

**Ethical Pluralism and Informed Consent in Canadian Health Care:  
Exploring Accommodations and Limitations**

by

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

## **Abstract**

Vibrant and evolving diversity has become an integral part of Canadian identity. Communities are experiencing an enrichment of new ideas, and unique opportunities to learn about those with whom we share the world. At the same time, we are witness to emerging tensions and value conflicts - especially in the health care system. This has given rise to what some have termed the problem of pluralism: the challenges associated with formulating public policy and shaping health care practices for parties who have deep moral disagreements.

It has been proposed that the practice of informed consent in health care is an effective solution to the problem of pluralism, as it allows individuals to make decisions according to their own moral commitments and control the care they receive. In this thesis, I argue that informed consent is not a value-neutral practice. Rather, it is grounded in particular values and beliefs, and reflects a particular understanding of health and illness. Consequently, I argue that the practice may not be able to fully address the problem of pluralism.

I begin by exploring the dynamics of ethical pluralism and the structure of the health care system in Canada. I focus, specifically, on the challenges that arise from this complex intersection of ethics and health. Next, I establish the ways in which the practice of informed consent is embedded with particular values. Finally, I discuss strategies for making the practice of informed consent more accommodating of diversity. I argue that there are, however, limits to the possible accommodations that can be made, due to the complexity of the issues and the structure of the health care system in Canada.

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# Chapter 1: Ethical Pluralism in Canadian Health Care

## 1.1 Introduction

Canada is home to increasing diversity. Communities are experiencing an enrichment of new ideas and different ways of life. As Canadians, we see growth and change, and are presented with new and unique opportunities to learn about those with whom we share the world. At the same time, we are witness to rising tensions and value conflicts that we may not feel equipped to address. The health care system, educational system, and other long-standing institutions are called into question as we work to ensure that each person is able to live according to their beliefs and values - that is, to live their good life.

Reflecting on this issue, I am met with many questions: How is the practice of informed consent in health care rooted in values? In what ways can we work to accommodate ethical pluralism in Canadian health care? Are there limits to this possible accommodation? It is on these questions that my work will focus. I will give arguments demonstrating that the practice of informed consent in Canada *is* grounded in particular values, beliefs, and assumptions. I will explore ways of easing the growing tension, and put forth strategies to accommodate ethical pluralism in the health care system. Finally, I will establish that there are, in fact, limits to the accommodation that can be provided in health care.

In this opening chapter, I aim to build a comprehensive foundation for my project. I will offer background information on the topic, and explain the key concepts that will be central to my arguments. To start, I will explore the vibrant and evolving diversity that has become an integral part of Canadian identity. Next, I will introduce the concept of ethical pluralism, drawing on the work of John Rawls to highlight the ways in which distinct value systems emerge

and exist in relation to one another. With this in mind, I will discuss the presence of ethical pluralism in the Canadian health care system, and the accompanying challenges (sometimes referred to as the problem of pluralism) that can arise from this interaction. I will, then, shift my focus to the work of Donald Ainslie, and explain his proposed solution for accommodating pluralism in health care settings. Finally, I will describe the practice of informed consent as it exists in the Canadian context, focusing specifically on its role in the health care system.

In Chapter 2, I will argue that informed consent in Canada is not a neutral practice. It is grounded in particular values and normative beliefs, and is informed by a particular understanding of health and illness. Accordingly, different patients will have different perceptions and experiences of the process of informed consent, depending on their moral views. As a consequence, it is my position that informed consent may not be able to fully address the problem of pluralism.

To establish my argument, I will explore three ways in which the process of informed consent in Canada is value-laden. To start, I will demonstrate that the practice is embedded with communication and decision-making norms that are not universal. In this way, informed consent emphasizes individual choice and autonomy over collective or family-centered decision-making. It also assumes that patients and families value full disclosure and open communication with their health care team. In reality, there are many moral communities for whom this kind of relationship is seen as inappropriate.

Next, I will call attention to the fact that there is a substantial power imbalance between patients and health care professionals. The latter hold notable positions of authority in society as a result of their medical knowledge and training, and control over access to treatments and services. In the current practice of informed consent in Canada, it is taken for granted that



patients have various inclinations towards authority - whether it be deference, neutrality, or distrust. I will argue that these inclinations can have repercussions for how patients perceive their relationships with health care professionals, and their ultimate decisions to accept or reject treatment.

Last, the practice of medicine may be supported by objective, empirical facts, but it also relies on the judgements of health care professionals. These judgements may be shaped by health care professionals' normative beliefs about health, illness, and dying, and can influence how they direct the process of informed consent for patients. Specifically, I will argue that a health care professional's judgements about a case may affect how they determine prognoses, what information they deem relevant to disclose to a patient, how that information is presented, and what treatment recommendations they believe to be appropriate.

In Chapter 3, I will discuss strategies for accommodating ethical pluralism in the Canadian practice of informed consent. I will start by arguing that medical practice should be rooted in an active resistance of assumptions. I will detail methods through which health care professionals can avoid relying on stereotypes, and approach patients with an awareness that they are complex, unique individuals. Central to my argument is the assertion that health care professionals must have the opportunity to learn about their patient's values and beliefs *before* beginning any discussion of the patient's condition.

Next, I will explore the idea of a 'lower' standard of informed consent as a mechanism for accommodating patients and families who value non-disclosure. Such a practice could be implemented in various possible forms. This 'lower' standard of informed consent would allow patients to choose to receive *less* information about their condition, in order to ensure that their care aligns with their values. In addition, I will present strategies for addressing patients'

deference or distrust towards authority. I will discuss training for health care professionals focusing on issues of trust, authority, and power. Such training would equip health care professionals with the tools to engage in meaningful collaboration with patients.

Finally, I will suggest that there may be limits to the possible accommodation of ethical pluralism within Canadian health care. This may be the case for patient requests that incur substantial costs, interfere with care, or violate professional or legal standards. Due to the complexity of these issues, and the structure of the health care system, it is my position that some tensions cannot be resolved. With this in mind, I will begin to build the foundation for my arguments. I will start this opening chapter with an exploration of ethical pluralism in the Canadian context.

## **1.2 Canadian Diversity**

A great diversity of moral views can be clearly seen in Canada. The country is home to a rich mosaic of diversity, due to its immigrant and Indigenous populations. This growing diversity exists along linguistic, religious, cultural, and ethnic dimensions. Historic French influence has created French-English duality in Canada, with the country being officially bilingual. Canada is also host to a mix of religious presence. Christian faiths are the most common, but non-Christian faiths such as Muslim, Hindu, and Sikh faiths are certainly on the rise (Statistics Canada). In terms of ethno-cultural diversity, the majority of Canadians identify their ancestry as 'Canadian'. Only Indigenous populations, though, are actually native to the country. Interestingly, in 2011, there were 13 ethnic origins that surpassed the 1-million mark. In terms of recent immigrants, Canadians reported nearly 200 countries as their places of birth. At the time of the 2011 Census, 20.6% of the population was foreign-born. In this respect, internationally, Canada is second only to Australia (Statistics Canada).

Internationally, Canada's efforts to become a country of diversity and acceptance have earned it a reputation as a successful example of a pluralist society. In 1971, Canada was the first country in the world to introduce official policy on multiculturalism. As a result of this initiative, the Canadian Multiculturalism Act (CMA) was enacted in 1988. The CMA declared that it is the official policy of the Government of Canada to support the country's growing diversity by ensuring that all individuals have equal rights, receive fair treatment, and are able to participate fully in the shaping of Canadian society.

The country's achievements on this front certainly call for celebration, but it is important to acknowledge that Canada is still a work in progress, and faces ongoing challenges. The urgent need for continued work is especially visible when one examines the past and present treatment of Canada's Indigenous populations. In particular, there is grave injustice in the conditions of Indigenous peoples' housing, education, employment, and health (Sawchuk 2). So, the country continues to work towards equality and inclusivity. With policies dedicated to supporting multiculturalism, it seems that diversity itself has become an essential part of the collective Canadian identity (Boutilier 3).

An especially striking illustration of this diversity in Canada can be seen in health care settings, where there are deep and unsettled disagreements about many ethical issues. Sure enough, "individuals from quite different ethnic backgrounds, with distinct personal narratives and communal histories, can encounter one another in the oncology unit, burn centre, obstetrics unit, hospice or critical care facility" (Turner 104). Each of these individuals will have their own moral doctrine that can greatly affect their experience as a health care consumer. Their beliefs may influence the way they understand health, illness, injury, and death.

Practically, this might mean that patients have remarkably different convictions about issues like advance directives, the disclosure of prognoses, the administering of treatment, and end of life care. In some cultures, for example, it is believed that reality is shaped by language, and the discussion of certain events can cause them to manifest (Goce and Zola 3). In fact, according to a European folk belief, if a pregnant woman is to see or even think of a person with a disability, they 'mark' their unborn child with the same impairment (Groce and Zola 3). Consequently, a patient who holds these beliefs may find it inappropriate for a health care professional to speak to them about illness, injury, or death.

Another illustration of the diversity in moral beliefs can be seen by looking to a moral community on Vanatinai, a small island near Papua New Guinea. In this community, those who (by Western standards), would be seen as unconscious, are actually viewed as already dead (Koenig and Gates-Williams 3). So, for members of this community, a person may die many times (Koenig and Gates-Williams 3). A patient in Canadian health care who holds such beliefs may have a vastly different understanding of particular conditions, and so, different expectations for treatment options and end of life care. In all, patients' beliefs and values may affect the way they understand and experience illness or injury, as well as their expectations and goals for care. In this way, health care settings are rich with illustrations of the vast ethical diversity in Canada.

### **1.3 Ethical Pluralism**

Ethical pluralism, put simply, is the idea that there are many different value systems in the world, because of different perspectives on moral issues. Between value systems (or, moral doctrines), there can be tremendous variation in the beliefs, practices and values that are considered acceptable and morally defensible (Turner 102). Consider, for example, the range of contrasting religious beliefs related to eating meat. Evidently, two moral communities may

interpret a given practice in two entirely different ways depending on the norms and values of the moral doctrine to which they subscribe.

