



Involving users in service planning: A focus group approach

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Summary This paper outlines the way in which a focus group approach was used to involve service users in the possible reconfiguration of follow-up services for breast cancer patients at a North London hospital. The focus group was used to identify the priority issues for users and the development of an objective questionnaire, to survey all current service users. Within the National Health Service (NHS) the concept of user involvement has been embodied in contemporary health policy, and has become an important constituent of current policy direction. This study was the first stage of a larger stakeholder project that aimed to involve service users and clinicians in developing a new model of breast cancer follow-up service. From the focus group emerged five key themes around breast cancer follow up. They were:

- The need for reassurance after the diagnosis of cancer.
- Continuity of care.
- Privacy and dignity and other elements of the examination technique.
- Information and the detection of new symptoms.
- The opportunity to discuss feelings and worries.

In this paper, the nature of breast cancer follow-up services is outlined, and the difficulties associated with such services are discussed. The background to user involvement within the United Kingdom is explored, and the strategies that have previously been used are considered. The practical issues involved in using the focus group approach are examined, and the experience of using such an approach is outlined in this study. The involvement of service users as a key stakeholder in the process of planning change, through a participatory research strategy, ensured that their voices were heard alongside those of both hospital and primary care staff.

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Zusammenfassung Diese Arbeit gibt einen kurzen Überblick über die Art und Weise, in welcher ein Fokusgruppenansatz eingesetzt wurde, um Dienstleistungsanwender an der möglichen Neugestaltung von Dienstleistungen in der Nachbehandlung von Brustkrebspatientinnen in einem Nord-Londoner Krankenhaus mit zu beteiligen. Die Fokusgruppe wurde eingesetzt, um die für Anwender vorrangigen Themen festzustellen und einen objektiven Fragebogen für die Befragung aller gegenwärtigen Dienstleistungsanwender auszuarbeiten. Im Rahmen des staatlichen Gesundheitsdienstes (NHS *National Health Service*) ist das Konzept der Anwenderbeteiligung in die heutige Gesundheitsstrategie inkorporiert und zu einem wichtigen Bestandteil der aktuellen strategischen Ausrichtung geworden. Diese Untersuchung war die erste Phase eines größeren Stakeholder Projektes, das die Einbindung von Dienstleistungsanwendern und Klinikern in die Entwicklung eines neuen Dienstleistungsmodells der Brustkrebsnachbehandlung zum Ziel hatte. Aus der Fokusgruppe ergaben sich fünf Hauptthemen im Zusammenhang mit der Brustkrebsnachbehandlung. Hierbei handelte es sich um die:

- Notwendigkeit der Beruhigung nach der Diagnose Krebs
- Kontinuität der Behandlung
- Vertraulichkeit und Würde sowie weitere Faktoren der Untersuchungstechnik
- Information und Feststellung neuer Symptome
- Gelegenheit über Gefühle und Sorgen zu sprechen

In dieser Arbeit wird die Art der Dienstleistungen für die Nachbehandlung von Brustkrebs zusammengefasst, und die mit solchen Dienstleistungen verbundenen Schwierigkeiten werden besprochen. Der Hintergrund der Anwenderbeteiligung im UK wird untersucht, und die zuvor eingesetzten Strategien werden betrachtet. Die praktischen Probleme im Zusammenhang mit dem Einsatz der Fokusgruppe werden geprüft, und die Erfahrungen mit dem Einsatz eines solchen Ansatzes werden in dieser Untersuchung zusammengefasst. Die Beteiligung von Dienstleistungsanwendern als wesentlicher Stakeholder im Prozess der Planung von Änderungen gewährleistet durch eine auf Mitbestimmung ausgerichtete Untersuchungsstrategie, dass ihre Stimmen neben denen des Krankenhauses und des primären Pflegepersonals gehört wurden.

