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Empowering genes or a fearful disease:
a critical evaluation of ascribing EMPOWERMENT
to BRCA tests

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ABSTRACT

Between 5 and 10 percent of breast cancer patients have a known genetic mutation located on the BRCA 1 or 2 gene. These mutations can be identified what results in knowledge about one's personal risk and this information can be used to decide how to change behavior: increasing surveillance, changing diet or opting for preventive medical interventions. When surveyed, consumers of genetic tests describe their reason to opt for these tests with the term empowerment. The providers of genetic testing also use the notion of empowerment to promote their testing services. This ascription seems based on an interpretation of the BRCA test as a way to overcome the seemingly helpless waiting for cancer to strike. The broad adoption of this ascription can be explained by enthusiasm of the breast cancer activist groups and medical researchers that contributed to the initial development of the test.

As several authors have suggested, however, there may be more to BRCA testing than the empowerment rhetoric suggests. Knowledge of one's BRCA status may alter the self-perception of the tested individual. She may start seeing herself as a 'person at-risk' or as even as an 'unhealthy' person. This may invite a psychological response labelled 'anticipated regret', and she may feel obliged to succumb to the authority of medical professionals, to assume the responsibilities of the sick, and to opt for preventive interventions. Thus, knowing one's genetic risk may not be just empowering. It can also steer decision making in a specific direction and make a person more dependent on professionals.

To evaluate to what extent and in what sense the combination of BRCA mutation testing and an online support forum can be considered empowering, I performed a content and a conversation analysis on a sample of contributions to a web forum on BRCA testing. These analyses show that promoters of preventative surgery frequently tried to convince others by addressing the feeling of regret these women would feel if they would develop cancer. Furthermore, the majority on the forum regarded preventative surgery as necessary due to their BRCA mutation, indicating that they perceive their own body as unhealthy. Besides these explicit remarks, there are also implicit ways to influence the opinion of women on the forum, such as disregarding the surveillance strategy as the minority option.

Thus, although testing for BRCA mutations in some respects can indeed be seen as a form of empowerment, the impacts of the test result are more ambiguous than the empowerment discourse suggests. Being diagnosed as a mutation carrier and exchanging about this status on a web forum with fellow BRCA carriers seems to influence the decision making about how to proceed in a specific direction.

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CHAPTER I: INTRODUCTION

SITUATION

Cancer is one of the most common diseases in western society and its consequences could be lethal. Therefore, most people would refrain from actions that might increase the risk of developing this disease, with the well-known exception of smokers. But what if the increased risk is part of your life or even of your body? Would you still do anything to avert cancer risks?

These questions may seem farfetched, but for a significant part of the population these questions are real. Ten to fifteen percent of women who develop breast cancer are carrier of a mutation on the BRCA 1 or 2 gene locations. (ACS, 2014) Being a carrier of these mutations decreases the ability of a cell to repair damage to the DNA and increases the chance to develop breast and ovarian cancer. Genetic tests are available to identify the mutation carrier status and to estimate a personal lifetime risk to develop breast and ovarian cancer.

After testing positive for a BRCA 1 or 2 mutation, a woman can react in roughly four ways (Salhab, Bismohun, Mokbel; 2010): (1) continue her life ignoring the risk, (2) increase surveillance to detect possible cancer at an early stage, (3) change in behaviour or diet or (4) reduce the risk through preventive surgery. The first option is understandable in situations where a person is tested to benefit a family member¹. The second strategy, increasing the surveillance to catch cancer in an early stage, involves regular self-examinations and visits to the doctor for an MRI multiple times a year. Changes in diet or habits can also be seen as a form of surveillance, because the woman takes precautions to minimize the risk. However, choosing this strategy does not completely eliminate the risk to develop a tumour. By changing behaviour only a small decrease in risk could be achieved and with more surveillance there is only the hope and not the assurance that a cancer is detected at an early, (hopefully) non-lethal stage. Lastly, to really reduce the risk of developing breast cancer women can decide for a medical fix, in the form of preventative surgeries involving a partial or complete removal of breast tissue.²

To reduce the increased risk of ovarian cancer, a BRCA mutation carrier has even less options. The chance of detecting this type of cancer through self-examination is minimal, meaning that the surveillance strategy is dependent on regular MRI screenings. As the chance to detect a growing

¹ Due to the high costs of testing, an often utilized protocol is to test the family member closest to the stem of the family tree. If that person has a negative result, it is unlikely that one of her children has a genetic deficit. (Boenink, 2011)

² Surgeries to remove breast tissue will be referred to as mastectomy or BPM, which is short for bilateral prophylactic mastectomy.

cancer cell at the right time is a matter of chance, ovarian cancer is often named the silent killer and choosing the surveillance strategy is not seen as a worthwhile alternative by women with a BRCA mutation. Thus, to prevent ovarian cancer the medical fix seems the only viable solution (Salhab, Bismohun, Mokbel; 2010). Women often describe the choice for this procedure as a no-brainer (BRCA forums) even though it results in an unnaturally early menopause, eliminating the possibility to bear children and causing hormonal troubles.

For members from families with a genetic predisposition to breast and ovarian cancer, these strategies nonetheless may provide a way to overcome the seemingly helpless waiting until cancer develops or not. By testing for the BRCA 1 & 2 mutations, women gain insight in their actual risk to develop breast or ovarian cancer, which can be utilized to decide between the mentioned strategies. Compared to the alternative, waiting helplessly for the disease to occur, gaining a risk estimate can be considered as a way of gaining power. Thus predictive genetic testing is frequently considered as a form of empowerment. The Oxford dictionary defines 'empowerment' as "both to give (someone) the authority or power to do something, and make (someone) stronger and more confident, especially in controlling their life and claiming their rights." (Oxford dictionary). As will be discussed in chapter III, the vast majority of people who opt for genetic testing describes their reasons for taking such a test in terms of empowerment. Furthermore, the providers of genetic testing use the term to promote genetic testing.

However, the positive association of the word empowerment might overrule other considerations in the decision to opt for BRCA testing. Prevention of a lethal disease can be utilized as a decisive argument in any decision process. This rhetoric is a slippery slope that can be applied in many situations, leading to a disruption of societal norms and values regarding when it is justified to remove body parts. By revealing the increased risk inscribed in our DNA and basing our life time decisions and medical interventions on this risk estimate, ethical boundaries are breached. Without these boundaries there is no implicit limit to the extent interventions are necessary or socially desired. Someone does not actually need to have a certain disease to have surgery; when we follow this line of reasoning, a probability that a disease might occur is sufficient. The disease itself would not have to be lethal, as the millions of breast cancer survivors could tell. Even the type of remedy does not matter, because to save a life even removal of healthy body parts is applauded. By accepting this moral change, limitations to how far someone should go to limit potential health risks seem to disappear whenever there is a possibility to prevent a negative outcome.

Testing for BRCA mutations in women that did not develop cancer may provide them with the knowledge of being at a relatively high risk for cancer. Arguably, the women who opt for BRCA testing, are already worried about developing cancer. The knowledge offered by a BRCA test redefines this worry into an actual estimate of future risk. Moreover, if one takes the genetic test based on the empowerment rhetoric, the medical fix is likely deemed the only option, as this is the only way to overcome the risk of breast cancer.

QUESTIONS AND CHAPTERS

Although no one will argue against reducing the occurrence of cancer and the possibility to save lives, a society where every limb is removed to prevent cancer to develop in that part of the body, seems rather ridiculous and undesirable. There seems to be some implicit limits as to when medical surgeries are acceptable. In this thesis, I start from the assumption that individuals differ as to what they consider acceptable and to what extent they take measures and that each individual should fully evaluate his or her situation before making a decision for a medical surgery.

Additionally it is assumed that in a western liberal society the ideas of the individual are accepted and tolerated as long as the decision of the individual is the result of educated decision making. By ascribing the term empowerment to BRCA testing, the associations of this term are also attached to BRCA testing. Potentially this could result in an unbalanced decision making process, because the positive associations of empowerment emphasize only one aspect of BRCA testing.

To evaluate to which extent the ascription of empowerment actually intervenes with decision making processes for BRCA testing, this thesis will research the interactions on an online support forum dedicated to BRCA related issues. By analysing the exchanges on the support forum these interpretations will be assessed and the ambiguity of the decision process will be tested.

To achieve this, the following questions are addressed:

MQ: To what extent and in what sense can the combination of BRCA mutation testing and an online support forum be considered empowering?

Sq1: Why are BRCA mutation testing and online support fora considered as a form of empowerment?

Sq2: Is empowerment the only reason to promote BRCA testing?

Sq3: What are the implications of alternative reasons for ascribing the term empowerment to BRCA testing?

Sq4: To what extent does the support forum indicate a particular reason for BRCA testing, and in what sense can the reasoning be considered ambiguous?

The first sub-question will be addressed in chapter II, by discussing three reasons for the ascription of empowerment to genetic testing. First, some scientific information on cancer, the BRCA mutation and BRCA testing is provided. Based on this background knowledge, I will show that there are indeed affinities the effects of BRCA testing and the definition of empowerment. However, this does not fully explain the widespread adoption of this term with its positive associations. To provide an explanation for this adoption, a short history of the technological and societal developments involving the BRCA testing technology is provided. A different explanation for this wide adoption, is also sought in the way BRCA testing is promoted. By comparing the developments of BRCA testing services in both the US and the UK, the influence of commercial interests and advertisements on the ascription of empowerment to BRCA testing will be evaluated.

Chapter III discusses the results of two surveys among people who have opted for genetic testing. The first of these indicates that indeed almost every consumer describes his/her reasons for opting for a genetic test in terms of empowerment (McAllister, Dunn & Todd, 2011, p.125). The other survey shows that the meaning of the 'empowerment' ascribed to genetic testing can be analysed as consisting of five dimensions: (1) informed decision making, (2) knowledge about risk and disease prevention and onset, (3) the ability to make efficient use of health and social care systems, (4) orientation towards the future of the individual self, family members and future descendants, and (5) emotional regulation (McAllister et al, 2008). Furthermore, providers of genetic testing services also utilize an idea of empowerment to promote genetic testing.

To address the second sub-question and to identify alternative considerations to opt for genetic testing, chapter III also elaborates on another aspect of genetic testing, namely the identification as a person 'at-risk'. Where providers present this identification as a camouflaged form of empowerment, this chapter discusses two alternative interpretations of the identification of a genetic predisposition. First, this identification may have psychological interference with further decision making, by means of 'anticipated regret'. Secondly, the identification as a person at-risk can also lead to a change in self-conception. A person at risk might start to think of him-/herself as unhealthy and experience the BRCA mutation as a form of disease. Using insights from Stempsey (2007) and Parsons (Crossley, 1998), I will argue that the identification of the at-risk status might also lead to social limitations based on rights and obligations to seek medical treatment.

The research in this thesis concerns an online support forum of women who concern heredity cancers. This is an example of a group that is united by sharing a particular biological characteristic. As Rose and Novas (2003) point out, such groups may lead to a form of 'biological citizenship': individuals identify themselves with their biological characteristics and society tends to identify and react to the individual as being part of this biological group.

The online support forum can be considered as a place where these biological citizens unite. The forum enables its users to share information about the disease and related issues and also sharing of experiences and compassion is facilitated by this platform. Through the online support forum BRCA carriers can be united in their struggle with the impact of BRCA testing.

To further explore the actual motives and reasons for BRCA-testing, my research will focus on the contributions and interactions on a web forum dedicated to BRCA-carriers. In chapters IV and V, the contributions to this forum are evaluated with respectively a conversation and a content analysis. The conversation analysis (Seedhouse, 2004). Reported in chapter IV, focuses on the action-reaction sequences that are expressed in a thread on the forum. This helps to interpret the way people on the forum are interacting with each other. Additionally, a few threads are addressed that provides specific information to understand the forum and the characteristics of members of the forum.

The content analysis (Stemler, 2001) presented in chapter V, concerns the opinions exchanged on the forum and at the specific way these are expressed. Focusing on specific topics selected from the

threads from the conversation analysis, the attitudes of the members about BRCA testing and related issues will be clarified. Furthermore, special attention will be given to the implicit exchanges among members of the support forum, these could be accounting for the influence of the online support forum on the individual. These two analyses of the online support forum will help to answer sub-question four.

This thesis argues that testing for a genetic mutation is more ambiguous than the positive association with empowerment suggests. By solely describing the BRCA mutation testing as a form of empowerment, the decision making process whether or not to opt for this test is influenced in a specific direction. By analysing actual behaviour of BRCA-carriers on an online support forum, other effects of identifying one's at-risk status come to light and provide a broader understanding of BRCA testing. Ultimately, this analysis enables people to make a more educated choice for or against BRCA testing.

CHAPTER II: HISTORY AND EXPLANATION OF BRCA TESTING

The main question addressed in this thesis concerns the ascription of the term empowerment to the combination of BRCA testing and online support groups. To gain a better understanding of this ascription and to explain why it has become widely adopted, this chapter elaborates on three potential explanations, referring to a lexical, historical and commercial reason. The lexical reason is explained through a short introduction to cancer and a more detailed description of BRCA gene mutations. It indicates to what extent the BRCA carrier status can literally be considered as a form of empowerment. If empowerment is considered as a form of taking control over the helpless waiting until cancer strikes, identifying one's BRCA mutation status will indeed be a form of empowerment.

The apparent lexicological match may indicate why the term empowerment could be utilized, it does not necessarily explain why it is employed with affiliated positive attitudes. By providing a short historical overview of developments in patient activism and technological advancements in genetics, it can be assessed if the wide ascription of empowerment to BRCA testing has an historical origin.

A different explanation for the ascription of the wide acceptance of the empowerment to BRCA testing, can be sought in the way that genetic testing services have been promoted. The advertisement and commercial interest could potentially be considered important for the way that BRCA testing is perceived. To evaluate if advertisement could be appointed as a reason, the development of genetic testing services in both the US and the UK will be compared. These two countries have a different outcome on health care, where the US has adopted a commercial and privatized system and the UK provide health care through a nationally operated system.

During the short history, there will also be some elaboration of the debates and discussions which occurred in during the developments. These indicate that the developments in BRCA mutation testing were not without critical evaluation. This is important to grasp as these critical standpoint can easily be overlooked when considering the current state of BRCA testing services.

LEXICAL

Cancer

In current western society, cancer can be considered as an important threat to society and daily life. Approximately, 855,220 male and 810,320 female Americans are annually diagnosed with a form of

cancer, being accountable for an estimated 585,720 deaths every year (ACS, 2014, p.10). These statistics make cancer the second most common cause of death in the USA.³

Cancers are defined by the National Institute of Cancer as “diseases in which abnormal cells divide without control and are able to invade other tissues (NCI, 2014).” Normal cell division occurs through mitosis, in which one cell divides into two identical cells and the old cell vanishes. Through mitosis, old and damaged cells are replaced to keep the body healthy. In a cancer cell the DNA is damaged or has mutated, causing the cell to divide uncontrollably (NCI, 2014). The produced new cells become a surplus and form a mass of tissue, called a tumour. If the surplus of cells is able to spread in the body, the tumour is called malignant and is diagnosed as a form of cancer (NCI, 2014).

There is a wide variety of cancers, most often classified on the basis of the onset location or on basis of their type of tissue (Mandal, 2012). In the US the most common types of cancer are prostate, lung & bronchus and colon & rectum (ACS, 2014). Among women, the most prominent type of cancer is breast cancer. Approximately 232,670 new cases are diagnosed annually, 40,000 of which are lethal, making this the second most deadly form of cancer for women (ACS, 2014).

BRCA

In approximately 10 – 15 % of the breast cancer cases, the cancer is partially caused by an inherited predisposition for cancer (ACS, 2014). The most famous causes of these predispositions are the BRCA 1 & 2 gene mutations, which are accountable for 5-10% of the breast cancer cases (ACS, 2014). If a non-carrier of the BRCA 1 or 2 mutations has a defect in DNA, the defect is repaired most of the time. The presence of a BRCA 1 or 2 mutation decreases the ability to effectively repair such defects. As a result, the defects leading to uncontrolled cell division in breasts and ovaries, are less often repaired and the BRCA mutation carrier has an increased risk of developing breast and ovarian cancers.

The decreased ability to repair defects in DNA results in an estimated lifetime risk to develop breast cancer that varies between 47% and 66% for BRCA1 mutation and 40% till 57% for BRCA2 mutation carriers (Chen & Parmigiani, 2007, pp. 1332).⁴ Moreover, the BRCA mutation carriers have an

³ As the support forum analyzed in chapter IV and V is primarily based in the US, the statistics utilized in this chapter concern the USA. Lethality and diagnosis rates vary among different countries, as environmental and social factors influence these numbers.

⁴ This is based on a review article; the actual lifetime risk is still a highly debated and subject in medical science. It should be kept in mind that the risk estimate is still a work in progress. Another thing that should be kept in mind when evaluating the experience of risk, is that different risk estimates have been published. Occasionally estimating a lifetime risk above this average, among which an

increased chance to develop ovarian cancer, of 40% for the BRCA 1 and 18% for the BRCA 2 mutations (Chen & Parmigiani, 2007, pp. 1332). Carriers of a BRCA mutation are also found to be at increased risk of other forms of cancer, like prostate and pancreatic cancer, but clear risk estimates are lacking here (Levy-Lahad & Friedman, 2007).

The term “lifetime risk”, utilized in the statistics above, indicates the percentage of women with a genetic predisposition that develop breast or ovarian cancer before the age of 70 (Chen & Parmigiani, 2007, pp. 1332). It represents an accumulation of the likelihood a BRCA carrier has to develop cancer in a year. The yearly cancer risk increases over time as a woman ages and external influences have had more chances to invoke the onset of cancer.

Describing the chance of cancer in terms of lifetime risk transforms the possibility of developing cancer into a numerical probability. Compared to the average lifetime risk of breast or ovarian cancer for women who do not carry a known genetic predisposition, BRCA carriers are at a relatively higher risk. This relative risk estimate is also utilized by providers of genetic testing⁵ in their promotion material. (Nordgren; 2012). By visualizing the relative risk in forms of a risk thermometer or warning signs when the relative risk is high, the genetic test providers try to motivate and provide a roadmap for improving health (Nordgren; 2012). In the next chapter the way providers advertise their products is discussed more elaborately.

As we have seen in the beginning of this section, cancer is one of the most deadly diseases in current western society. People may become afraid that they will also come to suffer from this disease, especially if there is a high incidence rate of cancer in the family already, resulting from genetically inherited increased risks. Knowledge of the actual risk a person is facing may influence decisions being made in life, such as when to have children or mortgages, and it enables the potential mutation carrier to deliberately choose for preventative surgeries. When evaluating breast and ovarian cancer risks in relative terms, a BRCA mutation carrier will always be seen as worse-off compared to non-carriers. Thus, BRCA testing can literally be considered empowering to the extent that BRCA testing enables the person to gain power over the waiting until the potential cancer develops.

BRCA HISTORY

article published in Science (King et.al, 2003). The people on the online support forum may have utilized these information sources in their decision process and formation of an opinion.

⁵ In the article utilized here, the companies providing genetic testing are providing their services directly to the consumers, making them so called direct-to-consumers companies. This means that a client can order a genetic test directly from the company tailored to the specific mutations that the client desires to know.

The brief summary of scientific knowledge about cancer and BRCA mutation provided in the previous section indicates that BRCA testing can indeed be seen as a form of empowerment. However, although it explains why the term is a suitable in the case of BRCA testing, it does not fully explain the positive attitude associated with empowerment by BRCA testing. A more diverse response might have been expected, as both genetic testing and empowerment are not viewed, valued and defined in the same way by different people. Still, there seems to be an agreement that the term empowerment can be ascribed to genetic testing.

This section explores two historical reasons potentially explaining why the ascription has been widely adopted. First, the situation from which BRCA testing originated is discussed to indicate the close link between BRCA testing and patient activism in the early nineties of the 20th century. Secondly, the developments in genetic testing services in both the USA and the UK will be elaborated. By comparing the services in these countries the potential effects of commercial exploitation of BRCA testing on the ascription of empowerment will be addressed. Lastly, the ethical debates, discussions and protests that occurred throughout the different development stages will be addressed, to indicate that BRCA testing was not always considered a positive development.

The source for this brief history of BRCA detection services is the book: *Building Genetic Medicine* by Shobita Parthasarathy (2007). This book reconstructs and analyses the implementation of BRCA detection technologies in the US and the UK. Parthasarathy assesses the developments with a focus on the interaction between both societies and the developing technology of BRCA testing. Due to this focus it is a suitable source for the short history needed in this chapter to provide an overview of the evolution of BRCA testing and the reaction of society.

Race for the human genome

Following the success of AIDS activist movements in the 1980s and early 1990s, American breast cancer patients mobilized public and political attention for breast cancer (p.4). This resulted in the Breast Cancer Action group being included in research funding decisions by 1990 (p.4). Another organization, the National Breast Cancer Coalition, was able to establish a network of breast cancer survivors, physicians, support groups and charities, eventually leading to the increase of research funds (p.4).

Moreover, technological advancements in genetic research resulted in the ability to identify specific gene branches (p.4-6). Scientists from around the globe participated in a race to discover specific genetic sequences related to diverse medical and biological issues. Due to a particularly high incidence rate of breast cancer in certain families, the idea that there was a hereditary basis for breast

cancer was considered likely. Therefore, the nucleotide sequence aligned with breast cancer was considered one of the biggest trophies of the so called Human Genome Project⁶ (p.4-6).

In 1994, a research team led by Mary-Claire King at the University of California, Berkeley, discovered that a mutation around Chromosome 17 was present in a considerable subsection of the breast cancer population (p.4-6). This location was marked as the Breast Cancer Susceptibility gene, which is now also known by its shorter form, BRCA-1. Soon after King's publication, a company named Myriad Genetics announced they succeeded in mapping and patenting the BRCA-1 gene sequence (p.4-6).

The discovery of King and her team was received with great enthusiasm in the medical sciences (p.4-6). However, the still unexplained clustering of breast cancer in non-BRCA 1 families made some scientists believe that at least one other gene mutation existed. In December 1995 this belief was justified, as the British Institute of Cancer research identified the BRCA-2 gene (p.4-6). Soon after this discovery, Myriad Genetics also succeeded in mapping and patenting mutations on this new location (p.6). These discoveries demonstrated that genetic differences influence the likelihood of a common disease, where previously the genetic component of disease was associated with rare disorders only (p.6). Therefore, the discoveries and mapping of BRCA 1 and 2 are considered to be scientific and medical successes (p.6) and a step forward in the fight against cancer.

As previously mentioned, the National Breast Cancer Coalition and Breast Cancer Action were influential advocacy groups involved in US breast cancer politics in the early 1990s. They viewed BRCA testing as a way to decide between a variety of medical options and to protect one against bad medical choices (p.57). Nonetheless, these advocacy groups were cautious about making genetic testing broadly available, as the knowledge resulting from the test was considered ambiguous. The test result would provide merely a risk estimate, not a certainty that the disease would strike in the future. Moreover, good medical counselling was scarcely available (p.58).

In a similar vein, a number of professional organizations that represented scientist and health care employees joined the discussion. Their contribution was emphasizing the uncertainty surrounding new genetic technologies, as well as promoting the necessity of concurrent clinical care (p.35). Moreover, the American Government was advised to treat genetic testing as a medical device, to widely assess laboratory accuracy and the test quality for clinical purposes, before making genetic testing are widely available (p.35). In addition, medical professionals should be re-educated to answer questions about genetic testing, since these questions would arise as the technology might be misunderstood (p.35).

⁶ The Human Genome Project was an international research effort to determine the entire human DNA sequence. Multiple universities and laboratories throughout the world have worked on mapping partial branches into one sequence. The project ended in 2003 when the researches had achieved all the goals set in 1988 (NHGRI, 2012).

Furthermore, the discovery of the BRCA genes resulted in critical public and scholarly debates about the potential identification and discrimination of people based on their DNA. One of the worries mentioned was that these technologies would lead to the reconstruction of social order along genetic lines. In such a social order individuals are defined and discriminated medically, socially and politically according to their genetic make-up (p.7-8). When people would be divided into genetic categories a range of dystopian scenarios could follow, such as the emergence of a genetic underclass of slaves, Nazi-Eugenics or remaining unemployed based on your inferior genes.

Other concerns were more practical, such as the possibility that health care quality would decrease or that funding and medical attention would be redirected to genetics (p.8). Also, the issue was put forward that test developers, health care professionals and regulators might have to deal with gap between the counselling available at that time, and the amount necessary when the tests would become publicly available (p.8). Another general worry considered the lack of regulation for new genetic tests and the way genetic knowledge would be stored and accessed (p.8-10).

From research to commercial service

The discovery of the BRCA mutation did not directly start a new way of treating patients, as the expectations surrounding the Human Genome Project envisioned. The hoped revolution was troubled by the situation that had been constructed around genetic testing. Starting from the heredity research institutions at universities, genetic testing services had gone through multiple developments until the current situation was established.

The first heredity research facilities opened in the first half of the twentieth century and were affiliated to universities. Genetic researchers were employed to conduct research as well as perform clinical procedures (p.28). Since health care in the US was a largely private affair, hospitals and doctors were employed through insurance companies and there was little regulation for these services (p.27-28). The genetic counselling session in these institutions aimed to provide information about genetic predisposition and possible decisions. However, the client was not directly advised, to avoid associations with eugenics (p.28).

The technological progress in genetics led to a change in the options for genetic testing services and multiple states created regulating agencies to ensure the quality of genetic test results (p.28-29). The first companies to provide BRCA testing services, Genetic Diagnostic Laboratories at the University of Pennsylvania and OncorMed, provided their services as a combination of counselling and research (p.68-72). They were also bound to strict rules and protocols created by the patient advocacy groups and biomedical professionals (p. 68-78).

One of these rules was to refrain from commercial exploitation of BRCA testing services until the technology was fully researched (p. 79-86). A private clinic, the Genetics and IVF Institute (GIVF) did not follow the protocols of the research facilities and provided a commercial BRCA testing service for the three most common genetic mutations in Ashkenazi Jews (79-86).

Shortly after GIVF, Myriad Genetics, the company that held the patent for both BRCA 1 and 2, also started its own testing service for the mutation (p. 86-92). The test it utilized simply provided a binary result whether or not a person had a mutation on the BRCA 1 or 2 locations. Furthermore, Myriad's test could be ordered without counselling, as was prescribed in the service of the other companies (p. 86-92). By 1999, Myriad Genetics had been able to force their competitors out of the market by utilizing a combination of legal threats and astute business manoeuvres. OncorMed was sued for patent infringement, which led to a settlement that allowed Myriad Genetics to purchase the patent in 1998 (p.115). In the same year they send letters to both GIVF and GDL, threatening them with a lawsuit if they refused to stop testing for BRCA mutations. GIVF immediately submitted, but GDL fought this accusation until a court order shut them down (p.115).

With the commercial service of Myriad Genetics also came a shift in the way genetic testing was perceived. Genetic testing had become a service aimed to provide a consumer with the option to demand more from health care professionals, resulting in many new responsibilities (p. 115). The closing down of competing companies resulted in Myriad's domination of the genetic testing market. This led to a new challenge for Myriad: broadening the market through increasing the usability of their test and through advertisement. Thus, the relation between BRCA testing and empowerment may have been strongly influenced by the promotion of BRCA testing as a positive option, as Myriad desired to increase the number of users of their genetic test.

BRCA history in Europe

In order to evaluate if the association with the empowerment notion is due to the advertisements of Myriad, the development of BRCA testing in the UK is discussed. In contrast to the largely private American health care practices, the UK has a government based health care system. Since 1948, the National Health Service (NHS) ensures a basic standard of medical care for the entire population at a low cost (p.45-51). Additionally, private insurance is available for those preferring a higher standard of health care.

Around the same time as their American colleagues, British genetic testing facilities were founded under the supervision of the NHS. The NHS invested in genetic testing with the idea that this new type of medical care would enhance preventive efforts and reduce the high costs of treatment for the eventual disease (p.92). However, knowledge about the existence of genetic tests was transferred by doctors to patients, as the NHS did not advertise these services (p.92).

In the first years the availability of genetic tests varied among UK regions, resulting in different waiting – times for a genetic counselling meeting, varying from a day to two years (p.100). These long queues led to the limitation of genetic testing to high risk individuals only. Test results were compared by different physicians, to create an ongoing medical management plan that was aimed at counselling of the individual and a better health care system as a whole. (p.100).

By the end of 1996, BRCA testing was available in most NHS regions, leading to clinicians and public health care officials voicing their concern about the diversity of regional testing systems. This resulted

in a national standard for BRCA testing (p.104). Within this new system of familial risk assessment a triage system was employed to prioritize individuals with the highest risk. Following the triage system a client was entitled to one of three levels of care: primary- care units (general practitioners), cancer units (oncologist or breast surgeons) and specialist cancer centres (where individuals could gain access to research protocols) (p.104).

The NHS offered free and equal, but limited access to users nationwide. The more open access to genetic testing led to a run on the use of these tests as people started to enact their right to good care. As the limitations such as effort and finance are omitted with the NHS approach to health care. This resulted in an increased workload for already stressed health care professionals and scarce resources being stretched further (p.115).

The increased enthusiasm of the British citizens to seek BRCA testing indicates that in the UK as well there is a positive attitude towards genetic and BRCA testing. By referring to the right to good care and actively visiting their physicians to find out if they are a person at increased risk, the British also seem to imply that health care is something to actively seek for, thus also expressing a belief in 'empowerment'. However, the influence of Myriad Genetics on the situation in the UK has been limited. Thus, the commercial interest and advertisements do not explain the widespread ascription of the term empowerment to BRCA testing.

Patenting Genetics

However, Myriad Genetics has also tried to gain a foothold in the European market for BRCA testing. Armed with the European patent for BRCA testing and their dominant economic position they tried to force competition out of the European market as well (p.175-178). The company threatened the British NHS with legal action following the supposed infringement of Myriad's European patent rights (175-178). The British health care professionals were not moved by this threat, nor by the promise of a better testing service. In response, the UK Department of Health and the NHS professionals released an official statement that questioned the patentability of genes (p.175-178).

In the USA, opposition to the patentability of genes was hardly organised, although the American Society of Human Genetics had intervened in an attempt by Craig Venter to patent the DNA sequence of an unknown organism during the Human Genome Project (p.178). The national discussion and activism about this issue eventually emerged in the early 2000s, but was not yet as strong as in Europe, due to a difference in academic culture of patenting organisms (p.178).

However, the European discussion about patenting genes enflamed the American debate and many resistance groups offered a clear position against the patenting of genes (p.183). In 2013 the American Supreme Court decided that DNA was not patentable as it is a natural product (GenomeWeb; 2013). However, the synthetic sequence and ways to identify abnormalities to natural DNA sequences, were granted a patent (GenomeWeb; 2013). As a result Myriad Genetics began suing different companies again (GenomeWeb; 2015).

CONCLUSION

Breast and ovarian cancer are amongst the most deadly diseases in western society. In five to ten percent of the cases, a known BRCA gene mutation plays a role. This mutation results in malfunctioning of the capacity to repair damage to the part of DNA that is regulating cell division. This damage can lead to an uncontrolled cell division and a form of cancer. This results in an estimated lifetime risk to develop breast cancer between 47% and 66% for BRCA 1 mutation carriers and 40% till 57% for BRCA2 mutation carriers. For developing ovarian cancer the lifetime risks are around 40% for the BRCA 1 and 18% for the BRCA 2 mutation carriers.

Before tests to identify a BRCA gene mutation became available, a woman with a high incidence of breast cancer in her family might worry that she would also develop breast cancer. By identifying the BRCA mutation this vague worry will transform into a more precise quantitative risk estimate. This knowledge can then be utilized to make life decisions and opt for measures to prevent the disease from occurring. Thus, in a very literal sense, testing for the BRCA mutation is a form of empowerment.

Although this does explain why empowerment is a suitable term to be applied to BRCA testing, it does not account for the wide ascription of empowerment to BRCA testing. One further reason for this can be found in the hopes and dreams of activist movements and the Human Genome project of the scientific community. By emphasizing the potential benefits of empowerment, much funding and research attention went in the discovery of the BRCA 1 and 2 gene mutations.

Another reason can be sought in the way BRCA testing services have become available and have been promoted. The first heredity research institutes, GDL and OncorMed, were affiliated to universities and provided a combination of counselling and research in accordance with protocols. The private clinic Genetics and IVF Institute breached this non-commercialization agreement by providing testing to people outside the strict medical protocols. The commercial service that Myriad Genetics provided, did not include the prescribed counselling and provided test results in a binary manner. Through this commercial position and the patents for BRCA 1 and 2, Myriad Genetics was able to push the other companies of the market.

This increasing commercialization of genetic testing services may seem to be a big influence on the way BRCA testing is conceived. However, developments in the UK show that the empowering attitude surrounding BRCA testing also emerged in a non-commercial environment. In the UK the NHS provided health care at affordable prices for the entire population.

Thus, BRCA testing can be considered as a form of empowerment as it enables a woman who thinks she is at risk of developing breast or ovarian cancer with a way to gain more insight and corresponding power to the seemingly waiting if cancer might develop. The ascription of the positive associations of this empowerment, can be explained with the enthusiasm of the activist movements and genetic researchers that contributed to the development of BRCA testing service of today. The way that BRCA

tests are promoted does not seem to be an explanation for this broad ascription, as the positive annotations are present in both privatized and public health care system.

