

Physician Engagement with Family and
Close Others of Patients during the Informed Consent Process

by

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Supervisory Committee

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Abstract

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The participation of family members or close others of a competent adult patient during pre-consent discussions with physicians challenges the integrity of confidential, dyadic interactions ordinarily regulated by ethico-legal rules designed to protect the patient's autonomy. Hence it is important to understand how experienced physicians navigate such 'triadic' discussions because their tacitly-applied communication skills during such encounters reflect their interpretation of patient autonomy as well as the complex role of families in medical decision-making. Formal training in the development of such skills is lacking in medical curricula.

Using the qualitative methodology of Interpretative Phenomenological Analysis (IPA) and through conducting in-depth interviews of purposefully selected participants, answers to this question were sought: What is the experience of Canadian specialist physicians in high-risk fields in their interactions with family of competent patients during the informed consent process?

The project design and analysis of the research data were guided by philosophical insights from law, bioethics, feminist and postcolonial theory. A central argument presented is that current approaches to informed consent, being rooted in law and bioethics, are excessively individualistic and hence do not adequately deal with the tensions that arise during multi-party clinical discussions. Many patients benefit from support of trusted relatives or friends when medical issues about their condition are discussed with the intention of securing consent. However, such family involvement is more than what health care professionals typically allow in compliance with typical ethico-legal frameworks. It is critical therefore to add a socio-political perspective rooted in the social sciences that constructively integrates the concept of relationality into clinical consent practice.

The research findings provide an explicit portrait of the tacit skills used by physicians as they navigate multi-party interactions, underscoring the complexity and unpredictable nature of triadic clinical interactions and identifying priorities adopted in balancing the interests of the patient with those of family members. The locus of control and authority during these interactions is identified, as are the measures taken whenever a patient's autonomy appeared to be compromised. The knowledge gained from this research is of value in medical education, as well as in the development of institutional consent protocols and policies governing provider-patient interactions.

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Dedication

For my Family and my Patients.

CHAPTER 1: Introduction

A Patient, Her Family, and Informed Consent: A Bruising Personal Experience

Late one afternoon a visibly anxious couple arrived at my neurosurgical clinic in Kuala Lumpur, one of Southeast Asia's many bustling and diverse cities. They were clutching bundles of reports and brain scans that belonged to Sophia (not her real name), a successful entrepreneur in her late forties with a thriving business in a nearby city. The benign brain tumour displayed on Sophia's MRI scans confirmed the cause of her worsening imbalance when she walked, her facial numbness, and her troublesome vertigo and vomiting. She had developed a massive basal meningioma: a slow-growing tumour that arises from the lining of the skull and progressively distorts and displaces the brain stem and cranial nerves, threatening vital functions — her vision, swallowing, coughing, breathing, and ultimately, her life.

I spent two hours with Sophia and her husband (a man of a different ethnicity from his wife), explaining the diagnosis and her prognosis if the tumour was left untreated. I presented a range of possible treatment options and cautioned about the risks of surgery. Having recently obtained a master's degree in medical law I was particularly sensitized to the legal standards of risk disclosure and the various elements of informed consent. By the end of this discussion I felt that I had made it clear that surgery would carry life-threatening risks.

Sophia appeared to understand what was at stake. She was understandably distraught and cried intermittently throughout our interaction, mentioning that she had young children and owned a business that depended very much on her personal involvement. She was the sole breadwinner in the family. I gave Sophia and her husband contact details for two other neurosurgeons in the city, and recommended that they seek a second opinion.

The next morning I received a message from Sophia's husband, saying they had both made a decision; they wanted me to proceed with surgery as soon as possible, and were both confident in my expertise and understood the risks involved. On the evening before surgery, I visited her hospital room to meet with Sophia and her husband, to ask if

they had further questions, and to introduce them to a neurosurgical colleague who would assist me during surgery. That colleague went through the risks of surgery, again, with the couple.

Surgery went on as planned, the following day. As expected, the tumour was large and difficult to remove completely because of the way it had insinuated itself between cranial nerves and other vital brain structures. After nine hours of microsurgery, Sophia was transferred to the intensive care unit where she was sedated and placed on assisted breathing. The next morning she woke up to speak to us, was able to obey commands, and moved all her limbs equally. We were pleased with the outcome at that point.

Unfortunately, twelve hours later Sophia became drowsy and much less responsive, which prompted us to conduct a CAT scan. The imaging demonstrated swelling of her brain, along with a small blood clot in her ventricular system that had become enlarged, indicating obstruction to the flow of her cerebrospinal fluid. Sophia was taken back to the operating room where a drainage tube was inserted to siphon off the brain fluid and to monitor her intracranial pressure. She was placed on coma-sedation with artificial ventilation support, to tide her over this critical period. Unfortunately Sophia continued to deteriorate over the next forty-eight hours and further CAT scans showed a delayed stroke of her brain stem, possibly due to thrombosis of the veins around the tumour site. Her pupils had become unreactive, indicating grave failure of brain stem function.

After the operation I had kept Sophia's husband apprised of her condition on a regular basis, communicating with him several times a day. Early on a Sunday morning, two days after she had deteriorated, the head nurse of intensive care called me to say that Sophia's family had demanded an urgent update conference. At that meeting I was confronted by a large gathering: her husband had called the patient's five siblings and her parents to the hospital. I discovered that none of Sophia's immediate family had been informed about her brain tumour or the seriousness of the surgery before that day. They were understandably very upset. During the meeting, Sophia's husband appeared to be under pressure from his in-laws because they had not been kept in the picture. I sensed that there may have been a measure of pre-existing intra-family tension present, bearing in mind that he was of a different ethnicity — a significant factor within some social local groups

— and older than Sophia, and that she had in fact been the major family breadwinner. He now claimed that I had not warned him and Sophia that surgery carried major risks.

I had never experienced such a difficult challenge during a family conference in my entire twenty-four years of medical practice, and nothing in my formal training had prepared me for it. The anger and frustration of Sophia's family was redirected at me and I found myself having to repeatedly give them detailed explanations of the medical condition that had brought her to the hospital in the first place.

Darkness descended over the intensive care waiting area over the next few days as Sophia's extended family and business clients, some of whom who were politicians and members of local royalty, showed up to pay their respects. Every time I passed by the groups of visitors congregating in several areas of the hospital, Sophia's husband would point me out as the surgeon who had 'damaged' his wife. Once a visitor pulled me aside to warn me that he had been making threats like, "*If I lose Sophia, I will make sure this doctor also loses his wife!*"

Sophia was removed from life support a week after surgery. Her husband wrote me long and accusatory letters twice after that, including one on the anniversary of her death. Those correspondences blamed me for his loss and insisted that I had not warned him and his wife about the seriousness of the operation.

1.1 – Physicians' Simultaneous Interactions with Patients and Families

It is typically only when an illness makes an individual a 'patient' that they are forced to confront their vulnerability and dependence on healthcare professionals and family members to cope with their needs. Anxiety or distress caused by the illness of a loved one, as well as cultural expectations, may cause family members to insist on participating in medical decision-making with the patient. This aspect of family involvement can unsettle the integrity of confidential physician-patient interactions, ordinarily guarded by well-established ethical and legal rules.¹ Institutional norms are

¹ The word 'patient' will be used herein to refer to a person who is *legally competent* to consent to an elective, non-emergency therapeutic procedure. The use of this term excludes situations where special legal rules governing consent for medical treatment apply, such as in emergencies involving an unconscious patient, in decision-making regarding minors, for patients with mental incapacity, or where futility of treatment is at issue.

formulated primarily to protect the patient's privacy and freedom to make decisions — rights that the healthcare professional is both obliged and authorized to protect.²

The process of obtaining a patient's informed consent with family members present may, however, be reframed as an opportunity for physicians to develop relationships with persons who are validly invested in the welfare of the patient and the outcomes of treatment.³ The decisional support of family members can contribute to the patient's own confidence, most notably if they are distressed by their illness and have been presented with the often overwhelming medical information necessary to come to an informed decision. These considerations may become increasingly relevant in an era when shared decision-making is upheld as a desirable goal within healthcare.⁴ Yet the eagerness of family members to participate in deliberations with (or on behalf of) their loved ones can be informed by complex cultural factors — factors which also determine their expectations of healthcare services in general.⁵

While the importance of the physician-patient relationship is central to the teaching of bioethics and medical law, physicians are not explicitly trained to interact with the family members of their patients, particularly when these persons are involved in medical decision-making. Various bioethical and legal rules focus on the individual and the integrity of the physician-patient *dyad*; hence the participation of third parties in clinical encounters (creating a *triad*) can represent a risk to the aforementioned, highly valued norms of privacy, confidentiality, and autonomy. Because physicians generally do not

² N Karako-Eyal, "Has Non-US Case Law Recognized a Legally Protected Autonomy Right" (2008) 10 Minn JL Sci Tech 671; N Hunter, "Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality and Participation Norms" (2010) 45 Wake Forest L. Rev. 1525.

³ Henceforth, for convenience the words 'family' or 'family members' will be used to describe relatives, 'close others', 'significant others' and various persons trusted by the patient to participate in decision-making about their medical care. It is understood that 'family members' may not be close, and conversely, persons close to the patient may not be literal family members. It is also acknowledged that the defining characteristics of a family incorporate a configuration of meanings informed by a range of ideas and practices that embrace diverse understandings of the socio-legal institution of marriage itself. See, for example JA Holstein & J Gubrium, "What is Family?" (1999) 28:3-4 Marriage Fam Rev 3, VL Bengtson, "Beyond the Nuclear Family: The Increasing Importance of Multigenerational Bonds" (2001) 63:1 J Marriage Fam 1; SB Boyd, "Marriage is more than just a piece of paper: Feminist Critiques of Same Sex Marriage" (2013) 8 NTU Rev 263.

⁴ C Charles et al. "Cultural Influences on the Physician-Patient Encounter: The Case of Shared Treatment Decision-Making" (2006) 63:3 Patient Educ Couns 262.

⁵ P Dilworth-Anderson, "The Cultures of Caregiving: Conflict and Common Ground among Families, Health Professionals, and Policymakers" (2005) 293:1 JAMA 104; FW Hickling, "Understanding Patients in Multicultural Settings: A Personal Reflection on Ethnicity and Culture in Clinical Practice" (2012) 17:1-2 Ethn Health 203.

receive formal training on how to best engage with patients' family members, they typically develop idiosyncratic approaches to such challenging interactions. These are influenced by a variety of elements, including their own familial experiences, their personal values, and the behaviours modeled by seniors in their profession.⁶ Other key factors are a physician's own interpretation of the concept of 'patient autonomy' and how strongly it must be protected,⁷ as well as the influence of the educational culture of a physician's communications training generally.

I argue that the skills that allow physicians to engage constructively with a patient's family are vital, and should not be left to an informal, and thus unpredictable (and potentially erratic) training process. Making explicit the tacit skills that experienced physicians use in navigating communications with family members, in winning their trust, and in recognizing their role in decision-making about care of the patient promises multiple dividends. First, because the quality of the relationships between physicians and patients' family members can have a critical bearing on several aspects of patient care — namely trust and confidence-building, planning of short and long-term medical interventions, and ensuring compliance with treatment — warrants more sustained and systematic attention to triadic relationships in clinical settings. Further, the potentially serious social, legal and financial consequences of poor clinical communications with patients and their families, for both individual practitioners and healthcare institutions, also support a more methodical approach and nuanced understanding of patient-family-physician interactions.⁸ Such knowledge is not only of use in medical education, but also in the framing of rules

⁶ E Boisaubin, "Observations of Physician, Patient and Family Perceptions of Informed Consent in Houston, Texas" (2004) 29:2 J Med Philos 225; American College of Physicians Ethics, Professionalism and Human Rights Committee et al. "Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships" (2010) 25:3 J Gen Intern Med 255.

⁷ Origin: Greek *autonomia*, from *autonomos* 'having its own laws', from *autos* 'self' + *nomos* 'law', The interpretation herein will be that applicable to individual persons — 'freedom from external control or influence; independence. Additionally, (in Kantian moral philosophy) the capacity of an agent to act in accordance with objective morality rather than under the influence of desires. Oxford Living Dictionaries. "Autonomous" [definition] (2015) online: <https://en.oxforddictionaries.com/definition/autonomous> (accessed 15 Oct 2016)

⁸ M May & DB Stengel, "Who Sues Their Doctors? How Patients Handle Medical Grievances" (1990) 24:1 Law Soc Rev 105; C Vincent, M Young & A Philips. "Why Do People Sue their Doctors? A Study of Patients and Relatives Taking Legal Action" (1994) 343 Lancet 1609; T Marjoribanks et al. "Physicians' Discourses on Malpractice and the Meaning of Medical Malpractice" (1996) 37:2 J Health Soc Behav 163; JL Ausman, "Trust, Malpractice, and Honesty in Medicine: Should Doctors Say They Are Sorry?" (2006) 66:1 Surg Neurol 105.

governing consent process and institutional policies aimed at constructive engagement with the public in healthcare environments.

Ultimately, there is both intrinsic and instrumental value in viewing the pre-consent process as much more than it constitutes at present, which is primarily a legally-oriented system of information transfer for the purposes of upholding patient autonomy. As Neil Manson and Onora O’Neill argue, if autonomy protection is an important value, then the extension of informed consent processes to achieve other purposes (such as trust-building or the opportunity for practitioners to engage constructively with the patient’s family members) should be welcomed.⁹

My research — informed by my own professional experiences; using data gathered through in-depth interviews with physician-participants; and guided by philosophical insights drawn from law, bioethics, and feminist and postcolonial theory — asserts that successful and constructive engagement with patients’ families materially contributes to the establishment of harmonious healthcare relationships. I begin the remaining sections of this introduction with personal reflections of my experiences working with families during informed consent processes,¹⁰ foreshadowing a more sustained discussion of informed consent in Chapters 2 and 7. I also provide recent examples of Canadian legal cases that illustrate the value of ensuring healthcare providers’ understanding of the ethico-legal¹¹ role of family members in medical decision-making. The reflections provide the background to the formulation of my main and supplemental research questions, which I delineate before describing my project’s key concepts. I then devote a section to discussing

⁹ NC Manson & O O’Neill, *Rethinking Informed Consent in Bioethics* (Cambridge: Cambridge University Press, 2007) at 33.

¹⁰ ‘Informed consent’ is shorthand for informed, voluntary, and decisionally-capacitated consent. Consent is considered fully informed when a capacitated (or “competent”) patient or research subject, to whom full disclosures have been made and who understands fully all that has been disclosed, voluntarily consents to treatment or participation on this basis. N Eyal, “Informed Consent” (20 September 2011) in EN Zalta, ed, *Stanford Encyclopedia of Philosophy* (Stanford: Stanford University, 2011) online: <https://plato.stanford.edu/entries/informed-consent/> (accessed 05 Nov 2016). The expression *informed consent* will be used herein to incorporate the connected processes of *pre-consent discussions* leading to *medical decision-making* by a competent patient.

¹¹ I use ‘ethico-legal’ to refer to both bioethical as well as legal principles, doctrines or issues because of the common historical development, philosophical goals and controversies of both these fields as they pertain to the issue of informed consent and personal autonomy in healthcare settings. See for example, RR Faden, TL Beauchamp & NMP King. *A History and Theory of Informed Consent* (Oxford University Press, USA, 1986); JL Dolgin, “The Legal Development of the Informed Consent Doctrine: Past and Present” (2010) 19:1 *Camb Q Healthc Ethics* 97.

the different theories invoked in the course of inquiry, which together provide a coherent framework upon which I elucidate my research findings. I end my introduction with an outline of the overall methodology of the project, summarizing briefly the essential components of each of the subsequent chapters.

1.2 – Personal Reflections on Families’ Participation in Pre-Consent Discussions

Throughout my career as a specialist neurosurgeon I obtained informed consent from patients on a regular basis, often involving my patient’s family members in the decision-making either simultaneously or separately. Because I practiced in a multicultural Commonwealth country, my patients were drawn from diverse socio-cultural backgrounds, and the relevant local ethico-legal frameworks were modeled on consent doctrines from English common law and North American bioethics. As clinicians, my peers and I were familiar with landmark United Kingdom cases such as *Bolam v Friern Hospital Management Committee*, and precedent-shifting Australian medical negligence cases like *Rogers v Whitaker*.¹² We were thus trained to be constantly conscious of our patients’ legal capacity to consent, our obligations to disclose risk at the requisite legal standard, and the importance of meticulous documentation of risk warnings presented to patients and their families.

As with most of my colleagues, I never received any formal training orientated to communications with family members of patients. We applied individual approaches to such interactions, modeled on the behaviours of our professional seniors, applying ‘common sense’ as well as our sense of empathy for anxious significant others. As may be expected, some seniors were better models than others, which could account for the

¹² *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 is an English tort law (medical negligence) case that established a rule for assessing the appropriate standard of reasonable care in cases involving skilled professionals (for example, doctors). The ‘Bolam’ test, as it is commonly known, calls for a standard that must conform to a responsible body of opinion, even if other professionals differed in opinion. In the case of *Rogers v. Whitaker* (1992) 175 CLR 479, a case involving standard of risk disclosure for a medical procedure, the principle articulated by the High Court of Australia shifted the rule from the ‘Bolam’ standard to one where the Court would be the final arbiter (not a body of medical professionals) of whether a medical practitioner had appropriately explained the significant risks of a procedure (i.e. those that might change the patient’s mind about whether or not to undergo it) before the patient could give valid consent. If a practitioner did not explain these ‘material risks’ that may then occur, it would be considered negligent. ‘Material risks’ included the loss of chance of a more favourable result, had a more experienced practitioner conducted the procedure.

variations in our styles and approaches. Additionally, we had been trained in a variety of Western and Asian medical schools, each with its own educational culture.¹³ Our communications training had clearly been delivered in a non-standardized manner and we were unaware of any rules governing these forms of interactions.¹⁴

Although local consent rules were silent about the need to engage with families of patients, practitioners who conducted high-risk procedures would never have considered undertaking any major procedure without involving the family in pre-consent discussions about risk.¹⁵ In our local collectivist cultural environment, families were frequently involved in the provision of care to the patient at home, or with taking responsibility for the financial burden of long-term medical expenses. Their interests were thus understandably intertwined with the patient's decision-making, most notably in the case of older patients even when they were legally competent.

More recently, as a co-founder of a new medical malpractice indemnity organization (Medical Defence Malaysia, Ltd.) that now offers legal defence services to its members, I became acutely aware of a wide variability in the communication skills of physicians.¹⁶ This variation was most evident in the aftermath of treatment complications and consequent malpractice actions initiated by family members against the doctor or institution. I was soon convinced that communications skills of physicians informed the risk of them being sued by patients or their representatives when things go wrong.¹⁷ I have additionally observed that the commitment to engaging with family members varies with the sectoral context, with practitioners in 'for-profit' institutions being keen to satisfy customer expectations and more willing to welcome family members' participation than

¹³ V Ambrosini, "Tacit Knowledge: Some Suggestions for Operationalization" (2001) 38:6 J Manag Stud 811; FW Hafferty & JP Hafler, "The Hidden Curriculum, Structural Disconnects, and the Socialization of New Professionals" in JP Hafler, ed, *Extraordinary Learn Workplace, Innovation and Change in Professional Education* (Dordrecht: Springer Netherlands, 2011) 17; SC Mahood, "Medical Education: Beware the Hidden Curriculum" (2011) 57:9 Can Fam Physician 983.

¹⁴ H Lempp & C Seale. "The Hidden Curriculum in Undergraduate Medical Education: Qualitative Study of Medical Students' Perception of Teaching." (2004) 329 Br Med J 770; Mahood, *supra* note 13.

¹⁵ I use the expression 'high-risk' procedure to refer to medical interventions which carried a significant risk of injury to life, limb, or cosmetic appearance; for example brain or spinal tumour surgery, cerebral vascular surgery, cardiac surgery and forms of plastic surgery.

¹⁶ Up until this local organization was launched, the only medical malpractice defence service accessible to local doctors was based in the United Kingdom, where experts who were located in a different legal and cultural environment had the authority to remotely determine the management of legal threats to Malaysian physicians.

¹⁷ May & Stengel, *supra* note 8; Vincent, *supra* note 8.

their counterparts in public institutions. These differences are relevant to subsequent discussions wherein I examine how power differentials between patients, families, and healthcare providers affect communication practices, especially in the event of unexpected treatment complications.

In much of the Majority World,¹⁸ particularly in Commonwealth countries, education about informed consent and its institutional governance appears to be driven primarily by legal, rather than ethical or sociological considerations. The applicable rules are largely influenced by English common law principles, with their corresponding philosophical and moral underpinnings. In this framework, the position of family and caregivers during the consent process remains unclear, even when the socio-cultural context of medical decision-making is one in which inter-relatedness is highly valued. In my opinion, based on several personal communications, many physicians in Malaysia, Singapore, Indonesia, and India sense a significant dissonance between informed consent rules, orientated as they are to the individual patient, and the actual clinical practice of obtaining consent.

1.3 – The Ethico-Legal Role of Families in Medical Decision-Making: Illustrative Canadian Legal Cases

The clinical practice conditions I have referred to so far are those of a collectivist cultural context; however, I have also considered whether the dynamics of the patient-family-physician relationship might be subject to different socio-legal norms in a Western country, such as Canada. Two recent Canadian cases illustrate the difficulty in anticipating the expectations of family members with an interest in participating in treatment decision-making in such contexts. In *Cuthberston v Rasouli*,¹⁹ a case heard before the Supreme Court of Canada, the main issue was whether physicians must seek consent from patients, their surrogate decision-makers, or an independent tribunal, in order to terminate life-

¹⁸ ‘Majority World’ — a term coined by Bangladeshi photojournalist and scholar Shahidul Alam to replace expressions such as Third World, Developing World, or Least Developed Countries, which arguably reinforce colonial representations of countries and regions in the Global South as backward or otherwise lacking. See S Alam, “Majority World: Challenging the West’s Rhetoric of Democracy” (2008) 34:1 *Amerasia* J 87; R Leong, “Majority World: New Veterans of Globalization” (2008) 34:1 *Amerasia* vi; OV Nandimath, “Consent and Medical Treatment: The Legal Paradigm in India” (2009) 25:3 *Indian J Urol* 343.

¹⁹ *Cuthbertson v Rasouli* 2013 SCC 53, [2013] 3 SCR 341.

sustaining treatments deemed medically futile.²⁰ Chief Justice Beverley McLachlin (writing for the 5:2 majority) stated at [1]:

This case presents us with a tragic yet increasingly common conflict. A patient is unconscious. He is on life support — support that may keep him alive for a very long time, given the resources of modern medicine. His physicians, who see no prospect of recovery and only a long progression of complications as his body deteriorates, wish to withdraw life support. His wife, believing that he would wish to be kept alive, opposes withdrawal of life support. How should the impasse be resolved?

A primary aspect of the conflict in this case was the disagreement between the patient's wife (herself a physician) and family, and the healthcare professionals responsible for his care. Amongst a variety of issues, respect for the religious beliefs of the family and the limits of the institution's resources were considered.²¹

A more recent case, *Hamilton Health Sciences Corp. v. D.H.*, involving the choice of treatment for a child with malignant disease, further illustrates the unpredictable difficulties that can arise in patient-family-physician interactions in Western settings.²² This case, heard before the Ontario Court of Justice, involved differences in opinion between the family members of an aboriginal minor (JJ) with leukemia and her hospital physicians. JJ's mother chose to give her child plant-based traditional treatments rather than medically recommended chemotherapy, ostensibly after observing some of the early side effects of the drugs. A newspaper, however, reported that the mother had changed her mind about chemotherapy very soon after an incident in the hospital, wherein a nurse allegedly made a sarcastic comment suggesting that a traditional First Nations healing ceremony conducted for the child was likely to be completely ineffective.²³

²⁰ This Ontario case represented part of a dispute between two particular physicians at the Sunnybrook Health Sciences Centre in Toronto and the family of a comatose man. It involved a 59-year-old mechanical engineer of Iranian descent, Hassan Rasouli, who entered a coma after contracting bacterial meningitis following brain surgery at Sunnybrook in October, 2010. The physicians, Drs. Brian Cuthbertson and Gordon Rubinfeld, claimed that Mr. Rasouli had entered a permanent vegetative state and that life support should be withdrawn in order to prevent a slow death from complications of being bedridden. Mr. Rasouli's family refused to consent, arguing that his religious beliefs should be respected and that, as a devout Shia Muslim, he should be kept alive on mechanical support "until all signs of life are gone."

²¹ Para 186, 196, 199.

²² *Hamilton Health Sciences Corp. v. D.H.*, 2014 ONCJ 603.

²³ G Galloway, "Native Mom who pulled Daughter out of Chemo Wants their Names Used," *The Globe and Mail* (21 November 2014) online: <http://www.theglobeandmail.com/news/national/native-mom-who-pulled-daughter-out-of-chemo-wants-their-names-used/article21715478/> (accessed 11 October 2016).

These cases exemplify the challenges that can be encountered when family members are involved in medical decision-making in a Western context.²⁴ Although these examples pertain to surrogate decision-making, I posit that similar complexities can arise when family members expect to participate in decision-making for competent individuals. Here, considerations of individual privacy, autonomy, and the risk of coercion arise — but so does an awareness of the interdependence of patients and persons they trust and who are close to them.

Common law consent doctrines have, by and large, remained silent about the obligations of healthcare practitioners to engage with family members in such situations.²⁵ In British Columbia, however, the *Health Care (Consent) and Care Facility (Admission) Act*, both codifies and adds to the common law consent requirements. Section 8, sets forth the position of family members with regard to their participation in the consent process:²⁶

*When seeking an adult's consent to healthcare or deciding whether an adult is incapable of giving, refusing or revoking consent, a healthcare provider (a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and (b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.*²⁷

Section 8(b) appears to give the healthcare provider discretionary power to permit family members to participate during consent discussions, and also to determine the scope of their input. This authority would seem to apply even when competent patients have themselves requested their family members' involvement in discussions. Additionally, family members 'allowed' to participate are only those who have accompanied the patient and who proactively offer their assistance. The implication is that no obligation exists for the healthcare provider to inquire about other family members whom the patient would prefer to include in medical discussions.

²⁴ L Eggertson, "Doctors should Collaborate with Traditional Healers" (2015) 187:5 Can Med Assoc J E153.

²⁵ J Coggon & J Miola, "Autonomy, Liberty, and Medical Decision-Making" (2011) 70:3 Camb Law J 523; J Miola et al. "One Size Fits All? On Patient Autonomy, Informed Consent and the Impact of Culture" (2014) 14-23 Univ Leic Sch Law Res Pap 1.

²⁶ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181.

²⁷ *Ibid.* For s7, see note 28.

Additionally, s8(b) determines the scope of family members' participation as being limited to assisting the patient with comprehension of matters mentioned in Section 7 of the Act.²⁸ Thus their role is limited to translation or help with understanding the risks or other medical details communicated by the practitioner. There is clearly no statutory obligation for the healthcare provider to invite the family's input in the final decision-making *per se*.

1.4 – Research Question and Key Concepts

The dynamics of the patient-family-physician relationship have the potential to profoundly impact patient privacy, confidentiality, and the freedom to make autonomous decisions; accordingly, these dynamics are bound by both socio-legal rules and bioethical norms governing patient consent in medical decision-making. In an effort to better understand these dynamics and how they operate both within and beyond established codes, my research addresses the question: what are the experiences of specialist physicians in high-risk fields in their interactions with the families of competent patients during the informed consent process? In the course of answering this question, I identify how a purposefully chosen set of experienced medical specialist practitioners in British Columbia, Canada, approach their interactions with patients from a diverse range of ethnic backgrounds, *alongside* their family members who participate in pre-consent discussions. Although these types of clinical interactions can put at risk the patient's freedom to be autonomous, they may also represent an opportunity for the patient to recruit the support of trusted close others in making a major medical decision.

I examine the experiences of specialist physicians (rather than family doctors) because these practitioners are commonly expected to communicate potentially serious risks to relative strangers — i.e., patients and their families — in a relatively compressed

²⁸ Section 7 of the *Health Care (Consent) and Care Facility (Admission) Act*:

When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands (a) the information given by the health care provider under section 6 (e), and (b) that the information applies to the situation of the adult for whom the health care is proposed. Section 6 (e) of the Act states: the health care provider gives the adult the information a reasonable person would require to understand the proposed health care and to make a decision, including information about (i) the condition for which the health care is proposed, (ii) the nature of the proposed health care, (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and (iv) alternative courses of health care.

time frame.²⁹ Physicians in high-risk specialties frequently need to warn patients (and their families) that their medical interventions could cause significant physical harm while simultaneously — and paradoxically — trying to build their trust. Hence, for practitioners, interactions with patients in the presence of family members can entail grappling with emotive decision-making demands tinged with fear and anxiety, within an ethico-legal framework that requires them to promote their patient’s autonomy.

The clinical application of informed consent doctrine is grounded in the understanding that a competent individual must be allowed to make an informed decision based on information offered by a practitioner, who is obliged to disclose the relevant risks of the intervention.³⁰ This key principle is central to the ethico-legal training of healthcare professionals, as well as in the framing of institutional consent protocols.³¹ Medicine and Law, however, tend to be dominated by positivist conceptualizations of consent, where the appropriate information (including risk percentages) for obtaining legal consent is viewed almost as a ‘thing’ that physicians give to competent patients, on an individual basis.³²

Section 8(b) of British Columbia’s *Health Care (Consent) and Care Facility (Admission) Act* inspired supplementary research questions guiding this project, the foremost being: what are the implications and effects of consent rules’ focus on the competent individual patient? I approach this question by arguing that the law of consent in British Columbia, may be interpreted as empowering healthcare providers with the authority to *unilaterally* determine the patient’s capacity to make an autonomous decision when exposed to their family’s ‘influences’ in decision-making. No provision allows the patient themselves to make that determination.

More generally, the ethico-legal doctrine of medical consent, as traditionally applied in practice, espouses a version of patient autonomy that is narrowly individualistic,

²⁹ Family physicians, on the other hand, usually have longitudinal relationships with patients (and families) and hence the nature of their experiences in the interactions with the latter can be expected to have a different quality. For example, in family practice there are often a wider range of opportunities to engage with the family without compromising the patient’s autonomy.

³⁰ S Burningham, C Rachul & T Caulfield, “Informed Consent and Patient Comprehension: The Law and the Evidence” (2013) 7 McGill J Law Health 123.

³¹ K Evans, *Consent: A Guide for Canadian Physicians*, 4th ed (Ottawa: Canadian Medical Protective Association, 2016).

³² J Nedelsky, “Reconceiving Autonomy: Sources, Thoughts and Possibilities” (1989) 1 Yale JL Fem 7; P Alderson & C Goodey, “Theories of Consent” (1998) 317:7168 BMJ 1313; GM Stirrat & R Gill, “Autonomy in Medical Ethics after O’Neill” (2005) 31:3 J Med Ethics 127; Manson & O’Neill, *supra* note 9, chapter 2.

static, and hence deeply problematic. Existing consent rules neglect the possibility that autonomy can be variable and potentially impacted by a variety of factors, such as fear, anxiety, and a sense of helplessness.³³ A limited and individualistic view of autonomy also discounts the possibility that most people's capacity to be genuinely self-governing can be contingent on the unique supports that shore up their personal confidence in decision-making. Such supports can, for example, come in the form of family — if family members are allowed to participate simultaneously in deliberations with healthcare professionals.

Support could take the form of helping the patient decipher large amounts of medical information offered by the practitioner, and also assisting in assessments of the trustworthiness of the professional.³⁴ Thus, in the face of a serious illness, the family's support may enhance the patient's degree of confidence in making an informed choice.³⁵ If that is indeed the case, any suppression of the agency of the patient's family through failing to acknowledge the value of their influence may well represent a *restriction* of the patient's freedom of choice. This viewpoint is consistent with the position that "respect for persons in virtue of their capacity for autonomy" should be taken as the most fundamental sense of a respect for their autonomy.³⁶

Another supplemental research question carries these concerns further, asking: are there additional consequences to patient health in minimizing the contribution of family members in the consent process? It is possible to view pre-consent deliberations as an opportunity to engage with family constructively in order to recruit their decisional support, especially when treatment risks are high. For example, in situations where further medical treatment appears futile, family members can provide information that will enhance the physician's understanding of the patient's values and priorities.³⁷ Conversely, it is possible that neglect of family members' concerns, by failing to engage with them effectively prior

³³ J Nedelsky, *Law's Relations: A Relational Theory of Self, Autonomy, and Law* (Oxford University Press, 2011) at 45.

³⁴ Manson & O'Neill, *supra* note 9, chapter 7.

³⁵ Stirrat & Gill, *supra* note 32; MJ Cherry, "Re-Thinking the Role of the Family in Medical Decision-Making" (2015) 40:4 J Med Philos 451.

³⁶ J Wilson, "Is Respect for Autonomy Defensible?" (2007) 33:6 J Med Ethics 353 at 200.

³⁷ JS Phinney & A Ong, "Cultural Values and Intergenerational Value Discrepancies in Immigrant and Non-Immigrant Families" (2000) 71:2 Child Dev 528; M Chettih, "Turning the Lens Inward: Cultural Competence and Providers' Values in Healthcare Decision Making" (2012) 52:6 Gerontologist 739.

to commencing high-risk interventions, may incline them to be litigious if treatment complications injure their loved one.³⁸

This brings me to a final, yet key supplemental question, bridging back to my central research query: what are the ethico-legal considerations that should govern triadic clinical interactions where physicians simultaneously interact with patients and their family members during pre-consent processes?³⁹ The social interconnectedness of patients, and the role of family and culture during medical decision-making, have been described extensively.⁴⁰ In the case of consent for minors and in genetic research, the ethico-legal position of family or guardians in surrogate decision-making is well established.⁴¹ Similarly, where the patient's decision-making capacity is at issue due to advanced age or mental illness, the position of family has been thoroughly examined.⁴² Literature about threats to the autonomy of a competent patient, posed by collectivist medical decision-making practices, mainly addresses the specific context of non-Western individuals living in Western environments.⁴³ Here, family is often regarded as a complicating factor in

³⁸ I have addressed the value of establishing effective communication with patients' families in the pre-consent period in my Master's project. R Veerapen, *The Experience of Malaysian Neurosurgeons with Physician-Patient Conflict in the Aftermath of Adverse Medical Events: A Heuristic Study* (MA in Dispute Resolution, University of Victoria, 2009) [unpublished].

³⁹ Simultaneous interactions between three parties; patient, family and physician. Often there are additional persons present, such as healthcare professionals or caregivers, making such interactions 'multi-party' rather than merely triadic. For convenience, henceforth reference will be made to 'physicians' and their ethico-legal obligations, recognizing that these obligations will in most instances apply to all categories of healthcare workers who obtain informed consent from patients.

⁴⁰ MG Kuczewski, "Reconceiving the Family: The Process of Consent in Medical Decisionmaking" (1996) 26:2 *Hastings Cent Rep* 30; J Marta, "Whose Consent Is It Anyway? A Poststructuralist Framing of the Person in Medical Decision-Making" (1998) 19 *Theor Med Bioeth* 353 at 199; M Kuczewski & PJ McCrudden, "Informed Consent: Does It Take a Village? The Problem of Culture and Truth Telling" (2001) 10 *Camb Q Healthc Ethics* 34; I Hyun, "Waiver of Informed Consent, Cultural Sensitivity and the Problem of Unjust Families and Traditions" (2002) 32:5 *Hastings Cent Rep* 14; R Fan, "Consent to Medical Treatment: The Complex Interplay of Patients, Families and Physicians" (2004) 29:2 *J Med Philos* 139; A Akabayashi & BT Slingsby, "Informed Consent Revisited: Japan and the US" (2006) 6:1 *Am J Bioeth* 9; A Ho, "Relational Autonomy or Undue Pressure? Family's Role in Medical Decision-Making" (2008) 22:1 *Scand J Caring Sci* 128.

⁴¹ EK Mårtenson & AM Fägerskiöld, "A Review of Children's Decision-Making Competence in Healthcare" (2008) 17:23 *J Clin Nurs* 3131; H Biggs, "Competent Minors and Health-Care Research: Autonomy Does Not Rule, Okay?" (2009) 4:4 *Clin Ethics* 176; K Hens et al. "Genetic Research on Stored Tissue Samples from Minors: A Systematic Review of the Ethical Literature" (2009) 149A:10 *Am J Med Genet A* 2346.

⁴² SYH Kim, JHT Karlawish & ED Caine. "Current State of Research on Decision-Making Competence of Cognitively Impaired Elderly Persons" (2002) 10:2 *Am J Geriatr Psychiatry* 151; PJ Moberg & JH Rick, "Decision-Making Capacity and Competency in the Elderly: A Clinical and Neuropsychological Perspective" (2008) 23:5 *NeuroRehabilitation* 403.

⁴³ F Moazam, "Families, Patients, and Physicians in Medical Decisionmaking: A Pakistani Perspective" (2000) 30:6 *Hastings Cent Rep* 28; I Hyun, "Conceptions of Family-Centered Medical Decisionmaking and

consent discussions because of their threat to the patient's autonomy.⁴⁴ This is in contrast to the understanding of families in medical decision-making in non-Western contexts, where the family is often acknowledged as being integral to medical decision-making for the individual.⁴⁵

Legal and bioethically rooted approaches to informed consent have only infrequently dealt with the tensions that arise when communication difficulties (including language barriers) occur between physician and patient, and have done so from a narrow, highly discipline-bound perspective. Adding a socio-political perspective, rooted in the social sciences, to the narrow, ethico-legal view of informed consent might, therefore, prove highly beneficial.⁴⁶ Many non-Western patients in a North American context do, indeed, prefer to involve different decision-makers, and welcome input from more sources than medical providers typically allow.⁴⁷

The general trend in North American healthcare is that patients (and their families) are increasingly being viewed as partners in decision-making, rather than passive recipients of physician advice.⁴⁸ Ultimately, both patients and family members are more likely to feel satisfied in their encounters with the medical system, or with individual practitioners, when they are apprised of the risks of an intervention, and are able to sense that their influence in the decision-making has been appropriately valued.⁴⁹ Respecting these needs of family

their Difficulties" (2003) 12:2 *Camb Q Healthc Ethics* 196; H de Haes, "Dilemmas in Patient Centeredness and Shared Decision Making: A Case for Vulnerability" (2006) 62:3 *Patient Educ Couns* 291; Ho, *supra* note 40; A LeBlanc et al. "Decisional Conflict in Patients and their Physicians: A Dyadic Approach to Shared Decision Making" (2009) 29:1 *Int J Soc Med Decis Mak* 61.

⁴⁴ Hyun, *supra* note 40; Charles et al, *supra* note 4; C Schäfer et al. "Medical Decision-Making of the Patient in the Context of the Family: Results of a Survey" (2006) 14:9 *Support Care Cancer* 952.

⁴⁵ C Kagitcibasi, "Autonomy and Relatedness in Cultural Context" (2005) 36:4 *J Cross-Cult Psychol* 403; C Kagitcibasi, *Family, Self, and Human Development across Cultures: Theory and Applications*, 2nd ed (Mahwah: L. Erlbaum Associates, 2007); YL Cong, "Doctor-Family-Patient Relationship: The Chinese Paradigm of Informed Consent" (2004) 29:2 *J Med Philos* 149; D Chunyan, "Family Members' Informed Consent to Medical Treatment for Competent Patients in China" (2010) 8:1 *China Int J* 139.

⁴⁶ JM Kaufert & JD O'Neil, "Biomedical Rituals and Informed Consent: Native Canadians and the Negotiation of Clinical Trust" in G Weisz, ed, *Social Science Perspectives on Medical Ethics* (Philadelphia: University of Pennsylvania Press, 1990) 41.

⁴⁷ DB Matthew, "Race, Religion, and Informed Consent-Lessons from Social Science" (2008) 36:1 *J Law Med Ethics* 150.

⁴⁸ MJ Barry & S Edgman-Levitan, "Shared Decision Making: The Pinnacle of Patient-Centered Care" (2012) 366:9 *N Engl J Med* 780.

⁴⁹ FL Lau, "Can Communication Skills Workshops for Emergency Department Doctors Improve Patient Satisfaction?" (2000) 17:4 *Emerg Med J* 251; DA Barr, "Race/Ethnicity and Patient Satisfaction." (2004) *J Gen Intern Med* 937; MM Mello et al. "Caring For Patients in a Malpractice Crisis: Physician Satisfaction and

members may thus have a significant bearing on the quality of trust in patient-provider relationships, a factor that potentially impacts the risk of complaints or legal action stemming from dissatisfaction or suspected malpractice.⁵⁰

1.5 – Theoretical Framework

This inquiry draws from three theoretical fields. The first is bioethics, a field that contributes those philosophical notions of self-determination that are integral to doctrines of informed consent. These notions, in turn, underscore the relationships between patients and healthcare providers or medical researchers. The second theoretical field is feminist theory, specifically the theories of the self originating in the 1970s strand known as ‘relational feminism’. These contribute key elements establishing the concepts of ‘relationality’ and ‘relational autonomy’ as describing alternative (and arguably preferable) approaches to understanding and supporting a person’s freedom and agency in healthcare interactions. Thirdly, I invoke insights from post-colonial theory as I examine alternative interpretations of patient autonomy supporting the concept of a ‘patient-family-physician’ relationship, as experienced in much of the Majority World. I provide preliminary and orienting remarks here, outlining the theoretical frameworks that I harness.

1.5.1 – Autonomy in Bioethics Theory

The complex concept of a person’s autonomy in Western intellectual traditions has roots in the Enlightenment. At least in part, it finds its roots in late 17th/early 18th century notions of puritanical personal religious responsibility, as balanced against the obligations of persons to a community designed to serve God.⁵¹ As a moral tenet, autonomy’s other anchor arises during the same period: in Natural Law’s⁵² endowment of individuals with

Quality of Care.” (2004) 23:4 Health Aff 42; SS Kim, S Kaplowitz & MV Johnston. “The Effects of Physician Empathy on Patient Satisfaction and Compliance” (2004) 27:3 Eval Health Prof 237.

⁵⁰ MA Hall et al. “Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter?” (2001) 79:4 Milbank Q 613; M McKneally et al. “Responding to Trust: Surgeons’ Perspective on Informed Consent” (2009) 33:7 World J Surg 1341.

⁵¹ BA Shain, *The Myth of American Individualism: The Protestant Origins of American Political Thought* (Princeton: Princeton University Press, 1994).

⁵² “The precepts of the natural law are binding by nature: no beings could share our human nature yet fail to be bound by the precepts of the natural law. This is so because these precepts direct us toward the good as such and various particular goods. The good and goods provide reasons for us rational beings to act, to pursue the good and these particular goods. As good is what is perfective of us given the natures that we have, the good and these various goods have their status as such naturally. It is sufficient for certain things to be good

rights of self-governance and the choice to pursue their own dictates.⁵³ One result of Enlightenment humanism and the consequence of liberal political philosophy is the value placed on individuals' ability to govern themselves, independent of their role or obligations in social structures or political institutions.⁵⁴ Over time, and as societies grew increasingly diverse, autonomy evolved into an "instrumental, political and moral response to the challenge of finding political harmony in a highly individualistic, pluralistic, and religious society."⁵⁵ In the latter half of the 20th century, the nature of respect for individual persons shifted from one centered on communal responsibility to one focused on autonomy in its individualistic or 'atomistic' interpretation.⁵⁶

Accordingly, and because they generally uphold individual rights as sacrosanct, North Americans have largely opted for individual choice in healthcare deliberations. Autonomy has thus arguably become "the central and most powerful principle in ethical decision-making in American medicine," although it is only a single facet of the complexity of moral praxis.⁵⁷ Its meaning is largely defined by how individual rights are shaped in balance with other moral tenets, such as beneficence and distributive justice.⁵⁸

More recently, autonomous and informed patients have been turned into consumers within a healthcare market that must be governed by sets of ethical and legal *rules*.⁵⁹ At the same time, complex social and economic developments over the last four decades have made medical information much more accessible to the public, which also fuels a move from a purely ethical to an 'ethico-legal' language and reasoning. As Carl Elliot has noted:

that we have the natures that we have; it is in virtue of our common human nature that the good for us is what it is." M Murphy, "The Natural Law Tradition in Ethics" (27 September 2011) in EN Zalta, ed, *Stanford Encyclopedia of Philosophy* (Stanford: Stanford University, 2011) online: <https://plato.stanford.edu/entries/natural-law-ethics/> (accessed 27 April 2017).

⁵³ AI Tauber, "Sick Autonomy" (2003) 46:4 *Perspect Biol Med* 484 at 485.

⁵⁴ J Christman, "Autonomy in Moral and Political Philosophy" (11 August 2009) in EN Zalta, ed, *Stanford Encyclopedia of Philosophy* (Stanford: Stanford University, 2011) online: <http://plato.stanford.edu/archives/spr2011/entries/autonomy-moral/> (accessed 27 April 2017).

⁵⁵ RC Fox, "The Evolution of American Bioethics: A Sociological Perspective" (1990) *Soc Sci Perspect Med Ethics* 201 at 209.

⁵⁶ Tauber, *supra* note 53.

⁵⁷ PR Wolpe, *The Triumph of Autonomy in American Bioethics: A Sociological View* (Upper Saddle River: Prentice Hall, 1998) at 43.

⁵⁸ Tauber, *supra* note 53.

⁵⁹ Tauber, *supra* note 53 at 484.

The law is the lingua franca of bioethics. The language in which bioethics is discussed revolves around largely quasi-legal notions such as consent, competence, rights to refuse treatment, to have an abortion and so on. Many writers have targeted the language of rights and autonomy for special criticism, suggesting that we need to develop an alternative vocabulary. This is an understandable suggestion, but I think the law's influence on bioethics has been much deeper and more subtle. It has given us a picture of morality as somehow like the law in structure — for example, as a set of rules that govern interactions between strangers. This picture of morality may work adequately as long as we are in fact talking about interactions between strangers, especially strangers whose relationship is adversarial. But it overlooks many kinds of questions that are crucial to morality, and it distorts many others.⁶⁰

Just as law advances through challenges to precedents, shifts in medical ethical discourse are often catalyzed by past abuses, which similarly expose the insufficiency of the prevailing framework. Notable changes came with the stipulations in the *Nuremberg Code* of 1947, which laid out the criteria for obtaining an individual's consent for medical research purposes, in the wake of the infamous Nazi Doctor's Trial.⁶¹ Progressive attacks on medical paternalism grew in the wake of controversies such as the Tuskegee scandal, in which both the diagnosis and treatment of syphilis were withheld from hundreds of black American men for almost forty years, in order to secretly monitor the long-term effects of the untreated disease.⁶² In addition to increased public awareness of the excesses of the medical profession, other complex social factors converged to produce a growing suspicion of authority. For example, in the Vietnam Era, confidence in government, business, and medicine overall was shaken and, in that climate, bioethics became the articulation of a form of ancient and thus legitimate moral governance of the doctor-patient relationship. What emerged in the wake of all of these factors, acting synergistically over the past

⁶⁰ C Elliott, *A Philosophical Disease: Bioethics, Culture, and Identity* (New York: Routledge, 1999) at xxviii.

⁶¹ J Katz, "The Nuremberg Code and the Nuremberg Trial" (1996) 276:20 JAMA 1662 at 1662.

⁶² From 1932 to 1972, US Public Health Service doctors diagnosed over 500 blacks living near Tuskegee, Alabama, as having contracted syphilis, but purposefully kept the patients ignorant of their condition for the sake of conducting a secret, clinical study of the long-term effects of leaving the disease untreated. The Washington Star exposed it on 25 July 1972, but by then over 100 of the subjects had died of the disease or related complications. In December 1974 an out-of-court settlement paid \$10 million to the study's 120 survivors, to persons who contracted syphilis from them, and to heirs of the deceased "Tuskegee Syphilis Scandal" in TL Purvis, ed, *A Dictionary of American History* (Cambridge: Blackwell, 1995) online: http://www.blackwellreference.com/public/tocnode?id=g9781577180999_chunk_g978157718099922_ss1-135 (accessed 15 October 2016)

century or so, was a demand for greater respect for patient autonomy, protected instrumentally by informed consent.⁶³

1.5.2 – The Rise of Principlism

The aforementioned heightened awareness of the moral agency of patients contributed to the development of ‘bioethics,’ a field distinct from its predecessor, ‘medical ethics.’ While *bioethics* generally encompasses a wide range of theoretical ethical issues and concepts related to biomedical technologies (such as consent, cloning, stem cell therapy, and the use of animals in research), *medical ethics* focuses more narrowly on the medical treatment of humans in particular, not just by physicians but also by any other healthcare providers.⁶⁴ The concerns that medical ethics addresses are hence directly relevant to the context of the engagement between healthcare professionals and the persons they serve. What are considered relevant are local socio-cultural factors such as the level of education of the public or the access to healthcare and the related power differentials that these may cause between lay persons and professionals in this field.

In the early 1970s bioethics was dismissively characterized as a “mixture of religion, whimsy, exhortation, legal precedents, various traditions, philosophies of life, miscellaneous moral rules, and epithets.”⁶⁵ To address this multivalent critique and help precipitate a more systematic approach to moral reasoning in bioethics, American philosophers Tom Beauchamp and James Childress elaborated a set of principles for use by both physicians and medical institutions. The ‘four principles’ approach, now commonly referred to as ‘principlism’, was described in Beauchamp and Childress’ 1977 textbook *Principles of Biomedical Ethics*, now in its seventh edition.⁶⁶ This publication represented a common disciplinary charter, offering an operationalizable tool for answering bioethical dilemmas.⁶⁷ The four principles are: i) respect for patient autonomy, or acknowledgement of the decision-making capability of autonomous persons; ii) beneficence, or the prevention of harm, provision of benefits, and balancing of benefits

⁶³ Tauber, *supra* note 53.

