinic
 North Western Health Board: Sligo General Hospital
 South Eastern Health Board: Waterford Regional Hospital
 Southern Health Board: South Infirmary Cork

In each of these sites, we were seeking as participants:

- women attending for the first time;
- women who have had a positive diagnosis of cancer;
- women receiving ongoing diagnostic tests;
- women who might have had a negative result but who were still receiving periodic check-ups.

The sample was to be self-selecting, with women being invited to fill out a questionnaire. We designed a one-page summary of the project's aims and objective to circulate to relevant clinic staff for their information and also for potential participants in the study.

The overall aim for data collection was as follows:

- forty completed questionnaires from women in each of the above settings;
- taped data from three focus groups of women from three of the settings;
- staff questionnaires on current service provision from each of the fieldwork settings.

A questionnaire for women respondents was designed and piloted, using several previous studies on breast cancer and studies, seeking consumer views on health care, to guide its construction. The cover sheet of the questionnaire had a written undertaking, that the confidentiality of each participant would be fully respected and that only the research team would see the actual completed questionnaire, as

distinct from the aggregate data. Where qualitative answers were contained in the questionnaire, we made it clear that anonymity in relation to those comments would be strictly observed and maintained.

Fieldwork commenced in November 1999 and was completed by the beginning of March 2000.

Fieldwork Sites and Interviewing Strategies

Each of the six breast clinics convenes on one day a week only, although in some clinics, it is possible for women to come back for results or to attend for an immediate follow-up consultation in the course of that same week. The clinics differ in the range of consultant expertise on hand. The clinic in Sligo, for example, has no resident oncologist, so women have to travel up to Dublin if they require either chemotherapy or radiotherapy. A radiologist travels from Dublin to assess patient need on a fortnightly basis. In Drogheda, the nurses can deliver oncology care for patients and there is also a visiting oncologist from the Mater Hospital in attendance. All services are not on the same site for women attending the South Infirmery Cork, and those who go on to require radiotherapy must attend at a different hospital.

In Waterford Regional, women can receive chemotherapy on site and for those women requiring prostheses, the service has also been specially developed on site, lessening the stress on women in the aftermath of surgery and eliminating their having to confront complete strangers for cosmesis. The breast care nurse has a well-fitted out, spacious room where she can see women in an informal atmosphere of privacy. In the South Infirmery in Cork, breast care nurses have also obtained a room which is cheerful and bright, where they can offer additional support to women.

In respect of waiting room space, only the Drogheda clinic is in a physical location in the hospital that enables it to offer women greater privacy. The other five clinics share waiting room space, often crowded, with other general clinics which are progressing at the same time. In Beaumont, for example, this means that the waiting room is for patients of both sexes. In St. James, people must often stand in corridors, because there is insufficient seating for the pressure of numbers.

Resources of staff, time and space are of course major concerns in the provision of clinical care. In respect of time, the Sligo breast clinic appears to operate under the greatest constraints, with an average of 20-22 women scheduled to attend each

week in the appointed clinic time slot of 12 noon to 1pm. We were told that the clinic often needs to run on to 1.30 or even 1.45 pm. in order to deal with that day's list. All save one of the clinics appeared to the team as physically very crowded; most entail long waits for the women presenting, compared with the actual time spent with the medical team. The medical staff are working under pressure to get through their lists for each scheduled sitting of a clinic.

It is somewhat problematic to carry out questionnaire research in such pressurised circumstances. The team did not wish in any way to add to the workload of staff nor did we wish to increase anxieties for the women who were waiting. However, seeing at first hand the way the breast clinics are working gave us greater understanding of how provision currently works.

Depending on the day and the circumstances of each clinic sitting, we employed three different strategies to obtain completion of questionnaires. Women who wished to participate were asked if they would complete the questionnaire while waiting and return it to us there and then; if they felt they wanted to fill it out in private, they were also given a stamped addressed envelope to post it back to us. Thirdly, if potential interviewees wanted to participate, a team member was available to go through the questionnaire individually. Women, depending on their circumstances, were generally eager to participate. However, it was often not physically possible for women to fill in the questionnaire in the very crowded waiting space. Some women said they did not want to do it that day because they were too distressed and anxious, either because of confirmation that they had just received about their diagnosis, or because they were anticipating bad news. Some felt unable to concentrate in case they would miss their place in the queue. In several instances, women who expressed interest, but wanted to do the questionnaire after their appointment, were asked to proceed at once after their consultation to another part of the hospital for further tests, and were unable to come back to where a team member was seated to collect a questionnaire for posting.

One interview with a woman took place almost at the very end of one of the clinics which had run overtime. The woman, for whom this was a first attendance, had not yet been seen at all that day. Of course, she could only partially answer the questionnaire, up to the point of her arrival at the clinic. However, her comments on the delay she had already experienced were highly relevant because she had a very strong family history of breast cancer. We will return to these comments in Section IV below.

Breast care nurses in all of the clinics did their best to provide us with a somewhat more private space where women could be introduced to the questionnaire and either go through it with one of the research team or take it away to fill it in and post back to us. Several breast care nurses undertook to introduce the idea of the questionnaire to potential respondents and to organise its distribution. But the nurses themselves were generally short of space, not having dedicated office space in the clinic where they could see a woman in private. Much of our work was done in corridors.

There were gains and losses in all these different approaches to data-gathering. The questionnaire by interview permitted women to tell their stories in detail. This took more time; on average about 20-25 minutes for each woman. More numbers were obtained if women felt they wanted to complete the form themselves but although the quantitative data was good, they were less likely to take the time to fill in the qualitative open-ended questions.

III Findings from the Quantitative Data

- *Total sample size
and demographic details*
- *Age range, education and
relationship status of respondents*
- *Respondents with Children and
Age Ranges of Children*
- *Discovery of Symptoms
and Initial Referral Process*
- *Initial Clinic Visit*
- *Satisfaction with First Visit*
- *Current Health Status and
Treatments to Date*
- *Distance from Clinic, Transport
and Time Spent at Clinic*
- *Social Support for Women*
- *Priorities for Breast Care Services*

Findings from the Quantitative Data

Total Sample Size and Demographic Details

In all, one hundred and ninety-one women completed questionnaires during the fieldwork phase. We did not reach the target of 40 per site in the timeframe available for the fieldwork. Two of the sites had a relatively small throughput of women and one of the larger sites found it difficult to accommodate the research team, given the constraints of space under which they regularly work. And women did need to be committed to undertake a questionnaire totalling fifty-one questions. All of our respondents did not necessarily answer all the questions, so percentage results presented below are based on the total number which answered that particular question, not on the total sample.

Age Range, Education and Relationship Status of Respondents

A substantial minority of women, just over 45 per cent, were in their childbearing years but the majority of the sample was comprised of women who are thought to be most vulnerable to breast disease, that is, those who have ceased childbearing.

Table 1: Age Range of Respondents

Age Range	Number	Percentage
< 20 yrs.	1	.53%
20-29 yrs.	23	12%
30-39 yrs.	32	17%
40-49 yrs.	29	16%
50-59 yrs.	42	23%
60-69 yrs.	21	11.2%
70-79 yrs.	6	3.23%
Totals	186	100%

Given the age range of women, the distribution of educational qualifications, not surprisingly, represented the limited opportunities for women before free secondary education, with 50 per cent of this sample having gone as far as Intermediate Certificate only.

<i>Table 2: Highest Level of Formal Education</i>		
Primary	36	19%
Intermediate Cert.	59	31%
Leaving Cert.	53	28%
Third Level Dip/Cert.	33	17.5%
Third Level Degree	8	4.3%
Totals	189	100%

More than two-thirds of the sample were married, with the next largest group, one-fifth, declaring themselves single.

<i>Table 3: Relationship Status</i>		
Current Relationship Status	Number	Percentage
Married	129	69%
Living with a partner	6	3%
Single	38	20%
Widowed	10	5%
Separated	5	3%
Totals	188	100%

Of one hundred and thirty-one women who answered the question on whether there was any family history of breast cancer, fifty women did have a history of breast cancer in their immediate family, usually either sister, mother or aunt.

Respondents with Children and Age Ranges of Children

One hundred and forty-nine women or 79 per cent had children, just under four-fifths of the sample. The age ranges of the children of these one hundred and forty-nine women, were as follows:

Table 4: Numbers and Age Ranges of Children of 149 Respondents

Children's Age Range	Number of Children	Number of Women	Number of Women as % of Total
0-4 yrs.	31	21	14.09 %
5-9 yrs.	49	38	25.5%
10-14 yrs.	70	53	35.5%
15-17 yrs	52	45	30.2%
18 yrs. +	249	79	53%

Note: Total percentage is greater than 100 per cent because some women had children in more than one age range.

An appreciable number of women, then, had children who are still quite young. The threat of breast disease in such circumstances must raise a great deal of anxiety for the women involved and indeed this is borne out in some of the qualitative comments in Section IV, below and in the literature review, Section VI, below.

Medical cover for respondents divided up as follows, with seventy-five women or just two-fifths of the sample having a medical card:

Table 5: Medical Cover Details

Medical Card	75	39.2%
PRSI	29	15.1%
VHI	54	28.2%
BUPA	10	5.2%
Other (work scheme)	1	52%
None	22	11.5%
Totals	191	100%

Discovery of Symptoms and Initial Referral Process

Education about breast disease concentrates on the importance of self-examination by a woman and this can achieve excellent results in early detection. Currently, for example in England and Wales, ninety per cent of all breast cancer symptoms are discovered by women themselves (England and Wales, Department of Health, 1998). In our sample, this percentage is nowhere near as high. One hundred and thirty-three women or sixty-nine per cent first discovered the symptoms leading to their referral while the next largest group to make the discovery comprised GPs at just over twenty-five per cent.

<i>Table 6: Discovery of Symptoms</i>		
Who First Discovered Symptoms	Number	Percentage
GP	49	25.6 %
Private Women's Health Centre	1	.5%
Hospital Consultant Doctor	2	1.04%
Self	132	69%
Partner	1	.5%
Other	6	3.14%
Totals	191	100%

There are several critical timeframes after the initial discovery of symptoms. The first of these, which occurs if the woman herself or a family member or partner has discovered the symptoms, is getting to a GP. Internationally, health education programmes on breast cancer emphasise that early detection is vital. Therefore if women are slow at taking the next step to the GP, it is important to know why so as to target public education messages towards women's actual situations. Fifty-nine women reported that they had waited from two weeks to over a month before they went to see their GP (twenty-five saw their GP between two weeks and one month after they discovered their symptoms and thirty-four women saw their GP more than a month later).

¹ The replies for others showed four routine mammograms, one of these in the United States, one person whose symptoms were discovered by her GP for a check-up, who did not manifest symptoms at that point but who was later found to have breast cancer.

