Evaluating Challenges to Patient Autonomy in BRCA Gene Testing, Breast Cancer Culture, and Preventative Mastectomy

by

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Abstract

In this project, I consider ethical issues surrounding genetic screening programs by specifically using the trend for women to ask their physician for BRCA1/BRCA2 gene screening and then trying to decide what should be done with the information if the test returns positive (for example, undergoing a preventative bilateral mastectomy to decrease one's risk for developing breast cancer). I begin my analysis with Beauchamp and Childress' (2009) principlist account and requirements for respecting patient autonomy in bioethical situations. I argue that their theory, although it provides realistic and practical guidance for many clinical decisions, inadequately addresses two significant challenges that genetic screening tests pose for autonomy.

The first challenge is illuminated by the feminist relational autonomy framework: social context influences patient decision-making through the values and narratives that inform women, but also that sociopolitical forces can interfere with the development of a woman's autonomy. To support this challenge, I draw on the prevalent social narratives of pink ribbon culture, genetic determinism, and other influential social forces to demonstrate the way in which a woman's social context can encourage her to make certain clinical decisions (such as undergoing the genetic test in the first place or undergoing an aggressive preventative surgery to prevent cancer development). Moreover, I consider how a woman's social context and social position influence the capacities they need to truly exercise their autonomy and make authentic decisions that align with their beliefs and values. I consider the suggestions of various relational autonomy theorists regarding macrolevel and microlevel solutions to help patients develop these capacities. In this section, I conclude that Beauchamp and Childress' (2009) theory of autonomy insufficiently considers the strong influence of social context on women's decision-making in the BRCA screening and prophylactic mastectomy decisions and argue that patient autonomy should be

fostered and not simply respected in situations where there are strong social influences on clinical decision-making.

The second gap in Beauchamp and Childress' (2009) theory is illuminated by the recent, yet extensive, behavioural economics and social psychology research on decision-making biases and heuristics. This body of literature suggests a significant challenge to patient autonomy and decision-making in general: humans make poor decisions, especially in contexts of high uncertainty. The nature of genetic screening is highly probabilistic with a significant margin of error. Patients and healthcare professionals both struggle to acknowledge the uncertainty within medicine; thus, creating challenges for what should be done with predictive estimations of a patient's risk for developing a disease. I draw on the libertarian paternalism framework for autonomy that suggests authorities (for example, medical institutions and physicians) should 'nudge' patients to choose certain options that align with the patient's values and preferences. The ethics of nudging, especially in the clinical context, is far from settled: nudges are designed to engage an individual's cognitive biases and heuristics in ways that encourage the agent to act in a certain way, while maintaining autonomy since nudging is not coercive and can be resisted. In this section, I attempt to classify and understand the different kinds of nudging (or "choice architecture") that could be used in this clinical example and evaluate whether or not any nudging is permissible to use to help women make better decisions regarding this uncertain, probabilistic information.

Although gene testing has been promoted as a way to empower people to exercise their autonomy and have more choice over their health, I believe that genetic testing (especially in considering my example of BRCA gene testing) brings these two challenges to autonomy to the forefront. Moreover, in light of these two challenges to patient autonomy, I worry whether it is a viable practical or theoretical aim to continue prioritizing our high value of patient autonomy in healthcare. If these two challenges pose such a threat to ensuring patient autonomy in clinical decision-making, my argument could entail that interference in autonomy through nudging is inevitable if we want patients to make good decisions and act in their best interests.

Preface

This thesis is an original work by Clarisse Paron. No part of this thesis has been previously published.

Dedication

What is true for physicians is equally true for patients. They, too, must learn that it is in their best interests to appreciate better than they now do that the practice of medicine is to a great extent still shrouded in uncertainty and that its practitioners, however competent and dedicated, are also fallible human beings. Only then will patients learn to question their doctors and to ask questions of their doctors (Katz 2002, xlviii).

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I. Introducing the Problem

Many of today's screening and diagnostic programs are a result of our improved knowledge of the human genome. With a greater understanding of the role of genetics in health and illness, medicine is promising to head towards a precision medical approach with the goals of better classifying diseases and improving prognostics, developing individualized treatment plans based on knowledge of how an individual's genetics influence the efficacy of pharmacological treatments, and even attempting to prevent illnesses someone may be genetically predisposed to from manifesting altogether. Unfortunately, medicine is nowhere close to fully understanding the complex relationship between genes and disease[1] and even further from using this knowledge to develop an accurate and reliable medical program tailored to each individual. Although medical researchers are in the process of reclassifying diseases based on biomarkers and better understanding the role of genetics in treatment, there is a large gap between many of these findings and how we are to use the information we have about the connections between genes and disease to modify clinical pathways and develop individualized, tailored approaches to disease treatment and prevention.

As genetic technologies become integrated into medical practice, researchers and practitioners need to be wary about the consequences of gaps in genetic knowledge on clinical practice and patient care. As we understand more about the role of genetics in disease, genetic testing has become a prominent aspect of public health practices and patient care. Genetic testing may be used for diagnostic, predictive or reproductive purposes. Diagnostic testing is frequently used to help confirm whether a patient's symptoms might be caused by a genetically-based disease. The goal of this kind of genetic screening is to pinpoint a diagnosis, hopefully provide

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[1] For example, the role of the environment on gene expression (epigenetics).

the patient with a more accurate prognosis, and then use this information to decide on a treatment plan for the individual based on whether they have a certain disease. Predictive testing, on the other hand, is conducted on individuals who are currently healthy (absence of signs/symptoms of disease) but might be at risk of developing an inheritable disease. Such diseases that are often tested for include Huntington's disease, cystic fibrosis, and breast cancer. This distinction is critical as predictive screening tests and reactive diagnostic tests are designed for different purposes, and therefore provide different reliability and accuracy of information to individuals. Since screening tests are designed to identify individuals at an increased risk for a disease, they are more sensitive; resulting in more false positives. Further, screening tests are based on probabilistic population data and predictive, correlative connections between certain biomarkers and disease, whereas diagnostic testing is designed to characterize someone's disease in order to inform physicians and specialists with how to proceed with diagnosis, prognosis, and treatment options for patients. Not only is the information obtained from a predictive genetic test highly uncertain, but so is the clinical decision that should be made based on testing indicating an increased risk.

Although an ultimate goal of a precision medical approach would be using genetic information to "facilitate the movement from a reactive to predictive medicine, there are no cures yet for most diseases identified as having a genetic basis" (Gannett 2016, pp. 51). Interesting ethical challenges arise from the transition from a pathophysiological, "reactive" approach to a precision (or "predictive") health approach: patients are receiving information about their genes that may correlate to a future disease states but have few to no clinical options for how to proceed with this information. Absence of a cure for many genetic diseases or even options for prevention of the manifestation of diseases leaves individuals in a cloud of uncertainty about what they are to do with the predictions and probabilities they receive from genetic testing about their future health—before they even show symptoms of disease! It seems futile to conduct predictive testing if there is little clinical utility in obtaining the test results just to cause fear and uncertainty about one's health. What seems peculiar, however, is the trend where many of these predictive tests are being used as if they were diagnostic tests. So, although predictive tests are conducted and only indicate an individual's estimated risk for developing a disease in the future, patients, healthcare providers, and clinical practices are supporting drastic, risk-reducing interventions on healthy individuals based on the probabilities and uncertainty of these test results. In other words, the distinction between predictive testing and reactive testing is becoming blurred as individuals start using their predictive testing results to inform 'treatment' decisions to undergo drastic interventions before they even develop the disease. While acquiring a deeper understanding of the role of genetics in disease prevention, diagnosis, and treatment is attractive, I believe that the ethical and social consequences of extensive preventative genetic testing have been inadequately explored.

In this project, I hope to illuminate a host of ethical issues surrounding pervasive predictive testing in clinical decision-making by considering the example of using BRCA1 and BRCA2 gene testing to predict whether healthy women are at an increased risk for breast cancer. The field of cancer medicine increasingly uses biomarkers "to check the risk for, presence of or progress of a disease or the effects of treatment" (Canadian Cancer Society 2018). A biomarker is a "cellular, molecular, chemical or physical change that can be measured and used to study a normal or abnormal process in the body" (Canadian Cancer Society 201). The genetic testing for oncogenes (or genes that are linked to an increased risk for developing cancer) is an example of how cancer medicine is using biomarkers to predict cancer risk in individuals. Some of the first two oncogenes ever discovered to be correlated with cancer are the BRCA1 and BRCA2 genes that increase a woman’s risk for developing breast and ovarian cancer. The BRCA1 and BRCA2 genes are tumour suppressor genes and are essential to genome stability through their role in DNA repair. With the mutation, the genes carry a defective allele that increases genomic instability and is thought to drive cancer growth (Alaofi et al. 2018). BRCA1 and BRCA2 mutations are autosomal dominant genes, which means that if a child inherits the mutated allele from their parent, their risk for breast cancer increases if the gene is expressed at the cellular level (Stanford Health Care 2018). However, the presence of BRCA gene mutations do not guarantee that a woman will ever present with breast cancer in her lifetime as there are multiple genes and epigenetic factors implicated in the presentation of breast cancer: only between 45-65% of women with a BRCA mutation will develop breast cancer in their lifetime (Stanford Health Care 2018).

Although the genetic tests for BRCA gene mutations seem quite sensitive and accurate, there is a heightened level of uncertainty for these currently healthy women identified with this risk as to what can be done to prevent them from developing breast cancer. After receiving knowledge of their genetic results, women identified at a higher risk for breast cancer will need to frequently (medically and personally) survey their bodies for any signs of cancer development and potentially modify other lifestyle factors that may increase their risk for breast cancer. With breast cancer accounting for 25% of all cancers among women (Canadian Cancer Society 2018), cancer screening programs are necessary for early detection of cancer before an individual becomes symptomatic. The Canadian Cancer Society (2018) attributes the high survival rates of early stage (1 and 2) breast cancer to Canada’s organized screening programs and being able to detect cancer at earlier stages since early detection of cancer often leads to better prognosis, less invasive and aggressive treatments, and reduced financial expenditure for cancer care. From our growing knowledge of the correlation between oncogenes (e.g. BRCA1 and BRCA2) and cancer incidence, medicine can identify which individuals should more frequently survey their bodies with the goal of detecting cancer as early as possible (i.e. reactive medicine): but, is unable to offer much advice on how these patients can prevent cancer from developing—other than increasing surveillance and modifying lifestyle factors that are believed to increase risk.

What is interesting, however, is the clinical trend where women, with an increased risk of breast cancer, are opting for invasive preventative mastectomies out of fear of breast cancer and the treatments that follow—even though these women are healthy and not yet diagnosed with breast cancer. Between 2004 and 2008, the rates of women undergoing (bilateral) prophylactic mastectomy increased by 36% (Alaofi et al. 2018)—and that was before Angelina Jolie publicized her decision to undergo this surgery based on her knowledge of being a BRCA gene carrier. Prophylactic mastectomies are extremely invasive surgeries where the goal of the surgery is to remove all of the breast tissue where cancer could develop (Alaofi et al. 2018). Even though, there is still a possibility for someone to get breast cancer after a mastectomy–since it is nearly impossible to remove all of breast tissue and cells–the risk reduction of breast cancer in women with BRCA1 and BRCA2 gene mutations is reported to be between 85% to 100% after having a prophylactic mastectomy, according to various longitudinal studies (Alaofi et al. 2018). So, instead of surveying their bodies more frequently (self-breast examinations, mammograms, blood tests, etc.) and fearfully waiting to see if breast cancer will develop, women are choosing to undergo an aggressive preventative treatment for a disease that they do not currently have.

"Despite the confirmed reduction in breast cancer risk after bilateral prophylactic mastectomy, it is reasonable to question whether this preventive procedure results in improved overall survival in the light of modern detection and treatment modalities" (Alaofi et al. 2018, pp.) or whether increased surveillance, early detection, and early intervention would result in a similarly positive outcome. In my survey of various studies and literature reviews, medical research confidently concludes that prophylactic mastectomies do decrease mortality rate and increase life expectancy: however, these conclusions are based on relatively small sample sizes, on following patients for short periods of time (1-3 years) post-surgery, and have been criticized for not minimizing selection, detection, and attrition biases in their methodologies (Carbine et al. 2018). Not only do these studies report overly positive results and have methodological weaknesses, but the studies did not seem to directly compare long term outcomes of risk-reducing bilateral mastectomies with increased surveillance for early detection and intervention of breast cancer. My worry then, is that healthcare providers draw on medical research to make recommendations to their patients based on scientific evidence that reports overly positive conclusions and overestimated efficacy of an intervention (i.e. the lack of long-term evidence demonstrating this estimation of risk reduction). The drastic overestimation of benefits of the studies (decreasing women's risk for developing breast cancer almost completely) and a downplay of the negative effects of such an aggressive, painful procedure, manipulates the information that a healthcare provider relays to women and influences their decisions.

To complicate the matter, the Canadian Cancer Society (2018) reports that early detection and early intervention have resulted in positive treatment outcomes and high survival rates. So, although increased bodily surveillance and screening does not decrease a woman's risk for breast cancer like a prophylactic mastectomy, it does not result in a significantly worse outcomes or survival than preventative mastectomy procedures and comes with fewer (immediate) side effects and no chance for post-surgical complications. Moreover, it has been scientifically proven that for most types of breast cancer, radiation is equally effective in treatment as a mastectomy, but has fewer side-effects like decreased recovery and rehabilitation time and reduced harm to one's self-esteem (Class notes, LABMP 400). So, the decision to survey the body more frequently will not necessarily lead to a reactive mastectomy if a woman were to get cancer since she will likely be offered less invasive treatments like radiation, especially if the cancer is caught at an early stage. Thus, the decision does not hinge on whether a woman should have a mastectomy earlier (as a preventative measure) instead of later (as a reactive measure), but whether women should use genetic testing results to make a clinical decision for an aggressive, preventative procedure instead of survey their body more frequently for signs of cancer development, knowing that there is a good chance of survival if the cancer is caught early and they can treat it with less invasive, but equally effective treatments (like radiation).

The clinical decision that these women are faced with is much more challenging and complicated than it appears at first glance: both decisions, whether to undergo genetic testing in the first place or whether to survey one's body more frequently for signs of cancer or undergo a preventative mastectomy, are riddled with uncertainty. While it might be helpful to know that a woman has an increased risk of developing breast cancer, there is no guarantee that she would ever develop it. Conversely, she could undergo a bilateral preventative mastectomy to try and reduce her risk for developing breast cancer but may still develop it. Kaplan (2000) argues that our social preoccupation with genetics and "how genes must be at the heart of [everything]" (p. 4) leads us to misunderstand the limitations of genetics research and how impossible it is to use this information to make accurate predictions. Kaplan (2000) argues that although scientists deny the genetic determinism thesis (i.e. "if a trait is genetic, one is (going to be) stuck with it" [p. 11]), other forms of genetic determinism creep into research and permeate social and political thought. Although researchers may reject that extreme form of genetic determinism, they are still engaged in research that believes genes are the natural place to look to explain any human trait and that traits with only partial etiologies grounded in genetics are thought to be “primarily genetic” (p. 12). These narratives of genetic determinism, I believe, influence women’s thoughts and conversations with their healthcare providers about breast cancer. Although there are many other risk factors for breast cancer, such as not having children or unhealthy lifestyle factors (Canadian Cancer Society 2018), women with a BRCA mutation “express ‘inevitability’ that if they do not make the difficult choices for prophylactic mastectomy and…they will develop cancer” (Hamilton 2009). Even though this perception is false, it demonstrates the fear that results from uncertainty about one’s health and what is in our genes might doom us to develop certain diseases. The decision to undergo a prophylactic mastectomy or continue to survey one’s body for signs of cancer exemplifies some of the consequences of how poor humans are at communicating uncertainty, understanding uncertainty, and making decisions about the future.

Psychology and behaviour economics research consistently demonstrates how poor humans are at properly framing risks, making overly confident decisions, predicting consequences, and letting irrelevant factors influence our decision-making processes (Sunstein 2017). These cognitive biases and heuristics come into play when the weight of the decision is left to the patient to choose the option they think is best for them. I worry that in this clinical decision, women are overestimating their risk for breast cancer and are making decisions that might not actually align with their values, beliefs, and preferences. They are simply acting on the fear of the uncertainty of knowing they are a BRCA carrier and neglecting to consider the other risk factors that might influence the development of cancer. A woman’s communication and relationship with her doctor plays a significant role in how this risk information is presented and how the options are laid out. Dealing with uncertainty in medicine, public health, and healthcare has been a hot topic the past decade. In Chapter 3, I will explore some of the ways we might be able to address the uncertainty around predictive genetic screening and what can be done to improve women's decision-making in high uncertainty and fear surrounding genetic deterministic thoughts.

To complicate this clinical decision ever more, women's decision-making processes are influenced by various factors within their social contexts. For example, one reason why the decision to undergo BRCA gene testing and risk-reducing mastectomies was made-known to the everyday person because of Angelina Jolie's publicized decision in 2013 to undergo the procedure (Stöppler 2018). The "Angelina Jolie Effect" was coined to express the significant rise in women requesting BRCA genetic testing and undergoing risk-reducing mastectomies (without a previous breast cancer diagnosis) since Angelina Jolie's opinion editorial in the New York Times (Liede et al. 2018). Furthermore, the culture of breast cancer survivorship and corporate interest in breast cancer research influences the expectations, obligations, and behaviours of women at risk for and diagnosed with breast cancer (King 2006, Sulik 2012). With its roots in the women's health movement in the 1970's, women were trying to draw attention to the lack of funding and research given to the most prevalent cancer affecting women in Canada and the United States. However, academics such as King (2006) and Sulik (2012) have critiqued the symbolic and financial support of pink ribbon activism which has transformed breast cancer into a market-driven industry of survivorship without effectively improving breast cancer prevention, treatment, or prognosis: "grounded in advocacy, deeply held beliefs about gender and femininity, mass-mediated consumption, and the cancer industry, pink ribbon culture has transformed breast cancer from an important social problem…to a popular item for public consumption" (Sulik

2012, p. 9). Inadvertently, this powerful and predominant sub-culture influences women's decision to act on their bodies and uncritically uptake BRCA gene testing and preventative mastectomies.

A way that pink ribbon culture[2] may affect a woman's decision to undergo a risk-reducing mastectomy is through the "overarching 'culture of survivorship' oriented to optimism, personal empowerment, and the 'survivor' as an identity category" that was produced through the pink ribbon movement (Sulik 2012, p. 30). Aronowitz (2015) suggests that even healthy individuals who are at an increased risk of cancer might identify with this collective survivorship identity/social category when they undergo extreme preventative 'treatments', such as a prophylactic mastectomy. *Previvorhood*—or "cancer survivorhood for people who are at risk for cancer but are not actually diagnosed" (Aronowitz 2015, p. 148)—may explain part of the reason why women at risk for breast cancer undergo aggressive preventative surgery because the pink ribbon movement overemphasizes the importance of individual and collective action to "promote women's empowerment and personal transformation" (Sulik, p. 35). The "empowered" breast cancer survivor does not question their options but trusts in medical science and advice. Accepting this standard for survivorship drowns out alternative ways of dealing with breast cancer and heroizes survivors (or previvors) who follow their social script. In Chapter 2, I will use the feminist relational framework to show how trying to decide whether one should undergo

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[2] Pink ribbon culture (PRC) is a Western sub-culture "with its own symbols, beliefs, values, norms, and practices" (Sulik 2012, p. 3). Grounded in advocacy for better treatment and more research for breast cancer, the pink ribbon was marketed as a campaign to increase awareness and funding for the cause. However, the social institutions that have capitalized on the movement have "transformed breast cancer from an important social problem…to a popular item for public consumption" (p. 9). PRC engages gendered stereotypes and an optimistic outlook on surviving breast cancer; thus, marginalizing voices that do not conform to the rhetoric of the culture. Sulik powerfully argues that despite the substantial funding raised for breast cancer via PRC, invested institutions have not made significant strides in curing or preventing breast cancer because they are more interested in profiting off of the cultural system.

a prophylactic mastectomy needs to involve a critical reflection of the personal and social values that influence these decisions.

I believe that this clinical situation exemplifies some of the challenges to patient decision-making posed by extensive genetic screening and capitalistic, patriarchal social forces. In bioethics, respect for patient autonomy is arguably one of the most important core values guiding medical practice. The principle of respect for autonomy is understood as "as the principle that health care professionals have an obligation to respect patients' autonomous choices" (Mackenzie 2014, p. 277). Respect for autonomy, or self-governance, "is considered particularly crucial in health-care settings because illnesses and injuries are physically and emotionally challenging for many patients, especially when the diagnoses are unexpected or grim or when the potential for adverse effect from medical treatment and abuse of power is high" (Ho 2014, p. 328). Healthcare providers and their patients are socialized differently and therefore make decisions based on different sets of values and beliefs. In a society that values independence and individualism, treating rational beings paternalistically (or making choices for them) is considered more harmful than if a patient were to refuse a treatment that might have been recommended by a HCP for their own good because denying a person's right to autonomy is viewed as denying them their moral status as persons (Ho 2014). "In contemporary health-care settings,…respect for patient autonomy is often manifested in an individualistic manner by obtaining informed consent, one treatment or procedure at a time" (p. 329): where individuals must be provided all the necessary information of the relevant alternative options so they can make an informed decision, free of coercion, that is based on their values for which option would be best for them. This notion of autonomy presumes that "if the patient had no serious cognitive or emotional impairment and was not subject to direct coercion by others, the person's healthcare decisions…should be considered autonomous…, even if these patients may not be exercising their autonomy wisely" (p. 330).

However, this minimalist conception of autonomy has been critiqued from feminist and libertarian paternalism positions for being an insufficient framework for difficult clinical decisions. In Chapter 1, I will consider the 'gold standard' framework of decisional autonomy (Beauchamp & Childress 2009), which offers an idealized way to respect patient autonomy in clinical settings. Grounding the rationale behind informed consent practice, the framework has been critiqued for the way it views decisions as punctate, one-off encounters with patients as well as its lack of depth for understanding the role of relationships and context in the way that patient's exercise their autonomy (Mackenzie 2015, Kukla 2005), as well as its idealized requirement for patient rationality in decision-making (Gorin et al. 2017). While relational autonomy theorists (e.g. McLeod & Sherwin 2000, Ho 2014) have tried to explain how a patient's embeddedness influences their decision-making, relational autonomy 1) has not been applied to contexts where high uncertainty plays a dramatic role in engaging a woman's cognitive biases and poor reasoning mistakes and 2) has been critiqued for demanding an unattainable level of autonomy and critical reflection from patients. One such framework in the philosophical autonomy literature, libertarian paternalism, recognizes how biases and heuristics affect patient decision-making and proposes a solution where physicians can reframe the way in which information is presented to a patient in a way that simplifies and decreases the uncertainty of the information presented to the patient—without compromising informed consent and still allowing the patient to choose their own path alongside the goal of decreasing the risk of patients 'going wrong' in their reasoning (Sunstein 2017, Gorin et al. 2017, Gelfand 2016). However, the ethics of using behaviour economic strategies and clinical nudges is far from settled (Holm 2017, Ploug & Holm 2015, Blumenthal-Barby 2016, Blumenthal-Barby & Burroughs 2012)—and so, I hope that considering this specific medical context, my project will contribute to the ethical resolution of how we ought to reconceptualize autonomy by: 1) acknowledging autonomy as a product of the social context in which healthcare decisions are made; and 2) recognizing that 'rational' decision-making is challenging to achieve in contexts of high uncertainty.

In this project, I will use the breast cancer and risk-reducing mastectomy trend as a way to analyze these two critiques of the decisional model of autonomy (i.e. synonymous to informed consent). In the first chapter of my project, I will elaborate on the decisional model of autonomy and explain these two critiques in more depth by drawing on the clinical decisions I described above (i.e. whether to undergo BRCA screening and then what to do with the information if the test came back positive). After I characterize this difficult decision-making context, I will briefly explain three potential solutions (or rather, ways to improve and simplify the decision-making process) to improve how autonomy is understood in contexts of genetic screening, reactive decisions, and high uncertainty. Chapters 2 and 3 of my paper will detail two alternatives to the decisional framework of autonomy: feminist relational autonomy and libertarian paternalism respectively. In evaluating the pros and cons of each framework within the specific clinical context, my goal is to better understand how to best negotiate the tensions between the various frameworks of autonomy in uncertain decision-making contexts. I hope that considering this specific medical context, my project will contribute to the ethical resolution of how we ought to reconceptualize the idealized framework of autonomy by: 1) acknowledging autonomy as a product of the social context in which healthcare decisions are made; and 2) recognizing that 'rational' decision-making is challenging to achieve in contexts of high uncertainty.

