Take Care!
The Ideal Patient and Self-Governing

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Abstract

In this thesis, a phenomenological approach is taken as the purpose is to discuss how the healthcare experiences of Swedish patients with chronic illness are affected by political state reforms and governing technologies. The thesis compares the discourse of Swedish healthcare policy with the discourse of healthcare in practice. Swedish healthcare has gone through major changes during the past decades, which have affected the state-to-patient relationship. This shift involved a transfer of responsibility from the state to its citizens, enabled through patient empowerment. In this change, a new ideal patient-role emerged, which is the patient as an informed and active consumer. What this thesis shows is the existence of a discrepancy between the ideal patient-role in governmental writing and the same ideal patient-role in the reality of the healthcare system. The ethnography consists of a literature study of healthcare policy documents and interviews with ten informants about their experiences of healthcare, in connection with the chronic diseases that affected their lives. The aim has been to examine the governing qualities of healthcare policy and practice, implementing Foucault’s theory of governmentality and technologies of the self.

Keywords: Governing technologies, Swedish healthcare, patient-physician-relationship, morality, neoliberalism, empowerment, chronic illness, self-care, consumer patient, healthcare policy, the Patient Act, public health.
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1. Introduction

Research Question and Focus

With patients’ experiences of healthcare and self-care in mind I argue that patients’ experiences can be viewed as examples of how individual actions and values are part of and perpetuate social and moral norms as tools of self-governing. If one understands culture as plastic and ever-changing, Swedish culture has, along the economic and political development that came in the shift from Keynesianism to neoliberalism gone through a transformation that overarches all social institutions. Neoliberal values of individualism and freedom of choice spurred a changed in the state-to-citizen relationship thus it transformed from being a welfare-state paternalism into becoming an emancipated individualism. Effectively this would bring forth the political interest in and encouragement of patient autonomy and place it in an ever more central position of the Swedish healthcare discourse. In my thesis, I present examples of how contemporary expression of this transformation can be witnessed in the actions and experiences of patients as well as in the language of governmental policy writing. By focusing on the art of governing or governing technologies (Foucault 1988, 1991; Foucault & Senellart 2008) and by examining the cause and effect between policy documents and the subjects being regulated by the documents (patients in their lived reality) I draw attention to what is attempted and what is accomplished through governmentality (McGee 2009: 479). From this perspective, it makes sense to perceive of social organisation as being created in a kind of moral feed-back loop; as the concoction of an overarching social morality and the actions (by patients and the government) enacting this moral. Since the focus of this thesis has been to discuss the discrepancy between what is constituted in law and policy and what is experienced by patients in healthcare practice I have chosen to dedicate this thesis to the inquiry of the moral universe of patients and the healthcare system.

My ethnography consists of two parts. One consists of face-to-face interviews and interactions with informants, conducted during the spring of 2017, in which I take a phenomenological approach to the issue. The other part contains a literature study of governmental policy documents such as bills, acts and political reports. Since this thesis has a strong focus on the patient-perspective I pose these question:

- What are the effects of governing technologies on patients’ healthcare experiences?
- How do patients react to the role of being a knowledgeable, engaged and empowered patient?
Key Concepts

Illness, Sickness and Disease

I have chosen to use Bjørn Hofmann (2016) three-part definition of malady to distinguish between different perspective of malady. Disease, illness and sickness are definitions of malady seen from different contexts. Disease is used in the field of medicine and refers to events and entities effecting the body and or the mind of a person. Illness is referring to the subjective mental and bodily experiences of the inflicted, meaning emotions and feelings, such as anger, anxiety, mania, pain, arousal, euphoria. And as stated by Hofmann “Sickness is a determination of the social status of the person being sick” (2016: 18). Hence, sickness refers to malady on a social level, constructed through social interactions and expressed through norms, morality, social roles, social positions, stigmas, laws and policies.

Swedish Healthcare and Self-Care

For chronic diseases and disorders, the larger part of Swedish patients’ treatment is done by patients themselves in their own home and everyday life, so called self-care. A smaller part of treatment is carried out as inpatient and/or outpatient healthcare in the setting of a hospital or outpatient clinic under the supervision of healthcare providers. In the Hälso- och sjukvårds lag (Health and Medical Service Act) (SFS 2017:30) healthcare is defined as “actions to medically prevent, investigate and treat disease and injuries; patient transports and; care of the diseased”¹ (SFS 2017:30, 2 chapter, 1 §). Self-care is defined as any healthcare action assessed by a legitimised healthcare-provider to be adequate for patient to manage on their own. Moreover, healthcare comprises actions deemed as requiring the presence or supervision of healthcare educated personnel for its execution (SOSFS 2009:6, 2 chapter, 1 §). Hence, from a legal and medical perspective, self-care cannot be equated to healthcare (Socialstyrelsen 2013; SOSFS 2009:6).

Ethics

Since my material contains sensitive personal data, data on personal health falls under this category, I follow the General Data Protection Regulation (EU) 2016/697. According to the regulation it is forbidden to store and process information concerning a person’s health unless the concerned part has clearly given consent for the management of such data for a specific

¹ Throughout the thesis, all quotes from sources originally written in Swedish has been translated by the author.
purpose (EU 2016/697 chapter 2 article 9). To make sure that the data is managed correctly I have used a written informed consent form containing information about the conditions for the study, such as: the purpose of the study; the informant’s rights during the project; procedures concerning the management of information during and after publishing. Due to the restrictions of the General Data Protection Regulation the informants are anonymized upon any publication. Informants rights was clearly stated: their participations were completely voluntary; they had the full right to decline from answering any questions; they had the full right to leave the project whenever they wished to do so. The following was also stated: the study was done in collaboration with the research and consultant company Kairos Future AB; all data produced during the study is in its complete form only available to the responsible researcher (Hanna Enbuske); project manager at Kairos Future has access to anonymized and edited material.²

**Empirics**

As I wanted to connect the processes of creating and practising norms and morality in two relating social contexts, that of healthcare policy and that of experienced healthcare practices, I found it suitable to adapt a multi-sited approach to ethnography and applied the method of following. This is a method of researching “the circulation of cultural meanings, objects, and identities in diffused time-space” (Marcus 1995: 96). Described by George E. Marcus as a strategy for mapping the routes of the chosen ethnographic subject of study it is a mobile ethnography leaping from context to context. In my fieldwork, I followed many things. I followed the informant’s stories of healthcare’s actions, I followed informant’s reactions, I followed emotions, norms, ideals and morality and I followed the language of policy. Primarily I wanted to follow all these things in the order from the experience of my informants and trace them backwards to various sources of policy writing. I wanted to understand what might have caused the informants stories to unfold as they did.

As a Swede born in Stockholm having lived many of my years in the region one can in a way say I did my anthropology at home. But since this fieldwork was focused more on a cultural space than a physical place I can also claim I was a not at all a part of the local. I have

² I have been applying the AAA code of ethics throughout the entirety of the research process from planning to publication. Due to my anthropological training I am much aware of the ethical concerns a study in this discipline requires. This awareness prompted me to extend and affirm the AAA code of ethics with the application of the data protection law (GDPR). On some issues, the AAA code of ethics overlap GDPR, such as: the regulation of collection use and storage of personal information; and the protection of informants' integrity and participation. Transparency on research purpose and third party’s involvement and use of data was provided through a written consent form handed to all informants.
myself been lucky to keep much of my health intact. I do not (that I know of) have anything that can resemble a chronic disease or illness and I have few close family or friends with these experiences. This was hence for me a new area of knowledge that my informants kindly shared with me. As for the study of policy. Besides my layman knowledge of the professional work of politics and policy writing this was the first time that I engaged in this subject on a deeper level and from the perspective of an anthropological researcher.

**Literature Study of Policy Documents**

The literature study started at the same time as the fieldwork and has been ongoing all through the writing process. More intensely from the summer of 2018. The aim with the literature study was to analyse the discourse of governmental documents to see how moral values and political ideals concerning citizens are distributed and shared through publications. My focus of analysis is *Patientlagen* (the Patient Act) (SFS 2014:821) and two governmental bills proceeding the Patient Act, *Patientlag* (Patient Act) (Socialdepartementet 2013) and *En förnyad folkhälsopolitik* (A Renewed Public Health Politics) (Socialdepartementet 2007). Other sources frequently used are various state public investigation reports authored by *Socialdepartementet* (Ministry of Health and Social Affairs).

**Interactions with Informants**

I choose to contact people with chronic diseases and disorders because of the significant responsibility that these patients take regarding their healthcare. Considering that chronic diseases are mostly treated through self-care, patient responsibility over healthcare is often seen as the obvious and only treatment option. I saw this as an interesting focal point for a fieldwork, to see how the individual experience of patients connected with the workings of an overarching social system. In total I met with ten people with one or more chronic illnesses such as diabetes type 1 and 2, kidney-failure, chronic inflammations and IBS. I met with them on approximately twenty occasions in total. I also met with and interviewed two diabetics nurses, and during participant observation, I encountered a physician and two dieticians. I choose not to include any data gathered from the encounters with care-providers because the amount of data gathered was too small to provide any sufficient analysis. I reasoned that a pure patient perspective would offer a more conclusive picture. Most of the informants participating in the study were women. Out of the eleven informants two of them where men. When it comes to age, the informants where spread evenly from their twenties to their
seventies. I explicitly mentioned in my initial contact with potential informants that I wanted to speak to people preferably in the counties of Uppland and Södermanland. In other words, the meetings with the informants had to be done in the proximity to Stockholm where I lived during fieldwork.

To find my informants I went online to various social media forums specific to chronic diseases and posted ads, saying that I searched for participants to my study. As I searched for informants I let the interest of the participants be the main factor for selection. This way of finding and selecting informants always poses the risk or chance of meeting a rather selective/specific group. Posting an ad on social media asking people to contact me in case of interest would likely attract people who are generally interested in sharing their stories. Which is what I experienced; some but not all off my informants where actively engaged in their own community and social network and wanted to share their story with me to contribute to the betterment of others in their situation. The flaw with this strategy of finding informants is narrowing the target group for the study. For example, engaging with people who do not use or have access to social media and/or internet or that are not the outreaching kind might have given a different picture. Other choices that probably influenced the composition of my informant group was the fact that the ad was written in Swedish.

In semi-structured interviews, where I used a list of topics to discuss during the interviews (Bernard 2011:209), the informants told me about their experiences of healthcare and self-managed home-care. I tried to keep a rather casual conversational tone to the interviews. To learn as much as possible about their experience of having a disease and being in contact with healthcare, after some small-talk and a formal introduction to the study, I always opened the interviews by asking my informant to tell me their “healthcare journey” as I called it. Without me leading them on too much, I wanted them to tell me about their experiences from their initial contact with healthcare when the disease/illness was first discovered and up to the moment of our interview. The larger part of the interviews was done in public places such as cafés, restaurants and libraries. In general, I met each informant on one occasion and each interview lasted between one-and-a-half hour to three hours but some of them I met with on several occasions. On a few occasions, I did participant observation as my informants met with their physicians. The times when the interviews were done in the informant’s home the interviews became more informal and we ended up socializing or “hanging out”.

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Footnote: All interviews were conducted in Swedish. Quotes from interviews has been translated by the author.
Theory: Governing Technologies

To understand the actions, experiences and attitudes of present day Swedish patients and to gain a more nuanced understanding of the logic of patient-empowerment I have chosen to apply to this thesis the historian Michel Foucault’s discussion and analyses of the development of western philosophy, specifically concerning the historical origins of what he named as *governmentality* and *technologies of governing* (Foucault 1988, 1991; Foucault & Senellart, 2008). Academics such as sociologist, Nikolas Rose (1999) and Robert Crawford (2006) have later developed Foucault’s theories by discussing the development and practice of specific governing technologies applied in neoliberal politics in the last decades of the 20th century and up till today. Furthermore, to analyse the connection between empowerment and neoliberalism I will draw from theories on market and technological development such as New Public Management and marketization (Lupton 1997; Nordgren 2008; Bodén 2016).

Rose develops in his book Power of Freedom (1999) a good discussion on the technology to govern trough morality, how subjects are stirred to concern themselves with the betterment of themselves. In the era of neoliberal governing with its emphasis on individual freedom, choice and empowerment Rose pinpoints a dimension of the technology of self-governing that make individual citizens morally obliged to care for the community. He names this dimension of governing, *ethopolitics* to points to the ethical communal aspect of self-governing. Crawford developed the concept *healthism* to discuss another aspect of Foucault’s *technology of the self* (1998). Healthism is a form of self-surveillance and self-refoming through the practice and concern for one’s own health and wellbeing. A healthy and abled citizen equals a morally good citizen. The final of my main theoretical sources is Barbara Cruikshank’s (1999) critique of the concepts of empowerment in whish Cruikshank considers the discourse of empowerment to be yet another tool of neoliberal governing to create autonomous subjects in order to transfer the responsibilities of nation states to its citizens.

Governmentality

Structures of power and politics and the organization of modern nation states has been the focal point of many of Foucault’s discussions. The concept of governmentality developed with a lecture series in 1978-1979 at Collège de France and spurred from his discussion on *biopower*, the governing of bodies, to address a dimension of ruling that exceed the physical bodies as objects and instead concerns the actions and conduct of said bodies (Foucault & Senellart 2008). The concept one can be use when speaking of the social structures that guide
the values, thoughts, behaviours and actions of groups and individuals. In other words, when one wants to address the regulation of social conduct. Governmentality thus refers to the way in which power is exercised over people, not through coercion but through “the ‘management of possibilities’ and the ability to ‘structure the (possible) actions of others’” (Foucault 2003: 138 in McKee 2009: 471). The technology of governing is easiest understood as a cluster of agents and actions working simultaneously and intertwined to regulate and influence the way subjects live their life (Li 2007: 276). The characteristics of governmentality is that it does not exist any single static power that controls the governed (citizen). The people subjected to governing are as active agents in this shaping of conduct as any political reform, market-force or social institution. Self-governing therefore becomes a key element of governmentality (Foucault 1988).

To provide a philosophical historical context to technologies of governing I will dedicate a moment to contemplate on its origins in the history of western philosophy. In a seminar series in 1982 named “Technologies of the Self” (Foucault 1988: 18) Foucault traverses back in history to Plato in ancient Greco-Roman culture and later Christianity to trace the lineage of what later could be seen in Rose’s ethopolitics (1999) and Crawford’s healthism (2006) to be technologies of self-governing. To make sense of his findings in this hermeneutic investigation of thought he establishes the concept technology of the self. We can through Foucault’s analysis of Plato’s Apology 29, where Plato writes about Socrates speaking before his judges, find grounds for the individual’s moral obligations towards the community. Socrates expressed in his speech the benefits of teaching citizen in “self-care” epimeleia heatou. “[I]n teaching people to occupy themselves with themselves, he teaches them to occupy themselves with the city” (Foucault 1988: 20). What Socrates encourage citizen to engage in is one of the main principals of the cities in Ancient Greco Roman culture. Namely the principle concerning the art of life and personal conduct, epimelsthai sauto, which can be translated as “the concern with self” or to “take care of yourself”, which meant to occupy yourself with “wisdom, truth and the perfection of the soul” (1988: 19, 20). When discussing Plato’s dialogue about Alcibiades Foucault finds interesting implementations to the concern with oneself that furthers the argument of the principle acting as a governing technology: 1) the principle applied universally to all areas of life and; 2) it implied an ongoing process of self-development from youth to death and it so became a lifestyle. Interestingly, Foucault points out that this ongoing process of self-care also suggests that “[p]ermanent medical care is one of the central features of the care of the self.” And so, “one must become the doctor of
oneself” (1988: 31). This last point I find very interesting since it provides a historical insight to the concept of healthism and today's practice of self-care.

By examining early Christianity, Foucault saw how the practice of caring for yourself had a slightly different motivation compared to the practice in Greco-Roman culture. In the later, self-care was motivated by the impact it had on the city, how citizens could contribute to the wellbeing of the city. In Christianity, it has a different focus. Working on the mental and bodily self is done to enable the salvation of the soul. This effort is motivated by an external source, God. The will of God becomes that who steers the moral compass and complete surrender of control over the own behaviour and personal will becomes the moral practice (1988: 44-49).

Much like Foucault, Max Weber draws in *The Protestant Ethic and the Spirit of Capitalism*, Weber's most famous work from 1904, the connections between capitalism and Protestant ethics. Weber means that the same ethics that one finds in the individual’s relationship to God, to take personal responsibility and to appropriate a strict ascetic work ethic to achieve spiritual salvation, one can find to be the foundation upon which capitalism evolved. To understand capitalism, Weber took from Protestant ethics the personal responsibility and moral duty to work for the betterment of the self and in extension the individual’s health. Consequently, since it is through the individual struggle, not through the church or healthcare that salvation or healing can be attained, not taking personal responsibility for one’s own faith and to lose faith in the personal ability to heal, appears here as signs of moral decay. To fall from the grace of God (Weber 1904).

