



E-Health

Do cancer-specific websites meet patient's information needs?

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ABSTRACT

Objective: To evaluate commonly used cancer websites' information provision, we developed and applied an Information Comprehensiveness Tool to breast and prostate cancer websites.

Methods: We first collated questions from a systematic literature review on patient information needs. We then classified the questions in terms of spectrum of care, theme, and nature of question. "Breast cancer" and "prostate cancer" were typed into Google, and websites listed on the first page of results were selected. Two researchers, blind to each others' scores, assessed the same websites using the coding system. Each question was scored on a 3-point scale as not (0%), partially (50%) and fully (100%) answered by two researchers. Average scores were calculated across all questions. Inter-rater reliability was assessed.

Results: We identified 79 general, 5 breast, and 5 prostate cancer questions. Inter-rater reliability was good, with an intraclass coefficient of 0.756 (95% CIs 0.729–0.781). 17 questions were not answered thoroughly by any website. Questions about "future planning", "monitoring", and "decision-making" were discussed least. Biomedical questions scored highest.

Conclusions: More comprehensive information needs to be provided on breast and prostate cancer websites.

Practice implications: This ICT can improve cancer information online and enable patients to engage more actively regarding their information needs.

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1. Introduction

Increased patient expectations about informed consent [1–7], disclosure [8–12], and participation in disease management [13], in the context of a shift towards patient-centred care [14–17], have increased the amount of information that patients expect and changed the manner in which they learn about their disease.

Improved information provision has been shown to decrease anxiety and fear about cancer and its treatment [18,19], correct erroneous beliefs [11,20], increase adherence to medical advice [6,21], and improve doctor-patient relationships [15,22], coping mechanisms, psychological wellbeing and quality of life [18,23–25]. Finally, improvements in patients' reported daily functioning and pain management have also been attributed to provision of accurate information [26].

Despite increased awareness among clinicians of the need for better information, many patients still feel like they do not receive enough [27–30] or that the information is unclear [2,31–33].

The psychological stress associated with receiving a cancer diagnosis [34–36], especially where there is urgency to start treatment [2,14,36], means that written information and tools, such as question sheets, can be a particularly useful resource [37] because patients can revisit them as their needs and circumstances change [36,38,39]. Written information has been shown to have many advantages, including helping patients obtain as much benefit as possible from the limited time with their doctor [11,37,38], increasing patient confidence in asking questions [9,11,38], and keeping family, friends, and carers involved [8,39,40].

The Internet is now an important source of health information [41,42]. A recent study of the motivations of online health information seekers found that the desire for reassurance, increased understanding and a second opinion to challenge other information were key drivers [43] leading to the Internet being increasingly perceived as a key source of health information [44]. The literature suggests however, that there are disparities in access to the Internet, mainly related to age, race, and education [45–47].

Several tools have been developed to help assess the quality of information available online, including The Health on the Net

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(HON) Foundation criteria [48,49] and the EC 'Quality Criteria for Health-Related Websites' [50,51]. These tools evaluate websites on criteria including transparency of authorship and the website's advertising policy. Neither use the patient's expressed information needs to evaluate the provision of information.

Information currently available on websites may be more reflective of professionals' priorities than those of the patient. With this in mind, we designed a multi-purpose tool for patients to use to become more informed and which can be used to evaluate websites. Specifically, we sought to evaluate how comprehensively commonly used cancer websites provide information on topics identified as important to patients, from their perspective.

2. Methods

We developed the Information Comprehensiveness Tool (ICT) to analyse websites according to their ability to satisfy patient information needs, and applied it to common breast and prostate cancer websites.

2.1. Development the ICT

2.1.1. Information needs for adults in Europe with cancer

A list of questions that might be asked by cancer patients was extracted from a systematic literature review of the information needs of adult patients in Europe (reported elsewhere). Of the 50 papers included in the literature review, 17 studied the needs of patients with different cancers, nine examined breast cancer, four examined prostate cancer, 5 examined site-specific cancers, ten studies were of non-cancerous conditions, and the remaining studies focused on a treatment or procedure such as amniocentesis. We did not make further use of the studies of site-specific cancers (other than breast and prostate) as they provided little information not available in other studies and were often highly specific (e.g. stoma care for colorectal cancer patients). Questions on chemotherapy and radiotherapy were included because they are commonly used treatments for various cancers and because we had sufficient information to develop a list of information needs (Fig. 1). While chemotherapy is not generally a first-line treatment for prostate cancer, it was included in the master list because it is still used as a treatment for many cancer patients.

