

Health Care in a Multicultural Canada: the Ethics of Informed Consent
and the Duty to Warn of Hereditary Risk

by

Poonam Dheri
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Supervisory Committee

Dr. Eike-Henner W. Kluge, Co-Supervisor
(Department of Philosophy)

Dr. Laura Arbour, Co-Supervisor
(Division of Medical Sciences)

ABSTRACT

Different people can have different cultural interpretations of the person—atomic versus embedded—and these may affect health care decision-making. This study examines both the ethics of variations in personhood as well as their implications for the doctrine of informed consent and the duty to warn of genetic disease risk. It argues that variations in personhood are consistent with the ethics of the Principle of Autonomy and the Canadian stand on informed consent, though autonomy and consent play out differently in practice on the two models. Also as a result of different interpretations of the person, the duty to warn of hereditary risk is found to be relevant to the atomic conception but unnecessary among embedded individuals.

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INTRODUCTORY REMARKS

Attention to cultural sensitivity in medical practice has risen steeply in the past few decades. More than ever, Canadian health care policy makers and practitioners are expected to be cognizant of variations in patient value-systems. Caulfield and Von Tigerstrom (2002) attribute these expectations to society's deep reverence for the inherent worth and dignity of the person, notions that are reflected in our international commitments (e.g. the *Universal Declaration of Human Rights* 1948). The position is that since the patient is the recipient of medical action—in that the medical action will affect their person—respect for persons entails that the competent patient be allowed to use their values to guide the course of their care. Ethically, this goes to the Principle of Autonomy, which is the right all individuals have to make decisions over their persons.

While the value of autonomous decision-making may be a constant across cultural divides, how it is expressed—or how it functions—appears to depend on how the notion of person is understood, and this can vary from socio-cultural context to socio-cultural context. For instance, current Euro-American ethics and law frame the person as an individual entity distinct from others. On this conceptualization, autonomy is attached to the individual who is seen as an entity that may be embedded in a social context but who, as an individual, is distinct and unique. According to this perspective, individuals are free to choose their own values and use these values in medical decision-making.

The alternative conception of the person is that the individual is an entity who is not distinct and separate from others but is someone who is intimately woven into the particular socio-cultural fabric in which they are embedded (Sandel 1982, MacIntyre 1981, Hardwig 1997). On this perspective, autonomy encompasses the collectivity, whereby the values of the collectivity guide the decision-making.

For the purposes of this thesis, the former view will be referred to as the “atomic model” and the latter as the “embedded model”. The descriptions of two models suggest a functional relationship between personhood, autonomy, and decision-making in that one's particular understanding of the person determines how one views autonomy and this in turn influences how they practice decision-making. Therefore, the objective of the following study is to examine the ethics of the two models and determine whether the varying views of personhood may indeed have implications for health care decision-making.

On the atomic model, decision-making centres on the individual alone as decision-maker. On the embedded model, decision-making is not centred on the individual but is extended to the group. However, to make a decision on either model is to choose from among options of which one is aware on the basis of the information that is at their disposal. Therefore, if the hypothesis that there are distinct notions of personhood and these affect decision-making is correct, one should expect a difference in the way person-relative information is handled in medical decision-making on the two models.

Yet, information itself can come in different flavours. For one, there is that information whose relevance or implications are confined to the health of the sole patient. There is also that information whose health implications extend beyond the individual patient and, in particular, to their consanguineal family or community.

In appreciation of this, the analysis of the atomic and embedded models is separated into two parts. Part I focuses on how the distinct models of personhood affect decision-making involving information centring on the welfare of the individual patient. It deals specifically with the issue of access to patient health information in serious medical contexts that potentially involve death and dying.

To put it more precisely, different people have different cultural interpretations or views about death and dying, and under some interpretations knowledge of a terminal disease or condition may cause the patient more harm psychologically than the harm caused by the physical progression of the disease (Ellerby *et. al* 2000). Patients subscribing to this view may not wish to be explicitly informed of their diagnosis or participate in decision-making but may still wish to receive medical attention. In these sorts of situations, the shared cultural value may be that the family has a responsibility to take reign of decision-making at the end of life. Rather than disclosing the patient's medical information directly to the patient, there may be preference for family-first disclosure where the family decides how much information the patient wishes to know before consenting to health care. The patient subsequently accepts or rejects proposed medical interventions on this adjusted information.

Because the patient-family unit is here embedded, they share the same values. Therefore, the view is that to filter the patient's medical information through the value-system of their family is really to filter the information through the values of the patients themselves. The perceived advantage of this method is that it saves the patient from having to receive information that is from their cultural standpoint undesirable or potentially harmful.

However, the embedded model of decision-making runs into problems with conventional Euro-American informed consent protocols, since patient information on these standards is normally disclosed first to the patient. It is only upon prior and full disclosure of applicable information that the competent patient is eligible to provide or refrain from consent to medical intervention. In other words, informed consent, as is evidenced by the name, is two-fold: it not only requires the patient's affirmation of consent but also requires that the patient is properly informed for that consent to be legitimate. Due to this individual or patient-centred design, current consent standards appear to reflect the atomic model of autonomy, and this has some worried that they may be transgressing on the cultural rights of minorities who view autonomy as embedded (Elliot 2001). As a result, some have proposed a revision of current informed consent procedures (Gostin 1995).

Part II of this study, on the other hand, focuses on how the distinct models of personhood affect decision-making that involves information that has potential health care implications for both the individual patient as well as others in their consanguineal setting. The discussion is narrowed to the genetics context, particularly with respect to the issue of control of genetic information about the individual patient.

In Canada, genetic information is treated as private and under the control of the patient—a treatment that also appears to reflect an atomic view of the person. However, since genes are inherited, an individual’s genetic profile can reveal information about their consanguineal relatives in addition to revealing information about the tested patient. Often times, the endowment has little or no material bearing on the health or welfare of others related to the individual through a bloodline. Sometimes, nevertheless, it may. For instance, a patient’s genetic status may reveal that their consanguineal relatives are at risk for carrying a certain genetic mutation. If the patient is aware that the mutation predisposes their relations to a genetic disorder that may have serious or deleterious implications for their health, a question that surfaces is whether the patient can have a moral obligation to apprise them of this risk.

Since the treatment of genetic information is currently based in the atomic model, there is debate about whether the atomic perspective can support the so-called “duty to warn”. That is to say, can the patient’s duty to minimize harm to others, supposing such a duty exists in this context, override their right to genetic privacy (i.e. their right of control over their genetic information)?

In contrast, the duty-to-warn debate on the embedded model is less defined. This is because the decision-maker on the embedded model is not the individual but the collectivity as a whole, and it is unclear how privacy applies. Since the two models appear to have different working understandings of privacy, the question of whether there is a duty to share information with at-risk relatives may receive different answers on the two models.

In each of the two health care situations examined by this study, the relevant information is about the individual and therefore any difference in how the notion of the individual is understood is likely to give rise to different ways of decision-making and how the information should be handled. They may also give rise to different rights and duties relative to access to patient information for informed consent and to control over one’s genetic information.

The rationale behind the study is that Respect for Autonomy is a fundamental principle in ethics. Because consent and privacy are both central to the delivery of health care services, it is important to know whether different cultural interpretations of the person—and hence autonomy—necessitate a revision of the informed consent doctrine or give different answers to the “duty to warn” in the genetics setting, respectively.

Cultural rights to self-determination also find judicial recognition in the *Universal Declaration of Human Rights* as well as the *Canadian Charter of Rights and Freedoms*. For example, section 15 of the *Charter* stipulates that the nation’s legislations and policies must take care to ensure that they do not discriminate on the basis of race, national or ethnic origin, or colour, amongst other things. Likewise, section 27 necessitates that the *Charter* be interpreted in a manner consistent with the preservation and enhancement of the multicultural heritage of Canadians. Therefore, an investigation into the distinct models of personhood and their implications for medical decision-making also seems to be supported by Canada’s constitutional and international obligations.

The study will be conducted with the following ethical principles in mind:

Principle of Autonomy/Respect for Persons: All persons are autonomous beings worthy of respect and as such have a fundamental right to self-determination that is limited only by unjust infringement on the rights of others (Kant 2012, Gewirth 1978).

Principle of Non-Maleficance: Everyone has a duty to minimize or prevent harm to others 1) insofar as it is possible to do so without undue risk to oneself and 2) where the nature of the harm is in keeping with the competent values of the recipient of the action in question (Beauchamp and Childress 2001).

Principle of Beneficence: Everyone has a duty to advance the good of others 1) if it is possible to do so without undue risk to oneself and 2) where the nature of the good is in keeping with the competently held values of the recipient of the action in question (Beauchamp and Childress 2001).

Principle of Equality and Justice: All persons, insofar as they are persons, are equal and should be treated the same. Exceptions to this must always be based on ethically relevant differences in the nature or the status of the person in question (Kant 2012, Rawls 1999).

Principle of Fidelity/Best Action: Whoever has an obligation also has the ethical duty to fulfill that obligation to the best of their ability (Ross 1938, Kant 2012).

Principle of Impossibility: A right that cannot be fulfilled under the circumstances that obtain is ineffective as a right, and an obligation that cannot be met under the circumstances ceases to be effective as an obligation, except when the impossibility is the result of inappropriate action by the individual who otherwise would have a relevant duty (Ross 1938, Kant 1998).

PART I

Cultural Variations in the Notion of the Person and their Implications for the Doctrine of Informed Consent

Introduction

The evolution of Canadian health law and ethics has been one that reinforces the patient's right to autonomy in the clinical setting: a sentiment that has provided the grounds upon which the current model for informed consent could be formulated. However, a number of clinical research studies suggest that different patients may perceive autonomy differently (Blackhall *et al.* 1995). As a consequence, the patients may prefer an “embedded” approach to health care decision-making as opposed to the “atomic” approach encapsulated in informed consent protocols.

Regardless of the model used, information is integral to decision-making. To make a competent decision, the decision-maker must be aware of the state of affairs and recognize that the situation in fact requires a decision. The decision-maker must also be aware of the options from among which they can reasonably choose. In medical practice, the former means that the decision-maker must have information about the diagnosis, prognosis, etc., and the latter means that the decision-maker requires information about possible choices in treatment or therapy. These requirements for decision-making—disclosure and comprehension—underpin the Canadian stand on informed consent (*Reibl v. Hughes* 1980).

On the atomic model, informed consent enjoins that the patient is appropriately informed prior to consenting to or rejecting the proposed medical intervention. Disclosure and comprehension thus centre on the individual patient. At times, however, some patients may not wish to know certain information about their medical status or participate in decision-making but may still wish to procure the relevant medical care. In cultures where it is believed that knowledge of information involving death and dying can cause the patient more harm than the loss of agency at the end of life, there may be a preference to extend decision-making to the family. The embedded model may prescribe family-first disclosure of patient medical information, where the family decides how much of that information is sufficient for patient consent purposes.

Since current protocols for consent in Canada, as they are enunciated in law and reflected in relevant codes of ethics (e.g. CMA 2004, CNA 2008; see also *Reibl v. Hughes*), reflect an atomic perspective, there exist concerns that the protocols may be incompatible with the cultural views of patients who view themselves as embedded (Elliot 2001). As a result, some commentators have recommended a revision of informed consent procedures to accommodate the various cultural perspectives of autonomy present in health care (Gostin 1995).

The aim of this section, therefore, is to analyze the ethics of the two models of personhood as well as any implications they may have for informed consent to determine whether revision is necessary. However, before addressing the specifics of this issue, it may prudent to first take a

look back at the history of informed consent in Canada and the context in which a greater appreciation for autonomy, in general, was set.

The Nature and History of Informed Consent

Canada—with the exception of the province of Quebec—follows the common law tradition, where evolving social, political, ethical, and pragmatic perspectives are judicially articulated and interpreted into legal principles. The recognition of autonomy as a fundamental principle in Canadian health law was perhaps first articulated in the 1935 case of *Mulloy v. Hop Sang*, where the patient was admitted to hospital with a serious hand injury following a motor vehicle accident. During an initial consultation with the physician, the patient requested that the hand be “fixed up” just enough so that he may have it examined at a larger medical centre in his hometown. He twice informed the surgeon that he did not want it amputated. In response to these instructions, the surgeon replied that his actions would be governed by what he found during the operation. The patient said nothing to this, but he did not speak English well. The physician, upon surgical inspection, found it medically necessary to remove the hand and proceeded to do so in spite of the patient’s previously voiced objections. In the subsequent lawsuit, the physician was deemed guilty of battery when he amputated the patient’s hand against his express instruction, even though it was medically necessary and likely saved the patient’s life.

The tort of battery is defined as the intentional and voluntary act of coming into contact with someone’s person without their consent, whereby that contact is considered either harmful or offensive to that person (Dukelow 2004). During the course of the trial it became apparent that the amputation occurred without consent and was considered offensive by the patient who valued his physical integrity.

The Court decision recognized that patient decision-making authority does not extend merely insofar as the right to consent to surgical inspection and does not hold only while the patient has capacity. Once the patient is under the anesthetic and no longer has capacity, it is inappropriate for the surgeon to contravene the patient’s previously expressed wishes as to the direction of the surgery and do what the surgeon considers to be in the best interests of the patient.