II. Patient Autonomy: Significance, Contemporary Conceptions, and Challenges

The situation outlined in the introduction exemplifies the difficulties with making clinical decisions in the modern medical world. The uncertainty involved with genetic testing and challenges with cognitive reasoning in understanding a patient's risk for a disease to how social forces, such as pink ribbon culture and the "Angelina Jolie Effect", can all influence healthcare providers and patients in decisional processes, it is critical to understand decision-making and find a framework that best guides decision-making in these challenging situations. With respect for patient autonomy as arguably the most valued principle guiding medical practice today (Kukla 2005), bioethicists focus on how to encourage respect for patient autonomy and ensure the conditions necessary for patients to make health decisions that align with their beliefs, values, and preferences. However, in a challenging situation like the one described in the introduction; autonomy frameworks are put to the test. In this project, I wish to evaluate three predominant theories of autonomy to better understand where these frameworks fall short. While weighing how these theories handle a situation like the one formerly described, I hope to find a solution that is able to address all of these complications while encouraging patient autonomy.

The subsequent three chapters will outline three different frameworks of autonomy, how they each deal with the challenges of the example, and where they might fall short. In the following section, I will conclude this project by directly comparing the various approaches and evaluate the best approach to address the issues surrounding autonomy in the example situation.

Chapter 1: The Decisional Model of Autonomy

Beauchamp and Childress offer one of the most historically influential accounts of autonomy as they were some of the first academics to justify informed consent based on arguments from autonomy, as opposed to a beneficence standpoint (Faden et al. 1986). Their work on autonomy was expanded on through their famous account of the principles, in addition to respecting autonomy, that ought to guide bioethical decisions. With their work often being referred to as the "traditional" account or "prevailing view" (Kukla 2005, p. 35), I will use their account as the starting point for my analysis. Beauchamp and Childress (2009) emphasize that the primary goal of their account of respect for autonomy is to provide realistic standards that guide real medical practice. Their emphasis on realistic and practical standards to guide bioethical decisions is similar to the way in which healthcare professionals most likely understand respect for patient autonomy. The practical approach to bioethics is a benefit of Beauchamp and Childress' account, which supports my choice of using their account as the starting point for understanding autonomy in the BRCA screening scenario detailed in my introduction. I will start by summarizing their account and then explain (in a theoretical way) how it could be applied to a woman's interaction with her physician regarding her options for managing her risk for breast cancer as a BRCA gene carrier. After providing a picture of what decisional autonomy could look like in this context, I will explain two significant factors that influence women's decision-making process in this situation and why Beauchamp and Childress' account of autonomy inadequately addresses these challenges. These two critiques will be detailed further in the subsequent sections as other theories of autonomy try to accommodate them.

Beauchamp and Childress' understanding of patient autonomy is often referred to in the literature as "decisional autonomy" (Mackenzie 2015); in this project, I will use the same language by using Beauchamp and Childress' account interchangeably with decisional autonomy. In considering the history of Beauchamp and Childress' account, it explains some of the framework decisions of their account. Because of the shift in trying to justify informed consent from beneficence to autonomy, Beauchamp and Childress place an ethical obligation on healthcare providers to respect patient autonomy in their practice. When informed consent emerged as a procedure necessary for patient protection, it was justified on the grounds that a patient deserved knowledge about their health status and treatments:

> The "beneficence model,"…depicts the physician's responsibilities of disclosure and consent-seeking as established by the principle of beneficence, in particular through the idea that the physician's primary obligation…is to provide medical benefits…The management of information is understood…in terms of the management of patients ("due care") generally. That is, the physician's primary obligation is to handle information so as to maximize the patient's medical benefits. Here, the principle of beneficence is used to provide clinical-specific meanings for the benefits and harms to be balanced by the physician (Faden et al. 1986, pp. 59).

Informed consent as justified through the beneficence model mainly served as a way to protect physicians against lawsuits by encouraging physicians to disclose more information to patients (p. 76). However, after many years of harm experienced by patients and research subjects because of physicians' paternalistic tradition to refuse to disclose information about diagnosis and treatment to patients (Katz 2002), it was realized that physicians were not in the best position to make decisions for what they thought would be best for their patient. It was wrong to assume that "the patient's personal choice and the obligation inherent in the physician's commitment tend generally to the same end," as "there can be divergence between the interests and goals of patients and those of physicians" (Faden et al. 1986, p. 135). Beauchamp and Childress' work in justifying informed consent based on autonomy is similar to how they explain autonomy as a principle for making bioethical decisions in their account.

Fundamentally, based on Mill’s principle of individualism and Kant’s philosophy on autonomy, Beauchamp and Childress recognize that what is truly best for the patient is what they decide for themselves, based on their values and preferences—even if a healthcare provider (HCP) does not agree with their patient’s choice. According to Mill and Kant respectively, it is intrinsically good for a person to be empowered to make their own decisions and morally condemnable to treat any person as a means instead of as an end—as long as it does not interfere with the autonomy of, or threaten the welfare of, another person. From these philosophies, justification of autonomy in healthcare and biomedical research stems from the idea that autonomy is inherently good for us: on one hand, “self-rule is central to a good life” and on the other, “autonomous choices promote our ultimate goals…on which physicians are not experts…and…that these goals define how well our lives go” (Eyal 2019, p. 7-8). Even if physicians may disagree with a patient’s healthcare decisions, they cannot coercively override their decisions: to “coerce rational beings even for their own good is to paternalistically treat them as if they lacked the capacity to shape their own lives—it is to deny them their moral status as persons” (Ho 2014, p. 328). Many bioethicists, including Beauchamp and Childress, support respect for patient autonomy based on the traditional views of Kant and Mill. Beauchamp and Childress (2009) state that respect for autonomy in their account “is to acknowledge [a patient’s] right to hold views, to make choices, and to take actions based on their personal values and beliefs” (p. 103). By respecting a patient’s right to choose, a physician is respecting them as an agent and not treating them paternalistically.

In Beauchamp and Childress’ (2009) account, respect for autonomy is not simply “noninterference in other’s personal affairs” but also “acknowledging the value and decision-making rights of persons and enabling them to act autonomously” (p. 103). Again, in considering the history of Beauchamp and Childress' account, their framework emerged in response to an imbalance of power in the patient-physician relationship that led to many patients and research subjects being harmed by the paternalistic decisions of healthcare providers. As a result, respect for autonomy in their view is largely directed towards the responsibilities and moral obligations of the healthcare provider to prevent harm towards their patients by respecting their patients' autonomy to make their own health decisions. To ensure that a patient's right to autonomy is protected, there is an onus on the healthcare provider to use their position of authority to ensure the conditions for patient autonomy are met in healthcare decisions. In the decisional framework, healthcare providers have two responsibilities to protect their patients' right to choose: a negative obligation that requires HCPs from violating patients' right to choose and a positive obligation that requires HCPs to engage in activities to ensure the fulfilment of patients' right to choose. The negative obligation requires HCPs to not unduly influence their patients' decisions. Decisional theorists want to ensure that the authority of the healthcare provider is not used to coerce patients into making certain choices and only interfering in a patient's autonomy if their decision encroaches on the welfare or autonomy of other persons.

However, simply ensuring that patients are free to make their own decisions is insufficient as a moral duty to protect patient autonomy, especially considering that the history of informed consent involved physicians disclosing only what they thought the patient needed to make an informed choice. Often, this information was very minimal as it was commonly thought that if patients were kept hopeful about their condition and treatment, they would recover faster (Katz 2002). Moreover, this "silent" patient-physician relationship perpetuated the attitudes that patients do not know what is best for them and that physicians were the authoritative expert (Katz 2002). To prevent this from happening, Beauchamp and Childress also require a positive obligation from HCPs in respecting their patients' autonomy and avoiding perpetuating patient dependency on the provider: "Respect for autonomy obligates professionals in healthcare and research involving human subjects to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision-making" (p. 104). These responsibilities will be discussed in more detail throughout the chapter, but for now, it is enough to establish that healthcare professionals have a duty to provide patients with sufficient and relevant information to make decisions that align with their preferences and beliefs, ensure that patients are able to make decisions for themselves by understanding information relevant to their values and preferences, and encourage patients to make decisions based on their preferences and attitudes.

Beauchamp and Childress (2009) do not require as much responsibility from patients as they do from physicians because they want to endorse an understanding of autonomy that is practical, realistic, and encompasses the diversity of how patients exercise their autonomy in healthcare decisions. Therefore, they disagree with the theories of autonomy that focus on developing a theory of autonomy, like feminist relational autonomy, over understanding autonomous choice in everyday situations: these "theories of autonomy feature the abilities, skills, or traits of the *autonomous person*, which include capacities of self-governance such as understanding, reasoning, deliberating, managing, and independent choosing" (*italics in original,* p. 100). A focus on choices instead of the general way a person conducts themselves allows more individuals and their choices to be considered sufficiently autonomous. If a theory of autonomy requires a more demanding account of autonomous choice, such as requiring a patient to reflect on their second-order desires or goals before making decisions, then the theory "presents an ideal beyond the reach of normal agents and choosers" (p. 101). Moreover, Beauchamp and Childress argue that:

> Even autonomous persons who have self-governing capacities and are generally good managers of their health sometimes fail to govern themselves in particular choices because of temporary constraints caused by illness, depression, ignorance, coercion, or other conditions that restrict their options (p. 100).

In this way, even people who reliably demonstrate autonomous action in other areas of their lives might not make an autonomous choice at every given time. Beauchamp and Childress provide the example of a research participant who does not read the consent form to participate in a research study. If the subject does not read the form, then they do not sufficiently understand what they are consenting to and, therefore, the individual is not making an autonomous choice. Notably, by elaborating an account of autonomy that is based on individual choice instead of a person's general autonomy, patient autonomy is exercised only through these healthcare encounters where decisions are made from the interaction between an individual and their healthcare provider. It is also more practical for the provider to assess if they are adequately respecting a patient's freedom to choose in each decisional moment. In other words, decisional autonomy uses specific decisions to account for respect for autonomy: where Beauchamp and Childress want to ensure certain conditions for respecting patient autonomy in "punctate decisions" (Kukla 2005) in healthcare settings. The focus on autonomous choice is practical for healthcare providers to assess and foster patient autonomy in each decisional moment (often, these are moments where informed consent is obtained or refused).

Beauchamp and Childress' decisional model of autonomy provides a relatively minimalist conception of autonomous choice where an individual acts autonomously if they "act (1) intentionally, (2) with understanding…, and (3) without controlling influences that determine their action" (p.101). In their perspective, autonomous choice is based on a "normal chooser" (p.

101) sufficiently satisfying these three conditions. For example, a condition that is necessary for one to exercise their autonomy is by making a planned choice (as opposed to accidentally choosing). They explain that one must intentionally act if they are making an autonomous choice and that intentionality to act cannot be a matter of degree. However, Beauchamp and Childress recognize that the other two conditions—i.e. understanding and level of coercion—may fall on a continuum. Because they advocate for a realistic and practical account of autonomy, the patient must understand the information presented to them to a substantial degree and act in a way that demonstrates substantial freedom from controlling influences. For healthcare professionals to ensure that a patient is able to meet the criteria for exercising their autonomy, HCPs need to judge whether patients have the capacity to sufficiently understand information, make a judgement about their values, voluntarily make a choice, and communicate this decision to their HCP (or a surrogate decision-maker). Capacity or competence in Beauchamp and Childress' account is closely linked to the concept autonomy: individuals need to "possess a certain level or range of abilities," to demonstrate the ability to make autonomous choices regarding their health (p. 113). In the decisional account, "competence to decide is…relative to the particular decision to be made" (p. 112). In other words, similarly to the conditions outlined for autonomy, the capacity for a patient to understand relevant information and sufficiently make a voluntary decision is decision-specific. For example, in clinical decisions that have a high level of risk or may pose risk of severe consequences, a higher threshold for understanding relevant information and an increased freedom from controlling influences would be necessary to meet the autonomy requirements necessary to consent for the procedure. Capacity in most situations is to be assumed unless there is reason to suspect otherwise (for example, if a patient was intoxicated and unable to think and communicate clearly). In summary, decisional autonomy places an obligation

on HCPs to ensure that patients have the freedom to make their own decisions absent from coercion and that they are given sufficient and relevant information to make their decision. Moreover, HCPs need to assess that patients have a sufficient level of capacity to make these decisions given the weight of the situation.

Although their account has been recognized as influential in bringing autonomy to the forefront of bioethics discussions, Beauchamp and Childress (2009) emphasize that their account does "not imply that [the principle of respect for autonomy] has moral priority over the other principles" (p. 99) as they support a principlist account for making bioethical decisions. In their framework, each situation requires the consideration and balance of the four principles that were traditionally thought to guide bioethical problems: autonomy, beneficence, nonmaleficence, and justice. However, if a patient is competent and able to understand the relevant information pertinent to a healthcare decision, they deserve the right to choose on behalf of themselves, despite the fact that their HCP might disagree that the patient's decision was the best choice. Balancing autonomy against other principles comes into play when an individual's autonomous action may interfere with the autonomy or safety of innocent others, if it endangers public health, or requires an unjust amount of resources to fulfil their autonomous request (p. 105). In the principlist account, physicians are fundamentally obligated to ensure that a patient has the right to choose what options work best for them (or even refusing treatment altogether), as long as the options provided to the patient are within the scope of the other principles. However, based on balancing the principles, patients are limited in what they can request for treatment. For example, some patients might not have access to certain treatments within the constraints of a publicly-funded healthcare system. So, although a patient might want a certain treatment because they think it will help them recover faster or the side effects/treatment regime fit better with their preferences and lifestyle, resources must be responsibly allocated to ensure that all patients have equitable access to healthcare. In a priniciplist account, autonomy is limited to ensuring that individuals have the right to choose as long as their choice does not infringe on the autonomy or welfare of other individuals. Moreover, the other principles come into play to assess other bioethical issues—such as ensuring access to treatment (which would fall under 'justice').

If we consider how decisional autonomy provides a theoretical framework to guide the patient-physician interaction in healthcare decision-making settings, I am hoping to illuminate some weaknesses of Beauchamp and Childress' account of autonomy. I want to clarify that I am not describing an exact clinical pathway or a real clinical encounter between a woman and her physician, but merely assuming in theoretical way how Beauchamp and Childress would suggest the interaction where a physician would present a healthy woman, who is at an increased risk of breast cancer, some options in dealing with her risk state. Decisional autonomy offers a prescriptive account of how the clinical interaction ought to go. In their account, Beauchamp and Childress tend to describe this account in terms of the positive and negative responsibilities of the physician in an encounter where a patient needs to make a specific health decision. To adequately fulfil their positive duty, healthcare providers need to provide information that a patient would need to make their decisions: information regarding "[d]iagnoses, prognoses, the nature and purpose of the intervention, alternatives, risks and benefits and recommendations are typically essential" (p. 128). In the example case, a woman likely had BRCA gene testing because she requested the test or her physician suggested it for her based on her risk factors for breast cancer (like a mother or sister who had breast cancer, thus suggesting a possible genetic connection). After being tested, she would be informed that she has either a BRCA1 or BRCA2 gene mutation, which increases her chance for getting breast cancer. In finding out how much the genetic mutation is estimated to increase her risk of breast cancer, her physician will present her with information about her risk state, risk reducing treatment options, benefits and costs of both options, and how this decision might impact her future health or medical routines. After the healthcare provider explains the results of the genetic test and how it would be estimated to increase the patient's risk of getting breast cancer, they would then tell their patient that there are two common options for women who have a high risk of breast cancer: 1) to more frequently medically and personally survey her body or 2) to undergo risk-reducing medical procedures like having a bilateral prophylactic mastectomy.

According to Beauchamp and Childress' (2009) account, the physician is responsible for disclosing sufficient and relevant information to the patient about both choices without coercing the patient to select an option (and also recognizing if there may be other blatant forces that are coercing the patient to choose). For example, the healthcare professional would be required to provide their patient with detailed information about both options—such as information on recovery and risk for complications from the surgery and what surveying her body more frequently might entail (like having mammographies more frequently or earlier than clinical practice guidelines recommend and monitoring her own health for signs of cancer, like lumps, weight loss, etc.). The healthcare professional has a responsibility to clearly and honestly answer the patient's questions or provide supplementary information (such as pamphlets or referral to a specialist or genetic counsellor) if the patient needs more information to make a decision. In presenting the information to the patient, the healthcare provider also needs to ensure they are not overtly coercing or manipulating a patient to choose a specific option but are leaving the decision up to the patient. The physician has a negative duty to ensure they are not unethically coercing a patient but are also asking the patient about other people or external factors that might be influencing their decision.

While Beauchamp and Childress recognize that some individuals and institutions might have authority and influence in an individual's decision-making, they assert that "no fundamental inconsistency exists between autonomy and authority if individuals exercising their autonomy in choosing to accept an institution, tradition, or community they view as a legitimate source of direction" (p. 102). In this respect, a patient can consider the opinions and recommendations of other sources to help them gain the information they might need to make a decision:

> We typically make decisions in a context of competing influences, such as personal desires, familial constraints, legal obligations, and institutional pressures. These influences usually do not control decisions to a morally worrisome degree. In biomedical ethics, we need only establish general criteria for the point at which influence threatens autonomous choice, while recognizing that in many cases no sharp boundary separates controlling and noncontrolling influences (p. 134).

While it is not an easy task to discriminate between acceptably influential pressures and unacceptably controlling ones, physicians have a duty to be aware of ways they might be unethically manipulating their patients (such as informational manipulation like lying, exaggerating, or failing to disclose) and other threatening situations that might be constraining the autonomy of their patients (such as social constraints like needing medications but not being able to afford it). Beauchamp and Childress do not want this to seem like an impossible task, as they are trying to advance a theory of autonomy that is sufficient, practical, and realistic. In the situation, a potential controlling influence could be a mother or sister who has breast cancer and is urging the patient to undergo a preventative mastectomy to avoid the treatments and fear that accompany a breast cancer diagnosis. The physician might be alerted to this coercive influence in a meeting with the patient if the patient mentions that her mother or sister thinks she should have the surgery. In Beauchamp and Childress' account, the physician should encourage the patient to make the decision for herself but acknowledge that the patient's family would influence her decision on the matter.

Returning to how the decisional account would look in the BRCA situation, the physician could provide their professional recommendation to the patient. If the physician provided sufficient information about the patient's risk state and their options, then the decision is left to the patient. As long as the patient's competency has no reason to be questioned, then the patient would proceed to decide on the option that they feel best suits their beliefs, preferences, and values. In the case, a woman who is presented with these options might decide to undergo a prophylactic mastectomy. If she did, she would be referred to a specialist to give her informed consent for the surgery. On the other hand, she might prefer to survey her body and try to make other lifestyle modifications to reduce her risk for breast cancer. She would follow her physician's timeline recommendations for getting more frequent mammograms, maybe she considers hormone therapy, and watches her own body more diligently for signs of cancer. As long as she was provided sufficient information about her risk and options from her physician and was not coerced into a decision, the patient is left to make this decision for herself.

Although Beauchamp and Childress' (2009) account is practical and works adequately for ensuring the respect for patient autonomy in many healthcare decisions, I will argue in the remainder of the section that it is insufficient in promoting patient autonomy in this context. Considering the exchange above, it seems that the woman with a BRCA gene mutation has the freedom to choose which option she thinks is best for her (increased monitoring or a prophylactic mastectomy) because her physician is fulfilling their negative duty to not overly influence or coerce the patient into a particular decision and their positive duty to provide sufficient and relevant information that is necessary for a truly informed choice. However, I argue that this is a minimalistic approach to patient autonomy for such a complex situation. In considering in the case of how women are increasingly undergoing genetic screening and healthy women who are at an increased risk for breast cancer are making the decision to undergo aggressive preventative surgeries, I hope to illuminate two strong critiques against the decisional model of autonomy: first, that it does not adequately acknowledge autonomy as a product of the social context in which healthcare decisions are made; and second, the decisional model inadequately recognizes that 'rational' decision-making is challenging to achieve in contexts of high uncertainty. In the next two chapters, I will explain these two critiques in more depth by turning to other theories of autonomy (a feminist relational framework and libertarian paternalism respectively) that try to better address these challenges to patient autonomy in clinical decision-making.

Chapter 2: A Feminist Relational Framework for Autonomy

The first critique against Beauchamp and Childress' (2009) account of autonomy comes from a feminist perspective on autonomy: namely, the decisional model provides too minimalistic of an account of autonomy because it neglects to adequately acknowledge that patient autonomy is a product of the social context in which healthcare decisions are made and that social oppression significantly affects an agent's decision-making. This critique is directed at Beauchamp and Childress' understanding of autonomy in their framework by focussing on local autonomy—i.e. how to "be autonomous with respect to a particular action, choice or decision" (Mackenzie 2014, p. 279)—and not giving enough attention to the factors that influence global autonomy (i.e. what it means to lead an autonomous life). There seem to be two main reasons why relational autonomy philosophers argue that it is inadequate to understand respect for patient autonomy solely as conditions to foster autonomous choices as opposed to autonomous agents: both of which I will unpack in this chapter. After detailing the critiques against the decisional model from a feminist perspective in Section A, I will explain how a feminist relational autonomy framework would address these issues better in regards to the prophylactic mastectomy scenario in Section B.

A. Feminist Relational Critiques of Beauchamp and Childress' Decisional Autonomy

Two feminist critiques against the decisional model of autonomy that I will unpack in this section hinge on Beauchamp and Childress' focus on local autonomy. First, this focus leads them to a robust account of respecting patient autonomy in moments of decision-making but does not adequately explain how a patient exercises their autonomy in self-management practices. Rebecca Kukla (2005) argues that healthcare is not comprised of only punctate decisions made in the clinic between a healthcare provider and a patient, but that healthcare requires patients to act conscientiously outside of meetings with their provider—that is, "[c]linicians use the weight of their medical authority and their ability to demand accountability as tools for fostering appropriate practices and inculcating ethics and techniques of self-management in their patients" (p. 38). Overlooking the importance of autonomy in ongoing healthcare practices is exemplified by the situation of considering the women, who are at an increased risk for breast cancer, are deciding whether to opt for an aggressive, preventative surgery or survey their body regularly for abnormalities. At first glance, the former choice seems like a punctate decision: a woman decides to undergo a prophylactic mastectomy by providing her informed consent for the procedure, while the latter decision involves more than simply declaring that the woman will survey her body more regularly and go for more frequent mammographies. It involves her changing her routine behaviours at home by self-managing the surveillance techniques her HCP instructed of her in their meetings. However, even after a risk-reducing surgery like a bilateral prophylactic mastectomy, the patient still has a risk of developing breast cancer and would still need to survey their body for signs of cancer. Surveillance is a significant commitment and responsibility for these women which should be considered in a framework of autonomy.

Secondly, Beauchamp and Childress' focus on local autonomy downplays the importance of understanding how a patient's social context influences their decision-making, their values, and the skills necessary to exercise their autonomy. Decisional autonomy has been critiqued by relational autonomy theorists for inadequately acknowledging how one's social context shapes one's autonomy and decision-making capacities. By drawing on sociological literature around pink ribbon culture (Sulik 2012, King 2005), cancer survivorship (Aronowitz 2015), and the "Angelina Jolie Effect" (Troiano et al. 2017, Liede et al. 2018), I hope to show that social context is highly influential in patient decision-making—specifically, if patients are not encouraged to reflect on how these socio-political forces may be influencing their autonomy. In complicating the decision to undergo BRCA testing and then deciding what should be done if the test returns positive, by considering the influential social forces involved in a woman's decision, I hope to demonstrate how an account of autonomy needs to consider these social forces on autonomy and provide a more robust solution as to how autonomy can still be promoted and protected regardless of these social influences than what is provided by decisional theorists. This critique will lead me into Section B, where I discuss how the feminist relational framework of autonomy focuses on protecting and promoting patient autonomy when social expectations, oppression, and marginalization impact a patient's ability for self-determination.

Unlike feminist relational autonomy theorists, decisional autonomy theorists focus on local autonomy: where to "exercise local autonomy is to be autonomous with respect to a particular action, choice, or decision" (Mackenzie 2014, p. 279). In other words, a patient's autonomy is respected through their autonomous choices and decisions made in their encounters with healthcare professionals. Recall from the previous chapter that Beauchamp and Childress (2009) defend the use of local autonomy in their framework for two reasons: firstly, by considering autonomy in terms of discrete decisions, it becomes more practical and realistic to guide HCPs in real clinical encounters; and secondly, "[f]ew choosers and choices would be autonomous if held to the standards of higher order reflection…which presents an aspirational ideal of autonomy" (p. 101). Because an individual's general capacity for self-governance fluctuates due to various temporary conditions that prevent them from governing themselves or making decisions, Beauchamp and Childress "concentrate on *autonomous choice* rather than on general capacities for governance and self-management" (p. 100, italics in original). However, a focus on respecting patient autonomy only in moments of decision does not adequately cover the diversity of ways that an individual can exercise their autonomy in healthcare. In the beginning of this chapter, I will argue that decisional autonomy, while it can adequately deal with most healthcare situations and tries to offer a practical and achievable standard of respect for autonomy in bioethics, is too narrow in scope for some situations. By drawing on the BRCA screening and prophylactic mastectomy decision example, I will demonstrate the inadequacy of Beauchamp and Childress' framework of autonomy which limits exercising autonomy to autonomous choices (local autonomy) without adequately considering the autonomous person (global autonomy).