CHAPTER III: GENETIC EMPOWERMENT

The previous chapter elaborated potential reasons for ascribing empowerment to BRCA testing. The first section of this chapter discusses research showing that both consumer and providers of BRCA testing actually ascribe the term empowerment to genetic testing. This research also shows, however, that the meaning of empowerment in these ascriptions is not uniform: the authors distinguish five different dimensions of the empowerment.

By describing genetic testing as a form of empowerment one aspect of genetic and BRCA testing is highlighted. However, other consequences of this technology remain in the dark. In the second section of this chapter two other interpretations of the information gained from BRCA diagnosis can be identified: decision making based on 'anticipated regret' and a shift in the perception of one's health status. Both may lead to a change of an individual's self-perception.

The third section subsequently argues that BRCA carrier status may also impact the way an individual is perceived by a society. Parsons interpretation of the sick role and a case study involving HIV positives are used to explore this consequence. In the last section, the conception of 'biological citizenship' developed by Rose and Novas will be discussed to explain how decision making regarding a biological characteristic may be influenced by a community of individuals sharing this characteristic.

THE EMPOWERMENT NOTION

The Oxford dictionary defines 'empowerment' as "both to give (someone) the authority or power to do something, and make (someone) stronger and more confident, especially in controlling their life and claiming their rights." (Oxford dictionary). Genetic testing is considered a form of empowerment. As McAllister and colleagues indicated in a 2011 survey showed, almost all people who opted for genetic testing (40 of 41 questioned) referred to the term empowerment as "a good overarching term to summarize the patient benefits" of genetic testing (McAllister, Dunn & Todd, 2011, p.125).

In an earlier study McAllister and colleagues had analysed the reasons given for ascribing empowerment to genetic testing. They distinguished four dimensions of empowerment: (1) informed decision making, (2) knowledge about risk and disease prevention and onset, (3) the ability to make efficient use of health and social care systems and (4) an orientation towards the future of the individual self, family members and future descendants (McAllister et al, 2008).

In this later, more refined questionnaire, these dimensions were expanded with 'knowledge about one's own status', which was added to the second dimension and the 'idea of hope' that could be added to the fourth dimension (McAllister, Dunn & Todd, 2011, p.126-127). Additionally, the patients they interviewed insisted on including a fifth dimension: (5) emotional regulation. In their opinion this was an important consequence of testing which was not sufficiently considered (McAllister, Dunn & Todd, 2011, p.127).

While insisting that emotional regulation and the knowledge about the own health status play a role as well, the interviewees expressed that the genetic test enabled them to become at ease with their situation and provided ways to interact with their friends and relatives about their situation (McAllister, Dunn & Todd, 2011, p.127-128). This result in the addition of emotional regulation to the dimensions of empowerment addressed in this thesis.

Other researchers have investigated the way providers of genetic testing services promote genetic testing. In his evaluation Nordgren (2012) indicates that prominent providers of genetic testing services, utilize a form of empowerment based two lines of reasoning. First, genetic information is provided directly to the client, surpassing the intermediary role of health care providers (Nordgren, 2012). Thus, the client acquires direct control about his/her own genetic information. For a mutation carrier this means that she is enabled to increase her knowledge about the disease and options, as well as to make an informed decision, without the interference of a genetic counsellor (Nordgren, 2012).

Secondly, the genetic tests enable the client to opt for certain medical procedures or undertake preventative measures that otherwise would not be considered⁷ (Nordgren, 2012). Similar to In line with the dimension of efficient use of health and social care systems, which consumers ascribed to empowerment; this interpretation of empowerment involves enacting on the possibilities attached to the diagnosis. This kind of promotion also links up with the informed decision making dimension, as it indicates that an action can be undertaken based on the genetic predisposition.

The way providers of genetic testing use the term empowerment, has some similarities with the reasons expressed by consumers for ascribing empowerment to genetic testing. The empowerment advertisements are expressing that genetic knowledge increases power by enabling individual informed decision making, the personal ability to seek knowledge about the disease and one's situation and allows the tester to make efficient use of their own health and social care systems (Nordgren, 2012). Furthermore, the way that the empowerment notion is utilized on the websites aims to provide the potential tester with the idea that genetic testing leads to emotional regulation (Nordgren, 2012).

To evaluate if these meanings of empowerment are indeed shared by women who were diagnosed with a BRCA mutation, this thesis analyses exchanges on an online support forum. The population of the chosen online support forum predominantly consists of women with a potential genetic predisposition for breast/ovarian cancer. In light of the five dimensions of empowerment ascribed to

⁷ The genetic testing companies used in this section are part of the direct-to-consumers market. This implicates that the first way of empowering named by this company, only holds for similar business models. Companies such as Myriad Genetics who have a business model involving universities or medical facilities might not endorse this type of empowerment.

genetic testing, the use of an online support forum itself can also be conceived as a form of empowerment. In the online support group knowledge about the BRCA mutation and experiences of being a mutation carrier are shared. This shared knowledge may also lead to informed decision making and an efficient use of health and social care systems. Lastly, by reading the experiences of others the individual may gain a richer understanding of her future and may also enable her to reflect on her own situation, leading to a form of emotional regulation.

In addition to promoting genetic testing services as a form of empowerment, some companies promote genetic testing with a different notion. They suggest that their clients may want to reflect on their personal identity, in relation to their risk status (Nordgren, 2012). The reason the companies promote genetic testing in this way is concerned with providing the consumer with a self-image based on their risk status and health condition (Nordgren, 2012). This account links up with the idea that a genetic predisposition status can be conceived as a form of disease and as being unhealthy, a view that will be elaborated in detail further on in this chapter. However, this line of reasoning is ultimately linked to the empowerment discourse, since the person is supposed to react to the at risk status to prevent the negative possibility (Nordgren, 2012).

THE AT-RISK STATUS

Anticipated regret

Where the providers of genetic testing utilize the at-risk status as an indirect form of empowerment, the implication of the at-risk status for a BRCA carrier is not widely assessed. Through testing for the BRCA mutation one's perception of oneself may change from being a person with a family history of cancer into a person with an established chance to develop cancer. This step may drive a desire for certainty, in which the potentiality of cancer seems to justify the eventual measures to reduce the possibility of cancer development.

Testing for BRCA mutation does not provide the individual with the knowledge that they are at an increased risk, as the family history already revealed that developing cancer is probable. The empowering element of BRCA testing is mostly in the interpretation of the BRCA carrier status. The BRCA mutation diagnosis leads to a decreasing possibility that a particular action or measure is taken while actually unnecessary, and it enables a woman with a range of new options and considerations. Before the test, the perceived risk of cancer was subjective and the decisions related to this interpretation were personal and emotional. With the test results, the chance of getting cancer is transformed into a precise risk estimate, meaning that the decision becomes more objective.

As Tymstra has argued, however, in decision making processes related to future risks, a mechanism called 'anticipated regret' is frequently at play. In this mechanism, the cognitive and emotional node of regret are scaled by the possibility that this feeling would occur (Tymstra, 2007). The feeling of regret associated with an undesired outcome, such as developing cancer, is attached to the likelihood on this

situation. By doing so, a situation can be compared to the regret that might be experienced when a different option had been chosen.

The term 'regret' is defined in many ways, though the majority acknowledges that regret is (a) considered aversive and would be avoided when possible; (b) an interplay of thoughts and feelings are involved; (c) It is distinct from other specific and negative emotions and (d) it involves a comparison between events or processes or a process that might have occurred (Connolly & Reb, 2005). Regret is associated with comparing the outcome of a decision with a better consequence that might have resulted from choosing a different option ⁸ (Connolly & Reb, 2005).

Regret after a decision is not an emotion that occurs spontaneously, it necessarily involves experiencing dissatisfaction. In a decision process there are three ways that dissatisfaction about the decision can occur. First, the eventual consequence of a particular decision might not be as good as it was imagined. Secondly, the result of an alternative option is preferred over the consequences chosen at the time. Lastly, the way the decision was made has been in hindsight be evaluated dissatisfactory (Connolly & Reb, 2005, p.S30).

Based on these three ways that dissatisfaction about the decision can occur, Connolly and Zeelenberg distinguish two components that postulate regret (Connolly & Zeelenberg, 2002). The first involves being regretful through association and comparative evaluation of the decision outcome compared to the outcome of a different choice. The other component involves the feeling of self-blame for having made this particular choice. Individuals tend to ask themselves if they performed well in the decision process or that the result is their fault, especially in cases where the bad situation follows taking action (Connolly & Zeelenberg, 2002).

A BRCA test can be considered as a technology in which the risk of an approaching disaster, cancer or death, can be estimated and made explicit for an individual (Tymstra, 2007). The actual risk the test is indicating plays a smaller role in the subsequent decision making than the emotional load of the perceived consequences, as shown in a small study performed among women who had a new baby. They were asked to subject their child to a test that could indicate that the risk that a child had a serious disease. Most women opted for testing their child, even though the chance of harmful side-effects was higher than the disease risk that the test would indicate (Tymstra, 2007). In this small research the women seemed to think in a binary way, by stating that they at least desired to avoid the worst situation and therefore preferred to deliberately put their child at risk (Tymstra, 2007).

The role played by regret in decision making is a topic discussed in a wide variety of decision making situations, such as consumer choices (Bathae, 2013; Shih & Schau, 2011), changing the starting

⁸ This distinguishes it from the similar emotion 'disappointment'. This feeling results from comparing the outcome with a situation where the decision maker would have had more luck (Connolly & Reb, 2005).

eleven of a soccer squad (Zeelenberg, van den Bos, van Dijk & Pieters, 2001), gambling (Li et al., 2009) and medical topics such as prescribing vaccinations (Chapman & Coups, 2006) and choosing for a HIV-vaccination (Ziarnowski, Brewer & Weber, 2009).

Van Dijk and colleagues used the concept of 'anticipated regret' to explain decisions for BPM after a BRCA diagnosis (van Dijk, van Roosmalen, Otten & Stalmeier, 2008). They argue that the decision to opt for BPM after a positive test result is actually made before the woman decides to do a BRCA test (van Dijk, van Roosmalen, Otten & Stalmeier, 2008). By deciding before they have the test result revealed, the decision is made solely on statistical risk estimates and expected feelings. The strategy to avoid all risks can also be regarded as a maladaptive way of coping with the uncertainty of a future undesired possibility (van Dijk, van Roosmalen, Otten & Stalmeier, 2008).⁹

Technology infused health

Similar to the identification of the at-risk status, providers of genetic testing services utilize the health status as a disguised form of empowerment. Straightforwardly stating that a BRCA test indicates who is at increased risk and should seek preventative action is not addressing all implications of the at risk status. Traditional diagnostic technologies used in the medical profession, such as MRI scans to detect cancer, detect a direct danger to the body which might justify a surgical intervention. The identification of an 'at-risk' state is different because it identifies a possible *future* development. However, as this section will address, conceptions of disease and health are not stable and dependent on the technological possibilities.

According to William Stempsey (2002), the interpretation of these diagnostic results and decision process to take measures following the result is intrinsically value laden (Stempsey, 2002). As he argues, "If health is essentially an ability to adapt to the challenges of various environments, then our conception of health will necessarily be altered as new technologies bring new knowledge of how to make new adaptations¹⁰" (Stempsey, 2006 p.240). This conventional process of health translates to the BRCA testing as a new way to distinguish the normal from the deviant, thus the healthy from the sick and the people at risk.

The conception of health Stempsey refers to in this quote is based on the philosophy of health of Georges Canguilhem (Stempsey, 2006). Canguilhem indicates that there is no understanding of health prior to the experience of disease. In relation to the 'future abnormality' the human can conceive its normal 'healthy' state (Stempsey, 2006). Health involves the confrontation with pathological conditions and adapting to them in life (Stempsey, 2006). Ultimately, this results in the

⁹ The solution this article proposes is for medical personnel to assist in the decision making, which is exactly what the empowering idea behind BRCA testing refutes.

¹⁰ With adaptations he means ways to regain normality, such as curing the disease or prosthetics to overcome disabilities.

setting of norms which are subjective to individual choices about what is conducive to life, by which Canguilhem means being well adapted to the environment. In this sense, health is not a state, but an activity (Stempsey, 2006). According to Canguilhem, this activity can be described as the continuous establishment of biological margins which correspond to the ever changing challenges of the environment and its influences on and in the body (Stempsey, 2006). If the human is unable to live up to the norms set within the margins of health, the human is classified as unhealthy and as having a disease (Stempsey, 2006).

After explaining this conception of health, Stempsey uses the work of Hans Jonas to discuss the role of technology in conceptions of health and disease. According to Jonas, the technology has evolved from a humble servant, to an established “transcendent end” (Stempsey, 2006). In this transcendent end, the operator of technology has changed from being the user of these technologies to being the object of the technology (Stempsey, 2006). As a result, what is considered to be normal is dependent on the current state of technology (Stempsey, 2006). Stempsey interprets this conception of technology for techno-medicine by stating that the effects of a disease are mediated by the diagnostic technology used (Stempsey, 2002, Ch5.4).

In line with his interpretation of Jonas, Stempsey uses Martin Heidegger’s ideas to reveal that technology is not stable. Heidegger describes technology as a “mode of revealing”, in contrast with the more common view of technology as a means to a particular end (Stempsey, 2006). Heidegger states that the ancient Greek artisans used technology solely with the purpose of revealing truth. Modern technology, however, does not reveal what is given by nature; rather it reveals how the world can be shaped to human ends (Stempsey, 2006).

Although Heidegger does not discuss techno-medicine, Stempsey argues his theory provides important insights in how techno-medicine influences conceptions of health (Stempsey, 2006). If the state of the human body is the kind of truth that is sought for in medical practice, any conception of health will be bound to the state of the revealing technology. The nature of the human being is not something to be discovered, but something to be invented technologically, blinding humanity for any other possibilities (Stempsey, 2006).

According to Stempsey, people should acknowledge that our conception of disease is dependent on a non-natural state of affairs in the body and on socially constructed categories (Stempsey, 2002, Ch4.2-4.3). When a disease is conceptualized as such, it has an implicit connection to the notion of ‘health’. Most conceptions of disease are characterized as a deviation from what is considered to be a normal or healthy human (Stempsey, 2002, Ch4.3) In current medical practice, the state of technology and the mode of perceiving human beings is different from our past perceptions of health and normality (Stempsey, 2006).

When the individual perceives the BRCA test result as a threat that requires surgery, the BRCA mutation is already perceived as a disease and as being unhealthy. A BRCA test is taken to identify if an individual is a carrier of a particular mutation in particular BRCA genes. The meaning of an

increased lifetime risk of breast and ovarian cancer is dependent on what is conceived as a threat that requires measures, and what as a mere stating of facts.

In itself, identifying a BRCA mutation as a form of disease can still be considered as a form of empowerment, as some of the providers of genetic testing suggest. When identified as unhealthy, a mutation carrier can be enabled to opt for particular options in health and social care. However, as will be elaborated in the next section, the identification of a BRCA mutation does not lead to informed decisions, nor does it deliberately lead to an efficient use of care systems. Together with the diagnosis of a disease comes a range of rights and responsibilities that diminish the potential of the technology to empower.

The Sick Role

In the conception process of health as Stempsey portraits, BRCA testing services could be seen as a new way to distinguish the normal from the abnormal, and thus the healthy from the sick. In order to evaluate if a BRCA carrier indeed gains power to decide about his/her future, the way the 'sick' are treated in the western society should be addressed.

An author who tried to make this clear was Talcott Parsons. His concept of the 'sick role' implies that identifying disease usually comes with a relief from social duties and responsibilities and the acceptance of additional obligations and expectations (Crossley, 1998). Although developed in the context of severe or chronic illness, his theory indicates that being sick is associated with changes in the way someone is treated in society (Crossley, 1998). According to Parsons, the experience of being ill is not only a physical and biological process, but also a social-cultural phenomenon, which allocates people to social roles embedded in institutional expectations (Crossley, 1998). The 'sick role' is characterized by four features: the relief from social duties and responsibilities, the inability to regain health, the obligation to seek medical care and an undesirable asymmetrical relationship with the medical personnel (Crossley, 1998).

Firstly, during the sickness the person is allowed to have a temporary relief from certain social duties and responsibilities (Crossley, 1998). For instance, an employee can abstain from working when he is incapable to work. In order to justify this claim medical practitioners are entitled to validate claims of sickness.

The second feature of the sick role is an individual's inability to recover from the ailment herself through an act of decision or will. As a result, the sick person is largely exempt from the responsibility of getting well; this becomes a social responsibility. While this responsibility is not applicable to the sick, they have the obligation to seek technically competent or medical help to overcome the sickness (Crossley, 1998).

This obligation means that the sick person is entitled to establish a doctor-patient relationship which is characterized by an asymmetry of knowledge, competence, authority and power (Crossley, 1998). Parsons values this situation as undesirable and argues that because of this undesirable character,

the situation of the sick is temporary as the sick would endeavour to become not only healthy, but also to become free from this dependency on the medical personnel (Crossley, 1998). This means that he would try to be as autonomous in the sick position as possible.

Of course, a BRCA mutation is not considered a disease in a more general understanding of the word. Because everyone is at a risk for something, the at-risk status can be considered as a sickness if the sick is performing in the expected role and conforming to some social norms (Kenen, 1998). Accompanying the at-risk status is the “gift of knowing”. Knowledge is considered good and it is enabling people to counteract high risks; however, society can enforce pressure to make the person at risk act in a specific way (Kenen, 1998), thus establishing a relationship similar to the one Parsons described with the sick role (Kenen, 1998).

The sick role as Parsons described it, has been widely criticized (Crossley, 1998). One of these critiques is that the asymmetric doctor-patient relationship implies a lack of empowerment from a patient towards his/her medical personnel (Crossley, 1998). According to this critique, Parsons rendered the patient as passive and failed to incorporate the agency and independence of a patient when coping with a particular disease (Crossley, 1998). Another critique is the presumed recovery (Crossley, 1998). When a patient is chronically ill his endeavour is not to relieve himself from responsibilities, but to limit the suffering from the illness, which can go beyond the biological knowledge of the medical personnel.

In response to these critiques Parsons denied that the sick role does not acknowledge patients' autonomy (Crossley, 1998). However, he stated that the social structure embedding the patient and medical personnel causes an asymmetrical relation, despite the effort of an autonomous patient or the duration of the sickness. Patients are, according to Parsons, handicapped compared to medical personnel in terms of “professional competence” and “professional concern” (Crossley, 1998). With the former he emphasizes the difference in levels of knowledge and skill about medical affairs, independent of personal exposure or experience to the particular disease. The latter is the ability of the medical personnel to perform as a general trustee of the health interests of the population, thus performing the role of an independent social controller who attempts to maximize the level of health and minimize the incidence of illness. The response to the criticism that the sick role is only applicable to short term diseases was to rephrase the goal of the medical personnel. Parsons states that in the case of chronic illness the objective for the medical personal and sick person is not to get better, but to try to achieve the best possible outcome.

HIV positives

In order to evaluate the sick role, Crossley surveyed the experiences of HIV positives. According to Crossley, people who are HIV positive have lived relatively long with their diagnosis and, despite mostly being asymptomatic, are forced to live with the disruptive symptoms accompanying HIV infections (Crossley, 1998). Moreover, they have the prospect that minor problems can develop into a range of other illnesses. Thus, HIV positives are in a situation similar to the chronically ill (Crossley,

1998). However, HIV can also be viewed as a terminal illness, as infected individuals are confronted with the imminence of their own death (Crossley, 1998).

Although HIV is not a genetic disposition, being diagnosed as HIV positive has considerable similarities to carrying a BRCA mutation, as Crossley acknowledges (1998. P.9). People diagnosed with either biological label have an increased risk to get a potentially lethal illness. Additionally, their diseases do not limit daily activities, but the sick are still obliged to perform in a particular way to avoid a further spread of the ailment. The HIV positive is entitled to take HIV suppressers and to use extra protection while having intercourse. In the same vein, a BRCA mutation carrier could be expected to take action following her diagnosis.

Crossley's data show that, in line with the sick role, the majority of HIV positives have exempted themselves from social responsibilities such as employment (Crossley, 1998). However, only one person was socially forced to stop working, as he was fired from his company, whereas the majority deliberately chose to become active for the HIV movement or to quite their job due to feeling stressed or lacking energy to work (Crossley 1998). This indicates that the first characteristic Parsons ascribed to the sick role, relief from social rights and obligations, is not applicable in this case, as the HIV infection does not lead to a push by society to enforce the rights and duties associated with HIV.

Furthermore, Crossley's data provide insight in the way HIV positives regarded medical personnel. The vast majority perceived a lack of knowledge and perceptions of uncertainty of the medical field (Crossley, 1998). Additionally they report that the authoritative attitude of the medical personnel was an annoyance because they refused to listen to informed patients (Crossley, 1998). These remarks show that the asymmetrical relationship that Parsons described is not as stable as he thought it would be. Moreover, the cases Crossley collected vastly revolted against the social obligations that were associated with HIV positives, such as refraining from sexual activities (Crossley, 1998).

An additional remark should be made to put the empowering effect of a HIV positive diagnosis into perspective. Where a large part of Crossley's sample population rejected social benefits, a considerable portion was attending support group meetings which were especially centred on the disease (Crossley, 1998). This action is conflicting with their attitude towards the HIV status: they reject being distinguished on the basis of their illness, but they do participate in activities especially for people with the disease. Furthermore, where the lives of HIV positives did not seem too influenced by society, a considerable part of the HIV positives reported that they felt it necessary to promote activism for the rights of HIV positives (Crossley, 1998). Thus, even when society as a whole does not enforce action, the narrow society of HIV positives encourages and promotes certain actions. In the next section, this effect will be elaborated more thoroughly, by explaining what Rose and Novas distinguished as "biological citizenship".

The remarks Crossley concludes on the basis of his/her research that the sick role as Parson described it, does not follow diagnosing patients with HIV, or people in a similar situation, such as BRCA mutation carriers. However, the sick role as described by Parson should not entirely refuted.

The study indicates that HIV patients are struggling against the established asymmetric relation, in a way similar to what Parsons claimed is happening in health care. This kind of struggle can also be labelled as a form of empowerment, where the patient tries to gain power over the medical decisions.

BRCA SOCIETY

Although the sick role has some limitations in describing the situation BRCA carriers are confronted with, the underlying idea of a necessary asymmetrical relationship is accurate when describing health care. Someone who is diagnosed with an abnormality, is obliged to take measures to regain the health status. However as Nikolas Rose and Carlos Novas argue, in in current western society “Biology is no longer blind destiny, or even foreseen but implacable fate. It is knowable, mutable, improvable, and eminently manipulable” (Rose and Novas, 2003, p.5). As they indicate in their joint 2003 paper “Biological Citizenship”, biological images, explanations, values and judgments have been entangled with a more general contemporary 'regime of the self'.

The term biological citizenship describes the formation patient of groups aiming to exert political power. Similar to the description of “biosociality” by Rabinow, these groups distinguish themselves and are recognized by governments in both biological and social terms (Hacking, 2006; Rose & Novas, 2003). In the reading of Rose and Novas, Rabinow showed that in situations where the vitality of an individual or a person cared about is endangered, the language these individuals use to understand and describe themselves becomes loaded with biological terms (Rose & Novas, 2003).

In this biological discourse, the human is conceived as a prudent yet enterprising individual, who should actively take part in shaping his or her life course through acts of choice (Novas and Rose, 2003). While stimulating individuals to become involved in their own health care, genetic testing is also transferring the responsibility to improve health to the people themselves (Rose & Novas, 2003). Through increased genetic testing possibilities, the responsibility to keep oneself healthy now implicates both ‘corporeal’ and ‘genetic’ responsibilities (Rose & Novas, 2003). Where it used to be that people were responsible for remaining healthy through evaluating what the effects of a particular behaviour or nutrition was on the health status. Through the availability of genetic testing services, people become increasingly responsible for evaluating if a behaviour is healthy in accordance to their DNA.

Historically, citizenship has been seen as a form of belonging to a nation and sharing a common ideal and a cultural or religious unity. However, according to Rose and Novas, modern nations consist of a diverse mixture of cultures, religion and ideals (Rose & Novas, 2003). As a result, national citizenship lost its suitability, and a different idea of community had to be established (Rose and Novas, 2003). With ‘citizenship’ Rose and Novas refer to the idea of citizen projects Marshall described in his 1950 paper (Rose & Novas, 2003). According to Marshall, citizens should be defined on basis of the way authorities consider individuals and small groups to be part of the population they control (Rose & Novas, 2003).

Being recognized as a biological citizen involves both an Individualistic and a collectivistic process. Individuals become aware of their biological characteristics, such as diseases and DNA, distinguishing them from others (Rose & Novas, 2003). Through establishing the connection with a particular biological characteristic, the individual does not only identify with that biological characteristic, but also affiliates himself with the groups affected by a similar ailment. These groups share a biological characteristic and form collaborations with medical personnel and legislators to create a political and social position (Novas, 2006). With these collaborations, patients and family members take an active stance towards overcoming problems related to the biological characteristics (Rose, 2006).

An example of a political point of view on the biological citizenship involving BRCA carriers is the tripartite methodology used by the UK health care system to classify risk categories to provide efficient care. Individuals who are at a higher risk get more care interventions reimbursed, such as surveillance and preventive procedures. A person who thinks s/he has an increased risk of breast cancer is asked to draw a family tree. After classifying her/him on the basis of these patterns that reveal the risk of having a BRCA mutation, the NHS allows the people with high risk only to take the BRCA test and utilize the results to recognize the person as a BRCA carrier and let him opt for the care to which carriers are entitled.

Classes of Biological Citizenship

Biological citizenship can be categorized in different types related to specific roles in the community (Rose and Novas, 2003). For instance, information biological citizenship involves the acquiring of scientific and medical knowledge about the condition (Rose & Novas, 2003). This type of citizenship can be seen in the variety of websites and information folders that make the known information available for a broader audience.

Another form is rights biological citizenship, which campaigns for better treatment or to overcome social stigmas (Rose and Novas, 2003). The cancer activist groups named in the previous chapter and AIDS advocate groups of the eighties are explicit examples of what Rose and Novas identify as rights biological citizenship (Rose and Novas, 2003). The activists identified themselves with having these diseases, and enforced political rights and duties for the people they represent. A different example mentioned by Rose and Novas is the group of Ukrainians who were affected by radiation from the Chernobyl nuclear leakage. They formed a support group to demand health insurance and social support. They argued they were citizens of the Ukraine and had therefore a vital right for health and well-being (Rose and Novas, 2003).

The last form named by Rose and Novas is digital biological citizenship, which is mainly concerned with sharing of experiences (Rose and Novas, 2003). Due to the increase in internet usage, the process of biomedical self-shaping has been intermingled with becoming part of a biological community. Websites provide locations where individuals can not only gain information on the specific biological subject, but also get in contact with people with the same biological characteristic. The

online support forum analysed in chapters IV and V of this thesis, can be conceived as digital biological citizenship.

Between the biological citizenship theory and the empowerment notion there are multiple connections. Foremost, by being recognized as groups with certain rights and duties, the groups gain a form of power when necessary. The type of groups actively enforcing that these rights are executed, the rights biological citizens, are actively trying to be recognized as a stakeholder to ensure that individual group members can make efficient use of health and social care. In addition, information biological citizenship through sharing information enables knowledge gathering and may lead to a form of informed decision making.

However, as Rose and Novas argue: “the other side of hope is undoubtedly anxiety, fear, even dread at what one’s biological future, or that of those one cares for, and might hold (Rose & Novas, 2003).” Attaching the term ‘empowerment’ to the combination of genetic testing with a form of activism, disregards the negative sides of genetic testing. By regarding genetic testing as hopeful empowerment, other potential influences on the decision such as anxiety and fear are disregarded.

CONCLUSION

Consumers of genetic testing refer to ‘empowerment’ as an important motive to use genetic testing services. Research has shown that the meaning of empowerment in their reasoning for ascribing this term to genetic testing consists of five dimensions: informed decision making, knowledge about risk and disease prevention, efficient use of health and social care systems, orientation and hope to the future, and emotional regulation.

Providers of genetic testing services also utilize ‘empowerment’ to promote their services. Their advertisements mainly focus on the idea that consumers are enabled by the genetic information to make decisions without contacting medical professionals, and that the test result allows them to consider preventative measures. Some providers address the identification of an at risk status as an additional reason to opting for a genetic test. However, in a more detailed evaluation of their reason for promoting genetic testing with this argument, it becomes clear that these companies see this identification as a form of empowerment.

What these providers of genetic testing do not fully account for, are the effects of this identification of an at-risk status. The BRCA test transforms the mere idea of potentially being at increased risk due to a family history of disease, into a concrete, quantitative risk estimate. Such a clear number enables the BRCA carrier to calculate the best way to proceed. Nevertheless, this does not mean that the decisions are made without emotional interference. Via the mechanism of “anticipated regret”, for example, the identification of the at-risk status may influence the decision process. The potential feeling of regret a woman might experience when she develops breast cancer while knowing the risk, can outweigh the desire to follow her own values.

A different implication of the at-risk status is that it may potentially be interpreted as a disease. Following Stempsey, the health status is dependent on what is considered to be normal. As a result, it is also dependent on what can be made visible by the current state of technology. This eventually leads to being unable to distinguish the person at risk from the unhealthy person.

By identifying being at risk as a disease, the potential BRCA carrier can be tempted to take on a 'sick role'. According to Parsons, being diagnosed with a disease allows an individual to derive certain rights and duties from their health status. In the sick role the person acquires a temporary relief from social duties and responsibilities. This situation is referred to as a socially and personally undesirable situation; therefore the person has the obligation to do everything possible to become healthy again. Due to his/her inability to regain health individually, the person is entitled to seek medical help to overcome the disease. The obligation brings the sick in an asymmetrical relationship with the health care professional. The relationship is necessarily asymmetrical due the difference in professional competence and professional concern between the sick patient and the experienced medical personnel.

In a survey conducted by Crossley, the situation of HIV patients was compared to the sick role prescribed by Parsons. The result of this survey showed that the demand on social rights and obligations was not applicable as HIV patients did not enact on their social rights and do not indicate they feel obliged by society to take medication. Moreover, the relationship established as a result of seeking help following their HIV diagnosis, does not seem to be as asymmetrical as Parsons indicated. The HIV positives do not perceive the supremacy of medical personnel to be established on their superior knowledge or concern, there are merely in a position with authority over health care decisions.

In a similar vein as the example of HIV positives, the sick role as described by Parsons does not fully account for the social impacts of one's BRCA status; the BRCA diagnosis is not limiting the interaction of carriers with society. By identifying the BRCA mutation the person involved does gain insights that s/he belongs to a subsection of the population. According to Rose and Novas, such identifications of biological characteristics are becoming more common in western society. As a result, these biologically constituted groups are also acknowledged by society, leading to a certain set of rights and duties based on the characteristic. The formation of biological citizenship is established on both the individual recognizing his/her biological characteristics and society recognizing these individuals as part of the same biological group.

Biological citizenship comes in a variety of different types. Some examples are the information biological citizenship that involves acquiring scientific and medical knowledge and rights biological citizenship that campaign for better treatment or overcoming social stigmas. In the next chapters the concept of 'digital biological citizenship' is utilized to evaluate the ambiguous reasons to opt for BRCA testing and its potential implications, as the exchanges of an online support group are studied through a content and conversation analysis.

CHAPTER IV: CONVERSATION ANALYSIS

As the previous chapter indicated, the term empowerment is applied to genetic testing by consumers and providers of this service. Providers of genetic testing services also promote genetic testing as an indication of one's at-risk or health status. Where the providers utilize this aspect of genetic testing predominantly as a hidden form of empowerment, the previous chapter provided a broader theoretical argumentation to suggest that the identification of the at-risk status is of more concern and that the reasoning to opt for BRCA testing is more ambiguous than the term empowerment suggests.

In both the current and the following chapter, the ambiguity of genetic testing is evaluated through two analyses of an online support forum. This chapter presents the results of a conversation analysis, where the next chapter discusses the results of a content analysis. The first is centred on unravelling the way exchanges evolve. The latter focuses on the actual expressions to identify the actual interaction between the forum and the members.

On an online support forum, experiences are shared between people who are in a similar condition. This may result in an emotional connection and the formation of collaborations (van Uden-Kraan, 2008, Ch.1). The posts on these forum can therefore be taken as expressions of the real attitude and emotional reactions of women who have experience with BRCA.

SAMPLE

In the past decennia support groups have arisen for a wide variety of conditions and more recently online variants have come about. These online support groups have some characteristics that make them preferable for the research in this master thesis. First, posting on the forum of an online support group is supposedly anonymous, often free of charge and both temporal and spatial constraints (van Uden-Kraan, 2008, Ch.2). This arguably enables people to share personal information about themselves without obligations¹¹ (van Uden-Kraan, 2008, Ch.2).

A second benefit of web fora for the research is that the data is easily accessible. What is posted on these fora is what the person deliberately intended to post. The ability to edit the post strengthens the intention of the expression, since the person posting could have changed it if it did not express their attitude at a second glance. It should be recognized that the moderator of a web forum is able to discard an unwanted post. For the effects analysed in this thesis, this is not a problem as the

¹¹ There is the possibility of so called 'flaming', which means that offensive comments are made to deliberately harm the people participating in the online support group. As a result of these offensive remarks the users of the forum might become less open in their exclamations, but its effect is probably limited, as the offensive posts can be reported and moderators try to delete these posts immediately (van Uden-Kraan, 2008, Ch.2).

moderators of the forum analysed here actively state that they respect every opinion and option. The moderator would rather discard offensive remarks, which can be regarded as non-representative of the opinion of the community, as one of the key ideas of a support forum is to be respectable for every member.

