

An investigation into the provision, fitting and supply of external breast prostheses: A national study

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Executive Summary

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Breast Cancer is one of the most common cancers affecting women in Ireland with approximately 1,726 women being registered with breast cancer each year (National Cancer Registry Ireland (NCRI), 2005). The majority of women with breast cancer have surgery as a form of treatment either on its own or in combination with radiotherapy, chemotherapy and/or hormone therapy (NCRI, 2005). An integral part of the recovery post surgery involves considering restorative options. For many women in Ireland this means being fitted with an external breast prosthesis. Currently, there are an estimated 16,000 women in Ireland who have undergone a mastectomy and require an external breast prosthesis. The overall purpose of this research is to gain an insight into women's experience of the provision, fitting, supply and use of external breast prostheses in Ireland.

Women have a right to be satisfied with their breast prosthesis, not least because in being supplied and fitted, they are recipients of a service, but also because it plays a role in terms of their psychosocial well-being. External breast prostheses are designed to restore the woman's self-confidence in her appearance, thus curtailing the impact of the disease on her psychological health (Shimozuma et al., 1999). The importance of a good-quality prosthesis and prosthesis-fitting service is paramount for body image, femininity, and psychosocial well-being following breast cancer surgery (Nissen et al., 2001; Mahon & Casey, 2003; Roberts et al., 2003; Murphy 2004; Breast Cancer Care, 2006).

Despite the importance of external breast prostheses, it is acknowledged by those working at both policy and practice level within the Irish context that there are potentially many inadequacies in the current system of care regarding breast prostheses. Indeed this research has arisen directly as a response to queries to Action Breast Cancer from members of the public who have found it hard to get information and good quality service in the provision of external prostheses following surgery. The

potential shortcomings in the provision, fitting, and supply of external breast prostheses in this country are confounded by insufficient research. It is argued by Hart et al. (1997) that the provision of breast prostheses is an area of a woman's post-mastectomy treatment that has the least amount of objective information available and that has been subject to the least amount of scientific inquiry. According to Healey (2003), a rigorous, evidence-based approach to the evaluation of external breast prostheses would enhance both the development of the service, as well as the adjustment, well-being and quality of life of breast cancer survivors. It is within this context that this research sought to:

- i. Assess factors and perceptions that impact on access, equity, quality, and affordability in relation to the needs of women requiring a breast prosthesis
- ii. Assess the type, content, timing and mode of providing external breast prosthesis information to women and how this might impact on their experience of acquiring or replacing an external breast prosthesis
- iii. Identify factors that promote quality in the supply, fitting and aftercare of all external breast prostheses and related products.

These objectives were achieved through a two-stage research project. The first part of the research employed focus group methodology to investigate women's personal and subjective experiences of the provision, fitting and supply of breast prostheses in Ireland. The second part of the research involved conducting a series of four concurrent national postal surveys directed at women with breast cancer and those involved in their care, notably breast care nurses, retail prosthesis fitters and bra fitters in department/lingerie stores.

PART 1 - FOCUS GROUP STUDY

The focus groups were undertaken to provide a detailed insight into the experiences of women in the provision, fitting and supply of external breast prostheses in Ireland. Their over-riding advantage was their capacity to provide women with the opportunity to share and recount their own experiences in their own words. Five focus groups with 6-12 participants in each were conducted. One group was run in each of the four new regional health authority areas in Ireland in 2005, except in Dublin where there were two groups. Forty-seven women in total participated in the five focus groups. The average age of participants in the focus groups was 57.8 years with a range of 38-80 years of age. The average length of time since being diagnosed with breast cancer was 8.1 years with a range of 1-32 years. The majority of women wore a single prosthesis.

With regard to the provision, fitting and supply of external breast prostheses, six main themes, each with their own sub themes, emerged (See Figure 1). These were:

1. *The fitting experience:* In particular, reference was made to the need for optimal fitting environments and suitable fitters.
2. *The prosthesis:* Most notably this pertained to patterns of use and its physical characteristics. Some women expressed satisfaction with the prosthesis. However, many women reported

experiencing problems with the weight, temperature, durability, movement, shape, texture, comfort and style of prostheses.