Rebecca Kukla (2005) has critiqued the decisional model based on its focus on local autonomy. She recognizes that practical medicine needs an empirical, working concept of autonomy out of which they have a protocol to guide practitioners in their goal of resolving concrete dilemmas within the practice of medicine. However, Kukla argues that the Beauchamp and Childress' notion of autonomy is "inadequate, and its inadequacy reflects and reinstates a history of considering only certain dimensions of health care as worthy of ethical attention" (p. 35). Because the decisional model focuses on the ethical responsibilities of healthcare providers to patients, autonomy turns on ensuring that HCPs provide relevant information to patients to make a voluntary and informed decision. As a result, respect for patient autonomy in healthcare situations is often realized through the moment when a patient gives or refuses informed consent for a procedure: "the concrete task of protecting and promoting self-determination in health care contexts can be understood as the task of ensuring patients' *informed consent* to medical procedures" (p. 35, italics in original). Viewing the principle of autonomy as so tightly connected to the principle of informed consent is problematic because it assumes that the "relevant 'unit' of autonomy…is the *punctate decision*—a decision made in response to a discrete choice that can be understood in isolation from the rest of the patient's healthcare" (p. 35, italics in original). This exclusive focus on decisions in medical practice presumes that all the important issues surrounding autonomy "arise only in response to discrete crises or choice points such as injuries, sudden illnesses, and therapeutic decisions" (p. 36). In her eloquently written article, Kukla's goal is to demonstrate issues regarding autonomy that arise in health care practices outside of decision-making with the HCP since it is largely the responsibility of the patients to execute many healthcare commitments outside of meetings with their HCP. She argues that by monitoring their own health, building health promoting habits, and following treatment plans outside of encounters with their HCP, patients are also demonstrating autonomy—but in a different way than in punctate decisional moments. Many of these practices, such as when women monitor their pregnancies, are not able to be conceptualized as a series of discrete decisions and therefore cannot be adequately accounted for in the decisional model of autonomy (Mackenzie 2014). For example, if a patient is instructed to take certain medications at multiple and specific times of day and around their eating schedules, they are not generally making discrete decisions each time they consume a pill. Instead, regularly taking medications is more of a habitual practice that requires patients to responsibly follow the medication regime. Routinized and ongoing practices are likely not grounded in discrete decisional moments that were informed and free from influence but instead norms (such as compliance with medical authority), which establish ongoing health behaviours and hold patients accountable to these practices.

Kukla's (2005) critique of Beauchamp and Childress' account highlights the need for an account that better captures the way patients can exercise their autonomy and the conditions necessary to ensure respect for autonomy in habitual, self-surveillance practices. The decisional model focuses so narrowly on autonomy in punctate decisions that a large part of the decision to undergo prophylactic surgery misses the fact that extensive bodily surveillance is still a significant consequence of the surgery just like with the decision to not undergo the surgery. Recall from the Introduction that prophylactic mastectomies can decrease a woman's risk for getting breast cancer by 85-100% (Alaofi et al. 2018). Although these numbers are likely an over-estimate of the efficacy of the procedure[3], the fact remains that even when a woman undergoes the surgery to reduce her risk, she is still at risk to develop breast or ovarian cancer in her lifetime. In both 'choices', the patient has a responsibility to survey their body for signs of cancer, since their risk is not eliminated with the surgery. I worry that the decisional model's focus on punctate decisions incorrectly frames this decision to women. Even if physicians explain to their patients that both options (undergoing a mastectomy or surveying the body) require surveillance, the way that autonomy is realized in medical practice is through informed consent (to undergo the surgery or not). A focus on obtaining informed consent for this punctate decision makes it seem like women are presented with a choice to undergo aggressive preventative surgery that will reduce one's risk *or* do nothing but wait for signs of cancer, which may influence women to choose the surgery even if it is not the best choice in light of their

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[3] The systematic review by Alaofi et al. (2018) and Honold (2018) recognized many methodological limitations of studies on the efficacy of preventative mastectomies in reducing risk for breast cancer. Many studies had only followed women for less than three years after their mastectomies. With women of different ages undergoing these procedures, many women might not even be at the age where they are at an increased risk for developing breast cancer. The studies were obtaining positive results (significant decrease in risk for breast cancer) because they had not followed patients long enough to really know if the mastectomy prevented breast cancer. Moreover, Alaofi et al. 2018 "question whether this preventive procedure results in improved overall survival in the light of modern detection and treatment modalities" (p. 70). Many studies did not sufficiently compare the risk reducing effect of preventative mastectomies to diligent bodily surveillance and the results of early detection (Honold 2018). The systematic review by Alaofi et al. (2018) raises some important questions in the domain of philosophy of science. For example, the pressure to publish significant findings and obtain positive results influences the study design and researcher choices for cut-off points and framing the research question. While these are important and valid concerns that further complicate the clinical practice surrounding prophylactic mastectomies—as medical research often has the goal of informing clinical practices and recommendations—it is out of the scope of this paper to address these questions in more depth.

values and preferences. I will return to this challenge in Chapter 3, where I will detail in more depth how cognitive biases and heuristics influence patients to choose certain options over others and how the decisional model inadequately addresses this concern. Without a more robust account of how patients exercise their autonomy in self-surveillance practices, the decisional model neglects to address how to respect patient autonomy in these practices and what a proper account of autonomy in these practices would look like.

This is a significant worry as surveillance practices that manage risk are now becoming a "central feature of the disease experience" (Aronowitz 2015, p. 25). The heightened interest in precision medicine and research regarding the connections between genes, health, disease, and risk are redefining disease (and risk) experiences. For one, medical improvements in technology and understanding of acute and communicable diseases have greatly improved human lifespan and quality of living. But as a result, chronic illness has become a greater burden on the healthcare system due to the increased amount of people who are aging. This longevity comes with significant changes in healthcare usage: "[f]or many patients, the experience of chronic disease is not dominated by symptoms of the pathological processes but by reading the body for signs of future problems, negotiating different secondary prevention measures[4], and making decisions about the future" (Aronowitz 2015, p. 36). As well, technology, such as genetic testing, has helped to detect chronic diseases at earlier stages or provide patients at risk for a disease with information about their increased risk state. Without these genetic testing advances, patients would not be afraid or uncertain about whether they might be at risk for a disease. They would live their life until they had a disruption in their health, go to their doctor, and then undergo

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[4] Secondary prevention is the "early detection of disease or other efforts to ward off the harmful effects of disease progression" whereas primary prevention encompasses efforts aimed at avoiding the disease in the first place (Aronowitz 2015, p. 27).

diagnostic testing to understand their symptoms, prognosis and treatment plan. However, these new genetic testing technologies are providing patients with information about their health that they would have never known before: “[t]he result will likely be more people who are aware for longer periods of time about possible future ill health and who will be advised to modify their lifestyle and undergo different types of surveillance and medical treatment” (p. 29). This risk information provided by genetic screening tests gives one the perception that if you are a carrier of a genetic mutation that is linked to a known disease, then it seems certain that you are going to get the disease (Gannett 2016). This deterministic idea is reinforced by the fact that many of the clinical pathways—whether someone is diagnosed with a disorder or at risk for a disorder—are the same.

With our increased knowledge of genes and their role in disease, genetic testing and screening programs are subsuming more individuals into disease categories. As a result, there is a converged disease experience where “the number of otherwise healthy individuals who are considered to be ‘at risk for’… a particular disease has grown immensely; their bodies have been subjected to increased surveillance; and the risk state itself has become more embodied and…disease like” (p. 22). With prevalent genetic screening programs comes increased expectations of bodily surveillance on patients—the more genes that have known genetic connections, the more diseases one will have to survey their body for. Furthermore, there are now opportunities for intervention at every point in the risk-to-disease continuum to address the uncertainty in the range experiences of survivorship, where individuals along this continuum are undergoing cancer ‘treatment’ even though they might not actually have the disease. In this way, individuals coping with the risk of getting cancer through to individuals undergoing interventions for late stage cancer all experience dealing with the uncertainty of their condition and coping with risk. A woman who may have tested positive for a BRCA gene and is at an increased risk for breast cancer, although she does not experience any symptoms of cancer, has a similar experience of treatment and the uncertainty surrounding her future compared to a woman who is undergoing interventions to treat her diagnosed cancer. Both the woman at risk for breast cancer and the woman who is undergoing treatment for breast cancer experience: similar choices and guidance in healthcare; similar worries and fears around the uncertainty of their condition; and share similar pressures for surveillance. The converged experience of people with a disease and people dealing with increased risk for disease, not only broadens the category of people who need treatment for the disease, but also blurs the line between "the perceived severity and spectrum of the disease with ripple effects on how people experience and understand their illness" (p. 39).

A troublesome consequence of the converged disease experience is that individuals who are at risk for the disease may feel pressured to undergo aggressive surgery because the experiences of being 'diagnosed' with a disease and being at risk for the same disease are strikingly similar. Aronowitz (2015) suggests that the increasing initiatives for early detection and screening practices for risk of chronic diseases, have caused an increased perception of the severity of disease—where this perception influences how people experience and understand their illness or risk for an illness. The converged disease experience causes individuals, who might have never developed a disease, to now be 'diagnosed' with increased risk for the disease because of genetic testing. An example of the effects of the converged disease experience is demonstrated by the increasing trend for women at an increased risk for breast cancer to undergo preventative mastectomies. Aronowitz (2015) notes that there is parallel decision-making between those who are diagnosed with breast cancer and those at risk for breast cancer: evidence suggests that "the incidence of prophylactic surgery for women with breast cancer increased for women at every stage, at an almost identical slope" (p. 38). In other words, one would expect that there would be more women undergoing mastectomies as their risk for poor outcomes increases based on their breast cancer diagnosis (i.e. more mastectomies at stage 4 cancer and much less in healthy women at an increased risk for breast cancer), but instead research has found that the rates for women undergoing this surgery was the same no matter what degree of risk or disease stage they were at. This trend seems to suggest that women are using their BRCA gene testing results as conclusive evidence they will develop breast cancer, as if the BRCA gene tests were diagnostic tests that hold more certainty regarding prognosis, even though they are probabilistic, uncertain screening tests. Moreover, it also seems to suggest that women are acting aggressively on their fear of breast cancer—even though they only have a chance of developing breast cancer or are diagnosed with cancer at an early stage[5], women are choosing the aggressive preventative surgery at the same rate that women who are diagnosed at late stage breast cancer are. The increase in genetic screening practices instills fear and uncertainty in healthy patients and motivates them to undergo treatment to control their fears and anxiety about the future of their health. Many individuals would prefer to undergo an aggressive preventative surgery if it alleviates their fear of the uncertainty whether they would develop cancer. The converged experience of risk and disease, as well as narratives around genetic determinism, plays an important role in an individual's decision-making regarding their increased risk state.

Regardless of being simply at risk for a disease, having prophylactic surgery, or being diagnosed with the disease, surveillance is a large part of the disease experience (Aronowitz

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[5] The Canadian Cancer Society (2018) reports high survival rates and excellent prognoses if breast cancer is caught in early stages (stage 1 and 2). With Canada's organized screening programs and clinical practice guidelines for mammography, most women who develop breast cancer have their cancer detected early and have great health outcomes.

2015). Kukla's (2005) critique of the decisional model of autonomy with its focus on punctate decisions becomes ever more relevant as genetic testing practices increase in popularity. As more individuals are 'diagnosed' with risk for a disease, surveillance and self-management practices will become a regular and normative expectation of more healthcare users. Moreover, it seems wrong to view the situation as a punctate decision after a healthy woman is told she has a BRCA gene mutation. If it seems like her choice is to either undergo a preventative mastectomy and reduce her risk *or* wait for cancer to develop, the choice is framed in such a way that manipulates a woman (by engaging her cognitive biases) to be more aggressive and proactive in response to her increased risk for breast cancer. Presenting this decision as a punctate decisional moment dichotomizes the decision-making process—even though surveillance is a large part of both decisions. An account of autonomy should not prioritize or encourage choosing a treatment or procedure over self-management practices. The way that decisional autonomy highlights respect for patient autonomy in decisional moments fails to capture how to respect patient autonomy ought to play out in these surveillance practices that cannot be adequately understood as punctate decisions.

More critically, I believe that the significance of Kukla's (2005) critique lies in the idea that since the bulk of our health care practices are comprised of ongoing practices of self-management and surveillance, it is critical to be aware that "medical institutions and professionals are responsible for establishing and inculcating these practices and holding patients accountable for them" (p. 37). These ongoing health care practices, standards, and expectations are not really self-determined, but rather *internalized* as result of the "complex set of interdependencies among personal choice, personal responsibility, external accountability, subjection to authority, self-discipline, the collection of information, and deference to the knowledge claims and demands of others" (p. 37). As a result, patients commit to health behaviours and surveillance in a habitual way that is guided and enforced by norms and the expectations of patients by medical authorities. Yet, that does not mean that in these habitual practices or self-management responsibilities that patients do not or cannot exercise their autonomy. Kukla argues that trust and deference to experts in our society is a responsible epistemic practice that guides many of our behaviours and commitments. So, compliance with the advice from a healthcare professional can be seen as autonomous if patients not only commit themselves by "doing what [they] are responsible for doing, but also [demonstrate] a willingness to stand by [their] commitment" (p. 39). Patients typically need expertise and guidance from medical authorities as they often have an inadequate understanding of medical information to make a responsible choice—we would have an "epistemic crisis" (p. 38) if we do not expect patients to trust in medical experts. As discussed in the previous chapter, Beauchamp and Childress agree with this sentiment as they view recommendations and relevant information essential to a patient's autonomous decision-making. Seeking out guidance and following advice from other institutional authorities in which a patient shares moral principles does not make the decision non-autonomous: authoritative influences happen on all decisions in all areas of life and it is normal for individuals to incorporate these influences into their decisional processes (Beauchamp & Childress 2009).

However, for patients to demonstrate autonomy and not simply mere compliance in following the directions of medical authorities, they need to have the capacity to assess their commitments, deference, and trust in these authorities and the practices they recommend. The decisional model of autonomy is unable to adequately capture, explain, and evaluate: firstly, how patient behaviours are influenced by normative forces outside of the instances of clinical decisions and whether these norms are harmful to patients; but secondly, to what extent patients should critically evaluate recommendations by healthcare authorities and how they ought to go about this process. I will further discuss the first inadequacy but will address the second in Section B where I discuss how a relational theory of autonomy is able to evaluate the forces that cause a patient to commit or change their ongoing health care practices and how patients' capacity for critical reflection ought to be fostered in medical contexts.

Conceptualizing autonomy only through decisional moments and punctate choices diverts attention away from a critical evaluation of the normative forces that influence one's commitment to self-management practices. Many of these ongoing health care practices that patients are expected to be accountable for, "may themselves embed respect or disrespect for the agents who enact them" (Kukla 2005, p. 42). For example, Sulik (2012) critiques medicine and society's exaggeration of the benefits and importance of mammography as an "institutionalized habit" that is hard to break (p. 20). The message that mammography is a screening technology that "saves lives" by helping women through "early detection of breast cancer" (p. 20) has pervaded breast-cancer awareness activities and public health information since the 1980's. She cites over 70% of 250 articles about breast cancer written between 1913 and 1996 in eleven of America's top magazines that convey messages about personal responsibility by encouraging women to examine their breasts and undergo routine mammography, while simultaneously reinforcing the need for women to trust in medical authority and opinion. How "individuals, the public, mass media, the medical system, government agencies, and the cancer industry understand and approach breast cancer" (p. 23) implicitly establish the normative forces and narratives that encourage women to be responsible for their breast health by engaging in these surveillance regimes and trusting in the expertise of medical authorities. For example, the primary aim of National Breast Cancer Awareness Month (NBCAM), which was founded by pharmaceutical corporation, Zeneca[6], in 1985, was to "promote mammography as the most effective weapon in the fight against breast cancer" (King 2005, p. xxi). The "NBCAM propaganda" (p. xxii) uses marketing strategies and relationships with other breast cancer organizations to "affect how their customers think about breast cancer" (Sulik 2012, p. 204). This movement—of using mammography as a way to promote early detection in a way that exaggerates the benefits of the technology and downplays the inaccuracies and risks of mammography—literally began because of its ties to Big Pharma as a way to help them market their own "revenue-producing solutions" (Sulik 2012, p. 206) to breast cancer[7].

Sulik (2012) mentions multiple ways in which women have been disrespected or harmed by participating in these normative mammography practices. For example, 75% of mammographies result in false-positives: which means that the results of the mammography are positively interpreted as cancerous tumours even though the tumors are benign or not even tumours at all. This high-rate of false positives that indicate suspicious areas on mammograms leads to a high percentage of women undergoing biopsies that are "invasive, anxiety-producing, and costly" (p. 181) to confirm whether the suspicious areas are cancerous. For many of these women, undergoing this invasive procedure serve mainly to ease the fear and uncertainty around inconclusive mammograms. However, such a high rate of false-positives is alarming because it suggests that the technology is perhaps being pushed too frequently and too early in women and recommended regardless of the presence of any additional risk factors. While these statistics

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[6] Now called "AstraZeneca".

[7] Such a solution is tamoxifen, a standard pharmaceutical therapy prescribed for the prevention and treatment of breast cancer that was created and patented by AstraZeneca (NIH 2019, Sulik 2012). Sulik (2012) claims that 12% of the company's profits come from oncology medications; thus, AstraZeneca has a vested interest in finding more cancer to treat and make money on. The power and authority of big pharmaceutical companies influentially impact standard clinical practices and how 'solutions' are promoted to the public.

demonstrate the limitations of mammography, it is the best technology we currently have for screening women for breast cancer (Hatch 2016). However, the overpromotion and reliance on regular mammography screening for women can be more harmful than helpful: Qaseem et al. (2007) recommend that the technology should only be used for confirming unknown breast masses and screening women based on a cost-benefit analysis if a woman possesses multiple risk factors that justify regular and early screening routines. Similar strides have been made with PSA testing for prostate cancer: the clinical practice guidelines have adapted to the high rate of false positives with the goal of "minimizing the harms associated with unnecessary prostate biopsy and discovery of clinically insignificant prostate cancer" (Rendon et al. 2017, p. 305). Now, PSA screening is only done regularly for men who have an increased risk for aggressive prostate cancer or men who possess additional risk factors. Burdan et al. (2010) call for increased attention to the research that supports clinical practice guidelines and recommendations, such as: financial and institutional conflicts of interests, low-quality systematic reviews, and biased methodology for translating research findings into clinical practice guidelines.

Moreover, it is estimated that between 25-40% of mammographies result in false negatives as the accuracy of the technology decreases for women with less dense breast tissue (Sulik 2012). Postmenopausal women fall into this category as they are a population at an increased risk for breast cancer because breast tissue density decreases with age; which unfortunately entails that the accuracy of detecting cancer significantly decreases for this higher risk population. Inculcating women to participate into these screening practices at an early age or more frequently than is justified places a hyper-responsibility on women to commit to these self-management practices. The extensive mammography messaging (from Komen and other breast cancer stakeholders) places an onus on women to protect themselves against breast cancer (Sulik

2012). While false positives are harmful in the sense they create unnecessary fear and lead to biopsies, false negatives can lead to feelings of guilt, confusion, and individual responsibility when a woman is diagnosed with breast cancer. Although she complied with the advice she was told by medical authorities and committed to these screening practices, she cannot help but feel a sense of individual blame and responsibility for developing breast cancer (Sulik 2012). Kukla (2005) argues that practices which place "an inappropriately high demand for self-sacrifice, self-discipline, and self-submersion…incarnate a damaging and denigrating lack of respect for the…patient as a person" (p. 42). By placing a hyper-responsibility on women to participate in this overpromising screening protocol, women are disrespected and harmed when they participate in these procedures that medical authorities and cultural narratives told them to commit to. In sum, the normative expectations and push for regular mammographies as an early detection measure might actually be more harmful to women because it leads to many unnecessary biopsies, creates more fear and uncertainty about breast health, and places a hyper-responsibility on women to adhere to these practices when the technology is not as accurate as it is made out to be (Hatch 2016).

Beauchamp and Childress' decisional autonomy, which is so focussed on ensuring the conditions for respecting patient autonomy in clinical, punctate decisions, fails to provide a framework to understand how a patient's autonomy, empowerment, responsibility, and self-management may be impacted by normative expectations and commitments. This inattention to the normative expectations influencing patient behaviour prevents a critical evaluation of the disrespect towards certain patients or patient populations that might be embedded in the practices themselves. A lack of attention to the ways that autonomy is embedded in self-management practices in the decisional model absolves the duty of health care professionals and authoritative social institutions of their responsibility for fostering a patient's critical reflection skills and accountability to their own ongoing health care practices. A practical concept of patient autonomy should be consistent with the idea that it is unreasonable and unrealistic for patients to make all of their decisions and that many of these health care practices are embedded in the authority and narratives of healthcare professionals and institutions. Both Sulik (2012) and Kukla (2005) demand: "[a]sking what is at stake, and for whom, will to help to unravel the uses and misuses of medical technologies, practices and protocols" (Sulik, p. 21). This requires "clinicians…to acknowledge the authoritative role they properly play in *inculcating* patients into normatively contoured health practices…and examine this role" (Kukla 2005, *italics in original*, p.43)—a significant piece that is missing from Beauchamp and Childress' account that plays a large role in clinical decisions like the BRCA testing and prophylactic mastectomy example.

Because the decisional account does not detail how to respect patient autonomy in self-management practices and commitments, it not only fails to address the role of medical authorities in respecting patient autonomy through these practices, but the decisional model also fails to address the role of patients in understanding and evaluating their commitments to these self-management practices. Feminist philosophers call attention to the role of the patient in reflecting and evaluating their goals, beliefs, preferences in their healthcare decision-making. Patients need to learn how to reflect on their commitments to these ongoing behaviours and whether it is reasonable to engage in the normative forces that produce the expectations and commitments that establish what means to be a 'good patient'. These ongoing practices require patients to "have the skills and motivation to enact this care…by regulating and disciplining their own practices appropriately" (Kukla 2005, p. 38). Autonomy needs to be conceptualized as distinct from punctate decisions to ensure that clinician responsibility extends beyond simply informing their patient of medical facts but also helping patients foster “appropriate practices and a responsible relationship to these facts” (p. 38). I believe that a large issue with Beauchamp and Childress’ account is the lack of detail on how patients should reflect and understand medical information, how the information relates to their values, and how this reflection should guide their decision-making. Although Beauchamp and Childress want a realistic account of what it means to be “substantially autonomous”, they do not provide enough direction regarding how physicians should guide patients through these evaluations or detail how patients should proceed with decisions regarding their health. Simply providing patients with more information does not guarantee that patients will make autonomous decisions. I will return to this issue in Section B where I discuss how feminist relational theorists provide more suggestions surrounding patient reflection.

The need to conceptualize patient autonomy beyond the moments of decision through an evaluation of the normative forces that inculcate patients into health practices (and the meaning embedded within those practices) leads into my second critique of Beauchamp and Childress’ decisional model: that is, by conceptualizing autonomy only in terms of local autonomy, decisional autonomy cannot adequately account for how one’s social context shapes a patient’s autonomy and decision-making. Relational theorists take issue with the traditional view’s focus on local autonomy in how it details the conditions that support an agent making an autonomous choice. A failure to consider how an agent’s global autonomy can be affected by social constraints, such as oppression and marginalization, prevents the decisional model from adequately understanding how these constraints might impact a patient’s local autonomy (i.e. autonomy in punctate decisional moments). In the feminist relational framework, “autonomy is both defined and pursued in a social context and that social context significantly influences the opportunities an agent has to develop or express autonomy skills" (Sherwin & McLeod 2000, p. 259). In this sense, a patient might not be expressing a truly autonomous choice if they make a decision that aligns with values and preferences that are a result of oppressive structures within their sociocultural context. The beliefs, values, and preferences that influence a person's decisions are arrived at through sociocultural values and processes (Zimmerman 2017): how we are socialized plays a large role in the way that we make decisions and exercise our autonomy. In the remainder of Section A, I will demonstrate two ways in which a patient's social context might compromise their autonomy using the BRCA example: first, by showing how social forces, norms, and expectations influence what information counts as relevant and how patient's understand it; and second, I will show how oppression and social forces could interfere with one's ability to flourish and develop the skills necessary to exercise their autonomy.

