

Online Patient Information about Breast Cancer

– A Discourse Analysis

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Abstract. Adequate information is crucial for patient participation in health trajectories. The objective of this study is to analyse how online health information about cancer is organised and presented. Updated information about breast cancer in Norway is available through different Web portals, provided by different intermediaries. The Norwegian Directorate of Health offers information on helsenorge.no (1); the interest organisation, the Norwegian Cancer Society, informs about breast cancer on their Web portal (2); and the patient organisation, The Breast Cancer Society, offers information for its members on a separate webpage (3). These Web portals provide information and communication services for citizens. In a critical discourse analytic approach, this study analyses and discusses how the information offered aligns with the objectives of patient participation.

1 Introduction

Health policies are increasingly promoting a more active patient role in decisions about their care [1]. Strategies and action plans have been adopted to drive digitizing of healthcare in order to strengthen patient engagement in medical decision-making [2][3][4]. Today, digital public services like helsenorge.no provide information about illnesses and treatment options to enable patients to make active choices about their health and available health services. At the same time, the development of mobile devices has increased the access and use of Internet offering users an unlimited amount of online health information.

Previous research shows that for patient participation to be efficient and valuable, three criteria must be fulfilled: 1) patients must have a certain level of health and eHealth literacy, 2) the information provided must be of adequate

quality, 3) health professionals need to recognise each patient's unique level of knowledge [5] and hold excellent communication skills. This will be further detailed below.

How patients comprehend and make use of online health information and to what degree this information enables them to make the appropriate decisions depend on their eHealth literacy level. However, the concept of eHealth literacy comprises several competencies and skills [6, 7]. A definition that takes into account both individual and contextual aspects is the one suggested by Griebel et al [8]:

“eHealth literacy includes a dynamic and context-specific set of individual and social factors, as well as consideration of technological constraints in the use of digital technologies to search, acquire, comprehend, appraise, communicate, apply and create health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan.”

A mismatch between provided online health information and patients' eHealth literacy level may result in lack of understanding of their own health condition as well as lack of knowledge and motivation for improving personal health. However, being able to seek and find information does not mean that the process of transforming information into knowledge is easy. This depends on the quality of the information. To exemplify, Gilstad's study [9] of online health information from the Norwegian authorities about lung cancer Cancer Patient Pathways (CPP), found that the information had an unclear addressee and was not targeted specifically to the patients, two factors that could possibly hamper the readers' understanding.

Patients often present to health-care providers with no prior knowledge about their condition. Health professionals must not only consider the clinical assessment, they also have to be aware of each patient's health literacy level in their patient communication. A potential gap between health professionals and patients regarding health and eHealth literacy may result in misunderstandings.

This paper addresses online health information, for which we use breast cancer care as an illustrative case. Studies show that online resources have become important references for patients navigating through the cancer journey [3, 4]. Particularly breast cancer patients demonstrate to be frequent users of online resources [11][12]. We aim to analyse and discuss the quality of the online information about breast cancer available in the Norwegian context based on insights from critical discourse analysis [13]. The following research question guides the paper: *What characterizes online health information about breast cancer for citizens in the Norwegian context?*

Brief description of Cancer Patient Pathways in Norway

In Norway, the national authorities introduced a Cancer Patient Pathways (CPP) programme in 2015 that included 28 different diagnoses [14]. The CPP for breast cancer was one of the four first CPPs to be introduced, along with prostate, lung and colon cancer. CPPs outline the best cancer care for specific tumor types, and

are developed to ensure that the disease trajectory is perceived as predictable and safe for patients and their families. Time must be predictable. In addition, patients should participate in decision-making regarding the diagnosis, treatment and recovery throughout the pathway. In such a process, understandable information about cancer diagnosis, treatment options and side effects is crucial to active participation by the patient. An assessment of the CPP showed that patients are so far quite positive, but 42% said they did not agree that there is good information available about how to prevent cancer [15].