**Ethopolitics**

To understand the government’s enthusiasm for patient autonomy and empowerment and to understand the historical origins of the prominent position that individualism has taken in present Swedish society, it is useful to take a moment to contemplate on Rose’s (2000) argument that, society at the turn of this century entered a new era of political ideas. To demark this turn he founded the expression ethopolitics, which is a concept that speaks of the moral politics that holds the individual, as an autonomous being, personally liable to work for the betterment of the community. The individual’s obligations towards the community are central to this concept, as well is the feeling of belonging to said community (Rose 2000: 1396):
Foucault, of course, identified the rise of disciplinary power, focusing on maximizing the utility and docility of individuals, and biopower, focusing on maximizing the health and welfare of the population. If discipline individualizes and normalizes and biopower aggregates and socializes, ethopower works through the values, beliefs, and sentiments thought to underpin the techniques of responsible self-government and the management of one’s obligations to others. In ethopolitics, life itself, in its everyday manifestation, is the object of adjudication. (Rose 2000: 1399)

According to Rose, a revitalized political visualization called third way politics emerged in the late 1990s. Third way politics has its origins in the political philosophical ideas at the end of the 20th century when it rose to popularity as an alternative to the polar-opposites; liberal individualism and; socialist collectivism. As a wager between the two ends of the political pole it was believed to embody the best of the opposing political worlds. Tony Blair was the one to invigorate this idea in his political rhetoric in 1998. We can see that his version of the third way was similar to that of the past century with only a small but crucial “addition of a certain therapeutic individualism (the language of self-realization)” (Rose 2000: 1397). Reading Blair’s take on third way politics we can understand this political strategy as being guided by a set of values. Unlike the political reforms like those of Keynesianism and neoliberalism, essential to third way politics is “a just society which maximizes the freedom and potential of all our people […] equal worth, opportunity for all, responsibility and community” (Blair 1998 in Rose 2000: 1397). The last pair of values identifies the relation, or “contract” to cite Rose, between the governing state and the governed citizen. In which the citizen to be worthy of the state-provided resources that enables a “good life” must contribute to a resilient community by “exercising active responsible citizenship” (Rose 2000: 1398).

Unlike other ideas of the 20’th century on what it is to be human, like the perfectly rational homo economicus, humans are in ethopolitics considered first and foremost to be ethical beings. Much like in classical neoliberalism personal autonomy is cherished as a citizen’s right. This however, do not implying “that individuals live their lives as atomized isolates” (ibid: 1398). With the addition of the ethical aspect of citizenship, citizens are in ethopolitics prompted to value the bond to the community

Chantal Mouffe deliberates on the problematics of the moralization of political life. She means that the introduction of ethics into politics (which according to her is the effect of neoliberal ideas) can have the dangerous effect of transforming politics into a fight between good versus evil. From politics being an agonistic relationship between adversaries that respect their difference in opinion and occupy the same political space with ethics it turns into an antagonistic battle where enemies, unable to share any common ground (Mouffe 2005: 5, 20). According to Rose’s theory on ethopolitics, the stress on individual moral responsibility
in Blair’s neoliberal New Labour politics, took what used to be the agonistic relationship between political left-right ideologies and turned it into a moral issue of right and wrong.

Rose concludes that through New Public Management reforms, the state outsourced social services. Consequently, this brought the effect of placing more responsibilities on citizen and lessening the benefits from society. Rose argues that the high focus on morality and communal contributions addressed in this context creates inexorable work ethics that is treating all individuals equally under the law of morality, regardless of social context and/or abilities (Rose 2000: 1406, 1407). The values informing this political idea are closely connected to other tools of governing such as healthism (Crawford 2006).

Healthism

Ethopolitics impelled a moral duty to concern oneself with the well-being of the collective. What correlates with the individual’s moral duty towards the collective is how personal health is made into a public concern. With this moral logic, the individual’s ability or inability to manage the own health is judged in the same way as, for example, how unemployed people and people on benefits are being shamed as they are seen as an economic burden to society. With the risk of falling ill and hence require state care and support individual health and wellbeing has turned into a public affair. Robert Crawford spoke of this tendency to estimate others behaviour and correct the own conduct to meet the social norms of well-ness and economic contribution to society as a “health-valuing culture”. Which he means has become a benchmark characteristic for modern identity creation. “Through health, the modern self demonstrates his or her agency, the rational capacity to re-make self and world” (2006: 402). With the first articulation of the correlation between lifestyle induced illnesses and their costly effect on society around two decades ago, this perspective has grown to hegemonic proportions. In Sweden, the growth of this kind of “health-valuing culture” or healthism to quote Crawford has been promoted by health political directives such as the bill on Mål för folkhälsan (Goals for Public Health) (Socialdepartementet 2002). With ethopolitics being a form of governing technology, personal health became the concept through which we would sift all problems in society in hope that they could be mended solely with efforts made on an individual level. In this ideology, the individual become the core agent of societies (health) problems. Further, when health crystalized as an individualized matter and entered the public discourse, as citizens were expected to make the right choices to prevent health risk-factors, health became increasingly treated as a commodity. Consequently, the commodification of
health created a shift in focus of corporate interests. As citizens increasingly related to health as a matter of individual responsibility and self-realization and took power in their own hands it shifted the focus of corporate interests towards the private consumer market, instead of as they had previously, trying to influence “the grounds for health regulations” (Crawford 2006: 408). Which they up till now believed to have the most power over the market that commodified health (ibid: 408).

**Thesis Disposition**

The thesis contains of six chapters. Chapter 1 provide information on research purpose and context, and methods used when collecting empirical data. The ethnographic chapters are ordered according to different perspectives. Chapter 2 is the first ethnographic chapter and it is based on material from literature studies of policy documents. The analytical focus of this chapter is the Swedish government’s values and ideals that is given voice through policy documents. At the same time this chapter provides a historical background to clarify the context. In chapter 3 I discuss the phenomenological perspective of the informants (patients). This chapter is dedicated to the patients experience of disease and how this affects their identity as patients and citizens. The chapter analyses the social norms and morals connected to the conditions of their sickness. Chapter 4 and 5 elaborate on patients’ experiences of relating to the governments ideal patient-role of being an informed and active consumer-patient. The chapters discuss the practical, moral and governmental consequences for patients when this ideal is applied in the practise of the Healthcare system. What has been revealed is the existence of a discrepancy between the ideal patient-role in policy writing and the same ideal patient-role in the reality of the healthcare system. Chapter 4 is focused on the experiences of informants who succeed at the ideal patient-role and chapter 5 presents the stories of informants who do not live up the requirements of the ideal patient role. Chapter 6 provides us with a conclusion and final discussion on the findings of the thesis.
2. From Paternalism to Individual Autonomy

In this chapter I will present an historical context to the central role that personal autonomy has been given in healthcare today. More specifically, how historical and current healthcare political directives and reforms presently affect patients’ experience of illness, self-care and provided healthcare. Through ethnographic research on state documents, prominently Patientlagen (the Patient Act) (SFS 2014:821) in correlation with theory on governmentality (Foucault 1988; Foucault & Senellart 2008) and the mapping of governing technologies, such as healthism (Crawford 2006) and ethopolitics (Rose 1999), I have noticed a shift in the relationship between healthcare-providers (as state representative) and patients (as citizen). What the state, through law and political directives promote as an ideal patient role is not consistent with the roles that patients themselves take as well as the roles addressed to them by healthcare policy and the healthcare system. I have traced this alteration of roles to a progressive shift in responsibility over citizens’ health from state to individual. An expression of this change can be seen in the encouragement of patient’s participation in and responsibility over their own healthcare. More on how informants perceive of this role is presented in chapter three, four and five. Scholars has traced this shift to the advent of neoliberalism in political, economic and social life around the 1980s (Foucault 1991; Rose 1999; Clarke 2005; Crawford 2006). With neoliberalism as my backdrop I will backtrack the origins of this increased individualization and patient empowerment in present day Swedish healthcare.

Historical development of Swedish Healthcare and Politics

The focus of Swedish politics has for most of the twentieth century been to build a well-functioning welfare-state. This started in the 1930s with a move away from a class and poverty riven society and the creation of the social reform-project Folkhemmet. A project which later came to stand for the large Swedish housing and social reform that panned out in the following 1930s to 1950s. This socioeconomic project, internationally known as the Swedish model, was largely based on Keynesianism and followed plan economic principles. Due to a growing critique of Keynesian ideals and the socio-political reform-project Folkhemmet in the 1970s, Swedish society experienced a transformation of social ideals from the belief in Fordist rationality and universal solutions to a believe if the solving of social problems through individual emancipation and citizen responsibility. The shift, that entailed a
change in the relationship between state and citizen did not only happen in Scandinavia, a wave of *responsibilization* (Rose 1999) drifted thought most westernized societies. Responsibilization is a term used by Rose to address the effects of the governing technology of *ethopolitics*. He used it to address the neoliberal action of shifting responsibility from state to citizen, increasing the responsibility of citizens and lessening the responsibility of the state. In several areas of society especially social services and social life citizens where encourage (through education and empowerment) to be more engaged, practically involved and take more responsibility for tasks that previously was handled by the state (Rose 1999: 139, 140; Bodén 2016). Anthropologist Annette Nyquist (2008, 2015) has analysed how this responsibilization was manifested through a reformation of the Swedish pension system that began in 1999. She concludes that citizens involuntarily and often with discontent had to take more economic responsibility for their future pensions. Through what they called education and information the state handed over the responsibility to the citizens. Due to this reform citizens often felt insecure and worried about their own ability to manage much of their future pensions on their own (2015: 267, 274). According to ethnologist Daniel Bodén (2016) the adaptation of new technology in the 1960s and the automatization of services provided by Swedish banks and agencies would contribute to a new chapter in social and economic politics as well as in the society. New technology was marketed as to give people more influence over their own time and existence by offering services to people on their own terms and with their convenience in mind (Bodén 2016: 53, 54, 68). This new ideal acted as a rupture with old modernistic ideals and this became the time when a large part of the world’s nations made their first move from Keynesian to neoliberal economic policies (Boden 2016: 69). The front figures in this total reshaping of political and social life was Ronald Reagan and Margaret Thatcher. Bodén marked these changes as the passing from modernity to late-modernity. Crawford (2006) contemplates further on the synergy of neoliberal tropes, such as freedom of consumer choice and individual emancipation, with the emerging “health-valuing culture”. Influenced by the increased marketization of society this was a culture that focus citizens’ attention inwards, creating an idea that social problems derived from personal doings (and failures) and could so be mended with the power of individual (consumer) agency and individual actions (Crawford 2006: 402):

In retrospect, I can also more fully appreciate how health practices of this era contributed to the ascendance of a neoliberal social order. The success of privatized, market solutions to public problems cannot be grasped without a clear understanding of how personal responsibility triumphed over a political morality premised on collective responsibility for economic and social well-being. Ideologically, the period
(roughly 1975–85) was a crucial turning point. Although other events were also at work (the first shock waves of the new economy, the beginning of a radical decline in the power of organized labour, a political realignment toward the right that exploited the politics of race, gender, sexuality, drugs, crime, taxes, family and nation), individual responsibility for health played a decisive role. (Crawford 2006: 409)

The Effect of Efficiency: The Birth of a New Patient Ideal

To clarify for the present discourse of Swedish healthcare and to understand the official focus on empowerment I find it relevant to provide some comments and elaboration on the marketization of healthcare and the role of New Public Management. Increased patient responsibility, portrayed as patient empowerment, is part of New Public Management strategies to increase efficiency within organizations. Due to the past decades’ increase of New Public Management reforms by which, social services have been the attention of privatization, the language and culture of state institution has grown increasingly similar to the language and culture of the private business market. Bodén means that in this marriage of so seemingly different organisational cultures the outcome is a change in the concept of being human. The appropriation by government institutions of the consumer concept, equated the meaning of “being human” with “being a consumer”. Because of its interchangeability, the consumer concept got in this context a legitimacy as being democratic and egalitarian. Likewise, could the consumer market “legitimize itself by proclaiming equal, and mutual trade relationships” (Bodén 2016:75). This effect can also be read in the linguistic changes of the healthcare discourse that has from the 1990s adapted a more business-like language. Lars Nordgren (2008) has researched this linguistic development through the 1990s and early 21th century. Nordgren noticed that the development brought with it a new customer patient-role that was “obliged to be active in seeking care, asking questions and collaborating in the care process” (2008: 516, 517) instead of patiently waiting to be helped.

Deborah Lupton (1997) noticed the same tendency a decade earlier when she in 1997 studied how the marketization of healthcare affected the patient-doctor relationship as it created a new “ideal-type” patient - the patient as the rational consumer. In Australia Lupton analysed the material from over sixty interviews with lay people on their thoughts on medicine and the medical profession. Taking note of the increased marketization of healthcare the material suggests that two main patient roles has emerged by which patients navigate their relationship to healthcare-providers: the role of the patients as self-reflective and active consumers; and patients as passive. The presence and practice of these roles can be viewed as an expression of both the development in governing and a marketization of healthcare
This development has been verified to still when Ida Linander et al. (2016) researched a similar topic and presented a study that looks at the procedure of “navigating and negotiation access to gender-confirming medical procedures” from care-receiver’s perspectives (2016: 9). Gender-confirming care was perceived by participant as difficult to navigate. This made them prone to take more responsibility over their care by becoming active agents in their care, and taking charge of their healthcare situation by attaining knowledge, support and medicine on their own. One of the possible reasons why patients took on this role Linander et. al, found in the healthcare-provider’s perception of the charge-taking behaviour of patients as a sign of either commitment, that expressed the urgency of patients need for care, or the maturity of patient’s decision to pursue care. By adopting this charge-taking role patients received the care they requested. Though the studies were conducted almost twenty years apart, they report on a similar context and reason for the presence of this type of patient role (Linander et al. 2016).

Revisiting Lupton and Nordgren studies, they both see the assumption of addressing patient-consumers with traits of rational, self-reflexive thinking and choosing. This is an assumption which they mean fails to recognize the dependent relationship that patients (because of their need of care) often have towards their physicians (Lupton 1997; Nordgren 2008). Grounded in the debate of the patient as customer, Nordgren concludes that the rhetoric transformation, from passive patient to active customer, that occurred in healthcare enabled by New Public Management might cause a negative impact on social equality. Besides the fact that this rhetoric enabled a shift in responsibility concerning healthcare production, from government to citizen (through among other things, patient empowerment and self-care), what Nordgren stressed is the fact that the customer-patient role presumes a subject that has the social position and agency to be active and make rational choices, as a true customer ought to. But as Nordgren concludes, something that I also have noticed in my ethnographic data, is that the customer-role is an idealistic state of being that not always matches the experienced reality of patients (Nordgren 2003, 2008).

By researching the marketization of elderly and child care in Sweden, England and Australia Brennan et al. (2012) present a critique of marketization and suggests that marketization rather than emancipating citizens, tend to erode the concept of public sphere in which services are provided by states as a right of citizenship and hence it creates inequality with respect to standard of quality and access of healthcare. They argue that in a free consumer market people with many socioeconomic recourses have easier access to service,
specifically services of greater quality, than people with less resources (Brennan et al. 2012: 388). In the same context one can debate the actuality of the individuals proclaimed agency. In a neoliberal market logic, how much agency to affect treatment and choice of medical aid do patients have in practice? On this subject Martha Szebehely (2011) conclude, in an analysis of the effect of privatization of Swedish elderly- and disability care and services, that the agency of elderly people receiving care from actors on the private market are somewhat limited. In some municipalities, when elderly people contacted their municipality to complain on their care providers, the response they got was that they were free to change care provider if they were discontent with the service or the care provider. Despite the efforts to expand elderly consumer’s agency with the option to choose care-provider Szebehely concludes that consumer choice, which is supposed to empower care recipients, can backlash on those recipients that are too weak to change care provider. Furthermore, the municipalities advice to change care provider if the elderly were unhappy instead of prompting the care provider to improve the quality of services, tell of the unbalanced agency and power dynamics between municipalities, private market and care recipient (Szebehely 2011: 248-250).

The Patient Act: How an Autonomous Subject is Promoted

First of January of 2015, Patientlagen (the Patient Act) (SFS 2014:821), took effect. The act was written with a clear focus on the patient perspective. In the first chapter, section one of the act, its purpose is clearly stated: “This act aims to strengthen and define the patient position within the healthcare institution. As well as to support patient integrity, self-determination and participation” (SFS 2014:821, 1 chapter, 1 §). Patient empowerment became a cornerstone in Swedish political discourse two decades earlier, when a change in public opinion led politicians to make patient empowerment an important political issue. This issue was not isolated to Sweden alone, the focus on patients’ rights was of concern in many parts of European politics during the later decades of the 20th century (HSU 2000, 1997: 50) and from the mid 1990s and up till today the focus of the issue has intensified. The interest and belief in citizen empowerment began in the 1970s when New public health through the 1974 Canadian Lalonde Report became a concept and an issue for politicians worldwide. The report got its reputation from its efforts to connect social determinants with health outcomes in populations. With this approach to health: lifestyle and behaviour rather than biomedicine became the key impact factors on health. Even though an awareness of the correlation between physical activity and health has existed as far back as the late 19th century with the
raise of the well-ness culture advocated by such prominent promoters of exercise as American physician activist John Henry Kellogg. However, with the reports recognition of the non-determinism of health “New public health” began to recreate the concept of health. Health was no longer a matter of faith or destiny, bad luck or bad genes, it was a matter of personal will and power (CANADA 1978; Skrabanek 1994:16; Lock & Nguyen 2010: 28, 295).

