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Content and Quality of Online Information on Womens' Breast Cancer

- Masterthesis -

in the study programme Health Sciences

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Hamburg, 18.04.2018

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Cancer is a word, not a sentence.

John Diamond

Abstract

This thesis examines online information on the topic of women’s breast cancer according to their content and quality and puts them in relation to the need of patients on valid, reliable and understandable information, especially, when they are confronting a severe disease.

The reason for conducting this thesis is that in times of digitalisation, the search for information via the internet is more common than ever and patients are confronted with a flood of online information on health-related topics. Research and communication on health information now occurs primarily via internet and therefore it can be considered crucial that the information that patients find is of high quality and can function as a basis for an exchange with the practitioners and as an information basis for the further course of treatment.

The aim of this work is to investigate which information interested persons, and above all patients, can find on the internet and how reliable, valid, and comprehensible this information is. In order to investigate this topic, the medically relevant foundations and the theoretical foundations of health communication were first presented. Subsequently, an analysis was carried out in which a relevant search term which was determined, and its resulting target pages were examined and evaluated using a quality checklist. The research approach of this thesis can therefore be described as explorative. The results of this thesis provide an insight into the results of the online search on breast cancer in women and its content and quality and show to what extent relevant information is presented to users and patients. With this in mind, this thesis could be interesting for health scientists, patients, and other stakeholders in the field of health communication.

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List of Abbreviations

afgis	Action Forum on Health Information Systems
AIDS	Acquired Immunodeficiency Syndrome
cf.	cited from
DCIS	ductal carcinoma in situ
e.g.	example given
et al.	et alii (and others)
f.	following [pages]
ff.	following [pages]
FQCI	Freiburg Questionnaire on Coping with Illness
HIV	Human Immunodeficiency Virus
HON	Health on the Net Foundation
Hrsg.	Herausgeber [publisher]
ibid.	ibidem (same source asprevious citation)
ICD-10	International Statistical Classification of Diseases and Related Health Problems
IQWiG	Institut für Wissenschaft und Qualität im Gesundheitswesen
MRI	Magnetic Resonance Imaging
NHS	National Health Service
no.	number
n.p.	no publisher
n.d.	no date
p.	page
TNM	classification system for staging tumours

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1. Introduction

In times of digitalisation, the search for information via the internet is more common than ever. Research and communication about health information in particular is done increasingly frequently via the internet (cf. Hurrelmann, Leppin, 2001). The internet is a medium which contains a variety of information and including articles, blogs, bulletin boards, and informational websites on health and diseases. If people are suffering from a severe disease, it is crucial that the information they seek and find online is valid, reliable, and of high quality.

For this reason, public health professionals need to monitor health-information seeking via the Internet for a variety of reasons. These include magnitude and diversity of use, diversity of users, and ultimately, implications for the health care system in terms of structure, health care interaction, and quality of medical outcomes (cf. Cline, Haynes, 2001).

The flood of poor information is high and very confusing for patients, especially when suffering from a severe disease, as information has a strong influence on recipients and can lead to confusion and fear when it is not clearly presented, is incorrect, or is of poor quality. This issue leads to the research question: Which content on the topic of women's breast cancer can be found via online research and how valid and reliable is the found content in terms of its quality for recipients/users?

Firstly, the topic of breast cancer in women with regard to its medical definition, epidemiology, diagnostics, and treatment is presented as the basis of this thesis. In addition, the physical and psychological strain on breast cancer patients is highlighted as a consequence of cancer diagnosis and treatment. Building on this, the area of health communication is presented as the second thematic basis of this work and explained by means of definitions, the presentation of the Internet as a medium for health communication, and its use and its impact on the perception of health and illness. The presentation of the importance of evidence-based online health information and the emphasis on individual institutions dealing with the quality management of online information in the health care system illustrates the essential connection between evidence-based content and quality with reference to the topic of this thesis. This topic is the scientific basis of this thesis, on which the following analysis is based.

The analysis of online content about breast cancer in women and its quality begins with an analysis of the topic-related search terms and keywords and their search volumes on the Internet. Through this, the top five target websites of the topic-related search term are identified, and their quality is examined with the help of a developed checklist. It should be emphasised that only German-language result pages originating in Germany were included in the analysis. The presentation of the epidemiological data also focuses on ill women in Germany. A study of Europe-wide or worldwide results would have gone beyond the scope of this thesis. In order to draw a comparison with international health information, however, the example of the NHS in Great Britain is presented.

The results systematically summarize the content of the pages and show the evaluation of the quality analysis. The website on breast cancer at the NHS is also presented in a short insert and compared with the found analysis results. The results section concludes with an examination of the significance of the results for breast cancer patients and a subsequent critical discussion of the results found. This section is followed by a resumé of this thesis.

2. Breast Cancer

This section of the thesis introduces the topic of breast cancer in women. For this purpose, a medical definition of breast cancer is given first. The medical definition describes the development of breast cancer and the accompanying physical changes. Subsequently, an overview of the epidemiological data is given to clarify the health-scientific relevance of the topic. The diagnosic process and treatment guidelines are also presented. This section concludes with an introduction to the effects of breast cancer on patients which presents the physical, psychological and social effects of the disease.

2.1 Medical Definition of Women’s Breast Cancer

Cancer originates when new body cells grow unrestrained and old body cells are not dying. The result is tumorous cell tissue which can be either benign or malignant (cf. Kreienberg et al., 2009). A malignant tumour of the breast is called breast cancer. The term refers, in this case, to the female breast. About 70-80% of the carcinomas affiliate with the ductal carcinomas which emanate from the cells of the milk ducts. About 10-15% of the breast carcinomas affect the lobular carcinomas which emanate from the cells of the breasts’ glandular tissue (cf. Andreae, 2009). If the tumour cells traverse and extend the natural tissue boundaries of the breast, they are medically referred as invasive. Invasive carcinomas are able to spread out into other regions of the human body and to form metastasis (cf. Kreienberg et al., 2009). As with other kinds of cancer, there are also special forms of breast cancer. One of these special forms is the inflammatory breast carcinoma with which the ductal carcinoma spreads out to the skin and expands then inflammation signs (cf. Andreae, 2009).

Because the ductal carcinoma is the most common form of carcinomas of the female breast, it is highly relevant to outline its specific characteristics. The cell changes on the inner wall of the milk ducts seen under microscopic examination look like cancer cells, but at the time of their discovery, they do not leave the place in which they originated, invade surrounding tissues and metastasize in other organs. This cell change is described as a ductal carcinoma in situ, shortly DCIS which means that it stays in one place (cf. Kreienberg et al., 2009). At this point it is important to outline that there is a difference between DCIS and breast cancer.

There are preliminary stages of breast cancer which include the intraductal atypical hyperplasia which means that altered cells are in the milk ducts, the lobular intraepithelial neoplasia which means that altered cells are in the lobules of the breast glands, the flat epithelial atypia which means that altered cells are in the covering tissue of the milk ducts and/or the lobules of the breast glands and another preliminary stage of breast cancer, the ductal carcinoma in situ. In contrast to the other breast cancer precursors, in situ ductal carcinoma is the most likely to develop cancerous cells and is therefore of high relevance (cf. Deutsche Krebsgesellschaft e.V.[1], 2018).

The cells of the ductal carcinoma in situ store lime and those micro calcifications are visible in a mammographic examination. Because they do not have the ability to metastasize in other organs, they are considered as cell changes and not breast cancer. However, the relevance of DCIS must be highlighted. Almost every fifth woman who is diagnosed with breast cancer for the first time after a mammographic examination receives this diagnosis due to the cell changes of DCIS. So far, it is not possible to give a medical prediction of how likely ductal cell changes in situ will turn from harmless to malignant. The scientific data on the effects of DCIS is rare, but it can be estimated that up to 60 out of 100 women who are diagnosed with ductal carcinoma in situ develop a malignant tumour of the breast (cf. Kreienberg et al., 2009).

In a mammographic examination, it is difficult to analyse the micro calcifications in order to classify them as normal which in this case means harmless, or as potentially harmful or malignant. This can lead to diagnostic over- or underestimations, but the micro calcifications of DCIS themselves can be seen on a mammogram very well and their discovery rate has risen significantly with the increasing application of mammography diagnostics. Since the introduction of mammography screening for early recognition of breast cancer, the number of DCIS diagnoses has increased by about 20%. Nevertheless, if micro calcifications are found and there is a suspicion for DCIS, a MRI and a biopsy should be conducted to confirm the diagnosis and give recommendation for further treatment (cf. Heywang-Köbrunner, Barter, 2015). It is medically recommended to treat all women with DCIS because, as stated before, estimations cannot be made as to whether it will develop into a malignant tumour. This means that even women for whom it is not necessary receive surgical treatment which is comparable to the treatment for localized breast cancer. Nevertheless, if the ductal carcinoma in situ is removed as a cancer precursor, the disease is almost always prevented (cf. Kreienberg et al., 2009).

2.2 Epidemiology of Women's Breast Cancer in Germany

Breast cancer is in the western industrial states (cf. Fischer, Hermann, 2014) and worldwide, with over one million new cases per year, the most common type of cancer which affects women (cf. Weyerstahl, Stauber, 2013). In line with this, breast cancer is also the most common type of cancer among women in Germany.

Over 72,000 women fall ill with breast cancer every year and the number is rising (cf. Robert Koch Institut, 2016). This amounts to a ratio of 123 new cases of breast cancer per 100,000 inhabitants per year (cf. Fischer, Hermann, 2014).

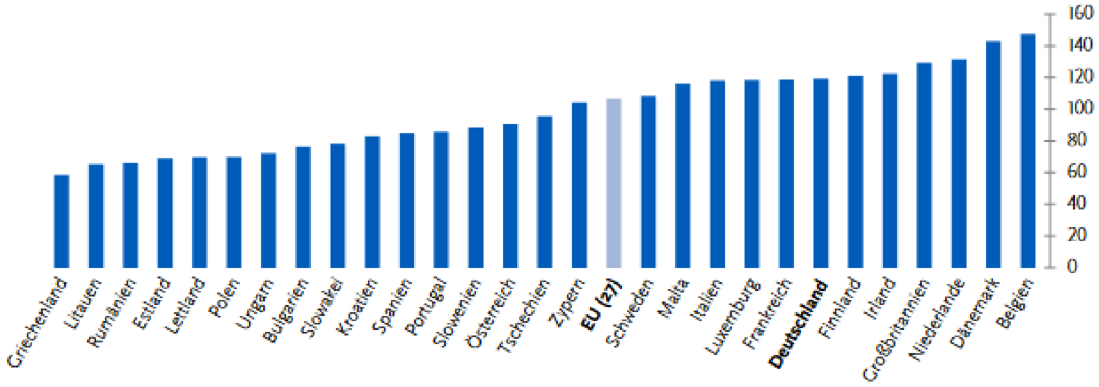

Figure 1: Age-standardised rates of new cases per 100,000 women in the EU Member States, breast cancer, 2012

Although most types of breast cancer are well treatable with radiation and chemotherapy, the highest mortality rate lies between age 50 and 70 (cf. Robert Koch Institut, 2016). With a mortality rate of approximately 18%, breast cancer is the most common cause of death of women in Germany. This is approximately 17,000 deaths per year and 41 deceased women per 100,000 inhabitants (cf. Fischer, Hermann, 2014).

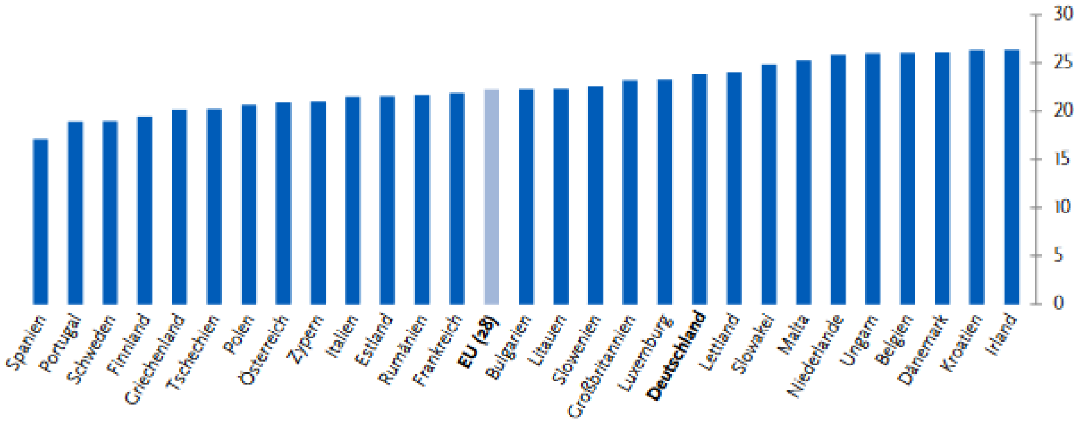

Figure 2: Age-standardised mortality rates per 100,000 women in EU Member States, breast cancer, 2011-2013

The probability of developing breast cancer increases with age but increasing numbers of young women are also being affected. Between the ages of 35 and 59, breast cancer is the leading disease, representing 40% of the malignant tumours and 30% of cancer-related deaths. Every eleventh woman in Germany will develop a cancerous disease of the breast in the course of their live. Following successful treatment, a definitive cure can be declared after a time span of 20 to 40 years after securing the initial diagnosis (cf. Fischer, Hermann, 2014).

In almost 95 percent of breast cancer cases, the disease occurs randomly and still with insufficient scientific evidence to determine the causes leading to the development of the cell changes. Although the causes are not known, scientific studies have identified several risk factors which lead to a higher rate of the development of malignant cell changes. Only about five percent of the breast cancer cases are caused by a predisposition due to hereditary factors and genetic dispositions (cf. Kreienberg et al., 2009).

2.3 Diagnostics of Women’s Breast Cancer and Treatment Guidelines

In most cases the diagnostic process for breast cancer starts with a suspicion due to pain or other discomfort, a routine examination at the doctors or even with the palpation of unusual changes of the breast during a women’s self-examination (cf. Kreienberg et al., 2009).

For a secure diagnosis, the palpation of both breasts and the lymph drainage way, a mammography as the most effective method of detecting precursors of breast cancer and cancer of the breast. The ultrasound examination of the breast is the imaging method of choice for women under the age of 40. Over the age of 40, the ultrasound examination is considered a supplementary method for clarifying unclear findings. The removal of a tissue specimen and examination under microscope is also essential. The removal of tissue can be done in two different ways. Either through a minimally invasive biopsy, including punch biopsy will be performed, or an open surgical excision biopsy. In the case of surgical biopsy, the tissue is removed during a surgical operation, whereas in a minimally-invasive biopsy the tissue sample is removed with a thin hollow needle, while the tumour is observed with x-rays or ultrasound (cf. Kreienberg et al., 2009).

Treatment guidelines exist for women with a breast cancer diagnosis which are of great importance for the women as patients, as well as for examiners. Germany enforces S3-guidelines for several diseases and treatments which are evidence-based and developed in cooperation with several scientific and medical institutions. The S3-guideline for breast cancer is based on the medico-scientific findings of the Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften e.V., the Deutsche Krebsgesellschaft e.V., and the Deutsche Krebshilfe and includes the consensus of medical professionals, guideline-users and patients. The grading of evidence of the studies which were used in the development of this guideline following the scheme for evidence graduation of the Oxford Centre for Evidence-based Medicine. This scheme classifies studies for different clinical questions, for example the benefits of treatments, their diagnostic value and the prognostic significance. The recommendations found in this guideline were developed through a consensus of experts and guideline-consultants. The given recommendations broaden the evidence-based content of the guideline to include specific expertise on the topic (cf. Leitlinienprogramm Onkologie, 2017).

