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CARE AND THE POTENTIAL OF GENETIC COUNSELING: A CLINICAL FIELDWORK

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Abstract: Recent decades have witnessed an innovation in genetics and biomedical practices, shifting the practice from treatment to prevention. Testing healthy individuals for genetic inherited diseases has now become increasingly common, preventing potential disease by offering early screenings, medication, or potentially surgery, reducing the genetic risk from developing into disease. Though, social scientists have raised concerns over how this technology of testing individuals will be utilized in healthcare and how at-risk individuals understand their new health condition, calling for a caring practice of genetic tested individuals. Conducting fieldwork in a counseling clinic in Denmark, this thesis yields insights in the caring practice of genetic counseling. Firstly, due to genetic tested patients' potential imaginations of being either sick or destined to be sick, a symbolic management of the clinic's interior disentangling its practice with disease is critical, generating a clinic of non-sickness. Meeting patients' needs is additionally emphasized as vital. This is articulated as 'meeting the patient where he/she is' constituting a caring practice which analyzes, measures, and evaluates counselee's social, bodily, and emotional needs. This caring practice, however, is challenged during telecare consultations, especially without a visual sense of counselees, making it difficult to hear and see the 'unspoken' needs.

KEY WORDS: Social anthropology, genetics, care, caring practices, telecare, potential

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Chapter 1 – Introduction

In 2005 Margaret Lock (2005) described the following metaphors as ‘the book of life’, ‘the codes of code’, or ‘The Holy Grail’, in response to the influential genetic research of the entire sequence of the human genome published in 2003 (Lock, 2005: 47-48). Developed with the primary focus of creating analytical tools for medical and genetic researchers, the human genome project has been fundamental to identifying more than 40 diseases linked with genes, such as early onset of breast/ovarian cancer, Alzheimer, and Huntington’s disease (Collins & Fink, 1995). Consequently, the results of the human genome project also yielded the potential to intervene in genetic conditions through genetic testing, revealing previously hidden health and family related issues of individuals’ pasts and futures (Taussig, Hoyer, Helmreich, 2013: 3). However, as genetics research expands, concerns over its social and ethical implications have emerged in parallel. Concerns mainly linked with how the research tools provided by the human genome project would be applied to clinical care, specifically the testing of people who may be at risk for genetically inherited diseases, but do not show symptoms (Collins, 1995; Bell, 1998). Concerning the latter, the influential sociologist Ulrich Beck stated: *“genetic technology, (...) and thus the social invisibility of the risk society, is no proof of its unreality; on the contrary, it’s a motor for the origin of the risk society”* (Beck, 1998: 45). Because of risks becoming invisible, the need for expert knowledge and technology increase to determine or interpret whether risks are real or not (Ibid. 4). Hence, the notion of risk has not just become more apparent to the human being today, it also shapes our perception of ourselves, calling for a practice of guidance and counseling. I will in this context be focusing on the expert and technological practice of genetic counseling, or the practice of counseling and calculating healthy individuals’ genetic risks.

Since the 1950’s genetics has undergone a shift in its practices, from treating symptoms to preventing diseases, hence surfacing a new practice within biomedicine termed ‘new genetics’, aimed at prolonging individuals’ life by informing them about inherited risks (Finkler, 2001; Novas, 2000). More specifically, the shift was guided by an establishment of a non-directive genetic counseling aimed at testing healthy and at-risk individuals for inherited genetic conditions. This practice is what has come to be coined ‘genetic counseling’. Corresponding with the practice shift in the new genetics, the definition of ‘patient’ has also shifted to what has been coined ‘genetically at-risk individuals’, living between sickness and healthy (Novas, 2000; Timmermans, 2010). Due to genetics' core focus on genetic heritage, a risk-diagnosis is never limited to the testing individual, but involves, voluntarily, or involuntarily, the tested individual's biological relatives. Involuntarily in the context of relatives who might not wish to know about the potential familial risk, impacting their life too. Furthermore, a risk-diagnosis also impacts future choices regarding family planning. The latter creates the ethical dilemma of: the right to know about one's genomes and the right not to know (McLean et al., 2013). In other words, whether a detected genetic risk should be shared with family members, even if they wish not to be informed, remains a complicated ethical question. Meanwhile, as genetic technology becomes increasingly affordable for private companies, so has the accessibility and affordability of commercialized genetic tests. A recent YouGov survey found that two in ten Americans have taken a mail-in DNA test, while 65% said they still wanted a test even if the result indicated an increased likelihood of developing a personal health risk (Orth, 2022). Commercial tests lack the counseling element: an in-depth explanation and interpretation of the result and its familial implications. As such, individuals risk misinterpreting and not fully understanding the concept of being 'genetically at-risk'. Results have shown how 'genetically at-risk individuals' are more motivated to seek out medical surveillance tools in order to monitor their health (Scott et al., 2005). Concerns have equally emerged regarding how genetic knowledge among at-risk individuals are utilized in social circumstances, fearing at-risk individuals might be treated as if they are sick, certain to, or destined to be so (Novas & Rose, 2000). Genetic testing therefore requires an element of care: careful communication of risks, ethical implications, and the complex content of genetic information for individuals wishing to be tested. As a result of the potential implications and potential outcomes of genetic risk-diagnosis, the practice of 'genetic counseling' in healthcare services has emerged in response. Carefully counseling healthy individuals who wish to be tested for risk conditions, helping interpreting test results, and potentially recommend medical interventions or surgical alternatives to reduce the genetic risk.

Though, care might appear irrelevant within the practice of genetic counseling in which a healthy individual chooses to be tested or not; seemingly undermining a concept of care in genetic counseling. Social science has over the last decade described two major discourses in practicing 'good care' in healthcare. On the one hand, the individualistic discourse of 'choice' has been articulated as dominant in Western healthcare systems, focusing on concepts such as patient-centered care, patient empowerment, and informed choice as 'good care'. In other words, letting the patient choose for him/herself is considered the best way to care for the individual. Contrary, others argue that individual choice does not lead to ‘good care’ but often clash instead, emphasizing a collective caring approach between healthcare provider and patients (Zolkefli, 2017; Mol, 2008). Anthropologists have long emphasized the concept of care as a human trait and a practice of tinkering deployed by health care workers attuning to the individual’s experience, habits, and tastes (Buch, 2015). Regarded as both a fundamental cornerstone in healthcare practices and a basic human trait, care has rarely seen theoretical utility in clinical genetic even though its need is evident. Moreover, while traditional notions of care are often closely associated with hospital wards, health management, and intensive care units (Long, Hunter, Van der geest, 2008: 74), these elements are not necessary in a context of genetic counseling, which calls for a different and meaningfully form of care practices.

Meanwhile in an age of technological and digital communication, the intersection of care and technology have increasingly become the objects of theoretical and practical investigation. This was specifically the case during the global Covid-19 pandemic, which saw the necessity and benefits of utilizing telemedicine under such circumstances (Monaghesh, 2020; Scheffer, 2022). Telemedicine physically removes the care provider from the same room as the receiver and shifts to a digital platform, thus providing telecare. Positive attitudes towards telecare have celebrated its easy and quick access to healthcare providers, ability to reach patients in rural areas, and possibility to better monitor patients health who otherwise would have been cut off of the opportunity (Tang, 2023; Sinha, 2000). In contrast, fears of telecare concern its potential of creating an undesirable distance to patients, in the worst case dying under the access or surveillance of electronic monitors absent of the presence of a warm hand (Pols, 2010).

Telecare has since 1990 been part of the Danish healthcare system while genetic counseling was first established in 1999. The Danish health care system is guided by the principles of equal access to hospitals and treatment for citizens, hence referral of genetic testing is free of charge (Gjødsbø et al., 2021: 31).

Objective and research question

It is within the Danish healthcare system, at a local genetic counseling clinic, the ethnographic fieldwork of this thesis is situated, investigating the aforementioned consequences and implications of genetic counseling, its particular forms of care, and its interfacing with telecare. My objective of this thesis is to understand how care is practiced in genetic counseling and how telecare influences the care practices. In doing so the following research question has been formulated:

"How is care articulate and enacted as a social practice in genetic counseling?"

Specific research questions

- *How is care perceived by the clinic's staff and patients?*
- *And how do telecare and patient assistive technologies intersect with and impact these care practices?*

Thesis structure

In this section I will briefly outline the structure, giving the reader a roadmap of the thesis. Chapter 2 gives an overview of previous literature in fields and topics most relevant to the study at hand: clinical anthropology, genetic counseling, care, and telecare. The overview discusses the findings of relevant qualitative, quantitative, and ethnographic studies and sets them in conversation with the thesis' central concerns. The chapter additionally locates gaps in the literature, which will finish with situating my study within the literature. Chapter 3 describes the methodological tools used for collecting and processing the data. This includes a description of the access to the clinic, the participatory observation, and a presentation of my 19 interviews and informants. The chapter also covers ethical considerations and reflexivity regarding my own positionality in relation to the empirical data. Chapter 4 presents the theoretical frameworks used to analyze the processed data. The chapter will discuss Carlos Novas' and Nikolas Rose's (2000) notion of 'genetically at-risk individuals', Taussig, Hoyer & Helmreich (2013) 'anthropology of potentiality', Annemarie Mol's (2008) 'logic of care', and, finally, Jeanette Pols' concepts of (2012) 'warm care and cold technology'. Chapter 5 begins with a field tour of the clinic, situating the field and describing the facilities and daily practices based on my observations and fieldnotes. The chapter then moves on to analyzing various care practices within the clinic based on data from counseling sessions. The chapter ends with analyzing the effects of telecare on the clinic's caring practices. Linked with the latter, the impact of 'Mit Forløb' ('My Course') will also be analyzed. Finally, chapter 6 presents a conclusion of the thesis' results.

Chapter 2 – Previous literature

The following chapter covers relevant research and literature on the thesis' central topics of concern. These topics include 'genetic counseling', 'care', 'caring technology', and 'telecare'. The review is based on focus on academic articles, systemic reviews, quantitative, qualitative, and ethnographic studies. The majority of the studies are from medical, psychological, genetic counseling journals, and medical anthropology sourced from Google Scholar and PubMed search engines.

The structure of the review will first outline the broad theme of genetic counseling and the counseling practice. Hereafter I will turn to the literature focusing on the counseling experience and the posed implications of genetic counseling. Next, I will move to the theme of care and anthropology. Finally, a section on caring technologies and telecare will follow. Finally, I will finish the chapter situating my research in the literature.

Genetic counseling

Because of the innovation in genomic medicine and the complexity of genetic information, clarifying genetic counseling as a field of practice has been a subject of genetic, psychological, and social science research over the last three decades (Resta, 2006; Meiser, 2008; Biesecker, 2001a; Rantanen, 2008). Reviewing the literature on the history of genetic counseling's goals, Biesecker (2001a) identify the following three historically developed goals: to prevent birth defects and genetic disorders, to help clients adapt and cope with genetic information, and for those receiving counseling to 'learn, understand, and cope'. An 'ideal' genetic counseling was identified to include the following: Trained professionals with genetic knowledge and awareness of ethical implications, assurance of clients' understanding, psychological support, informed consent, confidentiality of genetic information, family consequences due to testing, appropriate handling of potential discrimination, and ensuring counselee's autonomous decision-making (Rantanen et al., 2008). Rantanen's notion of 'ideal' genetic counseling is relevant for this thesis as it outlines the ideal practice, which I aim to build upon. As genetic counseling has expanded beyond laboratory and biomedical practices and into public health and social science, a redefinition of genetic counseling was needed to maintain a common base practice (Resta et al., 2006). Sparked by the National Society of Genetic Counselors (NSGC), the definition resulted in the following: *"Genetic counseling is the process of helping people understand and adapt to the medical, psychological,* *and familial implications of genetic contributions to disease"* (Ibid. 77). Relevant for the study at hand Resta (2006) states the following elements as central in genetic counseling: The process involves, (1) interpretation of family and medical histories to assess the chances of disease occurrence or recurrence; (2) education about inheritance, testing, management, prevention, resources, and research; (3) counseling to promote informed choices and adaption to the risk condition. In sum, I aim at building upon this literature with a clinical ethnography of genetic counseling and add empirical results to the complexity of the practice.

Counseling practices

The content and process of genetic counseling has previously been referred to as a 'black box', concealing the practices therein (Paul, 2014; Roter, 2006, Biesecker, 2001b; Ordonez, 2013). While communication is important in all forms of healthcare, it is of vital importance in genetic counseling. One might say it is genetic counseling's core task. In a systematic review of communication in genetic counseling, most quantitative studies found that clinician dialog predominantly consisted of topics such as biomedical or educational rather than psychosocial elements (Paul et al., 2015). However, communication within genetic counseling has previously been conceptualized in terms of 'teaching', emphasizing the transmission of information in a meaningful manner, and 'counseling', undertaking the task of helping clients to find a personal meaning and psychological sense in the given information (Roter et al., 2006). Based on 158 audiotaped consultations Butow & Lobb (2004) demonstrated genetic counselors' 'good practice' by giving detailed information on vital aspects related to familial breaster cancer. The concept of 'good practice' is of major relevance for this thesis as it outlines parallels to my focus on care practices and echoes my utilized theoretical frameworks on care. The articulated information included screening and management, genetic testing, cancer genetics, and prophylactic surgery. Echoing Butow & Lobb's (2004) research, a newer study from 2011 found that counselors' engagement in communication behaviors potentially elicit counselee's emotional expression and discussions of psychosocial concerns (Ellington et al., 2011). The latter study suggests genetic counselors' engagement behaviors may provide a facility of emotional processing among counselees and prediction of future cognitive and emotional processing (Ibid.). A study from 2002, among women with and/ without breast cancer, found that consultants tailor information to counselees. The tailoring of information was more depended on the individual counselee, especially if cancer was detected, rather than counselees expectations, psychological well-being, and knowledge of genetics. Anxious women or women with non-professional jobs were also subject to a tailored consultant behavior, inviting these women to ask questions and used diagrams more frequently (Lobb et al., 2002). Lobb's et al. concept of 'tailoring information' is of relevance for this thesis as I will be utilizing the concept later in the analysis.

A common and guiding principle of genetic counseling's practice is the notion of shared decision and non-directiveness (Kessler, 1992; Elwyn, 2000; Wolff, 1995; Hodgson, 2005; Weil, 2006). In 1992 Kessler (1992) argued that all genetic counseling entails influencing counselees. Directive counseling seeks to influence counselees' behavior in a specific way while non-directiveness attempts to influence counselees' way of thinking about decisions (Ibid.). Non-directiveness implies a counseling method which seeks to help counselees arrive at the best personal decision—for example, whether to get tested or not. The latter is best achieved by a dialogue of shared information and through discussions of views before agreeing to a decision for which both parties share a responsibility (Elwyn, Gray, Clarke, 2000). A later study from 2005 states the aforementioned dialogue also facilitates the option of counselee's exploring their decision-making processes and potential autonomous decisions (Hodgson & Spriggs, 2005). An interesting analysis demonstrates when counselees are being made aware of their riskiness, regarding reproductive powers, they are framed as having a capacity to choose their future, or in other words, the choice to decide what future they wish to live in. However, these choices are rendered where the future is knowable through the techno-scientific innovation and clinical practices (Latimer, 2007). Briefly returning to the most relevant aspects of the section's articles, I will be drawing from Butow's and Lobb's concept of 'good practice' in my examination of care practices within genetic counseling. Moreover, the notion of 'tailoring information' is also of relevance in my study of how care is practiced.

Experiencing genetic counseling

Counselees' expectations and their experiences associated with genetic counseling are closely related to of counselees' psychological status, accurate risk perception, and satisfaction (Pieterse, 2005; Lobb, 2004; Hallowell, 1997; Randall, 2008; Julian-Reynier, 1996; Michie, 1997). Investigating counselees' experience attending genetic counseling Peters, McAlister, and Rubinstein (2001) conducted an ethnographic fieldwork examining counselee's experiences within a clinical setting. Results indicated that genetic counseling is a complex social, emotional, and medical process. The study highlighted the following articulated themes: physical context, participants, counseling and cancer risk, kinship, and families, coping and support, food as a medium, and healing emotionally as well as physically. Among Peter's et al. (2001) addressed themes, physical context, participants, counseling, and cancer risk, and coping and support, are all of relevance for my study. All the latter themes appeared connected to how care was articulated, practiced, and understood in genetic counseling, hence its relevance for my study and focus on care practices. Reasons for attending genetic counseling might vary according to individual expectations. In a quantitative study investigating patients' rational of attending genetic counseling, results indicated 79% of patients expected information, 50% reassurance, and 30% help in decision making (Michie, Marteau, Bobrow, 1997). Though, a former study stresses 'prevention' as the main reason for attending genetic counseling (Julian-Reynier et al., 1996).