3. *Bras/swimwear*: Similar to the prosthesis, women also mentioned the physical characteristics, for example, limitations in the style, choice, material and quality.
4. *Cost*: Women raised the issue of the cost of the prosthesis highlighting the burden of its expense and the lack of uniformity with regards to entitlements.
5. *Information*: Women described a general lack of information, for example, in accessing post-mastectomy products, entitlements, and types of prostheses, bras and swimwear available. Women made suggestions about the future sharing and receiving of such information.
6. *Personal implications*: The personal implications of wearing/requiring an external breast prosthesis highlighted by the women were collated under four headings: coping with a new image; adjustment; lifestyle considerations; and coping socially.

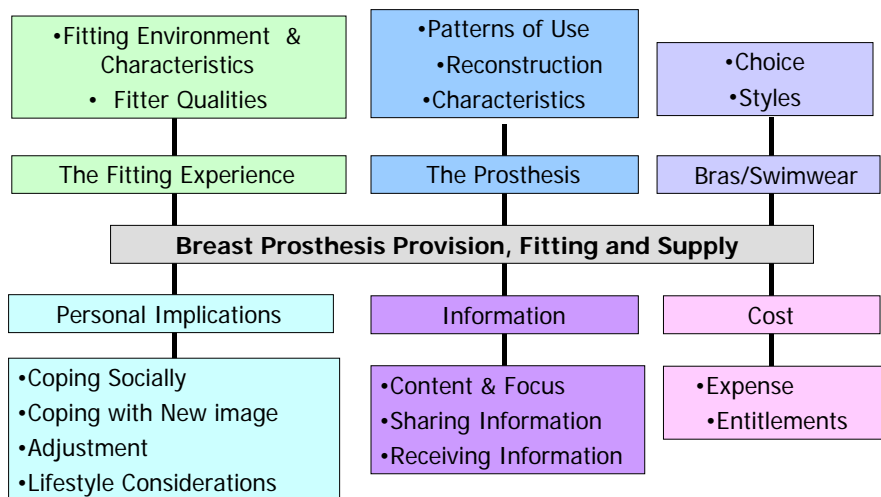


Figure 1: Summary of Focus Group Themes

PART 2 – NATIONAL SURVEYS

The second part of the study consisted of four concurrent national surveys. Survey 1 explored the experiences of women with breast cancer (n=527). Survey 2 investigated the views of breast care nurses (BCNs) (n=32). Survey 3 and Survey 4 documented the views of retail prosthesis fitters (n=12) and retail bra fitters respectively (n=6). The main findings from this part of the study are listed below.

Patterns of Prosthesis Use

- The majority of women reported using the full-weighted traditional silicone prosthesis (55.6%) or the light-weighted silicone prosthesis (21.6%) most regularly.
- 26.4% of women continue to use their temporary post-operative soft fibre filled prosthesis at least one year post surgery and 7.6% of women indicated that this was the type of external breast prosthesis that they used most regularly.
- 92.5% of women wear their external breast prosthesis all or most of the time.

- 61.8% and 62.2% of women perceived themselves to be limited in buying clothes and swimming because of the use of an external breast prosthesis.
- Almost half of the women considered that they were limited in sports and sexual activity because of their prosthesis and almost one-quarter of women perceived themselves to be limited in socialising.

Perceived Importance of and Satisfaction with External Breast Prosthesis

- Women, breast care nurses, commercial/retail prosthesis fitters and bra fitters perceived the external breast prosthesis to be important for balance, posture, shape, appearance to self, appearance to others, sense of well-being, self-confidence and femininity.
- The most important aspects of wearing an external breast prosthesis for women were shape (91%), self-confidence (90.9%) and appearance to self (90.4%).
- While women are generally satisfied with the external breast prosthesis that they wear most regularly, a sizeable proportion expressed dissatisfaction with various aspects of the prosthesis, in particular its weight (24.4%), comfort (17.3%) and movement with the body (14.3%).

Fitting

Temporary Soft Prosthesis

- 49.9% of women reported that they were fitted for their temporary soft prosthesis in a hospital ward. Some 41.7% reported that they were fitted in the breast care nurses' office.
- Women were generally satisfied with the environment within which they were fitted for their temporary soft prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (39.8%), display of products (35.4%), choice of products (35.8%) and time to look at products (30.3%). It is also important to note that one out of every five women expressed a level of overall dissatisfaction with the fitting environment for the temporary soft prosthesis.
- Women who were fitted in a breast care nurse's office were significantly more likely to rate the lighting, space, mirrors, privacy, display of products, choice of products, time to look at products, brochures and overall satisfaction with the fitting environment more positively than women who were fitted with their temporary soft prosthesis in a hospital ward.
- Women indicated that their preferred location for the fitting of the temporary soft prosthesis was the breast care nurses' office (71.8%). Similarly, 78.1% of breast care nurses pinpointed a 'specialised fitting room in breast care unit' as the location of choice for the fitting of the temporary prosthesis.