The S3-guideline for breast cancer consists of fourteen sections of information for examiners which are relevant for the adequate treatment of breast cancer patients. In the introduction, the major innovations to former existing guidelines are presented, the objectives of the guideline are clarified, and the used methodology is described. The following chapters present and explain successively options for breast cancer prevention, screening measures for early recognition of breast cancer, diagnosis and treatment options, as well as the adequate addressing of patient concerns. The types of treatments and therapies have been divided thematically according to the severity of the breast cancer disease. The first degree of the disease described in the S3-guideline, is the local breast carcinoma, the type of the breast cancer which has not or not yet spread in the surrounding regions of the body, hence metastasized. The second degree of the disease described in this guideline is the recrudescence, also known as returned cancer, as well as metastatic carcinoma. In this section of the guideline, the authors also included the topic of palliative care (cf. Leitlinienprogramm Onkologie, 2017).

Due to simplification the medical guidelines on the treatment of the primary disease of local breast carcinoma will be further presented. The previously described diagnostic methods for the secure detection of breast cancer are followed by therapeutic procedures to restore the health of the patient as well as possible. The treatment of the primary breast cancer disease consists of different treatment steps, depending on the age and physical constitution of the patient, as well as the current state of progression of the disease. Treatment steps can therefore vary in type and order from case to case. Typical components of therapy for primary breast cancer are adjuvant or neoadjuvant systemic therapy, surgical treatment, and irradiation therapy. Systemic therapy conducted subsequent to or before a surgery, adjuvant or neoadjuvant respectively, can consist of a combination of treatments with chemotherapeutic agents, antibodies, and endocrine therapy, also referred to as hormone therapy. Surgical treatment depends on the severity of the cancer. Surgery either preserves the breast or the cancer affected breast is removed; this is referred to as mastectomy. Typically, surgical treatment is followed by a pathomorphological investigation to forecast the success of the therapy and assess its possible outcome. The last treatment step for primary breast cancer disease is postoperative irradiation therapy. This is the most important and effective measure for reducing the risk for recurrence (cf. Leitlinienprogramm Onkologie, 2017).

Overall, it can be said, that the treatment and therapy of the primary disease of the local breast carcinoma has improved over time. The availability of safer and more accurate diagnosis and improved treatment possibilities shows a significant development in this area. Due to improved systemic therapy, progress in surgical methods, and postoperative irradiation, breast cancer treatments are increasingly successful (cf. Leitlinienprogramm Onkologie, 2017).

2.4 Effects of Breast Cancer on diagnosed Women

Being diagnosed with breast cancer and going through several treatments is not only physically exhausting, but psychologically stressful as well. This chapter describes the physical and mental effects of breast cancer on diagnosed women which who, from the diagnosis on, are in a constant battle against the serious disease and therefore face a variety of physical consequences caused by side-effects of the cancer treatment, as well as a variety of emotions.

2.4.1 Physical Consequences of the Disease and its Treatment

As with other disease treatments, breast cancer treatment has side-effects which affect women who are treated with chemo-medication, irradiation and surgery of the breast. Practitioners have to differentiate between side-effects which are objectively measurable and those who are subjectively perceived by the patient (cf. Leitlinienprogramm Onkologie, 2017).

To maintain and improve the patient’s quality of life and to optimize the tolerability and safety of therapy with cytostatic medication, antibody medication and other medical measures, as well as surgical interventions and irradiation therapy, oncologists and other treatment-involved practitioners use supportive care (cf.

Leitlinienprogramm Onkologie, 2017). Supportive care defines medication, whose contribution is scientifically significant and improves the compatibility of the system therapy (cf. Janni, Müller, 2017). Supportive therapy measures are an essential part of the oncological treatment concept. They are used to prevent and treat complications as well as side-effects during the cancer treatment and to practise modern cancer treatment options while minimising reduction of medication doses, discontinuation of the therapy or extension of treatment intervals (cf. Leitlinienprogramm Onkologie, 2017).

Nausea and vomiting are side-effects of chemotherapy or treatment with other medication, and irradiation which are most incriminatory to the patients. Vomiting can be prevented, but nausea is more problematic as it is a subjective sensation. In contrast to the more aggressive chemotherapy, vomiting during irradiation therapy is relatively low in its incidence and intensity (cf. Leitlinienprogramm Onkologie, 2017). Other side effects can include loss of appetite (cf. Isermann, 2006) or even loss of taste (cf. Jenik, 2004). These side effects are as problematic and incriminatory for the breast cancer patients as nausea or vomiting, as gaining weight after an inpatient stay in the hospital is much more difficult without an appetite (cf. ibid.). Besides loss of appetite, nausea and vomiting after or during chemotherapy, a variety of other possible side-effects exist. One side effect which is for the patient most visually recognizable, is the loss of body hair. This side effect is a physical consequence with a heavy psychological strain, as hair loss is a visual stigma that identifies one as being a cancer patient. Depending on the chemotherapeutic agents, the risk of loss of body hair can vary (cf. Hübner, 2014). Another side-effect which can occur is the risk of developing cancer-therapy induced osteoporosis which; the reduction of bone substance. This side-effect can occur during the cancer therapy in patients, who got into early menopause due to hormone treatment, however the medication administered during cancer-therapy is also a relevant factor in bone substance reduction. Bone mass density should therefore be regularly measured, especially in post-menopausal patients. Besides the risk of osteoporosis, ostealgia which is described as pain in the bones, may also occur as a side-effect (cf. Leitlinienprogramm Onkologie, 2017). One severe side effect, especially of chemotherapeutic agents, is neurotoxicity; damage to nerves in the body. This side-effect in the peripheral nervous system causes, for example, loss of sensation in the fingertips and toes, as well as a painful sensitivity to touch and is therefore a definite impairment to the quality of life of the patient (cf. ibid.). In addition to nausea and vomiting, diarrhoea can also occur as an outcome of antibody-therapy (cf. Hübner, 2014) as the gastrointestinal tract is affected. Chemotherapy also harms the gastric system and some patients can have a combination of diarrhoea and constipation during their systemic therapy (cf. Janni, Müller, 2017). This side-effect also places strain on patients who suffer from breast cancer and its treatment through the limitation on everyday activities and therefore decreased quality of life. Another side-effect of breast cancer treatment which can occur especially following surgical treatment is lymph oedema. This is an accumulation of fluid which is painless but gives the patient a feeling of tension or feeling of pressure. The lymph oedema is mostly located in the axillar region of the body, with a possible consequence of functional disorders of the limbs (cf. Hübner, 2014). Hot flashes, sweating, dizziness and headaches are also possible side-effects and vegetative syndromes of breast cancer treatment. Depression, insomnia, irritability, nervousness and abandonment fears are side-effects and mental syndromes resulting from breast cancer treatment. Changes in the metabolic system for example, are side-effects and organic climacteric syndromes of cancer therapy. These three types of syndromes are summarized under the term climacteric syndrome (cf. Leitlinienprogramm Onkologie, 2017). The combination of certain chemotherapeutics and medication in antibody-therapy can lead to cardiac insufficiency which is especially relevant for elderly patients. These side effects, which affect the heart are described as cardiotoxic (cf. ibid.). Alongside cardiotoxicity, cancer patients are highly susceptible to infections as chemotherapy drugs damage not only cancer cells but also the mucous membranes of the gastro-intestinal tract and in the oral cavity. Therefore, patients who receive chemotherapy are more likely than normal to get infections through viruses, fungi and bacteria (cf. Wilmanns, Sauer, 1988). Examples include bladder infections, kidney infections, vaginal fungi or fungal infections of the skin.

Although women who are diagnosed with and suffer from breast cancer now have a higher probability to be healed, a lower probability of a relapse and an overall better chance of survival, the given pharmaceuticals and treatments have a high impact on their weakened bodies which are in a constant battle against the disease. As shown in this chapter, cancer treatments have a variety of side-effects which negatively affect the patient’s body as well as their psyche. Breast cancer therapy, just as with every other cancer therapy, is a long process, in which the women have to be supported to not give up, even if the patient feels that the side-effects are too severe to handle.

2.4.2 Psychological and Social Consequences

To assist patients’ in coping with the stresses and strains of a cancer diagnosis as well as the cancer treatment itself, the S3 treatment guideline for breast cancer recommends psycho-oncological care. Psycho-oncology is a specific medical field which based on the exploration of various psycho-social aspects of formation, treatment and course of a cancer disease in children, youths and adults and is an integral part of the care of patients with breast cancer. This field of study gathers scientific and other relevant knowledge in order to improve the care and treatment of cancer patients. It is important that both cancer patients and patients with carcinoma of the breast receive patient-oriented information and advice from their practitioners, a qualified psychological assessment and identification of needs, and receive targeted psycho-oncological treatment to support the management of the disease and treatment consequences. In line with the S3 guideline, all members of cancer treatment should be included in the psycho-oncological care to provide a holistic treatment for the patients (cf. Leitlinienprogramm Onkologie, 2017).

The psychological consequences of breast cancer are as just important as the physical consequences and also affect the course of the treatment. It is not only the disease itself, but also the side effects of chemotherapy treatments, medications and breast surgery which can affect the patient and have a severe impact on the woman’s psyche. The own body image is perceived different by the patients, compared to their body image before the disease. In addition to this, some women feel weakened in their performance and perhaps for the first time in their life dependent on others. Furthermore, a loss of the breast through mamma carcinoma surgery is often associated with a sense of loss of femininity and can influence relationships with partners as well as sexuality (cf. Reuter, Spiegel, 2016).

Dejection, concerns, fear for their life and future, as well as anger and questioning possible causes of the disease are feelings which are usual for patients. Undergoing cancer therapy is often a time of uncertainty for women as their many open questions and hospitalisation lead to tension. Many patients are likely to be swept away thinking of past problems and experiences. Moreover, many patients feel emotionally alone, despite support from friends and family, because they do not feel understood by those who do not suffer from cancer. These emotions can lead to social withdrawal. Therefore, it is important that patients communicate with each other and talk to other patients who are sharing the same experiences (cf. Dorn, Wollenschein, Rohde, 2007).

As previously mentioned, hair loss is also a high strain for women who suffer from breast cancer, as it is one side-effect of the treatment which is clearly visible for the women and those in their surroundings. They may feel stigmatized as cancer patients and be afraid that the disease becomes the focus of conversations within their social network (cf. Hübner, 2014). In addition to this, the mental syndromes as depression, insomnia, irritability, nervousness and fears of abandonment in the climacteric syndrome described earlier are psychological consequences of breast cancer treatment (cf. Leitlinienprogramm Onkologie, 2017).

There are several coping strategies for patients, who suffer from severe diseases such as cancer and chronic diseases. The Freiburg Questionnaire on Coping with Illness (FQCI) designed by Fritz A. Muthny in 1989 is the most common instrument in Germany on coping strategies with severe diseases (cf. Isermann, 2006). It was developed on the basis of theoretical coping constructs and defines twelve coping strategies which are amongst others: problem analysis and solution behaviour, depressive processing, hedonism, religiosity, distrust and pessimism, cognitive avoidance, distraction and self-enhancement, social withdrawal and self-encouragement. A shorter version of the Freiburg Questionnaire on Coping with Illness defines five coping strategies which include, among other strategies from the longer version, problem-oriented coping, trivialization, and wishful thinking (c.f. Muthny, 1989).

3. Health Communication

This section of the thesis introduces the topic of health communication. First, the term is defined in order to provide a basic understanding for the further course of this chapter. The following sub-section describes how health communication in the digital world takes place via the internet and explains communication channels. In the connection the utilisation of online health communication is presented and the influence of media on the perception of health and disease is described. Furthermore, the benefits and harms of online health communication for patients are presented to underline the relevance of the topic of this thesis.

3.1 Definition of Health Communication

Health communication is a term which is difficult to define. It is not only communication about health, but also communication about the salutogenetic continuum of health and disease, in which humans are permanently located. Health communication focusses more often on concrete diseases, for example on HIV/AIDS and cancer (cf. Fromm, Baumann & Lampert, 2011).

To explain the term further, it is important to define each component. The most popular definition of health is that of the World Health Organization which defines health as *a state of complete physical, mental and social wellbeing and not merely the Absence of disease or infirmity* (WHO, 1946). This definition is often criticised because a state of complete wellbeing seems to be unrealistic. In 1987, Antonovsky brought the term health further from the term state. He defined health as a continuum and focussed on factors which contribute health, for example prevention and resources, instead of focussing on pathogenesis (cf. Antonovsky, 1987). The theory that health is not merely a static condition, but a dynamic equilibrium, was also supported by Hurrelmann the year 2000. He states that people are moving constantly in the dynamic balance between risk factors and protective factors that change depending on the internal (e.g. mental and physical) and external (e.g. social) requirements. Further social and cultural conditions also have an impact on this balance. In this case, illness can be defined as an imbalance of those factors. Therefore, health is understood as a *condition of the objective and the subjective feeling of a person which is given, if this person is in accord with their physical, mental and social development and with their external conditions of life* (cf. Hurrelmann, 2000).

One definition which sums up the important aspects of health communication is given by Hurrelmann and Baumann: *Health communication refers to the imparting and sharing of knowledge, experiences, opinions and feelings, the focus on health or disease prevention, or the health care process, health economics or health policy. The communication can take place on an interpersonal, organizational, or societal level, and be mediated directly-personal or through media. Health-related communication includes all communication content related to health, disease or its determinants, health-relevant communication includes all forms of symbol-mediated social interactions which influence - regardless of the intentions of the communication partners - the health behavior, directly or indirectly, or be initiated through it* (Hurrelmann, Baumann, 2014). This definition is more complex and shows the interdisciplinary associations between health and communication, as well as placing the focus on the interactions between the different stakeholders for health communication.

Another definition is given by Schiavo (2007): *Health Communication is a multifaceted and multidisciplinary approach to reach different audiences and share health-related information with the goal of influencing, engaging and supporting individuals, communities, health professionals, special groups, policymakers and the public to champion, introduce, adopt, or sustain a behavior, practice, or policy that will ultimately improve health outcomes.* In the context of this definition Schiavo has identified directions that represent the role of health communication. Therefore, health communication motivates, contributes to a modification of behaviour, conveys information, and influences individual and community decisions in order to increase knowledge and improve understanding of health-related issues, empower people and help in partnerships, as well as create a dialogue and exchange, and promote participation. These defined roles show the interdisciplinary nature of health communication (cf. Fromm, Baumann & Lampert, 2011).

These definitions clearly show that health communication is not focussing on health, but on all aspects of health and illness. It should reach all stakeholders of the health system and the society and improve health behaviour, health information, and to further health outcomes.

3.2 Health Communication via Internet

Health communication includes all internet-based applications which allow the exchange of individual communication on health information or the provision of mass communication on health information (cf. Rossmann, Karnowski, 2014) and is carried out via various communication channels. It can take place directly in person, in groups or via media, such as the press, radio, television or the internet. The spectrum of topics on health and illness in the media is very broad. How extensively health communication can be carried out via a specific medium, depends on whether the medium is suitable for the topic which being communicated. The internet is a medium that is suitable for reciprocal communication, in contrast to television and print media. That is to say that on the internet, media is quick to respond by users and an exchange can take place on health topics, for example via the comment functions in social networks and blogs. It has to be noted, that the subject of health and disease in all channels of media can be of an informative, yet also entertaining manner (cf. Fromm, Baumann & Lampert, 2011).