Asked to tick off all the reasons why this interval of more than two weeks arose, women replied as follows:

Table 7: Reasons Why It Was Two Weeks or Longer Before Going to GP

Wanted to avoid thinking about it	36
Not ready to deal with it	19
Transport difficulties	8
Work constraints	7
Practical difficulties w/ appt. times	7
Family constraints	4
Lack of confidence in health services	3
Cost of medical appointment	1
Other	26

Note: Total number of replies is greater than sample size who replied to this question because each woman ticked all categories relevant to her.

Some women who ticked the last category, above, 'other', also inserted these explanatory comments:

Table 8: Open-ended Comments on Why It Was Two Weeks or Longer to See GP

Pregnant at time
Out of country
Away from G.P during Christmas
Waiting to see if it would disappear
Waiting to see if it would go away.
Hoping pain would go away.
I was healthy
Wasn't really over worried about the bump.
Not over anxious.
Put it out of my head.
Fear – tried to ignore symptoms.
Feared what would be found out considering family history.
I reported it to a doctor over 2 years ago.
Don't know, long waiting lists.
Had appointment in 3 weeks, was told by GP it would take from 2 to 3 weeks
Waiting for appointment.
Nothing definite
Don't remember.

Twenty-five women reported that the most important reason for waiting two weeks or longer was because they wanted to avoid thinking about it, because they were not ready to deal with it, and because they were afraid. This number of women who said they wanted to avoid thinking about breast symptoms and their possible relationship to breast disease, and the sorts of reasons listed above, which elaborate on how women were thinking about it, indicate that the message of early detection leading to early treatment and cure of breast cancer is not getting across, and that many women are fearful of facing into a positive diagnosis of breast cancer.

Women were asked if, upon being told they were to be referred to the breast care clinic, they were given any written information about breast disease and what they might expect to happen at the clinic. Eighty-six per cent of our respondents said they were given no written information (one woman said however that her GP had spoken with her at length about what to expect). Fourteen per cent said they were given written information. When asked if they would have found written information helpful, or where they had been given written information, if it was helpful, sixty-one percent said written information would be a help. Thirty-nine per cent said they would not have found it helpful. One woman expanded her answer to state that she would have been too frightened if she had read anything in advance about breast disease.

Possibly the most important issue was how long the wait was between seeing her GP or whoever else referred her and her first clinic appointment:

<i>Table 9: Time Waiting for First Appointment</i>		
Interval of Time	Number	Percentage
< 2 weeks	112	62.2 %
2 weeks - 1 month	42	23.3%
> 1 month	22	12.2%
Don't know/ remember	4	2.2%
Totals	180	100%

While it is encouraging that 62 percent of women were seen in under a fortnight, there is clearly a strong case at many levels for arguing that these margins should be improved. This is an issue which also arose in the staff responses (see Section V, below).

Some of the 64 women who had to wait longer than a fortnight, filled in open-ended comments on why they thought this had happened.

Table 10: Open-ended Comments on Why It Was Two Weeks or Longer to First Clinic Appointment

My fault, I was out of country on date of first appointment.
Lack of confidence in Health Service.
Period of nurses strike.
Nurses' strike.
Nurses strike was beginning.
Strike.
Two months waiting to get in to see Dr. Nurse's strike.
Doctor's letter was mislaid in hospital.
Don't know why, probably busy. Waiting for 2 months for mammogram.
Don't know. Very annoyed - had to wait 6/ 8 weeks.
Don't know why. Very anxious time.
Don't know.
Don't know.
Don't know.
Don't know.
Don't know.
Waiting for available appointment.
No free appointment.
On the medical card therefore there is always a delay
I couldn't get an appointment for 3 months.
I think it was a few weeks before I got my first appointment, but I can't remember.
It can be very hard to get hospital appointment.
Waited for an appointment to be available
Waiting for an appointment.
Had to wait for 5 months. This caused anxiety. Dr. thought it was only cysts. Would like to have been seen sooner.
Just long waiting time due to large no. of people attending- couldn't "fit me in"!
They said the clinic was booked up and they couldn't get me in.
I've been waiting for an appointment to the breast clinic in _____ for 6 months and my doctor then had me referred to here in _____ due to delays in _____

Two women did not take up the appointments at first. But for the rest, the circumstances were out of their control. Many simply did not know. Although the breast care services are meant to be part of our national health programme, several felt that being on the medical card mitigated against their being seen sooner. In the case of one woman who wrote at length, going privately was the only option she had left after very long delays:

Although I first saw a GP within two weeks, she went on holiday & forgot to write a letter of referral. On her return, after 3 wks, & only when I phoned did the letter then go. I was waiting a further 3 wks & no appointment had come & I was told I would not get one until December/ January. I then had to go to another doctor who referred me privately to a consultant who saw me within 2 wks. This was at the hospital where I received excellent care.

Waiting for the first appointment is stressful for the most part, and the longer that women must wait the more stressful it becomes. Women were asked to tick all the ways they reacted while waiting for their first appointment:

Feeling anxiety	114
Trying not to think about it	93
Sleep disturbance	78
Feeling panicky	71
Not especially stressed	40
Other	10

Note: Total number of replies is greater than sample size who replied to this question because each woman ticked all categories relevant to her.

This table is interesting because it permits us to see how many women admit to anxiety at the same time that many of them also work hard not to think about what they might be facing. Those who were not especially stressed may have felt there was no great worry about their breast symptoms (this point is also made by one of the staff in their responses to this question – see Section V, below).

Some women wrote in comments to explain some of the other reactions they had during the interval when they were waiting:

Table 12: Open-ended Comments on How They Felt While Waiting

Quite afraid
Couldn't eat or sleep.
Scared.
Weight loss.
Waiting for results of biopsy required courage and patience.
Helpless / Vulnerable.
Lost half a stone in 11 days
Total fear of unknown.
I knew myself before I had the mammogram.
Very down in myself and worried for my child if the worst happened.
Waiting for results of operation - relief that glands were clear - this took weeks.

These are severe emotional reactions. Yet women are trying to get on with their lives while they wait. They have families to deal with, children to tend to, as well as other roles in life, in their workplaces and so on. Whatever about the vital necessity of improving women's survival chances if they go on to be diagnosed with breast cancer, they need as much a reduction in stress as possible to help contribute to those better outcomes and to enable them to go on with the rest of their ordinary living. The literature is very clear on the widespread reaction of anxiety and this needs to be tackled by reducing this interval of waiting to as small a margin as possible.

Initial Clinic Visit

For almost two-thirds of the sample, sixty-five per cent, the day they received the questionnaire was not their first attendance at the clinic. But whether this was a return visit or not, every woman was asked a series of questions about her initial clinic visit. Below are all the responses women gave about the range of tests and investigations they remember being carried out in their first visit:

Physical Examination	151
Mammogram	73
Fine Needle Aspiration	36
Breast Scan	27
Biopsy	25
Aspiration of Cyst	11
Other	1

Note: Total number of replies is greater than sample size who replied to this question because each woman ticked all categories relevant to her.

Mammograms and biopsies were the most common of the tests which could not be carried out in that first visit, and for which women had to return:

Mammogram	37
Biopsy	27
Breast Scan	14
Physical Examination	6
Aspiration of Cyst	5
Fine Needle Aspiration	4
Other	2
None	8

Note: Total number of replies is greater than sample size who replied to this question because each woman ticked all categories relevant to her.

In respect of each of these investigations, women were asked whether the staff satisfactorily explained each of the procedures they were undergoing. Fifteen to

² One women reported she had a cyst removed at her first visit

twenty-two per cent of respondents felt that they had inadequate explanations given to them by staff about these:

Table 15: Inadequate Explanation of Test Before It Was Carried Out

Biopsy	15%
Fine Needle Aspiration	15%
Mammogram	20%
Aspiration of Cyst	20%
Physical Examination	21%
Breast Scan	22%

Note: Total number of replies is greater than sample size who replied to this question because each woman ticked all categories relevant to her.

Satisfaction with First Visit

Women were asked two questions about their overall satisfaction with their first visit. In the first of these, they were asked to rate the staff as a whole:

Table 16: How Women Rated the Staff During First Visit

Rating	Number	Percentage
Excellent	116	64.5%
Very Good	44	24%
Good	15	8%
Fair	4	2%
Poor	3	1.7%
Totals	179	100%

They were also asked to rank all aspects of their first visit in a separate question. One hundred and forty-nine women ranked their experiences as follows:

<i>Table 17: Satisfaction with First Visit, All Aspects</i>		
Rating	Number	Percentage
Excellent	76	51%
Very Good	39	26%
Satisfactory	25	17%
Fair	6	4%
Poor	3	2%
Totals	149	100%

By and large, women also rated the amount of time they had with various staff favourably, with nurses getting a rating just slightly higher than doctors:

<i>Table 18: Satisfied with the Amount of Time with Staff</i>		
Sufficient Time With	Yes	No
Doctor	139 (83%)	28 (17%)
Nurse	121 (85%)	21 (15%)
Radiographer	56 (77%)	17 (23%)

This would seem to be a very encouraging picture for breast clinic staff of how they are relating to women in the midst of pressing clinical concerns. However, on further probing, forty per cent of women felt they left that first clinic appointment with unanswered questions and a somewhat different picture emerges when their open-ended comments are examined. Much of what is a clear communications problem can be attributed to the feeling of shock women experience when they actually confront a positive diagnosis of cancer. One woman wrote in detail about her state of shock:

I was so numb and upset with shock that I couldn't think of any questions at the time I was told I had cancer. I was advised to go home and think about any questions I may have and that they would be answered when I was admitted to hospital for surgery 3 days later.

This was not uncommon as the table below indicates:

Table: 19 Open-ended Comments on Shock Preventing Women from Asking Questions

Feeling panicky.

I was so anxious & nervous, didn't have the confidence to ask the questions.

I was in total shock & fear at the time. I could not take things in.

I was in shock.

Did not ask questions. Shock.

I couldn't think of them at the time.

I was trying to take everything in and felt it difficult to cope with all the information.

Was unable to ask any questions as I was in a state of shock after been told I had breast cancer.

In a panic. I could not formulate the questions in my head.

I was feeling so nervous & scared, the questions I wanted to ask went out of my head & I didn't think of them until later.

I was suffering from my nerves but this was not taken into account.

I went queer afterwards. Had to go on tablets. Very stressed.

All I wanted to hear was that I was OK. Once I heard that it was most likely not to be cancerous,

it was only when I went home that I wanted to know why they were leaving the lump there.

Left doctor too quick, wanted to ask questions.

I was apprehensive.

The initial shock of the diagnosis leaves one quite deflated and confused.

On the other hand, the literature is clear that precisely because women experience shock in such circumstances, clinic procedures should take this into account and build in explicit protocols to support women at this point (some of these models are discussed in Section VI, below). Women should not be the ones making allowances for their shock reactions.