⁶⁴ Medical ethics can thus be viewed as a field within bioethics.

⁶⁵ KD Clouser, “Bioethics and Philosophy” (1993) 23:6 *Hastings Cent Rep* S10 at S10-S11.

⁶⁶ TL Beauchamp & JF Childress, *Principles of Biomedical Ethics*, 7th ed (New York: Oxford University Press, 2012).

⁶⁷ Wolpe, *supra* note 57 at 39.

against risks and costs; iii) non-maleficence, or the requirement for not causing harm to persons (the maxim *primum non nocere* — ‘above all, do no harm’ — is one of the most quoted principles in the history of medical ethics); and iv) justice, or a fair distribution of benefits, risks, and costs.

Proponents of the form of autonomy in ‘principlism’ have been accused of distorting the relationship between individuals and the world by exaggerating the reach of individual agency and underestimating the impact of society or culture on an individual’s decision-making. This criticism is perhaps well-founded, since the principalist view of autonomy is rooted in the liberal tradition of valuing *individual* freedom and choice. The underlying assumption is that in order to be autonomous, a person must possess a measure of critical mental capacity sufficient to demonstrate voluntariness in decision-making and clarity of understanding. Such a person is able to act freely, according to a self-chosen plan, and to respect such a person’s autonomy is to appreciate their capacities and perspectives and to respect their right to hold independent views.⁶⁸ Such an understanding is categorized as a ‘procedural’ theory of autonomy.⁶⁹

‘Procedural’ theories have been the dominant models of autonomy since the 1970s. Using a procedural frame, if evidence of an individual’s reasoning process does indeed satisfy certain formal and procedural conditions (such as those laid out for medical decisions and consent), this is sufficient to categorize it as having been ‘autonomous.’ Such accounts do not require the individual to subscribe to specific beliefs, goals, or values; the standards or conditions that “operate as touchstones of autonomous reasoning” are external to the person.⁷⁰ In this proceduralist view, what matters is endorsement. That is to say, a person’s sense of engagement with their preferences or desires is demonstrative of an *autonomous will*: one that the individual actually wants.⁷¹

⁶⁸ TL Beauchamp, “The ‘Four Principles’ Approach to Healthcare Ethics.” *Principles of Healthcare Ethics* (West Sussex: John Wiley and Sons Ltd, 2007) 3 at 2007.

⁶⁹ N Stoljar, “Theories of Autonomy” (2007) *Princ Healthcare Ethics* 11 at 12.

⁷⁰ *Ibid* at 11.

⁷¹ HG Frankfurt, “Freedom of the Will and the Concept of a Person” (1971) 68:1 *J Philos* 5 at 5.

1.5.3 – From Atomistic to Relational Autonomy

Two different notions of selfhood underpin opposing conceptions of autonomy. The first is the liberal, individualistic, ‘atomistic’⁷² self, discussed earlier; the second is the communitarian notion of the ‘social’ self.⁷³ The atomistic notion maintains that underlying our social identities is an individual, deeply understood sense of identity associated with separateness, self-reliance, self-direction, and fundamental freedoms.⁷⁴ The communitarian notion, on the other hand, adopts a socially embedded view of the self, imagining it as being constituted by a “confluence of relationships and social obligations.”⁷⁵ In this *relational* view, the identity of individuals is dependent on social connectedness, and hence, persons who are isolated are pictured as incomplete individuals at risk of failure of self-actualization.

Various groups of scholars, writing from communitarian, feminist, and identity politics perspectives, have claimed that the model of the autonomous agent at the heart of liberal principles ignores the social nature of our being.⁷⁶ This social framing encompasses the relational nature of a person’s decisions and conceptions of human identity that fully consider embeddedness in family and other relations. From this assertion comes the rationale for ‘relational autonomy’, a term used to refer to an alternative conception: that of a free, self-ruling individual who is also constituted by social connectedness and mutual dependency.⁷⁷ The concept first arose through feminist critiques of traditional, excessively individualistic notions of autonomy and rights, which can risk attributing autonomy even to persons whose oppressive socialization circumstances have caused them to internalize and accept oppressive norms.⁷⁸

⁷² C Taylor, “Atomism” in S Aveneri & A de-Shalit, eds, *Communitarianism and Individualism* (Oxford: Oxford University Press, 1992) 29 at 29.

⁷³ MJ Sandel, *Liberalism and the Limits of Justice* (Cambridge & New York: Cambridge University Press, 1998).

⁷⁴ Tauber, *supra* note 53.

⁷⁵ *Ibid.* at 489.

⁷⁶ Nedelsky, *supra* note 32; L Code, *What can She Know? Feminist Theory and the Construction of Knowledge* (Ithaca: Cornell University Press, 1991); C Mackenzie & N Stoljar, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: OUP, 2000).

⁷⁷ J Christman, “Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves” (2004) 117:1/2 *Philos Stud Int J Philos Anal Tradit* 143 at 143.

⁷⁸ Nedelsky, *supra* note 32; Code, *supra* note 76; Mackenzie & Stoljar, *supra* note 76.

In *Law's Relations*, Jennifer Nedelsky engages with a range of legal, ethical, and social implications of the notion that an individual self can be actively constituted by the relationships through which a person interacts with others.⁷⁹ In Nedelsky's version of a relational self, what is central is an awareness of human dependence.⁸⁰ This is particularly relevant in a healthcare context, where the effects of ageing, illness, disability, and mental decline precipitate varying degrees of vulnerability. Unfortunately, references to this state of dependence in moral philosophical discussions have largely been tangential, in spite of the obvious link between a person's level of dependence and their ability to make truly autonomous decisions.⁸¹ Nedelsky further argues that dependence and interdependence are a constant part of the human condition — not just during illness, but also for just about every social activity that requires language and communication.⁸² A pertinent medical example would be the degree of comprehension and communication required by a patient in order to make an autonomous decision leading to consent to treatment.

When considering relational autonomy, Nedelsky emphasizes that she refers not only to intimate relationships but also to “nested structures of relations,”⁸³ or an individual's associations being nested in widening levels of relationships in their social world, all of which contribute to shaping the self. She also asserts that the ability to function autonomously is variable and lies on a continuum. Individuals thus function primarily with *partial* autonomy, always interacting with the intimate and/or social relationships that are constitutive of their autonomy.⁸⁴

Continuing to position relational and principlist autonomies in polar opposition, as can be seen in both academic work and practical perspectives, is probably unhelpful in resolving bioethical dilemmas. Further, the currently dominant and individualist bioethical accounts of autonomy might be reconceived in a manner that accommodates key components of relational autonomy. Worth considering carefully is the identification of particular constitutive factors for consideration in individual cases, recognizing situations

⁷⁹ Nedelsky, *supra* note 33.

⁸⁰ Nedelsky, *supra* note 33 at 9, 36, 86-87.

⁸¹ AC MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues* (Chicago: Open Court, 1999).

⁸² Nedelsky, *supra* note 33 at 28.

⁸³ Nedelsky, *supra* note 33 at 30.

⁸⁴ Nedelsky, *supra* note 33 at 177, 181, 183.

where in fact involving family may well enhance a patient's capacity to be autonomous. Hence, examining how physicians interpret and consequentially permit, encourage, or conversely circumscribe the contribution of family members in the procurement of the patient's consent, will help in our understanding of the degree to which the individualistic view of the patient is entrenched in clinical practice.

1.5.4 – Postcolonial Thought

Both the bioethical and relational approaches to conceptualizing autonomy in clinical practice are rooted in Western philosophical paradigms. To properly apprehend and assess the family's role in medical decision-making in communitarian cultures within the Majority World and related diasporic communities requires a turn to post-colonial theory. Briefly, postcolonialism is a field of inquiry that appeared in the 1970s to critique the study of 'Others' from the perspective of the mainstream, and to unsettle the traditional binaries (especially 'East' and 'West') that had, for a long time, structured colonial and postcolonial encounters in multiple fields.⁸⁵ As a body of scholarship it underscores the role that epistemology — the framing and construction of knowledge — plays in the maintenance of Euro-American hegemony (itself rooted in 19th century imperialism). At issue is not merely how colonialism exerted power through military and economic might (or, relevant to medicine, bodily control), but how it also acted as a cultural and subjectivizing force.⁸⁶ I draw from this field particularly when addressing the practical interpretation of autonomy in everyday clinical practice.

Exploring post-colonial ideas has helped me recognize how strongly prevailing ethico-legal consent doctrines are rooted in the individualistic values and interests of Euro-American culture, and are reflected in the foundational principles of consent protocols in Western healthcare systems. Many of these doctrinal principles with legal origins have been incorporated (sometimes uncritically) into bioethics training of physicians and

⁸⁵ GC Spivak, "Can the Subaltern Speak?" (1988) *Reflect Hist Idea* 21; EW Said, *Orientalism: Western Conceptions of the Orient* (London & New York: Penguin Books, 1995); D Chakrabarty, *Provincialising Europe: Postcolonial Thought and Historical Difference* (Princeton: Princeton University Press, 2000).

⁸⁶ A Nandy, *The Intimate Enemy: Loss and Recovery of Self under Colonialism* (Delhi: Oxford University Press, 1988); R Kapur, "The Citizen and the Migrant: Postcolonial Anxieties, Law, and the Politics of Exclusion/Inclusion" (2007) 8:2 *Theor Inq Law* 537; F Fanon, *Black Skin, White Masks* (New York: Grove Press, 2008); B Bhandar, "Plasticity and Post-Colonial Recognition: 'Owning, Knowing and Being'" (2011) 22:3 *Law Crit* 227.

institutional consent protocols in many parts of the Majority World.⁸⁷ For example, recent research in Southeast Asia illustrates the difficulties encountered when applying these Western bioethical rules in a collectivist social context. Clinical conundrums have been described, for example, when family members resist the disclosure of full details of cancer diagnosis and prognosis directly to the patient.⁸⁸

In Western healthcare contexts subject to traditional bioethical doctrines, it is advisable to remain conscious of the philosophical assumptions made about individuality and self-determination when framing institutional ethical protocols generally and not only when they impact the engagement with members of non-Western cultures.⁸⁹ In this dissertation, I argue that whenever family members from *any* cultural group participate alongside the patient in medical consultations with the physician, useful pointers for practitioners may be gained by examining alternative approaches to medical decision-making, in addition to embracing a broader, relational view of autonomy.⁹⁰ As we have seen, where the patient is legally competent, ethico-legal protocols typically do not provide for the input of family members, the discretion to exclude such input enjoyed by healthcare professionals ostensibly being justified by their obligation to protect patient autonomy. What is likely to be helpful for practitioners would be guidelines to help them navigate circumstances when the patient does not object to, or even requests, the participation of their family members in decision-making. If a relational view of patient autonomy can be understood and accounted for in consent protocols whilst providing adequate protections

⁸⁷ KB Nunn, "Law as a Eurocentric Enterprise" (1997) 15 *Law Inequal J Theory Pract* 323; JH Merryman & R Pérez-Perdomo, *The Civil Law Tradition: An Introduction to the Legal Systems of Europe and Latin America*, 3rd ed (Stanford: Stanford University Press, 2007), chapters I & II.

⁸⁸ A Lee & HY Wu, "Diagnosis Disclosure in Cancer Patients: When The Family Says 'No!'" (2002) 43:10 *Singapore Med J* 533; Chunyan, *supra* note 45; TE Chan, NS Peart & J Chin, "Evolving Legal Responses to Dependence on Families in New Zealand and Singapore Healthcare" (2014) 40:12 *J Med Ethics* 861.

⁸⁹ JA Carrese & LA Rhodes, "Western Bioethics on the Navajo Reservation – Benefit or Harm" (1995) 274:10 *JAMA* 826; Nunn, *supra* note 87; MJ Cherry, "Beyond a Western Bioethics: Voices from the Developing World [review]" (2003) 3:1 *Am J Bioeth* 67; MA Ryan, "Beyond a Western Bioethics?" (2004) 65:1 *Theol Stud* 158.

⁹⁰ R Qiu, "Bioethics and Asian Culture: A Quest for Moral Diversity" in R Qiu, ed, *Bioethics: Asian Perspectives* (Dordrecht: Kluwer, 2004) 1; MF Back & CY Huak, "Family Centred Decision Making and Non-Disclosure of Diagnosis in a South East Asian Oncology Practice" (2005) 14:12 *Psychooncology* 1052; J Nie & AV Campbell, "Multiculturalism and Asian Bioethics: Cultural War or Creative Dialogue?" (2007) 4:3 *J Bioethical Inq* 163; S Chattopadhyay & R De Vries, "Bioethical Concerns are Global, Bioethics is Western" (2008) 18:4 *Eubios J Asian Int Bioeth* 106; J Nie, "The Search for an Asian Bioethics" (2011) 1:1 *Asian Bioeth Rev* 86; Kagitcibasi, *supra* note 45; Z Wei, "The Tort Law of P.R. China and the Implementation of Informed Consent" (2014) 6:2 *Asian Bioeth Rev* 125; Karako-Eyal, *supra* note 2.

against coercion and oppression, a more constructive appreciation of the role and status of family in the process will be achieved. The examination of current practices of experienced medical professionals in navigating patient-family interactions is hence of value in contributing to our understanding of the advantages as well as the potential pitfalls and hazards in approaching patient autonomy with a relational lens.

Interestingly, several parallels can be found between post-colonial and feminist relational thought in terms of characterizations of physician-patient relationships, particularly the consideration of interdependence and social connectedness. There are intersections and tensions that continue to exist amongst these three theoretical fields mentioned above, particularly in terms of the interpretation of social embedding, the examination of power in patient-provider relationships, and in the comparisons of autonomous versus collectivistic decision-making.⁹¹ For example, the concept of honoring ‘truth-telling’ in healthcare demonstrates how the respect for an individual’s right to be informed (a principle integral to Western bioethics) intersects with contrary expressions of collectivist cultural values. In such societies, many families hold the belief that the disclosure of the full details of the diagnosis and prognosis of the illness directly to the patient can produce unnecessary distress and loss of hope. Such insistence on withholding the truth from the patient in Western healthcare settings can therefore produce clinical conundrums.⁹² With the increasing diversity of population groups being served, the matter of withholding the truth from patients could become a frequently recurring ethical issue with which physicians will need to grapple.⁹³

⁹¹ RJ Alfidi, “Controversy, Alternatives, and Decisions in Complying with the Legal Doctrine of Informed Consent” (1975) 114:1 *Radiology* 231; PNJ Kassim, “The Doctrine of Informed Consent in the United States, England, Australia and Malaysia: A Comparative Case Analysis” in P Nemie et al, eds, *Issues in Medical Law and Ethics* (Kuala Lumpur: Medical Law and Ethics Unit, International Islamic University Malaysia, 2003); AM Hedgecoe, “Critical Bioethics: Beyond the Social Science Critique of Applied Ethics” (2004) 18:2 *Bioethics* 120; R Baker & LB McCullough, “Medical Ethics’ Appropriation of Moral Philosophy: The Case of the Sympathetic and the Unsympathetic Physician” (2007) 17:1 *Kennedy Inst Ethics J* 3; Dolgin, *supra* note 11; N Karako-Eyal, “Physician’s Duty of Disclosure: A Deontological and Consequential Analysis” (2010) 14:1 *Quinnipiac Health Law J* 1.

⁹² R Fan & B Li, “Truth Telling in Medicine: The Confucian View” (2004) 29:2 *J Med Philos* 179; J Oliffe et al. “‘Truth Telling’ and Cultural Assumptions in an Era of Informed Consent” (2007) 30:1 *Fam Comm Health* 5.

⁹³ Such tensions will be addressed in various ensuing discussions, particularly those found in Chapters 2 and 7.

1.6 – Organization of Chapters

In Chapter 2, I present a critical review of the literature relevant to my project. This chapter begins with an examination of the existing work pertaining to the ethical and legal doctrines of informed consent, focusing primarily on the theoretical and practical interpretations of ‘patient autonomy.’ I then review texts that present a case for the re-conceptualization of patient autonomy in clinical practice; and incorporate feminist and post-colonial perspectives of the relationship between individual patients, their families, and healthcare providers. In a section titled, ‘The Family in Medical Interactions’, I review the literature on the practical impact of family members’ participation on the patient’s ability to act autonomously during clinical encounters. This literature is analyzed broadly under ‘Western’ and ‘non-Western’ categories, with the aim of illustrating similarities and differences in the interactive dynamics experienced in both individualistic and collectivist cultures. I also look at recent work exploring the practical outcomes of applying a relational approach to decision-making in healthcare.⁹⁴ To complete the literature review I examine the issue of physicians’ training in the interactive skills required to engage with the family members of patients. Understanding this particular body of writing is relevant to identifying possible training gaps, in order to make practice recommendations in my conclusion.

In Chapter 3 I present my research methodology, commencing with offering the rationale for my choice of a qualitative research design and, in particular, the appeal of Interpretative Phenomenological Analysis (IPA) as a suitable approach.⁹⁵ The IPA provides for in-depth individual interviews, which allowed me to capitalize on my ability to engage in substantive conversations with peers, with whom I share similar lived, professional experiences. I believe that privileged access to the research participants’ reflections has contributed to a richness of data likely unachievable without the advantages

⁹⁴ Chan, Peart & Chin, *supra* note 88; LKR Krishna, DS Watkinson & NL Beng. “Limits to Relational Autonomy – The Singaporean Experience” (2015) 22:3 Nurs Ethics 331.

⁹⁵ D Biggerstaff & AR Thompson, “Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research” (2008) 5:3 Qual Res Psychol 214. Interpretative phenomenological analysis (IPA) is an approach to qualitative research with an idiographic focus, aiming to offer insights into how an individual, in a given context, makes sense of a given phenomenon. This usually relates to experiences of some personal significance, such as a major life event, or important relationships. IPA’s theoretical origins are in phenomenology and hermeneutics but it differs from other phenomenological approaches partly by virtue of the grouping of interpretative, psychological, and idiographic components.

I enjoyed as a researcher. Data analysis involved my reflecting on the participants' reflections (conducting a 'double hermeneutic'), a process carefully aligned with the principles enunciated in IPA, striving to maintain objectivity and reflexivity throughout.⁹⁶

My research findings align along three major themes, the first two of which will be presented in Chapter 4, the third in Chapter 5. The first theme is the picture of the communications skills expressed by the participant-physicians, in particular the factors that influence their approaches to engaging with patients' families. The analysis helped me appreciate how participants had formed their opinions about the appropriate role of families during clinical interactions, along with how they have learnt to read families' 'personalities', internal dynamics, and conflicts. The second theme is practical and relates to the experiences of the participants during actual clinical interactions with patients and their families. The illustrations that were most relevant to my research question were found within stories of navigating difficult conversations related to risk disclosure, prior to obtaining consent. The third (and final) theme is challenges to patient autonomy. In Chapter 5, I present this theme through engagement with stories of situations where the participant-physicians sensed their patients' autonomy was threatened by family members' contributions to discussions and subsequent decision-making.

In the course of my analysis I identify five subthemes of challenges to patient autonomy. The first, titled "Recognizing Cultural and Language Factors in Truth-Telling," relates to interactions where the participants perceived that language barriers and cultural factors had challenged the patient's ability to be fully informed and make an independent treatment decision. Under a second subtheme of 'Navigating the Challenge of Patients' Waiver of Privacy and the Right to Decide,' I analyze narratives wherein patients deferred to their family members' decisions about their own treatment. I separate out stories where family members tended to dominate the decision-making process, grouping this set of findings under a third subtheme of 'Facing Undue Influences of Family Members.' Another subtheme, 'Respecting Autonomous Patient Choice against Family's Wishes,' gathers together stories in which the participants found themselves obliged to respect the choices of their patients, despite these decisions contravening medical advice or the wishes of the family, or both. Finally, under a subtheme titled, 'Manoeuvring to Protect Patient

⁹⁶ L Finlay, "Engaging Phenomenological Analysis" (2014) 11:2 Qual Res Psychol 121.

Autonomy,’ I look at cases where my research participants needed to manipulate conversations with family so as to allow their patients’ voices to be heard.

I analyze my research findings in Chapters 6 and 7, organizing the discussion by relating those findings to my research questions. Structurally, I address participants’ stories in line with the presentation of the research findings in Chapters 4 and 5. I examine relevant theoretical considerations of *dyadic* physician-patient relationships (PPR) in order to better understand the dynamics of *triadic* physician-patient-family relationships (PPFR).⁹⁷ I look at the effects that healthcare systems, in particular access to health services, may have on power differentials in the PPR and the PPFR. This is potentially a significant factor in physicians’ attitudes to families in healthcare interactions, alongside the nature of communications training within medical education curricula. Theoretical issues are illustrated by stories from the research participants, including those dealing with ‘truth-telling’ as an example of a conundrum resulting from the Western/collectivist ethical ‘clash’ in clinical interactions.

In the final chapter — Chapter 8 — I discuss the conclusions of my research and present the implications of my findings mainly as they pertain to medical education and the framing of institutional informed consent protocols in Canada. My inferences underscore the complexity and unpredictable nature of triadic clinical interactions and point to various priorities demonstrated by participants who balance the interests of the patient with those of their family members. Amongst my conclusions is an identification of the locus of control and authority during these interactions, and the steps participants took when their patients’ autonomy (as they understood it), appeared to be compromised.

Conclusion

The conversational dynamics during simultaneous patient-family-physician interactions have the potential to challenge a patient’s privacy, the confidentiality of their information, and their freedom to make autonomous decisions. My analysis of physicians’ attitudes and responses to deviations from traditionally private physician-patient interactions is aided by adopting an interdisciplinary approach, recruiting philosophical concepts from law, bioethics, feminist theory, and post-colonial thought. My project fills a

⁹⁷ Cong, *supra* note 45.

gap in the understanding of physicians' simultaneous interactions with patients and families during the informed consent process, by providing an explicit portrait of their tacit skills. This knowledge is of use in medical education in Canada, as well as the practical development of institutional protocols for consent and engagement with members of the public. The focus in the analysis and discussion of my data is practice-orientated, as a reflection of both my own career and academic path and my firm belief that successful and constructive engagement with patients' families materially contributes to the establishment of harmonious healthcare relationships.

CHAPTER 2: Literature Review

Introduction

In this chapter I review literature relevant to the ethical, legal, and communications issues that are most likely to materialize when physicians interact simultaneously with patients and their families. I focus particularly on interpretations and/or critiques of ‘patient autonomy’ as understood within ethico-legal doctrines of informed consent, given the risk that family involvement in pre-consent discussions will unsettle (normatively) private physician-patient communications, wherein patients are assumed to be free to act autonomously.

The literature review will be presented in three parts. In the first part I review a selection of physician-centred works that examine the factors influencing approaches to simultaneous communications with patients and patients’ families when obtaining informed consent. These factors include the ethico-legal governance frameworks that determine physicians’ obligations to patients and their families, the nature of the physician-patient relationship and the training aimed at developing physicians’ non-biomedical, ‘humanistic’ communications skills. In the second part of this chapter I review literature related to the notion of ‘patient autonomy’ and its different interpretations, specifically in the context of decision-making leading to the granting of consent. I commence with an examination of texts discussing the position of autonomy in Western bioethics, in particular ‘principlism’ (elaborating on the discussion in my Introduction). I follow this with a selection of literature critical of that particular bioethical version of autonomy, highlighting a narrowly individualistic interpretation that fails to consider the social inter-connectedness of individuals, especially when confronted with illness; and then a second sub-section that draws on non-Western perspectives to propose a ‘global bioethics.’ Final portions of this section deal first with a call to reconceptualize principlism in a way that responds to its critics, and then an attempted reconciliation of principlist and relational views of autonomy. In the final part of the literature review, prior to concluding this chapter, I examine works illustrating different experiences and understandings of the ethico-legal position and practical role of family in medical interactions meant to precipitate a patient’s informed consent.

2.1 – Physicians and Patient-Family Interactions

As my research explores the experiences of physicians in their interactions with patients and patients' families, it is necessary to first understand the ethical and legal frameworks that they practice within, the patient-physician relationship itself and the training that prepares physicians to conduct multi-party conversations orientated to risk disclosure and medical decision-making. I first review works concerned with the ethico-legal frameworks obliging physicians to communicate appropriately with patients and their families, and then discuss literature that examines elements of the physician-patient relationship, including the concept of shared decision-making in clinical practice. I continue with an examination of literature related to the development and refinement of physicians' communications skills — variously referred to as the tacit and 'humanistic' skills that, together with a physician's demeanour, constitute the practitioner's 'bedside manner.' These skills have a bearing on the patient's experience with the healthcare system, impacting factors such as their level of trust in care-providers or their compliance with treatment recommendations.⁹⁸

I focus on situations where the patient has the legal capacity to consent, as the ethico-legal obligations of physicians working with family or guardians during surrogate decision-making for minors are already well established, as are their obligations during consent for genetics research.⁹⁹ Similarly, where the patient's decision-making capacity is compromised for reasons of mental infirmity or illness, the physician's role has already been extensively examined.¹⁰⁰ A gap remains, however, in the understanding of best practices for physicians with respect to simultaneous pre-consent interactions with adult competent patients and their family members, both within Canada and internationally.¹⁰¹

⁹⁸ KC Calman, "Communication of Risk: Choice, Consent, and Trust" (2002) 360:9327 *Lancet* 166; RM Epstein et al. "Measuring Patient-Centered Communication in Patient-Physician Consultations: Theoretical and Practical Issues" (2005) 61:7 *Soc Sci Med* 1516; BD Silverman, "Physician Behavior and Bedside Manners: The Influence of William Osler and the Johns Hopkins School of Medicine" (2012) 25:1 *Proc Bayl Univ Med Cent* 58.

⁹⁹ Biggs, *supra* note 41; Hens et al, *supra* note 41.

¹⁰⁰ Kim, Karlawish & Caine, *supra* note 42; Moberg & Rick, *supra* note 42.

¹⁰¹ Kuczewski, *supra* note 40; Marta, *supra* note 40; Kuczewski & McCrudden, *supra* note 40; Hyun, *supra* note 40; R Fan, "Towards a Confucian Virtue Bioethics: Reframing Chinese Medical Ethics in a Market Economy" (2006) 27 *Theor Med Bioeth* 541; Akabayashi & Slingsby, *supra* note 40; HC Siong, "Urban Governance and Rapid Urbanization Issues in Malaysia" (2008) 13:4 *J Alam Bina* 1.

2.1.1 – Ethical and Legal Frameworks Governing Physician-Patient-Family Interactions

Informed consent law in Canada is comprehensively summarized by medical-legal theorist Patricia Peppin in “Informed Consent,” her chapter in *Canadian Health Law Policy*.¹⁰² In tracing the development of the legal doctrine of informed consent, she refers to landmark Canadian cases such as *Malette v Shulman*¹⁰³, *Hopp v Lepp*¹⁰⁴ and *Reibl v Hughes*¹⁰⁵, examining informed decision-making and duty of disclosure in negligence law and reviewing the relevant Canadian statutes governing consent. It is significant that Peppin concludes her chapter with a section on emerging issues, wherein she asks, “[h]as informed consent doctrine succeeded in enabling patients to participate in decision-making?”¹⁰⁶ Here she questions whether the current consent framework is able to provide an environment conducive to the achievement of the patient’s expectations of the doctor-patient relationship (for example mutual trust, listening skills, truthful disclosure, respect, and confidentiality). Peppin also identifies sociological concerns as important emerging issues, including power imbalance, dominance, and equality in the practitioner-patient relationship. (Note that she references concepts of inter-dependence promoted by relational theorists such as Jocelyn Downie, Jennifer Llewellyn, and Jennifer Nedelsky, whose work is discussed later in this chapter.¹⁰⁷)

Peppin’s concerns about the limitations of informed consent doctrine can also be identified in a close reading of the informed consent guidelines offered to Canadian physicians. Typical medico-legal guidelines remain silent about the position of family during a competent patient’s decision-making, prior to offering consent.¹⁰⁸ The Canadian Medical Protective Association (CMPA)¹⁰⁹, however, offers its members limited general

¹⁰² P Peppin, “Informed Consent” in JG Downie, T Caulfield & CM Flood, eds, *Canadian Health Law and Policy*, 4th ed (Markham: LexisNexis Canada, 2011) 153.

¹⁰³ *Malette v. Shulman* [1990] O.J. No. 450, 72 O.R. (2d) 417 affg [1987] O.J. no. 1180, 64 O.R. (2d) 243 (Ont H.C.J.).

¹⁰⁴ *Hopp v. Lepp* [1980] S.C.J. No 57, [1980] 2 S.C.R. 192 (S.C.C.).

¹⁰⁵ *Reibl v. Hughes* [1980] S.C.J. no. 105, [1980] 2 S.C.R. 880 (S.C.C.).

¹⁰⁶ Peppin, *supra* note 102 at 292.

¹⁰⁷ Nedelsky, *supra* note 32; J Downie & J Llewellyn, “Relational Theory & Health Law and Policy” (2008) *Health Law J* 193.

¹⁰⁸ Evans, *supra* note 31.

¹⁰⁹ The CMPA is a mutual non-profit organization that provides legal defence, liability protection, and risk management education for most physicians in Canada. It also provides compensation to patients and their families proven to have been harmed by negligent clinical care. CMPA. “About the CMPA,” *The Canadian*

advice on engaging with families. The ‘Cultural Safety’ section of the CMPA website recognizes the complexity of family dynamics, and also provides cautionary statements about the pitfalls of cultural stereotyping when attempting to understand the values and traditions of individual families.¹¹⁰ A December 2016 entry introduces a new website section, ‘Family Disputes and the Physician: Staying Focused on Safe Care.’¹¹¹ Here, the association advises members about the importance of awareness of relevant legal frameworks when encountering intra-family conflicts, particularly in situations that involve surrogate decision-making for patients without legal capacity to consent.

In addition to the CMPA’s advice, the Canadian Medical Association (CMA), a national voluntary association of physicians, addresses the navigation of difficult interactions through case studies illustrating the ethical challenges around the sharing health information with family members.¹¹² Here, the relevant sections of the CMA *Code of Ethics* are the preamble as well as Sections 22, 31, 33 and 35, which state:¹¹³

22. Make every reasonable effort to communicate with your patients in such a way that information exchanged is understood.

31. Protect the personal health information of your patients.

33. Be aware of your patient’s rights with respect to the collection, use, disclosure and access to their personal health information; ensure that such information is recorded accurately

35. Disclose your patients’ personal health information to third parties only with their consent, or as provided for by law, such as when the maintenance of confidentiality would result in a significant risk of substantial harm to others or, in the case of incompetent patients, to the patients themselves. In such cases take all reasonable steps to inform the patients that the usual requirements for confidentiality will be breached.

The preamble to the *Code* also contains a statement that:

Medical Protective Association (nd) online: <https://www.cmpa-acpm.ca/about> (accessed 7 December 2016).

¹¹⁰ CMPA, “When Medicine and Culture Intersect,” *Duties and Responsibilities: Expectations of Physicians in Practice* (March 2014) online: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/when-medicine-and-culture-intersect> (accessed 7 December 2016).

¹¹¹ CMPA, “Family Disputes and the Physician: Staying Focused on Safe Care,” *Duties and Responsibilities: Expectations of Physicians in Practice* (December 2016) online: https://www.cmpa-acpm.ca/en/duties-and-responsibilities/-/asset_publisher/bFaUiyQG069N/ (accessed 7 December 2016).

¹¹² CMPA, *Disclosing Personal Health Information to Third Parties* (nd) online: https://www.cma.ca/Assets/assets-library/document/en/advocacy/CMA_Disclosure_third_parties-e.pdf (accessed 8 December 2016).

¹¹³ Canadian Medical Association. *CMA Code of Ethics* (Ottawa: CMA, 2004) at 1-3.

Physicians may experience tension between different ethical principles, between ethical and legal or regulatory requirements, or between their own ethical convictions and the demands of other parties. Training in ethical analysis and decision-making during undergraduate, postgraduate and continuing medical education is recommended for physicians to develop their knowledge, skills and attitudes needed to deal with these conflicts. Consultation with colleagues, regulatory authorities, ethicists, ethics committees or others who have relevant expertise is also recommended.

Apart from the general recognition of potential ethical complexity, the CMA code does not offer pointers to physicians about how to effectively engage with family members of patients, either in situations where they have been welcomed by the patient, or where they insist on participating in treatment decision-making regardless. In British Columbia the legal position of family during informed consent discussions has been clarified by s.8 of the *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181 (discussed in my Introduction). Here, the contribution of family is clearly restricted to language support (i.e., translation), with no explicit provisions made for participation in medical decision-making alongside the patient.

By contrast, in the United Kingdom, the General Medical Council (GMC), which is the statutory body regulating doctors' practices, addresses the complexity of doctors' engagement with families during the consent process by providing explicit guidelines:

If a patient asks you to make decisions on their behalf or wants to leave decisions to a relative, partner, friend, carer or another person close to them, you should explain that it is still important that they understand the options open to them, and what the treatment will involve. If they do not want this information, you should try to find out why.¹¹⁴

The GMC additionally addresses situations where family members want the truth withheld from the patient:

You should not withhold information necessary for making decisions for any other reason, including when a relative, partner, friend or carer asks you to, unless you believe that giving it would cause the patient serious

¹¹⁴ GMC UK. *Consent: Patients and Doctors Making Decisions Together* (London: General Medical Council, 2017) online: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_index.asp (accessed 21 June 2016).

*harm. In this context ‘serious harm’ means more than that the patient might become upset or decide to refuse treatment.*¹¹⁵

Significantly, in a section titled ‘Consent Guidance: Involving Families, Carers and Advocates’, the General Medical Council advises its doctors that the patient should be accommodated if they wish another person to be involved in the decision-making process (and not only in the role of augmenting comprehension of the information being conveyed):

*You should accommodate a patient’s wishes if they want another person, such as a relative, partner, friend, carer or advocate, to be involved in discussions or to help them make decisions.*¹¹⁶

Although these various forms of advice to physicians are framed as ethico-legal *rules*, taken together they may also be viewed defensively as *advice* about conflict prevention (considering that families often file medical malpractice actions because of dissatisfaction stemming from ineffective communication with the healthcare provider).¹¹⁷ Other factors such as cultural sensitivity, demonstrations of empathy, or acknowledgement of the patient’s and their family’s medical knowledge also contribute to satisfaction with healthcare services encounters.¹¹⁸ Much of the research on this topic is ethnographic and aimed at understanding patients’ and family members’ (rather than physicians’) perspectives more thoroughly.¹¹⁹ The perspective of the family becomes especially

¹¹⁵ *Ibid.*

¹¹⁶ *Ibid.*

¹¹⁷ Vincent, Young & Philips, *supra* note 8; W Levinson et al. “Physician-Patient Communication: The Relationship with Malpractice Claims among Primary Care Physicians and Surgeons” (1997) 277:7 JAMA 553; GB Hickson et al. “Patient Complaints and Malpractice Risk” (2002) 287:22 JAMA 2951; AJ Gogos et al. “When Informed Consent goes Poorly: A Descriptive Study of Medical Negligence Claims and Patient Complaints” (2011) 195:6 Med J Aust 340.

¹¹⁸ JD O’Neil, “The Cultural and Political Context of Patient Dissatisfaction in Cross-Cultural Clinical Encounters: A Canadian Inuit Study” (1989) 3:4 Med Anthropol Q 325; Kim, Kaplowitz & Johnston, *supra* note 49; Barr, *supra* note 49; C Taylor & JR Benger, “Patient Satisfaction in Emergency Medicine” (2004) 21:5 Emerg Med J 528.

¹¹⁹ O’Neil, *supra* note 118; Moazam, *supra* note 43; J Neuberger, “The Educated Patient: New Challenges for the Medical Profession” (2001) 249:S741 J Intern Med 41; S Pandya, “Doctor-Patient Relationship: The Importance of the Patient’s Perceptions” (2001) 47:1 J Postgrad Med 3; HR Krause, A Bremerich & J Rustemeyer. “Reasons for Patients’ Discontent and Litigation” (2001) 29:3 J Cranio-Maxillofac Surg 181; RS McCord et al. “Responding Effectively to Patient Anger Directed at the Physician” (2002) 34:5 Fam Med 331; A Coulter, “Patients’ Views of the Good Doctor” (2002) 325:7366 BMJ 668; A Schattner, D Rudin & N Jellin. “Good Physicians from the Perspective of their Patients” (2004) 4:1 BMC Health Serv Res 26; L Fraenkel & S McGraw, “Participation in Medical Decision Making: The Patients’ Perspective” (2007) 27:5 Med Decis Mak 533.

pertinent when, in the aftermath of adverse medical events, the patient herself may not have survived or may have been left incapacitated. This leaves the healthcare professional with the responsibility of interacting with family members — a discomfoting challenge that could be mitigated through appropriate attention to building a relationship of trust with family members prior to commencement of treatment. Such an opportunity arises during pre-consent discussions and hence my project has been designed to better understand how senior clinicians engage with family members and navigate challenges that emerge during such interactions. Having a better understanding of how these physicians acquire communications skills during their formative years of education and training is certainly of value.

2.1.2 – The Physician-Patient Relationship (PPR)

The physician-patient relationship has been the subject of extensive analysis for several decades via a large variety of instruments, the sheer number of which implies that this complex social, economic, culture, and power-influenced relationship is difficult to define, standardize, or evaluate.¹²⁰ The qualities of, and expectations from, any PPR depend very much on the environmental context of the engagement between patient and physician. Here I discuss the relevant general understandings of this particular form of relationship and in Chapter 6, where I discuss my research findings, I focus on elements of the PPR in the context of Canadian healthcare.

Prior to the formal articulation of the doctrines of law and medical ethics in the 1970s, medical interactions in Western countries by and large occurred between persons who shared the same social space. It was common for physicians to have “ties of friendship, religion, ethnicity, or intellectual activity” with their patients.¹²¹ It was such interactions that shaped commentators’ understandings of the dynamics and ethical frameworks of a PPR that was based on a family practice model. By contrast, today’s hospital-based medical specialists and their patients are usually strangers to each other, and thus are less likely to share common cultural outlooks or values.¹²² The concentration of specialist medical

¹²⁰ RM Eveleigh et al. “An Overview of 19 Instruments assessing the Doctor-Patient Relationship: Different Models or Concepts are Used” (2012) 65:1 J Clin Epidemiol 10.

¹²¹ DJ Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991) at 127.

¹²² *Ibid* at 127-128.

services in urban medical centres, which have recruited professionals from geographically diverse settings, has compounded the social distancing of patients and their physicians. Patient-specialist interactions frequently occur in high-paced institutionalized settings where the clinical time-pressure impairs the formation of ideal PPRs founded on trust and empathic communications.¹²³ Presently, technology has become the more common basis for reaching a diagnosis, displacing detailed history-taking, a process that produces interpersonal engagement involving extended listening to the patient's story.¹²⁴ Breakdown of rapport within the PPR increases the risk of litigation against physicians and other negative consequences, such as a general decline of trust in the medical profession.

Loss of trust is also compounded by occasional reports that detail the frequency of medical errors in hospitals, or exposés about cases involving avaricious physicians.¹²⁵ As healthcare systems evolve and as the specialist physician is socially distanced from patients, the claim of Graham Scambler is pertinent in that, increasingly, the sociological study of relationships between doctors and patients now centres on physician-patient interactions or communication, rather than on their relationships *per se*.¹²⁶

In order to appreciate the complex dynamics that shape the interactions between physicians and *families* of patients, it is necessary to understand the significant historical developments that irreversibly altered the character of the PPR itself. In the 1960s and 1970s, several landmark legal cases and revelations of unethical research caught the public's attention, resulting in a progressive dismantling of the hitherto widely accepted practice of physician dominance and paternalism in medical decision-making.¹²⁷ Public trust in the medical profession was progressively eroded by the emergence of reports of

¹²³ *Ibid* at chapter 7.

¹²⁴ *Ibid*.

¹²⁵ R Morris, "Law and Medicine: Problems of Malpractice Insurance" (1971) 215:5 JAMA 843; LT Kohn, J Corrigan & MS Donaldson, *To Err is Human* (Washington DC: National Academies Press, 2000); JK Taitsman, "Educating Physicians to Prevent Fraud, Waste, and Abuse" (2011) 364:2 N Engl J Med 102; N Badlani, S Boden & F Phillips. "Orthopedic Specialty Hospitals: Centers of Excellence or Greed Machines?" (2012) 35:3 Orthopedics e420.

¹²⁶ Scambler, G. *Habermas, Critical Theory and Health* (London & New York: Routledge, 2001) at 46.

¹²⁷ Examples of landmark cases: a) *In Re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976) was a 1975 court case in the United States in which the parents of a woman who was kept alive by artificial means were allowed to order her removal from artificial ventilation; and b) the Tuskegee syphilis experiment was a notorious clinical research project conducted between 1932 and 1972 by the United States Public Health Service to study the natural progression of untreated syphilis in rural African American men, who thought they were receiving free health care from the U.S. government.

unbridled paternalism, reinforcing the sentiment that individual doctors should not be entrusted to make decisions alone in clinical situations with complex ethical and legal variables. Elements of the private and dyadic relationship between patients and doctors, once closely guarded and regarded by the medical profession as inviolable, gradually came under greater scrutiny and regulatory control by various authorities external to clinical medicine. The impact of professional ethicists, institutional committees, the media, the law, and religious authorities soon became evident. One of the systemic healthcare responses to the growing demand for greater patient involvement in medical decision-making was the development of the ‘shared decision-making’ approach (SDM).¹²⁸

The practice of SDM encourages greater patient participation in medical decision-making, manifesting the trend of retreat from physician paternalism and movement towards ‘patient-centred care.’¹²⁹ SDM has also been empirically proven to increase patients’ adherence to treatment while improving medical outcomes.¹³⁰ The principles and application of this approach, however, remain individualistically focused on the patient, and are not usually interpreted by physicians in ways that allow the recruitment of decisional support by related persons (despite the use of the descriptive ‘shared’).¹³¹ As John Hardwig has pointed out, the family’s interests, which could include their economic and social well-being, are potentially impacted by individual patients’ medical treatment decisions. Accordingly, he argues that with appropriate safeguards in place to protect patient autonomy, considering the family’s perspectives should be vital.¹³²

The ability of the patient to make decisions in an arrangement that encourages a ‘shared mind’ with trusted others is likely to enhance their decision-making capacity.¹³³ A case may thus be made for physicians to always view patients relationally, such that a wider

¹²⁸ L Sandman & C Munthe, “Shared Decision Making, Paternalism and Patient Choice” (2009) 18:1 *Healthcare Anal* 60.

¹²⁹ *Ibid.*

¹³⁰ Charles et al, *supra* note 4; Barry & Edgman-Levitan, *supra* note 48; VA Entwistle, A Cribb & IS Watt, “Shared Decision-Making: Enhancing the Clinical Relevance” (2012) 105:10 *JRSM* 416.

¹³¹ JL Hanson, “Shared Decision Making: Have We Missed the Obvious?” (2008) 168:13 *Arch Intern Med* 1368; G Elwyn et al. “Shared Decision Making: A Model for Clinical Practice” (2012) 27:10 *J Gen Intern Med* 1361; Barry & Edgman-Levitan, *supra* note 48; M Lipkin, “Shared Decision Making” (2013) 173:13 *JAMA Intern Med* 1204.

¹³² J Hardwig, “What about the Family?” (1990) 20:2 *Hastings Cent Rep* 5.

¹³³ RM Epstein & RL Street, “Shared Mind: Communication, Decision Making, and Autonomy in Serious Illness” (2011) 9:5 *Ann Fam Med* 454.

and arguably more credible interpretation of shared decision-making can be constructively applied.¹³⁴ The patient's ability to express personal choice or preference is often socially mediated, and so may be conveyed to close persons through a variety of nuanced non-verbal expressions, such as emotional responses or body language. The opportunity for genuine shared decision-making may hence be more meaningful for patients who are allowed to recruit the support of family during clinical encounters with physicians.¹³⁵ Clearly, a key factor that contributes to the success of a shared decision-making approach is the ability of a physician to communicate effectively.

2.1.3 – Development of Physicians' Communication Skills

Communications in clinical practice require a combination of compliance with ethico-legal rules and the exhibition of creative skills that allow adaptation to different family characteristics and needs. This form of creativity in clinical consultations has been likened to the skills of a jazz musician:

*Music is an apt metaphor for the practice of medicine. The best medical practice, like the best music, melds technical skill and expertise with individual artistry. The new paradigm of evidence-based medicine and the apparently conflicting concept of clinical experience represent these 2 aspects of medicine. To many physicians, evidence-based medicine seems rigid, highly structured, and uninspiring — as stilted and regimented as a poorly performed Bach fugue....The best medical practice is similar to neither baroque nor grunge music; instead it is like good jazz, combining technical mastery with the artistry of focused, personal improvisation. Clinical jazz combines the structure supplied by patient-oriented evidence with the physician's clinical experience to manage situations of uncertainty, instability, uniqueness, and conflicting values.*¹³⁶

A typical area where demands are placed upon physicians to be creative and capable of fluid improvisation in their communications, is when they interact with families from

¹³⁴ *Ibid*; RM Epstein, "Whole Mind and Shared Mind in Clinical Decision-Making" (2013) 90:2 Patient Educ Couns 200; V Entwistle et al. "Supporting Patient Autonomy: The Importance of Clinician-Patient Relationships" (2010) 25:7 J Gen Intern Med 741; Entwistle, Cribb & Watt, *supra* note 130.

¹³⁵ C Charles, A Gafni & T Whelan, "Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or, It Takes at Least Two to Tango)" (1997) 44:5 Soc Sci Med 681; JL Wolff & DL Roter, "Hidden in Plain Sight: Medical Visit Companions as a Resource for Vulnerable Older Adults" (2008) 168:13 Arch Intern Med 1409; Epstein & Street, *supra* note 133.

¹³⁶ AF Shaughnessy, DC Slawson & L Becker. "Clinical Jazz: Harmonizing Clinical Experience and Evidence-Based Medicine" (1998) 47:6 J Fam Pract 425.

cultures different than their own. Such situations call for astute cultural sensitivity — a topic that has now been examined extensively.¹³⁷ Similarly, the teaching of communications skills to medical students and residents has been the subject of detailed analyses; however, most of the focus has been on improving communications with individual patients (not family members) in order to develop constructive physician-patient relationships.¹³⁸

Pedagogical approaches to the development of communication skills in medical professionals fall into two broad categories: (a) oral presentations, written guidelines, and modelling examples; and (b) interactive training in the form of role-play, feedback, and small group discussions.¹³⁹ After a systematic search of scientific literature on the effectiveness of communication skills training for physicians, medical education researchers Marianne Berkhof et al. conclude that programs are more effective if they are learner-centred, practice-oriented, and delivered through interactive training that lasts for at least one day.¹⁴⁰ Because clinical encounters with patients can be qualitatively unpredictable, practicing communications skills in a clinical setting remains the most effective learning mechanism; guidelines and other didactic training methods are much less effective at developing the skills needed to adapt to different interactive dynamics. Practicing these skills — applying the qualities (such as empathy and cultural respect)

¹³⁷ C Gillotti, T Thompson & K McNeilis. “Communicative Competence in the Delivery of Bad News” (2002) 54:7 Soc Sci Med 1011; K Checkland, M Marshall & S Harrison. “Re-thinking Accountability: Trust versus Confidence in Medical Practice” (2004) 13:2 Qual Saf Healthcare 130; P Irving & D Dickson, “Empathy: Towards a Conceptual Framework for Health Professionals” (2004) 17:4-5 Int J Healthcare Qual Assur Inc Leadersh Health Serv 212; Schattner, Rudin & Jellin, *supra* note 119; Chettih, *supra* note 37; M Visser, L Deliens & D Houttekier, “Physician-Related Barriers to Communication and Patient- and Family-Centred Decision-Making Towards the End of Life in Intensive Care: A Systematic Review” (2014) 18:6 Crit Care 604.

¹³⁸ LC Zandbelt et al. “Determinants of Physicians’ Patient-Centred Behaviour in the Medical Specialist Encounter” (2006) 63:4 Soc Sci Med 899; M von Fragstein et al. “UK Consensus Statement on the Content of Communication Curricula in Undergraduate Medical Education” (2008) 42:11 Med Educ 1100; SM Shapiro, WJ Lancee & CM Richards-Bentley, “Evaluation of a Communication Skills Program for First-Year Medical Students at the University Of Toronto” (2009) 9 BMC Med Educ 11; W Levinson, C S Lesser & R M Epstein, “Developing Physician Communication Skills for Patient-Centered Care” (2010) 29:7 Health Aff (Millwood) 1310; BL Lovell, RT Lee & CM Brotheridge, “Interpersonal Factors Affecting Communication in Clinical Consultations: Canadian Physicians’ Perspectives” (2012) 25:6 Int J Healthcare Qual Assur 467; JC Wouda, & HBM van de Wiel, “Education in Patient–Physician Communication: How to Improve Effectiveness?” (2013) 90:1 Patient Educ Couns 46; M Claramita et al. “Doctor-Patient Communication in Southeast Asia: A Different Culture?” (2013) 18:1 Adv Health Sci Educ 15.

¹³⁹ M Berkhof et al. “Effective Training Strategies for Teaching Communication Skills to Physicians: An Overview of Systematic Reviews” (2011) 84:2 Patient Educ Couns 152.