According to Gitlow (2000), health communication via the internet can be divided into three main sections: Health Content, Health Communities and Health Provision. *Health Content* is the form of online health services which is the most frequently accessed, as it includes all offers of information and knowledge about health or disease. Comprehensive health portals that deal with all possible medical fields, or specific health portals to get a health specialty are belonging to Health Content. *Health Communities* are social networks that allow patients to share and discuss health related topics as well as health issues in a dialogue with each other. The patients both create and receive the content of these networks. In the case of Health Communities, it must be emphasized that only in rare cases are medical experts involved in the communication. Therefore, it can be assumed that the quality of the provided information may be poor and often has deficiencies. The *Health Provision* is the area of online communication which describes the direct contact between patients and health providers. In this way, patients can exchange information on special platforms and interact directly with physicians (cf. Gitlow, 2000; Rossmann, Karnowski, 2014; Hautzinger, 2003).

Considering health communication via internet, it can be seen that digitalisation and developments in communication technology have increased the possibilities of the breadth of the communication significantly. The internet acts as an interactive medium providing the possibility of a reciprocal communication between patients, physicians and other participants in the healthcare sector. An exchange via chat, e-mail, or comment functions in social networks offers the interesting option to always be informed and to be able to respond, regardless of place, in the shortest possible time (cf. Fromm, Baumann & Lampert, 2011). Therefore, benefits of online communication e.g. interactivity, hypertextuality, speed, timeliness, as well as independence from spatial boundaries can be seen. These benefits also demonstrate that nowadays there is an extreme difference in health communication. For both providers and recipients of health information, health communication varies depending on its channel, whether via traditional mass media, patient information leaflets, in face-to-face contact and dialogue with practitioners, or more or less anonymous via the internet. In addition to this, there are also a number of specific aspects which specify the relevance of health communication. A great variety of stakeholders can be seen disseminating information, as can the networking of different publication types and forms of communication. The stakeholders of online information and communication represent a wide range. Providers of health-related online self-help groups, patient organisations, government agencies, pharmaceutical companies, commercial vendors, health insurance companies, publishers, foundations, and private individuals, for example patients, represent stakeholders and therefore are interest groups of health communication. Besides this wide range of stakeholders and providers, an increase of publication types and communication forms on the internet can also be seen. Texts include hyperlinks which gives users of online media the opportunity to obtain information from a variety of different sources. Those sources can be, for example, published articles by journalists, scientific reports, studies or entries in online lexica. Pieces of information often contain links which provide more details on the information in question. The diversity of offers and range of information gives a variety of opportunities to all stakeholders and it can be stated that the information and communication range is extended by the internet. As a result, it has become easier for patients to learn independently and comprehensively and be more informed, enlightened and mature in communication with other stakeholders (cf. Hautzinger, 2003).

One one hand, it is positive that patients have the possibility to, for example, communicate directly with practitioners, therapists, and experts, but laity in health care creates the opportunity to post messages online which reflect only their subjective feelings. Thus, there can be seen a great danger that the ratio of information of laity and experts is unbalanced (cf. Fromm, Baumann & Lampert, 2011).

As said before, the internet is a medium which offers a variety of health-related information and is therefore playing a central role in modern communication (cf. Hurrelmann, Leppin, 2001). Today, health-related topics are the most searched for content on the internet and a steady increase in the number of web pages which supply specific health-related topics has been reported. This is resulting in both opportunities and risks in health communication. On one hand, patient able to communicate in a more informed and major way with their practitioners with their newly gained information. On the other hand, there is a risk for patients to develop a non-substantial knowledge due to incorrect or poor-quality information which is not beneficial for their treatment (cf. Stetina, Kryspin-Exner, 2009). These risks and opportunities will be presented in more detail in following chapters of this thesis.

3.3 Utilisation of Online Health Communication

The utilisation of online health communication is constantly increasing. This is reflected by the increasing supply of health-related web pages and thus, the number of the people who inform themselves online and have an exchange on health topics is also increasing. Here it is important to point out that this information exchange is now carried out not only by surfing on the internet but is heavily influenced by online social networks and health apps that can be downloaded by patients and interest groups on their smartphone (cf. Rossmann, Karnowski, 2014).

To explore this topic, it is important to first examine the types of people who use the provided online information on health-related topics. The typology of users of health-related information on the internet by Cain et al. (2000) illustrates the users' behaviour as well as their characteristics. Three types of health-related Internet users were distinguished: *The Well*, *The Newly Diagnosed* and *The Chronically Ill and their Caregivers*. According to Cain et al., *The Well* make up approximately 60% of the health consumers who are searching for health information via the internet. These consumers can be characterized as individuals, who are not constrained by a significant recurring illness and therefore not predetermined in their search patterns for information and services. Furthermore, they can be considered as people who think explicitly about health only on occasion and search for preventive medicine and wellness information out of interest. This is comparable to the way they look for news, stock quotes, and products. Online health consumers who belong to the "Well"- type tend to be fickle and appreciate the convenience of online search services. Further, they need health care episodically and tend to be cost-sensitive consumers and are therefore loyal to many types of health care providers and sources of health information. As a consequence, they use a variety of websites. *The Newly Diagnosed* type is a dynamic, smaller group of online health consumers. They make up approximately about 5% of the total and they demonstrate a very different set of online behaviours to Well-type people. In the first few weeks after their diagnosis, they search enthusiastically and intensively for specific online information and reach out to experts, family, and friends for exchange and advice. The Newly Diagnosed people are a group in between the Well and the Chronically Ill category. *The Chronically Ill and their caregivers* make up approximately 35% of the total online health consumers. They have the strong tendency to affect and be affected by online health care provision. These consumers search for health information more frequently than both other groups and are considered to be more loyal to websites that provide useable information and support for their specific disease. The Chronically Ill are, in contrast to the Newly Diagnosed, supported by few family and friends, who look for specific disease-related information and seeking support from other caregivers online (cf. Cain et al., 2000). This typology of users of online health information can be extended to people who can be characterized typically as young, highly educated and of high-income (cf. e.g. Trepte et al., 2005).

Users of health-related information on the internet have a stronger health awareness and distinctive health orientation. In addition to this, a significant correlation in the use of online health information and younger age, education and female gender is shown (Dutta-Bergman, 2003, 2004). Other research shows that men tend to use online health information more than women. The greater use of internet health information by women is argued to be because women often hold a role in the family where they make the health-related decisions for the family members (cf. Trepte et al., 2005). The extent to which the health condition affects the search for health information on the internet, however, has not yet been clearly determined in the research (cf. Rossmann, 2010).

Market analysis shows that if German consumers have general questions about health issues, the internet remains by far the most common channel of information. Research shows that 74% of respondents use the internet regularly or occasionally to receive general information on health-related topics. In contrast to online media,63% of people regularly or occasionally consume information via television, 56% of the respondents gather information via print media, and 54% receive health related information from friends and family members. When consumers seek concrete information, doctors and pharmacists are the most preferred sources for 53% of the respondents, in contrast to the search for general information where only 41% of the respondents prefer doctors and pharmacists as a source (cf. SKOPOS, 2012).

A recent study conducted by the IQWiG, the German Institute for Quality and Efficiency in Health Care, shows that the following groups in particular search for online information on health-related topics: users with acute or chronic disease, users with worries about their own health, people with a disability, and people who are caring for others who have a disability or disease. These users are usually looking for specific topics of their own concern or relevant information on health topics for their family and friends. Further reasons to undertake a search on health-related topics via the internet include questions about the medical care and procedures, and questions about their contact with medical practitioners. It can be seen that portals and special health pages are less popular than an entry in a health-topic related search. Dedicated health webpages are mostly visited by internet users with more experience in web-based searching. The results of the systematic review in this study also determined reasons for and against the use of the internet while searching on health information. As reasons for the use of the internet, the study identifies the unattainability and non-responsiveness of doctors, as well as the simplicity of the access to information via the internet and the possibility to search anonymously. Another positive example considered is the large amount of online information and the speed and the extent to which the information is available. As reasons against the use of the internet, the study identifies that other sources of information are available or that people without access to the internet do not have the possibility to search online for health information. Further reasons include that the internet is impersonal, and that people get confused by the amount and variety of information. Another important reason against the use of the internet or online media is the lack of skill in dealing with this medium, which leads to uncertainty in its utilisation. A further reason against the use of online information is that users have mistrust in health information from the internet (Zschorlich et al., 2015).

A study by the Health On the Net Foundation (HON), which was conducted in 2010, evaluated the use of the internet for health information. The study collected 524 responses from 60 countries around the world, of which the major respondents were from France, the UK, and the USA. The study states that 58% of the overall participants come from Europe. The target audiences were individuals or, more precisely, citizens/patients, who made up the majority of respondents, and medical professionals. 60% of the respondents reported reading newsletters as well as online communities and 51% reported participating actively in online communities such as blogs, forums, and social networks. About 44% of the participants reported using online communities to search for and retrieve health information more than three times a week. The starting point for a web-based search for 79% of the citizens was reported to be the need for clarifying medical information. 94% of the participants report using general search engines to search for health topics and are mostly, at over 60%, looking for diseases descriptions and medical literature. Only 28% were searching for clinical trials, 24% were searching for patient communities, and 22% for topics on alternative medicine. The participants also responded that the access to reliable medical information is perceived as important. Most citizens reported preferring to have the option of seeking complex medical information on websites and 57% of those respondents consider the information presented on consumer web sites to be often superficial. An interesting finding of this study is that 65% of the individual-participants believe they understand complex medical information. At this point it is important to state that 29% of the citizens/patients admitted to be anxious after looking for health information online, 22% were not sure if they were anxious, and 49% were not anxious after looking for health information (cf. Health On the Net Foundation, 2010).

In relation to the subject of this thesis, it is of interest to present a study by Ziebland et al. conducted in 2004. The aim of this study was to research how cancer patients are affected by the internet in experiencing their disease. The results of this study show that the either direct or indirect use of the internet was widespread and was also reported by patients at all stages of cancer care. The results state, that patients used the internet to find second opinions, seek support and experiential information from other patients, interpret symptoms, seek information about tests and treatments, help interpret consultations, identify questions for doctors, make anonymous private inquiries, and raise awareness of the cancer. Furthermore, the study stated that patients use the internet to reconsider and review their doctors' advice covertly and also to develop an expertise in their cancer which reflects their familiarity with computer technology and medical terms. One interesting finding of the study is that women with breast cancer were among the highest personal users of the internet as a search tool. The reason for this is considered to be the large amount of information and support resources for this disease which are available on the internet. The study concludes that cancer patients used the internet for a wide range of information and needed support which were unlikely to be found through conventional health care. Furthermore, the researchers conclude, that a serious illness often undermines people's self-image as a competent member of society. Therefore, it may be possible that cancer patients use the internet to acquire expertise on the topic of cancer to be able to display competence in the face of this serious illness (cf. Ziebland et al., 2004).

Another study by Rozmovits and Ziebland evaluated the needs and prospects of breast cancer patients and patients with prostate cancer on websites with health-related content. In a focus group discussion, the participants responded that their need for information can be described as complex. Furthermore, their need for information changed over time as the given information was often patchy, inconsistent, and contradictory as well as seemingly haphazard. Regarding the use of forums to exchange information of patients, the participants responded that the access to practical and experiential information from other patients is highly valued. Additionally, a clear preference for non-commercial sites for health information, as well as university websites and sites of well-known medical centres was reported by patients who have experience in using the internet. It is highly important to point out that the respondents stated that they were aware of the possible hazards of taking health information from the internet and therefore often compare information from several sources before considering them as trustworthy (cf. Rozmovits, Ziebland, 2004)

3.4 Influence of Media on the Perception of Health and Disease

Health related topics and their presentation have an influence on users. Which information online users, as well as users of other media channels, find and receive influences the perception of health and disease either positively or negatively. In this chapter, I am going to describe these effects and give a short insight into the change of the presentation of breast cancer in the media over the last few years.

For the introduction to this chapter, it is first important to outline the difference between health-relevant and health-related media content. Health-relevant media content is content that affects health-related attitudes, opinions and behaviour, and thus, the health condition of the user. Health-related media content is content which relates to the topic of health itself. The relevance for users is unessential. Explicit health-related media content refers to topics of health policy, diseases, health promotion, and prevention or treatment options. Health-related media content which is implicit needs to be interpreted by the recipient. Furthermore, health-related media content can have a direct impact, e.g. practise of safer sex after seeing HIV/AIDS campaigns in the media, or an indirect impact, e.g. change health behaviour after seeing a talk show on the topic of vaccination and discussing about it with friends and family members (cf. Fromm et al., 2011).

Mass- and online media are, on one hand, appropriate media channels to inform and elucidate on health issues. On the other hand, however, they also carry the risk that health related issues could become distorted and thus the recipient is at risk of a distorted perception. This distortion especially risks having a negative and hazardous impact on the representation of health, especially as the internet provides a seemingly limitless wealth of information which are difficult to be differentiated in quality (cf. Rossmann, 2016). A significant risk can be seen in the over-emphasis and under-emphasis of relevant health topics. This means, more precisely, that topics and diseases which are statistically more relevant are underrepresented in favour of the more mass media-suitable topics. In various media, more severe diseases will be presented in a way that attracts significantly more attention in the society. It is also apparent that certain diseases in the media are still taboo. Furthermore, the stereotyping of people with certain diseases is a major factor (cf. Kline, 2006) which plays an important role in the perception of health and illness in the media. In addition to the already mentioned problems in the representation of health and disease in the media, other problematic patterns of representation can also be observed. A form of stereotyping, the so-called victim blaming is one of these problematic representations. The diseased person is attributed with the responsibility for the disease, e.g. taking birth control, a pregnancy in higher age, or the intake of hormones during menopause as the causes of breast cancer in women. Social or political aspects are rarely mentioned in connection with the disease. Further, contradictory media statements lead to presentations of health and disease in the media which are in part paradoxical and lead to distortions in the perception of health and disease (cf. Fromm et al., 2011). Medicalization can be considered another problem in the representation of health and disease in the media. Medicalization refers to certain physical states in different stages of the human lifespan, e.g. normal pregnancy discomfort or menopausal symptoms or sleep disturbances, being presented as a problem in the media. The media suggests that the recipient’s only help for this seemingly medical problem is medication and leads to a distortion in health perception (cf. Fromm et al., 2011, cf. Kline, 2006).

The partially distorted representation of health and illness in the media can lead to a distorted perception of the media message about health topics and also lead to a distorted perception about the importance of this message (cf. Stehr, Rossmann, 2018). This assumption follows the so-called agenda-setting theory which states that topics which are often presented in the media are regarded as more important by the public than under-represented topics. Therefore, topics for the public and other interest groups are prioritized and allocated by the media beforehand (cf. Dearing, Rogers, 1996). The information provided through the representation of health and illness in the media leads to an increase of knowledge but cannot be received and understood equally by all the recipients of the information. In addition, more entertaining formats are used in the media to inform and educate the public about health and disease, as well as about behaviour which is conducive or harmful to health (cf. Stehr, Rossmann, 2018). An example of this can be seen in soap operas where characters eat healthy, are athletic, and do not smoke. This suggests implicitly health-responsible behaviour to the recipients (Fromm et al., 2011). The assumed over- or under-representation of certain diseases in the media can also project an incorrect association of the health risks to the receiver. Furthermore, exchanges among patients, e.g. in forums, have an influence on opinions, attitudes, and perception of health. The experienced peer support can lead to empowerment, which helps ensure that risks are adequately perceived and that patients gain from information which arises from the exchange of experiences. However, the exchange in online groups can also lead to health risks due to distorted perception as a result of under- or overestimation (cf. Stehr, Rossmann, 2018).