Addressing counselees' expectations

Ensuring a meaningful and helpful consultation for counselees', according to Biesecker & Peters (2001b), requires genetic counselors to focus on clients' needs, attitudes, expectations, and clients' awareness of the consultations' content. An older study concluded patients were less concerned and levels of anxiety were reduced when individual counselee expectations were met. However, meeting counselees' expectations regarding the providing of information, explanations, or help with decision-making were not found to produce better outcomes (Michie, Marteau, Bobrow, 1997). However, a later study guided by grounded theory indicates the relationship between genetic staff and counselees, significantly influenced the outcome of the counseling session (Skirton, 2001). A similar quantitative study by Hallowell et al. (1997) found that women attending genetic counseling showed an overall positive satisfaction. The same study also found that 37% of the women did not know what would happen prior their counseling session. In addition, 28% of the former study's informants felt they could not obtain a definitive risk estimate (Hallowell et al., 1997). Investigating counselees' expectations of genetic counseling, quantitative researchers showed an increase in perceived personal control of genetic problems, correct knowledge, and a reduction in anxiety and risk perception post consultations. Additionally, the results indicated a satisfaction regarding the extent to which counselees' needs were met (Pieterse et al., 2005). The concept of meeting counselees needs is of major relevance for this study as it draws parallels to a practice of caring for the counselee. Echoing Pieterse et al. (2005) positive result on counselees' accurate knowledge post consultations, a newer study ($n = 32$) demonstrates that increased knowledge is not associated with an increase in anxiety or depression (Randall et al., 2008). Parallel to Pieterse et al. (2005) results, an older quantitative study demonstrated how women's risk perception became more accurate post genetic counseling, only positively affected by marital status (Lobb et al., 2003). As the role of genetic information increasingly develops within cancer diagnosis, so too have worries about the patient burden of being genetically tested. This echoes a central relevance for the thesis as it calls for a caring practice to address in counseling sessions. Though, newer studies show a common appreciation of genetic testing among patients, stressing the offer as 'important' and amenable for the incorporation (Wright, 2018; Wevers, 2017; Strømsvik, 2022). Interestingly for the study at hand, results from a qualitative study indicates at-risk patients perceive themselves in a liminal position between sick and healthy, motivated, and seeking medical surveillance tools to monitor their state of health (Scott et al., 2005). Providing us with a vocabulary addressing at-risk individuals, Scott's et al. (2005) results are relevant to the thesis' goal of examining if care might help counselees in such liminal positions.

Social implications of genetic counseling

As the previously mentioned literature has demonstrated, communication is central to the practice of genetic counseling. Miscommunication, therefore, poses various threats to counselees' risk perceptions, health behavior, and decisions (Browner, 2003; Klitzman, 2010; Sivell, 2008). An older qualitative study identified the following five sources of miscommunication among pregnant Mexican-origin women: medical jargon, non-directive counseling, inhibitions of counselors stemming from misplaced cultural sensitivity, and problems with trust and translation (Browner et al., 2003). In a review article, Sivell et al. (2008) argues that previous literature has focused on perceived 'risk' in quantitative terms, resulting in individuals overestimating their risk. Evidence also suggest high risk estimates may lead to unwished-for medical surveillance and preventive measures by some individuals (Ibid.). Illustrations of genetics and statistics in consultations have also been demonstrated to create misconceptions between absolute risk, defined as the actual probability of an event to occur and relative risk, defined as ratio of a probability to occur (Klitzman, 2010; Noordzij, 2017). Misconception about one's risk may also undesirably shape views on decisions on reproduction (Klitzman, 2010). Corresponding with the Klitzman (2010) results, Hunt et al. (2006) demonstrates how counselors and counselees ascribe different meanings to genetic risk, affecting patients' decisions about prenatal genetic testing. While counselors' discussions on risk focused on identifying and controling potential problems in pregnancy, contrary counselees' main concern was in assuring the well-being of their baby (Ibid.). Additionally, Finkler (2003) have demonstrated how historical and cultural forces shape individuals' notions and perceptions of risk linked to genetic inheritance. Now, moving forward with a vocabulary of the social implications of genetic counseling, we may see the parallel to an examination of a necessary caring practice in genetic counseling addressed in this thesis.

Care and anthropology

During the last decade in particular, the social sciences have had an increasing interest in the subject and theory of care and care practices (Buch, 2015; Kleinman, 2009; Mol, 2008; Mol, 2010; Engster, 2005; Karlsson, 2020). In anthropology in particular, focus has shifted from suffering to theorizing the social care relations that sustain everyday life (Robbins, 2013). The word 'care' has been referred to as 'slippery' due to its multivocality in everyday and scholarly use (Martin, Myers, Viseu, 2015). Yet, in English the term connotes both an affective concern (the caring about) and a practical action (the caring for) (Buch, 2015). The latter corresponds with what has been referred to as 'care ethics', emphasizing that people can only exist in and through caring relations with others. However, care ethics have been criticized for seeing it as their task to define and describe the essence of 'good care' (Pols, 2015). 'Good care' has therefore also been guided by a moral valuation, as Karlsson & Pennbrant write, "*good care is true care*" (Karlsson & Pennbrant, 2020: 3). Other theorizations like justice theory and feminist care ethics stress that caring for others in a caring way is the most fundamental human value. Elaborating further that 'caring' includes everything directly related to helping others, meet their basic needs, develop their basic capabilities, and alleviate or avoid pain and suffering, in an attentive and respectful manner. Other theories on care have defined 'caring' as the necessary social practice vital to the maintenance and reproduction of society (Engster, 2009).

Influential anthropological researchers on care, inspired by care ethics, are, among others, Kleinman (2009), Annemarie Mol (2008, 2010), and Jeanette Pols (2012, 2015). Kleinman (2009: 293) argues care is closely related to what it means to be human. Moreover, he argues care is a 'defining moral practice' closely related to empathic imagination, responsibility, and solidarity with those in great need (Ibid.). Mol (2008), on the other hand, argues care is centered in complex negotiations regarding the notion of 'doing good', motivated to craft a sustainable way of living, or with reality. In addition, Mol coin the term 'care practices' defining what is done in care, which she argues is very depended on the complex social context and participants needs. Research on care practices thus imply an examination of ‘the good’ in various caring contexts (Mol, Moser, Pols, 2010: 13). Problematizing care ethics testability and empirical description of ‘good care’, Pols (2015) outlines ‘empirical ethics of care/empirical ethics’ as a successor in doing so. Stressing the possibility of empirical ethics to analyze various notions of what is good care within care practices. Urging for a sociology and/or anthropology of values which describes values in practices but does not interfere or dispute the values (Ibid.). Parallel with Pols’ (2015) empirical ethics Martin et al. (2015) stresses researchers to ask, ‘who cares’, ‘for what’, ‘why we care’, and ‘how care is done’ examining care; equipping us with a methodological toolkit to explore the care practices of genetic counseling. Newer theorizations on care have also included reinterpretations of Bourdieu’s habitus. ‘Caring habitus’ refers to habits, tendencies, attitudes, and behavioral patterns healthcare workers utilize when approaching patients. Moreover, caring habitus is argued to be closely associated with emotions as they guide healthcare workers decisions in care practices (Akgün, 2019). Because genetic counseling poses various social implications for counselees wellbeing post testing, care and care practices appear of great concern in addressing and potentially avoid such implications. The latter will constitute the main empirical and analytical concern for this thesis.

Caring technologies and telecare

With the increased implementation of technology in healthcare and medication the question of technology being ‘other’ to care and whether technology is a form of dehumanization have emerged over the past decades (Mol, 2008; Gadow, 1984; Lindén, 2021; Pols, 2016). Already in 1984, these questions were addressed stating that resuscitative and intensive care measures had spawned due to technology, undermining the values of dignity and autonomy (Gadow, 1984). As a result, Gadow (1984) argues for two distinct paradigms in patient care: touch and technology. While health care workers touch on patients refer to the acknowledgement of a subjectively experienced body, technology transforms the body into a machine or measurable object. An earlier review by Routasalo (1999) of health care workers practical use of touch found various positive effects on patients, among others, positive attitude towards the health care worker and an increased intake of nutrients. Yet, health care workers use of touch, if they considered it relevant, was closely related to their cultural background, experiences, and personality (Ibid.). Responding to patients needs is therefore argued to be a central activity for healthcare. Though, according to Pols (2016) healthcare workers ‘tinker’ by evaluating and adjusting their goals corresponding with patients’ needs and by what technology can offer.

An example of the increasingly implemented technologies in health care are communication tools such as electronic monitors, telephone, webcam etc. constituting the term ‘telecare’ (Pols, 2012; Gringsby, 1998; Sinha, 2000, Gjødsbø, 2021). Hence, telecare can be understood as an extension of the healthcare’s office, offering nothing more than what could be done within the office’s facilities (Gringsby & Sanders, 1998). ‘Telecare’ is an umbrella term referring to the technical devices used to care at distance, hence including the similar term ‘telemedicine’ (Pols, 2012). Telemedicine has shown to be useful in recent years with its capability of communicating with patients in rural areas and reduce infections during the Covid-19 pandemic. However, studies also demonstrate telecare is a good supplement to the physical consultation (Sinha, 2000; Kadir, 2020; Haleem, 2021). A qualitative study from 2010 found telecare was more intense and frequent than face-to-face contact and allowed more frequent consultations (Pols, 2010). The intensity meant skipping potentially irrelevant content and focus on the task at hand. Rather than distancing patients and health care professionals from each other, the opposite was observed (Ibid.). Echoing Pols (2016) thoughts that there exists no singular technology, but rather various practices involving different uses of technology, Oudshoorn (2012) concludes a similar result. Oudshoorn (2012) stresses that telecare devices cannot be inserted in patient homes without changing their meanings and lived experiences. Thus, telecare devices transform the home into a hybrid space in which private and public atmospheres are closely intertwined (Ibid.).

Research gaps and situating the study

Even though care has gained an increased scholarly interest over the last decade, studies on the unique care implications in genetic counseling remain few. Additionally, as telecare changes the notion of ‘care’, its impact on genetic counselors’ care practices has, to my knowledge, not yet been examined. Because of the ethical dilemmas entering a clinical setting, ethnographic studies are also lacking in the context of clinical care and genetic counseling. It is within these gaps my study is situated, providing an ethnographic account of how care practices within genetic counseling are articulated, utilized, experienced, and practiced physically and digitally.

My aim in this study is to shed light on the complexity of genetic counseling, understanding the social and caring dynamics between counselors and counselees in an everyday context, highlighting the care practices and how these are perceived, framed, and articulated, as well as addressing the implications of this care in the age of telecare.

Chapter 3 - Methodology

The following chapter will present the methodology of the thesis. This includes a presentation of the access to the field, a discussion of the qualitative methods used for the data collection and processing. Moreover, the chapter will also demonstrate an on-going reflexivity of my time in the clinic and finish with a section on ethical considerations.

The ethnographic study

This thesis is based on a qualitative fieldwork examining the care and telecare practices of genetic counseling. I found ethnography's methodological tool of fieldwork—participatory observation and interviews—relevant to investigate and gain an insight in the care practices as well as telecare. Deploying an ethnographic approach to my research question allowed me to carry out a unique and in-depth understanding of how and under what circumstances the social care practices are articulated, perceived, and practiced by the clinic's staff and patients. The fieldwork was carried out over a 7-week period at a hospital clinic in Denmark on every weekday between March and April 2023. I attended a total of 35 consultations between genetic counselors and patients and three consultations between doctors and patients. In addition, six patients, ten genetic counselors, and three doctors were interviewed. A single focus group interview of two secretaries was done as well. In total 19 interviews were recorded and transcribed. The interviews were carried out in-person and through phone calls in April 2023. As a way of guiding my interview questions I started with a participatory observation which would give me an insight to formulate later interview questions.

Fieldwork conditions and relations

As I sat out to do this thesis, it was with an interest in science and technology studies and medical anthropology, especially how expert knowledge on risks was constructed, communicated, and mediated through the use of technology. However, it can be difficult for a 'outsider' to gain access to hospitals, laboratories, clinics, and ambulatories due to ethical issues concerning staff and patient privacy. A close family member then recommended that I wrote her old workplace, a genetic counseling clinic, as she still had colleges working there. The main focus of the clinic is on genetically inherited cancer risks and other rare disease risks. I had limited knowledge about genetic counseling as a field of knowledge and practice at that time.

I then wrote an e-mail stating my purpose, intentions, and methods to the head of the clinic and department. A few days later I met with the gatekeeper of the clinic, who is also the chief doctor in the department, to discuss my potential research at the clinic. Due to my methodological choice of doing ethnography I knew I would have an inductive approach to the field, which made it difficult for me to articulate a specific object I were to study. I would, as Blommaert and Dong (2010) stress, see what theoretical issues emerged, thus yielding a focus for the thesis. This would come to challenge my time and legitimacy in the field greatly as my purpose of my presence was unclear to clearly state at times. It was then discussed that contacting patients with health risks posed potential ethical challenges due to the sharing of personal information and medical journals. In addition, as I stated my interest in how technology was used to communicate and mediate risks, I was explained the use of technology was limited. However, the gatekeeper had recently started a project on an application termed ‘Mit Forløb’ (‘My Course’) used by patients which she introduced as a potential object for my thesis. ‘Mit Forløb’ is an app and/or internet browser which can be accessed by any patient who undergo genetic counseling. The app/browser consists of animated videos, explaining the counseling session in detail, information pamphlets, and frequently asked questions and answers related to inherited cancer risks. My gatekeeper thus constituted what Eklund (2010, 143-144) coin a power dynamic and non-neutral part who had a separate motivation, investigating the impact of ‘Mit Forløb’, on behalf of my thesis which affected my fieldwork process. As a consequence, I was constantly trying to think the app and my gatekeeper’s interest into to the fieldwork process, forcing the app to be a topic within thesis. Though, Eklund (2010) also stress that gatekeepers are an integral part of the “journey” of qualitative research. As a result, I decided to incorporate the app as a secondary theme in the thesis.

Specifically, I decided to pursue the object of how the application ‘Mit Forløb’ was used and understood by patients as well how it affected patients’ course at the clinic, even though it was not my immediate interest and intended focus. This was what allowed my access to the clinic, thus my rationale of adopting the topic. However, I emphasized my inductive approach to my gatekeeper, and articulated that this approach would not guarantee that ‘Mit Forløb’ would be a central focus of the thesis. It was then agreed that whatever the focus would result in would also be something the clinic would learn a few things from. The agreement was in other words my criteria for gaining access to the field and would later on constitute some troubles for me in the fieldwork process. In addition, I was to sign a six-month contract of unpaid labor, a confidentiality form related to patients’ privacy, and agreed to always follow the rules of the clinic’s staff members. The contract then also established the power relations between me as research and the clinic’s personnel, who were the ones to determine what I could observe, attend, and do within the clinic.

A few weeks later, two employed genetic counselors sent me a five-week program for my stay in the clinic stating the planned activities I could (and could not) attend during my fieldwork. The two genetic counselors who had worked out the program would be future key figures in my fieldwork, constituting my contact persons and granting me access to various activities. The program constituted of 2-5 hours of access a day and would mainly involve activities together with my two contact persons. My freedom at the clinic at the beginning of my fieldwork was thus very limited to the program I had been sent. However, this program would later be canceled as I gained personal relations with my contact persons, due to me following various activities, and becoming familiar with the clinic’s general staff, I also started to gain the clinic’s trust. This trust resulted in me being allowed to act more freely without supervision, albeit still with some limits, and approach various staff members without appointments.

After spending about four weeks in the clinic, observing, engaging in small talk, asking questions, analyzing, and creating hypotheses, I started to identify patterns of how care practices were understood, practiced, perceived, articulated, and impacted. These dimensions emerged as a central focus for the thesis. While the care dimension emerged as a central theme, so did the theme of caring technologies or caring through communication technology. Because of the latter I expanded the perspective on care to include the clinic’s utility and practice with webcam and telephone consultations. This also resulted in a inclusion of the app ‘Mit Forløb’.

Participatory observations

Participatory observation is often referred to as a scientific method which allow the researcher to explore perceptions, cultures, group dynamics in the setting of informants and from the informants’ perspectives (Spradley, 1980). Historically pursued for much ethnographic research is Branislaw Malinowski's concept of 'going native', to understand the local point of views, perceptions, and practices in peoples own environments (Kanuha, 2000: 439). Thus, in order to examine the latter, I had to take active part in the activities I was allowed rather than just observing or interviewing informants. Hence, my aim of conducting participatory observation was to explore my informants everyday work lives, articulations of their perceptions, and immerse myself among their practices within the clinical setting.