Several women reported feeling that the clinic structure could not accommodate their questions:

<i>Table 20: Open-ended Comments on Clinic Structure and Pressure Preventing Questions</i>
Didn't feel he, the doctor, would have time for the questions.
The environment is not really conducive to asking questions.
Afraid to ask more.
Felt not taken seriously enough. Condition not taken seriously enough.
No opportunity to ask.
Very busy clinic. No opportunity to ask.
Didn't get to talk to nurse.
Not enough staff available at busy clinic.
I was rushed through. I did not see the breast care nurse.
Nobody told me what was wrong.
Not talking to nurse.

Several other women were clear that they wanted more information and even very specific information but that they were unable to obtain it:

Table 21: Open-ended Comments on Sufficient Information from Staff

Could have been better informed.
Wanted to understand the whole procedure, what is happening and what might happen.
I just wanted an answer, not to come back for the next 4 - 5 visits.
It's very worrying.
I expected to be examined fully (my breasts), I was very worried.
The lump was a 'cyst' but why did it happen?
Could it happen again (and yes 5 times).
Could I do something to stop them occurring?
Could they turn cancerous?
Not happy about them not doing a mammogram.
Wanted them to explain it in more detail.
I felt the doctor wasn't ready to discuss what might be wrong with me till he did some tests, so I felt I was wasting my time.
Because of the dismissive attitude of the doctor.
Did not explain things. I felt I was brutalised in _____.
It was very traumatic. I would not go back.
That is why I did not go back to _____.
The radiographer was vague regarding the 'shadow' on the x-ray which left me wondering and anxious.
On 2nd visit and 3rd, 'it' had diminished - what was it?
I still do not know.

These comments relate to the issues discussed in Section I, above, of the problem of determining satisfaction for women. The majority of the women enter the clinic stressed and anxious and there is a sense in which they are grateful for their care and attention, especially after a long wait to get to the clinic. But all their concerns are not being met, most especially, the full dimension of their psycho-social needs, in clinics which can often appear as almost chaotic in their organisation from the woman's view. If the criteria that are part of Wilding's model of quality care were in place, these comments would not be part of women's experiences because there would be built-in protocols to support women. Staff responses to our questionnaire and the background interviews indicated that staff are critically aware of the psycho-social needs which are not being met. But until the lack of planning and of resources is remedied, they cannot remedy the situation.

Current Health Status and Treatments to Date

As mentioned above, sixty-five per cent of our respondents had already attended at a breast care clinic whereas for thirty-five per cent, the day they got their questionnaire, was the day of their first visit.

As a whole, the current health status of respondents was as follows:

<i>Table 22: Current Status in Breast Care Clinic</i>		
Status in Clinic	Number	Percentage
Still undergoing diagnostic tests	15	11.5%
Have received diagnosis of cancer	25	19%
Diagnosis of other breast disease	4	3%
Follow-up check ups only	67	51.5%
Other	19	15%
Totals	130	100%

Respondents who answered the question on treatment recorded having the following:

<i>Table 23: Treatment/s Received to Date</i>		
Surgery – lumpectomy	31	15%
Surgery – mastectomy	35	17%
Chemotherapy	29	14%
Radiotherapy	27	13%
Drug treatment, like tamoxifen	23	11%
None	45	22%
Other	16	8%

Fourteen women reported having difficulty in accessing these treatments. When asked what these difficulties were, the following open-ended comments were made:

Table 24: Problems in Accessing Treatments to Date

Waiting list for breast clinic. Had to push for earlier date.
Shortage of beds in hospital
The radio machine is breaking down too often.
They need a new machine.
Problem, had to travel to St. Luke's. Had to wait long hours in St Luke's.
Backup treatment very bad in St Luke's.
Distance to go to St. Luke's quite difficult. Had to go every day. Brought by taxi. Bus not suitable. In bus for several hours travelling around city, very difficult when you are already feeling sick.
Had to travel 30 miles to Dublin to have radiography & chemotherapy.
Long distance to be accessed for the need to have chemo & radiotherapy.
Had to travel 30+ miles to St. Luke's in Dublin for radiotherapy. Didn't have transport or anyone available to bring me. Had to travel by ambulance provided by hospital which usually meant waiting for a full day at St. Lukes to be collected.
Travel 72 miles each way for radiotherapy.
Had to travel to Dublin for chemotherapy and radiotherapy
Radiotherapy available in Dublin (100 miles from my home) not in our local Regional Hospital (which is only 2.5mls approx. away) from our house.
Travelling to St. Luke's for treatment
Delay in getting a bed at St. Luke's for radiotherapy. Finally I had to stay at B&B for 1 week to get started. Obviously the sooner I started the sooner I finished. A few weeks delay, can't really remember how many.
No problem when I got into hospital, staff and service was excellent.
Chemo - no delay as this was at my home town in Waterford.
I had to travel up and down to Dublin weekly for 1 month for radiotherapy at St. Luke's Hospital - a distance of over 100 miles.
Had to come to St. Luke's, no radiotherapy in Sligo.

The bulk of these comments relate to the pressure women experience if they must travel away for radiotherapy and/or chemotherapy. It is simply not acceptable that women are put under that additional pressure, especially when both treatments can leave them feeling quite unwell in the immediate aftermath. For them to be absent from home, or to have to travel a long distance on a daily basis, certainly does not represent best practice for their overall care and recovery.

Distance from Clinic, Transport and Time Spent at Clinic

The practical issues of how far people live from the clinic, how long it takes them to get there, how difficult it is to arrange transport to suit clinic times and how long they can expect to be at the clinic all warrant examination because of the additional pressure under which they can put women.

Distance from the clinic was recorded as follows:

Distance	Number	Percentage
< 3 miles	66	35%
3 - 10 miles	53	28%
11 - 20 miles	20	10.5%
21 - 40 miles	32	17%
> 40 miles	18	9.5%
Totals	189	100%

So over a quarter of this sample were travelling an appreciable distance, which would not be possible to do without access to a car. Yet just over a third of women had access to a car themselves, with the majority of women relying on someone else to bring them to their appointments:

Mode of Transport	Number	Percentage
Public Transport	13	8%
Family Member's Car	67	39%
Friend's Car	20	12%
Taxi	10	6%
Own Car	63	35%
Totals	173	100%

Forty-seven per cent said that public transport was difficult; thirty-six per cent said that it was not while seventeen per cent did not know. But for anyone relying on someone else, or trying to fit in with a family member, clinic waiting times were a possible source of pressure. When asked what their average waiting time was, three-quarters of the sample said they were waiting at least one hour to two hours before being seen:

Table 27: Clinic Waiting Times

Time Intervals	Number	Percentage
< 1 hour	42	26%
1 - 2 hours	78	48%
2 - 3 hours	32	20%
> 3 hours	12	7%
Totals	164	100%

Social Support for Women

In a series of questions designed to probe the degree of support women felt they had received or not during their clinic sessions, seventy-nine per cent of respondents said they had confidence in the medical care they were getting, but a consistent twenty-seven per cent of respondents felt that they were not encouraged to ask all the questions they wanted to ask; that they were not listened to and that they did not feel free to talk about how they were feeling; and that they did not feel their names and details were remembered from visit to visit. Seventy-five per cent of women said they were offered no form of counselling. Only thirteen per cent of respondents were in touch with a voluntary support group about their breast disease and these were using either their local cancer support group or the Irish Cancer Society for the most part, although four people mentioned the ARC group in Eccles Street in Dublin.

For the most part, women found support from within their family:

<i>Table 28: Sources of Emotional Support for Women</i>	
Partner	82
Children/ family	75
Friend	53
GP	45
Support group	8
Counsellor	3
Other	8
Note: Total number is greater than study group of 191 because each woman ticked all categories relevant to her.	

However, in naming other people who were helpful, several cited the breast care nurse and one mentioned her consultant. Seventy-six per cent and seventy-seven per cent respectively felt that their privacy and dignity had been maintained by the staff's handling of them.

Priorities for Breast Care Services

In the final closed question, women were asked to rank their most important priorities for breast care services in the future, based on their experiences. The ranking below represents the urgency with which women want their symptomatic breast disease treated:

<i>Table 29: Five Most Important Priorities for Women</i>	
First appointment within one week of referral	70%
Having all diagnostic tests in one session, where possible	38%
Having any additional tests within one week	34%
Unhurried time to talk to consultants after test results	19%
Continuity of care – if second visit is required, assurance that I will see the same breast care nurse and consultant	15%
Note: Percentage totals are greater than 100 because women rated their priorities differently and the highest percentage ratings for each category make up this table.	

IV Findings from the Qualitative Interviews and Open-ended Responses

- *Information and Communication*
- *Staff Responses to Women and General Clinic Procedures*
- *Lack of Support from Clinic Staff*
- *The Strain of Travelling to Radiotherapy Sessions*
- *Themes from the Focus Groups*
- *What Improvements Need to Be Made to the Services*
- *Waiting in the Clinic, Waiting for Appointments and Waiting for Results*
- *Clinics, Staff and Clinic Protocols*
- *Information, Awareness and Screening Campaigns*
- *Support and Counselling*

Findings from the Qualitative Interviews and Open-ended Responses

Women were very positive about the breast services in their ratings, in the focus groups, and in their comments. Most expressed themselves as satisfied with their treatment and a number tried to make allowances for the fact that the services are so over-stretched. However, many women made a key distinction between the care itself and how the care was delivered. There was special concern around the issue of more supportive practices in the clinics.

In the questionnaires, forty-eight women or thirty-two per cent recorded that they could have been better supported in their experiences. Again, what must be borne in mind here is that for the most part, women have no different model of care with which to compare their experiences. If they did the percentage would undoubtedly be higher because the clinic system as it is currently structured can do so little to help in respect of psycho-social needs.

Forty women took the time to write in open-ended comments about how they could have been better supported.

Information and Communication

Information and communication procedures were commented on here as being insufficient for each of the women below:

<i>Table 30: Need for Better Protocols on Information and Communication to Provide Better Support</i>
More explanation
If a nurse could explain procedure, i.e. that you would be weighed & blood pressure taken and then a nurse would explain the examination to you.
Better communication towards me. Even though I am a nurse myself, I felt that there was a serious lack of communication leaving me in a state of confusion leaving the clinic.
I was not sure why I was coming today & as I had another appointment & the appointment letter didn't specify that it was for the breast clinic.
Should be encouraged to write down questions before coming to clinic.

Staff Responses to Women and General Clinic Procedures

Women expressed a sense of vulnerability because of lack of staff communication to them about protocols and procedures. Some staff appeared not to adhere to the basic courtesy of introducing themselves or their colleagues to women.

<i>Table 31: Courtesy and Communication from Clinical Staff about Procedures</i>
Not to be left naked (waist up) for 30 mins. in a room with no heat.
Dr. then entered with a chart (no hello) and asked me how my mastectomy went (I was in for a cyst). His patient was next door.
People entering the room as you are naked to speak to colleagues.
Doctor didn't introduce herself. A man sat there but was not introduced, but I didn't know who he was & why he was there.
Maybe more information. The radiographer was not pleasant, did not say a lot about the mammogram to me.
Explain in more detail why they would not remove the lump – whether it would go itself – Why there would be no more examinations once the lump was not cancerous – Could it become cancerous at any stage?
As I was very nervous on my first visit I would have welcomed some reassurance, and being told a bit more about the procedures.