In line with the subject of this thesis, it is important to point out that the foundation of German Cancer Help has clearly contributed removing the sense of taboo towards cancer from society (cf. Fromm et al., 2011). While the removal of taboos is an essential factor in the development of awareness on breast cancer in the media, studies show that the topic of breast cancer in today's media is increasingly over-represented. The reason for this is that from a journalistic perspective, breast cancer is now considered as media-friendly. The consideration of being media-friendly can be examined through seven key factors, namely breast cancer prevalence, the sexual and social meanings attached to breasts as a body part, the lack of stigma which can be seen as relative, the impact of breast cancer on younger women, the strong involvement of women who are diagnosed with or have healed from breast cancer, the association with celebrities, and media organisations' desires to reach female audiences as target groups. Public interest in dramatic fates which can be caused by a breast cancer disease also strengthens the presence of breast cancer in the media (cf. Kitzinger, 2002). Summarized, it can be said that breast cancer is a highly represented topic in the media, but which content is relevant and gives proper information to patients should be considered.

3.5 Benefits and Harms of Online Health Communication for Patients

As presented in the following chapters, health communication is an influencing aspect of the perception of health and diseases, and especially on severe diseases such as breast cancer. The over- or under-representation of health topics in the media as well as falsely or inadequately presented information can lead to distorted perceptions and to confusion for recipients of health information. This can both positively and negatively impact the recipients’ treatments, which in turn influences their quality of life. In this chapter, the benefits and harms of online health communication for patients will be described more clearly.

The Internet provides easy access to information on various health and disease topics, drugs, and research findings and offers a variety of information sources for users (cf. Levy, Strombeck, 2002). This wealth of online information creates the convenience for non-experts to conduct their own diagnosis and healthcare assessments, however these are based on limited knowledge of signs, symptoms, and disorders (cf. White, Horvitz, 2009). This self-interpretation of symptoms is increasingly prevalent activity among patients and increases the risk of symptoms being misinterpreted (cf. Luger, Houston & Suls, 2014), thus leading to uncertainty, confusion and anxiety. Another contributing factor to the confusion and anxiety of users of online health information can be seen in the almost unlimited access to information on the internet. The search for adequate and relevant information is often time-consuming and if there are seemingly no relevant or helpful information in a flood of possible sources, the user is more likely to be overwhelmed and confused (cf. Eysenbach, Jadad, 2001).

Because of the increased knowledge on health-related topics and concrete information on diseases, the role of the interaction between patients and health professionals is changing. Patients now have the possibility to participate in a growing number of disease-specific online communities that provide support, advice, and the opportunity to share experiences (cf. Levy, Strombeck, 2002). The easily accessible information of laity in health care, e.g. in blogs or forums, can lead to false information (cf. Fromm, Baumann & Lampert, 2011) and therefore to a higher risk of the patient not being as compliant and open to necessary treatment.

But the use of e-health portals to search for disease relevant information and to exchange experiences with other patients on their coping with a disease gives patients the opportunity to be more self-responsible and to be in a more compliant physician-patient relationship. These characteristics can be seen especially often with serious and chronic diseases, e.g. cancer, HIV/AIDS, or mental disorders such as eating disorders or depression. It can be concluded, that patients with severe or chronic diseases may find support by accessing web pages and by using internet communication platforms, e.g. message boards, chat rooms, and online forums or social media. These online communities can provide encouragement for the beginning of a therapy or treatment (cf. Leiberich et al., 2004).

As stated before, online health communication and information have led to a change in the role of patients. They are no longer passive consumers of health information and are now actively involved in taking a role in the delivery of health services in an online environment. As discussed, inaccurate or misleading information in blogs, forums, and on websites can be detrimental for patients. They can also influence the patients’ confidence in physicians and their mutual relationship, which can influence the treatment negatively (cf. De Martino et al., 2017). Further, the asymmetry of information is intensifying and becoming more problematic due to online health information searches. Health information should be applied and be understood on a case-to-case basis and cannot be applied in the same way for everyone, unlike general information on products which customers purchase (cf. Xiao et al., 2014) or rules which can be stated e.g. for a society.

This shifting role from the relatively uninformed patient to a competent patient influences health professionals as well. Three ways the health practitioner responds to this more informed patient by can be defined. He or she can feel threatened and be defensive in his or her response to the informed patient by asserting an expert opinion. This reaction indicates a health professional-centred relationship. The second possible response is that both the informed patient and the health professional collaborate in obtaining and analysing the information. This relationship is referred to as a patient-centred relationship. The third possibility is that the health professional helps the patient to get more adequate health information and will guide his or her patients towards reliable health information websites (cf. McMullan, 2006). This shows that online information on health topics and the shifting of the role to an informed and actively participating patient, as well as e-health usage, could also have a positive influence on compliance to treatment, an earlier start of expert-guided therapy, and basic- and aftercare which are independent of place and time (cf. Leiberich et al., 2004).

4. Quality of Health Communication

The following section of this thesis introduces the topic of quality of health information by giving a definition on information quality. In order to link the previous chapters with the objective of the analysis of the thesis, the relevance of evidence-based content for the quality of health information is then presented. The section ends with the presentation of relevant institutions and research programmes for the management of information quality in public health to outline existing concepts for health communication quality.

4.1 Definition of Information Quality

The quality of information can be defined as a measure of the fulfilment of the totality of the requirements which users have on information in general or a product which consists of information. Overall, the information should fulfil the need of the users (cf. Nohr, 2001).

To define information quality further, there are fifteen dimensions of requirements which influence the information quality and therefore frame the definition. The first dimension is accessibility. Accessibility can be characterized as the most direct way, mostly with simple procedures, to obtain the searched information. The second dimension is the appropriate amount of data. An appropriate amount of data exists if the information is given to an extent which is reasonable and satisfies the requirements of the user. The third dimension is believability, which is present when information is credible, certificates show a high standard of quality, or the gathering and dissemination of information was operated with discernibly high effort. The fourth dimension is that of completeness. Information of good quality is complete and available at specified points in time for every step in a process. The fifth dimension is the clarity of information, which can be characterized as a suitable and easily understandable format for users. The sixth dimension is the consistent representation of information. This means that information should be presented in a uniform way and continuously appear in the same way. The seventh dimension is the ease of manipulation. This dimension describes the ease of editing information and use of information for different purposes. The eighth given dimension is important; that the information is free of errors. Information can be considered error free when it matches reality. The ninth dimension is the interpretability of information. This dimension is present if information is unambiguously interpretable. It can be considered as such when it is interpreted in the same manner across users. The tenth dimension describes the objectivity of information. Information can be considered objective if it is strictly factual and free from opinion. Another important dimension of information is relevance, the eleventh dimension. This dimension states that information is relevant if the users are provided with necessary content. The twelfth dimension describes the reputation of information. Specifically, information can be considered of high standard if the information source, the transport medium, and the processing system have a high level of trustworthiness and competence. Timelessness is the thirteenth dimension of information quality. This dimension states, that information is up to date when it reflects the real and actual characteristics of the described object contemporarily. The fourteenth dimension is the understandability of information. According to this dimension, information can be considered understandable if users understand it immediately and are able to apply it for their desired purpose. The last dimension describes value-added information. That is to say, information can be considered to be of good value if its use increases quantifiable value; as for example a monetary objective function (cf. Wang &Strong, 1995; Rohweder et al., 2015). Nevertheless, information can also add qualitative value if it increases the knowledge and helps towards goals of the user.

4.2 Relevance of Evidence-based Content for Quality of Health Communication

Evidence-based information is a precondition for informed decision-making of patients and participation in health (cf. Hirschberg et al, 2013). As the further presented study on the use of the internet for health information by the Health On the Net Foundation (HON) evaluated, the most important barrier while using the internet to seek health information is considered by 80% of the participating users to be the information quality. Further, between 93% and 96% of the participants responded that the ease of finding information e.g. with a helpful, easy navigation, the online availability of information, its accuracy as well as trustworthiness and credibility are important factors when using online search for health information. About 83% of the participating users stated that they verify whether the website on which they are searching for online health information is trustworthy or not (cf. Health On the Net Foundation, 2010).

Health communication should empower patients to make informed choices for their treatment and therefore for their health (cf. Brown et al., 2006). As discussed in a later chapter of this thesis, patients who are seeking for information about their illness as well as treatments mostly prefer non-commercial websites which are published by institutions with established reputations (cf. Rozmovits, Zibland, 2004). It can therefore be assumed, that users of health-related websites are seeking for more evidence-based content in order to ensure their desired informational value is met. A study by Hirschberg et al. in 2013 showed that many participants who were test reading and therefore exploring informational content were not used to understanding evidence-based health information (cf. Hirschberg et al, 2013).

Overall it can be concluded that health information and health communication should therefore be reliable, understandable and trustworthy to be considered of high quality, but there may be a need for further information as well as education on the importance and understanding of this content. Evidence-based content ensures that the given information is scientifically researched and that the treatments the website gives information on are tested and that their efficacy is scientifically approved with qualitative or quantitative studies or clinical trials.

4.3 Institutions and Research Programmes for Information Quality Management in Public Health

In these chapters, four important institutions and research programmes are presented which are engaged in the topic of maintaining and improving information quality for users, especially patients, and who manage the development of better information quality in public health.

4.3.1 IQWiG

The IQWiG is the Institute for Quality and Efficiency in Health Care in Germany, which was founded in 2004. According to the institute, quality and efficiency are two crucial factors for good and efficient health care. The IQWiG is an independent scientific institute which is funded by the statutory health insurance and has the main task of examining the advantages and disadvantages of various medical services. The institute evaluates the benefits of pharmaceuticals, medical devices, surgical procedures, methods of diagnostics, and elaborates assessments for treatment guidelines for physicians as well as on for early detection of diseases and disease management programs. With their publications, the experts of the IQWiG issue statements which might be diagnostically and therapeutically useful and which can even be harmful. Furthermore, the institute offers information on advantages and disadvantages of examinations and treatments in the form of scientific reports and generally understandable health information for patients. The IQWiG is directly instructed by the Joint Federal Committee, the Gemeinsamer Bundesausschuss (G-BA), which is the highest decision-making body of the self-administration in health care, and by the Federal Ministry of Health, the Bundesministerium für Gesundheit (BMG). The G-BA includes representatives of doctors, dentists, hospitals, and health insurance companies and decides on the institute's studies about medical measures and what compensation they receive through the statutory health insurance funds. The IQWiG also, however, responds independently to open questions around health care issues. Since 2016, private people can also check proposals of medical examinations or treatment methods on the IQWiG website for their scientific evaluation. It is important to realise that the institute does not carry out any clinical studies, but systematically searches the literature for evidence-based studies from which particularly reliable results are drawn. In addition to this, the IQWiG also provides health information for all citizens which are easy to understand on the website gesundheitsinformation.de (Institut für Wirtschaftlichkeit und Qualität im Gesundheitswesen, 2016).

Since the release of the website Gesundheitsinformation.de in 2006, the institute has been fulfilling a part of its statutory mandate to educate the public in health-related issues. The website was designed and published as a guide and help for citizens to understand pros and cons of treatments and clarify treatment options, which should be helpful in the conversation with doctors and other health professionals. The Institute for Quality and Efficiency in Health Care has also published an English sister site which is called www.informedhealth.org (Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen, 2018).

4.3.2 Health On the Net Foundation (HON)

The Health on the Net Foundation was founded in 1995 and is a non-profit, non-governmental organization which is accredited by the Economic and Social Council of the United Nations and promotes and guides the deployment of useful and reliable online health information. Furthermore, they promote the appropriate and efficient use of online health information. The focus of the HON is to provide health information to citizens that respects ethical standards.

The foundation offers several services. The first service is the HON code certification, which is a certificate which aims to improve the quality of online health information. Because of the unprecedented volume of online healthcare information available, the HON code is a service which offers a multi-stakeholder consensus on standards to protect citizens from misleading health information. The second service is the HON search, which gives users the opportunity to search only reliable and trustworthy medical websites. The third service of the Health on the Net Foundation is the HON tools service. This service should help users to enhance and improve their online experience. The fourth service is called HON topics, which provides a varied list of reliable medical and health topics for users with which they can assess health information on the internet (cf. Health on the Net Foundation[1], 2017).

The most important service on the topic of quality of online information on health-related topics is the HON code. Because the Health on the Net Foundation was founded to encourage the dissemination of quality health information for patients as well as for professionals and the general public, this certificate is of high importance. The HON code certification follows ethical standards for offering quality health information. With this service, a health-related website is able to demonstrate their intent to publish transparent information. The more transparent the website is and the more the information is useful, objective and correct, the more trustworthy can the website is considered. At this point it has to be stated that the foundation cannot guarantee the accuracy of medical information presented by a website and its completeness at any given time. However, if a website possesses the HON code seal, it can demonstrate its intention to contribute to quality medical information through content which is objective and transparent. The HON code is described as the oldest and the most frequently used code for certification of medical information and health related information which is considered to be ethical and trustworthy. The process of receiving the HON code seal as a certificate actively involves the site owner and requires regular monitoring to take place after being certified. After the first year of the certification, the website has to be re-assessed and recertified. The certification process follows eight principles: authority; naming the authors qualifications, complementarity; giving supportive information, confidentiality; preserving the users privacy, attribution; citing the sources and dates of the given information, justifiability; stating objective claims, transparency; supporting access to the website and providing valid contact details, and financial disclosure; stating details of the funding and distinguishing advertising from other content.

The Health on the Net Foundation has elaborated the certificate and the code behind it to help standardise the reliability of medical and health information which are available on the internet (cf. Health on the Net Foundation[2], 2017).

4.3.3 The DISCERN Project

The DISCERN project was funded from 1996 to 1997 by the British Library and the NHS Executive Anglia and Oxford Research and Development Programme. It was kept running jointly by the University of Oxford Division of Public Health and Primary Health Care, the Help for Health Trust, and Buckinghamshire Health Authority. The project was initiated with the aim to develop an instrument which enables consumers and information providers to judge the quality of written consumer health information on treatment choices. Besides this aim, DISCERN was also developed with the intention of providing quality guidelines to authors who provide health information on the internet (cf. DISCERN[1], n.d.).

As mentioned, DISCERN was initially developed for use in printed patient information, but the instrument is also a useful tool for the evaluation of patient information on the internet. In the German version of the DISCERN tool, there were a few changes made by the German DISCERN-Team of the Hannover

Medical School, Institute for epidemiology, social medicine and health system research with focus on patients and consumers (cf. DISCERN[2], 2009).

On the internet, as well in print form, a lot of information for patients about treatment alternatives can be found. The problem is that not all of this information is of good quality and only a small percentage of information is based on high quality scientific evidence. This leads to confusion for patients, because some sources of information which contain inaccurate or confusing recommendations and patients have difficulties deciding which information is useful. The DISCERN tool can be used as a help for individual patients who want to make a decision about treatment or want to get further information about their treatment. Patients, their family members, their friends, and their carers can use DISCERN to assess the quality of written information. This enables the information to be more easily discussed with medical professionals and gives patients the opportunity to be more involved in the decision-making process about their treatment. The DISCERN instrument is a tool for the quality review of information for health providers of patients which also provides a checklist for authors and producers of patient information. The tool can also be used as a training instrument for medical professionals to improve their skills in the areas of communication and shared decision-making (cf. DISCERN[3], 2009).