First Silicone Prosthesis

- 62.1% of women reported that they were fitted for their first silicone prosthesis in a hospital setting whereas 18.8% were fitted in a specialised prosthesis supplier.
- Women were generally satisfied with the environment within which they were fitted for their first silicone prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (32.5%), display of products (27.0%), choice of products (25.6%) and space (22.6%).

- Women fitted with their first silicone prosthesis in a hospital were more satisfied with the privacy of the fitting environment than women fitted in a specialised prosthesis supplier.
- 51.4% and 24.8% of women indicated their preferred location for the fitting of the first silicone prosthesis as being the hospital and a specialised prosthesis supplier, respectively. Some 77.4% of breast care nurses indicated that their preferred location for the fitting of the first silicone prosthesis was the hospital, whereas 25% of retail prosthesis fitters identified a specialised prosthesis supplier as their chosen location for the fitting of a first silicone prosthesis.

Replacement Prosthesis

- The most common fitting environments for replacement prostheses, as reported by the women, were the hospital (46.1%) and the specialised prosthesis supplier (32.0%).
- Women were generally satisfied with the environment within which they were fitted for their replacement prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (24.0%), display of products (22.4%), choice of products (23.0%) and time available (18.5%).
- At the fitting for a replacement prosthesis, women who were fitted by a specialised prosthesis supplier expressed greater satisfaction with space, display of products, choice of products and brochures than women who were fitted in the hospital environment for the replacement prosthesis.
- 37.6% and 31.6% of women identified the hospital and the specialised prosthesis supplier as their preferred locations for the fitting of the replacement prosthesis. Some 42.3% and 27.3% of breast care nurses and prosthesis fitters identified the specialised prosthesis supplier as their preferred location for the fitting of the replacement prosthesis.

Overall Comment on Fitting Environment

- Women were dissatisfied with the display of products, choice of products and brochure availability across all different stages of fitting. While the hospital is the preferred environment during the earlier stages of fitting, there is a shift towards an increased preference for and attendance at the specialised prosthesis supplier as the woman becomes more accustomed to wearing an external breast prosthesis and replacing her prostheses.

Characteristics of the Person Fitting the Prosthesis

Temporary Soft Prosthesis

- The majority of women (68.0%) were fitted with their temporary soft prosthesis by a breast care nurse.
- Women were consistently and significantly more satisfied with the characteristics of the person who fitted them with a temporary soft prosthesis if that person was a breast care nurse or trained fitter.
- The majority of both the women (71.8%) and breast care nurses (93.1%) indicated that their preferred person to fit the temporary soft prosthesis was the breast care nurse.

First Silicone Prosthesis

- 59.7% and 29.9% of women were fitted with their first silicone prosthesis by a breast care nurse and trained fitter, respectively.
- Overall women were satisfied with the characteristics of the person fitting their first silicone prosthesis. However, 10.3% and 10.5% of women indicated a level of dissatisfaction with the time available and emotional support given by the person fitting the first silicone prosthesis.
- 58.1% and 35.3% of women identified their *preferred person to fit the first silicone prosthesis* to be the breast care nurse and trained fitter respectively. Breast care nurses and commercial/retail fitters identified themselves as the ideal people to fit the first silicone prosthesis.

Replacement Prosthesis

- 42.5% and 41.0% of women were fitted with their replacement prosthesis by a trained fitter and breast care nurse, respectively.
- Overall women appeared satisfied with the characteristics of the person fitting their replacement prosthesis. However, women indicated a level of dissatisfaction with time available (10.5%) and emotional support (8.5%) given by the person fitting the replacement prosthesis.
- There were no significant differences in women's satisfaction with the characteristics of the person fitting the replacement prosthesis between women fitted by a breast care nurse and women fitted by a trained prosthesis fitter.
- The majority of women (52.1%), breast care nurses (53.5%) and prosthesis fitters (72.7%) identified a trained fitter as the ideal person to fit the replacement prosthesis.