However, although 'going native' have been argued among anthropologists to be desirable, it too poses limitations. Among others, Jeffrey and Troman (2004: 536) stress between one and two years as the minimum in order to conduct a long-term ethnography, though the time in the field is also depended on the objective of the ethnography. In the context of my fieldwork and studied object seven weeks can't be considered a successful long-term emergence of myself in the clinic's practices. Responding to the time aspect of conducting fieldwork van Hulst, Koster, and Vermeulen (2015: 4) state ethnography often tend to focus on day-to-day realities, limiting ethnographers' knowledge of/and structure of their studied fields. This additionally, problematizes the notion of 'going native' in anthropology with the concept of 'the native anthropologist' which Narayan (1993: 676) emphasizes is assumed to be an insider who will forward an authentic point of view to the anthropological community. Moreover, Caputo (2000: 27) argues that conducting fieldwork in one's own culture can challenge the researcher, compared to foreign fields where difference might appear more obvious. As a Dane growing up in a nearby town of the clinic, sharing the same cultural background of the majority of the clinic's staff, and being part of the western medical discourse, this would challenge my approach of 'going native'. As a consequence of conducting fieldwork within my own culture I had to question my own intuitive answers for social behaviors among the clinic's staff.

In order to be a participant-observer, I had to follow the program, which was already formulated for me, prior my access to the field. The program's activities included my participation in consultations between genetic counselors, doctors, and patients, individual and group conferences, evaluation meetings, and explanations of computer programs for collecting family information and calculate genetic risks. Besides these activities I was also welcomed to observe the technical work done by secretaries, genetic counselors, and doctors. This work was mainly done alone at the computer.

Attending the various activities, I aimed at following Masons's (2002) participatory observations requirements of active participation: constant analysis, the ability to listen, communicate, interact with informants, and to try and integrate into their community and activities (Ibid. 87). Participating in the activities naturally made me feel as an 'insider' as I began to immerse myself in the clinical activities, gained the clinic's staff's trust, and started to understand the social norms. However, I was still an outsider in the sense that Webster and Rice (2018: 524) argue, as I did not hold a permanent position in the clinic, and, according to the clinic' staff, because I did not have a medical background. During the first week I was given a guest admission card which could be used to access the various departments. I had limited instructions as well as knowledge on what else I could access with the card, yet I only used it for what it was intended for.

Participating in the program's various activities I experienced a distinction between observing and participating. Because of my dual positionality of neither being a complete insider nor outsider, I could not fully participate in the program's activities, such as take active part in the consultations, articulate my thoughts at the individual or group conferences, or decide how I wanted to structure the program's activities. According to Ingold (2008: 387) the term 'participate' refers to "*do so from within the current activity in which you carry on a life alongside and together the persons and things that capture your attention."* Hence, I was partly able to follow Ingold's notion of participating in the clinic's activities. My complication of not being able to fully participate in the clinic's activities then led to what to Ingold's (2008) notion of 'observing' instead thus, *"to watch what is going on around and about, and of course to listen and feel as well."* Hence capturing the essence of my participatory observation (Ibid.).

Following the activities according to my program resulted in contact with other counselors, secretaries, and doctors who often asked questions about my study and focus. Following the inductive approach of my fieldwork, in which the data emerges from the field, would in addition challenge my legitimacy in the field as I had difficulties in stating my exact purpose and focus for my informants at times. Entering the field, as I noted in my fieldnotes, felt "*like a kid entering a candy store, watched closely by nearby adults"*, hence being analyzed and watched by the clinic's staff. Schwartzman's (1993: 49) statement of the researcher equally being watched and analyzed, just as the researcher observe and analysis his/her informants, thus reflected my experience and hesitancy of stating my purpose and focus.

Soon after I gained access to the field, feelings of chaos and frustration, due to the complexity of the clinic, lack of resolution related to a focus for the thesis, started to merge. Though, Lecoq (2002) states experiencing feelings such as frustrations, anger, and guilt are common feelings over fieldworkers' own functioning in their fields. Meanwhile, as I came to spend hours, days, and weeks in the clinic I started to understand the lingo and observe behavioral patterns and social practices which would come to form my final focus. In response, I turned to focus mainly on the consultations between genetic counselors, doctors, and patients as well as patients' first encounter with the clinic. The shift in the final focus was to investigate how the social care practices are practiced articulated, perceived, and how this impacted telecare practices. Due to the final shift in my focus, during a review of my fieldwork with my contact persons, I stressed my wish of following all counselors in as many consultations as possible and to interview them all. In addition, I stated my wish of interviewing patients and doctors. I emphasized voluntariness as vital for participating in either of my wishes. As a result of my final focus and wish, I was allowed to follow all genetic counselors between two to four times a day. I followed all genetic counselors except for one. In addition, all counselors were interviewed. Moreover, a plan was formulated in how I was to observe the consultations while also gaining consent to interview patients post consultations.

Central for my participatory observation during the consultations between genetic counselors, doctors, and patients was discreteness and silence. I knew the setting might be sensitive for patients and genetic counselors, hence my reasons for discretion. Besides being present in the consultation room, sitting on a chair in a corner of the room, active participation would be inappropriate and wrong of me, thus my aim of following Ingold's (2008) notion of observation, to watch, listen and feels, captures my participation in consultations. Before the fetching of patients in the lobby, doctors and genetic counselors asked if my presence was okay, it was emphasized that my presence was to examine the work of the doctors and genetic counselors. I did not experience any patients who did not wish for my presence during the consultation. In total I managed to attend 36 consultations between genetic counselors and three consultations between doctors and patients. In between consultations I had a few minutes to ask the doctor or genetic counselor questions related to the consultation, which I noted in my fieldnotes. The appropriate time to ask questions was important to me. I wrote daily detailed fieldnotes of my observations and experiences, as well as keeping a fieldwork journal to track my emotions, ideas, questions, and errors occurring in the field, hence attending to the personalized side of the fieldwork (Spradley, 1980: 71-72).

The semi-structured interview

Even though I conducted minor, yet valuable, informal interviews in between consultations and during lunch breaks with genetic counselors and doctors, it was difficult to grasp the individual experience and perception of care practices in such short conversations. Moreover, my contact with patients attending consultations, thus investigating their perceptions and experiences, was limited to articulations of stating my name, purpose, and focus prior the start of consultations. Hence, to better explore the perceptions and experiences of care practices and telecare, individually and in greater depth, I turned to interviews. Furthermore, applying interviews would allow me to make sense of my observations and thoughts of the clinic. My participatory observation of social patterns and behaviors have then been the foundation for my formulations of interview questions. Moreover, as my inductive approach resulted in the analytical focus on care practices and telecare, both topics also guided my formulations of interview questions. To distinguish between patients, doctors, and genetic counselors' perceptions and experiences two separate interview guides were made one for counselors, doctors, and secretaries and another for patients. I decided to make the interview semi-structured which, according to Kvale and Brinkmann (2015: 49), would allow me to better understand themes and experiences described by informants. Following a semi-structured interview guide also allowed me to follow potential new and interesting directions according to the informants' answers (Andersen, 2012: 149). Conducting the various interviews, I gained a knowledge of which questions were fruitful and which were not, adding and removing questions accordingly.

My selection of informants was at first to interview all genetic counselors and patients. Though, after some interviews and the final focus on care practices I found it interesting to interview the doctors too. This reflection would later result in interviewing the secretaries as well. All genetic counselors, doctors, and secretaries responded positively to my interview request. The selection of patients though constituted a selection bias. I had wished to select all patients who voluntarily wished to be interviewed, however it was decided that the individual genetic counselors would select my patient informants. During a consultation I would kindly be asked in the end to leave the consultation room, hereafter the counselor would ask the patient for consent to share his/her phone number with me concerning a future telephone interview with the patient. I would afterwards formulate a phone message stating my purpose, intentions, and my personal information which was messaged to patients who volunteered as informants with the intention of scheduling a telephone interview. A total of 20 informants were interviewed. All informants are anonymized with pseudonyms and displayed below:

Receptionists	Doctors	Patients	Genetic counselors
Alice	Eli	Emma	Miranda
Emily	Mary	John	Jill
	Sam	Megan	Kate
		Olivia	Ava
		Sarah	Mia
		Beth	Joan
			Tracy
			Taylor
			Amanda
			Emma

Because of lack of time my interview with the secretaries was done as a focus group, thus both secretaries were present in the same interview. Compared with interviews, focus group interviews yields a better understanding of social dynamics, interactions, and norms (O'Reilly, 2009: 79-80). Although I deployed the focus group method because of time shortage the method revealed norms and interactions surrounding secretaries care practices, which would potentially not have been uncovered through single interviews.

The age of genetic counselors and doctors varied between 32-69 years. Moreover, the educational background among counselors were mainly nurse, laboratory scientists, and midwifes. Finally, the clinical employment of both genetic counselors and doctors varied between 1,5 months to 16 years. The secretaries were between 38-49 years old and had been employed between 4-5 years. Finally, my patient informants varied in age between 47-76 and lived mostly in the hospital's town or nearby. In my interview with patients, I aimed at understanding their experience of genetic counseling as well their articulations of how they perceived care during their recent consultation. Even though my questions between patient interviews and genetic counselor, doctor, and secretaries differed, they both followed the same structure. The structure of both interview guides was structured around five different themes identified from my participatory observations and theoretical frameworks on care and telecare. I had included open questions to examine if any individual difference would occur throughout my interviews. Before the start of the interview, I had included a small briefing, describing the purpose of the interview, that it would be recorded, and stating the rights of the informants. The first theme involved a focus on the individual patient, genetic counselor, doctor, or secretary, exploring their background, attitudes, and their definition of genetic counseling. The second theme concerned the consultation itself, which, for instance, included the question of ‘what is the purpose of genetic counseling´. The third theme sought to investigate the dynamic in the consultations, asking the question ‘what is a satisfying consultation’. The fourth theme, identified through my participatory observations, was regarding uniforms, definitions of ‘care’, and contrasts to nurses’ work, asking the question of ‘what is care to you’. Finally, I wished to ask about impacts and attitudes towards the use of telecommunication and how it impacted care as well as their thoughts on ‘Mit Forløb’, resulting in questions like ‘how does the use telecommunication affect the relation with the patient´.

I aimed at conducting the interviews in-person, which from my experience, gives the interview a more personal dynamic and better trusting relation. All secretaries, doctors, and eight genetic counselors were interviewed in-person, in total 12 interviews were done in person. Two interviews of genetic counselors were done by telephone. Because of the difficulty of conducting in-person interviews with patients, I did telephone interviews with all patients. According to Andersen (2019: 201) conducting telephone interviews, researchers risk missing out on important body languages, attitudes, and individual behaviors due to the absence of bodily presence. Moreover, conducting interviews through technical solutions also risk electronic failures, bad connection and audio which might jeopardize the interview quality (Ibid.). I was aware of the former mentioned risks and took precautions, accordingly, hence I secured proper phone connection, audio, and that both parties loudly and clearly could hear each other. All interviews varied between 15 minutes to 1 hour and were all recorded. I had a special focus on the interviews with my patient informants as I knew the topic might generate unintended consequences talking about their experience of genetic counseling. As a result, I utilized extra sensitivity in my questions during patient informants’ interviews. As I focus on telecare as well it would have been beneficial to interview patients who had had consultations via phone or webcam. Unfortunately, this did not happen, as all patient informants had been physically present during consultations. This constitutes a bias for the thesis as I have not interviewed informants consulted through telecommunication.

Data processing

The empirical data from my interviews were all transcribed by hand and processed, together with my fieldnotes, through the digital program NVivo. Here NVivo served as an analytical tool for coding, arranging themes, and outlining the empirical data. Though, Atherton & Elsmore (2007) have stated the risk of ‘decontextualizing’ and ‘recontextualizing’ in utilizing digital tools for processing qualitative data, thus the risk pulling the data out of its original context. To counter this, I have transcribed the recorded interviews as soon as possible after its finish to better memorize the original context of the interview and stay true to the interview.

Ethical considerations

Conducting qualitative research constitutes various ethical considerations regarding informants' safety, anonymity, and consent. I have strived to follow the American Anthropological Association's (AAA) (2012) ethical guidelines conducting my ethnography. Ethics have been of importance since my ethnography already has taken place in a setting surrounded by ethical dilemmas and concern. Before entering the clinic, I signed a statement of confidentiality and promised not to speak about my results to any institution, nor publish anything before the head of the department had approved it. Following the AAA's guidelines, I have purposely anonymized all my informants and the location of the clinic. Instead, I have utilized pseudonyms to personalize my informants. Moreover, everyone I encountered at the clinic were informed of my presence and purpose, I also emphasized that questions about my study were welcome any time. Though, if asked I answered in a way so my informants would not ‘please me’ but stay authentic. Voluntariness was further emphasized and vital in my data collection. Additionally, before my interviews I briefed each interviewee and stated their anonymity, the purpose of the interview, and their rights throughout. Consent was obtained during the briefing as well. Because I was part of clinical setting, I was very much aware of own health condition, in case of potential infections, which could harm patients and clinicians. My clothing, behavior, and attitude was regulated according to the clinic, so I would not appear disrespectful to the clinic's practices. I always followed the lead and instructions of the clinic's staff without question.

Chapter 4 – Theoretical frameworks

In the following chapter I will present the theoretical frameworks for the thesis. Due to my inductive approach, I entered the clinic with no theoretical framework in advance. My aim was instead for the analytical theme(s) to emerge by themselves as a reflection of the clinic's actual doings. This resulted in three interconnected themes. Firstly, caring for the patient seemed of vital importance for all members of the clinic, as I repeatedly heard the notion of ‘meeting the patient where he/she is', while I was questioning the apparent necessary care toward patients. This led me to Mol's (2008) 'logic of care' in contrast to her 'logic of choice' as a theoretical framework to explain the clinic's care practices. Second, as I observed telecare consultations via webcam or phone, the aforementioned care practices changed to a new platform defined by the absence of the physical element, hence changing the traditional notion of care. The latter led me to Pols' (2012) notion of 'warm care' and 'cold technology' and how the two are linked and challenged. Finally, and less explicitly, after gaining an insight in the clinic's practices, I identified the absence of 'sickness' in the clinic's interior, even though the core practice of genetic counseling involved prevention of disease. This led to the final themes of non-sickness, potentiality, and being genetically at-risk, drawing on Novas & Rose's (2000) work on the at-risk individual and Taussig's et al. (2013) 'Anthropology of potentiality'. The chapter will dive into the above-mentioned works and elaborate their theories, which will later act as my theoretical backbone analyzing my data. Each theoretical framework will be followed by a brief paragraph stating my interpretation and relevance of the theory regarding the objective of the thesis.

'The logic of care and choice' within the practice of genetic counseling

'What is good care?' and 'what are the rationales behind care in healthcare', these are the questions Annmarie Mol (2008) raises in *The logic of care: The problem with patient choice*. To examine these questions, Mol conducted an ethnographic fieldwork attending consultations, sessions, medical treatment etc. focusing on diabetes patients' encounter with health care professionals in a Dutch hospital. Mol argues that Western healthcare has increasingly been devoted to the notion of 'patient choice' as complementary to 'good care' (Mol, 2008: 1). Mol discusses the problem of patient choice in the following:

"That the ideal of individual choice is so enthusiastically drawn into health care is not only due to its current general popularity in 'the West'. As patients we are treated as objects and made passive. This is a bad practice that should be stopped." (Ibid.).

As a consequence of individualism's 'choice' paradigm, the patient has been turned into a customer who may choose while care professionals passively provide patients with instruments tailored to each individuals need (Mol, 2008: 17). This is what Mol coins 'the logic of choice'. Studying healthcare professionals' care practices, Mol utilizes the notion of logic as a method of investigating the rationale behind care practices. Mol's purpose of utilizing logic is not within the philosophical domain, but rather to study the rationale behind the practices of care, demonstrating how certain practices are appropriate, or logical, in some contexts while not in others. The logic of care is therefore to be understood as a local situated rationale (Ibid. 8). Hence, the examined care practices of this study are to be understood as specific and local practices, which might not correspond with other similar clinics' care practices.

Central to the logic of choice is the treatment of patients as objects who are tested, treated, measured for infections, etc., made passive and often struggling to speak for themselves as autonomous subjects. In contrast to the logic of choice is Mol's 'the logic of care'. Both logics are present and complementary in healthcare, yet Mol stresses they often clash (Mol, 2008: 1). While the logic of choice starts from what one knows and want, the logic of care concentrates on what patients need (Ibid. 22). We are to understand the two logics as separate: the logic of choice applies to patients who chooses their care, while the logic of care surrounds healthcare professionals' care practices aimed towards the patient. The logic of choice emphasizes equality and individual autonomy as "*good*" and oppression as "*bad*", while the logic of care stresses attentiveness and specificity as "*good*" and neglect as "*bad*" (Ibid. 74). Though, Mol tries not to criticize either 'logics', but rather to uncover the different rationales behind the practices. According to Mol, the care team is not just limited to the people present in the consultation room, but includes all members of the whole department, clinic, or ambulatory. Secretaries who have arranged the meeting and greeted the patient on his/her arrival, doctors/nurses who might have offered critical advice for the doctor in the consultation room, and the following care professionals linked to the location of the consultation room then constitute the combined care team (Mol, 2008: 59). With Mol's emphasis of care as not limited to care professionals' practices, I decided to include an examination of the receptionists' practices and care practices in my analysis. Thus, care is a process, a matter of various hands working together towards a result, an interaction in which action goes back and forth among people (Ibid. 18).