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Introduction

Improvement in the early detection and treatment of breast cancer and a consequent reduction in the mortality rates associated with it have led to a rapid expansion in the number of patients accessing breast cancer follow-up services (Peto et al., 2000). This has resulted in a need to reconstruct the service to address the current situation to the best effect (Burnet et al., 2004). Over recent years there has been an increasing call to promote user involvement in health care. This is evident in a number of key policy documents such as Working for Patients (Department of Health, 1989), The Patients Charter (The Department of Health, 1991), A policy framework for commissioning cancer services; a report of the expert advisory group on cancer to the chief medical officers of England and Wales (Department of Health, 1995), The Cancer Plan (Department of Health, 2000a) and The National Health Service (NHS) Plan (Department of Health, 2000b).

This study explores some of the complex issues around breast cancer and the management of follow-up, once active treatment has been completed. The main aim of the overall study was to develop a model of breast cancer follow-up within a service that would meet the needs of all the stakeholders—the patients, General Practitioners (GPs) and the multidisciplinary team from the hospital breast care unit. This paper reports the first stage of the study, which aimed to identify the priority issues of follow-up from the patient perspective.

The purpose of breast cancer follow-up

An increase in the number of patients requiring breast cancer follow-up services is the result of earlier diagnosis and a lower rate of mortality. To cope with this increase and to meet the aims of the Cancer Plan (Department of Health, 2000a) a reconfiguration and development of existing

services at the study site was required. The starting point of this was to reconsider the purpose and practice of follow-up. Once breast cancer has been diagnosed and treated, routine follow-up in specialist clinics is standard practice in most countries (Dewar, 1995). Such follow-up involves regularly scheduled examination during the disease free period and the principle goal is to detect both local and systemic recurrence and new contra lateral breast primaries, as well as providing psychosocial support to the patient (Grunfield et al., 1999). However, there is much evidence to show that most breast cancer recurrences are not detected at routine follow-up visits, but by the patient themselves (GIVIO Investigators, 1994; Rosselli Del Turco et al., 1994; Dewar, 1995). A review of the American literature focusing on the timing and sensitivity of routine investigations found that the evidence was robust enough to make several recommendations (Smith et al., 1999). These recommendations suggest the use of monthly breast awareness, annual mammography of the preserved and contra lateral breast taking a careful history and carrying out a physical examination every 3–6 months for 3 years, every 6–12 months for a further 2 years and annually thereafter. The evidence was insufficient to recommend routine bone scans, chest X-rays, blood tumour markers or liver ultrasound. The Board of Directors of the American Society of Clinical Oncology has supported these recommendations (Smith et al., 1999).

Within the multidisciplinary team the traditional breast care nursing role was developed in response to work by Maguire et al. (1983) who highlighted the specific psychological and emotional needs of women diagnosed with breast cancer. By offering emotional support, and identifying those patients at risk of psychological morbidity, the breast care nurse was able to improve the outcomes of patient care (Maguire et al., 1983). The role of the breast care nurse is to provide support for women who have—or believe they have—breast cancer, and their carers. This is not only important during treatment and diagnosis but also during the follow-up period (Carroll, 1998).

Historically patients attending breast clinics expect to be seen by a consultant breast surgeon/oncologist or more junior staff member (Burnet et al., 2004). One of the ways nurses are involved in advancing practice is in nurse-led clinics. This is supported by Dinsdale (1999), who perceives government as being supportive of nurse-led clinics because of their impact on patient waiting times. However, it is important that nurses who take on this advanced role do so with the primary aim of improving the quality of life for their patients

rather than filling a void which the reduction in junior doctors' hours has initiated. In approaching these services from a holistic concept of care, nurses may identify patient needs which have not been met in the past. This, according to Moore (1997), may result in the use of nurses being less of a cost-cutting exercise than originally thought. Although it may be true that cost is not greatly reduced, it could be possible for nurses to improve patient outcomes overall.