Questions were extracted from articles on non-site specific cancers, followed by articles on prostate and breast cancer, chemotherapy and radiotherapy. For the purposes of this analysis, the questions were divided into three separate lists: one master list (potentially relevant to all cancer patients, 79 questions); one supplementary prostate cancer specific list (5 questions); and one supplementary breast cancer specific list (5 questions). Some information needs such as "How will I feel when investigative tests are carried out?" were only found in breast or prostate cancer-specific articles but were deemed relevant to all cancer patients and were thus included in the master list. Other specific information needs, like "What types of breast reconstruction are available?" were not relevant to all cancer patients and were kept in the site-specific lists.

All of the questions were allocated within three separate categories: spectrum of care (category 1), theme (category 2) and the nature of the question (category 3; see Fig. 1). The researchers developed the categories after reading the questions and deciding which topics allowed for intuitive and helpful analysis. The researchers then further organised the questions into sub-categories which would be most intuitive to non-specialists (i.e. most patients). When there was disagreement about how to classify a question, it was resolved through discussion until there was consensus.

Within category 1, questions were divided into sub-categories along the spectrum of care: 'disease', 'diagnosis', 'services'

'treatment', 'recovery', and 'quality of life.' This category captures the patients' trajectory through the illness.

Within category 2, questions were divided into 11 sub-categories. These are 'decision making', 'disease progression', 'future planning', 'general information', 'medication', 'monitoring', 'procedures', 'prognosis', 'psychosocial', 'self-care', and 'side-effects.' This illustrates the need for judgement; side-effects, for example, could also have been allocated to diagnosis or treatment, under the 'spectrum of care' category, but form a cross-cutting issue from a patient's perspective.

Finally, within category 3, questions were analysed according to their nature, that is, whether they were biomedical, practical or hypothetical/experiential. For example, questions like, "Can it metastasize? And if so, where?" were classified as biomedical, whilst practical questions included "How does getting one treatment affect my choice for other treatments?" Questions like "What will the quality of my life be? What will my future condition be like?" were classified as hypothetical/experiential.

2.1.2. Calculating scores

Numerous tools exist to evaluate websites against a range of metrics [52]. Therefore, our tool is designed to be as straightforward and intuitive as possible, so that it can be used by a wide range of stakeholders.

Using the ICT, five different types of scores can be calculated:

1. *Individual question scores* – Two researchers evaluated whether the website provided information on each question using a 3-point scale (yes = 1, partial = 0.5, and no = 0). A "yes" ranking (1 point or 100%) signified that the question was satisfactorily answered, "no" ranking (0 points or 0%) meant that the question was not addressed at all, and "partial" (0.5 points or 50%) meant that the topic was mentioned but not adequately explained or elaborated upon. If, for example, a website wrote that the patient may need a catheter but did not explain why or for what purpose, it was given a partial score (50%). Inter-rater reliability was measured by calculating interclass correlations between the ratings of the two researchers. As inter-rater reliability was good, the scores of the two researchers were averaged and the average score for each question across all websites was calculated. The proportion of websites that answered each question fully, partially or not at all was also calculated separately for breast and prostate cancer websites.
2. *Cumulative scores* – These were calculated for the block of 79 (non-site specific cancer) questions, and the two blocks of 84 (non-site specific + 5 breast or prostate cancer specific questions). For each block of questions, the mean cumulative scores of the two researchers were divided by the number of questions.
3. *Category scores* – We wanted to understand whether one sub-category of question within each category was more comprehensively answered than another. For example, is more thorough information provided on diagnosis than on recovery? Three separate series of subgroup scores were developed according to question category (see above: spectrum of care, theme, and nature of the question). Each category's mean cumulative score across all websites was divided by the number of questions in the category.
4. *Website scores* – When assessing how comprehensively information needs are met on individual websites, we averaged the total scores of the two researchers and divided the sum by the total number of questions (84).
5. *Website sector scores* – We assessed website differences by sector (for example, charity or government) in order to find which are more responsive to patient information needs. To do so, we averaged the abovementioned website scores within one sector.

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