Investigating diabetes patients Mol stresses innovation in medical technologies has changed the moral landscape of care. In this context Mol asks what good choices and care are. She stresses 'good', within the logic of choice, can be seen in the weighing and balancing of arguments, the pros, and cons, in order to judge what to do. Doing good within the logic of care is closely related to healthcare professionals' abilities of caring the best they can. Yet, healthcare professionals' act of caring the best, hence good, can never predict how an attempt will work out in practice (Mol, 2008: 78). As a consequence, a care team has to attend, persistently and unquestionably, to twists, problems, and complications. Therefore, good consultations are composed of a fluid exchange of experiences, knowledge, and words of comfort between the care professional and the patient (ibid. 74-76). Hence, care implies a negotiation about how different 'goods' might coexist in specific local practices (Mol, Moser, Pols, 2010: 13). In contrast to the above, Mol stresses care is bad when: patients are neglected, there is not enough time to listen to patients, and when health care professionals are not taking patients' daily lives into account. Additionally, healthcare professionals who fall back on protocols, old habits, or rush through consultations, are equally considered 'bad care', leaving the patient to themselves and, the complex task of assembling and understanding health related instructions or information (Mol, 2008: 84).

Crucial for Mol is the concept, among healthcare professionals' practices, of 'not abandoning the patient' but to keep on caring for the patient. Mol argues that care engagement, within the logic of care, is a matter of what she terms 'doctoring'. Doctoring is not something which is limited to doctors' practices but include the whole care team. Being knowledgeable, accurate and skillful are important traits, but being persistent, inventive, and attentive are just as vital to the logic of care (Mol, 2008: 55-56). 'Doing good care' is, then, a complex task with the risk of numerous errors to occur. Hence, good communication is a vital precondition for good care. Mol demonstrates 'good communication' by stressing how health care professionals need to pick the right words, accept patient silence, smile, look at the patient, and listen to the patient's stories, hence being adaptable to the patient's context. Exchange of patient stories during consultations is, according to Mol, within the logic of care, a moral activity in and of itself. Furthermore, moral activities do not limit themselves to verbal exchanges but include a physical, nonverbal form too, for example a hug, the injection of medicine, or bandaging (Ibid. 76-77). According to Mol the logic of care is not better or worse than the logic of choice, however, Mol asserts the logic of care is better suited dealing with patients' diseases in unpredictable bodies in times of biomedical certainty and uncertainty (Ibid. 83).

Evidently the logic choice is fundamental in genetic counseling based on the individual's autonomous choice of attending genetic counseling and ultimately deciding whether or not to be tested. Genetic counseling is in other words a clear manifestation of the 'choice' paradigm and individualization mainly associated with Western healthcare systems. Meanwhile, because of the absence of medication, treatment, and traditional nursing and patient practices, the notion of care seems of little relevance in the context of genetic counseling. However, deploying Mol's logic of care demonstrates how 'good communication' is closely associated with Mol's notion of doing 'good care' in a context of potential and prevention of disease. Though we are not to misinterpret Mol's notion of 'good' with the ethical notions of right and wrong. Instead, applying Mol's notion of 'good communication' as an analytical tool we may understand and reveal the local perceptions of doing 'good care'. Analyzing what locally is considered 'good communication' and care, also demonstrates the local perception of what is logically 'bad care' and should be avoided. A 'bad care' which should be avoided not because of ethical reasons but because of local perceived threats. Deploying Mol's logic of care as an analytical focus in this study will demonstrate how, when, and in what context practices of 'good caring commutation' are played out and why they matter in addition to being knowledgeable, accurate, and skillful. Finally, the logic of care also facilitates an analysis of how the care team does not just involve the apparent healthcare workers, but all of the clinic's associated members, all aiming at providing the best possible care experience for patients.

"Caring at a distance": the warm and cold technology of genetic counseling

Technology is vital in modern medical treatments and diagnosis of diseases. Over the last decades innovations in technologies, facilitating communications between healthcare professionals and patients, has increasingly been implemented in healthcare systems. 'Telecare' refers to the technical devices, such as webcams, telephone, and electronic monitors, and professional practices applied in the notion of 'caring at a distance': administered beyond the confines of the clinic, when a patient and healthcare professional may not be in the same physical space (Pols, 2012: 11). Yet, it is unclear what technology can achieve in the realm of telecare. Jeanette Pols' work 'Care at distance' investigates the latter by addressing three questions: what is 'good care practice' when telecare is introduced, what kind of knowledge does telecare bring with it, and what new routines follow from the introduction of telecare (Ibid. 14-16).

Central for Pols' work, and of analytical utility to this study, is her metaphorical use of 'warm care and cold technologies' related to the practices of care. The background of the metaphor can be traced to theories of medicine due to healthcare professionals contrasting telecare to warm human contact and care. ‘Warm care’ includes the notions and practices of sensitivity, empathy, and the ability ‘to be present’ for patients; while medical technology is assumed cold because it is considered rational and functional (Pols, 2012: 25). Pols’ metaphorical use of cold and warm also refers to the affective quality of relations between healthcare professionals, patients, and technological devices, where ‘warm’ implies the notion of “*good*” and well, contrary to ‘cold’ which is associated with unfeeling and neutral (Ibid. 45). Pols’ categorization of technology as ‘cold’ can be traced to the fear that technology might replace humans and the face-to-face contact. While machines cannot show emotions nor empathy they can’t love or care for us. Hence, Pols argues that the premise is that no individual can feel cared for without being on the receiving end of genuine concern and affection. Technology can only contribute to the cold and instrumental parts of care (Ibid. 25-26). On the contrary, Pols states, central in doing warm care is to ‘sense’ patients’ troubles as to identify the right kind of support and establish the relation between care professional and patient. Establishing caring relations include care professionals asking patients about their everyday life, with the purpose of interpreting any relevant signs or embodied implications that might be of importance to the patient and their condition (Ibid. 49-50). However, Pols stresses ‘good care’ requires both warmth and coldness in a mixed matter, emphasizing cold characteristics such as healthcare professionals’ knowledge of symptoms, the capacity to behave and react appropriately, and the ability to discern worries from symptoms as important elements in a ‘good caring relationship’ (Ibid. 36-37). ‘Cold’ is therefore not solely ‘bad’, but a necessity engaging in a good caring relationship.

Pols emphasizes caring is good when it seeks to fit the individual need of patients, hence tailoring the care. Therefore, warm care needs good relations and if relations are warm, telecare can then provide warm care (Pols, 2012: 33-34). If the patient were to either enter the hospital or the care professional was to meet the patient at his/her home, certain rituals of entering a new place, including doorbells, hanging of coats, handshakes etc., would be performed. The use of telecare skips these rituals. With a single click, patient and care professional are immediately visible to each other and within each other’s proximity. Pols stresses that such rituals might not pose implications for an individual familiar with technology and telecare, but for an individual unfamiliar with technology, the distance could pose a challenge in establishing a good caring relationship (Ibid. 113). In this example, Pols emphasizes senses are of great importance in doing good care which telecare practices challenges, hence constituting risks among healthcare providers in missing signs of trouble, non-verbal communication, and the human contact (Ibid. 46). Because of absence of senses Pols argues that the practice of tailor-made care equally becomes a complicated affair through telecare practices (Ibid. 53).

Conducting telecare practices Pols states that webcam is more demanding compared with telephone practices. Moreover, webcam restricts individuals to a specific location at a specific time, in front of a computer. Moving out of the webcams frame also means the immediate cut of contact between the two parties. Staying inside the frame and concentrate on the task at hand is therefore vital (Pols, 2012: 102). While not being present in the same room Pols argues that telecare creates the feeling of intimacy of being present in the same room, objectively and subjectively (Ibid. 106). Corresponding with the latter Pols emphasizes webcams are better at facilitating a feeling of being present in the same room, compared with telephones, due to its visual element creating a sense of an actual and more personal conversation. In addition, the aspect of 'seeing' the patient enables healthcare professionals to better 'read' the patient (Ibid. 100-101).

Webcam and telephone practices constitute what Pols terms 'topological reversed telepresence' defined by the feeling of either the patient or care professional being present in the other's space (Pols, 2012: 105). However, Pols emphasizes, while webcam practices have the capacity to support and strengthen intimate and personalized conversations, it additionally enables what patients might perceive as abuse of the intimacy (Ibid. 108). As a consequence, Pols discusses patient's feeling of one 'looking in' from an unknown location, by an unknown individual, while their location is fixed geographically and emotionally, it can be experienced as intrusive and threatening (Ibid. 105-106). Pols adds, knowing the care professional, prior to the webcam or consultation, is therefore stressed as important because the added visual element does not contribute to 'knowing the patient's story'. To counter patients' intrusive and threatening feeling care professionals need to be known to the patient beforehand, as the added visual element does not contribute to knowing the patient's story (Ibid. 107). Telecare then adds a burden for care professionals to correct the potential problems the devices introduce in order to ensure telecare fit the notion of 'good care' (Ibid. 53).

The webcam technology thus transforms the geographical distance into a relational distance. Pols argues that the role of the webcam becomes framing a relationship between its users, creating a mutual friendly, caring and understanding relationship (Pols, 2012: 111-112). Pols also argues that the conversation setup and context of the webcam create a natural, shared focus on the task at hand. Thus, framing the two parties focus on the computer screen. This implores both parties to invest their attention and not to be distracted and what Pols coin a hyper-intense face-to-face topology. However, Pols also stress, webcams have the ability to reinforce already existing traits of the social relationships between webcam users – strangers become stranger, the close and intimate relation become more so etc. (Ibid. 111-112). Implications of telecare are thus a direct threat to what Pols terms ‘the heart of good nursing’ (Ibid. 46).

Telecare practices related to webcam and telephone consultations had been implemented in the clinic of my fieldwork. Though, it was mostly perceived as a supplement to physical consultations by all my informants. Pols’ emphasis on ‘sensing’ patient’s troubles in order to give tailor-made care is of interest in the context of genetic counseling. Compared with other healthcare departments, genetic counseling often only sees their counselees once, putting pressure on sensing patients’ troubles and establishing a warm caring relationship, thus tailoring the care. We may view the latter as further problematized through telecare practices removing the physical patient from the room. In this study, I utilize Pols’ notions of warm care and cold technology to illuminate what is locally perceived as warm telecare practices and what the implications are of conducting telecare practices in the context of genetic counseling. Pols’ notion of a ‘good caring relationship’ draws a parallel to Mol’s similar term on ‘good care’. To distinguish the two terms, I will be using Pols’ term on a ‘good caring relationship’ in conversation with Mol’s logic of care, hence practice of doing ‘good care’.

Genetic counseling’s ‘genetically at-risk individuals’

With the emergence of social science research into biomedical practices, Novas’ & Rose’s (2000) article ‘Genetic risk and the birth of the somatic individual’ has been valuable in discussing the implications of genetic counseling. Novas and Rose argue that genetic counseling practices, over the last decades, have undergone a transformation from the early 1930’s to the early 2000. The authors track the practices of genetic counseling from within the eugenics and Nazi assessments of good and bad genetic qualities, related to some families’ restriction of childbearing, to the 1950’s and 1970s’ which saw the emergence of preventive genetic health models and non-directiveness counseling, focused on optimizing health and prevent birth defects. With the preventive approach and non-directiveness Novas and Rose point out that the normative ideal was for couples to use their genetic knowledge to act responsibly, choosing not to have kids and limit their family size. This is additionally what they state as the marker of the 'responsible subject' who considers hereditary knowledge in decisions of reproduction. Because of this, Novas and Rose emphasize the role of genetic counseling has shifted to guidance and helping individuals or couples relieve the anxiety or fear of diseases while being informed about risk. Furthermore, Novas and Rose stress that this shift has redefined the practices of genetic counseling from being concerned with the prevention of genetic diseases to focusing on communication of genetic risk, implementing psychology as the key tool in helping individuals cope and adjust to living with a risk (Ibid. 493-494).

Moreover, innovations in human genetics, molecular biology, and genetic medicine, or 'life sciences' have prompted a shift within the concept of 'personhood', modifying ideas about human identity and subjectivity. Though, re-examinations of diseases along a genetic axis does not, according to Novas and Rose, generate fatalism, it constructs obligations to act in the present regarding the potential futures (Novas & Rose, 2000: 485-486). As a result of the historical shift in genetic counseling and biomedical innovations, Novas and Rose term the birth of the 'genetically at-risk individual' in which new relations between the body, the self, and biological relatives have been established (Ibid. 488). Novas and Rose emphasize genetics are no longer just an individual concern, but a familial matter, reshaping ideas of marriage, kids, and kin, introducing the notion of genetic responsibility (Ibid. 487). Genetic counseling sessions, Novas and Rose argue, constitute complex choices as well as formulating 'life strategies' according to what at-risk individual's genes might hold (Ibid. 488). One central complexity revolves around the decision to disclose genetic information with kin who might be affected by the risk as well. Hence, Novas and Rose stress shared decision-making is a central technique helping individuals consider and understand the complexity of their potential new situation of being at-risk (Ibid. 495).

Importantly, Novas and Rose state how genetic knowledge of an inherited genetic risk condition might result in a treatment by themselves (or others, such as kin, health insurances companies etc.) as if at-risk individuals are destined or certain to develop their genetic condition. However, such treatment is based on misperceptions of the risk, which only constitutes a 'percentage' of individuals who will suffer from the unpredictable disorder. As a consequence, Novas and Rose state how the misunderstanding of such genetic knowledge might result in stigma, discrimination, even voluntary or involuntary self-surveillance or treatment, in the name of prevention (Novas & Rose, 2000: 486). Constituting the potential behavior and understanding of what I interpret as the two authors notion of the 'genetically at-risk individual'.

Novas' and Rose's article evidently draw a parallel to this thesis' field. While my focus is on care practices, Novas' and Rose's stated social implications of the 'genetically at-risk individual situates the relevance of a focus on care in the context of genetic counseling. In the forthcoming analysis I will be utilizing Novas' and Rose's notion of the 'genetically at-risk individual' and their stated potential social and behavioral implications of being categorized as 'at-risk'.

'The anthropology of potentiality' and genetic testing

As Novas and Rose formerly stressed, the re-examinations of disease within genetics construct obligations to act in the present regarding potential futures, Taussig, Hoyer, and Helmriech (2013) introduces the concept of an 'anthropology of potentiality' within biomedical practices. In doing so, Taussig et al. states "*to imagine or talk about potential is to imagine or talk about that which does not (yet and may never) exist"*, adding that potentiality can be understood as the flip side of 'risk' (Ibid. 4). According to Taussig et al. potentiality operates as either analytic or as object of anthropological studies. Potentiality as analytic implies working from the anthropological position of how humans deal with that which is not in existence. Taussig et al. argue that potentiality allows for a reflection on features of human condition, various enactments, contestations, and of human agency. They furthermore emphasize studying articulations of potentials in the field is a way to approach and name what is considered an empirical object of concern for the people anthropologists are writing about. Corresponding, Taussig et al. emphasizes the reflexivity of how potentiality might be differently configured across cultures (Ibid. 6). Relatedly, Taussig et al. denotes that 'potentiality' is used differently in the literature, emphasizing a 'slippages' of the word's meaning. Furthermore, they identify three patterns of how 'potentiality' has been utilized within the literature: the first denotes a hidden force determined to manifest itself, the second address the genuine plasticity or capacity to transmute into something completely different, and third examines a latent possibility imagined as open to choose, through which people can work on an object or subject in becoming something other than it is. Within these three patterns Taussig et al. seek to understand the contemporary imaginative space of potentiality and its effect on human relations (Ibid. 4-5).