Considering the user perspective

The involvement of the consumer in breast cancer treatment can be seen to have developed from the 1970s onwards with the creation of the Community Health Council as a major feature of the reforms in 1974. The concept of user involvement has become a key policy issue in health care during the 1990s, although it has proven difficult to implement (Taylor et al., 2004). The desire to involve users has persisted through a change of government (Brown, 2000). 'The New NHS; Modern and Dependable' (Department of Health, 1997) outlined changes that were to be made by the new government and the concept of user involvement appeared central to many of these changes. 'A First Class Service' (NHSE, 1998) claimed that the active participation and partnership of clinical professionals and patients throughout the NHS is needed. 'The NHS Plan' (Department of Health, 2000b) required each health authority to establish an independent local advisory forum chosen from residents of the area, to provide a sounding board for determining health priorities and formulating policies, including the Health Improvement Programme.

The present government's commitment to involving patients and citizens (i.e. users) in the NHS can be demonstrated in a series of documents. 'Shifting The Balance of Power within the NHS' (Department of Health, 2001a) sets out the government's proposals to shift power and resources in the NHS to frontline staff and service users. 'Involving patients and the public in healthcare: a discussion document' (Department of Health, 2001b) stresses that patient and citizen involvement in the NHS will be strengthened, and sets out proposals for implementing the vision of a patient-centred NHS outlined in 'The NHS Plan' (Department of Health, 2000a). Involving users in health service planning and delivery is not an easy process (Beresford and Croft, 1993; Goss and Miller, 1995; Cormie, 1999). Listening to users requires the development of different types of skills in order to hear and

understand voices that have previously been excluded from decision-making processes (Barnes and Bennett, 1998). User Involvement is not about user control but about providers listening to users so their views influence the provision of services (Andrews et al., 2004). The 'ladder' of user participation developed by Arnstein (1969) has proved of enduring value in setting out the possible interpretation of service users. However, it has been criticised that the ladder does not accommodate the complexities and range of user involvement (Small and Rhodes, 2000). The term user, consumer, client or customer depends on the role in which they are involved. Gilbert (1995) distinguishes between a commercial/economic approach in which consumers exert power through the choices they make. Hirschman (1970) describes 'exit' as consumers transferring their business elsewhere and 'voice' as seeking a change in service.

Whereas 'exit' is broadly compatible with a market approach, 'voice' accords with more a democratic approach where by service users, or the wider public might seek to influence the overall pattern of service.

(Small and Rhodes, p. 20).

There are differences between consumers from an economic perspective and that of service user within the health service.

Hence, the aim of the present study was to identify the priority issues of follow-up from the service user's perspective.

The focus group study

The design and methodology of the study

In order to achieve the aim of this stage of the study it was apparent that a qualitative approach to explore these priority issues was required. A Focus Group method was adopted for its facility to generate hypotheses and inform questionnaire development (Kingry et al., 1990). The roots of the focus group interview lie in the methodology of market research and social science (Morgan, 1993; Krueger, 1994). Market researchers make wide use of focus groups to obtain consumer feedback and consensus on advertising campaigns of product launches (Reed et al., 1997), while social science researchers have tended to use focus groups in a more explorative way. It has been suggested that focus groups encourage the exploration of feelings rather than the achievement of consensus (Millar et al., 1996).

It was felt that the use of a focus group to elicit service users' views would enable the facilitator to

manage time without excluding participants and encourage the mainstream discussion (Bulmer, 1998). Effective use of a focus group requires the group to share their views openly, and thus the facilitator's background is important (Sloan, 1998). The facilitator of the focus group involved in this study was known to the group and had developed a rapport with that group over a number of years. At the commencement of the focus group meeting participants were asked to write down their reasons for attending follow-up clinics. The purpose of this request was to generate discussion. Open questions were then generated from the themes to encourage further exploration, and notes were taken to capture the non-verbal data.