An example of how social forces, norms and expectations that arises from one's positioning in a western sociocultural context is evident when we consider the behaviours of women at risk for and diagnosed with breast cancer as a result of the culture of breast cancer survivorship and corporate interest in breast cancer consumerism. With roots in the women's health movement in the 1970's, pink ribbon culture[8] emerged as women were trying to draw attention to the lack of funding and research given to the most prevalent cancer affecting women in Canada and the United States. However, the increase in media attention, advocacy, and funding going towards the movement quickly elevated the status of breast cancer from a disease into an epidemic. The increased awareness and newly founded social import of the movement

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[8] Recall from the Introduction that pink ribbon culture is defined as an influential Western subculture that uses pink ribbon symbolism to not only increase awareness for breast cancer, but "turn breast cancer into a brand name with a recognizable logo" (Sulik 2012, p. 9). In this way, industries profit off of pink ribbon campaigns to continue the battle against cancer. The pink ribbon culture has become so influential that it resonates narratives, norms, and expectations of all individuals 'touched' by cancer to act in socially-mediated ways.

created the conditions for pink ribbon culture to emerge (Sulik 2012). Academics such as King (2006) and Sulik (2012) have critiqued the symbolic and financial support of pink ribbon activism which has transformed breast cancer into a market-driven industry of survivorship, without effectively improving breast cancer prevention, treatment, or prognosis: "grounded in advocacy, deeply held beliefs about gender and femininity, mass-mediated consumption, and the cancer industry, pink ribbon culture has transformed breast cancer from an important social problem…to a popular item for public consumption" (Sulik 2012, p. 9). As the pink ribbon began to permeate corporate marketing strategies and sponsorships, profit motives and corporate agendas began to define the movement as a way of life by gaining customer loyalty and public trust by marketing a cause that people could participate in through their consumerism.

The narratives and values amplified to the public through pink ribbon culture work to socialize individuals into how they ought to be experiencing breast cancer or acting as a supportive ally. For example, the *pink* ribbon engages gendered stereotypes and associating with femininity to promote narratives, norms, and values that instill a single way to experience breast cancer: "through socialization, individuals learn what is expected of them and how to behave" (Sulik 2012, p. 89). Some of the narratives that pink ribbon culture engages include: traditional feminine attributes of purity, nurturance, and selflessness; a heightened value of optimism; and pervading message that breast cancer is a transformative experience that women should embrace. When women are diagnosed with breast cancer, they are expected to "fight" and "battle" in the "war" on cancer (Sulik 2012)—these aggressive and masculine expectations disrupt their previous gendered socialization and pushed them into a new survivor identity. To restore normalcy, women diagnosed with breast cancer need to negotiate their identities with these new narratives and expectations. The 'ideal' breast cancer patient is a woman who embodies the survivor and hero rhetoric in the battle and war on cancer, but maintains her feminine role by remaining optimistic and light-hearted about her diagnosis, while still holding selfless and nurturing roles to "diminish the breast cancer disruption on the lives around her" (p. 286). Pink ribbon culture constructs an idealized model of survivorship that is embodied as the "she-ro": "an amalgamation of masculine and feminine ethos which enables her to garner social capital while accommodating the norms of pink femininity" (p. 101). The she-ro is valorized through pink ribbon culture; therefore, if a breast cancer patient does not conform to this illness identity, their voice and experience is oppressed and marginalized because they are viewed as deviant (Sulik 2012). In this way, social context provides and enforces the rules of engagement with pink ribbon culture by shaping: the way the public understands breast cancer, the rules of survivorship, and the specific ways of dealing with the illness. Understanding the social context is critical in understanding the ideological and emotional impact of pink ribbon culture on women and how it affects their decision-making.

A way that pink ribbon culture may affect a woman's decision to undergo a risk-reducing mastectomy is through the "overarching 'culture of survivorship' oriented to optimism, personal empowerment, and the 'survivor' as an identity category" that was produced through the pink ribbon movement (Sulik 2012, p. 30). Early detection and screening interventions function in broadening the cancer survivorship label and what counts as experiencing breast cancer. Although it seems strange to think of the woman who is healthy and shows no symptoms of cancer as a 'survivor', Aronowitz (2015) suggests that the definition of a "cancer survivor" has broadened to encompass "anyone touched by cancer" (p. 140). Aronowitz suggests that healthy individuals who are at an increased risk of cancer are encouraged to identify with this collective survivorship identity when they undergo extreme preventative 'treatments', such as a prophylactic mastectomy. (Recall Aronowitz's analysis of the converged disease experience, where treatment of breast cancer is similar to treatment of women who are at risk for developing breast cancer). By selling fear and uncertainty with the promotion of genetic screening tests, patients are drawn into the cancer survivor label and can justify aggressive risk-reducing surgeries to cope with their risk and enter into the "war" on cancer. If early detection and screening work to decrease people's fear of cancer, the "early detection" and screening rhetoric perpetuated by pink ribbon culture and social authorities function in broadening the cancer survivorship label and what counts as experiencing breast cancer.

Previvorhood—or "cancer survivorhood for people who are at risk for cancer but are not actually diagnosed" (Aronowitz 2015, p. 148)—may explain part of the reason why women at risk for breast cancer undergo aggressive preventative surgery because the pink ribbon movement overemphasizes the importance of individual and collective action to "promote women's empowerment and personal transformation" (Sulik 2012, p. 35). Since the "rules of survivorship specify how to feel… and how to…take on the role…of survivorship" (p. 287), pink ribbon culture demands compliance to the she-ro model of survivorship (and also previvorship). Part of being a she-ro involves being upbeat and optimistic while encouraging aggressive action in the "war" on cancer, even if it is through risk-reducing treatments, such as a prophylactic mastectomy. Sulik (2012) and Aronowitz's (2015) sociological analysis validates the strength of the pink ribbon culture in influencing women's decision-making through conventions of feeling and rules of engagement to embody the she-ro identity:

> These conventions…provide an explanatory framework that exerts social force on women's decisions, coping strategies, interactions with others, and sense of self…By analyzing the patterns…in women's behaviours, coping mechanisms, and cultural repertoires as women describe them…we see how social and cultural expectations become embedded within people's personal lives and how social rules are often simultaneous and mutually reinforcing (Sulik 2012, p. 286).

The powerful and predominant pink ribbon culture exerts such a social force on women that it is normal, or even expected, for them to uncritically uptake BRCA gene testing and undergo aggressive preventative surgery to be a pink ribbon survivor and experience the disease according to their social scripts and expectations.

Another way in which women's decision-making about BRCA gene testing and prophylactic mastectomies is affected by social narratives is through the information targeting women that is disseminated through medical authorities and pink ribbon corporations. Sulik (2012) argues that mass media operates as a tool and driving force for pink ribbon culture's platform and discursive framework: "Much of pink ribbon culture is now transmitted through an array of marketing strategies and modes of consumption that rely heavily on mass media to influence potential audiences and consumers" (p. 22). Personal stories, especially those that exemplify the she-ro experience, reverberate through the advertisements of breast cancer organizations, disseminating "cultural repertoires about how to deal with the illness" (p. 121). Mass media amplifies the voices of the she-ro, which "concretize[s] the rules of engagement for any woman who is diagnosed with, or at risk for, breast cancer" (p. 104). Like other advertisements directed to increase consumerism, famous individuals in Western society often have a large influence through advertising when they choose to promote certain social movements. Sulik (2012) mentioned a few famous women, such as Audrey Lorde, Demi Moore, Mary J. Blige, and Betty Ford, who had encountered breast cancer and used their social position to reverberate the she-ro rhetoric to the public. Many of these voices encourage individual responsibility by telling women to be proactive and protect themselves against breast cancer—in Sulik's examples, this often referred to messages urging women to undergo regular mammographies.

However, recently after Sulik's (2012) "Pink Ribbon Blues" was published, Angelina Jolie published an opinion editorial in the New York Times in 2013 encouraging women to undergo BRCA gene testing (Stöppler 2018). Using her personal story and famous outreach, she wanted to tell women her story so they could "benefit from [her] experience" (Jolie 2013). After losing her mother to breast cancer and discovering she was a BRCA1 gene carrier, Jolie opted for a risk-reducing mastectomy so she could "tell [her] children that they don't need to fear they will lose [her] to breast cancer". After reading Sulik's sociological analysis of the she-ro and pink ribbon culture, then reading Jolie's op-ed, the narratives Sulik had identified ring through Jolie's article. For example, Jolie cites that her main reason for undergoing the prophylactic double mastectomy is for her kids: "[my kids] know that I love them and will do anything to be with them as long as I can". A she-ro will do anything in her power to minimize the disruption of her illness to the people in her life she has always cared for; therefore, maintaining her femininity through her gender expectations to be a selfless and nurturing mother (Sulik 2012). Furthermore, she says that despite the severity and aggression of the surgery, "days after surgery you can be back to a normal life" and during the three months post-surgery she has "been able to keep this private and to carry on with [her] work" (Jolie 2013)—underscoring how selfless she was by not relying on the support of others and remaining optimistic through the procedure.

Moreover, by openly sharing her story with "any woman reading [her op-ed]", Jolie (2013) echoes pink ribbon rhetoric by discussing her encounter with breast cancer as a catalyst for her empowerment and personal transformation:

> Cancer is still a word that strikes fear into people's hearts, producing a deep sense of powerlessness. But today it is possible to find out through a blood test whether you are highly susceptible to breast and ovarian cancer, and then take action…Life comes with many challenges. The ones that should not scare us are the ones we can take on and take control of.

She now sees herself as an advocate for empowering other women to overcome their fear and risk of getting breast cancer and learn more about their “strong options” by learning about their own risk dispositions: “I want to encourage every woman, especially if you have a family history of breast or ovarian cancer, to seek out the information and medical experts who can help you through this aspect of your life, and to make your own informed choices”. Again, Jolie clearly resonates the same messages that the breast cancer industry does: take individual responsibility for your health by trusting and complying with medical authority. Jolie is the exemplary she-ro for BRCA gene testing and preventative mastectomies as she clearly demonstrates the perfectly negotiated ‘illness’ identity of breast cancer previvor. She aggressively takes on the war with cancer by being rational about her risk state (through educating herself on her options) then dealing with her risk state by taking action with prophylactic surgery. But to counter the masculine values associated with battling cancer, she demonstrates many ways in which she still maintains her femininity and gender role.

It has been demonstrated that since Angelina Jolie’s publicization in the New York Times, the number of women who had BRCA gene testing and prophylactic mastectomies has significantly increased: the “Angelina Jolie Effect” was coined to express this rise in women requesting BRCA genetic testing and undergoing risk-reducing mastectomies (without a previous breast cancer diagnosis) since Angelina Jolie’s opinion editorial (Liede et al. 2018). As a celebrity, her influence as a she-ro, as well as a notable public figure providing information to the public about oncogene screening and options, has clearly influenced other women to seek more information and act on their risk state. The BRCA testing and prophylactic mastectomy scenario exemplifies the significant influence of social forces on patient decision-making:

> The idea that users of health services should be able to make informed decisions about their medical choices seemingly places the control in the hands of the patients…In reality, the medical system, the breast cancer industry, and pink ribbon culture work together to control the

> information women need when making their choices, while defining the options available to them (Sulik 2012, p. 210).

If understanding of information is a critical component of ensuring respect for patient autonomy, then I believe a model of autonomy should strongly consider how social forces influence how patients understand the information not only provided to them by their physician, but also through other social narratives and messaging. A theory of autonomy that does not attribute import to the social forces that influence patient decision-making inadequately outlines the conditions for patient autonomy and, dare-I-say, offers an *unrealistic* and *idealized view* of patient autonomy. Thus, I argue that Beauchamp and Childress' (2009) decisional model of autonomy does not give adequate attention to the influential power of social forces on patient autonomy or decision-making.

Decisional theorists are concerned about a physician's responsibilities for ensuring the conditions for a patient to be able to exercise their autonomy: that is, ensuring patients have sufficient and relevant information to guide their decisions and that these decisions are made voluntarily and free from coercion. However, although they recognize worries regarding the adequacy of information conveyed to and processed by a patient, as well as threats to the voluntary condition, Beauchamp and Childress (2009) only articulate these threats to decisional autonomy as issues with how a healthcare provider communicates to a patient, how a patient's conditions may inhibit understanding of relevant information (like anxiety of being ill or intoxication), or how patients can be coerced by other individuals (such as HCPs). They attempt to address these threats by: encouraging healthcare providers to improve their communication skills to help a patient achieve adequate understanding necessary to make a decision; encouraging providers to be aware of how they might influence or manipulate patients in ways that are not compatible with autonomous decision-making; and encouraging providers to foster an awareness of when patient understanding may be compromised due to the stresses of their illness, presence of psychiatric disorders, or drug additions. In how Beauchamp and Childress address the concerns surrounding adequate and relevant information and the role of social context in their account, I do not believe they give adequate attention to the social forces that might be a threat to patient understanding or autonomous choice.

While I have tried to demonstrate a variety of ways that social context can influence women's decision-making in either requesting BRCA gene screening or deciding whether to undergo a preventative mastectomy (e.g. downplaying the role of patient autonomy in self-surveillance, the narratives pushing aggressive preventative surgery and early detection technologies, and other influential sources of information), it is also critical to recognize how an agent's social context can affect the values that influence their decisional processes and the opportunities (or lack of) to develop the capacities necessary to make autonomous decisions. Feminist relational theorists are concerned with the way in which social forces, like oppression, can "interfere with an agent's ability to develop or exercise autonomy effectively in specific ways" (McLeod & Sherwin 2000, p. 260). Dodds (2000) argues that there is a distinction between rational decision-making and autonomous decision-making: "Rational choices, choices made on the basis of principles of rationality, display some of the skills of autonomy competency but do not constitute autonomy. A person who is fully autonomous will make rational choices that reflect their authentic desires or values" (p. 227-228). This distinction can be traced back to Beauchamp and Childress' focus on local autonomy (or rational capacity needed to make an autonomous choice) and diverting attention away from global autonomy (or what it means to lead an autonomous life). By narrowly conceiving of autonomy in punctate decisions and ensuring that a patient is free to make their own decision so long as they have sufficient and relevant information to make a choice, the decisional account does not adequately consider how social forces might constrain an individual's capacities for autonomous choice. By only considering the HCP's duties to respect patient autonomy, the decisional model does not account for the conditions that might inhibit patients' development of the skills necessary for autonomous decision-making beyond the clinical environment[9].

One way in which oppressive social relationships interfere with an agent's capacities to make autonomous decisions is through corroding their self-evaluative attitudes that are necessary for "autonomous choice, judgement, and action" (Mackenzie 2014, p. 287). Relational theorists argue that self-evaluative attitudes (like self-trust and self-respect), that are necessary for an agent to reflect on their choices and make a judgement based on their values, are vulnerable to oppressive social forces. A theory of autonomy ought to recognize how these social forces might corrode an individual's self-evaluative capacities (an aspect of one's global autonomy) and, therefore, impair their autonomy in clinical decision-making. Sherwin and McLeod (2000) discuss one "particular dimension of oppression that interferes with autonomy, namely, oppression's effect on self-trust" (p. 261). They argue that an agent requires a certain degree of self-trust to act autonomously and make choices in their best interests. Oppression, by definition, devalues certain individuals by association with social groups. Oppressive attitudes are harmful because members of these groups may internalize the devaluation of their personal worth on an unconscious level in a way that might affect their confidence in their ability to make choices. As

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[9] In discussing the other bioethics principles, Beauchamp and Childress (2009) do address some challenges to decision-making that might lie out of a patient's control (which would affect their autonomy). An example would be if low-income patients did not have access to a certain medication. Beauchamp and Childress would invoke the principle of justice as a patient's autonomy would not be respected if they did not have access to certain opportunities. While Beauchamp and Childress do recognize some of these social influences, there are many other ways that social forces and conditions influence a patient's decision-making, such as by impairing their decision-making capacities, which is not given adequate attention in the decisional account. I assume, partially, because Beauchamp and Childress focus on the responsibilities of HCPs to respect patient autonomy but do not articulate any requirements for patients to demonstrate autonomy (other than by demonstrating capacity).

a result, “oppression tends to deprive a person of the opportunity to develop some of the very skills that are necessary to exercise autonomy by restricting her opportunity to make meaningful choices and to have the experience of having her choices respected” (p. 262). Relational theorists draw attention to the harmful effects of oppression that can undermine an individual’s self-trust by denying an agent a supportive environment to develop the capacities for autonomous decision-making.

An example of the way in which oppression might deprive a woman of the opportunity to develop the necessary skills to exercise her autonomy in the BRCA screening decision is through the silencing of diverse disease experiences that contradict the messaging of pink ribbon narratives. Sulik (2012) describes situations in which women’s lived experiences with breast cancer have been silenced by pink ribbon culture if they do not conform to the optimistic, transformative she-ro rhetoric. The predominant narratives and messaging that surround breast cancer experiences are defined by pink ribbon culture—these expectations lead many women to conform to the values laid out by the microculture. In her interviews with breast cancer survivors, Sulik observes many women, who have a deviant, ‘abnormal’ experience of breast cancer that contrast the predominant narratives, feel guilt, shame, or individual responsibility for their experience of breast cancer. By marginalizing and oppressing the diverse experiences of breast cancer, women are either pushed to conform to the predominant she-ro narratives to explain their breast cancer experience and join the “sisterhood” *or* feel guilty about their diverse experiences with breast cancer and be marginalized from support resources. The rules of survivorship (which specify how to experience breast cancer) and the conventions of feeling (that provide an explanatory framework for understanding one’s feelings in concordance with sociocultural expectations) exert force on a woman’s “decisions, coping, interactions, and sense of self" (p. 268). These social forces can interfere with a woman's confidence in her experience with breast cancer and how she makes decisions. This socially-prescribed, single right way to experience of breast cancer can corrode a woman's self-evaluative capacities as she internalizes these oppressive social expectations and which, according to relational theorists, can cause an impaired sense of autonomy: "oppression may shape agents' values and desires in ways that undermine their capacity for autonomous choice in certain matters" (Donchin 2000, p. 261). Beauchamp and Childress (2009) do not provide an account of the roles of HCPs, social scaffolding, or patients in how patients are to develop capacity to make autonomous decisions.

Another way in which relational theorists worry that social oppression and injustice can affect an agent's autonomy is by restricting "the range of significant options that are available to a person or social group" (Mackenzie 2014, p. 288). Oppression may limit the choices available to an agent depending on their social position or potentially creating a double-bind situation where the agent will suffer no matter which choice they choose (Sherwin & McLeod 2000). For example, King (2005) details how pink ribbon culture was involved in the promotion of early detection of breast cancer in the United States has led to the diversion of funding towards making mammography more accessible for women, while simultaneously preventing the funding for the research of "other approaches to fighting the epidemic" (p. 118). This preoccupation with early detection and mass screening has made mammography virtually accessible to most women, which has resulted in situation where financially and culturally marginalized women can get access to early detection. Consequentially, this increase in screening has resulted in increased breast cancer diagnoses and an increased demand for treatment. Although women who are economically disadvantaged and often racially marginalized are able to be screened for breast cancer and diagnosed early due to the promotion of screening and early detection programs, a large proportion of these women are unable to afford breast cancer treatment which has led to increased mortality rates for women of color that are positioned in a low socioeconomic status (King 2005). In this case, not only is a woman's social context affecting her autonomy by foreclosing certain options available to her, but she is placed in a double-bind. Either she participates mammography screening programs and discovers early stage breast cancer which she cannot afford to treat, or she does not participate in the screening program and risks a late stage diagnosis with a poor prognosis and no resources for treatment. While Beauchamp and Childress (2009) would employ the principle of justice to evaluate this inequity in treatment, relational theorists take their critique a step further by calling for increased attention to the social distribution of opportunities and whether these inequalities perpetuate injustice of certain social groups and inhibit the exercise of autonomy of individuals of those groups. More work needs to be done to better understand how genetic screening programs might foreclose certain options for oppressed individuals or prevent the development of autonomous capacities.

I have argued in Section A that Beauchamp and Childress do not attribute enough significance to how a patient's social context influences their decision-making, nor explain how their account can address the relational critique that one's social position can inherently impair an agent's autonomy—mainly because Beauchamp and Childress' focus is to provide a "realistic" account local autonomy and therefore do not sufficiently consider how an agent's global autonomy might inhibit their exercise of autonomy in clinical decisions. To support this charge, Beauchamp and Childress (2009) briefly mention this feminist critique against their account: that is, decisional autonomy "is inattentive to emotions, communal life, reciprocity, and the development of persons over time… [and] that such an account of autonomy focusses too narrowly on the self as independent and rationally controlling" (p. 102-3). Such a critique demands an account of autonomy that recognizes the "complex intersecting social determinants" because oppressive socialization "can impair autonomy… through forming an agent's desires, beliefs,…and attitudes and through thwarting the development of the capacities…essential for autonomy" (p. 103). In response to this critique, Beauchamp and Childress assert that "[s]uch a relational conception of autonomy is illuminating and defensible as long as it does not neglect or obscure the main features of autonomy that we analyze" (p. 103). However, in analyzing the example of women at an increased risk for breast cancer, I do not believe that this is a satisfying response to the feminist critique.

Donchin (2000) labels Beauchamp and Childress' recent versions of their account as *weak relational autonomy* since they "do not deny that communal life and human relationships provide the matrix for the development of self" (p. 238). However, they overlook the impact of one's social context on their autonomy in a few significant respects. While the decisional model recognizes that other individuals (such as healthcare providers and other relationships) could manipulate a patient in their decision-making, they do not underscore the significant influence of social forces, such as oppression or socialization, in patient decision-making or provide any suggestions for how healthcare providers could be aware of and attempt to mitigate the effects of these forces on patient autonomy. Respecting patient autonomy requires HCPs to consider how a patient's social context shaped their values and beliefs and helping the patient understand how these values come into play in clinical decision-making. Moreover, their exclusive focus on HCP responsibilities to ensure respect for patient autonomy distracts from the need to promote the develop a patient's capacity for autonomous decision-making. Beauchamp and Childress want to reject a more demanding account of autonomy that requires critical reflection and more authentic decision-making to keep their account practical and relevant. However, an individual's social position greatly impacts their ability to make these decisions: for example, how one's social position forecloses certain options or one's ability to trust in their own reflection and decision-making. As a result of their failure to articulate how the decisional model addresses the influence of social context on patient autonomy, I argue that Beauchamp and Childress' framework is unable to account for situations in which social context plays such a significant role on decision-making (such as the one I have been describing in this project). In Section B, I will explain how a feminist relational framework is better able to: underscore the significance of social context in autonomy; critique oppressive social scaffolding that prevents autonomous choice; and suggest how HCPs ought to encourage patients to evaluate these social influences and their own values and preferences to reach a more authentic decision.

B. Feminist Relational Approach & the BRCA Testing and Preventative Mastectomy Case

Even though Beauchamp and Childress believe that a relational account of autonomy is defensible and perhaps even complementary to their account, they do not articulate how social context could inhibit patient autonomy and what (if any) responsibilities patients or HCPs have to mitigate the effects of social forces when they infringe on autonomy—what Donchin (2000) refers to as *weak relational autonomy*. Instead, I argue in Section B that *strong relational autonomy* is necessary to better able negotiate these tensions, especially when we consider the BRCA screening decision and the consequent mastectomy or surveillance decision. The feminist relational framework is based on the premise that autonomy is a product of "ongoing interpersonal, social, and institutional scaffolding" (Mackenzie 2014, p. 285) and calls for careful "attention on the impact of social oppression and injustice on individuals' capacities to lead autonomous lives and to make autonomous choices" (p. 288). As a result, I argue that the relational framework is better able to evaluate how an agent's social context influences their decision-making (through their values, capacity development, and social relations) and calls for a deeper solution to respecting patient autonomy than the decisional framework for the scenario I described above. In Section A, I explained how a feminist approach to autonomy is able to illuminate the areas in which socialization and social position might come into play in medical decision-making and how these forces might influence a patient's capacity for autonomous decision-making. In this section, I will demonstrate how some feminist theorists (Dodds 2000, Donchin 2000, Sherwin & McLeod 2000) propose to ameliorate these challenges in what it means to respect patient autonomy.

Relational theorists often begin evaluating an individual's ability to exercise their autonomy by considering the agent's social location: whereas the decisional account "concerns [itself] only with judging the ability of individuals to act autonomously in the situation at hand, relational autonomy asks us to take into account the impact of social and political structures…on the lives of individuals" (Sherwin & McLeod 2000, p. 260). As a result, the relational model evaluates not only the individual's ability for acting autonomously, but also the impact of social forces, relationships, and social conditions on reducing an agent's ability to act autonomously. The goal of relational autonomy is to ameliorate the oppressive conditions of society that restrict an individual's ability to act autonomously while simultaneously encouraging the agent to develop capacities necessary for autonomous decision-making. As a result, most solutions offered by relational theorists seem to address both macrolevel threats to autonomy (like social structures, oppression, and discriminatory attitudes) and microlevel threats (such as how power dynamics in the patient-physician relationship affects autonomy), accompanied by solutions for how to foster autonomous capacity in individuals despite these threats. In this section, I will draw on various feminist relational theorists to extrapolate how some of their solutions might apply to the BRCA scenario and address some of the gaps in the decisional framework.