Lack of Support from Clinic Staff

Some women were also concerned about the way they were told about a positive diagnosis of cancer and the lack of support given to them at that point.

Table 32: Women's Expressed Needs for Better Support from the Clinical Staff

I think I needed to be assured that nothing was urgent as I was made to wait 3 Long Months till I had a scan to show me there was no cancer. I had two aunts Die from this disease and I felt there was nothing done to help put my mind at rest. No woman should have to deal with a wait as long as this. I couldn't eat or sleep. Lost four stone and my job and my family suffered.

My consultant could have tried to put my mind at ease.

I was lucky I had family and friends and I am inclined to accept what comes and make the most of a situation.

I had family with me, but did not realise I could have brought one in with me. This could have helped with questions being asked and answered with 2 of us listening.

The anxiety level meant that I forgot many of the answers to my questions. A tape of answers should be given out or some way for us to remember?

I feel that I did not get enough time - I was asked straight away if I wanted my whole breast off. I think it was such a shock - it would have been better if I could have gone away for a day to think about things.

There should be a person appointed to talk with in a room and give you time to discuss the positive result of cancer.

The Strain of Travelling to Radiotherapy Sessions

For the women we interviewed who had breast cancer and who required radiotherapy, the circumstances of travelling long distances was a tremendous source of stress, disruption and expense. Critically, it left women without support when they really needed it from their family, if they had to travel up to Dublin. One woman felt that the fact that radiotherapy services are located only in Dublin or Cork was just simply accepted by medical staff and that women were implicitly told that they should accept this and not be stressed by it. But women were upset, as the following comments indicate:

Table 33: Open-ended Comments on Problems with the Radiotherapy Services

There need to be more than 2 hospitals in Ireland where women can receive radiotherapy.

Radium and chemotherapy facilities should be available in local areas

Problem with having to travel to St Luke's. Had to wait long hours in St Luke's. Backup treatment very bad in St Luke's.

Distance to go to St. Luke's quite difficult. Had to go every day. Brought by taxi . Bus not suitable. In bus for several hours travelling around city, very difficult when you are already feeling sick.

Had to travel 30 miles to Dublin to have radiography & chemotherapy.

Long distance to be accessed for the need to have chemo & radiotherapy.

Had to travel 30+ miles to St. Luke's in Dublin for radiotherapy.

Didn't have transport or anyone available to bring me. Had to travel by ambulance provided by hospital which usually meant waiting for a full day at St. Luke's to be collected.

Had to travel 72 miles each way for radiotherapy.

Had to travel to Dublin for chemotherapy and radiotherapy

I think the situation with the radiotherapy is very bad . I had to come and stay for 7 weeks.

The VHI should be more flexible. I would have preferred to stay in B&B; this would have freed up the beds.

Radiotherapy available in Dublin (100 miles from my home) not in our local Regional Hospital (which is only 2.5mls approx. away from our house).

Travelling to St. Luke's for treatment

Delay in getting a bed at St. Luke's for radiotherapy. Finally I had to stay at B&B for 1 week to get started. Obviously the sooner I started, the sooner I finished. A few weeks delay, can't really remember how many.

No problem when I got into hospital, staff and service was excellent.

Chemo - no delay as this was at my home town in Waterford.

I had to travel up and down to Dublin weekly for 1 month for radiotherapy at St. Luke's Hospital - a distance of over 100 miles.

Had to come to St. Luke's, no radiotherapy in Sligo.

The travelling to Dublin from Waterford was very stressful, especially not feeling too good and having to be away from the family at a time like this. This must be dreadful for anyone. Otherwise the care was very good, no complaints.

Themes from the Focus Groups

The three focus groups emerged with many of the same themes we have already encountered. Most of the women who attended these groups had already worked through a positive diagnosis of cancer and were either receiving or had largely completed their treatment. Two groups were held in Cork and Sligo and the third in Dublin. One function the focus groups provided and for which the women expressed their appreciation was the opportunity to talk with others who had been through similar experiences. Women were anxious to compare notes with others who had had very similar courses or the same courses of treatment, for instance, so that they could make better sense of all they had undergone. The main themes were:

- Initial shock at diagnosis;
- Acute anxiety of waiting for first appointment and for test results;
- The crowded setting of the breast clinic;
- Value of breast care nurses;
- Lack of service provision – mammograms, other diagnostic tests and radiography;
- Impact of the disease on their families;
- Need for emotional support from family and friends;
- Better support and counselling services;
- Value of complementary therapies in supporting them during conventional treatment;
- Need for greater information and awareness.

Women commented on how shocked and devastated they were when they first noticed the symptom (lump or other change) and their fear in being referred. What made it particularly shocking for them was that each regarded herself as being very healthy and never ill. It was difficult for women to reconcile this with the sudden realisation that they had a potentially serious condition.

Waiting was a source of terrible anxiety. One woman with an inflamed and enlarged breast was refused a referral by her GP, while she was put on several courses of antibiotics. After these were completed and there was no improvement, the GP was still reluctant to write a letter of referral. A further five weeks passed before she got her first appointment at the breast clinic, where cancer was confirmed, after an additional three and a half weeks of waiting for the results of the mammogram.

Some women reported no delays in being referred to the clinic, while other women did have delays in getting the first clinic appointment, and also had to wait for the results of biopsies and other tests. But once there was a diagnosis, all were very satisfied that no undue delay had occurred in relation to subsequent visits to the clinic and in relation to further treatment and expressed themselves very satisfied with the standard of treatment.

Experiences varied as to what happened after they had been given a positive diagnosis of cancer and it appeared to depend on the availability of the breast care nurse. Women strongly recommended that people should be encouraged to be accompanied by someone close when they were likely to get bad news. All felt there should be someone on hand to help deal with the physical and mental shock effects 'not to be left walk out of the hospital cold'. One woman, having received a positive diagnosis, was so distressed that she went home and began to clean out her drawers and tidy her papers. There was no awareness for her, communicated by the staff that her prognosis was good and she reacted by taking it as a time when she must have all her affairs in order.

The organisation of the breast clinics came in for criticism. Why did so many women have to be called on the same day at the same time? Surely there was an alternative to the batch appointment system? The clinics were desperately overcrowded because of this system and this was not without stress. One woman pointed out that in maternity clinics, women chat easily to one another but in a breast care clinic, the feelings of depression, anxiety and fear are palpable:

Such a place – there are so many women sitting around in hard chairs, magazines that were there for yonks. Everybody is tense because everybody is in the same boat. You are sitting there for hours. I had an appointment for eleven am. and I was seen at three-thirty in the afternoon.

One woman talked of seeing a woman coming out from the consulting room, in floods of tears, with nowhere to go except the corridor to be consoled, having just received a diagnosis of cancer.

All the women felt it was important to have someone to whom they could speak, someone whose name they would get to know. Here the value of the breast care nurse, if they got to see her could not be underestimated. Those women attending where the breast care nurse had managed to achieve a private space where her patients could come, were full of praise both for the support and for the less

clinical atmosphere. Being able to ring the breast care nurse once treatment had begun was also a great support and comfort for them.

Not having all the services for testing and treatment on site was a great strain. Women in Cork had to go to a different hospital for some of their tests, and several found themselves 'flying around in taxis in nightgowns.' This was not an acceptable level of service nor was the lack of locally available radiotherapy. For women from the west to have to travel to Dublin was a huge hardship. One woman described crying the whole way up to Dublin on the train, having said goodbye to her children. Another felt strongly that she should have been able to have her treatment and get into her own bed in her own home that night.

Facing a positive diagnosis of cancer had a major impact on women and their families, but most were lucky and had close family members who were very supportive. They found it hard to imagine how they would have coped and felt strong without such support.

In the Dublin focus group, the issue of support for family members came up. Several women noticed that it was they who had to be strong for the others, rather than the reverse. Moreover, when they themselves were down, it had a very negative effect on their supportive others. Therefore, respondents tried to stay positive for the sake of their family.

This has two implications, the first being that staying strong for their families meant that they also needed someone outside for comfort and support that they did not feel they were burdening.

You need someone to lean on and you can't always get it from your family. Anyway, sometimes it is easier to talk to a stranger.

Secondly, they all felt that family members should be offered support for themselves as, in some respects, they were going through as much as the patients. Indeed, the respondents all considered that the experience had been worse for those close to them than it had been for themselves:

It's harder for people around you looking at you going through it.

Support services for their families were seen as an important element of care, but they only know of one group which provided this in Dublin. In Sligo, there was concern at the lack of counselling and support services for children of affected

women. Their experiences were that each child tended to react differently to this crisis and that each had needs which were going unattended.

The respondents varied in the extent to which they had accessed complementary medical sources to help their treatment/recovery. One took something that a relative recommended but would not have sought any such remedies herself. The second had used some complementary therapies before and continued to do so. The third had developed a specific interest in reading up about the disease and treatments and used complementary remedies to deal with some side effects and to become healthier in general. She had consulted some of the ward staff about the efficacy of some of the treatments and found a mixed response – some interested, some neutral, some very wary. She would have welcomed some more specific and positive guidance about the ‘fit’ between different treatment approaches. She felt it was left to her to find out anything that might be of help in ‘building myself up and staying healthy’.

On balance, there were few negative comments in comparison to positive ones. In the context of the experience of a very caring staff, one respondent remarked on one junior doctor who had something to learn regarding a good bedside manner. The practice of a consultant arriving into the ward at 7.00 am with an entourage of 10 + staff was experienced as very disconcerting by one respondent, who said that the combination of people and early time made her forget anything she had wanted to ask.

One respondent had been particularly satisfied that her surgery had incorporated breast reconstruction with the mastectomy. She thought the plastic surgeon had been very skilled and felt it had really helped her to never have to deal with having only one breast. She said she had been told that this was made available to her on account of her young age. She had heard of older women who were not offered this option and felt that this should be there for everyone who was having a mastectomy. She knew of others who had been offered the choice but had opted not to undergo the two together on account of the lengthy surgery involved.

Women spoke about the need for greater information and awareness at a number of levels. Some had not had adequate information to understand or deal with the effects of their treatments. One woman, for example, could have used information at an earlier point that would have helped to prevent a complication that had arisen. She went home after surgery and her wound became infected. Later, she attributed this to her taking long baths on discharge, thinking they would be beneficial. It was only afterwards that she discovered that baths are not

recommended, as they can be the cause of /or contribute to the development of wound infections.

Another information need arose in relation to the side effects of chemotherapy. More staff with knowledge about this should be available at the weekend. With the wards dealing with chemotherapy running on a Monday to Friday basis only, two women reported coming into A & E during the weekend feeling extremely ill from their chemotherapy but no one was on hand with the knowledge to deal with their problems.

