

Issues, needs and concerns of women with breast cancer in rural and remote areas of Scotland: implications for statutory and voluntary sector services

Study aim: to identify the needs and concerns of women living in remote and rural areas of Scotland who have completed treatment for primary breast cancer.

A mixed methods study was undertaken in 2013 using a supportive care needs questionnaire (SCNS-SF34) and then a semi-structured telephone interview with those reporting the greatest unmet need.

Sample characteristics: 44 (24%) of a potential 180 women returned the questionnaire.

- The mean age of the participants was 59 years (38-83 years). Mean age at diagnosis 52 years (35-81 years).
- All women received surgery (100%; n=44)
- Other treatments - hormone treatment was the next most commonly reported treatment (72.7%; n=32); chemotherapy (63.6%; n=28); radiotherapy (52.3%, n=23); biological therapy (13.6%; n=6) and complementary therapy (6.8%, n=3).

Quantitative results from SCNS survey

High unmet needs

Approximately half (n=21) of participants reported having 'high unmet needs.'

These related to:

- being adequately informed about the benefits and side effects of treatment (n=14; 32%)
- the fear of the cancer spreading (n=12; 27%)
- being adequately informed about the benefits and side effects of treatments before choosing to have them (n=11; 25%)
- concerns and worries about close family and friends (n=11; 25%).

Moderate to high unmet needs

Approximately 19% of the participants reported having 11 moderate to high unmet needs. These related to: 'health systems and information'; 'psychological' needs; 'physical and daily living'.

32% (n=14) of participants reported 'no unmet need' for all 34 items of the SCNS survey.

Qualitative results from telephone interviews

The semi-structured interviews were designed, conducted and analysed by two volunteer members of UK charity Breast Cancer Care's Service User Research Panel (SURP). Four key areas of unmet need emerged.

1. Social and financial impact of living in a remote and rural area

- Travel costs significantly increase during diagnosis and treatment, affecting patients' family finances.
- Time away from home – consultations/surgery/treatment could be in different towns and cities. This could involve complicated travel arrangements with family members unable to attend appointments too.
- Inability to attend support groups because of the distance.
- Problems with broadband access.

'We have no mobile phone signal and it costs £60 in a taxi to get the ferry. And then if it's cancelled because of the weather... The logistics are bad. If you have radiotherapy you have to live on the mainland and you are away from all of your support.'

2. Information and overview of care

- Difficulties making appointments.
- No clear patient pathway.
- Little provision of information and guidance in relation to immediate recovery times following active treatment, and how to manage when there is little support available locally.

- No support (either physical or financial) available for patients attending treatment appointments on their own and who are unable to travel home on the day, causing anxiety and worry.

'What would have been very helpful would have been if there was one point of contact.'

'I did not have a timeline for my overall treatment.'

'You're just thrown in there... nobody prepares you... it should be written down what the side effects are, what the drugs are for, none of that information was actually given.'

One participant (who lived 272 miles away from the cancer centre) described the benefit of having her care coordinated appropriately. Giving her confidence in her care as well as minimising the time away from her family.

'The breast care nurse at the hospital didn't want me away from home for months because of the kids so she tried to fit everything in so that I would go up one day, get seen by all the hospitals, stay overnight and home the next day.'

3. Concerns and worries of those close to them

- Worried about leaving family at home when attending treatment.
- Not always able to talk to family about emotions.
- Caused problems in marital relationships.
- Worried about what sort of impact it might have on children.

'Massive changes for my husband and self, I tried to protect everyone but I felt powerless.'

'My main concern was what would happen to my child if anything happened to me.'

Conclusions

The women from rural and remote areas of Scotland reported a unique set of unmet needs caused by their geographical location. It's critical that cancer services address these needs and make reasonable adjustments to the coordination of care and treatment for this patient group.

Cancer centres should consider enhancement of roles and responsibilities for 'key workers' (breast care nurses) to oversee a remote/rural patient's treatment plan. This should include the patients' own personal circumstances and any travel constraints. Patients should be signposted to information and support resources provided by Breast Cancer Care and other organisations, and promote the use of different media (for example, social media) to improve access to services and support.

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