Through all the reports, bills and directives that I have examined concerning the patient’s role in healthcare dating back the last twenty-five years, the patient is placed in the centre of the discussion and political work, emphasizing the importance of individual empowerment, integrity and responsibility (Ansvarskommittén 2007: 120, 121; Patientmakturedningen 2013; Socialdepartementet 2002, 2007, 2013). In 1997, the state initiated Committee for the Financing and Organization of Healthcare (HSU 2000) published their report Patienten har rätt (the Patient’s Right) in which one could read:

As a patient, one is from the beginning in a position of psychological disadvantage. The care-provider dispose of the recourses and the medical knowledge, meanwhile the patient is in a position of dependence where her life and health is at stake. Some patients can certainly experience a relief in handing over their problems to a knowledgeable professional, but many also feel exposed and powerless in the engagement with healthcare. It is therefore a pressing matter that patient’s interests are addressed and given a satisfying protection by the state. (HSU 2000 1997: 49)

With this report the intent was to investigate how to tackle patients’ disadvantageous position related to healthcare professionals and the healthcare organization. The committee was concerned that the psychologically subordinate position of patients in relation to healthcare professionals would render patient dependant on healthcare professionals, seeing that the caregivers had the advantage of disposing over medical knowledge and recourses. Hence the power balance in the relationship would be unjust. They were further concerned that this position would make patients feel vulnerable and powerless when engaging with healthcare (HSU 2000 1997: 49,50). This motivated the committee to argue for the strengthening of patients’ position. The government’s stance in the issue was motivated by a shift of public opinion. According to opinion polls and patient surveys they found out that the public’s attitude concerning the quality and service of received healthcare was changing. The public’s trust in Swedish healthcare was failing and a critique of the quality of received healthcare had started to show through the increasing number of patient complaints. In the HSU 2000 report a new generation of patients and a new patient role emerged. One which would symbolize the changing relationship between state and citizen, from state paternalism towards emancipating individualism. The new patient role demarcated the “traditionally passive patient” by patients
being more demanding and competent, seeking information and dialog and to an increasing extent being engaged in their own healthcare process (HSU 2000 1997: 65). Grounded both in the publics discontent with the service and quality of healthcare and the general shift in public opinion the committee saw a reason to call for increased patient participation in healthcare. The argument for strengthening the patient’s position was also supported by referring to the rapid development of the healthcare sector as well as the rapid change of citizens “preferences and consumption patterns”. The picture that emerge out of this new demanding and engaging patient-role was that of a young, educated, modern, multicultural citizen with low trust in authorities. This new patient-role was perceived as clashing with the traditionally hierarchical healthcare system (HSU 2000 1997: 65, 67, 75). Ten years later in a final report from Ansvarskommittén (the Responsibility Committee) named Hållbar samhällsorganisation med utvecklingskraft (Sustainable Social Organization with Growth-Power), one could conclude that this new patient role had prevailed:

During the last ten years, the patient’s position has been strengthened in many respects. The Patient has moved from being just “a patient” (one who patiently abide) to hold a position of increased responsibility and increased possibilities/rights. (Ansvarskommittén 2007: 142)

The attitude of patients being active rather than passive that could be seen in the report in 1997 has been consistent through the years and exemplifies the changing patient role. In 2012, the same rhetoric was found in the statement of Maivor Isaksson, at the time she was the director of information at Nya Försäkringskassan (The New Social Insurance Agency). Here, in a column in the branch magazine Dagens Socialförsäkring (Today’s Social Insurance), Isaksson discusses a rather prevailing view of the citizen and insured alike:

Another reason, is that one wants to emphasize that patients, clients and insured are not some passive ‘subjects’ rather they are active people with their own responsibility and choices. The counties and the municipalities clients shall, for example, be able to choose between different kinds of care at the same time as Försäkringskassans clients shall be able to actively participate in and have certain options concerning their rehabilitation. (Isaksson in Bodén 2016: 74)

Why the Emphasis on Patient-Centred Care?

From the 1970s and thorough the following decades the agenda of patient empowerment prevailed and grew in political interest both in Sweden and globally (Lock & Nguyen 2010: 295). When the Patient Act bill (Socialdepartementet 2013) was written in 2013 the government saw that, with the present attempts to increase the internal productivity of the
healthcare system the role of patients was often treated as having a small significance to this effort. But, with the increased believes in the importance of patient empowerment, one of the purposes with the Patient Act was hence to counter-balance the general focus within healthcare development issues as centred around organizations rather than patients (2013: 36). Another reason with the act, that also related to patient empowerment, was to collect all legislations that could be of relevance for the patient to make it easier for citizens to oversee their rights and what they could expect of healthcare as a social service. A third reason, maybe the most essential, that streamed lined the patient empowerment agenda was to render the “patient as an actor instead of merely an object of care provider’s actions” (ibid: 41):

A Patient Act will probably also generate a general impact on healthcare. To strengthen the patients position is according to many studies an effective way to improve the results in healthcare. In the long run this will even lead to a more effective use of healthcare recourses. (Socialdepartementet 2013: 41)

There is an overarching focus on patient empowerment for the sake of patients' health and wellbeing. This focus is not to be taken as mere altruism. Emphasising patient empowerment and encouraging patient participation was in fact motivated by the predicted heavy economic challenges that Swedish healthcare was facing. Patient empowerment is in the Patient Act bill addressed as a tool to tackle the economic restraints of a demographic progress which concludes that the elderly population in Sweden is expected to increase with thirty percent between 2010 and 2050. Hence, in this bill patients are explicitly seen as untapped resources that the healthcare sector in the future ought to utilize to “build systems within healthcare that in an effective way use all available recourses” (Socialdepartementet 2013: 36).

Consequently, later that year the Swedish government launched a directive to investigate how the healthcare sector could use the sectors resources in more efficie

Patient-Centred Care: The Empowered Patient

As we could see by the report Patienten har rätt (The Patient’s Right) (Socialdepartementet 1997) the relationship between state and citizen were changing. There was a rupture between
the old paternalistic culture and a new culture centred around individual emancipation and extended choices (Clarke 2005). What can be interesting to mention is that the change in focus, from collective to individual, got amped-up with the economic politics of the 1980s and 1990s. A reminiscence of this change in contemporary politics we can read in a report by The Public Health Agency of Sweden in which the increased individualization is correlated to a change in values among the Swedish population:

According to the WVS [World Value Survey], to a higher degree than the populations of any of the other countries participating in the survey, the Swedish population consider the individual to be the most capable person to decide right from wrong and to forge their life (compared to more traditional values and authorities) and that space for self-realization is more important than material assets to achieve a good life. According to this way of measuring individualization, Sweden has increased the degree of individualization since the 1980s. (Folkhälsomyndigheten 2018: 80)

Another such statement we can find in the bill En Förnyad Folkhälsopolitik (A renewed public health policy) (Socialdepartementet 2007):

In the bill the government outlines a renewed public health policy. Public-health-work ought to see the individual need of integrity and freedom of choice as a foundation, and reinforce the connection between health and the individual condition. (Socialdepartementet 2007: 1)

In line with the stated “need for integrity and freedom of choice” in the quote above we can in the previous quote from the report by the Public Health Agency of Sweden find another interesting issue: “space for self-realization is more important than material assets to achieve a good life” (Folkhälsomyndigheten 2007: 80). The correlation between these statements follows the idea that patient empowerment, accompanied by an increase of choices and autonomy, is positive for both public and individual health and for efficient use of recourses within healthcare.

A central theme to patient empowerment is patient-centred care. In recent years patient-centred care has gained in support and popularity within the healthcare discourse as several scientific studies supporting the positive effects of a patient-centred care on patient treatment and well-being, has been done, see (Curtin et al 2004; Olsson et al 2009; Avgar et al 2011; Docteur & Coulter 2012). It is explained as an approach to healthcare production that places patients in a central position and sees patients as: active participants in healthcare; holder of valuable knowledge; and as experts on their own illness-experiences and life situation. This can be read in the bill En förnyad Folkhälsopolitik (A Renewed Public Health policy):

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4 Authors emphasis.
To promote health in healthcare is, to a large extent, to view the individual patient from a holistic perspective and to support him or her to, as far as possible by themselves, take charge over their situations. There is a particularly high potential within primary care, to support the patient’s own ability to take responsibility for their own health situation as early as possible. (Socialdepartementet 2007: 74)

With this approach, an aim was to level the power balance between patient and care-provider. To see patients and care-provider as partners in a relationship opposite to the traditional paternalistic positioning of the patient as passive recipient of healthcare provided by a professional. Reviewing government bills and state ordered reports I have found that this is a current and generally held view in healthcare policy. Hence, I draw the conclusion that the perceived positive effect of patient-centred care is a strong reason behind the commissioning of the Patient Act. To provide further example of this it is in the Patient Act bill referred to the final report of *Patientmaktsutredningen* (the Patient Empowerment Inquiry) (2013). A report which concludes the following. In the current decentralized healthcare system patients run the risk of becoming passive objects with a diagnosis observing what is being done to them instead of actively engaging in their healthcare. Thus, to fight this effect, the authors of the Patient Act bill calls for a patient-centred care that sees the patient as a source of knowledge and a partner in healthcare (Socialdepartementet 2013: 37; Patientmaktsutredningen 2013: 76):

It seems that patients’ participation in planning, execution and follow-up [of treatment] increase both quality as well as efficiency within healthcare. Research shows that patients’ self-esteem and willingness to take responsibility are important factors for the outcome of treatment. Therefore, the patient ought to be viewed as a partner in relation with the care provider and should be given an active role in decisions concerning their own healthcare. Studies also show that support for patient-participation and self-care can radically decrease the numbers of doctor- and inpatient care-visits, decrease the number of sick-leave-days and increase the patient’s quality of life and self-esteem. (Socialdepartementet 2013: 36)

Patientmaktsutredningen (2013) concludes that encouraging autonomy and responsibility can have beneficial outcomes for both patient’s health and the healthcare system at large. With the increased patient-participation also comes an increased demand on patients to not just hold the knowledge needed to be able to actively participate in treatment and healthcare decisions but to have enough self-esteem and willingness to take responsibility (Nordgren 2008: 517). These factors are considered crucial for the outcome of healthcare (Patientmaktsutredningen 2013: 76). Interestingly, Patientmaktsutredningen also comment on the risk of pushing too much for the autonomy of patients. They mean that transferring too much responsibility of treatment from healthcare to patients, making laymen patients take responsibility for
treatment that they do not have the competence for, runs the risk of jeopardizing patients’ safety. The report concludes that this should be in mind when authoring the Patient Act (Patientmaktsutredningen 2013).

So, how did it get to this state where patient empowerment would attain such a central role in healthcare politics? I have noticed that the linguistics practiced in the examined policy documents are clearly influenced by the New Public Management discourse and a neoliberal rhetoric. Nordgren means that the rhetoric of patients being teamed up with healthcare-providers as co-creators of healthcare through knowledge production, is the effect of the linguistic change within the healthcare discourse that occurred with the onset of market and service-management. Through patient-centred care, patients are being reinvented. From previously just having the role as the hosts of health problems to be solved by healthcare alone patients are now seen as the recourses with which these problems should be solved. A change in rhetoric enabled for the adaptation of the idea of patients as value-creating customers. With this new labelling of the patient, assumptions about the patient’s performance is altered as well. Patients move, from being receiving patients to becoming active and (knowledge-)producing customers (Nordgren 2003, 2008).

As individuals make up the society, individual agency become a question of public health. In the bill 
*En förnyad folkhälsopolitik* (A Renewed Public Health Policy) (Socialdepartementet 2007) the government presented a revision of eleven goal-areas for public health policy, first suggested in the bill *Mål för folkhälsan* (Goals for public health) (Socialdepartementet 2002). In the later bill, in the first goal-area named *Participation and Influence in Society*, the government presents actions on how to enable this goal-area. The government states that there is a correlation between individuals’ health status and their agency, in other words their power to influence their own lifeworld and the society at large:

> If individuals or groups experience inability to influence their own living conditions and the development of the society, alienation and powerlessness emerge. Lack of influence and the possibility to have an impact has a strong correlation with health. (Socialdepartementet 2007: 42)

Henceforth, to increase people’s possibilities to influence their own lives the authors of the bill suggests extending peoples abilities to make choices concerning healthcare, social services and support. This can be read under the sub-heading *Influencing Everyday Life with Free Choices*:

> A cornerstone in the government work to increase Swedish welfare is the fact that people need to feel that they can influence their own situation and be given the
opportunity to make decisions concerning their own everyday life. Extra efforts need to be made to make sure that freedom to choose includes everyone, not least the groups in society with very few possibilities to choose, like the elderly, the sick and people with disabilities. (Socialdepartementet 2007: 45)

In the first bill in 2002, the focus on empowerment was not as explicit as in the later bill. In this first bill emphasize was rather on solidarity and of strengthening the sense of community within society (Socialdepartementet 2002). In the later bill the focus had changed and now, in the first chapter of the bill, empowerment and self-care are presented as useful tools to achieve the public health goals. There is also in this bill an enhanced focus on the agency and responsibility of individuals.

**The Governing Qualities of Healthcare**

As presented above patient empowerment is a central agenda of the Patient Act (SFS 2014:821). It has been shown how patients can contribute to society and their own health by becoming engaged and active co-producers of healthcare. Then, what exactly is healthcare? As it is stated in the Swedish constitution, citizens are protected against any forced physical interventions on the body (SFS 1974:152, 2 chapter, 6 §). Healthcare is thus articulated by the report *Patienten har rätt* (The Patient’s Right) as “[…] a benefit that patients can accept or decline when it is offered to her” (HSU 2000 1997: 53). This was initially written in the report to explain the motivation behind the formulation of the paragraph on patient consent in the fourth chapter of the Patient Act (SFS 2014:821, 4 chapter). However, what it also indicates is the government’s view of healthcare in terms of what practical implications it has for citizens. In the report *Patienten har rätt* (The Patient’s Right) healthcare is formulated as a voluntary social benefit and not a citizen’s right that can be legally enforced (HSU 2000 1997: 51). Later to be finalized as law in the very Patient Act, this specific formulation of healthcare was transferred from the report to the Patient Act bill. Below, one can read a formulation on the matter from the report *The Patient’s Right*:

It can be said already that the governments directive that has been given to the investigation clearly specify that the bill that the investigation will hand in shall not contain enforceable rights in the sense that decisions made within healthcare can be reviewed in court. With other words – laws and legislations in the context of healthcare shall continually define the obligations of the heads of healthcare, care-providers and employees and some – non-enforceable – patient rights. (Socialdepartementet 2013: 63)
The way the Patient Act is written reveals a power balance between state and citizen and it indicated the responsibilities of healthcare towards patients. However, without enabling patient’s to legally enforce those responsibilities the Patient Act practically rendered patients toothless. As we can see by the quote above the government indicates that the current positions of government and citizen shall remain intact. This presents a good indication of the governing attributes of the Patient Act. The fact that further my claim that the patient act functions primarily as a strategy to govern the conduct of citizen (and that the claims to empower and increase patient agency is just part of that strategy) is the fact that the Patient Act is not a rights-Act. Meaning, it doesn’t contain any enforceable rights that can be legally claimed in court. As shown above, this was never the intention with the act. The Patient Act was written as a collection-law to gather and present to patients and healthcare professionals what they can expect from healthcare. Indicating the area of rights and responsibilities for each role within healthcare (SFS 2014:821) (Lyckhage et al. 2017).

Even though the Patient Act presents what looks like empowering strategies, like presenting what healthcare ought to offer patients in terms of the availability of personal choices (Clarke 2005: 449). For example, in terms of treatment; medical aid; care-giver; and support such as second-opinion and indicating the scope of patient’s agency in the form of consent and the right to a second-opinion (SFS 2014:821, chapter 4, 7 -9) One can also see these rights as suggesting what is expected of patient’s in terms of requirements. Articulating the variety of available choices that the patients have at hand suggest that patients, as a morally responsible citizen, ought to take an active role in their healthcare by utilizing that availability. Finally, stressing the importance of placing patient’s in the centre of healthcare work (as the preparatory Patient Act bill do) inclines that patients are expected to also voluntarily move to the centre, activating the role of being the hub of knowledge and the driving force of healthcare work (2005: 451).

The standpoint of the Swedish government resonates with the changes that Clarke (2005) recognizes in the effects on citizenship in British New Labour politics. From a political science perspective, the empowerment and responsibilization (Rose 1999) of citizens can be viewed as a convert to hide economic and political intentions. For example, giving the patient a central role as co-creator of healthcare and motivating patients to take an active part in their treatment is argued to have positive effects on patient’s individual healthcare experience. When at the same time, there are economic incitements to motivate patients to take an active role in their treatments, transferring some of healthcare’s work-hours on to the patients (Clarke 2005).
Chapter Summary

In the shift from modernity to late modernity we have seen how the Swedish government shed most of its Keynesian, paternalistic, welfare politics to adapt a neoliberal politics praising individualism, empowerment and freedom of choice. With the marketization of the healthcare discourse that started in the 1980s, there developed a new ideal patient role, the patient as an engaged and knowledgeable consumer patient and a co-producer of healthcare. To form an understanding of why empowerment and patient autonomy has been given such a central role in the discourse of Swedish contemporary healthcare, recent development in Swedish healthcare politics was examined through the analysis of Patientlagen (the Patient Act) (SFS 2014:821) and other state documents dating as far back as 1997. Examining said policy documents drawing on Foucault’s theory on governmentality (1991) and Crawford’s concept of healthism (2006) reveals that patient empowerment is a central theme to Swedish healthcare policy that one can understand as a technique to govern citizens to take and increased responsibility for both their own health and for the healthcare practice.
3. Sickness and Morality

There are no doubts that society upholds norms and values concerning bodies and health. We are encouraged to take care of our bodies with the goal of living a long and vital life (Crawford 2006). And why should we be vital? In accordance to theories on governmentality and technologies of the self (Foucault 1988, 1991) and ethopolitics (Rose 1999, 2000) we ought to keep ourselves healthy so we can be productive members of society and contribute to its development and prosperity. These norms of productive ability moralize bodies. The healthier, stronger, more able and productive you are, the better moral you have. In the light of these norms it becomes interesting to discuss how the perception of self and sickness contributes to these norms. Henceforth, I will in this chapter elaborate on the experience of having a sick body and how to cope with social moral stigma relating to being sick. Moral stigma I mean in the sense, as in not being fully abled-bodied and therefore seen as a burden to society (Crawford 2006). Being an adult citizen and having a disease will many times lead to an inability to wage-work. Hence in this chapter I will also elaborate on how informants relate to the morals of wage-work. The content of this chapter is formed by the thoughts and reasoning of my informants. In their reasoning, I have noticed different techniques of coping with moral stigmas. I have also observed one dominant way of perceiving personhood and disease.