There can also be great diversity among the individual members of a particular moral community. Individuals may differ in the way that they interpret or practice the community's moral beliefs and values, resulting in considerable inter-group variation. So, while a moral community may have a shared value system or moral doctrine, it cannot be taken for granted that the community's individual members are homogenous. Accordingly, it is important to avoid making assumptions about any particular individual based on their membership in a moral community. In all, there is tremendous diversity to be found between, and within, communities. This is because, as Leigh Turner suggests, moral communities have different “ways of worldmaking” (Turner 103)

So, how is it that these diverse ways of worldmaking come to be? How is it that “without making any factual or logical errors, individuals who live in free societies will arrive at distinct and conflicting views about how best to live and about the demands of morality”? (Weijer et al. 199). The existence of ethical pluralism has made for fascinating explorations by many notable thinkers. John Rawls, for instance, has written thoughtfully about this topic. In his work, Rawls explores various ways that individuals may come to disagree about moral issues. In what follows, I will discuss three of the factors that are believed to affect the position an individual takes on an issue.

First, for any given case, parties may evaluate and understand the available evidence differently (Rawls 36). This may be because the evidence is complex, or because there are a number of pieces of evidence that conflict with one another. Second, it could be that parties agree on the relevant considerations for an issue, but disagree about their order of importance

(Rawls 37). Take, for instance, the issue of abortion. Often, both pro-life and pro-choice supporters see the value of preservation of life *and* bodily autonomy; their disagreement, however, stems from their views about which value should take priority in a situation where both are at stake. Third, one's position on an issue is often affected by their beliefs and life experience (Rawls 37). The way one prioritizes values and weighs evidence for an issue may be affected by their moral beliefs, culture, religion, ethnicity, social position and family structure – among others.

In further writing, Rawls asserts that pluralism is a permanent feature of any democratic society (Rawls 84). He explains, saying, “In a modern democratic society citizens affirm different, and indeed incommensurable and irreconcilable, though reasonable, comprehensive doctrines in the light of which they understand their conceptions of the good” (Rawls 84). Ethical pluralism is visible in disagreements about moral issues, like the significance of one's body, one's duty to help others, or what it means to achieve justice. In contemporary Canadian society, one can discover the depth of pluralism in the deliberations about women's reproductive rights or our environmental responsibilities. A feature of ethical pluralism is the existence of conflicting moral principles. These conflicting principles may exist between distinct moral doctrines, or may be present within a single moral doctrine. Regardless of how a particular value- conflict arises, it can often be traced to deep-rooted beliefs, which can, undoubtedly, create significant tension (Hare 35).

#### **1.4 The Problem of Pluralism in Health Care**

The difficulty, I argue, is that this deep moral disagreement makes it difficult to formulate public policy or shape health care practices. The creation and implementation of such guidelines affect not only health care professionals, patients, and family members, but the larger society, as

well. Take a moment to reflect on the debate surrounding an issue like abortion, or medical assistance in dying. Imagine trying to create a policy that individuals on all sides of the debate would find tolerable. It is my position that there is profound complexity to such a task, making it remarkably difficult – if not impossible.

I believe that this complexity exists because, if policy-makers or health care professionals are to act fairly, then there is no single moral doctrine on which they can rely for guidance. Within a unified moral community, one can usually appeal to an accepted moral authority (like a sacred text or religious doctrine) to make their case. But, in a pluralistic society, members of the population do not agree on a single moral doctrine. When developing policy or practices, then, there is no ultimate moral authority on which decisions can be based.

To endorse a single moral doctrine “would be unfair to those who subscribe to a conflicting reasonable doctrine; it would mean that the coercive power of the state would not be justified to them in terms they can accept, even while they are forced to abide by its terms” (Ainslie 1). If a policy is to place limits on the kind of lives that people can lead, it must be justified to those very people who will be affected (Ainslie 13). It must be shown that people have reason to accept these limits, despite their moral disagreements. To do otherwise, and force individuals to abide by moral principles in which they do not believe, would be unjust. Thus, policy-makers and health care professionals are assigned complex tasks. The former must work to craft policy that is fair, and can be justified to a diverse population, despite deep-rooted moral disagreements. The latter must try to navigate health care situations and provide care for pluralist parties who may have competing interests and goals.

Expanding on the last point, there are significant challenges pertaining to ethical pluralism and personal interactions in health care. The issue is made more complex with the

realization that there is ethical diversity on both sides of the patient-physician relationship. Both health care professionals and patients are multi-ethnic, multicultural, and pluralistic, with their own moral commitments, beliefs, and values. It is my position that it is crucial that both parties be able to act in a way that aligns with their moral convictions. I will argue that health care professionals ought to have control over their practice (within reasonable limits) so that they can act in good conscience; at the same time, patients ought to have the freedom to access - or refuse - treatments and services.

When health care professionals and patients have vastly different moral doctrines, finding a balance can not only be immensely difficult, but potentially hazardous. Studies have shown that substantial cultural differences between health care professionals and patients can lead to poor health outcomes for the patient (Pachter 691). This often occurs because the two parties have different values and beliefs, leading to differences in understandings of the patient's symptoms, condition, and options for treatment. Differences which, if overlooked, can jeopardize the therapeutic relationship and compromise communication between the health care professional and patient. In turn, the patient's satisfaction with their care, and adherence to treatment may suffer (Pachter 691). Thus, the greater the cultural distance between the two parties, the more likely there is to be miscommunication or misunderstanding, resulting in a greater risk of poor health outcomes.

Concerns are further complicated by the realization that individuals can revise their moral doctrine at any time. As revealed by Rawls, one's moral commitments can change for a number of reasons, be it life experience or the availability of new evidence. For a health care professional, this might mean reflecting on which services they provide and changing their practice. For a patient, this might mean consulting with their health care professional to ensure



their revised wishes are known and understood. In some health care settings where patients are receiving treatment over lengthy periods of time, this may be especially complex. In these cases, health care professionals must work diligently to ensure that they are aware of any revisions to the patient's moral commitments that would affect the care they expect to receive.

The challenges described in the above paragraphs make up what some have termed the problem of pluralism. Navigating this complex intersection of health care and ethical pluralism has become a substantial project for those working in bioethics. Bioethics is a relatively new, interdisciplinary field that examines ethical issues related to biology, the environment, human life, and health. There is particular interest in the implications for technological advances in biology and medicine. For instance, bioethicists might study research allocation in health care, issues surrounding the beginning and end of life, research ethics, or environmental responsibility. More specifically, this might mean unpacking issues like organ donation, abortion, medical assistance in dying, non-human animal testing, or stem cell research.

In studying the problem of pluralism in bioethics, we are called to reflect on many difficult questions: How does one navigate moral deliberation about a person's health between multi-ethnic, multi-faith, or otherwise pluralistic parties? How can health care practices be shaped so as to facilitate productive and respectful relationships between individuals that have vastly different moral doctrines? Instances of moral conflict in health care settings are not uncommon, and yet, there is little guidance about how they ought to be best addressed.

### **1.5 A Proposed Solution from Donald Ainslie**

Donald Ainslie is one thinker who has made notable contributions to the conversation about the problem of pluralism. In "Bioethics and the Problem of Pluralism", Ainslie analyses

the challenges that arise from ethical pluralism in health care, and argues that the doctrine of informed consent is an effective solution.

To start, Ainslie draws a distinction between two ethical projects. Bioethics, he explains, works toward creating public policy and norms for health care professionals (Ainslie 20). This approach to ethics is very much policy-oriented. Bioethics of everyday life, on the other hand, is the attempt to formulate moral principles and doctrines that help us to navigate the moral issues we face each day (Ainslie 2). Specifically, Ainslie is referring to the issues that stem from our biological nature, regarding reproduction, disease, disability, and mortality.

Ainslie emphasizes that policy-oriented bioethics and the bioethics of everyday life are not merely different approaches to an issue, but are essentially *complementary* tasks (Ainslie 20). He offers an illustration that is useful for understanding the distinction between these two ethical tasks, and their complementary nature. Consider, for example, that policy-makers are deliberating about when it is appropriate for health care professionals to withhold or withdraw life-sustaining treatment for patients (Ainslie 20). This question of policy can also be seen from the perspective of patients, by considering when patients can force health care professionals to continue or withdraw life-sustaining treatment (Ainslie 20). Although these two perspectives are framed in different ways, they are both primarily concerned with health care policy and practices.

There are important complementary perspectives for this issue in the bioethics of everyday life. These perspectives would focus on the individuals in the situation, drawing attention to the values and moral beliefs they might employ to navigate the issue. There may be questions raised about the disvalue (or value) of suffering, end of life care, preferred ways of dying, and one's ability to direct their own life (Ainslie 20).

Ainslie suggests that while policy-oriented bioethics tend to be the focus of the conversation, the importance of bioethics of everyday life must not be understated. His position, here, is rooted in his belief that each person ought to be able to appeal to their own moral doctrine to guide their life (Ainslie 19). Importantly, this includes drawing on their own moral principles when making decisions about their health care. A consequence of this is that individuals' moral doctrines must actually be able to provide guidance on such issues. As it stands, according to Ainslie, this is not the case. He argues that individuals' moral doctrines do not yet provide adequate guidance or support to navigate every day issues. It is for this reason that the bioethics of everyday life warrant further attention and examination. Without developing the bioethics of everyday life, Ainslie thinks, there will be little guidance for policy-oriented bioethics (Ainslie 20). Thus, he advances his project by exploring the values and moral beliefs with which individuals guide their lives.

Ainslie suggests that among ethically pluralist parties, there is, at least, one area of common ground: the value of one's body. Certainly, the level of value a person places on their body will vary depending on their moral doctrine; but, Ainslie thinks, every person – regardless of their moral beliefs – sees themselves as having a special relationship with their body (Ainslie 16). This special relationship may be as simple as the acknowledgement that we are each dependent on our bodies to interact with the world, and that a harm to our body is a harm to us (Ainslie 16). Given this, it seems reasonable to assume that each person will want to have control over who they let intervene in their body. It may be, then, that this common ground is a suitable starting point for trying to address pluralism in health care.

In light of this, Ainslie has expressed strong support for the doctrine of informed consent as an effective solution to the problem of pluralism (Ainslie 17). In his work, he argues that

informed consent “sets up conditions for bodily access that we can all accept, despite our different moral commitments” (Ainslie 17). There are two main reasons for Ainslie’s position, both of which I will explain below.

First, Ainslie emphasizes the practical value of patient autonomy, and in turn, informed consent. He argues that it is the only system that allows people who hold different moral doctrines to live together harmoniously (Ainslie 17). It is the only way, he thinks, to order the health care system in a way that respects each person’s moral commitments without interfering with the commitments of anyone else. Ainslie claims that informed consent protects each person’s right to make their own decisions about their body – regardless of what that decision is, in the end (Ainslie 17).