This recognition stems from the Principle of Autonomy, which roughly put is the right that all persons have to self-determination. Adjusted to the health care context, patients as autonomous decision-makers may choose whether or not to accept a proposed health care intervention (see also *British Columbia v. Astaforoff* 1983, *Starson v. Swayze* 2003). Their expressed wishes apply even when they no longer have capacity, regardless of whether the wishes were verbally stated or written in the form of an advance directive (*Malette v. Shulman* 1990). The invalidation of an advance directive due to a present lack of capacity on part of the patient would not only violate Autonomy, but also Equality and Justice, as it would discriminate on the basis of disability (*Charter* s. 15).

The fact that the physician likely saved the patient’s life was deemed irrelevant. The Court found that the physician did not have an overriding duty to save the life of the patient at all costs. Instead, it established that whether such a duty exists in a particular circumstance depends on the

competent wishes and values of the individual whose health care is in question. Therefore, had the physician complied with the wishes of patient and the patient subsequently died, the physician would not have been guilty of negligence.

Negligence consists of three factors that must be met simultaneously: (a) there must have been a duty to act, (b) the failure to act must have resulted in a loss for the person to whom the duty was owed, and (c) the person who had the duty must have shown heedless disregard for the life or safety of the affected person (Rozovsky 2009). Since the physician had no duty to save the patient's life against his wishes, there would have been no negligence if the physician followed the patient's wishes and the patient died.

In countries like Canada where health care is a matter of social right, the physician has an obligation to act in the best interests of the patient. However, it is now understood that acting in the best interests of the patient does not amount to making decisions for that patient (Kluge 2013). While physicians are experts in medicine, patients are experts in their values or "best interests". Because only patients can determine the trajectory of health care that fits within their definition of "best interest", decision-making power must unequivocally belong with the patient. It is on this realization that the atomic model of autonomy began to take centre stage in Canada.

Since *Mulloy v. Hop Sang*, Canadian medical jurisprudence has explicitly and uniformly moved towards the atomic model and a more patient-centered position to acknowledge their fundamental right to autonomy (*Parmley v. Parmley and Yule* 1945, *Murray v. McMurchy* 1949, *Reibl v. Hughes* 1980, *Hopp v. Lepp* 1980, *Malette v. Shulman* 1990, *Fleming v. Reid* 1991, *Ciarlariello v. Schacter* 1993).

This shift to emphasize autonomy in the healthcare setting has occurred hand-in-hand with the shift from away from a paternalistic model of the physician-patient relationship to a fiduciary standard of practice (*Reibl v. Hughes* 1980 and *Malette v. Shulman* 1990).

Under the paternalistic model, physicians practice medicine to the best of their ability and use their professional judgment to guide decision-making. In recent times, this approach has been dismissed as an ethically inappropriate mode of conduct on the account that it violates the patient's right to autonomy by compromising their ability to factor in their values. In *Malette v. Shulman*, for example, the Court of Appeal found the physician guilty of negligence and assault and battery when he administered a blood transfusion that saved the patient's life following a serious car accident. Though the patient had been bleeding to death, she had a card on her person at the time of the accident that stated that, as a Jehovah's Witness, she did not wish to receive any blood or blood products in the event of an emergency. The Court ruled that it was inappropriate for the doctor, who was aware of the card on her person, to use his values or those of the medical profession to determine what was in the best interests of the patient and contravene the patient's previously expressed wishes—even though the action would have almost certainly cost the patient her life.

The fiduciary model of medical practice, which has since replaced the paternalistic model, promotes mutual trust between the physician and the patient, recognizing patient values as the foundation upon which any health care intervention is to be conducted, while also respecting the

technical expertise of the professional (Beauchamp and Childress 2001, Kluge 2013, Picard and Robertson 2007, Veatch *et al.* 2015). The model both acknowledges the patient's right to agency and also respects the physician as a person with his or her own values and rights. This means, among other things, that physicians are generally not obligated to do something that is against their values and may refer the patient to another physician, terminating the physician-patient relationship (CMA *Code of Ethics* 2004, clauses 12, 17 and 19).

A greater appreciation for patient autonomy in the health care setting seems to have provided the ideal context in which the doctrine of informed consent could be adopted, though the understanding of autonomy was limited only to the atomic model.

The Canadian legal standard for informed consent is perhaps best captured in the case of *Reibl v. Hughes*. When the plaintiff, John Reibl, underwent surgery to remove an occlusion in one of his arteries, he was a year and a half away from retiring and securing a lifetime pension as a Ford Motor Company employee. During or immediately following the surgery the plaintiff experienced a massive stroke that rendered him hemiplegic. The Court heard that the risks attending the surgery or its immediate aftermath were stroke, paralysis, and even death. On the other hand, the risk involved with not undergoing the surgery was also stroke and resulting death. However, the surgery was not urgent in that it could have been safely postponed to a later time. Though the patient had formally consented to the operation, he had not been properly informed of the nature and the magnitude of the risk involved and stated that had he known about the gravity of the operation he would have elected to postpone the surgery until after such a time that he was able to collect his pension.

In its ruling the Court sided with the plaintiff and introduced what has since become the standard for what healthcare professionals need to procure for legally valid consent in Canada. The Supreme Court stipulated that the "informed" component of informed consent is binary in that it entails a standard of disclosure and a standard of comprehension. The standard of disclosure, or what the patient should be told unasked, is what the objective reasonable person in the patient's particular position would want to know (pp. 900-901). In other words, what should be disclosed is not what the statistically ordinary person would want to know before consenting to therapy or procedure. Rather, what should be disclosed should take into account the particular circumstances that surround the patient and that the disclosure should be tailored in a way that is sensitive to those particularities. This is often referred to as the *modified objective reasonable person* standard of disclosure.

Additionally, since English was not Reibl's first language, the Court made the distinction that being told something does not necessarily mean that it is understood. Thus, an additional standard of comprehension applies when obtaining informed consent for medical intervention (pp. 926). In order for a patient to be truly informed they need to understand the relevant information to the degree that they are aware of the options before them and understand the implications of each of those options. Therefore, the information should be disclosed at a level that that particular patient is able to grasp (adopted by the CMA *Code of Ethics* 2004, clause 22). This is known as a *subjective* standard of comprehension.

In summary, valid informed consent in Canada entails that a competent patient (a) must be disclosed unasked all information the reasonable objective person in their (social, cultural, financial, psychological, aspirational, etc.) position would want to know about their diagnosis and prognosis, and (b) they must have understood the divulged information to the degree that they are aware of their treatment options and the known risks and benefits associated with selecting or opting out of each treatment option.

In light of this, the development of Canadian informed consent, in principle, seems to be consistent with the ethics of consent under both the atomic and embedded model: it both ensures that the decision-maker's agency is maximized while at the same time ensuring that the patient's relevant cultural parameters are given due consideration.

To clarify, *Reibl* indicates that the standard of what should be disclosed depends in part on the patient's cultural values. However, in order to take the patient's cultural position or values into account on the embedded model, the information must be disclosed to the collectivity. This is because value determinations on the embedded model are performed by the collectivity as a whole. If, however, it is suspected that disclosure may involve information that could cause considerable psychological harm to the patient, the values of the collectivity may recommend family-first disclosure. Here, the family would appeal to the mutually held values of the embedding to ascertain the amount of information that is sufficient to meet the disclosure requirement of informed consent.

Because the amount of information that satisfies the disclosure and comprehension requirements of *Reibl* depends partially on the cultural position of the patient, Canada's informed consent standard appears to be sensitive to both models of autonomy—though in practice only the atomic model seems to be followed.

Empirical Evidence for the Embedded Model

While patient autonomy in the atomic model sense is central to current Canadian or Euro-American standards of informed consent, a substantial literature illustrates that embedded autonomy practices can run into difficulties in health care systems that adhere strictly to atomic standards (Akabayashi *et al.* 1999, Ellerby *et al.* 2000, Tsuchida 1992, Kaufert 1999, Gilbar and Miola 2014, Ho 2008, Stonington 2014, Hardwig 1990, Gilbar 2011, Blackhall *et al.* 1995, Winzelberg *et al.* 2005, Hamajima *et al.* 1996, Okamura *et al.* 1998, Marshall 2008, Orenals 2008). The following two cases from traditional Japanese and Canadian Aboriginal culture are provided as examples of cases that appear to reflect an embedded approach to clinical decision-making.

CASE 1. From Tokyo, Japan

A 62-year-old Japanese woman was admitted to hospital with symptoms of fever and severe back pain. Diagnostic testing revealed an advanced gall bladder cancer spreading to the liver and back. Due to a poor prognosis of survival, recommendations to forego chemotherapy or surgery were made and the suggestion was to proceed instead with a regimen of comfort measures and pain control.

The diagnosis was first discussed with the patient's husband and her son in the absence of the patient. The husband and son discussed it with the daughter and together the family requested that the patient not be told of her diagnosis. They explained that while still healthy, the patient had expressed a wish not to be told of a cancer diagnosis in the event she ever developed it.

After initial treatment for pain and fever, the patient stabilized and was competent to participate in decision-making. However, when the most responsible physician met with the patient, in the presence of the family, the physician respected that family's wishes and told her that she did not have cancer yet but, if measures for treatment were not taken, it would likely progress to cancer. In response, the patient asked for no further elaboration. Palliation efforts were continued and the patient died four months later without any apparent signs of suffering from physical pain. In the end, the physician never explicitly discussed the diagnosis of cancer with the patient. (Adapted from Akabayashi *et al.* 1999).

CASE 2. From Winnipeg, Canada

The patient, a 70-year-old Aboriginal elder who spoke only Ojibway, was admitted to hospital for a diagnostic investigation of prostate cancer. Following testing and biopsies, the patient, along with his son, met with the urologist and a cultural interpreter. The urologist explained that the patient had an advanced cancer metastatic to the bone. He explained that attempts at curative treatment would probably cause more risk and discomfort than would pain relief and other palliative measures. The interpreter began to translate the urologist's summary to the patient, but the son interrupted his explanation of the diagnosis. The son did not want the interpreter to use the Ojibway word *manitoc*, which references cancer through the cultural metaphor of "being eaten from within", in the explanation of the diagnosis. The son clarified that a direct reference to his father about his cancer will promote fear and pain and may bring death about faster. The urologist insisted that in order to give informed consent for treatment, the patient must understand his diagnosis. In response, the son stated that he will not lie to his father about the seriousness of his situation but will communicate it to him in a more gradual and indirect process. The physician, son, and other family members met again with the patient two days later to discuss palliative care options and to answer the patient's questions (Adapted from Ellerby *et. al* 2000).

Research by Tsuchida (1992), Akabayashi *et al.* (1999), Okamura *et al.* (1998), and Hamajima *et al.* (1996) into end-of-life issues in traditional Japanese culture appears to show a preference for embedded decision-making. Tsuchida notes that traditional Japanese culture is a highly integrated and contextualized society where matters of health, life, and death are viewed as a familial affair—if not the affair of the community as a whole—as much as they are viewed as the concern of the particular individual. Akabayashi *et al.* (1999) explain that the traditional Japanese view is that there is no need to be direct about delicate matters such as death, and to disclose a terminal diagnosis or poor prognosis directly to the dying patient is viewed as insensitive and cruel. The practice of non-disclosure for terminal illnesses such as cancer in Japanese culture has been documented as far back as 1984 (Matsuoka), though a more recent study by Akabayashi and Slingsby (2006) suggests the emergence of a trend towards individual autonomy in younger generations.

In the Canadian Aboriginal context, Ellerby *et al.* (2000) note that Aboriginal groups may balance the mental, physical, emotional, and spiritual domains of life differently than other cultures. They do not always believe that the patient's full participation or full disclosure of information to the patient is necessarily constructive, and it is the obligation of the collectivity to take care of matters decision-wise at the end of life, a view that may be indicative of the embedded perspective. There is a cultural perception that talking about death may trigger it to come sooner and that bad news may also crush patient hopes of surviving the disease. The patient's emotional state is sometimes seen as more important than knowing about the details of their condition and maintaining agency at the end of life (Ellerby *et al.* 2000, Kaufert and Lavallee 1999).

The embedded model is not entirely confined to the Japanese or First Nations setting. From Italy, Gordon and Paci (1997) document a range of embedded decision-making practices with regards to disclosure and truth telling to cancer patients. Through questionnaires sent out to physicians and nurses, they found that health care professionals in Tuscany did not always feel that full disclosure was appropriate for terminally ill patients, a view that also seems suggestive of an embedded perspective. While the survey deals only with professionals and does not include patients and their family, it may cautiously be taken as reflective of the values of the greater cultural community. The authors observed at the time of the study that the prevailing Anglo-American medico-legal framework, which emphasizes individual or atomistic autonomy and full disclosure for informed consent, appears to be challenging traditional Italian practices of concealment and protecting cancer patients through non-disclosure. Despite this, traditional practices of limiting disclosure and fabricating hope have continued “as many physicians, family members and patients still withhold important information from each other, often to ‘protect’ the other” (pp. 1433).