1.1 Theoretical and analytical perspective

Critical discourse analysis (CDA) is a theoretical and analytical approach that sees discourse as a form of social practice. Discourse is here defined as “language use as social practice” [13]. CDA is not interested in language per se, but the way language influences society and how social processes are linguistic by nature. CDA implies a dialectical relationship between situation, institution and social structures. This means that all situated discourse activities directly and indirectly refer to societal events, historically and contemporarily. These aspects influence the situated discourse event. Texts are influenced by previous texts, and discourses by previous discourses, and will again be an input for future texts and discourses intertextually or in ‘discursive chains’ [16] An important focus in CDA is to conduct systematic analysis of talk and text and other empirical communication data in for example mass media or through interviews in order to reveal what is actually going on in the social practice, and what the discursive consequences are. CDA focuses on two dimensions in the empirical analysis: *the communicative activity* and the *order of discourses*. A *communicative activity* is for example an online information site about cancer, or a consultation between a health-care professional and a patient. The *order of discourses* is for example the health authorities’ discourses, or the health-care discourses at a particular hospital. Due to limitations, in this paper we focus on the communicative activity.

The three dimensions to any communicative activity: text, discursive practice and social practice are illustrated by Norman Fairclough [17] :

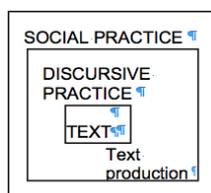


Figure 1: The three-dimensional model for critical discourse analysis (1992)

In a CDA, all three dimensions must be taken into consideration. First, the text and its characteristics should be studied. Secondly, the processes concerning the production and the consumption of the text should be identified. Thirdly, the social practice, for example what social event the text is part of, must be

examined. In this paper we analyze the three dimensions *text*, *discursive practice* and *social practice* in selected online information sites about CPP for breast cancer.

2 Methods and Materials

This study has a qualitative approach, and the data is online information on breast cancer for citizens. Updated information about breast cancer in Norway is available through different Web portals, provided by different intermediaries. The Norwegian Directorate of Health offers information on helsenorge.no [18]. The interest organisation, the Norwegian Cancer Society, informs about breast cancer on their web portal [19], and the patient organisation, the Breast Cancer Society, offers information for its members on a separate webpage [20]. As for the analysis, we explored and characterised the collected online information data with the framework of CDA.

The analysis includes a discussion in light of notions from CDA. In the following sections we describe the three web portals, and discuss them with a focus on the following dimensions: 1) addresser-addressee; 2) topic focus; and 3) medical terminology versus lay language use.

3 Findings

Case I: Breast Cancer Information from The Directorate of Health on helsenorge.no

Helsenorge.no [18] is a patient portal provided by the Norwegian Directorate of Health, and offers general health information and services for citizens, including general information about CPP. The portal is both targeting the citizen, by explaining the policies behind the implementation of CCP in Cancer Care and the concepts of care pathways, and provides some overriding information about specialist service care and its diagnostic work-up process. Importantly, this information is available in .pdf format, but cannot be ordered in paper version. Still, national authorities state that this information should be handed over to the patient during the GP visit.

From the CPP main webpage, there is a link to specific information concerning 28 different cancer categories. The link to breast cancer directs the reader to a digital pamphlet in .pdf format named 'Pakkeforløp for kreft Pasientinformasjon. Utredning ved mistanke om brystkreft' (Cancer pathway – patient information. Diagnostic evaluation with suspected breast cancer) [21]. The information is based on the same textual template as the other 27 cancer

categories.

The pamphlet for patients about CPP and examination at suspicion of breast cancer contains the following information sections: ‘general information’, ‘examination’ and ‘phases in the pathway’. The three phases are specified in a table, with a brief description of the respective activities and the expected time schedule. This pamphlet states that target patients are those hospitalized for cancer diagnosis and treatment.

