Portrayals of treatment decision-making on popular breast and prostate cancer web sites

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The objective of this study was to describe the messages about treatment decision-making on popular cancer web sites, with particular reference to gender differences. The two most popular UK based web sites for breast and prostate cancer were chosen. Qualitative and quantitative comparative content analysis of the two case study web sites were performed. Web site portrayals of treatment decision-making by men with prostate cancer emphasize the obligation to be decisive, using information derived from medical sources, with minimal consultation with families and friends. Portrayals of treatment decision-making by women with breast cancer emphasize their family obligations, their need to make decisions about matters other than treatment, their right to opt out of decision-making, to take time, sometimes change their minds, consult with families and friends, and thereby take non-medical factors into account. This study will help health care practitioners understand the different factors that men and women feel obliged to consider when making decisions about their cancer treatments, and the role of the Internet in reinforcing gender differences.

Keywords: Internet and health, gender and cancer, decision-making, health representations, new media.

INTRODUCTION

The ‘new medium’ of the Internet is an increasingly important source of information and support for cancer patients who say that they use it to check doctors’ advice, develop personal expertise in their cancer and make decisions about treatment (Eysenbach 2003; Ziebland et al. 2004). Social support and exchange of experiential information is also facilitated (Ziebland et al. 2004). ‘Old media’ (television, newspapers, magazines, self-help books) are increasingly rivalled by the Internet as preferred information sources (Satterlund et al. 2003). Studies of old media suggest that implicit messages about how to behave when sick are as influential as explicit medical information (Seale 2002a). Yet little is known about such implicit representations on the Internet, where studies of the content of web sites have until now been confined to evaluating medical accuracy or quality (Purcell et al. 2002; Eysenbach et al. 2002).

Messages in old media about how to behave when experiencing cancer reveal marked gender differences, with women being portrayed as more emotional, more skilled in managing emotions and more concerned with the impact of cancer on relationships than men (Lupton 1994; Clarke 1999a,b; McKay & Bonner 1999; Seale 2002b). Media portrayals of cancer patients’ decision-making have not been studied, though it is clear that many patients now want, or feel obliged, to participate in health care decision-making, with Internet use becoming a marker of general competence for some (Henwood et al. 2003; Ziebland et al. 2004). It is therefore important to understand media messages to patients about how they ought to make decisions, as this is likely to influence their relationships with health care providers. This study investigates gender differences in the portrayal of decision-making on popular cancer web sites.
METHODS

Sampling aimed to mirror the experience of health information seekers and took account of the following considerations:

- Analysis by Bader & Theoános (2003) of a large collection of cancer-related natural language queries to a popular search engine has shown that, where the site of cancer is mentioned, information about breast cancer is most frequently sought, followed by genitourinary cancers, within which prostate cancer is the most frequently mentioned.
- Evidence about the search strategies used by Internet health information seekers show that they generally start with popular search engines and rarely visit sites beyond the top 10 (first page) returned as ‘hit’ (Eysenbach & Köhler 2002).
- Because search engines rank sites by link popularity, certain sites tend to dominate in particular areas, with link popularity correlating highly with the number of visits a site receives (Hindman et al. 2003).

To mirror the experience of information seekers, the top UK sites returned in a Google search using the terms ‘breast cancer’ and ‘prostate cancer’ on 15th December 2003 were chosen for a detailed case study of portrayals of decision-making. The case study sites were Breast Cancer Care [http://www.breastcancer.org.uk] and the Prostate Cancer Charity [http://www.prostate-cancer.org.uk]. A separate analysis of ‘inlinks’ to these sites from other web sites (inlinks are hyperlinks to a site, as opposed to ‘outlinks’ made from a site to others) showed these to be the most popular UK web sites in their cancer category and this top place was repeated in a count of references to the URLs of cancer web sites made by UK newspaper journalists during 2003 (Seale 2005). This suggests that both new and old media point cancer information seekers to these sources above others. Each site has a large user forum where archived messages demonstrate their popularity in exchanging information, experience and support.