The DISCERN instrument was designed through a comprehensive development and evaluation process. The first step of this process was the analysis of a random selection of patient information on treatment alternatives for three different well-researched diseases, namely myocardial infarction, endometriosis, and chronic fatigue syndrome, by a panel of experts of the research group. In the second step, the researchers tested a preliminary instrument based on their analysis on randomly selected new information on the topic of the same diseases mentioned above. The instrument then compared the ratings of different evaluators. The final test of the DISCERN instrument was conducted with a nationwide sample of 13 members of self-help groups and 15 information providers on a random sample of leaflets from 19 major national self-help organizations. The researchers conducted the matching of ratings, as well as an additional questionnaire given to the patients which asked about the patient’s opinion on the reliability and applicability of the instrument. The result of the development process is a general guideline which helps patients to assess the content of patient information about treatment alternatives which can be applied and understood by users from different backgrounds. The DISCERN instrument is the first standardised catalogue of criteria for the quality of patient information. While the DISCERN instrument cannot be used to assess the scientific quality or the correctness of the used literature for a publication, it can be very useful for patients to assess the reliability of a publication as a source of information for decision-making purposes. The DISCERN instrument can be used to assess whether the sources of evidence are clear and the origin of the information on treatment alternatives is clear (cf. ibid.). The DISCERN instrument outlines fifteen criteria which a good quality publication on treatment alternatives should meet. The first and second criteria state that the information should have clear objectives and that those objectives should be targeted. The third criterion is that information is meaningful for the user. The fourth criterion is that the sources of information are clearly given and in the fifth criterion, the date of the creation of the information should be clearly stated. The sixth criterion states that the information should be balanced and unbiased. Further, with the seventh criterion, the given information should list additional sources of information. The eighth criterion states that information should refer to areas of uncertainty. The next five criteria determine the quality of information on the content on the treatment topic: information should describe how treatment works, describe the benefits of treatment as well as the risks, describe what could happen without treatment, and describe the effects of treatment choices on overall quality of life of the patients. The fourteenth criterion states that the information makes it clear to the patient that there may be more than one possible treatment choice. The final criterion states that the information should provide support for shared decision-making (cf. DISCERN[4], 2009).

4.3.4 Action Forum on Health Information Systems (afgis)

The Action Forum on Health Information Systems is a registered association which was initiated by the Federal Ministry of Health in 1999 for a quality-assured and demand-oriented information supply for patients and consumers. In addition to this, the association considers itself as a network for quality and qualification in which the quality assurance of health information is seen as a dynamic process which has to be systematically organized in interaction with users. The declaration of the afgis states that a comprehensive, high-quality and user-oriented range of health information is important as a foundation for users and patients to be able to behave independently as well as responsibly in terms of health and disease. In the development of the afgis, the registered association identified the creation and conceptual development of a continuous and structurally integrated quality assurance process for health information as a task of the highest priority in their work. The primary task of the afgis is to develop, test, and implement strategies, measures, criteria, procedures, methods, and tools for quality assurance and quality management in regard of the health-related information in the new media. Throughout the years following its initiation, the Action Forum on Health Information Systems organized itself into a cooperation network to devote itself to the development of quality standards. For the association, the transparency criteria were significant results of their work. They developed a basis for a quality testing process with a database model and further emphasised their focus on the quality assurance of online information through awarding websites of good quality with their trust mark, the afgis quality logo. The association's database stores provider-independent background information resulting from the quality testing of online resources which is available to online users and patients and the certification with their trust-mark has become standard. The afgis quality logo is awarded for one year at a time and marks websites as containing high-quality health information. Besides the awarding this logo, the association develops further standards which are highly important for online information in terms of comprehensibility, usability, and accessibility (cf. Action Forum on Health Information Systems, 2012).

5. Analysis of Online Content and Quality on the Topic of Women's Breast Cancer

This chapter of the thesis includes the analysis of the online content on women's breast cancer and its quality. The research question underlying this analysis is: Which content on the topic of women's breast cancer can be found via online research and how valid and reliable is the found content in terms of its quality for recipients/users?

To systematically investigate this research question, two hypotheses can be put forward to be confirmed or refuted in the analysis:

H0 = Online research on the topic of women's breast cancer does not provide high quality information with valid, reliable content

H1 = Online research on the topic of women's breast cancer provides high quality information with valid, reliable content

To conduct the first step of the analysis, a free keyword research tool from the dashboard of the website keywordfinder.com was used to find out the online search volume of keywords which are related to the topic of women's breast cancer, search terms which are suggested with the main searched key word, as well as autocomplete search terms and questions which are related to the main search word. The second step of this analysis was the use of the keyword search tool to identify the top five keyword related websites which are mostly targeted by users, according to the search volume of the selected topic related keyword. The third step of the analysis was the quality analysing process of the content of the top five targeted websites. Because Google is the most used search engine (cf. Statista, 2018), the analysis was conducted with the tool keywordfinder.com which uses Google data. Additionally, only topic related keywords in Germany and used German search terms were included. The results of the average search volume on keywords, suggestions, and questions were generated for a time span of 12 months, from February 2017 up to January 2018.

5.1 Online Search Volume of Topic Related Keywords

In the first step of the analysis, I used the keyword research tool to find out the average search volume of topic related keywords. From that, I collected a list of possible search terms. As stated beforehand, only German search terms which are related to my research topic were included and the location was selected as Germany for the search. Through the research for synonyms and cognate terms (SemaGer, 2018), five search terms were selected for analysis: “Brustkrebs”, “Mammakarzinom”, “Brustkrebs Symptome”, “Brustkrebsbehandlung”, and “Brustkrebsinformationen”. Because online search engines are searching for exact search terms on websites on the internet (cf. Oehlrich, Stroh, 2001), I decided to use foremost cohered words as well as easy and exact search terms. As previously stated, the results of the search volume are average rates generated for a time span of the 12 months from February 2017 to January 2018.

5.1.1 Analysis of chosen Search Terms

The first step of this part of the analysis showed that the search term “Brustkrebs” had an average monthly search volume of 27,100. The search term “Mammakarzinom” had an average monthly search volume of 5,400. The search term “Brustkrebs Symptome“ had an average monthly search volume of 5,400. Here it is interesting to point out that in comparison, the search term “Symptome Brustkrebs” has only 1,900 searches as an average monthly search volume. The fourth search term “Brustkrebsbehandlung” had only about 720 searches as an average monthly search volume and the fifth search term “Brustkrebsinformationen” had such a low search rate, that no average monthly search results were reported. The trend of the average monthly search volume of the search term “Brustkrebs” shows, that the term is highly searched with the search engine Google and that the average search volume over the year shows relative stability (cf. Keywordfinder.com[1], 2018).

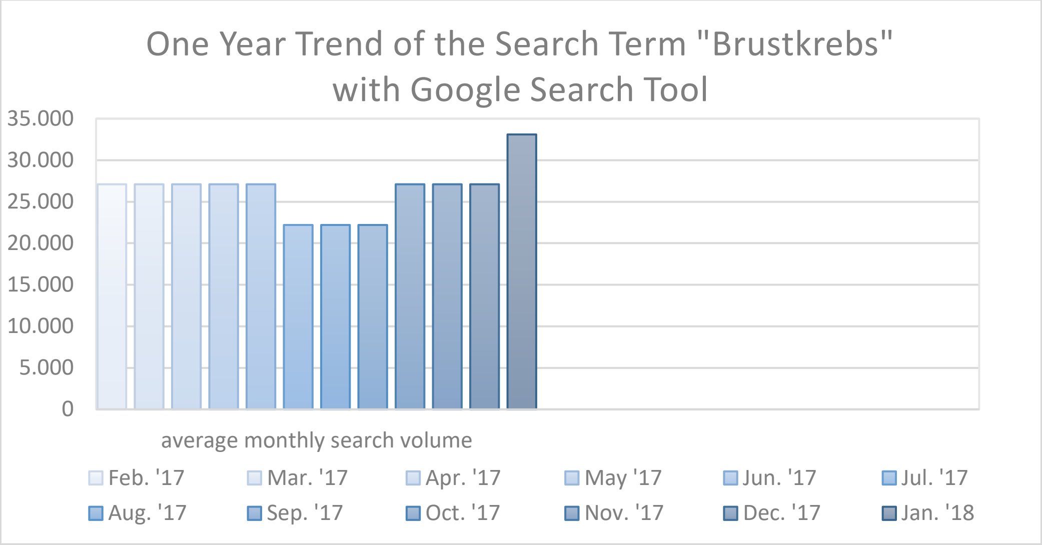

Figure 3: One Year Trend of the Search Term "Brustkrebs" with Google Search Tool, own figure, modified from Keywordfinder.com (2018)

This part of my analysis suggests that “Brustkrebs” as a search term, is the most relevant term for the continuing the analysis. Therefore, the search engine Google was then searched more actively to create a more precise overview on the chosen search terms. The keyword “Brustkrebs” provides approximately 1,260,000 result pages in the search with the search engine Google. Interestingly, about 3,360,000 result pages were estimated as a result if one sets a space character behind the search term. In comparison, a Google search for the term “Mammakarzinom” generates about 388,000 search result pages, the search term “Brustkrebs Symptome” generates about 635,000 search result pages, the term “Brustkrebsbehandlung” generates about 140,000 search result pages, while the term “Brustkrebs Behandlung” leads to about 961,000 search result pages. The last chosen search term, “Brustkrebsinformationen”, generated about 5,080 search result pages in the Google search, while the adjusted term “Brustkrebs Informationen” produced about 233,000 search result pages (cf. ibid.).

5.1.2 Analysis of Autocomplete for chosen Search Terms

In the second step of this part of the analysis, autocomplete suggestions for my chosen search terms were considered in order to get a more detailed overview of search behaviour and therefore of the possible results and more likely search terms. The autocomplete tool by Google is automatically generated by an algorithm. The algorithm works with different factors such as how often users searched for a term in the past. The autocomplete tool is designed to capture the diversity of the available online information and users may receive completions to a variety of popular topics, as well as topics of their own search history (cf. Google, 2018). The analysis of autocomplete suggestions for the chosen search terms with the keyword tool shows, that the search term "Brustkrebs", which is most relevant for further analysis, leads mostly to the autocomplete terms "Brustkrebs Anzeichen", "Brustkrebs Forum", "Brustkrebs erkennen" and "Brustkrebs Mann", followed by "Brustkrebs Metastasen" and "Brustkrebsvorsorge". These terms were sorted by their average monthly search volume. According to the search tool, the search term "Brustkrebs Anzeichen" has an average monthly search volume of approximately 4,400 searches, the search term "Brustkrebs Forum" has an average monthly search volume of approximately 1,900 searches, "Brustkrebs erkennen" has an average monthly search volume of approximately 1,300 searches, "Brustkrebs Mann" as a search term has 1,188 searches as an approximate average monthly search volume, and "Brustkrebs Metastasen" and "Brustkrebsvorsorge" both have an average monthly search volume of 880 searches (cf. Keywordfinder.com[2], 2018).

5.1.3 Analysis of Questions for chosen Search Terms

The third step of this part of my analysis is the identification of the most researched search terms regarding to questions which include the chosen search term. For reasons which will be explained further, I chose to analyse the search term "Brustkrebs" in terms of suggested questions with the used keyword research tool. As in the previous analysing steps of the chosen search term, the searched questions were sorted by their average monthly search volume. The analysis of the term "Brustkrebs" in regard to suggested questions yielded the following most searched questions: "Brustkrebsvorsorge ab wann","Brustkrebs was nun", "Brustkrebs wann Chemo", "Brustkrebs was mir geholfen hat", "Brustkrebs was tun", and "Brustkrebs welche Klinik". According to the keywordfinder.com search tool, the suggested question "Brustkrebsvorsorge ab wann" has an average monthly search volume of 89 searches in the 12 months from February 2017 to January 2018, the suggested question “Brustkrebs was nun” had an average monthly search volume of 70 searches, the suggested question “Brustkrebs wann Chemo” had approximately an average monthly search volume of 30 searches and the search questions “Brustkrebs was mir geholfen hat” and “Brustkrebs was tun” both had an average monthly search volume of 20 searches in the 12 month period. The searched question “Brustkrebs welche Klinik” had only about 10 searches as an average monthly search volume (cf. Keywordfinder.com[3], 2018).

5.2 Keyword Related Websites

The next step of the analysing process was the identification and the systematic review of the top five resulting websites for the search term “Brustkrebs”. This step was conducted with the keyword search tool keywordfinder.com, as well as with the search option of the Google search engine to obtain realistic results. The found keyword related websites were relevant for the second main step of the analysis, in which the quality of the content of these resulting websites was analysed. As pointed out beforehand, the focus was on the search term “Brustkrebs” because of its relevance, high search volume, the ease of writing due to lengths and usability for online users/patients, and because this search term is the main keyword in regard of the topic of this thesis.

5.2.1 Identifying the Top Five Resulting Websites

For the identification of the top five resulting websites, firstly the results for the searched keyword “Brustkrebs” were generated with the keywordfinder.com tool. According to this tool (cf. Keywordfinder.com[1], 2018), the first websites and their headlines obtained from the Google search were:

1. Krebsgesellschaft.de - Brustkrebs/Mammakarzinom
2. Krebsgesellschaft.de - Brustkrebs: Basis-Infos für Patientinnen und Angehörige
3. Krebsinformationsdienst.de - Brustkrebs: Informationen für Patientinnen, Angehörige und Interessierte

4. Onmeda.de – Brustkrebs (Mammakarzinom)
5. Wikipedia.de - Brustkrebs
6. Vitanet.de - Brustkrebs (Mammakarzinom): der häufigste Krebs bei Frauen
7. Apotheken-Umschau.de - Brustkrebs
8. Lifeline.de – Themenspecial Brustkrebs
9. Frauenärzte im Netz.de – Was ist Brustkrebs?

As a comparison, the results for the same search term according to autocomplete results and in questions were also checked. Autocomplete to “Brustkrebs Anzeichen” linked to the following websites and their headlines as results (cf. Keywordfinder.com[2], 2018):

1. Krebsinformationsdienst.de - Brustkrebs: Symptome – wann sollte eine Frau zum Arzt gehen?
2. Krebsgesellschaft.de – Brustkrebs Symptome
3. Frauenklinik Charité Berlin.de - Brustkrebs: Symptome, Diagnose, Behandlung
4. Apotheken-Umschau.de – Brustkrebs (Mammakarzinom) Symptome
5. Netdoktor.de – Brustkrebs Symptome
6. Onmeda.de – Brustkrebs (Mammakarzinom)
7. Go Feminin.de - Brustkrebs: 7 Symptome, die auf die Krankheit hindeuten können
8. Bild.de – Symptome früh erkennen – tut Brustkrebs weh?
9. Focus.de - Andere Zeichen als Knoten: Das können Brustkrebs-Symptome sein, von denen Sie vorher keine Ahnung hatten
10. Wunderweib.de - Anzeichen für Brustkrebs: Wenn deine Brüste plötzlich so aussehen, solltest du zum Arzt

For the Question “Brustkrebsvorsorge ab wann” the tool linked the following websites and their headlines as results (cf. Keywordfinder.com[3], 2018):

1. Krebsinformationsdienst.de - Brustkrebs: Früherkennung durch Abtasten und Mammographie
2. Microdosis.de – Brustkrebsfrüherkennung Ab wann ist die Früherkennung sinnvoll?
3. Berlin.de - Brustkrebsvorsorge: Was zahlt die Krankenkasse?