A more well-known survey from the United States provides further empirical evidence for the embedded approach (Blackhall *et al.* 1995). The study looked at the attitudes of elderly patients from different ethnic backgrounds (Korean American, Mexican American, European American, and African American) towards disclosure of a terminal diagnosis and/or prognosis as well as towards end-of-life decision-making. The findings showed that Korean (47%) and Mexican (65%) Americans were significantly less likely than European (87%) and African (88%) Americans to believe that metastatic cancer diagnoses should be disclosed to patients. They were

also less likely to believe that patients should be told terminal prognoses (35 and 48 vs. 69 and 63%, respectively) and that patients should make decisions regarding life-supporting technology (28 and 41 vs. 65 and 60%, respectively). The authors' findings suggest that Americans of Korean and Mexican extraction are more likely to exhibit a preference for embedded decision-making at the end of life.

Kaufert and O'Neil (1991), citing similar studies, note that much of the literature around informed consent seems to overlook the fact that "[i]ndividual and shared group language and culture influence the interpretation of illness and treatment options" (pp. 133). As a result, informed consent literature does not adequately consider the issue of communication between participants who do not share the same sociocultural framework and also the wider contextual factors that influence consent proceedings.

To expand on Kaufert and O'Neil's point, each individual through the process of growing up in a particular culture and learning its language, "acquire[s] a conceptual framework that limits the range of what is meaningful to [them]" (Kluge 2013 pp. 108). It is within this framework that one understands concepts of illness/health (or "best interests"). Individuals know what these terms mean to him or her—that is, what they mean in the particular sociocultural framework from which they operate. However, since different people hold different frameworks, these terms vary in meaning and significance. In addition to varying interpretations of illness, the role of the patient as it relates to a particular illness is also defined or influenced by their social context (Kaufert *et al.* 1999). Applied to the literature above, some patients may feel that in the event of a terminal illness or in end-of-life scenarios it is the family's duty to accept responsibility for their care and lead decision-making. A health care provider may violate the wishes of a patient if they act on the assumption that it is in the "best interests" of the patient to know about a terminal diagnosis or poor prognosis. This is because, of course, what is considered "best interests" depends on the values resident to their particular sociocultural framework.

As Kluge succinctly puts it, "[w]e tend to assume that because we speak the same language and because we function in the same national setting, we share the same general framework of concepts and values. But this is not necessarily the case...[s]ometimes a commonality of language and vocabulary hides a dissimilarity of perspectives and values" (pp. 108). Therefore, healthcare providers who are unaware of the different perspectives that underlie the decision-making process may, as one commentator notes, "inadvertently transgress the cultural integrity and personal dignity of some of their minority patients through well-meaning efforts to obtain informed consent in the usual patient-centered manner—contravening, in the process, the very principle of respect for persons that the doctrine of informed consent was meant to protect" (Hyun 2002 pp. 14).

It may also be worth mentioning here that simply because the literature provides examples of cultural groups that appear to favour an embedded approach to decision-making at the end of life, it does not mean that all patients from the represented cultures actually subscribe to that model. Ellerby *et al.* (2000) note that cultures and peoples are diverse so it is difficult to make generalizations. Therefore, how a particular patient views autonomy and practices decision-making in the healthcare setting cannot be assumed merely on the basis of their cultural extraction. While it is important to be cognizant of the various cultural perspectives that may be

present in health care, it does not in fact provide license to make assumptions about patient value systems. However, evidence of the embedded model of decision-making in the health care setting does suggest, at the very least, that an investigation into its ethics can find merit.

The Ethics

A. The Relationship between Personhood, Autonomy, and Decision-Making

On the atomic view, the person is seen as a discrete and sovereign unit in a larger social milieu. Since autonomy is here associated with the individual, decision-making falls within the domain of the individual. The embedded model, on the other hand, perceives the person as an entity that cannot be separated from their greater familial or social structure. Autonomy is thus not associated with the individual person-unit but distributed over the collectivity. Because autonomy is shared on this model, decision-making is a function of the collectivity as a whole.

This way of rendering the two models suggests that the notion of autonomy presupposes a certain conception of the person. However, the traditional Western development of the Principle of Autonomy seems to have proceeded primarily on the atomic view. For instance, on the Kantian account of Autonomy each individual is regarded as a rational agent. Due to this independently held rationality, each individual has the capacity for self-government—which is to say that each individual has the capacity to make decisions over their own self (Kant 2012).

While this may be true, simply because one has the potential for independent self-government does not mean one must actualize this potential—or at least this requires a separate argument. Because the right to Autonomy resides with the individual, and because rights are justified claims that the right-holder may choose to either exercise or refrain from exercising in a certain situation, the individual may choose whether or not they wish to utilize their capacity for independent self-government. However, the decision of an individual to refrain from exercising their right to self-government is the decision to subordinate their right to Autonomy to the rights of others in their embedding and thereby engage in the embedded view of autonomy. Therefore, though the traditional development of Autonomy may have proceeded on the atomic view, the Principle appears to accommodate both versions of autonomy.

If one were to then divorce the Kantian notion of Autonomy from any preconception of personhood, what is left is the idea of Autonomy as a *model* of decision-making. That is, rather than being interpreted exclusively as the right of the individual to self-government, the Principle of Autonomy can be expanded and understood as the right of a decision-making body to make decisions over itself. On this construal of the Principle, the decision-making body may be either the individual or the collectivity.

As was mentioned earlier, essential to either model of decision-making—that is, for decision-making as opposed to merely reacting—is information. In order for a decision-making body to competently make decisions over itself, the decision-maker needs information about the nature of the circumstances that require the decision as well as information about the different, feasible courses of action. Therefore, while the “decision-maker” or the “person” may differ on the two

models (i.e. the individual vs. the collectivity), the notion of Autonomy remains the same—they both need to make decisions over their person, where making a decision entails choosing from among options of which one is aware on the basis of the information that is available to them.

Reiterated in slightly different terms, the underlying logic of the Principle of Autonomy is conserved on both models of personhood. The difference is simply that how autonomy is expressed varies depending on who makes the decisions and hence needs the information. In light of this, the embedded model appears to be consistent with the ethics of Autonomy, though in practice it plays out differently.

That being said, it is important to note that because the right to Autonomy is inherently attached to the rational agent that is the individual, the crucial decision of how to view and practice autonomy also belongs to the individual. Consequently, though an individual can choose to forgo the atomic view of autonomy for the embedded view, this choice fundamentally belongs to the individual.

B. Informed Consent on the Atomic Model vs. the Embedded Model

Despite the fact that individuals may differ in how they make decisions, they may still reach the same decision output. In the end-of-life case examples, patients on either model may not wish to be told certain information about their medical status. The cultural views of both patients may be that values of preserving of agency can give way to values of minimizing psychological harm at the end of life.

On that account, what really seems to be at issue in these end-of-life examples is whether a patient can give consent in the absence of adequate or appropriate information. On the atomic model, when a patient prefers not to be told certain information about their medical status but still wishes to receive treatment, the request is commonly referred to as “the right not to know”.

The right to informed consent in Canada involves a standard of disclosure and a standard of comprehension (*Reibl v. Hughes*). This means that the patient has the right to know information about the nature of their medical condition as well as the right to know about the medical options that are reasonably available to them.

Rights, as one may recall, are justified claims that one is free to either exercise or waive at one’s discretion in a given situation. Thus, if a patient does not wish to be informed of certain information pertaining to their health, the patient can generally refrain from exercising their right to know and choose to consent in ignorance. In other words, the patient may waive their right to know certain information about their health status but may still retain the right to know about the options available to them. Any decision rendered in the absence of full disclosure, however, would not be informed.

Consent in the absence of adequate or appropriate information receives a different analysis on the embedded model. Here, the patient is not waiving their right to information about their medical status. Rather, since autonomy and hence decision-making is a function of the

collectivity as a whole, this right is extended to the collectivity. Because the collectivity is the decision-maker, and because informed decision-making requires knowledge about the patient's medical position, the right of access to patient medical information belongs to the collectivity as a whole. Depending on the particular circumstances at hand, such as those where there is concern that disclosure may include information that could cause the patient greater harm than the harm from exclusion from collective decision-making, the collectively determined values of the embedding may prescribe family-first disclosure of information. The family draws on the mutually accepted values of the collectivity to determine how much information the patient wishes to know before consent. This adjusted information is then disclosed to the patient and proposed medical treatments or therapies are accepted or rejected on this information.

On both the atomic and embedded views of the person, autonomy is still central except that autonomy is understood differently. Therefore, the schema of informed consent remains the same—the amount of information sufficient for consent depends on the patient's particular position and disclosure is conducted at a level that the decision-maker can understand—it is just that it results in different practice. As a result, it does not appear that the Canadian informed consent standard requires revision to incorporate embedded models of decision-making. Properly interpreted, the *Reibl* standard allows patients to consent without adequate or sufficient information on either model.

C. Values in Decision-Making

The practical fallout of the two models for informed consent reveals that in addition to information there is another component equally important to decision-making, which is values. Values are normally regarded as the drivers of human action in that they serve as the underlying purposes or forces that actually motivate one to make a decision (Gewirth 1987).

Whereas the view of the person determines *how* decisions are made, values determine *what* decisions are made. On the atomic model the decision-maker is the individual. Depending on the individual's values, the individual may decide in a particular medical scenario: (a) to make their health care decisions independently, (b) to make their health care decisions in consultation with others, or (c) to autonomously delegate decision-making authority to others. Therefore, even on the atomic model the family may participate in decision-making and disclosure of information could also be family-first.

On the embedded model, however, the decision-maker is the collectivity. Depending on the values of the collectivity, the collectivity as a whole may decide that in a particular medical context: (a) that the patient use embedded values to make their health care decision independently, (b) that the collectivity make health care decisions on behalf of or in consultation with the patient, or (c) that decision-making authority be delegated to a specific member of the collectivity. Individual decision-making is, thus, also possible on the embedded model.

The fact that it is possible for the family to participate in decision-making on the atomic model and that the patient can even make decisions independently on the embedded model raises an important point. The point is that independent decision-making without sufficient consideration

of the rights of others in one's embedding (the specific type of atomic decision-making will be discussed in Part II of this thesis) and collective decision-making that excludes the patient (the specific type of embedded decision-making examined in this part of the thesis) represent the two extremes of decision-making. In reality, decision-making practices likely fall on a spectrum somewhere in between these two extremes.

The purpose for concentrating on the two extremes of the atomic and embedded models of decision-making should therefore not be interpreted to suggest the need to classify patients as either atomic or embedded in medical practice. Rather, the purpose for narrowing the focus to the two extremes is to more easily illustrate the differences (and similarities) between the different decision-making models observed in health care and hence provide a starting point for ethical analyses.

The fact that literature discussions of alternate views of autonomy are for the most part confined to terminal or serious illnesses demonstrates this point. The literature's focus—intentional or unintentional—on end-of-life scenarios suggests that there may be restrictions on the extent and scope of embedded models that exclude patients from collective decision-making and that there is likely a gradient of the appropriateness for this type of decision-making. It is, in other words, possible that the ethical acceptability of the embedded model that excludes the patient in health care decision-making increases as the gravity of the medical situation increases.

This gradient could be a topic for further academic inquiry. Yet, before attempts can be made to provide a sketch of this harm/risk threshold or gradient, there is a more fundamental ethical problem facing the embedded model that requires resolve. The problem centres on the ethics of values.

The issue is that inclusion of *culturally based* values in decision-making for informed consent may have some intuitive appeal in the sense that it is a relatively straightforward solution and appears to be consistent with the push for cultural sensitivity. However, the inclusion of values merely on the basis of a culturally expressed desire has been met with some reservation (Hyun 2001, 2002). This is because cultures, both Western and non-Western alike, can have unjust customs and values, and traditional or historical acceptance of a particular set of values by a cultural group cannot alone provide justification for those values.

Decision-making on the embedded model tends to use culture-bound values, as value determinations are performed by the collectivity. Since the individual chooses the values on the atomic model, the atomic model may not appear to use culture-bound values on first appearances. However, this may not necessarily be the case. Generally speaking, atomic individuals tend to accept the values that are present in their embedding—the values that are considered acceptable by their society (Raz 2007). Therefore, when an atomic individual subscribes to the value-system of their particular sociocultural group, the atomic model does not appear to be any different from the embedded model with respect to the values that are used and represents an overlap between the two models.

When the collectivity generates the values that are adopted by its members, it prompts questions such as whether its individual members freely accept these values or even whether the members

freely concede to the idea of the collectivity as the decider-maker (Hyun 2002), along with the corollary question of whether the decisions of an individual can truly be considered “autonomous” (a question that falls outside the scope of this thesis).

Collectivities—whether they are the family or the community—are generally regarded as nurturing environments where individuals can find safe harbour and social acceptance without much effort (Margalit and Raz 1990). Though families and cultural groups tend to be viewed as accepting, open, and safe structures where each member is equally valued and respected, this is not always the case. As was mentioned earlier, families and cultures of both Western and non-Western extraction can have unjust beliefs and practices (Sen 1995).