To be clear, Ainslie is arguing that informed consent is valuable in a *pragmatic* sense (Ainslie 17). This is important to note because it distinguishes his view from those who argue that autonomy and informed decision-making have *moral* value. This is to say, those who believe that autonomy is valuable in itself – that it simply *is* good. Ainslie makes no claim about the moral value of patient autonomy. Rather, he suggests that it is important because of what it enables us to do - namely, maintaining peaceful relations within pluralistic societies by allowing each person to make their own decisions, according to their own moral doctrine.

Second, Ainslie argues that the doctrine of informed consent gives individuals the most control over their circumstances. The wishes of the patient take priority, whether communicated by the capable patient themselves, or the substitute decision-maker if the patient is incapable. According to Ainslie, this effectively prevents patients from suffering abuse or exploitation when they are ill and so, especially vulnerable (Ainslie 17). Ainslie thinks that informed consent also ensures that individuals are in charge of how their beliefs and values are expressed in their lives.

This is crucial, he thinks, given the rich diversity in society. Even individuals who hold the same moral doctrine may weigh values differently, or have distinct understandings of what they are called to do in a given situation. In all, ensuring that patients have control over their care is especially important, as those suffering from poor health may feel dependent and vulnerable. It is evident that Ainslie believes the practice of informed consent to be an effective tool for navigating the problem of pluralism in the Canadian health care system.

### **1.6 Informed Consent in Canada**

In Canada, the practice of informed consent is directed by professional and legal standards. The process of obtaining consent from a patient must meet certain criteria, and follow a series of necessary steps. In this section, I will offer a description and analysis of the way in which this practice functions in Canadian health care settings. First, the health care professional has an open discussion with the patient where they disclose all relevant information about the patient's status – such as diagnosis, prognosis, treatment options and accompanying benefits or risks. Then, with this information, the patient is able to make their own decision about how to proceed, and either give or refuse consent for any or all treatment. The idea is that the patient has the freedom to appeal to their comprehensive moral doctrine, and choose a path that aligns with their moral commitments and beliefs. They are able to exercise their autonomy and maintain full control over what happens to their body. In the following section, I will discuss the current practice of informed consent in Canadian health care settings.

In Canada, health care services are the responsibility of both the federal and provincial or territorial governments. There are various mechanisms in each province or territory that serve to regulate the practice of medicine and maintain standards for health care professionals. In Ontario, the rules guiding the practice of informed consent, specifically, are detailed in the

Ontario Health Care Consent Act. This policy outlines the standards that health care professionals must meet when dealing with consent to treatment in health care settings. Here, ‘treatment’ refers to any care that serves a health-related goal, whether it be therapeutic, preventive, palliative, diagnostic, or cosmetic (Health Care Consent Act). The practice is also monitored by the College of Physicians and Surgeons of Ontario (CPSO). In their guidelines on consent to treatment, the CPSO states that “patient autonomy and respect for personal dignity are central to the provision of ethically sound care” (College of Physicians and Surgeons of Ontario). In the following section, I will unpack the guidelines for the practice of informed consent in Ontario.

In a widespread interpretation, informed consent is rooted in patient autonomy. Accordingly, health care professionals in Canada must obtain valid consent before they can proceed with any and all treatment (College of Physicians and Surgeons of Ontario). This means that a health care professional cannot administer treatment to a patient unless one of two criteria is met: i) the patient is capable with respect to the treatment and has given consent, or ii) the patient is incapable with respect to the treatment, and their substitute decision-maker has given consent on behalf of the incapable patient. This two-prong system appears to be fairly straightforward, but there are terms and ideas that must be thoroughly explained. For instance, what is *valid* consent? How does a patient come to be deemed capable or incapable with respect to treatment? How are substitute decision-makers selected, and what are their responsibilities? The nature of each of these elements can affect how the practice of informed consent responds to pluralism in Canadian society.

According to the Ontario Health Care Consent Act, consent is considered valid when it meets five conditions (Health Care Consent Act). First, the consent must be provided by a

capable patient, or the substitute decision-maker of an incapable patient. Second, the consent has to be related to the treatment. Third, the individual giving consent (whether this is the patient, or substitute-decision maker of an incapable patient) must have been made fully informed. Being fully-informed means that the individual understands the nature of the proposed treatment, the expected benefits, possible risks, possible side effects, and likely consequences of choosing to refuse the treatment (College of Physicians and Surgeons of Ontario). The goal of this condition is to ensure that the patient or substitute-decision maker receives all the information that “a reasonable person in the same circumstances would require in order to make a decision about the treatment” (Health Care Consent Act). Fourth, the consent must be given voluntarily, free from duress or coercion. Finally, the individual giving consent must not have been misguided, and the consent not obtained through fraud. To achieve this, health care professionals must be open and honest when discussing treatment options with the patient or substitute decision-maker. As the practice of informed consent is grounded in patient autonomy, the patient has the right to withdraw consent at any time – regardless of health care professionals’ recommendations - as long as the patient is capable at the time of the withdrawal (Health Care Consent Act).

Next, I will explore the policy guidelines concerning capacity. In a health care setting, a patient is capable with respect to treatment if i) they can understand the information relevant to making the decision, and ii) they can understand the possible outcomes of proceeding with or refusing treatment. It is important to note that the standards for capacity vary depending on the patient, and the gravity of the decision (Health Care Consent Act). For instance, it is possible for a patient to be capable with respect to choosing their dinner, but not capable with respect to treatment. As explained by the College of Physicians and Surgeons of Ontario, “capacity is fluid,

it can change over time, and depends on the nature and complexity of the specific treatment decision” (College of Physicians and Surgeons of Ontario).

According to provincial policy, health care professionals are to presume that an adult patient (over the age of 18) has capacity with respect to treatment unless there is a reasonable basis for believing otherwise (College of Physicians and Surgeons of Ontario). A health care professional might have a reasonable basis for thinking a patient is incapable if they note that the patient is behaving in a bizarre or erratic manner, or demonstrating a lack of insight about their situation. If, at any time, a patient disagrees with their being deemed incapable, they have the right to apply to the Consent and Capacity Board to review the finding (College of Physicians and Surgeons of Ontario).

When a patient is deemed incapable with respect to treatment, a substitute decision-maker is authorized to make decisions on their behalf. As per Ontario policy, only individuals with particular relations to an incapable patient can be considered for the position of substitute decision-maker. The qualifying relations are listed as follows, in order of seniority: the incapable patient’s i) guardian, ii) attorney for personal care, iii) representative as appointed by the HCCA Board, iv) spouse or partner, v) parent or child, vi) sibling, or vii) other relative (Health Care Consent Act). When going through the process of establishing a substitute decision-maker health care professionals begin with the individual at the top of the list, and work their way down until they have found an individual who satisfies specific requirements set out in the Health Care Consent Act (Health Care Consent Act).

To start, a substitute decision-maker must meet a minimum age requirement. They must be over the age of 16, unless they are the parent of the incapable patient. Next, they must be free from any court order or separation agreement that would prohibit them from accessing the



incapable patient or making a decision on their behalf. Further, the substitute decision-maker must be available. Under the policy guidelines, this means that it must be possible to reach them and have them make a decision within a reasonable amount of time, given the circumstances (Health Care Consent Act). Finally, the potential substitute decision-maker must be willing to accept the responsibility of making the decision to proceed with, or refuse treatment.

Once an individual is authorized as a substitute decision-maker, they must ensure that their decisions concerning treatment align with the most recent wishes expressed by the patient (at a time when they were capable) (Health Care Consent Act). If the wishes of the patient are not known, or impossible to comply with in the circumstances, the substitute decision-maker must decide in the patient's best interests. In doing this, they are encouraged to consider the incapable patient's beliefs and values, and the consequences for proceeding with or refusing treatment.

If there is a case where a health care professional believes that the substitute decision-maker is acting against the guidelines set out in the Health Care Consent Act, they can apply to the Consent and Capacity Board for guidance on how the case should proceed (College of Physicians and Surgeons of Ontario). Of course, a substitute decision-maker has the right to withdraw consent to treatment at any time, regardless of health care professionals' suggestions, as long as the patient is incapable. Now, with a more thorough understanding of the system of informed consent in Canada, I will move on to explore the practice in relation to pluralism.

As it stands, the practice of informed consent is generally thought to be an effective tool for navigating the (so-called) problem of pluralism. The system is structured so that a health care professional gives a patient all the relevant information about their state of health, and treatment options. With this information, the patient can make their own decisions with regards to their

care. They can appeal to their comprehensive moral doctrine, and choose a path that best aligns with their moral commitments and beliefs. When proper procedures are followed, it seems that a capable patient is able to exercise their autonomy and have full control over what happens to their body.

## **1.7 Conclusion**

There are many ways that the practice of informed consent is useful for navigating the tensions that accompany ethical pluralism in health care settings. However, it is my position that it is an insufficient mechanism for addressing the problem of pluralism. As it stands, the practice of informed consent is embedded with specific values, and assumes a particular understanding of health and illness. In the coming chapter, I will explore the ways in which the current practice of informed consent is value-laden, and the profound challenges that consequently emerge.

## **Chapter 2: Informed Consent as a Value-Laden Practice**

### **2.1 Introduction**

In the previous chapter, I laid the ground work for this project by exploring the concepts and ideas that are foundational to my argument. I examined the growing diversity in Canada, and the subsequent emergence of new ethical dilemmas. Specifically, I unpacked the challenge of accommodating ethical pluralism in the health care system, which is known as the problem of pluralism. I gave an account of Donald Ainslie's work on the problem of pluralism, and explored his argument that the doctrine of informed consent functions as an effective solution to these challenges. Finally, I examined the practice of informed consent in Ontario.

Recall, the practice of informed consent is integral to many significant elements of Canadian society, in particular, the health care system. In the practice of medicine and therapeutic research, it is critical for legal, ethical, and regulatory interactions. To review, the practice of informed consent calls for communication between health care professional and patient. Professional and legal standards require that that diagnoses, prognoses, benefits or risks of treatment, and alternatives to treatment are discussed. With this information, the patient makes the decision to accept or refuse health interventions.

Given the above information, it may seem that informed consent is a neutral practice. Health care professionals ensure that the patient is given all the information about their circumstances, and they are able to decide how to proceed. It appears that they are able to draw on their own moral doctrine, and make a decision that aligns with their values and beliefs. Consequently, it is assumed that informed consent is value-neutral.