Taussig et al. states that framing something in terms of *potential* is also a political act, given the term's Latin associations with 'power' and 'force' (Taussig et al., 2013: 4-5). They extend this argument to their analysis of how potentiality works in biomedical practice, either by explicit naming or framing, or both, as a hoping idiom to imagine the benefits of new interventions (Ibid. 4). In addition, they note how Western biomedicine frequently stresses the idea that genes, cells, and/or bodies, contain 'potential' – a hidden force residing within, waiting to be uncovered by technological innovations (Ibid. 7). All the while, Taussig et al. argues that the hopeful idiom of potentiality is often used to describe human capacities to imagine particular futures and warn against undesirable outcomes. Potentiality, they write, can create both utopian and dystopian visions of the future (Ibid. 3-4). Moreover, Taussig et al. implies potentiality in biomedical practices indexes a gap between what is and what might, could, or even should be, opening up for a space of imagination of new bodies and extending life. Moreover, it is within this gap Taussig et al. argue potentiality produces and depends on views of life as susceptible to forming and reforming. Thus, the authors emphasize potentiality is to be understood both as a prism and a quality (Ibid. 5).

Moreover, Taussig et al. states that people ascribe potentiality to those things they believe can be manipulated, or what they desire to manipulate, in contrast to what is perceived to be beyond human control. In the context of the latter potentiality depends on what is understood as both feasible and desirable, whether it is located in a nature that can be manipulated (Taussig et al., 2013: 7). Furthermore, engaging with potentiality productively Taussig et al. emphasizes the importance of reflecting on tacit assumptions, investigate the naming and framing of that which is, not, and may never be, present, and understand the power dynamics which materialize in people's dealings with the unknown. Hence, a successful study of potentiality should achieve three objectives: be reflexive, keeping clear of universalism, and give room for subjectivity (Ibid. 12).

As Taussig et al. emphasize potentiality is a 'flip' side to risk, or as a capacity to imagine human futures we may draw out its analytical relevance in genetic counseling. Linked with Novas' and Rose's concept of the 'genetically at-risk individual' we may understand how the at-risk individual may perceive themselves and their risk-diagnosis, *potentially* resulting in negative social and behavioral outcomes. Being aware of such potential and perceptional links between risk-diagnoses and unwished social and behavioral outcomes calls for a caring attitude, suggesting a care for the potentially genetically at-risk individual's misconceptions of themselves and their risk. We may therefore find it relevant to utilize Taussig et al. notion of potentiality, analytically investigating how genetic counselors deal with at-risk individuals' potential perceptions of themselves and their risk.

Chapter 5 - The clinic and practice of genetic counseling

In the following chapter I present an analysis of the ethnographic material. First, I locate the field through a thick description of the clinic and its practices. I then draw upon the thesis' theoretical orientations to interpret and converse with my ethnographic data, beginning with Novas' and Rose's 'genetically at-risk' and Taussig's et al. 'anthropology of potentiality'. Next, I will utilize Mol's 'logic of care' in conversation with Pols' 'warm care' and 'cold technology,' to analyze the care practices. The chapter ends with an analysis on webcams and telephones impact on the clinic's care practices.

The (non)-normative clinic

"It is not sick individuals who enter the clinic like an in-patient ward, in that way it is perhaps more comfortable here because it is not so clinical. (...) often people associate hospitals as a bad and unpleasant place." (From the focus group interview on the categorization of the present clinic, with the receptionists Alice and Emily)

On my first day of fieldwork, I found myself in a backyard approximately 100 meters from the main hospital. I was guided by a display of the medical departments located in the backyard, these were among others a blood bank, center for pedagogy, and a sperm laboratory. I located the clinic in a nearby building and took the stairs to the second level. By this time, I was confused on whether I could say I was present at the hospital due to its separate location from the main building. Two closed doors were on located on my right and left. A single hand sanitizer was put on the left wall. If it weren't for the poster's writing on the one door saying 'Klinisk Genetisk Klinik' (Clinical Genetics), I would not have recognized the entry. I knew about the importance of limiting physical contact in a hospital/clinical setting, hence the reason for the hand sanitizer outside the clinic. I then sanitized my hands and used my elbow to enter the door.

Broken limbs, fevers, vaccinations, medical treatments, operations, diagnoses, have all directed many of us, at least once if not more, to encounter a clinic. Alice and Emily's quote at the beginning of this chapter echoes the general perception of a clinical setting as an 'unpleasant' place for the mind and body. Such a clinic would additionally, in my perception, often entail the presence of nurses and doctors working together with the aim of treating or curing what is known as the 'patient' within the clinical or hospital setting. However, as Alice's and Emily's words also describe, this particular clinic felt more comfortable due to the absence of unpleasant associations such as the presence of ill patients and in-wards, making it less 'clinical'.

The clinic itself is fairly small. It consists of a small lobby and a single corridor with chairs along the walls, spaced between tables, with hand sanitizers on top of each table. A coffee machine is located in the center together with a desk which is occupied by two receptionists. In the corner of the lobby is a staff room, with a small kitchen, a table, chairs, printers, and other administrative materials used inside the clinic. Six consultation rooms are located along the corridor. The first three are reserved for genetic counselors. The genetic counselors' consultation rooms are small and minimalistic. They contain a desk, three chairs, two computer screens facing the counselor, and a sink with soap and hand sanitizer. The last three consultation rooms were reserved for doctors. The doctor's consultation rooms were bigger, but their interior resembled the counselors' rooms, except for the plank bed in all doctors' rooms. However, during my fieldwork I never experienced, observed, or heard of patients undergoing examination on the plank beds. Hence, instead of arriving at what I would perceive as a regular clinical setting, I was, together with other non-staff members, greeted by Alice and Emily, the two receptionists, offered a cup of coffee before finding a seat while waiting to be fetched by either a counselor or a doctor, calling one's name as an indication of the consultation's start.

The hospital space and practice of genetic counseling

"Hospitals are ultimately liminal spaces, where people are removed from their day to day lives, taken into a betwixt and between space of being diagnosed, treated, operated upon, medicated, cleansed etc." (Long, Hunter, Van der geest, 2008: 73)

Not long after the fieldwork began, I was invited by Tracy, one of the genetic counselors, to see the second space in a nearby building and meet the related personal of the clinic. To my surprise we had to cross the main road separating the clinic from the main hospital where ‘the office’ was located. Entering one the of the hospital’s various entries, I would find ‘the office’ on the 6th floor. Here access could only be admitted if individuals were carrying an ID card. I noted my experience of entering ‘the office’ in the fieldnote below:

“Entering ‘the office’ was strange (...). To me the place seemed cold and full of electronic devices. Here are not any visible patients either. I asked the ‘chief bioanalytic’ how he would term the place, he answered ‘department’. However, during my time at the ‘department’, I saw neither activity of counseling nor blood tests. Most of the people in the ‘department’ were in their rooms, in front of the computers, typing, reading, writing.” (From fieldnotes).

Compared with the clinic’s managed absence of hospital and clinical associations, to me this place leaned more towards Long’s et al. notion of a place where people’s lives are being diagnosed, treated, cured medicated etc. White cloaks, journals, folders, freezers, and medical technologies were a much more common sight here compared with the clinic. Here people called ‘laboratory scientists’, wearing white cloaks and uniforms, handled the medical machines, noted down numbers and letters with pen and paper, filled up and removed items from freezers. These activities were strictly done by laboratory scientists. I would come to learn that ‘the office’ was either referred to as its formal address or ‘office’ because of its technical function among counselors and doctors. Previously consultations occurred here but were relocated to the clinic in 2019. In addition to the clinic’s main focus on consultation with patients, technical work is prepared ahead of consultations. Family trees are a main element in genetic counseling as they visually demonstrate families inherited cancer or genetic disease. When counselors’ and doctors don’t have patient consultations, most often they are working on family trees. The family tree works as a map for counselors and doctors to keep track of illnesses and diseases related to passed relatives, as well to calculate risks among patients’ living relatives. Gathering data on patient’s families means looking up data in central national registers, journals, records, and even digital parish registers. Working out such a family tree is not something that is publicly available and accessible for anyone due to ethical concerns, yet it is vital in genetic counseling. Family trees may stretch as far back as available data allow. The utilized technology in crafting, visualizing, and consulting individuals therefore resembles an important technical process in the overall counseling session. The main goal of genetic counselors’ consultation is to determine whether a patient should be offered a gene test to determine whether they are the carrier of a gene variant that would put them at risk of developing a disease. The patient groups directed to the clinic can be divided up in two groups. (1) Recently diagnosed patients with cancer. These patients are often, and as a first stop, offered a referral to the clinic as part of clarifying whether their diagnosed cancer is related to genes, hence posing a familial cancer risk. (2) Patients with a familial cancer history. These individuals have contacted their local general practitioner who then direct the individuals to the clinic for a consultation. Both patient groups rarely display any symptoms of disease.

The clinic of not-yet sickness

"The clinic is a place where one can feel safe as no one are walking around in uniforms, there are neither medical machines making strange noises. I actually think that it is calming the patients." (From Emma's interview, a genetic counselor, describing the importance of spaciousness of not making patients sick).

Given how the clinic struck me as different from my perception of a traditional hospital clinic, my attention was drawn to the symbolic and material culture at play, as a way to analyze how these differences related to this clinic's care practices. One of the elements that demarcated the clinic's space as 'different' from a traditional hospital clinic were its norms and practices surrounding staff clothing. Social scientific studies have previously examined the symbolic culture related to healthcare professionals clothing commonly associated with hospital and clinical settings (Blumhagen, 1979; Timmons, 2011; Jenkins, 2014). Originating from surgical rooms or scientific laboratories, Blumhagen (1979) argue how white cloaks have come to represent a social understanding of 'healer' in modern hospitals. White cloaks have also been demonstrated to create boundaries, status, as well as construction of professional identities (Timmons, East, 2011). Additionally, studies on material culture within healthcare have shown how homely interior of cancer clinics are active and co-constitutive of care and how materials permeate practices of care in relational and emergent ways (Martin, 2016; Buse, 2018). To see counselors and doctors wearing everyday clothing, such as sneakers, sweatshirt, and jeans in the clinic was a surprise and confused me – or, in the words of Mary Douglas (1966), struck me as a 'matter out of place'. Because of the absence of white cloaks and uniforms, the role of doctors and counselors was puzzling as I still viewed the clinic in a hospital setting, thus dealing with diseases, medication, and ill patients. Who works in a clinical setting wearing streetwear?

To examine my confusing perception of the clinic, I decided to investigate my patient-informants' perception of these practices. Jenny, a newly diagnosed woman with breast cancer, responded the following on whether she felt that she had been consulted in a hospital setting with nurses and doctors in her interview: *"Not really, based on the rooms [the lobby and consultation rooms] and the counselors dressing. I know hospitals can look different and it has clerks, but I think that was what made me feel like that".* Based on Jenny's words the central components of white cloaks, uniforms, and the clinic's facilities play an active and expected role in creating an impression of being part of a hospital setting. We might further interpret Jenny's feeling as parallel to Emma's quote at the beginning of the section stressing the aspect of patients feeling safe due to the absence of white cloaks and medical machines. As the former mentioned components are removed or reduced, the clinic becomes less associated, by some patients, with the general activities of a hospital, hence disease, medication, and treatment.

Meanwhile, during the focus group interview Alice, a receptionist, stated the following: "*Because the clinic is a place of consultation and not a place of treatment, I think it's correct not to wear uniforms or white cloaks."* Because of the clinic's focus on consultation rather than medical treatment, the presence of hospital equipment, tools, and medication is simply not necessary. This suggests another type of clinical practice. Furthermore, a presence of white cloaks might also have unintended consequences, such as patient's misinterpretations of healthcare professionals' function, the clinic's practice, the content of the consultations, and the presence of disease. Thus, the necessity for counselors, doctors, and even receptionists to wear uniforms or white cloaks is therefore reduced.

As a consequence of the absence of uniforms to mark their professional position, several counselors articulated a feeling of reduced authority and legitimacy in displaying their 'belonging' to the clinic, and that they suddenly had to consider their civil clothing. As Kate, one of my genetic counselor informants, articulated: "*Some of the referrals' are really sick, they have a knife to their throat (...) in such a case I do not like the idea of sitting in a sweatsuit or with a big flower in my hair (...) contrary it would also be inappropriate to wear funeral clothing."* Kate's statement suggests an acknowledgement of the complex practice of genetic counseling, illustrated by in her decision of what is appropriate clothing to counsel in. While a sweatsuit and flower might indicate a domestic and relaxed atmosphere, it would also display a sense of frivolousness toward ill individuals. On the contrary, too strict clothing such as funeral or formals associated clothing would suggest an exaggeration of patients' otherwise serious situation. Hence, while the absence of traditional clothing blur the positions and self-perceived authority among counselors, they navigate the gap by making informed decisions on what to wear instead. Though, these decisions are equally guided by the complex practices surrounding the counseling of patients. Clothing must therefore be neither too relaxed nor too strict.

Because of the minor differences in the genetic counselors' and doctors' practices, some doctors still preferred wearing a hospital uniform. This uniform did not consist of white cloaks but instead a light-blue t-shirt and pants, seemingly out of place to me as well—not with regards to gaining an authority within the clinic by wearing uniform or white cloak, but due to the absence of disease. I asked Sam, a head doctor of the department, about these choices, as she explained: *"I often examine patients physically, I press their belly and stretch their arms and leges, in such cases you do not want to wear your own clothing."* Physical examination is limited to doctors' practices which explains Sam's practice of examining patients. We may interpret Sam's words as dressing up in a uniform to gain the authority to physically examine patients. The uniform thus signifies legitimacy in her practice. Even though these patients might not display visible symptoms, nor be visibly sick, physical examination might reveal important aspects of genetic disorders. Yet, patients might not be aware of this practice prior their arrival in the clinic. In the context of the general absence of white cloaks and uniforms among clinical staff members, hence reduced sense of disease, the appearance of Sam's uniform contradicted this sense, as uniforms might also signal disease. In other words, the symbolic value of Sam's decision to wear uniform, legitimizing her practice, also contradict the intentional, or unintentional, purpose of creating an atmosphere of 'not-yet disease'. When I asked Eva, a genetic counselor, why she did not wear a uniform, during her interview, she answered the following:

"They [patients] are neither sick nor do we have physical contact with them. There is a difference between physical examinations (...), there are some fundamental hygiene reasons for wearing uniforms, but when we don't do that. It's a way to meet the patient in a dignified position."

We might interpret Eva's reference of referred patients as not being sick as the main reason for not wearing uniforms. The two main patient groups referred to genetic counseling are either patients with a cancer familial history or newly diagnosed cancer patients, yet the latter rarely display symptoms. Thus, because of the apparent absence of illness or disease related symptoms among both patient groups referred to genetic counselors practice, uniforms are not necessary. Genetic counselors' absence of wearing uniforms therefore seem more intentionally to reduce the symbolic value associated with a uniform in a clinical context. Patients sitting in the presence of an individual dressed in a white cloak or uniform, within a hospital clinic might therefore result in unintentional imagination of disease. Hence, removing uniforms and cloaks from the counseling practice also reduces patients' potential (mis)interpretations of disease, creating what Eva term a 'dignified position' between her and the patient. The symbolic value associated with uniforms was also addressed by Emma, another genetic counselor, who responded to my interview question about the absence of uniforms:

"A uniform signals disease (...). Of course, we are an authority but not like a surgeon. I feel like it lightens the consultation when you're not wearing one [uniform]. It presents an individual you can talk to. Of course, you can't talk with the patient as they were your friends there need to be a distance."

Emma's upper words echo Eva's. Emma, though, articulates explicitly the common association between uniforms and disease. However, Emma's answer also resonates with Eva's notion of 'dignified positions' when uniforms and cloaks are removed from the counseling context. However, by removing the white cloaks and uniforms from the counseling practice, with the purpose of limiting the sense of disease, Emma addresses a consequence of doing so. With the removal of counselors' cloaks their authority becomes reduced creating a smaller distance between counselor and patient. Hence, we may interpret the practice of decentering cloaks and uniforms as intentional creating an atmosphere of reduced disease and illness, though it comes with a symbolic cost of reducing the authority thus, distance between counselor and patient. Eli, a doctor at the clinic, captured the core aspect of the clinic's clothing norms and practices, answering my interview question regarding whether there were specific rules for doctors' behavior during consultations:

"There also exists a signal value based in us wearing civil cloth, a bunch of patients' value that everything is not provoking disease. Furthermore, we do not meet the patients at the main hospital but consult them in the clinic."

Reducing the provoking feeling/sense of disease is thus a main concern for receptionists, counselors, and doctors. Having the clinic located outside the main hospital building is then also important in reducing the association of disease. These ways of managing a distinct appearance and disentangling associations with a traditional hospital clinic is what I would argue is an active management that creates a clinic of non-sickness or not-yet sickness, or at the very least a reduced sense of sickness. Being aware of such a clinical and symbolic management may also draw a parallel to a potential reduction of patients feeling according to Novas' and Rose's 'genetically at risk' disentangling disease from genetic inherited diseases. Such a management might also demonstrate a caring practice of counseled patients' wellbeing.