The analysis process

The focus group interview was fully transcribed by the researcher. This aided transcription with the obvious factors of knowing who is speaking at any given time and identifying their contribution to the discussion (Krueger, 1994). The transcripts were copied for the group so that members could read it and validate what had been recorded. The question of participants validating transcripts did cause the researcher some concern as it has been reported that there is a risk that people will remember what they wished they had said or what they thought they had said, rather than what they had actually said (Mansell et al., 2004). However, in this study there was no need for concern as the participants validated what was recorded. The transcript was then subjected to a process of content analysis using the guidelines of Burnard (1991). The transcript was read three times and notes made on the general themes. The transcript was then examined again and the researcher attempted to write down as many headings as necessary to describe all the aspects of the content. This process continued until the entire transcript was absorbed. The next stage was to collapse the categories, condensing sub-categories into broader categories. The researcher examined the transcript statements and the theme of the statement coded and linked to a main category (Burnard, 1991). When all the data had been coded and sub-categorised condensed to a few broader categories each category was assessed and compared to determine whether it was saturated through a process of peer review (Field and Morse, 1990).

The sample

A purposive sample, to enable the specific needs of the breast cancer follow-up study (Robson, 1993) was identified through the local breast cancer

support group. Cancer support groups can potentially reduce distress by providing information about cancer and its treatment, offering emotional support, and teaching coping strategies. Cancer support groups function on the basis of mutual aid. They meet regularly for discussion with peers and this involves listening, reassurance, comfort, and caring. In contrast Krueger (1994) defines a focus group as a group discussion organised to explore a specific set of issues. According to McDaniel and Bach (1996) such discussion takes place in a social setting, moderated by a group leader, so as to generate descriptive or explanatory information. Other researchers simply refer to it as a process of group interaction that serves to generate data for analysis (Stewart and Shamdasani, 1990). It does not offer emotional support to those involved.

It was agreed that some members of the support group would meet as a focus group to discuss their experiences, feelings, perceptions and ideas related to the breast cancer follow-up service. The focus group met at a district general hospital in North London. The support group members will have had their breast cancer treatments at the hospital or many group members join the support group having had their treatments elsewhere.

Procedures

It was agreed that this interview would take place in the local hospital's postgraduate centre where the Support Group usually held their meetings. This ensured that the interviewees were familiar and comfortable with their surroundings. The use of the Support Group members as a systematic non-probabilistic sample ensured that the interviewees were informed respondents, as all were current patients of the service being reviewed, and ten members of the local breast cancer support group volunteered to participate in the work of the focus group. This enabled the group to be as homogeneous as possible—in that its members were all service users—but from a variety of backgrounds (Kitzinger, 1995). Their diverse backgrounds but similar experiences enabled maximum benefit to be gained from the different perspectives (Clarke, 1999). In considering the size of the focus group, the purpose of the group was considered (Parahoo, 1997), the researcher making an informed judgement as proposed by Sandelowski (1991). Thus the focus group comprised of ten women, all of whom had been diagnosed with breast cancer, had completed treatment and were being followed up

by the study site service or other local services within the cancer network.

Ethical issues

The study was formally approved by the Local Research Ethics Committee and access was approved by the Trust Chief Executive. All participants were given a detailed information sheet and they were given the opportunity to discuss any issues which needed clarification and have whatever questions arose from it answered. When the researcher was satisfied that the participants had been provided with all the necessary information, they were asked to sign a consent form. The information collected was about identifiable individuals therefore confidentiality was assured in producing the interview transcript by attaching a fictitious name to each participant. In line with the principles of good practice and relevant data protection legislation, the tape of the interview and the transcript were securely stored and were accessible only to the researcher.

The findings

Sample characteristics

Participants ($n = 10$) ranged in age from 44 to 61 years of age. The majority of participants were Caucasian ($n = 9$) with one being Afro-Caribbean. Nine were married with one participant widowed. They all had primary breast cancer diagnosed between 1983 and 1999. Primary treatments were at various hospitals within the local area. Four participants had cancer recurrence and one focus group member subsequently died. All members had breast surgery. Four participants had mastectomy, one went on to have delayed breast reconstruction. One participant had conservational breast surgery in 1987; she had local recurrence in 1999 and then had a mastectomy. One member was diagnosed in 1986 and in 1998 developed a new primary. Nine patients were referred through the symptomatic service with one patient referred through the breast screening programme. Four participants had chemotherapy following surgery and seven had radiotherapy and all participants had adjuvant Tamoxifen.