Framed in this way, as a neutral practice, informed consent does appear to be an effective solution to the problem of pluralism. The central concern in the problem of pluralism, as you will

recall, is determining how to accommodate diverse values, beliefs, and practices into the structure of the health care system. If the practice of informed consent is value-neutral, then it appears to be a fair and equitable way for pluralist patients to engage in health care decisions. It facilitates accommodation for pluralist patients, and so, resolves the tension that constitutes the problem of pluralism. It is my view, however, that this scenario does not reflect the reality of the practice.

In this chapter, I will demonstrate that informed consent in Canadian health care is not a neutral practice. It is grounded in particular values and normative beliefs, and reflects a specific understanding of health and illness. As a result, different patients will perceive and experience the practice in different ways, depending on their moral doctrine. Consequently, it is my position that informed consent may not be able to fully address the problem of pluralism.

There are a number of values embodied in the current process of informed consent. So, it seems suitable to divide this chapter into sections, each of which devoted to establishing a particular way that the process is value-laden. First, I will argue that the Canadian practice of informed consent is embedded with norms of communication and decision-making. There is a predominant emphasis on individual autonomy and choice, over collective or family-centered decision-making. Further, it is assumed that all patients want a relationship of full disclosure and open communication with their health care team. In many moral communities, though, this level of disclosure is seen as inappropriate.

Second, between the patient and the health care professional, the latter holds a wealth of authority and power. It is sometimes taken for granted that patients have various attitudes towards authority, whether it be deference, neutrality, or distrust. The power imbalance, then,

can affect how a patient perceives their relationship with the health care professional, and can have a direct impact on the patient's ultimate decision to accept or reject treatment.

Third, although the practice of medicine is based on objective facts and empirical information, it also relies on the judgements of health care professionals - judgements that may be influenced by their normative beliefs about health, illness, and dying. Accordingly, these judgements can impact how health care professionals understand, and direct the practice of informed consent for a patient. There may be implications for what information the health care professional deems relevant to disclose to a patient, how they frame prognoses, or what recommendations they think are appropriate in a particular case.

Throughout this chapter, I will expand on each of the above points. I will demonstrate the various ways that values are embedded in the process of informed consent, establishing that the practice is not value-neutral.

## **2.2 Decision-Making and Communication Norms**

The literature on ethical pluralism reveals that Western bioethics is exceedingly individualistic (Lasser and Gottlieb 112). The practice of informed consent is traditionally rooted in individual autonomy and self-determination. These values are not, however, assigned the same weight across all moral communities. There is a great diversity of beliefs regarding what Christine Grady calls the “enduring and emerging challenges” of informed consent (Grady 855). These unsettled issues relate to what information is disclosed to patients, how information should be disclosed, how much the person giving consent needs to understand, and how explicit consent needs to be. These points of tension effectively highlight a series of values that are taken for granted in the process of informed consent.

To start, the practice relies on specific communication norms such as full disclosure, open communication, and truth-telling. Additionally, it is assumed that all patients make decisions in a similar manner - that is, through rational risk-benefit analysis and individual contemplation. In exploring the literature on moral communities around the world, it is clear that these particular values are by no means universal. In fact, the literature reveals the prevalence of contrasting values. Notably, the role of family-centered decision-making and the significance of non-disclosure.

In moving forward to explore these themes, I would like to emphasize the importance of being cautious when making generalizations about moral communities. Often, there is significant inter-group variation regarding the values, attitudes, and beliefs of members. Consequently, one ought not to make assumptions about any particular person based on their culture, faith, ethnicity, or other element membership in a moral community. So, while I discuss the moral views of *communities* in this section, I acknowledge that the members of any given community are not all the same, and I am wary of making any generalizations to this effect. With this in mind, I will move on to discuss the first theme.

In contrast to Western individualism, many moral communities have social approaches to decision-making and consent. Family-centered decision-making, for instance, is particularly common in Asia and Latin America (Lasser 108). When a relative becomes ill, it is understood that family members are central agents in making decisions on their behalf – sometimes even when the patient is competent and capable (Turner 108). In one study, researchers conducted interviews in the United States and Japan to compare attitudes. They described a case in which a patient had been found to have cancer, but had not yet been told. Participants were asked to indicate who they thought the physician should disclose the diagnosis to: the patient, or the

family. The researchers found that 80% of Japanese physicians and 65% of Japanese patients believed the physician should inform the family of the diagnosis, and allow them to decide whether or not to tell the patient (Ruhnke et al 1174). In stark contrast, only 6% of US physicians and 22% of US patients agreed that the physician should disclose only to the family (Ruhnke et al 1174).

Such findings reveal tremendous variation in attitudes towards decision-making roles. They substantiate the existence of broad diversity across moral communities, especially between individualist and collectivist societies. Undoubtedly, the Western focus on individual autonomy and self-determination is not universal. In Canadian health care, then, it is essential that health care teams understand what kind of norms and values guide a patient's life. Imposing the individualistic process of informed consent on a patient who is accustomed to collective decision-making could result in misunderstandings, inadequate consent, and complications with care (Lasser 112; Ruhnke et al 1173). Consider, for example, a Korean patient who values collective practices of decision-making, and wishes to involve their family or community in the process. If the values of this patient are not acknowledged, and they are pressured to make a decision in an individualistic manner, their choice to give or withhold consent seems ethically problematic.

The above study also highlights that family-centered decision-making can be closely tied to the value of non-disclosure. This type of communication norm appears to be prominent in Chinese, Ethiopian, Italian, Japanese, Korean, and Navajo communities (Turner 106). In communities that value non-disclosure, communication between health care professionals and patients may look very different (Ruhnke et al 1173). For example, it is not uncommon for families to insist that diagnoses and negative prognoses be withheld from ill family members

(Turner 105). This seems to be especially true in cases of cancer, as the following case will show.

In their research, Barbara Koenig and Jan Gates-Williams outline a case that is helpful for illustrating the idea of non-disclosure. They recall meeting a patient who had recently emigrated from China with his family, and had been diagnosed with cancer (Koenig and Gates-Williams 245). The patient's eldest son attended appointments to help with translation, as his father was monolingual. When speaking with the father about his condition, the family avoided using the Cantonese word for 'cancer', instead favoring a more neutral word for tumor (Koenig and Gates-Williams 245). Sadly, treatment was ineffective and the cancer became immediately life-threatening. When asked to deliver this news, the son became very upset. He explained to the researchers, "For us Chinese, we are not used to telling the patient everything, and patients are not used to this either. If you tell them, they can't tolerate it and they will get sicker" (Koenig and Gates-Williams 245). In the end, the health care team decided to bring in a Cantonese-speaking nurse to deliver the news to the patient.

Upon reviewing this case, it is clear that the family's ideas of appropriate disclosure were much different than those of the health care team. The son was deeply uncomfortable as, from his perspective, he had been asked to do something morally indefensible. The conflict of values led to tension between the cultural commitments of the patient's family, and the legal obligations of the health care team. Unfortunately, in an already difficult situation, the parties involved felt the added burden of moral distress, as they tried to navigate the norm conflict. Such beliefs about the power of language and non-disclosure are not uncommon, and they are not exclusive to immigrant populations in Canada.



In 1995, Joseph Carrese and Lorna Rhodes started a project to explore the attitudes of a Navajo community in Northeast Arizona. They were curious about the community's attitudes towards truth-telling and communication. Through their work, they discovered that most of the respondents felt that it was morally indefensible to share bad news with seriously ill individuals (Carrese and Rhodes 92). This attitude stemmed from their beliefs about the power of language. In this community, there was a strong belief that language did not merely describe reality, but shaped reality. So, they felt that discussing negative information could actually cause harmful outcomes to occur (Carrese and Rhodes 95). For instance, discussing the possible complications of surgery with a patient might ensure that the patient does suffer those complications.

Understandably, then, members of this community had profound concerns and suspicions about suggestions to discuss advance directives, end-of-life care, and risks of treatment (Carrese and Rhodes 93). The community's health care professionals, instead, made it a priority to think and speak in a positive, uplifting manner (Carrese and Rhodes 95). Evidently, non-disclosure was a principal value in this community, and is central to the beliefs of many others.

It is apparent that there is great diversity in what is accepted and expected in health care settings. Patients and families may be accustomed to communication and decision-making norms that are not supported in the practice of informed consent. Western bioethics emphasizes individual autonomy, while many moral communities are centered on social decision-making and community agency. Further, informed consent relies on full disclosure and truth-telling, but many individuals find this inappropriate, favoring instead caring practices of non-disclosure. When faced with illness or injury, patients and family members respond in a number of different

ways, and expect different practices of care. As it stands, the process of informed consent takes certain norms for granted, privileging certain moral communities, and marginalizing others.

### **2.3 Understanding of/Experience with Authority**

The practice of informed consent is further embedded with values because of the involvement and direction of health care professionals. As a result of their training, knowledge, and professional abilities, health care professionals hold positions of authority in society. Consequently, in their relationships with patients, health care professionals hold a great deal of power.

In the Canadian process of informed consent, the health care professional involved will often make recommendations about a particular course of treatment. These kind of recommendations are intended to help guide the patient as they consider their options, and eventually, make a decision. The patient is under no obligation to follow the health care professional's recommendations if they prefer to pursue a different care option, or reject treatment all together. However, a patient's inclinations toward authority can have tremendous consequences for their pursuit of care.

In some cases, an individual's inclinations toward authority can be traced back to the moral community of which they are a member. Some moral communities are structured by hierarchical social systems that are central to members' way of life. In caste systems, for instance, society is segregated into groups, where the membership of each is determined by birth. Each group has different roles, limitations, and opportunities. Caste systems are most prominent in Asia, Africa and the Middle-East, and are exceptionally visible in India among Hindus (Sharma 245). If a patient is accustomed to a caste system such that they view health care professionals as occupying a high level of the hierarchy, they may not consider that they have the

option to disagree with their health care team. As a result, they may automatically accept whatever course of treatment is suggested (Lasser 113).

Similarly, patients may yield their decision-making agency not because they feel it is required of them, but because their moral beliefs make them inclined to trust authority. In one study, Martin McKneally and Douglas Martin examined this tendency in Ontario cancer patients. They found the feeling of entrustment to be a powerful element of many patients' experiences in the informed consent process (McKneally and Martin 266).