¹⁴⁰ *Ibid.*

alluded to earlier — brings us back to our jazz analogy, this time extending it to incorporate how musical virtuosos develop that elusive combination of technical skill and creative improvisation:

*Jazz cats use the term ‘woodshedding’ to denote a period of intense practice during which they aim to take their playing up a few notches. Developing expertise, whether we are speaking musically or talking about communicating with patients, requires a lifelong commitment to such practice. For physicians, the woodshed is not a practice room or an isolated space. No: clinical environments are the woodsheds; they are the only places in which one can hone communication skills. The idea of ‘shedding’ in the setting of routine practice challenges prevailing notions about communication skills training and has implications for how such skills should be learned, nurtured and assessed.*¹⁴¹

This resonates with Berkhof et al.’s observation that the only robust teaching environment is the clinical setting itself, the same space whose unpredictability demands creative improvisation in actual practice. Yet these mutually reinforcing understandings, important as they are, leave an important gap: such insights are still limited to the physician-patient dyad, a communication dynamic that has been studied in depth, with no similar focus on the development of skills needed to effectively engage with patients’ family members. This specific component of communications practice is often addressed only peripherally within discourses on the general education of medical trainees in bioethics, law and cultural proficiency and often left to unsystematic forms of training based on observing senior physicians. There is agreement about the need to formalize such training.¹⁴² As my project is aimed at understanding the skills — many of them tacit —

¹⁴¹ P Haidet & M Picchioni, “The Clinic is My Woodshed: A New Paradigm for Learning and Refining Communication Skills” (2016) 50:12 *Med Educ* 1208 at 1208. The ‘woodshed’ is the term used by jazz musicians to describe a place of intense individual practice where they hone their skills. The story goes that Charlie Parker, the greatest alto saxophone player in jazz history, spent months in his woodshed practicing, after an initial disastrous public performance with the Count Basie orchestra. When he emerged to play with Basie again, his virtuosity stunned audiences.

¹⁴² A Girgis, RW Sanson-Fisher & WH McCarthy, “Communicating with Patients: Surgeons’ Perceptions of their Skills and Need for Training” (1997) 67:11 *ANZ J Surg* 775; A Girgis, RW Sanson-Fisher & RA Walsh, “Preventive and Other Interactional Skills of General Practitioners, Surgeons, and Physicians: Perceived Competence and Endorsement of Postgraduate Training” (2001) 32:1 *Prev Med* 73; J Katz, *The Silent World of Doctor and Patient* (Baltimore: Johns Hopkins University Press, 2002); N Dogra, S Reitmanova & O Carter-Pokras, “Teaching Cultural Diversity: Current Status in U.K., U.S., and Canadian Medical Schools” (2010) 25:2 *J Gen Intern Med* 164; Hafferty & Hafler, *supra* note 13 at 17; Mahood, *supra* note 13.

that senior clinicians apply during triadic interactions, my research findings will contribute to the content of training curricula in this field of communications.

2.2 – Patient Autonomy

The focus in this part of the review is on the prominence given to ‘patient autonomy’ within the doctrine of informed consent in law and bioethics. I begin with a general overview of the conventional formulations of informed consent doctrine within three fields: law, bioethics, and clinical practice. These interpretations critically underpin the ethico-legal training of medical professionals, and this in turn impacts their clinical engagement with patients when obtaining consent. I then extend my earlier discussion of ‘principlism’ (in my Introduction) as a bioethical framework ordering consent doctrines.¹⁴³ I then examine works critical of the pre-eminence given to ‘patient autonomy’ in the bioethical application of informed consent doctrine, which question whether its narrow and individualistic interpretation accurately reflects the interconnectedness of individuals. I organize this critical literature into four broad areas: 1) theoretical arguments that directly question the basis for the pre-eminence of principlism’s individualistic autonomy; 2) critiques of the centrality of principlism in informed consent doctrines (as well as broader criticisms of the consent model and its operationalization); 3) communitarian and feminist literature advocating for the adoption of a wider, ‘relational’ interpretation of personal autonomy; and 4) post-colonial writings that present a non-Western picture of the patient in relationship with their family and healthcare practitioners during medical decision-making and proposes a ‘global bioethics.’ Finally, I present and engage with Raanan Gillon’s defence of principlism, as his attractive arguments offer a means of reconciling individualistic approaches to patient autonomy with those suggested by communitarian and relational theorists.

¹⁴³ Principlism refers to the four bioethical principles proposed by Beauchamp and Childress, namely: i) respect for patient autonomy, or acknowledgement of the decision-making capability of autonomous persons; ii) beneficence, or the prevention of harm, provision of benefits, and balancing of benefits against risks and costs; iii) non-maleficence, or the requirement for not causing harm to persons (the *maxim primum non nocere* – ‘above all, do no harm’ – is one of the most quoted principles in the history of medical ethics); and iv) justice, or a fair distribution of benefits, risks, and costs.

2.2.1 – Conventional Formulations of Patient Autonomy and Informed Consent in Law and Bioethics

The principles and application of informed consent in biomedical research and clinical practice emerged just over three decades ago, largely in response to what was perceived as unchecked paternalism in medical practice, offering patients and research subjects a means of protecting their self-determination and choice.¹⁴⁴ ‘Autonomy,’ etymologically derived from the Greek *auto-nomous*, meaning ‘self-rule,’ is critical to the concept of consent in medicine — it is, in fact, the most significant value to have influenced the development of contemporary healthcare law.¹⁴⁵ For several decades now the ethics of medical practice has been grounded in the notion that persons should have control over their own bodies and be free to make independent decisions about their medical treatment and to seek their own fulfillment.¹⁴⁶ Justice Benjamin Cardozo, in the landmark 1914 US case of *Schloendorff*, articulated the classic statement of the common law premise now embodied in contemporary consent doctrine, which is that a person retains the right to determine what a medical professional does to their body:

*Every human being of adult years and sound mind has the right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages, except in cases of emergency where the patient is unconscious, and where it is necessary to operate before consent can be obtained.*¹⁴⁷

Several decades after *Schloendorff*, forces external to medicine — mainly the activity of lawyers, judges and philosophers — began to progressively formulate the principles that underpin the legal and bioethical doctrines of informed consent as

¹⁴⁴ A Maclean, *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge: Cambridge University Press, 2009) at 111.

¹⁴⁵ “Autonomous,” *supra* note 7; M Brazier, “Patient Autonomy and Consent to Treatment: The Role of the Law?” (1987) 7:2 *Leg Stud* 169; DJ Rothman, “The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective” (2001) 9:3 *Healthcare Anal* 255.

¹⁴⁶ K Mason, G Laurie & AM Smith, *Mason and McCall Smith’s Law and Medical Ethics*, 9th ed (Oxford: Oxford University Press, 2013) at 6-7.

¹⁴⁷ *Schloendorff v Society of New York Hospital*, 211 NY 125 at 129-130 (1914).

understood today.¹⁴⁸ In essence, law's intention to protect patient autonomy is expressed as a legal requirement for physicians and other healthcare providers to disclose risk to patients at an acceptable standard, as a prerequisite to obtaining their consent. In other words: consent obtained must be appropriately 'informed.' Creating an entitlement to adequate information prior to making a treatment decision is an instrumental approach to ensuring that a patient's autonomy is protected. Interestingly, it was not until several decades later that this principle was explicitly elucidated in other jurisdictions.

In Canada, two 1980 cases (*Reibl v Hughes* and *Hopp v Lepp*) established the legal standard that now governs the risk-disclosure requirements of informed consent.¹⁴⁹ These cases clarified that the mere description of the hazards of treatment in general terms was insufficient. Risk disclosure must also take into consideration an individual patient's particular need for information about their illness, and the risks they were expected to take. Additionally, in *Reibl v Hughes*¹⁵⁰, and later in *Ciarlariello v Schacter*,¹⁵¹ the Supreme Court of Canada (SCC) unequivocally indicated that physicians were expected to ensure that their patients understood the information provided to them. In *Ciarlariello*, Justice Peter Cory held:

¹⁴⁸ The case of *Salgo v Leland Stanford Jr. Univ. Bd. Trustees* 154 Cal. App. 2d 560, 317 P. 2d 170 (1957) was one of the earliest US cases that reinforced the level of protection of patient autonomy in terms of requiring a measure of risk disclosure by physicians to facilitate informed choice by patients. *Salgo* involved a patient who awoke paralyzed after aortography, having not been informed that such a risk was possible. The decision held that failure to disclose risks and alternatives was cause for legal action on its own, reaching further than a case of battery. Later, in 1972, the judgement in *Canterbury v. Spence* 464 F.2d 772, 1972 contained the following words of caution: "[T]he physician must seek and secure his patient's consent before commencing an operation or other course of treatment. It is also clear that the consent, to be efficacious, must be free from imposition upon the patient. It is the settled rule that therapy not authorized by the patient may amount to a tort—a common law battery—by the physician. And it is evident that it is normally impossible to obtain a consent worthy of the name unless the physician first elucidates the options and the perils for the patient's edification." In rejecting the notion that a physician was only legally responsible to divulge no more than what other reasonable practitioners would divulge, the court's decision also states: "Respect for the patient's right of self-determination on particular therapy demands a standard set by law for physicians rather than one which physicians may or may not impose upon themselves."

¹⁴⁹ *Reibl v Hughes* [1980] 2 SCR 880; *Hopp v Lepp* [1980] 2 SCR 192. These two cases established a 'patient-centred' rather than the traditional 'reasonable physician' standard of risk disclosure. Without being requested, the surgeon should disclose material risks. Risks that are 'material' and hence must be disclosed are those that a reasonable person in the patient's position (which the physician knows or should know) would likely attach significance to, and want to know. The SCC indicated that even if a particular risk is a mere possibility, if its occurrence carried serious consequences potentially such as paralysis or death, it would be considered material.

¹⁵⁰ *Reibl*, *supra* note 7.

¹⁵¹ *Ciarlariello v Schacter* [1993] 2 SCR 119, 100 DLR (4th) 609.

Prior to Reibl v. Hughes, there was some doubt as to whether the doctor had the duty to ensure that he was understood. However, Laskin C.J. made it quite clear in that case that it was incumbent on the doctor to make sure that he was understood, particularly where it appears that the patient had some difficulty with the language spoken by the doctor. Indeed, it is appropriate that the burden should be placed on the doctor to show that the patient comprehended the explanation and instructions given.

Having established the ‘reasonable person’ standard for risk and benefit disclosure by healthcare providers in S6 (e)(iii), British Columbia’s *Health Care (Consent) and Care Facility (Admission) Act* then states in s7 that the healthcare provider is required to determine if the adult person is incapable of giving their consent. This determination is to be based on evaluation of the patient’s ability to understand the information that was provided under s6(e).¹⁵² The provisions of the Act are thus unambiguous about the link between comprehension of information by a patient and their capacity to consent. Later in this chapter I argue that a person’s ability to comprehend and navigate through the load of medical information offered to them during the risk disclosure process of informed consent may be enhanced by the participation of supportive family or close others.

Ensuring comprehension remains a problematic area in informed consent doctrine. Arguably, in focusing on the provision of adequate information by healthcare providers, the courts have not paid as much attention to whether those providers have ensured comprehension in the same way as the courts have defined capacity for understanding in mental health law.¹⁵³ In a sense, by determining a legal standard of risk disclosure without correspondingly requiring that there be sufficient effort by the provider to ensure that the

¹⁵² *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181. Elements of consent: 6 An adult consents to health care if (a) the consent relates to the proposed health care, (b) the consent is given voluntarily, (c) the consent is not obtained by fraud or misrepresentation, (d) the adult is capable of making a decision about whether to give or refuse consent to the proposed health care, and (e) the health care provider gives the adult the information a reasonable person would require to understand the proposed health care and to make a decision, including information about (i) the condition for which the health care is proposed, (ii) the nature of the proposed health care, (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and (iv) alternative courses of health care, and (f) the adult has an opportunity to ask questions and receive answers about the proposed health care. How incapability is determined: 7 When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands (a) the information given by the health care provider under section 6 (e), and (b) that the information applies to the situation of the adult for whom the health care is proposed.

¹⁵³ A Buchanan, “Mental Capacity, Legal Competence and Consent to Treatment” (2004) 97:9 J R Soc Med 415; V Richardson, “Patient Comprehension of Informed Consent” (2013) 23:1/2 J Perioper Pract 26.

patient understands the information provided, the intention of courts to promote liberty has placed patient autonomy at risk.¹⁵⁴ Adequate comprehension is, after all, the corollary of, and hence inseparable from, disclosure of risk. It goes to the heart of informed consent doctrine, and thus the protection of patient autonomy during decision-making seems futile without ensuring clear understanding of what is being consented to.¹⁵⁵

Academics and judges have, however, questioned the reasonableness of the legal burden of ensuring the patient's understanding in every case. Ellen Picard and Gerald Robertson have suggested that the nature of the obligations articulated in *Ciarlariello* were "too onerous and impractical," proposing instead that providers should only be expected to take "reasonable steps" to ensure patient comprehension.¹⁵⁶ Ensuring a patient's full comprehension may, indeed, be considered impractical, and therefore unachievable in clinical practice because of time constraints or individual patient factors (such as language difficulty). A question then arises about what further measures could be considered 'reasonable' in order to increase the chances that the patient genuinely understands the risks and nature of a proposed medical intervention. If ensuring full comprehension is too onerous a burden, providing information alone would seem ultimately pointless, or at the very least an incomplete attempt at satisfying the components of valid consent. It may be argued that fully specific 'informed' consent (as opposed to a more general, 'uninformed' consent) should not remain an ethical necessity because it simply defies a convincing definition. The use of decisional aids in the consent process may be one practical measure that assists with achieving this ideal.¹⁵⁷ I posit here that the recruitment of family members as decisional supports may be another constructive approach to improving patient comprehension (a claim I discuss later in my discussion of the research findings in Chapter

¹⁵⁴ G Sreenivasan, "Does Informed Consent to Research Require Comprehension?" (2003) 362:9400 *The Lancet* 2016; R Heywood, A Macaskill & K Williams, "Informed Consent in Hospital Practice: Health Professionals' Perspectives and Legal Reflections" (2010) 18:2 *Med Law Rev* 152; Burningham, Rachul & Caulfield, *supra* note 30; Richardson, *supra* note 153.

¹⁵⁵ Sreenivasan, *supra* note 154.

¹⁵⁶ *Ciarlariello Estate v. Schacter* [1993] 2 SCR 119; EI Picard & GB Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 3rd ed (Scarborough: Carswell, 1996) at 161.

¹⁵⁷ AM O'Connor, F Legare & D Stacey, "Risk Communication in Practice: The Contribution of Decision Aids" (2003) 327:7417 *BMJ* 736; AM O'Connor et al. "Toward the 'Tipping Point': Decision Aids and Informed Patient Choice" (2007) 26:3 *Health Aff (Millwood)* 716.

7).¹⁵⁸ The difficulties encountered in fulfilling the requirements of comprehension in operationalizing informed consent may be intrinsic to aspects of its framework, as I next address.

Neil Manson and Onora O’Neill question the structure of the informed consent process itself, characterizing it as impersonal and merely a technical scheme for transfer of information, rather than a constructive transaction between people that should go beyond simple information disclosure and acknowledgement of its receipt.¹⁵⁹ As these authors point out, in practice informed consent processes are unduly formalistic, demanding unachievable targets in terms of the determination, by healthcare professionals, about which types of information must be made available and which are ethically or legally permissible to hide from patients. Informed consent processes are perhaps better understood as being transactional communications between persons, wherein waivers of specific legal or ethical rights are offered. The ‘informing’ of the patient may be viewed as a secondary obligation.¹⁶⁰ In any case, risk projections of medical treatment are intrinsically unreliable as there often are unspecifiable eventualities that can be tagged on to any proposed intervention. Thus definitive specificity of informed consent is not possible, much in the way that it is not entirely possible for a healthcare worker to anticipate perfectly what a ‘reasonable’ individual patient would want or need to know. Persons differ in their ability to comprehend risks, as well as to infer what the consequences of their decisions may be.¹⁶¹

Because knowledge and power differentials between physicians and patients are predictably tilted in favour of the former, in order to be conscious of a patient’s ability to act autonomously it is crucial that physicians remain sensitive to the public experience of any routine institutional process, such as informed consent. Feelings of powerlessness may underlie a patient’s compliance with institutional protocols in order that they may benefit from essential health services. Under such circumstances, acquiescence cannot be truly

¹⁵⁸ RC Laidsaar-Powell et al. “Physician-Patient-Companion Communication and Decision-Making: A Systematic Review of Triadic Medical Consultations” (2013) 91:1 Patient Educ Couns 3; A Andrades, S Kausar & A Ambreen, “Role and Influence of the Patient’s Companion in Family Medicine Consultations: ‘The Patient’s Perspective’” (2013) 2:3 J Fam Med Prim Care 283.

¹⁵⁹ Manson & O’Neill, *supra* note 9 at 69.

¹⁶⁰ *Ibid.*

¹⁶¹ *Ibid* at 12.

autonomous behaviour, the intention of informed consent protocols notwithstanding.¹⁶² By limiting one's view of autonomy to being merely an expression of individualistic rational agency, consent doctrines may paradoxically be creating limits to the exercise of autonomy in medical decision-making.¹⁶³ After all, even the most competent person will be taxed in their attempts to meet the cognitive demands required to comprehend medical technicalities, while simultaneously displaying sufficient emotional strength to make potentially risky health decisions.¹⁶⁴

2.2.2– Patient Autonomy in Principlism

In clinical practice, the introduction of family members into ordinarily private, dyadic physician-patient interactions often unsettles the physician's confidence in the integrity of their patient's autonomy — a right which physicians are obliged to uphold.¹⁶⁵ That autonomy is one of the four tenets of Tom Beauchamp and James Childress' 'principlism' (along with beneficence, non-maleficence, and justice). These theorists recognize the need for a set of shared bioethical principles which would form a useful guide for workers in healthcare (a 'bioethical principle' being one that forms the basis of moral reasoning because it is an essential norm in a system of moral thought).¹⁶⁶ Yet the authors also caution that although rules or practical judgments in clinical practice can be formulated by *referring* to these four principles, they should not be *deduced* from them, even though the principles seem to place moral obligations upon healthcare practitioners.¹⁶⁷ Despite Beauchamp's refusal to offer a priority weighting of these principles in the event of internal conflicts arising from their application, he appears to uphold patient autonomy as foremost among the four.¹⁶⁸ To help resolve internal conflicts Beauchamp reminds us that discretionary judgment is a critical part of moral thinking that depends on principles and that often, principles must be specified to suit the circumstances of specific contexts. This process of 'specification' is hence necessary to reduce the indeterminateness of abstract

¹⁶² Nedelsky, *supra* note 33 at 135.

¹⁶³ Downie & Llewellyn, *supra* note 107 at 208.

¹⁶⁴ Manson & O'Neill, *supra* note 9 at 5.

¹⁶⁵ JL Wolff & DL Roter, "Family Presence in Routine Medical Visits: A Meta-Analytical Review" (2011) 72:6 Soc Sci Med 1982 823; Laidsaar-Powell et al, *supra* note 158.

¹⁶⁶ Beauchamp, *supra* note 68 at 3.

¹⁶⁷ Beauchamp & Childress, *supra* note 66 at 13-14.

¹⁶⁸ Beauchamp, *supra* note 68 at 3.

norms to provide them with definite, action-guiding content.¹⁶⁹ Beauchamp also maintains that the long-standing preoccupation in healthcare with beneficence in ethics should be re-directed to an autonomy-based model that incorporates a broader set of social concerns, especially those related to social justice.¹⁷⁰ The shift to prioritizing autonomy arguably contributes to increased recognition of the patient's right to choose and re-evaluation of the position of medical paternalism during medical decision-making.¹⁷¹

'Autonomy' as applied in bioethics generally refers to independence from outside constraints, along with the presence of critical mental capacities such as comprehension, intention, and voluntariness in decision-making.¹⁷² The obligation to uphold autonomy so described is negative as well as positive.¹⁷³ A negative obligation, for example, is that others should not control or constrain an individual's autonomous actions, while a positive one is the necessity for healthcare professionals to disclose information appropriately in order to foster autonomous decision-making.¹⁷⁴ Beauchamp extends this formulation to include the obligation of healthcare professionals to build or maintain patients' capacities for autonomous choice while helping to allay fears (and other factors) that might in any way attenuate their autonomous actions. Thus he cites "manipulative under-disclosure of pertinent information," or disregard of a competent patient's refusal of recommended medical interventions, as examples of disrespect for patient autonomy.¹⁷⁵ In alluding to the obligation to help improve a patient's capacity for autonomous choice Beauchamp fails to address the possible role of healthcare professionals in recruiting social enablers (such as family members) of a person's decision-making confidence. Other commentators such as Epstein and Schuldt have however recognized such positive effects. They claim that

¹⁶⁹ *Ibid* at 8; D DeGrazia & T Beauchamp, "Philosophy: Ethical Principles and Common Morality" in J Sugarman & D Sulmasy, eds, *Methods in Medical Ethics* 2nd ed (Washington: Georgetown University Press, 2010) 37.

¹⁷⁰ Beauchamp, *supra* note 68 at 3

¹⁷¹ BA Rich, "Medical Paternalism v. Respect for Patient Autonomy: The More Things Change the More They Remain the Same" (2006) 10 Mich State Univ J Med Law 87; D Scoccia, "In Defense of Hard Paternalism" (2008) 27:4 Law Philos 351; C Foster, "Autonomy Should Chair, Not Rule" (2010) 375:9712 The Lancet 368; D Scoccia, "The Right to Autonomy and the Justification of Hard Paternalism" in M Weber & C Coons, eds, *Paternalism: Theory and Practice* (Cambridge: Cambridge University Press, 2013) 74.

¹⁷² Beauchamp & Childress, *supra* note 66 at 58-9.

¹⁷³ JF Childress, "The Place of Autonomy in Bioethics" (1990) 20:1 Hastings Cent Rep 12; R Kukla, "Conscientious Autonomy: Displacing Decisions in Healthcare" (2005) 35:2 Hastings Cent Rep 34 at 200; Beauchamp, *supra* note 68 at 4.

¹⁷⁴ Beauchamp, *supra* note 68.

¹⁷⁵ *Ibid* at 4.

medical decisions by individuals are informed not just by their own perspectives but also by those that emerge from interactions among participants in triadic consultations.¹⁷⁶

Beauchamp admits that as with all moral principles, in particular contexts physicians may face challenges in the interpretation respect for patient autonomy. He argues that if, in fact, some restriction of patient autonomy is called for, the justification will always be found in one of the other four moral principles (such as beneficence or justice).¹⁷⁷ Potential controversies can arise, for example, when a person's right to autonomous expression demands action by others or where society (family included) may place restrictions on patients' choices, especially where they involve a conflict of values.

2.2.3 – Critiques of Principlist Autonomy

2.2.3 (i) – Theoretical Arguments against Principlist Autonomy as a Universal Norm

Robust theoretical critiques of the rationale for adopting principlism as a universal and preeminent norm in bioethics question its compatibility with the moral theories foundational to informed consent doctrine.¹⁷⁸ K. Danner Clouser and Bernard Gert (who coined the term 'principlism') argue that adherence to a 'four-principles' approach could be misleading in both theory and practice, as these principles are only labels for a group of related matters to be considered when grappling with a moral problem.¹⁷⁹ In particular, the authors find the dominance of autonomy in North American bioethics problematic, especially when principlism is promoted as universal. Their view is that the four principles are "ad hoc constructions," each focusing on key ideas of ethics theory — consequences from John Stuart Mill, autonomy from Immanuel Kant, justice from John Rawls and non-maleficence from Bernard Gert.¹⁸⁰ Thus, although they may serve as useful reminders of broader issues (such as justice or autonomy), because the four principles do not arise from

¹⁷⁶ Epstein & Street, *supra* note 133; AL Patalano & Z LeClair, "The Influence of Group Decision Making on Indecisiveness-Related Decisional Confidence" (2011) 6:2 *Judgm Decis Mak* 163; Epstein, *supra* note 134; Schuldt, JP et al. "Confidence in Dyadic Decision Making: The Role of Individual Differences" (2015) 30:2 *J Behav Decis Mak* 168.

¹⁷⁷ Beauchamp, *supra* note 68 at 4.

¹⁷⁸ KD Clouser & B Gert, "A Critique of Principlism" (1990) 15:2 *J Med Philos* 219; KD Clouser, "Common Morality as an Alternative to Principlism" (1995) 5:3 *Kennedy Inst Ethics J* 219; T Takala, "What Is Wrong with Global Bioethics? On the Limitations of the Four Principles Approach" (2001) 10:1 *Camb Q Healthc Ethics* 72.

¹⁷⁹ Clouser & Gert, *supra* note 178; Clouser, *supra* note 178.

¹⁸⁰ Clouser, *supra* note 178 at 224.

an integrated moral theory they should not be applied as problem-solving ethical guidelines in everyday clinical practice. In other words: the four principles cannot serve as action guides when much is left to individuals' determination of the limits of the applicability of each of the four principles.

A host of factors such as intuitions, idiosyncrasies, and personal biases are likely to influence an individual's thinking when making an ethical judgment — a choice he could validate, in a reverse-engineering fashion, by citing a closely related bioethical 'principle.'¹⁸¹ For example, in attempting to apply the principle of justice in situations related to the allocation and distribution of resources, principlism does not offer clear guidance for decisions about expensive treatment options in the face of resource constraints in a public healthcare system. Here, principlism merely acts as a reminder for the individual to think about justice when making such a decision.¹⁸² Clouser also claims that in addition to four principles not being systematically related, they have the potential to conflict with each other — for example, respecting a patient's autonomous choice could imply that harmful choices should also be honoured.¹⁸³

The pre-eminence of the principle of respect for patient autonomy has been so extensively critiqued that a full examination of this body of literature is beyond the scope of the current chapter. What still merit attention here, though, are the theoretical arguments examining other issues related to the application of principlism in clinical practice.¹⁸⁴ American philosopher Hilde Lindemann, for example, claims that the four principles are “too streamlined to engage the rich particulars of any actual situation.”¹⁸⁵ She asserts that for these principles to do their work, people's social circumstances, position, and relations with others must unfortunately be “abstracted away,” along with wide aspects of their histories, their relationships, and the history of medical practices in their societies.¹⁸⁶ She also criticizes American bioethics as being too limited in its theoretical resources to be

¹⁸¹ *Ibid* at 223.

¹⁸² *Ibid* at 225.

¹⁸³ *Ibid* at 224.

¹⁸⁴ RM Veatch, “Autonomy's Temporary Triumph” (1984) 14:5 *Hastings Cent Rep* 388; P McGrath, “Autonomy, Discourse, and Power: A Postmodern Reflection on Principlism and Bioethics” (1998) 23:5 *J Med Philos* 516; Stirrat & Gill, *supra* note 32; H Lindemann, “Autonomy, Beneficence, and Gezelligheid: Lessons in Moral Theory from the Dutch” (2009) 39:5 *Hastings Cent Rep* 39.

¹⁸⁵ Lindemann, *supra* note 184 at 40.

¹⁸⁶ *Ibid*.

effective in cross-cultural settings — an argument also forwarded by other commentators such as Tuija Takala, who rejects the assumption that there is a “common moral language that could be shared by all regardless of their background.”¹⁸⁷ Lindemann argues that the four principles fail to engage morally important relationships, such as friendship or love, that make individuals unique. She presents a compelling case for addressing American bioethics’ “ethnocentric arrogance of misplaced claims to moral universality” with its individualistic, self-deterministic valuing of autonomy.¹⁸⁸

Other arguments against the ‘four principles’ decry their common adoption based on community experience and non-North American empirical research — speaking to the limitations of a purely theoretical critique.¹⁸⁹ John Traphagan, for example, looks to alternative interpretations of autonomy encountered during his ethnographic and anthropological research in Japan.¹⁹⁰ He argues against universalizing principlism, maintaining that culture profoundly impacts the understanding of what it is to be a human being in society.¹⁹¹ Traphagan’s research also reveals the deep Japanese awareness of social interdependence and a preference for making judgments of moral behaviour based on situational context, rather than the application of universal moral rules. He thus advocates for a study of moral behaviour that is grounded on empirical knowledge rather than on theoretical principles, particularly those that have become normative (such as bioethics’ principlist foundations). Unfortunately, such an approach may be dismissed as moral relativism, a counter-argument that writers such as medical ethicist Gillon (discussed later in this chapter) use to support principlism’s legitimacy.

¹⁸⁷ Takala, *supra* note 178 at 73.

¹⁸⁸ Lindemann, *supra* note 184 at 40.

¹⁸⁹ Y Barth-Rogers & A Jotkowitz, “Executive Autonomy, Multiculturalism and Traditional Medical Ethics” (2009) 9:2 *Am J Bioeth* AJOB 39; SJ Calloway, “The Effect of Culture on Beliefs Related to Autonomy and Informed Consent” (2009) 16:2 *J Cult Divers* 68; MM Luciano, “Commentary: Autonomy and Relatedness Reconsidered: Learning from Indian Families” (2010) 16:4 *Cult Psychol* 497; JW Traphagan, *Rethinking Autonomy: A Critique of Principlism in Biomedical Ethics*, 1st ed (Albany: State University of New York Press, 2013).

¹⁹⁰ Traphagan, *supra* note 189 at 10.

¹⁹¹ *Ibid* at 72.

2.2.3 (ii) – Critiques of the Centrality of Principlist Autonomy in Informed Consent Doctrines

In their influential text, *Rethinking Informed Consent in Bioethics*, British philosophers Neil Manson and Onora O’Neill examine the extent to which ensuring an individual’s right to choose, as a mechanism for protecting patient autonomy, has become the primary justification for informed consent doctrine.¹⁹² They extend the critique of the pre-eminence accorded to patient autonomy originally articulated by O’Neill in her influential ‘Gifford and Reith lectures.’¹⁹³ In those talks, she argued the defectiveness of the individualistic version of autonomous choice and asserted that medical ethics, and particularly informed consent practices, should always be set in the context of relationships and community.¹⁹⁴ Manson and O’Neill maintain that if achieving the ability to make an independent choice through informed consent is a key measure of autonomy protection, then true respect for autonomy must mean respect for *any* choice, even an irrational or potentially harmful one. They claim that if we consider autonomy a matter of mere “reasoned or reflective choice,” it then becomes “hard to show that actual consent (so often less than rational, so often unreflective) operationalizes autonomy.”¹⁹⁵

Commentators from other fields of study such as the social sciences offer comparable perspectives. Because it may be assumed that patients are in the ideal position to determine what is best for themselves, given their resources and values and dependent relationships, a sociological lens offers a valuable perspective on the critique of the individualism inherent in consent doctrine and practice. In her examination of the American context, Dana Bowen Matthew highlights the concern about the practice of seeking a patient’s informed consent.¹⁹⁶ Her proposition is that, ironically, although questions about informed consent are formulated with only majority patients in mind, answers to those questions may be found through addressing the harms informed consent practices have caused to patients who belong to different religious, racial or ethnic groups.¹⁹⁷ By tracing the legislative history of informed consent, Matthew argues that there

¹⁹² Manson & O’Neill, *supra* note 9.

¹⁹³ O’Neill, O. *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002); O’Neill, O. *A Question of Trust: The BBC Reith Lectures 2002* (Cambridge: Cambridge University Press, 2002).

¹⁹⁴ O’Neill, *supra* note 193; Stirrat & Gill, *supra* note 32.

¹⁹⁵ Manson & O’Neill, *supra* note 9 at 20.

¹⁹⁶ Matthew, *supra* note 47.

¹⁹⁷ *Ibid* at 151.

has been a narrowing of the ethical intentions of the doctrine: from a means to ensure that physicians demonstrate beneficence, non-maleficence, and respect for patients' right to choose, to one with an unduly "myopic focus on individual autonomy."¹⁹⁸ To support a claim that a serious oversight of the current model is the assumption that all Americans share the same zealous commitment to protecting individuals' control over medical decisions, she cites several studies that, in fact, show that persons from most non-Western cultures prefer a family-centric decision-making process.¹⁹⁹

John Hardwig, and later Jeffrey Blustein (both American bioethicists), promote a similar view, discussing the role of family in decision-making and the likely challenges this poses for medical professionals who hold a 'traditional' principlist view of informed consent.²⁰⁰ Blustein concludes that part of the duty of physicians in respecting patient autonomy is to encourage and facilitate conversation between patients and close others (such as family members), "unless the *physician* has reason to think that such conversations will not in fact assist the patient in making autonomous decisions."²⁰¹ Interestingly, Blustein simultaneously challenges principlism as an established set of ethics governing the communication practices of physicians and defers to medical authority in conversations regarding informed consent. He appears to bestow physicians with final authority to decide what ought to constitute an environment appropriate for the exercise of individual autonomy, ignoring the patient's or family's perspective on what being autonomous could mean for them.²⁰² Further, this contravenes the wealth of work on the relevance of realigning the focus from individual autonomy in consent to acknowledging the value of families in enhancing the patient's decisional confidence.²⁰³

¹⁹⁸ *Ibid* at 159; JL Nelson, "Taking Families Seriously" (1992) 23:3 Hastings Cent Rep 6.

¹⁹⁹ Matthew, *supra* note 47 at 156-162; LJ Blackhall et al. "Ethnicity and Attitudes toward Patient Autonomy" (1995) 274:10 JAMA 820; G Frank, "Ethnicity and Attitudes toward Patient Autonomy" (1995) 274:10 JAMA 820; NS Jecker & JA Carrese, "Caring for Patients in Cross-Cultural Settings" (1995) 25:1 Hastings Cent Rep 6; KW Bowman & EC Hui, "Bioethics for Clinicians: Chinese Bioethics" (2000) 163:11 Can Med Assoc J 1481; Hickling, *supra* note 5.

²⁰⁰ J Hardwig, *supra* note 132; J Blustein, "The Family in Medical Decisionmaking" (1993) 23:3 Hastings Cent Rep 6.

²⁰¹ Blustein, *supra* note 200 at 12, emphasis in original.

²⁰² *Ibid*.

²⁰³ J Coggon, "Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?" (2007) 15:3 Healthcare Anal 235; J Coggon, "Best Interests, Public Interest, and the Power of the Medical Profession" (2008) 16:3 Healthcare Anal 219; Coggon & Miola, *supra* note 25; YM Barilan, "Informed Consent: Between Waiver and Excellence in Responsible Deliberation" (2009) 13:1 Med

Literature on the pre-eminence of autonomy in informed consent draws mainly from bioethics and law; the discursive predominance of these two fields is borne out by Jeremy Sugarman's analysis of 377 international articles and publications on research on informed consent.²⁰⁴ Less recognized are the contributions from medical sociologists, who maintain that current informed consent practices do not sufficiently consider the varied social dimensions of an individual's decision-making supports or constraints.²⁰⁵ Oonagh Corrigan, for example, asserts that bioethics reifies the process of consent by removing it from its social context and converting it to a mode of rational choice-based action by patients, guided by information from practitioners.²⁰⁶ She refers to this notion of consent as an "empty ethics" model that presupposes the offering of appropriate information to an autonomous individual as sufficient for him to make a conscious decision about participation in a given medical intervention.²⁰⁷ Corrigan also argues that the liberal concepts of 'freedom' and 'autonomy' are dualistically opposed to powerful and autocratic medical structures and practices. Such an arrangement overlooks that power is not just a phenomenon exercised as an *external* constraint, but that prevailing cultural norms, values and systems of expertise *internally* limit the way a patient's choices can be made.²⁰⁸

Pam McGrath, an Australian psychosocial health researcher, also addresses the issue of power in healthcare relations, asserting that the dominance and reification of autonomy as an abstract principle stifles evidence of power and control in biomedical discourse.²⁰⁹ She argues that bioethical reflection should shift from its primary basis in moral philosophy, to consider sociological notions of power, subjectivity and discourse.²¹⁰ Senior physician Donald Berwick, President and CEO of the American organization, the Institute for Healthcare Improvement, has addressed the practical effects of the ironic

Healthcare Philos 89; A Wardrope, "Liberal Individualism, Relational Autonomy, and the Social Dimension Of Respect" (2015) 8:1 Int J Fem Approaches Bioeth 37.

²⁰⁴ J Sugarman et al. "Empirical Research on Informed Consent: An Annotated Bibliography" (1999) 29:1 Hastings Cent Rep S1.

²⁰⁵ RC Fox & JP Swazey, "Medical Morality is Not Bioethics – Medical Ethics in China and the United States" (1984) 27:3 Perspect Biol Med 336; Wolpe, *supra* note 57; O Corrigan, "Empty Ethics: The Problem with Informed Consent" (2003) 25:7 Sociol Health Illn 768.

²⁰⁶ Corrigan, *supra* note 205.

²⁰⁷ *Ibid* at 70.

²⁰⁸ *Ibid* at 771.

²⁰⁹ McGrath, *supra* note 184.

²¹⁰ *Ibid* at 517.

persistence of imbalance of power in an era of ‘patient-centric’ medicine. In describing personal experiences of his encounters with the healthcare system, he examines the degree to which it is possible to shift the power to make medical decisions into the hands of patients, families, and communities.²¹¹ He describes ostensibly autonomy-protecting paternalism in healthcare as a form of disrespect and even violence to the patient, causing needless harm. The ‘violence’ here pertains to the manner in which hospital protocols regulating consent processes and information-sharing induce a “forced separation of an adult from a loved companion,” an outcome that certainly runs contrary to the principle of patient-centred care.²¹²

A similar appeal for a greater awareness of interconnectedness is made by psychiatrist Jan Marta, who argues that individuals’ emotional, linguistic, and socio-cultural dimensions are important considerations.²¹³ Attention to these elements within consent deliberations will help restore patients and physicians to their complete status as persons, from their limited status as merely “medico-legally constructed players” in a principlism-based model.²¹⁴ Marta reminds her readers that consent has been ‘appropriated’ by sets of professionals — from lawyers to bioethicists to government ministers — who develop the ideas and rules governing informed consent and, in the process, reduce the patient to a passive beneficiary of the products of this work.²¹⁵ Philosopher John Christman furthers the interconnectedness argument, claiming that if an individual experiences alienation through being distanced from the connections by which they defines themselves, such social patterning must be detrimental to autonomy. In other words: a person’s autonomy not only requires support, but also demands that communal and social structures shape it. He cautions, however, that “(i)t is one thing to say that models of autonomy must acknowledge how we are all deeply related; it is another to say that we are autonomous only if we are related in certain idealized ways.”²¹⁶

²¹¹ DM Berwick, “What ‘Patient-Centered’ Should Mean: Confessions of an Extremist” (2009) 28:4 Health Aff (Millwood) w555.

²¹² *Ibid* at 556.

²¹³ Marta, *supra* note 40.

²¹⁴ *Ibid* at 355.

²¹⁵ *Ibid* at 353.

²¹⁶ J Christman, “Relational Autonomy and the Social Dynamics of Paternalism” (2013) 17:3 Ethical Theory Moral Pract 369 at 158.

2.2.3 (iii) – Communitarian and Feminist ‘Relational’ Autonomy

Various communitarian and feminist scholars also claim that the model of the autonomous agent upon which liberal principles are founded ignores the social nature of our being, the relational nature of a person’s decisions, and conceptions of human identity that fully consider embeddedness in family and other relations.²¹⁷ They call, instead, for a *relational* autonomy.²¹⁸

Philosopher Antti Kauppinen describes the elements that would contribute to a social or relational autonomy, discussing the various capacities needed for “authentic self-determination,” drawing upon social philosopher Axel Honneth’s ideas.²¹⁹ Kauppinen examines the value of a social connectedness, which he claims will widen the view of the conditions within which an autonomous life could be led. According to Kauppinen, Honneth’s methodological starting point is a firm Hegelian²²⁰ insight: the dependence of autonomy on social relationships becomes noticeable when *disruption* of those relationships reduces a person’s capacity to make an autonomous choice. In other words, the unseen intersubjective dependence (for example, that which a patient may have on their family) emerges when there is a problem. Kauppinen believes that by systematic examination of such disruptions, insights into “autonomy-conducive” relationships that are firmly rooted in everyday experience may be obtained.²²¹ The separation of a patient (ostensibly to protect their autonomy/independence when obtaining consent) from their family members upon whom they usually depend when making major decisions, is an example of the disruption that Honneth has described. By interpreting patient autonomy individualistically as current bioethical doctrines demand, physicians may unwittingly be contributing to a scenario where such a detrimental disruption may arise.

²¹⁷ Nedelsky, *supra* note 32; Mackenzie & Stoljar, *supra* note 76; A Donchin, “Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles” (2001) 26:4 J Med Philos 365; Christman, *supra* note 77; Downie & Llewellyn, *supra* note 107; Maclean, *supra* note 144.

²¹⁸ See my Introduction (at 1.5.3) for a definition of this term and account of its origins.

²¹⁹ Kauppinen, A. “The Social Dimension of Autonomy” in Petherbridge, ed, *The Critical Theory of Axel Honneth* (Leiden: Brill, 2011) 255 at 15-17. (A detailed consideration of the work of social philosopher Axel Honneth, critical theorist of the Frankfurt School, is beyond the scope of this chapter.)

²²⁰ Georg Wilhelm Friedrich Hegel (1770–1831) is a German philosopher who attempted, throughout his published writings as well as in his lectures, to elaborate a comprehensive and systematic philosophy from a purportedly logical starting point. P Redding, “Georg Wilhelm Friedrich Hegel” (4 August 2015) in EN Zalta, ed, *Stanford Encyclopedia of Philosophy* (Stanford: Stanford University, 2011) online: <https://plato.stanford.edu/archives/spr2016/entries/hegel/> (accessed 27 April 2017).

²²¹ Kauppinen, *supra* note 219 at 15.

Several other writers have also discussed the role of family in promoting patient autonomy along these lines; for example, law professor Jennifer Nedelsky has re-examined, in detail, the theory of self, autonomy, rights and law.²²² Her writing on the ‘relational self’ may significantly inform future research by expanding our understanding of autonomy, and with it, the position of family in informed consent formulations. In *Law’s Relations*, Nedelsky engages with a range of legal, ethical and social implications of the notion that an individual self can be actively constituted by the relationships through which a person interacts with others.²²³ Her project here is to “advance a shift in the presumptions about the self and its core values so that a relational perspective becomes a routine part of theorizing about justice, equality, dignity, security, or autonomy.”²²⁴ Nedelsky acknowledges at the outset that tension between individualist and socially contextualized formulations of autonomy will continue until some of the key difficulties with understanding relational autonomy (such as in situations where there is a risk of oppression or coercion of the individual by the collective) are resolved.²²⁵

In explaining how autonomy is possible for a relational self, Nedelsky asserts that people are constituted but not necessarily *determined* by their relationships, and emphasizes that she is referring not only to intimate relationships but also to “nested structures of relations.”²²⁶ She claims that “parts of the dominant picture of autonomy as independence are not really human possibilities” and that “the aspiration to achieve them (to experience their illusion) can only come at the cost of subordinating the others who do the (unacknowledged) work made necessary by dependence.”²²⁷ She also conceptualizes autonomy as a *variable* capacity, as lying on a *continuum*, and as *partial*, since we are always interacting with intimate and/or social relationships that are constitutive of our autonomy.²²⁸ In fact, Nedelsky’s version of a relational human self is anchored in an awareness of human dependence and interdependence.

²²² Nedelsky, *supra* note 33.

²²³ *Ibid.*

²²⁴ *Ibid* at 9.

²²⁵ *Ibid* at 51-52.

²²⁶ See my Introduction for a discussion of this concept (at 1.5.3).

²²⁷ Nedelsky, *supra* note 33 at 45.

²²⁸ See the Introduction for definitions/explanations of these terms (at 1.5.3).

A vivid illustration of the pertinence of dependence on family supports in medical decision-making appears when considering the degree of comprehension and communication of consent expected from an ill but capable patient. In these circumstances, being able to depend on trusted others is critical, given the manner in which structures of contemporary healthcare practice create the risk of epistemic injustice through privileging specific styles of articulating symptoms or particular ways of understanding an illness.²²⁹ As Havi Carel argues, there is widespread familiarity with stories about doctors who do not listen to patients and of bureaucratic healthcare systems that make the experience of accessing healthcare impersonal, all resulting in feelings of helplessness in the patient navigating these interactions.²³⁰ Commentators such as Anita Ho and Abraham Schwab also address the implications of power imbalances attributable to epistemic differentials in healthcare settings, particularly when they involve persons with impairments.²³¹ In such circumstances, being able to depend on family members could arguably mitigate the difficulties experienced by patients. These concerns and the approaches taken to addressing them are illustrated in the discussion on non-Western perspectives of patient-provider relationships in the following section.

2.2.3 (iv) – Postcolonialism and Global Bioethics²³²

A significant body of informed consent literature in English has been published outside of North America and the United Kingdom. These works present alternative views of family participation in medical decision-making and informed consent, wherein conceptions of relationality and interconnectedness are illustrated. For the purposes of this discussion these works are grouped under the rubric of ‘global bioethics,’ a term that implies that the bioethical principles followed in these environments may reflect additional or alternative sociological models of doctor-patient relationships (DPR) compared to those

²²⁹ H Carel & IJ Kidd, “Epistemic Injustice in Healthcare: A Philosophical Analysis” (2014) 17:4 *Med Healthcare Philos* 529.

²³⁰ *Ibid* at 529.

²³¹ A Ho, “Trusting Experts and Epistemic Humility in Disability” (2011) 4:2 *IJFAB Int J Fem Approaches Bioeth* 102; A Schwab, “Epistemic Humility and Medical Practice: Translating Epistemic Categories into Ethical Obligations” (2012) 37:1 *J Med Philos* 28.

²³² The expression ‘global bioethics’ is used by some authors to represent bioethics writing that originates from sources other than Anglo-North American scholarship. This includes writing that is “Western” in origin but from primarily collectivist societies.

established within Western contexts.²³³ In commencing this section of the literature review, I draw attention to the consonances between the concepts of inter-connectedness that patients have with family as introduced in the writings from non-Western sources that I cite here, and the notions of relationality that are promoted by Western communitarian and feminist thinkers as discussed above. In examining this non-Western body of work it is relevant to consider how the ideas expressed help in recognizing how strongly Western ethico-legal consent doctrines are rooted within the values and interests of Euro-American culture.

Medical ethicist Yali Cong proposes a ‘doctor-*family*-patient relationship’ (DFPR) model (instead of a DPR model), claiming that it may already be the prevalent framework in China.²³⁴ This model expects that, after taking the physician’s recommendations into consideration, one family member will signal consent following discussions with familial co-decision makers. The family spokesperson acts as a bridge between the patient and physician, and the patient’s wishes are considered within this structure — they remain a significant stakeholder, possessing varying levels of influence on the final decision. Cong claims that this model strongly reflects Chinese Confucian cultural commitments.²³⁵ The DFPR concept, a model of collectivist medical decision-making based on family-orientated norms, may become important in theorizing informed consent in wider multicultural settings, not just in East Asia. This possibility has been alluded to in the writings of Western bioethicists who have made calls for a greater inclusiveness of the family in healthcare deliberations and decision-making.²³⁶

A leading proponent of an actual ‘Asian bioethics’ is the ethicist Ruiping Fan, who challenges a key notion he claims is held by Western bioethicists: that autonomy principles should be binding wherever bioethics is found in the world.²³⁷ He argues that there is no shared ‘abstract content’ between the Western bioethical and the East Asian understanding

²³³ H Sakamoto, “Towards a New ‘Global Bioethics’” (1999) 13:3-4 *Bioethics* 191; L Turner, “From the Local to the Global: Bioethics and the Concept of Culture” (2005) 30:3 *J Med Philos* 305; M Aulisio, “Bioethics in a Global Village” (2006) 6:1 *Am J Bioeth* 1; HT Engelhardt, ed, *Global Bioethics: The Collapse of Consensus* (Salem: M & M Scrivener Press, 2006).

²³⁴ Cong, *supra* note 45 at 149.

²³⁵ *Ibid* at 157-9.

²³⁶ Hardwig, *supra* note 132; Blustein, *supra* note 200; Schäfer et al, *supra* note 44; Cherry, *supra* note 35.

²³⁷ R Fan, “Self-Determination vs. Family-Determination: Two Incommensurable Principles of Autonomy” (1997) 11:3-4 *Bioethics* 309.

of autonomy. Fan asserts that the Western principle demands self-determination, assumes a subjective conception of the good, and promotes individual independence whereas the East Asian principle requires family-determination, presupposes an objective conception of the good, and upholds the value of harmonious dependence. These are fundamental, seemingly irreconcilable differences in the conception of autonomy.²³⁸

Fan and authors such as Chinese bioethicist (in the Confucian ethics tradition) Shui Chuen Lee, ground their argument on Confucian moral and ontological principles and their emphasis on recognition of the family as an entity existing in its own right. They claim that there are clear differences in approach to medical decision-making and truth-telling in the US, Hong Kong, and mainland China.²³⁹ Fan, however, acknowledges that some similarities do exist, such as the authority of the physician, or elements of family influences in decision-making.²⁴⁰ Although different moral and cultural assumptions influence the public's perception of the appropriate roles of patient, family, and physician, he cautions against oversimplification and essentialization of descriptions of ethical practices in healthcare. There can be significant diversity not just between countries, but also within them, as well as between and within their component cultural groups.²⁴¹ Other Asian writers, such as bioethicist Akira Akabayashi in Japan, have taken a wider approach than Cong, Fan, and Lee to the dilemma of preservation of autonomy of patients, by taking local cultural norms into consideration.²⁴² While Akabayashi acknowledges the differences in Western versus Asian approaches to informed consent, he reminds readers that the debates about cultural collisions in informed consent are not settled and need further exploration.

The notion of a distinct 'Asian' bioethics has been challenged by New Zealand-based bioethicist Jing-Bao Nie, who calls the idea "specious."²⁴³ He argues that there is already much of the East in the West and vice versa; and despite its North American origins

²³⁸ *Ibid* at 318.

²³⁹ Fan, *supra* note 237; Fan, *supra* note 40; Fan, *supra* note 101; SC Lee, *The Family, Medical Decision-Making, and Biotechnology: Critical Reflections on Asian Moral Perspectives* (Dordrecht: Springer Verlag, 2007).