Overall Comment on Fitter Characteristics

- Over all time periods, women expressed a consistent level of dissatisfaction with the emotional support given by the person fitting the prosthesis and the time available to the women. Furthermore over time, it is evident that an increasing number of women are fitted with their prostheses by a trained fitter and the gap in satisfaction ratings between the trained fitter and breast care nurse is reduced. In addition, while there is a clear desire to be fitted by a breast care nurse in the early stages, there is a clear preference for the replacement prostheses to be fitted by a trained fitter.

Mastectomy Bras

- The majority of women, who consider the purchase or availability of mastectomy bra products to be relevant to them, are dissatisfied with the availability of mastectomy bra products.
- 16.2% of women highlighted an overall dissatisfaction with mastectomy bras. In particular, dissatisfaction is expressed about the choice of bra styles (32.4%) and colour (32.7), value for money (22.4%) and appearance (20.0%).
- 41.8%, 22.4% and 18.2% of women were fitted for their bra in a hospital, lingerie shop/department store, and specialised prosthesis supplier, respectively.

- Women expressed a greater level of satisfaction with the characteristics of the person fitting the bra when fitted with either a breast care nurse and/or trained fitter than when fitted by a sales assistant.
- While the majority of women were satisfied with aspects of the environment where they were fitted for their mastectomy bras, approximately one in four women were dissatisfied with the availability of brochures, display of products and choice of products.

Other Fitting Issues

- Respondents to the breast care nurse questionnaire were particularly dissatisfied with the space (45.2%), display of products (36.7) and storage area for products (58.1%) in their fitting environment. This endorses the women's dissatisfaction with similar aspects of the fitting environment. However, while a sizable proportion of women (24%) indicated dissatisfaction with brochure availability, breast care nurses and prosthesis fitters did not.
- 75% of breast care nurses did not think that there were sufficient staff employed to meet the number of fittings required.
- 51.6%, 90.9% and 33.3% of breast care nurses, commercial/retail prosthesis fitters and bra fitters, respectively, consider that the *choice of products* available on the market satisfactorily meets the women's demands.
- 62.1%, 50% and 80% of breast care nurses, commercial/retail prosthesis fitters and bra fitters, respectively, reported that there were products not on the market that there was a demand for.
- When women were asked if they had a *choice of where to go* to get fitted for a prosthesis, 28.1% said they had, 36.0% said they had no choice, and 35.8% did not know. Despite only a minority indicating that they had a choice, 68.8% of women indicated that having a choice of fitting centres was important or extremely important.
- 26.4% of women indicated that *travel distance* to the fitting centre limited their ability to avail of replacing a prosthesis.

Waiting Times

- The average length of time between making the *appointment* and being fitted was 2.4 weeks (SD 2.6) (range 0.2-30 weeks)
- 72.4% of women indicated that their first silicone prosthesis was available on the day of fitting, 27.6% reported that it was not. For those women who did not receive it on the day of fitting, the average wait was 4.5 weeks (SD 4.2), range 0.5-25 weeks.
- 41.1% of women reported that their replacement prosthesis was not available on the day of fitting. For these women, the average wait was 22.3 days (SD 13.89), range 4-84 days.
- 80.1% of women indicated that they were fitted each time they got a new prosthesis; 53.8% and 81.8% of breast care nurses and commercial/retail prosthesis fitters, respectively, reported that in their experience women are always re-fitted prior to receiving replacement prostheses.

- 16.3% of women, who had not replaced a prosthesis, had had the same prosthesis for more than 4 years, despite recommendations that a replacement is advisable every 2 years. The average time specified for replacing the prosthesis was 2.3 years (SD 1.5) (range 0.5-12 years).
- 48.5% of women indicated that their bra was available on the day of fitting/purchase; 51.5% reported that the bra was not available on the day of fitting/purchase. For those women who indicated that the bra was not available, the average waiting time for receipt of the bra was 21.1 days (SD 13.3) with a range of 3-84 days.