Women were very keen that there be more widespread general campaigns about breast health. The perception that it was i) a killer and ii) a disease that affected older women needed to be tackled at the level of public education.

What Improvements Need to Be Made to the Services

One hundred and eight women were concerned enough at the end of a long questionnaire to take a bit of extra time and add comments about the future shape of the services that they felt might not have been covered in the questions themselves. The essence of these replies are set out the following pages.

Waiting in the Clinic, Waiting for Appointments and Waiting for Results

Easily the one improvement that women cited most frequently in overall service provision was to cut waiting times at all points in this process:

Table 34: Improving Services by Abolishing Waiting

Any woman discovering a breast lump (1) needs reassurance, (2) needs urgent appointment. Very difficult for women waiting

Need more clinics. Why only a Friday? - look at the volume of patients.

It seems to be rated as a minor/ unimportant/ women's issue/ woman over-react.

I'd like to see a small clinic which would deal with breast problems only.

I would like to be given a time, an appointment that would be kept.

Allot enough time for each person like an appointment book, so not everyone is down for 12:00, 1:00. People have to get out from work & do work by appointments. Thank you.

If the patient could be reassured that they would be informed immediately if the tests performed – mammogram/ biopsy - were positive, because the 2 weeks waiting can be the longest two weeks of your life!

Care should be as quick in Donegal as other counties.

If you do not have "family history" you still deserve to be dealt with within 2 wks.

Just don't waste time and don't cut to quick.

Woman should not have to wait for the results of tests it is the usual practice to have to wait 10 days – unacceptable.

I feel they are doing a pretty good job. But the waiting time is too long - a lot of time you have an appointment for 2:30- not seen until 5:30 pm.

Not having long clinics -the clinics are like cattle markets. 2) More staff - it is a problem when you ask to see a doctor. Getting the results back much more quickly - not having to wait very important.

The waiting for a check up and in the breast clinics should be eliminated completely as this adds to the anxiety and stress which is natural with this condition

The waiting area: overcrowded, no magazines, can feel the anxiety of the other women.

More information as to how long you will be- nearly a row about whose turn it is.

Clinics, Staff and Clinic Protocols

One woman wrote that she did not want to be quoted verbatim. She had found the experience of having breast disease which was non-cancerous, a recipe for humiliation. Three doctors talked over her head to one another about how to proceed with her case and she was then told that she did not require another appointment, in such a way as to make her feel that she had been wasting their time.

A number of other comments were made on the need to change attitudes of staff, and again, the value of the breast care nurse being emphasised:

Table 35: Women's Perceptions of Staff Attitudes

I believe the quality of care provided in the clinic is excellent however the way in which it is delivered is questionable.

The attitude of some consultants leaves a lot to be desired. The first one I saw was quite demeaning, implying that just because I was small breasted, I wouldn't miss them. May I add that this was not at the hospital I am now attending and where I have received nothing but respect and courtesy and also kindness at a very traumatic time in my life.

After my biopsy the locum consultant told me in front of 5 other patients that even if I had cancer, that was all the treatment I needed & then about 10 days later I got a word to come in for a full mastectomy.

Other than that I feel the care I received was excellent.

I would rather see more women doctors - more relaxing. Had a female doctor today. She knew what she was talking about. Feel embarrassed with male doctor.

More female consultants needed in this area; men are not in tune with women's feelings in this regard, even if they have years of experience.

Having the same consultant and breast care nurse at each visit.

Having a backup breast care nurse when the other nurse is away.

The breast care nurse was/is a very important person to me. It was good to have her meet my husband and me immediately on diagnosis of breast cancer. Going home with a 'temporary' breast form [prosthesis] was important for self-esteem.

There should be a specific clinic for breast care.

Special clinic, waiting room not mixed with diabetic clinic and other problems. Maybe a video on how to examine your breasts correctly.

What to do if you discover a lump. Where to go. What happens when you get there. You would then go into the doc or examination room with a relaxed feeling of not being alone and not feeling too self-conscious.

Information, Awareness and Screening Campaigns

Younger women with breast disease felt that this aspect was not well-publicised and that women needed to have the message of breast health and breast care reinforced for all ages:

<i>Table 36: Comments on the Need for Greater Public Awareness</i>
It is a sad and sneaky disease -fear is a terrible thing and women don't go to the doctor when they find a lump.
Since I was diagnosed as having breast cancer at the age of 26, I feel that young women should be more aware of the disease and they should have examinations at regular intervals also. Breast cancer is more common in older women but as my case shows it can happen to younger women.
Regular examination & mammogram should be made available from a younger age as a matter of routine.
It would be important to have mammograms available for people free.
There are so many problems women can have with their breasts, that these should be publicised. Then with more information we can understand better and not worry about the worst.
There should be more publicity – explain more - more education.
I just feel that it is important that if you have a lump that you get it seen to.

Support and Counselling

Finally, there were several comments on future improvements needed to deal with support and counselling:

Table 37: Improving Support and Counselling Services

Would have liked if someone had talked to me and tell me what they would have to go through, no point just having a phone no - need to have one.

The back-up I received in the pre-and post operative weeks and during chemotherapy was absolutely excellent. Once the treatment was over I felt I was on my own. I had been attending hospital at least once a week prior to this. 2 years on I feel very much on my own. My GP now answers questions and tries to help with the problems caused by the tamoxifen. I don't like to bother the breast clinic staff who are obviously working hard with women who have more urgent needs than mine. I do wish I had known about the side effects of the drugs.

I think support for husbands or partners would be useful.

If people need counselling that it would be available for them.

I think I would have liked to talk with another woman who went through breast cancer. The breast care nurse is very good, but there is nothing like talking to someone who has been through the same experience. I also would have liked counselling, more in depth than what is provided by the breast care nurse.

Voluntary listening service by support counsellors within each local area preferably by victims of breast cancer.

v *Responses from
Breast Care
Clinic Staff*

- *Time Frames, Waiting and Clinical
Appointments*
- *Level and Quality of Current
Service Provision*
- *Patient Needs*

Responses from Breast Care Clinic Staff

A short postal questionnaire was designed for breast care clinic staff members in the six study sites, to ascertain staff perspectives on issues like waiting times and clinic resources. This was in order to complement the data from women who participated in the fieldwork. The questionnaires were posted to the breast care nurses in these study sites who undertook to distribute the form to staff members. Stamped addressed envelopes for posting back were attached to each form. Again, these questionnaires were confidential, with no names appended to them and participation was entirely voluntary. Questionnaires were returned from four of the six sites; thirteen medical and nursing staff, including four surgeons, took the time to reply to the questionnaire.

It was especially useful to triangulate the data drawn from the women's responses with those of staff on the shape of current provision of services, to see where priorities merged and where they were different.

Time Frames, Waiting and Clinical Appointments

The waiting period between the consultation with the GP and the first clinic appointment is a time of major anxiety for women, as we have already discussed, and clearly the longer this wait continues, the more anxiety many women experience. When staff were asked about the average interval between the visit to a GP for a referral and a patient's first appointment at the clinic, nine respondents stated that the average wait was less than two weeks.

Four replied that on average the wait was between two weeks and one month. When asked to elaborate on the reasons for a delay of longer than two weeks, these four gave the following reasons:

Table 38: Reasons for Delays of More than Two Weeks

Inadequate resources
Urgent cases will be seen at the next clinic
High risk cases seen within two weeks
Inappropriate GP referrals

One staff member who replied that the average wait was under two weeks also commented on a problem with GP referrals, that often GPs did not indicate the level of urgency of a particular case.

Replies to the next question, about whether the duration of each clinic session is long enough, in relation to the demand for the service, were also an indirect comment on the problem of average waiting times for the first appointment. Twelve of the thirteen respondents replied that sessions were not long enough to cater for the demand they face.

Asked by how long clinics would need to be extended in order to meet current demands on their services, these 12 staff replied as follows:

<i>Table 39: Additional Time Needed to Meet Demands</i>	
Extra 1 – 2 hours per clinic	7
Extra _ day per week	2
Extra day per week	3

The timing of the clinic itself, especially in relation to the length of time actually waiting was a concern raised by women in the fieldwork. In particular, there were questions raised about ‘batch’ appointments, where everyone was told to turn up at the same time.

When staff were asked about clinic times, nine replied that so far as they knew, the timing of the clinic suited women, while four said they were uncertain. Of the four study sites where these staff respondents were located, two clinics operated the ‘batch’ system, with all the women being told to report at the same opening time for the clinic. Therefore it is not so likely that the clinic timing was suitable for women trying to deal with a clinic appointment where there was uncertainty as to when they would be completed. Two of the study sites are running rapid diagnostic assessments for women, whose cases are marked as urgent, and these women are given specific appointment times.

Staff perceptions of average waiting times a woman spends in the clinic at the time of her first appointment varied:

<i>Table 40: Staff Perceptions of Average Duration of Waiting/First Appointment</i>	
Less than 1/2 Hour	2
1/2 to 1 Hour	6
1-2 Hours	2
2-3 Hours	3

Reported times actually differed from within three of the same clinical sites (ranging from under a half-hour to 1-2 hours; and from under a half-hour to two to three hours). One explanation for this may be that some staff are more aware of how long women are waiting, owing to their location in the clinical system. The range of reported times within sites may also reflect the fact that where less urgent and more urgent cases are sharing the same clinic time, some women face long waits but do not necessarily see all the staff that other women see. Nine respondents reported that women waited for under a half-hour before they actually begin the round of consultation and investigation (where further waiting times will occur as each moves from one part of the clinical system to the next). Four reported that women will spend a half-hour to one hour before they are slotted in to the system and begin their round of consultation/investigation.

Reported average lengths of time being spent with each patient ranged as follows:

Less than 5 minutes	2
5-9 minutes	5
10-19 minutes	3
20-29 minutes	2
>30 minutes or as much time as the patient needs	1

Again, these times might well differ depending on the role each staff member has in the work of the initial clinical appointment. The four surgeons, who responded for example, reported an average of 5-9 minutes to 20-29 minutes, but those intervals would be very context-dependent on the case of each woman. What was an even more important question, then, was what respondents thought the ideal amount of time was that they should have with each patient:

Less than 5 minutes	1
5-9 minutes	3
10-19 minutes	3
20-29 minutes	4
>30 minutes or as much time as the patient needs	2

Six respondents reported needing longer than the current times they have to spend with patients, while one reported that the ideal was to spend as much time as

possible with the patient, according to her needs. This is an important finding, given that many women expressed concern and anxiety about having insufficient time in their clinic consultation, despite the long periods of waiting.

Level and Quality of Current Service Provision

Fieldwork visits indicated overcrowded waiting spaces for women, and often that space was being shared by other clinics running at the same time. This feature contributed to a general atmosphere of pressure with people crowded in on top of one another, as discussed above in Section II. However, staff respondents for the most part, did not see the waiting space as problematic for the numbers of patients attending. Ten recorded that there was sufficient room, and two only said there was insufficient room, with one respondent unsure. Eleven respondents judged the waiting space to be comfortable, and again only two judged it not to be comfortable.

