



Executive Summary

Accessing information and support from the NHS and voluntary sector: Experiences of older women (≥65) with breast cancer

Reducing inequalities in cancer care has been a key health policy issue for a number of years, yet disparities in incidence and outcomes continue. The focus on inequalities in the recently published Cancer Reform Strategy (Department of Health, 2007) demonstrates that inequity in cancer outcomes continues to be a pertinent issue. The Strategy highlights that inequalities in cancer outcomes are experienced by a range of different groups in society, including older people. Key aims of the Strategy are to reduce inequalities in cancer incidence and outcomes, and enhance quality and experience of care. Fundamental to this is equitable provision of information and support (Department of Health, 2007).

Studies suggest that older women trust information provided by hospital specialists, to the point where they do not utilise alternative sources of information and support (Silliman et al, 1998). However, there is concern that the quality of communication and interaction between older women and healthcare professionals declines with age, with specialists spending less time with patients the older they are (Maly et al, 2004). This may contribute to older women not receiving appropriate levels of information and support. There is potentially a role for the voluntary sector to play in meeting the information and support needs of this population.

Aims of the research

- Describe the information and support needs of older women diagnosed with breast cancer
- Identify the sources of information and support older women prefer to access
- Detail the factors that influence uptake of services provided by voluntary organisations

Sample

Twelve older women (≥ 65) diagnosed with breast cancer took part in the study. Four older women participated in a focus group, which guided development of a semi-structured interview schedule. Subsequently, eight telephone interviews were undertaken.

Brief Summary of Research Findings

Healthcare professionals' communication at diagnosis

- At diagnosis, older women experienced variation in the amount of information received and how it was communicated to them by healthcare professionals.

Patient-provider dialogue regarding treatment options

- Some women were actively involved in decision-making regarding treatment options, whereas others left it to their healthcare professionals.
- Some women felt they had not received adequate information, which excluded them from decision-making, particularly regarding mastectomies.

Accessibility and approachability of healthcare professionals

- Older women experienced difficulties access healthcare professionals.
- In particular, women would have preferred more time with their consultant.

Information and support needs at diagnosis and treatment

- Women trusted, and were reassured by, the advice and support provided by healthcare professionals.
- Older women tended not to seek additional information to that provided by healthcare professionals. However, they still reported unmet information needs. Women lacked information on their prognosis, treatment options and side effects of treatments.
- Emotional support needs were not discussed at length in the study. However, some women described being shocked and upset, and unable to talk about their diagnosis.
- Some women appeared not to need, or want, additional emotional support – they just wanted to 'get on with their lives.'

Experience of living with breast cancer

- Older women did not feel well supported post-treatment.

- Those diagnosed some time ago felt follow-up was not thorough and were worried healthcare professionals might miss disease recurrence. Those diagnosed more recently were generally happy with the follow-up process.
- Women diagnosed more recently appeared happy with the prosthesis fitting and lymphoedema services they received.
- Maintaining a positive outlook helped women adjust to life after diagnosis.
- Breast cancer also had an impact on relationships, including changing relationship/family dynamics.

Additional sources of information and support for older women

- Women felt they had to let their families know what type of support they wanted i.e. whether they want 'cosseting' or left to get on with their lives.
- Social support networks including friends and community groups were important sources of practical support e.g. shopping, housework, transport, etc.
- Meeting other women who had an experience of breast cancer was a beneficial source of support, providing practical 'tips' on what to expect with surgery, radiotherapy, etc., rather than emotional support.

Voluntary organisations that provide information and support

- Older women had little awareness of charities that provide information and support to people affected by cancer, and had rarely accessed them.
- None of the women in the study were told about Breast Cancer Care at diagnosis, regardless of when they were diagnosed.
- Voluntary organisations mentioned by some older women included: Breast Cancer Care, Macmillan Cancer Support, Cancerbackup, Breast Cancer Haven and Breakthrough Breast Cancer
- The organisation most frequently cited was Macmillan Cancer Support.

Perceived usefulness of Breast Cancer Care's services

- In the main, women would prefer to use face-to-face services, as opposed to online or telephone-based services. However, they suggested accessibility issues would prevent them attending face-to-face services.
- Peer support was also perceived as useful, but only if women were matched to someone who had been through a similar experience.
- There was a preference for services which have HCP involvement in their delivery.

Barriers to accessing voluntary services

- Preference for information and support from healthcare professionals
- Poor assessment of need, and lack of signposting, by healthcare professionals to appropriate voluntary sector services
- Lack of awareness of services provided by the voluntary sector
- Lack of accessible local, face-to-face services
- Older women want to 'get on with their lives' – often they have no need, or desire, to access additional services.

Conclusions

Healthcare professionals were the most important source of information and support for the older women in this study. However, many experienced poor communication with their healthcare professionals, and lack of involvement in decision-making regarding treatment and care. Also, their information and support needs appear not to have been met post-treatment. There is a need to assess the information and support needs of older women to understand what, if any, additional support services are required. There is potential for the statutory and voluntary sectors to work together, assessing older women's needs, and signposting them to services appropriate to those needs.

Recommendations

1. Better signposting and services marketing strategies for older women to statutory and voluntary support services is needed.
2. Highlight the importance of having an assessment process that identifies the individual information and support needs of older women.
3. Both the statutory and voluntary sectors should ensure accessibility to local, face-to-face services.
4. Statutory and voluntary sector service providers should consult older women regarding future service developments.
5. Healthcare professional communication training should include a focus on the specific needs of older women.
6. Explore innovative ways of working with the statutory and voluntary sectors to develop services and campaigning issues relevant to older women.

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