The healthy patient

My use and reference of 'patient' in my writings reflect the colloquial terminology used by counselors and doctors I met and observed during my fieldwork, even though the reference might not be correct. 'Patient' often describes individuals who are undergoing a medical treatment, hospitalization, or diagnosis. Nevertheless, 'patient' was the common reference within the clinic, even while staff members openly expressed ambivalence about its appropriateness. When I asked Kate, one of the genetic counselors, why the counselors and doctors used the term 'patient' she stated that she knew the term might not be correct and discussions had happened among genetic counselors and doctors as to whether they should change the term. During my interview with Emma, another genetic counseling, she stressed her dislike of the term 'patient' and preferred to use the word 'referred', indicating a neutral categorization. Discussing the latter topic with Tracy, she justified the common use of 'patient' in the following: *"You are considered a patient whenever and whatever the medical treatment or course you are undergoing in a clinic or hospital."* Furthermore, during the focus group interview Emily articulated her perception of the 'patient' directed to the clinic as 'healthy patients': *"I often think that I am working at a hospital, but I am working with healthy patients, even though we sometimes have patients undergoing chemo-treatments. It creates a new way of being at a hospital."* Emily's statement implies a temporary contradiction by stressing the paradox of working at a hospital but with 'healthy patients.' Lingering briefly with Emily's notion of 'healthy patient' we might interpret this as a redefinition of 'patient' due to the absence of visible symptoms, yet still undergoing a hospitalized treatment. Hence, one is considered 'healthy' as long as symptoms are hidden. This would also draw a clear parallel to the consequence of the new biomedical practice's re-cataloguing of already established notions, such as 'patient'.

Emily's notion of working with 'healthy patients' also appears to address a core concern of genetic counseling: how do one counsel a 'healthy patient' on the topic of preventing an inherited genetic risk of disease, without generating a potential sense of disease or certainty of disease? This seems contradictory and problematic in practice. Nevertheless, in the context of genetic counseling and the clinic's management of a space of 'non-sickness,' the question makes sense due to the absence of visible symptoms of disease and traditional hospital facilities. Moreover, when asked, none of my interviewed patients considered themselves as patients prior to receiving their gene test result. However, no one knows how long the 'healthy patient' will remain 'healthy' and even be considered healthy if a risk is detected. This uncertainty formulates a second question whether one can be considered 'healthy' if a genetic risk is detected and what it takes to be considered 'healthy' in biomedical practices and genetic counseling. In the context of genetic counseling the display of symptoms appears to be an association of 'unhealthy'. Though, being at-risk is not equivalent with the immediate or future display of symptoms as a result of the detection of a risk, nor are symptoms destined to manifest. Symptoms nor disease does not develop immediately after detection; thus, at-risk individuals can potentially live a 'healthy' life without (ever) displaying symptoms.

Because of the uncertainty of developing disease linked to one's genetic risks, constant monitoring of one's health pose a potential danger to patient behavior. Symptoms related to one's genetic risk would potentially be constantly monitored, analyzed, and sensed as a predictive behavior in response to individuals' genetic risk, or as Novas and Rose put it, 'in the name of prevention'. As a consequence, we may speculate whether knowing one's risk has the potential to create a sense of sickness or determined sickness close related to what is termed hypochondriasis or illness anxiety disorder. Studies have shown, for example, how worries are related to anxiety of developing cancer, especially the long-term impacts of both surgery and quality of life (Hallowell, 2016; Lynch, 2008). Any kind of anxiety related to risk is unwished and problematic for patients and healthcare systems. The latter was not explicitly articulated among my informants but are based on my theorization of such consequences. Creating a material space and feeling for patients attending genetic counseling of non-sickness therefore appears vital. This draws a clear link to the former section on the cultural symbolic and material dimensions on the clinic's facilities of non-sickness as well as the recent physical relocation to the present clinic. Hence, we may interpret the clinic's facility of non-sickness as focused on disrupting patients' potential perception between risk and determined sickness. Unraveling the symbolic associations of disease within the clinic creates a sense of a clinic of non-sickness, which also works to reduce patients' potential association between their risk and perceptions of determined sickness. Patients would, in other words, come to perceive their risk as only a potential for sickness.

The clinic of potentiality and the genetically at-risk

"In biomedical practices, potentiality indexes a gap between what is and what might, could, or even should be." (Taussig, Hoyer, Helmreich, 2013: 5).

How, then, does one counsel a 'healthy patient' on the topic of preventing an inherited genetic risk, without generating a potential sense of disease or certainty of disease? Or, in relation to vignette above, how does one counsel an individual on genetic risks without generating a potential (mis)understanding and feeling of uncertainty of what is, what might, could or should be? This is hypothetical yet important to address, as a potential misunderstanding of one's risk might result in an unnecessary self-monitoring, anxiety of disease, or unnecessary change in social behavior. Throughout this section I set out to analysis and discuss the latter.

To answer the upper question, we may theorize that the clinic's disentanglement of disease, creating a clinic of not-yet sickness, first of all play an important function, limiting disease association with the practice of genetic counseling and genetic risks. As this section's vignette illustrates the biomedical practices, including genetic counseling, has shifted the way in which we perceive the future through various potentials. A 'healthy patient' with a detected risk might develop disease, he/she could also live according to Novas' and Rose's 'genetically at-risk individual', without ever developing the disease, or because of age he/she should or should not be in danger of the risk's development into disease – none of the latter are certain, only potentials outcomes of the risk. Using Taussig's et al. words a genetic risk is a hidden force which may manifest itself. Drawing on Taussig's et al. three identified patterns of how 'potentiality' has previously been utilized, the most evident connection we may perceive is the first; a hidden force, in our context a genetic risk, determined to manifest itself. Yet, the ways in which this force, the risk, manifest itself are potential. For some it may manifest in fear, thus self-monitoring, unnecessary medication and change in social behavior in order to reduce the risk, for others it might generate as sense of confirmation of relatives' medical records, while some might not care about it. Patients' potential imaginations or perceptions of their risk are potentially many. Nonetheless, while the genetic risk is beyond human and technological manipulation, patients' perception of their risk is not.

As I have demonstrated in the former sections of 'the clinic of non-sickness', 'the healthy patient', and by the clinic's relocation, the clinic is actively pursuing a management of disentangling associations of the clinic with 'disease'. We may interpret these elements as closely related to a manipulation of patients' perception of their risk, by disentangling patients' potential undesirable imaginations of their risk and potential of disease. Due to clinicians' knowledge on genetic risks, they have a better statistical and medical understanding of its potential outcome than patients. Yet, patients imagined potential of their risk might correspond more with Novas' and Rose's notion of the 'genetically at-risk individual' resulting self-surveillance, stigma, or preventive medication to reduce the risk. Understandings of genetic risks might therefore not correspond between the two parties, due to different understandings and misunderstandings of what it means to live with a detected genetic risk.

Hypothetical speaking if genetic counseled patients were put in a setting of hospitalization, their imagination of their risk might be negatively influenced into a bad imagined potential of their risk. Negatively influenced as to consider their genetic risk to be equivalent with disease, or present symptoms, or it could develop into disease, or should develop into a disease due to the counseling's setting's interior, hence generating a patient sense of being 'genetically at-risk'. Unraveling the clinic with hospitalized elements of disease such as white cloaks, relocating the clinic, and the general absence of disease, the clinic might then manipulate patients' potential imagination of their risk to a limited understanding of only being a *potential*, by limiting their practices and interior's association with disease. The clinic's removal of white cloaks, their relocation, and general absence of a traditional hospitalized interior also suggests a parallel to Taussig's et al. statement that people ascribe potentiality to things they believe can be manipulated or what is desired to manipulate. Hence, we may interpret that the clinicians ascribe patients' imaginations of their risks to be potential and thus able to manipulate. Because of patients hypothetical negative influenced imagination of their risk's potential, being 'genetically at-risk', it may even be desirable to manipulate patients' imagination. Suggesting that the clinicians are trying to manipulate a specific potential patient imagination of risk not to be associated with disease or certainty for disease, but only as a potential of becoming sick.

We might the interpret the removal of white cloaks, the relocation, and the less hospitalized interior of the clinic as constituting a manipulated setting which act to, potentially, reduce the sense of disease and countering the feeling of being a genetically at-risk individual. This manipulation might positively affect patients who, potentially, would have misunderstood what it means to be diagnosed and live with a genetic risk. Hypothetically the latter would result in individuals, not perceiving themselves as patients yet, returning to their former social habits, routines, and practices, but as individuals with an awareness that they have a potential to develop a disease. Lingering at the hypothetical successful manipulation of patients' potential imagination of their risk might also imply a positive short and long-term focus on patients' emotional experience of attending genetic counseling and what it means to live with a genetic risk. A successful short-term emotional experience among patients might result in a feeling of not being sick nor destined to be so, as well as not to constantly fear the risk of becoming sick or display symptoms. Long-term wise we may interpret patients' not actively trying to reduce their risk through medication, changed social behavior, and unnecessary monitoring of one's health condition, as a proper and successful emotional manipulation. As stated in the theory section on Novas and Rose, the detection of genetic risks has become embedded in a notion of improving quality of life and maximizing life chances. Hence, clinicians' manipulation and awareness of patients' potential emotional response and imaginations of genetic risks may also illustrate a caring act of the patient's future bodily and mentally wellbeing, living as an individual with a genetic risk. Potentially countering patients' imagination from feeling, in Novas' and Rose's words 'genetically at-risk', to a sense of potentially developing a disease.

The potential familial and patient matter in genetics

Novas' and Roses' argument that communicating risk has become the central object of genetic counseling was reflected in the consultations I attended and observed. Both counselors and doctors would during the consultation describe general cancer statistics, genes, heritability, risk, and uncertainty, stressing various potential outcomes. The latter topics were all covered by counselors and doctors but articulated differently. The purpose of articulating the topics is to create a foundation for patients to make an informed decision of whether or not they wish to have a genetic test, hence gain knowledge about their potential genetic risk. Though, detection of a genetic risk is not certain if patients wish to be tested. Yet, Taussig et al. stresses that talking about potentiality or imagine potential is equal to talking about or imagining that which does not, and may never, exist.

Through the use of various gene testing technologies identifying genetic risks, I learned about the following three potential categorizations from my clinical informants on genetic test results: ‘detection of mutation’, hence potentially turning a patient into Novas’ and Rose’s ‘genetically at-risk’, ‘non-detected’, and third, ‘invalid test result’, indicating an unclear result on whether a patient poses a genetic risk. The latter categorizations correspond with Taussig’s et al. former words. We may in other words interpret the three categorizations of genetic test results as a way for clinicians to talk about that which is and does not exist but constitute various potentials. Under certain conditions patients can be considered at-risk due to their familial history, without being genetically tested.

Except for the non-detected genetic risk, the other two potential test results both constitute an uncertainty of the risk developing into disease. In other words, ‘risk’ is not equivalent with determination. Knowing one’s genetic risk is therefore not preventive but potentially predictive. Olivia, a patient-informant, described the uncertainty of risk related to the detection of a mutation as the *potential* to become a patient: *“I risk becoming a potential patient If a mutation is detected in me or my family (...). But I would not be a patient until I fall ill from my cancer.”* We may deduce from Olivia’s words, that ‘risk’, in the context of genetic counseling, functions as a double connotation implying the potentials of developing a cancer disease and becoming a patient. Though, Olivia also stresses an important distinction between the detection of a genetic risk and the notion of becoming a patient, emphasizing her falling ill as the pivotal point. Further deduced from Olivia’s words, living with a detected genetic risk does not transform individuals into patients, but rather into potential patients, who, in Taussig’s et al. words, are not sick yet, could, or should develop a genetic disease. This distinction is critical to raise. While a patient might act responsibly by monitoring and medicating one’s health, a potential patient is only potentially sick but may never be sick due to his/her genetic risk. Acting and behaving as a responsible patient in accordance with a potential disease is therefore unnecessary.

Furthermore, Olivia’s words also stress the matter of family, therefore corresponding with Novas’ and Rose’s notion that genetic risks are not restricted to single individuals but pose implications for families and potential future family constitutions. The family matter is evident during consultation where counselors and doctors ask about patients’ families. Meanwhile, the concern for family became obvious to me during a consultation with Kate, a genetic counselor, who I noted describing the following: "*Second patient is accompanied by her dad as a reinforcement of remembering what happened in the family. (...). At the end of the consultation Kate recommends a gene test for the patient and the father. I was surprised how and why Kate did so, since he was not the 'one who was consulted'.*" This encounter with Kate and the patient emphasizes the family matter in genetic counseling and risk but also its immediate implications and potentials of who else in the family might be carrying a genetic risk. Moreover, the encounter also demonstrates that even though a single patient might be consulted, the actual family, or genetically relatives, are tacitly also implicated in the configuration of risk. While Novas and Rose focus on the single genetically at-risk individual the term 'potentially genetically at-risk family' might be more suitable to utilize instead.

The practices of good care and good caring relationships

"But I have to say, when you get sick you become so tiny in a way, and in that case I think the vast majority need care, otherwise you really need to be a tough human being. The warm-heated care is what is needed." (From Jenny's interview, one of my patient informants, describing the feeling of being hospitalized)

Because of the absence of white cloaks, the clinic's relocation, and the general removal of hospitalized elements, as well as the mixed groups of patients, being newly diagnosed or healthy, the apparent need for a caring practice struck me as not necessary. However, my assumption on the appearance for care in the clinic's practice would soon be challenged. My assumption surrounding care related to kind and helpful nurses, physicians, or doctors' practices of caregiving, wearing white cloaks, caring for and taking care of sick patients by helping or nursing them with medication, treatments, or curing, looking after, and asking if patients are in pain or feel unwell. Echoing central elements from Jenny's upper vignette. It struck me as strange caring for one who was not sick or hospitalized, nor a traditional patient, on the matter of a potential disease and who only had to choose whether or not to be genetically tested. On the contrary, letting the patients choose for themselves whether or not they wished for a gene test seemed to me as more 'caring', allowing for more patient autonomy, ownership of one's health, and empowerment to make the individually 'right choices'. I would later come to learn that my perceptions of care were deeply embedded in the Western discourses of what Annemarie Mol terms the 'logic of choice'. Turning the patient into a customer who may choose his/her own healthcare. Though, as I attended numerous consultations the counseling practices became clearer, while patterns of a care practice slowly appeared as well. The care practices became clear to me as I began to understand the patient's ethical dilemmas of sharing information of inherited genetic risks with relatives, the difficult reflection on future family constitutions risking passing on an inherited genetic risk, and, as I have illustrated previously, misunderstandings of what it means to live with a risk. This would also lead to my examination of the complexity of 'care' and its many expressions within the clinic.

Investigating care my informants in the clinic had multiple ways of defining care and outlining their practices, which expanded my own conception of how care was understood and practiced in this specific clinical setting. During the interview asking about the presence of care in genetic counseling Joan, a genetic counseling, stressed that *"care is always an element in every healthcare job that deals with patients",* implying the central practice of care in healthcare in general. In response to the interview question 'what is care to you?' several receptionists, counselors, and doctors invoked associations with their family, as demonstrated in the interview with Mary, one of my doctor informants: "*When you are saying care, I think of it as it is, but I also think about my kids. But care is so much more than that."* Mary's association of care with her kids was echoed in the receptionist, Alice's emphasis on a 'loving care' towards the family: *"Care towards one's family is another form; it is a loving care. But here we follow more of a professional care".* Together, Mary's and Alice's words outline an important distinction in the care present in the clinic compared with the one given towards the family. Even though traits of familial and professional care might overlap the relation is different, which gives way for two different notions of care. Because familial care is embedded in a love for the family, it would be problematic and inappropriate to utilize it in a context of counseled patients and their families. A common articulation among all clinicians echoed the presence and importance of care in genetic counseling. To be kind and open were common articulations of care among the clinical staff members. More detailed articulations demonstrated the caring ability to embrace, grasp and attend to the patient in front of them. Linked to the latter Emma, a genetic counselor, stated care and empathy *"is the most important tool for a genetic counselor".* Eli, a doctor of the clinic, explained the methods of how he perceived care being carried out in genetic counseling:

"Social, physical, and conversational-wise. It is a way to conduct oneself to the patient and see where they are and to identify what they need and how they react to stuff. It is really what makes us irreplaceable with computers."