However, when asked whether the waiting space in the clinic offered sufficient privacy for women, only six replied that it did. Seven were certain that there was insufficient privacy for women. One respondent volunteered the suggestion that with very little cost, the reception/secretarial area could be screened off so that women had privacy when replying to the initial details which needed to be recorded at that stage. It does beg the question of whether there is sufficient room in these settings, if privacy while waiting is reported as an issue by the staff.

All respondents, save one, thought that the actual clinic itself ensures privacy for women but two respondents said that conditions of privacy would be improved if they had a separate specialist breast clinic.

Ten respondents reported that written information leaflets were available in the waiting room, one of these ten stating that a new leaflet on procedures in the breast clinic and the diagnostic clinic will be in place by the end of March, 2000. However, just leaving leaflets out in crowded waiting rooms, where there are mixed clinics may not be a sufficient solution to information-giving and a more focused, pro-active approach may be more desirable.

Questions about the range and quality of services that are currently delivered, revealed somewhat more confidence in the quality of the services than in the range:

Table 43: Current Clinic Provision

Staff Satisfaction	Yes	No	Total
Quality of Services	9	4	13
Range of Services	7	6	13

In written comments on how services might be improved, respondents made the following points:

Table 44: Staff Views on Where Services Need to be Improved

Screening and biopsy services need to be more accessible to all patients in need;
 Same-day biopsies are needed to relieve patient anxiety;
 More time needs to be spent with patients to improve services;
 Longer clinic times necessary to give more time to each patient;
 Each new patient needs to spend more time with breast care nurse;
 More senior staff are necessary to provide more expertise;
 Clinic and mammogram unit need to be on site together;
 More rapid access needed to breast diagnostic services, including mammogram and biopsy;
 Breast care nurse or breast cancer counsellor vital need;
 Same day investigations are needed for suspicious lesions;
 Clinic time should be in morning so tests can be run in the afternoon;
 this would also help the childcare issue for women;
 Pathology results need to be delivered in the same clinic visit so as to eliminate unnecessary second out-patient appointments.

Patient Needs

Asked about characteristics and reactions of patients at their first clinical appointment, all respondents, without exception, saw anxiety as the most common characteristic. Asked to grade the percentage of patients experiencing anxiety, approximate scalings ran from 50 per cent to 100 per cent of patients. One respondent made the point that perhaps five per cent of all patients are not especially stressed but this is because they do not suspect that there is any great problem in their referral in the first place. The next most common reaction respondents feel they see is that of women trying not to think about the worrying

consequences that they might be facing. Panic, followed by sleep disturbances were the other two reported reactions from ten and six of the respondents respectively.

Huge levels of patient anxiety where these cannot be met by sufficient services create problems of stress for the staff as well. When asked about additional staff resources to deal with the emotional and psychological sequelae for patients, all respondents said there was either a breast care nurse or a cancer nurse co-ordinator to whom they could refer patients and all said they referred often to this source. Referrals to a counsellor or a social worker were done only sometimes and referrals to a psychologist were rarely done. One respondent said that these additional services could be arranged if need be, while other respondents seemed less clear on the role that might be played by any other personnel than a breast care nurse. The role of a social worker did not seem to be at all well-defined for respondents, for example. All respondents said that they could refer women to a cancer support group but it was not clear whether this was a simple matter of providing information and women then self-referred or whether there was a more pro-active assessment with the woman of her support needs.

When staff respondents scaled the six most needed items of help and service that each saw as most integral to the work of a breast care clinic, they weighted items as most important in the following sequence:

One	First appointment within one week of referral	8
Two	Specialist breast care team	7
Three	Having all diagnostic tests in one session where possible	9
Four	Unhurried time to talk to consultants after test results	5
Five	Having any additional tests within one week	4
Six	Encouragement for the patient to be accompanied by a family member or friend for support	3

Interestingly, one surgeon weighted this last item as part of the care package, perceiving that immediate emotional support from a family member constitutes part of good care for a woman.

The list corresponds closely to what women themselves want, a prompt thorough and efficient assessment of their breast symptoms. But it is interesting as well that time to talk to a consultant ranked even above the need to have any additional tests within one week. This ranking question, taken alongside the perceptions of

patient anxiety and the assessments of the range of services currently on offer, suggests that health care staff are all too aware of what needs to be remedied to make service provision better and that part of this package is attention to women's psycho-social and emotional needs.

Staff responses indicate that they are carrying out their work in structures which they can identify as being clearly inadequate but at the same time, professionals are trying to do their best in a field which is facing them with great challenges, if for no other reason than the increasing numbers of women experiencing symptomatic breast disease. Staff working to the limits of their capacities are identifying some of the same issues which trouble women. These are also issues which have been identified in the literature on models of best practice as those most important to ensuring the total care for women, leading to better outcomes.

VI *Current Perspectives on Models of Best Practice*

- *Helping Women to Cope with Anxiety*
- *The Role of the Breast Care Nurse in Supporting Women in Treatment*
- *The Support Function in the Multi-Disciplinary Team*
- *Telephone Counselling*
- *Families Giving and Needing Support*
- *Breast Cancer and Its Relationship with Sexuality*

Current Perspectives on Models of Best Practice

Helping Women to Cope with Anxiety

In the literature on breast cancer, it is widely noted that women experience anxiety confronting this highly stressful event. MacPhail (1998) reviews the psycho-social aspects of breast cancer and argues that routine physical care of breast cancer as such does not reduce the psychological morbidity associated with it. To meet this need, what is termed psycho-social oncology is an important new discipline which has emerged. Thorough and sensitive attention to the psycho-social dimensions help bring about reductions in patient distress and also result in measurable improvements in quality of life measures.

Reaby (1998) has examined the way women establish coping patterns to help them deal with the prospect of breast cancer surgery and identifies four separate responses:

Vigilance - actively searching for information on their condition.

Satisficing or being satisfied – choosing the first solution that meets their objectives.

Complacency – accepting advice without questioning and fully comprehending.

Defensive avoidance – rationalising and avoiding discussion and consideration of the problem.

These are complex and quite different coping strategies. They are not mutually exclusive either. Our respondents reported elements of some or even all four of these strategies in the various stages they went through of investigation and treatment. In turn, this must pose great challenges to healthcare staff who seek to help alleviate women's anxiety. Even finding the time to talk with women and to help them identify what is happening for them seems a luxury when waiting times are so long and clinics are so crowded. Yet a considerable number of both women and staff, in questionnaires and interviews, gave priority to time to talk as an important aspect in an overall care package. This is also where Wilding's argument (see Section I above), on the total delivery of care enters in. If this issue can be accommodated, outcomes for women are far better, in terms of satisfaction, making it easier for women to deal with the realities of their situation whatever the eventual diagnosis is. Women have stated clearly in this survey that they require rapid, thorough diagnostic services. But they also want the delivery of those services to be greatly improved and to be reflexive and supportive of their individual needs.

Haber et al. (1996) have examined the emotional responses of women, families and healthcare staff, and also the psychological, social and behavioural factors that may influence morbidity and mortality. They explore the stages of breast cancer in the context of the patients' experiences and psychological reactions to the phases of diagnosis, treatment, post treatment, recurrence and terminal illness. They conclude that women need reassurance and support within a model of continuity of care, where there is a guarantee that trust and accurate information form a core part of a responsible approach to care.

This approach fits in with the work of Williamson (1996), who argues that rapid diagnosis should be followed by a session where the healthcare staff can outline treatment options for a woman, using good quality information and allowing her to express her fears and concerns at length. The woman should then have a few days to consider what she wants to do. This sequence of practices sensitively attends to her physical care but is also completely responsive to her emotional needs and her preferences. Ultimately, this produces better outcomes for the woman because she has been a part of the decision-making.

In a very recent randomised study, Frost et al. (1999) compared the satisfaction with overall healthcare of women with breast cancer who received their medical consultation in hospital with those who received it as part of a multi-disciplinary outpatient clinic. They also measured the physical and psychosocial adjustment of study participants. The study concluded that psychological outcomes were better for women in the multidisciplinary setting and that there are positive benefits of a multidisciplinary team approach in which a concerted effort is placed on providing information and psychosocial support in the outpatient setting. To establish effective psychosocial support, however, does require training in psychosocial and communication skills and there are models which have now been developed to train all members of a medical team, including oncologists, in these skills (Roter et al., 1998).

The provision of effective support strategies also requires the expansion of the multi-disciplinary team to include a number of professionals who can address the full range of needs; important aspects from specifically designed interventions like the Mayo Clinic Centre and the Rochester Institute Oncology Breast Clinic in the United States include the following elements:

- Information (facts provided and questions answered).
- Time spent with women
- Willingness of staff to listen
- Providing a sense of hope
- Positive attitude
- Straightforward approach in assessing the situation
- Consistent message among team members
- A resource centre
- A quiet room

For these to work, a complementary and co-ordinated approach must be developed for the entire team, both medical and psycho-social experts.

The Role of the Breast Care Nurse in Supporting Women in Treatment

Much recent literature cites the breast care nurse as someone who can provide ongoing support, information, comfort, counselling and practical help (Watson et al., 1988; Phipps et al., 1993; Wing, 1993; Murray, 1999). Thus, the breast care nurse

- provides information;
- provides discussion and support;
- provides continuity of care through the investigation diagnosis and treatment of breast cancer;
- enables the patient and her family to question and discuss treatment options;
- is the patient's advocate;
- liaises for the patient with all members of the health care team;
- promotes the team approach to patient care;
- ensures adequate prosthesis fitting;

The value of the breast care nurse in providing overall support is huge. For example, women who do not have strong pre-existing social support networks, can be very disadvantaged in facing up to breast disease. MacPhail (1998) argues that,

in such instances and many others, the emerging speciality of breast care nursing has already proven itself as a critical intervention in reducing or at least minimising psycho-social morbidity.

In the course of the fieldwork for this study, we encountered breast care nurses fulfilling many of these roles for women. For example, we encountered breast care nurses who helped to set up a support group; established the need for on-site fitting for prostheses; made it routine to talk with a woman in a room that is cheerfully decorated and guarantees privacy; offered a cup of tea, especially after a positive diagnosis of cancer had just been received; facilitated aromatherapy and relaxation; and worked with breast awareness, nutrition and health promotion.

Staff reported the frequency with which they turn to the breast care nurse to provide a support function. Women themselves expressed in written comments and in the focus groups, reactions to the breast care nurse which were uniformly positive.