If an individual member of a collectivity chooses the values of their embedding—values that provide the basis for determining who should assume decision-making at the end of life—simply because to do otherwise may strain their relationships within the collectivity and put their acceptance in the group in peril, then the individual’s freedom and the authenticity of their decision is undermined. Additionally, some patients may not even recognize or understand that they have other choices because other options may not exist or be workable within their particular socio-cultural framework (Hyun 2001). When there is no room for alternative views and values within a society, its members have no choice but to accept the prevailing views or values. And where there is no freedom of choice, there can be no genuine exertion of autonomy (Kant 2012).

An example may help to further illustrate this point. A certain cultural group may be of the view that elderly patients or patients whose health care is complex and cumbersome should hasten death by withholding consent for life-saving or -sustaining medical care so as to minimize the burden on the family. Patients on either model who accept these values may opt for palliation measures over other proposed treatments.

The concern in this example is whether the patient’s wish for palliation and rejection of other life-prolonging treatments are genuine or whether the individual has been unduly pressured to accept this particular cultural value. An additional concern is whether the cultural value is ethically acceptable, since the value may be treating members as mere objects to be used towards a sociocultural end (that can be disposed of when their usefulness to the group diminishes) and not as persons. For instance, if the cultural collectivity views individuals who prolong life as selfish and negligent in their duty to advance the greater good of the family, the patient may feel compelled to refuse medical care. The patient’s socio-cultural framework may not support the treatment option in that the selection of this option may elicit condemnation or rejection by the family and/or community. Alternatively, the patient, because of their cultural conditioning, may be unable to recognize treatment as a possible option.

Restrictions on the options that should reasonably be available to an individual violate the Principle of Autonomy. But, how exactly does one determine whether patient wishes are made in freedom-limiting conditions? This problem is magnified on the embedded model. Namely, how can it be determined whether the values of embedded patients are freely held when the values, by the very nature of the model, are determined by the collectivity? This then represents a

fundamental problem for the medical profession and society in general and the inclusion of cultural preferences in informed consent needs a way to appropriately circumvent this concern.

D. Competence

In order for cultural preferences to be ethically permissible for use in health care, the patient must genuinely accept these views, which is to say that they must be authentic to individual (Hyun 2001) and used competently. While the term “competence” is used by many different disciplines (e.g. psychology, law, and sociology), each context has its own precise definition of the term.

In ethics, competence has four distinct parameters: conceptual, emotional, valuational, and volitional (Kluge 2013). Each of these parameters, which are briefly described below, must be conjointly met for a patient to be considered competent.

Conceptual

The parameter that is most commonly associated with competency is conceptual competence, which has to do with an individual’s intellective and reasoning abilities. Namely, it is the ability of the patient to understand which information is relevant to the decision that is to be made and the ability to use that information to foresee the reasonable consequences of the decision. However, evaluating a person’s reasoning ability is not a straightforward matter. This is because conceptual competence can be broken down into several distinct categories of its own: cognitive, inferential, and mnemonic.

First, cognition refers to the ability to understand or grasp the relevant information. In the health care setting, or in any setting for that matter, cognition has nothing to do with the patient’s level of education. It merely involves the ability of the patient to process and understand relevant information, provided that the information is disclosed at a level that matches the patient’s particular level of training or education in the subject in question.

Second, inference refers to the ability of the patient to piece the provided information together and draw appropriate conclusions. By “appropriate conclusions”, one means to say that the conclusions drawn by the patient are similar to those that would be drawn by another reasonable member of society furnished with the same information.

Finally, there is the mnemonic aspect. This consists of the patient’s ability to remember or function intellectually beyond the present moment. This is important because when information is presented to an individual, it is not significant on its own. Instead, it gains significance once that information is personalized—that is, filtered through one’s memories and experiences and extended to one’s expectations of the future. Examples of patients who may be mnemonically compromised are dementia patients or others suffering from similar forms of neurodegeneration.

Emotional

The second component of competence is emotional competence. This component recognizes the psycho- socio-logical context of human persons (i.e. the context in which

human interactions are set and relationships are forged). Because of this context, the choices one makes are not purely cognitive in character but also involve emotions that are derived from one's interactions/relations with other persons. Emotional competence has two parameters: appropriateness and strength. Appropriateness, as is evident by term, refers to the propriety of an emotion in a given situation. For instance, if a person laughs hysterically at news of the death of family member, the person may be experiencing what is sometimes known as "emotional shock". The ability of a person to make a competent decision at that time is likely jeopardized. As to strength, an individual may hold an appropriate emotion, such as grief in the preceding example, but when the emotion is experienced very strongly it may also interfere with their ability to reason and fully understand the implications of their decisions, rendering the person momentarily incompetent.

Valuational

Valuational competence refers to the system or framework in which the values of the individual are held. However, simply holding a particular set of values does not in itself make one valuationally competent. In order to meet this condition, the values must exist in a value framework that is more or less logically consistent, the values must be relatively stable, and the values must be authentic to the individual.

First, in order to make reasoned decision, it is necessary that one's values be relatively consistent with one another. That being said, there are some circumstances where a valuationally competent person can hold conflicting values, such as the individual that generally values life over quality-of-life but feels that once quality-of-life slips below a certain level, maintenance of quality-of-life can supersede values of continued existence. In such cases, the individual is considered valuationally competent if their conceptual framework has a mechanism for rationally balancing conflicting values.

Second, there is the stability aspect. Individuals can competently change their values over time. However, the individual's value framework has to be relatively stable in that it cannot change dramatically from one moment to the next; otherwise, the individual is unable to extend the implications of a decision beyond the immediate present. Third, competently held values must be authentic to the individual in that they are not conditioned by others to accept those particular values.

Volitional

Volitional competence is loosely defined as the ability of a person to hold authentic values and to act on those values. This ability can be impaired in one of two ways: by internal or external parameters that limit an individual's freedom. Internal parameters may include such things as addiction or mental illness, where the individual can make a rational decision but is unable to act on that decision because of their underlying condition (e.g. an alcoholic makes a rational decision to quit drinking but cannot act on that decision because of the biological nature of their addiction). External parameters that limit freedom are physical coercion or undue enticement, where an individual is pressured in a physical sense to accept a particular decision. Situations where coercion is most commonly recognized are in power or dependency relationships. A subtler and hence frequently overlooked act of coercion is when the range of options that is otherwise available to an individual is limited

because of their social environment. When an individual accepts a value, simply because alternative value options do not exist in their particular society or if alternative values cannot be incorporated into the functioning of their particular society, then the individual has no choice but to accept that value.

The parameters of volition indicate that competency does not depend solely on the attributes of the individual. Competency also requires that the individual is first in an environment where there are no unjust restrictions on the range of options that are reasonably available to the individual. As Hyun puts it, “the actions and decisions of autonomous persons must be authentically ‘their own’ and not the products of wholesale indoctrination or manipulation” (2002 pp. 16).

Hyun’s article raises some further challenges that may arise when determining whether an individual is volitionally competent (2002). For instance, when there is suspicion that a patient’s values may be inauthentic, how does one access or gather the relevant information about their historical or social context to identify volition-limiting parameters without offending the individual and/or the collectivity? Supposing it could be determined that the individual’s values are inauthentic, how can this be explained to the individual, given that they may not be aware that their right to autonomy has been violated (Sen 1995)? When this is the case, denying the patient their express wishes may frustrate the patient, for they may feel that their “autonomous” adult wishes are being denied (Hyun 2002).

It may even be tempting in the latter scenario to give in to the wishes of the patient, lest one be perceived as culturally insensitive or morally imperialistic. However, cultural sensitivity is important precisely because it respects the fact that persons, in the genuine expression of their autonomy, come to see themselves differently as persons. Therefore, cultural sensitivity is to be lauded when it respects the autonomous wishes of patients—whatever those wishes may be and however different they may be from mainstream Canadian culture.

On the other hand, to unconditionally uphold the cultural wishes of patients would be “culturally sensitive” but in a perverse sense. Instead, it may be argued that to act on the wishes of the patient that are known or suspected to be inauthentic is to actively participate in the perpetuation of an unjust practice. It would be ethically irresponsible for health care practitioners, the medical profession, and Canadian society as a whole to hide behind the veil of “sensitivity” in such cases and not assist patients in taking advantage of and benefiting equally in the rights endowed to all human persons, including the fundamental right of how they wish to view themselves as persons. Strictly speaking, it would be to punish patients for merely being born into their particular socio-cultural environment—something entirely out of their control.

However, the question of how to elucidate whether an individual’s values are authentic to them—whether persons are truly “autonomous” or if there is really such a thing as “free will”—remains a perennial problem in ethics and philosophy in general. This issue may be irresolvable and, as was mentioned earlier, reaches well beyond the purview of this study. Yet, in the practical world, decisions of whether or not to act on the expressed wishes of patients need to be made and these decisions require sensible and workable solutions.

In the effort towards this end, Hyun suggest that an individual's authentic decisions are those that are made in conditions where it is realistically possible for them to critique their available choices. This does not mean that individuals actually need to critically reflect on the approval of their views or engage in any sort of sophisticated philosophical thinking for them to be authentic. Hyun notes that if serious critical reflection were required for autonomy, autonomy would be available only to philosophers and the academically inclined. Instead, he suggests that authentically held values are those that are internalized in an environment where the individual has access to alternatives that are sensibly available to others who are no more able-minded than them. Reiterated in slightly different terms, individuals in their acceptance of a certain view must be in a position where they are able reflect on it and have the option of rejecting it for other possible views *should they ever wish to do so*.

Applied to the informed consent context, if there are no reasonable grounds to suggest that a patient's waiver of informed consent or acceptance of an embedded model of decision-making was conducted in an environment with unjust social constraints, and was competent in the other relevant respects when their values were accepted, then the decision can be considered a genuine expression of the individual's autonomy. Health care providers and society at large would therefore have a duty to honour the autonomous wish of the individual, regardless of why the individual holds those particular values and even in the absence of critical reflection on their values.

E. The Embedded Model and its Limitations

Earlier it was suggested that the embedded model might not be appropriate for all decision-making in the context of health care. Instead, there is likely a gradient or sliding scale of defensibility, where the defensibility of the model increase as the seriousness of the situation increases. This section touches on some ethical principles that may be important to establishing such a gradient.

i. Beneficence/Non-Maleficance

In order for the embedded model to be ethically defensible, it must be in keeping with the Principles of Beneficence and Non-Maleficance. That is to say, it must be reasonable to believe that embedded decision-making will maximize the good and minimize the harm to the patient.

Because individuals other than the patient are involved in decision-making on the embedded model, Hyun notes that the ethical acceptability of the embedded model has additional requirements that move the focus away from the patient and to the collectivity involved in the decision-making (Hyun 2002). Namely, the collectivity must meet the standards of proxy decision-making: they must be competent and willing to assume decision-making.

The collectivity must also be well motivated (Hyun 2002). It is probable that patient absence from collective decision-making is permissible only if participation requires disclosure of potentially harmful information, such as end-of-life cases where it can reasonably be inferred

that disclosure of a terminal illness may cause the patient more harm than the harm that may be incurred from exclusion from decision-making. The collectivity should be able to demonstrate how the decision, in their view, advances the good or minimizes the harm for the patient. For instance, the decision to withhold information of a terminal illness can be defended on grounds of preventing a greater psychological harm to the patient. It is unclear, however, how decisions of non-disclosure could be reasonably defended in cases such as informing the patient that they are not ill, they are cured, they are pregnant, etc.

The notions of harm and good have additional implications. Just as Autonomy is interpreted differently on the two models, the Principles of Beneficence and Non-Maleficence may also materialize differently on the distinct models. This is because the notions of “good” and “harm” are value-laden, meaning that they are subjective concepts. Under Autonomy, persons have the right to choose for themselves what constitutes the good/harm. Since there are different models of personhood, how values and the consequent notions of the harm and the good are chosen will also vary. On the atomic model, the individual determines what they consider to be the harm and the good for their self. On the embedded model, the collectivity as a whole determines what comprises the harm/good for its individual members.

Not only can different sociocultural groups differ in what embodies harm, they may also differ in how they balance harms; that is to say, they can differ in what they perceive to constitute a greater harm. As a result, individuals and collectivities can vary in how they balance individual rights with societal obligations in a given situation.

While the Principle of Autonomy prescribes the minimum standards to which rights are subject (the equal and competing rights of other individuals), embedded individuals at the end-of-life examples may place a greater emphasis on their obligations to the collectivity than is required by these standards. In other words, they may feel that the rights of the collectivity outrank the rights of the individual in such circumstances.

Embedded (as well as atomic) individuals have the right to set the limits of their own autonomy, so long as the limits satisfy the minimum standards set out in the Principle of Autonomy. Under Beneficence and Non-Maleficence, the aim to minimize harm to members or to advance the greater good of the collectivity can therefore be legitimate motivations to withhold information from the patient on the embedded model (Hyun 2002). However, this aim is subject to a second principle: Equality and Justice.

ii. Equality and Justice

Competent Persons

Under Beneficence and Non-Maleficence, the goal of advancing the good of the collectivity can be a legitimate aim of the embedded model; however, applications of the embedded model must take care to ensure that they are in compliance with the Principle of Equality and Justice.