To ‘see where the patient is’ should not be misinterpreted with seeing where the patient is geographically located, but rather in what state of life the patient is currently in. By contrasting human care as irreplaceable with technology, Eli also emphasizes that care is strictly limited to the realm of humans, adding to Pols’ contrast between ‘warm care’ and ‘cold technologies’. However, while Eli states care is strictly limited to the human realm, Kate, a genetic counselor, stresses *“It is also care when you make a family tree or chitchat with the patient who might starts talking about a history related to their grandmother”*. Kate’s chitchatting draws a parallel to the human realm of ‘warm care’, while creations of family trees are done through the use of ‘cold technology’. Though, the creation of the family tree might be the object that enables Kate’s chitchatting, and thus a ‘good caring relationship’, echoing Pols’ statement that such a ‘good’ relation is depended on the use of both warmth and coldness. ‘Good’ in this context should not be misinterpreted with the ethical term, but rather in Mol’s term of caring to one’s best ability’ and Pols’ notions of establishing a ‘good caring relationship’. The creation of family trees is a central component in genetic counseling’s technical part, contrary to the social part of counseling, nevertheless we might interpret this part as closely linked with counselors’ caring practice of ‘knowing the patient’. Since family trees are the main source of knowledge prior consultations, the better and more accurate family trees are, the better counselors, or doctors know the patient and family history, hence the better one can care for them. Because genetic counseling is not an ongoing treatment and is often reduced to a single consultation, preparation of the consultations becomes vital in establishing a good and caring relation. This resonated with what Mia, a genetic counselor, explained as most important for her, before and during consultations: *“That I am prepared, know the reason and background for why the patient is directed to us, (...) and what we need to discuss.”* We may then interpret to be well-prepared is fundamental in doing ‘good care’ and to establish a caring relationship in genetic counseling. Meanwhile, Mia’s statement of preparation are dependent on a well-done technical practice, echoing Kate’s notion of the technical part closely related with a care toward the patient. Thus, while Eli stressed that care is what makes humans irreplaceable with machines, the warm and good caring practice of genetic counseling is very much dependent on the use of cold technology to perform ‘good’ care and establishing ‘good caring relationships.’

The notions of care illustrated so far has mainly focused on the softer and humane practices. Kate however, stresses that care might also be more direct and informative by reflecting her own need in the case of a detected mutation: *“If it was me who had a detected pathogen variant [mutation] (...),* *then care for me would be coming to a doctor who could give me facts, data, and risk information."* Kate's words correspond with Eli's emphasis that care is depended on what the patient need, which may vary, due to various patient needs. Or, as Emma, another genetic counselor, puts it "*it all starts by working out the patient's need and being on the same page"* suggesting doing 'good care' starts from what patients actually need. The various articulated notions of care thus draw a parallel to Mol's logic of care, concentrated on what the patient needs rather than what they want. Corresponding with the former mentioned notions of care, the identification of patients' needs was a common echoed articulation among counselors and doctors.

Due to varying age, gender, education, progress of disease, socio-economic status, but also emotional states of mind, prior consultations, patients' needs are rarely identical. Counselors and doctors in the clinic therefore stressed the importance of identifying the individual patient's needs and adjust accordingly, drawing a clear parallel to Mol's logic of care. During the interview with Emma, she articulated how she adjusted her care: *"You may change between using technical terms and in other cases using completely different words, you may not even mention 'genes' and how it works in the blood."* Emma's quote indicates an emphasis on an active adjustment to patient's background and need, compromising the content of the consultation to better explain, and thus care for, the patient. Emma's actively adjusted and conscious use of words suggests what Mol terms 'good communication' which she argues is a precondition for doing 'good care'. During consultations specific information and details need to be communicated for the sake of the patient to make an informed decision. This information might be sensitive. In cases of delivering sensitive information Eva, a genetic counselor, emphasized to do 'good communication' one might 'turn up or down' the amount and content of information:

"It is important for me to get a good connection with the patient because it might be a sensitive topic we will discuss (...) how much information should I give, should I turn up or down. It really depends on the relation, if that functions then there is no limit to what you can inform about."

Eva's statement draws a clear parallel to Mol's suggestion of 'good communication' as a precondition for doing 'good care'. We may therefore also interpret the establishment of counselors' 'good communication' with Pols' notion of establish a 'good caring relationship'. Thus, the central frame of identifying patients' needs and active adjustment to those needs act as the two main rationales for clinicians' practices of doing 'good care'.

Even though genetic counselors and doctors are the most apparent healthcare professionals of the clinic, care practices are not wholly restricted to either of the parties nor the consultation rooms. Meanwhile, as Mol states care is not just limited to the practice and consultation healthcare professionals, but include secretaries, laboratory scientists, porters etc. This led me to investigate the receptionist's function. As the clinic's receptionists, Alice and Emily, actually are the first individuals the patient encounter in the lobby, they too constitute a care element—indeed the first instantiation of care the patient meets when entering the space of the clinic. Because of limited space I won't be investigating the care practices of Alice and Emily. Though based on Mol's theorization of secretaries being a critical part of the whole care team, we may interpret Alice and Emily too constituting a care element and practice. Hence, the care practice of genetic counseling is not solely limited to the evident healthcare professionals inside the clinic but may include the receptionist's practices too.

The safe space and the sweet counselor

"It is something about emotions and to feel the space and of course a combination of what the patient is bringing, (...). Its focused-on empathy, to sense who I am meeting and how I am to mediate my task to, with the aim of the patient feeling enlightened and comfortable." (From my interview with Tracy, a genetic counselor, on how to 'meet the patient where he/she is')

As mentioned previously, the counseling practices between genetic counselors and doctors differ slightly. Genetic counselors' practices involve consulting patients on genetic tests and reaching a shared decision of whether the patient should genetically tested, while doctors' practices involve consulting patients with an already detected genetic risk or disease. Though, the structure and practices between the two consultations are similar. The following chapter will draw mainly on consultations with genetic counselors due to these being the main consultations I have attended.

During my interviews with counselors' and doctors' articulations on how they were supposed to look, feel, and behave during consultation were often described as to be kind, neutral, and 'sweet.' These affective expressions were described as motivated by the intention of creating a 'safe space' for patients to make an informed decision, as Tracy, a genetic counselor, puts it: *"I am thinking I should be kind but also as neutral as possible while making them [the patients] feel safe. To be as personally involved so they in the end feel safe, but still keep a professional face."* Tracy's creation of a 'safe space' for patients was generally reflected among all patient informants. Of course, the physical space has to be safe for sensitive information to be exchanged, which explains the closed doors during consultations. Meanwhile, Megan, a patient informant, emphasized during her interview how she felt safe due to the counselor's understandable language: "*I felt very safe during the conversation. She [the counselor] were relaxed, and she did not speak in medical terms."* From my experience attending numerous consultations statistics, medical, and genetical terms were often articulated in explanations on general genetic risks. This was often necessary to state for patients to understand the fundamentals on their decision whether or not to be tested. Yet, we may interpret Megan's feeling of 'safe' as linked with her being able to understand the content of the consultation due to the counselor's chosen spoken language, emphasizing a parallel to Mol's link between 'good communication' hence to do 'good care'. Additionally, following Megan's explanation of her counselor being 'relaxed, three common descriptions of counselors among patients were described as 'knowledgeable', 'listening, and 'sweet'. Being and looking 'sweet' might seem irrelevant in a counseling context on risks, disease, familial cancer etc. where facts, information and data appear more relevant to make decisions of having a gene test or not. During the interview with Miranda, a genetic counselor, she expressed a dispute of the description of being 'sweet' and emphasized how she would rather be described as 'competent'. She added the following:

"But if our point of departure is to be sweet then it is not in the context of being good with animals, but to feel met, that they [patients] not felt like they had to explain or argue for anything. I am sweet because I reflect her thought that it is correct that she requested genetic counseling."

To be 'sweet' then, in the context of genetic counseling, implies an emotional expression and acknowledgement of patients' needs and thus indicating a care engagement and caring practice among genetic counselors. Within the logic of care, Mol argues that care engagement is closely associated with being skillful, attentive, and persistent which all are important skills to possess as healthcare professional. Genetic counseling's care engagement can then be said to depend at least in part on being competent and sweet, though not only as an expression but also as a skill. The latter elements of sweet and competent were also stressed as important in Kate's interview, another genetic counselor. Compared with Miranda's dispute Kate emphasized that 'sweet' and 'competent' can go "*hand in hand*", as she further added:

"I don't think one exclude the other. (...). I like to be kind. (...). When you're sweet, kind, and open it is my impression that you can say everything. Then everything will be received nicely even though there might be something which is difficult.".

We may interpret Kate's words as mobilizing specific emotions with the aim of creating a safe space for patients and in which the potential amount and content of sensitive information can be exchanged. The mobilization of specific emotions, such as kind, sweet, and competent, might then act as instruments for counselors delivering and communicating the content of the consultations. In this way emotions become vessels in which counselors might deliver and engage in Pols' 'good caring relationships.'

The practice of meeting the patient where he/she is

When I inquired into the care practices of genetic counseling I would on numerous occasions hear this phrase repeated: 'meeting the patient where he/she is'. I quickly discerned that meeting the patient where he/she did not mean to meet up at a fixed location in time and space. Yet due to the ambiguity of the notion, I asked what the notion meant, and how it was practiced, resulting in various diffuse replies. Joan, a genetic counselor answered with the following during her interview:

"(...) it is something about sitting down together with them and ask about their expectations. (...) But to meet them where they are is to, if you for example have a patient referred to the clinic, (...), then my job is to figure out how much they know (...). It could also be a patient who doesn't have very much education and hardly knows anything about genes. Knowing where they are knowledge-wise, and need-wise is good."

Because patients referred to genetic counseling are never identical in the extent of their knowledge, their informational and emotional, needs may vary. Pols stresses to 'sense' whatever troubles, if any, the patient might carry as important to identify and practice the right kind of support in response, hence care for the patient. Furthermore, the notion of 'meeting the patient where he she is' echoes Pols' notion of caring being 'good' when it seeks to fit individual needs, hence tailoring the care to the specific patient. Following Pols, ‘meeting the patient where he she is’ indicates an active tailor-measurement of what care need to be given and under what circumstances. While the consultation starts behind a closed door in a consultation room, Emma, another genetic counselor, argues the measurement already starts when fetching the patient in the lobby: *“You’re meeting the patient in the lobby and already there I need to start figuring out what kind of individual I have in front of me.”* The result of ‘meeting the patient where he/she is’ in practice then varies according to the identified, measured, and adjusted care. Mia, a genetic counselor, explains in the following how she adapts her language according to practice of meeting the patient where he/she is:

”I can easily if I sense the patient is from the same province as I, consciously or unconsciously, adjust my language to theirs. (...) I think that’s important. Regarding my body language I use that a lot as well because I am horrible at drawing.”

Clinicians’ use of body language was also something I often observed during my fieldwork, varying from physical explanations with hands, the position of the body in the room, trying not to sit in front of the computer, nodding’s, eye-contact, and frequent acknowledging articulation of ‘yes’ or ‘no’. The latter observed practices relate to Pols’ notion of generating a good caring relationship by its emphasis on ethical relations which respect the patient’s subjectivity and acknowledge their thoughts and feelings. Listening to and acknowledging worries articulated among patients are also practices of doing ‘good care’ according to Pols. As Miranda, a genetic counselor, who emphasized the necessity of listening to patients sidetracks during the consultation, stated in her interview:

“If it is something that occupies the patient, i.e., if she is worried about her daughters dying of cancer then we need to talk about it. The patient needs to have a sense of me acknowledging her worries as a real fear, even though the fear might not be relevant.”

Miranda’s words reflect Mol’s emphasis that a consultation is not a debate where patients have to defend themselves, even though patients’ worries might not be relevant for the consultation nor the purpose of the genetic test. It also draws a parallel to Pols’ aforementioned emphasis on the ethics of relations. Listening, nodding, asking into patient’s sidetracks suggests a counseling practice which acknowledges patient’s daily lives and thus a locally percieved behavior of doing ‘good care’. Patient’s display of emotions was also known to occur during consultations. Mostly when patients were either afraid of becoming at-risk or when the family was heavily impacted by cancer. During a single consultation with Mia, I witnessed a patient suddenly turning sad, even shedding tears, to a question on the patient's deceased grandma. The episode was captured in the following fieldnote:

"The family tree and cancer information are discussed. However, when Mia reached the patient's grandma silence broke out and the patient starts shedding tears. Mia immediately says it's okay and why the patient is reacting in that way. Mia asks if it was because the grandma and the patient were close, the patients nods and replies 'yes'. Mia reaches out for the patient's hand and asks a little more into it. Mia finishes by smiling and asking if the patient is ready to continue."

Without even asking what the patient wants Mia's reaction implies an attentiveness to stop the consultation's formal structure and give space for the patient's reaction. Rather than asking 'why do you cry' or neglecting the patient's reactions but reaching out and touching the patient's hand asking about the relationship between the patient and her grandmother, Mia engages in what we may interpret as a 'good caring relationship'. Mia's reaction also demonstrates a physical dimension of doing 'good care'. Mia's 'good' attentive reaction of such emotional reaction might also suggest a parallel to Mol's logic of care where neglect is considered a bad response, suggesting the practice of a local perceived logic of doing 'good care' among counselors. In addition, Miranda stressed how she had tissues nearby if she ever felt patients needed them. She did so because of the following: "*then patients feel reflected and safe during the situation.",* echoing the former section of the creation of a safe space for patients. Moreover, Jill, another genetic counselor, stated, describing a similar situation to Miranda's and Mia's, how she would help the patient with psychological support or recommended contacting the Danish Cancer Society. This was not to rush through consultations, nor demanded of her, or to neglect the patient's reasons for attending the consultation. On the contrary. *"I do it because I can see they don't feel good, and I want them to feel better."* Jill replied to the interview question of why she did so. Jill's action of recommending additional support rather than staying silent or neglecting the option, is a clear parallel to Mol's notion of a logic of care. While Jill is not formally required to recommend or assist patients on other content besides the consultation's content, we may interpret her additional behavior as guided by a rationale of care and the identification of a need which she can fulfill, and not neglect. Rather than neglecting what Jill might identify as an evident patient need, which the consultation's content cannot provide, articulating such recommendations or offers anyway implies a rationale of doing ‘good care’, hence a local practice of a logic of care. Besides the parallels between the clinicians’ care practices and Mol’s logic of care, an additional logic became obvious in clinicians’ responses to my question on why the enacted care in general was needed. What would happen if the patient was not met where he/she is? Why is it necessary to care for the patient during genetic counseling? Asking these questions about the taken-for-granted gave various almost shocking responses among clinicians, as various counselors implied my question was almost illogical, as in: what else they should be doing? Emma replied with the following: “*It is necessary because otherwise the patient will have a bad course which may result in them canceling it, (…) it’s logic for chickens.”* Kate articulated the potential implications of getting a gene test as the very reason and necessity for the presence of care, to create a safe space for the patient to decide within. Replying to the question of why care is necessary Jill articulated the following: *“It is necessary because it’s part of being human and feel comfortable (…) not to feel like an invisible piece.”* The consequence of not caring is unknown yet constitute various risks, risks within the practice of genetic counseling that should be avoided. These risks might not be obvious, nor potential or explicit, to external healthcare professionals, family members, or citizens. They instead appear to exist locally within the clinic of genetic counseling. Risks that logically ought to be avoided. Hence the rationale, or local logic of care, behind the deployed care practices. A rationale we might understand as a log of caring for the potential patient.

Technology and genetics in the age of telecare

“The more important care is, the worse technology becomes” (Eli’s, a doctor at the clinic, reply during his interview on what impact technology has on care)

The following chapter will focus on the clinicians’ use of telecare. Using Pols’ words ‘telecare’ is an umbrella term implying technical devices and the professional practices applied in a ‘caring at a distance’ (Pols, 2012: 12). The often-associated telecare technologies are communication tools such as webcam, telephone, electronic monitoring, email, and websites. In the age of the smartphone ‘apps’ should also be added to the umbrella term as well. I will be focusing on the use of telephone, webcam, and the app ‘Mit Forløb’ (‘My Course’) throughout this and the next section. Combined with the latter, it constitutes what I will refer to as health information and communication technology (HICT). Finally, since the care practices are apparent among all the clinic’s staff members, I will be looking into the overall use and attitudes of telecare, but mainly focused on consultations.

Telecare happens frequently in the clinic, from consultations between clinicians and patients to receptionists calling, or being called upon, by patients. Prior to patients' arrival to the clinic the only way to contact the clinic is through phone, picked up by the receptionists. Patients are always welcome to ask questions and to change their consultation to another date or to a technological platform, hence webcam or telephone. Patients have to do so actively as the default attendance is in-person. Patients wish of shifting from in-person consultation to either phone or webcam is not something which frustrates clinicians, nor changes the content of the consultation. In addition, since January 2023 the program/browser/app of 'Mit Forløb' ('My Course') has been implemented. The app consists of various animated videos which gives the user visual animated information on the whole course of genetic counseling, from the moment the patient receives a referral to the second they receive the gene test result. Various other information as well as contact information are also found within the app. However, consultations can't happen through the app. The app is accessible for patients through an individual code send in their digital referral.