Dodds (2000) argues that support in decision-making is necessary for developing a person's decision-making capacity. While more information and opportunities offered to patients to take full control of their healthcare often encourages autonomy, there is no guarantee that the provision of more choices and information will always enhance their autonomy. "Autonomy competencies" (p. 226) are needed so that individuals can use the information and options they are provided to make more authentic choices. Developing capacities necessary for autonomy is influenced by one's socialization—individuals that belong to marginalized groups are not socialized in ways that encourages the development of the skills necessary for full autonomy (Dodds 2000). Since competency skills can be taught—by encouraging patients to ask questions, voice their feelings and preferences, and take responsibility for their own care—healthcare workers should encourage these behaviours in patients from a young age and provide children with more of an opportunity to have a say in their healthcare encounters. While this approach to care takes more time than is sometimes feasibly permitted in healthcare environments, Dodds argues that "[a]ssisting patients to make choices through active understanding of their wants and expressed preferences may well better protect autonomy," (p. 231) than telling patients more and more information about their options and risks.

In considering the genetic testing decision or the decision whether to undergo a preventative mastectomy, this solution might look like a woman's healthcare provider encouraging her to ask more questions, explore alternatives, and share their own thought processes in making the decision if they were in the patient's situation. Beauchamp and Childress (2009) recognize that healthcare professionals are also authorities that might influence patient decisions—patients often ask their HCP for advice and guidance in healthcare decisions of which they are unfamiliar. Beauchamp and Childress assert that recommendations are typically essential for valid consent (p. 128). Decisional theorists would deem most physician recommendations an acceptable form of influence so long as the information is truthful, accurate, and is not being used to coerce a patient into a choice. However, it can be problematic for their account that they do not elaborate on HCP recommendations to patients—without certain intentions, recommendations could be considered unethically manipulative. Baylis and Downie (2001) make a distinction between "morally acceptable recommendations that enhance decision-making and morally unacceptable recommendations that actually diminish patient autonomy" (p. 21). In their view, providing a recommendation is an important part of the patient-physician relationship, especially if the patient asks for a recommendation to help their decisional process. As such, healthcare providers are obligated to not only disclose relevant information for the patient's decision, but also any information that the patient is requesting (like a recommendation) because the patient considers it valuable to their decision. Morally-acceptable recommendations are ones that not only disclose the healthcare providers suggested course of action, but necessarily the justification and value judgements behind the recommendation. "Professional recommendations, not unlike personal recommendations, are necessarily value-laden as the information that physicians choose to disclose to patients and the manner in which they do so is necessarily informed by the values they hold" (Baylis & Downie 2001, p. 20). Therefore, healthcare providers need to disclose to patients how a physician's values might influence their recommendation and the decision *they* would select if they were in the patient's position—

especially since the values that physicians and patients hold should never be presumed to be the same.

A morally acceptable recommendation is one where the healthcare provider is aware of their own personal and professional values and recognizes that these values need to be set aside when they diverge from the patient's. A good recommendation, therefore, is one that is grounded in relevant informational details that a patient with a specific set of values would need to understand their decision and make a choice. If the healthcare provider does not know the relevant values or contextual factors in the patient's decision, Baylis and Downie argue that the HCP "must attempt to elicit the information" (p. 22) and encourage the patient to think about their values and the relevant details for the decisional moment. Recommendations given where a healthcare provider does not disclose their value judgements that have informed their decision can be manipulative. On one hand, the HCP is providing the recommendation based on the information that they (as trained professionals) would want to know if they were in the same position as the patient. However, based on a different set of values and beliefs, the information that a HCP might consider relevant may very well not be relevant to the patient. Disclosure of the HCP's value judgements in addition to their recommendation is necessary to ensure that patients are receiving the information that is relevant and sufficient to their decision. The HCP should not assume that they know what is in a patient's best interest, especially if they do not try to understand the patient's social background and value judgements that would be guiding their decision. Recommendations where the HCP does not disclose their value judgments that influence their preference are unethical because they are pushing their values and beliefs on the patient. These recommendations are unwarranted: as physicians, while they may be experts in medical knowledge, do not have special ethical knowledge of value considerations and should not use their authority to make these value judgments on behalf of patients (Baylis & Downie 2001). Empirical studies suggest that physicians have not "developed the skills to determine the information that serves their patients' best interests" (Beauchamp & Childress 2009, p. 122). Healthcare providers need to ensure that they are not pushing their values on to their patients by conflating a recommendation based from professional standards and experience with "decisions for or against medical care…[that] are rightly the province of the patient" (p. 122).

Rubin and Tanenbaum (2011) interviewed thirteen lesbian and bisexual breast cancer survivors about their opinions on reconstruction after their mastectomies. They found that most participants felt like opting out of reconstruction surgery was not an option, even though it is an elective procedure. Physicians either explicitly or implicitly downplayed potential risks of the surgery and tried to convince their patient why they were an excellent candidate for the procedure. Many participants felt like their worries about the reconstructive surgery were ignored and that undergoing reconstruction was the only right choice. Consistent with Dodds (2000) suggestions for fostering and developing autonomous capacities in patients, the participants in Rubin and Tanenbaum's (2011) study felt like the HCPs they had encountered did not want to engage with them, discuss alternatives, or come to a shared decision. Dodds (2000) ultimately calls for:

> A health-care worker who has sufficient information; who can listen actively to patients' identification of their concerns, desires, fears, and so on; and who can ask them how much they want to know and why will often better promote autonomy both in decision making and in the patient's capacity to learn to accommodate or respond to the changes in their health, so they can learn to live with, resist, or accommodate their altered circumstances (p. 232).

Anita Ho (2006), a feminist bioethicist, details her experiences with a surprising breast cancer diagnosis. In her "Breast Cancer Diaries", she reflects on her "humbling experience" (p. 86) of her own care. As she went through a lumpectomy and radiation treatments, she was forced to redefine her identity and body image. She identified much of her discomfort in the process because of a new self-consciousness about her breasts and the psychological challenges she was facing. Dodds (2000) notes how "[s]ignificant medical decision-making may confront a person with new information that challenges…her self-understanding and capacity to exercise self-direction" (p. 231). Ho (2006) identifies feeling torn between two opposing forces. On one hand, she reminds herself that her identity does not depend on her physical appearance and sexuality and she has an "ethical responsibility to reject patriarchal standards of what it means to be a woman rather than succumb to various stereotypes of sexuality and gender that continue to oppress women" (p. 87-88). But on the other, she tries to convince herself that she is "still a sexual being, and that breast cancer and surgical scars do not take away [her] sexual desirability" (p. 88). She feels, although she never previously cared about her appearance, that her breasts still somehow have inherent worth. She concludes her reflection by stating: "It is ironic that I am unable to defy the culture that I try to convince my students to reject. I feel embarrassed that, at the moment of truth, I have succumbed to the breast culture" (p. 88). Many of Ho's reflections are consistent with Sulik's (2012) analysis surrounding the socialization of women to trust in medical authority in breast cancer screening and treatment since the opinion of doctors is portrayed as truth in our society. Medicalization (such as the normalization of breast cancer screening and aggressive surgeries to remove breast cancer via lumpectomy or mastectomy) has been critiqued by many feminist scholars as patriarchal control of women's bodies. These scripts and narratives become so engrained in our society, that women are socialized to conform to them and not deviate against them—making it feel like they do not have much of an option but to comply with their physician.

Strong relational autonomy requires healthcare providers to pay careful attention to the details of their patient's life experience and environment (Donchin 2000). Because of Ho's experience working in bioethics, she was able to understand how her values, beliefs, and social context affected her experience with breast cancer and the medical system. But many patients do not recognize their own beliefs, values, and preferences, so reaching an autonomous decision would require HCPs to explore their patients' histories and social contexts to guide them to an authentic decision (Donchin 2000). Healthcare providers have a stronger duty to respect patient autonomy in a relational framework than in the decisional one: "Respecting autonomy would require recognizing patients' struggles to break free of oppressive authoritative influences and assisting them to sustain relationships essential to their self-identity" (Donchin 2000, p. 238). In Ho's personal account, this would require her oncologist to have deeper discussions with her about her hesitancies to ask questions about the procedure, worries about her body image and self-esteem, and exploring the context in which Ho is trying to make sense of her illness and her care experience. Instead of simply providing sufficient and relevant information to guide decision-making, a relational approach demands that providers: enter "into an interpersonal relationship with her patient" (p. 238); respond "sensitively to the meanings illness has for those in their care;…deploy their power and influence to restore and strengthen autonomy competencies; and…support patients' struggles to create new personal meanings out of the experience of disease, disorder, or disability" (p. 240).

Although there are many more ways that relational critiques come into play in the breast cancer experiences, I will finish this section by going further into one of the capacities that Sherwin and McLeod (2000) have identified as necessary for autonomous decision-making. As briefly alluded to previously in the chapter, Sherwin and McLeod identify self-trust as one of the autonomous capacities that oppression can interfere with. Oppression and marginalization can lead to an individual internalizing oppressive attitudes as lack of self-worth and devaluation. This lack of self-trust can then interfere with an agent’s ability to act according to their own interests. Since autonomy partly involves “reflecting on one’s beliefs and desires; making reasonable decisions in light of them; and acting on those decisions,” (p. 262) it is essential that an agent trusts in their capacity to make choices based on these beliefs and trust in their own judgement to make those decisions. Sherwin and McLeod suggest that self-trust develops when an agent has a certain level of support in their social environment: for example, by being provided opportunities to use and develop her capacities in decision-making and by receiving encouragement from others to trust her capacities to make decisions. In healthcare settings, where uneven distributions of power and authority are present, healthcare professionals need to be wary of exacerbating the power differential in the patient-HCP relationship and perpetuating oppressive attitudes in their interactions with patients.

Sherwin and McLeod (2000) describe three types of self-trust that are involved in different dimensions of autonomy. One of the types that they explain, that may play into the BRCA testing or preventative mastectomy decisions, is the trust in one’s capacity to choose effectively. This type involves “having good decision-making skills and also being situated to choose well, meaning that the agent is adequately informed of alternative courses of action and of whatever facts are relevant to her decisions… [by] trust[ing] her competency skills and the accuracy and adequacy of the information available to her” (p. 263). Oppression can limit an agent’s knowledge base for making decisions by ensuring that most of the information available to an agent are messages and narratives from the dominant group or influential institutions. Sulik’s (2012) analysis of pink ribbon culture could be an example of this form of oppression—by silencing the experiences of women that do not conform to the prevalent she-ro script, the kinds of information available to women to make decisions regarding their health is limited to what they are told by dominant messaging. The information that is relayed to women through these prevalent cultural messages about the lives of the members of the dominant group is limited to the risks or benefits these privileged members would incur by making decisions about their own healthcare about the values that guide them. Relational theorists would want to challenge this dimension of oppression by encouraging members of minority or oppressed groups that their opinions, values, and experiences are equally credible as the ones of the dominant group and by ensuring that the other voices and experiences of other breast cancer survivors are also being circulated.

Sherwin and McLeod argue that healthcare providers have a deeper responsibility to understand their patient's values but also reflect on their role in a culture that is perpetuating oppressive values and how this insensitivity may influence a patient's decision-making and autonomous capacities (like self-trust). For example, Rubin and Tanenbaum's (2011) analysis of breast reconstruction decisions among minority women post-mastectomy describes how most participants felt pressured by their physicians to undergo reconstruction: "Physicians framed breast reconstruction as a 'natural' step in treatment…[and] reasons for opting in…were viewed as self-evident" (p. 406). Rubin and Tanenbaum cite multiple feminist scholars that have analyzed the "heteronormative assumptions embedded in the clinical and social management of breast cancer" (p. 402). Breast reconstruction is advocated as an important step in restoring femininity, sexuality, health and wholeness of breast cancer survivors (and previvors). Sherwin and McLeod (2000) warn that HCPs should refrain from perpetuating cultural standards of beauty that are embedded in certain medical procedures. If physicians are concerned with promoting the autonomy of their patients, they should "encourage their patients to consider the forces that lead to these choices, as well as alternative responses" (p. 270). Moreover, the authoritative position of healthcare professionals in the patient-physician relationship challenges a HCP's "ability to appreciate the type of information the patient might need to know in order to choose wisely in her circumstances" (p. 268). Healthcare providers cannot communicate the information they think is the relevant to their patient based on the provider's value judgements if they were the ones in the patient's position making the decision. Providers should not assume what information would be relevant to the patient without trying to better understand the patient's social context and the values that are most important to them in this decision, while simultaneously recognizing how their values (and therefore the judgements based on their values) may differ from a patients and should not be imposed on the patient.

These feminist suggestions to ameliorate the impact of oppression on patient decision-making and the development of autonomy capacities barely scratch the surface of possible solutions to foster patient autonomy in this context. Because oppression is so complex and interwoven into our social scaffolding, a feminist relational framework calls for "understanding the political nature of oppression and recognizing the importance of finding ways to empower patients by helping to restore their autonomy…[and] requires broadscale social and political change" (Sherwin & McLeod 2000, p. 276). The solutions and suggestions offered by the feminist framework goes beyond healthcare providers and the healthcare system and demands a holistic approach to fostering patient autonomy. In this section, I have highlighted a couple of the recommended responsibilities of healthcare providers in protecting strong relational autonomy, which contrasts to the relatively minimalistic duties set out by the decisional account. I have tried to show that ensuring the conditions for local autonomy (i.e. simply providing information and ensuring freedom from coercion by others) is insufficient in ensuring patient autonomy, especially in decisional contexts that are greatly influenced by social forces and narratives.

Beauchamp and Childress' dismissal of the oppressive forces and social context that influence individual autonomy is strongly misguided. While I appreciate their efforts to create a framework that attempts to achieve an attainable level of autonomy, I believe their minimal account of autonomy does not encourage HCPs to go beyond their duties of providing information to the patient and allowing the patient to voluntarily make the decision for themselves. These responsibilities seem to play out in practice as healthcare providers fulfilling their duties to respect patient autonomy by obtaining informed consent (Ho 2006) and not working to develop a stronger interpersonal relationship with the patient and encouraging a patient to reflect on the values that are guiding their decision. HCPs should have a strong obligation to help a patient develop autonomous capacities by encouraging conversation about a patient's values and the ways that social forces may complicate decision-making. Beauchamp and Childress' failure to articulate the extent to which patients should reflect on their values and make judgements based on their values in clinical decision-making prevents one from recognizing when an agent uncritically makes a decision due to their upbringing or socialization and not as "authentically one's own" (Mackenzie 2014, p. 280).

Since a feminist relational framework offers a multifaceted and rich account of the autonomous agent by "considering the rich and complex social and historical contexts in which agents are embedded" (Mackenzie & Stoljar 2000, p. 21), it is best able to provide an account of patient autonomy that addresses how complex social influences impact a woman's decision to undergo a bilateral preventative mastectomy based on her BRCA mutation. However, critics might argue that a feminist account of autonomy could fall short in the situation because of its demanding expectations of healthcare providers to take the time to encourage a critical evaluation of a patient's values so they can make more autonomous choices. A feminist framework acknowledges that patients might not have the autonomous capacities to make an authentic decision, and thus it calls for healthcare providers and institutions to create opportunities and an environment that fosters the development of these capacities. Some of these capacities are strongly influenced by social factors, such as self-trust and self-respect; however, some capacities necessary for good decision-making cannot be adequately encompassed under a relational view of autonomy. Some capacities that the feminist framework has not really addressed are patients capacities to understand probabilities and risk, how all humans (including those in authoritative positions) make reasoning errors and succumb to cognitive biases and heuristics, and the way in which humans have a tendency to make poor decisions under high uncertainty and with complex factors. Because of Beauchamp and Childress' minimalist account of respecting patient autonomy, they too do not detail the extent to which patients might make poor decisions regarding their health and what obligations HCPs or other medical institutions might have to mitigate an individual's propensity to poor reasoning while still respecting patient autonomy. In Chapter 3, I will discuss another framework that tries to address this challenge to autonomy.

Chapter 3: Challenges to Rational Decision-Making and Patient Autonomy

Behaviour economics and social psychology research has demonstrated a plethora of reasoning errors that the human mind is victim to. Contrary to mainstream historical philosophy, this research has proven that humans are not as rational as we once thought we were. Academics, such as Sunstein (2017), Conly (2012), and Blumenthal-Barby (2016), argue that these reasoning errors lead to poor decision-making and, as a result, can negatively impact autonomy. In this chapter, my goal is to explore how women at risk for breast cancer may experience reasoning mistakes (due to their own cognitive biases and heuristics) and whether this significantly affects their decision-making processes in the clinical environment. For example, women in this context may experience a relative risk bias or a "stronger inclination to [act] when presented with the relative…risk than when presented with the same [information] described in terms of the absolute…risk" (Blumenthal-Barby 2016, p. 6). Women with BRCA mutations are told that they have an increased risk for developing breast cancer compared to women without the gene mutation, but it is impossible to accurately predict the absolute risk in which these women may develop breast cancer (Kaplan 2000). If women who have tested positive for a BRCA mutation succumb to the relative risk bias, they may be more inclined to undergo an aggressive preventative mastectomy because they have overestimated their risk for developing breast cancer. Blumenthal-Barby (2016) argues that cognitive biases and heuristics can impact how a patient understands the information presented to them, interfere with a person's ability to develop a plan of action, and act as a controlling or alienating influence on decision-making. If certain biases and heuristics significantly compromise any of these components necessary for patient autonomy, is it ethically justified to use paternalistic means to mitigate poor reasoning errors in clinical decision-making?

In Section A, I will explain the behaviour economics research in more detail by drawing on examples of biases and heuristics that might interfere with autonomy in this clinical situation. I will then argue that the decisional model of autonomy does not adequately account for these possible reasoning errors and provides an insufficient solution to this problem. Moreover, I consider a consequence of this psychological research—that is, if we cannot make rational decisions, then we should not have the freedom to make our own decisions—thus, posing a potential regression into paternalism. In Section B, I will evaluate libertarian paternalism as a solution for promoting patient autonomy while attempting to mitigate the negative impact of biases and heuristics on an agent's decision-making.

A. Cognitive Biases and Reasoning Errors as a Challenge to Rational Decision-Making

In *Principles of Biomedical Ethics*, Beauchamp and Childress' (2009) recognize some challenges in determining what an adequate level of understanding should be to ensure patient autonomy. To respect patient autonomy, the decisional model obligates healthcare professionals to: 1) avoid coercing patients to make a certain decision and 2) ensure that HCPs are providing sufficient and relevant information to patients so the patients have an adequate understanding of the aspects and consequences of decision; therefore allowing patients to make the best decision for themselves based on how their beliefs and preferences align with the information they were provided. As you may guess, patients demonstrate a "wide variation in their understanding about diagnoses, procedures, risks, probable benefits, and prognoses" (p. 127), which has always proposed a challenge to practically assessing autonomy and capacity in clinical settings. Beauchamp and Childress identify many reasons patients may exhibit limited understanding in clinical decisions: such as how one's illness could affect their mental state (e.g. being nervous, immature, or irrational) or breakdowns in communication between the HCP and patient. Although Beauchamp and Childress recognize the debate surrounding what constitutes an adequate level of understanding for patient autonomy (and consequently informed consent), they assert that an adequate grasp of important information and relevant beliefs about the nature and consequences of their actions is sufficient to provide valid informed consent and exercise one's autonomy for most medical decisions. Moreover, they assert any skepticism regarding their account is generally from a misunderstanding about how much patients are expected to comprehend information or sufficiently appreciate its relevance to participate in clinical decisions. Beauchamp and Childress believe that these criticisms come from conceptions of an improper, idealized standard of understanding that hold that autonomy can only be protected if actions are "*fully* informed, voluntary, or autonomous" (p. 128). They believe these critiques can be easily avoided with their practical and reasonable standards for adequately informed, voluntary, and autonomous actions.

In addition to those challenges to understanding mentioned above, Beauchamp and Childress (2009) touch on how a patient's understanding of information can be impacted by problems with how a patient processes the information they receive from a healthcare provider about their diagnosis, prognosis, or treatment choices. Behavioral economic and social psychology research has demonstrated that the way in which risks (associated with treatment or prognoses) are disclosed commonly lead people to "distort information and promote inferential errors and disproportionate fears of some risks" (p. 130). For example, when people are given a hypothetical choice between either radiation or surgery as treatment for lung cancer, studies have demonstrated that people's decisions are different when risks are framed in terms of survival or death, even though the information is the same in both scenarios (Beauchamp & Childress 2009).

When people were presented with probability of survival for undergoing radiation or surgery for lung cancer, more people thought that they would prefer to have the surgery. However, when people were presented with these two options in terms of probability of mortality, more people changed their mind and selected radiation over surgery. Beauchamp and Childress conclude from this example that framing effects (e.g. presenting risk of death from surgery) make a decisive difference to patients, even though the choice was identical in both situations. Beauchamp and Childress worry that these framing effects (which clearly play into both the decision to undergo BRCA screening and whether one should undergo a risk-reducing surgery, which I will return to later) reduce a patient's understanding so substantially that their choice for a procedure may not reflect an "autonomous authorization" (p. 130). If framing effects prevent an individual from sufficiently understanding the risk of death, and the risk of death is a significant factor in the individual's decision, then how information is presented to a patient can actually interfere with autonomous choice.

Although Beauchamp and Childress recognize that a patient's understanding can be influenced not only by the amount of information presented, but also how information is delivered to a patient, their account does not sufficiently deal with the challenges of framing effects in light of current behavioural economics and social psychology research. In the remainder of this section, I will argue that the decisional account fails to sufficiently appreciate the extent to which a range of cognitive biases (including, but not limited to framing effects) affect people's decisions and autonomy or propose an adequate solution to ensuring patient autonomy despite this problem of framing effects and other reasoning errors. To explore the first problem in more depth, I will draw on Kahneman's (2013) cognitive research on human information processing and Blumenthal-Barby's (2016) work on the impact of biases and heuristics on patient autonomy and decision-making. To critique Beauchamp and Childress' minimalistic solution to the problem of how a patient's biases might impact their autonomy in clinical decisions, I will draw on Conly (2012) and Sunstein's (2017) call for a stronger solution to the problem. After I elaborate on both of these gaps in the decisional account, I will then discuss the libertarian paternalist solution to the problem in Section B.

Behaviour economics and social psychology research have identified a wide range of cognitive biases and errors in human decision-making. In the areas of marketing, these cognitive biases have been strategically exploited by advertising campaigns, which subconsciously encourage individuals (by playing on these biases and reasoning errors) to buy certain products or services. Only recently, however, has the field of bioethics been considering the implications of these reasoning errors in patient decision-making and autonomy. Blumenthal-Barby (2016) notes how many bioethicists have only narrowly considered the effect of one or two cognitive biases on decision-making—just like Beauchamp and Childress' (2009) small mention of framing effects in the *Principles of Biomedical Ethics*. Sunstein (2017) and Blumenthal-Barby (2016) argue for the need to more comprehensively understand the multitude of cognitive biases, their impact on autonomous decision-making, and effort to remove or counter the effect of these biases. Many biases, while they serve adaptive purposes to help humans make decisions more quickly by using fewer cognitive resources (Kahneman 2013), lead to many errors in judgement and decision-making, consequently impairing an agent's ability to make autonomous decisions that align with their beliefs and values (Blumenthal-Barby 2016).

Kahneman's (2013) Nobel-prize winning research on his "two-system" theory for information processing, judgement, and decision-making challenges the prevalent assumption that humans are rational and logical by demonstrating that human "minds are susceptible to systematic errors" (p. 10) and that "emotion…looms much larger in our understanding of intuitive judgements" (p. 12) than previously thought. In *Thinking, Fast and Slow*, Kahneman (2013) presents findings of his research on cognitive biases and heuristics by metaphorically describing human mental processes like two agents (i.e. System 1 and System 2). The rational and deliberative thought processes that allow humans to have agency and control their own experiences (and have been idealized since Enlightenment philosophy) are part of the "slow thinking" (p. 13) system. System 2 is effortful and deliberate: it "allocates attention to the effortful mental activities that demand it, including complex computations…[and] are often associated with the subjective experience of agency, choice, and concentration" (p. 21). The extensive research on the distinction between fast and slow thinking, however, has demonstrated that System 1 is actually more influential in human decision-making and agency than System 2. System 1, the "fast thinking" (p. 13) system, is quick, automatic, and intuitive: it works with "little or no effort and no sense of voluntary control" (p. 20) and effortlessly originates intuitions, impressions, and emotions "that are the main sources of the explicit beliefs and deliberate choices of System 2" (p. 21). System 1 is adaptive—as it learns associations and patterns, System 1 allows us to do many activities and make everyday decisions in autopilot since it conserves energy by not requiring significant cognitive resources. But, as much as "we identify with System 2, the conscious reasoning self that has beliefs, makes choices, and decides what to think about and what to do," (p. 21), System 2 is "lazy" (pp. 30) and is only significantly engaged when it detects an error or System 1 runs into difficulty. This "division of labour" (p. 25) is very efficient and allows us to optimize information processing and minimize the effort expended on mental tasks. Most of the time, System 1 accurately models familiar situations, makes adequate short-term predictions, and appropriately reacts to challenges or obstacles.