²⁴⁰ Fan, *supra* note 237; Fan, *supra* note 101.

²⁴¹ Fan, *supra* note 237 at 146.

²⁴² A Akabayashi, MD Fetters & TS Elwyn, "Family Consent, Communication, and Advance Directives for Cancer Disclosure: A Japanese Case and Discussion" (1999) 25:4 J Med Ethics 296; A Akabayashi & MD Fetters, "Paying for Informed Consent" (2000) 26:3 J Med Ethics 212; Akabayashi & Slingsby, *supra* note 40.

²⁴³ J Nie, "The Specious Idea of an Asian Bioethics: Beyond Dichotomizing East And West" (2007) *Princ Healthcare Ethics* 143 at 143.

and domination, bioethics was a global phenomenon from the beginning. Nie refers to Filipino bioethicist Leonard De Castro, another skeptic of the pan-Asian proposal, who warns of the danger of universalizing norms to apply to multicultural societies of a large and plural continent.²⁴⁴ As De Castro notes, similar social structures to those informing discussions of patient autonomy inside East Asia are also found outside of it.²⁴⁵ There are, for instance, South Asian and Middle Eastern authorities who have articulated perspectives on medical ethics and, in particular, the position of family in medical decision-making leading to the procurement of consent, again, not-unlike the perspectives championed by Western, feminist medical ethicists and communitarian thinkers.²⁴⁶

In a much-cited paper within the field of cross-cultural psychology, Turkish social psychologist Cigdem Kagitcibasi examines the complex construct of an autonomous self within a model of family change reflecting the pattern of urbanization and socio-economic development in the Majority World.²⁴⁷ Recognizing that there are differences in the definitions of autonomy in psychological and philosophical thought, she construes autonomy in terms of agency, which also involves volition. She questions the importance and indeed even the existence of autonomy in collectivistic cultures but also proposes the notion that *separateness* and *relatedness* can be equally agentic and volitional.²⁴⁸ This understanding is pertinent to the field of medical decision-making that leads to the offering of consent by an individual patient, and must be considered when critiquing the individualistic interpretations of patient autonomy that are central to principlism-based consent protocols. Kagitcibasi, however, reminds us about the inherent dangers of essentializing the understanding of autonomy in consent, by pointing to evolving changes in social, economic and psychological roles of families and the complexities of various combinations of independence and interdependence these changes will likely produce.

²⁴⁴ LD de Castro, "Is There an Asian bioethics?" (1999) 13:3-4 *Bioethics* 227.

²⁴⁵ *Ibid* at 228.

²⁴⁶ MA Kara, "Applicability of the Principle of Respect for Autonomy: The Perspective of Turkey" (2007) 33:11 *J Med Ethics* 627; Nandimath, *supra* note 18; Barth-Rogers & Jotkowitz, *supra* note 189; Luciano, *supra* note 189; D Tsai, "Reflections from Taiwan on Unsought Truth-Telling: Comparison with Lessons From Saudi Arabia" (2012) 9:4 *J Bioethical Inq* 415.

²⁴⁷ Kagitcibasi, *supra* note 45. 'Majority world' refers to the part of the world where the majority of the world's population outside of the Euro-American West live, where cultures are collectivistic and where conceptions of autonomy and individuality are substantially different from those in the West.

²⁴⁸ *Ibid* at 404.

Hence her claims reinforce the positions of Nie and De Castro on the need for diverse approaches to the interpretation of autonomy within Asian cultures.

The call for greater cross-cultural awareness of a patient's social connectedness also comes from Israeli ethicist Yohanna Barth-Rogers, who reminds Western secular ethicists that individual autonomy is not a defining principle in the moral systems of most of the world's citizens. Within the Jewish tradition, for example, unlimited human autonomy is not a crucial value. Barth-Rogers reinforces her argument by drawing comparisons to the position of patient autonomy adopted by Confucian East Asian cultures, wherein there is also a greater emphasis on beneficence and shared decision-making. The common view about consent in both, concerns the viewing of a patient as a person (as Nedelsky also describes²⁴⁹) closely connected to a network of family, community, and greater society.²⁵⁰ Certainly there are challenges in incorporating a 'principlist' form of autonomy (i.e., that of Beauchamp and Childress, discussed earlier) into ethico-legal consent protocols in family-centric societies; however, it still remains unclear exactly how an alternative approach based on relational autonomy principles can be integrated into clinical practice. Although some scholarship has recently examined this integration, it has done so to a quite limited extent.

A recent empirical study conducted in Confucian-influenced but Westernized Singapore, by palliative care physician and bioethicist Lalit Krishna and his team, examined the prospects of adopting a relational autonomy approach in palliative care settings. The authors found few indicators of any shift towards individual decision-making, but instead that family decision-making practices remained prevalent.²⁵¹ Significant ethical concerns were identified, one being the real risk of family-physician collusion and the use of various means of stymying direct patient involvement in discussions so as to avoid the need to break bad news.²⁵² Some families believe that receiving bad news damages a patient's hope, a factor felt to be critical in prolonging life.²⁵³ The authors argue that the practical application of a relational concept of autonomy carries an unpredictably

²⁴⁹ See this chapter, Section 2.2.2.

²⁵⁰ Barth-Rogers & Jotkowitz, *supra* note 189.

²⁵¹ Krishna, Watkinson & Beng, *supra* note 94.

²⁵² *Ibid* at 332.

²⁵³ *Ibid* at 332, 333.

complicated, contextual, and fluid range of cultural, ethical and psycho-social considerations, such as the family's financial responsibility to care for older patients or filial obligations to 'save face' when making decisions in situations where further medical treatment is futile.²⁵⁴

Krishna et al. make recommendations for alternative clinical protocols that might help reconcile individualistic and relational approaches to medical decision-making in palliative care contexts. One of their key recommendations is for a multidisciplinary team to review each specific case, not to circumvent autonomy but to "encapsulate it within specific limits," in view of the multitude of factors involved when a family-connected person faces a terminal illness.²⁵⁵ This Singaporean study reminds us why the application of a relational approach to patient autonomy in clinical practice protocols will be complex, as it involves a diverse set of considerations (such as unique intra-family dynamics or the relationships of power and dependence between healthcare services, be they public or private, and patients and their families). This echoes Nedelsky's caution referred to earlier (on p 23), that the understanding of the notion of relational autonomy is to be given effect in clinical practice is incomplete. Not the least amongst the needs for the future in this field is a more nuanced understanding of how physicians and other healthcare practitioners interpret 'patient autonomy', and the impact that family members' input has on it during triadic clinical interactions. A better understanding of the experiences of senior medical practitioners with both of these phenomena is thus of value, particularly when attempting to identify an acceptable approach that gives due regard to the perspectives of both relational theorists and proponents of principlism. One such attempt is made by British physician and ethicist Raanan Gillon, and his arguments are discussed in the next section.

²⁵⁴ *Ibid* at 337.

²⁵⁵ *Ibid* at 337.

2.2.4 – Gillon’s Defence of Principlism

In the face of mounting criticism, theorists have emerged to champion principlism and argue for its retention and one such thinker is Gillon, who asserts that the formulation of ‘principlism’ is sound, even when the underlying moral theories appear incompatible.²⁵⁶ He embraces a Millian (after British philosopher John Stuart Mill)²⁵⁷ understanding of autonomy: deliberated self-rule, or the tendency and ability to think for oneself, to make decisions about the way one wishes to lead one’s life based on that thinking, and then to enact those decisions. Through upholding the principle of respect for patients’ autonomy as the “first [principle] amongst equals” (and the underlying basis for the rest of the ‘four principles’), Gillon argues that principlism does actually provide a safer, “globally ecumenical” path forward, navigating between the extremes of moral imperialism and moral relativism.²⁵⁸ Principlism thus provides a basis for the “enlightenment project of a universal (or at least very widely accepted) and universalizable set of ethical commitments.”²⁵⁹ According to Gillon, principlism avoids moral imperialism because of the “prima facie nature of the principles, along with morally legitimate differences in their interpretation, in their prioritization in particular circumstances, and in decision-making about their proper scope of application, as well as a principle that positively encourages respect for people’s own deliberated thoughts for themselves.”²⁶⁰ Principlism may thus prove compatible with the wide range of non-relativistic moral theories and perspectives, if one takes into consideration the provision that allowances must be made for these deliberated thoughts to include consideration of other principles (such as family harmony) that are of value in some cultures and within individual families.

Gillon addresses those critics of principlism who are concerned about the dominance of autonomy and its potential moral hegemony over other perspectives by presenting an elegant piece of reasoning. Respect for autonomy demands respect of *all* perspectives of autonomous agents, including respect for their moral autonomy. People’s cultural environments significantly influence their autonomous beliefs, including their

²⁵⁶ R Gillon, “Ethics Needs Principles – Four can Encompass the Rest – and Respect for Autonomy should be ‘First among Equals’” (2003) 29:5 J Med Ethics 307.

²⁵⁷ Note that Beauchamp and Childress also use a Millian understanding of autonomy.

²⁵⁸ Gillon, *supra* note 256 at 311.

²⁵⁹ *Ibid* at 309.

²⁶⁰ *Ibid* at 309.

moral positions. Respect for autonomy thus builds in a *prima facie* moral requirement to respect both individual and cultural moral variability. Such an account does not entail any substantive ideal of independence nor does it demand that an autonomous agent's values be developed in the absence of social forces.²⁶¹

Gillon characterizes respect for autonomy as being a “complexifier of the notions of beneficence and non-maleficence when applied to autonomous agents, and recurrently as an element within the harmonies of justice in all its various manifestations.”²⁶² He goes so far as to say that this approach to autonomy is “indefinitely complexifiable,” enough to be compatible with the insights of a variety of alternative approaches and enhanced by consideration of human virtues, ideals and persons' desires to exceed the bounds of duties.²⁶³ By explicating autonomy in principlism and widening its scope to allow for the possibility that the autonomy of an individual may beneficially be viewed relationally, Gillon may have addressed only some of the primary concerns of relational theorists. A mere awareness of the diversity of influences on autonomy can be problematic, because what is crucial is the ability to identify just which influences do in fact promote a version of autonomy that is associated with an improved capacity of the individual to make a confident choice, especially in the context of medical decision-making.

Further, ethicists who uphold an individualistic version of autonomy do not directly address the role of family in supporting the decision-making capacity of patients. Their discussions of this role commonly place family as a *challenge* to the autonomy of a competent patient. Thus the ‘four principles’ approach does not offer coherent guiding principles to help address situations where a patient autonomously chooses to include their family's active input in the informed consent process — and Gillon does not resolve this impasse. In fact, the author himself acknowledges that both recognizing and placing a value on the complexity of a patient's self-conception can be challenging in practice. Gillon cites the example of Jehovah's Witnesses' attitudes to blood transfusion as illustrative of the way people vary in their perceptions and evaluations of their own needs, making it difficult for others to accurately gauge what a beneficiary regards as a benefit.²⁶⁴

²⁶¹ AC Westlund, “Rethinking Relational Autonomy” (2009) 24:4 *Hypatia* 26.

²⁶² Gillon, *supra* note 256 at 311.

²⁶³ *Ibid* at 311.

²⁶⁴ Gillon, *supra* note 256 at 310.

In concluding this section, it is worth noting bioethicist Daniel Callahan's²⁶⁵ views on the future role of principlism.²⁶⁶ Writing at about the same time as Gillon, he presented a sobering reminder about why bioethics had gravitated towards an ethics of autonomy in the first place: because it suited the ideology of a 1960s-era America, a society emerging from revelations of atrocious violations of the integrity of individuals, by researchers and other medical professionals, in a paternalistic healthcare community.²⁶⁷ Callahan concludes that the 'four principles' approach is too narrow and too individualistic to do the work of medical ethics, describing this approach as lending itself to "tidy, mechanical and deductive reasoning" that does not sufficiently account for the complexity of the world.²⁶⁸ We have seen, however, from Gillon's argument about that ethics and particularly the 'complexifiability' of the interpretation of the autonomy in principlism, that Callahan's may not necessarily be an entirely valid claim.²⁶⁹

2.2.5 – Reconciling Principlist and Relational Views of Autonomy

Is the harsh dichotomy between individual and relational approaches to understanding autonomy warranted? Can the tensions inherent in an antagonistic, individual-versus-relational perspective be resolved? To begin with: the concept of *autonomy* may, too often, be confounded theoretically with the concepts of *individualism* and *independence*. By way of contrast, social psychologists approach these concepts using self-determination theory (SDT), a 'macro' theory of human motivation and personality. SDT focuses on the degree to which an individual's behaviour is self-motivated and self-determined, and is concerned with the impetus behind choices made without any external influence or interference. This conceptualization may arguably provide a bridge between the individualist and relational positions on autonomy, by highlighting the possibility that a person may well be acting autonomously having willingly chosen to be dependent on another and relying on their care.²⁷⁰

²⁶⁵ Co-founder of the Hastings Centre and its Emeritus President

²⁶⁶ D Callahan, "Principlism and Communitarianism" (2003) 29:5 J Med Ethics 287.

²⁶⁷ D Callahan, "Bioethics: Private Choice and Common Good" (1994) 24:3 J Hastings Cent Rep. 28.

²⁶⁸ Callahan, *supra* note 266 at 291.

²⁶⁹ Gillon, *supra* note 256 at 311.

²⁷⁰ EL Deci RM Ryan, "Self-Determination Theory" in PA van Lange, ET Higgins & AW Kruglanski, eds, *Handbook of Theories of Social Psychology* (Los Angeles: SAGE, 2012) 416.

In a Saskatoon-based study of 559 students from four culturally different nations, a group of social psychology researchers concluded that people engage in any type of cultural practice (collectivistic or individualistic) with varying levels of autonomy, all with distinct implications for well-being.²⁷¹ The more autonomous the enactments of an activity, the greater the association with well-being. This supports SDT's claim that autonomy (when defined as volition or the inner endorsement by one's action or lifestyle), is a basic, universal human concern — although some SDT theorists may cast autonomy as being mainly an attribute of 'Western' individualism. SDT does not conceptualize independence or separateness as universal needs; instead, humans are thought to thrive best in contexts of relatedness and mutuality.²⁷² According to the Saskatoon study, there may be individual variances in internalization of culturally dominant practices, but persons can still act autonomously, even while adopting values and behaviours that lend priority to a particular group.²⁷³

As discussed earlier, proponents of the form of autonomy in principlism have been accused of distorting the relationship between individuals and the world by exaggerating the reach of individual agency and underestimating the impact of society or culture on an individual's decision-making. Further, for many patients, merely being presented with a medical diagnosis and recommendations of potentially dangerous treatment abruptly precipitates significant dependence on others. To relational theorists, the principlist view of such a person as an autonomous decision-maker while stripped of social relations is, of course, manifestly unacceptable. Yet defining persons as being necessarily related in particular ways (such as by blood, as with family) might ignore fluxes in the quality and character of such relationships, or the diversity of intersecting cultural and situational influences on a person's self-conception.²⁷⁴ For this reason it is difficult to arrive at a semblance of a model for normative thinking regarding a person's autonomy. It may be argued — as Gillon would assert — that an individualistic conception of the self is, indeed,

²⁷¹ V Chirkov et al. "Differentiating Autonomy from Individualism and Independence: A Self-Determination Theory Perspective on Internalization of Cultural Orientations and Well-Being" (2003) 84:1 J Pers Soc Psychol 97.

²⁷² EL Deci & RM Ryan, "The 'What' and 'Why' of Goal Pursuits: Human Needs and the Self-Determination of Behavior" (2000) 11:4 Psychol Inq 227.

²⁷³ Chirkov et al, *supra* note 271.

²⁷⁴ Christman, *supra* note 77.

compatible with a conception of autonomy, if it takes into consideration relevant constitutive factors.

2.2.6 – Relationality: The Congruence of Perspectives

In concluding this section of the chapter, I draw attention to the remarkable consonances in the recognition of the significance of the inter-connectedness of individuals with their family members, variously presented within the moral theories of ‘non-Western’ biomedical ethics, and those prominent in Western communitarian and feminist thought. Recognition of this congruence supports the notion that an East-West binary in viewing autonomy in healthcare decision-making may not be justifiable. There is also not much to be gained by placing theoretical streams that privilege relatedness entirely in opposition to principlism, except where the interpretation of the latter is rigidly conflated with individualism and independence, as may be the case for example, in the current application of institutional consent protocols framed on Western ethico-legal lines. As Gillon has argued, by viewing autonomy instead as being complexifiable and contextual (see above discussion, p. 58), the interpretation of autonomy in principlism and relational approaches may be helpfully reconciled.²⁷⁵ Hence, the question of how individual clinicians interpret autonomy in clinical practice is critical to answer — the study of triadic patient-family-physician interactions in the context of medical decision-making provides an opportunity to do so.

2.3 – The Family in Medical Interactions

The primacy of principlist autonomy in bioethical reasoning translates into a very particular, concern-laden framing of familial roles in medical decision-making leading to the granting of consent. Accordingly, the general challenges experienced during encounters where family members are present have been well documented, including physicians’ concerns about individual privacy, patient autonomy, and the risk of coercion.²⁷⁶ Family is

²⁷⁵ Gillon, *supra* note 256.

²⁷⁶ F Lang et al. “Interviewing when Family Members are Present” (2002) 65:7 *Am Fam Physician* 1351; Fan, *supra* note 237; A Ho, “Family and Informed Consent in Multicultural Setting” (2006) 6:1 *Am J Bioeth* 26; Schäfer et al, *supra* note 44; BC Schouten & L Meeuwesen, “Cultural Differences in Medical Communication: A Review of the Literature” (2006) 64:1–3 *Patient Educ Couns* 21; A Ho, “‘They Just Don’t Get It!’ When Family Disagrees with Expert Opinion” (2009) 35:8 *J Med Ethics* 497; M Cordella, “A Triangle that May Work Well: Looking through the Angles of a Three-Way Exchange in Cancer Medical

often portrayed as complicating medical consent discussions, and as the party threatening several bioethically sacrosanct patient rights.²⁷⁷ Insoo Hyun, for example, cautions that an adult individual's waiver of their right to consent in deference to their family's wishes may not always be genuine, and merits closer examination.²⁷⁸ I have not thoroughly reiterated the negative potential of family participation in consent processes here, because this has been discussed consistently and in-depth in the existing literature, and that literature constitutes the foundation of the currently normative and dominant model of patient autonomy.²⁷⁹

The potentially positive contributions of family to enhancing the patient's decisional capacity have also been articulated theoretically and empirically, through research using discourse analysis and ethnographic methods.²⁸⁰ Writers from a variety of fields have identified how family support can, for example, enhance the decisional confidence of the patient and promote their autonomy.²⁸¹ The call to reconsider the positive aspects of family members in medical decision-making has most recently been made by

Encounters" (2011) 5:4 *Discourse Commun* 337; Laidsaar-Powell et al, *supra* note 158; B Clough, "What About Us? A Case for Legal Recognition of Interdependence in Informal Care Relationships" (2014) 36:2 *J Soc Welf Fam Law* 129.

²⁷⁷ Hyun, *supra* note 40; Charles et al, *supra* note 4; Schäfer et al, *supra* note 44.

²⁷⁸ Hyun, *supra* note 40.

²⁷⁹ Blustein, *supra* note 200; C Levine & C Zuckerman, "The Trouble with Families: Toward an Ethic of Accommodation" (1999) 130:2 *Ann Intern Med* 148; C Levine & C Zuckerman, "Hands On/Hands Off: Why Healthcare Professionals Depend on Families but Keep Them at Arm's Length" (2000) 28:1 *J Law Med Ethics* 5; FM Chen et al., "Role Conflicts of Physicians and their Family Members: Rules but No Rulebook" (2001) 175:4 *West J Med* 236; I Hyun, *supra* note 40; RA Burt, "Resolving Disputes between Clinicians and Family about 'Futility' of Treatment" (2003) 27:6 *Semin Perinatol* 495; Hyun, *supra* note 43; Fan, *supra* note 40; C Tamura, "The Family-Facilitated Approach Could Be Dangerous If There Is Pressure by Family Dynamics" (2006) 6:1 *Am J Bioeth* 16; Ho, *supra* note 40; Calloway, *supra* note 189; K Cheng, T Ming & A Lai, "Can Familism be Justified?" (2011) 26:8 *Biethics* 431; R Gilbar, "Family Involvement, Independence, and Patient Autonomy in Practice" (2011) 19:2 *Med Law Rev* 192; R Gilbar, "Asset or Burden? Informed Consent and the Role of the Family: Law and Practice" (2012) 32:4 *Leg Stud* 525.

²⁸⁰ RD Adelman, MG Greene & R Charon. "The Physician-Elderly Patient-Companion Triad in the Medical Encounter: The Development of a Conceptual Framework and Research Agenda" (1987) 27:6 *Gerontologist* 729; AE Beisecker, & WP Moore, "Oncologists' Perceptions of the Effects of Cancer Patients' Companions on Physician-Patient Interactions" (1994) 12:1-2 *J Psychosoc Oncol* 23; Cordella, *supra* note 276; Greene, MG & RD Adelman. "Beyond the Dyad: Communication in Triadic (and more) Medical" in LR Martin & MR DiMatteo, eds, *The Oxford Handbook of Health Communication, Behavior Change, and Treatment Adherence* (Oxford: OUP, 2014) 136; L Willoughby et al. "Being Heard: The Role of Family Members in Bilingual Medical Consultations" in E Stracke, *Intersections: Applied Linguistics as a Meeting Place* (Newcastle upon Tyne: Cambridge Scholars Publishing, 2014) 22.

²⁸¹ JB Brown et al. "Roles and Influence of People who Accompany Patients on Visits to the Doctor" (1998) 44 *Can Fam Physician* 1644; Levine & Zuckerman, *supra* note 279; MA Habiba, "Examining Consent within the Patient-Doctor Relationship" (2000) 26:3 *J Med Ethics* 183; Schäfer et al, *supra* note 44; RA Burt, "Invitation to the Dance: Lessons from Susan Sontag's Death" (2009) 39:2 *Hastings Cent Rep* 38.

applied ethicist and philosopher Mark Cherry, who challenges the claim that the family is no more than a social construction.²⁸² He highlights the ontologically central position of family in human flourishing, asserting that this justifies a family-oriented approach to medical decision-making. Moreover, Cherry argues that the rationale for denial or disruption of family decisions by institutions, state actors, physicians, and other healthcare professionals constitutes an interference that must meet a substantial burden of proof. He claims that individualistic views of the family have effectively driven a “social wedge” between parents and children; indeed, between members of families.²⁸³

Similarly, recently British legal commentators such as Roy Gilbar and José Miola have focused on the individualistic interpretation of patient autonomy that underpins consent doctrines in English common law, arguing that the law has discounted the real influence and role of family in medical decision-making right across cultural groups.²⁸⁴ These authors propose that there is potential for English law to better recognize the value of relationality when attempting to protect patient autonomy. However, in their theoretical analysis, Gilbar and Miola firstly reinforce the essentialist dichotomy of British-non-Western (immigrant, collectivist) approaches to decision-making and largely conflate the interpretation of autonomy with *independence* in the context of medical decision-making.²⁸⁵ Clearly, a preference for either individualist or collective decision-making can exist amongst members of both majority and non-Western cultures in Britain, and I believe that this will also be the case in Canada. I argue in my Introduction that the law governing informed consent in British Columbia may be viewed as being narrowly individual-focused, but I also claim that the authority to include or exclude family members from consent discussions is vested only in the healthcare practitioner who is obtaining consent. Hence the opportunity to honour a patient’s collectivist preference in decision-making is tied to the manner in which the practitioner interprets patient autonomy and whether the family poses a threat to it, in individual cases. Hence my research that examines the

²⁸² Cherry, *supra* note 35.

²⁸³ *Ibid* at 458.

²⁸⁴ Gilbar, *supra* note 279; Miola et al., *supra* note 25.

²⁸⁵ K O’Donovan & R Gilbar, “The Loved Ones: Families, Intimates and Patient Autonomy” (2003) 23:2 Leg Stud 332; R Gilbar, *The Status of the Family in Law and Bioethics: The Genetic Context* (Aldershot & Burlington: Ashgate Publishing, 2005); Gilbar, *supra* note 279; Coggon & Miola, *supra* note 25; Miola et al., *supra* note 25.

physician-patient-family triadic encounter will contribute to the knowledge of how, despite the traditional, principlist legal consent framework, a relational approach to autonomy may (or may not) conceivably operate.

In considering institutional governance of medical consent, it is clearly necessary to consider the socio-cultural needs of the public being served, such that the intended protections of ethico-legal rules remain relevant. Unsurprisingly, in many communitarian societies (including diasporic ones), family members expect to participate actively in treatment decisions that affect their loved ones, giving rise to various ethical challenges — again, concerns about privacy, autonomy, and coercion in particular.²⁸⁶ Much of the literature analyzing the threat to patient autonomy posed by collectivist medical decision-making addresses the specific context of individuals from non-Western communities within Europe or North America, and has been significantly influenced by anthropological and cross-cultural research.²⁸⁷ Unfortunately, although several writers have contributed to the field, this research stream remains narrow and further work would be highly valuable.²⁸⁸

Research on non-Western communities has also focused on challenges posed by the cross-cultural interaction itself. For example, commentators from both Western and non-Western healthcare environments have addressed the different expectations of patients and their families from non-Western communities in their engagement with medical professionals, especially in the face of communication difficulties. Their analyses examine two broad areas: the family's active participation in decision-making, and their requests (or insistence) that the truth be withheld from the patient. For example, Fuusje de Graaff and his Dutch co-workers examined the importance of professional care providers being able to competently manage communications in triads, a common configuration in which Turkish and Moroccan immigrants in Holland access cancer care. The researchers found

²⁸⁶ Moazam, *supra* note 43; AM Jafarey & A Farooqui, "Informed Consent in the Pakistani Milieu: The Physician's Perspective" (2005) 31:2 J Med Ethics 93; M Claramita et al. "Doctor-Patient Communication in a Southeast Asian Setting: The Conflict between Ideal and Reality" (2011) 16:1 Adv Health Sci Educ 69; Andrades, Kausar & Ambreen, *supra* note 158; Claramita et al, *supra* note 138.

²⁸⁷ A Kleinman, "Culture, Illness, and Care – Clinical Lessons from Anthropological and Cross-Cultural Research" (1978) 88 Ann Intern Med 251.

²⁸⁸ Moazam, *supra* note 43; Hyun, *supra* note 43; de Haes, *supra* note 43; Siong, *supra* note 101; LeBlanc et al, *supra* note 43.

perceptual differences between members of these groups and healthcare workers in the understanding of what constituted ‘good communication’ during such interactions.²⁸⁹

In addition to communication hurdles, differences in underlying expectations can be a source of difficulty even in normatively non-Western societies. Practitioners trained in Western medicine who serve patients and families in collectivist societies may experience some tension when they comply with local consent protocols framed according to Western, individualistic, ethico-legal paradigms. One major source of dissonance between local community values and ethico-legal consent doctrines is the contentious issue of whether or not it is appropriate to withhold the truth from patients.²⁹⁰ Some of the discursive clashes in these settings is unsurprising considering the far-reaching influence of English and European legal doctrines on healthcare governance frameworks within former colonies.²⁹¹ In fact, a significant number of doctors in Commonwealth countries still obtain their medical indemnity protection, medico-legal education, and legal support from a London, UK-based medical malpractice defence organization, the Medical Protection Society.²⁹²

Overall, despite a growing body of literature on triadic or multi-party interactions between physician, patient and family,²⁹³ as well as robust work on the effect of familial presence during routine medical visits,²⁹⁴ what remains lacking is research that directly

²⁸⁹ FM Graaff et al. “Talking in Triads: Communication with Turkish and Moroccan Immigrants in the Palliative Phase of Cancer” (2012) 21:21-22 *J Clin Nurs* 3143.

²⁹⁰ Lee & Wu, *supra* note 88; Back & Huak, *supra* note 90; M Ito, N Tanida & S Turale, “Perceptions of Japanese Patients and their Family about Medical Treatment Decisions” (2010) 12:3 *Nurs Health Sci* 314; Cheng & Lai, *supra* note 279.

²⁹¹ J Dupont, *The Common Law Abroad: Constitutional and Legal Legacy of the British Empire* (Littleman: Fred B. Rothman Publications, 2001); University of Ottawa. “Common Law Systems and Mixed Systems with a Common Law Tradition” *JuriGlobe: World Systems Research* (nd) online: <http://www.juriglobe.ca/eng/sys-juri/class-poli/common-law.php> (accessed 29 June 2016).

²⁹² MPS UK, *The Medical Protection Society*, online: <http://www.medicalprotection.org/uk> (accessed 28 July 2016).

²⁹³ H Waitzkin, “Information Giving in Medical Care” (1985) 26:2 *J Health Soc Behav* 81; RM Coe & CG Prendergast, “The Formation of Coalitions: Interaction Strategies in Triads” (1985) 7:2 *Sociol Health Illn* 236; Adelman, Greene & Charon, *supra* note 280; RJ Botelho, B Lue & K Fiscella, “Family Involvement in Routine Healthcare: A Survey of Patients’ Behaviors and Preferences” (1996) 42:6 *J Fam Pract* 572; Beisecker & Moore, *supra* note 280; O Karnieli-Miller et al. “Are You Talking to Me?! An Exploration of the Triadic Physician-Patient-Companion Communication within Memory Clinics Encounters” (2012) 88:3 *Patient Educ Couns* 381; Greene & Adelman, *supra* note 280.

²⁹⁴ ML Clayman et al. “Autonomy-Related Behaviors of Patient Companions and their Effect on Decision-Making Activity in Geriatric Primary Care Visits” (2005) 60:7 *Soc Sci Med* 1583; ML Clayman & MA Morris, “Patients in Context: Recognizing the Companion as Part of a Patient-Centered Team” (2013) 91:1 *Patient Educ Couns* 1.

examines physicians' own perspectives on (or experiences of) their patients' families' participation in decision-making, along with physicians' attitudes about (or responses to) any resulting compromise of their patients' autonomy.²⁹⁵ This problematic gap in knowledge exists despite wide recognition that the input of family inevitably influences the outcome of interactions between physicians and patients — an arrangement that is common enough in any social system. Here, several identifiable relationship dynamics are at play: physician/patient, family/patient, and physician/family. These interactions are ultimately informed by the degree to which genuine patient or 'consumer choice' is realistically possible within any system, particularly Canada's public healthcare scheme, in which resources (including or especially physicians) are strained.²⁹⁶

Similarly, although a generally better understanding of the diversity of the roles and expectations of families in consent processes in both Western and non-Western settings has emerged, several problematic issues remain in clinical practice. One of the practical difficulties is in the identification of precisely which members ought to be included in the category of 'family' (and hence invited or allowed to contribute to decision-making) for individual patients. Where this can be safely established, another challenge lies in distinguishing between genuine support and coercive influences, or input from individuals who may not have the patient's best interests at heart.²⁹⁷ Physicians need skills and experience to make these 'social diagnoses' of family members and relevant determinations of their internal dynamics. My research project aims to contribute to an understanding of how these particular skill sets are constituted and actively developed. Although the training of physicians in exhibiting skillful management of their relationship-building with their patients' families will contribute constructively to an important aspect

²⁹⁵ AD Barone, WC Yoels & JM Clair, "How Physicians View Caregivers: Simmel in the Examination Room" (1999) 42:4 *Sociol Perspect* 673; Lang et al, *supra* note 276; O'Donovan & Gilbar, *supra* note 285; Gilbar, *supra* note 279.

²⁹⁶ FS Omole et al. "Interacting with Patients' Family Members during the Office Visit" (2011) 84:7 *Am Fam Physician* 780. A currently trending issue on Twitter is #CanadaWAITS, a hashtag under which hundreds of Canadians have been sharing their experiences of "excruciating" wait times in emergency rooms and with referrals. The topic has received millions of views. See: N. Stechyson, "Canadian Patients And Doctors are Sharing 'Excruciating' Wait Times On Twitter," *HuffPost Canada: Living* (3 November 2017) online: http://www.huffingtonpost.ca/2017/11/03/canada-doctor-patient-wait-times_a_23266026/?utm_campaign=canada_newsletter

²⁹⁷ A Donchin, "Autonomy and Interdependence: Quandaries in Genetic Decision-Making" in C Mackenzie & N Stoljar, eds, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: OUP, 2000) 236; Donchin, *supra* note 217; Hyun, *supra* note 40; Hyun, *supra* note 43.

of their approach to obtaining consent, there are other aspects of informed consent protocols (such as documentation or the legal standards of risk disclosure) which I do not address in my project.

An analysis of the literature indicates that there is an incomplete understanding of a physician's role, attitudes and perspectives during discussions where families participate, particularly the measures they take to protect patient autonomy in the face of overt or potential coercion. Increasingly, families expect to be actively involved in medical decision-making that affects their loved ones. Although broad principles that guide physicians (and other healthcare workers) in navigating such interactions are readily available, there remains a place for more nuanced and culturally-orientated training that raises communications standards. Hence the value of empirical research that identifies and analyzes the tacit or explicit skills that senior physicians apply during triadic or multi-party clinical encounters.

Conclusion

In this literature review I have presented discussions on the main approaches to conceptualizing patient autonomy, indicating a divergence between individualistic principlism and those accounts that emphasize the interconnectedness of individuals in medical decision-making. I have also argued that there is general consonance between the relational views of a competent patient proposed by Western communitarian and feminist thinkers, and those of non-Western ethicists who value the importance of considering the patient in relationship to their family during consent. I have also presented a 'bridging' argument that offers a means to reconcile differences between principlist and relational concepts of 'patient autonomy', the clinical construal of which remains challenging. What becomes evident from examining the literature is that there is incomplete knowledge of how medical practitioners ought to best interpret their patients' ability to be autonomous during consent discussions in the presence of family members, especially if a relational view of autonomy is adopted. Research that contributes to filling that knowledge gap will therefore be of value in medical education on the topic of informed consent as well as on the framing of institutional consent protocols.

CHAPTER 3: Methodology & Method

Introduction

My study was designed so as to learn about the experiences that physicians have, in simultaneous interactions with patients and their family members or close others, during the informed consent process. The research was conducted according to the Interpretative Phenomenological Analysis (IPA) methodology, which involves in-depth individual interviews and an idiographic approach to the data.

In this chapter, I first state the research question and then discuss the objectives of the research, in the course of which I describe the issues that prompted my choice of research topic. Next I describe the analytical framework and the conceptual design of the research, providing a context for the study — including comments about relevant sections of the law of consent in British Columbia. I then describe how I arrived at the choice of my methodology and provide a general description of the key attributes of the IPA approach. With this background in place, I then identify the paradigmatic position my work has adopted and describe the major characteristics of the research design. This includes a discussion of the inclusion and exclusion criteria for the selection of participants, and the approach taken in developing interview questions. I next discuss the issues of trustworthiness and credibility of the project, along with the ethical issues associated with the research; and follow this with a description of participant recruitment and associated considerations, such as informed consent, confidentiality, and the risks of potential distress to the participants. I conclude this chapter with a description of the approach taken to the analysis of the research data, and comment on the limitations of my research.

3.1 – A Priori Assumptions

In this project, I assumed that within any community of physicians there would be a reasonable individual understanding of the overarching ethical and legal rules under which medical practice is conducted. These are the frameworks that govern most aspects of the interface between the medical profession and the public. I also assumed that the application of the ethical and legal principles governing these interfaces could be

ascertained by using empirical research methods that facilitate the capture of tacitly-held knowledge within the community of practice.

I assumed that physicians should be cognizant of their ethical and legal obligations to the public they serve, and that trust, responsibility and mercy are phenomenological essentials in their domain of practice. Moreover, I assumed that physicians are also aware of their fiduciary responsibility for the care of their patients, while being conscious that the law clearly determines the standard of risk disclosure that must be met in order to obtain valid consent prior to medical interventions. For convenience, unless specified otherwise, I use the word ‘family’ to refer to both the adult family members and/or close others of the patient, with the full realization that family members may not be close, and close others may not be related.

3.2 – Research Question and Objectives of Research

3.2.1 – Research Question

What is the experience of specialist physicians in high-risk fields in their interactions with the families of competent patients during the informed consent process?

3.2.2 – Objectives of Research

My research aimed at exploring and understanding the experiences of a purposefully selected group of specialist physicians²⁹⁸ in their engagements with the families of their patients during the informed consent process. In particular, it was designed so as to better understand how these physicians interpret their legal and ethical obligations to promote and protect their patients’ autonomy and independent choice, in the context of family participation, during the process of obtaining informed consent. Such simultaneous, three-party interactions have particular characteristics and dynamics; they are ‘triadic,’ as differentiated from the ‘dyadic’ individual interactions that occur between doctor and patient.²⁹⁹ Furthermore, my intention was to discover the rationale that physicians apply if they ever recommend the recruitment of family input during discussions about treatment

²⁹⁸ Physicians working in high-risk medical fields were invited to participate. The definition of ‘high risk’ field and the inclusion and exclusion criteria for participant selection are provided in Section 3.7.2 of this chapter.

²⁹⁹ Laidsaar-Powell et al, *supra* note 158.

risks. More broadly, one of the objectives of my project was to discover how physicians view the social role of a patient's family in shared decision-making. This is a particularly important consideration, bearing in mind that with the changing demographics in many Canadian cities, physicians are routinely and increasingly called upon to engage with non-European families — families from cultures in which major decisions are often made collectively. I also aimed to discover how Canadian-trained physicians learn the skills for engaging with the families of their patients, along with their impressions about the value of formally incorporating relevant training aimed at developing such skills within medical school curricula.

3.3 – Explanation of the Objectives of My Research

A physician's approach to family is practiced with a diverse range of styles, and degrees of empathy and patience, and is often significantly impacted by time constraints. Various factors inform the attitude toward family, such as the values held by the individual practitioner, the culture of medical education in the environment(s) where they were trained, or the specific communications and bioethics principles they learned both formally and informally.³⁰⁰ Additionally, the degree of awareness of legal and ethical obligations may also reflexively determine how physicians establish the parameters for triadic clinical interactions, particularly if threats to patient autonomy are either anticipated or sensed during such encounters. This is relevant because the quality of communication with family may have a bearing on the risk of conflict in the aftermath of adverse treatment outcomes.³⁰¹

As discussed in the Introduction, the law generally remains silent regarding a physician's obligation to engage with family directly, and appears to empower the physician to promote or suppress the agency of the family during discussions that precede the patient's giving consent. A physician who interprets consent law narrowly could assume that a seemingly rational and legally competent patient does not require family members to be simultaneously present for decisional support.

³⁰⁰ Lempp & Seale, *supra* note 14.

³⁰¹ Vincent, Young & Philips, *supra* note 8; JK Robbennolt, "What We Know and Don't Know about the Role of Apologies in Resolving Healthcare Disputes" (2004) 21 Ga St UL Rev 1009.

How physicians engage with family of competent patients during risk disclosure and the obtaining of informed consent requires closer examination.³⁰² It is likely that these skills are held and practised tacitly by physicians and are, in lay terms, described variously as ‘communication skills,’ ‘bedside manners,’ ‘empathy,’ and ‘cultural sensitivity.’ Bearing in mind the ethnic diversity of Canadian society, my research included physician-participants who practice in multicultural environments. I felt that it highly likely that such doctors would have rich experiences in engaging with families from a variety of ethnic and cultural backgrounds, compared to those who practice in less diverse communities.

My research also aimed to discover to what degree physicians believe that such interactive skills are crucial in clinical practice, and to find out how these skills are learned. I hoped to obtain an understanding of how medical training prepares doctors for the expectation that they should be competent in dealing with family — especially during informed consent processes, where protecting patient autonomy is a primary goal.

3.4 – Analytical Framework

The analytical framework for my research incorporates theories from bioethics, medical sociology, and legal philosophy. Tensions exist between these fields in the interpretation of medical consent, recognition of social embedding, and interconnectedness. Perspectives also differ with regard to power imbalances in healthcare and the value placed on individualism in decision-making.³⁰³ I situated my project in a space from which I was able to draw constructively from these various ways of understanding the physician-patient relationship. A relational theory lens was applied substantively throughout my study, especially with regard to how physicians understand autonomy, self-determination, independence, and interdependence.³⁰⁴

³⁰² Schäfer et al, *supra* note 44.

³⁰³ Hedgecoe, *supra* note 91.

³⁰⁴ Nedelsky, *supra* note 33; Christman, *supra* note 77.

3.5 – Conceptual Design

3.5.1 – Relevant Law

In my study, referenced case law has been restricted to relevant Canadian legislation governing the consent process in healthcare, and since my research was conducted in British Columbia, the relevant statute referred to is the *Health Care (Consent) and Care Facility (Admission) Act*.³⁰⁵ The pertinent portions of this Act are Sections 6, 7, and 8, which regulate elements of consent-taking. Of particular note is Section 8, which states that,

*When seeking an adult's consent to healthcare or deciding whether an adult is incapable of giving, refusing or revoking consent, a healthcare provider a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.*³⁰⁶

Section 8(b) can be interpreted to mean that the person (such as a physician) securing consent for a healthcare procedure has discretion over whether or not to allow family members to be present during the process of acquiring that consent. How physicians interpret this law is part of the focus of my research.

3.5.2. – Arriving at a Choice of a Research Methodology

Interacting with patients' families during the consent process (especially for high risk procedures) can vary from being emotionally challenging to being a professionally fulfilling opportunity to offer comfort, reassurance, and clarity. This understanding comes from my personal experience as a specialist surgeon in a high-risk field for more than twenty-five years, combined with my understanding of the similar experiences of many medical colleagues. I have discussed personal reflections on the participation of families in pre-consent discussions in my Introduction (Section 1.2, p. 7). Here I expand on those reflections in order to offer a more detailed understanding of the phenomenon I chose to study.

³⁰⁵ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c. 181.

³⁰⁶ *Ibid* at s8.

The experience that specialist physicians have in their interactions with patients' families is complex, and influenced by cultural, situational, and other factors (such as the extant local medico-legal climate). The ready availability of medical information on the Internet, generally higher education levels among the public, increased expectations of success in healthcare interventions, and perhaps a high litigation environment combine to make constructive family engagement a key skill in clinical practice. The skills needed to engage with patients' families refine as a physician's clinical career progresses, and therefore, a better understanding of the approaches that senior physicians take when discussing high-risk treatment with families can be useful for medical education purposes. These skills are often applied tacitly and are not routinely taught in medical curricula, hence the value of discussing these experiences with purposefully selected physicians.³⁰⁷

My intention was to explore and understand how physicians experience and navigate the various challenges that arise from discussing risky treatment options with family members, in the presence of the patient — a triadic interaction which has so far been investigated largely from ethnographic or quantitatively-designed or meta-analytical viewpoints, and only rarely from a primarily physician perspective. Family members may, understandably, have a deep interest in the outcome of treatment of their loved ones, and thus may be anxious and emotionally distraught. I have aimed to understand better how physicians reconcile the need for being explicit about risk disclosure with the imperative of maintaining trust, and how, in the process, they comply with their legal and ethical obligations to protect patient autonomy. I felt it was also important to learn how physicians negotiate the challenges that may arise from intra-family or patient-family disagreement in this context. These types of interactions are informed by intricate variables and subtleties and I believed that, because of my professional background in medical practice, I would have sufficient awareness of their scope to be able to research the topic effectively.

However, although I may have a strong personal interest in the topic, I was also aware that other physicians might not necessarily share my concerns to the same degree.

³⁰⁷ WT Branch et al. "Teaching the Human Dimensions of Care in Clinical Settings" (2001) 286:9 JAMA 1067; AL Suchman et al. "Toward an Informal Curriculum that Teaches Professionalism – Transforming the Social Environment of a Medical School" (2004) 19:5 J Gen Intern Med 501; AL Suchman, "Advancing Humanism in Medical Education" (2007) 22:11 J Gen Intern Med 1630; A Cottingham et al. "Enhancing the Informal Curriculum of a Medical School: A Case Study in Organizational Culture Change" (2008) 23:6 J Gen Intern Med 715.

Accordingly, in conducting my research I used an approach that allowed participants to tell me their stories with a degree of freedom and depth of reflection unencumbered by my own biases and the effects of my personal connection with the topic. I valued a research method that offered an opportunity for deep and candid researcher-participant conversations, in which both are able to communicate with mutual trust because of similar professional backgrounds.³⁰⁸ Although such an arrangement may have had some pitfalls, mainly related to researcher bias (discussed later in this chapter), overall it had several advantages. For example: the data was richer than if I had collected it via other methods (such as questionnaires or structured interviews), or if it had been collected by a researcher who did not have the benefit of a lived experience with the phenomenon being studied. It was because of these factors that I selected Interpretative Phenomenological Analysis as the methodology that would best meet my research requirements.

3.6 – Methodological Context: Interpretative Phenomenological Analysis (IPA)

In this section I will provide a general description of the IPA methodology, a discussion regarding its theoretical foundations, and the rationale for choosing to use this particular approach for my project. Although its roots are in psychology, IPA has recently gained wider acceptance as a useful methodology for various forms of health research, partly because of its adaptable and non-prescriptive nature. IPA is an approach to qualitative and experiential research informed by concepts derived from phenomenology, hermeneutics, and idiography — each of which I will now describe, in turn.³⁰⁹

Phenomenology, the philosophical approach to the study of experience, has varying emphases united by a common focus on the things that matter to individuals, and which constitute their lived world. A phenomenological approach thus provides a rich source of ideas about the examination and comprehension of this lived experience.³¹⁰ As Max van Manen explains it, phenomenology is unlike most other sciences in that its intention is to gain an insightful picture of the way in which individuals experience the world “pre-

³⁰⁸ L Coar & J Sim, “Interviewing One’s Peers: Methodological Issues in a Study of Health Professionals” (2006) 24:4 *Scand J Prim Healthcare* 251; J Taylor, “The Intimate Insider: Negotiating the Ethics of Friendship when doing Insider Research” (2011) 11:1 *Qual Res* 3.

³⁰⁹ JA Smith, M Larkin & P Flowers. *Interpretative Phenomenological Analysis: Theory, Method and Research* (London: SAGE, 2009) at ch. 2.

³¹⁰ *Ibid.*

reflectively, without taxonomizing, classifying, or abstracting it.”³¹¹ He asserts that, from a phenomenological perspective, to do research is to constantly question the way individuals experience the world as human beings. Van Manen also reminds researchers who use this approach to adopt a certain attitude by practicing thoughtful and vigilant awareness of the things of the world *as individuals live them*, rather than *as they (researchers) conceptualize or theorize them*.³¹² The phenomenologist thus “directs the gaze toward the regions where meaning originates, wells up, percolates through the porous membranes of past sedimentations.”³¹³ Participants chosen for a phenomenological study should thus be viewed as individuals who have come to interpret and understand their world by shaping their personal stories into a form that has meaning to themselves.

IPA’s theoretical underpinnings are derived from the form of phenomenology that originated with Husserl’s attempts to develop a philosophical science of consciousness, while also incorporating concepts from hermeneutics and symbolic interactionism. It proposes that although an individual may ascribe meanings to an event, these are only accessible through an interpretative process. IPA, therefore, acknowledges that the researcher’s engagement with the participant’s ‘text’ contains an interpretative element, while additionally assuming an epistemological stance.³¹⁴ Through a carefully interpretative methodology, which involves repeated and close re-reading of the interviewees’ narratives, it is thus possible to better understand the nuances, feelings, and meanings that my project’s participants have experienced during triadic clinical encounters. Such depth of understanding of individual experiences is less likely to be achieved by using a quantitative method or a largely descriptive qualitative approach.³¹⁵

The aim of IPA is to explore, in detail, the processes through which participants give meaning to their experiences by examining accounts of what they have been through, having reflected upon them to some degree.³¹⁶ IPA research focuses on individuals’

³¹¹ M van Manen, *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy* (Albany: State University of New York Press, 1990) at 9.

³¹² M van Manen, “Writing Qualitatively, or the Demands of Writing” (2006) 16:5 Qual Health Res 713.

³¹³ M van Manen, *Phenomenology of Practice: Meaning-Giving Methods in Phenomenological Research and Writing* (Walnut Creek: Left Coast Press, 2014) at 12.

³¹⁴ Biggerstaff & Thompson, *supra* note 95.

³¹⁵ Smith, Larkin & Flowers, *supra* note 309; J Pringle et al. “Interpretative Phenomenological Analysis: A Discussion and Critique” (2011) 18:3 Nurse Res 20 at 22.

³¹⁶ JM Brocki & AJ Wearden, “A Critical Evaluation of the Use of Interpretative Phenomenological Analysis (IPA) in Health Psychology” (2006) 21:1 Psychol Health 87.

subjective reports, rather than the creation of objective accounts. The researcher's attempt to access the "participant's personal world" is complicated by the participant's own conceptions — which are nonetheless required, in order to make sense of their personal world through interpretative activity.³¹⁷ There are, therefore, two aspects of the IPA approach at play in each analytical account: firstly, the reflections of the participant, and secondly, the combined reflections of both the participant and researcher, the latter being central to the analysis and research.³¹⁸ The limitations of the approach will thus be the adequacy of the participant's ability to articulate their thoughts and experiences, as well as the researcher's interpretive thoroughness when examining the data.³¹⁹

Besides phenomenology, the IPA approach is informed by hermeneutics. This theory of interpretation addresses the need to reveal the original intentions of the narratives of participants, and to examine the relationship between the differing contexts of the production, as well as the interpretation of the text.³²⁰ For example, an individual physician may have several roles: clinician, manager of funding resources, educator, and mentor or even administrator. Hence in interpreting data from such a participant's interview, it will be important to recognize that these different roles are likely to inform their narrative. Added to these factors is the possibility that the physician may have had a previous negative personal experience of conflict with patients' families, perhaps including being a defendant in a malpractice claim. Therefore IPA is just as concerned about how a phenomenon *appears* as it is with the detailed understanding of the phenomenon *itself*. The researcher analyzing the data should thus be aware of, and attempt to understand, the factors that could have informed the manner of its emergence in each individual case studied. For example, in studying interviews with physicians who routinely engage with families of patients with advanced cancer, one should expect that the approach to developing rapport (including the choice of language for risk-determination) will significantly differ from the approach adopted by surgeons who deal with high-risk procedures for potentially curable conditions.