The participants were asked to write down the rationale for attending follow-up at the very beginning of the group session. From the written information the main reason for attendance was for reassurance that the cancer had not returned. Many participants wanted information on new treatments and further tests.

Five key themes emerged from the focus group interview:

- The need for reassurance after the diagnosis of cancer.
- Continuity of care.
- Privacy and dignity and other elements of the examination technique.
- Information and the detection of new symptoms.
- The opportunity to discuss feelings and worries.

The experiences of the focus group were rich in data and as the discussions took place the emotion within the group intensified as participants explained their experiences (Stewart and Shamdasani, 1990). These experiences should influence planning and delivery of breast cancer follow-up by providing a perspective grounded by their own experience-based understanding of the disease (Gott et al., 2000).

The need for reassurance after the diagnosis of cancer

The word cancer has a metaphoric quality in our culture. The conceptual impact of the word can be seen to arise from the perception of cancer as a deadly disease, and a threat to life. Once diagnosed, mental adjustments and changes of attitude occur to enable the person to cope with their new circumstances. This adjustment is partly directed towards living with the fear that the disease will recur. Women in this study expressed concern in this regard and talked about their need for reassurance. They welcomed their regular checks at the hospital and wanted to be reassured that they were in good health and that no further lumps had appeared.

You know every three months you will be seen. I feel much better for it. (Jane)¹

It's for reassurance and if there is anything untoward they will find it there and then the speed with which they will then follow it up is hopefully going to be quick. (Anne)

They also talked about the need for an 'official' check, which made them feel secure. They described the examination by the doctor as an important part of the system; it provided security and peace of mind.

Whatever, it put your mind at rest, perhaps given you false sense of security, but you know you're being officially checked for lumps. (Ellen)

Someone is keeping an eye on you.... (Deidre)

I do not 'check' myself every month but rely on the twice a year check from the doctor, for reassurance. (Ellen)

In the study it was found that follow-up appointments are often allocated to junior doctors who focus on the treatment aspects of care, while being inexperienced in handling the emotional elements of the disease. The women, however, perceived this *modus operandi* as satisfactory. They were reassured to know that clinically there were no problems detected.

Follow-up and the knowledge that one is 'being kept an eye on' had a positive effect on feelings of security. This reflects Leydon's study in 2000 which demonstrated that frequent references were made by women in relation to the importance of gaining reassurance, vital for maintaining hope.

The recent publication: 'The Supportive and Palliative Care Guidance' (National Institute for Clinical Excellence, 2004) discusses the importance of rehabilitation and psychological assessment following a diagnosis of cancer. Furthermore, the document emphasises the importance of assessment throughout the patient pathway. However, the participants in this study felt that appointments with the doctor were reassuring to know that clinically there were no problems detected and they did not discuss a need for psychological and emotional assessment.

Arman et al. (2002) discovered that women who experienced breast cancer found themselves in a situation that changed their lives, their perspectives on life, and their relationships. Nothing was now experienced as it had been prior to the diagnosis of breast cancer, and everything in their lives became centred on the event. Most people with cancer are vulnerable, hypersensitive and afraid of dying (Jensen et al., 2000). The need for reassurance described by the women in this study demonstrates the anxiety they experience and how the need to deal with this is an essential element of their after care.

Continuity of care

Participants in the group identified that their care was fragmented within the follow-up setting. Locally the clinics are organised in such a manner that the consultant will see all the new patients or people with difficulties. Those women returning, therefore, for follow-up appointments with an uncomplicated recovery would not see the consultant, but would find themselves meeting with another junior member of the consultant's team, who would probably be a different person at each

¹Names have been changed to maintain confidentiality.

visit. The focus group appeared to understand the organisation of the follow-up clinics but expressed the need to see the same person. There appeared to be a distinction between understanding the co-ordination of the clinics and the importance of continuity of care. The women described how being seen by different doctors prevented them building a patient-doctor relationship and they felt disturbed when a doctor had to read copious notes and ask the same questions.