At the beginning of their treatment, despite having had very little contact with their health care teams, many patients exhibited a great deal of confidence in the intentions and abilities of the health care professionals. Many patients believed their health care team cared for them, and would work competently and effectively towards a good health outcome (McKneally and Martin 266). Researchers noted that many patients seemed to idealize the health care professionals, focusing on their positive qualities and minimizing shortcomings (McKneally and Martin 266).

These patients' choice to consent to treatment was driven by their inherent trust in – and deference to – authority. Many shared that they did not see themselves as making a decision to give consent. Rather, they felt they were simply accepting the recommendation of an expert (McKneally and Martin 267). This very passive position to consent could be troublesome. It contrasts the theoretical understanding of the process of informed consent, whereby patients are thought to autonomously weigh the risks, benefits, and possible alternatives to treatment, coming to a rational decision. The presence of an authoritative figure, it seems, leads many patients to yield their agency.

On the other side of this issue, there are many moral communities that have deep-rooted distrust towards authority. Often, this is because the community has suffered mistreatment,

abuse, and exploitation at the hands of government officials or national institutions (Lasser 113). A striking example can be seen in Canada's Indigenous populations who have endured appalling historical relations and ongoing injustice. Indigenous communities have been subject to generations of discrimination, mistreatment, and broken promises. Think, for instance, of the government-funded forced sterilization of Indigenous women that occurred across Canada, peaking in the time immediately after World War II into the 1970s (Pegoraro 162). This legacy of colonialism has understandably, left many Indigenous people viewing health care professionals with suspicion.

The repercussions of this profound distrust is illustrated by Jacklin et al who studied the health care experiences of Indigenous people in Canada. They interviewed a number of people living with type 2 diabetes who self-identified as Indigenous. Some participants shared that their interactions with health care professionals stirred memories of their experience in residential schools. This often happened when a health care professional acted in a prescriptive or authoritative manner (Jacklin et al 108). Such actions emphasized the power imbalance and triggered many participants to feel the need to resist the health care professional's advice, or avoid interactions with them all together.

Researchers also noted that there was a prevalent fear among participants of being used as "guinea pigs" to test experimental treatments (Jacklin et al 108). There was a suspicion that they might be treated differently than non-Indigenous patients. Researchers emphasized that these concerns were not baseless as many were derived from past experiences where the participants, or members of their community, had suffered such mistreatment.

This adverse inclination towards authority is troublesome because it means that patients who, justifiably, distrust the health care system may not get the care that they need. The practice

of informed consent presumes that patients make the choice to accept or reject treatment rationally and objectively. However, when patients have an automatic response (like distrust) to health care professionals - even if that response is justified - they may be prevented from conducting a fair evaluation of the treatment options. They may prematurely dismiss options that are, in fact, well-suited for their condition, and align with their values and beliefs. In this way, patients' distrust or suspicion of authority can colour their experience and undermine the opportunities that the process of informed consent is supposed to provide.

Ultimately, patients' understanding of, and experience with authority can have serious implications for how they perceive the process of informed consent. Patients may automatically defer to authority, whether because of the community hierarchy they are accustomed to, or because of an inclination to trust authority figures. On the other hand, patients may feel substantial distrust and suspicion towards authority after having been subject to mistreatment. In either scenario, the authoritative presence of health care professionals influences patients' participation in the informed consent process, and compromises their ability to take control of their care.

## **2.4 Value Judgements in Medicine**

Another way that values enter the process of informed consent is through health care professionals' normative judgements. Health care professionals are educated in the 'hard sciences' (biochemistry, physiology, anatomy, etc.) and are trained to work with objective studies and empirical facts. However, there are elements of the practice of medicine that leave health care professionals to make value judgements about health and illness. The concern, then, is that these normative judgements may affect how health care professionals understand and participate in the process of informed consent.

The respective works of Leigh Turner and Renee Anspach reinforce this point. Both authors argue that decision-making in medicine is fundamentally social, and that there is not always a clear distinction between facts and values (Anspach 215; Turner 114). Studies have shown that the judgements of health care professionals' are based only in part on objective information (like a patient's signs, symptoms, and test results) (Anspach 215).

Their judgements are also based on social norms, cultural assumptions about gender, the perceived social status of the patient, and the patient's ability to advocate for themselves (Anspach 215). Further, their position will be influenced by their particular understanding of health. So, a health care professional may use their expertise to assess the facts of a case, but the judgements they form are just as likely to be shaped by norms and social factors. Clearly, then, these professional judgements are not value-neutral.

One substantial reason that value-laden judgements are of concern is that health care professionals often make treatment recommendations to patients. If their judgements have been informed by moral beliefs, then the recommendations they offer would seem to be biased. There are many unsettled issues in medicine regarding understandings of health and illness. Subsequently, for each of these issues, there is a great diversity of opinions among health care professionals.

Consider that judgements regarding health, illness, and normality are necessarily value-laden. For instance, what is *normal* functioning? What is considered an impediment or disability? What is *good* health? What is a *good* quality of life? Although these questions are rooted in medicine, they are fundamentally normative. A person's position on any given issue will depend on their moral beliefs and life experience. Evidently, then, a health care

professional's position can affect how they view a particular case and what recommendations they offer the patient.

Further, such normative judgements can affect the amount of information health care professionals disclose to patients. Ontario guidelines on informed consent require that health care professionals provide to patients all the information that a reasonable person would need in order to make the decision to accept or reject treatment. But who is the reasonable person that policy-makers have in mind? This guideline can be interpreted in various ways, leaving health care professionals to determine the appropriate level of disclosure on their own. The degree of disclosure they decide on might be acceptable for some patients, but may result in other patients feeling like they have been given an inappropriate amount of information – whether it is too much or too little.

Next, the subjective beliefs of health care professionals can affect not only their recommendations for treatment and what information they disclose, but how the information is disclosed. Depending on a health care professional's beliefs about a case, they will present information a particular way (consciously or not). This is concerning because studies have shown that individuals will make different choices depending on *how* options are presented (Gonzales et al 2). This occurrence is due to a cognitive bias referred to as the framing effect (Gonzales et al 2). To illustrate this effect, imagine that individuals are asked to evaluate strategies for addressing a hypothetical epidemic (Gonzales et al 2). According to the framing effect, a person is more likely to avoid risk when a case is presented in a positive manner (say, in terms of saving lives). If, on the other hand, the case is presented in a negative manner (such as the potential of minimizing deaths), the person is likely to favor options with greater risk (Gonzales et al 2).

In health care, the framing effect has meaningful implications for the process of informed consent. A patient's decision regarding treatment will likely be affected by whether the options are presented positively or negatively – that is, in terms of success or failure, survival or death, etc. (Wilson et al 53). A health care professional's beliefs about a case can have profound implications for how they deliver information to the patient, which can directly impact the decisions being made regarding treatment.

In his work, Barry Hoffmaster draws attention to an apt illustration of these issues. He explains that in neonatal intensive care units, there are times when a severely ill baby is allowed to 'declare itself' (Hoffmaster 1426). This means that the baby 'makes a decision' about its care, by making a significant turn for the worse, or showing clear improvement that justifies aggressive treatment (Hoffmaster 1426). Here, health care professionals and parent(s)/guardian(s) defer to the baby to decide how to proceed.

It seems clear, though, that this process is subject to one's beliefs. The parties involved must judge what qualifies as a significant turn for the worse, or how much improvement justifies treatment. Further, as discussed above, the health care professional's perception of the case will affect what information is disclosed and in what manner, as well as what recommendations they offer to the parent(s)/guardian(s).

As a final note, it is crucial to recognize that health care professionals sometimes disagree about prognoses, which can affect their involvement in the informed consent process. Renee Anspach studied this occurrence during her time in a neonatal intensive care unit. She found that prognostic disagreements often occur between doctors and nurses (Anspach 227). Anspach traced this disagreement to their different "modes of knowing" (Anspach 227). Doctors, who spent little time with the infants, often made judgements based on physical signs and symptoms,



the results of diagnostic tests, and medical literature. Nurses, on the other hand, spent a great deal of time caring closely for the infants and so, often made judgements based on their interactions.

Anspach's findings here, are fascinating, but troubling. They suggest that the parent(s)/guardian(s) of infants with identical conditions could be disclosed different information based on the normative judgements of their respective health care professionals. Different modes of knowing, then, can have substantial implications for health care professionals' understanding of a patient's condition.

In all, within the seemingly objective practice of medicine, health care professionals frequently make normative judgements about health and illness. There are many unsettled moral issues in medicine, and each person's position on a given issue will be grounded in their own modes of knowing, beliefs, and experience. Accordingly, health care professionals understand and approach the practice of informed consent in different ways. The position held by a health care professional will affect their value judgements about prognoses, what information to disclose, the manner that the information is disclosed, and the treatment recommendations they offer to a patient. The values of the individual health care professionals on a case, then, shape how the patient experiences the process of informed consent.

## **2.5 Conclusion**

In closing, it is evident that informed consent in Canada is grounded in values, and so, is not a neutral practice. First, as I have demonstrated, it relies on Western norms of communication and decision-making, specifically prioritizing individual autonomy over social decision-making, and truth-telling over caring practices of non-disclosure.

Second, it has also been established that many patients have strong beliefs about authority, which can affect their perception of the informed consent process. Some are inclined to trust authority and may automatically yield their agency to the health care professional. Others may have deep-seated distrust and suspicion towards authority, and may feel the need to resist help from health care professionals. In both cases, patients' inclinations compromise their autonomy and control.

Last, I determined that the normative judgements of health care professionals can have substantial implications for patients' experience of the informed consent process. Health care professionals' moral beliefs can affect how they understand a patient's condition, how they deliver information and how they feel treatment should proceed. Undoubtedly, informed consent is not sufficient for addressing ethical pluralism in health care, because the practice itself is value-laden.

## **Chapter 3: Methods and Limits of Accommodation**

### **3.1 Introduction**

In the previous chapter, I established that informed consent in Canadian health care is not a value-neutral practice. I argued that it is grounded in specific values and moral beliefs, and reflects a particular understanding of health and illness. Throughout the chapter, I unpacked three significant ways that values are embedded in the practice of informed consent.

First, informed consent relies on communication and decision-making norms that are not universal. It assumes that patients are comfortable with full disclosure when, in fact, many moral communities value caring practices of non-disclosure. It also emphasizes individual choice over family-centered decision-making. Second, different patients can have varying inclinations towards authority, which affects how they respond to health care professionals' recommendations and their ultimate decision to accept or reject treatment. Patients may automatically defer to authority, or they may display distrust and suspicion. In either case, their understanding of authority can affect their experience in the informed consent process, and compromise their ability to control their care.