However, to maintain efficiency, reduce cognitive effort, and react quickly, System 1 employs heuristics (or mental shortcuts) to navigate through everyday tasks, while System 2 is reluctant to “invest more energy than is strictly necessary” (p. 31). In certain situations, these heuristics and biases lead to systematic errors—especially in decision-making situations that involve statistics, probability, and uncertainty (Kahneman 2013). System 1 is continuously generating ongoing basic assessments in real time with little to no effort. Kahneman argues that these basic assessments “play an important role in intuitive judgement” (p. 89) because they can be substituted in more difficult situations or challenges—this is the basis for our cognitive heuristics and the reason why our heuristics and biases can lead to poor reasoning errors in more complex situations and decision-making. One of the ways Kahneman identifies that System 1 generates intuitive opinions in complex situations is by substituting an easier, but related, question and then answering it. In fact, substitution can be a great strategy for answering challenging questions if System 2 is engaged since the strategies are deliberate and precise; however, when System 1 substitutes challenging problems for easier ones the substitution heuristics are not deliberately chosen but scattered, imprecise cognitive computations can lead to serious reasoning errors. Moreover, since much of this process is automatic and the intuitive answer comes easily, System 2 might not catch the error, modify the heuristic employed, or reject System 1’s initial intuition.

Blumenthal-Barby (2016) asserts that cognitive biases can violate normative principles that that are often rules to follow for good judgements and decision-making. For example, framing biases violate the principle of invariance which “holds that the same information presented in different ways should be understood and weighed the same” (p. 5). Framing effects or framing bias can arise frequently in medical decision-making when patients are told probabilities for survival or mortality for choosing to undergo a certain procedure. A patient exercising rational decision-making in this context (by engaging System 2) would use the principle of invariance to educate their decision; for example, by understanding that a 10% chance of mortality is identical to a 90% chance of survival. However, studies report that the way information is framed based on survival or mortality significantly impacts decision-making (Blumenthal-Barby 2016). Based on Kahneman's (2013) two-system model, these findings can be explained by System 1 incorrectly substituting an easy question ("How do I feel about this?") for a difficult question ("What do I think about this?"), while the lazy System 2 does not recognize this reasoning error and System 1's emotional intuition in the decision. In this study referenced by Blumenthal-Barby (2013), the emotional response from thinking about death (even if there is a small chance of mortality from the surgery) distorts our expectations about the frequency in which these events occur. Moreover, we are able to easily think of various risks when we have a more intense emotional reaction to a certain risk or consequence. As a result, the participants in the study generally decided against the surgery option when it was presented in terms of mortality but preferred the surgery when it was presented in terms of survival because of the affect heuristic: where "people form opinions and make choices that directly express their feelings and their basic tendency to approach or avoid, often without knowing they are doing so" (p. 139). These are just two examples of how human minds are susceptible to certain biases—Blumenthal-Barby (2016) has identified nineteen different types of biases and heuristics in a systematic review of empirical research and calls for increased understanding in how these numerous, prevalent biases might impact autonomous decision-making.

Cognitive biases and heuristics can interfere with any of the three components that Beauchamp and Childress' require for a person to exercise their autonomy: intentionality, understanding, and freedom from controlling or alienating influence (Blumenthal-Barby 2016). In the following paragraphs, I will explain how Beauchamp and Childress' three requirements for patient autonomy can be impacted by biases through hypothetical examples that might arise within the BRCA screening and preventative mastectomy context. To begin, Blumenthal-Barby (2016) argues that cognitive biases may diminish autonomy by "acting as controlling or alienating influences on decision making" (p. 11). In other words, Blumenthal-Barby worries that an agent may feel alienated from their decision if they learn that their decision-making process was clouded by some of these biases and reasoning errors. If an agent does not think they authentically made the decision, then the decision may not have been made autonomously. For example, let us recall the framing bias discussed earlier where people tend to make different (hypothetical) decisions for surgery depending if the information was conveyed to them in terms of survival or mortality rate. After the survey, say the researchers informed a participant of the framing bias in their decision to undergo surgery because the consequences of the surgery were framed in terms of mortality rate and not in survival rate. The participant might feel like once they thought about the question in terms of survival rate, they would have confidently selected the surgery. Even though this is a hypothetical survey, it is reasonable to extrapolate this case to a real patient who might be very upset with their decision to forgo surgery in reflection on their decision and thinking about the choice in terms of mortality rate. If a patient learns about some of the biases that might have resulted in a certain choice, they might feel alienated from their decision, beliefs, and values; thus, the bias can lead to a threat to their autonomy.

Another way in which a patient might feel alienated from their decision is if they realized how many irrelevant factors influence our decision-making processes. Sunstein (2017) and Kahneman (2013) cite many studies that have demonstrated how people's choices can be affected by factors that they would deem to be irrelevant or insignificant in their decision—completely threatening “our self-image as conscious and autonomous authors of our judgements and our choices” (Kahneman 2013, p. 55). For example, priming effects, such as how the weather impacts one’s mood or even simply the color of packaging a product is sold in, can influence our decisions. In Kahneman’s (2013) “two-system” theory, priming phenomena greatly affect our first impressions in the basic assessments continually conducted by System 1. As much as System 2 tries to justify its reasoning for the choice made, we do not have conscious access to the impressions and intuitions formed by System 1. Moreover, the decisions made by System 2 are based on the intuitions, impressions, and feelings generated by System 1. While there may be ways to minimize the influence of irrelevant factors (like order, color, or environmental cues) on decision-making and still make a decision that best aligns with one’s values and beliefs, the influence of these irrelevant factors is robust (Kahneman 2013). If these seemingly irrelevant factors significantly influence our decision-making (to the point at which we feel alienated from our initial choice in the presence/absence of priming effects), these biases can threaten autonomy (Blumenthal-Barby 2016).

The second component Beauchamp and Childress (2009) require for one to make an autonomous choice is intentionality—or making a decision that an agent planned to do (as opposed to accidentally or mistakenly chose). Blumenthal-Barby (2016) argues that biases and heuristics can impact intentionality in three ways: biases and heuristics can “cause a bypass in in planning that results in a person feeling as if she did not do something that she actually intended to do”; “clash with and override what a person has decided on and intends to do”; or “interfere with a person’s ability to make a plan or form an intention” (p. 10). For example, the availability bias (or “associating the probability of an event with the ease with which an occurrence can be brought to mind" [p. 11]) can impact the second way in which biases can threaten one's intentionality of a decision. Thinking about a woman who is weighing out whether she should ask her doctor to be tested for the BRCA gene, the availability bias might impact her decision if she had a close friend (or even an acquaintance) recently diagnosed with breast cancer. She would have never intended to have the BRCA gene test done because she had no increased risk for breast cancer in her family, but knowing women who were recently diagnosed with breast cancer and never had the BRCA test made her easily think she could have an increased a risk of getting breast cancer because her friend developed it. The availability bias causes "[o]ur expectations about the frequency of events [to be] distorted by the prevalence and emotional intensity of the messages to which we are exposed" (Kahneman 2013, p. 138). In other words, the more one hears about breast cancer, BRCA screening, and preventative mastectomies (either from others in their personal network or the mass media messaging from the players in pink ribbon culture), the more likely one is to quickly associate those messages with their own situation. Similarly, Blumenthal-Barby suggests that the bandwagon effect could also impair autonomy if an agent intended a certain action but changed their mind when they discover that other people (or the majority of people) are doing a different action. For example, knowing that Angelina Jolie had BRCA screening and knowing that many other women were undergoing BRCA testing, a woman is more likely to opt for BRCA screening the more women she knows who had the test based on the bandwagon bias. The decision to undergo a preventative mastectomy could also be affected by the availability bias or bandwagon effect—that is, knowing that it was a more common decision to undergo the surgery could cause woman to abandon her previous decision and adopt the more popular one. If these biases counter what a person initially intended to do, the bias interferes with autonomy.

Another example of how a bias might negatively impair autonomy by countering what a person intended to do is with the commission bias: “the tendency toward action rather than inaction” (Croskerry, as cited in Blumenthal-Barby 2016, p. 6). Aronowitz (2015) notes that “many women and their doctors feel…screening …is the only positive action they can take to allay their fears and control the uncertainty associated with being at risk for cancer” (p. 49). As mentioned earlier, screening is becoming a normal part of every disease experience across the risk-to-disease continuum. The more that screening practices become available and routine part of the diagnosis process, the more of a role that screening plays in creating fear and uncertainty in developing a disease. This “self-reinforcing cycle of risk creation and risk reduction” (p. 49) creates more opportunities for people to succumb to their cognitive biases, such as the commission bias. Studies show that when research participants are faced with a hypothetical cancer diagnosis, a high proportion of participants say that they would rather pursue aggressive surgery, even if it significantly increases their chance of death (Blumenthal-Barby 2016). Now that there are other procedures besides screening, like preventative mastectomies, that people can choose to undergo to decrease their risk, the commission bias might encourage people to act as extremely as the system allows to decrease their anxiety about their risk state. We can imagine a situation where a woman has considered the consequences of both options of undergoing a prophylactic mastectomy or increasing her body surveillance after finding out she has an increased risk for breast cancer and even thought that surgery was not worth the risk, but then succumbed to the pressure to do something about her risk state.

The final example that I will discuss that demonstrates how the intentionality component of autonomous decision-making can be inhibited also arises in situations of high uncertainty. The ambiguity aversion bias “involves an intense aversion to uncertainty” (Blumenthal-Barby 2016,

p. 8) and can arise if a person has to make a choice between two highly uncertain options. For example, if a woman tests positive for a BRCA mutation, she will have to decide between two choices that bring with them considerable uncertainty (especially if one considers the lack of scientific evidence comparing the efficacy of a prophylactic mastectomy and increased body surveillance/early detection and intervention in good health outcomes). If a woman feels like both options are so adverse, she might fail to form an intention about which choice to pursue. If a patient is completely unable to form a plan about what to do, they are unable to exercise their autonomy in the decision they are faced with. In the decisional framework, these examples are highly problematic for autonomy because Beauchamp and Childress (2009) define intentionality as an all-or-none requirement: if an agent is not intentional in choosing an option, then the choice is not autonomous.

Intentionality is not quite as simple to achieve as Beauchamp and Childress make it out to be. Beauchamp and Childress want a practical and realistic standard of autonomy that does not rely on making decisions that align with second-order desires. They assert that expecting this level of reflection of patients in medical decisions is an idealized and unachievable standard of autonomy. However, the research on biases that can impact an agent's plan to make a choice brings up concerns about how an agent's intentions should be prioritized. In the earlier examples, if a woman had decided that she did not want an aggressive surgery prior to knowing that preventative mastectomies might be the more popular choice, should her original intention to not undergo the surgery override her change of mind caused by the bandwagon effect? Or, should her temporally recent intention even if it was influenced by her own cognitive biases be respected as her exercising her autonomy? Beauchamp and Childress' (2009) decisional model does not give a clear answer—Blumenthal-Barby (2016) argues for a deeper understanding of how biases influence intentionality and how a woman may have arrived at these intentions and her attitude towards the intentions. Although Blumenthal-Barby does not elaborate on this solution, I believe the relational approach might be able to fill this gap. In considering a woman's values and belief system and her social context, a relational approach could help a physician determine if her choice to undergo (or forego) a preventative mastectomy was intentional or a result of cognitive biases (like the bandwagon effect or commission bias).

The final way that Blumenthal-Barby (2016) argues that biases can impact autonomy is by negatively distorting a patient's understanding of the choice or its consequences. Earlier, I mentioned some difficulties in what constitutes an adequate level of understanding in Beauchamp and Childress' perspective. Biases and heuristics further problematize the approach to determining what threshold of understanding is necessary for one to exercise their autonomy. For example, the optimism bias, where people "overestimate benefits and underestimate costs" (Kahneman 2013, p. 252), or the impact bias, the "tendency to overestimate the long-term impact of an event" (Blumenthal-Barby 2016, p. 9), can cause individuals to distort the information that they are provided and choose more risky options instead of rationally weighing out the gains, losses, and probabilities of their choice (Kahneman 2013). Even though there are many negative reasons or potentially harmful consequences of undergoing such an aggressive preventative surgery, these two biases may cause women to overestimate the pros of undergoing a mastectomy ("I will *never* get cancer"), downplay the harms or risks of the surgery ("death and/or serious complications will not happen to me"), distort their understanding of what life will be like after the mastectomy ("I will be back to normal in no time"), etc. In considering the surplus of biases and heuristics researched, it seems impossible to be able to control and mitigate the negative effects they have on a patient's understanding in every healthcare decision made.

Beauchamp and Childress only require agents to have a realistic and sufficient level of understanding of the nature of the choices and the possible outcomes of the decision to meet the conditions for an autonomous choice. In the decisional account, some of these biases or heuristics might not distort an agent's understanding of a decision substantially enough that it would be impossible to ever make an autonomous decision. However, I hope that it is clear from some of the examples that I have provided that biases and heuristics are a significant cause for concern when they interfere with Beauchamp and Childress' minimalistic conditions for autonomy. In the BRCA situation, where all of a woman's choices are made based on probabilistic estimations of risk to develop breast cancer, cognitive biases can have a significant impact on patient autonomy.

Our increasing knowledge of these cognitive biases and reasoning errors begs the question if medical authorities and institutions have a moral obligation to reduce problems of information processing in patient decision-making. In the same vein, however, this raises the issue: to what extent is informational manipulation ethical in medical decision-making? In the remainder of this section, I will discuss Beauchamp and Childress' solution to some of these biases, how their solution is no longer adequate in light of the decades of evidence of cognitive biases and heuristics in decision-making, then discuss another framework that calls for a stronger solution to minimize the effects of these biases on patient decision-making. The solution that Beauchamp and Childress propose is "the need for better understanding of techniques that will enable professionals to communicate both the positive and negative sides of information" (p. 130). This solution fits with the decisional account because of the framework's emphasis on the HCPs negative and positive duties to ensure patient autonomy. To an extent, the HCP is responsible for being aware of how the technical and anxiety-inducing information that they present to a patient might be interpreted or understood by a lay-person. For example, if HCPs understand that patients are more inclined to make different decisions if the information they are presented about a certain option is framed in terms of survival versus mortality rates, then the HCP should be somewhat responsible for conveying both rates to patients or helping a patient realize that the two numbers are the same so they can make an informed decision. I believe Beauchamp and Childress are correct in their solution by calling for HCPs to have an increased understanding of was to better communicate information to patients and the way that cognitive biases can impact understanding.

However, I have two worries about Beauchamp and Childress' proposed solution to minimize the impact of cognitive biases on patient decision-making. My first, and more minor point, is that Beauchamp and Childress narrowly focus on the framing effects bias and the solution they provide seems to be directed at minimizing the framing bias in particular. Extensive research has demonstrated that the framing effect bias can change people's decisions completely based on how information is framed (Beauchamp & Childress 2009, Kahneman 2013, Blumenthal-Barby 2016). Because the decisional account focusses so heavily on HCPs providing sufficient and relevant information to their patients to make an informed decision, the framing effects bias can significantly impair this important component of the decisional account. So, the solution that Beauchamp and Childress provide would likely be sufficient for the framing bias: that is, helping clinicians understand the importance of communicating to patients in ways that are cognizant of the positive and negative sides of information (e.g. survival/mortality). However, as Blumenthal-Barby (2016) mentions, there are so many more classes of biases and heuristics that can interfere with patient autonomy in a multitude of ways (i.e. alienation, intentionality, and understanding). Some of these biases interfere with other components of autonomy aside from understanding, and it is unclear from Beauchamp and Childress' solution if HCPs are also responsible for being aware of other biases and trying to employ techniques to minimize any of these other biases. One can quite easily imagine how unreasonable this task can become with the amount of biases that can interfere with patient decision-making in addition to all the other information and training HCPs need to undergo.

This critique leads into my second issue with Beauchamp and Childress' solution to minimizing information processing errors on autonomy: to what extent should HCPs be responsible for understanding the kinds of biases that might influence their patient's decision-making and how much should they try to minimize these reasoning errors? The decisional account places a larger responsibility on healthcare professionals to uphold their positive duty and negative duty to respect patient autonomy, than it does on the patient to make the decision (recall: they do not require higher order reflection, just simple measures of capacity). If the healthcare provider is obligated to protect patient autonomy in these ways, does it also require them to be aware of all these biases and strategically work to minimize their effect when they are communicating with patients? Moreover, what strategies are morally permissible to use to manipulate the way information is presented to decrease the impact of biases on patient decision-making? Beauchamp and Childress leave this area open—however, I believe this will be an ongoing question when I discuss other perspectives in Section B that argue for an increased responsibility for HCPs, medical institutions, and government to intervene in patient decision-making by reducing the impact of cognitive biases and heuristics on healthcare decision-making. Moreover, I worry that these solutions to decrease the impact of biases on decision-making might be too manipulative or coercive according to the decisional account (by breaching the negative duty for HCPs to ensure that a patient's decision is made free from coercion). I will return to this issue in Section B when I discuss Blumenthal-Barby (2012), Levy. (2017) and Sunstein's (2017) solutions to the problem and assess whether these "techniques" could fill this gap in Beauchamp and Childress' account. In sum, Beauchamp and Childress, although they acknowledge the challenges to autonomy that arise with the framing bias, do not: 1) discuss other biases and their impact on autonomy; 2) describe what techniques HCPs could use to mitigate the effects of these biases and if this might place too much responsibility on HCPs in clinical settings; or 3) explain which techniques may be morally permissible or impermissible according to their account. In the next section, I will discuss another possible solution to mitigate the effect of cognitive biases and reasoning errors on patient autonomy.

B. The Ethics of Choice Architecture in Patient Autonomy

As mentioned in the previous section, research demonstrates that cognitive biases and reasoning errors significantly prevent individuals from making good decisions. Because of the research demonstrating the prevalence and impact of these errors, libertarian paternalists also believe that a stronger solution than what Beauchamp and Childress (2009) proposed is necessary to ensure that individuals are able to make better decisions without succumbing to biases and heuristics. In this section, I will evaluate a libertarian paternalist solution to the problem by drawing on the screening and risk-reducing problem from the Introduction to better illustrate my argument. Before I get into the other solution, I address a significant worry that the behaviour economics and social psychology research poses for autonomy.

In light of the behaviour economics and social psychology research, which suggests people are poor decision-makers because of their cognitive biases and reasoning errors, some wonder if we should bother protecting autonomy and avoiding interference in individuals' lives above all else, even if it means that people will sometimes choose poorly. In Conly's (2013) opinion, autonomy is "not valuable enough to offset what we lose by leaving people to their own autonomous choices" (p. 1). Since we are poor decision-makers, we should have authorities and experts helping us make better decisions instead of "leaving us to struggle with our own inabilities and to suffer the consequences" (p. 1). She argues that autonomy is not intrinsically good for us if we make poor decisions for ourselves. If people are so irrational and make such poor decisions that they harm themselves or thwart their future goals, then should these decisions be removed from individuals and be given instead to the government and other authorities to make these decisions for us—thereby protecting individuals from themselves? In light of the research demonstrating our inadequacies in making decisions, Conly (2013) argues that we need laws, rules, and systems that "force people to do what is good for them" (p. 3).

Žitinski (2012) defines paternalism as "interference in the freedom of another person's action without having a permission to do so" (p. 166-7). Historically, this has been the position in medicine where patients were expected to trust in their doctor's expertise and comply with their health advice or suggestions for treatment. Faden, Beauchamp, and King (1986) and Katz (2002) have acknowledged the origin of paternalistic medical practice as the Hippocratic physicians of Ancient Greece. The model of medicine practiced by the ancient Greeks was a paternalistic one, which focussed heavily on principles of beneficence and nonmaleficence to guide physicians in determining what treatment would be best for his patient. Patients were expected to follow the doctor's orders and blindly trust them without question: the hallmark of this attitude is the "practice of silence", where patients' were not invited to participate in their own medical decision-making (an attitude that Katz (2002) argues is still prevalent today). As a way to reinforce therapeutic efficacy, patients were expected to put their full trust and vulnerability in the hands of the doctor who had the professional skills necessary to improve the patient's condition as they were morally committed to their patient's beneficence. As such, patient liberty was not part of the ethos of Hippocratic authoritarianism: the "persistence of ancient attitudes" (Katz 2002, p. 5) kept conversations about self-determination, consent, disclosure, and patient equality out of medical practice until recently. In the twentieth century, people began to reject paternalism because in many cases, doctors were simply not in the best position to know what was best for the patient. The movement towards respecting patient autonomy in medical decision-making was advanced on the premise that patients are in the best position to know what is in their best interest. Because of the harms caused by paternalism, many have argued for respect for patient autonomy to underlie most medical decisions (as long as it is balanced with the other bioethical principles).

As mentioned throughout this project, there is a large amount of uncertainty in predicting whether a woman is at an increased risk for developing breast cancer. Aside from being a BRCA oncogene carrier, there are many other heritable and environmental factors that influence a woman's risk for developing breast cancer. Because of the high uncertainty in predicting a woman's risk to develop breast cancer, the nature of the surgery, and the complex social and individual values at play in the decision, it would be more harmful to force women to choose a certain option (even if it might not be the best option for them) than it would be to let them make the decision themselves. Many women fall in the middle of the risk spectrum and it would seem very harmful to either force them to undergo (or forego) the aggressive surgery if they wanted the opposing choice. The individuals who are in the middle of the spectrum are the ones who are likely going to be struggling against their biases and committing reasoning errors because of the high uncertainty of their situation. However, because of the high uncertainty and limited predictability of their situation, it would be completely unethical to remove the decision from the woman and give it to a physician or other medical institution.

While Kahneman's (2013) research demonstrates that the expert is often in the best position to make decisions in their area (because they rely on intuition they developed through experience, they are less susceptible to cognitive biases), this is not the case for situations of high uncertainty. In *Snowball in a Blizzard*, Steven Hatch M.D. (2016) discusses the "underestimated imperfection of results" that has gotten patients and doctors "into trouble by neglecting uncertainty when they interpret results" (p. 103). Uncertainty plays a large role in medical practice—diagnoses and prognoses are just educated guesses. The uncertainty of estimating a patient's risk for a disease causes us to see "diseases that aren't really there" (p. 34). New technology and improved understandings of disease has helped us find disease earlier and improve the ways that we treat diseases, like cancer. However, Hatch argues that even doctors believe in their diagnoses and prognoses so powerfully that they neglect evidence against their position. Estimating a woman's risk for developing breast cancer based on a risk factor like a BRCA gene could easily be influenced by psychological biases and errors which can disrupt how doctors understand and communicate uncertainty. Placing too much faith in modern medicine can lead experts, such as doctors or expert researchers that create clinical practice guidelines, to ignore the uncertainty and overestimate the certainty of the information they have access to and influence their confidence in their educated guesses (in the forms of risk assessments, diagnoses, or prognoses). So, although Kahneman (2013) and Conly (2013) argue that experts are often in the best place to make decisions because they are less susceptible to cognitive errors and reasoning mistakes, Hatch (2016) draws on many modern day examples that demonstrate the extreme uncertainty in some areas of medicine to explain the significant discrepancies between an expert's confidence in their interpretation of uncertain research results, as well as how attitudes about uncertainty, can lead to controversy among the experts.

Whether to undergo BRCA screening and then how to proceed after a positive result, should be considered for each individual who needs to make the choice. Two women can have the same estimated risk to develop breast cancer, and it might be better for each of them to choose a different option (i.e. undergo a preventative mastectomy or not). Paternalism in this case would likely cause more social or psychological harms to outweigh the benefits it might offer—highly individualistic decisions are not well-suited to paternalistic regulation. We would risk similar harms to individuals that arose from traditional paternalistic practice since coercive paternalism would blanket the experiences, preferences, and values all women to act in the same way. Some paternalistic regulations may be well suited for many public health issues, such as combatting vaccine hesitancy or prohibiting smoking. In these cases, it is clear that the majority of people share the same long-term goal—to live a longer, healthier life—and the paternalistic regulation is helping people achieve that goal with a relatively low harm attached (Conly suggests helping people quit smoking by banning cigarettes). Sunstein's (2017) extensive research and surveys on nudging demonstrates that individuals generally accept nudging if it has legitimate goals and is consistent with the interests and values of most choosers. By extension, some paternalistic regulations may also receive widespread support if the majority of people accept the goals of regulations and the regulation is consistent with the values of most individuals in society. In the preventative mastectomy decision, however, individuals might have drasticly different ideas about the quality of life that each option might provide. Neither choice is necessarily going against the individual's ultimate goals of their life, but that does not mean that each option is what would be best for the individual. So, while the choice is an important one that is often complicated with cognitive biases and misunderstanding of the uncertainty of one's risk to develop cancer, it could be much more harmful for an individual to have a decision forced upon them (especially if it is the option that is against their preference). Paternalism is not a viable solution as a way to force certain women to undergo BRCA screening or to either survey their bodies or undergo a mastectomy if the test is positive, and should be avoided at all cost because every woman in this situation would have different values, beliefs, and preferences and these unique differences would not all be respected by a forced decision.