Unless there are justifiable grounds to do otherwise, Equality and Justice on the embedded model entails that each member of the collectivity should be treated the same and should have access to

the same options and opportunities that are available to other members in that particular familial or cultural collectivity. In other words, the collectivity should recognize the equal worth of each member and should view each deserving of equal respect and dignity.

This line of reasoning can be extended further still. Familial or cultural collectivities are themselves embedded in a greater national collectivity, which is itself embedded in a larger global collectivity. Equality and Justice therefore seem to entail that members of smaller collectivities should be entitled to the same rights and freedoms that are afforded to all members of humanity.

This notion is mirrored in the *Universal Declaration on Human Rights*, which stipulates that “all human beings are born free and equality in dignity and rights” (Article 1) and that these rights are inalienable from the individual. Since the *Declaration* ascribes these basic rights to the individual and not the collectivity, it appears to reflect an atomic view of personhood. Article 27 further states that “everyone has the right to freely to participate in the cultural life of the community”, the operative word here being “freely”. While individuals have the right to associate in culture, this right unequivocally belongs with the individual. Therefore, if an individual freely chooses to participate in an embedded culture, this right is guaranteed by the *Declaration*. To ascribe the right to culture to collectivities instead of individuals would be to defeat the very purpose of the *Declaration*, which is to offer individuals protection from potentially unjust collectivities—whether the collectivity is the family, the cultural community, or the state.

The atomic reflection of human rights in the *Declaration* is, thus, consistent with the ethics of the embedded model as it was previously introduced under the Principle of Autonomy. Namely, since the right to Autonomy is inherently attached to the rational agent that is the individual, the fundamental decision of how to view and practice autonomy also belongs to the individual. Moreover, the Courts also seem to echo this construal of Autonomy in *R v. Big M Drug Mart* (1985) when they comment “liberty does not mean mere freedom from physical restraint. In a free and democratic society, the individual must be left room for personal autonomy to live his or her own life and to make decisions that are of fundamental personal importance” (pp. 368).

Incompetent Persons

The Principle of Equality and Justice gives rise to another issue. Namely, if the embedded model is available to persons with capacity, justice demands that the model must be equally available to persons who lack capacity, such as children or cognitively impaired individuals (*Charter* s. 15).

Due to concerns of unjust cultural or familial views and values, the use of an embedded model of decision-making by individuals with capacity was argued to be subject to the condition that the model is authentic to the individual and is accepted competently. But, if Equality and Justice entail that the right to embedded decision-making applies equally to persons who lack capacity, how is it possible to provide incompetent persons access to the embedded model while at the same time ensuring that this vulnerable patient group is protected from unjust cultural or familial structures?

Hamilton Health Sciences Corp. v. D.H. (2014) provides a case example of this equity issue. The case was in regards to J.J., an eleven-year-old First Nations patient diagnosed with acute lymphoblastic leukemia. The Court found that there was insufficient evidence to suggest that the patient was capable of making her own decisions with respect to the treatment of her leukemia. J.J.'s mother, who was also her substitute decision-maker, was deeply committed to her aboriginal culture and wished to pursue traditional means of treatment in lieu of the proposed chemotherapy. With chemotherapy, however, health care providers assessed J.J.'s probability of survival to be approximately 90%. At the rejection of consent to chemotherapy, the hospital and the local children's aid society submitted an application to an Ontario Provincial Court to overrule the mother's decision under the *Child and Family Services Act*. In the end, the presiding judge dismissed the application and permitted the mother to use her cultural values to determine what was in the "best interests" of the patient.

In the ruling, the judge replaced the individual rights and freedoms of the child with the cultural rights of her proxy but did not provide justification for the substitution beyond the mere cultural preference of the mother. The decision, therefore, neglected to consider the appropriateness of the embedded model in the obtaining circumstances. In other words, it failed to acknowledge—let alone offer any guidance on—the limits of the embedded model of decision-making.

Another case involving the rights of children and the rights of their cultural embedding found its way up to the Supreme Court of Canada in 2009 (*A.C. v. Manitoba*). A.C. was admitted to hospital when she was 14-years-old with internal bleeding caused by Crohn's disease. Because she was a Jehovah's Witness, she refused the receipt of blood. Her parents, who were her substitute decision-makers, were also devout practitioners of the faith and agreed that this decision was in the best interests of the child.

In *A.C.*, the Supreme Court found that when there is not enough evidence to suggest that a child has reached a level of maturity where they can competently make the medical decision in question, there could be no duty to respect their decision. The Court also sustained the substitute decision-maker may not use their own values, whether they are culturally based or not, to determine what is in the "best interests" of the patient. When determining what is in the "best interests" of the patient, the patient's substitute-decision maker must use the *competently-held values of the patient* to determine if the acceptance or rejection of a proposed treatment measure is in the patient's best interests when the patient has competently-held values.

The problem in both A.C.'s and J.J.'s case was precisely the fact that the patients had not yet developed their value systems and thus did not have competently held values. If A.C. and J.J. have not yet developed their value systems and the substitute decision-maker is not ethically permitted to use their own values, on what values ought the medical decisions of children be made?

The Court in *A.C. v. Manitoba* ruled that when the values of the patient are unknown or have not yet been developed, the appropriate decision is the one made on the objective reasonable person standard. On this standard, the values used in decision-making are those that another reasonable member of society would use.

The ethical basis for the reasonable person standard is that though children are likely to going to acquire the values of the familial or cultural unit into which they are born and raised, this does not mean that they will invariably do so (Kluge 2013). The fact that a presently incompetent child is a member of a family/group that holds a particular cultural view or value neither provides license to assume that the child will hold that view in the future nor does it provide license to impose the value on the child. It may be politically or socially convenient solution, but the ethics do not seem to support such a thesis. Children, in other words, should not be discriminated against just because they—through no choice of their own—were born into a particular cultural or subcultural community.

Nevertheless, an argument that can be raised against the reasonable person standard is that it appears to reflect the atomic perspective. It is probable that the decision made by a “reasonable person” from Canadian society is going emphasize the importance of individual or atomistic autonomy. This is because the objective reasonable person is the statistically normal person in society, and in a country where there is great reverence for the individual rights and freedoms of the human person, the reasonable decision is likely going to be one that aims to preserve these atomic values. One may therefore wonder whether the embedded perspective would ever be considered “reasonable” on the reasonable person standard in Canada and thus made accessible to incompetent persons.

Though the reasonable person standard may express the atomic view, this does not mean that it will always dismiss the embedded model of decision-making. This is because an appropriately applied standard would give due consideration to Beneficence and Non-Maleficence. That is to say, a “reasonable” decision would take into account both the treatment’s chances of success as well as any psychological harm that may be incurred to patient from forcible treatment and denial of the right to follow their developing view of autonomy (*A.C. v. Manitoba*).

The right of children to follow a developing embedded view of autonomy in itself raises an important issue. Namely, the embedded model of autonomy or decision-making generally involves the participation of the collectivity as a whole, including the patient. Members of the collectivity together decide on matters of values. However, incompetent patients such as children are limited in how much say they have in collective decision-making and hence value determinations. While a mature seventeen-year-old may be able to actively engage in collective decisions of views and values, a five-year-old cannot participate to the same degree. Therefore, the permissibility of the embedded model for children may be commensurate with the level of ability of the child to meaningfully partake in collective decision-making. This point seems agreeable with sentiments expressed in *A.C.*, which state that the best interests standard “operates as a sliding scale of scrutiny, with the child’s views becoming increasingly determinative depending on his or her maturity” (p. 2).

Children such J.J. and A.C. who are found to lack the degree of capacity necessary for the decision at hand have not yet had the opportunity to determine how they wish to view themselves as persons. They can only do so if they can grow older. One, however, must be alive in order to grow older. Hence, the Principle of Autonomy seems to entail that the appropriate or “reasonable person” decision is the one that grants children this opportunity (Kluge 2013).

Under Autonomy, every human person has the right to self-determination, including the fundamental right to develop his or her own conception of the person (and thereby the basis of their values). This, as was argued earlier, is also reflected in the *Universal Declaration of Human Rights*, which stipulates that all human beings are endowed equal in rights and that these rights are inalienable from the person. Though the reasonable standard may reflect the atomic perspective, the standard is arguably defensible in the sense that it does not function to impose the atomic view on incompetent children. Rather, the significance of the atomic execution of the standard is that it encapsulates the basic principle that underwrites Autonomy, which is that one's right to determine how one sees oneself as a person and hence views autonomy belongs firmly with the individual.

Therefore, while equality and justice would appear to indicate that incompetent children have a right to embedded decision-making, this right is not absolute and can be justifiably overruled by the duty to protect a more fundamental right—the right of children to determine for their own whether indeed they view themselves as embedded.

Equality and Justice, construed differently, can provide further support for the reasonable person standard in this context. This is because health care as a social right is based on this Principle in that an equitable society has a duty to minimize health-based differences among its members so that each may take equal advantage of the opportunities available within that society. The Principle accordingly places a duty on part of the substitute decision-maker or the embedded collectivity to treat the presently incompetent person as justly and fairly as possible. This, however, does not mean to treat them like any other child in their family/community, as family or cultural communities can have inherently unjust structures. Rather, fairness means allowing the child to receive the same health care treatment any other child within society is likely to receive.

“[S]ince in Canada health care is a matter of social right, the standard of what constitutes a level playing with respect to health care decisions is not what is equitable within a particular family unit but within society as a whole. Therefore, while a competent patient may decide to depart from the social norm in matters of values, a substitute decision-maker cannot, in equity, assume that someone who has never been competent has departed from that norm or will in fact do so” (Kluge 2013, pp.148).

All in all, being a member of an embedded community should not reduce a child to something less than a person, and it seems that there are limits to the extent that the values of a child's family or cultural community may overrule the values of their larger national society. As was previously noted, the collectivity in which the child is embedded is itself embedded in the larger collectivity of Canadian society. In some cases, the values of the latter collectivity may justifiably overrule the values of former.

This concept is not novel and is comparable to the situation that is faced by nation states that are embedded in the global society. Though nation states have the right to rule within their territorial boundaries, a right that reflects an atomic view of the autonomy of groups/states, their governance is subject to the condition that they do not unjustly impeach on the basic rights and liberties of individuals who fall under their rule. In the end, the global values articulated in the

Universal Declaration of Human Rights can take priority over the values of the individual sociocultural group—regardless of whether that group is the nation, the cultural community, or the family—when it comes to fundamental rights (see Article 30).

The above discussion of incompetent persons has only dealt with one sub-group: children. There still remains the issue of rendering the embedded model of decision-making accessible to congenitally incompetent persons—persons who have never been competent and are not expected to be competent in the future. Permanently incompetent persons present a more complex problem because unlike children who will eventually grow older and become competent, permanently incompetent persons will not. Such persons will never be able to determine for themselves how they view themselves as a person. For incompetent children, the reasonable standard takes into account the fundamental right of children to grow and develop their own views and values. But, how can the reasonable person standard be used for persons whose values were never or will never be known? An ethically acceptable informed consent policy will need to appropriately address this issue.

Conclusion

A number of clinical research studies illustrate that different patients practice different models of decision-making for informed consent, especially at the end of life. It is argued that both the atomic and embedded model can be justified under the Principle of Autonomy; however, their employment is subject to condition that the right to choose how one views personhood and hence autonomy belongs inescapably with the individual. It is for this fundamental reason that the atomic views encompassed in the reasonable person standard and the *Universal Declaration of Human Rights* are ethically justified.

Existing Canadian case law on informed consent, when properly read, allows patients on both models to consent in the absence of appropriate or sufficient information. On the atomic model, the individual is the decision-maker. Therefore, the right to information about one's health status and the right to information about one's available medical options belong with the individual patient. As a result, the patient may waive their right to their medical information and choose to consent in ignorance.

The decision-maker on the embedded model, on the other hand, is the collectivity. Thus, the right to information necessary for decision-making on this view belongs to the collectivity as a whole. Under a limited set of circumstances, such as those that involve death and dying, family-first access to patient information may be permissible. The family, drawing on the mutually held values of the collectivity, determines how much information is sufficient for the patient to consent to medical intervention.

Since the two models differ on how the notion of the person is understood, the models give rise to different ways patient-relative information is accessed in informed consent. This investigation has dealt only with the right of competent patients to waive their right to informed consent or practice the embedded model of decision-making. However, since s. 15 of the *Charter* outlaws policies that discriminate on the basis of age and disability, a legally (and ethically) acceptable

policy integrating the embedded model into clinical practice will need to address the rights of incompetent persons, while keeping in mind the vulnerability of such patients.

PART II

Cultural Variations in the Notion of the Person and their Implications for the Duty to Warn of Hereditary Risk

Introduction

The first part of this study has dealt with how the different notions of personhood—embedded vs. atomic—affect decision-making involving information whose health implications are generally confined to the individual patient. The particular emphasis was on access to patient information for informed consent. This second part of the thesis is concerned with how the distinct models of personhood affect decision-making involving information that may have health implications for others in addition to the individual patient. This issue is examined in the genetics context, specifically as it relates to the individual's right of control over their genetic information.