Cost

- 35% of women who had replaced their prosthesis received it free of charge.
- 2.9% of women who receive their replacement free of charge do not have health insurance or a medical card. Conversely, there are approximately 16.3% of women who indicated that they have a medical card and do not get their replacement prosthesis free of charge.
- The average cost for each prosthesis bought was €125.4 (SD 53.4) (range €15-€300); 43.3% of women who were paying for their prosthesis indicated that the cost of the prosthesis influenced when they replaced it.
- The average cost of each bra bought was €38.6 (SD 15.8) (Range €5-150).
- 48.3% of women indicated that the cost of the mastectomy bra influenced when they replaced it.
- The average cost of a mastectomy-pocketed swimsuit was €77.4 (SD 27.49) (range €5-150).
- All commercial/retail fitters contract directly with the insurance companies; 91.7% (n=11) accept the medical card. Of these, 81.8% process the claim on the client's behalf. None of the bra fitters contract with the insurance companies nor do they accept the medical card.

Information Needs & Provision

- 46.0% of women indicated that they had not received information on prostheses and bras.
- One in three women was dissatisfied with the information they received on entitlements. Approximately one in four women was dissatisfied with the information they had received on cost of prostheses, types of bras, costs of bras, mastectomy swimwear, and location of fitters.
- The top three preferred ways of receiving information on prostheses and bras were (1) face-to-face meeting with breast care nurse; (2) information booklet; and (3) other women with experience of breast cancer or from the retail fitter, both of which had similar mean rankings.

Adjustment

- On average the cohort of women in this sample have good quality of life and a low number of arm and breast symptoms.
- Women who had replaced their prosthesis but did not receive it free of charge and who indicated that cost influenced when they replaced it had significantly lower scores in each of the quality of life domains than woman who said that cost did not influence when they replaced their prosthesis.
- Higher levels of satisfaction with aspects of the external breast prosthesis were associated with higher quality of life scores in each of the WHOQOLBREF domains (i.e. physical health, psychological, social relationships and environment) and fewer breast and arm symptoms.

Professional Development

- 69.0% of breast care nurses and 33% of commercial/retail prosthesis indicated that there was insufficient opportunity for professional development in the field of prosthesis fitting. Forty percent of bra fitters considered that there was insufficient opportunity for professional development in the field of mastectomy bra fitting.

Standards of Care

- The majority of services had a follow-up service for issues related to fitting and also a follow-up service for complaints. However, these were localised follow-up services.
- While nurses are bound by their professional code of conduct, there are no national or external service guidelines and protocols for commercial/retail prosthesis fitters or bra fitters.

RECOMMENDATIONS

Overall, this research provides a detailed picture of women's experiences in the provision, fitting, supply and use of external breast prostheses in Ireland and has informed the following recommendations.

1. Develop protocols, standards, and best practice guidelines in the provision, fitting, and supply of external breast prostheses for women in Ireland as a matter of expediency.
2. Make available professional development opportunities for those fitting external breast prostheses that augment existing expertise and where necessary, the capacity to provide emotional support.
3. Establish a standardised complaints/satisfaction procedure in order to further develop the service.
4. Provide optimal fitting environments that incorporate:
 - a display and choice of products, and brochures of same;
 - sufficient time to peruse and fit products;
 - adequate privacy and space;
 - good lighting and ventilation;
 - available mirrors.
5. Develop and expand fitting options in supportive environments in a range of geographical locations. Women need to be given a choice in where they are fitted with their prosthesis and by whom, recognising that breast care nurses may be the most appropriate in the early stages post-mastectomy with retail fitters becoming more so as time progresses.
6. Disseminate information on the types and costs of prostheses, locations of fitting centres, entitlements, and available supports using multiple formats including brochures, face-to-face meetings with breast care nurses and fitters, roadshows and mailshots, across multiple time periods including before and after surgery and at replacement prosthesis fitting. Readily

available information stimulates self-help and informed choice. Women must be made aware of their entitlements and know how to access the services they require.

7. Develop a buyer's specification for the range of prostheses and post-mastectomy products that should be supplied.
8. Address equity in the provision of breast prosthesis services throughout the country. All suitable products should be available to all women in all parts of the country. Products should be available to all women in a timely fashion and there should be equitable costs and expenses nationwide.
9. Lobby the Irish Government to ensure financial protection in the purchase of breast prostheses and mastectomy bras.
10. Monitor and re-evaluate women's experiences as services develop and change.
11. Incorporate this research and its findings into future health policy and strategies at national, regional and local levels.

To conclude, it is imperative that the empirical evidence base and recommendations made are used by policy makers and practitioners to facilitate women's experiences in relation to external breast prostheses.

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