Every single time I go someone has to get this file—three inches thick—and they've to ask you the same questions. (Anne)

Every time you want to see, as the years go by, you see someone different. I didn't enjoy that at all. (Grace)

The participants were able to explain the benefits of seeing the same person and finding comfort in the knowledge that the doctor was familiar with their case.

.....If you had someone, same person, even though they see lots of people in the meanwhile, you have something to build on. (Anne)

..... even if you were to see the same follow-up doctor each time so you could build a relationship. It's like going to your GP. I like going to the same GP all the time because they know me. (Joan)

I think the most important aspect has got to be the continuity of care. Whether it's a consultant at least the same doctor so you can build a rapport. (Ellen)

Pennery and Mallet (2000) suggest that continuity of care would improve professional relationships allowing the patient to be seen as a person and not a number, and this certainly appears to be reflected in the views of the women in this study. However, though there was some discussion that continuity was the significant factor, they did not express a need to see the consultant but rather to see the same doctor or Breast Care Nurse on each successive visit.

Even down to ***** (the breast care nurses). When we go there we know we can go there, we know we can see either one and they'll be there. (Helen)

In line with Adewuyi-Dalton et al. (1998) the participants of the focus group identified the importance of continuity of care following such treatment, and they reported that they preferred to build a relationship with the professionals they dealt with. When a woman faces uncertainty related to a chronic illness her belief that she can

control the outcome of the illness and her ability to do so may be adversely affected (Dirksen, 2000). It can be argued that the current organisation of follow-up care within the study setting does not facilitate this level of support, which requires the development and nurturing of a therapeutic relationship over time. The findings from the focus group indicate that women do want to build a patient-doctor relationship and that this would enhance their ability to have confidence and cope with their condition. Dirksen (2000) suggests that a woman's belief in and use of self-control skills in developing a pro-active survivorship should be supported.

Privacy, dignity and the examination technique

Women experience breast examination by different doctors and their concerns regarding privacy and dignity are intrinsically linked to examination technique.

During the focus group interview, some participants became very emotional when discussing instances when their principles of integrity had been breached. They discussed how it made them feel: frustrated and angry.

I was trying to get undressed she was trying to examine me. I said hang on, let me get undressed first I felt like... (quite tearful)... I'm wasting my bloody time coming here. (Joan).

These women describe vulnerability and emphasise the importance of privacy during examination. Patient integrity is one of the important aspects of ethical reasoning (Beauchamp and Childress, 2001) which clearly underpin the nature of care. When this integrity is breached it adds to the stresses these women encounter.

However, this experience was not shared by the entire group. Some patients described a very positive experience when they explained that the doctor is in another room and they do not have to get undressed in front of anyone.

Now mines totally different. The doctor in one room, a proper examination. (Kim)

In the clinic. You get undressed, it's all very tasteful. (Jane)

A number of participants commented on the process of examination and the possible variations in technique that they had experienced. They were often judgemental about their examinations and were able to identify the parts of the physical assessment which, they felt, were good.

Predominantly women in the posttreatment period are examined by different members of the clinical team:

Right, when I go to the breast clinic. He comes in and asked how you are? Stands in front of you examines you all around. You lie back and he examines both breasts. Asking you all the time have you any worries? How do you feel?... . (Joan)

You sit on the couch first of all, raise your arms, then he lays you down examines the breast for quite along while and over the other side and sit you up listen to your chest. (Mary)

I never seen once then she decided to put her hands around me, said ok get dressed. She just run her hand along it like that, just walked away and started writing on a bit of paper. (Joan)

Inconsistencies in the examination technique seemed to generate some concern amongst the participants and alongside the breach of her principles of integrity, one patient recounted how she felt she was inadequately examined. In most studies that have focused on breast examination, the technique of examination has not been well described. It is unclear therefore how much variation there is between clinicians. Findings from the studies that used examination of silicone breast models demonstrated that the accuracy of test performance correlated with the duration of the breast examination, the effectiveness of the breast examination technique and perhaps with the examiner's experience (Barton et al., 1999). Certainly the women in this study were able to recognise and appreciate experience and consistency in their physical examination.