Morality and the Able Body: Experiences of Self and Illness

One issue that prevailed in my informants’ statements was that they all made a distinction between themselves and their disease or disorder, as in, they all considered themselves to have a disease in the sense that they, their person, were separated from their affliction:

I’m trying to see myself as a healthy person with a chronic disease. I’m not sick here, [she says and points to her head]. My head and everything else works fine. I just have an inflammation in the stomach that doesn’t show on the outside. When I don’t have relapses [in the disease] and feel sort of okay, I can basically do anything that anyone else does. (Veronica)

For Veronica and the other informants, it was important to emphasize that the disease is not part of their identity or personality and most of them made practical measures not to be reminded of their sickness. This is also the case with Sara that I met in the spring of 2017. At the time of our talk she had been diagnosed with diabetes type 1, half and a year before. Early

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5 All interviews with informants was originally conducted in Swedish. Quotes has been translated by the author.
on during our talk I ask Sara to tell me how it all started, about her diagnosis and how she experienced being ill and getting treatment. Sara doesn’t like to be reminded that she is ill. When she first got her diagnosis, she didn’t feel any symptoms at all. She didn’t feel ill and lying in the hospital next to very sick people was hard. In her experience, she was all fine and well:

> It’s something that you can get obsessed about, in the beginning I got really obsessed about it. [Thinking that] I now have a chronic disease, like ‘I’m sick now’. But I try not to think that I’m sick, I just have a disease. I’m well, yes, I just have an extra, minor malfunction, kind of…There is a little something wrong with my body but I feel well. And I am well otherwise. (Sara)

She shows me a tattoo on her upper right arm, a row of symbols that say “I’m greater than my peaks and valleys”. She did it as a reminder of the hardship she has overcome in life. When Sara was diagnosed with diabetes type 1 and hospitalised to stabilize her blood sugar she had a phobic fear of needles but the experience of neither feeling or identifying herself as ill motivated her to get discharged from the hospital and return home as soon as possible so she could go on with life as she used to. Her motivation to be discharged was so strong that she overcome her fear of needles and learned to take her own insulin shots in the matter of a few days. The tattoo can be interpreted as Sara’s way of showing her identity, that she is more than just a sickness. That the sickness ought not to overshadow her person or being. The tattoo becomes a reminder that she wants to live life as unhindered as possible.

Ian Hacking (2006), in what he calls the *making up people* argues that social roles and classifications of people are cultural produced and susceptible to change. Sciences use of categorization, he means enables to create types of people that in some ways are new to the world. He uses the example of how the psychological condition multiple personalities did not exist in 1955 but it did so in 1985. What he means effects the existence of multiple personalities is not so much weather it is considered a clinical condition or not. It has more to do with how people experience themselves, how they relate to people around them and how they live in society (Hacking 2006). Just as Hacking understand human *being* as culturally created, Tanya Titchkosky (2011) makes a compelling argument in the *person-first* discussion about the cultural influence of social norms and bodies. She argues that prioritizing person before disability, as in *people with disabilities* rather than *disabled people* holds the power to reduce people to their mere conditions. With this linguistic practice disability is not understood as a “proper or expected aspect of personhood, but instead as a danger to personhood” that devalues disability and create it as a problem and a social and physical
restrain that hinders people to live full and vital lives. Person-first language call for caution. “We should cautiously move disability to the rear and move personhood to the front” to minimize the risk of disability diminishing peoples’ social statuses and positions (Titchkosky 2011: 54).

Using Titchkosky’s argument I interpret the informant’s want to use the person-first language as a sign on what kind of norms that exist in their social context that prompts them to distance themselves from their disease. The act of shying away from bodies that are seen as disabled automatically creates those bodies as lesser than bodies that are more able to be productive. Consequently, drawing on ethopolitics and healthism, less abled bodies are perceived as less moral and incomplete participants of society. Building on Rose concept of *ethopolitics* (1999), Crawford traces the distinction between self and sickness and the unpleasantness in being reminded of the body’s condition to the moral stigma attached to being sick and not being able to participate in society as a fully capable citizen:

The AIDS epidemic demonstrates once again how health is employed as an identity strategy and dividing practice, opposing a healthy Self to an unhealthy Other (Crawford, 1994). The ‘diseased’ Other who ‘carries’ and metonymically comes to represent the feared disease, whose invisible presence contaminates the pure space of health, must be physically and culturally isolated. The presence of disease and ‘the diseased’ is a nearness that threatens by reminding the healthy that their health is tenuous. (Crawford 2006: 414)

By this, sickness becomes and embodiment of *otherness* as in the unhealthy or immoral. Hence to sustain the self-image of being healthy (and moral) a common reaction is the want to put space between self and the sickness to avoid being associated (or socially contaminated) by ill-health and immorality.

**Sara: Embracing Autonomy**

On some occasions, when the patients are autonomous and competent enough, the experience of extensive self-care has shown by some of my informants to be emancipating and voluntary. Sara is willingly embracing her autonomy and personal self-care. When talking with Sara about personal responsibility and whether the state or the individual ought to be responsible for the individual’s health and wellbeing she told me she’s happy to take on more responsibility. Increased autonomy would mean fewer reminders that she is sick. She told me that since she wants to live life as close to what she used to before her diagnosis she is happy with the low rate of engagement from healthcare:
In my case, it has been quite good [being autonomous]. But this might be connected to the fact that I don’t want to feel ill. I go to my regular check-ups two times a year. If you would put more responsibility over my wellbeing on healthcare, that would probably mean that I would have to see them even more often to talk about me being sick and all. (Sara)

As medication and regular check-ups at the health care centre are constant reminders of Sara’s physical condition she means that more engagement would only mean more reminders that her health and body is compromised by a physical deficiency. In this sense, the disease has disabling connotations as Sara associates it to being restrained. Besides, she thinks that more engagement is not necessary as she feels at ease with adjusting her insulin dosage on her own if it is needed. Being proactive and engaged is encouraged by her physician. To the discussion on more engagement from healthcare she adds:

I think that, since I have tried to learn as much as possible, it [the self-care] works quite well. But I can imagine that it is much harder for those who don’t dare it. I take chances, right. ‘Now I’m dropping, God, that’s weird…Then, let’s try this!’ The doctor think that’s super good of me. But I understand if people think it’s difficult. (Sara)

I agree with her and say that I think many people would not do anything without their physician’s advice. “It all depends on how well you know your body” she says, “And I have gotten a pretty good understanding of my body. So, I don’t feel I would do anything drastic. If I’m dropping to fast, then I just adjust it back again.” The relaxed attitude she seems to have towards her diabetes, she says, is connected to the lack of fear of the harms that her physical condition can cause. She goes on to comment that many people with diabetes are afraid of fainting and losing consciousness when they are out in public or home alone because of a too fast drop in blood-sugar. But Sara I not, because she is still in the” honeymoon phase” as she puts it. Which means that her body still produces some insulin and therefore she has not been in any real danger yet. When she drops at night or early morning her body wakes her up. She thinks the lack of fear might have a positive effect on her will to be autonomous, as she doesn’t feel the need for more support by her social network or healthcare. Sara’s emphasis of her own abilities to be autonomous and her willingness to take responsible for her own self-care by wanting to learn as much as possible about the disease both express how she perceives of herself as being a responsible and moral patient and it express what kind of self-governing she enacts to live up to, what she thinks is, the ideal patient (the autonomous). Consequently, for Sara that is very capable of being responsible and autonomous, to be expressing her own abilities and motivation to be autonomous by comparing them to others’ inabilities and fears
also expresses a moralizing over the behaviour and abilities or inabilities of others. Further, this reveals what kind of moral norms of healthism that are active in this context concerning patients’ abilities and inabilities (Crawford 2006).

From a neoliberal perspective, it can be safe to say that Sara is an exemplary patient. Besides her will to be autonomous she also stand for most of the cost of her medical aid herself. Of course, this is not force upon her, by her county she is offered an analogue glucose meter for free. Nevertheless, she chooses to pay about 12006 Swedish kronor each month to purchase the disposable sensors for a digital glucose meter. She can use the subsidised meter just as fine, however, she reasons that the quality of life that the digital meter brings her is worth the extra cost. “It enables me to live a life like I want to and not just a life that I accept” she says. Besides the feeling of autonomy that the digital meter provides there is a morally motivated side to her reluctance of using the analogue meter. She feels a pressure not to take to many blood tests since she thinks that the disposable test strips are a substantial cost for healthcare.

Sara is embracing her diabetes type 1 diagnosis as she is proud of being able to take care of her disability, as she phrases it. Which she does mostly on her own. For Sara, tending to her care on her own is a measurement of personal capability and thus, being autonomous becomes something to strive for. When Sara was younger she was shy and had quite the low self-esteem. This got better as she grew older and enrolled to the university. In the context of student life, she found a place where she could grow confident and take on roles and responsibilities that she had not dared to do before. Besides the social context, she attributes her boosted confidence to her diabetes. Being able to successfully treat the diabetes on her own creates a feeling of accomplishment and capability that has spread even outside of the realm of body-functions and medical treatments. In line with critical empowerment theory a crucial part of successful self-help is a strengthened self-esteem. Cruikshank take self-esteem to be emblematic for governing technologies in liberal democracies and underline the importance of a boosted self-esteem to perpetuate the self-governing:

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6 Equivalent to approximately 115 €.
In the quote above, as Cruickshank talks about the governable self-to-self relationship she refers to the final report by the California Task Force to Promote Self-Esteem and Personal Responsibility (1990). Much like the bill *En förnyad Folkhälsopolitik* (A Renewed Public Health Politics) (Socialdepartementet 2007) the Task Force was installed to present a program for solving California’s social problems such as, gender inequality, poverty and crime. Cruickshank speak of these programs as *technologies of citizenship* (1999: 88). The language tells of a strong ideology and belief in citizen’s empowerment and responsibility. Here it is shown how different powers and governing technologies cause the effect of increasing the citizens wish to become morally good and responsible citizens. The ideology of caring for the community, making it your own responsibility as a citizen to take on the role and be the instrument of social salvation clearly, outmost explicitly stated in the Task Force report, illuminates the ideology of neoliberal democracies (Cruickshank 1999).

**Lars: Not Accepting Sickness**

For ten years Lars had kidney failure and was treated with dialysis as he was waiting for a kidney transplantation. Lars related to his failing kidneys by not accepting the sickness. This is another aspect to disease and social norms. Acknowledging or ignoring disease is the issue of sickness acceptance and whether it is considered by patients as good or bad for the disease treatment. Lars thinks that you shouldn’t accept that you are sick. For the sake of personal motivation, you should *imagine* that you are well, hence you should keep working as long as you can. From his perspective, getting up in the morning to go to work turned into an external motivation to stay active. When we talked about sick-leave and long term sick-leave Lars remarked that he can imagine that it is easy to get depressed if one stays at home doing nothing and he thinks that he would have been worse off if he had done that. He sometimes gets angry over the way other people talk on Facebook, when they say they lack the energy to workout. “Sometimes I have replied and said ‘Off course you have the energy. Everyone has energy to do at least something. Just to carry a grocery bag, that is exercise too!’”. Lars has always seen himself as the active type, a full-time wage-worker that on his spare time makes sure he is physically active and engaged in the local sports club. So, it was quite the adjustment he had to make when he didn’t have the same energy as before.

Lars non-acceptance of the disease and his dislike for inactiveness is moved by Lars willingness to continue life as normal and active as possible. His standpoint tells of a
governing technology in working. For Lars, being active is seen as having a positive effect on disease treatment and being passive has negative connotations. Hence, because of the perceived risk of getting worse off and even depressed if one give in to the feeling of illn

ey, you fear and shy away from that feeling by staying active and condemning inactiveness. By drawing on Foucauldian ideas that subjects are produced by the system Clarke means that conduct is morally coded and created in a scale of wanted (empowered, wage-working and active) and less wanted (passiveness, anti-socialness and criminal) social conduct. One can hence see Lars reasoning as the effect of a self-governing strategy and his opinion of activeness thus becomes an indication of where on the moral scale he wants to remain (Clarke 2005: 454).

Emma: Defending Actions

Emma is a sporty woman in her twenties studying a degree in IT at the university. She lives with her boyfriend in a small two-bedroom apartment in the heart of a suburb in the outskirts of Stockholm. The first time I met her she invited me to her home and we sat down at the kitchen table overlooking a small centre with all the necessities for everyday life. Emma had recently been discharged from Danderyd hospital after her initial diagnosis and treatment for diabetes type 2 and was transferred to her local healthcare centre for long-term treatment. Even though she knew that she sooner or later would get diabetes since it runs in her family she was surprised to get it this early. All the women on her mother’s side including her mother got diabetes type 2, but after menopause. When I asked her how she feels having diabetes type 2, she seems baffled to get that type, the kind one associate with poor health and lifestyle. She emphasised that her disease it is due to genes not to a faulty lifestyle, the only difference with the rest of her family is that she got it now in her twenties. Which, Emma says, is unusual for diabetes type 2 if you like her have lived a healthy life without being overweight. As we spoke, Emma seemed to want to clarify the moral aspect of her situation so she gave me an example as she glances out the window overlooking a construction site on the centre square below:

Sure, when I’m stressed I occasionally eat unhealthy food. But I don’t over-do it. The workers that go out eating every day and still look super slim, their lifestyle is worse than mine who buys a kebab once or twice a month because I don’t have the energy to cook. They should get diabetes all the time. In a way…it’s hard. I understand why they call it lifestyle related, that you have lived in a bad way, kind of…that you have eaten the wrong things and not exercised and all that. […] It’s like with people with diabetes type 1, many of them get sad when people start to compare them to type 2 diabetics and I get sad when someone compares me with a super old diabetic that doesn’t knows
squat about exercise. It's like this, yes, I have type 2 diabetes, I understand that it is categorized as age, obesity and lifestyle related diabetes but I have never in my life done anything that has caused this. It's simply in my genes. I knew that I would get it sometime during my life but I didn't know that I would get it this young. And I didn't know that my diabetes type 2 would be this complicated, so that they would classify me as a diabetic type 1. (Emma)

To get a better understanding of what forms of governing that might be active in the context of diabetes type 2 one can place Emma’s words in the discussion on healthism and ethopolitics. Following healthism and ethopolitics, the regulation of social conduct comes as much from external forces such as media, peers and social institutions, as it comes from within in the form of thoughts and perception. The action of Emma, to reason and explain the behaviour of herself and others, can hence be understood as an effect of the governing of social conduct by governing the mind.

The informants use of person-first language can be read as an action they take in order to live life as unhindered as possible. From the perspective of healthism, this can be interpreted as informants not allowing for anything to hinder them if they have the will and power to influence it. This means that moral conducts concerning health and lifestyle conditions their efforts to live an unrestricted life. Following ethopolitics, if the person has the power to affect their life situation they are morally obliged to do so and are personally responsible for any potential failure. Here Crawford reflects on how the development of neoliberal tropes is entangled with these morals and responsibilities.

What has become clear in hindsight is that individual responsibility for health, although not without challenge, proved to be particularly effective in establishing the ‘common sense’ of neoliberalism’s essential tenets. In contrasting a vision of autonomous, prudent and self-responsible individuals to images of the careless and the foolhardy, a link was easily made to the burden of social spending: the virtuous would have to pay taxes to provide medical care for those whose unhealthy lifestyles led to overutilization of medical care (Crawford 2006:410).

**Morality of Wage-Work**

As we have seen previously in this chapter, to be sick is morally frowned upon by society. The common denominator of informants’ experiences is the moral perception of their diseases, how society and themselves morally judge their sickness. This moralization parallels, or more correctly, attaches to and extends the moral of (work)able-bodies (Rose 1999: 156, 157; Titchkosky 2011). To elaborate on the idea of sickness being immoral, this
strain of thought can be examined from another social factor, one closely connected to the social shaming of sickness and the informant’s experiences of the shaming gaze of others. By tending to *ethopolitics* I want to discuss the moral connotations of the ethics of labour in a neoliberal state. Here one can see that the ideology within the bill *En förnyad folkhällopoltik* (A Renewed Public Health Policy) (Socialdepartementet 2007) is strikingly similar to the ideology of British New Labour’s political and governing project (Clarke 2005; Rose 1999):

Public health work [...] requires *shared responsibility* and cooperation between different areas of responsibility. The responsibility for public health work is not limited to those agencies and organizations that already have a pronounced responsibility for public health issues. The responsibility is beyond that. Efforts must be made from most sectors of society – from the public, from the private, and from non-profit organizations, as well as from *people themselves*. (Socialdepartementet 2007: 23) (original emphasis)

An essential characteristic of ethopolitics is the sense of connection or bond that subjects have towards the community. The bill highlights the causality between public health, wage-work and *social bond*, which is the bonding of subjects that happens within a community. Sociologist Travis Hirsch who articulated the *social bond theory* (1969) connects the absence of social bond to delinquent behaviour. Social bond, he explains, is the social attachment that subject within a society have, to their family, peers and others in the community. Accepting and conforming to social norms and values like abiding to the authority of law and engaging in social activities, Hirsch means, can lessen criminal behaviour (Hirsch 1969). As seen by the quote below and as the theory suggest, in the bill *En förnyad folkhällopoltik* (A Renewed Public Health Policy) (Socialdepartementet 2007) the authors make the connection between delinquent behaviour and a weak social bond:

Societies and places that uphold strong social bonds are characterized by people being socially grounded, socially active and have good possibilities to influence their local environment. The opposite applies to societies and places with a weak social bonding. Where distrust as well as hostility, violence and aggression is widespread. (Socialdepartementet 2007: 8)

The authors of the bill continue by suggesting that wage-work act as an identity creator that offers citizens social status and partly models their self-image. They also make a correlation between unemployment and severe negative public health effects. But unemployment they mean, do not only negatively affect the unemployed individual it also affects the social network of the unemployed:
Unemployment effects health as a whole, from health-behaviour, symptoms of illness and social effects of illness to clinically diagnosable un-health and death. [...] It is important to highlight the indirect health effects caused by unemployment. Not only the unemployed suffer the negative economic, social and health consequences of unemployment. Even the families of unemployed especially the children suffer. Increased unemployment greatly affects the working conditions for the person that is still working. Overtime work as well as negative stress increases. The socioeconomic security is threatened and the fear of termination increase. (Socialdepartementet, 2007: 8, 9)

The bill’s articulation of the devastating effects that individuals’ actions (as in being unemployed) have on the community is yet another example of a governing technique that places moral and social responsibility on the individual citizen. Not only for the sake of one’s own health but for the sake of the prosperity of society.