However, much of this work was developed individually by nurses as an extension of their clinical role because they were very committed to developing good support. This level of work was not necessarily officially recognised for its value. In many cases, support was achieved in an informal way rather than as part of formal clinical procedures. This was often owing to the fact that clinics were so overcrowded and understaffed. Women themselves said it was a hit and miss affair whether they got to see the breast care nurse or not, and this fits in with the fact that often there were no specific protocols as part of the clinic's strategy to incorporate her work. Some did not know until much later in their treatment that there was a person called a breast care nurse to access. Opportunities for women to sit and converse with the breast care nurse could not be utilised because staff lacked even their own room where patients could be seen in the same clinic session. Also, not all nurses on duty in the breast clinics have had the advantage of the specialised course that comprises breast care nursing (this course is a post-registration course usually undertaken at the nurse's own expense).

The Support Function in the Multi-Disciplinary Team

The Royal College of Nursing in the UK advocates that every woman who has or fears she has breast cancer should have access to a breast care nurse. The College argues that breast care nurses are not only an asset to the patient but to the team as well in dealing with often stressful situations. Several breast care nurses referred to the emotional strain of their working situations and that also suggests that

where breast care nurses are the only source of trained emotional support, there should be other professionals who can be called on to supplement that counselling role, as part of the multi-disciplinary team.

Women with breast disease need interventions which will give them a sense of control over their treatment, decision-making and their prognosis (Bourjolly, 1999). Otherwise, they are likely to face feelings of powerlessness and lack of control, which only adds to their overall anxiety levels.

The University Health Network, based in the Princess Margaret Hospital, Ontario, Canada, has developed a model of care for women with breast disease, which is multi-disciplinary and community-based. Their preventative model of psycho-social care includes survivors of breast cancer and community agencies as part of their team resources to assist patients and families with treatment, decision-making, coping with diagnosis, prognosis, and participation in their care.

This kind of model automatically incorporates the valuable notion of continuity of care. Beddar et al. (1994) indicate the importance of continuity of care in oncology nursing, which can entail many elements, including

- Information and education
- Counselling and psychological services.
- Pastoral and spiritual care
- Nutritional counselling
- Pain and symptom management
- Physical therapy and cosmesis
- Support groups and services

Other elements include practical ones, like transport assistance and childcare, or more complex emotional ones, where the needs of the rest of the family also become an issue in treatment, may demand the inclusion of social workers specially trained in oncology, as part of the multi-disciplinary team. Smith et al. (1998) explore the principles of training social workers in oncology, acknowledging how the complexity of psychosocial issues associated with cancer has created the demand for highly skilled practitioners. In their study, they define oncology social workers as

'primary providers of psychosocial services in major oncology treatment centres and community health care settings...because of the knowledge about cancer and its psychosocial impact and because of their practice versatility. Oncology social

workers are trained in prevention, education, advocacy, research and counselling.'
(Smith et al. 1998: 1061).

The tasks of the oncology social worker could thus encompass:

- Assisting adjustment to illness counselling and individual, family or group psychotherapy;
- Providing psycho-dynamic psychotherapy, cognitive-behavioural approaches, relaxation techniques, guided imagery, transpersonal and /or existential psychotherapy, supportive psychotherapy;
- Discharge planning;
- Assessment, information sharing, patient education, resource linkage, concrete services, practical help, family aid, environmental interventions;
- Carrying out referrals for psychiatric, psychological, social and spiritual resources;
- Advocating for patient and family needs, inpatient, outpatient, at home, and in the community with staff, extended family, and friends.

The main role that the oncology social worker can play in a multi-disciplinary team is the recognition of the interconnectedness of the patient to many different levels of relating. The patient is for example, also a mother, a partner, a relative, an employee, etc. with many different expectations attached to her, which are additional to her illness. Smith et al. (ibid.) emphasise how the oncology social worker can assist the team, because she/he can help the patient move beyond the disease process, to attend to very practical matters that may affect the patient's quality of life.

Telephone Counselling

Bucher et al (1998) have looked at the role that telephone counselling can play as an additional support strategy. They argue that the telephone offers a rapidly available combination of intimacy, safety, and mutual support for people (this is relevant here in Ireland, especially for women living at some distance from their place of treatment.) Its use, however, should be incorporated into a comprehensive cancer care strategy.

Families Giving and Needing Support

In a more informal way, but also playing an important part for the woman are her family and friends. Beisecker et al (1996) have studied the value of companions for cancer patients during medical appointments, and concluded that family and friends provide an excellent support system when accompanying patients to medical appointments. They help to boost patients' emotional state, helping also to ensure the patients' compliance with medical instructions. The authors stress particular times when this companion support is highly relevant: when tests resulted are discussed and when decisions need to be made as a result; and at the beginning of treatment. Their respondents were patients and companions, the latter who stated that they would like to be present when there were specific interests or concerns which impinged on them and about which they would need to be fully informed. While more than a quarter of companions interviewed stated that a nurse or doctor had asked them to come along, the patients interviewed were clear that whether or not they are accompanied should be their choice. What this also means is that medical staff cannot presume that support is there for a woman but that it may need to be negotiated, not least because partners and family members have their own complex needs.

Blanchard et al. (1996) suggest that spouses of cancer patients have four prominent concerns: dealing with the threat and fear of negative outcomes associated with cancer; helping the patient cope with the ramifications of cancer; managing changes and disruptions of daily life resulting from the disease; being hesitant to discuss concerns and issues about the disease with the patient. Bearing this in mind, they designed a study to evaluate the effectiveness of a Coping With Cancer intervention programme for patients and their spouses. Their results indicated that the programme when used with spouses was effective in lowering the patients' level of depression. There is a strong likelihood that the reason for this outcome was the improvement in communication between spouses and patients. Patients also reported appreciation that their spouses were receiving external support and therefore that the couple did not have to carry her/his own burden and their joint worries unaided. Northouse et al (1998) also emphasise the importance of assisting couples, not just patients to manage the adjustment difficulties associated with breast cancer.

Lederberg et al. (1998) examine both the effects of cancer on the entire family and the supportive role of the family in providing care for the patient. They define the family as an extended system of support for women, but one which may well

require help to enable that support system to work at optimum levels. Thus assistance may be needed in the following major areas:

- Education about cancer;
- Improving family communication;
- Smoothing the family/treatment-team interface;
- Provision of practical and counselling services;
- Mobilisation of support services.

Families can make major contributions, helping women to adapt to their new circumstances. However, children have special needs in this change process which must be taken into account. McCorkle et al. (1998) and Shands et al. (2000) indicate the importance of how children whose mothers are affected actually learn about cancer and all its effects, including psycho-social effects. In mothers' reported methods of interacting with their school-age children about their breast cancer, they tended to assume a teacher-educator role for their children, rather than an interactive emotive-expressive parenting role. They also tended to use medical knowledge that is not easily comprehensible for children and thus may have exposed the children to emotionally laden or potentially frightening words, images or experiences. Thus women with younger children may need guidance to help them explain the illness in the most effective and understanding manner possible.

In our sample, almost a fifth of our respondents had children nine years of age and under, while fully thirty-four per cent or 150 women had children ranging from babies up to fourteen years of age. Findings like those of Shands have implications for healthcare staff who have the work of counselling and support. Based on their research findings, Shands et al. argues that materials need to be developed that help mothers to use language appropriate for the ages of their children, if they find themselves dealing with a positive diagnosis of breast cancer. Women may also need help in learning how to enable their young children to ask questions and express feelings, so that children can understand and better manage what is happening related to the breast cancer.

Breast Cancer and Its Relationship with Sexuality

Lamb (1995) outlines how, as more women become cancer survivors, sexuality and fertility have become more paramount issues in cancer care. Both the disease and the treatment used can produce both short-term and long-term effects that can complicate women's responses to sexual expression and fertility. In turn, these have implications for nursing care. It requires an understanding of sexuality as a critical

'quality of life' issues to enable women to explore their needs and come to terms with changes imposed by cancer.

Only 19 per cent of our sample or twenty-five women reported a positive diagnosis of cancer (of 130 who had completed their full schedule of diagnostic tests). But this group of 25 spanned the range of age groups and for each one of them, a positive diagnosis means an adjustment around sexuality. For example, for women of childbearing age, decision-making about pregnancy amongst women already treated for breast disease, including cancer is a growing reality. There is also the change in women's age at first birth, with women becoming progressively older, so more women with breast cancer may not have had children when first confronted with breast disease (Siegel et al., 1997). In one study, women's concerns in these circumstances were fear that the disease might recur; that the child might have a birth defect caused by chemotherapy or radiation as part of the treatment the woman had received; fear that the child might be born with a susceptibility to cancer; and fear that caring for the child might be too stressful (ibid.). If the doctor and medical team physician were not forthcoming with information, a woman interpreted this as a 'negation of her femininity and a fear that her prognosis was poor' (Siegel et al., 1997:41).

Carpenter et al. (1999, 2000) have studied menopausal symptoms in breast cancer survivors and have concluded that typical symptoms such as joint pain; feeling tired; trouble sleeping, hot flushes are a more significant and pronounced problem for breast cancer survivors. They argue that nurses have an important role in informing patients that these symptoms may be more severe following breast cancer treatment. Women can be informed of the range of alternative therapies available, which may help in reducing their symptoms. The possible side effects of Tamoxifen in altering women's desire for sex warrants further investigation (this issue came up for one of our respondents who was too embarrassed to raise the issue with the breast care nurse who did not raise it herself).

Utley (1999) has explored the meanings of cancer for older women (65-77 years) who are long-term survivors of breast cancer and found that for them cancer has a host of meanings, negative and positive: cancer as sickness and death; cancer as an obstacle; cancer as transforming. On the basis of her data, she argues that knowledge of the survivors' meanings of cancer may help to paint a new vision of cancer survivorship as a potentially positive and transforming experience. She argues that such an understanding can help nurses when they are recommending different types of resources to women, including counselling, as well as the types of information and support they provide. This issue is very pertinent as survival rates increase.

vii Recommendations

- *Translating Women's Needs into Recommendations*
- *Timeframes for Initial Clinic Visits and Diagnostic Tests*
- *Communication and Information in the Clinic*
- *Breast Care Nurses, Emotional Support and Continuity of Care*
- *Privacy and Space in the Clinic*
- *Treatment Issues*
- *Ending Treatment and Aftercare*
- *Counselling and Support Groups*
- *Expanding the Multi-Disciplinary Team to Meet Women's Needs*
- *Additional Information Campaigns*
- *Conclusion*

Recommendations

Translating Women's Needs into Recommendations

These recommendations are based on fieldwork and data from the following sources:

- Women from six different clinical sites who volunteered to complete a questionnaire during their clinic visit or to complete it afterwards and post it back to the research team;
- Women from three clinics who participated in three focus group interviews;
- Clinical staff who volunteered to complete a questionnaire about current provision from four clinical settings.

This data has also been triangulated with a literature review of models of current best practice.

The recommendations below give special weight to the views of women who have thought carefully about their experiences and volunteered their time and attention in order to seek improvements in services for other women in the future who need specialist breast care services. This is a client-focused study where the women participants themselves are the experts on their personal situations as patients within currently available service packages. The objective of this report is to give their critique as wide a hearing as possible.

