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English summary

'The doctor will tell me when there's something wrong'

a qualitative research into patterns in the information behavior of health consumers

Many health consumers have trouble finding reliable information. And the information that is found is often irrelevant or hard to understand. Access to health information on the internet is important for health consumers, because it is a psychosocial and emotional coping strategy: for many of them, searching on the internet for information is a way of coping with a new health issue. This is consistent with the increased expectations from healthcare organizations that health consumers are expected to play an active role with respect to their health and make informed decisions. Therefore, it is essential that health information meets the needs and demands of health consumers. This thesis aims to contribute to optimizing online health information from the perspective of the user. A key aspect of this is the information behavior of health consumers. Three phases of information behavior are central in this thesis: the emergence or lack of information needs; the choice for a particular information source or channel; and searching for information on the internet. By studying the information behavior of health consumers in detail, analyzing the underlying motives, and exploring whether patterns in the information behavior can be observed, insights are gained and translated into optimization of online health information. The main question of this thesis is therefore:

- *Are there patterns to be observed in the information behavior of women with an abnormal cervical smear who were referred to the cervix outpatient clinic for further investigation and possible treatment?*

This research question is divided into the following sub-questions:

- *Which level of health literacy do the participants of this study, consisting of women with cervical dysplasia, have?*
- *Which information needs do they have and what motivates those needs?*
- *Which information sources are consulted and what motivates their choices for these sources?*
- *Which search strategies do they employ and what motivates these strategies?*

Research has been conducted on the information behavior of healthcare users, but most studies have examined the behavior of the general population with regard to general information at one single time. In addition, usually this type of research is based on subjects who are not real patients themselves at the time of examination, and the study

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was conducted in a laboratory set-up. Finally, usually only the needs and behavior are identified without gaining insight into the underlying motives, while insight into the motives in particular provide instructions for tailoring information. In this thesis, these three shortcomings are eliminated. The present study took place in the context of a general, top clinical hospital in the Dutch Randstad. Real patients undergoing a treatment process at an outpatient clinic were included.

Chapter 2 first sketches the context. During the consultation, the caregivers of the hospital are faced with patients who have searched for and found information on the internet. Interviews were conducted to explore the experiences and attitudes caregivers of this hospital have with regard to the online search behavior of patients. It describes that at the time of data collection, in the perception of the interviewed caregivers, health communication via digital media did not play a major role in this hospital. Online patient education was seen as support for physician-patient interaction and as a recruitment tool for the hospital, rather than as a primary source of information for patients. Therefore, referring patients to background information on an external website was considered as a complement to the personal conversation between physician and patient. Caregivers cited reliability, credibility and factual correctness as quality criteria for online health information. When patients brought accurate, relevant information to the consultation, caregivers considered this to be a positive contribution to the physician-patient contact. However, it was not uncommon that patients found irrelevant or incorrect information on the internet. When patients brought up that kind of information, caregivers had to invalidate that information, which put extra time pressure during the consultation. Since the start of the study in 2008 - the period in which the interviews were conducted - the situation has changed. In 2016, the hospital's website contains a variety of interactive and multimedia applications. In addition to the previously discussed findings, the interviews also yielded an informed choice for a case study concerning the examination and treatment of cervical dysplasia on the cervix outpatient clinic of the gynecology department.

Chapter 3 describes the case in more detail. Every year several hundreds of thousands of Pap smears are conducted. Approximately one in twenty Pap smears turn out to be positive, which indicates cervical dysplasia. When moderate to severe abnormalities are found, the woman in question is referred for further research to a gynecologist. The present study of this dissertation concerns the examination and treatment of cervical dysplasia in the cervix outpatient clinic of a general, top clinical hospital in the Dutch Randstad. The examination and treatment of an abnormal Pap smear appeared to be both interesting and relevant for a study into the information behavior of the health consumer because it touches on a variety of emotionally charged issues: the risk of cervical cancer, sexually transmitted Human Papillomavirus, and a possible desire to become a mother.

Anxiety and uncertainty caused by these circumstances form the basis of information behavior. During examination and treatment, patients receive information from the cervix out-patient clinic at different times. A content analysis of the given patient information was conducted. The results demonstrated that it is like a blueprint of the treatment program that the patient will undergo and aims to facilitate a smooth process of the treatment program. While this information is accurate and efficient from a medical perspective, and will probably meet the cognitive information needs of patients to the maximum extent, the information may not align with the experience of patients and affective information needs may remain unanswered.