The conversation analysis, as well as the content analysis in the next chapter, will be limited to the main section of one online support forum, accountable for over 32.000 posts¹². This forum is part of a broader American community of women who are concerned with hereditary breast and ovarian cancer. The posts are divided into several threads that concern a wide variety of topics, ranging from breast cancer diaries to fund raisers.

For the conversation analysis several threads were selected to limit the analysis to the topics that most members are concerned with. First, the selection was limited to threads with 50 replies or more. This selection is based on the idea that more replies means a higher portion of the community finds this topic of enough concern to express their opinion and view about it. The next step in the selection was conducted by reading the opening posts and discarding threads in which BRCA related issues were not addressed or another form of genetic testing was discussed. Through this selection the threads were excluded that did not represent issues directly related to hereditary cancer. Following these two selections, 84 threads were analysed that were accountable for 2.375 replies.

The communication between members of the community also occurs through a personal message system. Although this might be a valuable source for researching the attitude of the forum members, it would require a direct interaction with the members, which might influence their attitude to BRCA testing.¹³ Furthermore, the messages posted on the forum are more representative of the community's views, because the message is readable for every participant on the forum who can also reply to the post if it does not represent her attitude.

The data gained from reading and analysing the posts on the support group are only used for the academic purpose of writing this thesis. These posts are openly accessible to everyone who agrees to the terms in the disclaimer. There are no commercial interests in the use of this data and the goal of collecting these statements is educational. Furthermore, to protect personal information the names of the forum itself and of individual posters are not mentioned in this thesis. Moreover, specific threads are anonymized by providing only a Roman numeral to indicate which thread belong to which

¹² On the 30th of June, 2014.

¹³ Using the personal message system would imply actively intervening with people on the forum, through asking questions or making contact. These actions necessary to gain access to personal messages would interfere with the exchanges between members and make it unable to neutrally describe the effects of these exchanges.

summary, and specific statements are translated into a more common formulation, to reduce the chance that the personal information.

METHOD

The conversation analysis presented in this chapter describes the interactions between the members on the forum. In this kind of analysis the most important parameters are the adjacency pairs and their sequential placement of a message, or their turn in talk (Lamberichs, 2003). Adjacency pairs are words (or phrases) that are usually connected to each other to form a direct sequence in speech, for example a question and its answer. Sequential placement is the position of a particular exclamation in the sequence, which invokes a power. With this power a certain action or multiple actions are evoked and a range of options are provided for the next turn in talk, to perform a corresponding action, in line with the adjacency pairs (Lamberichs, 2003).

By utilizing adjacency pairs, the conversation analysis depends the subjective interpretation of a representative notion to distinguish what action is meant with it (Lamberichs, 2003). When a post tries to describe a particular feeling the readers of that post will read it in a particular sense. Through categorizing the words that belong to a particular action, a conversation analysis can provide a quantifiable estimate of what action-reaction sequences correspond to the thread. By statistically evaluating these occurrences among different threads the way different members interact on the forum can be evaluated.

The communication on an online forum can be considered as a form of sequence where the 'repliers' are responding to the earlier posts. The conversation analysis conducted in this chapter is collecting the replies of an action of a particular type and comparing them to the action proposed in the opening posts. Evaluating these posts and the kind of responses a particular type of opening post gets, reveals the way that the forum values the particular action from the opening poster. Additionally, the number and ways in which the forum itself is characterized are identified to provide insights in the way the forum is considered by its members. Moreover, threads that provide specific insights in the way the forum members interact with each other are also summarized at the end of this chapter.

The actual numbers mentioned here should be interpreted carefully, since the members of the forum communicate freely; the use of clear statements that represent actions is limited and a particular post can be regarded as performing multiple kinds of actions. As a result, the ascription of a particular category to a word is essentially a subjective procedure, thus the result of this conversation analysis is merely one interpretation of the actual dynamics of the forum.

Opening post

An action in the adjacency pair is initiated by the first person that posts a statement. In the format of an online forum, the topic and action sequence is initiated by the post starting the particular thread. As we saw already when discussing biological citizenship and the five dimensions of empowerment relevant

for BRCA testing, roughly two different functions of an online support group can be distinguished: education and emotional support. The education function can be understood as the possibility to exchange information about BRCA issues, the surgeries and cancer in general. This function is related to the informing, informed decision making and the effective use of social and health services dimensions of empowerment, as well as the information type of biological citizenship.

Furthermore, the online support forum can be considered as a place where women can express their experiences with hereditary cancer, and where other members of the forum can reply to this with comfort and support, thus strengthening the emotional troublesome position these members are in. This emotional support function of a support group is related to the digital form of biological citizenship Rose and Novas envisioned, as well as to the emotional support dimension of empowerment and genetic testing.

The educational role of the forum is mainly displayed when advice is sought for; posts in this category are identified with 'AA', for asking advice. The emotional support role comes to the fore when people are expressing their experiences, therefore posts in these categories are labelled with a 'I' for informing the forum about the problem the opening poster is encountering. Further differentiation is made based on the more specific topic addressed in the thread. Additionally, the posts have been distinguished between posts in which posters look for advice or support for themselves (FS) and posts that have the purpose of helping (FO). An overview of all categories used when sorting the opening posts is given in table 4.1.

| | | |
|-----|-----------------------|--|
| AAM | Asking Advice Medical | These threads address health related questions about a particular surgery or particular symptoms. |
| AAB | Asking Advice BRCA | These threads address worries connected to BRCA mutations or testing. |
| AAO | Asking Advice Other | These questions address issues that are not directly related to the other two forms. This includes themes such as: working through grief moments or health system. |
| ID | Informing Disease | Threads of this type start with elaborating the disease that the Opening post has. Such as cancer or an allergic reaction. |
| IS | Informing Surgery | Threads of this kind start with information about a surgery that is scheduled or has been previously done. |

| | | |
|----|-----------------------|--|
| IF | Informing Frustration | Threads of this kind start with expressions of frustration and use the message board to vent. |
| FS | For Self | Posts of this kind are made to gather information about questions one has or ask for care for the poster herself |
| FO | For Others | Posts of this kind are made to gather information about questions others have or are asking for care for the misfortune of others. |
| O | Other Reasons | These threads are posted neither to be educational nor to ask for emotional support. |

Table 4.1: This table represents the different categories in which the actions in a First Post are divided.

Conversation Actions

The replies posted by other users create an action-reaction sequence by reacting to the action proposed in the opening post. A reaction can either be in the form of a direct reaction to the action, thus forming an adjacency pair, or a reaction that was not intended by the original post. The categories in which the different replies are divided are similar to the categories used in the opening post as they similarly differentiate between educational (A for advice) and emotional supporting actions (S for supportive).

The difference between the supporting actions should be made particularly clear as it may not be evident. Providing comforting support occurs when the poster is aiming to express condolences, hopes and compassion with the situation of the opening post. Posts of this kind express that the poster is sympathizing with the opening poster and provide the feeling of going through the emotional process together. Whereas Comforting Feedback expresses that a particular action taken by the opening poster is good or bad and can be interpreted as an effort to make the first poster refrain from doing wrong and applaud behaviour the responder considered good.

Additionally, the posts are evaluated based on the source of their information or compassion. A post could either be referring to own personal experiences or history, or it could have a second-hand source. The difference between these categories is the personal involvement with the advice or comfort and the related objectivity of the reply.

| | | |
|-----|------------------------|--|
| AM | Advice Medical | These posts consist of information about cancer or BRCA issues as well as suggestions for surgical procedures. Questions formulated in the replies are also included in this category. |
| ASD | Advice to see a doctor | These posts consist of explicit advice to visit a particular medical professional, ranging from a surgeon to a psychiatrist. Also posts that were especially positive or negative about a particular practice were included in this category, as they display a form of implicit advice. |
| AO | Advice Other | These posts provide information and suggestions about issues not directly related to the medical field. Ranging from advice to deal with friends/family or to relieve stress, to recommendations for books to read, bathing suits to buy and music to listen to. |
| CS | Comforting Supportive | These posts provide comforting statements to the first posters that expressed their troubles and emotional hazards. Such as condolences, prayers and expressions to indicate that the member in troubled times is not alone in her worries. |
| CF | Comforting Feedback | These posts aim to provide positive feedback on the way a first poster dealt with problems and negative feedback on the people and infrastructure that seem responsible for a negative outcome. |
| OCC | Other / Chit chat | This category consists of comments not related to an action of the other categories or are every day chit chat. Items such as bumping threads ¹⁴ , or discussing a conference visit were in this category. |
| SO | Own Situation | This category is used if the poster refers to personal history and experience as a backing of her post |
| SS | Second-hand Situation | This category is used if the post is backed with more objective experiences from other people or with academic literature. |

Table 4.2: This table represents the different categories in which the actions in replies are divided.

RESULTS

Based on the criteria mentioned earlier, 85 threads were selected that both have enough replies to be considered important for the community and most relevant for a specific hereditary cancer forum. These threads consisted of 85 opening posts and 6.314 replies, which is an average of 74,3 replies per thread. The distribution of actions provided in the opening posts and in the replies are presented respectively in Table 4.3 and 4.4. For more detailed statistics about the occurrence of specific topic see attachment I.

¹⁴ Posting a word or phrase to revitalize a thread that has been idle.

| | # | % |
|-----|----|----|
| AAM | 33 | 39 |
| AAB | 9 | 11 |
| AAO | 22 | 26 |
| ID | 25 | 29 |
| IS | 23 | 27 |
| IF | 26 | 31 |
| IO | 6 | 7 |
| FS | 61 | 72 |
| FO | 29 | 34 |
| O | 6 | 7 |

| | # | Avg % |
|-----|------|-------|
| AM | 1590 | 29,6 |
| ASD | 427 | 8,1 |
| AO | 1522 | 29,5 |
| CS | 1907 | 32,4 |
| CF | 1311 | 22,7 |
| SS | 530 | 9,4 |
| SO | 2128 | 40,7 |
| OCC | 472 | 9,0 |

Table 4.3: This table indicates the occurrences actions of a particular category, both in absolute number of threads, as well as in the percentages of total threads.

Table 4.4: This table indicates the occurrences of replies in which the particular action is percent, both in absolute number as in an average occurrence per thread.

Opening post distribution

Table 4.3 displays the amount of times that the opening post displays a particular action and the percentage of cases in which this action is present. The topics displaying a supportive action of informing the forum about their situation and thus asking for comforting remarks of other forum members are distributed evenly. Only topics that provide information about non-BRCA related issues have a relatively low percentage. This can be explained by the selection of topics related to BRCA issues. Educational actions of topics involving asking for and providing information about the topic are distributed more uneven. Asking for advice about the BRCA gene occurs in only 11% of the opening posts, where asking for medical advice is accountable for 39% of the cases and other advice was sought for in 26% of the threads.

There is a high percentage of opening posts created to help the opening posters themselves, compared to the threads dedicated to helping others. This suggests that a post is often started because a person ran into problems that cannot be solved individually and therefore sought help.

Distribution of replies

The second column of Table 4.4 displays the times that a post displayed a certain response and the third column displays the average percentage within a thread of posts with this action. Compared to the distribution in Table 4.3, the ratio between educational and supportive reactions varies from the one in the opening actions. Moreover, the distribution of specific topics within a thread also shows a

difference compared to the opening posts. Comforting compassion remarks are made more often than compassionate remarks in the form of feedback. The relative distribution of advice topics also shows that the amount of medical and other advice replies is almost equal. Responding posters apparently do not give much advice to see a doctor, possibly because the recommendation to see a doctor or a specific practice can be considered too personal to discuss.

Chart 4.1 displays the distribution of replies displaying a particular educational action within a thread. The high percentage of Other Advice replies, visible on the right side of Chart 4.1, was further evaluated by looking at the actions described in the opening post. In line with what would be expected the majority of opening posts asked for advice in the other category. A more surprising result is the high correlation between the top twenty percentages of AO post and the threads that are selected to represent the attitude of the forum in the content analysis elaborated in the next chapter. Especially, the topics involving convincing relatives and friends were located at the highest percentages.

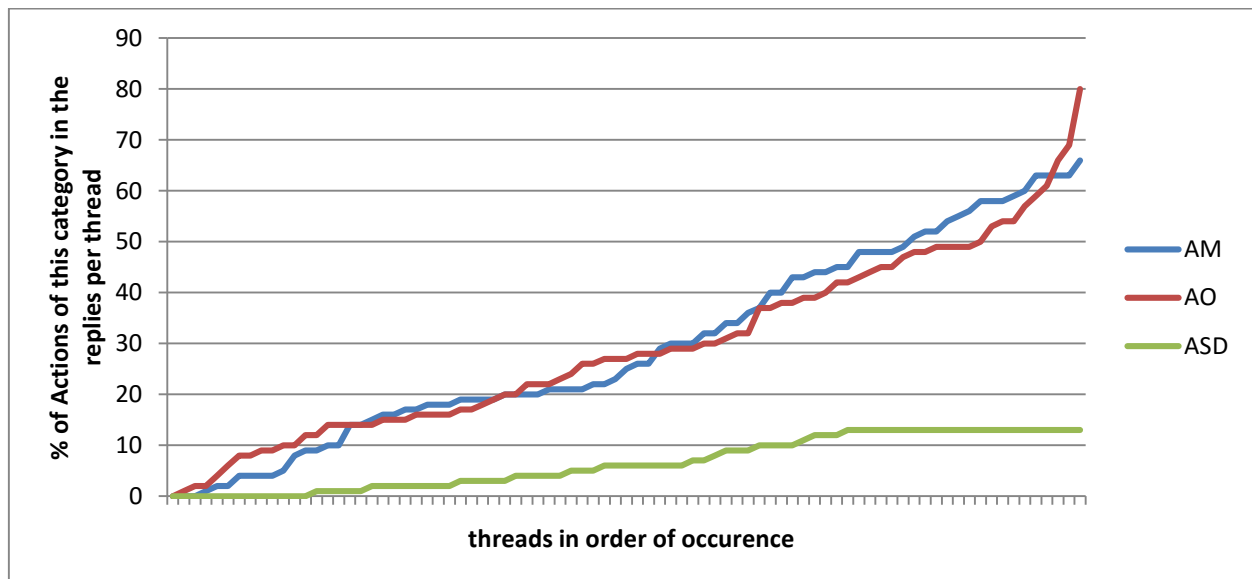


Chart 4.1: Distribution of % of educational replies amongst the threads

The distribution of threads of comforting replies shows a different picture, as displayed in Chart 4.2. Supportive and comforting feedback are present in a similar amount of threads where there is a percentage of comforting remarks below twenty percent. In threads with a higher percentage there is a sharper increase in percentages per thread, indicating that comforting replies are clustering more in particular threads and are as result more indicative for the particular reaction.

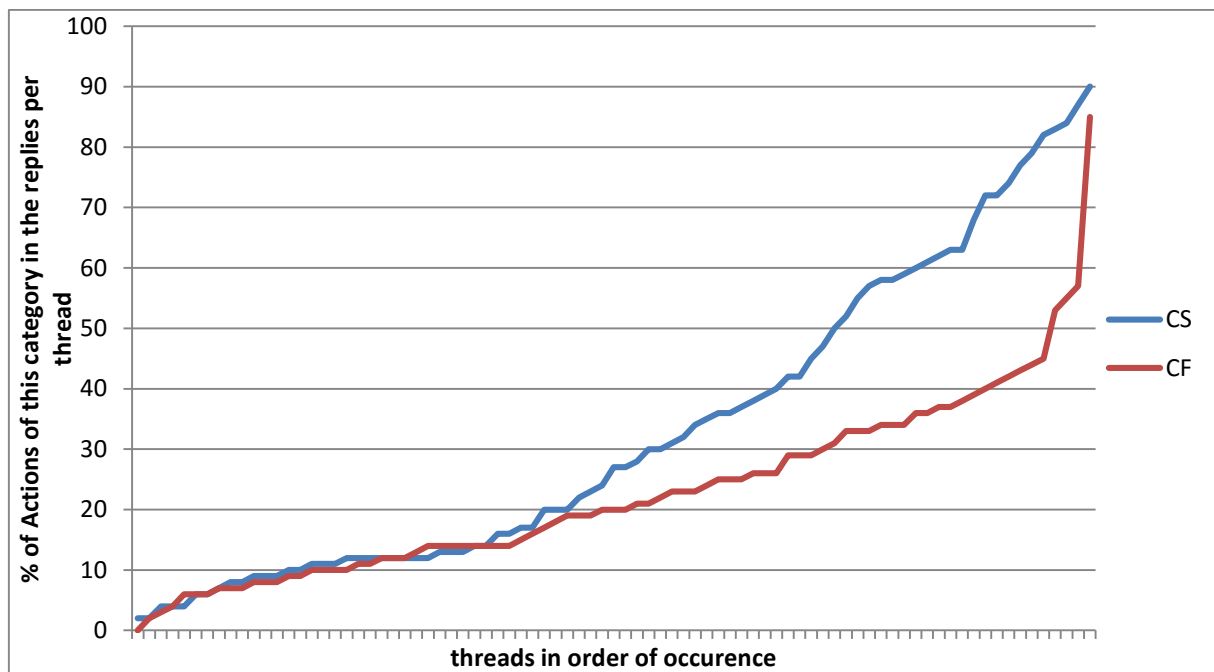


Chart 4.2: Distribution of % of Comforting Replies amongst the threads

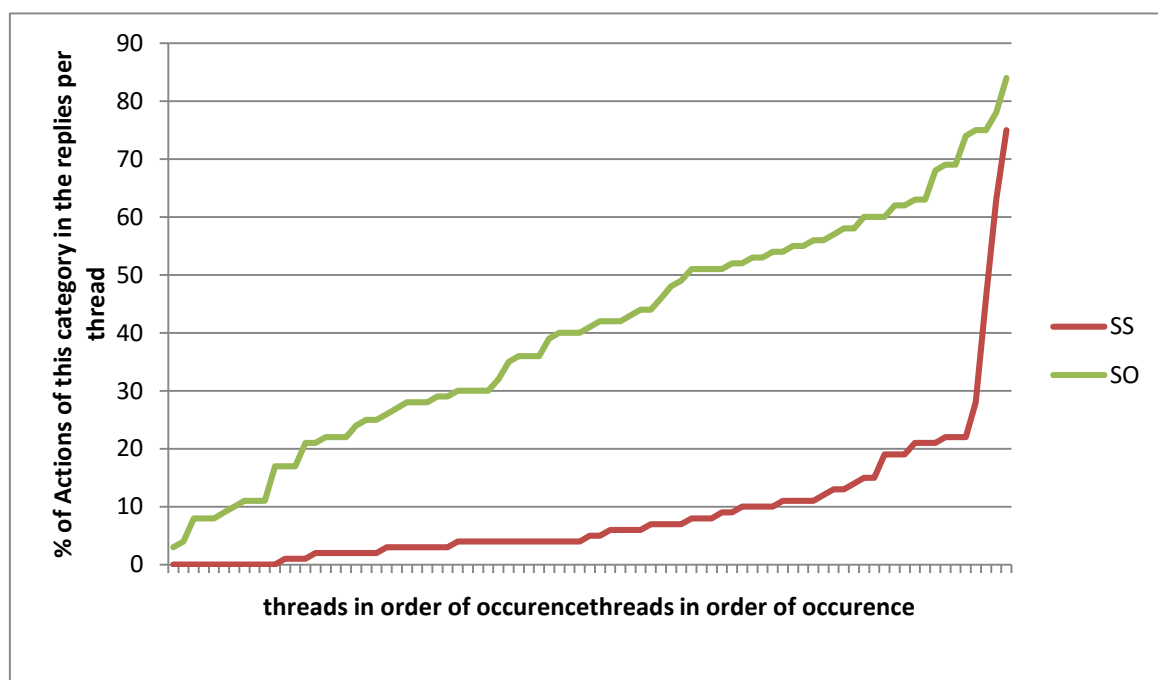
The high percentage of comforting support in a thread can indicate that the emotional state of an opening poster is leading to a high number of members acting in a supportive way. By browsing through the opening posts with a high percentage of such support, it is noticeable that in many cases the opening poster is in a bad emotional situation. This is also displayed in the action taken in the opening post: among the twenty-five threads with the highest percentage comforting support statements, the actions in the opening post were mostly posting information about the bad situation of the poster and thus asking for support. Only 7 cases asked for advice, with questions for medical advice being 5 of them. In the threads with the lowest number of comforting support statements the opposite trend was visible: from the bottom twenty-five there were 14 informational actions. Most of them, eleven over five, were posted in combination with a question.

Looking in more detail at the opening posts that caused the strange peak of Comforting Feedback on the right, provides an explanation for the abnormalities of these percentages. The four posts that construct this peak are started by women that had done something unusual and were considered brave by the forum members. The thread with the highest percentage consists of positive feedback to the publishing of a BRCA related story in a newspaper. The second contains a story about a husband and family who are against the BPM the first poster has planned and describes her efforts to opt for the surgery. The responses by the board members support her actions to have the surgery. The third thread is opened by a woman who felt despair when she was diagnosed with cancer, while she still urged her husband to go on a holiday. She was provided with help to make good decisions in her moments of despair and she got feedback on her bravery to send her husband on holiday. The last thread with many comforting feedback is opened by a poster describing the experience of feeling

different from other cancer survivors and the replies consisted mostly of remarks that this idea is new and inventive. This last thread will be elaborated more extensively in the remainder of this chapter.

Sources of Advice

Table 4.4. displays the distribution of replies referring to either the poster's own experience or second-hand experiences or academic literature. The replies that had own experience as a source show a steady increase from about 15 % till about 65 %, and sharper increases on both the lowest and highest percentages. The replies that consisted of second hand sources are less diverse and have overall a lower percentage. The thread that deviates from this steady slope and has an interesting high percentage of second hand sources is about Australian experiences with the health care system. Since this support forum is primarily based in America this would explain the high percentage of second hand sources.



The threads with a high occurrence of own experience do not show a clear topic that would explain this statistic. However, when viewing the action of the opening posts of these threads, there is a high number of actions asking advice. In the top twenty-five all opening posts ask for advice of which 15 about medical topics, 6 about BRCA and 12 about other topics. This means that responses too many questions about medical and BRCA issues are given based on the personal experiences of responders. By providing an answer based on personal experiences and personal worldviews, the advice can be highly subjective. It is questionable whether a woman that interacts with the site to be educated and to get advice on how to cope with her issues, desires the responses to be highly subjective.

Naming the support group

The findings above show that the educational and the supportive roles of the online support forum display distinctive action-reaction sequences. Furthermore, the replies primarily consist of subjective views about a topic, as the majority of posts refers to the posters' own opinion and experience. To assess how the people on the web forum are considering the advice they get, it is instructive to look at the way they refer to the forum.

In the vast majority (393 times), the forum is referred to with the name of the community or simply as 'board' or 'site'. However, sometimes board members used a different reference for the members. Besides some comical references such as "lead of the crappy 3 musketeers", most other references suggest a particular meaning. In 53 cases, a poster referred to her fellow members as "friends" or equivalent terms. This indicates that the members on the forum are considering each other as people with whom they have long-lasting relations and whom they know on a personal level.

This apparent relationship is even stronger when the support forum members are referred to as "family" or "sisters", which occurred in 44 and 63 posts respectively. Referring in this way to other members of the forum is revealing that posters feel as if they share a deep bond. As most people on the forum are carriers of a specific genetic mutation, the references to familial bonds could point to a feeling of affinity. This feeling might be induced by the notion that the women on the forum share a biological characteristic or even because they share an empowerment idea. However this kind of observation is not grounded in the data and is merely speculation.

These three specific ways of referring to members on the forum, could indicate how the given advice is considered. When other members are seen as friends and family, one would expect that their advice is also considered in a similar way as advice and support given by a biological relative or an offline friend. Since the majority of references to members of the forum are made with only referring to the forum, this relationship is not always noticeable. An offline friend or family member is known in multiple ways and their advice and support can be evaluated based on all other ways and experiences the BRCA carrier has shared with her. A forum friend is only known through the forum and there is hardly a shared history that can be used to evaluate the advice. Thus, one may wonder whether the advice and support exchanged online are sufficiently critically evaluated.

DISCUSSING THE STATISTICS

The online support forum is part a biological community (Rose and Novas), where the members search for information (information biological citizenship) and exchange their experience (digital biological citizenship). By analyzing how the forum members respond to each other, the conversation among people with issues related to a similar biological characteristic can be evaluated.

Some of the opening posts consist primarily of actions to gather advice for the person posting the threat. By asking these personal advices, the opener indicates that she identifies with the other members of the forum. Moreover, by openly informing the other members with problems the individual

encountered, the opening poster accepts the risk of humiliation. This indicates that the forum is considered to be a safe haven. One reason for this, might be shared biological characteristics of its members.

In the replies trust is established between the individual and the community by showing supportive compassion and demonstrating to the poster, that she is not alone in her situation. Furthermore, by providing advice based on personal experiences, the repliers deem their experience as a valuable source for advice to others, implying that their situation is similar.

Thus, both the individual and the community acknowledge the identification with the biological community. The relation between the individuals and the community is also reflected in the way the members refer to the forum. While the forum is impersonal referred in 393 incidences, a considerable portion of posts indicate a more personal relation amongst members on the forum: In 53 cases the other members are seen as friends, which can indicate that the members share a similar experience, as friends do. However, the 44 and 63 posts that referred to the other members as respectively family and sisters indicate a connection between members that not only is similar in situation, but also in lives.

Through these references to other users as “relatives” or “friends,” the way that experiences and advice is considered among a part of the forum members can indicate an interference between objective knowledge and subjective values. As the people who opt for genetic testing indicated in the previous chapter, empowerment involves deciding for the own future in line with the knowledge about yourself and your desired future. The advice and information other forum members provide consists of a mixture of objective facts and subjective experiences. The advice may lead to interference with the decision making by entangling the individual values and the values gained from the forum. As a result the knowledge about the experience is not objective interfering with the knowledge gaining aspects of BRCA testing. Furthermore, through belonging to this group the informed decision making dimension is altered as the decision gets colored by the advices provided on the forum.

SPECIFIC THREADS

Besides information gained from analyzing the statistics of all the posts, information on some additional threads can provide insights in the way that the forum users interact with each other. Compared to the threads analyzed in the next chapter, the five threads reviewed in this section represent some specifics characteristics of the community. By analyzing these threads in this section an understanding can be created of who are the women that visit such a forum and what they consider as important aspect of the forum.

Ages of Action

The posting under the first thread reveal the situation the women are in and specifies the age: the kind of BRCA mutation, the measures the users took, and at what age they the users did learned about

their genetic status and the age, when they did take measures. The statistical information about these threads is presented in Attachment I.

A striking characteristic of these women was that the vast majority has a BRCA 2 mutation (BRCA2 50, BRCA1 5 and Missing 13). This result indicates that, despite a lower lifetime risk, women with a BRCA2 mutation seem more active to be on this web forum. The majority of women (35 out of 46) who revealed their diagnosis with a BRCA mutation had performed both forms of preventative surgeries. In most cases (27), the women had undergone both surgeries within two years after their BRCA mutation diagnosis. Despite their increased risk on cancers, only 7 had developed breast and 2 had developed ovarian cancer before undergoing preventative surgeries. Based on the risks named in chapter II, this number of women who developed breast cancer is considerably lower than the expected 50% of a population with BRCA mutation carriers.¹⁵

In chart 4.4 the distribution of ages on which a forum member had expressed to have tested for the BRCA gene, opted for a BPM or an Ooph. As becomes visible in this chart, most of the women who filled in their ages for the operation opted for Ooph. There is only a small group of women who took the test for the BRCA gene in each age group. However, we need to take into account here that 21 women did not report on the age when making use of the BRCA test. In contrast, only 11 cases that did not mention their age, in which they did undergo an Ooph. Furthermore, three women who did not opt for the Ooph procedure explained they would follow the surveillance strategy until they had children. Additionally three women were inconclusive about their end date of surveillance.

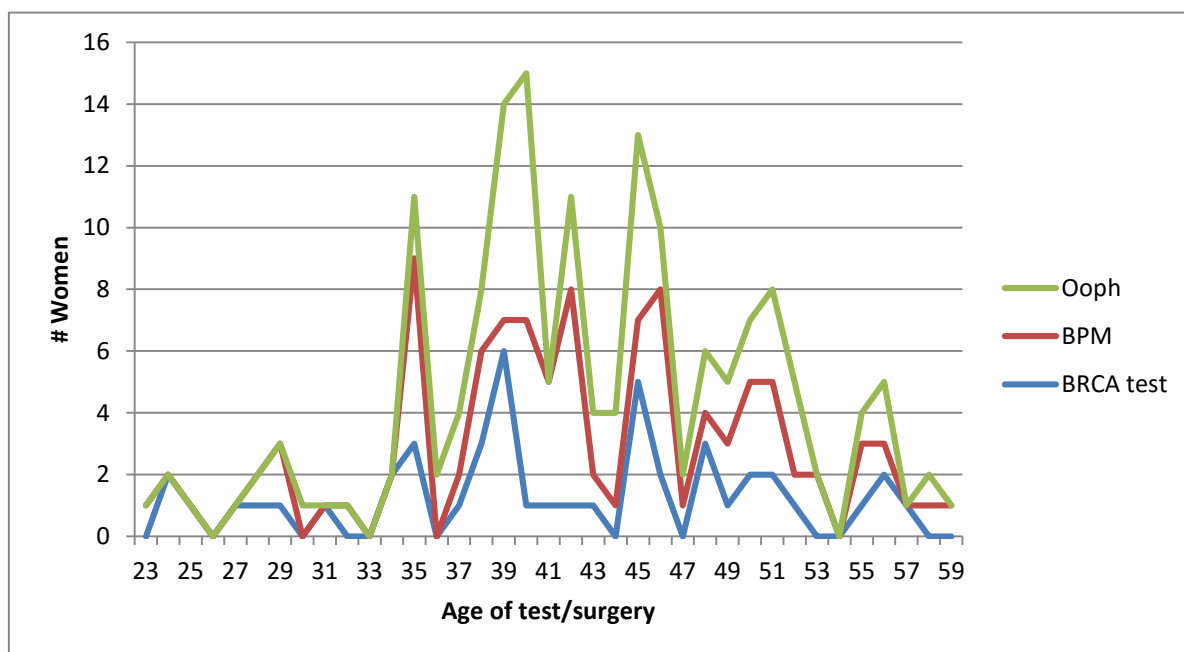


Chart 4.4: Ages on which women tested for the BRCA mutation opted for BPM or Ooph.

¹⁵ This was expected, as the preventative surgeries indeed decrease the chance on developing cancer.

These statistics indicate that the vast majority of women that have responded on this thread opted for preventative surgeries. Most of them even had both surgeries done within two years after their diagnosis. This statistic indicates that being involved on the online support forum also increases the uptake of preventative surgeries. Since empowerment can be ascribed to both being active on the support forum and opting for genetic testing and undergoing preventative surgeries, this statistic seems to suggest that the BRCA testing was indeed empowering.

Comments on the Board

This section consists of a summary of two threads in which issues with interaction on the support forum are addressed. One of these threads, created in 2005, expresses discomfort with the continual reminding that the source of information of posts is not medical professionals and decisions taken by individual members ought to be respected. The second thread, started in 2010 and addresses the decreasing activity on the support forum. An additional topic discussed in this thread is how moderation could prevent the long lasting members from leaving the forum.

The opening post of the 2005 thread addresses the annoyance of new members being advised by other members to not “take medical advice from the board”. This had occurred on several occasions and several other members have complained about it as well. According to the opening post the community the members should recognize that they are only experts for themselves and not necessarily for others. Hence, sharing one’s own experience is considered to be valuable; yet, there are no universally correct answers.

The responses in this thread exclaim the idea that most people are smart enough to consult with their medical team. While the tone of a post may be considered as harsh, this is considered to be acceptable, because the contributors are just normal people, who sometimes let their emotions flow into their posts. The goal of the online support group and website (supporting each other) is still reached.

According to a member, the positive experiences from other people and recommendations they make, are evaluated for herself and these other experiences help her guide her own choices between the suggestions. However, a different member states the wish for more discussion on the boards about surveillance, so that she would be able to make a more informed choice. She further adds, that surveillance should be compensated for the lower amount of people who chose this strategy does not provide suited weight in the discussion. This indicates that the knowledge gained from the forum is considered one-sided and surveillance is a minority issue which needs compensation to act as a good alternative.

During the replies the moderator of the site at the time, responds with her ideas about what the site should look like and how its role should be in the decision process of people. She acknowledges that the board consists of women with “extremely diverse, savvy and proactive” ideas. Therefore it is possible that the personal experience is often affecting the personal posts and advice. Moderators of the forum try to welcome everyone and not over moderate the boards, therefore they need to remind

the members about their differences and respectfulness to others, as well as respecting the medical personnel that are helping them. She closed her posts with the statement “Only together can we provide a strong enough voice to advocate for more research and resources. “

This last comment may seem strange, as it is pointed towards a form of rights biological citizenship, whereas the issues involved were mostly about the information spread and the exchange of experience. This statement can be explained through perceiving the forum as only a part of the overall community, where a people in the community on the forum and website are involved with rights biological citizenship. As stated before, the forum is affiliated with a website dedicated to providing the information about BRCA issues, thus the online support forum can also be considered as information biological citizenship.