In Pennery and Mallet's study (2000) the quality of the consultation was criticised by many patients. The majority described feeling rushed, and they wanted more time during consultations, the opportunity to discuss feelings and worries. This appeared an important aspect to follow up care for the focus group.

Information and the detection of new symptoms

The importance of information at the time of diagnosis and accurate information about the disease and new treatments in the future were a focus of discussion within the group. At diagnosis the amount of information and the sensitivity of its delivery were discussed at length.

I had to know everything, the worst and the good. I was hooked then. I got everything so I

knew what to expect. The side effects of the chemo and the frightening statistics—the survival rate you know. (Jane)

I saw the breast care nurse and another doctor. I sat down he said I've got the results, it's cancer.'em. He was very young. Very matter of fact. He said it was a very large tumour, we need to chemo—lose your hair. That's what silly hats are for and I'd just thought I'd got lost at some of the things. He said come back and see another doctor. At this time I was bawling. He said cry as much as you want to now. He said when you come back on Thursday the other doctor will explain what kind (of treatment) you need, lots of aggressive treatment..... I could not believe how insensitive he'd been that you go back and you're told... .

(At this point Jane was crying).

My doctor was absolutely wonderful. He sat down. He was calm. He drew me a diagram explained everything. I'd gone on my own. He said come back next week with my husband. We had four appointments in a row. He asked me whether I had any questions. He spent time with me. He listened to my options, what was best for me. We agreed and compromised. (Anne)

The women particularly highlighted their reliance on the follow-up appointment in relation to detecting new symptoms and clarifying information related to their disease.

Because at seven years I would have been discharged I would loved each one of you to have seen it (recurrence on the mastectomy scar). No way would I have ever seen that. To this day I could not believe he (the surgeon) saw it. I had lots of questions, especially about Tamoxifen and other drugs. (Mary)

Ever since (the poor examination on the last clinic appointment and a recurrence in the group) this has happened to ***** I feel anxious and my last examination wasn't too good. (Joan).

Within the discussions the participants felt the information regarding recurrence and symptoms would have to be carefully delivered.

I think I would be panicking. (Marion)

So would I. (Grace)

In relation to breast awareness one participant explained she was not breast aware and relied on the clinic appointment. Accurate information about the disease and new treatments appeared to be an important part of follow up. Within the media there is often confusing messages to patients. Within the

group one participant explained she was not breast aware. There is disagreement between clinicians and breast cancer charities in relation to breast awareness. Spurgeon (2001) argues that physicians should no longer routinely teach women breast self-examination as a screening technique for cancer. Yet Breast Cancer Care (2001) encourages women to be breast aware as part of their general health routine. In clinical practice too, women are advised to report any changes both physical and visual to either breast. The plethora of information so readily available to the internet browser can also generate confusion in the mind of the breast cancer patient. In this context it is interesting that Leydon et al. (2000) highlights how important the follow-up visit is for obtaining help in interpreting and evaluating additional information from independent sources. However, within the study one participant explained her reliance on follow-up for breast awareness.

The only reason I come back is I don't check myself every month now... I take the view I found it in the shower last time but I don't physically check myself, it's perhaps cavalier but knowing your going to be checked once, twice a year, whatever, it puts your mind. Perhaps gives you a false sense of security, but you know you're being officially checked for lumps. (Ellen)

Hope and fear are intertwined and patients oscillate between the desire for more information and the avoidance of new information that might threaten them. Leydon et al. (2000) suggests that hope might be promoted through silence, periods of self-censorship and a failure to seek information. Such strategies enable patients to circumvent information that may threaten their hope of recovery.