Because genes are the basic units of heredity, the genetic make-up of an individual can reveal information not only about that particular individual but also about members of their consanguineal family. In some situations, a patient's genetic status may show that their relatives are at risk for carrying a genetic mutation that could have serious or deleterious implications for their life or health. When this information is brought to the attention of the patient, a question that surfaces is whether or not the patient has an ethical obligation to apprise relatives of this risk.

On the atomic model, a case against sharing patient genetic information may be advanced from privacy. The right to privacy is grounded within the ethics of Autonomy, as Autonomy is the right to self-determination and the right to control over oneself includes the right to control knowledge about oneself. Consequently, if a patient prefers to keep their genetic information private, the patient may generally refrain from sharing their information with others.

However, even on the atomic model the right to Autonomy is not absolute and must be balanced against competing duties. For instance, individuals have an obligation under the Principle of Non-Maleficence to minimize harm to others when possible. Since the failure to warn could result in harm to relatives, it is arguable that individuals can have a duty to share their information with the potentially affected family. A key problem on the atomic model, therefore, appears to be how to reconcile the patient's right to privacy with the patient's duty to minimize harm to those consanguineally related to them.

While the right to privacy is understood easily enough on the atomic perspective, it is not so well understood on the embedded model. This is because privacy seems almost antithetical to the embedded concept in the sense that it can be thought of as the ability to detach or seclude the unit that is one's person from the social webbing within which it is embedded.

On the embedded model, health care decisions are made by the collectivity as a whole. In order for the collectivity to participate in the embedded model of decision-making in the medical genetics clinic, the collectivity would first need to know about the patient's genetic status, which seemingly defeats the notion of privacy. It also raises the question of what the duty-to-warn would look like on this model, supposing such a duty exists.

Because genetic information in Canada is currently treated as private and under the control of the individual—a treatment that mirrors the atomic view—there is uncertainty about whether the patient has a duty to minimize harm to relatives through warning. Supposing that the patient does have a *prima facie* duty to share their genetic information, the next question is whether this duty can override the patient's right to privacy. However, while the tension between privacy and warning appears central to the atomic model, it does not appear to be as central to the embedded model.

Due to their different understandings of the individual, the two models may differ in how they handle an individual's genetic information, and this may in turn give rise to different rights and duties in the genetics setting with respect to the issue of sharing genetic information. As a result, this section of the thesis examines the ethics of the “duty to warn” separately under the two models.

The Embedded Model

On the face of it, the embedded notion of the person seems to present a serious dilemma for duty-to-warn analyses. Namely, how can this conception of the person be reconciled with autonomy as it is recognized by the *Universal Declaration of Human Rights*, both with respect to self-determination as well as privacy?

On the embedded model, autonomy is shared over the collectivity. Since privacy is simply an extension or specific interpretation of autonomy, privacy is also distributed to the collectivity on this model. On this understanding, the notion of privacy does not appear to operate within an embedded collectivity—at least not in the same sense that it does on the atomic model. So how then can the duty-to-warn be presented from this model, assuming the duty exists?

The task of framing the duty-to-warn under the embedded matrix may upon first observation appear insurmountable. However, it may be useful to perhaps step back and not look at the “duty to warn” on embedded model from the perspective of autonomy and privacy, as one does on the atomic model. Instead, it may be more appropriate to focus on what is essential to the embedded model of decision-making, which is that it is a *model* of decision-making.

As far as the purposes of this study go, decision-making has two logically distinct parameters: values and information. If one is to put aside the value parameter, one is left with the informational aspect. As it is, one cannot make reasonable or informed decisions without sufficient information.

On the embedded model, decision-making is a collective endeavor and the collectivity that is involved in the decision-making must have any information that is relevant to the decision to be made. In the genetics clinic, the collectivity requires the patient's relevant genetic information to participate in the embedded model of decision-making. However, in disclosing the information to the collectivity for the purposes of decision-making, the collectivity—which usually includes consanguineal relatives—will simultaneously be warned of any apparent risks to their health.

Therefore, if an individual's genetic information is relevant to decision-making, then it must be shared with the decision-making body because unless it is shared the collectivity cannot make an appropriate decision, thereby violating the inherent logic of the embedded model. Since the patient's genetic information is argued to be necessary for decision-making in the genetics context, the embedded model appears to inherently mandate that this information be shared.

When information is shared on routine, it erases the matter of privacy (at least insofar as it relates to privacy amongst members of the decision-making collectivity). In doing so, it also dispenses with the need to bring Non-Maleficence, and by association the duty-to-warn, into the picture. This is because information on the embedded model will be shared with those involved in the decision-making regardless of the nature of that information. That is, the information will be shared irrespective of the implications—good or bad or none—it has for the patient or for others in their collectivity, since information sharing is essential to the embedded model of decision-making. The issue of determining whether there is a duty to share an individual's genetic information on the embedded model, therefore, does not appear to be a matter of privacy versus warning but rather a matter of whether the individual's genetic information is relevant to the decision that needs to be made.

While the duty to share patient genetic information may not exist between members of the same embedded collectivity, the duty may arise on the embedded model when the information has implications for others who are not a part of the decision-making collectivity but are nonetheless genetically connected to the patient. In other words, there may be instances where the patient's genetic line extends beyond this particular group, and the patient's genetic information may have implications for others who are not part of the immediate embedding and thus not involved in decision-making. In this case, the patient may be considered "atomic" relative to the consanguineal individual that is at risk and the duty-to-warn issue emerges again. Whether the embedded patient has a duty to warn others beyond the immediate collectivity requires, like the atomic model, justification from Beneficence and Non-Maleficence. Though the following section examines whether Beneficence and Non-Maleficence can lend support to the duty-to-warn on the atomic model in the genetics context, the findings can be extended to the analogous situation on the embedded model where the at-risk individual is not included in the patient's decision-making collectivity.

The Atomic Model

The duty-to-warn is a pervasive issue on the atomic model. This is because on the atomic perspective the decision-maker is not the collectivity but the individual, and so information is not shared as a rule on this model. If a patient on this model chooses to make their health care decisions independently, their consanguineal relatives will likely not be apprised of any genetic risks that may arise unless the patient agrees to disclose the information. Therefore, it appears that the central issue on this model (and on the embedded model where the potentially affected individual is not a part of the decision-making collectivity) is determining whether the patient has a duty to warn relatives of genetic risk and, if they do have such a duty, whether this duty can outweigh their right to privacy.

More concisely, the issue here is one of defining the limits of privacy. Whereas Part I of the thesis touched on some of the ethical bounds that surround collective decision-making involving information that centres principally on the individual, Part II of this thesis now investigates the potential limits on independent decision-making that deals with information whose implications reach beyond the individual patient. The discussion will be guided by the following case study:

A young South East Asian man had a cardiac arrest in his sleep. Fortunately, this was witnessed by his wife who started CPR. Genetic testing detected a SCN5A mutation and he was subsequently diagnosed with Brugada syndrome, a genetic heart arrhythmia condition that can predispose individuals to sudden cardiac death. The patient has two brothers and one sister: one brother and sister live in Vancouver and the remaining brother lives in the Philippines. A family letter was provided by the genetic counselor for distribution to family members, since the siblings are at 50% risk of also developing the condition. The risk can be minimized/ameliorated through the avoidance of certain medications, avoidance of fevers, and if necessary a defibrillator can be implanted. The man is very upset by the prospect of providing this information to his siblings, even though two of them have children who may also be predisposed. The brother in Vancouver works in the hospital in radiology and is known by members of the genetics team.

The Right to Privacy vs. The Duty to Warn

There are many practical reasons for why a patient may wish to keep information about a genetic diagnosis private including estrangement, shame, fear of social stigmatization, the possibility of discrimination, the cultural significance or interpretation of the disease, or other psychological harms (Laurie 1999). Ethically, however, one normally does not need a reason to exercise a right that is fundamentally theirs. The right to Autonomy entails that members of society have a duty to respect the autonomous decisions of the competent individual. This principle is also reflected in the Canadian judiciary. For example, in *Charter* cases, one does not need to prove that an infringement of a *Charter* right caused harm to their person in some way. Rather, they merely have to prove that their right was unjustly infringed (*Cheskes v. Attorney General* 2007).

Therefore, if a patient wishes to exercise their right to privacy over their genetic information, this right usually ought to be respected regardless of the reasons for the wish.

In the field of genetics, however, a positive diagnosis for a disorder could indicate a familial disposition. In some cases, if at-risk relatives are warned in time and the disease is detected early, there may be measures available to prevent or dampen the onset of disease symptoms. Even if there are no prevention or treatment options available, timely knowledge of one's risk can help minimize the psychological impact of the disease when symptoms do start to appear and can allow one to structure their life within the scope of the disease. Moreover, timely knowledge may also aid in future lifestyle, career, or reproductive choices.

Since individuals have an obligation under Non-Maleficence to prevent or minimize harm to others when it is possible to do so, it may be argued that patients can have a duty to warn relatives of a hereditary disease risk. Assuming that patients can have this *prima facie* duty, the next question is which right—the right of the patient to privacy or the right of the family to know about their genetic risk and have harm minimized—prevails.

In support of the latter right, some commentators criticize the way genetic information is presently stewarded. Currently, patient genetic information is treated like conventional medical information. Though health care professionals are able to stress the importance of warning at-risk relatives when patients insist on full confidentiality, the information is typically cloaked in confidentiality. Knoppers (2002) argues that this practice “ignores the unique character of genetic information and shields individualism (however ill- or well-motivated) from any form of familial or communal scrutiny” (pp. 85). She believes that “the very nature of genetic information, as both individual and universal, now mandates its treatment as familial” (pp. 86).

In other words, Knoppers argues that genetic information is different from standard medical information and therefore should not be subject to the same expectations of privacy/confidentiality. Instead, the familial aspect of genetic information ought to be recognized and reflected accordingly in health care practice and patients should expect to share this information.

Parker and Lucassen (2004) similarly postulate that the results of genetic tests should generally be considered familial information in a “joint account” rather than private information in a “personal account”. They assert that because genetic information is familial by nature, “justice demands the routine sharing of the benefits of genetic information except in exceptional circumstances” (pp. 167).

Knoppers *et al.*, hence, appear to advocate a paradigm shift in the way medical genetic information is viewed. They argue that the presumption of confidentiality that is typical for conventional medical information should give way to a presumption of sharing for genetic information, except in rare cases where there are compelling grounds to act in the contrary. Treating genetic information thusly would eliminate the need to propose a duty to share genetic information from Non-Maleficence, since sharing would be mandated by the very nature of the information.

However, the assertion that the inherent familial nature of genetic information commands that it be shared does not stand unopposed. Liao (2009) believes that the “familial thesis” needs to be revisited and refined. “Without refinement, the impression one gets from the idea that genetic information is familial in nature...is that there is very high correlation between knowing that an individual has the genes for a particular genetic disease and being justified in believing/infering that a relative will also have this particular disease” (pp. 307).

He observes that genetic inheritance is a complicated affair and is perhaps instead understood more accurately in terms of probabilities. Whether an individual’s family member carries the same gene abnormality and whether the disease will actually be expressed in the family member is subject to a number of factors, which include among others: the way in which the gene is inherited, i.e. in a simple Mendelian fashion, maternally, etc.; the penetrance of particular condition, i.e. dominant, recessive, etc.; the genetic relationship between the two family members, i.e. monozygotic twins, mother and son, etc.; the nature of the genetic disease, e.g. single gene/mutation versus multiple genes/mutations; and the susceptibility of the gene to spontaneous mutation, e.g. one in three cases of Duchenne muscular dystrophy is the result of a spontaneous mutation (Wood 1987).

The interplay of these factors can give rise to many different scenarios in the clinical setting. Liao provides an example of one such scenario involving two sisters to illustrate this complexity:

Sister 1 has young son who has recently been diagnosed with Duchenne muscular dystrophy, and Sister 2 is thinking of parenting and would likely consider pre-implantation genetic diagnosis or make other informed reproductive choices if she knew about her nephew’s diagnosis. The first sister refuses the offer to inform her sibling, stating that she should be personally responsible for her own choices. Taking the various factors raised above into account, Liao calculates that the probability that the second sister will have a son with Duchenne muscular dystrophy is 5.5% (see article for full details).

Liao highlights that how “familial” genetic information is depends on a number of variables. While the probability in the preceding example is fairly low, other genetic cases can be as high as 50 or even 100% in some rare instances, such as genetically identical twins. In light of these considerations, he suggests that the proposal that genetic information should be shared with family by default may be too rash.

As a result, others have suggested that whether the information should be considered individual or familial depends on the calculated probability of transmittance—the probability that the relative inherited the same gene. They contend that sharing may be required in circumstances where the probability of inheritance succeeds a certain threshold. There is, however, little consensus on what this threshold may be or how it may be determined.

However, the probability determinant is likely an inadequate tool for helping decide whether sharing is required in the obtaining circumstances because it ignores the severity factor. It is arguable that a low probability of inheriting a severe condition mandates different consideration than a low probability of inheriting a condition with a low severity factor.