The 2010 threads starts with an opening post expressing gratefulness about the information and support members of the forum had given to the author of the post over the past years. After these remarks she voices her discontent that the forum has lost respectful discussions. The day before she started this thread, the opening poster found out that the moderators were removing posts with controversial content. She would have agreed to removal of disrespectful posts, but the removed posts were not of this sort. With great sadness she reports hearing her long lasting friends on the forum say they feel limited in expressing their opinion and are leaving the boards as a result. A later post indicates that she had already expressed this concern to the moderators in many occasions, but a change in this attitude has not been perceived.

In replies from other long-term members this idea is shared and some respond that they did not feel treated rightfully. Moreover, some women admit they were reluctant to post because their post may end up in a deleted hornets’ nest. Due to these reluctant attitudes towards posting, some members do not feel as connected to each other as they used to. As a result many old members have left the board for other sites or to face their offline life.

When a disturbance is experienced in the ability to have a discussion, the utilization of an online support forum can be considered limited in providing empowerment. The individual who contacts the online support forum argues in favor of having a wide range of possibilities reflected on the forum, where the pros and cons of each element are expressed and where the individual can evaluate her options. For the empowerment aspects of BRCA testing this disturbance leads to improper knowledge about the situation and could result in a not fully informed decision.

Another view on the deleted posts is expressed in the difference between the amount of respect a poster thinks a post expressed, and what the reader receives from the same post. Some posts remind the members, that many women on these boards are dealing and facing risk on a disease and, therefore, not all posts will be equally evaluated by the poster and the readers of the post.

Replies from new members shine a different light on the issue of deleted posts. They express to use the site in order to make informed decision, because they do not know what information and opinion is deleted. They are concerned about not getting the whole story, because what they find on the forum is

not complete, especially when the deleted posts are from members who lived through the different experiences. However, they are reassured by both old members and the board representative, that the information is still good, but not as diverse as it could be. As argued earlier, it is this diversity that would lead to a good informed decision making, thus these issues are relevant for the empowerment.

A representative from the organization responds to these accusations with stating that they removed the posts because they were not considered supportive or not meeting the guidelines of the board. Furthermore, she seconds that respectfulness is relative and can differ between the poster and the reader. Posts are deleted when a reader reports the post to the moderator, who will delete them if they consider it to be necessary. Furthermore, she reports that the amount of posts that are deleted does not differ from previous years.

The additional issue expressed in the 2010 thread is the amount of “guests” that are posting on the forum. Some people find it harder to establish an emotional relationship with a user that posts as “guest.” A different issue with guest contribution to the forum is, that some members dislike the overall orientation of these post is negative. There are also reports on some snarky comments made by “guests.” But this is nothing specific for the 2010 thread. Rather, this complain has been made since the forum exists.

The representative of the organization responds to this discomfort by saying that the board is frequently assessing the possibility for guest posts. From these assessments they concluded that the “guest” option is available for people who are not comfortable with sharing information. This point is supported by replies from users who express their reason for posting as guest, such as dislike towards establishing relationship on the forum, being afraid of being “banned” from the forum, if they express controversial view. Some also state that their family or friends are on the forum, too, and thus they feel they cannot really express all emotions.

Of more concern to this thesis is the reply of someone expressing that she only posts as guests because she feels unsupported in her controversial choice. She feels that not all members realize, that new comer are often emotional and mentally fragile. She also indicates that the forum is experienced as a place where minority decisions are not truly supported and the women feel hesitant to express their decision.

As can be deduced from this last issue, some members of the forum report to be hindered in establishing a relationship with people posting as “guest.” Thus, the biological characteristic alone is not enough to be accepted as a part of the community as the forum members want to know the individuals’ stories. Some members are troubled by the incoherence of guest posts. Another person reports that she no longer feels comfortable with posting under her real name, because she feels excluded from the community after having opted for a minority option.

Deciding process

This thread is started by a prominent member who enquired for the reasons of women for opting for preventative surgeries to provide new members with “a better handle” for their decision to have surgeries. The opening poster holds the view that no woman wants to remove her breast and ovaries unless it would be necessary to preserve life. In her own case, the opening poster explains, the choice for preventative surgeries seemed “easier” as cancer had already developed and a breast reconstruction seemed imminent. Now, when she thinks about opting for a surveillance strategy, a nagging voice in the back of the head is saying cancer could eventually grow.

The majority of responses in this thread based their decision on a high occurrence of breast and ovarian cancer in their families. One member voiced the belief that when she does not take preventative measures she would definitely get cancer. In some other cases the members reported their fear that a BRCA carrier would be unable to see her child grow up. On a different account a member expressed that she chose the surveillance strategy, but it felt insufficient and she could not find a reason to abstain from preventative surgeries.

A considerable amount of posts express that the poster developed cancer prior to being diagnosed with BRCA mutation. Thus, they knew where they were running from and have opted for preventative surgeries almost immediately after the test result is known. The fear of a recurrence is too severe to cope with and prevention seemed the only good solution. In four other instances, the BRCA carrier opted for a surveillance strategy and eventually developed cancer. As a result they advise to choose preventative surgeries with the motivation that it was better to not get cancer at all then to identify it in an early stage.

Other members express that knowing about one’s own BRCA status causes stress to act upon the information gained but it does not provide a clear following step. One of these members developed several fibroadenomas, but did not have a known BRCA mutation, which made her decide to have preventative surgeries. Another member without a clear family history got diagnosed with small lumps in her breasts but was also not a known mutation carrier.

Lastly, someone new to the site expresses that she tested positive for a BRCA mutation shortly before and thinks it is a great comfort seeing all these women in the same situation. She started to test for the gene mutation at the age, where her mother got lethal breast cancer.

Following the posts in this thread, it seems that the main reason for these woman to opt for preventative surgery was to prevent breast cancer from developing. As they say, no one would want to have preventative surgeries when they do not seem necessary. Apparently, the BRCA mutation diagnosis, indicating that they are at a high risk of developing cancer, is the threshold for these women. Taking the BRCA test is thus seen as a form of empowerment where the potential BRCA mutation carrier takes action against potentially developing cancer in the future.

What this thread also indicates is that BRCA test is seen as the decisive step before opting for preventative surgeries. The women report that through the perceived increased risk of cancer, they feel stressed to have these surgeries as the BRCA reveals the actuality that cancer might develop. The BRCA status is conceived as a form of disease, where the only symptom is the diagnosis. A medical fix seems eminent as the chance indicates that cancer could become reality, and that potential outcome is so undesirable that it should be prevented at (almost) all cost.

The women who developed cancer advise other forum users to opt for preventative surgeries before the cancer would develop. Otherwise they would risk eventually getting cancer and may not see their children grow. These statements indicate that a form of anticipated regret is regarded important for the decision making process. The “feeling in the back of the mind,” is also a striking example for how the decision making is influenced by anticipatory regret. Rather than taking an informed decision, the potential regret steaming from any other strategy seems to push the woman into a particular direction.

A different cancer

The last thread discussed in this chapter is started by a woman who felt a distance between women who had a mastectomy to survive breast cancer and women, like herself, who had the same surgery as a precaution. She expressed that normal breast cancer survivors do not have to worry about recurrence breast cancer nor about increased risk for ovarian cancers. Additionally, she explains that many normal breast cancer survivors did not have to witness so many losses of mothers, sisters and other family members as BRCA positives.

This uneasiness with breast cancer survivors is seconded by three members who do not think their stories match well with the stories of normal breast cancer survivors. As the post of one member reveals, the survivor community does also not know how to react to genetic predispositions. One member expresses that when she considered herself a breast cancer survivor she would feel disillusioned, distrusting her breast and questioning why she would have breast cancer. Only after knowing her family history and opted for preventative surgeries, she stopped worrying and came at ease with her situation. Another member remarks that every cancer survivor would be afraid of recurrence, the BRCA status only provides a clear guideline on how to limit the risk.

A member expresses she feels so different due to her BRCA status and that she does not want to identify herself with the genetic status. Moreover, she is met with distrust, when she identifies herself as breast cancer survivor because of her relatively young age. Two other members express they had issues with answering if they had a medical condition as they thought of themselves more as “mutants” than as being ill. Moreover, one member expresses she initially felt “angry about losing the genetic lottery” and is worried about passing her gene to her children. Only later on she experienced the BRCA status as a possibility to be empowered and partake in preventative surgeries.

Besides these difficulties with thinking of themselves as members of the breast cancer community, some women expressed that the medical personnel did not understand their situation and have

treated them wrongly. One member told about her issues with the medical personnel to accept the possible breast cancer despite her young age. Where the medical personnel desired to test for a range of other possible diseases, she immediately indicated that biopsies were needed.

From this thread can be deduced that being at risk for cancer is experienced differently from actual developing cancer. Even if the BRCA mutation carrier developed cancer, she does not recognize herself as a real cancer case. Neither is she recognized as such. The difference is that the BRCA carrier is already warned by her family history, that the cancer might develop. A feeling of regret might be closely related to this experience as the discomfort of a BRCA carrier who developed breast cancer can be formed through her refusal to opt for preventative surgeries when ignoring the family history. In addition, if the woman has had preventative surgeries there was a chance that the surgery was unjustified, which could result in a distance to perceiving yourself as a real breast cancer survivor. Still, as the woman might not have developed cancer and the prevention is not justified, this can also be considered as a cause of the discomfort in identification as a cancer survivor.

CONCLUSION

The conversation analysis of the conversations on an online support forum for hereditary cancer revealed some characteristics of these conversations. The online support group is a community that allows people with a biological characteristic to contact each other and share their experiences. From a selection of threads the specific actions ascribable to a post are accumulated. Through analyzing the patterns, in which these actions partake, a representation is created of the conversations between women with BRCA related issues.

At first glance the interactions on the forum do not reveal a specific emphasis on the sharing of experience. The opening posts of the threads are rather educational or compassionate actions. Predominantly, the replies were of the category that would be expected from the adjacency pairs. Moreover, most threads were created for personal interest compared to posts to contribute for others.

The sources for a post are predominantly the own interpretation and experience of the posters themselves. In cases where the experiences are asked for or compassion is desired this does not pose a problem. However, in threads where people ask for specific information about procedures and medical advices, the information gained might be colored by the own vision of the repliers. Only in topics that specifically need external sources, these are consulted. Through this identification the community may potentially influence the values that the individual base their decision for preventative surgeries on. However, further research is needed to study these potential influences.

By describing the ways that the members on the forum are addressed indicated the way that the forum is conceived by its users. Where most posts address the forum simply as the forum or similar, a considerable amount of posters utilized references affiliated with family and friends. These reference seem to suggest, that the information shared on the forum is considered similar to information share

with friends or relatives. In addition, these ways of referring to the other users of the forum can also be seen as a way to acknowledge each other's biological citizenship.

Besides the characteristics gained from analyzing the action-reaction sequences, some specific threads were selected to reveal further characteristics of the forum. In one of these threads, women posted their ages on which they tested for the BRCA gene and had their surgeries. This thread reveals that a high percentage of women performed both surgeries within two years after they discovered their BRCA status. This fast reaction to the BRCA mutation diagnosis may raise some questions about timeframe in which the BRCA carrier gain information about their situation and their evaluation of possible measures to take. Again, this result is not a clear indication that there is more to BRCA testing than just empowering. It merely suggests that the BRCA diagnosis does not only provide power over potential disease, but also means to cure it by being a binary guide that justifies proceedings. .

Two different threads are mostly focused on discussing the reliability of the support forum as an information source. The lack of discussion, due to continual referral as non-expert opinions, deletion of conflicting ideas, and the high amount of anonymous "guest" posts, may interfere with a broad evaluation of the different strategies. As a result the support forum does not offer a clear and diverse evaluation of BRCA issues and is interfering with the ability of the BRCA test to provide the base for informed decision making and to provide knowledge about the one's own situation.

Another thread indicates reasons to decide for preventative surgeries. The major influences to opt for preventative surgeries identified in this thread are: family history of breast and ovarian cancers, distress about the surveillance strategy, and fear of recurrences. These reasons can be considered similar to reactions expected when the BRCA test is considered as an identification tool for diseases and when anticipation regret is utilized to decide for BRCA testing.

The last posts under evaluation in this chapter indicate that women who have the BRCA mutation do not feel corresponding with other breast cancer survivors. Despite having many resemblances, the women who opted for preventative surgery express to feel different in perceiving anxiety about cancer and feel misunderstood by breast cancer survivors. The identification of a BRCA mutation carrier can become the source of a feeling of regret when cancer actually develops as she has been aware of her increased risk. In addition, the BPM that both the BRCA carriers who opted for preventive surgeries and breast cancer survivors have endured, is considered differently, because the BRCA carrier experienced additional regret as her surgery could have been unjustified.

CHAPTER V: CONTENT ANALYSIS

Since BRCA testing is a form of genetic testing, the members of the online support group for BRCA related issues can be considered similar to the consumers addressed in the survey, addressed in Chapter III. As a result, the five dimensions that came forth in that research, should be considered as also representing the reasons to apply for genetic testing of the women on the online support forum. The conversation analysis conducted in the previous chapter indicates that being part of the BRCA community involves a process of conforming to the ideas of the community. The influence of the support forum on conceiving BRCA testing as empowerment is predominantly visible in the limitation on informed decision making and knowledge gaining. Though, an actual direct influence was not perceived, as the information gained in the conversation analysis predominantly reflects the sequences on the forum, without evaluating what actually is exchanged.

In the following chapter the results from a content analysis of the interactions on the forum will be presented. In this more detailed analysis of the conversations will provide an overview of the statements that people on the forum make on particular topics. The topics have been selected based on two modes of BRCA related issues: reaction strategy and interaction with others. Based on these two kinds of issues the forum is evaluated to reveal if these five dimensions are reflecting the reactions that an empowering technology would comprehend.

Under the first mode, threads are selected that involve reaction strategies on BRCA test results. As described in Chapter III, in order to be considered as a form of empowerment this knowledge must result into an action. Threads that discuss the different strategies a BRCA carrier may also contain responses to the BRCA mutation diagnosis. The power that in this mode is sought for is a way to overcome the potential lethal disease. Without the BRCA carrier diagnosis the woman was to wait if a potential cancer would develop or not. By testing for the gene mutation she would be more educated in choosing ways to prevent cancer from developing and prevent her from suffering the perceived troubles she experienced when her family member had cancer.¹⁶ By selecting threads that involve first mode the attitudes of BRCA carriers can be analyzed on the three of the dimensions of empowerment: informed decision making, efficient use of care systems, and future orientation¹⁷.

For the success of this dialogues in resulting in empowerment, the emotional state of the BRCA carrier is important. As Parsons (Crossley, 1998) described in the sick role, the medical personnel occupy an

¹⁶ Before a woman has reasons to believe she carries the BRCA mutation, she would have a family history of cancers. Otherwise the claim that a genetic predisposition ran in her family would not sustain.

¹⁷ The informed decision making dimension of empowerment is applicable to the decisions made by BRCA carrier herself, otherwise this would not be considered as a dimension of the term empowerment. Similarly, the BRCA mutation diagnosis would only lead to efficient use of health and social care, if the options and decisions would be given to the person at the center of the available health and social care systems, as she would be the person with the best view of the possibilities.

asymmetrical position compared in health care, based on knowledge, competence, authority, and power. To engage in a dialogue with the medical professional the BRCA carrier should at least be as emotional stable to pursue her own values and opinions about the possible strategies to opt.

The second mode involves issues that the BRCA carrier experiences in the interaction with family members and friends. Selecting threads on this form of issues leads to analysis which primarily addresses the emotional regulation dimension ascribed to empowerment. In a less direct way, these threads would also reveal if the future orientation and efficient use of care systems dimensions are applicable to BRCA testing. The dimension that would not directly be perceivable is the dimension of gaining knowledge about the risk and disease prevention and onset, as empowerment in this dimension involves a different, more objective, way of enacting, namely through knowledge sources such as the medical personnel or the website itself.

Besides these two forms of issues that have been discussed other issues of the BRCA mutation status have been expressed in the Opening Posts, for instance: the role of the insurance company is one another way to address the empowerment, but these kind of issues are too dependent on the specific situation. A general statement about its role in empowerment, would be inconclusive. Due to the lack of time, this thesis is limited to these two, as topic involving these issues would allow to cover the dimensions of empowerment enabled by an online support forum.

METHOD

The statements presented in this chapter have been derived from the original threads by a three step method to indicate the kind of attitudes expressed on the forum. Firstly, based conversation analysis performed in the previous chapter, a subset of threads has been selected in which the Opening Posts involves an issue related to the two modes of empowerment named in the introduction to this chapter. The threads consist of 18 threads involving the reaction strategy mode and 7 concerning the interaction to others mode.

Secondly, from the threads selected in the first step the statements relevant to the topic were selected and summarized in the reports displayed in Attachment II. In order to reveal the potential impact of an individual's opinion on the opinion that a majority has on the board, the persons posting these statements have been divided into four categories of posters. "Opening poster" refers to the person that starts a thread. By starting a thread this person is revealing that she finds this topic of high importance and would not categorize it as a subject that would be submitted under a different thread. This means that throughout the thread this posters opinion is highly valuable.

A different kind of post that is highly valuable is a reply from a person that is involved with every topic on the board. Based on their noteworthy presence in the conversation analysis performed in the previous chapter, these people are called "prominent members". Since these members post almost everywhere, their opinion could be argued for to correspond neatly to the majority of ideas that are communicated on the boards.

The two other categories are “members” and “guests”. As a member of the site, the person has registered and potentially is sharing her ideas through multiple boards. However, their impact on the site is not as memorable as from a prominent member, thus it is unknown to what extent their ideas reflect the average opinion of users of the forum. Whereas people with a guests username who had not subscribed to the forum for this particular post. Therefore their correspondence to the shared ideology on the site is not perceivable.

Besides these categories there are some people that should be named extensively in specific topics. Some people, such as the so called “queen of surveillance”, should be regarded as being similar important for a particular subject then major contributors of the forum, as they mentioned their attitude multiple times this highly influencing the attitude to the specific topic. Also when the person claims in her post that she speaks for the moderators or is one of the founders of the community, these posts are recognized as a board post.

As a last step, the reports were analyzed and the most relevant posts were distilled to elaborate more on the ways that BRCA testing could be considered empowerment. With the posts that indicate the issues these women have with the selected topics, general statements could be made to reflect the majority opinion of BRCA mutation carriers. Additionally, these views will be discussed in light of the theories and data presented in the previous chapters in order to clarify if the way the women on the online forum discuss their issues related to the BRCA status should be considered as a form of empowerment.

MEDICAL EMPOWERMENT

The empowerment ideology implicates that a BRCA carrier will take an active role in the collective decision process. By informing herself on the risk of cancer, the carrier of a BRCA mutation can evaluate her personal risk and as a result make the decision that is most suited. While doctors and other medical personnel still would be contacted to discuss the options, the decisions about how to proceed could be made in a collaboration between the medical personnel and the BRCA carrier, in which the patient takes an active role. This increased involvement in medical decision making touches upon three of the five dimensions of empowerment. Testing provides insights in the individual lifetime risk for developing breast and ovarian cancer, enabling her to gather information about the subject, and making decisions with a vision of the future.

By analyzing the regrets that the women voice on the forum, the validity of this medical empowerment claim can be asserted. A BRCA carrier would post her regrets on the forum when the result of the decision taken does not live up to the expected. The regret voiced in the selected data can be both seen as an emotional reaction to the procedure and dissatisfaction with the end result. We will address the forms of regret voiced about the end result first, before turning to the emotional reaction.

We can distinguish four categories of dissatisfaction with the end result, which are brought up in Opening. Firstly, the BRCA carrier can voice here regrets about the decision process, due to the way

she has been treated by her medical personnel. Regrets in this field are an important for the empowering ideology as the struggles between the BRCA carrier and medical personnel indicate that the decisions had not been taken in a balanced manner, where all parties have an equal saying. Secondly, there was dissatisfaction voiced about the result of a BPM, because the posters were unsatisfied with the aesthetic result of the surgery. This was mostly voiced with regards to a negative impact on the posters' sex life. Regret based on similar grounds was voiced against the Ooph procedure, though the unnatural early menopause was mostly named. Lastly, threads about the surveillance strategy can also be regarded as a critique on the preventative surgeries, but these posts also allow an alternative interpretation of the information gained from BRCA testing.

Emotional load

The decision to perform a preventive surgery, which implicates that a female body part is removed, involves emotional hesitance to a great extent. (II)¹⁸ Multiple women described that they occasionally felt anxious and doubtful whether they would go through with preventative measures. (V) This feeling is understandable as the women decide on performing a surgery which would remove her feminine parts. Even though, the risk on complications is not substantial and the female parts are not necessary for survival, there is some risk involved and some change in aesthetics is inevitable. Members suggested that these feelings should be addressed before opting for the surgeries, as the BRCA mutation carrier should be at ease with her decision. (II, III)

However, the women on the forum who opted for the preventive surgeries, utilized on multiple occasions statements such as "being intellectually ready" to indicate their desire to perform preventative surgery. (II; V; III) Similarly feelings of doubt and anxiety are regarded as "the wrong state of mind". (II; V; III) Thus, the women seem to indicate that performing the surgeries is the right action as a response to assessing the risk, whereas the emotional hesitations are regarded as bad and temporary. (II; V; III)

In various examples presented in this chapter, a similar line of reasoning can be noted. There are multiple cases where posters on the forum are balancing minimize risk and dissatisfaction. (II; V; III) Many posts on the forum remind the members to respect every opinion on the subject as all women are different and thus are in a different emotional situation that lead to individual experiences and thoughts. (V) However, often warnings are attached to this sort of statement that cancer can develop before someone is emotionally ready. Some women describe a pressure steaming from these warnings, which could influence their own emotional balance. (V) These posts are responded to by members and prominent members, with expressing their satisfaction with postponing the surgeries until they accepted their body. (V) A guest reported that she was satisfied even to have waited until the cancer developed. (V)

¹⁸ The roman numeral between brackets indicates that the previous statement was derived from a thread summarized in Attachement II.

Ostensibly, the emotional reaction to the BRCA mutation diagnosis is conflicting with the emotional regulation dimension of the empowerment ascription to genetic testing (Connolly & Reb, 2005). The prosperity on preventative surgery rather seems to generate despair and anxiety. However, the emotional regulation dimension is mostly about providing the mutation carrier with a way to discuss her situation and not about leading her directly to emotional stability. While the statements about “being intellectually ready” are in line with the idea of emotional regulation, the other posts indicate that, that not all women are successful in regulating their emotions and end up in an uncertain situation.

As it seems, those who ascribing the term “empowerment” to BRCA testing do neglected these negative effects. Nevertheless, these emotional reactions following the BRCA test indicate that the test has not only positive dimensions. The emotions may be initiated by the conflict between action and values or based on a fear for negative results; still they are part of the experience of undergoing genetic testing.

As these emotional struggles indicate, the BRCA mutation diagnosis could count as a distinctive test to justify preventative surgeries. Where the aesthetic changes and the surgery are feared, preventative surgeries is was should be done. In this process, it does not seem that the BRCA test empowers them to actively lower the risk of cancer, rather it allows them mentally to justify the removal of the breast tissue. The intelligent state referred to, clearly displays the identification of the at-risk status is of predominant concern.

Improper medical personnel

A story from a woman who had developed an infection following her BPM, reveals that the medical personnel does not always provide proper follow-up care. (V) She did not get a nurse appointed to her and the chart was handled wrongly, which resulted in her needing to tell her story three times and eventually getting medication prescribed which she was allergic to. (V) Two prominent members respond to this story by stating that medical personnel could not be fully trusted in the medical concern for their patients. As in this situation the aim was not to make the patient healthy, but to get her out of the hospital, with an improper prescription of medication as a result. (V) Two other members expressed similar experience and tell they prefer to go to pharmacists as they are more fit in selecting the right medication. (V)

Additional stories report that the medical professionals are not able in all cases to keep up with the knowledge about genetics and medical research. (I; V) In some cases the medical personnel responded insufficiently to the options suggested by the BRCA mutation carrier. (I) As a result the medical personnel were instructed to treat the patient not in line with the suggestion made by the BRCA mutation carrier. (I) In some cases the instructed treatment did not work properly, leading to problematic side effects and even the development of cancer. (I)

Experiences of this sort are responded to with anger towards the way these medical personnel treat their patients. A popular opinion on the forum was that these doctors are fully responsible for the

problems that occurred. For instance, when a woman developed breast cancer after her idea to have a BPM was not followed, the medical personnel are to blame. Medical personnel who either read these experiences on the forum or were addressed by a letter, respond with apologies and promised efforts to educate themselves to prevent similar situations in the future.(I)

Also some posters noted that the options available were not carefully discussed between the medical personnel and the mutation carrier. (XVII) Two posts report they feel scared about their BPMs coming too late after reading these kind of stories. One member reports about her conflict with the medical personnel who told her she is too young for an Ooph, while she thought of herself as a ticking time-bomb where cancer could strike regardless of her age. (XVIII)

This story is responded to with an experience from a different member whose doctor told her that she will not develop cancer when surpassing your mothers lethal age. (XVIII) As she developed cancer a few years later, she suggests that at least increased surveillance measures are needed when the woman gets older. (XVIII) Two other guests respond that they also feel that doctors do not really understand what it means to be at high risk, and that they are too hesitant to not overly alarm their patients. (XVIII)

The experiences expressed in these threads indicate that the empowerment the BRCA mutation carrier aims for is not acknowledged by all medical personnel. According to the five dimensions named in Chapter III, BRCA testing should enable informed decision making and allow efficient use of health and social care systems. Essential for these two dimensions of empowerment is the recognition of the patient by the medical personnel as a partner in the dialogue about the decision and her ability to explore options. When these roads are hindered by the medical personnel, the BRCA test cannot be considered empowering in these dimensions in some case. However, since BRCA testing is a relative new technology and there are also many experiences where the dialogue did take place and the options were available, this conclusion does not hold true for BRCA testing as a whole.

Pushing decisions

Similar to the issues discussed in the previous section, some posters report feeling pushed in their decision following a BRCA mutation diagnosis. In some instances the women on the forum express that their decision to opt for preventative surgeries was to some extent pushed by their medical personnel. (V; XII) One guest reports she thinks these pushes for a specific medical procedure only happened in the US. (V) However three replies reveal a different story as one member said she felt empowered in making an individual choice, while a different member is confessing that the push she experienced was caused by the possible breast cancer. (V) Lastly, a guest responds that the BPM choice was not pushed; the decision for surgery after developing cancer feels more like pushing. (V)

A different guest reports on her problems with the insurance company that does not want to pay for the surgeries. Moreover, she was unable to choose a healthier lifestyle, as the first reply advised her, due to her husband not complying. (XVI) Also a guest points out that she also feels like she is been treated by her doctors as if she is a special case. She expresses feeling frustrated that she thinks

removing body parts is “normal,” but also experiences herself as a pioneer to whom the concept of “normal” does no longer really apply to. (XVI)

Similar to the findings in the previous section, these experiences reveal that empowerment is not achieved in every situation. If the women experience a push of some sort, it implies that the decision on BRCA testing is not made solely by the woman who is at risk, this could be seen as an interference with the empowerment aspect of BRCA testing. The problems with insurance companies and the husband also indicate that the BRCA mutation carrier is not enabled in all cases to efficiently use the health and social care options. Nonetheless, the remark made in the previous chapter is still valid, as these examples are mere special occasions and they do not reflect the whole technology.

Dissatisfying BPM

Dissatisfaction following the result of a BPM is reported occasionally in combination with discomfort prior to the surgery. Some women, who thought before the surgery that the results would not necessarily meet their expectations, regret their decision later on to some extent. (I) However, also women who regarded the surgeries as “not much” feel regretful about the loss of feminine body parts. (I) The reported regret comes in both an emotional reaction as well as physical discomfort such as occasional aches and pain when touched. (I)

The most common dissatisfaction named is grounded on the changes in sexual activities. When the female parts of a woman are removed, women report a loss of libido due to hormonal changes or at least a change in the sexual acts. Among the members of the forum this idea is regarded as merely a temporal issue that mainly takes place in the head. (VII) It is suggested that a woman should perform sexual activities after surgery similar to prior to the surgery. By doing so the mental annoyances eventually would go away (VII). Talking to the bed partner and going to a therapist were also suggested to overcome this annoyance. (VII) However, in one case, the improper communication with the partner eventually resulted in dissatisfaction and a disruption in the relationship. (IX)

Issues with the change of sexual patterns are reported because with the BPM the nipples and breasts have lost sensation when touched. (VII; IX) A guest and a member voice their opinion that the medical world is lagging behind in providing a proper reconstruction that spares sensation. One of these members even stated: “to me sensation may be more important than perfect looks!” The loss of sensation issue is making them hesitate about opting for the surgery. One of these hesitated members expresses that because she is a lesbian, she does not decide on BPM as breast sensation is regarded of upmost importance in this community (IX)

Although forms of dissatisfaction were named that did not involve sexual practices, these mostly address practical problems caused by an improper surgical procedure or with not yet having reached the breast reconstruction stage. Examples of these sorts of dissatisfaction are overly expanded and hurting nipples, unnatural breast size, non-aesthetic pleasing breasts, and visible scars. These practical problems are considered minor issues and most women on the forum consider the BPM as good and satisfying.

However, one member who posts as a guest for this topic is expressing her regret doing the BPM when she still was emotionally wrecked from the Ooph three years prior. (IV) At the time of this post, she is one year post-op and regrets the BPM, because she thinks that her breast and body look ugly. (IV) A guest has responded to this harshly by stating that the member should “get a grip”, and that she should be glad she did not die of cancer. (IV) Although this is only the opinion of one guest and it is responded to with the pledge that everyone should be able to express their emotion on this board, posting of regrets do not seem to be the well accepted norm. (IV) Rather, the atmosphere on the web forum is somewhat hostile to negative comments on preventative comments as can be seen in the necessity perceived by the board members to deliberately make room for posts that voice regrets to be made without judgment.

A similar experience of regret after a BPM is based on the occurrence of side effects to the BPM procedure. In a story from the woman who got an infection following her BPM, the responses did not relate to the procedure. (IV) The new disease was considered as a different development separate from the deliberate risk that the woman took when she opted for the surgery. (IV) In a different thread an Opening Poster discusses her experience with discovering a lump in her breast, despite having had a BPM done. (VI) As it turned out the lump had grown in the scar tissue that grew as a result of the BPM. This discovery is responded to members with disbelief and the statement that she did everything right and thus should not have developed cancer. (VI) Two other members and a guest express that the story of the Opening Poster is their reason to not opt for the surveillance strategy. (VI)

As these multiple examples indicate, the women are not always satisfied with the result of BPM in every case. This justifies the emotional hesitation discussed earlier, as apparently the risk of undesired consequence is present in the BPM surgery. The main source for dissatisfaction, the negative impact on the sexual activity, can be considered as an important change to the lifestyle of the women. Similar to what has been argued in the previous sections, these expressed discomforts seem to be considered as mental annoyances and therefore of less importance and retainable by ignoring and accepting the discomfort and changing routines. The decision for a BPM does not only involve making an informed decision and having a future orientation, as the dimensions of empowerment entail. The regrets that are expressed suggest that the situation of being a BRCA carrier dedicates the choice for preventative surgeries on them. In the threads discussed above, there is no regard for the surveillance strategies, though this options would also empower them to decrease their risk of breast cancer.

The members on the forum are expressively using anticipate regret, by comparing the regret after the BPM with the potential regret of the cancer and use this comparison to convince themselves and others that the regret should be overcome. The BPM is perceived as a necessity due to their diagnosis thus the women on the forum react to it in a similar the way as a sick person to a disease. As described in Chapter III, a sick would need to seek for ways to overcome the differing from normal or at least to minimize the risk of the abnormality to limit social responsibilities. By describing the surgery as necessary, the BRCA carrier acknowledge that this ailment would interfere with the future

functioning. That the diagnosis is merely a categorization enabled through the determining technology is omitted.

The one member that considered her BPM result as undesirable is not considered to have an acceptable opinion. The negative responses to this post created an unfriendly atmosphere where people with similar regrets might not feel welcomed to share their experience. The necessity of reminding the forum, that all options should be met with respect, does not really resolve the obvious tension. These reactions indicates the existence of a majority opinion on the forum about what is appropriate for a BRCA carrier and what isn't.

Dissatisfying Ooph

The forum members express themselves differently about the Ooph surgery then they do about the BPM. To avert breast cancer, surveillance is still an option, ovarian cancer is regarded as a "silent killer". However, removal of the ovaries and parts of the uterus, as involved in this procedure, also cause emotional stress, due to often unnatural early menopause and the loss of fertility.

With two threads opening in 2008, two in 2009 and one in 2012 it is noteworthy that these discussions are not held within the timeframe that most posts in the sample were posted, 2005. Of course this does not indicate that the issues discussed are not relevant for all times, but it reveals that the issues were of lesser priority. A second noteworthy point is that within these three threads one guest is vividly taking part in the discussion and started the last thread herself. However, in posts of a different subject, she does not come forth as a major contributor to the forum. Furthermore, the prominent contributors to this forum have not responded to this thread, which is also indicating that these concerns may not be shared with all members and the posts do not reflect the majority opinion.