4. Zentrum der Gesundheit.de - Nebenwirkungen von Krebstherapien: Mammographie – Experten raten ab
5. Netdoktor.at - Mammographie
6. Krebsgesellschaft.de – Brustkrebs Früherkennung
7. Netdoktor.de – Brustkrebs: Vorsorge
8. Mammo-Programm.de – Schritt 1: Sie bekommen eine Einladung
9. Krankenkassen.de – Vorsorgeuntersuchungen: Nicht in ausreichendem Maße wahrgenommen
10. Oncology-Guide.com – Brustkrebsvorsorge

To decide which websites to include in further analysis, the results on the term “Brustkrebs” were sorted for overlap with the autocomplete and question results in terms of the content of their landing pages as well as their headlines. Webpages which were high in the order of results were also included. After the sorting process, the final top five websites for the quality analysis were:

1. Krebgesellschaft.de - Brustkrebs: Basis-Infos für Patientinnen und Angehörige
2. Krebsinformationsdienst.de Brustkrebs: Informationen für Patientinnen, Angehörige und Interessierte
3. Onmeda.de - Brustkrebs (Mammakarzinom)
4. Apotheken-Umschau.de - Brustkrebs
5. Wikipedia.de – Brustkrebs

It should be emphasized that the top five websites discovered also show high monthly landing page click rates based on the search term. The landing pages of the topic pages of Krebsgesellschaft.de achieve between 4,000 and 7,000 expected visits per month, the target page Krebsinformationsdienst.de achieves 2,000 expected visits per month, Onmeda.de and Wikipedia.de achieve approx. 1,000 expected visits per month for the search term “Brustkrebs” to the Landing page, and the topic side of Apotheken-Umaschau.de obtains approximately 515 expected visits per month (cf. Keywordfinder.com[1], 2018).

5.2.2 Systematic Review of Top Five Keyword Related Websites

Based on a short systematic review of the selected Top 5 websites, the decision was given a second review again to ensure the relevance of the pages for the quality analysis. First, a closer look was taken at the landing pages which were the target pages linked by Google. It was important to check which topics are mentioned on the landing pages, how clear they appear at first glance, and whether they appear to be rather important for further analysis or not. In a further step, a closer look was taken at the topic content of the landing pages. In order to prepare the quality analysis more precisely, pages were looked at individually to see which provided more basic information and which of the pages provided more precise topic-relevant information. After the short systematic review, it was decided to include the websites identified by the first analysis step in the further analysis as they give a good overview of the commonly found result pages and show in themselves a content-related, thematically-aimed, and overview-related variety which this thesis aims to shed more light on.

5.3 Quality Analysis of Information on Identified Top Five Websites

For the quality analysis of the identified top five websites a checklist was developed which was used on the identified landing pages from the first step of the analysis. The following chapter presents the tool developed for the analysis of the quality of the found websites, the website content, and the given information on the search term “Brustkrebs”. The systematic approach of the developed tool on the identified websites is also described.

5.3.1 Presentation of the Tool for Quality Analysis

To analyse the quality of the website’s content, a reliable tool is needed. As a tool for this analysis, a self-developed checklist was used in line with the DISCERN tool which was presented briefly in the description of the DISCERN project in a previous chapter of this thesis. In this chapter, the checklist and its rating will be described briefly. In addition to the use of the basis of the DISCERN instrument, quality logos were searched for on the websites, either the HON logo or the afgis logo in order to further investigate if the top five websites had passed through quality testing. Both quality logos are included as a criterion in the developed checklist.

As stated before, the DISCERN tool consists of 15 questions which state 15 criteria for a good quality publication about treatment alternatives. Although, the topic of this analysis contains general information for patients on breast cancer and not treatment alternatives, the DISCERN instrument is well evaluated and suitable as a basis for this analysis as well. In line with the DISCERN instrument (cf. DISCERN[4], 2009) and a checklist from the website patienten-information.de (cf. Ärztliches Zentrum für Qualität in der Medizin, 2015), a checklist for the quality of the content of the identified top five websites on the search term “Brustkrebs” was developed. The checklist consists of 14 criteria evaluating the following factors: the clarity of the aim, the author/publisher, the sources of information, the independence of the sources, the respectability of the information, the actuality of information, relevance, relevant medical information, uncertainty of treatments and diagnostic procedures, understandability, usability for shared-decision making as well as the presence of the HON or the afgis certification, and the user-friendliness and the accessibility. Websites were analysed to see if the criteria were fulfilled completely, partially or unfulfilled. The developed checklist can be found in the appendix of this thesis.

5.3.2 Systematic Approach on Keyword Related Top Five Websites

The described checklist was used for the systematic analysis of the quality of the content of the identified top five websites. Each website was systematically compared against the determined criteria on the checklist and given marks as to which criteria were fulfilled completely, partially or were not fulfilled. As described briefly in the previous chapter, the developed checklist consists of 14 criteria. For the first criterion, the clarity of the aim of the website, the website and the given information were analysed as to whether they had stated the aims clearly, who the information is for, and which intention the website has. For the second criterion, the clarity of the author/publisher, the website was checked to see if the author/publisher of the content/information was named and if the website stated her or his qualification. For the third criterion, the sources of information were analysed to see what sources were used, if there were clinical trials, guidelines and other evidence-based literature as references, and if the sources were presented clearly on the websites. The fourth criterion was the clarity of the independence of the sources. For this, the information on the website was analysed for objective or subjective manner and whether there was a variety of other sources of information, besides the given, on this website, as well as if other relevant information on this topic was linked on the website. For the fifth criterion, the clarity of the respectability of the information, the website was analysed for any obvious advertising and additionally if the headlines or the further content of the website could lead to anxiety, discomfort, or uncertainty of the patients. For the sixth criterion, the clarity of the actuality of information was analysed against when the information was published and if the publishing date had a direct reference to the content of the website. The seventh criterion is the clarity of the relevance and usefulness. With this criterion it was analysed whether the website provided information to answer the user's question, as well as if the information could be considered relevant, realistic, and appropriate for the searched term. The eighth criterion is the clarity of the relevant medical information. For this criterion the content was checked for if the diagnostic process, the possible treatment options and the benefits and risks were described regarding side effects, complications or influence on quality of life. For the ninth criterion, the clarity of uncertainty of treatments and diagnostic procedures, the content was analysed to check if the website had given information on treatments or diagnostic procedures which are yet uncertain and not evidence-based standard. The tenth criterion is the clarity of understandability. With this criterion the wording of the publication was analysed to see if it could be considered understandable for a layperson. For the eleventh criterion, the clarity of usability for shared-decision making the information on the websites were assessed as to whether or not they were useable as a basis for conversation/discussion with practitioners, as well as family members and friends. With the twelfth and thirteenth criterion, websites were checked for certification from either the HON logo or the afgis logo. The last criterion, that of user-friendliness and accessibility, was analysed through how many times the link had been clicked to get to detailed content on the website, as well as if the links were easy to find or more hidden in the content.

6. Results

This part of the thesis presents the results of the analysing process. First, the content of the identified websites is summarized and compared with the content of the thematic website of the National Health Service afterwards. The results of the quality analysis will then be presented and the importance of these results for breast cancer patients and their treatment will be addressed.

6.1 Descriptive Summary of Content of found Online Information

In this chapter of the thesis a descriptive summary of the found content of the identified top five websites is given. Firstly, a presentation of the summarized content will be given, followed by a comparison of the content of the top five websites in summary and the content on the search term “breast cancer” on website of the British National Health System, the NHS. The purpose of this insert is to briefly introduce a national website that provides relevant and qualitative information for users and patients. The NHS, the UK's national health care system, provides health information on its website that is easy for insurance policyholders to find and be used by patients. While German insurance companies also provide information about illness and health, there is no single point of contact due to the wide range of health insurance companies in the legal and private sectors.

6.1.1 Content of Top Five Websites According to Descriptive Analysis

The first examined website identified in the analysis is Krebsgesellschaft.de. The landing page essentially provides basic information which can however only be accessed by patients or users through further links on the page. The website provides a short informative text on the incidence and mortality of breast cancer. In addition to this text, you will find links to further, more detailed information on basic information for patients, expert discussion, current interviews and reports, contributions for patients, news on the topic, congress reports, as well as links to tips and brochures. Below the first section there is a link to the landing page of basic information for patients on breast cancer. After this short section there is a field on the landing page where users can register for the Cancer Society newsletter. In the next section on expert discussions, various contributions from discussion rounds by experts of the cancer society are presented. Here, too, users have the opportunity to follow the proposed contributions via links. Numerous links to interviews with medical experts on breast cancer then follow. These links to expert interviews are extended to include expert contributions for patients in yet another following topic section. Subsequently, congress reports are made available in link form for interested users of the website. The site concludes with links on breast cancer which the Cancer Society has compiled for patients, links to brochures on breast cancer for patients, and a link to patient advice from the national cancer societies (cf. Deutsche Krebsgesellschaft e.V.[2], 2018). The page identified in the analysis can be described as an overview page that does not provide the expected information at first glance but provides a good amount of informational input for the user. In order to carry out a more concrete evaluation according to the topic of this thesis, the information page for patients of the German Cancer Society was added to the content and quality analysis.

The linked website of the German Cancer Society on basic information for patients on breast cancer is another overview page but has more patient-specific topics and links. This page is aimed directly at patients and their relatives which can be read in the first section. The landing page, as well as the first overview page resulting from the analysis, provides links in its first section which provide a table of contents and an overview of the topics. The linked topics are: general information and causes of breast cancer, prevention and early detection, diagnosis, classification and course of disease, therapy, aftercare, quality of life, and self-help. In the section General Information and Causes of Breast Cancer, links to the following topic pages are provided for users: breast cancer: definition and frequency, the breast - anatomy and function, risk and cause of breast cancer, and breast cancer in men. Registration to the newsletter is offered to the users between the individual sub-topics. In the next section of the page, the topics of prevention and early detection are presented. Here, too, it can be clearly seen that the Patient Information page is purely an overview page, as links are provided for patients as in the previous sections. The linked topics are: Breast cancer: Early detection, and screening and mammography screening. Between these two topics there is also a sign up field for participation in a study by HAW Hamburg which is concerned with improving the information material for mammography screening. The section on prevention and early detection is followed by the section on diagnosis. This section provides an overview of further links to the main topics of breast cancer symptoms, self-examination of the breast, and diagnostic procedures for breast cancer. Following this section, the topic block on classification and the course of the disease begins. In addition to the link to information on the classification of breast cancer, there are two further links to information on the tumour biology of breast cancer and on the course of the disease. The following section contains a link to information on the treatment methods for breast cancer. The topic section about aftercare contains two links to further topic pages that deal with the question of what happens after breast cancer therapy and a further link to important information on the aftercare of a breast cancer disease. The last, and probably largest, section of the overview page for patients and relatives is the section on quality of life and self-help. In this section, patients are given the opportunity to find out more about sexuality in breast cancer, rehabilitation after breast cancer, life with the disease, the desire of younger patients to have children after breast cancer, and about various self-help groups through various links to other information pages. (cf. Deutsche Krebsgesellschaft e.V.[3], 2018).

The second examined website is that of the German Cancer Information Service. This page appears to have a very clear layout and a user-friendly structure. The headline states that the information on this page is for patients, relatives, and interested parties. The short introductory text explains to users that breast cancer is the most common cancer in women and that the provided linked texts describe the main early detection, diagnosis, and treatment options for breast cancer. Information on risk factors and early detection of breast cancer is also provided. Links and references to further reading are also included for experts. Furthermore, the introductory text informs the users that information helps to deal with the disease and is helpful for shared decision making with their practitioners as well as reducing patients' fear of the disease and its consequences. After a short reference to sources, links, and the last version of the website, the user gets an overview of the linked content, which can also be found on the left side of the overview page. The first linked section is an introduction to breast cancer which provides information on anatomy, frequency of breast cancer, and tumour biology. The second section, which is linked on the overview page, provides the user with information on risk factors for breast cancer. The third section links information on the topics of early detection and breast cancer screening. This section contains information on scanning, ultrasound examination, and mammography procedures. This is followed by the topic block link on symptoms of breast cancer, to which the topic of suspected breast cancer and possible examination procedures for clarifying findings are linked. The sixth section provides information on treatment options for breast cancer, followed by two linked sections on limited tumours and local recurrences. The ninth section provides information on metastases and treatment for advanced breast cancer. In the tenth linked section, the topic of breast cancer and everyday life is addressed and information on living with and after the disease is provided. The next section is a link to information on breast cancer in men, followed by a concluding link to further information for patients, such as addresses, links, and brochures (cf. Deutsches Krebsforschungszentrum, 2018).

The third of the identified websites from the analysis is the website onmeda.de. The target link found in the search on the search engine Google led, as with the other identified web pages, to a search term related target page. On the page for the search term "breast cancer" there is a large topic headline and a very short introductory text below which presents breast cancer as the most common cancer. Below that is a large image showing a silhouette of a woman holding the well-known pink breast cancer ribbon in the front of the image. Below the picture begins the actual, informative content of the website. The user is first presented with a table of contents for an overview of the website’s content. The table of contents contains links for the user to the topics of overview, causes, symptoms, diagnosis, therapy, progression, prevention, and to further information. The table of contents on the onmeda.de topic page gives an indication of the importance of early detection measures followed by a short definition of breast cancer. Below, users will find a picture gallery with 22 pictures through which they can click with brief facts on the subject of breast cancer. The definition and the picture gallery belong to the topic overview. The second section deals with the causes of breast cancer. Users can first read an overview of risk factors which are then discussed and examined in more detail. In this section, patients receive information on the risk factor age and of hormone replacement therapy during menopause which includes a brief note on taking the contraceptive pill and the risk factor of genetic predisposition, especially on tumours and genetic tests. This section is followed by a framed note on cancer screening which contains links to screening and mammography. The third section of this topic page deals with the symptoms of breast cancer. Here, users and patients find information on signs of possible breast cancer, an overview including images showing in which breast areas breast cancer is more common, followed by information on the incidence of breast cancer in general. The fourth topic area of the website provides information on the diagnosis of breast cancer. First, the typical diagnosis is described in this section, followed by information on the classification of the tumour, the ductal carcinoma in situ, the lobular carcinoma in situ, and the inflammatory carcinoma. The fifth topic area contains information on therapy for breast cancer. First, a general introduction to the topic is given and the user gets an overview of factors that determine the course of the therapy. After this overview, a sub-section on surgery begins. Here the user receives information about the breast preserving operation, the so-called radical operation, and the removal of lymph nodes. In the subsequent section of the topic area of breast cancer therapy, the user receives information about follow-up therapy after surgery; namely radiation therapy, chemotherapy, endocrine therapy/antihormone therapy, and antibody therapy. For each of the described therapies the user receives more precise but brief information which describes possible advantages and risks of each course of treatment. Subsequent to the description of therapy options for local breast cancer, the therapy of metastatic breast cancer is described. Following an introduction to the topic and a definition of metastases in breast cancer, users receive information on the administration of bisphosphonates in bone metastases as well as on angiogenesis inhibitors and tyrosine kinase inhibitors that stop or block the growth of cancer cells. The sixth topic area of the website provides information on the topic of the progression of breast cancer. The first subsection presents the users with information on the topic of reconstruction of the breast and a computer animated video which shows the possibilities of reconstruction of the breast. Subsequently, the users receive information on aftercare and rehabilitation following breast cancer treatment. The seventh section of the topic page addresses prevention of breast cancer. Users first receive information about the early detection of breast cancer, followed by another computer-animated video that demonstrates how a self-examination of the breast by palpation can be done. After a short notice regarding the free early recognition examination at the gynaecologist from age of 30, the users receive information about mammography screening for women who are between the age of 50 and 70 years old. Lastly, the users have the opportunity to follow links to further information on the website. In a dropdown list on further information, the users find links to ICD-10 diagnostic keys, reading-recommendations from the website's editorial department, recommendations for links to other informational websites, links to self-help groups and counselling centres for breast cancer patients and their family members, and book recommendations (cf. Gesundheitsportal Onmeda, 2017).