Chapter 4 elaborates on the group of women who participated in this study: how do they use computers and the internet, and what level of health literacy do they have? Health literacy concerns the skills required to obtain, understand, assess and apply health information. To obtain insights for a better match between information supply and information needs, first a thorough understanding must be obtained in computer and internet use and the level of health literacy of the target group. The health literacy of the participating women was explored by using a combination of three instruments: the short Test Of Functional Health Literacy in Adults (S-TOFHLA), the Set of Brief Screening Questions (SBSQ) and the eHealth Literacy Scale (E-HEALS). The intention of combining instruments that: a) measure directly and indirectly; b) measure general health skills and health skills in the context of the internet; and c) measure different constructs was to obtain a well-founded impression of the level of the health skills of the sample.

The level of health literacy turned out to be above average. With the S-TOFHLA and SBSQ, ceiling effects were achieved. As far as is known, the S-TOFHLA has not been used previously in a Dutch version. In previous studies, a Dutch version of the SBSQs appeared to be an adequate instrument to distinguish between adequate and inadequate health literacy. The scores on the SBSQ indicated that the participating women had an above-average level of health literacy, which is to be expected, considering the characteristics of the sample, like age and education. The scores on the e-HEALS also suggested an appropriate level of health skills in the context of the internet. Because the participating women showed so little difference in their level of health literacy, this feature was not included in the further investigation into patterns of information behavior.

Chapter 5 describes how the research questions were translated into research methods. Qualitative methods were used to gain insight into the information behavior. These involved interviews with women and observations of their online search behavior. In qualitative research, it is not the intention to quantify data or to pursue a statistically representative sample. The research data were studied and presented in context. Combining interviews and observations made it possible to study what the participating women *say* they do and what they *actually* do. It is assumed that such a combination of research methods, triangulation, leads to a greater reliability of the findings. As usual in qualitative research, the role of the researcher and the methods used were reflected on

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with fellow researchers in all phases of the study. Reflection reduces the potential bias, optimizes the process and contributes to a more effective data collection. On the basis of the insights acquired, adjustments were made in the analytical instruments when necessary.

Chapter 6 reports on the information needs of the participating women. If someone is facing a new health situation, such as an abnormal Pap smear, it usually causes uncertainty and anxiety. These emotions are considered to be at the basis of an information need. Information needs can be understood as the awareness of a gap between what one knows and what one needs to know in order to meet a particular need. Searching for information is motivated both by cognitive needs - reducing a knowledge or understanding deficit - and by affective needs - reducing negative emotions such as anxiety or uncertainty and maintaining hope. Whether motivated by cognitive or affective needs, information can also be avoided. Less attention is paid in the literature to the nature and the underlying motives of information needs. This research focusses on these aspects.

Throughout the whole treatment program, the participating women reported having information needs. Right after the diagnosis, the respondents experienced a lot of anxiety regarding different topics, but not always the same. The information need was greatest at this stage. It is known that women with an abnormal Pap smear consider their condition to be more serious than actually is the case. The type of questions they reported matched the assessed seriousness. After the gynecological follow up, the fear was reduced, with the exception of women with a serious medical history. Participating women reported to be relieved that their condition seemed to be less serious than they initially thought or because the abnormal cells had been treated. The information need in this phase was limited. In the third phase, where the participants were scheduled for a check-up, anxiety and uncertainty increased again. Similarly, the need for information also increased. Whether participants would search for or avoid information and what kind of information met their information needs was related to personal factors. For example, one respondent coped with her anxiety by avoiding information and another coped with her anxiety by seeking as much information as she could. Summarizing then: information needs were both cognitively and affectively motivated, and the topics on which women needed or avoided information were prompted by situational characteristics: a) the duration of the dysplasia; b) life stage; c) an established HPV infection; and d) previous medical experience. It is known that health consumers select specific information sources with specific needs; based on their beliefs about the information source, they decide what source meets a particular information need.

Chapter 7 describes which information sources the respondents reported having consulted for particular information needs and what the underlying motives for their choices were. The findings from the interviews demonstrated that the respondents primarily consulted the following information sources: the doctor, the clinic assistant, the information leaflet, the nurse during an educational consult, the gynecologist, an acquaint-

tance with medical expertise, an experienced acquaintance, online peer support forums and informational websites. These information sources were valued along several dimensions. Inductive analysis showed the richness of the dimensions.

The identified dimensions from the interviews (inductive) were mirrored on the five themes that are known from the literature (deductive): medical expertise, relevance, anonymity, accessibility and emotional support. Almost all sources were valued both positively and negatively on each dimension. For example, one respondent thought of her GP as an accessible source and another thought her GP was not accessible at all. The internet was considered to be reliable by some and as highly unreliable by others. Hence the valuation of a particular source of information was very personal. In addition, the respondents usually consulted more than one source for their information needs. They did that not only when they had not been able to find a satisfying answer, but for example also to gather as much information as possible from different perspectives and to verify information they previously obtained - which is also assumed by the 'channel complementary theory',

Chapter 8 discusses the observed online search behavior of the participating women. Reported search behavior and observed behavior are compared. This research focusses on the motives women have for their activities on the internet and the impact these motives have on their search strategies. Almost all participants said they started their search on the internet with a Google search. When looking for specific information, many of them failed to formulate effective queries: their queries were either too general or too specific. As a result, they were mostly directed to information from sources that they actually considered not reliable, such as peers, or information which is not intended for patients, such as professional information for caregivers. Using specific queries did not often result in reliable medical information being found. In literature this is usually attributed to a lack of medical knowledge of health consumers and a vocabulary gap with caregivers.