The communicative activity

Addresser and addressee

The addressee of the CPP information for breast cancer is not explicit. However, there are markers in the text that indicate the addresser’s intention (or lack of intention) about who is the main addressee. An example of such a marker is the use of *nouns*. The introduction clearly states that ‘at suspicion of cancer, the general practitioner will refer you to CPP’, and in the next section ‘it is emphasized that you as a patient will have good information and user participation’. The nouns are second person, singular. In addition, the text offers a neutral addressee: ‘The goal of the CPPs is that cancer patients shall experience an organized, holistic and predictable pathway (...)’. The next section starts with the headline ‘What happens when I have been referred to a CPP?’ Here, the noun changes and the patient is first person, singular.

In the next section, the pathway coordinator is introduced. The text is here assuming that the reader is already in a CPP, and informs about the scheduling of consultation and of predictability in terms of time frames for the pathway. In the final sentence, the reader is informed to contact the coordinator, the general practitioner or a specialist doctor at the hospital in case of questions.

Another marker for addressee is the positioning of the actors, for example the citizen and potential patient, the next of kin, the general practitioner and the hospital. The text does not refer to specialties or persons when describing the examination and the other activities at the hospital. There is one incidence of who the actors may be, when referring to the decision-making: ‘Decisions about your treatment will be taken in interaction with you, usually based on considerations in an interdisciplinary team-meeting’. The actors in the team-meeting are not known, neither how or in what way they share the decision-making about treatment options with the patient.

Switching between noun and other terms in the same section: ‘For some, there will be medical reasons that the pathway should be longer or shorter than the times stated in the CPP. One reason may be that you have other illnesses that need to be investigated, stabilized or treated before investigation and any treatment against cancer can be carried out. Occasionally, the patient wishes to postpone the investigation or treatment’. We see here that there is a mix of labelling patients in general and the explicit patient ‘you’ in the same sentence.

Identification of topic focus in the text

The online information about breast cancer at the patient portal helsenorge.no

includes several topics. One topic is *population health information*, for example patients' rights: 'The purpose of the Cancer Patient Pathway is that cancer patients should experience a well-organized, comprehensive and predictable course without unnecessary non-medical justified delays in investigation, diagnosis, treatment and rehabilitation. It is important that you as a patient get good information and opportunity for user participation'.

In the pamphlet, there is some information about diagnosis, for example breast examination, ultrasound/x-ray and biopsy. In addition, we find information about the CPP process from visit to general practitioner to treatment, and recovery, for example: 'CPP includes investigation, treatment, follow-up and possible treatment of relapses'. The CPPs also describe rehabilitation, symptomatic treatment (palliative), supportive treatment and nursing.

An important objective for the CPP is predictability for the patient regarding time. There is some information about time in this portal: 'This is called care process time. Phase 1: The time from when the hospital receives your referral to when you present for start of examination, Phase 2: The time from when you present for examination until examination is finished, Phase 3: The time from the determination of cancer until treatment starts'. In this Web portal, there is neither specific information about risks nor about symptoms. There is no special focus on practical issues concerning for example 'being a patient'.

Medical terminology versus lay language use

Generally, it is a straightforward text with use of 'lay' terms. Medical terms are noted in parenthesis: 'supporting care providing relief from symptoms symptom (palliative care)'. However, some terms are taken for granted, that regular citizens with no prior experience with health care might not be familiar with, for example the terms: 'Specialist health-care service, radiotherapy, medication treatment, follow-up regime'. These terms are not explained in the text or illustrated in visual presentations on the Web portal.

Case II: Breast Cancer Information from The Interest Organisation Norwegian Cancer Society

The interest organisation, Norwegian Cancer Society, offers information about breast cancer from a link from the main page [19].

The communicative activity

Addresser and addressee

The primary addresser of the information about breast cancer from the Norwegian Cancer Society is a specialist nurse. She is presented with her title and picture. The information is updated 31.03.2017. The addressee of the information is not explicitly mentioned. The text refers to different terms that may refer to the idea of an addressee, for example, in this very same section: 'Some women have occasionally fluid from the nipple. Particularly this applies to middle aged women'. In the following sentence, a noun is introduced: 'If you get blood-mixed

fluid (...)' The addressee is not clear and explicit.