Veronica: Being Work Shamed

We know by now that there are numerous socially correcting norms for bodies and behaviours, which behaviours that become extra vivid when one, like Veronica, has a body under siege that controls and forces one to the fringes of normality. Veronica suffers from Irritable Bowel Syndrome (IBS). The disorder comes in cycles of calm periods and sudden painful relapses that make her literally tied between the bed and the toilet. The relapses that wear down the immune system are very straining for the body and it makes her physically and mentally exhausted. Besides that, the symptoms grow worse with every relapse she is struggling with the pressure from social norms of being a good mother and wife and a productive member of society. Veronica recently got a new job with a trial period at a preschool. The two first months at the job she got a virus infection followed by an IBS relapse that lasted a month. Relapses are just what to expect when you get colds she says, and continues:

I’m terrified that they will say ‘Thank you but goodbye. You being off work like this, it is not sustainable.’…But what am I to do? I can’t control it. It comes so suddenly.
(Veronica)

To find a job that suits her situation is difficult. “I won’t be able to work full time and be the ‘average Joe”’, she says, and tells me how bad she feels because she is not equally able as her husband to contribute to the family economy nor does she have the energy to be a good mother and wife. During the periods when she is able to work and gets home in the evening after a workday she is too tired to play with her son and falls asleep with him at his bedtime at seven. This behaviour nags here already bad conscious. On top of that, a lot of the jobs she
has tried are too stressful for her. Some of this stress derives from the feeling of being an unpredictable employee since she does not know how much or even when she can work, when suddenly her body can refuse and she must call in sick. The optimal solution, she thinks would be to have a job where she can work from home and adjust the hours to her ability.

From the looks of her, you can’t really tell that she is ill. This has sometimes proven difficult for her as it renders her a target of other peoples’ unawareness and sometimes-ignorant attitude towards her illness. Often, when people lack the experience of hardship and limitations they have a hard time imaging other people’s struggles. Veronica sometimes feels like she is not being taken seriously. She thinks that people do not grasp the severity of her illness. This often happens in her contact with healthcare and it also happens with friends, family and others in her surroundings. Frustrated she tells me, that people do not understand that her inability to work is involuntary. She is very tired of explaining to people that she is not afraid of working nor is she lazy. It’s the opposite, she loves to work:

> The heart and mind says yes but the body says no…It’s allot of this [talk that] ‘one should be strong, one should be proactive and successful.’ A lot of it comes from society but also from my own surroundings. ‘You’re awfully sick a lot? Yes, I am, but there is a reason for that!’. (Veronica)

**Ellen: Narratives of Work Ethics**

The way societies moral guidance works on the subconscious level can sometimes be expressed in the way informants emphasize certain behaviours and disguise others. When I asked Ellen if she ever thought about death during her sickness, she responds:

> Back then, when I was more or less severely ill, my kidneys were actually really ill, then I didn’t think so much about it. I was too busy with everything else. Now, in hindsight I have realized how sick I was. I was pretty sick. I had severe kidney-failure because I had only eight percent [kidney function] And then imagine that I worked full time for several months with only eight percent [kidney capacity]. Don’t ask me how I did it, but I did! (Ellen)

Ellen is very happy with the way her employer and colleagues reacted to her being ill and not working full time. She tells me that her employer never once brought her sick-leave up to a discussion. She has always been open with her illness and she feel that she has gotten the support that she needed.

What is and is not brought up in a conversation and the way things are expressed, if they are expressed with surprise, gratitude or as something obvious, can tell of the logic of moral conduct in that culture. I suggest that a way to learn about the content and scope of a moral
logic is to look at how the logic is being applied in a situation and what reactions it causes in subjects. In the example with Ellen, she evaluated the morality of her employer and colleagues by analysing how they reacted to her work impairment. The gratitude of Ellen towards her employer for not questioning her sick-leave can thus tell of what can and cannot be expected by employees, and what cultural conducts that are obvious and those that are not. To express the alarming condition of her illness, she mentions her ability to work full time despite her failing kidneys. In this way, the more-than-capable-body, struggling against its own deterioration and succeeding it, becomes part of the narrative that perpetuates a broader social moral. The narratives of work, ability and the able body tell of a morality that is linked to surrounding social contexts such as caring for your community, deciding right from wrong and distinguish goodness from evil. Rose reasons that, since societies problems are being rephrased and understood as mostly ethical (instead of structural, economic, social etc.) new procedures for governing this novel dimension of humanity develops. The effectiveness of these procedures relies on the citizens’ feeling of moral obligations towards the collective. By encouraging that feeling, the aim is to motivate citizens to solve social problems through individual self-managements. With this new form of governing one can clearly notice the shift of responsibility from the state to its citizens, as social problems get personal solutions (Rose 2000:1396-1399).

**Chapter Summary**

In line with theories on healthism and the neoliberal believes in individual capability and responsibility over one’s own health, it has been shown in this chapter how there exists a social morality of bodies and sicknesses. With the help of Rose’s (1999) theories on ethopolitics it becomes clear that this morality strike differently on different bodies, depending on how well they can contribute to society and the community. The practice of this social morality is a technology of governing the conduct of citizens (Foucault 1988, 1991). I could verify the existence of this technology through my informants, when they expressed thoughts about the pressure of living up to societies expectations on them. For instance, such concerns could be: the strife of being a good mother; wage-working as much as possible; and not being constrained by the feeling of illness. Not only were the social norms manifested in the informants’ feelings. They were also expressed as political ideology in the bill *En förnyad folkhälsopolitik* (A Renewed Public Health Policy) (Socialdepartementet 2007).
The informants were much aware of what was expected of them. They did not explicitly express this awareness through what they were doing. This awareness was rather expressed in statement of what they did not do, what they could not do and what they were not. Like Veronica when we talked about her work-life, “I won’t be able to work full time and be an ‘average Joe’”. Or Emma on the surprise of getting a diabetes type 2 diagnosis so early in life. “I have never in my life done anything that has caused this. It’s simply in my genes”. The rhetoric technique of justifying and defending their being and actions (or lack of actions) can provide information about the informants’ position in society. It also gives a sense of how widespread and well established the norms of (work-)ability are. Most informants made a distinction between their person and the disease. They did this in order to live life in the same manner as they did before they got sick, not letting the disease limit their agency more than necessary. This act of separating personality and disease is an effect of the social pressure of being a good citizen.

Often, when informants could, they abided by the social norms but when they were unable to live up to the social norms they expressed to me the stress of not being able, and explained why they couldn’t live up to expectations. It was a sign that they were much aware of the social norms at play. Even if informants did not conform to societies sought after conduct they were made very aware of what those wanted conducts where. To clarify, even though informants didn’t always act according to the moral system they always needed to act in relation to societies moral system. This awareness of social norms I find telling for governing of the self and it makes this technique of governing more of a regulator of mind and morality than a regulator of bodies and actions (Foucault 1988).
4. The State Ideal and the Critical Consumer

The relationship between the Swedish state and its citizens has throughout the 20th century been characterized by a shift from an explicitly governing paternalism to inexplicit governing through individualism. This meant a shift concerning the division of responsibility over citizens’ health and lives, from Government to individual. Whilst there has, throughout the 20th century occurred an increased believe in and cherish of the individual’s capacity to make moral judgements and take responsibility for their own life as well as for the betterment of society the social and moral control of the Government has not automatically lessened, it has just taken a less apparent shape (McKee 2009: 469; Rose 1999). The moralizing of bodies that was discussed in chapter three is not only found in the subjective experience of patients, it is also found in the whole of society as a cultural trope where some actions are morally more justified than other (Crawford 2000). Consequently, it is found in the healthcare system as well. Judging from the content and rhetoric of the policy documents presented in chapter two, an ideal citizen/patient role is emerging, the patient as knowledgeable, active and autonomous. Since individual citizens make up the body of society individual health-risks are addressed as a public health issue. Hence, responsibilization and citizen empowerment has become important technologies for governing. Below is a vivid example provided by sociologist Richard Sennett from his study on how the autonomy-ideal affects both individuals and organisations. The example is taken from a high-tech firm and deliberates on a manager’s sought after qualities in staff members. The example is quite far from the context of patients and healthcare, nonetheless it is a telling example on the logic behind self-governing and responsibilization:

In going through the personnel records of a high-tech firm with a revolving-door management, I was struck by how often the words needy and dependant were used as negatives. One personnel manager told me she looked for something like self-discipline without dependency in her employees. This makes institutional sense. The operations are fragmented, either geographically on the periphery in big firms or internally in medium-sized organizations when many unconnected activities go on at the same time. Under such conditions people are indeed on their own, left to their own devices as how best to respond to targets, commands, and performance evaluations from the center. The celebration of self-management is, though, hardly innocent. The firm need no longer think critically about its own responsibilities to those whom it controls. (Sennett 2006: 59, 60)

It is easy to see the structural similarities of the big high-tech firm and the fragmented and compartmentalized state of today’s Swedish healthcare in which patient most often are
referred to a new healthcare contact for every new symptom. Relating to the attitude of the personnel manager who looked for self-governing qualities in her staff is the emergence of a new patient role, the patient as a knowledgeable and active consumer (Lupton 1997; Nordgren 2008; Linander et al. 2016). I am not claiming that the practice of addressing patients as consumers is common in Swedish healthcare today, even though it was debated among healthcare professional in the late 1990s (Nordgren 2003, 2008). In fact, I have not heard or seen any widespread explicit use of the patient as consumer expression in my ethnographic data. Still, through my informants, I can conclude that this specific patient role, is more often than others adopted by informants when meeting healthcare. In the efforts to live up to this ideal, patients practice specific moralizing conducts and acts of self-governing. I have observed two patient phenomena relating to this role. First of all, informants who can embrace this patient-role actively seek information and knowledge which they use in their meeting with healthcare. The second phenomenon is that these patients also more or less willingly take responsibility for issues that previously have been the responsibility of Healthcare professionals. Considering the rhetoric construction of the patient shown in policy documents in chapter 2, the observed patient behaviour fit well with the governments vision of ideal patients, as people that want to take responsibility of their health and lives by actively engaging in their own healthcare, which they ought to do through the attainment of knowledge and the exercise of self-care. Ideally, they should also contribute to the betterment of public health by being a co-producer of healthcare (Socialdepartementet 2013; Rose 2000). However, even if the informants acted according to the ideal that was not a guarantee that they were able to reach the ideal. The two phenomena of patients being knowledgeable and self-sustainable in healthcare lead to the construct of a third behaviour that shows how informants have embrace some of the state’s ideal patient role but not all of it. This behaviour is henceforth a form of reaction to the state ideal. The behaviour that emerges is that of patients not just passively accepting care but actively engaging in healthcare to the point that they start to critically reflect on the suggested healthcare and demand and suggest treatment alternatives to an increasingly greater extent. The role that emerges is that of the critical consumer-patient. This means being knowledgeable and actively seeking to attain more knowledge to inform and educate yourself. It also means being able to process what is happening with yourself in the healthcare system and critically reflect on the way healthcare is treating you. With the increased marketization of healthcare Lupton (1997) observed this new form of patient role in the attitude of lay-patients and she underlined how the new role merged the behaviour of the consumer and the behaviour of the reflexive subject creating a
critically reflexive consumer patient that is autonomous, knowledgeable and active in healthcare; “There is [...] a congruence between the notions of the "consumerist" patient and the "reflexive" actor. Both are understood as actively calculating, assessing and, if necessary, countering expert knowledge and autonomy with the objective of maximizing the value of services such as health care” (Lupton 1997: 374). In informants’ stories, I have observed various signs of informants acting to live up to the moral virtues of being a critical (and reflexive) consumer. A patient concept that has blossomed in the recent year’s public debate on chronic illness healthcare and patient empowerment that correlate with the state ideal and the critical consumer-patient, which I have also observed in some of the informants, is the concept of e-patients (Bertholds et al. 2018-11-18). This term is often used to address patients with chronic conditions who seek information and knowledge about their conditions online (used in the same way as the eHealth concept) (Hewitt-Taylor & Bond 2012). Another way to use the term that connects to the patient empowerment agenda is to refer to e-patients as patients that are “empowered, engaged, equipped, and enabled” (e-patients.net 2018-11-18). In Swedish, the term spetspatient, roughly translated to expert-patient, is used within the same discourse. This term refers to patients that are very knowledgeable of their own condition and actively seek patient-autonomy.

To address the actions that informants as critical consumers take to self-govern I draw on Albert Hirschman’s three-part concept exit, voice and loyalty (Hirschman 1970 in Hartman 2011). The concepts are used in a market context and explain consumers’ choices of action when the quality of goods or services are experienced as dissatisfying. In a healthcare context, exit means leaving the present care-provider seeking healthcare elsewhere, voice stand for the patient’s ability to use their voice to complain about present healthcare services and loyalty explains the social relation between patient and care-provider.

**Joakim: Being the Hub of Knowledge**

A cause for the clash between different set of knowledge-practices we can originate to the power-knowledge balance between laymen and experts. This is made vivid as Joakim challenges the competence hierarchy and power-dynamics between patient and doctor. Joakim have gone through two kidney transplants and several months of dialysis. When he first fell ill back in 2004, he got a transplant, which lasted eight years. He has always been engaged in his disease and treatment. He thinks this is appreciated by the physicians and he thinks his engagement has helped him to get along with his doctors:
It is not unusual that they get a question from me that they don’t know the answer to and have to check it up and give me a call back with a reply or reply in our next meeting. That’s kind of how healthcare works nowadays. You need to keep track of yourself because you never know what doctor you will meet. It is impossible for them to keep track on everything when you have this and that. And you know, my record is thick, it’s not something you read through just like that. You need to know what you are looking for. Then it happens like that, that you need to keep track yourself. And I think that’s good if one can do that. It is worse off with the elderly and those with dementia that can’t, don’t, have the ability to keep track. (Joakim)

Since Joakim is the one who has gone through the whole treatment with self-care of dialysis, dietary restrictions and medication he is used to be the one who has the most knowledge of his medical record and he want healthcare to recognize the knowledge he has about his own healthcare history. He holds up his thumb and index finger as to demonstrate the thickness of his medical record. It looks about the thickness of a standard binder. Only one time he recalls getting angry at a doctor. This happened in 2012 when he got severely ill for the second time and met a doctor that he didn’t get along with. This doctor made changes to his treatment and medication without telling him. She took away a drug that Joakim had been told by healthcare was very important for him to take and never miss a dosage. “And then she just takes them away without telling me. That’s not the way to act”. The reason he got so crossed with her was because she acted in opposite of Joakim’s experience of how healthcare usually works. “Since it is so often me who in a way is responsible for my care it is immensely reckless of her to not tell me what she is doing.”

When Joakim expresses that he’s aware of the restrained situation of healthcare and that he knows what can be expected of healthcare and what he as a patient is expected to do in return, he acts as a reflexively thinking consumer that knows and takes his patient responsibility (Lupton 1997: 374). This is a form of self-governing by which he enacts the role of being a responsible patient. Another way Joakim shows that he can self-govern and be autonomous in a satisfying way, is when he shows his patient responsibility, both by being engaged in healthcare, seeking knowledge by asking his physician questions and by being the critical consumer that questions the actions of healthcare.

**Wilma: A Shift in Perspectives - Salesmen Rather than Consumers**

Wilma has diabetes type 2. She is outgoing and makes it her case to get to know everyone at the ward she is listed at. Having the experience of building relation to care provides at different locations is something that Wilma uses as a leverage in negotiating medical treatment. “I have gotten to know everyone. I’m just too much. When I need to get it my way,
I make it happened” she says with a small laughter. As wanted by healthcare policy, Wilma is obliging to the ideal patient role of being a responsible patient by engaging and collaborating in the healthcare relationships at hand. By not just patiently waiting for healthcare to suggest treatment Wilma shows that she is a proactive and responsible patient that makes and effort to gain the healthcare she seeks (Nordgren 2008: 516, 517).

At one point, back in 2016, when Wilma was listed at Danderyd hospital for treatment she tried to get treated with an insulin pump. When she didn’t receive the medical aid she wanted, she got really upset and change to Karolinska University Hospital. Even though she changed hospital she really misses the nurse at Danderyd. During our meetings, she told me about one other coaction after the move to Karolinska when she threatened to move back to Danderyd to get the help she wanted. Wilma tells me, that when her present nurse found out she wanted to move again, she fought to make her stay. Here Wilma show signs of being a critical consumer that uses her consumer power to exit (Hirschman 1970 in Hartman 2011) the situation when healthcare cannot offer her the care she wants.

In Wilma’s records, it still says she has diabetes type 1. This is a misprint she will make us of as long as it gets her the care she wants. And even though Wilma recently got a changed diagnosis she refuses to be remitted to the outpatient clinic since she has doubts about the knowledge and competence at the outpatient clinic. This opinion is so strong that she even told her nurse as Karolinska that she didn’t want to be anywhere else than there.