Analysis

The advanced search facilities of Google enable a keyword search on pages within a site. Comparative analysis of these keywords was used to identify passages of text relating to decision-making which were then scrutinized for implicit messages. Other areas of the web sites were also examined for information about decisions that were not returned in the keyword search. Thus a combined qualitative and quantitative content analysis is presented here.

RESULTS

Overview

Table 1 compares the rates at which keywords returned pages relating to decisions made by people with cancer and their doctors. The prostate site rarely depicted decision-making by doctors alone. Treatment decisions made by people with cancer were more commonly mentioned than their decisions about other things. The proportion of each site devoted to decision-making, on this measure, was roughly similar (14% prostate, 16% breast).

Breast cancer

Decisions not involving treatment

Women were described as having to make a wide range of decisions outside those that involve the immediate issues of treatment. These included issues concerning fertility (for example, whether to start or end a pregnancy) \( n = 6 \), whether to take part in activities to raise money for the charity \( n = 6 \), how to tell children and other people about the cancer \( n = 5 \), how to make other decisions about child care \( n = 3 \), how to proceed with regard to breast reconstruction \( n = 3 \), hair care \( n = 2 \) and in one case introducing a partner to the visual appearance of a mastectomy scar, whether to take part in clinical trials \( n = 3 \), whether to opt for the charity’s peer support service \( n = 3 \), and decisions about jobs \( n = 1 \), divorce \( n = 1 \), diet \( n = 1 \) or lifestyle in general \( n = 1 \).

Treatment decisions

Women with breast cancer were explicitly given ‘permission’ to opt out of decision-making and to rely instead on their doctors should they wish \( n = 3 \), as where one woman was quoted saying ‘I needed the decision taken out of my hands.’ The more frequent depiction of decision-making by doctors alone (see Table 1) also suggests support for this mode of decision-making. The difficulty and stress involved in being a decision-maker was mentioned six times ‘[It was an incredibly hard decision to make].’ Decision-making was said in four instances to be subject to variation arising from the individual or from personal preferences (‘Decisions about treatment can also vary from one person to another so it is important to talk to someone who is familiar with your situation’) or, in two further instances, to be subject of later changes of mind. If women chose to be decision-makers, they were encouraged \( n = 5 \) to avoid making rushed decisions ‘[You need] plenty of time to make your decision’.

Consultation with
family and friends was advocated in four instances (‘Take time to discuss the [decision with] your family’). The advice given in a section of the web site entitled ‘After the diagnosis’ encapsulates these themes:

Once your doctors have all the information together they will consider the best treatment for you. This is the point where you can decide how much, or how little, involvement you want. Everyone is different. Some women want to know everything they can about their disease and expect to be fully involved in making decisions about their treatment. Others may want to be well informed about what is going on but are happy to leave the treatment choices to their doctors. Some may want to know as little as possible and leave all the decisions to the specialists. Whatever you decide, you don’t have to be rushed into treatment. A few extra days to think about what you really want, and a chance to discuss your options with your partner, friends, family or GP, will make no difference to the progress of the disease.

Thus women with breast cancer were portrayed as being involved in a network of relationships, the disease requiring (but not compelling) them to make decisions about a variety of matters in addition to preferred treatment, these decisions and their consequences being widely discussed and debated. Medical advice is one amongst several other sources to take into account, though the option of relying on doctors to take decisions is always present.

### Prostate cancer

Advice about prostate cancer almost exclusively concerned decisions about treatment and emphasized the decisive role of the man with prostate cancer. The four

| Table 1. Occurrence of keywords relating to decisions* on two cancer web sites |
|-----------------------------------------------|------------------|------------------|
| **Decisions about treatment**               | **Prostate**     | **Breast**       |
| Made by doctors                             | 1 (0.6%)         | 21 (2.8%)        |
| Made by person with cancer                  | 17 (10.5%)       | 66 (8.9%)        |
| **Decisions about other things**            | **Prostate**     | **Breast**       |
| Made by person with cancer†                 | 4 (2.5%)         | 36 (4.8%)        |
| Total pages on site                         | 162 (100%)       | 745 (100%)       |

*Decision or decisions or decide or deciding.
†Discussions of decisions made by people without cancer have been excluded (for example, where the web author felt the government ought to make decisions about breast cancer policy or service provision).

where other kinds of decision were involved included two where the decision whether to give money to the charity was discussed and two referring to the issues involved in deciding whether to take part in a clinical trial. Decisions about family matters, lifestyle and cosmetic issues were not mentioned.