³¹⁷ JA Smith, M Jarman & M Osborn, "Doing Interpretative Phenomenological Analysis" in M. Murray & K. Chamberlain, eds, *Qualitative Health Psychology* (London: SAGE, 1999) 218 at 218.

³¹⁸ JA Smith & M Osborn, "Interpretative Phenomenological Analysis" in JA Smith, ed, *Qualitative Psychology: A Practical Guide to Methods* 2nd ed (London: Sage, 2003) 51.

³¹⁹ C Baillie et al. "Ultrasound Screening for Chromosomal Abnormality: Women's Reactions to False Positive Results" (2000) 5:4 Br J Health Psychol 377.

³²⁰ Smith, Larkin & Flowers, *supra* note 309.

In both these situations, while the anxieties of the family may be high, their outcome expectations are fundamentally dissimilar. Hence it is important to understand how and why important differences in the experience of family interactions may appear, despite apparent similarities in terms of discussing risk.

Finally, the third major concept in IPA, ‘idiography,’ refers to a study that has been derived from the analysis of individual cases, which makes it possible to make specific statements about those individuals. This is in comparison to a *nomothetic*³²¹ study, where the analysis is at the level of populations and groups, and where one can make only probabilistic claims about the individual.³²² An idiographic study involves starting with the meticulous analysis of data from a single interview, working until a degree of ‘wholeness’ or *gestalt* is reached, before moving on to a similarly detailed examination of the data from the next participant’s narrative, and so on, through the whole set of interviews in the study.³²³

The idiographic commitment to the individual operates at two levels. First is the thorough, systematic, in-depth analysis of an individual case with unwavering attention to detail. Second is the understanding of how a certain event, process, or relationship (an experiential phenomenon) can be understood from the perspective of a particular group in a particular context.³²⁴ In my research, for example, understanding why a participant expressed that family engagement is a demanding or onerous task entailed considering the various reasons why that participant *believed* it was so. For instance, they may have faced a complaint or medical malpractice claim in the past, raised by a patient’s family. Or, the participant may have had an extremely busy practice that simply did not allow the development of relationships with patients’ families to the degree that she would consider ideal. As a result of this commitment to idiography, IPA uses small, purposively selected, and carefully situated samples.

³²¹ “Relating to, involving, or dealing with abstract, general, or universal statements or laws.” Merriam-Webster Dictionary Online. “Nomothetic” [definition] (2017) online: <https://www.merriam-webster.com/dictionary/nomothetic> (accessed 24 February 2013).

³²² Smith & Osborn, *supra* note 318.

³²³ JA Smith, “Reflecting on the Development of Interpretative Phenomenological Analysis and its Contribution to Qualitative Research in Psychology” (2004) 1:1 Qual Res Psychol 39 at 41.

³²⁴ Smith, Larkin & Flowers, *supra* note 309.

Idiography does not totally renounce generalizations, but prescribes a different approach to establishing them by locating them in individual stories (e.g., the narratives of individual specialist physicians), and building on them deliberately by linking them to the narratives of the other participants in the study.³²⁵ A reader of such an IPA study may make connections between the findings of the research and their personal and professional experiences, and what the existing literature on the topic indicates. This is how an IPA study allows for theoretical (as opposed to empirical) generalizability, with the strength of an IPA study being gauged by “the light it sheds within this broader context.”³²⁶

In summary: IPA is an inductive approach where examples are examined in order to make higher order generalizations (bottom-up rather than top-down, or from the specific to the general). It does not test hypotheses, avoids prior assumptions, and is aimed at exploring meanings that participants assign to their experiences. Participants are viewed as ‘experts,’ offering details of their experiences through the telling of their stories; hence the purposeful invitation of individuals to participate in the study. The researcher attempts to reduce complexity in the experiential data via thorough and systematic analysis, making sense (secondarily) of the meanings that the participant has first reflected upon with respect to their own experiences.³²⁷

3.6.1 – The Giorgi-Smith Debate on IPA as a Phenomenological Methodology

The validity of IPA as a truly scientific phenomenological research method was challenged by psychologist Amedeo Giorgi, one of the founders of the ‘Duquesne School’ of Psychology,³²⁸ which bases its method on principles laid out by philosophers such as Edmund Husserl and Maurice Merleau-Ponty. Amedeo Giorgi directly criticized the approach taken by IPA’s leading proponents, emphasizing that phenomenology is primarily a philosophy and as such it requires a particular form of method and accepts particular arguments as valid.³²⁹ Giorgi claimed that advocates for IPA use “mostly content definitions”³³⁰ of phenomenology, which are not sufficient for an authentic sense of

³²⁵ R Harré, *Social Being: A Theory for Social Psychology* (Oxford: Blackwell, 1979).

³²⁶ Smith & Osborn, *supra* note 318 at 56.

³²⁷ K Reid, P Flowers & M Larkin, “Exploring Lived Experience” (2005) 18:1 *Psychologist* 20.

³²⁸ A Giorgi, *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. (Pittsburgh: Duquesne University Press, 2009).

³²⁹ A Giorgi, “Phenomenology and the Practice of Science” (2010) 21:1 *J Soc Existent Anal* 3.

³³⁰ *Ibid* at 5.

psychology — especially if a method of analysis was being proposed. He also argued that a theoretical justification was lacking, the focus of IPA being merely descriptive of the research process. Giorgi asserted that the originators of IPA had not sufficiently related it to the method of philosophical phenomenology, and in fact suggested that IPA should have been named ‘Interpretative Experiential Analysis’ instead.³³¹ He also levelled the accusation that IPA did not make sufficient methodical demands on researchers, and called for a greater intersubjective attitude that would allow other researchers to utilize IPA’s methods so as to be able to correlate knowledge obtained by their own approach.³³² Giorgi felt that there was too much freedom given to the researcher in the analysis phase, to implement their “conscious activities”³³³ when interpreting the data. Essentially, Giorgi found the paucity of rigid rules in IPA to be disconcerting, and thus found it challenging to recognize this method as sufficiently scientific.

Jonathan Smith of London’s Birkbeck University, one of the leading proponents of IPA, responded to Giorgi’s article in a 2010 paper. In it, he reiterated that IPA is indeed phenomenological because it is concerned with participants’ lived experiences, and is indeed hermeneutic because it posits that the latter’s experiences are only accessible through a process of interpretation by both the participant and the researcher.³³⁴ He refuted the validity of Giorgi’s critique because it was based on the reading of only two book chapters, without considering the larger body of IPA literature and research reports. Smith referred readers to a range of articles that Giorgi had failed to analyze, which he felt would readily assuage concerns about IPA being a scientifically valid research methodology.³³⁵

3.6.2 – Rationale for the Selection of IPA to Answer the Research Question

An IPA approach was well suited to my research question and objectives. By listening very attentively to the participants’ stories, and bringing to light their meanings, I personally gained a deeper understanding of these experiences in a way that allowed me

³³¹ *Ibid* at 6.

³³² *Ibid* at 9, 10.

³³³ *Ibid* at 10.

³³⁴ JA Smith, “Interpretative Phenomenological Analysis” (2010) 21:2 *J Soc Existent Anal* 186.

³³⁵ M Larkin, S Watts & E Clifton, “Giving Voice and Making Sense in Interpretative Phenomenological Analysis” (2006) 3:2 *Qual Res Psychol* 102; Smith, *supra* note 323; JA Smith, “Hermeneutics, Human Sciences and Health: Linking Theory and Practice” (2007) 2:1 *Int J Qual Stud Health Well-Being* 3; A Eatough & JA Smith, “Interpretative Phenomenological Analysis” in C Willig & WS Rogers, eds, *The SAGE Handbook of Qualitative Research in Psychology* (London: SAGE, 2007) 179.

to clearly describe them to different audiences. An IPA approach was also suitable because of my personal ‘deep interest’³³⁶ in the complexities of physician-family-patient interactions, especially in situations where there are high risks of adverse treatment outcomes. I am, however, reminded of van Manen’s sobering caution that,

*qualitative method is often difficult, as it requires sensitive interpretative skills and creative talents from the researcher. Phenomenological method, in particular, is challenging, because it can be argued that its method of inquiry constantly has to be invented anew and cannot be reduced to a general set of strategies or research techniques. Methodologically speaking, every notion has to be examined in terms of its assumptions, even the idea of method itself.*³³⁷

With this understanding about the need for academic rigour, combined with cautiously justified creativity, I proceeded to frame the details of my research approach. I studied several IPA dissertations and academic papers, from fields of work similar to mine, to understand how other researchers developed and rationalized their method of data collection and analysis. In so doing I improved my overall understanding of the scope, limitations, and value of phenomenological research.

3.6.3 – Collection of Data Using Interviews, According to IPA

As a data collection method, narrative-style interviews respect the recommendations of IPA, and produce rich data since they allow participants to speak freely and reflectively, and to develop ideas and present their concerns at length. Because of my personal familiarity with the phenomenon being examined, I felt that this form of interviewing was easily managed and was suited to in-depth, personal discussion. I was able to build rapport readily and engage in a dialogue with each participant, as this approach allows an interviewer to modify initial questions in the light of participant responses. Narrative, in-depth interviewing offered a degree of freedom to cautiously take conversations to areas interesting and relevant to the research question, whenever the opportunity arose.

³³⁶ van Manen, *supra* note 311.

³³⁷ van Manen, *supra* note 312 at 720.

3.6.4 – Scientific Philosophy: Paradigm Frameworks of My Research Project

It is necessary to clearly establish the philosophical parameters undergirding my qualitative enquiry.³³⁸ Accordingly, in this section I locate my work within the spectrum of scientific theoretical paradigms relevant to qualitative research, which methodologists Egon Guba and Yvonna Lincoln described in 1994 and later modified in 2011.³³⁹ I am aware that no qualitative study's choice of paradigm is likely to go unchallenged by proponents of competing paradigms, hence the discussion in this section is aimed at explaining the categorization of my research paradigm per Guba and Lincoln, as well as clarifying the purpose and hermeneutical approach of my study.³⁴⁰

In the context of research, a paradigm can be defined as a “set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organized study of that world.”³⁴¹ The paradigm selected for a research project provides guidance about the philosophical assumptions that the researcher will make, and also influences the selection of the research methodology, the research tools, participant selection, and how the data is collected. Joseph Ponterotto, as well as Beth Haverkamp and Richard Young, provided useful descriptions of qualitative research paradigms and purposes. The discussion in this section draws primarily from their work.³⁴²

I developed the rationale for my research project by understanding how my primary purpose intersects with my foundational scientific paradigm. I adopted the theoretical research paradigm of *constructivism-interpretivism* (explained below), which influenced my choice of IPA as a suitable methodological approach to design my research project and

³³⁸ JG Ponterotto, “Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science.” (2005) 52:2 J Couns Psychol 126 at 127.

³³⁹ EG Guba & YS Lincoln, “Competing Paradigms in Qualitative Research” in NK Denzin & YS Lincoln, eds, *The SAGE Handbook of Qualitative Research*, 1st ed (Thousand Oaks: SAGE, 1994) 105; YS Lincoln, SA Lynham & EG Guba, “Paradigmatic Controversies, Contradictions, and Emerging Confluences Revisited” in NK Denzin & YS Lincoln, eds, *The SAGE Handbook of Qualitative Research*, 4th ed (Thousand Oaks: SAGE, 2011) 97 at 98.

³⁴⁰ NK Denzin & YS Lincoln, *The SAGE Handbook of Qualitative Research*, 3rd ed (Thousand Oaks: SAGE, 2005) at 97.

³⁴¹ WJ Filstead, “Qualitative Methods: A Needed Perspective in Evaluation Research” in T Cook & R Reichardt, eds, *Qualitative and Quantitative Methods in Evaluation Research* (Beverly Hills: SAGE, 1979) 33 at 34.

³⁴² Ponterotto, *supra* note 338; BE Haverkamp & RA Young, “Paradigms, Purpose, and the Role of the Literature Formulating a Rationale for Qualitative Investigations” (2007) 35:2 Couns Psychol 265.

collect and analyze my data. This paradigm would also determine the future evaluation of the rigour and trustworthiness of my research.³⁴³

The three essential qualitative research paradigmatic frameworks proposed by Guba and Lincoln in 1994 were the realist/postpositivist, the critical/ideological, and the *interpretive/constructivist* paradigms.³⁴⁴ The authors added another paradigm to their framework in their 2011 text, after acknowledging John Heron and Peter Reason's argument for the recognition of a '*participatory/cooperative*' paradigm.³⁴⁵ In the *realist/postpositivist* paradigm, the ontological assumption is that reality exists separate from the perceiver. The researcher is postured as an observer with an objective, detached role, suppressing values so as not to bias the research findings. The *critical/ideological* paradigm, instead, assumes that while an identifiable reality does exist, such a reality may be reflective of the oppressive influences of a variety of socio-political and historical factors.³⁴⁶ This paradigm is one of emancipation and transformation, in which the researcher's proactive values are central to the entire research project.³⁴⁷ Important to critical theory is the emphasis on the dialectical researcher/participant interaction, which is aimed at liberation from oppression and the establishment of a more democratic and just social order.³⁴⁸ The relationship between participant and researcher is thus both transactional and subjective, and the researcher who adopts this paradigm explicitly hopes and expects that their value biases will influence the research process and outcome.³⁴⁹

Research within a *participative/cooperative* paradigm assumes a worldview where critical subjectivity can be enhanced by critical inter-subjectivity. In this collaborative form of inquiry, all engage together in democratic dialogue as co-researchers and co-subjects. Heron and Reason call this 'co-operative inquiry,' where researchers and participants collaborate to define the research questions and the methodology for that exploration

³⁴³ SL Morrow, "Quality and Trustworthiness in Qualitative Research in Counseling Psychology" (2005) 52:2 J Couns Psychol 250; EN Williams & SL Morrow, "Achieving Trustworthiness In Qualitative Research: A Pan-Paradigmatic Perspective" (2009) 19:4-5 Psychother Res 576.

³⁴⁴ Guba & Lincoln, *supra* note 339.

³⁴⁵ Lincoln, Lynham & Guba, *supra* note 339; J Heron & P Reason, "A Participatory Inquiry Paradigm" (1997) 3:3 Qual Inq 274.

³⁴⁶ Haverkamp & Young, *supra* note 342.

³⁴⁷ Ponterotto, *supra* note 338.

³⁴⁸ JL Kincheloe & P McLaren. "Rethinking Critical Theory and Qualitative Research" in K Hayes et al, eds, *Key Works in Critical Pedagogy* (Rotterdam & Boston: Sense Publishers, 2011) 285.

³⁴⁹ Ponterotto, *supra* note 338.

(which they call ‘propositional knowing’). Following this, together or separately, they apply this methodology where they practice (‘practical knowing’). This then points to novel forms of encounter with that particular world (‘experiential knowing’) and ways are found to represent this experience in significant patterns (‘presentational knowing’). Following this is a revision of the propositional understanding of the originating questions. Co-researchers hence work in several cycles, through the above four forms of knowing, in order to refine and deepen complementary grounding in each other’s experiences.³⁵⁰

My own research did not aim to be transformational in the manner that would be expected in a critical/ideological approach. My intention was to understand the experiences of a selected group of physicians in engaging with patients’ families, from their point of view. Hence I adopted an *interpretive/constructivist* paradigm, which is post-modern and relativist in ontology, positing multiple, equally valid social realities. Within this paradigm, knowledge was co-constructed and interpreted as it emerged from my interaction with the research participants. My role in the co-construction of meaning was examined with a clear understanding of the influence of my personal values, my beliefs about ethics in medical practice, my understandings of the physician-patient relationship, and my lived experience of participating in informed consent processes for almost three decades as a specialist surgeon.

I remained aware that, as a researcher, my access to esoteric and specialist ‘insider’ language (which in practice separates medical professionals from laypersons), presented many advantages — but that it also carried some risks.³⁵¹ These risks could have appeared in the form of over-identification with the participants when I first developed the research questions, or when I conducted the interviews, or when I approached the data analysis. I have attempted to be continuously conscious of my reflexivity and the dangers of imposing my academic and professional versions on participants’ experiences. Therefore, identity management was a thoroughgoing consideration. I have clearly limited, introduced, and

³⁵⁰ Heron & Reason, *supra* note 345 at 283.

³⁵¹ AJ Meehan, “Some Conversational Features of the Use of Medical Terms by Doctors and Patients” (1981) *Med Work Realities* Routines 107; BMN Ochieng, “‘You Know What I Mean:’ The Ethical and Methodological Dilemmas and Challenges for Black Researchers Interviewing Black Families” (2010) 20:12 *Qual Health Res* 1725.

defined my ‘presence’ within this entire research project at all times, and remained focused on the primary purpose of my study.³⁵²

I came to understand that challenges to the trustworthiness of my project could have come from subjective biases surfacing at several points: from the selection of research participants, to the formulation of the interview approach and questions, and also in the interpretation of the research data. I remained conscious of the fact that my familiarity with the various demands placed upon a physician during interactions with patients’ families had limitations in the context of my research. Specifically, I have not practiced clinically in Canada, and thus have not had direct experience of engaging with families as a physician amongst Canadian families. Thus, when I interviewed the participants, I was conscious that there were some aspects of physician-family interactions that I considered interesting, challenging, or otherwise worthy of discussion may have had little or no relevance to the participants.

Similarly, while some experiences regarding triadic physician-patient-family interactions may be common to medical specialists worldwide, the demographic that my participants serve, and the nature of the Canadian public medical system, have different characteristics from that of my previous professional environment. Additionally, the familial-interactional experiences physicians have are informed by several variables ranging from public expectations of the health system, to the overarching legal governance of healthcare, to the cultural and educational background of the community being served, to the economics of healthcare funding and health insurance. These factors are complex, causing physician experiences to vary from one environment to another. As Edward Bruner cautions, I have aimed to be a researcher who “appears not as an individual creative scholar, a knowing subject who discovers, but more as a material body through whom a narrative structure unfolds.”³⁵³ I remained conscious of these words as I formulated the interview strategy, as well as the wording of the interview questions.

IPA explicitly acknowledges the experience of the researcher, to the extent that their lived experiences are able to positively inform the formulation of the research

³⁵² M Hammersley & P Atkinson, *Ethnography: Principles in Practice*, 3d ed (London: Routledge, 2007); Ochieng, *supra* note 313.

³⁵³ Bruner, EM. “Ethnography as Narrative” in VW Turner & EM Bruner, eds, *The Anthropology of Experience* (Urbana: University of Illinois Press, 1986) 139 at 150.

questions as well as the conduct of the interviews.³⁵⁴ However, coming to this research with a background in medicine, I was conscious of the influences of positivist dogma, which proclaims that “perspectivity is bias.”³⁵⁵ These influences could inform a misconception that any issue being studied is independent of the researcher and the preferred research method, and that there are physical correlates in nature that lend themselves to measurement and logical deduction. Accordingly, I aimed to understand how my own medical career experiences allowed access to better understanding of the phenomenon I was researching, and to fully appreciate the potential of a well-designed qualitative study.

I thus recognized my biases and was conscious of the various ways in which they may have influenced my approach as a researcher. In particular, I was aware that any emotionally traumatic past experiences of mine, in interacting with family members, could have coloured my choice of words, my tone, and my attitude in interviews. These previous negative experiences may have (and indeed, were likely to) have influenced my theoretical orientation and position on the legal governance of medical practice, possibly resulting in a degree of clinical defensiveness. I did not assume that the participants had similar attitudes with respect to legal liability while interacting with patients’ families. I remained cognizant of the purpose of my project and the requirements of phenomenological research.

3.6.5 – Purpose of the Study

The usual purposes for qualitative studies fall under one or more of three categories: a) theory or construct-orientated research, b) action or change-orientated research, and c) practice or evaluation-orientated research.³⁵⁶ The goal of ‘theory-orientated’ research is to develop a theory or a model, or to elaborate on components of a theory in other dimensions. Research with an ‘action-oriented’ purpose explicitly aims at effecting change and is designed with a particular identified need in mind, such as a community problem. My

³⁵⁴ Smith, Larkin & Flowers, *supra* note 309.

³⁵⁵ CT Fischer, “Bracketing in Qualitative Research: Conceptual and Practical Matters” (2009) 19:4-5 *Psychother Res* 583 at 589.

³⁵⁶ HF Wolcott, “Posturing in Qualitative Inquiry” in MD LeCompte, WL Millroy & J Preissle, eds, *The Handbook of Qualitative Research in Education* (San Diego: Academic Press, 1992) 3; Patton, MQ. *Qualitative Research & Evaluation Methods*, 3rd ed (Thousand Oaks: SAGE, 2002); CJ Yeh & AG Inman, “Qualitative Data Analysis and Interpretation in Counseling Psychology: Strategies for Best Practices” (2007) 35:3 *Couns Psychol* 369.

research had a ‘practice-orientated’ purpose, with the aim of examining a particular problem and improving specific practices by providing a rich and detailed description of a certain process. With that research purpose in mind, I accepted that the themes that I developed would probably not be as elaborate or detailed as with theory-orientated research, since my goal was a deeper understanding of a specific experience of a selected group, as opposed to a broad and abstracted understanding of the issue (as would be the case in a theory-orientated project).

For example, one of the themes that emerged during data analysis was how the physicians protected their patients’ autonomy. Identifying such a theme may have practical implications for practitioners in similar circumstances, and could also inform the training of physicians, as it is a clinically-orientated theme. If the purpose of my research had been to develop theory about protection of patient autonomy, or to explore a similar theory in greater depth, my project would have required a methodology supporting broader generalization and abstraction than an in-depth study with a relatively small number of participants.³⁵⁷ The ‘practice-orientation’ of research is especially useful where the research participants have not previously contributed to the understanding of the phenomenon or problem being investigated, but are nevertheless persons whose perspectives have potential epistemic value.³⁵⁸

3.6.6 – Summary of Major Characteristics of the Research Design

My study was conducted within a constructivist/interpretative paradigm, with a practice-orientated purpose, using a qualitative methodology that was appropriate for data collection, and analysis with a pragmatic and exploratory purpose. This approach promoted a philosophical hermeneutical understanding, based in the belief that ‘understanding’ is an active, constructive process, where meaning is developed through a process that takes place between researcher and participant. I was able to broaden my perspectives and views to incorporate those of the participants in the research, developing a deeper understanding of the issues as the study proceeded.

³⁵⁷ U Kelle, “‘Emergence’ vs. ‘Forcing’ of Empirical Data? A Crucial Problem of ‘Grounded Theory’ Reconsidered” (2005) 6:2 *Forum Qual Soc Res* 1.

³⁵⁸ Haverkamp & Young, *supra* note 342.

3.7 – Method

3.7.1 – Procedures

Once my supervisory committee approved my research plan, I obtained approval from the University of Victoria's (UVic's) Human Research Ethics Board (HREB) prior to commencing participant recruitment. I did not anticipate any major barriers to ethics approval for my study because there were no predictable knowledge or professional power imbalances between the participants and myself. Additionally, anonymization processes to ensure the participants' privacy were stringent, as were the measures to ensure the confidentiality of information, and the safe handling and destruction of data. Individual patient and health institutional information was not to be referenced at any stage of the interviews, or the study in general. Furthermore, the participants were to be interviewed outside of an institutional setting, as individual practitioners acting in a private, personal capacity. The recruitment process (including the invitation letter and consent form) was vetted by my supervisory committee prior to my submitting the HREB application.

3.7.2 – Inclusion and Exclusion Criteria

Physicians invited to participate were specialists who previously practiced, or currently practice, in high-risk medical fields such as neurosurgery, cancer therapy, intensive care, or emergency medicine. The reason for choosing this particular group is that their routine care of patients with high-risk conditions, or recommendation of high-risk procedures, would increase the likelihood of engagement with family members. For example, a neurosurgeon routinely undertakes procedures that carry a risk to life or a risk of permanent brain damage. Thus there is a high likelihood that such a specialist would ensure that the patient's family or close others were apprised of the risks, particularly if they bear some responsibility for the patient's longer-term care. This choice of participants was expected to provide richer data compared to that deriving from physicians who practice in low-risk fields, in which they likely have less need of contact with family members.

I excluded family physicians because the drivers for their engagement with family are fundamentally different from those of specialist physicians, who largely interact with patients and their family as relative strangers. Family doctors are expected to have longer-term relationships with their patients and their families, and the relational nature of that

form of doctor-patient-family triad is qualitatively different.³⁵⁹ The other group of physicians who were excluded were those who work in fields where the legal and ethical principles governing physician-patient-family interactions have clearly defined and well-established considerations. It is for this reason that physicians from fields such as paediatrics, geriatrics, intensive care, and organ transplantation were not recruited.

3.7.3 – Geographical Context

This study was conducted in two urban centres in British Columbia, namely Victoria and Vancouver. The medical services for high-risk fields are well represented in Victoria, and I was able to recruit suitable participants in that city. Although Victoria is considerably less diverse than Vancouver in terms of population demographics, I learned during our discussions that the eight Victoria-based participants did indeed have experience working with multi-ethnic patients and families, both in their current practices as well as in prior places of work.³⁶⁰ Most of them had previously worked in larger Canadian cities such as Toronto, Calgary, or Vancouver, which have more ethnically diverse communities; or in rural locations with a higher proportion of aboriginal persons than Victoria. It is important to note that in many non-Western cultures, medical decision-making is collectivist, and hence the idea of patient autonomy and independence was expected to carry different meanings.³⁶¹ Additionally, the expectations of the physician-patient relationship may differ significantly from that seen in Canadian society generally.

3.8 – Ethical Issues

3.8.1 – Research Ethics Approval

This was obtained from the Human Research Ethics Board (H.R.E.B.) of the University of Victoria, renewed July 05, 2016 (See Appendix I.)

³⁵⁹ J Hardwig, “Support and the Invisible Family” (1995) 25:6 *Hastings Cent Rep* S23; NS Jecker, NS. “The Role of Intimate Others in Medical Decision Making” (1990) 30:1 *Gerontologist* 65; Brown et al, *supra* note 281.

³⁶⁰ Statistics Canada, “Population by Selected Ethnic Origins, by Census Metropolitan Areas (Vancouver)” *2006 Census* (14 August 2009) online: <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo27y-eng.htm> (accessed 5 February 2013).

³⁶¹ Kagitcibasi, *supra* note 45.

3.8.2 – Informed Consent

As detailed in the recruitment strategy below, fully informed consent was obtained from all participants prior to their being interviewed and, in addition, withdrawal processes were clearly indicated.

3.8.3 – Participant Confidentiality

All identifiable details provided during the interviews were anonymized and only the researcher was aware of the participants' identities. No other participants' names were mentioned during any interview. The participants consented to the interview being recorded and that the de-identified recordings would be transcribed by the researcher as well as a professional, external transcriptionist, working under a non-disclosure/confidentiality agreement (Appendix II). The participants were also informed that they would not be identified in any report or publication. They were given contact details of the researcher's graduate supervisor and relevant institutional information (also included in Appendix III).

3.8.4 – Potential Distress for Participants

Participants were informed that, at any time during the interview, they were free to take several measures, such as insisting on a change of topic, taking a break, stopping the interview, or withdrawing completely. In the design of this study the researcher remained aware that recollections of experiences of engaging with patients' family members could be disturbing to participants if these had involved negative outcomes (for example, adverse media attention, formal complaints, disciplinary actions, or medico-legal disputes).

3.8.5 – Recruitment of Participants

While waiting for HREB approval I developed a list of potential participants who met the inclusion criteria detailed above. I started by discussing my project, including the criteria for participant selection, with contacts in my medical network at the Island Medical Program at UVic as well as within my professional and personal networks in Victoria and Vancouver. Invitations to participate were sent to 19 specialists and apart from one individual who was a spouse of a colleague, I did not have a prior personal or working relationship with any of the physicians invited. I received a total of nine positive responses,

eight from Victoria and one from Vancouver. In order to address the risk of breaches of confidentiality I did not invite participants who had unique (and thus easily identifiable) practices in a particular specialty within their city.

I invited physicians directly by email and in the case of the two senior most participants, I also delivered invitations personally, through their private or institutional offices as advised by their medical office assistants. The letter of invitation (see Appendix III) was accompanied by a letter of introduction that indicated my background, my research question, a summary of the objectives of the research, a sample consent form, and a withdrawal form. These documents detailed the measures that would be in place to ensure their privacy and confidentiality, along with information about the recording, storage, and disposal of interview recordings upon completion of the project. I also indicated what the interview process and format would look like, and that the participants were free to choose a venue with which they were comfortable. Participants signed a formal consent form just prior to starting each interview, and a withdrawal form was left with them (also included in Appendix III.)

3.9 – Sample Size

There does not appear to be a clear ‘formula’ with which to estimate the ideal sample size in a qualitative study such as mine. In Mark Mason’s analysis of 560 qualitative Ph.D. studies using interviews as a means of data collection, there was such a wide variation in volumes of participants recruited that the author concluded the impossibility of providing precise recommendations for an appropriate number of participants in proposed qualitative research projects.³⁶² Much depends on the topic, research question, and objectives of the study. Going by my experience with interviewing neurosurgeons for my Master’s research, which used a heuristic methodology to explore their experiences with adverse medical events, I anticipated that I would be able to achieve the purpose of my study by interviewing approximately eight to twelve participants. Jonathan Smith and Mike Osborn support this perspective by indicating that, rather than the number of

³⁶² M Mason, “Sample Size and Saturation in PhD Studies Using Qualitative Interviews” (2010) 11:3 Forum Qual Soc Res 1.

participants, hermeneutical inquiry is validated by the completeness of the topic examination, and the extent to which the interpretation increases our understanding.³⁶³

3.10 – Participants

Nine participants were interviewed individually, using a semi-structured question format, with the interviews lasting from sixty to ninety minutes. All were specialists in medicine with experience in post-residency practice ranging from seven to thirty-nine years. Eight were male and one was female. Except for one physician who trained in medicine as an undergraduate in the United Kingdom (but received specialist training in Canada), all participants were Canadian medical graduates. All had experience working as physicians outside of British Columbia as well. One of the male participants was of Asian origin and one participant was a retired surgeon who was actively involved in medical education. The following is a brief description of each participant, with pseudonyms used. In view of the relatively small medical community in Victoria, details about the clinical practices of these participants, along with other demographic data, have been intentionally left out, in the interest of maintaining anonymity.

Vic 01 is a retired general surgeon, currently actively involved in medical education.

Vic 02 practices in a haematology cancer treatment field.

Vic 03 is a cancer specialist who participates actively in teaching medical students.

Vic 04 is a specialist surgeon in the process of winding down his practice before full retirement.

Vic 05 is an intensive care specialist.

Vic 06 is a post-graduate educator and an Emergency Room (ER) physician.

Vic 07 is an ER physician working out of a different hospital than Vic 06.

Vic 08 is a senior ER physician.

Van 01 is a specialist plastic surgeon who practices in Vancouver.

3.11 – Conduct of Individual Interviews

I approached the interviews having prepared, for my own guidance, a ‘virtual map’ of the interview process. This map took the form of a template outlining the details of my interaction with the participants: my introductory remarks, obtaining of the participant’s

³⁶³ Smith and Osborn, *supra* note 318.

signature on the consent form, a reminder about their freedom to change the topic of discussion and the withdrawal process, and finally, a list of the interview questions. The questions I asked were kept open and expansive, and I welcomed unanticipated changes in direction. By providing a descriptive introduction to my research and a draft consent form on first contacting participants, they arrived already informed about what to expect during the interview, including possible interview questions. They were apprised of my research objectives and of the specific context of their interactions, which would form the basis of my project. Moreover, they were made aware that I was specifically interested in their interactions with the family of a competent patient with full capacity to consent, and not their interactions with families of children or legally incompetent patients. (As stated earlier, in such situations the ethico-legal position of family in procuring consent is well established and hence not the focus of my project.)³⁶⁴

At the interview, I started by introducing myself and indicating the reason for my interest in this topic: that I have personally experienced challenges (without going into detail) in interacting with families of patients in the realm of high-risk consent processes. I felt it was important to include this declaration in my introduction, as they would be put at ease by my admitting to having personally experienced struggles and vulnerability as a physician. I was aware of the value that this posture, as a researcher, could have in encouraging candidness by framing the conversation as one with a medical colleague.³⁶⁵

Participants were asked general and open questions so as to encourage them to tell their stories in as much detail as possible. The principle was to get at what the participants' experiences were from the "inside-out" and not attempt to create representations of what they thought they have experienced.³⁶⁶ I avoided "why" questions, as these could either have been interpreted as threatening, or have prompted the feeling that I was probing for information they had not felt comfortable sharing voluntarily. 'Why' questions could also

³⁶⁴ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c. 181, ss. 7, 11; *Infants Act*, RSBC 1996, c 223, s 17.

³⁶⁵ OG Aasland & R Førde, "Impact of Feeling Responsible for Adverse Events on Doctors' Personal and Professional Lives: The Importance of Being Open to Criticism from Colleagues" (2005) 14:1 *Qual Saf Health Care* 13; FJ Lee, JB Brown & M Stewart. "Exploring Family Physician Stress: Helpful Strategies" (2009) 55:3 *Can Fam Physician* 288; V Akre et al. "The Communication Atmosphere between Physician Colleagues: Competitive Perfectionism or Supportive Dialogue? A Norwegian Study" (1997) 44:4 *Soc Sci Med* 519.

³⁶⁶ C Geertz, *The Interpretation of Cultures: Selected Essays* (New York: Basic Books, 1973).

have encouraged intellectualizations, as they might have called for participants to formulate generic or summary responses, as opposed to focusing on specific accounts of experiences, thoughts, and feelings, which form the best kind of interview data for IPA.³⁶⁷ Wherever possible I worded my prompting questions in the participant's own phrasing.³⁶⁸ For example, I asked follow-up questions like, "You mentioned that it can be challenging to conduct discussions with family members if they are recent immigrants and new to Canadian society — would you mind telling me a bit more about that?"

Throughout the interviews I remained conscious that the aim of the IPA approach was to explore, in depth, the processes through which participants make sense of their personal experiences. I therefore engaged in the conversations in a manner that I felt would encourage self-reflection on their part. Having opened each interview with a brief account of my own experience with conflict in family interactions, I then invited the participant to recount a significant episode or experience where engagement with a patient's family members had posed an ethical, legal, or other form of challenge. I then followed-up with probing or prompting questions only where necessary, either to encourage their exploration of a particular experience in greater depth, or to draw the conversation gently back to the focus of my research. Sample interview questions were included in my letter of invitation to the participants (see Appendix III)

I followed the advice of both Steiner Kvale and Max van Manen about listening to 'hear' what was being said between the words, as well as in the silences — being aware that, sometimes, pauses in the conversation may represent meaningful communications about the topic being discussed.³⁶⁹ For example, I remained conscious that a break in the conversation while discussing particular medico-legal challenges could have been a signal about discomfort with the topic, possibly because of a prior incident.³⁷⁰

I realized that it was sometimes counterproductive to introduce new questions that potentially interrupted the flow of the participants' stories. The few direct questions that I

³⁶⁷ Smith, Larkin & Flowers, *supra* note 309 at 68.

³⁶⁸ M Savin-Baden & L Van Niekerk, "Narrative Inquiry: Theory and Practice" (2007) 31:3 J Geogr High Educ 459.

³⁶⁹ S Kvale & S Brinkmann, *Interviews: Learning the Craft of Qualitative Research Interviewing*, 2nd ed (Los Angeles: SAGE, 2009).

³⁷⁰ This did not occur even once during any of the interviews, but had it done so I would have proceeded cautiously after indicating that I have had personal experience with facing medico-legal challenges, and could well understand if they preferred not to discuss their own experiences any further.

asked pertained to medical education, and I put these to the participants only if the topic had not been addressed directly or indirectly earlier in the conversation. The intention was to hear the participants' opinions about whether skills in family interactions had been adequately taught in their medical school, and whether they felt this was an important enough skill for a physician to have that it warranted inclusion in Canadian medical school curricula.

The interviews were conducted in a setting of the participant's choice, and most of these environments were free from interruptions and noise. In order to obviate the need for organizational approval, I conducted the interviews at sites where the practitioners could take part in the research as private individuals, instead of as employees or staff members of any particular institution. The interviews were recorded on a digital recording device with a suitable 'back-up' analog tape-recording device and a second digital device. I kept field notes about intonations, gestures, and physical expressions, or any other non-audible observations that occurred during the interview process. These notes contributed to the data.

3.12 – Data Analysis

To analyze the data I proceeded with the general understanding that Heideggerian philosophy underpins much of interpretative methodology. Central to my own understanding was Heidegger's view that relatedness is essential, and that we cannot deliberately choose to take up a specific form of relationship with any variety of objects that make up our world just to meet perceived needs — including that of research.³⁷¹ As a researcher using IPA, I understood myself to be part of that 'world' and that it was not possible for me to remove myself (my feelings and thoughts) from it in order to attempt to discover how things 'really are,' as far as the experiences of the research participants were concerned. Thus, as a researcher, any discoveries I made must be seen as having been informed significantly by my relationship with the subject matter. This underscores the

³⁷¹ M Heidegger, *Being and Time*, trans. J. Macquarrie and E. Robinson (New York: Harper & Row, 1962); D Polkinghorne, "What Makes Research Humanistic?" (1982) 22:3 *J Humanist Psychol* 47; JD Crist & CA Tanner, "Interpretation/Analysis Methods in Hermeneutic Interpretive Phenomenology" (2003) 52:3 *Nurs Res* 202.

importance of being reflexive during the data analysis and, indeed, the entire research process.

I aimed to discover new understandings of the subject matter on its own terms, and was conscious of potential risks to research credibility posed by inadvertently allowing predetermined assumptions, opinions, and expectations to influence data interpretation.³⁷² Although I remained conscious of my preconceptions and biases at all times, I was mindful of Juliet Corbin and Anselm Strauss' assertion that "(T)oday we all know that objectivity in qualitative research is a myth,"³⁷³ and that my responsibility as a researcher was, instead, to remain sensitive right through the process. This would mean using my experience and knowledge with insight, awareness, and reflexivity throughout the collection and analysis of the data, so that the participants' views were recorded diligently and presented impartially.³⁷⁴ I recognized that, ultimately, a major strength of my study would be the depth of understanding that it provides to the reader, supported by a compelling and trustworthy case for the manner in which the data was interpreted.³⁷⁵

I was aware that a hermeneutic process in my research would be iterative and non-linear, and that within such a circular method I should anticipate examining the data and the emerging interpretations simultaneously, without losing sight of each participant's unique story and context. As mentioned earlier, I began the interpretative process on the first sets of data while continuing to interview subsequent participants. From the experience of the interviews and the examinations of the first one or two interview transcripts, I was able to evaluate whether my interview technique, or other elements of the data collection (such as suitability of venues), were lacking in any way. Accordingly, I made any necessary amendments for the subsequent interviews. I remained open to allowing my initial data interpretations to guide the questions in subsequent interviews so as to provide a richer understanding of the experiences being studied, as well as to improve the focus of the later interviews.³⁷⁶

³⁷² Larkin, Watts & Clifton, *supra* note 335.

³⁷³ J Corbin & A Strauss, eds, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* 3rd ed (Los Angeles: SAGE, 2008) at 32.

³⁷⁴ *Ibid* at 32.

³⁷⁵ A Rubin, "Standards for Rigor in Qualitative Inquiry" (2000) 10:2 Res Soc Work Pract 173 at 174.

³⁷⁶ Crist & Tanner, *supra* note 371.

In essence, I sought to understand the meanings attached to the participants' experiences of engaging with patients' families. As a researcher I thus approached the data with two primary aims. First, I attempted to understand the participants' experiences of this engagement, realizing that access to this was necessarily incomplete and complex. My second task was to parse what these experiences were like. This involved a process of interpretative analysis, in which I aimed to locate my descriptions in a wider socio-cultural and possibly even a theoretical context. In the later stages of data analysis I strove to produce a critical and conceptual commentary in a somewhat hypothetical manner, attempting to understand the meaning behind participants' stories in relation to specific circumstances in their professional lives.³⁷⁷

As I anticipated, the data (notes and interview transcripts) were voluminous and diverse, given the intended depth of the interviews as well as the subjective nature of the responses to interview questions. I used the services of a professional transcriptionist and read each transcription while listening to the audio recordings to ensure accuracy and to correct errors — which occurred, as it turned out, mostly because of the use of technical medical terminology. Field notes taken before, during, and after each interview, and a description of the unique professional backgrounds of the participants, were documented and became part of the data.

Following a general scheme recommended for IPA studies by Jonathan Smith et al., I conducted the analysis of each transcript thoroughly before moving to the next.³⁷⁸ My first step in analysis was to interrogate the text thoroughly, making notes that were descriptive of what the participants said, and adding comments on their choice of language. As I re-read the text I next made further comments that were conceptual in nature, including observations about how I was able to identify my own role and perspectives in relation to the generation of particular statements by the participants. These notes and comments were added to the overall data set for later analysis.

I next began to identify the themes that emerged from interpreting my notes and comments, and produced concise statements of which of these themes I felt were important. As van Manen has recommended, I identified themes by attempting to determine the

³⁷⁷ Smith & Osborn, *supra* note 318.

³⁷⁸ Smith, Larkin, & Flowers, *supra* note 309.

meaning of a specific anecdote or story, asking myself questions such as, “What is going on here?” or, “What is the whole point of this story?” or, “What does this particular recollection of an episode of an engagement with family mean to the particular participant?”³⁷⁹ To keep track of the comments, emergent themes, and their location within the text, I used a process that involved electronic tagging within the proprietary software program Evernote,³⁸⁰ and linking them back to the exact location in the word processor text manually.³⁸¹

Following this I began to organize the analysis by identifying connections across the themes, guided by the research question and objectives, and organizing these using an electronically tagged mapping system described above. Examples of tags used were: *Tx Recruitment of family*; *Tx Intrafamily conflict*; *Tx Family frustration*; *Tx Physician manipulation of decision making process*; *Tx Family ally*; *Tx Family dominance*. Although such entries ultimately grew large, I could use Evernote's search function or its ability to list the notes by tags, to make cross-references as the process of my data analysis moved forward. If super-ordinate themes from the themes with similarities appeared, I ‘merged’ the identified themes by adding a new tag or by parking them alongside similar themes as a cluster, with the view of potentially organizing them within a super-ordinate theme.

I remembered that my role in the analysis was not to generate an ‘insider account,’ but to seek meaning and commonality beyond that account.³⁸² Finally, I conducted the process of abstraction, identifying patterns and developing superordinate themes, giving them new names. Once I felt that thematic analysis was near complete, I sent each

³⁷⁹ van Manen, *supra* note 311.

³⁸⁰ 2014 Evernote Corporation (www.evernote.com).

³⁸¹ The MS Word transcript was first set up with line numbers in landscape mode. Next the page was split such that comment balloons took up the right half of the page. Comments that were descriptive, linguistic, conceptual and later subject or themes for various block sections were entered using different fonts, bold text, colours, and italics. Individual notes in Evernote were created for each participant containing field notes, analytical approaches and other comments. As themes emerged from the analysis of the transcripts in the Word document, they were named as a new entry in a comment balloon, then again in the Evernote note, citing the line number in the original transcript in Word or the comment number. Then, the note with the same named theme was tagged using Tx to start the name of each theme to allow access to all the themes more rapidly. Each time a new theme was created the note was tagged with a Tx category aided by the Evernote drop-down list of existing themes. Evernote's search function was used to then cross-refer as the analysis process moved forward.

³⁸² Larkin, Watts & Clifton, *supra* note 335.

participant the transcript of their interview with my comments, asking them for feedback. Each theme was named and accompanied by a short explanation, and illustrated with a corresponding extract from the interview transcript. I invited the participants to comment on whether they agreed that I had been accurate in identifying the theme, as well as the appropriateness of the chosen quotations *vis a vis* the theme in question.³⁸³

3.12.1 – A Note on Reporting the Findings of My Research

The actual reporting of my findings, particularly the analytical components, was an integral component of the research, and I approached it with close consideration of how I followed the phenomenological method throughout the project. I hope that my writing has adequately and competently articulated the contexts of meaning in which the participants found themselves, while recognizing the “complexity and instability of textual meaning, the language games and narrative practices that give expression and interpretation to human experience.”³⁸⁴ I found that the act of writing itself caused insights to emerge, as it had interpretative implications. As van Manen has indicated, it was precisely within the process of writing that the data was accessed and interpreted, and the central nature of my research questions were perceived. Hence my writing up of the research findings is not merely a representation of the knowledge produced by the research.

I hope that beyond mere descriptions and analyses of the experiences of the participants, what I have written will evoke understandings that may lie beyond the reach of the text itself.³⁸⁵ I found that in the process of the actual writing, I gained further insights into the phenomenon I set out to investigate, finally achieving the objectives of my research.

3.12.2 – Trustworthiness and Credibility

My research had a clear focus right from the outset, and I took measures to ensure that the data obtained was ‘good’ data. I indicate this by describing, in detail, the attention that was paid to the interview process and to the interpretation of the findings, both of which diligently followed the principles of IPA research (as described earlier).

³⁸³ WE Woloshyn, *‘More Perfect’: Towards a Phenomenology of Perfectionism* (MA in Education, Simon Fraser University, 2007) [unpublished].

³⁸⁴ van Manen, *supra* note 312 at 714.

³⁸⁵ *Ibid.*

In reporting my research, illustrative extracts from the interviews were selected to support any identified theme, and also to give the reader a sense of its breadth and depth. These extracts were selected so as to represent the overall data, and not chosen from a limited number of participants.³⁸⁶ They will also serve to convince about the concreteness of the findings by situating the reader in the context of the phenomenon while providing illustrative links to the participants' experiences in their life-world.³⁸⁷

Throughout the writing of my research findings I attempted to clearly show how my research has maintained its orientation to the phenomenon I chose to investigate. At each stage of the research process I accounted for the decisions being made, for example the participant selection criteria or the reasons for adopting a particular approach to the interview questions.³⁸⁸

I aimed at achieving 'balanced integration'³⁸⁹ in the reporting of my research by clearly articulating the philosophical basis for my approach and how this fits with both my profile as a researcher and my research topic. I attempted to demonstrate how the philosophical concepts behind the constructivist/interpretative paradigm and exploratory purpose of my project intersect clearly with my research method and the research findings. I aimed to maintain a balance between the voices of the participants and the principles that underpin the entire research approach.³⁹⁰

'Integrity of data' refers to its adequacy or dependability. In my final discussion chapter I review the IPA-compliant method that I used for data collection, demonstrating clearly (as Michael Patton reminds researchers about data integrity) that my research was a "systematic process systematically followed."³⁹¹ Thus far I have referenced and articulated my analytic strategy as being compliant with the methodological rigour required of IPA. To add to data integrity, I attempted to ensure a degree of data richness through the incorporation of a reasonable diversity of participant perspectives in terms of specialty,

³⁸⁶ JA Smith, "Evaluating the Contribution of Interpretative Phenomenological Analysis" (2011) 5:1 Health Psychol Rev 9.

³⁸⁷ M van Manen, "From Meaning to Method" (1997) 7:3 Qual Health Res 345.

³⁸⁸ L de Witt & J Ploeg, "Critical Appraisal of Rigour in Interpretive Phenomenological Nursing Research" (2006) 55:2 J Adv Nurs 215.

³⁸⁹ *Ibid.*

³⁹⁰ D Turner, "Horizons Revealed: From Methodology to Method" (2008) 2:1 Int J Qual Methods 1.

³⁹¹ Patton, *supra* note 356 at 546.

age, and experience, as well as the demographic mixture of the patients and families they served.

This being said, the diversity of the data may have been limited by the fact that I was only able to recruit only one female participant and one non-Caucasian from a total of nine interviewees. That my participants were overwhelmingly white and male likely has an effect on the data collected. For example, in relation to gender, there can be differences between female and male physicians in terms of their communication styles, which in turn shapes their relationships with patients.³⁹² Correcting for this possible difference is difficult. The proportion of female to male participants in my study parallels the demographic ratios noted in the surgical specialties in Canada, where, for example, only 10% of neurosurgeons and 11% of cardio-thoracic surgeons are women. There is a similar under-representation of women in surgical practice in the United Kingdom.³⁹³

It is also worth noting that there is a risk of essentializing when speculating that female physicians in high-risk fields are likely to have substantially different experiences of patient and patient-family interactions than their male colleagues. Clearly, multiple and critically intersecting factors other than gender can be expected to inform the types of physician experiences that are the focus of my research. For example, racial and cultural differences between physicians and patients and their families, knowledge differentials between experts and the public, or even the practical implications of long referral times are all potentially significant influences.³⁹⁴ In observing the characteristics of a group of women surgeons, anthropologist Joan Cassel notes that “[T]here was a temptation to sort the women surgeons into opposing groups: good/bad, warm/cold, maternal/non-nurturant,

³⁹² KP Derosé et al., “Does Physician Gender Affect Satisfaction of Men and Women Visiting the Emergency Department?” (2001) 16:4 *J Gen Intern Med* 218; RL Street, “Gender Differences in Health Care Provider–Patient Communication: Are They Due to Style, Stereotypes, or Accommodation?” (2002) 48:3 *Patient Educ Couns* 201; DL Roter & JA Hall, “How Physician Gender Shapes the Communication and Evaluation of Medical Care” (2001) 76:7 *Mayo Clinic Proc* 673; DL Roter & JA Hall, “Why Physician Gender Matters in Shaping the Physician-Patient Relationship” (1998) 7:9 *J Womens Health* 1093; DL Roter, JA Hall & Y Aoki, “Physician Gender Effects in Medical Communication: A Meta-Analytic Review” (2002) 288:6 *Jama* 756; KD Bertakis et al., “The Influence of Gender on Physician Practice Style” (1995) 33:4 *Med Care* 407; JA Hall et al., “Gender in Medical Encounters: An Analysis of Physician and Patient Communication in a Primary Care Setting” (1994) 13:5 *Health Psychol* 384.