Identification of topic focus in the text

There is no introductory text. The information starts with a list of nine symptoms of breast cancer. This is followed by a text that specifies one of the symptom descriptions for women and men.

The next section concerns 'causes and prevention', including factors that increase and decrease the risk of having breast cancer as well as genetic factors.

The third section offers information about examination and diagnostics, and gives advice about self-examination of breasts, clinical mapping at suspected breast cancer, the consultation with the doctor and the CPP. The information about the CPP consists of a link to an information pamphlet from the Directorate of Health, which is identical to the one linked to from helsenorge.no. The fourth section concerns treatment. The main topics are: surgery, radiotherapy, chemotherapy, hormonal treatment, symptoms of oestrogen deficiency, targeted therapy and zoledronic acid. Subsequently, the text deals with the time after treatment. The main topics are: reconstruction of the breast, prostheses and follow-up. This is followed by the three sections: late effects, breast cancer metastasis, and incidence and survival.

Included in the text (all sections) there are several links, i.e. how to prepare for the meeting with the GP, techniques the GP can use to check that communication has been understood and about complementary treatment, covering among others what the patient should be aware of. On the right side of the page there are links to other pages concerning practical issues, for example: contact information, research information, cancer coordinators and membership of the organisation.

In this information portal, we find population health information, for example the procedure for examination of breasts. Moreover, the portal offers information about symptoms. The information starts with a bullet-point list of nine symptoms, followed by a longer section about leakage. None of the other symptoms listed as bullet-points are mentioned. However, in the next headline and section, changes in the shape and the skin of the breast are briefly discussed. The text also includes a comment on the incidence of breast cancer for men.

There is considerable focus on risk information in the text from the Norwegian Cancer Society. A series of risk factors for breast cancer are listed: 'early first menstrual period and late menopause, i.e. a high number of menstrual periods, no childbirths, childbirth only after the age of 35, overweight, night work, alcohol and increased risk with increasing intake, previous radiation therapy against the mammary gland, prolonged use of oestrogen supplementation in connection with menopause'. Only by reading the list, even the healthiest person may be worried.

The list of risk factors is followed by a list of factors that may reduce the risk: 'to give birth to the first child before the age of 25, to give birth to more than one child, to breastfeed, physical activity'. In this simplistic and somewhat moralistic list, which is not supported by evidence or references, the reader can be led to think that there is a direct connection between lifestyle and the risk of breast cancer. However, evidence-based research demonstrates that many other factors, such as genetics, influence the risk of breast cancer [22] The addresser touches upon the issue of inheritance in the next section, making claims about genetics,

but without reference to research or other documentation. In the final section there is claim about risk: 'Risk increases with age, about 80% of those affected are over 50 years old. The risk of breast cancer is very small for young women. On average, breast cancer affects approximately 160 women under 40 years each year'. There is no reference to evidence.

The Web portal from the Cancer Society also offers information about diagnosis. A separate section concerns examination and diagnosis. In the first heading, the citizen/patient is the actor. The next section assumes the health-care professional to be the main actor, with the patient as the object of examination. No actors are explicitly mentioned. The most common examination techniques are listed: clinical examination, mammography, ultrasound, MR, cell sample and biopsy.

In addition, the website offers information about practical issues concerning 'becoming and being a patient'; for example, advice about how to communicate with the doctor and what to think about in relation to that. The text also raises the issue of psychological problems and provides links to a webpage with advice for the patient.