Third, in practicing medicine, health care professionals often make normative judgements that influence how they guide patients through the process of informed consent. These judgements can impact how they determine prognoses, what information they think is relevant to disclose to patients, how they choose to present that information, and what treatment recommendations they think are appropriate in a given case.

In all, it is clear there are many ways in which values are colouring the process of informed consent for patients. In this chapter, I will present strategies for accommodating ethical pluralism in the practice of informed consent. First and foremost, I will argue that an active

resistance of assumptions should be at the center of health care professionals' practice. It is crucial that health care professionals approach patients with an awareness that they are complex, unique individuals. I will offer methods that health care professionals can employ to avoid relying on stereotypes and come to understand the values that guide their patients' lives. Primarily, I will argue that it is crucial for health care professionals to take the time to learn about patients' values and beliefs *before* they begin any discussion about the patients' condition.

Second, as we have seen, many moral communities value practices of non-disclosure, where negative information is not shared with patients. In light of this, I will argue that, in some cases, a 'lower' standard of informed consent may be appropriate. In these cases, patients would have a discussion with their health care professional about their beliefs, and request that certain information be withheld. This request, in turn, would be noted in the patient's records.

Third, I will discuss how to address patients' deference or distrust towards authority. I will argue that these two concerns can be addressed in similar ways. I believe health care professionals ought to receive additional training focusing on issues of trust, authority, and power dynamics. Then, in their everyday practice, they can implement specific strategies targeted at building trust, promoting partnership, and balancing power. The goal of this is to create meaningful collaboration between the health care professional and patient, where both parties are active in contributing to the patient's care goals.

Finally, I will suggest that there may be a limit to the possible accommodation of ethical pluralism in Canadian health care. The concern regarding health care professionals' normative judgements, for instance, is exceedingly complex. I believe that there may not be a way to resolve such issues. I will, however, propose methods that may, at least, help to alleviate some of the existing tension.

These limits to our accommodation exist due to the structure of the health system, and the various types of concerns that we face. Some tensions can be resolved fairly easily. Consider, for instance, an Islamic patient who requests that their body be turned to face the East after death. Health care professionals can accommodate this patient's wishes without causing much (or any) disruption.

Other times, however, patients' wishes may be more difficult to accommodate. This might be the case if the requests would interfere with care, incur substantial costs, are controversial and/or make health care professionals deeply uncomfortable, or violate professional or legal standards. For example, imagine a family who requests indefinite life support and care for a brain-dead patient, because they believe they are 'still there' (Koenig and Gates Williams 248). Or, for an example in the context of informed consent, imagine that a family requests that a health care team withhold information from the patient, and refrain from disclosing a diagnosis. These more complex cases stand in stark contrast to the first, and illustrate a number of the concerns described above.

The problem, here, is trying to accommodate ethical pluralism within the existing structure of informed consent in health care. As we move through the chapter, it may become clear that many of the strategies I put forth are connected. This is because they center on building relationships and inclusivity, and learning to approach others with an open mind.

### **3.2 Resisting Assumptions**

In response to the problem of pluralism in Canadian health care, some would suggest creating a guide of sorts to which health care professionals could refer. The idea is that the guide would outline the beliefs and practices of various moral communities. It is my belief that this proposed solution is misguided - the reasons being twofold.

First, I would argue that it simply is not practical to think that such a reference guide could be created. The diversity in Canada is vast and growing. Some estimate that there are hundreds of moral communities in the country, each with intricate beliefs and practices (Masi VI 538). Further, it may be the case that a community's beliefs are evolving over time, such that any reference guide might quickly become out of date. Second, and more importantly, the apparent danger of this kind of document is that it could lead easily to stereotyping. If health care professionals come to rely on such generalized guidelines, they may make assumptions about their patients and overlook important individual features.

My proposal, in contrast, is to actively and consistently resist making assumptions about patients. A person's ethnicity, culture or religion may be an important part of who they are, but simply assigning them to a generalized category based on these features would be irresponsible. Stereotyping in this way could lead to inadequate care, patient dissatisfaction, and poor health outcomes. As stated by Koenig and Gates-Williams, "patients should never be approached as empty vessels, as the bearers of particular cultures" (Koenig and Gates-Williams 247). Coming to understand patients' wishes and motivations is a more complex - and in the end, worthwhile - project.

Of course, this is not to say that health care professionals should not have an understanding of the populations they serve. It would certainly prove helpful to be aware of the moral communities in the area where they practice. For instance, understanding that many Asian cultures prioritize community and family-centered approaches over individualism may help to facilitate relationships with patients who express these values. The difficulty, again, is ensuring that one does not use this general awareness to make assumptions about any particular patient based on their membership in a moral community.

Rather, health care professionals ought to approach patients with the understanding that they are complex, unique individuals. Moral communities throughout Canada are not mutually exclusive, nor are they entirely distinct from one another (Hamilton 585). A person's moral beliefs, then, may represent a mix of ethnicities, cultures, and religions. It is also likely that their beliefs have been further influenced by factors like their personal experience and relationships, among others (Hamilton 585). In all, any given person's values may be shaped by a number of diverse sources that have a bearing on their health care wishes.

Given the arguments established in the previous chapter, it is clear that patients often approach health care settings with extraordinarily diverse moral doctrines. These values and beliefs are often meaningful aspects of the patient as an individual. It may be these moral principles on which the patient relies to direct their life. The trouble is that the health care professional may be entirely unaware of the presence of these values and beliefs, or their significance to the patient, until the provision of care has already begun.

It is my assertion that health care professionals can address this issue by having thoughtful, intentional conversations with their patients about such matters *before* they begin the process of informed consent. It is crucial that the health care professional start with this conversation, to ensure that the patient receives effective and appropriate care. Consider, for example, that there are many instances where patients seek medical help while also seeking help from a cultural healer (Pachter 691). In these cases, it is essential that the patient's health care team is aware of all forms of care the patient is receiving. Otherwise, the patient may be at risk of inadvertent drug interactions or side effects.

Moreover, by coming to know their patients as individuals first, health care professionals will demonstrate their investment in patients' well-being, and foster strong therapeutic

relationships. It will make certain that health care professionals are aware of the patients' values, beliefs, expectations, and wishes before any treatment is offered. Accordingly, health care professionals will be more successful in thwarting the misunderstandings and value-conflicts that, as I have demonstrated, can jeopardize patients' health outcomes.

Health care professionals can employ this strategy at a number of levels. First, health care professionals ought to have a conversation with their patient directly. They can take this time to ask questions, and allow the patient to tell their story. This can be an exceedingly useful way for the health care professional to learn about the values that guide the patient's life and their goals for treatment. At the same time, they can discuss what level of disclosure the patient is comfortable with (to be expanded on in the following section), and come to understand how they make decisions and on whom they rely for support.

Second, it can also be useful to make connections with the patient's family (provided, of course, that this is something with which the patient is comfortable). In doing this, the health care professional should listen to how the family talks about the patient and their condition. The language used can give crucial information about how they understand health and illness, and consequently, how the health care professional should present information in subsequent discussions. It is also important to recognize any existing power dynamics in the family. Consider, for instance, that there may be a family member with a great deal of influence over the patient. Understanding the patient's close relationships will allow the health care professional to provide more meaningful support throughout the process of informed consent.

Third, the health care professional can acknowledge any bigger picture influences that may be bearing on the patient. It is important to consider the historical and political context, for example, with patients who may have suffered discrimination, poverty, or a lack of access to



care. With this, health care professionals should be encouraged to make use of community resources. Depending on the case, appropriate resources might be interpreters, community leaders, or any other resource that would help to strengthen the therapeutic relationship and support the patient.

These initial meetings and conversations will help the health care professional come to know their patient's values and beliefs. In doing this *before* they begin to analyse the patient's condition, or develop ideas for treatment, they ensure that the patient will receive appropriate care. However, this strategy also requires a considerable investment of time and energy. This may be demanding for health care professionals who are under pressure to be as efficient as possible. In this way, the growing diversity in Canada can be onerous for physicians, nurses, social workers, or ethicists who want to deliver effective, patient-centered care. For, in more homogenous societies, health care professionals and patients are likely to have a shared understanding of what practices are accepted and expected (Koenig and Gates-Williams 246). Although these demands on health care professionals are unfortunate, they may be necessary for supporting patients' care.

### **3.3 Considering a 'Lower' Standard of Informed Consent**

As you will recall, issues surrounding disclosure are becoming common in Canadian health care settings. Many moral communities (like the Navajo) value caring practices of non-disclosure which are not supported in the current process of informed consent. Throughout the literature on disclosure in health care, a discussion has begun to surface regarding the possibility of a lower standard of informed consent (Taylor 512). In essence, the idea is that patients could request to receive *less* information from their health care professional. Hence the labeling of this practice as a *lower* standard of informed consent. I argue that this mechanism is a viable and

appropriate solution to the current tension between patient wishes, and professional/legal requirements.

Taylor suggests that, in practice, health care professionals could start a conversation with their patient, like those described in the above section (Taylor 512). Throughout this conversation, the health care professional would come to understand the patient's wishes regarding disclosure. Patients who value non-disclosure could request that particular information be withheld, opting for a lower standard of informed consent. With this, the health care professional could make note of this request in the patient file (Taylor 512). The note, for example, could read "John Smith requested that he not receive information regarding risks of treatment when deciding whether to accept or reject treatment". This is just one example of a possible mechanism by which a lower standard of informed consent could be supported. Certainly, there are other methods that health care professionals could employ to make information available to patients without requiring them to access it. An alternative, for instance, could be for the health care professional to create an audio file detailing the relevant information, enabling the patient to listen to the file if they so choose<sup>1</sup>. In any case, importantly, the health care professional would ensure that the patient knows they are free to revise their position at any time, and receive information that had been previously withheld.

In this work, it is not my goal to endorse any particular mechanism for practicing a different process of informed consent. Rather, I aim to establish the value in allowing patients to opt for a lower standard of informed consent, if they so wish. I argue that it is a useful method of accommodating ethical pluralism in health care, as it allows patients to control the information they receive, ensuring that their care aligns with their values.

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<sup>1</sup> Thank you to Katy Fulfer for providing this example.