³⁹³ K Peters & M. Ryan, “Machismo in Surgery is Harming the Specialty” *BMJ Careers* (6 May 2014) online: http://careers.bmj.com/careers/advice/Machismo_in_surgery_is_harming_the_specialty (accessed 7 December 2017).

³⁹⁴ Matthew *supra* note 47

compassionate/unfeeling. But this is an oversimplification which obscures rather than illuminates what is going on.”³⁹⁵ Cassel further highlights the wide variation in the social or cultural preferences of patients, some possibly feeling less comfortable with a ‘maternal’ than a ‘paternal’ surgeon, being “reassured by an aloof, commanding, authoritarian surgeon – a godlike, Old Testament figure.”³⁹⁶ Other studies, for example that conducted by Marie Dusch *et al* in California, conclude that patients do not overtly prefer a surgeon based on gender, but rather look to characteristics that indicate competence, and as such, any anxiety regarding ‘traditional’ gender biases in the patient, felt by female surgeons, may be unwarranted.³⁹⁷ Similarly, Haley Nolan *et al*, in their study of patient preference for physician gender in the emergency department, report that the large majority of patients surveyed did not express a physician gender preference, but instead prioritized timely and expeditious care by *any* physician, male or female.³⁹⁸

Despite these cautions against essentializing gender (and other) differences, and my best efforts to diversify my sample set, I acknowledge that the overwhelming whiteness and maleness of the participants is a limiting factor. I also recognize the challenges in achieving a balance between subjectivity and reflexivity in approaching the formulation of the questions and in engaging with the data. These challenges were articulated earlier in this chapter, and an attempt was made to demonstrate, wherever appropriate, the full recognition that my own experiences were separate from the participants’ stories, and that there was a “continuum of connection and separateness between the researchers and participants.”³⁹⁹

I do realize that in IPA, maintaining epistemological openness has its risks. Michael Larkin *et al.* characterize this as ‘epistemological eclecticism,’ and it may be seen to have posed problems to the project.⁴⁰⁰ I attempted to ensure that the framework of my research was consistently coherent and clearly positioned, such that it makes sense for my particular research and data analysis. Finally, I attempted to ensure trustworthiness by ensuring the

³⁹⁵ J Cassell, *The Woman in the Surgeon’s Body* (Cambridge: Harvard University Press, 2000) at 129.

³⁹⁶ *Ibid* at 149

³⁹⁷ MN Dusch, PS O’Sullivan & NL Ascher, “Patient Perceptions of Female Surgeons: How Surgeon Demeanor and Type of Surgery Affect Patient Preference” (2014) 187:1 J Surg Res 59.

³⁹⁸ HA Nolen *et al.*, “Patient Preference for Physician Gender in the Emergency Department” (2016) 89:2 Yale J Biol Med 131.

³⁹⁹ Williams & Morrow, *supra* note 343 at 579.

⁴⁰⁰ Larkin, Watts & Clifton, *supra* note 335.

clear communication of the results of my study and how it is ‘socially valid’⁴⁰¹ both in terms of contributing to changes in the training of physicians, and in influencing the interpretation of patient autonomy in the medical informed consent process. The interpretations of my research have been made evident to readers of my published results. I also include participant quotations, discuss current theory and practice, and link my results to relevant literature regarding the reconceptualization of informed consent and shared decision-making in healthcare. Throughout, I aim to demonstrate clearly how I have answered my research question.

3.13 – Transferability Limitations of My Study

The findings of this study are likely transferable only to limited contexts where the healthcare system produces similar physician-patient-family relationship dynamics as in the circumstances in which I conducted my research. I have provided a detailed account of my methodological approach, my method of data collection and a clear description of the socio-cultural context of my research. In doing so, and in alignment with the position that authorities in qualitative research Lincoln and Guba take on the matter, I have fulfilled a qualitative researcher’s key responsibilities. These do not include a duty to provide a potential applier of qualitative research findings with an “index of transferability”.⁴⁰² The responsibility to make judgments about transferability lie with the latter.

Healthcare delivery models with privatized, for-profit health services are likely to generate different experiences. Several factors influence this, such as medical insurance policies, ‘consumer-orientated’ services that drive competition between professionals and healthcare institutions for clientele, and not least, relevant consent law and the medical malpractice environment. Other influential factors are culture and the historical nature of the local relationship between the public and the medical profession.

⁴⁰¹ Morrow, *supra* note 343.

⁴⁰² YS Lincoln & EG Guba, *Naturalistic Inquiry* (London: SAGE, 1985) at 316.

CHAPTER 4: Research Findings I – Sociological

Introduction

In this chapter I present the findings of my research, conducted using the methodology of Interpretative Phenomenological Analysis (IPA) with the aim of understanding the experiences of a group of specialist physicians during simultaneous interactions with patients and their family members during the consent process. Two major themes are reported here. A third, which focuses on the challenges to patient autonomy, will be presented in Chapter 5. A detailed discussion of the findings is presented later, in Chapters 6 and 7.

According to the principles of IPA, this data analysis is to be viewed as one possible interpretation of the personal experiences that the individual participants reflected upon as they discussed their triadic interactions during the consent process. This ‘double hermeneutic,’ which is a feature of IPA, could well produce different themes for different interpreters. However, given the similarities between my previous professional and clinical experience and that of the participants, I hope that this report will provide a rich, rigorous, and unique perspective on the phenomenon under investigation. Whenever appropriate, verbatim quotes from the participants will be used to illustrate the analysis.

This report is structured around three major (superordinate) themes, with several sub-themes. The first of these major themes paints a picture of the participant-physicians themselves, in particular the factors that contribute to their attitudes and approaches to engaging with patients’ families. This includes their views of the role of family in the interactions, their impressions of individual families’ personalities, and their internal relational dynamics. The second major theme includes a description and analysis of the participants’ experiences within actual interactions with patients and family. In the next chapter (Chapter 5) I report on the final themes, which focus on situations where the autonomy of patients appeared to be threatened by the presence of family during discussions, and describe the responses of the participants to this phenomenon. Table #1 presents a summary of the three main superordinate themes and sub-themes.

Table 1: Superordinate Themes and Sub-Themes

<p>1. EXPERIENCING THE TRIADIC INTERACTION SUB-THEMES:</p> <ul style="list-style-type: none"> • Considering Culture • Working with Inter-Professional Teams • Facing Conflict in Triadic Interactions
<p>2. REFLECTING ON THEIR PREPAREDNESS AND POSITIONING FOR FAMILY INTERACTIONS SUB-THEMES:</p> <ul style="list-style-type: none"> • Reflecting on Interactive Skills • Understanding the Role of the Family • Grappling with Families' Personalities and Intra-Family Conflict • Approaching the Engagement of Patient and Family
<p>3. STRUGGLING TO PROTECT PATIENT AUTONOMY (See Chapter 5) SUB-THEMES:</p> <ul style="list-style-type: none"> • Recognizing Cultural and Language Factors in Truth-Telling • Navigating the Challenges of Patients' Waiver of Privacy and the Right to Decide • Facing Undue Influences of Family Members • Respecting Autonomous Patient Choice against Family's Wishes • Manoeuvring to Protect Patient Autonomy

4.1. – The Triadic Interaction

Triadic encounters in clinical practice are those where, in addition to the physician and patient, another individual is present. These forms of interaction are seen increasingly in geriatric practice, given the growth of the aging population, or if translators are needed when physician and patient do not speak the same language.⁴⁰³ The impact of the third person's presence on the patient-physician encounter is often unpredictable depending on the role they adopt, for example, either remaining a passive listener or becoming a vocal advocate for the patient. The third person's unforeseeable influence is a potential source of frustration for the physician who may become uncertain about to whom questions or answers should be directed.⁴⁰⁴

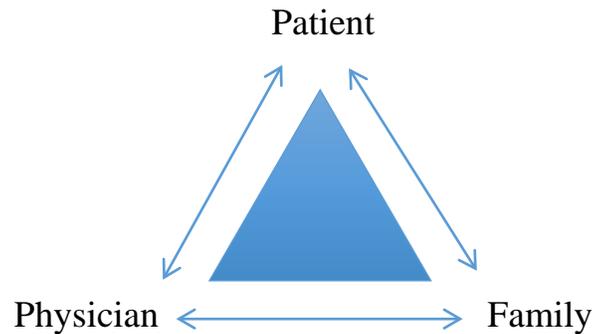
In this section I present the emergent themes that relate to such 'triadic' interactions that occurred between the patient, family and physician, where the change in dynamics of

⁴⁰³ Greene & Adelman, *supra* note 280 at 136.

⁴⁰⁴ *Ibid.*

the usual dyadic doctor-patient conversation introduces an element of tension, as discussed earlier (Chapters 2.3 and 3.3).⁴⁰⁵

Figure 1: Schematic of the Triadic Interaction



As the schematic above suggests, two of the three parties may also develop alliances or ‘coalitions’⁴⁰⁶ during such exchanges, with positive or negative effects. For example, the physician and one or more family members may combine their influences to convince an adult patient to accept a particular line of treatment with which the patient is hesitant to comply. Or, a family member with a strong influence on the patient might develop a ‘family coalition’⁴⁰⁷ that could exacerbate resistance to the physician’s treatment recommendations.

4.1.1. – The Triadic Dance Metaphor

The metaphor of a dance may provide a useful lens to focus appreciation of why tensions develop in a triadic interaction of this nature. The metaphor represents a fluid interaction of three parties who are expected to hold their conversation within a designated setting while following a rhythm. The setting and rhythm, in turn, are determined by structural factors such as wait-lists and the limited choices within Canada’s public healthcare system, or by the knowledge and power of the physician (who is effectively a gatekeeper of health services). Other factors influencing the outcome of this ‘dance’ may

⁴⁰⁵ Coe & Prendergast, *supra* note 293; M Tsai, “Who Gets to Talk? An Alternative Framework Evaluating Companion Effects in Geriatric Triads” (2007) 4:1 Communication 37; Laidsaar-Powell et al, *supra* note 158.

⁴⁰⁶ Coe & Prendergast, *supra* note 292.

⁴⁰⁷ *Ibid.*

be the degree of dependency precipitated by the person's illness, and the cultural background of the family.⁴⁰⁸ All of these elements are largely beyond the control of the patient or family members, and it is thus possible to imagine why their power to lead this three-way 'conversational' dance is necessarily restricted.⁴⁰⁹

4.2 – Superordinate Theme: Reflecting on their Preparedness and Positioning for Family Interactions

Overview

Vic 03: I'm with that patient for 5 or 10 minutes. They go home and they are with their [...] family, and if my treatment fails to secure his cancer and he died of his cancer, his family is going to be looking after him, not me. The family have been bereaved, not me. They are going to be doing the work, they are going to be doing the caring and the suffering and the bereaving and so forth, so they are still more important to that patient's life than I am.

In this category of the 'participant within the triad' I have included several sub-themes, offering a picture of the participants' interactive qualities. First I present a report of their reflections on the influences that have shaped their clinical communications style — for example their formal medical training, or the informal or 'hidden' curriculum in medical education.⁴¹⁰ The latter refers to the formative influence on medical trainees derived from observing senior physicians managing complex communications with seriously ill patients and their families, often within a hospital setting. Under such circumstances patients and family members, often under a degree of pressure to make decisions, are likely to defer to the opinions of specialist physicians. The trainees of those physicians are thus at risk of exposure to the negative aspects of 'physician dominance.'⁴¹¹ By contrast, in family practice settings, trainees work with physicians who are comfortable

⁴⁰⁸ HM van de Bovenkamp, *The Limits of Patient Power: Examining Active Citizenship in Dutch Healthcare* (Rotterdam: Optima Grafische Communicatie, 2010).

⁴⁰⁹ Charles, Gafni & Whelan, *supra* note 135; M Schermer, "Mr. Boskoop and Mrs. Huisman: Control, Trust and Autonomy" in M Schermer, ed, *The Different Faces of Autonomy : Patient Autonomy in Ethical Theory And Hospital Practice* (Dordrecht & Boston: Kluwer Academic Publishers, 2002) 157; Charles et al, *supra* note 4; S Conly, "Coercive Paternalism in Health Care: Against Freedom of Choice" (2013) 6:3 Public Health Ethics 241; A Aggarwal, J Davies & R Sullivan, "'Nudge' in the Clinical Consultation – An Acceptable Form of Medical Paternalism?" (2014) 15:1 BMC Med Ethics 31.

⁴¹⁰ Lempp & Seale, *supra* note 14.

⁴¹¹ Mahood, *supra* note 13.

with uncertainty and complexity and hence more likely to be open to sharing decision-making with patients.⁴¹² Besides the influences of more experienced professionals, the development of interactive skills is informed by the formal training in healthcare law that physicians receive as undergraduates. Canadian physicians are additionally offered medico-legal educational materials such as the *Good Practices Guide* of the Canadian Medical Protective Association (CMPA), an organization that provides medical indemnity to the majority of physicians in the country.⁴¹³

Next in the report is an analysis of the participants' perceptions of the role of families in clinical encounters during consent taking, including how they assess their behaviours, peculiarities, and internal relational dynamics. After establishing this background, I will report on the approaches the participants assume in actual interactions with family members.

4.2.1 – Reflecting on Interactive Skills

This subtheme includes the participants' reflections on the manner in which their medical training and their maturation as a clinician influenced the development of the interactive skills that they currently apply. This incorporates a discussion of how such skills are influenced by psychosocial and ethico-legal considerations.

All the participants reported that physicians' communication styles, attitudes, and postures towards patients and family are quite variable, ranging from outright paternalism to high levels of collaborativeness and willingness to consider patients as partners in decision-making. Describing a colleague who had expressed difficulty in working with families, Vic06 said,

⁴¹² Future of Family Medicine Project Leadership Committee, "The Future of Family Medicine: A Collaborative Project of the Family Medicine Community" (2004) 2:suppl 1 Ann Fam Med S3.

⁴¹³ CMPA. "Good Practices Guide," *The Canadian Medical Protective Association* (2016) online: <https://www.cmpa-acpm.ca/serve/docs/ela/goodpracticesguide/pages/index/index-faculty-e.html> (accessed 10 April 2017).

I've got a colleague who confided in me recently that that is his one biggest beef and largest stressor in the practice of emergency medicine. I mean he can comfortably resuscitate people, he can deal with drug abusers, with out of control people with behavioural things, but when he gets an overbearing family member he struggles to avoid losing his temper and acting unprofessionally because it just can act as such a switch to him.

When asked why he thought this doctor reacted in this manner to such dealings with family members he continued,

This particular physician I think comes from an era — like I'm a baby boomer-aged guy. I think we have probably not been raised in as much of a 'father knows best' environment than the generation — oh maybe we were raised watching father knows best. Yeah, this guy tends to run a little bit on the, "I'm the doc here" mode.... I would see myself as being far more open to involving the family in a discussion, or perhaps having better skills at trying to diffuse a situation, although I have certainly gotten myself into some discussions that have generated complaints.

Vic 03 and Vic 06 also pointed out that a physician's overall experience of their own family may have a bearing on the way they view the families of their patients. As Vic 06 said:

And so that brings up an interesting point... it's like, "What's your family like as a practitioner?" You know, you are dealing with a spectrum. Docs are humans too, right. We are on the same spectrum that everybody else is around cultural, religious values. We may be coming... like, what are our views around parenting, around the need for — do we encourage our kids to be autonomous, how do we deal with our elders, you know....

Vic 06's observation is consistent with the well-established understanding of the impact of family culture and parental influences on an individual's socialization and, by extension, their ability to interact with strangers in a professional setting.⁴¹⁴

Besides the intrinsic, personal values and experiences that the participants considered contributory to the interactive skills possessed by physicians, they also acknowledged the influence of mentors and senior colleagues. All of the participants were able to identify individual doctors who, even up to thirty years earlier, had modelled

⁴¹⁴ Charles et al, *supra* note 4; JE Grusec, "Socialization Processes in the Family: Social and Emotional Development" (2011) 62 *Annu Rev Psychol* 243.

positive or negative behaviours towards patients and families that significantly impacted medical trainees, contributing to the development of their interactive styles. As undergraduates or residents, the participants generally indicated that they received little (if any) explicit or formal training in communication skills; much was learned in the course of gaining work experience. Vic 04, however, said that he learnt how to engage effectively with families mostly from the years of working as a general practitioner before becoming a specialist surgeon:

I don't think it was so much the teachers — I didn't learn much from the teachers, but partly. Medical school was very important, informative for myself, but the years in general practice, you know, you live with that community and you saw the people everyday, so you kind of had to behave yourself and do a good job, I found — yeah.

Despite his initial statement about not learning very much about communications from teachers, he went on to describe the attributes of particular role models.

My Professor (PA) in Edmonton. He was a very engaging man and people really liked him. He was good with the patients and I emulated his way of practice a lot, just because of the way he was... PA. I think if you knew PA... he was a very strong influence on me. And (GM) also was very excellent in terms of his rapport with patients. People liked him and he explained and he was always very deliberate and did a good job, so those two mentors in Edmonton I had, I remember them very clearly as good practitioners.

Dr. H, our professor of medicine in Saskatoon, he was an internist and actually worked mostly from Toronto — I have a great deal of admiration for Dr. H and the way he just practiced medicine. He was kind of like Lillian Moser type of guy and he was an influence, so there were some very good people who are good examples.

In engaging with families, most participants identified the listening skills of physicians as being a key attribute. Vic 08 cited research finding doctors believed that they were listening to patients (before they started speaking) for much longer than they actually did. Vic 08 even lamented that medical students today generally appear to be more interested in learning about clinical procedures than about talking with patients. Vic 03 went as far as to say that communication skills do not just apply to his work as a physician, but to all spheres of life — including with his family and any other persons — and that it

would be a “*real blow emotionally*” to him if any negative patient/family interaction could be attributed to a communications failure on his part. Adapting communication style to different families was important to him because “*some families don’t talk about stuff — it’s accepted as that something important that is going on and nobody talks about it.*”

Besides communication skills, the psychological profile and emotional intelligence of a physician could be the important factors in successful communications with families. In view of this, Vic 03 felt that the selection of individuals for medical training should not be based on academic grades alone:

My take on it, especially having worked with a fair number of medical students... is that emotional intelligence is something that is both innate and acquired, and you have to have a certain level of it to start, but the more you have to start, the easier it is to acquire more because it is like if you can’t run it is hard to get good at running [chuckle]. It is such a tragedy nowadays that we choose medical students based on their ability to pass examinations ‘cause that is the exact opposite of what you want as a physician.” You don’t want intelligent people doing medicine; you want people who are well organized and empathetic and intelligent people are often the least desirable.... I mean I think we try much harder now to choose those people for medical school than we used to, but as I said, people think this is a joke, but its true...you have done well to get a medical school class that only has one or two psychotics! If you can minimize the number of psychotics in a medical school class, you’ve done a good job. You can’t expect to get rid of all of them....

Referring to an event where a group of doctors had attended a workshop on medical education, Vic 03 continued,

We were all sitting down reminiscing about the murderers and the rapists and the people we had in our medical school classes, you know, but everyone was able to identify at least one person from the medical class who fell into that category.

Achieving a credible level of humanistic and interactive skills as a physician appears to be an unpredictable and unstructured process with variable outcomes. To avoid such inconsistency, all the participants felt that it was worth formalizing training in this sphere, even though these skills may eventually emerge as the individual’s clinical experience grows:

Vic 03: You don't have to formalize anything, but if you formalize things it implies that you have studied the problem, you have analyzed the data, you've looked for a solution, you are applying a solution and you are going to measure your results. I think there should be a curriculum and I think it should be examined and people should be failed if they are not good at it.

Besides training and early influences of mentors, another factor that shaped the participants' approach to the triadic interaction was their consciousness of the legal and ethical principles governing the obtaining of informed consent. All the participants were asked whether their awareness of the law that governs their clinical interactions is an important influence in their approach. The responses were, generally, that bioethical principles were the primary influences, rather than the law. This was especially so with the participants who were involved with medical education at undergraduate or residency level. In fact, none of the nine participants identified their legal obligations as being the predominant consideration in their interactions with patients or families during the consent process.

Our discussions regarding the impact of the law of consent on triadic interactions were frequently drawn to a limited aspect of the informed consent process: the variations in the practice of obtaining documentation of the patient's signature on a form, as legal evidence of assent to a procedure. For example, Vic 07 complained that specialist physicians commonly delegate the responsibility for obtaining a patient's signature to other hospital physicians or to nurses. Vic 05 also expressed his disquiet about this practice, as he felt that both the patient and the person requesting the signature often lacked understanding of the risks or other pertinent medical details. Both these participants implied that such a practice violated the legal principle that the responsibility for obtaining patients' consent and its documentation belonged to the person performing the procedure, and hence delegation of this duty to others was improper. Vic 05's concern was compounded by sense that, besides the lack of full comprehension about the procedure, patients offered their signature on a form merely in deference to the authority of the healthcare worker with whom they were dealing:

Vic 05: One thing that I don't like about the consent-obtaining process is that the orthopaedic surgeon will breeze through on their way to the OR and say to the nurse at the bedside, "Make sure that we have consent for a

total knee revision or a revision of this total knee arthroplasty and please make it so by 2:00 p.m.” or something like that. You know.

It feels like, “Are you kidding me? You want me to get this consent?” And yet that does seem to be — that does seem to happen. The neurosurgeon will ask for somebody else to get consent on the EVD⁴¹⁵ placement and that is below the standard...it seems to happen a lot...and it is surprising.

And the person receiving and giving the consent doesn’t really know, they just see the nurse as the authority, or me. Like I will sometimes get a consent for a PEG⁴¹⁶ tube, you know, but I’ve seen colons perforated by PEG tubes and people develop terrible peritonitis and terrible wound infections as a result and I tell them that that could happen, but just to kind of smooth the process I do obtain the consent, but I do give it in the best way that I can, even though I’m not doing the procedure.

Vic 03 claimed that he has frequent discussions about law and medicine with his own family (he has one daughter who is a physician and another who is a lawyer), and was emphatic that it was bioethics and general principles of communication that were the determinants of his approach to consent, and not the law. When asked directly about how cognizant he was of the British Columbia law governing the protection of patient autonomy in consent-taking and communicating with families, he said,

Probably pretty ignorant, I’d expect. But I don’t practice law, I practice medicine, and when you practice medicine you do the best for your patient, not the best for the law in my opinion, and the law will have to catch up later. But I mean the issue it not that complicated in my experience. You just ask the patient, “Do you want this person there?”

When Vic 08 was asked if he felt obliged to comply with legal rules which determined which family member he was supposed to communicate with during medical decision-making, he responded,

I got into in fourth year teaching it, so I kind of knew there was a pecking order, but I must admit on the practical front I go for the first available person, you know, unless they are in conflict. In other words, if I’ve got a

⁴¹⁵ External ventricular drainage: insertion of a tube into the brain ventricle to allow drainage of cerebrospinal fluid.

⁴¹⁶ PEG: Percutaneous Endoscopic Gastrostomy is a procedure in which a tube (PEG tube) is passed into a patient's stomach through the abdominal wall, to provide feeding when the patient cannot be adequately fed orally.

common-law wife or a spouse there to help out or to help in the decision, that's what I am going to go for. If I don't and I've got a son or daughter, I'll go for that. I don't always sit on it and say, "Okay, this is the order I'm going to go and then go for the wife or spouse first and then the siblings in that order." I'd say no, most times I don't think about it.

Similarly, with Vic 07,

I think I rely — I think the ethics — there is almost a subconscious understanding of what you think is right or wrong, you know...so I think in certain situations, yeah, we are more likely to rely on that subconscious ethical perception and less on what documented written law states.

Although all of the participants had sufficient awareness that the law governed their interactions with patients and their close ones, they were not immediately familiar with the particular details of the law governing informed consent. The participants appeared to be guided by principles of bioethics and moral behaviour that they learned along the way, over the course of their careers. This appeared to be integrated with their understanding of legal principles imparted during undergraduate or residency training, or from medico-legal educational materials directed at them by their malpractice indemnifier, the CMPA.

Despite the general consensus amongst the participants that ethical consciousness eclipsed legal consciousness, all the participants referred to several measures that would keep them 'safer' in the event of legal challenge. For example, ensuring documentation of their exchanges regarding consent:

Vic 03: What you write there is part of a document, which is at some point in the future may be scrutinized by others — and in fact will be read by your colleagues — I always tell them that, you know, the document — the thing you wrote in your chart, the notes you write in the chart in 20 years time a student is going to read that and think, "That guy's my senior resident or my consultant. What a load of crap!" You know [chuckles], written 20 years ago. So think what you are writing. When you write a document or when you write in a chart or dictate a note you are creating a document, which is a public document, which will live forever, and which has legal implications.

Vic 04: When I write...I don't consider the hospital consents of any value. I mean that's the hospital. The documentation I view is — I just make a note on the consultation or the chart if I'm in the hospital and say that I have talked to the patient and give a general rundown of the discussion I had, but

I do not try to put everything into it because if you try to do that and you miss out one thing — but I give kind of coverage, I say I have had that conversation and any judge would look at this as, “Yes, he did talk to the patient, the patient knew what was happening” and so on.

Vic 01 and Vic 02, in discussing particularly difficult conversations with relatives of their patients, noted:

Vic 01: Some relatives never do get over it, but you’ve got to explain it and put it on paper, you’ve got to document it in a progress note in the chart that this is what you did ‘cause if it goes to court, then it’s an issue...I always have the legal issue here. Everything that I do I always think about the consequences of what can happen if I don’t do it and I always think that way. I always think that way. So when I talk to patients I say things that would help me as well as them. Yeah.

Vic 02: When things don’t go right, people get angry, right, and they could see you as the lightning rod of their anger ‘cause you are the one who prescribed the treatment. I mean thankfully that doesn’t happen very often, but it has happened before and it taught me that, well, I have to be very careful about my documentations...so I would say, “I discussed with patient’s sister about this issue.” You know. And my consultation note I usually always say, you know, “Patient was assessed in the company of sister/daughter” or, you know, just making friends and just making sure that someone else has heard what I said.

Besides routine documentation of patient and/or family interactions as a component of defensive medical practice, if they suspected there could be a particularly high risk of legal challenge, some of the participants felt it was important to take strategic measures that could potentially be of value to them. One such measure was to obtain (and document) multiple specialist opinions through case conferencing:

Vic 03: If we think there is a situation like this, you know, a patient’s family or a patient might be unhappy with the decision — take it to a conference and get the experience of your colleagues because it is much more defensible to have the opinion of your colleagues.

So in this particular case, this patient who is a lawyer and a nurse, qualified in both disciplines, asked about a treatment we wouldn’t normally recommend for her disease and so I presented it at conference and I’d rather have people say, you know, “This guy must be out of his mind, why are we discussing this case?” I was able to say, you know, “I’m presenting

this case on behalf of this patient who is a lawyer and a nurse so we can cover all the angles.” “Oh then that’s fine because we understand where this case is coming from, cause she is a lawyer” [chuckle]. So we make more effort for lawyers to make sure we’ve dotted the i’s and crossed the t’s.”

Active recruitment of the family of the patient during consent communications is another defensive strategy that participants used. This will be discussed later, in Section 4.2.4.

4.2.2 – Understanding the Role of the Family

The participants held a range of notions of what the role of the family should be in the triadic clinical interactions, and these beliefs informed how they respected, valued, or at times ignored or discounted the family members’ input. Besides viewing family in legal terms as witnesses to risk disclosure, family was also viewed as a source of history; as an interpreter or translator if there were language difficulties; or, at times, as an ally with whom the participant could form a ‘coalition’ to influence a patient’s decision:

Vic 01: Then I say, “Is your family here, do they know what is going on?” And then they will say yes or no and then I say, “We should get a family member to be here so I can talk to you about that and your family should be in the room when I am writing down this stuff for you to understand so that when you go home, you will forget some of the stuff I tell you and I want you to talk to your friend who will remember some of the information.” And that’s an important issue.

When asked why he thought that family was important in such situations, Vic 01 continued, using the term ‘corroborating,’ which has legal inferences:

Well what happens is that they come in, you tell them that this is likely a cancer and they just lose all perspective of what life is all — what’s going on. Just sort of...it’s a shock to them, it’s a shock and they may not remember any of the conversation we had, even the consent or discussion, so that’s an important issue.

So then their friend is there and they say, “Yes, you did say this, and yes you were told by Dr. [Name] that this is a surgical procedure being done, also chemo and you will get radiation.” And that’s an issue that it’s a corroborating experience.

The participants mostly saw the role of family as an interpreter of medical information, especially when the patient is ‘stressed’ by onerous news about their illness. Van 01 also pointed out that, on occasion, family members themselves derive benefit from being able to receive the medical information directly from the doctor:

Van 01: That situation sometimes occurs when I don't think somebody understands very well and they can use somebody, an extra person, to help them to understand or explain it again or... you know... so that it is not a one clinic interaction and then it is gone or they just didn't get it. I think family and support people can help the patient sometimes because they go home with that person [chuckle] and that helps sometimes.

Another situation would be super stress, you know, “you've got malignant melanoma” kind of discussions. And then it just becomes a question, you know, “It would be really good for us to... this is a lot to absorb... we should meet again tomorrow or next week or whatever and give you a chance to absorb it and if you would like to bring somebody with you.”

A lot of patients really like to have a family member or somebody that they are close to come with the appointment and I don't mind that at all and I'm happy to explain to whoever you would like to have with you in whatever way that I can help them too.

Vic 03 appreciated the patient's wife as source of a more complete and accurate history in situations where the patient may withhold information from the doctor for a variety of reasons, not just because of language difficulties. To him, the spouse of a middle-aged man is a valuable source of a more complete history about the patient, one who can often “keep the patient honest.”

You never want to see a man my age without their wife 'cause they never tell you the truth, you know. I say to them, the line I used is... the wife will say to the husband, “Did you tell him about the crushing chest pain?” — “Oh, I didn't want to mention that; I didn't want to upset the doctor so we didn't talk about that.”

So you want the wife there to keep the patient honest — and as people get older they forget stuff and having their spouse there — it's actually funny, I really enjoy to have a patient, you for example, there and the family is sitting beside you and you ask the question of the patient, “Do you have any pain?” — “No, no,” the patient is saying, and the family are nodding vigorously out of sight of their family member [chuckle], so you get — that's

as much information you might experience from the family as you do from the patient.

Vic 03 acknowledged the value of having family members present in encounters such as the one he described, appreciating their positive influence on the patient's willingness to be more forthcoming with the description of his symptoms. In this case, the recruitment of family input during history-taking was fortuitous and served to improve the physician's understanding of the patient's clinical picture.

The participants also related situations where they actively recruited family input for more specific reasons. Individual family members were occasionally identified as potential allies for the participants during triadic interactions. The purpose of recruiting such persons went beyond their utility as interpreters or translators, to obtain support in convincing the patient to comply with the recommended treatment. Vic 08 described such an engagement in an ER setting, where he had communicated primarily with the patient's wife because the patient (who was a legally competent adult) was unable to clearly describe his symptoms or the treatment he had recently received overseas. Besides that, his decisions appeared to be clouded by significant anxiety about his future health:

I think I was looking for an ally with her to come on board with me in my concern, or our concern for his welfare. So I wanted her...I was hoping she was...I guess be on my side is pretty strong...I wanted her to align with my concern about him rather than being at odds or in conflict with what I wanted for him or what I thought was best for him rather ...not what I wanted for him.

When faced with a large family group in an emergency room setting, participants reported actively identifying an ally amongst the members present in order to navigate the challenges of communicating effectively in the context of a multitude of voices.

Vic 07: Yeah, often times there is someone in the room that is maybe — that appears more reasonable or calmer or seems to understand, or at least their plan seems aligned with your plan as the doctor...when you have a teammate, right? You learn to read people — you learn to read the room a little bit when you walk in.

It was noteworthy that none of the participants indicated that engaging with family members of competent individuals was undertaken in order to elicit or consider their contributions to decision-making about the patient's medical care. The participants viewed the family primarily as a source of clinical information that they could not elicit from the patients themselves. This approach differed from the triadic interactions that have been reported in other cultural contexts,⁴¹⁷ where the family's role in consent discussions is integral to medical decision-making, going well beyond merely providing information. The analysis of this observation will be elaborated upon in Chapter 5, in the discussion about patient autonomy during triadic interactions.

4.2.3 – Grappling with Families' Personalities and Intra-Family Conflict

Participants began to form impressions of individual families' personalities and their internal relational dynamics early in their interactions, and being able to 'read' a family's characteristics was viewed as being critical for effective communication and prevention of potential conflict:

Vic 05: I try to attach myself to the person I perceive is the most rational [chuckle] and the person who seems to best balance or straddle the two worlds between the family dynamics and their ability to understand the world of the Intensive Care unit. So, I try to target that person because I feel that if I am trying to sway a patient or a family in one direction or another, because I think sometimes that is our job, we do sometimes know — well often we know what the right thing to do is, we have a strong sense of it — I'll try to make that person a bit of an ally in the process.

At one end of the spectrum family members were viewed as being well-informed medically, and at the other as being incapable of contributing usefully to treatment choices. The participants also described how they recognized the families' cohesiveness, their decisional ability, and the level of anxiety about the patient's illness, as well as the dominance of some members of the family in the decision-making process.

The participants were asked explicitly about their experiences in interacting with medically well-informed family members, especially those lacking a healthcare background but had accessed relevant information on the Internet. They generally felt

⁴¹⁷ Cong, *supra* note 45.

comfortable with such interactions because it made discussing medical risks and benefits easier and saved time. Vic 08 pointed out that, despite these advantages, engaging primarily with such family members could risk isolating the patient from the discussion. He described examples of such interactions, one of which involved a husband who was a specialist physician:

I actually had a...surgeon bring his wife in with chest pain. He had just retired and ...he was known for his roughness and he started telling us what to do and the nurse went ballistic. And she came to me and she said, "I can't go in there, I can't go in there." So I had to go in and I talked to him...

What I said to him was I said, "You know, you've got a difficult role to play now and it is no longer your role as a doc here. You are an advocate and a support for your wife. You are her best friend. That's the role you are going to play right now. You are going to step down off your doctor role and control role 'cause you can't control that, that is our responsibility, we are going to take on that responsibility with you and I don't want you to interfere with her care." That's a side bar.

No, it's difficult to deal with patients who do start with "I've read this" or "My friend had that" or "I looked up a Google search." They take more time, they definitely take more time, and like I said to one lady the other day, when she was worried about X, Y and Z, and I said, "That's a case of one, and we deal with cases of thousands and most times this is what happens. I know that was your grandmother's experience, but not here."

Yeah, informed patients can be actually a bonus in terms of their information. They come informed and it is better to keep them informed. I don't want them reading the chart necessarily [chuckle], I've seen them up reading charts, and you gotta watch that they are not crossing a line.

To be informed as a spokesperson, to be informed and help in decisions is good, but I don't want to be over here making a decision with the son and the father is over there who is fully aware and fully cognizant of everything, but isn't getting any information 'cause I am talking to the son who is a physician. It has its own dangers. That the patient now is further pushed away and you start dealing with the relative or in this case the medical person and not talk to the patient, which means when you go to talk to the patient, you've got to stop talking medicine too and not using words like infarction and speak to them so that they can understand what you are saying, not speak in medical jargon.

I've gotten into a conflict a couple of times that way though where the son or daughter — actually a brother — disagreed with the care, which was

tricky. Took his sister out and literally walked her out of the Emergency Department. Yeah. But that doesn't happen very often.

Van 01 reported that she routinely encourages patients and their family to look up information on the Internet and will often guide them with keywords, welcoming questions from them afterwards. She felt that this practice allows for a “good discussion” with her. On similar lines, Vic 05, when asked directly what his thoughts were about the informed contribution of family of competent patients during consent processes, said:

I do really welcome that because I like to work with people whose families I think are thinking and don't see themselves as passive receivers or consumers of medical advice. I think the sceptical or the thoughtful patient and family member is maybe in some ways a better ally because they are more interested in their own health, which is what we share an interest in. So I kind of think those people are cool and neat that they do their homework and sometimes I find myself educated by them in some way.

It depends on what's behind the family's intent when they are...are they trying to undermine my advice or authority? I don't have any view about it basically and I do welcome those kinds of things because ultimately I think people...the patients and their families...I feel that they probably feel better served if they feel like they were listened to and what they thought counts, it matters in the process.

Even if they have a “fantastic health outcome” from our point of view, if they didn't feel like...if they felt somehow slighted or undervalued in the process, they may have a less than ideal perception of what happened to them.

Vic 05 and Van 01's attitudes exemplify the approach taken by physicians who recognize the validity of the family's own needs in their interactions with healthcare professionals.⁴¹⁸ The pertinence and legitimacy of such needs has been drawn from the periphery of ethical considerations in healthcare practice, into a more central focus, by ethicists and commentators.⁴¹⁹ It is submitted that being comfortable interacting with well-

⁴¹⁸ K Lj et al. “Family Members' Perceptions of Palliative Cancer Care: Predictors of Family Functioning and Family Members' Health.” (1995) 12:4 J Palliat Care 10.

⁴¹⁹ President's Commission for the Study of Ethical Problems in Medicine, Biomedical, and Behavioral Research, *Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship* (Washington: President's Commission for the Study of Ethical Problems in Medicine, Biomedical, and Behavioral Research, 1982); RD Stapleton et al. “Clinician

informed families may not be a common experience amongst physicians for a variety of reasons, such as time demands or the anxiety provoked by family members' emotional responses. The sheer diversity and complexity of family characteristics and relational dynamics also creates difficulty in anticipating families' expectations.⁴²⁰ Some physicians may not tolerate having their authority challenged by knowledgeable family members whose roles in care-contexts has been described as that of 'critics' or 'quality control' agents who are ever-vigilant about the details of the patient's treatment and progress.⁴²¹

Participant Vic 01's thoughts about the well-informed family reflected some of these physician anxieties. He viewed such interactions as potential challenges to his authority in what he described as a 'game,' ostensibly with winners and losers, envisaging a scenario where expert medical professionals are taunted or potentially intimidated by knowledgeable laypersons. However, he was appreciative of the time it saved him in having to educate about the patient's medical condition:

You shouldn't feel intimidated. If you are intimidated you've lost the game because you are the professional and they are here, they get this stuff off Google, and sometimes they come in and almost taunt the doctor, taunt him. You know, you don't want that, so that's an important part. But by and large most of them will come in well meaning in saying, "This is what I understand, I've done my work on Google, and this is what I understand." And you say, "Yeah, that's perfect, I'm really pleased you have done that because I don't need to spend as much time with you going into the details. Is there something else I can add to that?" You don't change your routine for the amount of information they bring in... "This is my routine and then what you've got is value-add."

The extent to which families differ in their degree of involvement in medical decision-making about the patient affected the participants' approach to engaging with them. Vic 02 described an encounter with a large family where an older patient, who was mentally capable, appeared to be coerced by her family members into undergoing chemotherapy:

Statements and Family Satisfaction with Family Conferences in the Intensive Care Unit" (2006) 34:6 Crit Care Med 1679; Levine & Zuckerman, *supra* note 279; Gilbar, *supra* note 279.

⁴²⁰ Levine & Zuckerman, *supra* note 279.

⁴²¹ E Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (Chicago: Aldine Publishing Company, 1968).

The family members were actually exceedingly pushy for her to get chemotherapy, even though she was well into her 80s and was quite sick and frail, and they declined the option of using a professional translator, 'cause obviously part of it was that they wanted to shield the elderly grandmother from the "bad" news. So it took actually a lot of time to getting through the process and making sure that she has a concept of understanding what is going on...it took a lot of discussions, lots of family meetings, so finally we convinced the family members at least to disclose what was going on rather than just saying, "Well you are sick, therefore you need the treatment."

In this exchange, Vic 02 identified possible cultural factors influencing this family's unwillingness to fully inform the patient about her illness. (Cultural influences in such triadic interactions will be discussed in detail later, in Section 4.2.1). The participant, however, persisted in his efforts to ensure a modicum of comprehension on the part of the patient, despite the family's attempts to shield her from the news of her grave illness. This discussion over an elective procedure took place in the doctor's office setting, and hence it lacked the urgency that can be experienced by the different parties in scenarios where futility of treatment is broached. Vic 05 described one such situation that he found distressing, where the family was dominant in decision-making:

It was just not done within his family to admit that he could be dying. They just wanted absolutely everything done and done again and done over again and there was just no end in sight to the man's suffering as long as the family was calling the shots.

And it did seem like we were putting the poor guy through just torture toward the end and I'm sure they were motivated by their perception of love and concern, but it was just — I do remember feeling in my head, "These people are crazy, I can't believe they want this done. I hate talking to them because I just think they are always making bad decisions."

But, you know, I guess the ethical climate now in healthcare is that — at least I perceive it to be — that we don't have a paternalistic or we shouldn't have a paternalistic attitude anymore. We should give full information to families and have a kind of approach of some shared decision-making, if that is what they want.

And you have to gauge the families and the patient's wishes, like where do they put the locus of power, do they want the doctor to make all the decisions, do they want all the power in all the decision-making authority

— fine — but you have to gauge that early on in the interaction and then act accordingly.

Vic 05 felt that since families differ in their approach to decision-making for health issues, it was necessary to assess each family's decisional patterns early on, in order to gain an understanding of where the locus of power resides. He disagreed with the manner in which this particular family made decisions, and felt that by insisting that medically futile treatment be continued, they were merely prolonging his suffering.

Vic 03 described an example of how he occasionally attempts to improve his understanding of the family's concerns and thoughts by eavesdropping on their conversations while he is conducting the clinical examination of the patient privately, in the same room. He acknowledged that in cancer treatment, the specialist must always be aware of the family's interests. His appreciation of their opinions did not, however, translate to direct consultations with them about a decision but instead remained indirect — a somewhat oblique approach to understanding what decisions would be acceptable to them:

We have curtains in our room, you know, so I draw the curtain and then I examine the patient and they, generally speaking, have the family there and I carry on talking to the patient and listen to family interaction when I'm doing that, and they sometimes will chat amongst themselves, but mostly they are listening to what I am doing. And then when I get the patients dressed and I draw the curtain back again and we talk about the diagnosis and prognosis.

And, again, for me it's very helpful to have the family there because it's rare, that they don't participate, and it is very rare that they don't ask questions and in most cases if it comes to making a treatment decision, in most cases the patient will say will look at his family...in many cases... "What do you think you I should do?" and in most cases the family will say to the patient, "Well I think this is your decision." And actually that is the dynamic, you know.

The participants occasionally came across a family dynamic where a particular family member dominates the discussion. As will be discussed in greater detail in the next chapter, which addresses patient autonomy issues, most participants noted that navigation of situations where a dominant family member challenges independent decision-making

by the patient takes special effort. Van 01 described how she experienced some disquiet during an interaction with a couple that was provoked by ‘interference’ of the husband of the patient with a chronic disabling illness that had rendered her physically dependent:

Just the interaction between the patient and the spouse during the process, which bothered me, in part because I almost got the feeling that the husband was interfering with her, her....my engagement with her in getting consent and explaining pros and cons and what would be involved in that type of thing; so that is probably why it stuck out in my mind.

When asked what she meant by ‘interfering’ Van 01 continued,

Not me — with her a little bit, I’d say, and was a little bit domineering in the discussion, yeah. So it made it harder to be sure when you are trying to make sure that the patient understands and you check back and get them to explain back there was...you know, he was talking a lot and I was a bit worried that he might be coercing her in some way, although it wasn’t really quite that bad, but I’m very sensitive to these things. So, yeah, I was just a bit uncomfortable.... She is a quiet person to start with. She has had her MS for quite a long time now, it is a slowly progressive, her type...and he is clearly the dominant partner in the household.

Participants came across situations where differences of opinion between family members, together with deference by the competent patient to family members’ decisions, caused difficulty in obtaining permission to proceed with treatment. Vic 08 described two such situations. In the first case, the patient’s family members did not agree with each other and the locus of decision-making became confusing as a result:

It was obviously a family where all members could contribute and it wasn’t the son was the only one... it is the son who is actually on the phone...it is the son that she defers to and not the daughters who actually live in Victoria... and it gets a bit tricky as to who has the right here, who is the one we are going to listen to?

With the second case he felt frustrated while seeking the patient’s own decision in the presence of her family, because of her persistent deference to her family members:

...in this particular case the patient didn't (decide) and was deferring to the sons and daughters and that made it really frustrating because I was explaining the problem. It was a woman — I was explaining the problem to the woman, the patient, and the family was present, but she was deferring to the daughter, she wouldn't make the decision and that was really awkward because I wanted her to decide whether we were going to move ahead or not. And she wouldn't take a stance, she wouldn't make a decision. She was cognitively intact and could make that decision, but she was deferring it to the family.

Vic 02 noticed that families tend to defer to the particular member who is the most “treatment seeking.” He felt that anyone present who did not appear to agree with active or aggressive treatment plans would be judged negatively by the others as being disinterested in exhausting all options:

There is always a spectrum of opinion, right, but most of the time they would follow the opinion of the one that is the most treatment seeking 'cause a lot of times there is a lot of family dynamic, right, so if they — (pause) it is a bit of a (pause) losing proposition or a guilt proposition if, you know, one of your siblings say, “Oh, mother should have this” and if you said no to it, there is a lot more guilt, right, unlike if you have a consensus-driven process that all four agree that they should do that, then that is fine.

‘Guilt’ or ‘self-reproach’ were expressions many of the participants used to explain what they sometimes felt were behind unreasonable decisions or attitudes of family members. Participants recognized that a parent’s illness often precipitates feelings of remorse amongst their children, for not having had the opportunity to participate sufficiently in medical decision-making or the care of their loved one. This form of ‘guilt’ manifests in a variety of ways, from the insistence on continuation of the parent’s treatment in the face of medical futility, to demonstrating aggressiveness towards healthcare staff. The following are four participants’ descriptions of such encounters:

Vic 01: It's a guilt situation. There is a guilt mechanism or a support mechanism that they weren't part of — that's really what it is. It's related to — they feel like they are one big family, but they are not, because they haven't been in association with them, and distance is a real issue — distance. It can be distance emotionally or distance from Calgary to Victoria, right, so I'm sure I had some people like that....

Vic 05: Well this is another soft impression that we have in ICU. Quite a common scenario is the elderly patient who lives here in Victoria whose adult children live somewhere else in Canada and then have to come in at the last minute when there is a crisis... but more times than I can count, the sort of water cooler conversation around the ICU when we are talking about that family and that patient is, you know, “Those kids feel really guilty ‘cause they haven’t been around to look after mom and now she has fallen and broken her hip and they want everything done.” You know, they want the full cardiac resuscitation in the event of a big MI, even though that’s not appropriate — because they feel guilty, because they are not here.

It’s hard to confirm though, right, ‘cause you can never say, “Are you just making this decision because you feel guilty ‘cause you are not here to look after your parents when they need you?” You know. And yet you have the feeling that it’s a real phenomenon, but it’s hard to confirm. The situation that it seems to be most evident in is the absentee child.

Vic 08: I had a daughter recently who broke down in emerg who had family guilt. Her mother is still in hospital. Her elderly mother reluctantly got brought to hospital. The daughter must have gone out or something happened. Mom is at home, goes out to do something and falls down, ambulance scoops, brings to me. Doesn’t want to go. Ambulance driver says, “You gotta go.” She has various physical deformities and can’t. He says, “You have to go.” Brings her to me, she is a reluctant customer, cognitively pretty intact — not 100%, but doesn’t really want to be there, but isn’t managing at home at all, the more I ask.

I talk with the daughter. Daughter is pacing, she is impatient, she is upset, she is missing work. I talk to her and I say, “You know, what is it, what is going on?” — “Well I take care of her and I work, I can’t manage” ... and she starts crying and crying and she is full of guilt and remorse and she is working and she can’t take care of her mom. Here is her mom who has taken care of her all these years, and now her mom is not working, but she has her two kids to manage, she’s got her husband and she’s got her job and she can’t take care of mom, so she’s got this team of people to take care of mom and it isn’t working. It did work for a while, but it has obviously fallen apart.

And her guilt was horrendous, just phenomenal. She poured this stuff out and out. I spent some time with her, talked about it, and said — anyway, in the end I said, “You need to let me admit her, she has to come in to hospital. You need to sort her out, she needs some placement. We need professionals to assess her and see what her needs are and the professionals with you can decide on whether she goes home or not.” The last time I looked it is three weeks and she is still in hospital.

Guilt. She was really guilty — sometimes it comes out as anger. Hers did initially. The nurse said to me, “That daughter has a real attitude.” And she came on to me pretty strong, but then she mellowed and her mother’s well-being was the main focus — we kind of got it focussed over here on mother — but then she opened up about her own guilt. She was letting her mother down, it was her fault, she didn’t take care of her mother.

Yeah, the daughter who does take care of mother — who does everything for mother — and the son who flies in from Toronto episodically and says, “We should do this and this and this” and the daughter says, “Are you nuts? I’m doing that already” or something to that effect and you get real conflict.

Vic 07: Hmm...it happens very frequently. You know, we’ll have elderly patients that come in quite ill and family coming that they may not have seen in a long time, and they all of a sudden want a lot of therapy or interventions that maybe I don’t think are in the patient’s best interest and it is quite clear that the family are just pushing for treatment to say that they have done everything, potentially thinking that maybe there is some guilt because they haven’t seen their friend or family in a while or are feeling a bit guilty about that.