The thought that regrets and decision issues involving Ooph are not of primary concern for the majority of members, is shared by two of the Opening Posters. (XI) According to them, most women on the forum have done the Ooph surgery, as if there were no cons to it, whereas they experiences anxiety when they think about removing her ovaries. (XI) Some other members and multiple other guests have experienced similar troubles while deciding for Ooph. (XI) They express that deciding for BPM was easier as the breast did not perform a function whereas the ovaries did. (XI; XII)

The prominent member responded to these hesitations with her own story. (XI) She has been in the same positions as the hesitating women, but eventually reached an age when menopause would inevitably come naturally and decided that it was time for the surgery. (XI) Additionally she reports that despite being a BRCA-2 mutation carrier, she does not have a family history of ovarian cancer. (XI) In response several members who had a dense family history of ovarian cancer incidences responded with incentives to opt for the surgery. (XI) Some guests report in a different thread that they are also waiting until their yearly risk has increased, in order to mentally validate the procedure. (XII)

Regrets about the procedure are mainly aimed at the troubles with the early menopause, although one Opening Poster has read some articles that indicated a link between Ooph, hearth and bone diseases.

(XIII) Another member expressed that she was advised to postpone removing her ovaries for this reason. (XIII) However, other members interpreted this link in such a way that the disease was also a result of the early menopause. (XIII)

The issues following the early menopause mostly involve problems with sexual activities, such as a hormonal change and loss of libido. To overcome these sex related issues members suggested taking additional hormones to regulate the sexdrive. (VIII) Moreover, women with these issues were advised to start experimenting with their husbands to reclaim a regular sex life back. (VIII) One woman remarks to this advice, by stating that when you are single you can forget about experimenting with your partner. (VIII) Another member reports that in her opinion, this must to be the reason that most women, who were single when having mastectomies, will remain single. (VIII) However, some other members report that after the ovaries were removed, their orgasms have lost their usual “zing”. (VIII) This is regarded as a great lost and some women added that they wished they had a more active sexlife in their youth. (VIII) Other members report insufficient natural lubrication in the rare moments they are in the mood, and as a result they are advised to use fabricated lubrication. (VIII)

The characteristics of the posts on this topic and the thoughts expressed by in the posts indicate that issues with Ooph are not regarded as a prominent concern for people with a BRCA mutation. This is remarkable, since the statistics presented in Chapter IV suggest, that most BRCA mutation carriers had performed these surgeries. It might be reasonable to account for this difference by pointing to the opinion often expressed that deciding to have an Ooph is a “no brainer” because the possibility that ovarian cancer is detected in a late and lethal state is thought of as revolting. Thus the association between the BRCA status and a form of disease is even more present than in the topics related to BPM surgeries. Additionally, the role of anticipated regret in the decision making before the surgery is directly perceivable in the labeling as a “no brainer”.

Still some women report to be anxious about ovary and uterus removal or to be dissatisfied with the sexual result. Similar to the reactions after a BPM surgery, they compared the experienced anxiety to the anxiety about death - and this line of reasoning was posted to influence the opinion of the hesitated and dissatisfied. The sexual issues are attained with a change of routine and external lubrication. Thus, emotional issues about the Ooph are regarded as a minor hurdle that could easily be overcome by reassessing the situation and the remaining annoyances should just be accepted. The question remains to what extent the decision for an Ooph is made out of free choice and to what extent the potential regret of the fearful cancer is destabilizing the decision process.

Surveillance

Throughout different posts there appears to be a minority for which the named issues resulted in refraining from surgeries as they followed the surveillance strategy. This strategy consists of self-examination for breast cancer surveillance and two annual medical screenings to detect breast and ovarian cancer at an early development stage (Vasen et. al., 2005). These women, as a result of a dialogue with their medical personnel or on an individual decision, chose to not partake in surgeries

and utilize the knowledge gained from BRCA testing to overcome the worst effects of cancer. The ability to choose surveillance strategy can be considered part of the empowerment notion as it enables the dimensions: informed decision making and efficient use of social and health care system.

One of the Opening Posters, who felt emotionally incapable of opting for surgery and therefore chose surveillance, expresses that the majority of forum members do not choose this strategy. (XIV) A few replies, including replies from two prominent members, responded, that even though the majority has chosen the surgical option, there are multiple people doing this option and the forum would like to hear these voices more often. (XIV) Additionally, multiple remarks are made indicating that the subset of women on these boards did not represent the average population as the responses of women who had surgeries overpowers the voices of the women under surveillance. (XIV) Therefore, users are advised to not take findings on this board as a basis for their own decision (XVII)

Several other posters also report on their decision to take the surveillance strategy based on their emotional state. Whereas one finds the early menopause a hurdle, four other had discomfort with a potential unnecessary surgery. (XV; XVI) Furthermore, three members report that they doubt the increased risk was as high as was generally understood. (XIV) Therefore, two of them decided to enroll in a research to eventually refine the statistics at a high risk clinic¹⁹. (XIV)

Members who did not chose the surveillance option report that the fear of ovarian cancer was a decisive factor as well as the incapability of ovarian screening to detect cancer in an early stage (if at all). (XIV; XV, XVI) Moreover, some members report that the type of cancer that would be detected is dependent on the type of screening since not all cancers are detectable with every screening method. (XIV; XV, XVI)

The Opening Poster is discussing her decision for the surveillance strategy in a thread half a year later, on the evening before she has her Ooph surgery. (XV) Although, she decided to take the surveillance route after the previous thread, she changed her decision two week prior to this post after one fibroid gave relentless pain and a test revealed that she had a 10 percent chance of having breast cancer. (XV) The decision to change strategies resulted in an emotion mixed between on the one hand strong and vocal relief on and on the other hysteria and shame. (XV) On this last day before the surgery she expresses that it feels surreal to be on the verge of an unnatural abrupt menopause. (XV)

The change in strategy was responded to with the same line of thought as the opening poster: They express feeling similar scares when they first heard about the BRCA mutation status and planned the

¹⁹ In order to find out which percentage of women with a BRCA status eventually develop cancer, women who choose the surveillance strategy can only be utilized. Women who have opted for preventative surgeries cannot be utilized for the incidence statistic because they are not an accurate representation of a BRCA carrier.

surgeries. (XV) One of the posters expresses that her reason for choosing the surgeries was that cancer looked inevitable based on the stories she read on the forum. (XV)

A different thread is started by an opening post from a woman who decided between PBM and surveillance. (XVII) As she understands it surveillance is the majority option for women with BRCA mutations. (XVII) Moreover, she acknowledges that for these women, there also need be women who were eventually diagnosed with cancer. (XVII) Ideally, she wants to manage the frequent appointments of surveillance options without any findings of cancer. (XVII) She values her chance on living that kind of life on about 60%, and if it turns out that she is one of the unlucky 40%, the cancer would be found in an early treatable stage. (XVII)

A guest responds with stating that surveillance is not as easy as the opening post perceives it and it does not guarantee that the cancer is found early, as in her case a cancer cell was missed. (XVII) That is seconded by another guest, who states that the detection is depended on the state of technology and the expertise of the medical personnel. (XVII) Others voice similar warnings to urge for changing the strategy based on their personal experience or the experience of relatives. (XVII)

However, women who opted for surveillance and developed cancer express that they do not regretted the life they had before the cancer was detected. (XVII) They were at ease with the possibility of cancer developing and cherished their moments in a healthy body. (XVII) In addition, a prominent member reports to be grateful that she had the chance to have children before undergoing Ooph. (XVII) Lastly, a person states that she chose the surveillance strategy, because: "We can't cut off every part of our body that might hurt us. Being alive is inherently risky." (XVII; XVIII)

Also some notes are made about the availability of options not carefully discussed by the medical personnel and the mutation carrier. (XVII) Two posts report that through these kinds of stories they feel scared that their BPMs might come too late. (XVIII) As mentioned earlier a member tells about a conflict with her medical personnel who told her she was too young for an Ooph, while she thought she was a ticking time-bomb where the cancer could strike regardless of her age. (XVIII)

Where the possibility of choosing the surveillance strategy could be understood as "empowerment", surveillance is not regarded as valid option on the forum. The effort to ensure a safe harbor of the support forum for women who opted for this strategy implies that choosing this strategy is odd. Though, in the western society, surveillance is the most occurring strategy for women with a BRCA mutation (Machado & Braga, 2013).

As can be deduced from the endeavors of the posters to convince the women with a surveillance strategy to change to preventive surgeries, the arguments used in the context are again in the form of balancing the undesired cancer with the possible reasoning for surveillance. Thus a subsection of the women on the forum seem to associate the mutation with a disease that needs medical attention, for which surveillance does not sustain as an alternative.

Alternative prevention

In the vast majority of posts that have been analyzed for this thesis, the main way to prevent getting cancer is through technology and the medical world. Though, it is broadly recognized that developing cancer has an external component, even if the patient has an inherited predisposition for cancer. (XVI)

Only the chronological first thread in the sample discussed risk management through dietary. What can be seen as an indication that this is not considered as a viable option for the majority of women on the support forum. The thread is started by a board representative who enquired for experiences and ideas from women that chose the surveillance option, with the idea in mind to create one of the safe harbors referred to earlier. (XVI) The first respondent to this enquiry indicates she utilized both medical tools to detect cancers as well as changed her diet to lower her risk. Her new diet consists of healthier and mostly vegetarian food, which according to scientific knowledge lowers the risk for various kinds of cancers. (XVI) As an additional risk minimizing strategy she stopped drinking alcohol, since she regarded it as unsafe. (XVI)

Despite these efforts to lower her risk on cancers, she expresses to experience sadness and anxiety about developing ovarian cancer. (XVI) Since she had a similar age at the time as a family member has been diagnosed with breast cancer in an age similar to her own, she feels the emotional stress associated with the genetic predisposition. (XVI) Her response to these forms of stress was to start meditating with a genetic disease preventing mantra. (XVI) The most important struggle the person who changed her diet reports, is the chance that she would die at a middle age, while she still strives to accomplish something big for society. (XVI)

The way that the women on the forum are responding to their increased risk of breast and ovarian cancer, is also noticeable in their ideas about different issues, such as insufficient vitamin D levels. Vitamin D is created when direct sunlight shines on human skin. Insufficient levels of this vitamin are reported to lead to various forms of cancer. (XIX) In a thread that discussed this issue people were advised multiple times to take supplements. (XIX) Non-medical solutions such as going outside or eating fish were never mentioned.

RELATIVE SUPPORT

Making empowered decisions on medical procedures does not merely involve the patient and the concerning medical personnel; relatives and friends also have an effect on the decision through acting supportive or reacting negatively towards the patient. Especially with genetic testing where the results of the test also concern relatives²⁰ patients need the support and understanding of their relatives.

²⁰ A positive diagnosis of a BRCA mutation indicates that a family member has a change to have inherited the same genetic mutation, a direct family member has 50 percent chance of possessing the same genetic mutation. By testing for this gene mutation the family members also will gain knowledge about their risk on developing cancer, meaning that taking a BRCA mutation test also concerns them (Boenink, 2011).

Additionally, the emotionally hard decisions about the operation is also likely to result in an uncertain situation where the patient would seek support to proceed. Thus, in order for BRCA testing to be empowering in the emotional regulation dimension, the patient needs to be strengthened by their surroundings to proceed.

From the threads selected to evaluate the supportiveness and concern of the family members and other people that closely influence the decision process, roughly three topics can be distinguished. Firstly, the influence and experiences with the reaction from the close ones with whom opting for or against the surgeries are discussed. As a second topic are the attitudes of relatives to the effort to get them tested for a BRCA mutation. The last topic, on which threads have been selected, concerns the range of opinions about on BRCA testing for children and young adults.

Responses to the option of surgery

The previous section showed that some forum members experienced a negative attitude from their medical personnel when they sought to discuss surgical proceedings. When faced with such a negative attitude, an empowered woman who is strengthened in her ideology would circumvent these situations by, for instance, switching medical personnel. Whereas a woman who does not experience full empowerment through her surroundings would be more easily tempted to stay with the troublesome medical personnel and would allow the medical decision to conflict with her values.

One of the Opening Posters expressed that she switched medical personnel when she discovered a change of color of a lump inside her breasts and after having a bad history with her medical personnel. (XX) However, her relatives expressed to be discontent with this switch and told her to drop this 'proactive headache' and to follow the advice from her initial medical personnel. (XX) In the view of her relatives, she should avoid oncologists for the coming years, no matter how the lump would develop and she should always follow the expert opinion. (XX) It should be noted that besides these non-supportive relatives, she also has a father that supports her decision, who will be discussed in a later section. (XX)

The replies voiced that everyone deserves a medical professional who listens and provide emotional support, therefore switching doctors is recommended because being proactive is valued good and may prevent lethality. (XX) The negative attitude of the relatives is condemned by a prominent member as stubborn and uneducated. (XX) As a mockery of this view, the prominent member reports that a family member once called BPM barbaric, when informed of the gene mutation and risk. (XX) From this story the prominent member deduced that although family might think they give genuinely good advice, they can be misguided, and should not always be followed. (XX)

A similar experience was voiced in a different thread where the Opening Poster has continually been reminded by her relatives that scheduling the surgeries in the holiday season was not well timed and she was asked if she could not reschedule it again. (XXV) The Opening Poster reports that her family seems to think that because the surgery has been rescheduled already, it can be delayed for another month, because they cannot find a babysitter for their dogs. The forum replies to this story similarly to

the previous one where the family is considered selfish and self-absorbing, and it is questioned if they should be included at all. (XXV) The moderator from the site responds that the forum can often be a better source for venting than uncooperative family members. (XXV)²¹ Whereas other members voice that the Opening Poster should not hold grudge against her family members as people handle stressful situation in various ways. (XXV)

A different note was visible in another thread, where members describe that the negative side of their family had a mixed feeling of relief and guilt towards the mutation carrying half. (XXIII) Also two members reported that, besides a bit irritated, they feel to some extent jealous towards her non-carrying sisters, since she did not have to go through all her troubles. (XXIII) In the same thread we also find voices that express the hope for their sister to find a mutation, otherwise there would be not clear cause for her ovarian cancer. (XXIII) Moreover, one member also confessed her wish for a positive test result for her brother in order for him to take genetic testing more seriously and to provide more support. (XXIII)

According to these threads, the attitude of family members towards the mutation strongly differs among different cases. Where some relatives respond angry, others express a form of sympathy for the troubles these women have to endure and the bad luck they seem to have. But the remarks reveal that in each case support and understanding is desired. When the women seek these reactions from their family members, who ought to be in the same situation, the BRCA carrier occasionally receives a conflicting opinion. As a reaction the BRCA carrier engages in a discussion to make others understand her situation. This is an action based on her BRCA mutation status that can correspond to empowerment, as it shows that the BRCA carrier is able to argue for her own informed decision and is as emotionally reassured to stand by her point.

Family attitudes

Besides views about the surgeries that a BRCA carrier is deciding to perform, family members are also asked for support by the BRCA carrier. Testing for a BRCA mutation does not only provide a result on cancer risk for the family member who has been tested. A sibling has a 50% chance to have the same gene mutation as a BRCA carrier (Boenink, 2011). Since the sibling shares the DNA, they are arguably in a similar position, as a person opting for the BRCA mutation test, in terms of family history and experiences with cancer. However, as will be visible in the following threads, the siblings do not always voice the same attitude as the BRCA carrier.

In efforts to inform other people about the BRCA mutation and preventative surgeries, multiple women report that their family and friends do not want to listen and do not respond to their efforts to convince them. (XXI; XXIII) Additionally, when some needed emotional support following their BRCA status, no one offered a shoulder to cry on. These actions from family members and friends were deemed to be

²¹ The numerous times posts referred to their fellow members as “family” and “sisters”, as indicated in chapter IV, reflects this statement.

due to selfishness in the same way as the reactions to surgeries. Moreover, these selfish reactions were also attributed to an inability to understand the situation of a BRCA mutation carrier. (XXI; XXIII)

Less negative sounds are voiced in relation to the avoiding behavior of the differences in comfort zone and realm of experience. If the BRCA carriers would not have been affected by the gene mutation, they would also avoid the subject. (XXI; XXIII) A different member sees preventing diseases as an act of courage that is unrelated to normal living and a member reported that the reaction from the family members is highly influenced by the way they are raised. (XXI) Additionally, a member tries to put the BRCA worries into perspective as she tells the story of being genetically predisposed for Huntington disease, which would also result in a change of attitude towards the mutation. (XXI)

In one of the threads, one of the siblings that were subjected to persist pushing of a BRCA mutation carrier, voiced her opinion. (XXI) She expresses that despite having developed cancer, she does not regret the refusal of BRCA testing. In hindsight she would not have tested because the time that passed had remained free of concerns. This view was confirmed by two other members who also had siblings that had similar opinions in hindsight. (XXI) Therefore, some doubts were raised about the extent that trying to convince a refusing sibling helps. Instead some experiences suggested a contrarily effect where the refusal is strengthened by a continued avoidance of the subject. (XXI)

When a BRCA carrier tries to convince her male siblings often there are other issues embedded in his attitude towards BRCA related issues. For instance, the previously mentioned father, does not seem to be as supportive as previously expressed. Although he supports his daughter in the decision to be proactive and to seek for genetic information for her own sake, he does not allow himself to be tested. Even when his daughter needed his test results for to get approval for her own BRCA test from her insurance company, the father refrained from testing. (XX) A prominent male member put the view of the father into perspective as there are roughly two reasons for this reluctance. Firstly, many people are unaware of the gene being transferable from male onto female. Secondly, he experienced that males find it hard to accept that they could possibly have passed the gene on to their children. According to one member, this is worrisome as the male BRCA carrier can pass over the BRCA gene to their children (XX, XXIII)

Furthermore, in a different case where the males in the family did test for BRCA mutations, the pressure did not stop. Two male cousins that have tested positive for the BRCA mutation did not opt for preventative surgeries²², as they express to be reluctant to the idea that cancer would affect them. (XXIII) The Opening Poster whose cousins these males finds their position discomforting and wish to convince them to take action. (XXIII) Similar to their female counterparts male carriers have an increased risk towards breast cancers compared to other males. However, their lifetime risk is still

²² Similar to the female counterpart, males can diminish their risk of breast cancer by removal of breast tissue.

lower than non-BRCA mutation carrying women. To what extent males should opt for mastectomies and what other cancers these males are predisposed for is under discussion in this thread.

On the one side there are the women that express they follow the opinion that male mastectomies are to extreme. This view on male BRCA carriers is not shared by all members. Some women expressed that the biggest problem with male breast cancer is the lack of regular breast exams, which cause the males to detect a cancer merely late in its development. One guest and one member expressed that out of this fear her father and her brother have planned preventative surgeries. A prominent member responded to this story that without surgeries the fear of cancer is hard to get rid of, even if the risk is as little as for males. This was responded to by multiple members, including a prominent member, by stating that not every risk justifies a procedure and they should be weighted in accordance.

When a forum member tries to convince her close family members to opt for genetic testing, they express to be worrying that the family member does not react to their increased risk and could develop cancer. These stories reflect the idea some BRCA carrier voiced, namely that having a BRCA mutation implies having a disease and needing medical help. Moreover, when a family member responds with a different set of values, these are not acknowledged and some posters sought of ways to force family members to take a test. Especially the reaction of male family members was refuted, even though they have a different risk estimate and values.

Similar to the reaction from family members to the issues the BRCA carriers face, the responses from family members they want to convince to get tested is responded to with a variety of reactions. The relatives who refused testing had a wide variety of reasons for doing this, such as being emotionally not ready and hesitance towards the influence of the test on their lives. Even though some posts informed members to stop trying to convince their relatives, the overall tendency is to continue convincing because they could be at risk of cancer and death.

The support and recognition the BRCA carriers seek are also similar to cases where a disease is diagnosed. They seek for relatives to go with them to the hospital and show compassion with the worrisome state of mind caused by the BRCA mutation identification. In some of the stories they are referring to rights and duties associated with a disease, such as the woman who expected their family members to agree with her scheduling the surgery in the holiday season. Even male relatives should be sought to convince for they are also at risk of late detecting if they have cancer. It seems that even if the males have reacted empowered by making an informed decision, they would still be at increased risk and some women regard that as a disease to be overcome.

Child testing

The dimensions of empowerment ascribed to genetic testing do not include nor justify an age limitation. As a result, even children should be allowed to gain access to the genetic information, since even at a young age woman should be able to make life decisions. However, not all members of the online support forum do agree to the idea of child testing.

The discussion is started by one of the Opening Poster whose daughter asked her to be tested for the BRCA mutation. (XXVI) The Opening Poster responded that the daughter has no need to worry before her thirties. (XXVI) Moreover, she is thinking about taking her daughter to the next meeting with her genetic counselor to let her be informed before she would test. (XXVI) Where a member and a guest respond that informing the daughter through the genetic counselor was a good idea, multiple other members argue that they would refrain the daughter from testing because she is too young. (XXVI)

A twofold motivation was expressed by the members, to indicate that a child can be too young. (XXVI) Firstly, some members express that the emotional stability of a child is not sufficient to cope with such problems. (XXVI) It is stressed that the women should be fully ready for either result of BRCA test. (XXVI) The other motivation for delaying testing is based on the potential limitations that BRCA knowledge would lay on life decisions. It would be a real shame if the child would not go through her normal stages with teenage things and college on her mind due to decisions following a genetic predisposition. (XXVI)

However, some members had a different idea about genetic mutation testing. One member told that she decided that her daughter was mature enough to get herself tested, despite being only nineteen. (XXVI) Additionally she expressed to feel shocked about the number of women that have their BPM in their twenties. (XXVI) Four other members said that the daughter of the Opening Poster seemed to be well, because she was proactive and seemingly capable to understand genetic problems. (XXVI)

Moreover, one member reported to feel afraid that the daughter would get cancer before the child is tested. (XXVI) A different thread discussed the development of breast cancer in a nineteen-year-old daughter of the Opening Poster. Although, in this case, it turned out to be fibroadenomas, throughout the thread the members thought it was a form of breast cancer. As a result most posts were voicing condolences to the daughter with cancer. Some member, including two prominent ones, express the opinion that your child having cancer is even worse than having cancer yourself. Another member considers it to be unfair that the daughter would not be able to experience being a woman before cancer would strike her in her female parts. (XXVII)

Conclusively, members advised to be open with daughters about the gene mutation as that would reduce stress. One member, who did test her young child, reflected on it as taking a hard emotional burden on herself, with the goal to educate herself to be ready for the time her child would have questions. (XXVII) The negative attitudes were addressed by stating the intention to refrain from influencing decisions of her child and that she will keep the test results a secret for many years to come. (XXVII) When asked if she looked at her daughter differently, the woman admitted feeling differently about her daughter in her heart and expresses the hope that the child does not notice it. (XXII; XXIII)

Where the forum encourages women to test for the BRCA mutation, the members of the online support forum disagree about limiting testing based on age. It seems that "empowerment" in the context of genetic testing presupposes that the potential mutation carrier has developed a form of fear

that she would develop cancer. A child or young adult should only be tested if they already developed an understanding of the BRCA situation and they should have been able to live a considerable part of their life like normal girls.

This line of argument is also applicable for women of an older age. There is no need for them to be tested if they did not fear developing cancer before and they also have a right to live like normal women. But sadly, as the women on this online support forum indicate, there are women who develop a fear for cancer and are forced to make decisions a normal woman does not have to make, such as early menopause and sensation loss of the breasts. From this line of reasoning, identifying the BRCA status is not conceived as a way of empowering, rather it is a diagnosis of an abnormality, necessitating abnormal decisions on the basis of a status induced by the BRCA testing technology.

OPINIONATE CITIZENSHIP

In chapter III the notion of biological citizenship has been introduced as a way for people with a particular biological characteristic to collaborate within a society. The online support forum is given as an example of digital biological citizenship in sharing of experiences. Based on the conversation analysis presented in chapter IV it could also be identified as a form of information biological citizenship. The content analysis presented in this chapter indicates that the support forum can be considered as a third mode of citizenship, not identified by Rose and Novas: opinionate citizenship.²³ On an online forum are, besides the expected experiences, also opinions and attitudes exchanged. These exchange of attitudes could influence the attitude and actions of other individuals on the forum.

The selected thread contains expressions of opinion and advice about medical decisions and the BRCA situation. As a result, a direct exchange of opinions is noticeable on the forum. This is, of course, what would be expected from such a support forum. Since the women on the forum experience the BRCA and the medical procedures in their own way, they have a particular opinion about the situation from their own perspective. As we have already seen, these personal perspective are seen as a valuable addition to the other sources of information available and are one of the reasons, why people join the forum. When these perspectives are considered as merely the perspective of someone else who has the same situation, these direct exchange of opinions is not troublesome for the informed decision making, as it provides a broader perspective of the situation.

More troublesome are the implicit opinions and attitudes expressed through a combination of posts. The advice is then not only perceived as one perspective compared to a different view, it establishes an attitude towards a particular view and a concealed influence on an individual's perspective could be

²³ This term is not named by Rose and Novas as an example of the biological citizenship. It is constructed for the purpose to describe the exchanges of attitudes and opinions and could eventually result in a stratified view for the people that share the same biological characteristic.

expected. Implicit attitudes, that share a particular tendency, are translated into a feelings attached to particular views and this may result in a change of the individual user's attitude.

One way that these implicit opinions influence the individual is through the occurrence of a minority opinion. By labeling an opinion as a minority opinion, implicitly it is seen inferior; otherwise the majority would have chosen this position. The feeling of being part of the minority is explicitly addressed in the section about surveillance, but also implicitly through a combination of other posts. By deliberately creating a safe environment on the forum for the surveillance strategy, the implicit association is made that this decision is easily attacked and their arguments would not sustain as a valid alternative to the major opinion.

In the way that opinions, situations and actions of the family and friends are regarded, this minority effect can also be observed. The users seem to turn to the forum to seek for encouragement when their expectation for support and understanding are not met by their families and friends. As a result, the BRCA carrier comes to the forum both emotional wrecked by the BRCA diagnosis and the family troubles. Her postings are unlikely to be replied to with conflicting and critical opinions, as this may seem to be offensive. Thus, the threads that discuss these conflicting experiences with family and friends tend to be in line with the majority view.

A second way an attitude is implicitly exchanged, is noticeable in the replies to hesitations and negative ideas about the end result of a preventative surgery. The reaction is not as compassionate compared to replies more in line with the majority view. Perceiving dissatisfaction as a form of temporary annoyance that only needs some emotional coping is welcomed with sympathy and considered as a part of the process that every woman needs to go through. However, when the regret was expressed about choosing for preventative surgeries, she did not receive as much support and understanding, implicitly associating negative ideas about the preventative surgeries as invalid. Even though some women stated that every woman is entitled to their own opinion, regretting the surgery was considered as a rare and strange opinion.

The last way in which implicit opinions and attitudes are influencing the individual attitudes is through the dependency on the support forum to share experiences. Not all family members or friends react as supportive or understanding as it is desired. Where the BRCA mutation carriers expects to be encouraged to proceed with the preventative surgery, they are met with abhorrence and conflicting values in some cases. When the relatives and close friends are responding in this way, a distance is created with the BRCA carrier. This difference is recognized by the BRCA carriers as being due to the possession of the gene mutation, as it leads to thinking about themselves mostly in relation to the potential cancer. In contrast, the support forum consists of women who are in a similar situation and can provide the desired encouragements and support. By sharing the story and acquiring acknowledgement from the forum members the individual BRCA carrier is accepted as part of the biological community and into the friendly and familial relationship identified in the previous chapter.

Thus, in the selected threads mentioned above can be concluded that, although the members of the support forum might ascribe the term empowerment to reasons for BRCA testing, the term is misplaced when considering the implicit minority opinions. As it seems, to be accepted as part of the community, the opinion should be in line with a majority view; otherwise the person is entitled to discuss her issues in a protected environment. While the community claims to tolerate every opinion, there is a tendency associate with the majority. Thus, alternatives to preventive surgery are being disregarded.

CONCLUSION

The conversation analysis presented in the previous chapter does not provide clear evidence that the ascription of empowerment to BRCA testing is insufficient. Through the content analysis displayed in this chapter, the actual exchanges between users of the online support group have been analyzed.

In multiple posts women express that BRCA mutation testing is empowering and as a result they made an informed decision about measures to be taken based on the known risks. However, the distress and hesitance the women express when considering BRCA testing and taking preventative surgeries indicate that the BRCA mutation diagnosis leads to conflicts with values such as a “natural body” and “do not cut into healthy skin”. These emotional reactions to the BRCA testing and preventative surgeries conflict with the idea of “being intellectually ready”, in which the surgeries are considered as the most logical and “best” action to proceed with following a BRCA mutation diagnosis. The overriding of these personal values is instigated by the belief that the abnormality of a predisposed risk on breast and ovarian cancer can only be overcome through a medical fix.

This is strengthened by abstaining from options to reduce the risk of cancer without involving the medical professionals. As only the chronologically first thread in the sample, concerned the issue of dietary changes. Furthermore, in the thread that discussed the effects of Vitamin D on the cancer risk, the dominant idea was to take a supplement. Where no one mentioned the non-medical option of going outside.

In principle, the empowerment ascribed to BRCA testing could also result in deliberately choosing the surveillance strategy. However, choosing this strategy is not considered in a similar way as preventative surgeries. When a woman chooses the surveillance strategy, many replies expressed that she is taking a risk on developing cancer and dying. With the same line of reasoning women are advised to not delay their preventative surgeries.

On the question whether children or young adults should be tested for the BRCA mutation the opinions are divided. About half of the women implicitly argue for a limitation to the extent that BRCA testing should be available. There is no need for young women to worry and the risk of cancer should not influence their life decisions. The women in favor of genetic testing of children voice a message that everyone should be able to influence their lifetime decisions. This discussion can also be applied to women of all ages, as the arguments are not bound by age. Where an adult woman is encouraged

to gain knowledge about their genetics and opting for preventative surgeries, the discussion indicates that being of a certain age is an implicit element in the empowerment ideology.

Based on the threads discussed above, the ascription of empowerment seems to be lacking to account for all aspects of BRCA testing. Moreover, the alternative influences on opting BRCA testing named in chapter III are visible in the sample of threads discussed in this chapter. The women utilize the anticipated regret decision mechanism to decide for proceedings based on evaluation of the potential feelings of regret for both the potential developing of cancer and the breaching of the ethical values. The expressions directly aimed at changing the mind of other members are mostly amplifying the risk aspects and can be argued to originate from regarding the BRCA mutation as kind of disease or through the use of anticipated regret in the decision process. Statements such as “do surgeries before it is too late” and “I want to live to see my children grow old” reflect these origins.

In the situations where the BRCA mutation is considered as a distinctive feature between healthy and unhealthy, it is closely related to what Stempsey argued about the state of technology determining the perception of healthy. The support and recognition the BRCA carriers seek are similar to cases where a disease is diagnosed. They seek for relatives to go with them to the hospital and show compassion with the worrisome state of mind caused by the BRCA mutation identification. In some of the stories they are referring to rights and duties associated with a disease, such as the woman who expected their family members to agree with her scheduling the surgery in the holiday season. This means that the sick role as described by Parsons is also perceivable in the comments on the forum. However, in multiple posts the decisions made by medical personnel are refuted and their competence doubted. The women on the forum encourage their own decision to be valued as well, when proceeding surgeries are discussed, where medical personnel are reported to occasionally provide bad advice, allegedly based on their own values.

Thus, the implications of diagnosing as an unhealthy person does not directly lead to a societal pressure to opt for preventative surgeries. As these threads indicate, the motivation to regain health does not follow from societal pressure; rather the individual woman expresses her desire to seek BRCA testing and preventative surgeries.

As Rose and Novas have argued with regards to digital biological citizenship, the sharing of experiences plays an important role on the forum. Besides the sharing of information and experience the support forum is a place where opinions are shared and attitudes are formed by the members. Thus, we can identify a different kind of biological citizenship: the opinionate biological citizenship.

Where in many cases an opinion is explicitly expressed what another member could read and interpreted as one opinion about the subject. Opinions are also shared implicitly, by associating an atmosphere with a particular idea or strategy. These implicit opinions can graduate influence the individual's opinion about a subject. The first way that implicit opinions are endangering the individual opinion, is through deeming a particular opinion as a minority view. This leads to a more negative association with the minority option as the majority allegedly would choose the best strategy. Also, by

explicitly describing a thread as a safe environment for people with a particular opinion or by stating that even this opinion should be tolerated, the opinion is associated with weak and susceptible for “better” opinions.

Implicit opinionating can also be noted in the replies to hesitations and negative ideas about the end result of preventative surgeries. Despite deliberately stating that every woman is entitled to their own opinions, members are not as keen on providing compassion to the posts that do not indicate the majority view. Finally, implicit attitudes build on the dependency on the forum for support, when family members and friends do not provide the ‘right’ reactions. Since there is a clear majority on the forum, most expressions of minority opinions and of experiences with other strategies are immediately devalued through the reactions of other forum members. By doing so, a particular position is continually encouraged and the room for individual evaluation is limited.