The predominant characterization of treatment decision-making was that it was something done by the man with prostate cancer, using medical information gathered from sources like the web site itself and, more particularly, from doctors. At various points on the site men were urged to ask questions (sometimes described as ‘the right questions’) of their doctors. Printable lists of questions relevant to particular kinds of consultation that men could then take to the consultation were provided (‘our handy question sheet’).

A role for family and friends in talking through treatment decisions was largely absent. Of the 17 times that treatment decisions were referred to, 14 involved decisions by the man alone, with only three being said to involve other people (two doctors, one nurse). The one that involved a nurse emphasized the role of the nurse as an ‘informed and skilful friend’ who might also be involved in ‘talking to families’. The advice given in a section entitled ‘Learn about prostate cancer’ encapsulates these themes:

Understanding the illness is an important way for regaining control over your life. Learning more will help you make informed decisions about the treatment options available to you. Knowledge will also help you discuss your illness with other people, which can help them come to terms with a difficult discovery. This part of The Prostate Cancer Charity web site aims to help you learn more about prostate cancer, to empower you and help you live with cancer, however, you choose to treat it. ‘I now know many treatments, therapies, practical tips, and jargon galore. Knowledge really is power.’ Bill

The quote from Bill was the only occasion on the site where the words of a person with cancer were quoted, a marked contrast with the breast cancer site which contained extensive personal stories, diaries and interviews written by people with cancer. ‘Other people’ in the extract are conceived not as assistants in decision-making, but as beneficiaries of discussion with an already-knowledgeable cancer patient. Power and control are said to be fuelled by information and realized when ‘informed decisions’ are made.

Thus men with prostate cancer were encouraged to be fully informed treatment decision-makers, conceived as
fairly isolated actors, deciding on the basis of actively sought-for medical advice.

CONCLUSION

These findings show how these cancer web sites reinforce popular views about differences in the behaviour and responsibilities appropriate to men and women. Women with cancer are portrayed as inhabiting a network of relationships that have to be managed and consulted when deciding on treatments and the consequences of disease. Permission is given to allow others to make decisions and, paradoxically, this can itself be understood as a conscious choice. Decision-making is thus shown to be complex, involving emotional and social aspects of the disease as well as medical factors.

Men with cancer are portrayed as more isolated, obliged to take charge of decision-making, discouraged from adopting a passive role. The stress of decision-making for men is not discussed and family and friends are said to play a limited role. Personal stories of cancer experience are rarely presented. While medical information assumes priority in making decisions, paradoxically men are encouraged to see themselves rather than their doctors as the chief decision makers. They are, in this sense, ‘obliged to be free’ (Rose 1999).

Awareness of these differences may be important for health care practitioners who treat the people with cancer, given the rising popularity of web-based health information. It may help to understand why some men with cancer do not consider the views of their families very fully, do not take non-medical factors into account and find it hard to let doctors influence decision-making. It may help to understand why some women may seem indecisive, others want to opt out of decision-making, or take treatment decisions that are not exclusively informed by medical information.

LIMITATIONS OF STUDY

Selection of web sites was based on the proxy popularity measure of the Internet and newspaper inlinks in the absence of more direct information about which cancer web sites are visited by particular groups of cancer patients. Sampling could mirror user experience better were such information available. Study of other popular web sites, including those of generic cancer organizations, would extend the evidence base. The degree to which these implicit Internet messages influence behaviour remains to be answered.

REFERENCES