A change in the way genetic information is treated (from individual to familial) does not appear to provide a suitable solution to the question of when patient genetic information should be shared. However, even if the treatment of genetic information continues to be like that of conventional medical information and under the control of the patient, it is important to note that the patient's right to privacy—like all rights—is not absolute and is limited by competing duties. It may therefore still be possible to share patient genetic information when the information is under the control of the individual, though a separate case would need to be made that the patient actually has a duty to share this information. As well, the issue of whether this duty can justifiably replace the individual's right of control would also need to be settled.

i. Non-Maleficence/Beneficence

The probability that a consanguineal relative has the same hereditary condition as the patient refers to a calculation in the abstract and not the actual situation as it is. In the actual situation, the relative either has the condition or does not have the condition. Warning the relative of hereditary risk, thus, will not change the status of the actual condition—which is to say, it will not change the fact the relative has the condition or does not have the condition. Rather, warning will only change the knowledge status of the family member, as they will now be aware of a genetic risk to their person.

Therefore, the question at hand is whether the patient has a duty to change the knowledge status of a relative (i.e. a duty to warn), and this study examines whether this duty can find grounding in the Principle of Non-Maleficence.

The ethical Principle of Non-Maleficence stipulates that individuals have a right to have harm to their person minimized. However, the matter of harm raises the issue of what falls under the rubric of harm as well as what degree of harm is sufficient to override patient rights to privacy.

First, there is the issue of whether a failure to warn will actually result in harm to the relative. In reference to the Brugada case example, awareness of genetic risk may allow the patient's siblings to get tests done early. If the relatives are aware of the information, they can take advantage of prevention/mitigation measures and make informed decisions in areas such as health, career, and other future life choices such as procreation.

When no prevention/mitigation opportunities are available, an argument that is often cited is that warning will not prevent harm to the patient because the disease symptoms will manifest regardless of whether or not the relative is warned.

However, this argument appears to take on a very narrow definition of what falls under the rubric of harm. Though knowledge of the disease through warning may not prevent harm caused by the disease itself in physical terms, knowledge about the genetic disposition may allow the relative to take advantage of surveillance or counseling services that could help manage associated psycho- or socio-logical harms and provide information useful for structuring one's life within the scope of the disease. Additionally, warning may allow relatives to engage in informed and

responsible reproductive decision-making. Arguably, the tested patient's duty to minimize harm includes the obligation not to initiate a causal chain that will predictably lead to harm for any persons who might be born (Kluge 2013). Consequently, if a patient is aware that their relations have children or may have children in the future, the patient's ethical responsibilities may extend towards them as well.

Another argument against warning is that knowledge of a genetic risk may cause the relative more harm psychologically than the harm caused by the physical onset of the disease. However, harm is inherently a value-laden concept, meaning that its constitution differs from person to person. Therefore, whether the disclosure or the actual genetic condition would cause the family member more harm is really for the respective family member to decide. Of course, the relative cannot make a decision on this matter unless they are warned of their genetic risk.

It would be ethically inappropriate for the tested patient to use their values of harm to determine whether the relative ought to be warned. This can also be combined with some recent empirical evidence, though in reference only to multifactorial genetic disorders, that suggests that knowledge of carrier status does not have significant psychological impact when individuals receive appropriate counseling (Heshka *et al.* 2008).

It may also be countered that the duty to warn relatives of hereditary risk and maximize their opportunities for informed choice, when taken alone, suggests that there is a duty to assist others with their decision-making. This can be a difficult claim to make, for there are all sorts of information that can have adverse implications for one's health and well-being both inside and outside the health care context. As the Principle of Impossibility states, any right or duty that cannot be met under the circumstances ceases to be active as a right/duty. One, therefore, cannot have a right to know about all harms that could potentially affect their person, since it would be impossible for members of society to meet this right.

However, this inference may too miss the mark. For instance, in the Brugada case example—and as may generally be the case in the genetics context—it is possible under the circumstances to apprise family members of their genetic risk. But perhaps more importantly, this inference introduces a second component that is relevant to harm considerations, which is the degree of harm. In other words, the duty-to-warn likely has a severity gradient where the higher the severity of the disease, the stronger the grounds for a duty to warn.

Taking these points together, what seems to follow is that when it is possible to inform relatives of genetic risk, and when the severity gradient is sufficiently high, relatives can have a right to that information. They can have this right not simply because it facilitates their decision-making, but because it is possible to minimize harm and maximize their opportunities for informed choice. Therefore, when it is possible for the patient to warn consanguineal relatives of a serious genetic predisposition without incurring harm to their own person, the patient can have a duty to provide them with this information.

This, however, provokes the question of what constitutes a "serious harm". As well, it may also be argued that disclosure of one's genetic information to family members may in fact cause

undue harm to the patient. Namely, the patient may feel that disclosure of their diagnosis would harm their person in some manner.

Because what qualifies as “harm” and how these harms stack up against one another is person-relative, different people will give different answers. In terms of determining which harm—the harm to the patient from warning or the harm to the relative from the failure to warn—outranks the other, the patient may give one answer and the relative another. As a result, the objective reasonable person standard is suggested in order to ensure that the equal and competing rights of all those implicated are adequately taken into consideration. That is to say, given the particular circumstances that surround the case, would the reasonable person in the patient’s position view a greater risk of harm to the patient from disclosure or to the family from non-disclosure?

ii. Causality

Deciding what a reasonable person in the individual’s position would do and how this relates to the duty not to cause harm—how Non-Malfesance plays out in real terms—is not, however, a simple matter. Thus, another position that is sometimes used to counter the duty to do no harm is that the patient is not the agent causing the harm: the natural expression (or inexpression) of the mutated gene is ultimately responsible for the harm (Laurie 1999). Non-disclosure by the patient therefore would not inflict any additional harm, since the affected individual would already carry the defective gene and any harm caused by its expression will occur whether the individual knows about it or not.

In other words, the argument is that the duty to do no harm applies only when a physical action of the individual may cause harm to third parties. Irrespective of opportunities for prevention or management measures, since it is not an action of the individual but the progression of a disease state that is the source of the harm, the individual is not neglecting in their ethical responsibilities. Any harm that befalls relatives from natural causes is, then, not the result of a failure of one’s duty to do no harm.

Liao (2009) makes a similar claim. In the genetics setting, “the kinds of harms at issue are not ones of causing harm, but rather ones of allowing harm to take place. We can all argue that with respect to causing harm, the threshold of risk of harm should be very low. Indeed, if any action of mine even has even a small chance of causing you harm, then certainly I should take steps to refrain from taking such an action; or, if such an action were unavoidable, then certainly I am obligated to inform you of it. But, arguably, the situation is not symmetrical with respect to allowing harm” (pp. 308).

These types of arguments, however, require one to take a closer look at how causality relates to ethical obligations. In terms of causality, once a causal chain of events has been initiated, there are a number of outcomes that may result. For instance, when the geneticist or genetic counselor informs the Brugada patient that his consanguineal relatives are at risk of carrying the same genetic condition, the patient can now expect two possible general outcomes for his family:

- (1) the outcome if patient action is performed (he warns family members of risk), or
- (2) the outcome if patient action is not performed (he does not warn family members).

If the patient chooses option (1) and informs relatives of their hereditary risk, the patient can reasonably expect the relative will now have a choice—the choice of whether or not to act on the information and seek the relevant genetic testing and counseling. Likewise, if the patient selects option (2) and does not warn family members, the patient is aware that their action takes away this choice. The relative will be denied the option of early testing and other prevention or management services.

As outcome (2) illustrates, a failure to act can cause an outcome as much as can a physical act. Ethically speaking, failing to act and *allowing* harm to occur is really not any different from physically acting and *causing* harm (Rachels 1975).

Because the patient is the agent that decides between (1) and (2), and because the patient can reasonably predict the casual chain of events that are likely to unfold from their decision, they are ethically responsible for the outcome that follows. The notion that individuals are responsible not only for what they cause but also what they can prevent is in fact the same principle that underlies the tort of negligence in criminal law.

The claim that nature is the dominant agent that causes the harm—because it is ultimately the expression of the gene that results in the harm (Laurie 1999)—also seems to misrepresent the issue at hand. This is because the laws of nature are always present: nature is always the dominant cause that leads to an outcome good or bad. “The real question is not one of dominance or physical activity but of responsibility and control. Moral responsibility is assigned only on the assumption that one has the power to determine how a casual chain of events unfolds” (Kluge 2013 pp. 196). Therefore, the first question to ask in the genetics setting is whether the patient is in a position to influence how the causal chain of events will play out. If the patient is not in such a position, then there is no ethical duty to act in a specific way. But if the patient is in such a position, then the question becomes one of whether the patient has a duty to influence the events in one way rather than another (Kluge 2013).

Since the Brugada patient is in a position where they can influence the casual chain of events, the question to ask is whether he has a duty to influence the events in a certain way. As was shown from Non-Maleficence above, relatives can have a right to know of genetic risk to their persons when it is possible to do so and the severity gradient is sufficiently high. Determinations of whether the severity of the harm to the health or life of the relative is high enough to outweigh the right of patient to privacy in the given circumstances are perhaps best performed on the reasonable person standard. Therefore, if it is reasonable to believe that the harm to the patient from disclosure outweighs the potential harm that may be incurred by the patient, then there is no duty to warn under the circumstances. On the other hand, if it is reasonable to believe that the potential harm to the relative from insufficient warning in time surpasses the harm that may be experienced by the patient from the abrogation of their privacy, then there is an ethical duty to warn under the existing circumstances.

Judicial Considerations

i. Legal Reflections of Beneficence and Non-Maleficance

The analysis of the duty-to-warn issue on the atomic model (and the comparable issue on the embedded model when the at-risk individual is not a member of the embedded collectivity) suggests that when the potential harm to the relative from a lack of warning is higher than the harm to the patient from a violation of their privacy on the reasonable person standard, the patient can have a duty to act and warn relatives of their hereditary risk.

This duty is argued from the Principles of Beneficence and Non-Maleficance and these may have some legal reflection, primarily in what is often referred to as Good Samaritan law (British Columbia, *Good Samaritan Act* 1996; Alberta, *Emergency Medical Aid Act* 1980; Saskatchewan, *The Emergency Medical Aid Act* 1978; Manitoba, *The Good Samaritan Protection Act* 2006; Ontario, *Good Samaritan Act* 2001; Quebec, *Civil Code of Quebec* Article 1471; Newfoundland and Labrador, *Emergency Medical Aid Act* 1971; Nova Scotia, *Volunteer Services Act* 1989; Prince Edward Island, *Volunteers Liability Act* 1994; Yukon, *Emergency Medical Aid Act* 2002; Northwest Territories, *Emergency Medical Aid Act* 2003; Nunavut, *Emergency Medical Aid Act* 1988).

However, the notion of Good Samaritan is interpreted differently in different socio-cultural settings (e.g. Quebec and Europe vs. common law provinces/countries). In Canada's common law provinces and territories, Good Samaritan legislation is typically limited to emergency situations. It offers legal protection to individuals who provide reasonable assistance to those who are, or who they believe to be, injured, ill, in peril, or otherwise incapacitated. The protection is intended to reduce bystanders' hesitation to assist for fear of being sued or prosecuted for unintentional injury or wrongful death should they make a mistake in treatment.

For example, B.C.'s *Good Samaritan Act* (1996) stipulates:

- (1) A person who renders emergency medical services or aid to an ill, injured or unconscious person, at the immediate scene of an accident or emergency that has caused the illness, injury or unconsciousness, is not liable for damages for injury to or death of that person caused by the person's act or omission in rendering the medical services or aid unless that person is grossly negligent.
- (2) Section (1) does not apply if the person rendering the medical services or aid: (a) is employed expressly for that purpose, or (b) does so with a view to gain.

Therefore, it seems that the notion of Good Samaritan cannot be equated with the Principles of Non-Maleficance and Beneficence in common law provinces. This is because the Good Samaritan legislations of common law provinces do not actually place a duty on bystanders to assist—even when it is possible to do so without undue risk to their person (McInnes 1992). Rather, they merely serve to provide protection to those who act as good Samaritans and voluntarily come to the aid of persons in need. Adjusted to the genetics setting, patients in common law provinces do not appear to have a legal duty under Good Samaritan legislation to come to the aid of their consanguineal family and warn them of their risk for having inherited a

serious or debilitating condition. Since there is no duty to act, patients in common law jurisdictions would not be considered negligent under Good Samaritan legislation if they refrained from warning relatives.

Quebec, however, does impose a duty on everyone to help those whose life or health is in jeopardy and this duty extends beyond the emergency context to everyday dealings in life. Under Quebec statutes, every person is obligated to act like a *bon pere de famille*, which broadly translates as a good caretaker of the family. Failure to do so amounts to fault and legal wrong (Schwartz 1987).

This duty is articulated in section 2 of Quebec's *Charter of Human Rights and Freedoms* (1975), which specifies:

Every human being whose life is in peril has a right to assistance. Every person must come to the aid of anyone whose life is in peril, either personally or calling for aid, by giving him the necessary and immediate physical assistance, unless it involves danger to himself or a third person, or he has another valid reason (1975, c. 6, s. 2).