A solution that has been offered to mitigate the negative effects of cognitive biases on autonomous decision-making is by using a person's predisposition to fall prey to reasoning errors to actually help them make decisions that are in their best interests. "Nudging" describes techniques and strategies that play on a person's reasoning errors to help them make a choice that aligns with their best interest. In bioethics, the framework of libertarian paternalism suggests using choice architecture ("the background against which people make choices," Sunstein 2017, p. 3) in ways that encourage patients to choose what is in their best interests—even if the choice is made subconsciously or without a patient's awareness. In current bioethics literature, the ethics of using behaviour economic strategies are being evaluated in health policy: where, "choice affecting features of the decision environment that do not restrict the range of choices," are being used to 'nudge' individuals towards particular health decisions (Gorin et al. 2017, p. 32). Although nudges have been extensively discussed in public health and health policy, there is a gap in the literature investigating how physicians might use nudges to influence patient decisions in a clinical context. In this chapter, I will evaluate clinical and institutional level nudging as a solution to helping patients make decisions in contexts of extreme uncertainty, such as the BRCA screening and preventative mastectomy decisions. I will first explain nudges and libertarian paternalism in more depth by using Sunstein's (2017) classifications of nudges to assist my explanation. Then, I will evaluate whether any kind of nudging (public health or clinical) could be ethically permissible in clinical decision-making by using the BRCA context as my example.

Libertarian paternalism suggests that policy-makers and authoritative individuals (such as healthcare professionals) should design "[c]hoice-affecting features of the decision environment that do not restrict the range of choices" (Gorin et al. 2017, p. 32) to influence people's decisions. These choice-affecting features or "nudges" engage an individual's own reasoning errors and biases to encourage them to make a decision that is in their best interests. Choice architecture—the background against which choices are made (Sunstein 2017)—is simply used to nudge individuals in the direction that is best for them. Libertarian paternalists suggest using the irrelevant factors that influence individual choices to actually encourage individuals to choose the option that best aligns with their values and preferences. For example, people who care about the environment are more likely to buy things that come in green packaging, even though the color of the package seems irrelevant to an individual's decision, it has a significant effect on consumer purchases (Sunstein 2017). There are many ways in which private and public actors trigger our emotions or invoke mental heuristics to influence our decision-making (Sunstein 2017). Nudging has dominated discussions at the government and institutional level because it has demonstrated efficacy in steering the population to better choices for themselves while preserving agency in a cost-effective manner: "In domains that include savings policy, climate change, corruption, and health care, among others, behaviorally informed approaches have attracted considerable attention, and on countless occasions, led to concrete reforms, with significant benefits for many millions of people" (p. 2).

One of the more attractive reasons academics such as Sunstein (2017) have endorsed nudging is because they argue that nudges preserve personal autonomy and agency. Unlike with coercive paternalism which forces individuals to act in a certain way, choice architecture does not eliminate options or choices from individuals. The choices remain available to agents but the way that nudges are integrated into the choice architecture (often subconsciously) encourages people to select certain options over others. In this way, freedom of choice is still preserved as long individuals can resist the nudge (Sunstein 2017). For example, policy-makers can influence individuals to act a certain way by changing a default action to something that is better for individuals or society. Some countries have adopted organ donation for transplantation as the default option to fulfil the high demand for organs in their health system. This way, if citizens do not deliberately make the decision to have their organs donated, they will be donated for transplantation by default. The choice remains for individuals who feel strongly against organ donation to opt out of the default if they do not want to donate their organs; however, by changing the default, the individuals that do not act to opt in or out to a certain action will be helping the public health system. Nudges seem like they might be the perfect solution to helping individuals make better decisions that align with their best interests because they minimize the negative effect of cognitive biases in poor decision-making, while also preserving one's freedom to choose (because individuals can resist the nudge and pursue their own choice).

However, a common critique of nudging is that it is just a hidden form of paternalism. To elaborate on this concern, one might worry that the "use of nudges…may undermine individual autonomy by substituting the 'nudger's judgement of what should be done for the nudgee's own judgement'" (Gorin et al. 2017, p. 33). Essentially, the worry is that using nudges would be too paternalistic as the policy-maker's (or medical authority's) values and judgments would decide actions of the citizen (or patient). The individual would be nudged in a direction that might be inconsistent with their values and preferences. Such nudging would run contrary to the bioethical principle of respect for autonomy. For example, a default might be put in place that actually goes against the values of the majority of the population. In some jurisdictions, organ donation for transplantation as the default option could go against the religious values of many members of the population. While those individuals could opt out of the default, the nudge towards organ donation would be unethical because more people than not would not want their organs being donated after their death. Importantly, Sunstein (2016a) distinguishes libertarian paternalism from paternalism: "insofar as [choice architects] attempt to use choice architecture to steer choosers in directions that will promote their welfare…as judged by choosers themselves" (p. 54), then nudges are not considered purely paternalistic in two ways. Firstly, nudges are not coercive because individuals always have the freedom to resist the nudge (Sunstein 2016a); thus, preserving an individual's autonomy and freedom to choose. Secondly, Sunstein argues that choice architecture is "means-oriented" (p. 54), as it does not attempt to alter people's ends: "Many nudges are entirely focussed in helping people to identify the best means for achieving their preferred ends" (p. 55). For example, if a nudge helps someone to correct their bias and select the better option that aligns with their preferences, then the nudge is helping them to achieve their end. In paternalistic cases, someone may be forced to act in a way that does not align with their values because the authority thinks that a different end might be better for the individual. Libertarian paternalists are not only concerned with promoting someone's welfare (by helping them make a decision that aligns with their long-term ends) but encourage choice architecture because it is consistent with a libertarian view on autonomy: individuals are in the best position to know what is best for them and they should be free to choose.

As mentioned earlier, there are many biases and reasoning errors that people are susceptible to—Blumenthal-Barby (2016) identifies at least nineteen different categories of biases and heuristics. Because there are so many ways in which biases can interfere with good decision-making, it follows that there are many ways in which nudging can be employed to play on these biases to encourage certain decisions. In thinking through the moral permissibility of using nudges in the medical context, I have found Sunstein's (2017) categorization of nudging helpful for my analysis. He describes two main categories of nudges: educative and noneducative. Educative nudges teach people to become better choosers: "disclosure requirements, reminders, and warnings…are specifically designed to *increase people's own powers of agency*—perhaps by augmenting their knowledge and capacities,…jogging their memories,…appealing to people's highest goals and aspirations,…[or] making relevant facts salient" (*emphasis in original,* p. 3). An example of educative nudges are the graphic images and facts on the labels of cigarette packages: these nudge people to think about the unhealthy consequences of smoking to encourage them to rethink their unhealthy habit. Quite obviously, these kinds of nudges seem ideal because they are not only effective in swaying individuals to act a certain way but also help people learn from the architecture to make them better choosers. From an ethical perspective, these nudges seem unproblematic: they encourage people to make better decisions by nudging them to reason better but still ensure autonomy and freedom by allowing people to resist the nudge and choose another pathway if they prefer. For example, when conveying uncertain information about genetic tests to patients, the nudges that help patients resist succumbing to their biases and misunderstanding of probabilities would help patients make better decisions that align with their values and not be swayed so easily by the optimism bias, framing effects, the bandwagon effect, etc. Quite intuitively, educative nudges would be widely accepted by individuals as they work to help people resist their own reasoning errors to make better decisions for themselves (and this has been supported by evidence [Sunstein 2016b]).

Noneducative nudges, on the other hand, "are designed to preserve the freedom of choice," but do not "increase people's capacity for individual agency" (Sunstein 2017, pp. 3). Noneducative nudges redesign choices in a helpful way, and allow people to go their own way, but do not make people better informed. Examples of non-educative nudges include default rules (such as if one was automatically enrolled in a program to donate their organs after death) or how products are ordered and arranged to encourage one to be drawn to certain items (like grocery store shelves or menus). These nudges can still be helpful and increase people's welfare, for example by drawing someone's eye to healthy options so they would need to resist the nudge to choose an unhealthy option. This is the category of nudging that I am most interested in evaluating—are non-educative nudges morally permissible to help women make better decisions about BRCA screening or preventative mastectomies if they do not help people reason better? To draw on an example, behavior psychology research has demonstrated that when people are presented with two choices, they are more likely to select the first option. If a physician presents two options to a patient, the physician can nudge the patient to choose the option that they think the patient would prefer simply by presenting it to the patient chronologically first. This nudge clearly does not help a patient to reason better or more deeply reflect on their values and preferences but instead uses the patient's cognitive biases to nudge them towards one option over the other. Is this an ethical use of choice architecture?

While Sunstein (2017) demonstrates many examples of noneducative nudges that seem harmless, beneficial, and even accepted by the majority of individuals, many of these nudges are created by policy-makers and institutional authorities and are designed to encourage the population to act in ways that are better for their overall wellbeing (i.e. the nudges appeal to a value or long term goal that the significant majority of the population holds). For example, noneducative nudges where grocery stores arrange healthy food choices at eye level in grocery stores. These nudges would likely be welcomed by the majority of people as they help them to make better choices and decrease the effort needed to make these decisions. However, I worry about the ethics of using non-educative nudges in situations where individual choice and autonomy should be at the forefront since there are substantial disparities in values or preferences between individuals in similar situations. To explore this issue further, I propose another distinction to evaluate the ethics of nudging in the BRCA screening and mastectomy clinical decision: institutional nudging (e.g. nudges created by the government) and interpersonal nudging (e.g. clinical nudging between a HCP and their patient). Sunstein (2017) primarily discusses institutional nudging: "If governments can achieve policy goals with tools that do not impose high costs and that preserve freedom of choice, they will take those tools seriously" (pp. 2). However, there is more recent literature discussing clinical nudging—where HCPs are drawing on the behavior economics research to nudge their patients to make decisions that are better for their health. I think in both decisions regarding BRCA screening, both of these kinds of nudging could come into play. It is critical to note, that in both of these distinctions of choice architecture that one can still separate out educative and noneducative nudges. The four kinds of nudges that I will refer to in the remainder of the chapter are: institutional educative, institutional noneducative, interpersonal educative, and interpersonal noneducative nudging. As established earlier, educative nudges are ethically permissible as they nudge people to reason better and make better decisions that align with their personal beliefs and values. In the following paragraphs, I will primarily consider whether institutional and interpersonal noneducative nudges are morally permissible using the BRCA screening and preventative mastectomy decision examples.

As extensively discussed in Chapter 2, social context and influences can significantly impact patient autonomy and decision-making. Not only are patients a product of their social context and relations, but they receive a great deal of information and influence from social institutions about normative behaviour. One of the ways institutional nudging could be used in this decisional context is to buffer the strong messaging from pink ribbon culture on women's decision-making to undergo preventative mastectomies and uncritically uptake BRCA screening. Many of the messages distributed in pink ribbon culture urge women to comply with medical authority and seeking aggressive and urgent measures to prevent their breast cancer. An "empowered" breast cancer survivor does not question their options but trusts in medical science and advice (Sulik 2012). This trust in medical science rhetoric permeates pink ribbon culture through mass messages from invested corporations and institutions involved in the consumerism of the brand (Sulik 2012). "[P]ink ribbon culture has succeeded in spreading the message that its cultural leaders have figured out how to best fight the war on breast cancer" (pp. 275); thus, the prevalent messaging surrounding breast cancer is likely not very relevant for patients to make a decision because much of the information communicated to the public drives the cancer industry's profit from the ongoing fight against breast cancer and resonates rhetoric about being a 'good' cancer survivor (or previvor) and not about the patient's own goals or values. For example, although there are no proven methods of prevention or cure for breast cancer, screening tests, such as mammography and BRCA gene testing, are cast as "early detection tools" (Sulik 2012). These technologies are strongly promoted even though there are major problems with the use of mammography and gene testing for mass screening (Sulik 2012, Hatch 2016) and the efficacy of risk-reducing treatments, such as prophylactic organ removal, is largely overestimated (Alaofi et al. 2018, Aronowitz 2015). Through this mechanism, the informational messages conveyed through pink ribbon culture increase the breast cancer industry's ability to generate profit because they can now market early detection tools and risk-reducing treatment; thus, making profit from a wider population. Moreover, increasing the number of cancer survivors (and previvors), as well as increasing the perception of the severity of disease, pink ribbon culture affects how people experience and understand their illness (Aronowitz 2015). As a result, association with breast cancer survivorhood affects how patients understand the information that is presented to them from mass media.

Even if doctors were not influenced by the social messaging around breast cancer, the information they communicate to their patients might be competing with the implicit messaging patients receive in their socialization with the sub-culture. The relevancy of the information provided by one's physician might be overshadowed by the way that pink ribbon culture shapes what one believes to be important. Institutional nudges created by the medical profession or public health sectors could help to buffer some of the exaggerated (and often incorrect) information provided by private players in the breast cancer industry (e.g. Komen for the Cure) and help women who are at an increased risk for breast cancer reason better about their situation and how their values might play into their medical decision to request BRCA screening and whether to undergo or forego a preventative mastectomy. Blumenthal-Barby & Burroughs (2012) describe six different ways in which nudges have been used to help people change health-related behaviours. One way that could be used on the institutional level is by disincentivizing women to undergo BRCA gene screening unless their physician suspects a genetic connection to breast cancer. Instead of allowing anyone to request the BRCA test from their physician, perhaps the test could cost a small fee (e.g. \$100-\$200) to take. By offering this disincentive to undergo the test, women who might be worried about developing breast cancer (but do not have any genetic risk factors for it) because it seems like “everyone” is getting tested for the gene (bandwagon effect), the media and other informational sources make it seem like the frequency of the gene in the population is higher than it actually is (availability bias), or thinking that they should do something about their health rather than waiting for symptoms (commission bias), etc., might be nudged to refrain from getting the test done or at least weighing their reasons better to justify the cost for the test. More careful consideration needs to be given to this kind of nudging in genetic screening and whether it would improve women’s welfare (perhaps by avoiding the possibility of getting a false positive when they have no reason to suspect a genetic link to developing breast cancer). This nudge is complicated by the availability of personal genetic testing kits (like 23andMe™) that enhances the social narratives around genetic determinism and precision medicine.

Another kind of choice architecture that could be used by medical authorities to contrast some of the aggressive messaging of pink ribbon culture is by sharing stories of women (e.g. through pamphlets or advertising) who had different breast cancer experiences, aside from what the ‘good’ breast cancer survivor (or previvor) does according to pink ribbon narratives. For example, maybe sharing stories of women who chose to monitor their bodies for breast cancer and because of early detection, never had to undergo a preventative mastectomy because radiation yielded a great outcome. Or, perhaps, the physician could share stories of women who opted for the preventative mastectomy and regretted their decision. By broadening the narratives available to women, it might help to counter the optimism bias, availability bias, or bandwagon effect that might be influencing women to select preventative mastectomies without sufficiently considering their options and how the surgery might not be the best choice for their values or preferences. Feminist theorists would advocate for this kind of educative nudges because these nudges would encourage women to evaluate their social context, seek out reasons that motivate their choices, and improve their understanding of how their values and beliefs might play into a decision such as the one to undergo a preventative mastectomy, while simultaneously dismantling harmful gendered scripts that only support one kind of survivorship.

However, sharing these personal voices that counteract the dominant narratives permeated by pink ribbon culture are not purely educative nudges that encourage women to reason better. Sharing narratives leaves salient, emotional impressions on people and nudges people "by making use of the principle that people are influenced by novel, personally relevant, or vivid examples and explanations" (Blumenthal-Barby & Burroughs 2012, pp. 4). Salience and affect are powerful nudges that are not primarily used to better inform people but instead elicit strong emotional associations that can powerfully shape an individual's decisions and behaviours. While this kind of nudge is particularly effective, it raises some important ethical considerations. First, let us imagine a series of narratives in a campaign to share the stories of women who have had different experiences with breast cancer at various stages from just being at risk for developing cancer to stage IV cancer that took the form of a noneducative nudge (i.e. these narratives did not share much of an educative component like previously discussed, but were primarily created in a way that left a strong emotional impact on the target audience). On one hand, if the private sector is appealing to salience and emotion to get the pink ribbon messaging across, government and medical authorities should be able to use similar techniques to balance out the kinds of messaging that people are receiving.

However, while we might expect private industry to use marketing strategies to manipulate our consumer habits, we might not expect such manipulation from policy-makers or leaders in medicine. Blumenthal-Barby and Burroughs (2012) argue that "manipulation always involves some infringement on a person's autonomy" (pp. 4) as it "occurs when one influences another by *bypassing their capacity for reason,* either by exploiting nonrational elements of psychological make-up or by influencing choices in a way that is not obvious to the subject" (*italics in original,* pp. 5). Manipulation itself is not inherently unethical or malicious, but one can imagine situations where it might be challenging to discern whether certain nudges are simply manipulative and ethically permissible, or coercive and morally problematic. According to philosophers, such as Sunstein (2017) and Gorin et al. (2017), nudges are not coercive because people are still able to opt out of the default pathway or resist the nudge to choose and make their own decision. Yet, noneducative nudges operate without our awareness of them because they play off of our System 1 cognitive biases and heuristics, thereby bypassing one's capacity for reason. Along this line, manipulation can thereby prevent exercise of autonomy because the person may not consider the options or information necessary for their choice and "threatens the agent's ability to act in accordance with her or his own preferences" (Blumenthal-Barby & Burroughs 2012, pp. 5). I will return to this concern when I discuss clinical nudges, but for now, I believe this kind of manipulation at the institutional level would be justified as it is helping to balance out the messaging permeated by pink ribbon culture and provide a chance for women whose stories have been marginalized from the dominant narratives to be distributed.

Policy-makers and medical authorities should carefully evaluate how institutional nudges could influence people's decisions before implementing them. Overall, Sunstein (2016b) argues that most people support nudges. Although more people support educative nudges that "appeal to conscious, deliberative thinking", there remains significant support for noneducative nudges that "affect subconscious or unconscious processing" (pp. 177). As mentioned earlier, libertarian paternalism supports the idea that nudges need to be designed to help the individual achieve their long-term goals and not what the authority thinks the nudge ought to achieve. Evidence demonstrates that people reject nudges when they suspect that the motivations of the nudger are illicit and do not support the ends of the nudgee (Sunstein 2016b). Policy-makers and institutional authorities need to consider the goals of the people they wish to nudge if they want effective, popular, and ethical choice architecture. In the BRCA situation, this might be challenging to achieve. In the public health arena, it is safe to assume that many people want to live a healthy life. So, implementing nudges that generally support those ends will be accepted by the majority of the population; thus, would be generally accepted by the population because the nudges support the values held by the majority. However, undergoing genetic screening or deciding whether to undergo preventative surgery is a very individualistic decision. All women would agree that they do not want to develop breast cancer, but that does not mean that surgery is a good option for everyone at an increased risk. At the institutional level, nudges that prevent harms from false positives and nudges that encourage women to understand how their values might be affected by different choices would be more consistent with the values and ends held by most people; therefore, institutional nudges (educative and noneducative) ought to carefully consider the consequences of the choice architecture on the target population, especially when it comes to individualistic healthcare decisions where it is challenging (if not impossible) to pinpoint the values that the majority of the nudgees hold.

Clinical nudges, on the other hand, are a bit more complicated to assess the moral permissibility of. I am defining interpersonal nudges as the nudges that people use with each other: for example, between two spouses, a speaker and his audience, or a healthcare provider and their patient. For the purpose of this paper, I will only discuss the last kind of nudging, called "clinical nudging", where nudges are used by a healthcare provider to encourage a patient to act in a certain way. Similar to institutional nudges, to avoid unethical paternalism, the choice architect should only nudge an individual to act or choose in ways that is consistent with the individual's values, beliefs, and ends. However, what interpersonal nudges bring more predominantly to the forefront of the discussions surrounding the ethical permissibility of nudges in the clinic is "the moral status of manipulation" (Blumenthal-Barby 2012, pp. 349). Before I delve into understanding the challenges with understanding manipulation in clinical nudging, it is important to recognize that clinical nudging itself is not purely an interpersonal nudge, but rather a hybrid of interpersonal and institutional nudging[10]. Although a healthcare provider would use nudging to manipulate a patient to make a certain decision or act in a certain way, many of the interactions, expectations, and behaviours that typically characterize the patient-physician relationship are governed by social and institutional norms that originated from historical, socio-cultural values and influences (Recall: Kukla (2005) in Ch. 2). Moreover, the clinical nudge is similar to a purely institutional nudge because of the asymmetry in the power relationship between the HCP and the patient. These social influences and norms as well as power dynamics create more concern over the ethical permissibility of nudging as manipulation in the clinical setting. In purely interpersonal nudging, manipulation and persuasion are a part of human nature—most people would not be concerned if someone was trying to nudge their spouse to pick a certain restaurant to go for dinner. However, when an authority uses their

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[10] In fact, because of this distinction, clinical nudges might be better off as classified separately as it contains elements and ethical considerations of both institutional and interpersonal choice architecture.

position of power to manipulate someone by bypassing their reasoning capacities and awareness with nudging, it seems suspicious.

Blumenthal-Barby (2012) calls for conceptual revisions to better understand the grey area of manipulation and how it could interfere with autonomy. In bioethics, influence is often categorized into: rational persuasion, manipulation, and coercion. While most bioethicists seem to agree that persuasion is acceptable while coercion is morally impermissible, Blumenthal-Barby (2012) argues that some kinds of manipulation are morally permissible while others are morally condemnable in the clinical context. Interestingly, she roughly distinguishes manipulation in a similar way as Sunstein (2017): reason-bypassing manipulation bypasses "a person's reasoning capacities and often their awareness", while reason-countering manipulation "operates by countering a person's reasoning capacities" (pp. 349) and the person is aware that they are being influenced (c.f. noneducative vs. noneducative nudges). Reason-bypassing manipulation is a concern, not because the nudge was so significant that someone could not resist it, but because they did not know they were being nudged in the first place (Blumenthal-Barby 2012). However, as previously mentioned when I was discussing the ethics of institutional nudges, Sunstein (2017) provided evidence that most people accept noneducative nudging as long as it agrees with the majority. But, one also expects the government to influence the population to act in certain ways that are conducive to their health that the majority would not oppose.

Do we expect our physician to influence us to do things that are good for our health? Of course, that is part of their training. But do we expect our healthcare providers to influence us without us knowing—by using nudging to bypass our reasoning capacities and manipulate us without our awareness? For example, I would fully expect my physician to try to persuade me to follow my medication regimes, exercise regularly, and eat healthy, but I do not expect them to use framing or defaults to nudge me to act in certain ways without my awareness. Blumenthal-Barby (2012) argues that our expectations of the duties we have to one another in our interpersonal relationships is a "major factor at play in the ethical permissibility of nonargumentative influence [i.e. manipulation]" (pp. 357). In the patient-physician relationship, the patient expects a high degree of transparency, justifications for recommendations, promotion of their best interest, and respect for a patient to exercise their autonomy from their physician.

If reason-bypassing (or noneducative) nudges violate these expectations of our physician to uphold their duties in the interpersonal relationship with their patient, then these nudges are morally condemnable. For example, if a physician uses the framing bias to nudge a woman who is a BRCA gene carrier and is at an increased risk for developing breast cancer to undergo a preventative mastectomy. The physician knows that if they frame the surgery in terms of survival as opposed to mortality, while emphasizing the positive consequences of the surgery and downplaying the negatives to engage the optimism bias, then this use of nudging is an impermissible kind of manipulation. In this example, reason-bypassing nudges violate patient autonomy "insofar as the patient is not aware of the fact she is being intentionally influenced" (pp. 358) and her physician is not encouraging the patient to consider the options and how they align with the patient's values and preferences. Moreover, because the physician is not upholding the patient's expectations of their relationship, noneducative (i.e. reason-bypassing) nudges can significantly damage the trust in the relationship. Even if a physician has good intentions behind using reason-bypassing nudges to influence their patient to act in certain ways, nudging could violate the expectations the patient has of their physician and how the patient expects their physician to act and communicate within their professional duties. So, while noneducative nudges might be morally permissible at an institutional level, I worry that they could undermine the trust in the patient-physician relationship because we expect our physician to manipulate us towards health-centered behaviours in much different ways than the government or public health institutions.