Compared with in-person consultations telecare-based consultations do not differ much. The biggest difference is the most obvious: the physical absence of the patient. Still, the setup inside the consultation room is equal to the setup if the patient attended the consultation in person. The clinicians are in other words located in front of the computer, which now has a mounted a webcam on top of it. After a few clicks counselor and patient are visibly present in front of each other. The same is true for telephone consultations. Though, instead of clicking with the mouse and mounting a webcam, the clinician type in the patient's phone number and wait for the other party to pick up the call. Both telecare practices start up the same way by the clinician introducing him/herself and stating that they are the patient's contact person. However, the caring practices utilized within physical present patients were often more challenged in telecare practices. The latter led me to pursue and answering the question how do one meet the patient where he/she is, when they aren't physically present?

Common for telecare practices was the intense focus on either computer screens or telephones at hand. Eli stated the latter by emphasizing how *"(...) some senses are reduced while others are* *reinforced in a way.”*. Eli’s reinforced senses suggests the intense looking and focus on the displayed patient on the computer screen during webcam consultations, and the intense listening to the telephone’s audio. Both practices are synonymous with what Pols term ‘hyper-intense face-to-face topology’. Most often clinicians would state, if they shifted away from the camera or consultation for a few seconds, due to them taking notes by hand or turning their focus to the patient’s journal on a second screen. Clinicians’ necessity of stating so indicates the intense investment in telecare practices, that demonstrates the mutual investment in the task and consultation at hand. In continuation of Eli’s quote, while clinicians had the opportunity of drawing or utilizing pictures inside the consultation room, they would instead use their body language to demonstrate and explain how, for example, inherited genes worked. During a webcam consultation I observed how Miranda, a genetic counselor, with both arms in front of her, between her face and the computer screen, demonstrated how genes were inherited. The lacking option of drawing or utilizing pictures was stated as ‘problematic’ in the context of some patients, stressed by Amanda, another genetic counselor: *“Sometimes you can have patients where it helps to draw something for them, that is difficult to do through telecare. (...) I miss the option of displaying something visually.”* Visualization of genes as an explanation for some patients also suggest the intention of doing good care, by identifying oral explanation of the topic might not be helpful for the patient. Restricting the otherwise caring practice in physical consultations.

However, clinicians and receptionists expressed a general positive attitude towards telecare practices. Emphasizing the option as a ‘fantastic offer and alternative’, assisting, helpful, and a care relief for patients. Clinicians and receptionists were especially positive about telecare as it gave patients the option of structuring the consultation according to their needs, stressing the acknowledging frustration among patients who had to take a day of work, drive far, find parking space, unable because of kids etc., which could be avoided by telecare. Because genetic counseling is not a medical treatment, the need for physical examination is not needed, with the exception of the doctors’ practices. The importance of a physical location for counselors and patients to conduct the consultation is therefore not necessary as it can be carried out via telecare.

Even though the general attitudes towards telecare was positive, most clinicians preferred in-person consultations or a mix. The in-person preference was often articulated as being ‘in tune with the patient’, better sensing the patient, and the challenge of caring for patients through a webcam or telephone. As Eli stated in his interview: *“It is better because you can feel the patient in another way. It’s hard to articulate what precisely it is, it’s something unconsciously, nevertheless, you easier and faster tune in on them when they are present.”* What Eli finds hard to articulate might suggest a parallel to the practice of meeting the patient where he/she is, in telecare practices. The identification of patients’ needs and adjustment to those needs become challenged in the absence of the physical and visible patient. Patients explicit and/or implicit socially, emotionally, and bodily needs become blurred in the practice of telecare. Relatedly, most clinicians preferred webcam over telephone as long as no technical issues intervened. The reason was stressed as due to the ‘loss to technology’ as Eva, a genetic counselor stated: *“Again it is the aspect of not seeing them [patients] that is important regarding their body language and especially if they turn sad, then it’s just easier on video or physical consultation.”* Compared with telephone consultations webcam grants the option of a visible patient, who in other words become more personal. As has been demonstrated earlier, the visibility of the patient is important in clinicians’ approach to identifying visible and unspoken needs, thus echoing Pols’ results on webcam’s better facilitation and establishment of a ‘good caring relationship’.

Whereas in-person consultations allow the clinicians to use all their senses identifying the patient needs, webcam remove the physical dimension, while phone consultations are limited to only listening and speech. The gradual absence of clinicians’ senses of the patient’s needs therefore also risk the good and caring relation between the two parties. This draws a parallel Pols’ argument that warm care is dependent on good and warm relations. If relations, in other words, are good warm, telecare can provide warm care. ‘Hearing’ patients’ displayed needs or ‘listening’ to the unspoken need, during telephone consultations is thus a challenge in establishing a warm and caring relation between clinician and patients. Moreover, the embodied care practice of reaching out for the patient’s hand, if clinicians see it as necessary in doing good care, is not an option as Mary, another doctor, stated it: *“If I am seeing the patient turning sad over the webcam, I do not have the option of reaching out with a hand or give a napkin or to make sure they don’t leave crying.”* Whether telephone or webcam, warm care is ultimately restricted from the physical care practice. This embodied care can’t be fully replaced, no matter how long clinicians try or adjust.

Jill, a genetic counselor, would also stress the difficulty in establishing a relation with patients during telephone consultations: *“You don’t have a picture of them, (...). There’s something* *happening as well when I have telephone consultations, compared with in person, they are shorter, it becomes more like the banker and focused on facts."* Jill's words stress the removal of the skills of being kind and sweet associated with the local notion of doing good care, to be mainly focused on the second element of good care - being knowledgeable, during telephone consultations. Jill's analogy of becoming the 'cold banker' draws a parallel to Pols' notion of cold care, emphasizing the neutral and unfeeling aspects, thus a contrast to the human warm care. Jill's articulated problem of not being able to see patients during telephone consultations often resulted in clinicians lack of remembering the patients, as Kate, another counselor, described it: *"Over time I had a difficulty remembering patients. If I for example had consultations and did not take notes, I have a hard time distinguishing patients (...) I don't have a visual element to relate the consultation with.*" Even though the hyper-intense focus on listening during telephone consultations would suggest a better memory, without the visual element of patients, clinicians risk forgetting the patient and the outcome of the consultation. These implications are not a major threat to the telecare practices but demonstrate the relational and caring dynamic when patients aren't visibly present, suggesting a parallel to Eli's starting vignette of the section, the more important care is, the worse technology becomes

Implications and impacts of 'Mit Forløb' ('My Course')

"*I think the purpose [of the app] is for them [patients] to be better suited prior the consultation, but also to answer some of their questions. So, I guess it is a tool before, during, and after consultations."* (From the interview with Joan, a genetic couselor, sharing her thoughts on the purpose of 'Mit Forløb')

As stated in the latter section, the clinic has since the beginning of January 2023 implemented the app called 'Mit Forløb' ('My Course'). I will refer to this as the 'app' or 'Mit Forløb'. The content of 'Mit Forløb' is accessible via an app or through an internet browser. Because 'Mit Forløb' basically outline the whole course of genetic counseling it also demonstrates and explain the various phases of the course. From my experience of attending numerous consultations patients rarely knew the full content of their consultations. Because of latter Tracy, a genetic counselors stated how it created *"another footwork communication-wise as of getting to the actual and important content."* The actual content would in this case be about whether the patient has understood the risk information and potential implications of getting a gene test. Prior consultations' start, it was not uncommon for patients to answer clinicians that they had no idea on what the consultation was or would be about. Clinicians would then explain the content and purpose, in other words, doing Tracy's 'footwork communication'. In continuation of Tracy's statement, she added the following: *"But I am sensing that those patients who have watched the videos have gained a better understanding of what the consultation is about."* Tracy's statement draws a clear parallel to Joan's vignette of this section, suggesting that the content of the app helps patients prepare for the consultation.

The general attitude among clinicians regarding 'Mit Forløb' was positively articulated as 'fantastic', 'descriptive,' and 'preparing patients for the consultation.' Though, 'Mit Forløb' was rarely referred to or actively used in consultations between patients and clinicians. A possible reason is the app's implicit effects on consultation, informing them on the content and matter of genetic counseling. The use of the app is not a precondition for the consultation but an assisting tool for both clinicians and patients to focus on the most important matter at hand, patients' choice on a gene test. Moreover, because of the app's accessibility during the whole course, patients can also use the app to recall content from the consultation. In addition, the accessibility of the consultation's content through 'Mit Forløb' was sometimes stated as helpful for patients during consultations, as Tracy would elaborate on in her interview:

"Among patients who I can feel are having difficulty understanding the content of the consultation, I sometimes say 'otherwise go home and watch the videos, it might supplement your understanding of the content'."

Because the oral explanation of genes, combined with drawings utilized images, or body language, might not be sufficient explanations for specific patients' needs, 'Mit Forløb' offers an additional support for such patients. The option of rewatching and listening to explanations also adds to a potential better understanding. Replying to the interview question whether my patient informants had used the app, most answers were either 'no' or that they had not been told it was an option for them to use. However, one patient informant, Olivia, had been using the app prior the consultation, stating her experience in her interview: *"It was okay. The app answered some concrete question I would have asked during the conversation. (...). What happened after the consultation etc."* Olivia demonstrates the explicit intended use and purpose of the app clearly and how it prepared her by ‘answering some questions’ prior to the consultation. Due to the provided information from the app’s content, it enlightens patients on the course’s content of genes and risk as well. This feeling was also reflected in the clinicians’ positive attitude, and reflected in my fieldnote from attending a consultation and chatting with Joan:

“Compared to other consultations this one is very short, approximately 20 min. (...). The patient has watched the videos prior the consultations. We discuss that the videos make the patients more enlightened to counsel when they have watched the videos.”

The reason for the consultation only lasting 20 minutes might be related to patients being enlightened on the consultation’s topic or highlighting Tracy’s words from another fieldnote: *“much of the content on genetics, (...) is being cut off”* focusing the consultation on the important matter of the patient’s choice, reducing the consultation time. However, Tracy also stated a fear to ask about patients’ use of the app, captured in my fieldnote: *“Tracy also stresses she sometimes feels scared asking about whether patients have watched the videos. She fears it will disrupt the relationship. Feels it is like asking if the patient has done their homework.”* Tracy’s fear of asking about the patient’s use of the app suggests a fear of appearing as an authority, which she interprets might jeopardize the caring relationship, as she might capture the patient in not being informed on the consultations content. Other clinicians did not express this fear of asking about patient’s use of the app, suggesting that Tracy’s fear is an isolated incidence. However, drawing a parallel to Tracy’s fear and the reduced consultation time, Sam, a doctor of the clinic, articulated a worried response regarding the app:

“That must be the ulterior motive behind the app, to shorten consultation, so it’s not just made to inform patients, but also to reduce the valuable time we have to council, which I don’t like. I already think we except too much of our patients.”

We may deduce a similar fear among Sam’s statement as demonstrated in Tracy’s. Though, instead of a fear based on mentioning the app, Sam’s fear is about how the app’s content might reduce the valuable counseling time. Sam’s worries may also indicate a shift from the counseling’s warm, and necessary, care practices, to a replacement of a cold technology. Even though I only seldom experienced consultations to be 20 minutes or shorter, arriving patients who had watched the videos sometimes resulted in shorter or longer consultations. Due to the purpose of genetic counseling, informing patient's on whether or not to have a gene test, and the app's content, the in-person consultation and genetic counseling seemed to me potentially replaceable with app. In other words, with the access to 'Mit Forløb' and a gene test on a nearby hospital seemed like a plausible replacement for in-person consultations and actual genetic counseling. Following this impression, I asked the clinicians if 'Mit Forløb', or other technologies, could replace genetic counseling. Mia, another genetic counselor, perceived 'Mit Forløb' as a "*one-size fits all"* stressing that the app might not be applicable in all contexts of genetic counseling due to various counseling styles, patient needs, families, etc. While Mol's and Pols' notions of 'good care and caring relationships' implies the identification and care adjustments to patients' needs, 'Mit Forløb' represents, on contrary, a general care focused on visually informing patients on the content of genetic counseling. Doing 'good care' is then very depended on the human interaction, implying what Jenny, a patient informant, stated in her interview: *"That dimension of human contact, that is one I think we should be aware of not replacing a computer with always."* Based on Jenny's words care is deeply embedded in humans and therefore perceived as a human trait. The utilization of 'Mit Forløb' and Jenny's perception is therefore closely linked with Pols' central argument: "*that no individuals can feel cared for without being the receiving end of a real concern and affection*" (Pols, 2012: 26).

Chapter 6 – Conclusion

Recent decades have witnessed increased innovation in biomedical technology and practices. Technological innovations now make it possible to detect inherited genetic risks of disease, ethnic origin, and sequencing genes. The increased innovation has generated a shift in the practice from treatment to prevention, symbolizing the shift to a 'new genetics' (Finkler, 2001). In response to the shift in the biomedical practices, social scientists have articulated various concerns of how the new practices are utilized in healthcare (Novas, 2000; McLean, 2013, Timmermans, 2010). Because genetic testing is not limited solely to testing individuals' conditions, but include the whole family unit, the choices of being tested thus need to be considered carefully. Detection of a genetic risk may also generate misinterpretations and misconceptions of what it means to be at-risk of a genetic inherited disease. Because of limited ethnographic material, this thesis yields an insight into the complex practice of genetic counseling besides my main focus on care.

Conducting my fieldwork resulted in three interconnected themes which emerged along my focus on care. First, I noticed a managed absence of the symbolic associations of disease, creating a sense and theme of what I have termed ‘clinic of non-sickness.’ The clinic of ‘non-sickness’ is closely linked with the absence of white cloaks, relocation of the clinic itself from the main hospital building, and clinical perceptions of ‘healthy patients’. Utilizing Novas’ and Rose’s (2000) notion of ‘genetically at-risk individual’ and Taussig’s et al. (2013) ‘anthropology of potentiality’, I have demonstrated how the management of the clinic of non-sickness, disentangle the clinic with disease, with the implicit purpose of manipulating and reducing patients feeling of being sick and at-risk. This focus on patients’ perceptions of their risk also reveals a caring concern for patients’ emotional wellbeing: a caring practice. Patients experience of the clinic as a space non-sickness was not explicitly articulated but patient emphasis was instead put on the feeling of being ‘safe’, which I interpret as a successful management of patient’s perception of genetic risk and disease.

Second, examining the care practices of genetic counseling had me focused on clinicians who all enacted a practice focused on patients ‘needs.’ The practice of doing so was articulated as ‘meeting the patient where he/she is.’ This is not to be misinterpreted with a geographical location, rather it is a practice of measuring and evaluating the individual patient’s needs, analyzing their bodily, social, and emotional needs, acting accordingly, constituting a social caring practice. In addition, rather than describing clinicians being competent, nursing, or hardworking, my patient informants perceived counselors to be ‘sweet.’ However, patients’ description of clinicians being ‘sweet’ implies the acknowledgement of patient’s rationale of attending genetic counseling, indicating the perception of sweet as parallel with a perception of feeling cared for. Mobilizing specific emotional expressions and skills of being sweet and competent may also act as vessels for clinicians to communicate difficult and sensitive information, hence constituting a caring attentiveness towards patients. Utilizing Mol’s logic of care and Pols’ notion of a ‘good caring relationship’ the practice of meeting the patient where he/she is’ implies a local perceived practice of doing ‘good care’, hence, caring practice. This was further emphasized as I encountered articulations of it being illogical not to care for the patient, constituting a local perception of caring for the potential patient and a local logic of care. This logic is motivated by clinicians locally perceived fears of the potential dangers of not caring for the decision maker, stressing the notion of meeting the patient where he/she is as locally and logically situated.

Thirdly, while telecare has been implemented in healthcare so has it been in genetic counseling. Using Pols' work on telecare, one way telecare impacted the caring practices was by disrupting the ability to read, analyze, and measure patients' 'unspoken' needs. This was especially evident in telephone consultations, challenging the caring practice of meeting the patient where he/she is, thus posing a challenge to what is locally conceived of as 'good care.' The visual aspect of webcam on the other hand allowed for the latter, indicating the visual dimension as critical in identifying patient' needs. In addition, my fieldwork and interviews have shown how the implementation of the app 'Mit Forløb' ('My Course') a health information and communication technology, makes patients more enlightened on the content of consultations and can reduce consultation time. I have also shown how the app 'cuts off' formal content during consultations, shifting the focus to individuals' needs and the caring task. However, patients use of the app was rare, only one informant had used the app prior the consultation. Additionally, clinicians' attitudes towards the app showed an overall positive attitude. Yet, I caught one incident of fearing to ask patients about their use of the app, a fear based on the feeling that it might disrupt the caring and trusting relationship between the genetic counselor and patient. Suggesting a need for a careful implementation of health and communication technology in the practice of genetic counseling.

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