It is noteworthy that the focus of the narratives, above, was on the role and concerns of individual *women*. These persons had either deferred to the opinions of the rest of the family while refusing to make an independent decision, or had complied with the wishes of a dominant spouse. One individual expressed exceptional guilt for being unable to take care of her elderly parent to a degree she would have liked, because of the demands of her career and the needs of her children and spouse. Such examples of women who have embraced the responsibility of being the principal care-giver within families are consistent with empirical observations that it is primarily female family members who bear the physical and emotional burden of unpaid care of dependent individuals.^{422,423}

⁴²² L Crossman, C London & C Barry, “Older Women Caring for Disabled Spouses: A Model for Supportive Services” (1981) 21:5 *Gerontologist* 464; EP Stoller, “Males as Helpers: The Role of Sons, Relatives, and Friends” (1990) 30:2 *Gerontologist* 228; MGH Dautzenberg et al. “The Competing Demands of Paid Work and Parent Care Middle-Aged Daughters Providing Assistance to Elderly Parents” (2000) 22:2 *Res Aging* 165; E Dentinger & M Clarkberg, “Informal Caregiving and Retirement Timing among Men and Women Gender and Caregiving Relationships in Late Midlife” (2002) 23:7 *J Fam Issues* 857; J Fast et al. “Characteristics of Family/Friend Care Networks of Frail Seniors” (2004) 23:1 *Can J Aging* 5; J Sims-Gould & A Martin-Matthews, “We Share the Care: Family Caregivers’ Experiences of their Older Relative Receiving Home Support Services: Family Caregivers’ Experiences” (2010) 18:4 *Health Soc Care Community* 415.

⁴²³ While recognizing that there are important and wide-ranging considerations related to gender and care-giving by family members as well as the interactions of women with healthcare professionals, these are areas of study that lie beyond the scope of my project.

Vic 07 continued by describing how he needs to “*read people*” and “*read the room*” when he is about to enter into an engagement with anxious family members in an ER setting. He explained the value of being able to quickly sense which persons are most likely to be a source of disagreement with the physician and other healthcare professionals. Such adaptation to the family engagement environment occurs quickly and subconsciously. He also described how he has learned to “*take control*” of such situations:

Well often times — you know, a lot of times you just get an idea from people’s body language or their expression or their tone within a few seconds of how this interaction is going to go, you know.

So you may have the patient on a stretcher and somebody sitting by the bed and a couple — of family members standing nearby and within just entering the room, you know, you’ll see some people might be scowling or clearly agitated, or other people might be calm and smiling and look more receptive.

So as soon as you enter the room and especially after you start talking for a minute, you can often times get a feel of what people’s attitudes or their overall mood is like at the time. And especially in emergency ‘cause things can get volatile sometimes, you had to learn how to control those sorts of situations and know like you say who your allies are and who in the room is the potential to, you know, make things go off the rails. Yeah.

It happens almost subconsciously and relatively quickly. I might see a patient for four or five minutes on a primary assessment, and that is when I am doing most of my fact finding, so a lot of that happens subconsciously as you enter the room and you introduce yourself and, you know, it can happen relatively quickly, I think.

So, you know, when I see the patient — the nurses have usually seen the patient first, they’ve given me a brief description of what the problem is on paper, so I can read it, so you have a bit of a sense of when you go into the room about what is happening, but often times you will walk in and you will introduce yourself and, yeah, you will for some reason say, “Would you mind just giving us five minutes and then we will bring you right back.” Yeah, that happens all the time. Get them to leave just for a few minutes. Yeah.

We have to remove those distractions sometimes. There are some times when it is clear that they need somebody with them or they should have somebody with them, or that it doesn’t matter, but there is other times when

it is clear that you need to clear the room and just be one on one with the patient. Yeah.

The participants identified two forms of anxiety amongst family members: one about under-treatment of the patient; the other that they, or the medical staff, had prematurely given up hope for recovery. This overt expression of family anxiety appeared to coerce medical staff to persist with aggressive medical interventions in spite of their own disbeliefs about their usefulness:

Vic 05: One conceit that the Intensive Care team has about itself is that — I hear this said a lot — is that the patient probably doesn't want what we are doing to them, but the family wants them. And I'm only vaguely aware of this research idea that patients...individuals would choose certain interventions or aggressive interventions for their loved ones that they wouldn't necessarily choose for themselves under the same circumstances. Have you heard that idea?

So, I'm sometimes aware that I might be bumping up against that, you know, where — as an example and this is fairly typical, but somebody who has got a poor cough and swallow and needs to be re-intubated for the second or third time and their co-morbid problems are such that, patients may undergo re-intubation or prolongation of their Intensive Care stay almost against their wishes, but it is hard to know what their wishes are sometimes.

You know, they are not very capable of expressing them, but their families are probably in some way prolonging their care that they get because they don't — you know, they don't want to see their loved one undertreated, and they don't want to be perceived as giving up hope for the recovery of their loved one.

Engaging with overbearing family members can be significantly stressful to some physicians, as Vic 06 related:

It doesn't have to be from a different culture, it can be from within our own culture, but a parenting environment where it has been an overbearing parent.

You know, I've got a colleague who confided in me recently that that is his one biggest beef and largest stressor in the practice of emergency medicine. I mean he can comfortably resuscitate people, he can deal with drug abusers, with 'out of control' people with behavioural things, but when he gets an overbearing family member he struggles to avoid losing his temper

and acting unprofessionally because it just can act as such a switch to him. And so that brings up an interesting point it's like, "What's your family like as a practitioner?"

The participants' stories describing their involvement with their patients' families' personalities, and with observing their internal dynamics, clearly demonstrate how complex the interfaces between families and specialist physicians can be. While constructive engagement with family is important for a variety of reasons, this process presents additional demands on physicians' time and may require deeper commitment to communicating and managing conflict. The participants recognized the additional difficulty presented if domineering family members unduly influence a patient's independent decision-making. The structure and practices of the healthcare system, combined with the prioritization of individual rights of the patient, and ignoring dependent family relationships, may cause physicians to miss opportunities to develop partnerships with family members — and worse still, to become adversaries.⁴²⁴ Carol Levine and Connie Zuckerman state that physicians' privileging of individual autonomy (as proposed in bioethics and law) also results in wariness of the "often unexpressed and 'subjective' emotive and relational aspects of the patient's life."⁴²⁵ Participant accounts also indicated the difficulty in identifying patients' family values, which combine cultural, religious, and personal life-experiences. When these complexities compound the challenges faced in anticipating individual families' expectations, it becomes possible to appreciate why consent-taking by physicians is at risk of gravitating to a less impeded routine, centred on individual patients' consent without consideration of the family's input.⁴²⁶

4.2.4 – Approaching the Engagement of Patient and Family

In this section I will discuss the participants' reflections of their approaches to engaging with family members, bearing in mind the impressions they had formed earlier about the families' role, personality, and attributes. I will first describe the participants' general approach and, following that, specifically how they actively recruited families for the consent process, or how they intervened to manipulate or 'control' the decision-making

⁴²⁴ Levine & Zuckerman, *supra* note 279.

⁴²⁵ *Ibid* at 6.

⁴²⁶ *Ibid*.

within the context of a triadic engagement. The actual dynamics of these engagements will be discussed later, in Section 4.3 of this chapter.

Vic 03 described the importance of adapting his communication style to each individual family engagement, illustrating this with a story of a meeting with a large family to discuss a male patient's cancer treatment:

I remember the room was full of people, there was just enough chairs for everyone — and there was probably a combination of brothers/sisters/parents/children and so forth. And we started discussing this patient's illness and the treatment options, and I don't remember what the illness was now and what cancer he had, but there was sort of a stunned silence in the room when we started talking about this and I can't remember now if it was then or afterwards, one of the family members contacted me and he was very upset and said, "We don't do this sort of thing in my family; we don't sit and talk about stuff like this, we never talk about serious issues like my dad is dying of cancer."

And he was very upset about it because he had been put in a situation where he had to listen, and participate, you know, in a discussion about diagnosis/prognosis/treatment... and this is why I use it when I talk to medical students, you know, that importance of adapting our style of communication or our desired outcomes and communication with those of the families that we are dealing with, 'cause some families don't talk about stuff — it is accepted as something important that is going on and nobody talks about it [chuckle].

Vic 05 described what he does to assess the family's decisional dynamic in situations where that process is not clear, so that he understands at the very outset what his role is relative to the family's role during medical decision-making:

Well I may point blank ask them, you know, "How do you want to make these important decisions? Are you the kind of people and family that would" — I literally say this — "Do you just want to hear everything that I have to tell you about the procedure or the issue I'm talking about and then you make all the decisions or do you want to kind of put some of that on to my shoulders. I'm happy to do that, or I can take all the responsibility and give you my recommendation about what we should do and then we can go with that if you are comfortable with that." And you just kind of let them think about it.

I also see consent — and again because we are talking often consent for withdrawal for life support or other things — I see it as a long conversation. I don't see it as something that should be decided in one point of time because I wouldn't trust necessarily somebody myself, to make an important decision based on one or even two meetings.

Vic 05 also related his cautious and respectful preliminary assumptions in situations where he is unsure about the nature of a particular family's internal relationships and dynamics:

There is always underlying this just a deep respect for the autonomy of the patient and the much more profound and longstanding relationship and meaningful relationship that the family has with the patient versus what I have with the patient. I have a meaningful and profound relationship with a patient, but it's not anything like what the family has, so the consent-obtaining process has to be respectful of all that.

One of the participants (Vic 06) related his approach to initial 'reading' of the dynamic, in a particular family, in order to sense where the locus of decision-making resides, or should reside:

I guess — I think in many things we do in life you kind of go down almost a binary decision tree, right. If I look — I'm trying to read the language and the interaction. Often I haven't had a chance to study the interaction between these family members prior to this moment.

Let's start with the situation of the adult child whose parent wants to be part of this interview. There are two — well I guess there are three potential answers to the question — do they want them in there, do they not want them in there, or, I can't tell, I haven't got clue. But I'm looking for some assessment of that decision early on in terms of how I am going to play this and then you are also trying to read the parent in terms of what sense do I get between this interaction.

Is this an overbearing parent who is going to have the potential to overrun even a grown child's attempts at autonomy in this situation based on how their relationship as a family has grown over the years? So, I've been in that situation where I have thought — you know, like I usually sort of say to the adult child or to the adult with an adult child wanting to come in — “How do you feel? Would you like him or her to be there?”

Establishing a trust-building approach by the use of empathic communication with patients and family was a thread that ran through the conversations with the participants, although it was not always explicitly mentioned as such.

Vic 02: You articulate to them what would be best for your loved one. And most of the time they actually will respect it — and they do know that I'm not here to resolve their family dynamic; I'm here to act in the best interest for your loved one...They see that. It is trust building. No matter which culture, they can see that, it's not that hard. Yeah.

When asked about introducing this in medical curricula Vic 02 continued:

I think it is important for them (medical students) to understand don't — [pause] — even though they may come from a different culture/different ethnicity, you have to respect the culture. However, there is basic tenet of good medical practice — translates the same, doesn't matter what culture you go to.

You know, when people — when family members phone you to discuss their loved one, return the call. When they express concern, you address their concern, active listening, you know, listening to them. You may not agree with what they say, but at least you should listen and articulate why the 'protocol for MD Anderson'⁴²⁷ is not the right thing. Talk to them about these things and at the end of the day you actually seldom get into a lot of conflict with them.

The participants recognized that the family members themselves — and not just the patient — need support and comfort when faced with difficult medical decision-making.

Van 01: I think we tend to think of, you know, it is about the patient — patient-centered care — but it is family-centered care too and we do help families and I mean I think that is part of our job even though the patient may be the number one focus and we don't do things for family that is going to compromise the patient. On the other hand, you know, we have responsibility to help families too. It's not — we don't just help the patients themselves. I think that is part of what we do too as physicians and surgeons.

⁴²⁷ A particular chemotherapy protocol which the family asked if their loved one should be undergoing, instead of the one being recommended by participant Vic 02.

Vic 05 provided another example of supporting a family member in his intensive care unit, where the patient wanted his life support stopped but his wife had great difficulty in accepting this plan:

You don't want to add insult to injury so the family — especially the wife particularly is already suffering greatly because she sees that her husband is pulling away from her and she wants to hold on to him — so even though he is perfectly within his rights to do so and we would be in our rights to extubate him.

Still, it's such a final thing, you know, the pulling of the trach out and the giving of the morphine is such an almost irreversible thing and it is so important that I think his wife needed a bit more time to at least have her wishes expressed.

You don't want to rush anything like that for sure and you want to make sure that the people who will have bitter regrets or — even if not regrets a lot of grief after the fact — have the chance to say their say and not feel rushed when there is so much on the line. So that's why I waited and spent a lot of time.

Participants' active recruitment of family members for triadic discussions was done for a variety of reasons, such as very serious illnesses or complicated treatment recommendations, which carried significant risks. The latter are the main reasons for bringing family into discussions, but sometimes the reasons for doing so were less obvious.

Vic 02: So looking at whether the patient actually understands what you say and... what I call the bedside non-scientific observation, right, 'cause a lot of time when you talk to the family member and they just give you the glazed eyes, you know they are not getting it, and then you should talk to someone else.

Vic 03 described why the input of the family could become a precondition for their becoming a credible substitute decision-makers should the need ever arise in the future. Being a cancer-care physician, he has often observed how the participation of family in decision-making emerges and escalates as the patient's clinical condition deteriorates, and how he has come to view the patient and family as “one unit:”

It is easy for family to misunderstand and that's why we have a reason to having them there, of course, is they can't say what their dad wants unless they have been part of the conversation, so if their dad, for example, should deteriorate down the road and the family have to make a decision because their dad can't, then they have been there for that discussion.

In most cases in most families they have a very good understanding already. But in families where they haven't been talking about these things — that's vital — and they can't fulfill that role on behalf of their parents unless they have been part of a discussion.

So I think the family and the patient are one unit, I want them to be there, and I want them to be involved both in giving me information and hearing what I have to say about explaining the illness and the treatment options.

When asked what reactions or changes would ensue if policy required that physicians enquire of every patient whether they would prefer to have a family member present during consent discussions, Vic 03 felt that this would change the practices of some physicians because of the additional burden of communication. He described the reasons for his personal policy of including family in discussions, citing his own example of having being geographically distant from his elderly parents at the end of their lives:

I always encourage patients to have their family in the room. But would it change the way physicians practice medicine is what you are asking really — it wouldn't change my practice — I think it probably would, because I am sure there are physicians who find it more convenient not to have the family there because they get a quick interaction with the patient.

I'm sure there are physicians who find patients asking questions a big pain in the butt and the quicker they can get that patient out of the room and the next patient in that seat, you know, the more income they can generate or the easier life they will have, but I think that is a false economy.

And within the practice of my area, and I recognize that every field of medicine is different, you know, I mean if you are running a walk-in clinic, you are running a different clinic practice than an oncologist, in the Cancer Clinic. But in my field of medicine, my practice would be much more complicated and anxious for me if I didn't have that communication with the family. It is very much in my interest as a physician to have a family involved in the patient's care and I mean another example of something that I do routinely is invite people who are there whose family lived elsewhere to have them call me.

I will often say, “Well if your daughter/son has questions, ask them — I give them my card and say — ask them to give me a call.” And I will generally say to the patient if I’m not certain, “Are you happy for me to pass — and they almost always say yes, like very, very irregular situation where people don’t want their family members to know what is going on. And in the rare situation — and part of the reason why I do that is because my dad and mom died in England and I was in Canada and I know what it is like having family members overseas and when you are not there and you don’t know what is going on.

The safety of the patient is another reason for recruiting family, even if it appears to be against the wishes of the competent patient:

Vic 08: As we all get older where they may be some apparent cognitively intact, but their judgment is starting to slide and their insight into their situation, you know, they have multiple falls at home, the ambulance tells me the apartment is a mess, they haven’t been able to take care of themselves, and they are saying that they are perfectly okay, and I’m thinking, no, that is not the case here....

And I’ll get the nurse on the phone — “Get me a daughter, get me a son, find me somebody and bring them in.” I don’t want them just on the phone; I want them here physically. It is not common every day, but it is common enough that I know it is — in the elderly population it is fairly common that a situation arises where an intervention is necessary. They are not safe to discharge.

So, the word “cognitively intact” is tough, but they are alone with me, there is no family physically present. Now if they are alone in the community and there is no family and they moved here from Saskatchewan and the family is all remote, occasionally I get them on the phone if they exist, but there is a fair number where there is no family. That’s tougher. To make that jump or that step where you make a decision against their will to stay, it’s not easy to do, it’s really tough to do.

Vic 04 described how it is unsettling for him not to have family members present during the consent process because he fears being “*caught out*” if a patient ever did badly after an operation. His use of the expression ‘*caught out*’ indicates that he had some concern about the consequences, for him, of not having had the opportunity to caution the family even if the patient was competent and had been adequately warned about treatment risks. Being able to have a prior interaction with family can help mitigate the unpleasantness of

engaging with frustrated and angry family members to explain the reasons for unexpected complications:

Vic 04: One of the things that bothered me in terms of giving consents is that I haven't always had the other family members — I tell the patient, but the rest of the family isn't there, and I am always concerned of being caught out — say the patient did badly — and all of a sudden you are talking to people about a big problem that they never heard about, which is — if I recall, I've never had a serious problem with that, but it has always been a concern of not having the entire family there.

There could be different reasons, sometimes they weren't available, sometimes there wasn't any, sometimes there just wasn't time or whatever, but having a complication or a problem, I mean that family hadn't really known the details was kind of difficult.

I remember one patient had a head injury — actually this wasn't a consent — I hadn't got back to the family, he was in ICU for a couple of days — they were very infuriated because I hadn't got back with them — but not many of those things have happened over the years.

Vic 05: I think you do really want family in with the consent-obtaining process often almost for two reasons: To make the family feel — if the patient wants the family there (repeats this) — to make the family feel like they are important, which they are in the whole process, and that their input has value and that we are doing a good job of communicating important things that are happening to the patient with them.

But also to protect myself or ourselves in case anything does go wrong, you don't want the family to feel anger or resentment because something went badly and they didn't even know that that was an option. Even if the patient himself or herself was fully apprised of all the risks and benefits and the worst happens and you have — I don't think it is necessarily very reassuring just if you have a piece of paper that says, "Look, he signed this, we had a conversation about it so the fact that he has had a stroke now after his carotid endarterectomy and you didn't know that was a possibility, too bad" — you know [chuckle]. I mean we never say that, but you could understand a family member that didn't have the chance to listen in on the conversation and they feel hard done by if things do go badly.

All the participants described situations where they would actively recruit family members' participation in decision-making about the patient's care. These included the preparation of the family for long-term care as, occasionally, the patient themselves is not

convinced this is a necessary arrangement. At times, the reason for seeking family input was to reassure them that they were “*being listened to and what they thought counts*” (Vic 05). Such input would be actively sought even if the treatment risks were low, because family members could feel “*slighted or undervalued*” during the consent process for not being apprised of their loved one’s status, and for not being given the opportunity to participate in the planning of care. It also appeared that this lack of involvement could produce a degree of distrust in the local health service being provided, as Vic 01 had experienced:

You have to tell them about what’s going on in detail and then when you look at them and say, you know, you have to find out their home situation and if it is a colostomy or if it’s going to require a long hospital stay, then you have to involve the family and sometimes what you do is you phone the family member that is not there and say, “Has your wife or husband told you about the problems that they’ve got?” Or the daughter. Some of them will say, you know, “They are not here, but I want you to phone my son, would you phone my son?”

Yeah, they ask you to do — “phone my son” or “phone my daughter” because they have not talked to them for a while, they feel a bit disjointed, so they feel like they are not involved. So then if I phone, then they get more involved, so that’s another way to do it.

Victoria is a land where the geriatrics move out here and they don’t bring their kids, right, so they are here, they get sick, and then all of the sudden family is somewhere else, so that happens.

Sometimes — first of all they don’t trust anyone and they may not trust the medical care in Victoria, so I have to go through all that again and then they say, “Well maybe I should take my mother back to Toronto” or somewhere else for treatment. And I say, “That’s fine if that’s what you would like to do.”

On the other hand, by and large they go along with what is going on and it’s not an issue once they get involved. It’s not an issue once you get involved because you can explain it all away.

Some of them are quite upset because they didn’t get involved with their mother earlier on, or their parents earlier on and they watch them get this problem and now it is too late ‘cause the cancer is very extensive and they require maybe additional surgery.

As seen from the preceding stories, the participants appeared to have several reasons for actively recruiting family members during consent discussions. The priority was to offer information about the patient's medical condition such that they could better prepare themselves for care planning — or for the prospects of a negative outcome. Some information sessions were emphatically family-centric, geared primarily to support the relatives directly affected by their loved one's illness and its treatment. The participants also described physician-centric motives for family conferences, one being conflict prevention should there be an unwanted treatment outcome. Another physician-centric motive was the active recruitment of one or more members of a large family as allies, in order to form a 'coalition' capable of applying pressure on the patient to accept the physician's recommendations.⁴²⁸ Such a measure could be considered merely functional — a way to avoid time-consuming or contentious interactions with a large family, with their different opinions, in order to expedite decision-making for the patient's benefit. Alternatively, and more worryingly, such a practice can be viewed as a form of oblique and veiled parentalism that ultimately manoeuvres the patient's decision-making to align with the physician's ideas:

Vic 05: I try to attach myself to the person I perceive is the most rational [chuckle] and the person who seems to best balance or straddle the two worlds between the family dynamics and their ability to understand the world of the Intensive Care unit. So, I try to target that person because I feel that if I am trying to sway a patient or a family in one direction or another, because I think sometimes that is our job, we do sometimes know — well often we know what the right thing to do is, we have a strong sense of it — I'll try to make that person a bit of an ally in the process...

Vic 07 reflected on the situations where he sensed physicians feel strongly about the importance of communicating with the family about the patient's illness without the patient's knowledge. In doing so they might be applying their own values, justifying their skirting around the principles governing confidentiality and patient autonomy by concocting an assumption that the patient has diminished capacity and is hence unable to fully comprehend the implications of their illness.

⁴²⁸ Coe & Prendergast, *supra* note 293.

Vic 07: And then sometimes, you know, we justify things to ourselves as physicians and say, “Oh, this patient is clearly ill and they are delirious right now.” So convincing ourselves that they are incompetent or don’t understand so that we can either talk to family more or give people more information sometimes.

I mean not very often. I can think of those situations where patients — but I feel like I am almost imposing my own values, but if I think they’ve got a day to live and they are telling their family that everything is fine, then sometimes I convince myself that this patient really doesn’t understand — I’m telling myself they don’t understand, they must be incompetent, so I should inform this family what is really going on here.

In this section I have reported on the theme of the preparedness and posture of the participants within the triadic interaction, describing their accounts of the development of their interactive skills and their opinions about the importance of such skills. The participants described a diverse range of families’ personalities, noted the value of being able to recognize different intra-family dynamics relevant to decision-making, and talked about their reasons for recruiting the input of family during consent taking. They described situations where they moved decision-making processes along by forming coalitions with particular family members, and discussed how they navigated the challenge of communicating in the context of large families containing a variety of opinions about what was best for the patient.

4.3. – Superordinate Theme: Experiencing the Triadic Interaction

Three specific areas will be presented in this section of the report: cross-cultural considerations during family interactions, the participants’ experience of working with families as part of an inter-professional team, and finally, the participants’ experiences of conflict escalation leading to disputes with patients’ families.⁴²⁹ The emphasis in this final section of the report is, therefore, on the actual, contextual experiences of the participants

⁴²⁹ For the purposes of this discussion a ‘dispute’ is distinguished from ‘conflict’ in the following manner: conflict is a state rather than a process and persons who have opposing interests, values, or needs are in a state of conflict. Conflict may be *latent* and not acted upon, or *manifest*, in which case it is brought forward in the form of a dispute or disputing process. A conflict can thus exist without a dispute, but a dispute cannot exist without a conflict. Yarn, DH. “Conflict” in DH Yarn, ed *Dictionary of Conflict Resolution* (San Francisco: Jossey-Bass, 1999) 115.

during especially demanding triadic interactions with family members, highlighting the dynamics involved and the measures taken to navigate these processes.

4.3.1 – Considering Culture

Most of the participants related stories of communications challenges related to factors influenced by the cultural background(s) of the patient and their family. In fact, Vic 02, who grew up abroad and belongs to a non-Western ethnic community himself, raised the matter of culture very early in our conversation:

I think what stood out to me is when the patient doesn't speak English and using either a translator, or family member as a translator, and it will become a very difficult process to actually get to consent. So even though we have a professional translator — and I use that quite liberally -but at the end of the day you always wonder, “Do they actually get it?” Do they actually understand the process, ‘cause a lot of the time you think about the process of consent — it’s very cultural.

They have to understand what is the context and what’s the relationship between the doctor and physicians. For people that are not — who didn’t grow up in Canada — they have a very different concept between the physicians and the patient than people that are from here, so, it is a very dynamic process, right.

If you think about it, it is not so much what I say, the why and what we do and what are the risk[s] and then by the time they say yes to it, what do they mean by yes?

Vic 02 expressed his doubts about whether persons who have difficulty in communicating with physicians because of language constraints do actually understand what they are consenting to. He implied that these individuals, who mostly belong to non-Western immigrant communities, might also have different expectations of the doctor-patient relationship compared to persons who have grown up in Canada. By using the expression “*not so much what I say, the why and what we do and what are the risk[s],*” Vic 02 expressed his uncertainty about whether such patients assigned importance to medical information offered, and also declared that the process of consent is “*very cultural.*” His impressions were that medical informed consent amongst this particular population of non-Western individuals may sometimes be offered on the basis of factors

other than on their comprehension of medical information and risk disclosure alone — factors such as trust in, or deference to, medical authority.

There can be wide variation in the way families respond to news about an illness of close one, and how they expect or choose to interact with physicians. Vic 03 recognized that cultural norms can vary significantly when it came to the family's inclination to keep the truth from the patient about their illness, particularly if it involves a cancer diagnosis. He related how he adapts his style of communication to the family's characteristics:

Some families don't talk about stuff — it is accepted as something important that is going on and nobody talks about it [chuckle].

Whereas, there are other families that are very relaxed — in fact, the majority of families I deal with are very relaxed and I use a lot of humour in my clinic. I apologize sometimes and say it is because I'm English and I have a warped sense of humour, but patients seem to be happy about that, you know, and we make jokes and we keep — we talk about serious things, but we do it in a relaxed way.

All the participants agreed that it was important for physicians to be sensitive to the unique culture to which each patient and family belonged, and to adapt their approach accordingly. The importance of cultural awareness amongst healthcare workers has been recognized by leaders in the field, and 'cultural sensitivity' training is now commonly recommended for employees of health authorities.⁴³⁰ Vic 06 is involved in delivering training of this nature, which he described as being largely focused on First Nations cultures, and his claim about such indigenous emphasis is confirmed by examining the content of official websites that publicize such training.⁴³¹ However, he acknowledged that persons from *any* non-Western culture might "*find themselves very threatened by their interaction with the healthcare system.*" He found that this factor made it seem unreasonable to isolate the patient from family members, who provided language and other decisional supports, in order to protect privacy and personal autonomy (as would be

⁴³⁰ B Majumdar et al., "Effects of Cultural Sensitivity Training on Healthcare Provider Attitudes and Patient Outcomes" (2004) 36:2 J Nurs Scholarsh 161.

⁴³¹ Island Health, "Island Health Named One of Canada's Best Diversity Employers," *News Releases: Vancouver Island Health Authority* (11 February 2014) online: http://www.viha.ca/about_viha/news/news_releases/nr_diversity_award_11feb14.htm (accessed 10 July 2014); Provincial Health Services of BC, *(ICC) Training* (nd) online: <http://www.culturalcompetency.ca/training> (accessed 10 July 2014).

ethically required of a physician). This difficulty is compounded by resource limitations in terms of translation services in his institution.

Vic 06: One needs to have an understanding of how various cultures may differ in their issues around autonomy, especially those in which extended family have a much more involved role in the treatment of their elders, in particular, but their families in general than our sort of nuclear family here, you know, which can result in a whole other set of issues around [chuckle].

So I think that, you know, I may not even know what cultural background someone is from, so I think rather than sort of a “Oh, you are an Indo-Canadian,” therefore I think I know these things about your culture in terms of integrating that.

I think it just makes you even more aware — the need to be even more aware of those things we talked about off the top around reading the cues. And, if someone has to be there as an interpreter, you know, your family is your most available interpreter; it is very difficult to sort of say, “Okay, I need you to leave the room now, because I need to conduct a physical examination,” but I still need to give instructions to somebody who doesn’t speak my language, you know.

You get in to some very — what can be very hard to navigate situations, especially if this is a nephew or some distant relative, or you’ve just had to ask someone from the cleaning staff to come in and act as an interpreter, because yes, we’ve got availability of professional interpreters available, yeah, with hang time of who knows how long and a resource implication of who knows what, so those are concerns.

Vic 08 expressed several concerns in obtaining consent from patients and families from non-Western cultures. One such concern was about the accuracy of information being conveyed to the patient, either because of his mistrust in the quality of translation or because he sensed that there was a degree of reinterpretation or ‘filtering’ by family members. However, he felt that in such circumstances he had no choice but to defer to the family’s decision-making protocols, or what he believed to be the customary practice in their culture. He also described a range of difficulties he has experienced in the consent process with aboriginal persons with large accompanying families, and also with some patients from ethnic minorities:

The culture thing is tough because it depends on the culture...we were talking about the Indian family where the son is in India and the mother is going to defer to him no matter whatever, no matter if the daughter is sitting right in front of you. That was the culture and that was the way it was going to go down and there wasn't anything that I could say that was going to change that.

The aboriginal culture is tougher still because a lot of it is...the family wants to make a decision as a group, which gets tough, but what is tougher is the communication problem is tough in terms of you are asking, but nothing is coming back at times and you are not — connecting is really difficult.

I think I am used to a different kind of connection and the more patient I can be and sit back and wait, the better I know it is, I'll be able to connect better. But with the aboriginal it is really difficult 'cause often they aren't saying anything and I know that there is something bad here. They are not saying anything, but I'm worried there is more than what I have learned. You know, there is much more information I'm not getting...often aboriginals who are off reservation take on a more — I don't know if is a Canadian culture — but you know what I mean. Yeah, you are not dealing with a different culture.

The communication is totally different. And there are a few other differences of cultures as well. I haven't run into too many times where — Middle East culture I did a couple of times where I had to talk to the man and not the woman and I was really uncomfortable with that. I was REALLY uncomfortable. I had to ask him if she had chest pain. I had to ask him and I was trying to gradually turn so that I was looking at her and talking to him [chuckle].

The participants discussed ethnic and cultural influences in clinical interactions primarily with regard to language and communication, and the comprehension of medically relevant information. Some of the participants acknowledged that it was challenging for them to engage with patients and families from non-Western cultures either because of communication difficulties, or because of the expectations of family to participate in decisions. However, they did not offer clear descriptions of how they navigated the complex ethical conundrums that arise when collective decision-making practices of the family threaten independent decision-making by the patient. In other words, the considerations of 'culture' in our discussions did not extend beyond the practical exigencies of obtaining informed consent. The participants' concern appeared to be language translation and, eventually, a sense of assurance that there was an acceptable

degree of comprehension on the part of the patient, rather than whether there was any suppression of the patient's free choice, shrouded by their own unfamiliarity with the cultural norms of the family.

4.3.2 – Working with Inter-Professional Teams

An inter-professional team approach to engagement with family members removes the pressure from the participants' interaction during consent processes. This is primarily because the responsibility for communicating technical information, risk disclosure, and the addressing of concerns is shared with, or may be delegated to, other healthcare professionals providing care for the patient. As Vic 02 explains:

Well, I mean thankfully people don't practice on their own these days, right, so you often get — you have social workers, you have nurses and, you know, they actually provide excellent advice on what they observe and what would be the right thing to do and then you have a family meeting and then talk to them about issues.

So we know that outcomes are better when the patient actually knows what they are getting, all their family members actually know what they are getting, understanding how to manage the toxicity of your treatment, and understand the potential risk of the treatment.

We also know that a team-based environment actually helped them to know that there are more than one person looking after them, so the rest of the team actually are also being the eyes and the ears.

It is important for the team to have the same vision about the patient, 'cause if the team have a very different vision, people can hear mixed messages, and when they hear mixed messages it could be quite challenging.

Vic 02 also felt that the team approach to communicating with families could improve outcomes of treatment for particular patients, as it facilitates recruitment of family members into the decision-making process and greater engagement with the clinical progress of the patient:

Well thankfully as you pointed it out, you know, I find it exceedingly helpful to have a team because I no longer have to be all things to all people. I could just say, "Well these are the plans. If you have any concerns, I'm happy to talk to you again, but on the day-to-day clinical care, it is delivered

by someone else and it is often nurses, it is often pharmacists, and the pharmacist will come and talk to you about the medications.” There is a lot more contribution from other paramedical staff.

When asked whether he felt if family members were more involved nowadays with decision-making than they used to be in the past, Vic 02 said,

I think it has always been like that, but now they are more vocal, I think that’s the difference, right, because now the relationship between the physicians and patient has changed. In the past, the physician was up there and patient is just here so be grateful to get what you get.

But now physician is sort of being seen as a healthcare provider, so you [are] really here to provide services for your patients, so people are more willing to raise questions, to ask questions. And part of it does lead to a better outcome when we engage our patients, right.

... We also know that in a team-based environment actually helped them to know that there are more than one person looking after them, so the rest of the team actually also being the eyes and the ears.

The relief from bearing the sole responsibility for communicating risk and advising the family was also recognized by Vic 05 — though with some reservations. He had anxieties about the risk of mixed or contradictory messages being conveyed to members of the family by different staff members separately, and preferred family conferencing with the whole team present. His concern was based on the nature of acutely evolving clinical scenarios seen in intensive care:

That’s a big problem. I’m sure that’s a big problem. You can’t be sure, because I know that good and not so good nurses are saying things that I would or would not agree with, to family members, and to different family members who hear them differently, you know.

So it’s really ideal in my view to have several meetings with as many people in the family and the patient themselves, if possible, in the patient’s room, so that everybody is at least hearing the same words. Whether they hear the same meaning individually, I don’t know.

You get the family member who says, “Oh, but this doctor said this” or “This nurse told me this” and you feel like you are being played off somebody else and, of course, that other person is not there to clarify exactly what they did say or what they meant. I like the phrase — apparently

this is a phrase in aviation, I heard this at a conference one time which was something like, “Said is not necessarily heard, heard is not necessarily understood, understood is not necessarily done.”

4.3.3 – Facing Conflict in Triadic Interactions

The participants described a variety of situations where tensions in patient-family interactions escalated to outright disputes. To conclude the section, I will report on the participants’ stories of such conflict, the ethical and legal conundrums they precipitated, and the participants’ experience in managing them. As Vic 02 relates:

At the end of the day it’s a tough position because, you know, on one hand you know the right thing to do is this, but if the family member is wanting to do that, you have to negotiate that, you can’t really just say, “Well I’m just going to do that.” Unless what they want is completely wrong, but all the time it matters and it’s not right or wrong, it is a spectrum, so you can’t really say that that was completely wrong.

You know, in the worst case scenario you could always get one of your colleagues to see them as a second opinion so they can talk to them in a fresh angle, they can think about it with them, talk to them about what is the limitations, and go on from there.

Vic 02 also described the work of an inter-professional team in the consent process (see Section 4.2.2, above, on the role of inter-professional teamwork):

Unfortunately, you know, you can’t really affect the family dynamic, but what you can tell is that at the end of day — articulate to them that the vision is to allow their loved one to have the best outcome. The best outcome doesn’t necessarily mean to be alive at all costs; the best outcome sometimes could be enjoying an excellent quality of life towards the end.

So these are the statements or the negotiations that I use, is to find a common vision and what is important for them to see is also you are acting at the best interest of the patients and that actually goes a long way, yeah, because if you show that you actually care, they know that you care and they know that you are actually spending the time to discuss with them.

I mean they may be very angry and upset because of the nature of the evolution, the nature of the disease, or how they cope with the bad news, but at the end of the day it makes a lot more sense to them when you are actually visible and talk to them, you go and have the discussion with them about the other issues. Most people tend to be very reasonable when you

say, “The best outcome for your loved one is this, and we then should work towards that goal and we should have a consensus about how we are going to approach that.”

Having drawn from his specialist experience, Vic 02 categorically indicated that he often ‘knows the right thing to do’ in the patient’s best interest. Hence, in effect, the ‘best choice’ of treatment is not necessarily a negotiated agreement that takes into consideration the families’ opinion. Yet Vic 02 understands why the family may be “*angry and upset*” in some situations, and so he draws on his negotiation skills to bring them in line with his considered thinking about what is best for the patient. This being said, though, he characterized ‘reasonableness’ of the family in terms of their compliance with his recommendations, and in the “*worst case scenario*” (non-compliance and a state of irreconcilable differences in opinion) he would recommend that they obtain a second opinion from another specialist.

Vic 03 reflected on how the environment of family encounters could feel like being in a “*cauldron*” — that is to say, circumstances were unstable and the atmosphere was filled with strong emotions:

I have put myself in a situation — I mean I did at one time do a lot of palliative care as well in Manitoba and that’s a bit of a cauldron as you can expect because you are dealing in life and death situations on a daily basis, so I think when you work in that field, either you do it because you want to do it and you get good at it or you get out of it. And so you become comfortable talking about difficult issues with strangers, that’s what we do as physicians. You know, we walk into a room, introduce ourselves to a stranger, and by the end of the time we are talking about the most intimate details of their life and their death — that’s what we do, that’s our job.

Vic 04 related an incident where he was called into the hospital for a second opinion on a surgical colleague’s patient, and how he immediately sensed the anger amongst the family members. He attributed this “*chaotic*” scenario to a communications breakdown rather than medical error or negligence. By going through all the steps in examining the patient as deliberately as possible in the presence of the family, and updating them with information, he was able to defuse their anger such that the situation finally “*was all calmed down:*”

This patient came in very badly injured. There was a large family involved and a couple of — was seen by a series of doctors and there were some delays and the doctors had not dealt with the families at all. In fact, I think they didn't do a very good job at all.

And I got called into the situation sort of as another opinion, because the particular neurosurgeon who was involved, the situation got out of control on him, so I went in to the intensive care and I didn't know just exactly what had happened, and so I went in there, went over the chart, went over the details, examined the patient and the family was there when I was doing all this, and then I took the whole bunch into the room and I went through the whole process step-by-step just from what happened here, what happened there, this, this, and this is where we are now, and this is what we are going to do, and I know this is very bad, and so on and so on.

But I remember going into that situation and it was chaotic actually and just step-by-step and took my time, just did every detail, they were all there, they all heard it, and by the time we finished it was all calmed down, so I did a good job there. And, you know, it didn't take that long either. It didn't take that long. But just came in with a totally different attitude than what the other guys were doing. I just forget the details. They didn't do anything negligent or anything, it was just kind of messy.

Vic 05 described another conflict situation in an intensive care unit, in which the family had demanded that the staff persist with active treatment in the face of medical futility despite recommendations of the doctors to the contrary. It caused him to think that, “*these people are crazy, I can't believe they want this done (to the patient). I hate talking to them...*” The tension he experienced in working with that family was compounded by his awareness that the current ethical climate in healthcare decries medical paternalism.

Refusal of medical advice was a source of frustration for Vic 01, who felt that general distrust in ‘mainstream’ medicine, and differences in philosophies regarding health, were sometimes a source of tension between him and family members. He described a situation where he felt his recommended surgical intervention offered the best opportunity for cure, and that delaying it would be detrimental to the final outcome:

There are one or two that refused and these were individuals that really didn't trust the medical system; they had a great distrust of it and this was quite a problem for me because I felt that they required surgical intervention and they did not want to have surgical intervention. They wanted to just watch this and they were going to try some alternate

medicine, so it is an issue in relationship to their philosophy and theirs were a philosophy that differed.

This didn't happen very often, probably once a year, and this was quite upsetting to me because I would meet with them once, twice, three, four times and they would come back to my office and in spite of everything that has been done they wouldn't change their minds. And then I followed up in three to four months and sure enough the cancer would progress in spite of the naturopathic treatment and they would consent for surgery if it was still applicable, right, and it would be much later and not as good an outcome.

Participants described how they occasionally found themselves mediating conflict amongst family members over treatment issues, and if necessary, leveraging their medical authority to clarify and resolve differences of opinion. Family members who arrive from out of town and join the discussions late can produce an added burden for communications and re-explanation. They might also present a new source of tension in a previously comfortable triadic relationship, because of their limited understanding of the clinical progression with the patient, or vastly different opinions about what the treatment plan should be.

Vic 01: There is one situation where a lady had ulcerative colitis and she was not doing well — she got worse in relationship to her disease and she required surgery for the ulcerative colitis and she ended up having an ileostomy and all of her colon taken out and she was so ill. She was really ill because the ulcerative colitis was so extensive.

Her husband, I think, was quite informed, like he was very accommodating, and I talked to him every other day or every third day whenever, but I didn't realize that she had a sister and the sister came in from some other city and was really difficult in that she couldn't believe that her sister had an ileostomy and had her bowel taken out and was so sick from this... "Why would you create this major illness to my sister when she was so healthy the last time I saw her?"

And that was a major issue in relationship to sitting down with her and going through all the stages of ulcerative colitis and some of them don't respond to medical therapy and this one did not. I told her, you know, "You are going to have to talk to your sister how she feels about this because we went through these stages ourselves and you weren't here. Find out for yourself from your sister whether this in fact was something that you could have been part of if you were here, but you weren't part of it, so now I have to find out if I'm telling you the truth." And that was a real issue for her.

She really didn't think that I was — I was just doing another operation, nothing to do with her sister, so that was an issue for me. I really felt that I was being put on the spot there even though the husband was okay. He didn't want me to get into this, but since she was sort of a bother to him too 'cause they didn't really like her, but now she wanted to get involved in the family dynamics and I dealt with it in relationship to saying, "This is what has happened."

And the husband would tell her to "Shut up and just leave things alone, things are going well, my wife was really ill and now she is getting better." But she wouldn't so finally I said, "Okay, this is what you have to do if you really want to get through this." And she understood this, but she really never really got over it. Some relatives never do get over it, but you've got to explain it and put it on paper, you've got to document it in a progress note in the chart that this is what you did 'cause if it goes to court, then it's an issue.

Vic 01 believed that physicians should document such conversations with family members for reasons of legal safety, in case it 'goes to court' in the future. He recognized that the dissatisfaction of even one family member increases the risk of a medico-legal action, even though he may not be anxious about the standard of his medical care.

Vic 05 described a situation where there was disagreement about treatment between family members and the patient himself. As a physician, he found himself interposed in this conflict, which occurred in a terminal care setting. The patient, who was mentally competent, wished to be allowed to die:

There was a man who was fully conscious and he had had a rough go after bilateral lung resections for a couple of metastatic tumours. I think the primary was colon, but these were fairly isolated, very slow growing, and he had excellent lung function to start with and so the Thoracic Surgeon in his wisdom took out a part of the right lung and then six months later, part of the left lung.

But after the second lung resection, it seemed that he was not left with really enough residual lung function to carry on for very long...and he had just had enough of it and he insisted to his family that he be disconnected from mechanical ventilation and allow to die.

And we actually sort of — the family — particularly his wife — felt very betrayed by this decision on his part. She felt like she had supported him the last three years as he suffered one complication of cancer surgery and chemotherapy, etc., after another.

He was still a robust-looking man and had had all his marbles upstairs, was very intelligent, but she wanted him around and he did not want to stay around. But, that was very much an in-room kind of everybody around the bedside, including some of his adult children, grappling with this issue of should he be allowed to die.

And one sort of intermediary step that he was kind of talked into by his GP and by his wife, maybe even to some extent by the thoracic surgeon and our team, was getting a trach⁴³² ‘cause we thought, you know, “Well let’s trach you and see if — let’s go for several months ‘cause maybe your phrenic nerve will heal again and maybe you will get your ventilatory capacity back.”

And he went with it, he did the trach, but it always felt like he was being talked into it and two or three days after the trach was in he said, “No, I want this out, I want this out.” And I remember he was very clear about it, his wishes were very consistent and persistent, they didn’t seem to be overly influenced by an obvious depression...and his wife was falling over, you know, very emotional, which was a little out of keeping for her usual demeanour, like she was very, very emotive around this whole thing and eventually because he was compos mentis, whatever the right term is — he was able to uphold his wishes and the trach was removed and he died.

This was a situation where the autonomous decision of a patient was upheld against the general disagreement of family members. Vic 05 went on to discuss how he approached the difficult dynamics with the family, balancing off the spouse’s valid emotional response to her husband’s decision, but also upholding his right to make an autonomous decision and respecting his wishes. He refers to a sense of hesitation with the final intervention, even though there was no legal basis for not proceeding. Here, too, family consent was not a legal requirement, since the patient had capacity, but Vic 05 considered the family’s emotional situation and provided them with an opportunity to be prepared for the finality of the act.

In this section I described participants’ reflections about their experiences during several scenarios where interactions with family were significantly complicated by cultural

⁴³² Tracheostomy.

issues or serious differences in opinion over complex treatment options. The participants stressed the importance of remaining attuned to a family's cultural uniqueness because of its bearing on relationship-building and, by extension, the patient's compliance with recommended treatment. They discussed the advantages of a team-based approach to working with families (especially for situations such as cancer care), but also identified its pitfalls (caused by contradictory messaging by different professionals involved in the patient's care).

Conclusion

In this chapter I presented an analysis of the participants' descriptions of several aspects of their experiences with triadic interactions with patients and their families. Starting with their reflections on the development of their own interactive skills in this context, the report continued with their reflections on the role of families in consent processes, their experiences with different family personalities, and intra-family dynamics during clinical encounters. Finally, my report presented participants' experiences during actual meetings with families and patients where cultural and other factors contributed to disputes, including descriptions of the participants' responses.

I recognize that this is a limited account of the possible range of interactions between the participants and their patients and families, as my study was not designed to fully explore myriad physician-patient-family interactions during the course of patient care. Within triadic interactions, the various sources of tension, conflict, and dispute over medical consent and risk disclosure were well illustrated by participant's stories of clinical encounters. The pertinence of these tensions is better appreciated in light of the currently recommended regime of shared decision-making (SDM) in healthcare, according to which the patient's opinions are to be given due regard by physicians.⁴³³ That, together with the readily available information on the Internet, has ushered in changes in the degree of

⁴³³ Charles, Gafni & Whelan, *supra* note 135; A Towle et al., "Framework for Teaching and Learning Informed Shared Decision Making" (1999) 319:7212 *BMJ* 766; Charles et al, *supra* note 4; G Makoul & ML Clayman, "An Integrative Model of Shared Decision Making in Medical Encounters" (2006) 60:3 *Patient Educ Couns* 301; M Edwards, M Davies & A Edwards, "What are the External Influences on Information Exchange and Shared Decision-Making in Healthcare Consultations: A Meta-Synthesis of the Literature" (2009) 75:1 *Patient Educ Couns* 37; MC Politi & R L Street, "The Importance of Communication in Collaborative Decision Making: Facilitating Shared Mind and the Management of Uncertainty" (2011) 17:4 *J Eval Clin Pract* 579.

dominance of medical practitioners — a gradual erosion of the “social monopoly of expertise and knowledge”⁴³⁴ that doctors have been reputed to exploit in managing encounters with patients.⁴³⁵

The participants uniformly recognized that their skills in family engagement (incorporating communication, conflict management, and balancing medical authoritativeness with inclusivity in decision-making) were mostly acquired from earlier exposure to senior physicians, rather than from didactic undergraduate education. They agreed, however, that formalizing the requisite training to help equip physicians with such skills is of value. Yet some of the participants pointed out that there were innate personality traits, psychological characteristics, and personal values informing physicians’ approaches to the families of their patients. To compound matters, the behavioural modeling that occurs in clinical settings depends very much on the styles and dispositions of mentors. Numerous challenges must therefore be considered in the development of a functionally comprehensive training scheme aimed at improving the interactive skills and cultural competence of physicians. Besides reflecting upon the acquisition of interactive skills, the participants described a variety of factors that helped them ‘diagnose’ families and influenced their management of conversations surrounding consent in triadic situations.

The families’ unique internal dynamics, character of communications, customary decision-making approaches, and their own needs were amongst the features that the participants were able to recognize as being pertinent. Many of those features are determined by cultural beliefs and expectations of the healthcare system and doctors. The role of families in triadic encounters was uniformly perceived as being informational, rather than decisional in nature. Families were viewed primarily as additional or confirmatory sources of historical information about the patients’ symptoms or complaints, and were, in fact, not invited to contribute to clinical decision-making *per se*. This finding seems to indicate that the privileges, rights, and/or responsibilities within the notion of ‘shared’ decision-making (described above) are restricted to individual patients’

⁴³⁴ B Turner & C Samson, *Medical Power and Social Knowledge* (London & Thousand Oaks: SAGE, 1995) at 47.

⁴³⁵ M Hardey, “Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise” (1999) 21:6 *Social Health Illn* 820.

contributions, and not shared more inclusively with trusted others, despite their obvious interest and participation in the health concerns of the patient.

The complex issues that colour triadic interactions of physicians with patients and families, along with the requisite skills to successfully engage with them, were amply illustrated by the stories the participants shared. Emphatic listening was highly valued, as was the recognition of the needs of the family themselves for information and support during emotionally stressful times.