CHAPTER VI: CONCLUSION

Cancer is one of the most dreadful and lethal diseases facing western society. Therefore, technologies to limit the chance on developing cancer and its horrifying consequences of cancer are a priority for medical research. The identification of mutations on the particular locations in the DNA of women that developed breast cancer, could be considered as one of the success stories in medical research and of the Human Genome project. These locations are identified as BRCA 1 or 2 and result in inherited reduced ability to repair DNA defects and an increased expected lifetime risk of developing breast and ovarian cancers.

Women who have reasons to believe they are carriers of this mutation, for instance due to a high rate of cancer in their family history, can opt for a test to identify their genetic predisposition. The information gained can be utilized to decide on one of the available strategies, namely: ignorance, increasing surveillance, behavioral change, or medical interventions. The possibility to react to an inherited possibility of a future disease raises new questions, one of which is to what extent preventive surgeries are acceptable.

In liberal western society many individual choices are accepted, tolerated and allowed as long as deciding occurs with careful decision making. When asked, most of the consumers of genetic tests expressed that they would describe their reason to opt for these tests with the term “empowerment” (McAllister, Dunn & Todd, 2011, p.125). In the ascription of this term lies a potential threat to careful decision making, as the association affiliated with “empowerment” may interfere with the considerations for BRCA testing and in the decision process based on the test results. This thesis elaborated that testing for the BRCA mutation is more ambiguous than the empowerment term entails.

Sq1: Why would BRCA mutation testing and online support forums be considered as empowerment?

In order for a genetic test to be empowering, the tester should be enabled to react to the result by taking action against the powerless waiting until the disease strikes. When “empowerment” is seen as ‘gaining power or authority’, it is applicable in the literal sense to BRCA testing. Providers of genetic testing services ascribed empowerment to the tests in two ways (Nordgren, 2012): by enabling the consumers to solely make decisions without contacting medical professionals and by allowing those who tested positive to consider preventative measures.

Furthermore, a survey among consumers of the genetic tests pointed to five dimensions of empowerment to genetic testing (McAllister, Dunn & Todd, 2011, p.127): informed decision making, knowledge about risk and disease prevention and onset, the ability to make efficient use of health and social care systems and orientation or towards the future of the individual self, family members and future descendants and emotional regulation.

These five dimensions indicate that online support fora could also be considered as empowering. The exchanges of experience on an online support forum, and the provision of information about the

experiences with BRCA issues and different options available to BRCA carriers, may lead to increased knowledge, more informed decision making and an efficient use of health and social care. Additionally, the users' capacity for emotional regulation may be increased due to the joint experience of struggle against cancer in the online community. Online support fora can also be considered to be in line with the gaining power and patient activism ideas of empowerment.

However, this only explains why the term empowerment is applicable to the situation, it does not provide a reason for the broadly accepted ascription of this term with its related associations. These positive associations of empowerment are of most concern for the educated decision making needed to justify the decision for BRCA testing. As the short history of BRCA testing services indicated, the positive associations of BRCA testing stem from the scientists and cancer patient activist groups in the 1980s, who saw genetic diagnostics as a way to overcome the dreadful cancer. The commercial exploitation does not suffice as a reason for the wide spread adoption of the empowerment term, as the empowering idea is attached to BRCA testing in both the US and the UK despite their differences in health care service.

Sq2: Is empowerment the only reason for deciding for BRCA testing?

When a BRCA mutation is identified, the consumer does not gain the knowledge of being at increased risk. The BRCA carrier already knew this, because of her or his the family history. What the BRCA test produces is a risk calculation, based on the presence or absence of a mutation. By knowing this calculation, the chance on breast and ovarian cancer can be utilized in the decision process for choosing a strategy.

One of the decision mechanisms enabled by the estimate is "anticipated regret". In this decision making strategy the chance that a specific result will occur is combined with the expected emotional feeling of regret if this result occurs. In the case of deciding for the BRCA testing the statistical information of risk on cancer is be compared to alternative options, such as keeping your personal values. Here, the fear for cancer can transform into a regret that would overrule almost every other consideration, thus harm the educated decision making.

A different way that the at-risk status could be evaluated is by framing mutations of the BRCA genes as a form of disease. The person could identify herself as being unhealthy, just because a diagnostic technology identified the abnormality. With the identification of the BRCA mutation as a disease comes the self-understanding of the carrier as a "sick person." The "sick role" (Crossley, 1999) can be characterized by the rights and obligations both the sick and society have attached to the ailment. One of these obligations is to become healthy again, which could result in a necessary asymmetrical relationship with the health care professional. The relationship is necessarily asymmetrical due to the difference in professional competence and professional concern between the sick and the medical personnel. This asymmetry could interfere with educated decision making, because the medical personnel is instructed to make you better. By regarding yourself as sick and engaging in an

asymmetric relationship, the decision process can be highly influenced by the opinion of the medical personnel.

Sq3: What are the implications of these alternative reasons for ascribing the term empowerment to BRCA testing?

Once the individual perceives herself as “unhealthy” or “at-risk”, the question is if that person should do something to prevent cancer. With the knowledge from BRCA testing you are deliberately deciding on what risk you allow. Since there are no clear guidelines you could follow, this decision is likely to be highly emotionally laden. It is you who could get the feared cancer and potentially could die. The values you previously had, are weighed in a different light when there is an actual risk involved. This means that the decision you personally have to make is changed by the information the genetic test provides and this could alter the considerations you normally address to base your strategies and life decisions on.

Furthermore, perceiving yourself as unhealthy puts a social and psychological pressure on you to seek medical help. When you have the knowledge you are prone to get cancer at an early age, the strategy you proceed with is also of concern for your family and surroundings. Being sick and unhealthy obliges you to do your best to diminish the risk and this involves you rely on the medical professionals. In the case of BRCA carriers, no direct medical interventions are necessary as being only at-risk does not result in direct burdens on society. Only if the BRCA mutation leads to cancer, these burdens on society would come in the form of absence of work and needing care.

Still, it is plausible that by having the BRCA status someone would want to derive some form of rights, for instance adequate counseling and possibilities to have surgery. Especially since, with the empowerment ideology in mind, BRCA carriers are uniting themselves as biological citizens, to exert these rights. The formation of such a biological citizenship is established by both the individual who identifies with her biological characteristics and the association that recognizes these individuals as part of the same biological group. In this recognition process lies the potential problem that individual choices and values dissolve as result of the shared ideals of the group.

Sq4: To what extent does the support forum indicate a particular reason for BRCA testing and in what sense can the reasoning be considered ambiguous?

The conversation analysis did not reveal staggering results as the action-reaction sequences are mostly in line with what would be expected from the adjacency pairs. One of the most striking conclusions from this analysis was that the threads are created to fulfil a need for the individual who posted it and that the reactions were predominantly based on responders’ own experiences and opinions. A second finding is that by repeatedly describing the other members of the forum as a friend or family member, the way that the interactions are perceived could be considered similar to the information coming from close friends.

Five threads were discussed to provide a few characteristics of the members on the forum. Firstly, the majority of women opted for preventative surgeries within two years after diagnosis of the BRCA mutation. This small timeframe between testing and surgery indicates that the test is either utilized as a decisive tool to determine if an individual should proceed in surgery or the test information provides such an emotional load on the BRCA carrier that she feels a haste to have preventative surgeries.

The second insight indicates that either way the decision is predominantly made with emotions. The prominent influences on the decision to opt for preventative surgeries were: a worry stemming from a family history or past experience of breast and ovarian cancers, distress about the surveillance strategy, and fear of recurrences.

Furthermore, there is a lack of discussion of multiple viewpoints, resulting in an unclear and narrow evaluation of the problems and opinions about choices and options BRCA carriers are faced. With such a personal decision a clear and critical evaluation of all possible options is crucial. When such discussion is lacking, it is questionable whether the personal values are truly taken into account in the evaluation of options.

Lastly, differences and misunderstandings are noticeable between breast cancer survivors and women who had surgery as a preventative measure. The women who are at increased risk are confronted with the choice of either doing something to decrease the risk or having to live with the thought that they did enough to evade the disease. In this argumentation, a form of anticipating regret is recognizable among the women of the forum. Together with the fast and emotional reaction to the test result, this indicates a more ambiguous decision process than is captured by the term “empowerment.”

Where the conversation analysis merely indicated that there could be something more to BRCA testing than is captured by the term “empowerment,” the content analysis confirms that the reasoning for BRCA testing is indeed more ambiguous. Despite the numerous posts where women directly exclaimed that BRCA mutation testing was empowering, the analysis revealed that the arguments were more in line with the alternative decision making factors mentioned earlier.

Firstly, there seems to be a conflict between what the women strategically choose to do and what their values tell them to do. With expressions such as “being intellectually ready” and the “best” action, these women do not express that they want to lower the risk of cancer, but they *must* have preventative surgeries in accordance to their potential cancer. Some of the expressed hesitance to undergo preventative surgeries indicates that the surgeries indeed conflict with values that the women have, but they feel the need for these preventative surgeries to remain alive.

Furthermore, the view is being expressed that a woman who has decided to opt for the surveillance strategy in response to a BRCA mutation diagnosis is in constant fear and reminder that the cancer might strike. The idea that the medical fix of preventative surgeries is necessary indicates that the at-risk status is seen as a form of disease. These two observations indicate that the employed strategy is more in line with anticipating regret than with empowerment.

The use of the online support forum corresponds to both the information and the digital forms of biological citizenship Rose and Novas distinguish. Through the content analysis a different form could also be distinguished: the opinionate biological citizen. This new form of biological citizenship indicates that within the conversations of the biological community, an influence on the opinion of its members can be perceived. By sharing these opinions, explicit advice and implicit attitudes are expressed that could infringe with the expected informed decision making enabled by the empowering BRCA testing and the liberal western society.

Besides explicit advice that is deliberately asked for, there are also many implicit opinions influencing the individual's decision making, without realizing. For instance, the surveillance strategy is deemed as the minority option what could result in this view being seen as inferior to other strategies. By explicitly indicating that a special safe haven needs to be created where women can share their opinions on this minority option, that view is implicitly regarded as unable to withstand discussion.

Lastly, it should also be noted that the women on the online forum are divided about the desirability to test children and young adults for the BRCA mutation. Where on the one hand women are encouraged to gain knowledge about their genes and potential risk indications, children and young adults should be able to live a normal life. Apparently, around half of the women on the forum think that there should be an age restriction for girls who want to take the test. In my view, promoting BRCA testing on the basis of the idea of empowerment implies that everybody should be allowed to use the technology. However, some women exclaim that there should be an age limitation for young women to be tested. Their arguments that young women should not be made afraid by the prospect of cancer and that they should make life choices ignorant of the cancer risk, could also be applied to older women. Thus, an implicit limitation to the ideal of empowerment is noticeable, indicating that at least some women perceive the test as overly steering decision making.

MQ: To what extent and in what sense can the combination of BRCA mutation testing and an online support forum be considered as empowering?

Consumers and providers of genetic testing services BRCA testing alike consider the tests to be “empowering.” The test enables a woman who is warned of an increased risk to gain more certainty and it could help against the seemingly helpless situation of waiting before cancer develops. Preventing lethal diseases is something that no one would object to.

However, there is more to BRCA testing than the empowerment notion emphasizes. The information gained can lead to perceiving yourself as a person at risk. This may influence decisions about how to proceed as well as life time decisions. As the women on the online support forum express, the BRCA carrier status increases the fear cancer will strike. Their dependency from the medical professionals to provide them with help puts them in the same position as a sick person. They are willing to take surgery with all its risks involved, only to evade *the risk of cancer*.

This result might seem unimportant, but I think it is important that the option of “not knowing” becomes regarded in the public domain as a valid alternative. Where BRCA testing is positively valued and

preventative surgeries are increasingly accepted, the right to not know your answer and to refrain from testing for the mutation, has no voice in the public and academic journalism, other than stating there is such a right. By explaining the ambiguity of the interpretations of BRCA test results, this thesis provides some arguments to enhance the right not to know. A truly liberal western society should not only tolerate actions in line with what is considered to be good and empowering. Refraining from these actions should also be considered as a good alternative.

DISCUSSION

Much attention of the academic literature is aimed at increasing the risk estimate for BRCA mutation carriers. This enables people who desire to be educated about their risk to anticipate their chances of getting cancer. It enables them to envision what risk they want to take and it could motivate them to change behavior and diet to influence the external risk factors. Still, it is questionable if the knowledge of increased risk is necessary for deciding on measures to reduce one's risk. Maybe limiting the possibility to get breast cancer should be done independently of knowing the risk due to your genetics.

In my reading of the academic literature and public media discourse, the knowledge about genetic components is regarded as a holy grail everyone should strive for. Choosing to refrain from gene mutation testing is not considered a valid but not a good choice. The popular media also emphasize the potential of BRCA testing to save lives. In both cases the negative sides of BRCA-testing are sometimes mentioned but in a non-convincing way, stating that people should also have the right not to know.

This thesis aims to strengthen the right not to know, as it provides the readers with insight in the influences the detection of BRCA status may have on one's perception and decision process. Furthermore, it addresses the predominantly positive view on genetics and its ability to be empowering. In further discussions about genetics and risk averting behavior the results of this thesis can be utilized as it provides some realism to the hopes and dreams often ascribed to genetics.

However, the insights offered do have some limitations, since they are based on the content and conversation analysis of only one online support. For one, the primary location of the forum is the US, but as the comparison with the UK already indicated, people in other countries in the western world could have a different opinion on health care. As there is a more individualized attitude in the US, whereas the opinion of a genetic counselor takes a more prominent position in another society. As the role of the medical professional increases, so does the identification as a sick person. However, it would probably also entail that the endeavor to convince others to choose preventative surgeries would decrease, as the counselor would base their decision on protocols and procedures. In order to strengthen the validity of this thesis, further research needs to occur on fora in different countries.

We need also take into account that the majority of post are placed between 2004 and 2010 with the majority of posts in 2005. Since my research was conducted in 2014, in the meantime there have been a major changes in the adoption of the internet. This support forum was chosen as it is an easily

accessible community where a considerable amount of posts is available. There are some other online locations for people with the BRCA mutation. Often these are sub forums of a broader breast cancer forum. Furthermore, on other form of social media, such as WordPress and Facebook, there are also some BRCA community formation. For this analysis these new forms were less suitable as the exchanges of only a few people would be perceived.

That the source of the research is somewhat dated, does not mean that the perceived identifications and exchanges of opinion are not valid. The analyses indicated that at least there were people who interpreted the BRCA test results as the at-risk and unhealthy status. I reckon that it is very unlikely that society has changed so dramatically that the people with these interpretations of the de risk do not exist. However, it would be interesting to evaluate the effects of recent developments such as the surgery of Angelina Jolie and the debate on patentability of genes, on the percentage of these women in the BRCA population. Therefore, one interesting topic for future research would be an evaluation of more recent forms of communication between BRCA mutation carriers.

Lastly, by analyzing an online support group, the research has only evaluated the effect of BRCA testing on a limited population. Being a member of an online support forum for women with the BRCA mutation can be considered as a big step in identifying yourself with the particular community. Women can also have the mutation without really identifying themselves with the community, and these Women may not change their perception in the same way. Another interesting topic for future research, therefore, would be to evaluate whether these women have a different interpretation of the test result, or whether they only have a different reaction to the test result (e.g., by doing interviews).

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ATTACHMENT I: CONVERSATION ANALYSIS

Characteristics of the individual threads

Table 1: Occurrence rate of post with a particular action among the different threads.

| No | First Post | Replies # | AM% | ASD% | AO% | CS% | CF% | SS% | SO% | OCC% |
|----|------------------|-----------|-----|------|-----|-----|-----|-----|-----|------|
| 1 | AAM, AAO, FS, FO | 50 | 16 | 4 | 80 | 14 | 6 | 4 | 84 | 0 |
| 2 | AAM, AAO, FS | 50 | 48 | 4 | 28 | 12 | 24 | 0 | 62 | 8 |
| 3 | AAM, FS | 50 | 52 | 2 | 50 | 8 | 12 | 2 | 60 | 6 |
| 4 | AAO, IF, FS | 50 | 60 | 10 | 30 | 10 | 4 | 7 | 56 | 0 |
| 5 | AAB, IF, FS | 50 | 40 | 0 | 54 | 24 | 14 | 5 | 54 | 4 |
| 6 | AAO, FS | 50 | 30 | 10 | 48 | 22 | 10 | 9 | 54 | 2 |
| 7 | AAM, FS | 50 | 66 | 6 | 40 | 14 | 10 | 5 | 52 | 70 |
| 8 | AAM, ID, IS, FO | 50 | 44 | 14 | 10 | 30 | 44 | 10 | 46 | 2 |
| 9 | AAB, AAO, FS | 50 | 58 | 22 | 18 | 12 | 12 | 75 | 40 | 14 |
| 10 | ID, FS | 50 | 20 | 16 | 26 | 68 | 26 | 3,6 | 36 | 2 |
| 11 | AAM, ID, IF, FS | 50 | 20 | 0 | 14 | 62 | 25 | 15 | 28 | 6 |
| 12 | ID, IS, FS | 50 | 30 | 6 | 16 | 42 | 34 | 0 | 24 | 10 |
| 13 | AAM | 51 | 59 | 33 | 24 | 6 | 14 | 4 | 40 | 2 |
| 14 | IS, IF, FS | 51 | 20 | 12 | 31 | 45 | 23 | 11 | 35 | 0 |
| 15 | IF, FS | 51 | 4 | 2 | 27 | 59 | 29 | 11 | 29 | 0 |
| 16 | AAO, IS, FS | 51 | 22 | 6 | 69 | 39 | 41 | 2 | 4 | 0 |
| 17 | AAB, FS | 52 | 21 | 6 | 38 | 4 | 8 | 6 | 75 | 8 |
| 18 | AAM, AAO, FS | 52 | 63 | 6 | 42 | 8 | 19 | 11 | 69 | 0 |
| 19 | AAM, FO | 52 | 63 | 18 | 37 | 10 | 25 | 3 | 52 | 2 |
| 20 | ID, FS | 52 | 58 | 12 | 29 | 2 | 6 | 4 | 48 | 8 |
| 21 | AAB, SO | 53 | 0 | 0 | 2 | 17 | 26 | 0 | 62 | 21 |
| 22 | AAO, FS | 53 | 32 | 8 | 66 | 4 | 10 | 3 | 60 | 4 |
| 23 | AAM, FS | 53 | 58 | 13 | 32 | 2 | 6 | 3 | 58 | 4 |
| 24 | AAM, IS, FS | 53 | 34 | 25 | 49 | 13 | 21 | 4 | 53 | 11 |
| 25 | ID, IS, FS | 53 | 43 | 23 | 28 | 32 | 55 | 6 | 42 | 2 |
| 26 | AAM, ID, FS | 53 | 19 | 19 | 45 | 38 | 26 | 6 | 42 | 12 |
| 27 | AAM, IF, FS | 54 | 30 | 9 | 54 | 20 | 7 | 4 | 69 | 4 |
| 28 | AAO, FO | 54 | 21 | 4 | 57 | 37 | 9 | 8 | 68 | 11 |
| 29 | AAM, AAB, FS | 54 | 17 | 7 | 59 | 6 | 13 | 7 | 63 | 19 |
| 30 | AAM, ID, IS, FS | 54 | 37 | 9 | 22 | 34 | 17 | 0 | 44 | 28 |
| 31 | AAO, IF, FS | 54 | 2 | 0 | 39 | 61 | 19 | 0 | 30 | 15 |
| 32 | IF, IO, FS | 54 | 9 | 0 | 26 | 17 | 37 | 46 | 28 | 35 |
| 33 | IS, FS | 55 | 20 | 14 | 45 | 31 | 9 | 0 | 36 | 2 |
| 34 | AAM, FS | 56 | 34 | 16 | 14 | 4 | 11 | 4 | 30 | 23 |
| 35 | IS, IF, FS | 56 | 16 | 20 | 20 | 57 | 20 | 13 | 25 | 14 |

| | | | | | | | | | | |
|----|------------------|-----|------|-----|-----|-----|-----|-----|-----|-----|
| 36 | AAM, AAO, IS, FS | 57 | 21 | 4 | 49 | 40 | 18 | 28 | 75 | 4 |
| 37 | AAO, IS, FS | 57 | 40 | 0 | 49 | 11 | 37 | 11 | 63 | 4 |
| 38 | AAM, FS | 58 | 48 | 0 | 19 | 12 | 2 | 21 | 43 | 9 |
| 39 | AAM,FS | 58 | 48 | 12 | 29 | 12 | 0 | 8 | 21 | 5 |
| 40 | IF, FS | 59 | 8 | 2 | 15 | 47 | 14 | 22 | 49 | 51 |
| 41 | AAO, IS, IF, FS | 59 | 19 | 2 | 22 | 27 | 14 | 0 | 22 | 22 |
| 42 | ID, IS, FS, FO | 59 | 0 | 2 | 0 | 83 | 8 | 0 | 10 | 14 |
| 43 | IF, IO, FS | 60 | 10 | 3 | 28 | 90 | 57 | 0 | 28 | 0 |
| 44 | AAM, FS | 68 | 63 | 18 | 16 | 50 | 34 | 3 | 51 | 4 |
| 45 | AAM, AAO, FO | 68 | 49 | 19 | 29 | 12 | 21 | 3 | 40 | 16 |
| 46 | AAO, IF, FS | 69 | 22 | 2 | 61 | 12 | 19 | 19 | 78 | 7 |
| 47 | AAM, AAO, ID, FS | 69 | n/a* | n/a | n/a | n/a | n/a | n/a | n/a | n/a |
| 48 | AAM, AAO, IS, FS | 70 | 51 | 10 | 43 | 9 | 33 | 4 | 74 | 3 |
| 49 | AAM, IF, IO, FO | 70 | 56 | 11 | 27 | 9 | 30 | 4 | 60 | 3 |
| 50 | ID, FO | 70 | 17 | 0 | 1 | 63 | 29 | 1 | 11 | 6 |
| 51 | AO, FS | 72 | 14 | 25 | 49 | 42 | 11 | 10 | 53 | 8 |
| 52 | ID, IS, FS | 72 | 21 | 0 | 10 | 72 | 22 | 7 | 8 | 3 |
| 53 | Am, ID, FS | 73 | 52 | 16 | 38 | 23 | 16 | 4 | 58 | 4 |
| 54 | AM, FS | 73 | 45 | 3 | 30 | 16 | 14 | 7 | 55 | 18 |
| 55 | ID, IF, FS | 73 | 18 | 0 | 14 | 7 | 29 | 10 | 11 | 0 |
| 56 | AM, IS, IF, FO | 74 | 4 | 18 | 42 | 30 | 38 | 21 | 41 | 4 |
| 57 | O | 76 | 18 | 1 | 14 | 74 | 42 | 10 | 17 | 0 |
| 58 | AO, FO | 78 | 19 | 15 | 44 | 13 | 12 | 21 | 51 | 12 |
| 59 | AO, FO | 79 | 43 | 10 | 53 | 35 | 33 | 4 | 56 | 6 |
| 60 | ID, IS, IF, FS | 80 | 9 | 1 | 4 | 63 | 34 | 0 | 3 | 0 |
| 61 | ID, IF, FS | 81 | 32 | 1 | 12 | 79 | 15 | 6 | 25 | 0 |
| 62 | ID, IF, FS | 83 | 23 | 7 | 8 | 58 | 31 | 1 | 30 | 2 |
| 63 | AB | 84 | 48 | 13 | 48 | 11 | 36 | 3 | 55 | 4 |
| 64 | ID, FO | 84 | 25 | 6 | 17 | 27 | 20 | 1 | 32 | 2 |
| 65 | ID, IF, FS | 85 | 2 | 0 | 2 | 72 | 33 | 0 | 8 | 1 |
| 66 | AAB, FO | 89 | 63 | 3 | 47 | 16 | 43 | 2 | 26 | 4 |
| 67 | AAO, FO | 89 | 4 | 0 | 17 | 12 | 85 | 22 | 17 | 4 |
| 68 | AAB, IF, FS | 90 | 14 | 3 | 39 | 52 | 53 | 2 | 8 | 2 |
| 69 | IS, IO, FO | 91 | 45 | 20 | 15 | 11 | 36 | 4 | 42 | 13 |
| 70 | ID, IF, FS | 93 | 15 | 5 | 12 | 55 | 25 | 9 | 17 | 3 |
| 71 | AAM, IS, FS | 96 | 55 | 33 | 32 | 9 | 3 | 4 | 44 | 15 |
| 72 | AAM, ID, FS | 98 | 18 | 5 | 9 | 87 | 7 | 22 | 22 | 3 |
| 73 | ID, FO | 99 | 4 | 2 | 8 | 84 | 14 | 19 | 21 | 4 |
| 74 | IS, FS | 100 | 5 | 1 | 9 | 28 | 8 | 2 | 29 | 40 |
| 75 | AAM, AAB, FS | 103 | 36 | 6 | 22 | 36 | 14 | 8 | 57 | 12 |
| 76 | AAM, FO | 110 | 0 | 1 | 20 | 82 | 10 | 63 | 39 | 3 |
| 77 | IO, FS, FO | 111 | 1 | 0 | 16 | 13 | 39 | 2 | 22 | 26 |
| 78 | AAB, FO | 115 | 54 | 4 | 37 | 20 | 7 | 2 | 51 | 7 |

| | | | | | | | | | | |
|----|-----------------|-----|----|----|----|----|----|----|----|----|
| 79 | AAM, IF, FO | 140 | 29 | 9 | 14 | 12 | 14 | 3 | 11 | 3 |
| 80 | ID, IF, FO | 141 | 19 | 2 | 23 | 36 | 45 | 13 | 30 | 7 |
| 81 | ID, IF, FS | 159 | 26 | 6 | 15 | 77 | 23 | 15 | 27 | 3 |
| 82 | ID, IS, IF, FS | 168 | 44 | 13 | 16 | 58 | 20 | 14 | 36 | 1 |
| 83 | AAM, IS, IF, FS | 181 | 10 | 3 | 6 | 60 | 40 | 19 | 9 | 0 |
| 84 | IS, IO, FO, FS | 202 | 26 | 5 | 27 | 20 | 23 | 12 | 51 | 17 |

*This is the choices poll thread, discussed in more detail in Chapter IV. These posts are following a certain form that is not represent able for an ordinary thread. Including it in the analysis would infringe with the statistics.

Reference to the forum

Table 2: Number of time the web forum is referred to with a specific term

| No | Replies | FORCE | Family | Sisters | Friends |
|----|---------|-------|--------|---------|---------|
| 1 | 50 | 3 | 0 | 0 | 0 |
| 2 | 50 | 2 | 0 | 0 | 0 |
| 3 | 50 | 7 | 0 | 0 | 0 |
| 4 | 50 | 1 | 0 | 0 | 0 |
| 5 | 50 | 15 | 0 | 0 | 0 |
| 6 | 50 | 0 | 0 | 1 | 0 |
| 7 | 50 | 0 | 0 | 0 | 0 |
| 8 | 50 | 1 | 0 | 0 | 0 |
| 9 | 50 | 2 | 0 | 0 | 0 |
| 10 | 50 | 1 | 0 | 1 | 0 |
| 11 | 50 | 1 | 0 | 1 | 0 |
| 12 | 50 | 0 | 0 | 0 | 0 |
| 13 | 51 | 0 | 0 | 0 | 0 |
| 14 | 51 | 1 | 0 | 0 | 2 |
| 15 | 51 | 8 | 1 | 0 | 0 |
| 16 | 51 | 0 | 1 | 0 | 0 |
| 17 | 52 | 2 | 0 | 0 | 0 |
| 18 | 52 | 1 | 0 | 0 | 0 |
| 19 | 52 | 6 | 1 | 1 | 0 |
| 20 | 52 | 0 | 0 | 0 | 0 |
| 21 | 53 | 5 | 1 | 0 | 1 |
| 22 | 53 | 0 | 0 | 0 | 0 |
| 23 | 53 | 0 | 0 | 0 | 0 |
| 24 | 53 | 4 | 0 | 0 | 0 |
| 25 | 53 | 3 | 0 | 1 | 0 |
| 26 | 53 | 4 | 0 | 1 | 0 |
| 27 | 54 | 0 | 0 | 0 | 0 |
| 28 | 54 | 0 | 0 | 0 | 0 |
| 29 | 54 | 3 | 0 | 1 | 0 |
| 30 | 54 | 4 | 0 | 0 | 0 |
| 31 | 54 | 0 | 0 | 0 | 0 |
| 32 | 54 | 11 | 2 | 3 | 0 |
| 33 | 55 | 0 | 0 | 0 | 0 |

| | | | | | |
|----|-----|----|---|---|----|
| 34 | 56 | 2 | 0 | 0 | 0 |
| 35 | 56 | 3 | 2 | 2 | 2 |
| 36 | 57 | 2 | 0 | 0 | 0 |
| 37 | 57 | 3 | 0 | 0 | 0 |
| 38 | 58 | 0 | 0 | 0 | 0 |
| 39 | 58 | 1 | 0 | 0 | 0 |
| 40 | 59 | 14 | 0 | 0 | 0 |
| 41 | 59 | 1 | 0 | 0 | 0 |
| 42 | 59 | 0 | 0 | 0 | 0 |
| 43 | 60 | 12 | 2 | 0 | 1 |
| 44 | 68 | 2 | 0 | 0 | 0 |
| 45 | 68 | 8 | 0 | 0 | 0 |
| 46 | 69 | 0 | 0 | 0 | 1 |
| 47 | 70 | 6 | 0 | 0 | 0 |
| 48 | 70 | 1 | 0 | 0 | 0 |
| 49 | 70 | 1 | 0 | 0 | 1 |
| 50 | 72 | 1 | 0 | 1 | 1 |
| 51 | 72 | 3 | 0 | 6 | 0 |
| 52 | 73 | 4 | 0 | 0 | 0 |
| 53 | 73 | 0 | 0 | 0 | 0 |
| 54 | 73 | 4 | 1 | 2 | 1 |
| 55 | 74 | 4 | 0 | 3 | 0 |
| 56 | 76 | 11 | 1 | 2 | 2 |
| 57 | 78 | 13 | 0 | 2 | 3 |
| 58 | 79 | 17 | 1 | 4 | 0 |
| 59 | 80 | 1 | 0 | 1 | 3 |
| 60 | 81 | 1 | 0 | 1 | 2 |
| 61 | 83 | 0 | 0 | 0 | 0 |
| 62 | 84 | 9 | 3 | 2 | 1 |
| 63 | 84 | 2 | 0 | 1 | 0 |
| 64 | 85 | 12 | 2 | 4 | 1 |
| 65 | 89 | 5 | 0 | 0 | 1 |
| 66 | 89 | 10 | 2 | 2 | 0 |
| 67 | 90 | 19 | 0 | 2 | 0 |
| 68 | 91 | 13 | 0 | 1 | 0 |
| 69 | 93 | 8 | 8 | 0 | 2 |
| 70 | 96 | 8 | 0 | 0 | 0 |
| 71 | 98 | 3 | 0 | 0 | 1 |
| 72 | 99 | 3 | 1 | 6 | 3 |
| 73 | 100 | 1 | 0 | 0 | 0 |
| 74 | 100 | 4 | 4 | 0 | 2 |
| 75 | 103 | 14 | 0 | 1 | 0 |
| 76 | 110 | 8 | 2 | 0 | 2 |
| 77 | 111 | 34 | 4 | 0 | 12 |
| 78 | 115 | 8 | 0 | 0 | 3 |
| 79 | 140 | 0 | 0 | 0 | 0 |
| 80 | 141 | 11 | 0 | 5 | 1 |
| 81 | 159 | 7 | 5 | 1 | 0 |

| | | | | | |
|----|-----|---|---|---|---|
| 82 | 168 | 3 | 0 | 0 | 1 |
| 83 | 181 | 9 | 0 | 4 | 3 |
| 84 | 202 | 2 | 0 | 0 | 0 |

Choices Poll

Table 3: A summary of the information of individual support forum members based on their post in the Choices Poll thread. The first column indicates what specific type of mutation these women had (if mentioned). Columns 2 to 4, indicate the ages that women said to have tested, had preventative surgeries. The fifth column displays the years between testing for the mutation and having done both preventative surgeries. The right column indicates if the woman had deliberately chosen a different strategy or if and when she developed cancer that would have influenced her decisions as well.

| Mutation | age tester | Age BPM | Age Ooph/BSO | Difference until both surgeries | Special |
|----------|------------|---------|--------------|---------------------------------|----------------------------|
| BRCA2 | | 45 | | | Surveillance |
| BRCA2 | | 53 | 46 | | |
| BRCA2 | | | | | Surveillance |
| BRCA2 | 45 | 45 | 45 | 0 | |
| | | 35 | 40 | | |
| | | 40 | 40 | | |
| BRCA2 | 31 | 35 | | | |
| BRCA2 | 50 | | 51 | | Considers BPM |
| BRCA2 | | 48 | 48 | | |
| BRCA2 | 52 | 52 | 52 | 0 | |
| BRCA2 | 51 | 55 | 51 | 4 | |
| BRCA1 | 45 | | 44 | | OC44 |
| BRCA | 55 | 55 | 55 | 0 | |
| BRCA2 | | 44 | 45 | | BC 44 |
| BRCA2 | | 41 | | | |
| BRCA2 | | 42 | 43 | | BC42 |
| BRCA2 | | 42 | 45 | | |
| BRCA2 | 34 | 35 | 40 | 6 | |
| BRCA2 | 51 | 51 | 52 | 1 | |
| BRCA1 | 56 | 59 | 56 | 3 | |
| BRCA2 | 42 | 42 | 42 | 0 | |
| BRCA2 | 39 | 39 | 39 | 0 | |
| BRCA2 | 39 | 40 | 39 | 1 | |
| BRCA | 40 | 41 | 40 | 1 | |
| BRCA1 | 48 | 50 | 49 | 2 | |
| BRCA2 | 25 | 28 | | | |
| BRCA2 | 43 | 43 | 44 | 1 | |
| BRCA2 | 24 | | | | Surveillance till children |
| BRCA2 | 39 | 40 | 36 | 1 | BC 35 |
| BRCA2 | 39 | 46 | 40 | 7 | |
| BRCA2 | 41 | 42 | 42 | 1 | |

| | | | | |
|--------------|----|----|----|-------------------------------|
| | 41 | 40 | | |
| BRCA | | | | BC |
| BRCA2 | 45 | 46 | 45 | 1 |
| BRCA2 | 27 | 29 | | Surveillance till children |
| BRCA2 | 38 | 40 | 39 | 2 |
| BRCA2 | 45 | 46 | 44 | 1 |
| BRCA2 | 56 | 56 | 56 | 0 |
| BRCA2 | 37 | 37 | 39 | 2 |
| BRCA2 | 49 | 51 | 50 | 2 |
| BRCA2 | 46 | | 47 | Breast surveillance |
| BRCA2 | 38 | 38 | 45 | 7 |
| BRCA2 | 48 | 50 | 49 | 2 |
| BRCA2 | 57 | 58 | 58 | 1 |
| BRCA2 | 29 | | 37 | |
| BRCA2 | 35 | 35 | 36 | 1 |
| BRCA2 | 50 | 51 | 51 | 1 |
| BRCA2 | 39 | 40 | 39 | 1 |
| BRCA2 | | 49 | 40 | OC 40 |
| BRCA1 | 34 | | 39 | |
| BRCA2 | | 50 | 50 | |
| | | 42 | 43 | |
| BRCA2 | 46 | 47 | 46 | 1 |
| BRCA | 35 | | 35 | BC 39 |
| | | 23 | | |
| BRCA2 | 48 | 49 | 48 | 1 |
| BRCA2 | 45 | 46 | 45 | 1 |
| BRCA | 35 | 35 | 40 | 5 |
| BRCA2 | 38 | | 38 | Considers BPM |
| BRCA | 28 | 28 | 37 | 9 |
| BRCA | 24 | 28 | 30 | 6 |
| BRCA2 | 39 | 38 | 39 | 0 |
| BRCA2 | | 53 | 52 | |
| BRCA1 | | 35 | 35 | |
| BRCA | | | | Considers Ooph and BPM |
| BRCA2 | | | | Surveillance |
| BRCA2 | | 42 | 42 | |
| BRCA2 | | | 38 | |
| BRCA2 | | 32 | | Surveillance till children |

ATTACHMENT II: DESCRIPTIONS OF THE THREADS DISCUSSED IN CHAPTER IV

Comments about the board

In order to validate the findings that come from a detailed analysis of some important topics in the forum, I have summarized two threads from my subsection of the forum that indicate the issues that some people have with the board. The first article named here is a thread from 2005 where discomfort is expressed with the way that people are reminded that the forum does not get its information from medical personnel and every decision should be respected. The latter post is from a later date indicating some issues that have caused the board to be less active as previously. Also the repliers want to give the board feedback on how to change the moderation in order for long lasting members to stop disappearing.