This concept may be controversial, but I argue that it can be justified on several grounds. First, implementing this practice works to support good health outcomes for patients. Consider, for example, a Navajo patient who has deep-rooted beliefs that language shapes reality. Such a patient may wish not to hear the risks of treatment, as they believe that this discussion will directly *cause* those outcomes to occur. Insisting that this patient hear the risks of treatment, is to jeopardize their health (Taylor 512). This is because in some cases, patients with such beliefs will refuse treatment after being forcibly told the risks (Taylor 512). The imposition of these practices may also discourage such patients from accessing health care again in the future. As a result, these patients are vulnerable to suffering worse health outcomes.

Next, a lower standard of informed consent promotes the mental and emotional well-being of patients. Imagine that the Navajo patient, after having been told the risks of treatment against their wishes, decides to proceed with treatment. They are likely to experience distress and anxiety, as they now feel vulnerable to bad outcomes. It is not, "for example, pleasant to live in the belief that one will soon suffer a fatal heart attack, irrespective of whether or not one actually does suffer a heart attack" (Taylor 512). Understandably, this kind of fear and dread can be irreparable.

Finally, allowing patients to opt for a lower standard of informed consent will help to foster relationships and build trust. To respect a patient's wishes is to affirm that they are an equal partner in the therapeutic relationship. It is to acknowledge the importance of their beliefs, and validate their role in the process of healing.

Each of the lines of justification described above are also supported by the principles of bioethics. Chiefly, the principles of autonomy, nonmaleficence, and benevolence. An individual's autonomy is their ability to enact self-determination and self-governance (Lützné et al 132). To

support a patient's autonomy, then, is to allow them to make their own choices and direct their own life. Accordingly, when a patient is permitted to opt for this lower standard of informed consent, their health care professional is respecting the patient's capacity to act autonomously, and determine what information they wish to receive.

Next, the principle of nonmaleficence too, is promoted in the lower standard of informed consent. Nonmaleficence calls health care professionals to refrain from causing harm to patients in their practice (Beauchamp and Childress 114). With the lower standard of informed consent, health care professionals can withhold particular information (as specified by the patient) that could otherwise have caused the patient substantial discomfort or distress. Preventing such harm is crucial because, as explained earlier, forcing the patient to receive unwanted information can jeopardize their physical and mental well-being, causing long-term repercussions (Taylor 512).

Last, the option of a lower standard of informed consent would allow health care professionals to abide by the principle of benevolence. To act in the spirit of benevolence is to promote kindness, altruism, and humanity. It is not to merely refrain from doing harm (as with nonmaleficence), but to actively advocate for the good of others (Beauchamp and Childress 165). With the lower standard of informed consent, health care professionals can offer sensitive, effective care. They can tailor the process of informed consent to their individual patient, allowing them to live according to their moral beliefs and values.

Now, it is clear that there are some concerns with implementing this strategy. Chiefly among them, is that a lower standard of informed consent is not supported by professional and legal standards, and so, leaves health care professionals vulnerable (Lasser and Gottlieb 113). Evidently, the current health care and legal systems are not yet in a place to accommodate such a change. That is not to say, however, that they *cannot* accommodate this change in the future.

There are compelling reasons to support this practice. I believe that with relatively minor changes to the current professional and legal standards, a lower standard of informed consent could be implemented, and could become an integral part of accommodating ethical pluralism in health care.

### **3.4 Building Partnership to Navigate Distrust**

One of the principal concerns identified in the previous chapter is patients' perceptions of authority, and how these perceptions can compromise the decisions patients make about their care. In this section, I will look first, at addressing patients' distrust of authority. To work towards a solution for this concern, it is important to understand the nature of distrust. Therefore, I will lay the foundation for my proposal by drawing on some insightful sources of literature on the topic.

In essence, to trust someone is to be vulnerable to them. As captured by Annette Baier, trust is "accepted vulnerability to another's possible but not expected ill will (or lack of good will) toward one" (Baier 235). The truster believes that they will not be taken advantage of, but is vulnerable to possible negligence, abuse, or ill will at the hands of the trusted. A person is further vulnerable to the actions of the entrusted person, even if those actions are motivated by good will (Baier 236). The trusted may overstep the scope of that with which they were trusted, and do too much. For instance, consider a house guest who unexpectedly paints your living room while you are at work because they think the house needs some colour. Surely, the house guest had good intentions, but they still did not act the way they were trusted to. On the other hand, the entrusted person might be incompetent, and so, fail to act capably and appropriately with that which they were trusted (Baier 236).

In health care, patients are vulnerable in their relationship with health care professionals. This vulnerability can exist in a number of forms. For one, patients are the ones who have reached out, and are seeking help from the health care professional. Patients have to disclose personal, sometimes sensitive information about themselves, trusting that it will be kept confidential. Additionally, in some ways, they are at the health care professional's mercy in terms of receiving prescriptions or being granted access to further tests. In all, patients are put in a position where they must trust that their health care professional will act in their best interests.

Accordingly, health care professionals can jeopardize trust when they go against patients' interests. This could mean that the health care professional does too much and oversteps (like the house guest), or does too little and fails to satisfy the patient's wishes. As discussed above, these violations of trust can be motivated by intentions that are good, or bad. In any case, violating a patient's trust can have lasting repercussions for how they approach health care professionals and the health care system in the future.

Health care professionals, then, must work to build a relationship with patients who are wary or distrustful of authority. There are a number of strategies that health care professionals can employ to work towards this goal. To start, it is crucial that the health care professional takes time to focus on relationship-building (Thom 1997). They ought to meet with the client and participate in an open conversation, as described earlier in this chapter. The health care professional should get to know the patient as a whole person, and learn about their values and preferences. They ought to empathize with the patient, acknowledging their concerns and goals. It is also essential that the health care professional works to balance the power in the relationship, and build a partnership with the patient (Thom 1997). This might mean giving the patient options for how to proceed and being open to their ideas or suggestions. An important

part of this partnership will also include admitting to mistakes, and honouring commitments. Overall, the goal of this step is to ensure that patients feel they are an equal in the relationship.

Next, it is important to ensure the patient receives competent clinical care. This means thoroughly evaluating the patient's condition by going over their history, giving a thoughtful assessment and showing a willingness to refer to specialists. The latter can be especially important as health care professionals are sometimes viewed as 'gatekeepers' to further care (Thom 1997). Then, after having a comprehensive understanding of the patient's condition, the health care professional must work to provide effective treatment. This includes ensuring correct diagnoses, offering appropriate treatment options, and working hard to help the patient achieve a good outcome. Of course, these elements are essential characteristics of good care and, so, may already be part of many health care professionals' practice.

Addressing distrust in Indigenous patients may, understandably, take more effort on the part of the health care professional. Researchers have found that many concerns expressed by Indigenous patients are related to the themes of history, trust, and time (Towle et al 344). The theme of *history* refers to concerns about the legacy of colonialism and residential schools (Towle et al 344). To address this as a health care professional, one should ensure they understand the history of injustice and ongoing mistreatment of Indigenous people in Canada.

In the theme of *trust*, Indigenous patients recounted experiences of health care professionals being very impersonal and distant (Towle et al 344). These concerns call health care professionals to invest in their relationship with the patient. It is important for patients to feel they can discuss their feelings of distrust, and have space to share past negative experiences. It is also essential that health care professionals ask questions about the individual's beliefs and practices, as they may play a prominent role in the patient's healing. Concerns surrounding *time*

often centered on Indigenous patients feeling rushed and insignificant in the eyes of their health care professional. In light of this, health care professionals need to dedicate time to their patients. Avoiding rushing patients, and understanding that a good relationship may take time, are critical components of this strategy.

### **3.5 Addressing Deference with Meaningful Collaboration**

Just as patients' distrust of authority is concerning for the practice of informed consent, so too, is patients' automatic deference. Recall, that deference may take place when a patient is accustomed to a hierarchical culture or caste system such that they feel they must yield to health care professionals. It could also be that a patient is simply inclined to trust authority and so, accepts any recommendations from health care professionals without hesitation. I argue that both of these issues can be addressed with similar strategies: i) training health care professionals on the dimensions of power, and ii) practicing meaningful collaboration with patients.

The goal of this training is to support health care professionals' awareness of the power they hold, and come to understand how this can affect the care that patients receive. As a result of their extensive knowledge, experience, and expertise, health care professionals have a great deal of power over their patients (Gabel 1158). This power imbalance can be compounded depending on patients' experience with, or understanding of authority. In this proposed training, health care professionals would learn to recognize the power dynamics in their clinical relationships. They would be taught about the different forms that power can take, and appropriate uses for power (such as advocating for a patient), versus inappropriate uses (such as coercion). It is crucial that they have an understanding of how the power they hold can influence patients' decisions, and ultimately, their care.



When considering patients who are inclined to trust authority, specifically, it is helpful to explore the concept of trust. In his work, Tony Gilbert suggests that there are two types of trust: interpersonal and impersonal (Gilbert 569). Interpersonal trust is built between individuals over time. It relies on personal qualities, competence, and commitment to standards of behaviour (Gilbert 569). Impersonal trust, on the other hand, "is based on the proposition that trust pre-exists the involvement of any individual and, crucially, does not require knowledge of any other individual within the system" (Gilbert 569). Put simply, the person trusts the system in which the professionals are situated, and so, automatically trusts the professionals.

In the case of health care, impersonal trust is necessary for interpersonal trust (Gilbert 569). The concern is that patients who have an inclination to trust authority figures rely solely on impersonal trust. They do not take the time to assess their health care professional or attempt to cultivate interpersonal trust. They yield their autonomy to a particular health care professional, based on their perception of health care professionals and the health care system, *in general*.

If the goal is to prevent health care professionals' authoritative presence from influencing patients in this manner, it may be that the solution is for health care professionals to withhold treatment recommendations. They could provide information about the patient's condition and treatment options, but refrain from giving their professional opinion on which treatment is most appropriate (Quill et al 764). They could answer all of the patient's questions, albeit, objectively. Throughout the process of informed consent, health care professionals would need to avoid showing preference for any one treatment over another, even if they feel strongly about the case (Quill et al 764). They would need to work diligently to appear neutral.

My concern is that restricting health care professionals from offering recommendations seems to eliminate the humanity from their practice. It precludes health care professionals from

offering guidance based on their expertise or experience, essentially confining them to the role of information dispensaries. I believe that this "artificial neutrality" (Quill et al 765) would impede their ability to support the patient, and may, ultimately, diminish the therapeutic relationship. Additionally, some patients may feel that this practice is patronizing. They may wish to draw on their health care professional's counsel as a resource, and resent the suggestion that they are too impressionable.

