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Using others' experiences. Cancer patients' expectations and navigation of a website providing narratives on prostate, breast and colorectal cancer

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ABSTRACT

Objective: To understand what cancer patients expect and may learn from other patients' experiences, as analyzed and sorted for presentation on a website called krankheitserfahrungen.de (meaning "illness experiences").

Methods: Mixed methods approach including log file analyses, survey data analyses and thematic analysis of focus group discussions.

Results: Users highly valued the wide range of patient experiences presented. The academic leadership of krankheitserfahrungen.de made them trust the information quality. Reading, watching and listening to other cancer patients' experiences gave users a feeling of hope and confidence. Searching for persons with similar experiences was a major way of navigating the website.

Conclusion: Patient narratives as presented on krankheitserfahrungen.de provide a helpful resource, supporting cancer patients' engagement with their disease. Having access to such research-informed accounts of everyday cancer experiences was seen as a great contribution to existing available patient information.

Practice implications: When health information websites include experiences, they should adhere to quality standards of qualitative research and encompass a wide range, so that users are able to find patients similar to themselves. Filter options are a helpful tool. A mix of written text and videos is beneficial, as users have different preferences. The inclusion of patient photographs and video interviews facilitates authenticity and closeness.

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1. Introduction

Feeling informed about their illness supports cancer patients' well-being in multiple ways. Higher information levels are positively associated with cancer patients' quality of life and satisfaction [1], their health-related quality of life [2] and having a feeling of control over their life [3], and are negatively associated with anxiety and depression [2].

A current systematic review of cancer patients' information seeking identified prognosis, disease and treatments as cancer

patients' top three priorities [4]. In Germany, a representative survey among cancer patients found that they most often searched for information concerning treatment, treatment effects and living with cancer [5]. However, informational needs and use of information sources may differ widely among cancer patients according to their type of cancer [6], socio-demographic characteristics [7], stage of disease and treatment phase [8]. Because of this multiplicity of informational needs, even among patients suffering from the same cancer, the provision of diverse and individualized information seems the best tool for meeting every patient's needs [9,10].

Websites on cancer often focus on biomedical information and lack information on the wider experiences and social effects of diagnosis, treatment and living with cancer [11], aspects that some cancer patients and their family members alike wish for more

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information about [12–14]. The DIPEX International project works towards closing this gap by developing websites with individual patients' experiences. The collection of patient narratives is based on academic interview projects using the maximum variation sampling approach, and analyzing interviews thematically for presentation online [15,16]. The UK website healthtalk.org has over ninety health conditions online [17]. The German website krankheitserfahrungen.de (meaning "illness experiences") has modules on chronic pain, diabetes type 2, epilepsy and inflammatory bowel disease as well as on three major cancers namely breast, prostate, and colorectal cancer [18,19].

For the modules on prostate, breast, and colorectal cancer, patients' experiences were collected and structured in analogy to themes that emerged in the thematic analysis of the interviews and presented via text, video and audio files, based on the DIPEX methodology. There are two ways in which users can approach the content of each module: via thematic pages that include experiences of different patients on a specific topic, or via person pages on which an individual person's experience with cancer is presented (see Fig. 1).

The aim of this paper is to investigate how a website that presents narratives of cancer patients is used by other cancer patients, and what users expect and learn from such a website.

2. Methods

2.1. Structure of the website

The various cancer modules on krankheitserfahrungen.de are structured in a similar way (see Fig. 1). The content of the prostate, breast, and colorectal cancer modules can be approached via thematic pages or person pages.

The thematic pages are structured into four major themes: "diagnosis," "treatment options," "living with cancer" and "messages." Furthermore, there are themes that are available for only one cancer entity, such as "support" (prostate cancer), "womanhood: breast and body" and "experiences with the health care system" (breast cancer), and "stoma" and "medical examinations" (colorectal cancer).