2005 post starts with the FP describing the situation of a new member that gets advice and is immediately reminded that people should not “take medical advice from the board”. The FP has seen this several times and is frustrated that some people are forgetting that this is a message board and the tone on which something is said does not transfer. She wants to stress that the community should recognize that they are experts about themselves, but not necessarily for others. Sharing of own experience is good, but they do not know the right answer.

This opening posts is responded with the idea that most people on the board are smart enough to consult with their medical team. That sometimes the voice may look harsh caused by the fact that the contributors are just normal people, who sometimes let their emotions flow into their posts. But that does not matter because the goal of force, supporting each other is still reached. In addition, the reply emphasized that he is graceful the provided information of the forum and genetic counselors in general, so that young women who are confronted with BRCA+ can be informed about potential help.

The latter point is reckoned and strengthen with that she uses experiences of others to formulate questions for her own doctors. Which would also identify which doctor is more knowledgeable what creates a more fruitful relationship. Another post states that she does not recollect people pushing advice onto her, the positive experiences from other people and recommendations they make she evaluates for herself and guides her own choices between these suggestions. (Happy) Where someone else says that she wished that there was more discussion on the boards about surveillance, so that she would be able to make a more informed choice, when surveillance is overcompensated.

During the replies the person responsible for the site at that time, was also responding with her ideas about what the site should look like and how its role should be in the decision process of people. She acknowledges that the board consists of women with “extremely diverse, savvy and proactive” ideas. Therefore it is possible that the personal experience is often effecting the personal posts and advice. Force tries to welcome everyone and not over moderate the boards, therefore they need to remind the members about their differences and respectfulness to others, as well as respecting the medical personnel that are helping them. She closed her posts with the statement “Only together can we provide a strong enough voice to advocate for more research and resources. “

The 2010 post starts with the FP expressing her gratefulness about the information and support FORCE had given her over the past years. After these remarks she voices her discontent that the forum has lost respectful discussions. The day before the FP found out that FORCE moderators were removing posts with controversial content. She would have agreed to removal of posts that are disrespectful, but the removed posts were not of this sort. With great sadness she reports hearing from her long lasting friends on the forum, that they are leaving the boards, because of they felt they were not able any more to say what was on their minds. In later posts she expressed that this already has been said many times to the moderators, but a change has not been seen.

In replies from other long-term members this idea was shared also by other members of the site who also responded that they did not felt treated rightfully. First the replies admitted they were reluctant to post because their post may end up in a deleted hornets' nest. Because of these reluctant attitudes

towards posting, some members do not feel as connected to each other as they used to. As a result many old posters have left the board to turn to other sites or their offline life.

Another view on the deleted posts is expressed in the issue some people have that there is a difference between the respect that a poster thinks is expressed in a post, and what the reader is getting from the same post. People should not forget that many women on these boards are dealing and facing risk on a disease, therefore not all posts would be equally evaluated. The moderators of FORCE are doing the best they can with the increased size of the community.

Replies from new members shed a different light on the issue of deleted posts. They expressed to use the site in order to make informed decision, because they do not know what information and opinion is deleted, they feel concerned that the story they receive is not complete. Especially, when the deleted posts were from the long term members that have lived through the different possible experiences. However she is reassured by both old members and the FORCE representative, that the information is still good, but not as diverse as it could be.

The representative from the FORCE board responded to these accusations with stating that they remove the posts because they are not considered supportive or not meeting the guidelines of the board. Furthermore she seconded that respectfulness is relative and can differ between the poster and the reader. Posts are deleted when a reader reports the post to the moderator, who will delete them if they value it necessary. Furthermore, she reports that there the amount of posts that are deleted does not differ from previous years.

Another issue that has been expressed in the 2010 thread is the amount of guest that are posting on the forum. Some people find it harder to establish an emotional relationship with a user that posts as a guest. A different issue with guest contribution to the forum, is aimed at the topic that these posts entail, it is reported that the orientation of these post is negative, to the dislike of some members. Also there is a report of some snarky comments made by guests, but this is from all times.

The representative of the FORCE board responds to this discomfort with saying that they are frequently assessing the possibility for guest posts. From these assessments they concluded that the guest option is available for people who are not comfortable with sharing information. This point is supported by replies from users who express their reason for posting as guest, such as (guest) dislike towards establishing relationship on the forum, being afraid of banned from the forum if they have controversial issues or their family or friends are also on the forum, thus they feel they cannot really express all emotion.

Of more concern is the reply of someone expressing that she only posts as guests because she feels unsupported in her controversial choice. Expressing that she feels not all members realize that new comer are often emotional and mentally fragile, indicating that there really can be an type of guiding in the forums.

Deciding process

This thread is started by a prominent member who desired to understand the reasoning of women for opting for preventative surgeries. With the answer to this question is to provide new people on the board with “a better handle” on their decision to have surgeries following their BRCA mutation status. The first poster views that no women wants to remove their breast and ovaries unless it was necessary to preserve life. In the case of the first poster, the choice for preventative surgeries seemed “easier” as cancer had already developed and a breast reconstruction seemed imminent. Now the idea against surveillance has grown that when opting for that strategy there is a nagging voice in the back of the head that says cancer could eventually grow.

A member expressed that she based her choice on the three occurrences of ovarian cancer in a few years and she did not want to die before her children were adults. What psychological stress does this knowledge of BRCA status pose, if one is not ready to act upon the information or does not have a clear plan of how to proceed individually or perhaps, as a couple?

Another prominent member was also struck with breast cancer before she had opted for her surgeries. However, this prominent member told that the real reason for choosing this option was a fear to get cancer again and not being as lucky this time.

Four other member stated that her BRCA diagnosis was influenced by the high amount of breast and ovarian cancer incidences in her family.

A different member expressed that she chose the surveillance strategy after testing positive for the BRCA gene mutation, however eventually changed her mind and took both preventative surgeries. The main reason she encountered was that she had no reason to not consider the surgeries and only a lot to lose.

A different member expressed that her mother already was a BRCA positive so she took preventative measures. After testing positive for the BRCA gene herself, a couple of years later, she completely removed the ovaries and did a BPM.

A different woman had a high incidences of breast cancer in her family and had removed her ovaries as she was recommended since her mother had ovarian cancer. She did keep her breasts however, so she eventually developed breast cancer, which made deciding for a BPM a no brainer.

A different member had chosen for the surveillance strategy as the BRCA mutation was found to be running in her family. However she eventually developed breast cancer as well what made her change her mind about BPM and Ooph, which she will have after she had giving birth to her children.

One member expressed that after getting two fibroadenomas and getting information about the cancer occurring in her family, she decided on eating healthier and start exercising. After discovering two additional fibroadenomas, she got scared and asked for the genetic status of her mother, who turned up to be negative for both mutations. When her sister also got two lumps, this member decided that she also would get preventative surgeries.

One member expressed that she took the surveillance strategy until her husband was diagnosed with cancer. With the rhetoric of I do not want to get cancer at all, not only identify it at an early stage, this member opted for surgeries.

Despite no family history of breast cancer one member got diagnosed with two small lumps in her breasts. As she was Jewish descent from her father side and she overlooked that part of the family, she tested for the mutation, which turned out negative. However, she still has some family history which does not rule out that she will get cancer, she was not yet really at a risky age, she did not trust surveillance, and she did not want cancer because she had children to raise and did not desired taking tamoxifen and wanted to avoid radiation.

Based on her family history of breast cancer one member stated "I don't want to have surgery...I have to have surgery. I WILL get cancer if I don't. A bold statement to make? Maybe...but I just know it."

One member expressed that at the time she was diagnosed with BRCA mutation she valued the surgeries horrifying. But after being at FORCE for some time and reading all the stories of what BRCA actually means, she decided to partake the preventative surgeries.

A member discusses the situation at home in her youth where her grandmother was dying of ovarian cancer, five years later her mother herself got breast cancer and died a year later. Despite these incidences they were not considered as high risk so were forced to have a high surveillance routine. After testing for the BRCA mutation she immediately planned preventative surgeries.

Another member had a mother with breast cancer and survived, later she had a recurrence and survived as well.

A guest had breast cancer and got tested when she heard about the increased risk for ovarian cancer. After getting the test results she went on a vacation to Europe for a month where she had a nervous breakdown and contacted two foreign oncologists. These oncologists insisted that she could wait with Ooph, also the medical professionals at home suggested to not do anything. However the guest opted for both surgeries, but is hesitated to do the BPM as she is afraid that taking chances with her health would leave him motherless.

A different member was diagnosed with breast cancer and had a grandmother who died of breast cancer, however she did not think she had a hereditary cancer. But she tested anyway and turned out to be a BRCA mutation carrier. In order to see her kids reach adulthood she scheduled BPM and an Ooph immediately.

One member discovered her BRCA result while in chemo, and had BPM when the therapy ended. She already had her ovaries and uterus removed, because she considers them thinking time bombs.

One member based her decision on an aggressive recurring cancer of one of her sister and knowing her BRCA status, because she has done everything in her power to prevent this disease she is at peace with her body.

After several cases of cancer in her family one member expressed to live in fear of getting breast cancer. Eventually she tested positive for the BRCA mutation and will have her ovaries removed soon. A BPM however, she finds herself not yet ready for and wants to wait until more people have positive experiences with a new procedure.

A member had a mother and eight aunts who all died of breast cancer so, she had always known there was hereditary cancer in her family. Also he sister had developed ovarian cancer and two cousin's breast cancer. Eventually she got cancer and tested positive for a BRCA mutation which resulted in BPM, but her daughter tested negatively.

One guest expressed that she took BPM without a family history or BRCA status, which she valued made the decision more difficult for her. However she had two aunt and a mother that were diagnosed with breast cancer but survived, making her contact the community.

Lastly, someone new to the site expressed that she had tested positive for a BRCA mutation shortly before and thinks it is a great comfort seeing all these women in the same situation. When she was the age her mother got lethal breast cancer she started to test for the gene mutation

A different cancer

This post is started by a woman who ever since she knew her BRCA status is feeling different from the normal breast cancer survivors. Normal breast cancer survivors do not have to worry about resurrecting breast cancer nor about increased risk for ovarian cancers. Moreover, many normal breast cancer survivors did not have to witness so many losses of mothers, sisters and other family members as BRCA positives. However, she is also not similar to breast cancer survivors as she did not actually get cancer, since she had performed preventative surgeries after hearing her BRCA status.

Another member is expressing to still be in the closet about her genetic status, because she feels as if she is different and freakish. She also reflects on the mean misunderstanding look she gets when she tells she is a cancer survivor, as she is still so young.

A prominent member expressed that she could not put herself to present at and breast cancer survivor rally. She states that the diagnosis, treatment and recovery should be the most monumental experience of a breast cancer survivor, where for her it is only a small part of the issue.

Another member expressed her difficulties with the medical community to accept her breast cancer situation at such a young age. She could not get her medical personnel to agree to have biopsies as they wished to test for a range of other diseases.

After a cancer diagnosis one member expressed that she felt disillusioned, distrusted her own breast and questioned why she would be the one that had breast cancer. After recovering from the cancer she learned of her family history of cancers and planned preventative surgeries. As a result she did not worry anymore about recurrences and felt that she was home free.

A member felt that when she developed two breast cancers, she felt differentiated from the breast cancer community because of her young age and the limited knowledge of early breast cancer in the 70s. Twenty-five years later she was diagnosed with BRCA mutation and started to feel uncomfortable with the face of a breast cancer survivor she ascribed to her persona in the past decades. Also the breast cancer survivor circle she was once a member from reacted reluctant to BPM and Ooph and refused to talk about the BRCA status.

A different member expressed that she felt scared about a recurrence after her breast cancer diagnosis. The BRCA diagnosis did also make at first feel her “angry about losing the genetic lottery” and afraid that she passed the gene through to her daughter. Later on she valued that the BRCA status solved the puzzle for her and ascribed the BRCA mutation to be a main cause for her unfortunate breast cancer. Now she feels empowered to do something to limit her risk and she partake the preventative surgeries.

One member expressed that she thinks every young women that develops cancer is afraid of a recurrence. The BRCA status enables carriers to identify a clear and present danger and provides a clear view on what to do next.

One previvor also elaborates on her bad experiences with getting mammograms because people and medical personnel don't seem to get the realness of a genetic predisposition.

Another women expressed her troubles in answering the question: “Do you have a medical condition?” In another occasion she felt desperate as her gynecologist told her that she was at to high risk and she should visit a local cancer center.

One member expressed that when she organized a walk to raise funding, she bailed because she did not want to be around many people that celebrating their various fights against cancers.

Another member expressed that she also was not able to walk with other survivors and limited herself to raising funding for the cause.

A different member express to be in denial about her family history and that she might have passed it on to her daughter and son.

There is also a member expressing she does not feel an real previvor as her BRCA statutes turned out to be inconclusive, but still having her BPM because she experienced some risk.

Another member expressed that she does not feel she is part of the breast cancer survivors because she will be pre-giving.

Another member expressed that she did not belong to breast cancer survivors and that her medical personnel are treating her uneducated and she needs to enforce the decisions she had made.

Another member expressed she does not know in what category she fits and that her medical personnel are unable to treat her right.

ATTACHMENT III: DESCRIPTIONS OF THE THREADS DISCUSSED IN THE CONTENT ANALYSIS

FORMS OF REGRET

(I)

In the 2007 thread the FP, who is an influential member, described the bad treatment by the breast surgeon. In a letter she post on the forum, instead of sending to him, she expresses to felt betrayed by whom she thought was the best and emphatic doctor. When he reassured her that she only needed a lumpectomy with chemo to cure her from cancer, despite her asking for a mastectomy. A year past the surgery, she told him she was a BRCA1 gene carrier and asked for a change of plans. He responded with “now we’ll watch you like a hawk”, but instructed the office staff to reduce the appointments from once every 3-6 months to yearly. FP had agreed to these plans because she trusted the surgeon, and eventually got a recurrence in her lymph nodes and probably her lungs. As a result she feels dropped by the surgeon as he provided with improper care for her. One of her biggest regret is that she always had to look for information on the procedure herself and did not already move to a different doctor.

The responses to this story were mostly from members that were horrified by this situation. Their main problem is that the attitude and knowledge of the doctor was aversive to BPM, and blames the doctor that the cancer had grown. Many replies expressed a similar experience of members who also faced with doctor that do not provide every option to detect and prevent cancers, or were not fully knowledgeable about the BRCA gene. One of these experiences was given by a doctor at a non-oncology ward, who regretted how her colleagues were uneducated about the BRCA gene mutation.

This doctor additionally told about her efforts to reeducate her colleagues, which she described as helpful to vent her own feelings and encourages others to also let their doctor know how they feel. One of the dissatisfied patient responded that she already wrote a letter and read it in front of the malfunctioning doctor, who gravely apologized and told her that with other patients he would be more on the look-out.

After some days, the first poster reports about the meeting she had with her doctor the day before. She states that after a while discussing possible side effect of the medicine they were going to use, she stopped and told he she had something to say. Then she told him all the dissatisfying things that happened to her and her opinion on all the bad judgments he made in this occasion. The doctor apologized profusely and told her that the treatment should start with him for now, but when she would find it time to switch doctors everything would be in order.

This last situation at the doctor’s office was replied by members that feel oncology wards treat people impersonal and that giving the doctor feedback helps. One reply from a member who is also a physician indicated that it is caused by the overdevelopment in the field, that enables the doctor to have increased responsibility which allows for the lesser doctor to make these kinds of mistakes.

(II)

This thread begins with the first poster who opted for BPM surgery due to her BRCA1 mutation. She states that “Intellectually” this was the right option for her to do, but now she is grieving the loss of her breasts. Before her surgery she already had doubts and anxiety for the breast removal, but at the time she felt, she was in the right frame of mind. The surgery itself went perfect and she is happy with the result of reconstruction, but she feels depressed about having no feeling in the new breasts, except for an occasionally ache. She expresses missing the nipple sensation and her own real breasts and nipples, which were important in her sex life. Therefore she asks the boards if this feeling will go away and how she can help to excel the progress.

Many members and one guests report the same feeling prior to the surgery. Of these, three opted for counseling before the surgery to help her accept the situation pre-surgical. One of these suggested that a BPM is favored over getting cancer, which would mean a hard procedure. However, a new member reports that she did not think much of the surgery, but is currently feeling regretful at this great loss another member tells that she had waited until she was twenty years older and reports that it was not recommendable. The additional years would have been filled with breast examinations, doctors' visits and overall fear for breast cancer and the surgery.

About the feeling of grieve after the surgery the replies were varying. One member reported that she felt a form of grieve, but only because she did not have reconstruction yet. A main contributor responded that she opted for BPM with this reasoning, but cannot stand her husband touching her breasts now. Two other members responded with a story about their children, which by remaining cool, have helped them overcome their troubles with the breast after surgery.

In order to overcome these feelings of anxiety and doubt, another major contributor and a member tells that the grieving occasionally is part of the natural healing process and maybe a little counseling would help drastically. Another member report that they feel as if they did not grieve properly about this important change in their life, and she is afraid that she is occasionally bursting out in an emotional attack.

(III)

The first post is concerned that she did not asked her doctor all relevant questions about BPM. Therefore she asks both for experiences of regret with a BPM and for experiences of women who did not have all they should have known before the surgery took place.

Initially no forms of regret about having a BPM were voiced. The posters were relieved that they did not have to do MRI and other surveillance procedures any more. A guest and a member even reflected on the BPM as the best decision they ever made. Another member placed some more critical notes by stating that prior to the surgery they had to come to terms with the issues of sensation loss, scars, change of shape and planning the surgery.

A post from a member that is repeated by three guests stated furiously, that no one in their right mind would regret preventative mastectomy over getting cancer. She tells that she waited too long for BPM and cancer struck before she had the surgery. In her opinion the chemo is bad and the fear of recurrence is the worst feeling in the world. Therefore she would do whatever it takes to prevent cancer and save her life.

The sort of regret that is reported mostly concerns the particular procedure. In one case the doctor over-expanded the nipples what made the result unsatisfying, but this resolved when she got used to them. Other members voiced that they rather had chosen a different size that would be more appealing. In cases from other members the doctor did not give a full overview about the possible reconstruction procedures that would have resulted in a nicer looking result.

A guest that did not have a BPM has some additional questions about if feeling of the self is the same before and after the surgery and if they could do the same activities as prior. This question is addressed with some people that voice being uneasy about themselves after the surgery. One member, who uses a guest alias for this topic because she feels she can get crucified when she posts this feeling of regret. Initially she thought that after her BRCA2 and cancer diagnosis she would do everything to prevent future cancers. But when she had her ovaries removed, she experienced an emotionally hard time, resulting in prolonging the BPM for three years. A year prior to this post she had done the BPM surgery, but still feels emotionally a mess about it. She thinks her new breast look ugly, hates her body and tries to hide her scars. She wants to advise people to be emotionally completely ready before doing the surgery and get counseling when this seems necessary.

Some guest responded to this story of regret in a harsh way stating that the guest should get a grip on her emotional situation. Whereas two other guests reflected on this idea with saying that people should be able to express their concerns and regrets on this forum, even if it means that they are in an emotional hard state. Lastly, some people reported that they did not feel regrets after the surgery, but were also worried that they would have, if the result was worse.

(IV)

This thread is different from the others on this topic as the main reason for posting this experience is to let the other know what happened to the FP. Namely, the FP was a woman who unfortunately suffered from an infection in her hip drains after the BPM. She reports her decision to stop with taking antibiotics because she got diarrhea from them. These antibiotics where used to prevent infections and stop taking them is the cause of the infection. Due to the infection she was put back into the hospital for surgery, a CAT scan and surveillance. But her nurse failed to chart her properly and she needed to remind each doctor of her situation. Eventually, she was prescribed augmented and discharged at the hospital. She discussed this option with her father on the phone, who reminded her she was allergic to penicillin and that she needed to go back to the doctor to change prescription. So she did and eventually got an apology and a recipe for CIPRO.

That evening, she had an allergic reaction to the CIPRO, and she developed huge welts all over her body. So she went back to the hospital and got the medication prescribed that was causing diarrhea. As a result she voiced her hesitance to opt for her Ooph surgery, who was scheduled for December. She changed her mind because of this bad situation with the BPM and put the Ooph on the shelf for now. However, she is still reporting multiple times that she is very pleased with the BPM and seems to disconnect her infection from the surgery itself and make it part of her own malfunctioning body.

Two major contributors to the forum were voicing that this was the reason for them to not fully trust medical personnel, because in their opinion the wrongly chosen medication is due to the bad doctors. Whereas two members are responding positively about pharmacists who they believe have often a better preparation to “fully integrate path physiology of disease and the biochemical impact of prescription medications”.

(V)

This thread starts with the question: if there are people who experience regrets after a prophylactic surgery. The first poster expresses that she doubts her choices after several months. Intellectually, she thinks she made the right decision, but she also has some emotional troubles with regrets for the surgery or anger issues because she has to deal with the situation.

A major contributor and another member responds that she does not experienced regrets herself, but she learned from other experiences voiced on the forum, that everyone is different and experiences the situation in their own way. The only regret she came up with were that she did want to have surgery prior to getting cancer, by which she did not succeed in. Two other members had also experienced cancer before they had fully accepted to do a mastectomy. Also one member was just in time with her BPM because in the removed tissue a tumor was found. They strongly advise people who are hesitated to choose the easy preventive surgery over the hard chemo period of having cancer.

Two members that are in the middle of their decision making process report that indeed this is the biggest fear they are trying to avoid. They do not feel that emotionally they are really ready, but while reading through this thread they feel they should decide for the BPM soon. Additionally, one of these members named the potential loss of activity as a hard point in their decision process. This was responded by a member to be a merely temporarily problem as she could ride horses after six weeks post operation.

A member that did not have a BPM and is investigating her options, also expressed that she initially felt angry for having the gene mutation, but later on accepted the situation. Mainly because she experienced some positive recovering stories of relatives who had cancer. Currently she is feeling pressured to utilize a BPM surgery, because she is afraid of getting cancer before she has done the surgery. In her opinion it would be financially better to do a preventive surgery compared to cancer and also she thinks her health would return faster to normal after a preventive measure. She does not opt for Ooph because she still wants to get children and she heard of an increased risk for dementia and early Oophorectomy.

Some other members also expresses that the regretful feelings after a BPM does not weight up against getting cancer. She reported that being a BRCA mutation carrier had changed her outlook and her body. However it also made her stronger closer to her family, more appreciative to friends and aware of her blessings. On the downside, she also feels anger that she and her family have to take these decisions and are under these high risks on cancer. This anger is so severe that she even reported to look at her family categorizing them into BRCA, non-BRCA and unknown categories.

Multiple other members and guests have voiced their anger that they are faced with these choices and all. But they feel still luckily that they are provided with a choice, compared to immediately getting struck with cancer. Also a member is voicing her issue with the financial aspects of BRCA testing, since she did not have a savings account that could subside her best procedure and also could not sustain her for the long period she was unable to work.

A new member has responded as well with the question if the members feel themselves again after the surgery. She experiences a form of depression after her BPM last week and hope that she did not make the right decision. She knows she is lucky to could have opted for this preventive surgery, but still wished sometimes she had made a different decision.

The main contributor that has been called in this tread before is responding to this new member by saying that she should remain patient and feeling regretful after a major surgery such as BPM is normal. Eventually recovering from the procedure emotionally and physically is different for every person and should not be rushed and she should congratulate herself for being pro-active. Additionally a member told the new member that has regrets to take some comfort from the site. Another member advised her to give the anesthetics time to get out of her system, before she would get used to manage her feelings again.

One guest informs that her things she is the only one that is glad that she delayed mastectomy until the cancer was diagnosed, because she had a hard time accepting her body after the surgery. Two other member also voiced that they were glad to wait one because she felt that the mutilation of her body due to a gene was something she found hard to tolerate, and is still not feeling the same.

To follow on this issue a guest posts that she has the idea that BPM are pushed in the USA. Which was responded by another guest stating that she did not feel pushed, merely supported by her oncologists and genetic counselor. On the contrary she reports that the conservation surgery done when she had breast cancer felt pushed by the medical personnel at the time. She thanked this shift in experience to the changes in culture and medical procedural standards. Another member also voiced that she did not feel pushed, rather empowered to make the best choice individually. A different member told she felt pushed by the knowledge of what a breast cancer surgery was involved with.

A second issue that the first post addresses is how to deal with the loss of libido. This issue is thought of as a situation that should be expected when opting for such a hard surgery. The hormones are under a shock due to the removal of the womanly parts, what causes for difference in feelings. However some women have reported that it is only a mental issue that is in the brain.

Other members report that it is a combination of both, that the mind should readjust to the new situation and that sexual experience can come back. Some suggest that experimenting and being clear to your partner can result in a readjustment of the libido. As one member reported that her husband did not have coped well to the sensation less boobs and looks puzzled in the bedroom. One other member suggested taking testosterone hormones, what helped her get over the libido issues.

Making the husband more involved in the issues you are faced with is an advice that is given not only to overcome the libido issues, but also to prevent communication issues. (Linda 43) As one member reported that when the cancer was diagnosed, her husband could not cope with it very well and utilized his secretary to keep him company.

Additionally, some remarks must be made about two members who were actually not feeling regrets at all. One of them voiced that she does not experience regrets as her struggles with BRCA had helped others along the path. While the other revealed she was relieved she would be able to be proactive, which was a choice her mother did not get to make.

(VI)

The first post begins with telling the board that she wished she would come back to the boards with the good news of celebrating her 2 year breast and cancer free existence. However she is sad to inform that a lump has been found three weeks ago, that it is breast cancer. Apparently, when she had her BPM after having cancer, a cancer cell had contaminated the scar tissue and grew until now.

This experienced is answered with disbelief on the forum, as two prominent and other members thought that she did do everything correctly to prevent the cancer from reoccurring. Some members are viewing this situation as a reason not to opt for surveillance and postpone a surgery,

SEXUAL ISSUES

(VII)

The first thread that is being analyzed is started by a guest who expresses sadness that her breast are not involved in her sex life. Before her BPM surgery, the breast region was very important, but with the loss of sensation in these parts, it had changed. However she tells that she does not feel regrets after the surgery, and that she was fully aware that it could occur. Still the sad feeling about it remains.

Many replies from other members and guest indicate that she is not alone in this feeling. A guest reported that she finds it difficult to have orgasms after the surgery. (1guest1) Although one tells that due that her breast look better than before, her husband is more sexually driven which in turn, makes her feel more sexy. Another guest and a member inform that she rather misses these sensations than to get breast cancer and die. This is seconded by a member that tells the sex life just needs to adjust by losing foreplay. One other guest and a member replies that the medical world is lagging behind, and that she rather have ugly breast then losing sensation.

Four guests had expressed that this is an issue that makes her hesitant to have a BPM. Where a member acknowledges it is also for her a bitter pill to take. One of these members explicitly stated that it is a big issue in the lesbian community where the sensation is highly important in the sexual contacts.

Other issues were indicated to lie in the appealing part of the breast, as a guest refusing her husband to look at her breasts because she is afraid her would get disappointed in them as they do not look like they did before. A member shares a similar story, that she does not think she will ever be ready to show her husband her new breasts. (1x) a guest even spills that she is hesitated to let her husband look at her breast pre-op since he might get disappointed in the result. A member tries to reassure her

with her own experience where the husband does not mind the changed boob, and that these surgeries might have saved her life.

(VIII)

This thread is started by a guest who admitted that she thought that there were two types of orgasm: clitoral and vaginal, of which the last type are actually uterine contractions. If this finding is indeed true, then she asks herself if this should not be part of the consideration which surgery to uptake for ovarian removal. She does only recollect that vaginal dryness and a decreased sex drive were considered to be considerations discussed.

One reply was from a guest who actually felt that after her Ooph surgery with a spared uterus she got more intense orgasms. She dedicates this effect to her new energy for life or a change in hormones. A different guest and two members reported that the ovary removal did not change her sex drive as it was already altered by taking hormones, but felt still disappointment that her orgasms were a little bit changed, foremost in the zinging edge. Possibly she has this feeling because she visited a specialized doctor who carefully did this surgery to preserve sensitivity. A member reported that she also felt like the edgy feeling was missing, but this resolved over time.

Another guest is responding that she is afraid of her husband touching her, though she already is a month post operation. She currently feels so sore and uncomfortable that she would not even imagine about possible changes to her orgasm. She is then suggested to start slowly in order to not lose grip on their sexual attraction.

Another guest tells about her sex life after the surgery as if it was great. The first time it turned out as a disaster, but together with her husband she experimented and eventually got it right again. A different guest seconded this idea and told that it is important to tell your husband how you feel after surgery. In order to prevent them from getting the feeling like they are not stratifying you. While a different guest suggested to try vibrator for yourself to start to understand your own body again.

The guest who has altered her orgasm lost her zing, states not that she regrets making sex not of higher priority in her life. A different guest responds to this that she had a life concerning mostly about sex and said that this made her decision to have a mastectomy more easily. A member tells that she does not want to mingle with her current sex life and is therefore hesitated to perform this surgery.

A member points out a new important point, that the people are discussing to overcome their problem in sex life by experimenting with a husband, does not work well when you are single. Another member discusses this issue that in her experience single women who do a mastectomy remain single, possibly due to uncertainty and self-imaging issues.

(IX)

The first poster starts off by stating she feels a form of pressure from her husband to do their normal sex routine. Though, she feels able to cover his need to some extent, he clearly expresses his expectations for more. The first poster was highly sexually charged before her surgeries and the birth of her children, but always felt some pressure to perform. The husband continually references to sex, both vocally and physically, and is forcing his expectations of a daily sexual encounter.

The responses were mainly aimed at the husband who, in the opinion of some guest, does not have a normal sex drive and acts selfish and instead should be supportive and loving to the first poster. One member told of a friend who was in a similar situation where the husband would interfere with her taking antidepressants because it would interfere with the sex life. Two guests and two members also expressed to have been in the same situation where her husband did not stop asking for sex, even

though they was suffering from a depression. Eventually the guest divorced her husband, because his behavior would not change.