Subsequently, the text raises two topics, 'treatment' and 'after treatment'. In the 'treatment' section, there are several sub-topics ranging from treatment methods to symptoms and specification: 'surgery, radiation therapy, chemotherapy, hormone therapy, symptoms of oestrogen deficiency, targeted drugs, zoledronic acid'. When mentioning zoledronic acid, there is information about side effects: 'If you have dental problems, zoledronic acid can damage the jaw and jaw bone. Your teeth must be checked and possibly pulled out before starting treatment. You are offered another medication that strengthens bone health if the teeth problems persist'.

Medical terminology versus lay language use

There is a high frequency of medical terms in this text, for example under the section of biomarkers: 'The biomarkers are: Hormone sensitivity, if the tumour is "nourished" especially by the hormones oestrogen and progesterone. HER 2 positive, presence of a special marker that says something about cell division activity. Level of Ki 67, another feature that says something about cell division activity'. This text is difficult to understand for a non-specialist, let alone a lay person.

Case III: Breast Cancer Information From the Patient Organisation, The Norwegian Breast Cancer Society

The Breast Cancer Society is an independent society, but collaborates with the Norwegian Cancer Society [20].

The communicative activity

Addresser and addressee

From the main page, there is no introduction regarding the addressee. However, on the link 'About us', there is a statement about the goal of the society: 'The

Society aims at supporting persons with breast cancer diagnosis and with identified mutations in their breast cancer genes, and works to maintain their interests'. In addition, under the link 'Services', there are links to pages called 'Somebody to talk to' and 'For next of kin'.

Identification of topic focus in the text

The main webpage of the Norwegian Breast Cancer Society (BCS) offers an overview of different information supported by the BCS including links to the respective webpages.

The left side menu has structured fields listing headlines about 'Rosa sløyfe' (pink ribbon), how to become a member, contact, local organisation, arrangements and volunteer gifts/support.

The mid-panel advertises with a video about this 'Rosa sløyfe'. This mid-panel also provides short headlines denoting on the spot news (including links to research news about treatment effects as well payment for membership of the organisation).

The top panel has links to news about breast cancer (following the link you find text about symptoms, diagnosis, treatment, side effects, men with BC), under 45 (a special subgroup, then you can receive some financial support), services and resources provided by the organisation, contact information.

The link in the top panel titled 'about breast cancer' directs the reader to an information site with facts about breast cancer and a list of risk factors. In addition, there are links to information sites about 'symptoms' and 'Diagnostic workup of patients with suspected cancer'.

The site can be characterized as having elements of population health information. There is considerable focus on risk. As in the information site from the Norwegian Cancer Society, we find a bullet-point listing of what can increase and decrease risk for breast cancer on the page 'about breast cancer'. There is considerable information about symptoms, specified on a separate website. A bullet-point list of typical symptoms is listed, followed by general information about self-examination and a link to the procedure of how to check own breasts [23].

In the subsequent section on symptoms, the reader finds information about triple diagnostics: clinical examination by a doctor, mammography and/or ultrasound and biopsy.

In addition, there is information about diagnosis. There is a separate menu with links to information sites about mammography, treatment, inheritable breast cancer, metastatic breast cancer, triple negative breast cancer, breast cancer for men and after treatment.

The home page of the Breast Cancer Society offers information about personal experiences with breast cancer. In addition, there is a link to 'Somebody to talk to', which explains about different social activities.

The information about CPP consists mainly of a link to the general information from the Directorate of Health.

Medical terminology versus lay language use

The page about mammography presents the facts in readable and lay language, without medical terminology and with a focus on the practical questions that the user may have.

Quite the reverse, the information about triple negative breast cancer contains several medical terms and names of medication that was not clearly explained: ‘When cancer cells can divide without being dependent on oestrogen, hormone blocking treatment like tamoxifen and aromatase inhibitors has no effect. At the same time, cancer cells do not utilise growth stimulating signals that pass through the HER2 protein. Without this property, targeted treatment against HER2, like Perjeta and Herceptin, is inactive’. Clearly, this is information understandable for a specialist, but unavailable for a lay person.