The fourth of the identified websites from the analysis is the website apotheken-umschau.de. The target link from the analysed Google results takes the user to an overview page on breast cancer. After the headline there is a schematic image of the female breast on the website. Below is a table of contents of the page, which is declared as an overview. In this directory, users find links to headings for structure of the breast, causes and risk factors, symptoms, early detection, diagnosis of the disease and prognosis, whether a tumour is still benign or already breast cancer, therapy, special situations, aftercare, and a link to consulting experts and specialist literature. It should be noted here that these links continue and link to more detailed topic pages. The website also has a sidebar with topic related articles on breast cancer. The first section after the table of contents is a text describing breast cancer as a turning point in life. This text provides users with an introduction to the aims of the information on this website. Above the first section and on the right hand side of the website can be seen a pop-up window with advertisement on e.g. clothing. The next section provides users with brief information on the incidence of breast cancer, followed by a positive description of the success of early detection. The subsequent section describes the factors on which the prognosis of breast cancer depends. The fifth section describes the risk factors that can lead to or promote breast cancer. Following this section, users receive information on the symptoms that may indicate breast cancer. This is followed by the section on early detection and diagnosis of breast cancer, which is longer than the previous sections. Here, users receive information on early diagnosis examinations such as mammography screening and on diagnostic procedures such as biopsy. At the end of the text in this section, users are informed that individual diagnostic procedures are described more in the section of early detection, diagnosis, and prognosis. The seventh section of this page informs users about breast cancer therapy according to national treatment guidelines. Here, therapy options such as surgery, chemotherapy, radiation therapy, and anti-hormone therapy are briefly described, and the importance of therapy is pointed out according to scientific guidelines. Following this, users see a schematic image of the structure of the female breast with labels on the tissue which also allows them to zoom in closer. Below the picture is an explanation of this schematic. The last section informs patients and users of the website about breast cancer centres and provides a link to the further page on expert advice and technical literature which provides more detailed information. At the end of the website, links to more information on breast cancer are provided (cf. Apotheken-Umschau, 2017)

The fifth and final website of the selected websites in the analysis is the website Wikipedia.org. As with the four other websites, the target link found in the search through the search engine Google led to a search term related target page. The article on the Wikipedia page begins with an introductory text after the headline, next to which a graphic of the ICD-10 classification of breast cancer can be found on the right. Under the introductory text, users find a table of contents with twelve main points, some of which are divided into subsections. The twelve sections of the article are: epidemiology, causes and risk factors, protective factors, early detection and screening, diagnosis, classification, therapy, history, breast cancer signs in art, literature, web links, and item references. The first section on the epidemiology of breast cancer provides information on the incidence and mortality rates and contains two tables. Furthermore, this section also discusses the topic of breast cancer in men. The second section informs the user about causes and risk factors. It is divided into the subsections genetic risk factors, hormonal factors, left-handedness, the frequency of higher infestation of the left breast, and other risk factors. The third section deals with protective factors. However, only one protective factor against breast cancer is mentioned here, which is classified as low in protection at the end of the section. The fourth section provides information on early detection and mammography screening. This section is divided into the subsections of self-examination, early detection of cancer by doctors, and early detection of breast cancer through blind and imaging procedures. On the right side next to this section, users find pictures of a mammographic screening in which breast cancer had been detected. The fifth section includes information about diagnosis. The first sub-section informs the user about clinical examination, the second focusses on the diagnostic imaging, the third deals with the removal of tissue, and the fourth section addresses gene expression tests. Here, pictures of patients with a retracted papilla of the breast and ultrasound images of tumours or bone metastases are shown to the users on the right-hand side of the website. The sixth section of the web page provides information on the classification of breast cancer tumours. This section first describes histological classifications which are illustrated to the user with two images on the right of the page. The user is then presented with information about the degree of differentiation and the TNM classification and the following information outlines the division of the tumour in stages. Connected to these, the users can receive information about hormone receptors and HER2 status, which are also supported by a table. A further short text and table give users in the information to risk groups, followed by a short section about text to molecular-tumour-classifications. The seventh topic on the website provides users with information on therapy. After an introductory text in which users are briefly informed about breast cancer centres, treatment guidelines, disease management programs, and tumour conferences, the first subsection on neoadjuvant therapy begins. The second subsection deals with operations. In this section, users receive information on breast preserving surgery as opposed to mastectomy, surgical removal of axillary lymph nodes, and non-invasive tumour removal. Here, too, images of operations in which the tumour has been removed and, among other things, images of before and after a breast-conserving operation can be found on the right-hand side of the page. A surgically removed carcinoma is also shown. The third subsection provides information on adjuvant therapy for breast cancer. Here users can find information on chemotherapy, a few brief notes on antibody therapy, radiation, anti-hormonal therapy, pre- and post-menopausal therapy, androgen receptor-dependent tumour types, and more detailed information on antibodies. The following section provides information on the treatment of metastatic breast cancer tumours and information on aftercare for breast cancer. This is followed by the eighth section, which provides information on the history of breast cancer. Here, medical-historical data and facts are provided for the user. The ninth section of the Wikipedia article shows some illustrated examples of breast cancer signs in art. Sections ten, eleven, and twelve show the user literature such as guidelines, guides or textbooks, as well as web links and individual references with which the article was written (cf. Wikipedia, 2018).

All pages have a similar thematic structure but vary in the way in which information is provided and in its user-friendliness. On many of the pages it is necessary to click through to the desired informative content, which could be negative for inexperienced users. It is also noticeable that pages with purely health-related content show fewer images than websites that are not specific to the topic of health. The layouts also show strong variations. The site of the cancer information service is very clearly structured, followed by the site of the German Cancer Society. The Onmeda site is more modern in layout, but places advertisements which may initially give users doubts about its seriousness. It can be assumed that a clear layout and a straightforward structure of the web pages should convey trustworthiness. The Apotheken-Umschau website is strongly reminiscent of its print version and its overview page provides only general information. As on the Onmeda website, a lot of scrolling is necessary to read the content. This is also not optimal for an overview page, as it give an unstructured impression to users. It is also noticeable that websites 3 to 5 have many links in the text, which may confuse users if they do not have an online affinity. Too many links in a text can also be distracting. On the positive side, the links within the text are usually explanations of words.

6.1.2 Comparison of Content: Germany vs. Great Britain

The National Health Service is the public health service of the United Kingdom (cf. National Health Service[1], 2016). In contrast to the wide range of health information provided by the German health system on various websites, users of the NHS can find summarised information on health topics on its website. It should be emphasised that this is a place for the whole UK that bundles information for patients and insured people, while in Germany people ask for information from their health provider, their doctor, or one of the many statutory or private health insurance companies. When looking at the website of the German Federal Ministry of Health in the role of patient, for example, an article on cancer in the glossary of terms can only be found after a lengthy search. On the target page, the Federal Ministry of Health refers to the German cancer aid and links its website (cf. Bundesministerium für Gesundheit, 2018).

On the NHS website in the section Health A-Z various diseases are found in alphabetical order. Patients and users can also access a detailed page on breast cancer. On this page, the headline immediately catches the eye and refers thematically only to the topic of breast cancer in women, which is not initially apparent in the A-Z overview. Below the headline is a table of contents which lists the individual thematic points of the page. These include an overview, symptoms, causes, diagnosis, treatment, living with breast cancer, and prevention. The content of the page can also be found in more detail on the left under the blue overview banner. The first topic of the overview page provides users with more general information on breast cancer, including epidemiological data. The second section deals with the symptoms of breast cancer. Here six main symptoms are briefly listed in bullet points, but there is a link at the end of the section that leads to more detailed information. The third section provides information on the causes of the disease. Although the exact causes of breast cancer cannot be determined, possible influencing factors that can lead to the disease are listed here. This is also done in a short overview which is concluded with a link to more detailed information. The section on breast cancer diagnosis is very short and, as with the previous sections, concludes with a further link. The section following provides users with information on the most common types of breast cancer and some information on types that do not occur too frequently. The fifth section covers the topic of mammography. The users are presented with the advantages and risks a mammography can bring. Here, too, links are provided to more detailed information and users have the option of searching for and finding screening services in their area. The sixth section of the overview page provides information on the treatment of breast cancer. The three most typical treatment steps, chemotherapy, surgery, and radiation, are mentioned and described very briefly and in summary. The user is then linked back to the more a detailed information page. The penultimate topic of the overview page gives a brief overview of the topic of living with breast cancer and is followed by the topic of breast cancer prevention. Both sections close with links to more detailed information pages. At the end of the website in the right-hand corner, the user has the option to click back to the main contents, comparable to a next page in a book, referring to the table of contents at the beginning of the overview page (cf. National Health Service[2], 2016).

In summary, the information on the NHS website is short, concise, and clearly arranged for users and patients. The author of this thesis holds the opinion that this site is very well suited as a first point of contact for information. Users are not made insecure by advertising or inappropriate information and receive important information with just a few clicks. The overview page also provides links to more detailed information. Specifically, the more detailed topic pages offer very well prepared and above all easily understandable collection of information. Some of the content of the identified German websites also demonstrate this, but they are more likely to be found via search engines and may not necessarily be used or regarded by German patients as the first point of contact.

6.2 Quality of found Online Information

The following chapter sums up the results of the quality analysis of the identified five websites. As stated beforehand, the quality analysis was conducted with a self-developed checklist which is in line with the DISCERN instrument and a checklist of the Medical Centre for Quality in Medicine in Germany.

6.2.1 Quality of Top Five Websites according to Analysis

The first website identified in the previous analysis was the page Krebsgesellschaft.de, in particular the overview page on basic information for patients. The first quality criterion from the developed checklist, the clarity of the aim of the website, was fulfilled by this page. In one sentence right at the beginning of the page it is made clear that patients, relatives, and interested parties will find information on diagnosis, therapy, early diagnosis, aftercare, and life after and with the disease on the page. The second quality criterion, the clarity of the author/publisher, was not fulfilled as the landing page is an overview site which only links to further information and more detailed content. On the further linked pages of the website Krebsgesellschaft.de, this criterion was fulfilled. The third criterion, the clarity of the sources of information, was also not fulfilled on the overview page for patients. As with the criterion beforehand, it is fulfilled on the linked detail-pages, where you can clearly find the sources of information and their references. The fourth criterion, the clarity of the independence of the sources, is fully fulfilled on the website. The information is of an objective manner and there is a variety of other relevant information linked. The clarity of the respectability of the sources, which is the fifth criterion, is fully fulfilled. There is no obvious advertisement on the web page and the headlines and the content sound informative and hopeful to users. The sixth criterion, the clarity of the actuality of information, was partially fulfilled. Only the last date of actualisation of the landing page and the last content actualisation could be seen, which indicates that the website is reviewed regularly. But there is no exact publishing date given. The seventh criterion is the clarity of the relevance and the usefulness. This criterion was partially fulfilled on the landing page. The page for basic information for patients gives a good overview, but further clicks on links are required to obtain more detailed information. The linked content is, however, realistic and appropriate and answers questions that patients might have. The eighth criterion, which is the clarity of the relevant medical information, was considered to be partially fulfilled as the diagnostic process, treatment options, as well as benefits and risks are described in detail in the linked content, but not on the overview site itself. The clarity of the uncertainty of treatments and diagnostic procedures, which is the ninth criterion, was also considered partially fulfilled. In further linked content the website gives information on diagnostic procedures and treatments which are yet not evidence-based standard, but it is clearly stated that further discussion with the patient’s treating physician is needed. The tenth criterion is the clarity of understandability which was completely fulfilled by the website. The wording can be considered understandable for a layperson and explanations for specific treatments or wordings are linked. The clarity of usability for shared decision making, which is the eleventh criterion of the checklist, is fulfilled by the linked content and can be considered partially fulfilled by the overview website. The given information is useful for a discussion or conversation with practitioners and family members. The website clearly fulfils the twelfth and thirteenth criteria which are the certification with the HON and afgis logos. The last criterion is that of user-friendliness. This criterion can be considered completely fulfilled, as the overview page for patients provides seven main links at the top of the page which link to the main informational content. While many more links are found in the following content of the website, which can be time consuming for users to follow, the overall structure of the page is very easy to follow and clearly structured.

The website Krebsinformationsdienst.de on the topic of breast cancer identified in the former analysis completely fulfilled the first quality criterion, the clarity of the aim. The landing page of the Google search clearly states the aim as well as who the information is for. Additionally, the landing page gives an overview on topics of interest for patients, relatives, and other interested parties. The second quality criterion, the clarity of the author/publisher, was not fulfilled on the landing page. There was no information on an author or a publisher on the overview website. The clarity of the sources, which is the third criterion, can be considered partially fulfilled. The overview page didn’t mention any sources and the linked content pages only referred to a few sources for the user. The fourth criterion, the clarity of the independence of the sources, was considered as completely fulfilled. The information on the website is of an objective manner and there is a variety of other information on other health relevant topics given. Further to that, the overview page contains a variety of links to more detailed information on the topic breast cancer. The fifth criterion, the clarity of the respectability of the information, was considered completely fulfilled. There was no obvious advertising on the website or in the headlines, and the further content does not lead to anxiety or discomfort. The focus is clearly on the content and the given information and the website appears to have a clear layout which is not distracting to users. The clarity of the actuality of information, the sixth criterion, is not fulfilled on the overview page but completely fulfilled on the linked pages. The publishing date is stated, as well as the last date of content update. The seventh criterion, the clarity of the relevance and usefulness of the information was considered completely fulfilled. The linked content on the page gives information to answer the questions the user might have, and the information is realistic and appropriate for the searched term. The eighth criterion, which is the clarity of the relevant medical information, was also considered completely fulfilled. On the further linked pages, there was information on diagnostics, treatments, and the influence on quality of life edited for the user. The ninth criterion, the clarity of uncertainty of treatments and diagnostic procedures, is not fulfilled on the landing page, which is just an overview page. This criterion was, however, considered completely fulfilled on the detailed pages which are linked on the overview page. The tenth criterion, the clarity of understandability, can be considered completely fulfilled by the website. The used wording is understandable for laypeople and in the further linked information there are explanatory links in the text. The clarity of usability for shared decision-making, which is the eleventh criterion, was considered completely fulfilled. The website Krebsinformationsdienst.de recommends to the users on the landing page that patients should speak with their practitioners regarding health information and that the internet is not a replacement for physician-patient contact. The eleventh and twelfth criteria, requiring the HON and afgis certifications, were not fulfilled by the website. The last criterion, user-friendliness, was considered fulfilled. On the landing page, there are thirteen links to further and more detailed informational content. These links are well described and easy for users to find.