The idea that the husband act out of the ordinary is strengthened when the first poster reports that the husband already had issues with his sex drive, already before they had met. Apparently the husband had impregnated two women in Hong Kong, what shows that he has a lack of self-control. Furthermore, the first poster reports that the relatives of her husband is also very selfish and has never made a warm gesture towards her. The relatives had for instance refused to call when she had her surgeries done, but are still complaining over every little ache they have themselves.

A member and two guest reflects on the husband issue that it is indeed disrespectful and that he is making the sex meaningless, as it is not an expression of love anymore. Another guest mentioned that she once also once married to a man who viewed sex as a marital right, and she also divorced him eventually.

Eventually the husband is posting in person himself about his view on this situation. He expresses that he was already aware of the problems his wife was baring. The situations that the first poster described was in his opinion and act to slowly push her into a more active phase with respect to their love-life, as it has been a long time since the surgeries. The accusation of not being normal he waves away because his real willingness is much lower as the first poster had described, though he acknowledges that they should visit a counselor to help them.

A guest responded to his story with that it was not true because it did not match up with the story that the first poster had told. He should listen more to what his wife tells and change his behavior in the process. Another member told the husband to not overdo his trying to have sex so much as the first post had described. A guest then responds that it is a visages circle where it keeps getting worse and indeed the counselor would be a good idea.

This confession instigated another husband to start explaining his view on the sex life. In his case, the wife complains about the lack of sex, and even started to harass him. His issue with sex is both that he is too busy with working and he feels to pressure to perform spectacularly as it is never enough. (1x) Also this different husband is being told that he does everything wrong and should listen to the needs of his wife more.

(X)

This thread is started by the first poster expressing that the healthy sex life she and her husband had, is changed to rather troublesome experience after her Ooph. The issue is that the husband is still touching her in the same way as he used to do, which are turning him on. However, due to the surgery she does not feel anything anymore with those touches, and touching her there is causing her to feel uncomfortable. Despite his understanding of the changed physical responses, he keeps doing the same routines. When it does not work anymore he is reflecting it onto his own performance and it hinders the mood.

Additionally she gives an extensive summary of the things that have changed due to the surgery. Firstly, her libido has reduced dramatically, what means that she does not care about having sex and having an orgasm. Secondly, her natural lubrication has dried during the rare moments she is in the mood. Thirdly, her clitoris has shrunk and does not get erected when she is turned on. Lastly, she misses the days where she was extra fertile and she was a raging animal who attacked her fiancé when he entered the room. These effect are causing her to not feel like a woman anymore and make her worry what would happen when she will have her BPM.

One member reported that she felt pumped with desire the month that was between the surgery and the posts. Despite thinking her hormonal circulation would be messed up. However, three member and

three guest reported that they had similar feelings and experienced the comparable situations when they had the surgeries. They also recommended some product that would help with the vaginal dryness.

A member advised to make dealing with these issues, to become part of the preparation for the surgeries. It is not just the part about accepting that the ovaries are removed, but also that dealing with life after surgery is different. Two members replied that the current medical situation is created because people genially do not want to talk about these issues. If people would be more open about them there maybe could come more options. Which was backed up by a guest, that expressed the option that are available did not work for her. One of these members added that she would gladly exchange a small amount of risk for this increase of quality in life.

Ooph

(XI)

The first post of the 2008 thread begins with a guest posting her idea that most women seem to have taken an Ooph surgery. She follows with questions about the pros and cons of surgical menopause, and expresses that she will not opt for surgery anytime soon, as she find this a big leap. Lastly she expresses her hope for an improvement in the ways to early detect ovarian cancer. After a few replies the first poster tells that she is going to have a BPM, but is still reluctant towards an Ooph, despite being in her 40s.

The major contributor to this issue expresses that she tried hard not to choose surgery, but has eventually scheduled it. Her issue with the Ooph surgery is that it starts an early surgically menopause, but she figured that menopause is inevitable and the loss of anxiety outweighs her presumed unpleasantness. Also she noted that a big contribution to her decision process was her age, desire to have children and attitude towards taking hormones. This first point is strengthen by a later post where she expressed she would not have done is before her 40s because of her world view. In another post she tells that she is BRCA2+ without a family history on ovarian cancer. Also she would express her strong sex life as an important part of her life.

The trouble with opting for an Ooph is also reported by some other members and some guests as a big leap to be taken and a really different and harder story then with the BPM. As she reported that the breast did not fulfill a function, whereas the ovaries did. This does not mean that they will never have an Ooph, only which they haven't put their head on it for now.

Proceeding with Ooph is supported by the motivation of a close family history of ovarian cancer. This is followed by the idea that the replier should have every measure taken in order to prevent the ovarian cancer from occurring, so is one guest removing her fallopian tubes to get a risk reduction without causing early menopause.

Additionally some people, who had experienced the Ooph surgery, responded with some remarks about their feelings after the operation. The surgery itself has not caused problems, maybe because she had both the ovaries and uterus at the same time removed. It was also reported that she found this procedure was far easier to get her head around then the BPM. In one case it was even reported that the sensation of an orgasm had increased. However, a few negative consequences have been mentioned, such as menopausal issues, libido loss, drier hair and skin and potential increased risk of heart disease.

(XII)

In the second thread about this subject the first posts are from a guest who questions the positive view most women seem to have about removing their ovaries. She wants to know if there are women with a different view.

The first reply was immediately from a woman who had chosen to wait with her Ooph, but found a suspicious spot on the fallopian tube thus potentially has got ovarian cancer. This woman decided to wait with Ooph until her late thirties, because she worried that the loss of hormones would lead to heart diseases.

Moreover, a woman responds who wishes to wait till her 40s for fallopian tube removal and her 50s for the whole ovaries. The idea of prolonging ovary surgery is replied by four guests that considered their risk of ovarian cancer not yet high enough compared to health risks and quality of life issues Ooph may cause. Three other members and two guests also report that they find it difficult to opt for the procedure as to their idea there are too many troubles attached to them.

In this thread there is also some frustration mentioned that some women experienced with their medical practitioner. They report to feel pushed by their doctors to proceed with the surgery and have been told that their choice of surveillance was a bad choice to make.

(XIII)

The first post of this last thread is, as stated earlier, started by the primary poster on this particular topic. She starts the thread by questioning if medical personnel are still recommending the Ooph procedure, despite some studies indicating negative effect of Ooph on the life span, due to heart and bone diseases. Due to these studies she starts to feel regretful towards the surgery she had done since the first thread.

Some members reported that they were given the advice to wait a while before removing all or partial ovaries. Where another member explains that medical personnel weigh treatments between risk and benefits and that many doctors value the risk on late ovarian cancer detection of BRCA carriers as outweighing risks on reduced lifespan. A member and a guest have voiced similar remarks stating: "there's no question that the Ooph is the right decision." With the remark that it is still a matter of when and stating that she would have rather waited longer.

SURVEILLANCE

(XIV)

The first post is from a member who is thinking of opting for just a surveillance option. Together with her surgeon she had decided that surveillance is a psychologically satisfied option. However she feels alone in this decision as she does not perceive others that have the same strategy. For this reason she asks other members that share her strategy.

The first few replies were telling the first post not to worry about being the only one, there are others who opted for the same strategy. Although it is acknowledged on multiple occasions by prominent posters that the major contributions to the forum come from the surgical camp. Throughout the remainder of the thread many people voiced that they were happy to hear the surveillance voices on this site.

Two members reported that they doubted that the increased risk was as high as the geneticists quoted. Two even decided to be enrolled in a high risk clinic where she is examined to eventually refine the statistics. One mentioned that the early menopause is a problem for her and followed four

other members with surveillance strategy, who said they based their decision mainly on the fear of doing an unnecessary surgery. This story was seconded by another member who feared surgery and therefore opted for surveillance, but did not recalled feeling anything of the sort when she had done her BPM after getting cancer. So she recommends taking preventive BPM, which was responded to have worked by a guest.

The members that did not have surveillance option report to take the surgeries because they felt feared for ovarian cancer. Others have voiced their concern that ovarian surveillance was still imperfect and the detection of a cancer cell often too late. Two other members made the practical reminder that when you are pregnant the surveillance methods are delayed, making the cancer easier to come unnoticed, so she did a BPM to prevent cancer from occurring in the pregnancy period.

Two member and a guest warned that when opting for surveillance it should be known that not every detection measure is able to detect every kind of cancer. Different types of cancer are detectable with different measures. She said that you are made dependable on the expertise of your doctors to detect cancers at the right time.

One guest made a remark about the relation between a strong family risk and opting to not go on the surveillance route. She is wandering because she has a strong family history and is thinking to take the surveillance strategy. The queen of surveillance acknowledges that a bigger family history can be an influence on the decision, she also responds, and that she chose surveillance despite the dense cancer history. She blamed the cancer occurrences to bad external influences, such as smoking, that have caused for the cancer to struck, not only the increased genetic predisposition. This response is seconded by three other members, although one did add that the link is strengthen with personal involvement with the healing process of cancer.

(XV)

Last thread was started because the first poster had an idea to follow the surveillance strategy. However this thread is again starting with the same member with telling the board that it is the last night she did a Jewish ritual to end the menstrual and fertility time. In the time between the last thread and the current she has abandoned her strategy and is having a mastectomy tomorrow. She made this decision two weeks before this post and told several friends, of whom was at least one other FORCE member.

The decision to change strategies was that after nine years of undiagnosed or misdiagnosed bleeding fibroids, one of the fibroids gave a relentless pain. The gynecologist recommended her to get a TAH-BSO procedure and that her MRI was a close negative, meaning that she has around 10% chance of already having breast cancer. Besides being a horrifying procedure, the first post thought the procedure might not work properly, as in some cases it has the opposite effect. Therefore she takes a MRI what turned up negative.

These situations have led her eventually to rethink her strategy, by using a comparison between her risk of ovarian cancer and fatal traffic accidents on a bridge. With this statistical game, the shocking experiences of the bleeding fibroids and her doctor recommending it, she came to the conclusion that for her it would be better to take an Ooph. About the idea about the mastectomy is a mix between relief, strong and vocal and hysterical and ashamed. In this last day before the surgery she expresses that it feels surreal to be on the verge of unnatural abrupt menopause.

About the BPM surgery she is still undecided. She feel strongly that she will not die of breast cancer with intense surveillance. However, she does not know if the stress of having anxiety for every procedure, will be bearable, as she was a wreck when a little spot was found. She is now bargaining that a little procedure of three hours that would relieve her from this anxiety, would indeed look beneficial.

The first responses were from members who shared the line of thought with the first poster. The scare of ovarian cancer is to freighting for them so when they heard about their BRCA status they got their surgeries planned. Although at first the procedure seemed to be barbaric and horrible, after the procedure they feel calm and secure. Two member did also report that a reason for her to take the procedure was from all the stories she had read on the forum, and that she thought that the cancer would be inevitable. One member told even the first post that she looked up to her, for being so courageous in doing the surgery, where she herself did not find the courage yet.

Two members who had breast cancer before they knew their BRCA status, report that they do not wish anyone to have this disease. They voiced their congratulations that the first poster is taking these steps before the “suckiest” situation would arise. However one of these members voiced the concern that her child would not be able to learn about menstruation from her mother.

An interesting post came from a member that highlighted the influence of the doctor on the decision process, in the story of the first post. She wanted to express that the doctor in this case did not pushed or guided the decision for surgery, but was just giving the information that the first post asked him to do. Compared to other stories she heard from people who were talked into these procedures by doctors and relatives, for this member it was a form of relieve. This post was directly responded to by the first poster, with the fact that she did not even tell her genetic counselor about her doubts in the decision process, because she valued his contribution as lacking in knowledge and care.

After one page of many comments on the decision factor of the first post that came from the surveillance routine to eventually doing the surgery. The second page and later was filled with ordinary comments about how the first poster experienced the procedure herself. Mostly it were encouraging comments to show compassion before the surgery was done and supporting replies to news about the success of the procedure.

(XVI)

This is one of the earlier posts in the selected data, therefore it is interesting to see what the primary concerns were when the community was not that widespread. Additionally it would allow to see a pattern indicating of thought that would have started without the influence of the community as it became larger and modern ideas and preventive measures.

The first post is from the representative who voiced the hope that some of the people who chose not to have surgery will post their experiences, ideas and questions. Because she wants to make a safe haven of the forum for people that have this strategy.

The first respondent indicates that she uses multiple indication tools to help her surveillance for cancers. Additionally she changed her diet to accompany her cancer avoidance. She utilizes a combination of healthier, mostly vegetarian, foods with scientific knowledge that indicated these foods were indeed lowering the chance on cancers. In a later post she also advised to stop drinking alcohol as there has not been a scientifically established safe amount. Moreover she gave the advice to drink lots of water in order to help wash pollutants out of the body, which would lead to longer lives.

However this first respondent does feel sad and scared about the difficulty of detecting ovarian cancer in time. As she has multiple family members that died of breast cancer that started at an age close to hers, she does also feel the emotional stress that is attached to the genetic predisposition. Her answer for these emotional issues was to start meditating more on a mantra that had proven to prevent genetic diseases. Her biggest issue is that she would probably die at a middle rather than an old age and she wants to accomplish something big for society before her death.

This story is responded to by a member that tells her goal is to prevent her offspring to have to deal with these surgeries. She reports that her family members, who did surveillance, did encounter cancer

at an early stage but also died from it. Therefore she chose to do a preventive measurement, because alternative treatments she did not rely on. The board representative replied to this message with that it was better to post it on a different thread. But the first responded argued that a healthier died has proven to be limiting the risk, suggesting that she should try it.

Additionally there came some posts from members who likewise had chosen surveillance strategy over surgery. One member told that undergoing surgery does not feel right for her, and despite some troublesome exams, she is happy with her health regime. She was busy with the day-to-day business that she surpassed her mother's lethal age what made her at ease with herself. Also she did not opt for genetic testing, because it did not feel necessary.

A guest responded to this story stating that to think that when you surpass your mothers lethal age your will remain cancer free. Her doctor had told her the same thing, but she eventually got cancer a few years later. Therefore, she suggested that at least increased surveillance measures are needed when the women get older, which was seconded by a guest. Two other guests responded that they did also feel that doctors do not really understand what it means to be at high risk, and that they are too hesitant to not overly alarm their patients.

A different guest reports on her problems with the insurance company that does not want to pay for the surgeries. Resulting in her trying to enforce the healthier died as the first responded had told her, which is being made hard by her husband who only wants to eat meat.

In posts from 2 years after this thread had started four members stated that they were also opting for the non-surgical route. They surely expressed like feeling they are alone on this route and are hoping that better screening and cancer treatments will be available if they eventually would get cancer. Also a guest points out that she also feels like she is been treated by her doctors as if she is a special case. She expresses feeling frustrated that she thinks removing body parts is "normal", but also experiences herself as a pioneer where normal does not really applies to.

(XVII)

The first post states that she is in the middle of deciding between BPM and surveillance. As she understands it surveillance is the majority option for women with BRCA mutations. Moreover, she also acknowledges that from these women, there must be women who were eventually diagnosed with cancer. Ideally, she wants to manage the frequent appointments of surveillance options, without ever finding cancer. She values her chance on living that kind of life on about 60%, and when she is one of the 40% unlucky persons the cancer would be found in an early treatable stage. What she asks from the board, is to verify these statistics that she concerns with in her decision process.

A guest responds with stating that surveillance is not as easy as the first post perceives it, and it does not guarantee that the cancer is found early, as in her case a cancer cell was missed. That is seconded by another guest, who stated that the detection is depended on the state of technology and the expertise of the medical personnel.

Three members responded with disbelieve on the decision as she could not live with the continued worry whether she would develop a cancer as they have experienced with some relatives. Also a story about a women whose surveillance did not catch the cancer on time, made her more fearful towards this option. Additionally two guest and two member also reported that their cancer had not been detected by the surveillance option. Also in the case of one member, she had seen that ineffectively of the surveillance strategy on her sister so she had chosen preventive measurement.

The Queen of surveillance and two member responded as well with their story, expressing that they did not feel regretful that their cancer struck when they was under surveillance. It was just a matter of chance that they would get it and now have cherished the moments in a healthy body. (Elaine44)

Another prominent member responded that she was not regretful that her cancer was discovered before she had done preventive surgeries. Surveillance had given her a chance to get children and her doubt she would have been ready at the time. Another member chose surveillance because in her opinion not every body part should be removed because people think it would be potentially dangerous. Being alive involves taking some risk and the most important part of it is being at ease with the risk taken.

There were also multiple remarks that the subset of women, who were on these boards, did not represent the average population as the responses of women who had surgeries overpowers the voices of the surveillance women. Therefore readers of the thread were advised to not take the findings they did on this board to be of great influence on their decision. Also some notes were made about the availability of options not being carefully exchanged by the medical personnel.

(XVIII)

This thread is started by the first post who had a BPM last week, although the surgery went well, the breast surgeon diagnosed a form of breast cancer in the removed tissue. After doing a year of surveillance this form of cancer did not show up on the MRI and mammogram she had last year. Therefore she advises the people who are reluctant for the surgery to reconsider if the risk is not too high.

This story was responded to with some people expressing compassion for the cancer diagnosis and a guest and two members congratulated her to have done the surgeries. Additionally a member reported that the situation the first post describes is her biggest fear, going into her own surgery.

Additionally three members reported that her story was similar to that of the first poster, where she also had a tumor in the removed tissue. Also a prominent member tells regrets her medical personnel to have missed invasive cancers on the surveillance charts.

One member and a guest have reported that through these kinds of stories they feel scared that their BPMs would come too late. The member even tells about her conflict with the medical personnel who are telling her she is too young for Ooph, while she thinks she is a ticking time-bomb where the cancer could strike despite her age.

(XIX)

In the opening post a member expresses that she has been taking Vitamin D supplements as she concerns about her levels being too low, due to her living environment and her age. She also explains that her friend was diagnosed with MS and has low levels of Vitamin D despite therapeutic doses. From her own research she concludes that Vitamin D is responsible for hosting disease such as MS and some cases of cancer and a level of 30 or 40 (ng/ml) should be preferred. The opening poster self has a level of 87 and claims that everyone can benefit from getting this important test for good health.

This post is responded by 3 guests with verification the importance of taking the Vitamin D and testing for appropriate levels. After a few replies there was shift in the discourse towards 6 members discussing the amount of supplements people should take. This amount seems to vary between a daily dose of 2000 IU to 12000 IU (international Units (40 UI = 1 mcg)).

Additionally, one member pointed out that she had read that many people in the US lack Vitamin D, because their lifestyle does not include outdoor activities. This is a problem for people who take calcium supplements, as Vitamin D is necessary to absorb the calcium. Which in turn is critical when breast cancer is estrogen positive and your medication depletes the estrogen levels, causing for a depletion of bone density. A different member explained that the alleged correlation between Vitamin D and MS, is not proven.

A guest responds to this story with stating that some people have a skin that is less prone to Vitamin D production. Furthermore, she and a member state that people at increased risk of cancer should try to avoid being in the sun. Thus, 6 replies explicitly explain that is easier to take supplements to be sure your Vitamin D levels are in the normal range. A different member also expressed she avoids the sun because she is BRCA2 and has a level of 16 as a result.

Furthermore, another member posts an academic article explaining that there is a high frequency of vitamin D deficiency among US citizens and women with this deficient have a 73% increased death rate than normal levels due to a correlation with forms of cancer such as breast, colon and pancreatic cancers. Also, one member posted an article that explained the easy absorption of Vitamin D3 by the body.

RELATIVE SUPPORT

(XX)

The first poster begins by telling her current situation that she finds frustrating. The day before this post she had discovered that a lump inside her breast changed in color and size. She has not tested for the BRCA gene mutation and did not perform a surgery except for a partial thyroidectomy. She visited her oncologist, who examined her and redirected her through to her breast surgeon. However, the first poster does not feel comfortable with visiting this person again. During her last visit he barely took notice of her individual and personal situation and responded negatively to the concerns that the first poster was spilling. Therefore she felt hurried, rushed and not taken seriously, and explained this experience to the oncologist. He then referred her to a different breast surgeon and advised her to be careful and proactive with her family and personal medical history.

However, her relatives expressed she should drop this 'proactive headache' and follow the advice from the breast surgeon. She should avoid visiting the oncologist the coming years, no matter how the lump would develop and should always follow the expert opinion. It should be noted that besides these relatives who respond negatively, she also has a father that supports her decision. The first poster indicates that she finds anger towards the attitude of her relatives and asks the forum if this feeling is justified.

The replies indicated that the forum does not find it strange that the first post reports to be angry. One member stated that everyone deserves a medical professional who will listen a help put your mind at ease. Being proactive about your own health issues and look for a skillful doctor who is willing to listen to your concerns is what she recommends. A different member seconds this idea by voicing the experience of her mother who is still alive because she insisted strongly to her doctors that she needed a biopsy on her lung. While a prominent contributor uses the example of a friend to indicate that women should proactively avoid medical malpractice. Another prominent contributor told the first poster to at least get a second opinion, as multiple diagnoses can also provide the best care.

The relative part of her story was responded to by a prominent member voicing his experience with stubborn family who, when being informed about the gene mutation and its risks, called the decision to have BPM barbaric. This story indicated that although family might think they give genuinely good advice, they can be misguided, and should not always be followed. Moreover, the role of the father in this decision process is celebrated by both this prominent member and two different members.

Later on the first poster is elaborating more on the situation whit her father. She expresses that although he does comply with her finding her BRCA mutation carrier status, he does not want to know himself. This is troublesome as she would need him testing before it is beneficial for her to get tested. A prominent member reported that the fathers' hesitance probably comes from two reasons. Firstly, many people are unaware of the gene being transferable from male or female. Secondly, he

experienced that males find it hard to accept that they could possibly have passed the gene on to their children.

(XXI)

The first post starts declaring that the way family and friends are responding and not responding to conversations about genetic testing and possible surgeries. After she started to discuss the details and possible outcomes with a friend, when the first poster was feeling depressed, the friends stopped responding despite the first person leaving three messages on her answering machine. A similar experience she had with her aunt on the non BRCA carrier side of the family, in an email the first poster explained her problems with BRCA, which did not get responded to. However, the first poster was always a shoulder to cry on when the aunt had divorce drama. From these experiences the first poster concluded that the BRCA subject is too much for people to take or that she should not expect people to return the support she gives herself.

A member replies to this story by stating that probably the persons who are thought of as good friends, do not support the decision to have surgery. Meaning that when BRCA carriers need support the most they do not get it, except from forums like these. A member supported this statement by giving multiple examples of people in her family and friends that did not want to discuss BRCA troubles with her. When for instance she called her brother and relatives with the message "I know you heard I have the gene ... please call me", from these people she did not get a response. Her brother added to his refusal to talk his opinion that he would not have chosen to test and the trouble she experienced is brought on herself. About this the member responded that these people just do not understand and cannot understand because they are not in their shoes. Luckily this member has an additional support system where she can vent her ideas.

A guest reported that her colleagues did not voice their support or get-well card and were thinking she just did a boob job. A different member reported that her husband does not get any of it because he is from families that hardly get sick. A member voiced a similar opinion, when she stated that if she would not have been affected by the gene, she would avoid the subject as well.

As an advice two members stated that everyone has a different comfort zone and some things are outside their realm of experience. An event such as divorce is hard to relate to and the response is then not something they can prepare for. Two members and a guest responded that this is a good advice and in their experience should be utilized more. A member goes even further by stating that preventing diseases is an act of courage and maybe that's too much to relate to. What was responded to by a member telling that a big chunk of the responses are influenced by how people are raised?

To put the BRCA worries into perspective, a member told a story about her co-worker who has Huntington disease running in her family. The best that these people can receive is an age by which their symptoms start, and there is neither a cure nor preventive measures to take.

(XXII)

The first poster tells that she has two male cousins that have been tested to be BRCA carriers. They are reluctant towards the idea that cancer would affect them. To the discomfort of the first poster who desires that they act proactively. Therefore she asks the forum members for experiences of males with cancer that she can pass through to the cousins, in order to convince them to take action. Furthermore, she asks for opinions about males getting mastectomies and if doctors are willing to perform these surgeries.

A member told that her grandfather has cancer and also carries the gene mutation despite not being tested. Also another member reports that the males in her family did not get tested but have been

diagnosed with cancer. Additionally she reported that the primary care physicians of these males suggested that they did not have to test because they were male.

A member expressed that she is grateful for this thread to have been started as her son is a carrier, but lacks information about what kinds of cancer he is predisposed for. A prominent member explains that her son is in the same position. To the range of her knowledge the increased risk for male breast cancer is still lower than the risk a non-BRCA mutation carrying female is exposed to. Therefore, for her and for her doctors, performing a mastectomy seems very extreme. This idea is seconded in by two members and a guest who added that the major problem with male cancers is late detection, as a result the physicians at high risk centers recommend regular breast exams.

One guest describes a different case, where her father is planning preventive surgeries and is overly afraid of cancer, whereas he does not take actions that would be more beneficial for his cancer risk reduction, such as reduce weight and stop smoking. If the choices of her father were not blinded by his emotional needs, she would feel more supportive in these decisions. A prominent member responds that the fear of cancer, even if it is small as for males, is hard to get rid of, without having done surgeries.

In general the advice that the members would give to male carriers, was that they would take their risk seriously and contact genetic counselors, in order to evaluate their options and strategies. In one experience, a brother was suggested by his physician to perform a double mastectomy in order to eliminate any risk. By which a prominent member, a member and two guests responded that not every risk justifies a procedure and should be weighted in accordance.

A different issue that has been discussed in this thread, was about BRCA mutation testing of children. One member expressed that she has tested her young daughter for a gene mutation. She does not have the intention to influence the decisions her child makes and does not wish to tell her for many years to come. This situation is valued by her as taking a huge emotional burden, to educate herself in order to be prepared for the time her child has questions about the mutation. When a guest asked her if she looks at her daughter differently, she has to respond that she feels different in her heart about her and hopes that the child does not notice it.

After an Asian guest expressed his experiences with his physician suggesting a BPM or taking the medicine Raloxfine, a member asked him to verify her idea that an oriental diet would reduce cancer risk. To this risk estimate, the Asian guest could respond to, he merely could state that cancers do occur.

(XXIII)

The first post is in this thread merely one question, therefore the circumstances of the poster are not elaborated. She asks for experiences and feeling from other BRCA mutation carriers, towards siblings who did not test for the gene mutation yet.

In the first reply a member expresses that she thinks she would be very irritated at them and that she feels a little bit jealous towards her non-mutation carrying sisters. Especially when they act as if they do not understand her problems and express that the member is at fault for her troubles. A member describes the half of her family that had been negative for the mutation, had mixed feeling of relief and guilt towards the other half. Also another member describes the call she got when her sister turned out to be negative, in tears the sister expressed she felt like leaving the member alone. Whereas another member expressed she feels jealous about the careless existence of her sister who in her opinion is bragging about her health status.

A member who had a similar experience as the first poster, describes herself praying harder for her sister to get a negative carrier status, because she does not want her to go through the same troubles

as she did. A member tells a similar story about finding the BRCA testing and surgeries much harder for her daughter than her own BC experience. Additionally the relation between this member and her sister had strengthened when they had both struggled through these procedures. A different member also wishes that his sister would get tested, for she has children and grandchildren who might also be at increased risk.

A different guest expresses that she hoped her sister would test positive for the mutation, as she already had ovarian cancer and the family history was so revealing that a genetic disposition would always be on the cards. She also expressed that she wished her brother would get a positive test result so he would take the genetic risk more seriously and show more support. A different member also told that she wanted to test to unravel the strength of the gene that she gives through to her children. Also two members expressed a sister and a mother not being receptive for all the knowledge that she gave her to guide her decision. One member even expressed that her sister called her life decision stupid behind her back, which was responded to by another member as wrong to be judging decisions of others.

Eventually one response came directly from one of the siblings as described in the experiences above. She expressed that after her sister pushed her to get tested, she refused and continued with twice yearly mammograms, until she finally got cancer. In hindsight she still says she would not have tested for the gene mutation, because she did not want to become ultra-concerned. Two members expressed similar thoughts towards her own siblings, who she let to refuse testing if they did not want to get overly insecure.

One member expressed her doubt for the extent that it helps to try to convince a refusing sibling. She thinks that it works in a negative sense that the refusing sibling is increasingly stronger refusing to be convinced every time by her relative who has thought she found an answer, to a question the sibling is not asking. It is to her experience that her siblings were naming her living in a state of fear, when she pushed them more. This is strengthened by another member who distinguishes between two kinds of people: quietly accepting people and people with their eyes wide open and questioning the world, in this division the BRCA tested are in the second category.

(XXIV)

The first poster has tested positive for a BRCA2 gene mutation and she has four sisters of whom one tested but did not yet have results. She asks the board for experiences with siblings having the mutation, because she heard that when you are positive then most likely your sisters are also positive, despite hearing different experiences. She clearly does not want her sisters to have to deal with being a BRCA carrier.

As a response to this question, the forum gave the status of the people tested in their families. Additionally, almost all posts tried to clarify that for each individual has a 50-50 chance of inheriting the mutation. This means that the initial idea of the first poster has been falsified.

One member states that the 50:50 chances does only cover for first degree relatives. The chances for a real family are depending on personal and family history and sometimes on the test result of other members. By which she means to illustrate that if a non-tested family member gets cancer, the chance that she has a genetic mutation is increased. And when a person tests at a higher age, the chance that it would indicate that she has the gene mutation is lower.

Eventually the test results of the sister of the first poster came in and she was also positive. However when she had gone to her doctor she got advised to do surveillance on her breasts, because there has been no issues with them. The first poster got a different advice from her own doctor, making her confused about the procedure, because she thought they had the same risk estimate. Which a member responded to by stating that it is a personal choice.

(XXV)

The first post describes the frustration of one member towards her family, who keep reminding her that planning her surgeries in the holiday season is not of good timing. Her dad can skip work for a day what costs him a lot of money and the other relatives cannot even find a babysitter for their dogs. The family thinks that because the surgeries have been rescheduled already, it can be delayed for another few months. On top of all her troubles the first post is doing an interview for a big magazine to increase the awareness of her support group.

The reaction of the family is being described as selfish and unsupportive, and the first poster should think about refusing the family members to come at all. In the experience of this member and of another guest the self-absorbing people are a drain on the energy, which she does not have to spare at such a surgery. The moderator responds that if she needs to vent to people who can relate the forum is often better than uncooperative family members.

Two different members and a guest stated that people handle stressful situations in various ways, meaning that the first poster should not hold a grudge against her family members, as this is maybe their way of handling it. A prominent member asks if the family members are acting differently than normal, because that would indicate the statement that the previous member stated.

YOUNG AND TESTING

(XXVI)

The first post describes the surprise she had when her daughter bothered her to be tested for the BRCA mutation that runs in her family. In response the first poster told her daughter that she does not have to worry until she is in her thirties. But she is also wondering if it would be wise to take her daughter to the next genetic counselor meeting.

A different member expresses that should would take the daughter to the genetic counselor, in order to still her youthful curiosity. A Guest seconded this idea, but also added that she would refuse the daughter to be tested, until she would be eighteen. A member and two guest more strongly recommends that the girl is way too young. As in her own experience, when she tested at the age of twenty-three, she was not yet grown up enough to cope with the emotional weight. She voices that making different life decisions because of a predisposition for cancer would be a real shame. Additionally it is important to understand if the woman is fully ready to hear she is positive for the gene mutation. Another member expressed that her girl had different things on her mind growing up, such as college, that it would be better if the women would first settle down before confronting herself with the BRCA issues.

Another member has a different idea about testing at such a young age, since she decided that her daughter was mature enough at nineteen to visit the genetic counselor and get tested. Additionally she reported that she felt shocked when she visited a support group where many women had their BPM in their twenties. Two members expresses that the daughter apparently is old enough to understand the genetic problems and testing for the mutation may relieve her of some stress. This is seconded by two guests who advised that the daughter would otherwise do it a year later, therefore guiding her through the process would be a good idea. Another member tells that she is afraid that the cancer will struck before such a young girl is tested.

One member told that a mother should at least be open with her daughter about the BRCA gene mutation. Since in her case she kept the information to herself, what led to her daughter having to go through the status of shock and knowledge gathering herself? This daughter expressed that if her mother would have been more open about the predisposition she would have been less stressful. This idea was seconded by a member who had a similar experience but being the daughter in her case.

Another woman who had her daughter tested expressed that it is also a hard time for herself during the waiting for the test results. Also a potential issue with being denied by insurance companies, due to a known BRCA status is addressed this idea is being refuted by a wife of an insurance broker, who asked her husband for clarification.

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In the year prior to this thread the first poster had described that her daughter had a breast lump removed, which was only a fibroadenomas. Now, the daughter is diagnosed with endometrial stage 1 cancer and a surgery will have to be performed to cure her daughter. As a result of this diagnosis the daughter has changed her diet, to try to be more in control. Eventually the lump was good to be cut out and it turned out to be another fibroadenomas.

The board is responding with condolences towards the discovery of cancer and state that it is really unfair for women to have been struck by it at such a young age. Additionally, some members, including two prominent one, expressed that their children having cancer is even worse than their own bad experiences. One member voiced that it is unfair that the daughter cannot experience being a woman before the cancer would strike her in exactly the female parts.