The challenge, especially given the fact that there are many kinds of nudges that play off of our cognitive biases in different ways, is to discern whether the use of any noneducative (or reason-bypassing) nudges are ethically permissible in a clinical context. Because of the nature of the patient-physician relationship, even nudges coming from a well-intentioned physician could destroy the trust and integrity of the relationship and undermine patient autonomy. What I propose we consider, is whether there are any noneducative or reason-bypassing nudges that could be morally permissible because they “nudge to reason” (Levy 2017, pp. 498) after consideration of the potential consequences, decisional context, and individual patient. While this seems inherently impossible given that noneducative nudges are designed to purposely bypass our reasoning capacities by engaging our cognitive biases subconsciously, Sunstein (2017) explains that sometimes noneducative nudges can nudge a person to reason better. Even though they are primarily created to simplify the decision-making process because they are not cognitively demanding, noneducative nudges might actually convey information and may appeal to reason. For example, Sunstein argues that some default nudges could fall under this category: if a default option nudges someone to learn about the reasoning behind the default, then some noneducative nudges can work in a similar way to educative nudges. In this case, the default is a nudge to reason because “it changes minds by making them more responsive to genuine evidence” (Levy 2017, pp. 498).

To consider an example in the clinical setting, let us imagine an exchange between a woman who is a BRCA carrier at an increased risk for breast cancer and her physician, where they are discussing whether a bilateral preventive mastectomy or increased bodily surveillance would be a better option for her. Maybe the physician thinks that using salience or affect will help nudge the patient to reason better in this context so the physician recommends a video of women (recall from my example in institutional nudges) who were in different stages of breast cancer sharing their survivorhood and previvorhood experiences for the patient to watch. Even if the videos did not discuss all of the consequences, options, and value judgements of each woman in her experience of being at risk for or having breast cancer, the videos would probably evoke strong emotions in the woman who is watching these different narratives. These affective responses "orient us toward some responses and away from others, thereby *enabling* deliberation" (Levy 2017, pp. 499). In reflection on these videos and considering her situation, the woman who is deciding whether to undergo a prophylactic mastectomy may be prompted to by these strong emotional associations to understand how her values compare to the other stories and help her make a better decision that aligns with her values and preferences. However, more work needs to be done to carefully assess various noneducative nudges and the ways in which they do nudge a patient to reason. Healthcare providers are responsible for fostering a trusting and supportive relationship with their patients, which involved being wary of how their presentation of information and choices could influence people's decisions and their exercise of autonomy (Gorin et al. 2017). In sum, "noneducative nudges can promote autonomy in addition to welfare" (Sunstein 2017, pp. 4) as long as they are nudges to reason and are not purely architectural, where they completely bypass someone's deliberative capacities in making a decision. As long the nudges help a patient reason better, they are promoting autonomy: since “people care greatly about having agency” (Sunstein 2017, pp. 8), all ethical considerations of nudging should be done on an individual basis, after careful consideration of the patient’s social context and values (through a relational perspective), and only if the nudges (either educative or noneducative) help a patient reason better and make a decision that better aligns with their values.

III. Conclusion

In this project, my aim was to obtain a better understanding of the challenges to autonomy within the context of genetic testing, precision medicine, and preventative treatments. In the introduction (Section I), I elaborated on the example situation that was drawn on throughout the project to better understand these challenges and approaches to autonomy. With great strides being made in genetic research since the Human Genome Project, medicine has been hopeful that this research would change medical interventions from a pathophysiological, reactive direction to an individualized, preventative approach to patient care. The breast cancer example was selected because the BRCA genes were some of the first to be identified as correlating to chronic disease, which has led to a trend where women were requesting BRCA screening tests from their physician and then seemed to select extreme treatments as a preventative measure over surveying their bodies for early signs of cancer. I wanted to draw attention to this example because it could be a template for future trends as a result of new genetic discoveries and their links to chronic disease. While precision medicine promises to eventually tailor preventative measures and pharmacological interventions to the individual based on their biomarkers and risk for disease, the research is still in its infancy for what we are to do with the information that we are discovering about our genes and health. This gap in our knowledge seems to be encouraging preventative treatments for diseases that one might be predisposed to, but without precision medicine interventions, individuals are undergoing aggressive procedures to alleviate their anxiety about their unknown risk states.

Consequently, the impact of genetic research on medical practices brings up many questions about patient decision-making and implications for patient autonomy—a core value guiding contemporary western medicine. In a society where medical paternalism is rejected out of worry for the harms that might arise when a physician makes a decision on behalf of a patient, respect for autonomy is encouraged. In Chapter 1, I discussed the standard model of autonomy, or Beauchamp and Childress' (2009) decisional autonomy framework, which is most closely aligned with how respect for autonomy is realized in medical practice (i.e. through informed consent). The decisional model emphasizes the positive and negative duty for healthcare providers to avoid unduly influencing their patients by encouraging the patients' freedom to choose and providing sufficient and relevant information to patients so they can make a decision based on their values and preferences. In practice, this would look like physicians informing women of their option to undergo genetic screening for a BRCA mutation, then informing women about options following the positive result of their BRCA test, and allowing them to choose the option that the woman thinks would be best for her—assuming that she was provided relevant and sufficient information to make the decision herself and was not unduly coerced by her physician (or an external influence) into making a decision.

While the decisional account offers the most realistic and achievable account for patient autonomy in medical practice, I argued that there were two gaps in the account that were illuminated by the BRCA testing and preventative mastectomy trend. The first critique came from a feminist relational perspective that argued the decisional account does not adequately account for how a patient's social embeddedness influences their autonomy. Feminist theorists argue that Beauchamp and Childress' account focuses too heavily on local autonomy (how autonomy is realized in punctate decisions) and neglects to demonstrate how autonomy is an ongoing practice that often happens outside of decisional moments. In the preventative mastectomy example, this approach to autonomy dichotomizes the choice that a woman has to make between waiting and surveying her body for cancer or undergoing a preventative surgery to reduce her risk to develop cancer. In both decisions, however, there is a large component of patient responsibility and autonomy to be responsible for ongoing, habitual practices (bodily surveillance for cancer in both choices that may be ongoing for the remainder of the woman's life)—a focus on punctate decisions downplays certain global autonomy considerations. With our preoccupation with extensive genetic screening, Aronowitz (2015) has argued that healthy individuals at risk for a disease and individuals with the chronic disease have a converged disease experience—at all points in the risk-to-disease spectrum, the patient will have a role in surveying their body and considering interventions (preventative and reactive) once they are 'diagnosed'. This converged disease experience and high uncertainty about their condition motivates women who are at an increased risk for breast cancer to undergo aggressive treatment to alleviate their anxiety about their risk state. By focussing on punctate decisional moments, the decisional account (in addition to social influences) incorrectly dichotomizes the decision by neglecting to emphasize the importance of bodily surveillance in both choices—the decision is framed in a way where women feel like their only choice is to undergo preventative mastectomy to control their anxiety over their risk state.

Moreover, by focussing on punctate decisions, the decisional account diverts attention away from the normative forces and values that influence one's decision. The significance in Kukla's (2005) critique of the hyper focus on punctate decisions in the decisional account is that harmful norms and values may be embedded in these medical practices themselves. By not adequately acknowledging how one's social context shapes their clinical decision-making, Beauchamp and Childress' framework does not identify how medical authorities, healthcare professionals, or patients should be assessing these practices and values. With such a detailed account of the obligations of healthcare providers communicating to patients in ways to respect their autonomy, the decisional account neglects to address how patients should be reflecting on their values and making decisions or how the norms and values that guide healthcare practices should be critically evaluated. Feminist theorists argue that clinical decisions cannot be made if patients do not understand how the technical, medical information they are provided about their condition relate to their values or society's values and how to make a decision consistent with those values.

In some clinical decisions, this level of reflection is unnecessary; however, in the clinical example situation, social forces (such as pink ribbon culture and the "Angelina Jolie Effect") are highly influential, even manipulative, in a woman's decision regarding whether to get tested for the BRCA gene or undergo a preventative mastectomy. The decisional account does not provide any direction in what should be done by healthcare providers or medical institutions to counterbalance these social forces and promote patient autonomy. A patient can only make a truly autonomous decision if they make a decision that aligns with their values and preferences—how one is socialized plays a large role in how they make decisions and what values they hold. Pink ribbon culture amplifies narratives about survivorship (and previvorship) to instill a single way of experiencing breast cancer into women with breast cancer or those at risk for developing it. These narratives further reinforce appropriate behaviours of cancer survivors, including taking aggressive action in the war against cancer by undergoing radical, preventative mastectomies. With such a heavy focus on how information is communicated to patients in the decisional account, it is critical to acknowledge how social forces influence patient autonomy, offer solutions to reflect on and counteract harmful narratives, as well as recognize the potential lack of opportunities that are necessary for patients to develop the capacities necessary to make autonomous decisions. The decisional account at most offers suggestions for how healthcare providers should communicate to patients but neglects to advance the ways in which a fully autonomous patient should make a decision that aligns with their values and preferences. Capacities, such as self-trust and self-respect, may be influenced by one’s social context (such as oppression or marginalization in society, norms that regulate clinical relationships and encounters, or dominant social messaging like pink ribbon culture).

As a solution to this gap in the decisional account, in Chapter 2 I turned to the feminist relational framework (what I called “strong relational autonomy”) to better evaluate how an agent’s social context influences their autonomy and proposes a deeper solution to fostering patient autonomy in the clinical context. In considering the BRCA screening and preventative mastectomy example, I proposed both macro and microlevel solutions to respecting patient autonomy from a relational perspective which included ways to mitigate the effects of oppression and social forces on patient autonomy (e.g. by preventing opportunities to develop autonomous capacities or buffering the harmful rhetoric of pink ribbon culture) and improve the communication and relationship between the patient and physician that would facilitate deeper discussions regarding patient values so a patient can arrive at a fully autonomous decision. Despite the strong critiques against the decisional account, the downfall of the feminist relational framework is its lack of an alternative, stand-alone framework for autonomy. While it provides a critical lens to the social forces that shape individuals, relationships, and social constructs, it is challenging to picture what an alternative framework of autonomy would be without the decisional account. After I finish summarizing the rest of my project, I will return to this important conclusion.

The second gap in the decisional account that was illuminated by the BRCA testing example has arisen in light of the recent behavioural economics and social psychology research that demonstrates how poor humans are at making decisions, especially under uncertainty. In Chapter 3, I drew on this research to depict how our cognitive biases and heuristics can compromise aspects of Beauchamp and Childress' model of autonomy (i.e. patient understanding, intentionality, or authenticity). Again, in some clinical decisions, these biases may not significantly interfere with autonomy (e.g. routine procedures, with little harm to the individual and result in great benefit). However, in the BRCA testing and preventative mastectomy decisions, all of the information provided to patients about their prognosis is an estimation and patients are making drastic decisions about their health without much certainty about their risk state or future health. By drawing on Kahneman's (2013) research, which provides evidence that human minds make more errors when making decisions under high uncertainty, and Blumenthal-Barby's (2016) systematic review of the various kinds of reasoning errors that patients can make in health decisions, I explained a few ways in which our cognitive errors can interfere with the conditions necessary for autonomy according to the standard model.

I concluded that Beauchamp and Childress' (2009) solution to some of these errors in information processing was inadequate in light of the current research regarding the extensive biases and reasoning errors that humans are susceptible to. Beauchamp and Childress only highlighted one bias (framing bias) and proposed the solution that healthcare providers need to be cognizant about how information is framed to patients in a way that minimizes the effects of the framing bias on their decision. What is missing from the decisional account, however, is what ought to be done to minimize the effects of the other biases that patients could fall victim to? How much of a responsibility should HCPs and medical authorities have to reduce problems of information processing in patient decision-making? With the plethora of cognitive biases investigated, it would be impractical and too burdensome to expect healthcare providers to be aware of all the possible biases that might interfere with patient autonomy and attempt to avoid them in every conversation with their patients. This begs the question: what should be done to minimize the reasoning errors that interfere with patient autonomy? Or, does this evidence that humans are poor decision-makers entail that individuals cannot be trusted to exercise their own autonomy? In light of the extensive evidence that humans are susceptible to poor reasoning errors in health decisions, I addressed a significant worry that if we are unable to make good decisions for ourselves, it is inevitable that we will fall back to paternalism and allow medical authorities to make decisions for us. I argued that in such contexts of high medical uncertainty and a diversity of patient values and goals, it is more harmful to force a woman to undergo (or forego) BRCA screening and/or a preventative mastectomy than it would be for her to make her own choice—even if it is a poor one that is not in her best interest.

As a stronger solution to address this gap in the decisional account, I drew on the libertarian paternalist framework which suggests choice architecture and nudging that use a person's predisposition to cognitive biases to make a decision that is in their best interest. A worry about nudging is that medical authorities, like physicians, may use nudging to manipulate their patient into choosing the option that the physician thinks is best for the patient; thus, leading to similar harms as traditional paternalism. However, I have agreed with proponents of libertarian paternalism (i.e. Gorin et al. 2017, Sunstein 2017) that nudges may be ethically permissible if choice architects are using nudging to simplify decision-making by guiding the individual to choose what option would align best with the individual's values, beliefs, and goals—a decision the person would make for themselves if they were not victim to reasoning errors or cognitive biases. Moreover, as long as nudges are relatively easy to resist, then choice architecture is not paternalistic as it preserves the agent's freedom to choose.

To better understand the moral permissibility of nudging in healthcare, I drew on Sunstein's (2017) distinction between educative and noneducative nudges and further separated these categories into institutional, interpersonal, and hybrid (or clinical) nudging. In these contexts, I argued that educative nudging is nearly always permissible: it is designed to "increase people's own powers of agency" (Sunstein 2017, pp. 3) by engaging their deliberative capacities. Educative nudges work to minimize the negative effect of one's cognitive biases on their autonomy by using their cognitive biases to reason better. Towards the end of Chapter 3, I explored whether noneducative nudges (institutional and clinical) would be permissible since they do not increase or improve people's capacity for autonomy. Noneducative nudges are manipulative as they often operate without our awareness. If noneducative nudges bypass an agent's capacity for reason, thereby threatening the agent's ability to act in line with their own preferences (Bumenthal-Barby & Burroughs 2012), are they preventing her from exercising her autonomy?

In Chapter 3, I arrived at two conclusions about the ethical permissibility of using noneducative nudges to manipulate patients into selecting an option that aligns with their best interests. Firstly, noneducative institutional nudges can be permissible if the motivations of the choice architect help the individual being nudged to act in a way that aligns with their values and goals. However, nudges need to be carefully evaluated so that they do not assume or ignore the diversity of individual values and goals in such a personal healthcare decision like the BRCA screening and preventative mastectomy decisions. What I suggested that could be effective, as long as the majority of patients approved, is educative or noneducative institutional nudges that counterbalance the messaging from pink ribbon culture. By offering a diversity of narratives of women's diverse experiences of breast cancer (or being at risk for breast cancer), these nudges might help women to think about how their decisions might agree with or conflict with their values and beliefs—demonstrating that there is not one right way to experience breast cancer survivorhood (or, in this case, previvorhood). When considering clinical nudges, however, I arrived at a different conclusion. Clinical nudges are conceptually challenging because they have elements of interpersonal and institutional nudges as the relationship between a patient and their physician is asymmetrical. With the healthcare professional being in a position of power over the patient, using noneducative nudges to manipulate the patient into choosing a certain option could damage the trust we have in our physician if they break the professional expectations the patient holds of them. I concluded that the only noneducative clinical nudges that would be permissible would need to be: reason-countering (or in some way nudge a person to reason better and are not purely architectural); only used after careful consideration of the individual's values, beliefs, and preferences; and if educative nudging strategies are unavailable or have already been attempted. The trust in the relationship between the healthcare provider and patient, as well as respect for patient autonomy, should be at the forefront of all nudging considerations.

Throughout this project, my understanding and appreciation for the complexity of autonomy in the healthcare context has evolved. After considering the trend for BRCA testing and preventative mastectomies, I have realized that each of the frameworks I described (decisional, relational, and libertarian paternalist) recognize different challenges to autonomy and offer unique perspectives to mitigate those weaknesses. For example, the decisional account arose in response to medical paternalism and provides a tangible framework to promote patient autonomy by protecting a patient's right to choose (often through informed consent practices). The relational framework recognizes the extensive ways in which social forces can interfere with autonomy and offers structural (macrolevel) as well as interpersonal (microlevel) approaches to encourage patient autonomy despite oppressive social scaffolding. The libertarian paternalist framework is concerned with maximizing both patient welfare and autonomy by helping people make decisions that align with their best interest, despite the fact that they might make poor reasoning errors and make decisions against their interest.

Yet, there also seemed to be significant drawbacks to each framework. Obviously, I outlined the flaws of the decisional model quite extensively throughout this project. But, the feminist and libertarian frameworks have their own issues as well. Although the feminist relational framework offers strong critiques of the decisional account and draws our attention to significant challenges to patient autonomy in our patriarchal, capitalist society, it is unclear what the framework would look like in practice if it were to replace the decisional account. Each feminist theorist offers a different perspective on autonomy and important considerations within the health context that the diversity in approaches to patient autonomy vary significantly within feminist philosophy. How should these considerations be weighed? What would some of these recommendations look like in practice? While some feminist critiques can be incorporated and complement the decisional framework, some critiques seem fundamentally incompatible with the decisional account. Because Beauchamp and Childress advocate for such a realistic, even minimalistic, account of autonomy, some of the feminist suggestions (e.g. critical reflection for more authentic decision-making) would contradict the standard model. Beauchamp and Childress want a practical and realistic account of autonomy, and for those reasons they have lowered the threshold necessary for the average patient to be autonomous (i.e. through sufficient and relevant information and being relatively free from coercion). However, many feminist critiques demand a level of communication, understanding, reflection, etc. that decisional theorists would consider to be impractical in practice.

On the other hand, the libertarian paternalist framework, while it tries to address the challenges to autonomy that arise from human irrationality and cognitive reasoning mistakes, might be too liberal in a clinical context. In Chapter 3, I struggled to think of ways in which noneducative nudging might be morally permissible in the clinical context. My primary worry would be that a HCP would nudge a patient to select a certain option without having a strong enough understanding about the individual's social context, values, and ends (not in a malicious way, but because the libertarian paternalist framework did not provide any recommendations for how HCPs ought to go about this). Leaning on the feminist framework could help HCPs to obtain a better sense if noneducative nudging could work for a specific individual, however, a libertarian might argue against such an extent of interference. Libertarian paternalism emphasizes freedom to choose and individual agency—without considering how oppression and other social forces may be foreclosing opportunities for individuals to exercise their autonomy or understand their authentic values and preferences that should guide their decision. Moreover, while choice architecture has proven to be effective in manipulating populations to behave in certain ways, it cannot replace the basic conditions for decisional autonomy and shared decision-making when nudging happens at the interpersonal level. Manipulating populations to accomplish certain goals for the overall health and well-being of a population (with potential for great benefit and low risk) is very different than entrusting a healthcare provider, who is also a person subject to reasoning errors and cognitive biases, to manipulate a patient that is struggling to make a very personal, uncertain decision in a clinical setting. With the extensive behavior economics and social psychology research detailing all of the cognitive biases and reasoning errors, I believe more research needs to be conducted to help resolve whether noneducative nudging would be permissible in highly personal decisions in the healthcare context.

Because each of these frameworks contributes in a significant way to understand and promote patient autonomy in medicine, my perspective has drastically shifted. Initially, the goal of this project was to evaluate the perspectives and see which one could best accommodate all of these challenges because I believed that the frameworks were mutually exclusive and essentially incompatible with each other. However, after my research, I believe there are ways in which the theories could accommodate for each other in a way that negotiates the tensions between each theory. In future research projects, I hope to better evaluate the ways that the theories could offset each other to best promote patient autonomy, especially in contexts of high uncertainty where there are significant social forces influencing patient decisions. Until then, in light of the research from this project, I will describe some of the tensions and compatibilities that seem to arise from my analysis.

Firstly, I would like to emphasize that the feminist critique of the decisional account is not simply their lack of appreciation of the social factors that influence patient autonomy. I think Beauchamp and Childress (2009) would agree that these factors highlighted by feminist philosophers would be compatible with their account and would remedy the critique (recall my discussion on their account being weakly relational). However, what the critique really illuminates is that Beauchamp and Childress want a minimalistic conception of autonomy where they outline the conditions necessary for physicians to respect patient autonomy (i.e. the physician has positive and negative obligations to ensure that patient autonomy is respected). What I think is critical from a feminist perspective is that they call for obligations of physicians (and other social factors and institutions) to *foster* patient autonomy. It is not simply the physician's responsibility to correct any information distributed by pink ribbon players that cloud a patient's understanding of their situation, but the fact that many of these patients might not have had the opportunity to develop the capacities necessary to exercise their autonomy and make an authentic choice (like self-trust or value reflection). Moreover, there is no guidance in their account with how a patient should be an agent in their own medical decisions in addition to the obligations of the healthcare provider to create the conditions for patients to exercise their autonomy. So, while Beauchamp and Childress want a minimalistic account of autonomy that is practical and realistic, I am inclined to support the feminist call for a stronger duty to foster patient autonomy in certain clinical situations. Therefore, the decisional framework does not adequately account for how one's social embeddedness influences or interferes with autonomy. In situations where social influence can greatly impact clinical decision-making, I think a stronger relational account is necessary to go beyond simply the conditions necessary for respecting autonomy but instead helping foster autonomy (for example by helping patients reflect on their values to understand if a certain option better aligns with their values, therefore allowing them to make an authentic decision).

The second gap in the standard model is the doubt caused by decades of behaviour economics research on the ideal of rational decision-making. Because of cognitive biases and heuristics, humans have been demonstrated to be poor decision-makers especially in decisions that involve high uncertainty. In Chapter 3, I explained how these biases and heuristics can interfere with the conditions necessary for autonomy (adequate understanding, making an intentional or authentic decision). Of these two concerns (i.e. one from the relational framework and one from the libertarian paternalism framework), I believe the first concern can be adequately addressed and possibly even resolved through feminist critique. The feminist relational approach (which does not offer a replacement framework of autonomy that could stand alone without the standard model) nicely supplements the gaps where social influences may threaten autonomy. Moreover, the feminist model offers suggestions for how the medical system and society in general can better encourage the development of decision-making capacities so patients can learn to make more authentic decisions that align with their values and beliefs. The only to this compatibility would be that Beauchamp and Childress want a realistic and achievable account of respect for autonomy—the feminist framework often requires increased time and resources from the healthcare provider to develop and foster these capacities in their patient interactions. However, it does not seem that this demanding solution would not compromise much else in their framework since it adds to the already articulated standard account.

The second challenge, however, not only poses an issue with the framework articulated by Beauchamp and Childress (2009), but also begs the question whether we should place such a high value on autonomy in healthcare at all. The decisional account and the feminist account rely on the premise that humans can make rational decisions on behalf of their own well-being. Even if they do not always make the best decision for themselves, it is less harmful to the patient to make their own choice. Consequently, the emphasis on adequate and relevant information being provided to the patient, as well as making the decision free from coercion to obtain informed consent and respect autonomy, is misplaced if cognitive biases and reasoning errors prevent people from meeting these requirements. In light of the extensive research on these informational processing problems, I argue that this is poses a much larger threat to autonomy than the feminist concern with the standard account. If the only solutions to address the problem that humans are poor decision-makers is paternalism or libertarian paternalism, then the only solution involves some kind of interference in clinical decision-making and patient autonomy. In light of these two challenges to patient autonomy, I worry whether it is a viable practical or theoretical aim to continue prioritizing our high value of patient autonomy in healthcare.

Although gene testing has been promoted as a way to empower people to exercise their autonomy and have more choice over their health, I believe that genetic testing (especially in considering my example of BRCA gene testing) brings these two challenges to autonomy to the forefront. If these two challenges pose such a threat to ensuring patient autonomy in clinical decision-making, my argument could entail that interference in autonomy through nudging is inevitable if we want patients to make good decisions and act in their best interests. In some clinical cases where it might be less harmful for patients to make their own decision even if it is not the best decision for their own self-interest, I doubt that this is the case for gene testing right now as patients are choosing to undergo aggressive preventative surgeries based on probabilistic genetic knowledge. If we can ever achieve a precision medical model, where genetic testing would lead to a clear clinical pathway articulating a biomolecular intervention to respond to the genetic information, undergoing genetic tests would lead to certainty in prognosis and prevention. Until then, knowing about our genetic makeup might just cause more anxiety about our future health and prompt aggressive, preventative action because we do not know what should be done based on our genetic information. We are left to resort to pathophysiological treatments (prophylactic organ removal) to ease our anxieties and fears about our risk propensity to diseases. I am inclined to suggest that genetic testing should only be done if women have multiple risk factors that greatly increase their risk to develop breast cancer. Without sufficient justification to undergo genetic testing or prophylactic organ removal, we can avoid inducing the fears that accompany genetic testing and futile (or harmful) aggressive preventative interventions that many women do not need to consider. With the increasing trend towards a precision medical approach, prevalent genetic determinist narratives, and influential social forces, more work needs to be done to better understand how to protect or reconceptualize patient autonomy so that patients can make the best decisions for themselves about the uncertain future of their health based on their genes.

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