The person pages start with an overview of all persons whose experiences can be viewed on the website with or without a photograph, according to the person's wishes. On an individual's person page, his or her personal story is presented, including text passages from the interview and – if the person agreed – audio and

video files. More than half of all persons sharing their experiences on krankheitserfahrungen.de are represented through photo and/or video. A filter option on the person pages allows the user to filter for "age" and "time since diagnosis," as well as "age of children when diagnosed" on the breast cancer website only, and "stoma," "type of colorectal cancer" and "sex" on the colorectal cancer website only. In total there are 27 thematic pages and 42 person pages on prostate cancer, 33 thematic pages and 43 person pages on breast cancer, and 38 thematic pages and 42 person pages on colorectal cancer.

2.2. Overall study design and sampling

We used a mixed methods approach that combined the analysis of log file data, survey data and qualitative interview data. We first asked colorectal cancer, breast cancer and prostate cancer patients to test the then not yet publicly available modules on krankheitserfahrungen.de for two weeks. Participants of each patient group were granted access to the website module specific for their disease and their website activities were tracked and recorded. Afterwards, they filled in the German version of the e-Health Impact Questionnaire (eHIQ) [20] and commented on their experiences with the website in focus group discussions. The study was approved by the University of Freiburg ethics committee (EA/247/12) and was reported to the Charité-Universitätsmedizin ethics committee (EA4/053/12). Funding was granted by the German Federal Ministry of Health (NKP-332-041).

Study participants were recruited in January 2014 (colorectal cancer) and January through March 2015 (breast and prostate cancer). Recruitment venues included presentation of the study to support groups in rural and urban areas and to the oncological outpatient services of diverse hospitals in Berlin and Freiburg. A press release was also published. Sampling strategies were aimed to create a diverse set of potential users. Our goal was a study sample of 20 persons per cancer type; 60 study participants in total. The study sample was determined based on other qualitative online user studies [21]. Eligibility criteria for the study included being aged 18 years or older, having a cancer diagnosis of the respective cancer entity, having internet access and being willing to attend a focus group discussion and sign a consent form.

2.3. Quantitative data collection and analyses

Study participants were given access to the corresponding cancer module site for two weeks. To assess patients' attitudes towards health-related websites in general and their perception of krankheitserfahrungen.de in particular, we used the eHIQ [20]. The eHIQ was filled in by patients after having tested the website and before attending focus group discussions. The questionnaire entails 37 items in total. For each item, participants are asked to rate their agreement to a statement on a scale ranging from 1 (strongly disagree) to 5 (strongly agree).

The eHIQ data was entered into SPSS Statistics Version 23 and analyzed for each patient group separately, as well as encompassing the total of all study participants. Items were split into eHIQ-Part 1 (11 items) to analyze participants' general attitudes towards health information online and eHIQ-Part 2 (26 items) to analyze participants' specific perceptions of krankheitserfahrungen.de. Data was analyzed descriptively. For analysis purposes, the five-point response scale was reduced to three points, indicating either disagreement, indecision or agreement. Totals and percentages were calculated for each response category.

To study users' navigation and their preferred pages on the website, we conducted a transaction log analysis with the log information that was recorded by the web server. Log information recorded included date and time of request and the file name of the

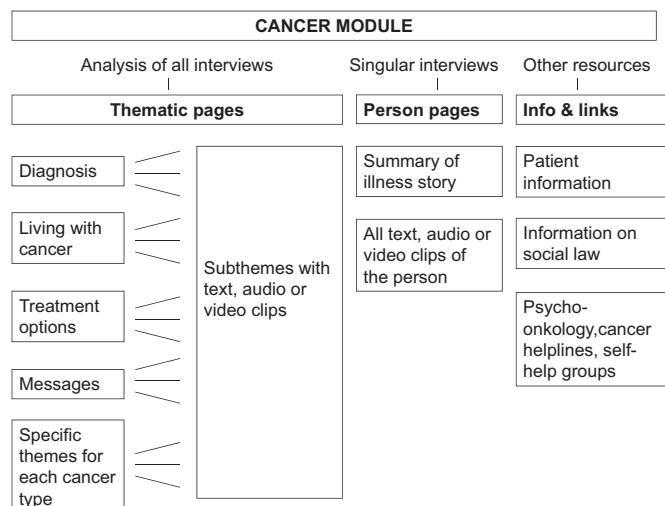


Fig. 1. Structure of cancer modules on krankheitserfahrungen.de.

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