Wilma has gotten all educations there is for diabetes. When she came to Karolinska they let her try the insulin pump but when she sat at the introduction course learning to manage the insulin pump she couldn’t go through with it. Thinking that her diabetes was so much easier than everyone else’s made her feel bad for taking resources from those who need them better. Other patients at the course tried to make her feel better by saying that everyone reacts differently to their diabetes but for Wilma it didn’t help, it had affected her mentally. The moral pressure not to waste society’s scarce resources can weigh heavily on patients causing conflicting motivations in patients. At the same time as Wilma used her power as a consumer to get the care she wanted, when she finally got it, she did not feel entitled to the resources at her disposal.

As we have seen by Wilma’s experience she adapts the role of the consumer patient that utilizes her agency to exit and change care-provider when she is dissatisfied (Hirschman 1970 in Hartman 2011). However, in difference to Lupton (1997), Linander (2017) and Nordgren (2003, 2008) that has observed patients acting as active consumers on a free market of social services, I have met informants who, in their quest for the preferred medical aid and
treatment, adopt the role of salesmen that “sell” and legitimize their illnesses as products. Hence, to get a different understanding of patients’ agency within healthcare one can place patients on the opposite side of the free market, not as consumers that through the exchange of recourses acquire the services of a market, but as salesmen or job-seekers presenting their recourses for a market.

**Elisabeth: One Can Be Too Autonomous**

Elisabeth is in her fifties and was recently diagnosed with diabetes type 2. She presents herself as a self-thought accountant that is devoted to her job. She runs her own accountant firm and before the diagnosis she enjoyed working around 65 - 70 hours a week, which she has been doing for the past twenty years. Even so she is not the type who gets stressed. When she got the diabetes diagnosis, she took it as a welcomed wake-up call. The physician had told her that if she had continued living like she did she would have gotten a heart attack or a brain haemorrhage within the next five years. Thanks to a drastic change of diet she is now what is called a “zero”, a symptom free diabetic. Elisabeth is part of healthcare’s success story of autonomous and recovering patients but accounting for the lack of help and support from healthcare she is much unwilling to ascribe here success to healthcare. She tells me that her recovery is all thanks to her own efforts since she has practically been forced to manage her disease on her own. In this situation, we can find a good example of the governing technology of healthism and how self-governing is practised to achieve moral height. By self-treating her disease to the extent that she is symptom free and practically not anymore in need of healthcare is not only emphasizing her own effort and success in reaching (and overachieving) the ideal patient role as active and autonomous. It is also a form of self-governing that both show Elisabeth’s personal moral achievements and revile the social moral norms she unavoidably need to relate to concerning that she has diabetes type 2. A disease associated with being lifestyle inflicted (Crawford 2006).

Being a healthcare success is frustrating for Elisabeth and she feels that healthcare does not seem to have any interest in finding out more about her and her life situation. Elisabeth want the individualised treatment-plan that healthcare has written about in their guidelines. So far it has been absent in Elisabeth’s care. “They say that they will create an individual treatment plan but they don’t. If they just took five seconds to ask who I am they would understand what they need to do and don’t.” Instead she is met with prejudice ideas of how a woman in her fifties should react and act to a diabetes diagnosis.
If you have accepted your faith when you are sick and you are driven and make the best of it then you don’t get along with healthcare because they don’t want that kind of patients. They want those they can pad on the back. It’s a lot of this ‘feeling sorry’ attitude. [...] And then unfortunately, if you’re a woman meeting healthcare then you’re treated as a nervous wreck and pampered with. It is a lot of pampering and that makes me panic. (Elisabeth)

Her experience is that healthcare is very good at handling patients who either have difficulties in making the necessary changes needed for a satisfactory self-care or who suffer psychologically from receiving a diabetes diagnosis. But when she faces the news of a diagnosis as a possibility rather than a burden then healthcare stands perplexed and doesn’t know what they can offer her. Mutual requirements between patient and healthcare provider is what Elisabeth wish for. It is the same approach she applies to her work life and clients. She tells me about one time when she got in conflict with healthcare because she stopped taking her medication without consulting her healthcare-provider. The healthcare-provider then replied that healthcare can’t take responsibility for her treatment and health if she didn’t abide to their recommendations. If she didn’t she had to manage on her own, the healthcare-provider added. This reluctance of healthcare-providers to assist patients that decide to self-medicate and self-treat has also been observed in the study by Linander (2016). In the study healthcare providers showed unwillingness to control the hormone levels of patients waiting to undergo gender-confirming medical procedures when patients on their own initiative had started to self-medicate with hormones (Linander 2016: 2016). Elisabeth think refusal is a peculiar reaction from healthcare and she compares it to her approach to her clients. In her line of work, she provides the clients with informed recommendations so the client can make informed decisions about their economy. Elisabeth would never dream of terminating a relationship with a client just because she disagrees with the client’s decision.

Listening to her experiences I can with certainty say that Elisabeth is what one can call an *e-patient* (Hewitt-Taylor & Bond 2012). Shen admits that she is a demanding patient. When she gets interested in a subject she reads all she can find on it. Most often she is more updated on diabetes than the nurses and she demands good arguments and opposes treatment when she disagree with it. But being an autonomous, informed and active patient has not granted her easier access to healthcare. Elisabeth would nothing more than to be autonomous in a way that suits her life. For her, the problem is not healthcare’s engagement in her, it is that they don’t understand her and have no interest in finding out who she is. She feels that healthcare doesn’t know how to handle patients that are autonomous and driven. This has put her in conflict with healthcare:
They cannot handle it if you are interested. Nonetheless, that is what they say they want you to be. They want everyone to take care of themselves and achieve healthy levels. But if you do that then they don’t like you because then you are demanding and a burden. It is frustrating to see and if you feel frustrated and difficult then you don’t want to go there [to the health clinic]. Why should I talk to a person who doesn’t like me? (Elisabeth)

With her bad experience of healthcare, Elisabeth rather manages all her care on her own. For example, as a symptom-free diabetic she would gladly monitor her levels herself and make the necessary test when she feels it is needed without going through the hoops of meeting a physician or nurse. That is not possible in the present healthcare system that requires medical actions to be approved and monitored by a health-care provider.

**Karin: When Knowledge Get You in Trouble**

Typical for governing practices in late modernity is that the governing is partly based on the subjects voluntarily subduing to being governed. In this context, the governor is dependent on upholding the credibility as the hegemonic holder of power over the governed. Consequently, subjects mistrust in authorities is a sign of a weakening of the governing power. When subjects stop believing in the traits that render authority its credibility as power holder, such as knowledge and competence, the present power-dynamics is at stake (Foucault 1991). As the social structure shifted with the onset of neoliberalism and as marketization of social services transformed what it meant to be human (Bodén 2016: 75) a new patient role emerged that with its presence challenged the current order of power. The essence of the critical consumer-patient was the very questioning of authoritarian knowledge and subsequently its power (Lupton 1997).

During fieldwork, I came across another example of the critical consumer patient in the form of a parent to a patient with chronic illnesses. Karin is mother to Tobias, a teenager who needs a lot of care and support. Tobias has Down Syndrome, Autism and a language disorder. The many years of struggle to obtain treatment and help from healthcare, school and social services has made Karin skilled at arguing for her son’s cause. When Karin has experienced a healthcare that is lacking in competence her way of approaching healthcare has been to take a pro-active role by attaining more knowledge about her son’s situations and conditions and using that to ensure that her son get the care he need. When I ask her to give me an example of this kind of battles, Karin tells of the time when they she and her husband noticed that Tobias had trouble urinating and didn’t want to urinate. They felt that Tobias needed a genital surgery but when they took their concerns to the physician, the physician refused to perform
it. He told them that surgery is not a simple matter. If they operate then maybe they need to do surgery in the urinal tracks as well. Karin recount him saying “these kinds of children they don’t need to”, referring to children with disabilities, like Tobias. Receiving that response from the physician Karin asked for a second opinion and got it. When she did, the first physician got really upset and took it as critique of his competence. “Don’t you think I know my work. Don’t you believe I know what I am doing?”, she recalls him saying. She told him that she had no opinion on his competence, it was his attitude and treatment that she disliked so she wanted someone else to examine Tobias. With the second physician, it was no problem getting the surgery. According to him it was not a big surgery. Later when they did a biopsy on the removed tissue they found that Tobias had a chronic disease called Lichen Sclerosus. A genital disease causing Tobias a lot of pain when urinating. Pain that Karin think he had been living with for a lot of years counting that they already five years ago contacted healthcare and asked for a medical contact when they noticed that Tobias had problems. When they finally got the second opinion and got clearance for the surgery and could go through with it, two years had passed. I asked Karin what she thought, why it took so long to get the surgery. If she believed it had anything to do with bureaucracy. She guesses that healthcare grew tired of them for nagging so much. At least that is how she experience it. After two years of waiting in the surgery que, she went to their paediatrician and complained that noting seams to happened. As a result, they got a scheduled surgery within two weeks. “This is not the first battle, it is one of many that we have gone through” she says.

As Tobias has a language disorder it is sometimes difficult for Karin to know what causes him to be in pain or unease. Because of this, Karin need to act as a kind of detective, putting two and two together. This has made here extra skilled at “reading” Tobias. One would think that this detective-skill would help Karin and Tobias in their meetings with healthcare professionals, but she shared with me her many stories of frustration when her concerns about Tobias health were ignored by physicians:

Many times, it’s like this, as a parent to a child with disabilities that can’t explain how they feel or what symptoms they have and all these things. Then, we [parents] need to guess and use our intuition when there is nothing concrete to put your finger on. And this is sometimes frustrating. We kind of need to be detectives all the time. This is where you need help from physicians, but physicians don’t want to be detectives, not really. They want evidence and facts. (Karin)

She tells me that Tobias is now undergoing a kidney investigation and possible surgery. She says the urologist can’t or won’t do anything if there is no reliable way of proving that the medical intervention will have a good result. She reconnects to the discussion about the
surgery that Tobias went through and reasons that, if that surgery was so successful and the physician did not believe in it at first, maybe they should give this a chance as well. She continues and speculates on the possible positive effects the surgery can have on Tobias health. She wonders what effect the surgery would have on Tobias kidney functions and autism. With a hint of dejection, she asks me: “Who will help me? There is no one”. She told me she had asked the Urologist on the matter but he said he didn’t know:

H – Who should know then? Is it you who should?

K – It becomes me, because no one else knows.

When Karin tells me about her son’s situation she unfolds a picture of a compartmentalized system of physician and care-contacts so focused on their own special area of expertise that they don’t see Tobias as a whole person. She starts to account for all the care contacts only around Tobias (one of her three children). The list is long, one for his kidneys, one for ear nose and throat, one for his eyes, a cardiologist, one for the lungs, a urologist, an orthopaedic, a special dentist and on top of that, all the contacts in school, the municipality, the social security agency, and other agencies. One year she counted that he had 72 different contacts:

Most often we have 72 different contacts that we need to argue with because we don’t get the support or care we feel that we need. We very often get opposed. So, it is important to have lots of energy and strength to fight all these contact. And then off course, you should pick your battles. (Karin)

When her other son got leukaemia as a 2-year-old, she again experienced non-compliance and medical mistreatments from healthcare. Karin had noticed odd symptoms on her son which she told the physician. But, after a first quick examination the physician wanted to send them home with antibiotics. Even though her son couldn’t stop bleeding after a blood sample to check for infections, they didn’t take notice of that and wanted them to go home. But Karin didn’t want to go home as she saw that her son got worse as they spoke, which she pointed out to the physician with no luck. Back home she called the childcare unit at the local hospital and got an appointment the day after. Two physicians examine her son and this time they could tell just by looking at him that it was critical, either he had a serious case of blood disease or blood infection. They transmitted him to the regional hospital and when they came up to the child oncologist ward they ordered a blood work. When the test results came back they discovered that his haemoglobin level was on 33. Karin told me it should be around 100 - 120 and if you have levels lower than 80 you get a blood transfusion. “He had the lowest
levels they had ever seen on the child oncology ward”.

As for the medical mistreatment by the first physician, she thought of filing a complaint but at the time she had no energy for it. The manager at the outpatient clinic wanted her to have a sit down with the physician that had mistreated her son and talk it through. She questioned why she should need to talk to a person that do not take her seriously. I asked her if she has any idea why they wanted her to talk to the physician. She didn’t know but guessed they saw it as a chance for her to express her opinions. She turned them down. Instead she ordered a transcript of her son’s medical records in which she saw that the physician afterwards had added that he during the examination had felt for her son’s internal organs. But according to Karin, he didn’t because her son was too angry to be touched.

K – He didn’t feel his stomach at all. If he would have done that he would have felt that the inner organs were enlarged.

H – Had you felt that they were enlarged?

K – No, I didn’t have the competence to do that at the time, I really didn’t.

H – No, I’m thinking that one shouldn’t need to have that competence?

K – You know what, I don’t think that either. Parents worry need to be enough and the doctors need to provide for the competence. It’s the same in school. I should not need to have special educational competence, but I have to because the teachers don’t.

The last statement of Karin is telling for the approach that she has developed in here experiences with a malfunctioning healthcare. Karin had a strong feeling all along that something was wrong with her son’s health and in the end, she was glad that she didn’t settle with the first physician’s diagnosis.

Besides the battles with healthcare and the school Karin and her family need to go through the bureaucratic hoops of the social security agency to get the right to special service and assistance for Tobias in his everyday life. The Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387) is a law of right that shall guarantee a good standard of living for people with extensive and permanent disabilities Socialstyrelsen (2007). To get assistance Karin need to re-apply every second year and the last time she did it, in March 2016, the processing of their case took 10 months. The bureaucracy of applying for social support and financial aid, getting rejected, arguing for your case and then finally getting approval, is sending a clear signal to patients and kin. “You always feel that you don’t have the right to it, that you shouldn’t”, Karin remarks when she mentions the debacle of getting sickness compensation for herself when she was on sick-leave
for occupational burnout and child-care allowance for Tobias (and Jacob when he had leukaemia). For Karin, the role of being informed and active is a role that she didn’t take on all voluntarily, neither is it completely forced upon her. It is a role that she has partly grown into and partly embraced because of the circumstances she has found herself in. At the same time as she experiences this adaptation to be out of pure necessity since there is rarely anyone but she and her husband that fight for her children’s rights and health. Throughout our whole conversation, Karin kept coming back to one specific narrative that tells of a governing technology in working. The fact that Karin felt the need to take on the task of fighting to get her sons the treatment they need shows that she embraced the role of the critical consumer. Karin equipped herself for these battle by becoming knowledgeable and using that knowledge to suggest treatment alternatives and questioning authority. In her narrative, the act of actively pushing for care becomes a moral virtue that patient ought to reach for to be responsible patients and in her case a good mother. The amount of responsibility Karin need to take on to tend to her children’s healthcare simultaneously as she struggles with a slow and bureaucratic system, she says, is typical for families with children with disabilities. “We were right in the end but one should know that you have the right to it and then also that you have the energy to try to get it”. This comment is telling for the attitude that Karin has developed during the years of relating to healthcare. In accordance to the critical consumer-patient role, Karin is practicing her patient responsibility by always critically analysing the suggestions and replies of authority.

**Clashes with Healthcare and Ideal**

What the experiences of informants witness of, is the range of self-governing that is at work when patients try to access healthcare by trying to embody the state’s ideal patient-role. This sometimes result in patients getting into conflict with healthcare. From the experiences of Elisabeth, it shows that the range in which patient can access and exercise patient autonomy is quite narrow and has its clear limits. The ideal patient has the right amount of will to be autonomous and execute that autonomy in a way that the healthcare system is equipped to cater for. In this sense, Elisabeth is not an ideal patient. Not achieving (but over achieving) the ideal patient-role Elisabeth instead adapted to the alternative role of the critical consumer patient. But viewed from the perspective of Patient-Centred Care Elisabeth is doing exactly what is wished for of patients. She actively engages in her own care, becoming the resource by which she solves her health problems (Nordgren 2003, 2008). What is not unfolding as
expected in this situation, if we linger in the patient-centre care perspective, is the development of the partnership between patient and care-provider. In Elisabeth’s relationship to healthcare the requirements of the two parties is unevenly met as she presents herself as overachieving her requirements and experience healthcare as drastically underperforming theirs. In a neoliberal self-governing context, this can cause patients to make use of their own resources and seek alternative ways to treatment or a cure. Subsequently, patients’ themselves voluntarily take part in the transfer of responsibility for citizens’ health from state to citizens (Cruikshank 1999: 48; Nyqvist 2008, 2015; Rose 1999). Furthermore, the states reasoning that patient empowerment enables an effective use off all resources to ease the economic burden of future healthcare, legitimizes the transformation of patients into potential resources. With this logic, the question of responsibility is always present. As the Swedish government, in line with a marketization of society through New Public Management reforms, has outsourced many of its former social obligations towards citizens so has the personal responsibility for each citizen risen accordingly (Rose 1999; Crawford 2006).

Similar to Elisabeth’s experience, Karin’s experiences also stand as examples of the narrowness of the ideal patient-role. To meet the requirements of the ideal patient-role and to make it functional in the practice of the healthcare system means to be just the right amount of engaged and informed. Succeeding the ideal patient-role do not make it any easier to access healthcare. Quite the reverse it required patients to more often engage in arguments and fights with healthcare. As the informants adapted to the attitude that healthcare never comes easy, that it’s never free, in the sense that you have to make an effort to get it. This created an idea of how a moral and responsible patient should act. Questioning treatment and criticizing healthcare became the common way of interacting with healthcare and the critical consumer became a moral ideal. In other words, not placing demands on healthcare and not expressing criticism is the same as not taking responsibility for you care. The responsible consumer-patient doesn’t just agree without first reflexively evaluating what is offered to them. To uncritically abide to healthcare’s suggestion becomes in this context an immoral act. The implications of the second phenomenon observed in patient behaviour, that of patients taking responsibility for issues that previously have been the responsibility of healthcare professionals I have seen various examples of when informants embody the informed and active consumer patient. In their role as critical consumers, at some occasions informants adapted a market logic when referring to or interacting with healthcare. For example, to present a critique of the inability of the healthcare systems to handle demanding and autonomous patients Elisabeth, who works as an accountant consultant, compared
healthcare’s strategy of relating to demanding patients with her own strategy of relating to demanding clients. And Wilma strategically utilized her power to choose and re-listed herself to different hospitals as a form of coercion when navigating healthcare to get the treatment she wanted.