There is an ethical consideration in inviting potential respondents to re-live what have often been very painful, anxious, or even frightening circumstances, as many of them have dealt with the consequences of a life-threatening illness. The counter-argument relates to the value of having their perspectives taken into full account in the restructuring of breast care services. Women's voices must play an integral part in our understanding of what comprises best practice in health service provision in this area.

Acting on women's requests for swifter diagnosis; focused, more immediately available treatment options in terms of time and location; and more supportive and holistic care practices will translate to far better survival rates and will contribute to a framework for women's health services which will make a substantial contribution to the overall confidence of Irish women about their own well-being. Thus, the recommendations set out below are all interconnected for women. One aspect cannot be implemented and others left aside. The changes in

resourcing to bring about these best practices, we argue, will also benefit the care teams involved at clinical level.

Timeframes for Initial Clinic Visits and Diagnostic Tests

The overwhelming majority of women discover symptoms of breast disease themselves, through self-examination, and thereafter go to their GP. It is the next several steps in the referral and diagnostic chain of events where delays are commonly experienced. In this study, time delays of three types were reported:

- Delays in having the first clinic appointment;
- Delays during the first clinic appointment because there are too many patients and insufficient clinic time;
- Delays in obtaining all necessary diagnostic tests so that women must return to another clinic session in order to have their complete diagnosis.

Lack of resources, insufficient numbers of specialist staff, and lack of rapid delivery assessments on-site can all contribute to each of these time delays. The emotional impacts on women are increased anxiety levels. The majority of women reported both that they felt anxious and that they were trying not to think about their situation while they waited for their first clinical appointments. Staff reported the majority of women, from 50 per cent to 100 per cent in their experience, as suffering from anxiety in the course of their first appointment. A top priority for women in this study is to have this situation rectified. This is also a top priority for the staff who replied to the questionnaire designed for them. It also forms part of the Patients' Charter, where in Section Two, it states that people have the right to be given an appointment within a reasonable space of time and that each person should be given an individual appointment time.

Recommendation Women with symptomatic breast disease must be seen by a specialist breast clinic team within **one week** of a GP referring them for further investigation.

Recommendation Women should have all their diagnostic tests completed in their first clinic session. Where current resourcing does not permit this, and until the implementation of changes to make this possible, initial diagnostic tests and any additional tests should be completed within **one week** of a woman's first clinic appointment.

Recommendation Women should have specific clinic appointment times that can guarantee they will wait no more than half an hour before beginning their round of consultation and diagnostic testing which will take place in that session.

Communication and Information in the Clinic

Each woman has multi-faceted physical, social and psychological needs as she enters into a clinic for breast disease for the first time. Therefore the stated objectives of best care practices must include a range of supports for women to help them deal effectively with their clinic consultation. Reported problems encountered in the course of this study of less than adequate reception procedures and communication and information-giving in the clinic setting urgently need to be rectified. Women were sometimes given a positive diagnosis of cancer in less than ideal circumstances with medical staff trying to deal with frequently overcrowded and over-stretched clinic settings. Women were sometimes left on their own outside the consultant's door, having been given a diagnosis, with no further staff contact. No one had accompanied them to their clinic visit so they were in deep shock and on their own.

Recommendation Every effort should be made to ensure sufficient reception staff on duty and sufficient clinic time and spacing of appointments for women, so that the woman can be registered, settled in, and have explained to her the clinic routine, and the names of the consultant and breast care nurse on duty that day.

Recommendation Well-presented and well-illustrated information on breast disease and the range of diagnostic tests a woman can expect to undergo during her clinic visit should be presented to her in leaflet form by the receptionist as the woman is booked in. This information leaflet should be compiled in a way that respects women with different reading abilities and disabilities such as reduced vision. The Eastern Health Board Black and White Guides on Women's Health provide a relevant model for this information leaflet, one which has already been tested and found successful.

Recommendation It should be a standard part of clinic routine that once a woman has seen the consultant, had her tests, and been told of her diagnosis that she should then be directed immediately afterwards to the breast care nurse who can spend some time with her, listening to her and helping her deal with her reactions, concerns and her questions.

Recommendation Women who have been given a positive diagnosis should be given an information leaflet specifically explaining the range of treatments and presenting them with a checklist of questions they will want to have answered at their next visit, when they return for treatment. The leaflet should also have information on cancer support groups such as ARC and the Irish Cancer Society.

Breast Care Nurses, Emotional Support and Continuity of Care

In a busy clinic setting, the breast care nurse provides a key linking and support role between the doctor, other medical personnel like radiographers, and the woman herself. Women in this study were very positive about the role the breast care nurse (or nurses where the team was larger) can play in ensuring continuity of care and in giving much needed support, practical information and help in learning about unfamiliar medical terms. Breast care nurses have a special value giving woman to woman support on sensitive issues that women find difficult to raise with a male doctor. However, many are currently working in unacceptable conditions and these must be rectified and new conditions set in place for the breast care nurse to carry out this important role.

Recommendation The breast care nurse must have privacy, time and space in which to carry out her work. Each breast care nurse or nursing team where there is job-sharing) requires a dedicated room to carry out her work within the larger clinic setting.

Recommendation The brief of the breast care nurse must be set out clearly so that she is not asked to take on other non-nursing tasks but can devote her time to patient support.

Privacy and Space in the Clinic

Women were upset by overcrowded waiting rooms, a generally depressed and anxious atmosphere and very inappropriate mixed-sex waiting rooms, shared with other clinics running concurrently. A strictly scheduled appointment system, which has already been discussed above, would reduce the overcrowding and deal with one dimension of the loss of privacy.

Recommendation Where possible, breast care clinics should occupy hospital space and a time slot which can ensure a dedicated clinic and waiting area for that purpose only at that time.

Treatment Issues

For the most part, women expressed satisfaction with most aspects of their treatment, following a diagnosis for cancer. Some experienced delays in treatment which contributed to their fear and anxiety. Some experienced problems with five-day a week wards only for treatment. For women in several of the clinical settings, there was considerable concern arising from the stress they had experienced in having no radiotherapy and chemotherapy locally available. This meant that they were also cut off from immediate support from their family at a point when they badly needed that to help deal with the physical impact of treatment. Family members could rarely afford to take time off to travel up to Dublin with them and staying in alternative accommodation from the family home was experienced as very stressful. Childcare was also a problem for many younger women in trying to attend to their clinics and treatment regimes. Low-income women, not in possession of a medical card, found the costs of travelling to treatment sessions where public transport was very difficult to access, a considerable drain on their resources.

Recommendation There should be expert medical advice available for women at the weekends, especially if they are undergoing treatment like chemotherapy where they are likely to be quite ill afterwards.

Recommendation It is critical for women to have radiotherapy and chemotherapy, as well as the full range of diagnostic services, locally available or, at the furthest, regionally available so that they can travel there and back comfortably and safely in the same day.

Recommendation Low income women who do not hold a medical card but who require radiotherapy and chemotherapy in centres where public transport is very difficult to access should be able to reclaim travel costs from their Health Board.

Ending Treatment and Aftercare

A number of women with breast cancer spoke about how fearful they were after a long and continuing involvement with the medical services to suddenly come to the end of their treatment and be simply told that they need not return. They reported a profound sense of insecurity.

Recommendation Each woman who has reached the end of her treatment should be given the opportunity to avail of a final discharge interview with the breast care nurse in which the woman can review the whole of her treatment, ask questions

about her future about any necessary aftercare. The discharge interview will enable the woman to achieve some sense of completion and closure around this major life readjustment she has undergone.

Counselling and Support Groups

Amongst the many ramifications of breast disease, women must deal with the fear and threat of a possible negative outcome, concerns about their partners' and families' reactions and needs, their own sexuality and physical appearance, practical concerns like childcare, returning to employment after treatment and so on. Many women cope well in making these transitions, the more remarkable given that medical and nursing staff are themselves coping in circumstances which are not conducive to the best care of women's psycho-social needs.

A well-resourced role for the breast care nurse should ensure that she can be the first port of call for women, giving them permission to speak about their anxieties and fears, giving them the information and basic counselling that they need. However, if a woman's needs go beyond that, the breast care nurse should be in a position to act by referring the woman to the team social worker. However, individual counselling is not always appropriate. Some women in the research indicated that they have already benefited by informal support groups. These could be an important additional resource for women.

Recommendation Breast care nurses should be able to identify women who need specialised counselling and suggest and refer them on to a specialised counsellor or social worker.

Recommendation There is a role for the social worker as a lead support person in liaising and helping to set up support groups.

Expanding the Multi-Disciplinary Team to Meet Women's Needs

The multi-disciplinary breast care team should be able to meet women's physical, psychological, information and education needs and those of their families. To be able to do this adequately, the team must be fully inclusive of the professionals whose expertise feed into these areas. In time, given the changing ethnic composition of contemporary Ireland, the team will require the inclusion of expertise on different cultures.

Recommendation To deal with the full range of needs and to impact most favourably on outcomes, the multi-disciplinary team must be staffed by the full range of medical staff. But it must also be expanded to include, as a matter of course, fully-trained and equipped breast care nurses and social workers and trained counsellors/psychologists.

Recommendation Ethnically sensitive awareness will need to be built into breast care teams for the near future in order to offer treatment to women coming from very different cultural backgrounds who may have different psycho-social needs around breast disease.

Additional Information Campaigns

The research indicated information needs at several other key levels. These are addressed below.

Recommendation GPs need to be updated about current protocols on breast cancer treatment so that they target their referrals indicating urgent and less-urgent diagnostic needs.

Recommendation A dedicated telephone advice line for breast cancer only, run by a group like the Irish Cancer Society could fulfil an additional support need for women, enabling them to explore and make sense of their symptoms and reactions during treatment and recovery.

Recommendation A general public information campaign should be initiated to reinforce the message that breast health is an issue for women at all ages and not just post-menopausal women.

Conclusion

The comments that women have made to us in the course of this research, along with the quantitative findings, the focus groups and the replies from clinic staff all point to the validity of Paul Wilding's model of quality care. The four elements which Wilding cites: accessibility, acceptability, effectiveness and openness are as yet unmet targets in the provision of quality care services for symptomatic breast disease. A review of the services such as has taken place recently and an expansion in the provision will make a major contribution to moving the process on. But to make these objectives a reality will also require a new way of viewing this important service for women. Breast care services are not just a technical matter,

demanding first-rate specialist training, staff and technology. They also require a recognition of the psycho-social dimension and the first-rate provision of psycho-social services to attend to that dimension.

One respondent framed the matter this way:

I think doctors should understand a lot more about how much worry and stress goes with the feeling women have about breast cancer. A lot of women can't cope with the long delays between tests. Please help change this as it's just not acceptable. Thank you.

We will leave the last word to another respondent:

This survey is a step in the right direction.

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