The third website with information on the search term of breast cancer identified in the analysis was the website onmeda.de. This landing page partially fulfils the first quality criterion; the clarity of the aim. The aim is not clearly stated, and it is not stated for which parties the information is presented. However, at the end of the page, contains a disclaimer which states that the website is only of informative matter and that online information is not a replacement for the contact with a health practitioner. The second criterion, the clarity of the publisher/author, was also considered partially fulfilled. While the website names the editorship of onmeda.de as author and publisher of the content, this statement is not exact and does not indicate any qualification. The third criterion, the clarity of the sources, was considered completely fulfilled. In a drop-down bar in the given content of the website under the headline “further information” references and further links to other informational websites and literature can be found. It should, however, be pointed out that this drop-down window could easily be overlooked by the users, as it has to be clicked before it opens. The clarity of the independence of the sources, which is the fourth criterion, can be also considered completely fulfilled. The information is of an objective manner and in the previous described drop-down bar, the users find links to further information online as well as literature recommendations. The fifth criterion, the clarity of the respectability of the information, was considered partially fulfilled. The given content is informative and objectively edited, there are no uncomfortable headlines which could lead to anxiety, but there were obvious advertisements e.g. ALDI, Disneyland, Bepanthene crème, or YOGI tea, in advertising blocks that appear in pop-up windows on the website. The clarity of the actuality of the information, the sixth criterion, was considered completely fulfilled as the publishing date is given directly at the beginning of the website. The seventh criterion, the clarity of the relevance and usefulness, was also considered completely fulfilled. The website gives a good overview on the topic of breast cancer to the user and the page is not merely an overview page, as the previous landing pages of the google search. The user finds a variety of information which is well structured, concise, realistic, and appropriate for the searched term. The eighth criterion, the clarity of the relevant medical information, was considered completely fulfilled, as the diagnostic process, treatment options, benefits, and also side effects are described well and in an informative manner for the users. The clarity of uncertainty of treatments and diagnostic procedures, the ninth quality criterion, was considered unfulfilled as the website only gives information on standard treatments according to treatment guidelines on breast cancer. The tenth criterion, the clarity of understandability, was completely fulfilled. The content is written in easy, understandable wording for laypeople, patients, and other interested parties and links were available throughout the text for further explanation of medical terms. The next criterion, the clarity of usability for shared-decision-making, was considered completely fulfilled, as patients or other users have the opportunity to use the given information as a basis for a conversation with their practitioners or family members. The twelfth and thirteenth criteria, certification with the HON and afgis logos, were both fulfilled. The site is marked with both logos as an indication of good quality information. The last criterion, user-friendliness, was considered completely fulfilled as the side-bar with the table of contents links to each topic section. Although there are more than 40 links in the content, they are all explanatory, easy to find, and do not affect comprehensibility of the text.

The fourth identified and analysed website is the page on the topic breast cancer on Apotheken-Umschau.de. The first quality criterion was considered completely fulfilled on the landing page because the website gives a very clear statement on the aims for the user as well as a well hint and explanation about navigating through links on the chapters listed in the table of contents. The second quality criterion, the clarity of the author/publisher, was not fulfilled as there is no publisher/author or qualification given on the website. The clarity of the sources, which is the third criterion, was considered unfulfilled. There are no sources besides websites named on the landing page. The fourth criterion, the clarity of the independence of the sources, was considered partially fulfilled. The landing page gives objective information, but other sources of information can only be found in links to consulting experts and literature. Few other information sources are linked on the landing page. The clarity of the respectability of the information, the fifth criterion, was considered partially fulfilled. There was few advertising on the page, but the content and headlines were clearly informative and did not lead to anxiety, discomfort, or uncertainty. The sixth criterion, the clarity of the actuality, was partially fulfilled on the website. Only the date of the most recent update is available, no publishing date of the information can be found. The clarity of the relevance and usefulness of the information, the seventh criterion, was considered completely fulfilled by the website. The landing page on the topic of breast cancer gives a very good overview for patients and the information is appropriate for the search term. The eighth criterion, the clarity of the relevant medical information, was considered partially fulfilled. As stated before, the website gives a good overview, but this could be improved with more detailed information, especially on the medical content. The ninth criterion, which is the clarity of uncertainty of treatment and diagnostic procedures, is not fulfilled by the overview website, but is illustrated in the linked content. The clarity of understandability was clearly fulfilled. The wording was understandable for a layperson and medical terms are linked to explanatory content. The clarity of usability for shared-decision making, the eleventh criterion, was fulfilled. Users have the possibility to use the found information, especially on the linked detailed pages, as a basis for a conversation with their practitioners and other parties such as family members. The twelfth and thirteenth criteria were not fulfilled. The website was not certified with either the HON logo or the afgis logo. The website fulfils the last criterion, user-friendliness. There were over 30 explanatory and forwarding links on the website and the content can be considered as very detailed for an overview web page, which is both positive for patients and user friendly.

The fifth identified website in the previous analysis was the landing page on the topic breast cancer of the page Wikipedia.org. The first quality criterion, the clarity of the aim of the website, was considered unfulfilled. The page only states that the information is on human breast cancer, not who the information is for. The second quality criterion, the clarity of the author/publisher, was also not fulfilled. No information on an author/publisher or their qualification could be found. Here it is worth noting that Wikipedia is a website on which laypeople as well as experts can publish information. The third criterion, the clarity of the sources of information, was considered partially fulfilled. There were references to literature and web links on the website and there were 139 sources listed for the given content. Some sections on the landing page were not adequately presented, and some sources were missing. The clarity of the independence of the sources, the fourth criterion, was considered completely fulfilled. The content was of an objective nature and there were a variety of other topic-related sources linked on the website. The fifth criterion, the clarity of the respectability of the information, was considered partially fulfilled, with a tendency to be unfulfilled. Although there is no advertising on the landing page and the headlines are clear, exact, and informative, a variety of pictures of patients, extracted tumours, and pictures of breast surgery are present. These pictures could lead to anxiety, discomfort, and uncertainty for patients. Further content, such as self-contradictory information on factors that were considered protective against breast cancer, may also create a sense of uncertainty. In addition, various content which may be considered strange for the users was also present. For example, tactile examinations were introduced as a preventive measure which can be performed by blind people, and an increased risk of developing breast cancer in left-handed people is mentioned. This information could also lead to uncertainty and doubt in patients. The sixth criterion, the clarity of the actuality of information, was considered completely fulfilled. The first date of publishing as well as the date of the most recent update is given on the web page. The clarity of the relevance and usefulness, the seventh criterion, was considered completely fulfilled. The website gives a good overview of the disease, diagnostics, and therapy. The eighth criterion, the clarity of the relevant medical information, was also considered fulfilled. The diagnostic process and treatment options were described very well. The next criterion, the clarity of uncertainty of treatments and diagnostic procedures, was considered completely fulfilled. Links to specific genetic marker tests, which are not a standard therapy in breast cancer diagnostics, can be found. The tenth criterion, the clarity of understandability, was considered fulfilled. The wording is understandable for a layperson and terms which are not easy to understand had links to explanatory pages on the terms. The clarity of usability for shared-decision making was considered partially fulfilled. The given information was at times confusing, but the baseline information is appropriate for starting a conversation with the patient’s practitioner. The twelfth and thirteenth criteria were not fulfilled. The website was not certificated with the HON logo or the afgis logo for good quality online health information. The last criterion, user-friendliness, was considered partially fulfilled. There were over 60 links within the text, most of which were term-explanations, and the information is structured as an ongoing text, however the layout of the content could be overwhelming for users. There is a lot of text which seems to be incoherent on closer inspection.

In summary, each of the top five pages had its pros and cons. The pages of the Cancer Society and the German Cancer Information Service presented very detailed and objective information on the subject of breast cancer for users. Onmeda.de also provides good quality information on breast cancer, despite not belonging to an institution. The quality analysis also showed that the website Krebsgesellschaft.de and the site Onmeda.de were awarded the two quality logos of HON and afgis for good health information on the Internet. This award confirms quality and trustworthiness to users. The identified pages all deal with the different steps from the diagnosis of breast cancer treatment, through therapy, to aftercare, and also early detection. This point is also positive and illustrates the variety of information provided by the various online sources.

The majority of the identified pages were overview pages where the more relevant and detailed information could only be accessed via links. The links on the Krebsgesellschaft.de and Krebsinformationsdienst.de pages were very user-friendly as they were easy to find and well positioned on each website. This makes it easy for users who do not have much experience with searching online for information to find their way around the landing page. The landing pages on Onmeda.de and Apotheken-Umschau.de must be regarded in different ways. They provide a large section of informative content on the landing page and elaborate on it with links to, for example, explanations of words. The fact that the Apotheken-Umschau landing page on the topic of breast cancer is an overview page is not clear to users at first glance due to the variety of information associated with a lot of text. In contrast to this, the landing page of Onmeda.de is not just an overview page which is also clearly visible for the user. The Wikipedia page on breast cancer had the lowest quality results. Even though the information provided is backed up with references, the user-friendliness of this page is to be criticized. The images and sometimes conflicting information could lead to confusion and discomfort, especially for women with breast cancer or relatives who are looking for information.

In conclusion, the results of the analysis show that the null-hypothesis H0 is not confirmed. Thus, the counter-hypothesis H1 can be accepted, since the analysis shows that online research on the topic of women's breast cancer provides high-quality information with valid and reliable content. However, one cannot conclude on the totality of all results of an online search on the searched topic.

6.2.2 Meaning of the Results for Patients and Breast Cancer Treatment

The results of the analysis show that a lot of good quality information can be found on the Internet by searching with an online search engine. High-quality websites can also be found high up in Google's results list and are therefore often clicked and visited target pages. The content of the pages also show that they are well suited as a foundation for an exchange with the attending physician and can also have a positive impact on shared-decision making. As already explained in the body of this thesis, cancer patients not only struggle with a life-threatening disease, but also with fear and insecurity and need information that is reliable in order to deal with their new life situation in the best possible way. Content that can be found on the internet is not intended to make patients feel insecure and anxious, but rather to convey objective connections, advice, and essential information. Guidelines and evidence-based information on treatment and diagnostics help to ensure that patients are informed and not only laypeople in doctor-patient contact. Good information can also help within the treatment process to compensate information asymmetries between the doctor and the patient as far as possible and create a basis for discussions and exchange with practitioners. Health-related content should constitute a reliable and trustworthy basis for the patient by informing users about essential basics as well as risks and uncertainties. Here, it is of great importance that neither the layout, nor the headings or the content, whether in text or images, should result in the patient feeling uncertainty or fear. To inform people about risks or dangers in case of treatments is essential, but the content of these instructions should be designed objectively and create confidence in patients regarding their cancer treatment. The diagnosis of breast cancer, as with diagnoses of other serious diseases, can be overwhelming for patients. Support and good quality information is essential to overcome the challenges of cancer treatment.

7. Discussion

The results of the analysis in this thesis show that access to online information of good quality is possible. It should be emphasized, however, that the results of a search using an online search engine can change with only the smallest deviations in the search term. In this analysis, the most quantitatively relevant and thematically obvious search term was determined by means of a keyword analysis and this search term was selected as the basis of the main body of research. It should be noted that real users or affected patients can also choose other terms in their search behaviour and the results may differ. Even though the majority of searches match the determined search term, it should be noted that the other thematically matching keywords also have a high search volume.

The result of the analysis with regard to content and quality of the online information was initially not expected. Due to the variety of information and the different search results in the enquiry, it was expected that hardly any relevant results providing good quality which were also valid, trustworthy, and reliable for patients would be found. Certifications with quality logos are a reliable indicator for patients to find out how trustworthy and of what quality the content and information on the websites are. For this purpose, however, it is necessary to make these certifications better known in the patient environment.

The analysis of the search terms and their monthly search volume and the determination of the resulting target pages also shows a tendency similar to research literature and scientific studies, namely that users of online information tend to prefer institutional websites. This can be assumed from the high number of clicks on the institutional pages Krebsgesellschaft.de and Krebsinformationsdienst.de for the chosen search term, but the exact reason for visiting the target pages cannot be determined from this data. Another factor besides the trustworthiness of the website owners, in this case medical institutions, which could increase visits to a page, is the rank of the website in the Google search results list.

Nevertheless, further research on the utilisation-behaviour of breast cancer patients regarding online information is necessary to confirm and validate these results. It would be interesting to examine what patients want to research on the internet and what basic information they need to feel confident and well-informed. On this research topic, blogs and online forums on the topic of women’s breast cancer could also be included to examine their function in influencing as well as supporting breast cancer patients. Further research could shed more light on the relevance of the information found for doctor-patient contact and shared-decision making. Such an investigation could be carried out on the basis of this thesis but would have gone beyond the thematic framework of this work. This thesis sheds light on what kind of content the broad field of the internet offers for users and patients and how difficult it can be to distinguish high quality from lower quality information. This is made especially difficult when researchers try to assume the role of a patient in the search for information.

8. Résumé

The scientific investigation of this thesis aimed to answer the question: Which content on the topic of women’s breast cancer can be found via online research and how valid and reliable is the found content in terms of its quality for recipients/users? To answer this question, hypotheses were put forward and a qualitative analysis of online content on breast cancer was conducted. The analysis included the determination of topic-related keywords and their search volumes, the determination of the target pages, and their examination of content and quality. A checklist was developed and used for the quality analysis which is based on existing checklists.

The results of the thesis show that the majority of the identified and analysed landing pages of the search engine Google are of good quality and contain reliable content. Even when pages of good quality have minor weaknesses in the page structure and usability for the patient/user, the information provided is comprehensible for laypeople. Pages that have an uncertain background with regard to authors and some sources of information, on the other hand, also show good information, but show considerable weaknesses in comprehensibility, consistent reliability, user-friendliness and, above all, patient-friendliness of the information.

In summary, the internet is a good source of information with a very high number of users, but it is also a fast-moving medium in which information can be added or removed in a very short timeframe. For this reason, in particular, it is important in the medical and health-related context to provide reliable and, above all, scientifically verified information and to focus on providing websites that present such content. Nevertheless, patients can find comprehensive and reliable information with simple search terms but need more support to find the relevant content from the variety of results. The reason for this is that the variety of information can be overwhelming for patients and users, especially when there is a serious illness such as breast cancer. The step-by-step approach to understanding medical-scientific online content for patients should be more integrated and promoted in the approach and communication of public health. When information is understood, it serves the exchange with the practitioner and prevents excessive information asymmetries which can thereby have a positive effect on compliance and understanding of treatment.

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Appendix

Checklist for Quality of Content of Top Five Websites on the Search Term "Brustkrebs"

Note: The following checklist is developed in dependence of the DISCERN instrument and the checklist of the website patienteninformation.de.

	Quality Criteria	**Description**	**Fulfilled (fully, partially, not)**
1	Clarity of the aim	Has the information stated its aims clearly? Who is the information for and which intention has the website?	
2	Clarity of the author/publisher	Is the author/publisher named? Does the website state his or her qualification?	
3	Clarity of the sources of information	What are the sources of the information? Are there clinical trials, guidelines and other evidence-based literature as references?	
4	Clarity of the independence of the sources	Is the information on the website of an objective or subjective manner? Are there a variety of other sources of information, besides the given, on this website? Are other relevant information for this topic linked on the website?	
5	Clarity of the respectability of the information	Is there obvious advertising on the website? Are the headlines or the further content of the website leading to anxiety, discomfort, uncertainty?	
6	Clarity of the actuality of information	When were the information published? Has the publishing date a direct reference to the content of the website?	

7	Clarity of the relevance and usefulness	Does the website give information to answer the users questions? Is the the information relevant, realistic and appropriate according to the searched term?	
8	Clarity of the relevant medical information	Is the diagnostic process described? Are the treatment options described? Are the benefits and risks described regarding side effects, complications or influence on quality of life?	
9	Clarity of uncertainty of treatments and diagnostic procedures	Does the website give information on treatments or diagnostic procedures which are yet uncertain and not evidence-based standard?	
10	Clarity of understandability	Is the wording of the publication understandable for a layperson?	
11	Clarity of usability for shared-decision making	Are the information useable as a basis for conversation/discussion with practitioners, as well as family members and friends?	
12	HON certification	Is the website certified with the HON logo?	
13	afgis certification	Is the website certified with the afgis logo?	
14	User-friendliness	How many clicks on links have to be done, to get to detailed content? Are the links easy to find or more hidden?	