While selecting a search result, respondents were often juggling between various criteria: reliability, relevance, appropriateness and accessibility. During the interviews, prior to the observations, the respondents said they used objective criteria to assess the quality of the information that appeared on their screen. But the observations showed that in fact they often used heuristic criteria to estimate reliability, such as how the name of the website or the sender 'sounds', the look and feel of the website, searchability, language and loading time of the website. These heuristic criteria were more influential than objective reliability. This inconsistency between what women did in reality and what they said they claimed they did can be explained as follows: the information looked for had to meet not only rational standards such as the medical expertise of the source, but also subjective measures such as compensation for emotional needs. The participants wanted to be reassured. In general, reliable, relevant background information on examination and treatment was quite easily found. However, once the information needs became more specific or personal, it was more difficult to find information

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that met all the criteria.

Chapter 9 compiles the results of the previous chapters. At first clusters were made of: a) the reported information needs; b) the reported use of information sources; and 3) the observed online search strategies. Within the various information needs, three clusters were identified, within the use of information sources four clusters were identified, and within the online search strategies three clusters. The next step was to study whether patterns could be observed within these clusters. Five patterns of information behavior were found, and each of these patterns was given an illustrative term: a) inactive; b) sensitive; c) selective; d) constructive; and e) assertive.

The a) 'inactive' respondents said they were not concerned about the current health issue and wanted to keep it that way. They reported almost no information needs and were not motivated to seek information. b) 'Sensitive' respondents reported being anxious. The main goals of their information behavior was to be reassured and to not become distressed any further. They had a preference for information from their health care provider and only sought information on the internet about very urgent matters. Once they were reassured, they hardly needed any more information. Anxiety was also prominently present with the c) 'selective' respondents, but they were drawn more specifically to undesirable information. Medical expertise or reliability was subordinate to relevance. They consulted sources that were readily available to them. The most noticeable motivation of d) 'constructive' respondents was their need to know what their health condition meant and how it would be treated, so that they would be prepared for what was to come. To achieve that, they consulted various available sources. The internet was appreciated because of the large amount of information available. Their information needs were met as soon as they found a satisfactory answer. For e) 'assertive' respondents, it was also important to know about their condition and treatment, but their need to know was motivated by a strong need for participation. Respondents consulted several medical experts or even scientific sources - also less accessible sources. On the internet they were keen on reliable, expert information. With the information they obtained, they confronted their gynecologist.

The described patterns are not complete in themselves: there is a greater or lesser degree of overlap between the groups. It is also likely that health consumers may change patterns during the treatment program. This is why the patterns should not be considered as defined groups, but rather as a selection of dominant characterizations of information behavior.

The final chapter, **chapter 10**, reflects on the findings of the present study. The description of the five patterns shows the variety in the information behavior of health consumers and specifies the often dichotomous description in the literature of information behavior. It can be imagined that similar patterns also occur in other health contexts, such as patients who have been referred to a medical specialist following another screening that detects a certain type of cancer; patients with a sexually transmitted disease; and

patients in other research and treatment programs with strict protocols.

The aim of the study was to gain insight into the information behavior so that instructions could be formulated to achieve information that is effective. If the numerous characteristics of information behavior are clustered into search patterns, the number of variants on the information will remain manageable and the information can be tailored to these patterns. That is why in chapter 10 recommendations are proposed for tailoring information to the identified patterns. Also some generic adjustments are proposed to further optimize the supply of information in the most cost- and time-effective manner possible. To this end, this thesis made an attempt to achieve a more optimal connection between the online information supply and the needs and skills of health consumers.

After outlining the recommendations, the method used is reflected upon. Amongst other things, the chapter discusses the rapid technological developments that strongly influence online behavior, such as increasing opportunities for interaction and networking through social media and the rise of e-health tools. These developments will greatly affect online search behavior. Despite this, the findings of this study are still relevant, since the focus was mainly on the underlying motives for the information behavior. With regard to the analysis of the inductive method (i.e. from the retrieved results) it is concluded that although this method is very time-consuming, it has proved to be valuable, because the real-life situation was fully simulated. If strictly deductive analysis (i.e. based on theoretical models) had been used, the wealth of considerations, needs and behaviors would not have been exposed. Finally, the limitations of the method and analysis are discussed, and the thesis concludes with some suggestions for future research.