4 Discussion

This study provides a critical discourse analysis of three web portals offering information to breast cancer patients. The following analytic notions appeared as useful for providing knowledge about how the three sites presented the online information for the readers: 1) addresser/ addressee; 2) topic focus; and 3) medical terminologies versus lay language use.

Overall, there was great variation in content between and within the studied web portals, which in itself may complicate the usability of the information. This aligns well with previous research exposing that readability and usability of patient information – online and paper based – continue to be a challenging issue [24]. Further, main findings of our study show a) a lack of focus on the addressee, b) unclear description of the term risk, and c) lack of references to evidence.

The content of the studied web portals reflect no explicit addressee. If mentioned, there is an implicit reference to who is the target group for the organization. The unclear addressee is also apparent in the text, for instance in the one about CCP. Here the web portals provide links to the online resources of the Directorate of Health while at the same time offering copied text from the pages. However, the three web portals differ in focus. While one focus merely on the CCP description, the other two note several specific facets within and across the cancer pathway. Examples of the latter include symptoms, risk factors for breast cancer, and how to prepare for the GP encounter. This finding raises the question whether the CCP information is meant for citizens or health-care professionals? In comparison, the work of Gilstad [9] showed that the information about the CPP can be read as instructions to the hospitals rather than information to the citizens. Likewise, the study of Tran et al [11] underline that making the content of online resources suitable for intended audience is an area for improvement.

Another finding from this study concerns the somewhat normative presentation of the degree of risk apparent in the text. Moreover, the texts focus on risk aspects concerning causes of breast cancer and refer to lifestyle issues. However, available literature shows that the concept of risk has multiple definitions like danger, probability, unexpected event etc [5]. When web portals highlight risks and causes of risks without describing these concepts, this might cause misunderstanding among patients that can lead to miscommunication between patient and health professionals.

To avoid false or misleading information, patient information should refer to evidence. However, our findings show that the lack of references to available literature is common throughout all three Web portals. Claims and statistics are presented without reference to research-based knowledge. In addition, throughout the texts there is a code-switch between medical terminology and lay language use. Well-informed patients are crucial for involvement in their own care and decision-making processes, and hence online information should seek to minimize bias and possible misleading material.

Implications

Patient information can be provided in different ways. Our study has shown that the information about breast cancer available in Norwegian web portals has a potential for improvement. As breast cancer patients are active Internet users [6], further development should not only emphasize to make the content suitable for the intended user, but also to clarify whom the target user is: Is the woman with a newly discovered lump in the breast? Or the one undergoing different breast cancer treatment? Or – their next of kin? Is it the citizen seeking information about risk factors for developing breast cancer? Other research highlights the importance for authors to pay attention to the design of patient information in order to increase readability and usability[7]. From this perspective, critical appraisal of the applied literature should be included.

CCP In the perspective of these findings

Based on the findings, how does the information offered align with the objectives of patient participation? Being able to make informed decisions requires that the citizen is well-informed.

One question that arises from the findings concerns the readership: Who is the target reader for the different information sites about breast cancer? Is it the one experiencing a suspicious lump in the breast? Is it the one undergoing breast cancer treatment? Is it the one seeking information about risks of having different cancer types? Should health professionals be familiar with these sites? What about next of kin? It is important to know who the target reader is in order to provide information that appeals to and helps the reader.

5 Conclusion

In order to create online patient information about breast cancer of good quality, authors of must pay attention to a few fundamental aspects: First, it is crucial to have a clear idea about the addressee of the information. Secondly, it is important to be aware of how to present issues concerning the term risk. Thirdly, the author should be consistent in making references to evidence and knowledge. In order to make decisions about treatment, patients need reliable information. Patient organizations have a particular responsibility for providing high quality, understandable online information for the heterogeneous group of patients. Good information and communication may provide the patient with the necessary knowledge and motivation for carrying out treatment and, if necessary, life style

changes in the everyday life. A healthy citizen is not only important for the person and caregivers, but is also for the socio-economics in society.

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