Internet support for people who are affected by breast cancer

OVER the past few years the internet has become part of everyday life and people of all ages now use it as a fast and easy way of obtaining information. It would seem logical when someone is affected by breast cancer that the internet may be used for information. However, the quality of information can vary from excellent to appalling and an internet search on the subject of breast cancer might result in nearly two million websites to view. This could be daunting for many people, and nurses are in an ideal position to guide people to websites that can give them accurate and up-to-date information.

Education
The internet is a valuable resource for educating both patients and professionals. For people with breast cancer, it can supplement the information their breast care team has given them. Its main advantage is that it gives people the opportunity to obtain information and to learn more about their situation at their own pace. It is available 24 hours a day and for people with breast cancer who are leading busy lives, this can be an important source of information and support.

For nurses caring for people with breast cancer, it is important to establish their information preferences. Some actively avoid information while others seek out as much information as possible. While individuals' needs are different, a patient's need for information also changes at each part of the breast cancer journey (Luker, 1996). For the individual who has a need or a desire for information, the nurse should be able to suggest websites from reputable organisations as a good starting point. The two main sites for providing educational material about breast awareness for the public are:

- The Breast Care problem site: www.breastcare.co.uk
- The Breast Cancer Care website – section on breast health: www.breastcancercare.org.uk/breastawareness

The British Medical Journal has created an online class focused on improving breast cancer services in the UK:

- www.besttreatments.org/class

The breast cancer problem site: www.breastcancer.org.uk

The CancerBACUP website: www.cancerbacup.org.uk

Diagnosis
A total of 39,500 women are diagnosed with breast cancer each year in the UK (Cancer Research UK, 2002). Men can also develop breast cancer, although it is far less common than in women. In the UK there are approximately 270 men diagnosed with breast cancer each year.

At the time of diagnosis, people with breast cancer will often be asked to make informed choices regarding their treatment options. Patients require information to help them make their treatment choice and while it is always preferable that their breast care team gives them information, the internet can be a means of learning more about breast cancer. This may generate further questions and issues, which a patient may need to have answered by his or her breast care team. This may cause problems in busy clinics. However, considering the need for people to make an informed choice regarding treatment, this should not be viewed negatively by clinic staff but as a means of ensuring access to all levels of information.

The main organisation in the UK dedicated to providing information and support for anyone affected by breast cancer is Breast Cancer Care:

- www.breastcancercare.org.uk
- www.ukbcc.org.uk/new/useful.htm

The Breast Cancer Care website offers a postcode search where patients can find out the five-year survival rates for their area.

Nurses are responsible for finding current, accurate, readable information to help patients and their families cope with cancer (Wilson et al, 2000). Nurses caring for people with breast cancer are in an ideal position to guide them to websites that will support the verbal information they have been given. This should be considered part of the information and support they provide.

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ABSTRACT
Leadbetter, M. (2003) Internet support for people who are affected by breast cancer. Nursing Times: 99: 14, 26–27. People of all ages now use the internet as a fast and easy way of gaining access to health information. It would seem logical, therefore, to use the internet as a resource when someone is affected by breast cancer. However, the quality of information available on the web can vary from excellent to appalling and an internet search on the subject of breast cancer can result in nearly two million possible websites to view: a daunting prospect for many people. Nurses are in an ideal position to guide people to reliable websites that can provide accurate, up-to-date information. This article provides useful websites and advice on how to ensure that the sites accessed are offering credible information.
is a cancer information website with a detailed section on breast cancer. This is well used by people affected by cancer. Interestingly the main users of the website have been shown to be carers and relatives of people affected by cancer. The information requirements of carers are often neglected, but in a recent study of carers needs, receiving information was considered of high importance (Soothill et al, 2001).

Twenty per cent of women diagnosed with breast cancer in the UK are premenopausal: almost 8,000 women under the age of 50 will be told that they have breast cancer each year (Cancer Research UK, 2002). Younger women are often faced with specific issues and to address their needs the Lavender Trust was set up in 1998. The trust raises funds to provide services for younger women with breast cancer and activities are detailed in their website:

- www.breastcancercare.org.uk/fundraising/TheLavenderTrust

For men with breast cancer there can be a problem obtaining information relevant to their needs. The internet provides some sites for men such as:

- interact.withus.com/interact/nbc

This can be a good source of information and support for what can be an isolated group of men.

Questions

Several of the main UK cancer organisations, such as Breast Cancer Care and CancerBACUP, offer an ‘Ask the nurse’ service. This is a confidential, free service whereby a question can be sent to a team of nurses who will research and answer the question. The person asking the question will usually receive an answer in a few days.

As a nurse working in a regional cancer centre for the last 19 years, I was initially surprised at the complexity of some of the questions sent to the ‘Ask the nurse’ service at Breast Cancer Care. However, the reality for many is that time spent in discussion with health care professionals can often be shorter than desired and there are always those questions someone meant to ask, but when in the ‘clinical setting’ simply forgot to ask.

The patient’s information needs at the time of diagnosis are now acknowledged, although less is known about the long-term information needs of people with cancer (McPhail, 2000). The internet is a means by which people can gain access to relevant information and support at any stage of their illness. Many women who were diagnosed several years ago take part in the chat room discussions on the Breast Cancer Care website and offer support, advice and empathy in a positive way.

Global Information

Information available on the internet can come from anywhere in the world and it is important to check which country the website comes from. There are many US sites, which can be interesting to use but not everything in the USA is relevant to people in this country.

Three detailed US sites to start with could be:

- www.susanlovemd.com/home_frames.html
- www.nci.nih.gov/cancer_information/cancer_type/breast
- www.imaginis.com/index.asp

NHS Information Strategy

Modern health care includes the provision of information that is accurate, relevant and cost-effective. One of the objectives of the NHS Information Strategy (1998) is that patients have access to accredited, multimedia background information and advice about their conditions. This was an objective following the Calman-Hine report (Doh, 1995) which advocated that ‘patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards’ (section 3/paragraph 3).

Information is vital for people with breast cancer so they can feel confident about making informed consent to treatment. For people with breast cancer there is a vast amount of internet information available. Nurses can play a valuable part in encouraging and guiding women to reputable websites. Nurses are also in an ideal role to develop the information provided in the clinics and wards by giving women access to the internet while attending the hospital. Some hospitals have information resource rooms for patients to obtain information. However, it would be desirable if internet access could be made available in outpatient clinics and in the ward day rooms for patients and carers to use.

The future

When women affected by breast cancer log on to websites there are tools to distinguish the good sites from the bad. The triangle mark displayed on any information indicates that it meets the needs of the Centre for Health Quality Information, which assesses the quality of the information to ensure it is accurate, clear and relevant:

- www.hiquality.org.uk

‘Discern’ is an assessment applied to information, which looks at reliability, detail of information and treatment choices from the perspective of a user or patient. A scale of one to five is given to rate the reliability and details of the information. The Discern tool is widely used in written patient information and can now be used to rate website information.

- www.discern.org.uk

While many people have internet access, this is not the case for the whole population. Internet access is now available in most libraries and JobCentre offices in the UK, as part of the implementation of the NHS Information Strategy. It could also benefit many people if individual hospitals provided access to internet information.

Providing information can help patients accept their diagnosis (Sawyer, 2000). While the breast care team should always be the first option of people affected by breast cancer, the organisations providing information and support via the internet can be a valuable supplementary resource for people affected by breast cancer and their families.

For related articles on this subject and links to relevant websites see www.nursingtimes.net

KEYWORDS

Breast cancer • Internet • Patient information

REFERENCES