Every person has a duty to abide by the rules of conduct incumbent on him, according to the circumstances, usage or law, so as not to cause injury to another. Where he is endowed with reason and fails in this duty, he is liable for any injury he causes to another by such fault and is bound to make reparation for the injury, whether it be bodily, moral or material in nature (1991, c. 64, a. 1457; 2002, c. 19, s. 15; I.N. 2014-05-01).

Article 1471 of Quebec's Civil Code also offers protection to those who make reasonable efforts towards this duty:

Where a person comes to the assistance of another or, for an unselfish motive...he is exempt from all liability for injury that may result, unless the injury is due to his intentional or gross fault (1991, c. 64, a. 1471; I.N. 2014-05-01).

The notion of Good Samaritan can therefore be equated with the Principles of Non-Maleficence and Beneficence in statute law jurisdictions such as Quebec. Applying Quebec statutes to the field of medical genetics, if the tested patient can prevent or minimize harm to the life or health of a family member with relatively little or negligible risk to oneself, and the potential harms to the relative outweigh potential harms to the patient, the patient may have a duty to warn consanguineal family. It is arguable that patient action is legally mandated under Quebec law—though this specific argument has yet to be examined by the province's legislature or brought before its courts for judgment.

To take stock, while there may be an *ethical* duty to warn under the circumstances, whether there is a parallel *legal* duty to warn appears to depend on the jurisdiction. In common law jurisdictions, the Good Samaritan doctrine does not mandate patient action and simply protects those who act as good Samaritans. In statute law jurisdictions like Quebec, the statutes mandate

action by those who should act like good Samaritans—in this case the patient—and holds those who are negligent in this duty liable.

Though the duty to warn of genetic risk may not find legal recognition in common law provinces, the duty does appear to be supported from the ethics as well as by Quebec statutes. The different interpretations of Good Samaritan law by the different jurisdictions are revelatory of their ethics. In common law provinces, because there is no legal duty to minimize harm to others and warning by patients is only voluntary, the Good Samaritan doctrines found in most of Canada appear to represent an extreme version of the atomic model. That is to say that the individual right to autonomy appears to be absolute and does not adequately factor in the rights of other members of society. Quebec's Civil Code, on the other hand, requires that each individual act as good caretaker of the family. The requirement recognizes the embedded context of the individual and acknowledges that there are circumstances where individual rights can be justifiably overruled by the rights of others. In other words, Quebec's "Good Samaritan" laws are consistent with the ethics of Autonomy in that they acknowledge that this right is not unlimited.

While the ethical principles of Non-Maleficence and Beneficence may not be formally recognized in common law Canada, it may nevertheless be worth mentioning that the incorporation of these ethical principles into the law has been advocated before (McInnes 1990). For instance, in 1897 the Law Reform Commission of Canada (LRCC) recommended that the country take a firmer stance with regards to the duty of Canadians to help one another. The recommendations were phrased as follows:

10(1) Endangering. Everyone commits a crime who causes a risk of death or serious harm to another person: (a) purposely; (b) recklessly; or (c) through negligence.

10(2) Failure to Rescue.

(a) General Rule. Everyone commits a crime who, perceiving another person in immediate danger of death or serious harm, does not take reasonable steps to assist him.

(b) Exception. Clause 10(2)(a) does not apply where the person cannot take reasonable steps to assist without risk or death or serious harm to himself or another person or where he has some other valid reason for not doing so.

Unlike common law Good Samaritan legislation, the proposed Duty to Rescue requires that individuals offer assistance to those in peril when it is reasonable to do so and holds those that are negligent in this duty liable for their inaction. Clause 10(2)(a), which builds on the cardinal values embodied in Quebec legislation, would therefore create a new crime in Canada and, as the LRCC sees it, bring the nation's "law into line not only with ordinary notions of morality but also with the laws of many other countries, for example Belgium, France, Germany, Greece, Italy, Poland and some of the United States" (pp. 68), which acknowledge Beneficence and Non-Maleficence as fundamental legal principles.

ii. Legal Reflections of Causality

The genetics context is not the only context in which a patient's medical information can have implications beyond the individual. The so-called "duty to warn" usually refers to general issue of divulging deleterious information to third parties. Historically, this duty has surfaced in the context of communicable disease or mental illness (From Canada: B.C.'s *Public Health Act* Regulation 4/83 1983, *Smith v. Jones* 1999, *R. v. Cuerrier* 1998; Internationally: U.K. General Medical Council Guidelines 2013, *W. v. Egdell* 1990, *Tarasoff v. Regents of the University of California* 1976). Canadian law and policies covering the matter acknowledge that there are certain circumstances where threats to public safety may be sufficient to override obligations of confidentiality. To use B.C.'s *Public Health Act* as an example, the *Act* provides a list of communicable diseases that must be reported. If a health care professional or institution (physician, laboratory technician, hospital, etc.) knows or suspects a person to be suffering from or having died from a reportable disease, they must notify the regional health authority's medical health officer without delay. The medical officer, upon verification, forwards the report to the provincial health officer and if necessary the provincial officer will bring it to the attention of the public. In an analogous vein, case law outlines the conditions that permit physician disclosure of patient psychiatric states (*Smith v. Jones* 1999).

In both these cases, the duty to warn is based in causality. For infectious disease, the infection will cause the harm if and when it is transmitted. For psychiatric illness, the clearly expressed intention of the patient to cause harm to an identifiable person or group of persons will cause harm if and when it is translated into action by the patient. Therefore, there are specific public health measures already in place that recognize that the individual's right to privacy is not absolute and is subject to the equal and competing rights of others.

It may also be possible to argue a legal duty-to-warn in the genetics context from causality, where lack of information about hereditary risk will cause harm to consanguineal relative if and when the disease becomes symptomatic. Here, lack of information is the casual agent of harm because it deprives the consanguineal relative of choice—the choice of whether or not to seek the relevant medical care—and this leads to inaction on part of the relative, which can in turn lead to psychological harm or insufficient intervention in time. Since the information that the consanguineal lacks is under the control of the patient, the patient is in a position where the decision not to disclose the information to the relative makes the patient casually responsible for the harm that follows. When it is reasonable to assume that the potential for harm to the family member is greater than the harm that is posed to the individual from a violation of their privacy, and when the patient can reasonably inform their consanguineal family of their genetic risk, the patient is argued to have a duty to warn. In such cases, the duty-to-warn appears to be another example of a public health concern that can justifiably overrule the patient's right to autonomy on the atomic model and in analogous circumstances on the embedded model.

Conclusion

This second part of this thesis contemplates the individual's right of control over genetic information on the two models, specifically in situations where the information may have adverse implications for others beyond the sole individual. On the embedded conception, it is argued that the issue is generally not a conflict between the individual's right to privacy and duty to minimize harm to others but of whether the individual's genetic information is required by the collectivity to fulfill the mandate of embedded decision-making. The Principle of Autonomy seems to play a greater role on this model, as the autonomous agent on the embedded conception is the collectivity as a whole. Because the individual's genetic information is necessary for embedded decision-making in the genetics clinic, the information must be disclosed to the collectivity and this in turn ensures that the collectivity is warned. Put more succinctly, the very nature of the embedded model involves the sharing of information. When information is shared as a matter of course, the duty to warn does not arise among embedded members.

On the atomic model (and on the embedded model where the individuals potentially affected by the patient's genetic information are not encompassed in the embedded collectivity), the patient's duty to minimize harm through warning does run up against the individual's right to privacy, and the Principles of Beneficence and Non-Maleficence appear to play a more central role. When consanguineal relatives are predisposed to a serious genetic condition, warning may allow timely access to preventative or mitigation opportunities. Even if preventative measures are not available, warning can still minimize harm to relatives by providing them with the opportunity to prepare psychologically for the condition before its onset. Depending on the potential severity of the disease, the patient's duty to minimize harm to other individuals in society may outweigh their right to privacy.

Since the embedded model is inherently built on values that emphasize the good of the collectivity as whole over individuals in isolation, the duty-to-warn lacks materiality in so far as the embedded collectivity is concerned. The atomic model, in contrast, is fashioned on values that emphasize the rights and freedoms of the individual person. However, even this model recognizes that in some circumstances the equal and competing rights of others in the individual's social embedding can justifiably overrule the rights of the individual. Therefore, the fact that the duty to warn is often irrelevant to the embedded model but does arise on atomic model suggests that the different conceptions of the person can give rise to different rights and duties in different settings. The genetics setting is one such example but there may be others.

CLOSING REMARKS

This study proceeded on the conjecture that there are different cultural conceptions of the person—atomic versus embedded—and that these influence how autonomy is viewed, which in turn has consequences for decision-making. Since decision-making is central to the delivery of health care, the objective of this thesis was to analyze the ethics of the two models and determine whether in fact they had any implications for medical decision-making.

In terms of the ethics, it was argued that the different views of the person appear to be agreeable with the ethics underlying the general Principle of Autonomy. Though the distinct models may result in differences in the way autonomy is practiced, they do not appear to require a philosophical reworking of Autonomy. Because both models can be understood from the traditional development of Autonomy, their use and acceptability in a particular situation can be interpreted from existing ethical frameworks.

Variations in the view of the person were also found to have practical significance. Part I examined the effects the distinct models of personhood had for decision-making involving information whose health implications were largely confined to the individual patient. The section looked specifically at consent decisions at the end of life. The issue was that in some situations patients—regardless of the conception of the person under which they operate—need to make health care decisions that require knowledge of information that is from their cultural perspective unwanted or harmful, such as information involving a terminal diagnosis or prognosis. However, depending on the model on which they do operate, how this information is disclosed for decision-making was found to vary.

Put differently, the distinct models were found to have different implications for the disclosure requirement of informed consent. On the atomic model, the individual may waive their right to disclosure and choose to consent without appropriate or sufficient information. On the embedded model, the individual's right to disclosure is not waived but is extended to the collectivity. To prevent unnecessary psychological harm to the patient at the end of life, the values of the collectivity—and hence the values of the patient—may indicate the exclusion of the patient from decision-making. However, since the remainder of the collectivity stays on as decision-maker, Autonomy entails that they have a right to the patient's relevant medical information. Based on the mutually held values of the collectivity, the collectivity decides how much of this information is sufficient to meet the disclosure standard of informed consent. The general or theoretical outline of informed consent therefore appears to be the same on the two models—both entail a standard of disclosure and a standard of comprehension—but how informed consent plays out in practice varies depending on the model.

At the same time that this study advocated that our ethical commitments oblige us to include the embedded model of decision-making in informed consent, it also positioned itself as a cautious critic of the embedded model. Namely, the analysis in Part I suggested that the embedded model may not be acceptable for all medical decision-making and there is likely a sliding scale of acceptability. Moreover, the embedded model is argued to be permissible only insofar as it

preserves the fundamental rights of liberties of individuals as they are encompassed in the *Universal Declaration of Human Rights*.

In Part II, the implications the two models had for decision-making involving information that had significance for others besides the patient were examined. The section focussed principally on the issue of sharing information in the genetics context. It was argued that when the potential for harm to a consanguineal relative from non-disclosure can reasonably be seen to be greater than the harm that may befall the patient from a violation of their privacy, the patient's right to privacy can justifiably be overruled and the patient can have a duty to share this information. The duty-to-warn was therefore found to be an example of the limiting clause on the Principle of Autonomy—i.e. “limited only by the unjust infringement on the rights of others” on the atomic model and on the embedded model when the at-risk relative was not a member of the patient's decision-making collectivity.

On the other hand, when the at-risk consanguineal individual was a member of the patient's embedded collectivity, the embedded model was found to have no relevance for privacy in the genetics setting. Rather, the duty-to-warn was here simply an implication of the embedded approach to decision-making. Because the decision-maker on the embedded model is the collectivity, and since the collectivity requires the patient's genetic information to engage in embedded decision-making, the model inherently mandates that the information be shared with the collectivity. When information is shared on routine between members of the collectivity, it dispenses with the need to put forward a duty-to-warn among those members.

In summation, the overreaching conclusion of this study is that how patients view themselves as persons impacts how they engage with the medical system. Because these views are often carried over into the healthcare setting and can affect the delivery of health services, they merit consideration in health care policy and procedure. While this study confined itself only to the implications the two models had for informed consent and the duty to warn of hereditary risk, there may be other aspects of health care influenced by varying takes on personhood.

It may, however, be useful to remember that this study dealt with two very specific types of decision-making—i.e. collective decision-making that excludes the individual in informed consent and independent decision-making that fails to adequately consider of the rights of others in the medical genetics setting. Therefore, the medical contexts that were the focus of this thesis involved the extreme ends of both models of decision-making. As was mentioned earlier, decision-making in other medical contexts may fall somewhere along the continuum between these two extremes, and the model of decision-making followed may not be as evident. It may thus be difficult to ascertain the implications the varying views of personhood have for these other contexts. Nevertheless, Canada's commitments to being a multicultural and inclusive society seem to suggest that these too be explored.

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