The relationship between patient and healthcare-provider is complex. As well as it can be motivated by a joint goal of increasing the health and well-being of the patient it is a relationship containing two parties that have different motivation, position, agency and stakes at risk. The care-provider is there in a work-related matter as a professional and the patient is there on a private matter in the role of a layman citizen with a health problem (Nordgren 2003: 8). In a time when patients rarely have one permanent contact with healthcare Joakim felt the need to be the overseer in charge of his medical records because he doubted the healthcare-provider’s ability to manage this task due to healthcare’s restrained time-recourses. The reaction of Joakim can be interpreted as a sign of him embodying the critical consumer patient that has a sound suspicion against authoritative knowledge. It is also a sign of him being a responsible patient that willingly expand his role as a self-governing subject by taking an increased responsibility over his own healthcare. In this case, by being the hub of knowledge.

This chapter has presented examples of how patients manage the state’s ideal as it enters the practice of healthcare. To end this chapter I want to take a moment to discuss patient autonomy which is central to the state’s ideal patient role. As shown above, self-governing your behaviour by aspiring to be autonomous on order to reach the ideal patient role, do not always result in desired treatment from healthcare. I argue that patient autonomy and choice, as it is portrayed in a context of neoliberal marketization, is an illusion. I base this claim on the fact that this is not the experience of my informants. Among my informants there were few possibilities to make significant choices concerning care-provider, treatment, medication et cetera and when informants got the sought-after treatment it was often preceded by argumentation and discussions. The emphasis on increased choice is a crucial part of neoliberal political strategies to increase individualization and individual self-realization. But instead of empowerment working, as some theorist claim, to render subjects enabled, free and with more agency, empowerment can be said to give subjects a false sense freedom. Analysing New Labour politics, Clarke (2005) has alike Cruikshank (1999) spotted the logic flaws in the neoliberal emancipation of individuals and calls it a form of mock autonomy. Seeing that this readiness to grant citizens more rights in practice offers citizens a quite limited agency to use their autonomy since they are prompted to us it responsibly, not acting
in a way that could harm the own health like “binge drinking or over-eating” (Clarke 2005: 451). Barbara Cruikshank (1999) scrutinize the agenda of those who work to empower subjects. She means that empowerment is a technique of governing that creates self-governing subjects, exercising power upon themselves so the governing agents does not have to. Subjects self-esteem is crucial to this form of governing since a heightened self-esteem enables/encourage subjects themselves to act and to take responsibility to better their life situation (Cruikshank 1999: 91). The fact that autonomy in practice did not providing informants with more agency, on the contrary it gave them less agency since it encouraged patients to aspire to the, hard to achieve, ideal patient role, goes to show that empowerment and the aspiration to achieve the state’s ideal works as techniques of self-governing. Techniques which was frequently deployed by informants.

Chapter Summary

As my ethnography shows, informants’ experiences of taking an active and responsible approach to care and treatment have various effects on the patient to care-provider relationship. Patients activated different techniques of self-governing to cope with the state’s ideal patient role. The state’s encouragement of patient to actively participate in healthcare can sometimes cause conflicts when informants practice this engagement. Despite taking an active and engaged approach to healthcare, which is seemingly what healthcare want them to do, several of my informants disclosed to me their experiences of conflicts with healthcare. The most significant reason these informants ended up in conflict was the fact that they reacted to the state’s ideal by embodying another patient-role, the critical consumer. As struggle became a given in the work to attain treatment, active engagement in healthcare by fighting, criticising and demanding, became a signs of patient responsibility and moral height. Elisabeth and Karin were two informants who embraced the critical consumer role. In opposite to Karin and Elisabeth, Joakim got along well with healthcare. A prerequisite for this happening was firstly, that Joakim didn’t, to any mayor extent, adopt the role of the critical consumer. Secondly, Joakim did not assumed the healthcare system to be able to take responsibility for his whole healthcare. To make sure treatment was successful he willingly adopted responsibility over his own healthcare. Specifically, by being very knowledgeable of his medical history and when necessary providing the healthcare system with information about his medical history. I take Joakim’s attitude of not assuming to much of healthcare and him being aware of his own responsibility as a patient, to be telling for the informed and
active patient role that he embodied. Wilma’s experience of practicing consumer choice was a clear example of when patients adopt the consumer patient role. Still in her practice of consumer choice she was struck with feelings of guilt for taking healthcare’s scares recourses. This goes to show that different technologies of governing can sometimes collide. The technology of neoliberal patient empowerment and the technology of ethopolitics caused in Wilma an internal moral conflict when the consumer practice collided with the feelings of guilt towards her collective (society).
5. Not meeting the Requirements

As portrayed in the last four patient stories of highly autonomous and sometimes overachieving patients there is a discrepancy between the intention behind governmental policy and what happens in patients’ healthcare reality. This is leading on to the final ethnographic chapter of this thesis in which it will be elaborated on the subject of patients who have difficulties living up to roles of being autonomous and responsible patients. The experiences of accessing healthcare is both linked to patients’ illness-experience and to healthcare’s approach to patients and illnesses. Strikingly many of my informants have experienced struggle to receive the healthcare they feel they need. For active patients, this originated in their embodiment of the role as critical consumer patients seeking to engage in healthcare in a demanding and critical way. For other patients, this struggle emerged because their inability to live up to the ideal patient role. These informants felt stress and anguish for not being able to be the knowledgeable and responsible patient that social norms urge them to. The reasons for their inabilities will be exemplified in this chapter. A common characteristic among these patients is the moralizing around their inabilities. Remarking what they can’t live up to and reflecting around the reasons why shows how moralizing is used as a tool to self-govern and to express to others, their remorse for not being able to live up to social ideals.

Veronica: It’s just IBS, the Hardship of Having a Discredited Disease

Veronica has struggled all her adult life to urge healthcare to take her IBS disorder seriously and do a thorough medical investigation of her condition. This has proven to be difficult. Most of the times when she seeks healthcare she leaves the clinic with a temporary “band aid” of pain relievers and a refill of fluids:

The worst thing is that you don’t have any control what so ever. You just have to live with it. And then, to get the nonchalant response from healthcare to, ‘Go home and ride it out’. They have no bloody clue of what that really means. (Veronica)

After three medical visits for stomach problems Veronica got diagnosed with Irritable Bowel Syndrome. This was eighteen years ago. The doctor left her with not much else than a name for her illness. No treatment, no recommendations or even information on how to cope with the disorder was given. When the doctor had solved the riddle of her symptoms she was sent home to figure out the treatment on her own because healthcare had no actual knowledge of how to treat the disorder. One time several years later a physician at the emergency room
made a remark on her disorder and said: ‘It is a funny thing this IBS because there is no science to it’. Veronica didn’t think the situation that had led her to the emergency room where she now sat in agony, receiving fluids on drip, was the least bit humorous. The experienced lack of interest from the scientific community and the feeling that healthcare does not seem to recognise the severity of the disorder, has left Veronica on her own to try and figure out a functional treatment.

To become the ideal patient that is actively engaging in healthcare by attaining knowledge about their own illness requires there to be any knowledge to attain. Since there has not been much research done on IBS as a disorder, the knowledge Veronica need to accumulate to become knowledgeable do not exist. This has left her with no tools to fight. Hence, Veronica can’t even beguine to aspire to become a responsible patient and prove herself as morally good.

In the emergency room the humorous physician had left Veronica in the medical office to go and check her medical records. When he came back he concluded that it was only IBS. Veronica was prescribed with pain relievers and sent home to endure the relapse. This was the first time she had felt so ill that she decided to seek emergency help instead of booking an appointment. The day after the visit to the emergency room Veronica still felt ill so she visited the outpatient clinic to get a physician’s sick note. At first the physician told her that she doesn’t write sick notes for IBS. When Veronica asked why, she then replied that Veronicas vital signs were good enough for her to work. This made Veronica furious and she clarified to the physician that she works with kids and can’t leave them 10 - 15 times a day “to take dump”. It just doesn’t work, she said. The physician replied that she can prescribe sick-leave but that is no guarantee that the social security agency would accept it. Hearing that made Veronica burst into tears, she had enough. The physician complied with her and wrote a sick note recommending one week of sick-leave. “When I left, I felt like, dammit, no one listens! It’s not like I’m home because I like to get a reduced economy” Veronica comments. Not only does Veronica lack the tools of knowledge needed to act as a responsible patient. As the comments on the humorous side to IBS, made by the first physician show, Veronicas possibilities to become the responsible patient and enact self-care is severed as her disease is not even morally recognised by the healthcare discourse as a proper disease. This is further ensured by Veronicas difficulties in attaining sick-leave, as that physician clearly did not took her condition seriously. Veronica is an example of a patient that fails to live up to the ideal patient role. Not because she lacks the personal motivation to become the idea patient. But because the healthcare discourse doesn’t recognise her illness as a proper disease. This has
disqualified Veronica right from the start. Regardless of, that this is not caused by Veronica, as the logic of ethopolitics says, citizens are equally responsible for the community regardless of personal ability or inability or its causes. Hence, society has marked Veronica as immoral (Crawford 2006).

The friend that accompanied Veronica to the emergency room questioned the physician’s recommendation to go home and wait for the relapse to cease. “She has been trying to ‘ride it out’ for a month now” the friend told the physician and continued: “How should she ride it out? She needs nutrition!” The physician replied that Veronica’s vital signs were too good for her to be given additional nutrition except for what was already provided in the drip. Veronica asked what she should do if she went home and again couldn’t eat for yet another three weeks, if she then were supposed to come back to get another bag of nutritional drip? “Yes…that is how it works.” the physician replied. In the logic of healthism, as Veronica fails to find a cure for her disease it becomes a personal failure.

One week later she is back at the outpatient clinic. Because of the nonchalant attitude of the first physician, this time she asked for another physician. The new physician tells her what she has already heard before, that her levels are fine, but he adds that her body is exhausted because of the relapses. He recommends her to go back to the hospital’s emergency room to get another refill of nutrients andcombe back to him the following days. Taking his advice, she visits the emergency room and comes back to the outpatient clinic some days later. The physician looks at her medical records and notice the numerous occasions when she has sought care and ask her if anyone have ever remitted her to a gastrologist? No, she replies. He then proceeds by remitting her to a gastrologist at the local hospital. After all the years of feeling indifferent to healthcare Veronica is baffled and relieved to finally meets a physician that listens to her and takes her illness seriously. He prescribes her with medicine for some of her other maladies and ask her if there is anything else he can do for her. No, she says, she is just grateful and relieved that someone listened. It only took one attentive doctor to provide her with the healthcare she so much sought after. Judging by the rarity of that occurring in Veronica’s treatment history, seeking care has turned into a less than obvious matter. With the indifferent attitude and treatment, she has felt from most healthcare providers, seeking care nowadays feels more like a waste of healthcare’s time. The only reason she does it is to get the physician’s sick note to hand to her employer and the social security agency.

Veronica’s feeling of not being taken seriously and not being listen to all these years reveals that she lacks the agency of voice (Hirschman 1970 in Hartman 2011). Her inability to become a responsible patient has left her with low expectancies on healthcare, long ago she
lost the expectancy of healthcare to provide her with treatment. She simultaneously lost the expectancy of being recognised by healthcare as a proper patient. Now the only thing she continues to fight and strive for is that healthcare should recognise her qualities as a patient enough to grant her sick-leave when she needs it. As well as patients should be knowledgeable and able to use that knowledge to fight for their rights as patients. To be able to claim your rights as a patient you also need to have a proper disease that is recognised by the discourse as a proper disease.

Even though healthcare policy seeks to empower patients by prompting the healthcare discourse to see patients as co-creators of healthcare the experiences of Veronica tells that of the opposite happening. Instead of Veronica being approached as a partner in healthcare work, here an opposing knowledge discourses is placed against her knowledge discourse. Veronicas self-experienced knowledge of how her work-ability is effected by the pain and disability of her illness is placed against the professional medical knowledge of how the body is affected by the same illness.

Relating back to the morality of wage-work and the immorality of being on sick-leave. Before Veronica can even contest the immorality of not working she is being disqualified by the healthcare system since it does not see her illness as a legitimize cause for sick-leave.

**Emma: In the Wake of Empowerment**

To access treatment patients are more and more forced to embrace an active and demanding approach to healthcare. This can be noticed both by patients’ experience of lack of outreaching support from healthcare and by patients’ perception of being assumed to take on the autonomous role and manage most of their treatment in the form of self-care. What moves these two causes is the informants experience that they in order to get help need to have a disease that is seen by the healthcare discourse as being a proper disease. This was shown in the previous experience of Veronica. This is also the case for Emma that has diabetes type 2. Before her diagnosis, despite having a mother that have been treated for diabetes for over ten years, Emma had never let anyone check her blood glucose levels. But after a longer period of feeling stressed, thirsty and making more frequent visits to the bathroom she decided during a visit to her parents to borrow her mother’s glucose meter and check her blood glucose levels. The word “error” appeared on the display. She and her parents understood that something wasn’t right. The next day she went with her mother to Danderyd hospital. On arrival, they took her in immediately when they saw that her glucose levels were soaring around 30
mmol/L. The reference value for fasting plasma glucose (FPG) is 4.0 to 6.0 mmol/L (Andersson 2016). Everyone with a FPG higher than 7 mmol/L will likely be diagnosed with diabetes. After the immediate diagnosis and care that first day she stayed in the care of the hospital for a while so they could educate her in self-care and monitor her progress. When her physician at the hospital deemed her able to manage her treatment on her own she got remitted for outpatient care at her local outpatient clinic. In the move from inpatient to outpatient care she felt that healthcare somewhere lost interest in her. From having frequent contact with the hospital’s nurses and physicians on a weekly basis, there was now little reaction. Emma worried whether healthcare would do a proper follow up on her diagnosis or not. Because, despite their professionalism upon her arrival to the emergency room Emma was unsure whether they had given her the right diagnosis (diabetes type 2), considering that she has never lived especially unhealthy and she is not obese. And in opposite to a textbook diabetic type 2 that can treat their illness with diet and lifestyle changes, it doesn’t matter what she eats or do she is still dependent on her insulin:

I feel like I’ve fallen through the cracks. Will they try to figure out what type I am? Will anything happened or will I always have a [diabetes] type two diagnosis and never be able to get the help I would need If I had a [diabetes] type one diagnosis? (Emma)

In the Patient Act (SFS 2014:821, 6 chapter, 1 - 3 §) it is stated that: “Patients need for safety, continuity and security shall be provided for”. Which further said, can be provided through the possibility for patients to choose a permanent contact in primary Healthcare. Emma wished she had a permanent diabetes nurse in the outpatient clinic, someone who she can call when she has problems. She explains that there is one diabetics physician at the centre working part-time and some diabetes nurses but that’s it. The physician who got her remittance from Danderyd was Emma’s asthma physician. Who, Emma assumes, know nothing about diabetes. She went to see him once, but then nothing really happened. To explain their lack of engagement she reasons that either or must be the reason. Either they don’t take her seriously enough, or they think she has enough self-control and knowledge to manage her self-care and is in no need of their help anymore. I asked her if she believes that they trust her to be able to care for herself:

Somehow yes. Since not much has happened. When they discharged me from Danderyd they told me ‘Now, as you have learned how your body reacts, would something happened you just need to take some extra doses of insulin.’ […] I have been cheating almost every day since they discharged med from Danderyd. When they said that they weren’t a hundred percent sure of what diagnosis to give me. I just felt
like, okay... so why do I do this? Why should I take these [insulin] shots all the time when no one cares? So... I stopped taking my insulin. I stopped for whole week. I don’t know why I did it. Then I noticed that I felt so much worse without it. (Emma)

Emma coped with the feeling of disinterest from healthcare by cheating with her treatment, skipping her insulin. She knows this is irresponsible and will only affect herself in the end but she did it because she felt like no one cared what happened to her. What can Emma’s seemingly irresponsible reaction tell about the relationship between the healthcare system and the patient? In Emma’s case, it can be a way for her to show her discontent with the system and treatment. In a system that cherish personal responsibility, to resist and neglect responsibility can also be a way to exercise agency and power in a restrained situation.

**Outpatient and Inpatient Care**

An issue that separates the care for type 1 and 2 diabetes is the contact and relation with healthcare. By some of the informants I have spoken to, Emma being one of them, outpatient care at local clinics is perceived as providing less quality and less specialized professional care compared to inpatient care at hospitals. “[Diabetics] type two’s end up at their family physician and the type one’s get to stay at the hospital where they are better supervised. So, there is a lot of type two’s who are being left out in the cold” Emma says. The type two’s who attended the daytime diabetics course at the hospital at the same time as Emma had lived with diabetes for seventeen years but never once changed their medication. “And then you have me who, during the period of three months has tried every possible medication there is for type two diabetes” she continues. For Emma, there is quite the stretch from her experience of quick and efficient emergency care and initial care-education and treatment at the specialized endocrine ward in the hospital to arriving at the local healthcare centre where she experienced a low frequency of contact with healthcare personnel that only had basic knowledge of diabetes. Emma think this difference in treatment is telling for the difference in getting a diagnosis at a hospital or at a health care centre and she means it really sets the tone and effect of further treatment. The contrasting experience between inpatient and outpatient healthcare and the fact that healthcare was so quick in trusting Emma’s ability to manage her self-care contributed to Emma’s feeling of being abandoned by healthcare.