In light of these concerns, I propose an alternative strategy. I argue that health care professionals should be able to continue offering treatment recommendations by building them into a practice of meaningful collaboration with patients. Quill et al have done thoughtful work on decision-making practices, which, I believe, can be applied to these issues of authority and power. Based on their findings, I will propose suggestions for addressing patients' deference in the process of informed consent.

To start, health care professionals can engage in open and honest communication with the patient and their family. Along with learning about the patient, they can talk about their own values and experiences, and admit their biases (Quill et al 765). They should acknowledge the power dynamics in their relationship, and discuss the importance of the patient making the decision that is right for them. In doing this, it is the hope that the health care professional and patient will explore each other's perspectives, coming to understand how they each view the situation and what their goals are. Additionally, this communication will allow the health care professional to offer more wholesome treatment recommendations, by considering the patient's clinical condition as well as their personal values and experience (Quill et al 765).

It is important that the relationship is not seen as one-sided, with the health care professional simply imparting information on the patient and directing their treatment. Rather,

both should understand that they are active, contributing parties. When it is time to evaluate treatment options, the health care professional should try to involve the patient in setting goals and evaluating progress. Such methods may encourage a passive patient to start taking a more active position in their care.

Disagreement between health care professional and patient can be seen as an opportunity for exploration. It might indicate that the two have different understandings of the condition or treatment, or that they have ascribed different meanings to some aspect of the situation (Quill et al 766). By determining what they agree on, they can uncover from where, exactly, the disagreement stems. Doing this will help to deepen and enrich the therapeutic relationship. It will cement the relationship as not only professional, but personal (Quill et al 766). Being able to engage in this process without dominating or pressuring the patient will require health care professionals to have training about balancing power - as discussed earlier in this section.

Of course, in the end, decisions concerning care rest with the patient. If the health care professional and patient still find themselves in disagreement, the former, at least, has a chance to come to understand why. Upon understanding the patient's reasons for their position, it may be easier for the health care professional to accept the decision (Quill et al 766). If, however, they are uncomfortable with the patient's wishes, they have the option to discuss this with the patient and refer them to another health care professional.

One of the leading assets of this approach is its emphasis on relationships. To withhold treatment recommendations altogether, I believe, would be to leave patients isolated, lacking the support they may desperately want. This, at a time, when they may be feeling vulnerable and frightened in the face of illness or injury. The proposed relationship-centered approach, rather, works to build connections between the patient and their health care team (Shepherd and

Mohrmann 261). It supplies the patient with all the resources they may wish to access (including the opinion of the health care professionals), and empowers them to take control of their care.

### **3.6 The Limits of Accommodation**

If you recall, at the beginning of this chapter I discussed a pair of cases. The two cases had different features such that one could be easily addressed, and the other, could not. The first was an Islamic patient's request to have his body turned to face the East upon his death. The second was a family's request for ongoing, indefinite care for a brain-dead patient. Our ability to make such accommodations depends on the specific features of each case. Unfortunately, in some cases, the complexity of the issue is so profound that there does not seem to be a reasonable path to resolution.

I believe this to be true regarding the case of health care professionals' (Acosta-Masquera 71). In most cases, they are attempting to act objectively and provide unbiased, effective care. Accordingly, I do not believe it is reasonable to think that this is an issue which could be addressed. Further, while I believe that the influence of one's values on patient care calls for attention, it is not clear that the presence of values in health care is something that needs fixing. One's values and beliefs are essential parts of their humanity. And, as highlighted earlier, the humanity of health care professionals is an important part of the care they provide. It is through this humanity that they make meaningful connections with patients, and foster therapeutic relationships.

So, while I do not believe that this issue can (or maybe, ought to be) resolved, it is worth examining. Research on this topic will help us to become more aware of these dynamics in health care, and better understand the nature of the issue. It may be that there are strategies for making health care professionals more aware of how their personal beliefs affect their clinical

judgements and practice. For instance, it may be that health care professionals are encouraged to participate in a workshop, during which they practice critical reflection and self-awareness. It may be something similar to cultural competence training. In this kind of workshop, though, instead of focusing on the beliefs, attitudes and values of patients, they would turn inward and focus on their own.

Regardless of what direction this research may take, it is crucial that it remains a project motivated by knowledge, and not blame. To have beliefs and values that guide one's life is to be a human being. It is not, in any way, something deserving of shame or blame. Health care professionals, like everyone else, are people driven and shaped by values. Unavoidably, the things we care about - consciously and unconsciously - affect the lens through which we see the world.

Continuing to examine the limits of accommodation, it is worth reflecting on my proposal regarding the lower standard of informed consent. Although I believe this strategy works to effectively support pluralist patients and ease the tension of the problem of pluralism, it also has the potential to create substantial complications. Earlier in this chapter, I discussed how the lower standard of informed consent might function for a patient who requests that the risks of treatment be withheld. Consider, in contrast, a patient who opts for the lower standard of informed consent, and requests that *all* information about their health be withheld. They insist that they do not wish to receive information about any condition they maybe have, or receive any form of diagnosis. However, despite their wishes on disclosure, the patient *does* want to receive treatment.

Such a case raises difficult ethical and practical questions. If the patient does not wish to know about their condition, then, presumably, they do not want to receive information about

treatment options either. How, then, are decisions to be made about the patient's care? It would seem that the patient is not in a position to make any such decisions themselves, as they would be doing so without any context or understanding of the circumstances. Should a substitute decision-maker be authorized, just as in the case of an incapable patient?

If, by chance, the patient *did* want to receive information about treatment options and make their own decision, it is not clear that the health care professional could deliver the relevant information without revealing the patients' condition. Imagine, in any case, that the health care professional succeeds in explaining the patient's treatment options without divulging information about their condition. It is possible that the patient may select a treatment which is not optimal for their particular condition and circumstances. Consequently, the health care professional may experience considerable distress. They may believe that the patient has made an ill-advised choice, given their ignorance to the critical information about their case. In light of these extensive concerns, I believe it is reasonable to argue that there be a limit to how much information patients can request health care professionals withhold.

These considerations also raise questions about some of the other strategies proposed in this chapter. As noted earlier, many of the strategies put forth rely on relationship-building and open, honest communication. Recall, for example, my suggestions for addressing patients' deference to authority. I argued that health care professionals could engage in meaningful collaboration with patients. This would entail conversations where both parties would share their values, beliefs, experiences and biases. They would acknowledge the power dynamics in the relationship, and work towards a balanced partnership. What, then, of a patient who opts for a lower standard of informed consent and requests not to participate in these crucial conversations?

If the patient does not wish to have open, honest communication, then the health care professional's ability to build trust and partnership is weakened.

These challenges can be traced, primarily, back to competing goals and interests. While abiding by a patient's request and withholding particular information is to respect their autonomy; health care professionals may find this practice deeply uncomfortable. They may feel that they are acting against the principle of beneficence, as the patient's health outcomes are put at risk. Further, as noted earlier in this chapter, engaging in this lower standard of informed consent would violate the professional and legal standards to which health care professionals are bound. Evidently, the health care system in Canada is not yet equipped to address these issues, or accommodate such requests.

### **3.7 Conclusion**

Of course, I am aware that the strategies I have proposed call for resources - whether it is time, money, or effort. This is especially challenging given that resources are already scarce in Canadian health care. Health care professionals are under substantial pressure to be efficient, and so, rely on short appointment times to see as many patients as possible each day. In order to move towards addressing any of these issues, then, health care leaders must first believe in the importance of this project. It must be made clear that to accommodate ethical pluralism is to ensure more effective patient care, and help meet wider health goals such as adherence to treatment.

At the outset of this project, I posed a series of questions: How is the practice of informed consent in Canadian health care grounded in values? In what ways can we accommodate ethical pluralism in health care? What are the limits of this possible accommodation? In this thesis, I worked to offer thoughtful and effective answers to those questions.

In Chapter 1, I started by exploring diversity and ethical pluralism in the Canadian context. I discussed the ways that distinct value systems emerge and interact with one another, and how these value systems can create value-conflicts and tension. It was then that I introduced the problem of pluralism, focusing on the existence of ethical pluralism in the Canadian health care system. I gave an account of Donald Ainslie's work, and his proposed solution to the problem of pluralism: the doctrine of informed consent. I closed the chapter with a comprehensive look at how the practice of informed consent functions in Canadian health care settings.

Next, in Chapter 2, I presented my argument that the process of informed consent in Canada is not value-neutral, as implied by Ainslie's view. I demonstrated that informed consent is, in fact, rooted in specific values and beliefs, and reflects a particular understanding of health and illness. In particular, I examined three significant ways that values are embedded in the practice: through decision-making and communication norms, assumptions about patients' perceptions of authority, and the normative judgements of health care professionals. Consequently, I established that informed consent is value-laden, and so, is not able to fully address the challenges of the problem of pluralism.

Finally, in Chapter 3, I presented strategies for accommodating ethical pluralism in the practice of informed consent. I suggested that health care professionals initiate conversations with patients about their values, beliefs, expectations, and goals *before* any discussion of illness or treatment. I also gave arguments to support the idea that patients could opt for a lower standard of informed consent, and request that particular information be withheld in their decision-making process. Last, I proposed that patients' deference or distrust of authority be



addressed by introducing additional training on power dynamics for health care professionals, and encouraging health care teams to engage in meaningful collaboration with patients.

I also, however, argued that there are important limitations to the possible accommodation that can be provided in the Canadian health care system. I suggested that some challenges regarding ethical pluralism in health care are profoundly complex, such that resolution or accommodation may not be possible. This is the case, I argue, with two notable issues: health care professionals' normative judgements, and the potential implementation of a lower standard of informed consent. Due to the considerable challenges identified, it is my position that these issues cannot be accommodated within the structure of the Canadian health care system - or, at least, not yet.

The important thing to note, then, is that this project is just beginning. The issues I have identified and the strategies I have proposed are merely the start of a conversation. Further research is needed to continue this work and shape the strategies that will, hopefully, become integral parts of Canada's health care system. Ralph Masi has suggested that, "the art of medicine is based on the art of communication, which must encompass compassion, empathy, and understanding (Masi VI 538). If, moving forward, this project continues to be guided by these values, I believe it has the potential to shape the future of patient care in Canada.

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