The opportunity to talk about feelings and worries

Participants talked about the need to be able to discuss worries and feelings and they stressed the importance which they would assign to this discussion.

If someone took fifteen minutes to take an interest in you as a person, and how you are doing, I think it would be half the battle is knowing that the person is going to be there to talk to you, the feeling of confidence, that the person will tell you honestly in a proper way what's going on. Really and truly I feel it is part of the therapy. (Anne)

If I have any worries that I can discuss them in the clinic. (Marion)

The importance of having time to talk in the follow-up setting is evident and coincides with the work of Pennery and Mallet (2000) who found that 18 out of 24 women felt that they were being hurried and that the time given to them in the breast cancer follow-up setting was too short. Women attending the clinics are aware they are one of many and they therefore experience a conflict between needing the doctor's time and feeling that his time is precious. This then can lead to dissatisfaction with the service and a non-fulfilment of their needs.

Conclusion

Breast services are under increasing pressure to provide prompt and appropriate care throughout the process of diagnosis and treatment up to and including the period of palliation if it is needed (Burnet et al., 2004). The mortality rates from breast cancer in women under the age of 70 have shown a sharp and sustained fall as documented by Peto et al. (2000). These advances in treatments mean patients are being cured and have a lengthened survival. With this increased workload there is much debate as to whether there is a need to follow-up patients. Brada (1995), for example, questions the necessity of routine follow-up clinics, referring to them as a time-consuming and expensive 'ritual pilgrimage' that patients hope will increase their chances of a cure (Brada 1995); however, others (Adewuyi-Dalton et al., 1998; MacBride and Whyte, 1999; Pennery and Mallet, 2000) endorse the value of follow-up clinics.

It has been extensively identified in the literature that, following treatment for cancer, many patients are faced with a range of short- or long-term problems such as depression, anxiety, fear of recurrence, loneliness, body image changes, and effects on family relationships, social environment and finances (Molassiotis et al., 2000). The findings from this focus group indicate that women are not wholly satisfied with the service they receive. They indicate the need for a more personal service with continuity of care. They highlight the importance of privacy and trust and would welcome the opportunity for time to talk about their worries and concerns. They demonstrate a reliance on the doctor for reassurance but also indicate that there are other health professionals that could fulfil at least some of their needs.

The patient has been re-instated at the centre of the planning and delivery of service, and, as such, service user involvement at all levels of the service planning process is paramount. Documents

published by the Department of Health (1995) have highlighted the importance of the increasing level of user involvement in the organisation and delivery of services. The role of the focus group in participatory research strategies represents a useful route of enquiry in pursuing this aim. In the stakeholder involvement project the focus group approach was an effective means of ascertaining the experiences and needs of service users. It was instrumental not only in the development of a valid questionnaire to explore the findings in greater breadth, but also as a source of very rich, meaningful data that moved beyond normative perspectives to capture real experience.

The process of organising and managing focus groups is time-consuming but, as a data collection strategy, it is rewarding for the richness of the data collected. Relationships between the respondents and the researcher require some thought. Many have concerns regarding bias. Others, however, argue that researchers and their role is an essential part of such projects. The therapeutic role of the researcher enabled the researcher to support the group and from the elicited information to consider issues of nursing care which would benefit from change. Positive group dynamics and interaction clearly enhance data collection. The group discussed at length many sensitive and personal issues. This lends support to the view of those who recommend using groups that consist of people who know one another, rather than following the more traditional research tenet that researcher and participants should be strangers.

The qualitative approach provided the platform for the patients to tell their stories and provide valuable information about local services. The use of the focus group provided a valuable opportunity to explore also the thoughts and feelings of respondents in relation to breast care services in more depth than would have been feasible either in a questionnaire survey or through personal interviews. The themes generated are very important to users and their recovery from breast cancer. As Brada (1995) stated: "Oncology must take the initiative to develop a rational and more effective alternative before the traditional system is simply axed as a cost-saving exercise."

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Further reading

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