An issue that affect the patients experience of healthcare and has direct linkage to the feeling of abandonment is the non-voluntariness of freedom. In a market driven logic, the freedom of the individual is well cherished. But the voluntariness of this freedom has been questioned by some researchers. Rose (1999) points to this in the governing technology of
responsibilization. Social anthropologist Annette Nyqvist recognised the same tendency in her study on the reformed Swedish pension system. A reform that can be seen as a technology of governing (Nyqvist 2008, 2015):

> The technicalities of the pension scheme shift responsibility from the difficult political decision of lowering pensions, or raising retirement ages, or both. With the design of the current system, the responsibility of adjusting pension levels is divided and relocated at both an individual level (where it is up to each citizen to secure her or his future pension) and to a distant national and global economic level of demography, growth rates, and market mechanisms. (Nyqvist 2015: 268)

On this issue Bodén explains that in the context of a market driven logic, focus lies on the individual as a consumer that become someone that can influence the market and the services to fit their own needs by the power of their consumption (Bodén 2016: 75). This development can leave some groups in society especially vulnerable. Marcus Lauri (2016) voices critique towards this logic and means that the medical consumer is an individualized role characterized to be optimistic, proactive, rational, responsible, and informed, that shifts attention away from the quality problem in healthcare and toward the quality of the person (Lauri 2016).

If one take into consideration the fact that healthcare is a system that assumes the patient to take much responsibility and add to this Emma’s doubts in the competency of the healthcare personnel at the outpatient clinic where she was listed at and her worries that healthcare won’t make the effort to re-evaluate her diagnosis, Emma had no choice but to become autonomous and manage on her own. So, what did Emma do when she faced a dead end in the outpatient clinic? In the last of our conversations she told me that she had gone online to and internet forum for patients with diabetes and there she had learnt by a peer how to write her own remittance to a specialised endocrine ward for a second opinion on her diagnosis. She got the appointment in the summer and was now just waiting for the months to pass. The actions of healthcare and the reactions of Emma propelled her to actively take charge of her own healthcare by seeking a second opinion. In this way, the experiences of struggle were recreating Emma’s behaviour to fit the state’s ideal patient role of being active and autonomous. Here one can see how a governing technique of restraining the direct access to wanted healthcare recourses is steering patients towards the more wanted self-governing patient behaviour that treats struggle as a virtue. Yet again it shows that, to be a responsible patient informants need to actively fight and demand healthcare.
Lena: The Not Knowledgeable Patient

Lena suffer from multiple diseases among them a rare form of Vasculitis, a chronic blood vessel inflammation that makes the body turn on itself. In 2012 Lena got diagnosed with occupational burnout. At that time, she went to the hospital because she felt that there was something very wrong with her body. Even though the physicians did several tests they couldn’t find anything wrong with her. Two years later, the day before Midsummer Eve she started to feel very ill. She felt nauseous, her whole body swelled up and her skin cracked. As her feet also swelled up she had trouble walking. On Midsummer Eve, she was rushed to the hospital and was taken to the intensive care unit. At first the doctors thought she suffered from a severe allergic reaction. Then they discovered her vasculitis, and as they did, they also found out that she had eczema, allergies, asthma and Chronic Obstructive Pulmonary Disease.

The vasculitis appears as relapses of inflammations that can affect various parts of the body and the places of inflammation can change from one relapse to another. The most demanding things with the disease is the long recovery period after relapses and the numerous contacts she has within healthcare, not to mention all the medications: twelve pills in the morning; four at lunch; five in the evening; iron injections three to four times a month; various ointments; and the asthma medication. On top of that, when she was hospitalized to treat the vasculitis her kidneys collapsed and she got severe kidney failure. Which is a challenging disease in itself with all the dietary food and fluid restrictions and possible dialysis. During relapses the disease is suffering on both the body and the mind. In these moments, it is hard for Lena to keep up the spirit and it has happened on many occasions that she has told her family that she doesn’t want to live with the disease. This is unsettling for her family. When she got the burnout, she got remitted to a psychiatric ward for a month. It has also happened that Lena after the burnout has mentally collapse and needed medical attention. On these occasions, she has herself called for the psychiatric mobile team to come and talk to here and evaluate her need of hospitalization.

At one point Lena’s Vasculitis disease was so bad she couldn’t walk up the flight of stairs to her apartment. Without an elevator in her apartment building, her brother offered her to come stay with him and his wife until she got better. Lena is very appreciative of his hospitality and support through the whole sickness process. Ever since here occupational burnout in 2012 she has had trouble processing information. In the situation where she needs to take in information, like when listening to healthcare and the professional language of
doctors, her brother has been of great support. When Lena fell ill and her kidney started to malfunction she met a nephrology physician. Lena had a bad start with her physician. Right from the beginning Lena experienced that the physician was more focused on Lena as a medical object rather than as a suffering human being. “She was only interested in the test results and then she only discussed the results with here medical students ‘let’s do this and let’s do that’ instead of talking directly to me.” After that Lena asked her brother for support and to follow her to her next meeting with her physician. So, in the next meeting with the physician she was accompanied by her brother During the meeting she had trouble understanding the professional language the physician used. But since she was afraid of speaking up because of the title and position of the physician she remained quiet and pretended that she understood. Intentionally or unintentionally, the professional language of the physician had the effect on Lena that she felt ignored and patronized. As her brother heard how the physician used a technical medical language that even he thought was too difficult to follow, eventually he got so crossed with the physician and told her that neither him nor Lena could understand what she was talking about, it was above their comprehension. The physician reacted by getting angry and asked them to leave. The brother then replied that they would request another physician because of this physician poor skills in interacting with patients, and so they did.

Paradoxically, even though it is stated in the Patient Act that information provided to patients need to be adjusted to the receivers “age, maturity, experiences, linguistic background and other individual prerequisites” and that it is the responsibility of the provider to make sure that the receiver understands the information (SFS 2014:821, 3 chapter, 6 – 7 §). See also , attaining knowledge remains as a prerequisite for being a responsible and empowered patient, regardless of personal ability. Because of Lena’s difficulties of attaining information, it makes it hard for her to live up to the moral expectations of being an ideal patient.

Lena have worked through many treatments for Vasculitis with not much luck. One of the possible treatments for Vasculitis is to kill all the infections with chemotherapy. It is a rather effective treatment but after receiving it once with the excruciating feeling of the body being burned from the inside out, Lena clearly understood why some cancer patients chose to stop their chemotherapy. When the physician told her that she would needed to undergo another round of chemo Lena tried to explain to the physician that she could only manage that if she would be placed alone in a single room with dim light and silence during the treatment. Otherwise she wouldn’t make it. The physician replied that hospital couldn’t offer her that.
Hearing that, she told the physician that if they couldn’t give her the things she asked for then she rather not do the chemotherapy at all. She would rather be in pain. As the physician knew that chemotherapy was one of the few treatment options for Lena she was keen on somehow getting Lena to consent to treatment. When Lena did not budge on her conditions for undergoing chemotherapy and the physician couldn’t comply to her conditions. Then, the physician’s final response was to call for a psychiatrist that told Lena that she had two choices, either she went through with the chemotherapy or they would forcibly remit her to a psychiatric ward for evaluation. When elaborating on the social conditions for, what Nordgren (2008) names as the customer-patient, he name two important skills that patients need to hold. I would argue this concerns any patient role that aspire to responsibly and morally enact autonomy. Besides being active in healthcare he mentions one skill that is of particular interest in the situation that just unfolded with Lena’s refusal to accept treatment. Nordgren emphasized the patient’s ability to make rational choices (2003, 2008). Waging the options of no treatment and painful treatment, in the context of healthism where individuals ought to make the best possible choices for their health, Lena did not make a rational choice when refusing treatment. Since healthcare’s reason for turning down Lena’s demands for undergoing treatment possibly has an economic side to it, that the ward didn’t have those recourses, one can also applying ethopolitics to this example. As ethopolitics emphasize the immorality in irresponsible use of communal recourses, Lena’s demands would result in irresponsible spending of communal resources makes her choices even more irrational. The rational choice of Lena would be to comply to suggested treatment. This also points to the fact that autonomy ought to be enacted responsibly (Clarke 2005).

**Chapter Summary**

In these three stories knowledge and information played a vital part in patients’ healthcare experience. Attaining knowledge has been shown to be a requirement for the possibility of becoming an informed, active and empowered consumer patient. Patients failing to attain and using knowledge in their engagement in healthcare did this out of different reasons. Veronica’s failure in getting access to information placed her from the beginning in a disadvantageous position in her strive to get access to treatment and live up to the ideal of

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7 In healthcare’s work to empower and include patients in the healthcare process, the matter of evaluating patients’ ability to make rational decisions concerning their health and treatment is a common issue for healthcare providers. To aid this kind of work the National Board of health and Welfare published the national guideline, Din skyldighet att informera och göra patienten delaktig; Handbok för vårdgivare, chefer och personal (art. 2015-4-10), (Socialstyrelsen 2015). See also, Utredningen om beslutsohmönga personers ställning i vård, omsorg och forskning (SOU 2015:80), (Socialdepartementet 2015).
being a responsible patient. Here situation worsened by the fact that the healthcare discourse didn’t recognized her illness as a valid and proper disease. This made her immoral in the context of social norms and it disqualified her from even trying to prove herself as a morally good and justified patient.

Lena is unable to govern herself. Because of this she fails in living up to both the state ideal of being a responsible, self-governing and autonomous patient, and its counter role, the critical consumer patient. In two ways Lena is unable to live up to the ideal. As Lena has difficulties attaining and processing information she is unable to act responsible by attaining knowledge and using that knowledge to participate in the co-production of healthcare. She is also unable to make rational choices as a critical and reflexive consumer.

Emma felt out of place with being autonomous. When healthcare’s medical interventions came to an end with a care-provider’s expression in the belief in Emma’s ability to manage her self-care, it caused in Emma an increased feeling of being neglected by the healthcare system. This resulted in the feeling of not having access to healthcare. Emma’s reaction to this non-access was to renegotiate her diagnosis. She reasoned that if she were able to change her diagnosis to diabetes type 1 she would have access to the healthcare she desired. Emma experienced that diabetes type 2 was seen by the society as a less proper and justified disease than diabetes type 1. Through her own perception this made her less moral than people with diabetes type 1. Emma’s way of coping with this immorality was to self-govern by trying to morally uplift herself by renegotiation her diagnosis.
6. Conclusions

**Governing the Moral Body**

“Take care!”: a mundane greeting of departure, a goodbye in the words of concern. The exclamation mark underlines a call for action, to take care but of what and whom? By contextualization it is implicitly understood that what is left unnamed is you and yourself. When the phrase is stated in the context of the healthcare system it indicates one party’s concern for the actions of another. The phrase is not uttered solely out of good intention. It is a call to do what is considered right and good; in other words, a call to follow a moral conduct. Morality is found to be a key element in the creation of patients as it informs how and what patients should do. How they should feel, how they should react and act, what they should believe, and what social norms they ought to follow, or at least be aware of. Even though the informants interviewed for this thesis did not always act according to the moral system, they always needed to act in relation to the moral system.

**Governing the Self**

In the experiences of my informants I found two forms of governing that regulated their conduct. Governing was first of all implemented by informants being aware of which social norms were active, then they self-regulated their conduct accordingly. Such awareness of social norms can be explained by Foucault’s theory of governing of the self. This technique of governing is a regulator of minds and emotions rather than a regulator of bodies and actions (Foucault 1988). It also makes this governing potentially highly effective as it works proactively on an individual level and can by few means cause effects on a grand scale in society. The informants exhibited an awareness of moral norms in the way they coped with their diseases and their, more or less, abled bodies. In the practice of person-first language (Titchkosky 2011) almost all the informants distinguished between their personhood and their inflections. For most informants, it felt odd to think of themselves as being sick they rather perceived themselves as having a disease. Because they associated being sick with being restrained from living life to the fullest, it is my conclusion that this separation between personhood and disease serves the purpose to ignore the fact that they were sick. This act of separation can also be explained by informants’ awareness of what social norms they needed to fulfil, especially when they were sick, to become full member of society. They were always expected to contribute to society by wage-working, taking care of their own health and
engaging in the community. The informants often experienced the impact from these norms through the comments of others or – more often – through their own anguish of being potentially judged for their actions (or lack of actions). An important observation is that the practice of perceiving personhood as separated from disease also reveals an underlying set of moral norms connecting sickness, disability and productivity. This has unsettling implications: while the unproductive body is perceived as immoral because it cannot contribute to society as it ought to (Crawford 2006) and sickness is hindering the body from being productive, by extension sickness becomes an immorality.

The Call of Others

Another aspect of governing patients’ behaviour operates through external subjects as they advise or direct patients to act in specific ways. This aspect can be found in policy documents, in the law (such as the Patient Act), in medical recommendations and in statements of concern. A significant aspect of the Patient Act is that it does not contain any legal rights for patients it only states what healthcare is required to do and provide for patients. Nevertheless, as patients have no possibility to legally enforce those obligations, it becomes clear that the Patient Act functions more as a tool for governing patients’ conduct than providing patients with legal rights. In short, the self-governing mechanism of the Patient Act and policy documents functions with a double movement: by telling disempowered patients what to expect of healthcare; and through the encouragement of patient empowerment, which in turn regulates their autonomous behaviour in relation to an often-distant healthcare. If this contradictory system seems confusing for the reader, one might imagine how it is for the patient.

A Discrepancy Between Policy and Practice

Patient empowerment has been part of a lengthily social reform project. During forty years of policy writing, patient empowerment got an increasingly central position in the Swedish discourse. This reformation paralleled a global economic and political shift with the advent of neoliberalism. In order to change the attitude and conduct of citizens, the concept of empowerment became an effective tool to transform citizens into autonomous subjects. Empowerment hence became a social intervention that enabled a shift of responsibility over social services from the government to the individual. Despite the discursive enthusiasm for patient empowerment it is a problematic form of public health intervention that spawned a
new ideal patient role, the role of the patient as a knowledgeable and active consumer patient. As this thesis has shown, this is one role that patients need to take on more often than other by either adjusting to it or adopting it. The ideal-patient role had many direct effects on patients. It informed their actions as patients, it affected their ability to receive treatment, and it affected informants’ relationship to the healthcare system. For example, the ideal-patient role created specific expectancies on patients of being self-reliant and taking responsibility for much of their healthcare. On paper, the description of the ideal patient as actively engaged and self-propelled emerged. But to transfer the ideal from paper to practice appears as difficult as well as contradictory. Consequently, a discrepancy emerged between how patients were supposed to act according to the ideal expressed in policy documents and how patients who enacted this ideal were treated in the practice of the healthcare system. Whilst some informants could handle the conditions that the ideal patient-role brought others were not as comfortable or able to adapt. However, these informants were still expected to take responsibility for their health as much as the next. When they failed to do so it led to a feeling of abandonment. This goes to show that the ideal patient-role of being autonomous, knowledgeable and active was difficult for patients to achieve and to some of the informants I have spoken to, it was not at all accessible. However, no matter how difficult it was to reach this ideal all the informants expressed the importance of being autonomous. In a way, being dependent on the healthcare system became the manifestation of patients’ inability to achieve autonomy. Subsequently, not being able to reach the ideal patient-role was seen as a moral failure.

Conditioned Freedom

What has also been shown is how limited the freedom of patient seems to be. As some informants have experienced, healthcare personnel in a sense still act according to a traditional healthcare hierarchy, telling patients what they ought to do, which recommendations and treatments they should follow and how to act. The actual space for patient influence on healthcare decisions is very limited. And then, after listening to recommendations, patients are most likely assumed to be autonomous in their self-care. As an effect, if patients don’t act according to care-provider’s expectations and wishes they risk being perceived as demanding, difficult and an obstacle in care-work. This logic of cause and effect follows critical empowerment theory as well as criticism towards neoliberal economy which both claim that freedom in a neoliberal context is not freedom in the fullest sense: it is
a conditioned freedom. Patients are free as long as they act according to norms and recommendations (Cruikshank 1999; Clarke 2005). There is an inherent unfairness in this patient-role. Freedom of choice is more available and accessible for patients that are already prone to be active and engaged. The patients who embraced the ideal patient-role of being active, informed and autonomous while following healthcare recommendations were encouraged to persevere in such autonomy as this was easing the burden of healthcare. Paradoxically, this would lead to less medical attention when they needed it the most.

In a healthcare system that is increasingly built on patients being self-propelled and able to practice self-care in a satisfying way, those who are not living up to the autonomous ideal run the risk of being neglected or left out of the healthcare system. However, whilst many informants were encouraged to act according to the ideal patient-role, they at the same time experienced a struggle of receiving wanted healthcare. Surprisingly, most of the informants experienced difficulties in receiving the help that they needed from the healthcare system; as matter of fact, this seems to be true regardless of how able they were to meet the requirements of the ideal patient role as informed, active and empowered consumers. Most patients experience access to healthcare as a struggle, to the point that they never assumed or expected help to come easily: this created an interesting moral reaction. In assuming struggle, informants propelled the moral idea that to be a responsible patient one needs to take an active approach to healthcare by demanding care and be prepared to argue for once case. While the ideal patient-role existed in policy documents, patients’ expectation of struggle created a counter-reaction to the ideal role, and so they adapted to the role of the critical consumer-patient. Thus, from their own perspective, the struggle to access healthcare became a moral virtue. This in turn can have the effect of a further limited patient agency. Informants’ general perception was that they had good reasons to fear to be neglected, no matter how autonomous, well-informed, able or active they were.

In this light “Take care!” shifts from an interjection of greeting towards a threatening imperative.
Bibliography