CHAPTER 5: Research Findings II – Patient Autonomy and Privacy

Introduction

In the previous chapter I discussed the research findings that illustrated aspects of simultaneous, triadic interactions between the participants, their patients, and the patients' family members. Bioethical and legal rules governing the obtaining of informed consent do not require physicians to consult family members if the patient is competent, but it is easy to imagine why their presence and participation during discussions will impact the nature (and possibly the outcome) of the proceedings. It may be argued that, if autonomy is viewed in relational terms, the supportive input of family or loved ones could, in fact, enhance a patient's decisional confidence, which in turn contributes to their ability to act autonomously. Given that informed consent doctrines demand that an individual's choice should be free and unfettered, inclusion of another party's influence may cause some anxiety to the physician.⁴³⁶ Triadic clinical encounters might, therefore, be particularly stressful to those physicians who believe that autonomy should be viewed strictly in terms of an individual's independent expression.

A key objective of my research is understanding participants' experiences of impacts on patient autonomy caused by the presence of family members during clinical consent encounters. It is for this reason that I have chosen to present my analysis of autonomy-related data in this separate chapter. Descriptions of the participants' active responses to perceived threats to their patient's independence, posed by the input of family members, are also contained herein.

I start by explaining the usage of the expressions 'patient autonomy' and 'patient independence.' Variations in the philosophical definitions of 'personal autonomy' have unfortunately made it difficult to reach a consensus on how the principle of 'patient autonomy' in healthcare ethics and law ought to be interpreted and applied in clinical

⁴³⁶ SD Mallery, B Gert & CM Culver, "Family Coercion and Valid Consent" (1986) 7:2 *Theor Med Bioeth* 123; Blustein, *supra* note 200; O'Donovan & Gilbar, *supra* note 285; S Petronio et al. "Family and Friends as Healthcare Advocates: Dilemmas of Confidentiality and Privacy" (2004) 21:1 *J Soc Pers Relatsh* 33; Gilbar, *supra* note 279.

practice.⁴³⁷ Autonomy is variously construed as a right or a value or both, and several authorities consider its overly individualistic interpretation in healthcare to be a social constraint arguably surmountable by conceiving of it relationally.⁴³⁸ Although the expressions ‘patient’s autonomy’ and ‘patient’s independence’ appear to have been used interchangeably by the participants in the narratives, they are clearly not synonymous; further, I believe that all participants were aware of the key differences between the two. In my analysis of the research findings I have therefore tried to apply these words in a manner that best represents my understanding of their use by the participants.

My discussion of the findings is organized under five subthemes. The first, titled ‘Recognizing Cultural and Language Factors in Truth-Telling,’ provides examples of interactions where the participants perceived that language and cultural factors interfered with the patient’s ability to act autonomously. Within the second subtheme, ‘Navigating the Challenge of Patients’ Waiver of Privacy and the Right to Decide,’ I analyze situations where the participants encountered patients who chose to waive their right to make independent decisions, deferring instead to their family members. Next I present a description of the participants’ responses to situations where family members tended to dominate the decision-making process, under a subtheme titled, ‘Facing Undue Influences of Family Members.’ Following this is a section that emerged from analysis of stories where the participants found themselves obliged to respect certain choices of their patients that were contrary to either to medical advice or the wishes of the family, or both (‘Respecting Autonomous Patient Choice against Family’s Wishes’). Finally, under a subtheme titled ‘Manoeuvring to Protect Patient Autonomy,’ I analyze a few examples where the participants found it necessary to actively manipulate the tone and dynamic of the triadic interaction, in order to protect their patient’s independence.

⁴³⁷ Tauber, *supra* note 53; AI Tauber, *Patient Autonomy and the Ethics of Responsibility*, 1st ed (Cambridge: The MIT Press, 2005); Stirrat & Gill, *supra* note 32; GM Stirrat et al. “Medical Ethics and Law for Doctors of Tomorrow: The 1998 Consensus Statement Updated” (2010) 36:1 J Med Ethics 55; Gilbar, *supra* note 279.

⁴³⁸ Christman, *supra* note 77; K Atkins, “Autonomy and Autonomy Competencies: A Practical and Relational Approach” (2006) 7:4 Nurs Philos 205; Downie & Llewellyn, *supra* note 107; C Mackenzie, “Relational Autonomy, Normative Authority and Perfectionism” (2008) 39:4 J Soc Philos 512; Nedelsky, *supra* note 33 at 1.

5.1 – Superordinate Theme: Struggling to Protect Patient Autonomy

The subthemes presented in this section are:

- Recognizing Cultural and Language Factors in Truth-Telling;
- Navigating the Challenge of Patients’ Waiver of Privacy and the Right to Decide;
- Facing Undue Influences of Family Members;
- Respecting Autonomous Patient Choice against Family’s Wishes; and
- Manoeuvring to Protect Patient Autonomy.

5.1.1 – Recognizing Cultural and Language Factors in Truth-Telling

Some patients depended entirely on English-speaking family members to communicate their consent, which raised concerns about the level of their comprehension of the issues involved. Vic 07, who has had much experience in working with Asian families in an emergency room setting, provided an illustration:

Yeah, we have the East Indian and Asian populations here that come through a lot. Sometimes it depends on — sometimes there can be a communication barrier, so sometimes, for instance with slightly older patients, I’m doing everything through the children who sometimes speak better English, so sometimes they come in with lists of things or problems — I don’t know if it is their own notes or parents’ notes or what, so that happens a lot.

Let’s say maybe somebody’s blood pressure is markedly elevated or something and I am discussing with them that I think that they probably should start on medicine. Sometimes older people will say, “Oh no, I don’t want medication, I’ll just leave it alone,” but then their children will be present and they will say, “No mom, no dad, this is good for you, you really need to do this, you should do it,” so they will convince the parent to do it and then I’ll write the prescription and give it to them. So that happens frequently.

Vic 07 described triads where the English-speaking family members functioned as *de facto* proxies for older patients because of language difficulties. He was willing to accept a competent older patient’s assent to the children’s cajoling as being indicative of voluntary consent. Although the final outcome was the patient’s compliance with his recommendations, the interaction likely represented much more than a matter of success at translation — it possibly stood as an example of a cultural phenomenon in which an

individual rejects an allopathic medical practitioner's advice because they have a different explanation for their illness.⁴³⁹ The story also highlights the risk to a patient's autonomy that can arise from their inability to communicate in the language of the healthcare professional, and where the resultant dependence on family members for translation allows the latter to control the dialogue with the physician.⁴⁴⁰ Vic 07 appeared willing to believe that closely-knit families can be trusted to articulate the patient's values and choices, even though the evidence for the patient's independence was ambiguous.

Vic 02 reflected on a similar situation where he found it necessary to ensure that a non-English speaking older female patient from a non-Western culture had at least a basic understanding of her medical condition before proceeding. He was determined to ensure her comprehension because, although he could not understand their communications in Punjabi, he was able to sense that the family members were exceedingly "pushy" and coercive. He concluded that the family's concern about the patient's possible reaction to details about her illness and its treatment underlay their refusal of the services of a professional translator. The amount of effort that it took for him to convince them that the patient should be reasonably informed further suggested their intention to exert control over the dialogue:

The particular episode that was challenging was someone that was an elderly woman with lymphoma and primarily only speaks Sikh [sic]. And the family members were actually exceedingly pushy for her to get chemotherapy, even though she was well into her 80's and was quite sick and frail, and they declined the option of using a professional translator, 'cause obviously part of it is they wanted to shield the elderly grandmother from the "bad" news. So it took actually a lot of time getting through the process and making sure that she had a concept of understanding what was going on.

Well it took a lot of discussions, lots of family meetings, so finally we convinced the family members at least to disclose what was going on rather than just saying, "Well you are sick, therefore you need the treatment."

⁴³⁹ Kleinman, *supra* note 287.

⁴⁴⁰ CC Wilson, "Patient Safety and Healthcare Quality: The Case for Language Access" (2013) 1:4 Int J Health Policy Manag 251.

Besides the ethical concerns introduced by the family's communications practices, Vic 02's example differs from the scenario related by Vic 07 because it additionally involved the complex issue of truth-telling in healthcare.⁴⁴¹ Here, the family insisted on pursuing the option of risky treatment for the patient while keeping her in the dark about her condition. Ensuring a modicum of awareness and comprehension (“*at least to disclose what was going on*”) gave the team sufficient confidence to proceed, despite it being evident that her comprehension was suboptimal and her independence was fettered in several ways.

Participants related more stories of families' attempts to shield the patient from the full picture of their medical condition. The next narrative illustrates the hesitation that a patient's children had in revealing the truth of an advanced cancer diagnosis to their parent:

Vic 03: One of the things I have recognized for years in the Chinese-Canadian culture it is said, you know, and it's true from my experience, that children don't tell their parents when they have a final illness or a fatal illness. I think that is so amusing because if that is true, and it seems to be true, those parents who are dying of cancer must have done exactly the same thing for their parents, so when they see the doctor shuffling off with the family members and everyone talking in hushed voices, they know they are dying of cancer because that is what they did for their parents.

So it's not that their parents don't know that they are dying of cancer, it is just they have this accepted pattern of behaviour where the only person that mustn't be told, to whom we mustn't talk about it directly, is the dying person, Everyone else deals with it. So as long as the dying person knows who they are 'cause all the cultural... relationships come into play. So it is not that they don't know, it is just that given their culture — so you can talk about it in way that doesn't upset anyone, knowing that they know they have cancer and they know they are dying, and they are quite happy with it because they know this is their accepted cultural role. I don't have any objection to that.

Now, of course, within our legal system, the legal system objects to that because it implies that that person doesn't have autonomy, but that is nonsense. That person has chosen that role voluntarily because it is within their accepted cultural norms. That person wants to speak out and say,

⁴⁴¹ A Surbone, “Information, Truth, and Communication – For an Interpretation of Truth-Telling Practices throughout the World” (1997) *Ann N Y Acad Sci* 7; PC Hebert et al. “Bioethics for Clinicians: Truth Telling” (1997) 156:2 *Can Med Assoc J* 225; Kuczewski & McCrudden, *supra* note 40; A Surbone, “Persisting Differences in Truth Telling throughout the World” (2004) 12:3 *Support Care Cancer* 143.

“Hold on a minute, everyone out, I’m going to talk to this doctor on my own.” They would do so if they wanted to. If they had their lawyer there, the lawyer might insist on it.

A Chinese-Canadian lawyer might not, but a European-Canadian lawyer might say, “Hold on a minute, my client’s care is being compromised here. He or she is not being allowed to participate in decisions. I want this family out of the room, I want this decision to take place between you and me and my client.” That would be a funny way of practicing medicine — it could happen, I suppose.

Although recognizing the norms of a patient’s culture, Vic 03 asserted that family members’ attempts to conceal bad news from a patient in a clinic environment were a pointless exercise. He felt that, because patients are surely able to sense when bad news is being discussed based the behaviour of their next of kin and the doctor, a patient’s autonomy is surely compromised by not adopting a truth-telling approach. However, Vic 03 also argued that the patient’s conforming to a cultural norm by voluntarily waiving the right to be informed could be read as a demonstration of autonomous behaviour, and hence worthy of respect.

The stories in this section illustrate how language barriers within physician-patient communications threaten the validity of the informed consent obtained, given that comprehension of the nature and risks of a proposed intervention is critical to consent doctrine in law and bioethics. The participants’ illustrations also demonstrate how a patient’s autonomy can be further undermined when a family’s practice, for cultural reasons or otherwise, involve withholding the truth about the seriousness of the illness. The participants demonstrated how sensitized they were to such challenges to patient autonomy, as evidenced by the measures they took to rectify the situation whenever it emerged.

5.1.2 – Navigating the Challenge of Patients’ Waiver of Privacy and the Right to Decide

Observing patients waiving their right to decide and deferring to their family members’ opinions was troublesome for Vic 08, who had expectations that patients should always be encouraged to express their independent choice. He described his response to such situations:

It is harder if the patients won't make the decision when they can — much tougher. You don't always follow the legal right. I mean it should be the wife or spouse first and then the family.

A few times I have had the son or daughter disagree with the spouse and they have been at loggerheads, you know, where the son says — this is not too long ago — son says, you know, “We've got to move Dad back and put him in a nursing home.” And they started this right when I was there and the wife says, “No, no, no, he is fine, I want to take him home.”

The flip side; they can't manage him at home anymore and the son or daughter want them to stay there. I can't discharge them then and I'm stuck in that decision-making mode of I want to send them home, or I want to keep them and get them into a home and they are in a conflict of who makes the decision.

Ultimately, the wife I usually defer to if they are intact, if the patient is not able to make the decision. In this case the patient could make the decision, but it wasn't realistic.

This example illustrates the difficulty that the participant faced with the logistics of arranging for a patient's care, because the patient had passed the decisional responsibility to family members, who were then unable to agree on a common plan. In this case, the patient's own decision would have helped move the process along. The story also demonstrates the frustration felt when working with patients who have the legal capacity to decide, but lack the willingness or confidence to do so.

Besides stories of waiving the right to decide, the participants described situations where mature patients choose to waive their right to privacy by requesting that their family members be present during the interaction:

Vic 07: So if somebody comes in with a mood disorder or I have concern about, you know, their frame of mind or I am about to ask sensitive questions, yeah, those people. Even if the patient says that, “Oh, I'd like mom and dad to come with me” — yeah, sometimes it will happen, they will say, “This is my mom and dad, can they come with me?” And I'll say, “I'd prefer if we just met alone for a few minutes please.”

And some patients get disturbed or thrown off by that, but sometimes I insist because I think I need to get unbiased information from the patient that they may be embarrassed to disclose. Similarly, I think sometimes you wonder is there — not coercion — but intimidation of patients...by the other people

and although they may act like they want their family there, maybe they really don't, but they are feeling pressured by their family or whatever so I think that way if I make the decision and tell them — 'cause sometimes I ask.

For minor (medical conditions)...if patients come in with a cut I'll say, "Do you mind if your mom and dad come in while we do this?" And they will say yes or no or they don't really care, it's a cut. But if they come in because they are depressed or whatever, then in some cases I make the decision so that the patient is not the one having to explain why their mom or dad can't come in or what not. I'll tell the family they have to leave, regardless of what the patient may think they want.

Vic 07 distinguished situations where the presence of the family posed a low risk to the patient's privacy and autonomy from instances where it would be unacceptable to compromise the privacy rights of a patient, especially if it involved mental health. He admitted to overriding mature patients' requests for the family to be present during the consultation whenever he felt that the patient might be doing so under duress. In such situations he would take the responsibility for insisting on privacy, while acknowledging that there are situations where the input of family could be of value.

Vic 06 identified circumstances where he would welcome or permit the presence of family, primarily depending on whether he felt the family could contribute positively to his knowledge of the patient's history:

My default position is that I would like to take an adult patient in, begin the interview, if the family member objects to that with a younger patient where it is a parent, I will often say, "Well, perhaps if you've got something that you feel is important to contribute, you could just allow us to sort of begin as we usually do between doctor and patient, and then I'll come back and we can get you involved." But at times the patient will intervene and say, "No, I want her (or him) present."

I generally then say — if it is clear that the patient needs to have — wants the person there — then I will invite them in. That can lead — and so this can go the opposite way as well where you are talking about a parent who is the patient and the family member may want to come along.

Now with the elderly, there is a very good chance based on my experience that they have a reason for that, and yet my feeling is that the default position on that one should be that I should offer the parent an opportunity to tell their story free of their adult child's presence, unless — again, when

I read that encounter if the parent wants the adult child to come in I may then sort of — and this has sometimes taken place in a crowded waiting room in front of an audience — and so I may ask them to sort of come in the examining area and we'll have a negotiation around, "Do you feel that there is something that your mom or dad isn't able to tell me that you feel you need to be present?"

But most often I think I'm skilled enough to tell fairly early on in an interview if a patient is not able to provide me with accurate information and, you know, in emergency medicine we do value collateral history, especially in dealing with patients for whom, you know, insight/competence/ability to make decisions may be compromised.

As commented on in the previous chapter, the above story is another instance of the participant harnessing the input of the family only as an information source, rather than for their role as emotional or decisional supports for the patient. In all the scenarios Vic 06 mentioned, he demonstrated authority to control the composition of participants in the triad, based both on his assessment of their value as an information source and the risk they posed to patient privacy and independent expression. He had firm ideas about the role of the family in the interaction, and kept the focus on the patient's ability to decide the level of family involvement in each case.

Vic 08 discussed situations where there is a medically knowledgeable third person present, and how that poses a risk of inadvertently sidelining the patient from the discussions. In such circumstances he ensures that the patient is sufficiently engaged, especially if it appears that they might make an uninformed choice when deferring to a relative with the better understanding of the medical facts:

The hardest part for me has been making sure the patient stays connected. When that happens, the medical person — relative — the hardest part for me is making sure I don't ignore the patient if the patient is ultimately the one that makes that decision and needs to know and everything else. The problem is they will sometimes defer to the relative.

Whether a family member can always act as an ally for the patient is unpredictable, as shown in the next story that Vic 08 recalled. Here the patient was a young adult male with epilepsy, who was examined in the ER soon after a seizure that had probably occurred due to non-compliance with anti-epileptic therapy. His mother was present during the

interaction and a question arose about whether he had been driving his work vehicle despite having stopped his medications:

I said, “You know, he is not connecting the dots. He first told me this and then that, then he told me this, and you say he isn’t taking anything and he says he is okay, I don’t think he is that okay, I really think he should stay here.”

And she said no and of course he pulled his stuff and left, and the grounds to hold him were pretty narrow. The mother was an ally to him, but she wasn’t — I would have loved for her to have said — and maybe I should have got her aside, but she just showed up and I didn’t get a chance to talk to her beforehand.

I would have loved her to have said, “No, son, I think you should stay and listen to the doctor.” But, she took him home and was willing to take him so she was compliant with him, so I don’t know what was going on there. Living with mother at age 35 is worrisome [both chuckle]. That part I worried about too. And he was self-employed.

The scenario illustrates the result of the participant not being able to engage satisfactorily with family members, resulting in him losing the opportunity to offer counselling about the patient’s well-being, even though the latter was a competent adult. There was also a public safety and legal concern that involved the obligation of the physician to report that an untreated epileptic patient still held a valid license to drive for work purposes.

The stories in this section demonstrate the participants’ commitment to ensuring that their patients exerted the right to make their own choices, even where the patients had explicitly welcomed family participation in the interaction. Participants ensured that patients were fully engaged with the decision-making process and were apprehensive of any family input that tended to suppress the patient’s voice. The phenomenon of what the participants considered excessive influences of family is further explored in the next section.

5.1.3 – Facing Undue Influences of Family Members

Participants described their experiences in working with families where a spouse or family member would interrupt or dominate the discussion to such an extent that the

physician found it necessary to take measures to ensure the patient was able to make an independent choice:

Vic 08: I have done it a few times where I have walked in and there is a woman there who is there who can speak and is aware and awake and I am trying to get a history and he is answering me — it really worries me. I ask her the question and he responds. Then I stop him and I say, “I really get a better idea of the history if I can get it from the patient.” And then if he pushes, I’ll get them out of the room.

And it depends on the problem. You know, for example, if it is a gynae problem I usually try and get the husband out of the room ‘cause I’m not going to find out — it is so personal that some people — it depends on the patient, but sometimes they don’t want to share it with anybody, let alone their husband, they don’t want to talk about it — I’ll sometimes get them out of the room then.

But sometimes not and it is a bit worrisome when the spouse answers all the questions. You wonder about, as you said, is he beating her? Is that what is going on here? A couple of men who insisted to stay during the pelvic exam — then I knew, the flags all went up.

Wouldn’t leave the room for the pelvic exam. He said, “This is not right.” Even in our society there is not...something wrong here. So now I kind of put my foot down and say, “No, you can’t do this and dah, dah, dah.” And then I get to talk to the woman and it is kind of a chit-chat way, I’m doing the exam and she is a bit nervous, and then I get to ask a few questions. That’s a dangerous — yeah, that’s a dangerous flag when he won’t leave the room.

I had it once recently too with a son with a father and I thought there was a bit of abuse going on. The father was with it and I got the son out of the area somehow, I can’t remember how I maneuvered it, ‘cause the nurse too was suspicious. You know, “Jesus, what is going on here? Is something else happening here?” Why don’t we get him out of here somehow — send him to the parking lot or send him for food or something so that I could talk to the guy.

Nothing was happening — at least nothing he owned up to — but people who speak for you sometimes don’t speak for you [chuckle], right.

The participant easily identified and dealt with the problem caused by the dominant behaviour of the spouse and parent in the scenarios described; however, it requires significant clinical experience to identify less blatant encroachments on the independence

of a patient. Vic 06 described his approach to engaging with family members without any prior knowledge of the dynamics of the family. He first ‘diagnoses’ the situation, to discover whether the patient truly agrees to or appreciates the family member’s presence. If he is unable to determine that immediately, he remains wary about the patient’s autonomy being suppressed during the interaction, while recognizing that family dynamics are variable and nuanced. He felt that if the patient has the capacity to be autonomous, they are able to consent voluntarily to include their parent in the discussion:

Often I haven’t had a chance to study the interaction between these family members prior to this moment. Let’s start with the situation of the adult child whose parent wants to be part of this interview. There are two — well I guess there are three potential answers to the question — Do they want them in there? Do they not want them in there? Or, I can’t tell, I haven’t got clue, but I’m looking for some assessment of that decision early on in terms of how I am going to play this and then you are also trying to read the parent in terms of what sense do I get between this interaction.

Is this an overbearing parent who is going to have the potential to overrun even a grown child’s attempts at autonomy in this situation based on how their relationship as a family has grown over the years? So, I’ve been in that situation where I have thought — you know, like I usually sort of say to the adult child or to the adult with an adult child wanting to come in — “How do you feel? Would you like him or her to be there?”

Because really this is a person who should be autonomous and be able to make that decision. So now you have to accept in that situation that there could be differing dynamics around what is going to happen, but when they come in then I am sort of in a situation where I am starting with essentially a situation where the patient has granted me verbal consent to take a history in front of a family member.

Vic 06 also describes his approach to dealing with interfering family members in order to protect the privacy of the patient and to promote their independent choice:

And, at the first interruption that someone tries to become an overbearing collateral history-giver — that’s something that I had suspected could have been a problem, now I have identified it in my mind as an issue — I will say, “Excuse me, I am going to ask you to hold on to that, but right now I am conducting an interview with your daughter/son” — whoever has consented to have them in the room.

At the second interruption I'll say, "I'm sorry, I think at this point I'm going to ask that you wait in the waiting area and I'll come and get you when we can sort of have a patient encounter where you are not going to be interrupting us. You know, it's time now that — and sometimes I have warned people a couple of times and they will just sit there and fume.

Other times they have left and come back with both guns drawn and smoking. They are so angry that I should have insisted upon some autonomy and to me those are always indications that this is a challenged family relationship. But those sociological features are huge determinants of health, so it is important information.

Vic 06's description of the action he takes with an 'interfering' family member demonstrates his ability to maintain control of the exchange by exerting his authority as a physician. The sequence also reveals the way parties who engage in this manner within a healthcare environment unquestioningly accept physician authority over group interactions, even when a competent patient consents to the involvement of family. The participant's justification for his action, which in this case caused some conflict, appears to stem from the medical-ethical moral principle that privileges an individualistic formulation of patient autonomy. Such justification may arguably be supported by an interpretation of the law governing medical consent that views it as creating discretionary powers for physicians to include or exclude the input of family members during consent processes.⁴⁴²

Threats to the autonomy of a patient also came from other sources, such as co-religionists and family members professing a particular faith, as described by Vic 02:

You know, for example, the very interesting dynamic is the Jehovah Witness...usually the patient is — ambivalent about the refusal of blood products, so not an outright no, but not an outright yes, sort of sitting in the

⁴⁴² See for example, British Columbia's *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, in particular s8(b) and the inclusion of the expression 'may allow': s7 When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands (a) the information given by the health care provider under section 6 (e), and (b) that the information applies to the situation of the adult for whom the health care is proposed. s8 When seeking an adult's consent to health care or deciding whether an adult is incapable of giving, refusing or revoking consent, a health care provider (a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and (b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.

middle. But at the end of the day they often have a strong proponent, whether that could be the spouse, it could be the family members that say, “Well you shouldn’t do that,” or they usually bring in someone from the church as the advocate to make sure the patient will actually adhere to the principles of the religion, right?

So in a lot of these types of cases I would ask the patient “I want to have a private meeting just between you and I, and then we can decide what would you like me to do in the greater scheme of things.” But a lot of time they don’t really want to do that [chuckle]. I think there is a lot of peer pressure and social pressure in these types of circumstances, so I don’t press very hard for it, but I do see people that regret the decision that they make.

I mean most of the time you can call it an opinion, right, because if the patient says no, what am I going to say — yes? So you get on with that. Or the patient will come in and say, “Well I was with the Jehovah Witness, but now I have this acute illness, I want to get blood transfusion.” So that’s easy, so they’ve internally sorted out the dilemma, right.

The scenario above presents an iconic and recurring dilemma that physicians encounter: where ethical concerns about patient autonomy conflict with the bioethical principle of beneficence, complicated in this case by unique socio-cultural and healthcare implications of a specific religion’s dictates.⁴⁴³ The practical measures that should be adopted by healthcare professionals to navigate such challenges, being inherently contextual, remain a topic of ongoing debate, despite having been addressed in healthcare discourses for several decades.⁴⁴⁴

Similarly, other participants sometimes wondered if the family is able to fully appreciate the best interests of the patient. Vic 05 provided an example of such a situation in an intensive care setting, where medical — and nursing professionals recognized that a patient’s wishes were being ignored or reversed:

I hear this said a lot — is that the patient probably doesn’t want what we are doing to them, but the family wants them. And I’m only vaguely aware of this research idea that individuals would choose certain interventions or aggressive interventions for their loved ones that they wouldn’t necessarily choose for themselves under the same circumstances.

⁴⁴³ Gillon *supra* note 256.

⁴⁴⁴ Gilbar, *supra* note 279; M Sjöstrand et al. “Paternalism in the Name of Autonomy” (2013) 38:6 J Med Philos 710.

Vic 05 reported that professionals working in intensive care environments do recognize when family surrogates choose treatment options that they themselves — let alone the patient — would find unacceptable. Notably, professionals who work in healthcare fields that necessitate close and frequent interactions with patients and families regarding critical medical decisions, become very familiar with the patterns of responses of families to the complex ethical dilemmas involved.

From the illustrations cited in this section it is clear that in most instances, the participants managed to retain overall control of the conversations whenever patient autonomy was threatened by particularly strong influences of family members. There were, however, some circumstances where their ability to temper the ‘undue’ influence of family was hampered by inability to overrule religious obligations, despite the obvious detriments to the patient’s safety and well-being.

5.1.4 – Respecting Autonomous Patient Choice against Family’s Wishes

The participants discussed several instances where patients chose to conceal the full details of their illness from members of the family. Vic 07 described one such situation, wherein he felt inclined to inform the family of a terminally ill patient about the patient’s true condition. In so doing, he was aware that he was manipulating the decision-making process:

There are also situations where personally you think the family should know something that maybe the patient doesn’t want the family to know, so there is sometimes a conflict about that, about whether a patient may be dying and you’ve told the patient that, and they are competent and they have family there and maybe they are withholding information from the family or the family don’t quite understand exactly how serious things are, so that is a tough time, especially to decide what to reveal to patients’ families or to discuss...that’s a tough one.

It really depends and I think — and then sometimes, you know, we justify things to ourselves as physicians and say, “Oh, this patient is clearly ill and they are delirious right now.” So convincing ourselves that they are incompetent or don’t understand, so that we can either talk to family more or give people more information sometimes. So sometimes, you know, I think — yeah. I mean not very often.

I can think of those situations where patients — but I feel like I am almost imposing my own values, but if I think they've got a day to live and they are telling their family that everything is fine, then sometimes I convince myself that this patient really doesn't understand — I'm telling myself they don't understand, they must be incompetent, so I should inform this family what is really going on here.

Vic 07 found it difficult to accept that a patient facing imminent death would want to conceal the seriousness of their condition from family members, but also realized that he was at risk of applying his personal values to the situation. Yet he believed that it was important enough to breach a legal and ethical principle (of respecting a competent patient's wishes, along with privacy legislation) by creating a fiction in his mind that positioned the patient as being cognitively impaired to the level of actual incompetence.

The participants described other examples where respecting a patient's autonomous choice was particularly difficult because it did not make sense or went against the family's wishes:

Vic 01: The other area of concern is Seventh Day Adventists and I have been in that situation where people do need to have blood and I will get other people in the room to discuss this and I usually lose, but they have to sign their consents that they don't want blood even though they deserve it. And I have had one that went on to die. I did the surgery, didn't have blood, and then 10 days later died. Yeah.

Very difficult, very difficult. What happens is they can be saved by just giving blood, blood-products and choose — I think it was a man — he was very obstinate.

In this setting of informed refusal, the participant would be expected to proceed with the surgery under conditions of increased risk and compromised safety, in order to respect the autonomous choice of an informed patient. The participant usually recruits the family's input ostensibly to help reverse the patient's decision, but this seldom changes things. The degree of his disappointment is evident in his use of the description, "I usually lose," as well as his sense of regret that a life was lost because of inability to offer a simple transfusion of blood.

In the stories included in this section, the participants were called upon to respond to situations where, from a medical perspective, the patient did not appear to be making

logical or reasonable choices. Such decisions were disappointing to the participants, but nevertheless, in each instance they honoured the patient's right to make them.

5.1.5 – Manoeuvring to Protect Patient Autonomy

The participants occasionally found it necessary to use novel interactive manoeuvres to protect their patient's independence during triadic encounters:

Van 01: I use little strategies like I speak so very clearly at the patient and I ask of the patient very direct questions so that I get, you know, you can almost visually or by your attention almost exclude the partner.

And then I give the partner some time as well to have their say and have a direct interaction, so I try and split it up in a situation like that so that I'm having a conversation with them separately, not together, even though generally speaking I would ordinarily have a conversation with both of them and look back and forth. That's a tactic that I use if I find there is a domineering — the patient has a domineering partner or family member — so that's just a strategy.

Van 01's approach to a domineering family member's interference in the conversation is significantly different from that of Vic 06's, described on page 166, although in both cases the priority was to ensure that the patient was able to make an independent decision. Here, she was able to continue within the triadic dynamic while ensuring that she could hear the patient's voice sufficiently without having to ask the family member to leave the room. Both these scenarios occurred in an office setting, for a non-urgent decision. The situation may be different in emergency settings, as in the next story.

Vic 07 commented that my interviewing him provided an opportunity to reflect, for the first time, on his experiences engaging with patients in the presence of family members in an ER setting:

Most of the procedures we do in Emergency are what I would consider necessary and so usually I involve the family at the same time, unless the patient has objected and they have asked them to step out.

Most of them are in the room when I have discussions around consent. And they do — now that I think about it — there are points where they maybe interfere — well they add to the process or they interject, you know, even

though the patient on their own is fully competent. You know, they add comments or they try to allay their anxiety.

The patient may be anxious about what I am suggesting, and they try to interfere, so I wonder — I have never thought about it until this point — I wonder if they are interfering with patient autonomy. That's the first I have thought of that.

Vic 07 felt that these different forms of family input (interferences, interjections, and comments) represent attempts to allay their own anxieties. He also described a reverse situation, where he suspected that pressure from relatives was in play, although the patient gave the impression that they were comfortable with family being present. At times, when he sensed that there was undue influence of the third party in the triad, he resorted to a few conversational and physical manoeuvres to rebalance the discussion:

I've had family that have stressed and pushed me, but often times it is with the agreement of the patient. Like I'll have a patient that I have seen and assessed and I'm starting investigations or treatment for something or other and you will have family that are really pushing you and things, but the patient is sometimes just sitting there quite passively.

Like the last time I remember was just a lady who was 60-65 and her two children were there in their 30's and I can't remember what the particular problem was, but I was investigating her and then starting some treatment and she was stable and it wasn't any real critical situation, but some family are very vocal and aggressive and, you know, "What's going on? Could it be this?" "Are we doing this?" And you just wonder if the family understand or they really get it, you know. But the patient is just sitting there relatively passively.

I think I always try to go back to the patient — you know, the patient is sitting there, we are all sitting there in the one room and say — well...and I almost try to stand — I almost position myself next to the patient and say, "This is what is going on with your mom and this is what we are doing and she is okay now."

It is just psychologically trying to calm those people down and explain to them what is happening 'cause most of them don't have medical training, they don't understand. I mean Emergency is a foreign environment. You know, they watch things on TV, they think everybody is supposed to have an MRI of their brain and all these things and, you know, you are trying to explain these things.

But luckily if the patient is onboard with you as the physician, it makes it a little bit easier to deal with those guys, I think.

In his practice as an ER physician, Vic 07 is often confronted with large accompanying families, and finds it necessary to isolate the patient in order to allow space for a private conversation:

We have to remove those distractions sometimes. There are some times when it is clear that they need somebody with them or they should have somebody with them, or that it doesn't matter, but there are other times when it is clear that you need to clear the room and just be one on one with the patient. Yeah.

We have what we call an ambulatory area in our emergency room, it's almost like a waiting room, and the physician, me the doctor, will actually have to go and actually get the patient from that sitting area and bring them to an examination room to do a history and physical and sometimes you will say, "Okay, you know, Joe come on with me." And then five people will stand up and all follow Joe and then so even at that point sometimes, you know, you are saying, "Okay, you guys just wait here. Me and Joe are going to go."

And some people get offended by that. Some family or friends get offended that they are being asked, but usually it works out okay, you know. Especially with adolescents. I find a lot of teenagers — obviously parents look a little bit disturbed that you are going to talk to their teenager without them, so that's an issue sometimes.

Here, the participant refers to his ability to sense when the patient needs to have an accompanying family member present during the consultation, and when privacy is a priority. He recognized that his insistence on isolating the patient during the clinical interaction risked upsetting those family members who expected to participate.

Vic 07 made no mention of whether he thought it was necessary to seek the patient's agreement to being isolated from their family — an issue which another ER physician-participant did reflect upon:

Vic 06: One of the most common scenarios I encounter is the expectation of a parent to accompany an adult child into an interview in the same way that they have become accustomed to acting when their children were younger, but are now really, in my view, interfering or influencing the patient's autonomy.

I may come upon that situation in a couple of different ways. One is in which I enter into a room or a stretcher bay to begin my interaction with the patient and a parent or other family member is present, so in that case I may need to actively ask that person to leave, or alternatively I may be actually going to get the patient from a waiting room, in which case I find it generally a little easier in that I ask for the patient by name, they stand up, I say “Could you please come this way” and then the family member begins to follow us as if their expectation is that they will be a part of this patient encounter. In which case I usually sort of say, “Could I please ask for you to have a seat in the waiting area and we’ll let you know how things are going?”

And it is not unusual for the person to object to that and to feel that there is a need to accompany the patient and then it is an interesting — a couple of interesting things happen — one of which is you really need to then begin to use your experience in reading the interaction between these two family members in determining how this thing is going to go.

Vic 06 explained his approach to making judgments about the relational dynamics between the patient and family, and the advisability or acceptability of family involvement. He also explained how he tailored his conversations accordingly. Vic 06 has encountered parental concern and the desire to be involved in medical decision-making even with mature children. Although he understood the reasons for this concern, his preference was to create the opportunity for a private discussion — free of interferences, no matter how well-intentioned.

Participant Vic 03 felt that the issue of family members’ participation in discussions was not a complicated matter — he would simply request that the patient make the call about whether to have a third party present. Yet he also said that he would “*take responsibility*” for navigating any challenges if he felt that that party was exerting undue influence on the patient. What became evident from my conversations with all of the participants was the general assumption that physicians held the authority to decide whether a patient was likely to benefit from the participation of family, and had the power to control the dynamics of the interaction. The ability to control who participated in triads even appeared to extend to situations where the patient indicated some dependence on family members for support, either from explicit requests to be accompanied, or from the participant’s reading of the overall family dynamic.

Even in triadic interactions with parents of paediatric patients, Van 01 described how she takes active measures to ensure that the children are given the opportunity to express themselves independently:

I have conversations with the children and not just the parent and I go back and forth so that I, you know, even if I've got a nine year old who is, you know, going to have an operation I will make sure that the child has a chance to ask questions and that I'm engaging and not just talking with the parent, but I'm engaging with the child too.

And then in that situation sometimes I'll just talk to both. I can think of another situation I had not that long ago, about a year ago now, with a child in school who had a pilonidal... chronic pilonidal, and the general surgeon asked me to help to do a flap. And, you know, I just think it is so absolutely imperative to, you know, in that situation it was easy to go back and forth between them so that I am looking and talking to the other and look back and forth and engage both of them together, but it is very much dependent on the dynamic between the two and sometimes the parent forgets that the child needs to have a little bit of participation in the process as well.

Van 01's practice demonstrates recognition of the right of minors to be informed, and to be allowed an opportunity to express themselves despite their legal incapacity to consent and their obvious dependence on their parents. Her approach reveals an understanding of patient autonomy as being a value and a right, and aligns with current beliefs about the importance of facilitating direct participation by minors during medical encounters.⁴⁴⁵

The stories recorded in this section illustrate the various interactive skills and techniques applied by the participants to promote or protect their patients' autonomy and independence whenever the input of family members puts these rights at risk. Their reflections also display the extent to which physicians exert protective authority over their patients' independence even when patients have requested or consented to their families' participation.

⁴⁴⁵ AM van Dulmen, "Children's Contributions to Pediatric Outpatient Encounters" (1998) 102:3 Pediatrics 563; J Bridges et al. "Ethical Relationships in Paediatric Emergency Medicine: Moving beyond the Dyad" (2001) 13:3 Emerg Med 344; K Tate & L Meeuwesen, "Doctor-Parent-Child Communication. A (Re)View of the Literature" (2001) 52:6 Soc Sci Med 839; K Tate et al. "Doctor-Parent-Child Relationships: A 'Pas De Trois'" (2002) 48:1 Patient Educ Couns 5; Greene & Adelman, *supra* note 280.

Conclusion

The participants described a range of situations in which the presence of family in triadic interactions threatened the privacy and autonomy of their patients. In my report, these situations were grouped under five subthemes. I first discussed the findings related to the subtheme of culture, language and truth-telling, which was followed by a description of situations where patients waived their privacy and decisional rights. Next was a discussion about the undue influences of family members, followed by a report about situations where the participants found themselves needing to respect their patients' autonomous decisions when those decisions went against their families' wishes. Finally, I presented the analysis of the strategies and manoeuvres taken by the participants to protect their patients' autonomy.

My discussions with the participants were not aimed at directly exploring their theoretical understanding and interpretation of patient autonomy. In the context of clinical interactions, however, they seemed to equate real or potential interferences in their patients' independence or privacy with encroachments on their 'autonomy.' They thus appeared to take protective measures almost instinctively to safeguard the dyadic physician-patient space so as to protect their patients' interests, even when the latter welcomed the presence of family members.

A variety of socio-cultural, religious, linguistic, or behavioural factors contributed to the sense that patients' independence was being threatened. The participants have come to expect such challenges routinely, given the increasing cultural diversity of the communities that they serve. Additionally, a better-informed public with ready access to a vast amount of medical information via the Internet has redressed knowledge imbalances between medical professionals and laypersons. As would be expected, the result is improvement in the capacity (and with that, the inclination) of family members to contribute to the medical decision-making process.⁴⁴⁶

Whether or not the participants attempted to curtail or moderate the influences of family during triadic encounters depended on a few factors. One of them seemed to be the strength of their belief that all competent patients should be free to make autonomous

⁴⁴⁶ Gilbar, *supra* note 279; Andrades, Kausar & Ambreen, *supra* note 158.

decisions, and that the presence of other persons should not compromise this freedom. Another factor was the general shift in the approach to medical decision-making towards embracing the concept of ‘patient empowerment.’ It is thus of value to view the ethical and legal conundrums related to autonomy, illustrated in this chapter, in light of the rebalancing of power between healthcare professionals and the public that has taken place over the last three decades.

The rejection of physician paternalism and the recognition of the positive benefits of patient participation in medical decisions has spawned the practice of shared decision-making (SDM) in healthcare.⁴⁴⁷ While laudable in its intentions, the application of SDM, which implies greater collaboration between healthcare providers and patients and their families, has had limited success. Patients continue to depend on physicians to interpret the complex medical information they have ready access to. Many patients, particularly those belonging to the generations that traditionally deferred to medical professionals, hesitate to express their treatment preferences to physicians.⁴⁴⁸ Moreover, structural limitations of public healthcare systems, which are often associated with long wait-lists and restricted access to specialist care, may further undermine the prospects of genuine and equitable sharing of responsibility for medical decisions.

As with other areas of social research, it is hazardous and essentialist to ascribe some of the difficulties encountered in the family interactions to the influence of ‘culture’ alone. Empirical research clearly confirms that within every medical encounter, particularly if family and close others are involved, one can expect additional and plural factors (such as socioeconomic and education) to be relevant.⁴⁴⁹

In several cases, language difficulties and the dependence on family members for translation raised well-recognized concerns about whether a patient’s decision-making can

⁴⁴⁷ Barry & Edgman-Levitan, *supra* note 48.

⁴⁴⁸ JR Adams et al., “Communicating with Physicians about Medical Decisions: A Reluctance to Disagree” (2012) 172:15 *Arch Intern Med* 1184; DL Frosch et al. “Authoritarian Physicians and Patients’ Fear of being Labeled ‘Difficult’ among Key Obstacles to Shared Decision Making” (2012) 31:5 *Health Aff (Millwood)* 1030; A Ackerman, R Auer & R Gonzales, “Cultural Capital: Accounting for Power in Patient-Physician Interactions” (2013) 173:5 *JAMA Intern Med* 393.

⁴⁴⁹ J Hamann et al., “How Do Patients from Eastern and Western Germany Compare with regard to Their Preferences for Shared Decision Making?” (2012) 22:4 *Eur J Public Health* 469; MD Fetters et al. “The Family in Medical Decision Making: Japanese Perspectives” (1998) 9:2 *J Clin Ethics* 132; Ito, Tanida & Turale, *supra* note 290; C Ng et al., “An Overview of Patient Involvement in Healthcare Decision-Making: A Situational Analysis of the Malaysian Context” (2013) 13:1 *BMC Health Serv Res* 408.

indeed be independent under such circumstances.⁴⁵⁰ Participants identified a further phenomenon of ethical significance that can arise from the practice of families concealing the truth from patients. In the context of triadic interactions, this is only possible when patients do not speak the physician's language. Additional complexity was seen to arise when truth-telling was not accepted as a practice in particular cultural groups, in which case the participants faced an added dilemma in having to judge whether the values of a healthcare system that promotes such an approach should apply.⁴⁵¹

The participants responded to the phenomenon of competent patients waiving their right to privacy, or to independence in decision-making, by intervening to advocate on their behalf and ensuring they were offered a safe physical or conversational space. It is arguable, however, whether such actions are in effect paternalistic, albeit motivated by the intention of autonomy protection.⁴⁵² In some of the stories discussed, the patients had consented to the presence of their family members and, by implication, their overall contribution to the triadic dialogue. Yet in no instance did the participants acknowledge that they had turned to family members to seek their opinion about possible treatment options for the patient; the contribution of family members was valued only for the additional historical information it offered in relation to making a clinical diagnosis.

The strategies utilized and manoeuvres applied by the participants whenever they felt it was necessary to isolate the patient from the influences of their family members generally achieved their intended purposes — although not all families readily appreciated the reasons for their exclusion from the physician-patient interaction. In all the instances discussed, it was clear that protecting and promoting patient autonomy was a major priority and that the participants retained substantial control over the impact that family members had on the interaction.

⁴⁵⁰ RD Seidelman & YG Bachner, "That I Won't Translate! Experiences of a Family Medical Interpreter in a Multicultural Environment" (2010) 77:4 Mt Sinai J Med J 389; PN Butow et al. "Interpretation in Consultations with Immigrant Patients with Cancer: How Accurate Is It?" (2011) 29:20 J Clin Oncol 2801; C Brisset, Y Leanza & K Laforest, "Working with Interpreters in Healthcare: A Systematic Review and Meta-Ethnography of Qualitative Studies" (2013) 91:2 Patient Educ Couns 131.

⁴⁵¹ Surbone, *supra* note 441; Kuczewski & McCrudden, *supra* note 40.

⁴⁵² Sjöstrand et al, *supra* note 444.

CHAPTER 6: Discussion [A] – Sociological

Introduction

The difficulty in appreciating the legal position of families may arise in a number of situations.⁴⁵³ My research explored the experiences of physicians specializing in high-risk medical fields during their simultaneous interactions with legally competent patients and their families in informed consent discussions. The aim of my project was not to develop generalizable conclusions, but to understand and interpret the participants' experiences more vividly and thoroughly, particularly with regard to the various ethical and legal challenges that can arise with the inclusion of third parties to the interaction.

I present the discussion of my research in two chapters: In this first one I first situate my findings both theoretically and sociologically. In particular, I discuss the various factors that inform participants' attitudes and approaches to working with families in different situations. In the following chapter (Chapter 7), my discussion concentrates on the research findings that illustrate the participants' perceptions of the challenges to their patients' autonomy resulting from the participation of third parties in clinical interactions.

Relevant theoretical considerations of physician-patient relationships (PPRs), discussed earlier in Chapter 2.1, undergird an understanding of the triadic relationship between patients, physicians, and their families — that is, the 'physician-patient-family relationship' (PPFR). Different elements of a healthcare system may also exert an influence on the PPR and PPFR, and hence merit elaboration herein, especially the power relations that inform the experiences and attitude of physicians in their engagement with family members. I also consider a few theoretical influences that shape physicians' perceptions of the family's roles in healthcare interactions, for example the relevant ethico-legal regulatory frameworks or the interactive skills training that physicians are exposed to in the Canadian context. I discuss certain broader historical developments that have impacted aspects of governance of the medical profession in Canada, which may also have a

⁴⁵³ This was illustrated in a 2014 case in Ontario, where a First Nations parent withdrew consent for leukemia chemotherapy treatment for her 11-year old child (that child having been deemed incapable of consenting). The mother – the consent-giving party – opted to remove her daughter from the hospital to seek Indigenous traditional treatment, despite a 90% possibility that chemotherapy would cure her. Her decision was upheld by the Court, which reasoned that her constitutional rights as an Aboriginal person protected her from child apprehension under Ontario's *Children and Family Services Act*, RSO 1990, c. 11 Section 72(1) 5. See: <https://www.ontario.ca/laws/statute/90c11#BK117>. Galloway, *supra* note 23.

significant bearing on the nature and quality of the PPR. This relationship is also influenced, to a degree, by the way the Canadian version of socialized medicine as a public-private partnership indirectly compounds the power imbalances between patient and provider, in part by limiting the public's access to specialist medical services.

6.1 – Physician Relationships with Patients and Family

Although the relevant communications dynamics and the ethico-legal challenges that emerge in triadic or multi-party clinical encounters have been widely explored, there has been much less direct examination of the physicians' perspectives regarding family participation in decision-making processes.⁴⁵⁴ The default PPR model in Western healthcare discourse remains focused individualistically, on the patient herself, whereas there are variations in the types of approaches to such a relationship (as discussed in the Literature Review, Section 2.2.2 iv). For example, ethicist Yali Cong in Beijing proposes a formulation characterized as a 'doctor-family-patient relationship' (DFPR).⁴⁵⁵ This type of arrangement is based on culturally Confucian, family-oriented norms that may arguably become pertinent even in Western, multicultural settings during informed consent processes. Underpinning this relationship structure is an emphasis on the Confucian recognition of the family as an entity existing in its own right, irreducible to the collective interests of its individual members.⁴⁵⁶

Given the current, dominant understanding of the PPR in the Western context of my research, there is very little empirical basis on which to ground an argument for a formal physician-family-patient 'relationship' *per se*. I therefore base the subsequent discussions in terms of *communications* and the dynamics of *interactions* between physicians and their patients' families, rather than *relationships*.

⁴⁵⁴ Barone, Yoels & Clair, *supra* note 295; Lang et al, *supra* note 276; O'Donovan & Gilbar, *supra* note 285; Gilbar, *supra* note 279; Gilbar, *supra* note 285; Waitzkin, *supra* note 293; Coe & Prendergast, *supra* note 293; Adelman, Greene & Charon, *supra* note 280; Botelho, Lue & Fiscella, *supra* note 293; Beisecker & Moore, *supra* note 280; Karnieli-Miller et al, *supra* note 293; Greene & Adelman, *supra* note 280.

⁴⁵⁵ Cong, *supra* note 45.

⁴⁵⁶ Lee, *supra* note 239; Cong, *supra* note 45.

6.1.1 Contextual Background Impacting Physician Views

Four key background elements potentially contributed to the nature and quality of the participants' approach to the families of their patients: the general impact of health systems on PPRs and power differentials; some work-environment features of the Canadian health system; certain aspects of the regulatory framework governing physicians' clinical practices in British Columbia; and factors of the participants' medical education and training that likely contributed to the development of the skills they apply when interacting with patients' families.

6.1.1 (i) – Impact of Health Systems on the Nature of Patient-Physician Relationships & Power Differentials

The structure, organizational culture, and ethos of the healthcare system in which a physician practices are likely to influence the nature and quality of the PPR. For example, empirical research demonstrates that many practice parameters, such as physicians' patterns of patient referrals for clinical investigations or their choice of interventions, are affected by factors such as physician reimbursement.⁴⁵⁷ As the level of trust in medical professionals is a function of several intersecting interpersonal and institutional factors, it is not difficult to imagine how the structures within a healthcare system can impact the interfaces between physicians and their patients and patients' families.⁴⁵⁸ For example, the limited ability to exert choice within a resource-strapped system with long wait times reinforces the power differentials between members of the public and all categories of healthcare professionals.⁴⁵⁹ In the 1990s it was recognized that American patients (then commonly characterized as 'consumers' of healthcare services in a competitive industry) had begun to expect better explanations about their illnesses, more treatment options, and greater ability to choose between those options. Added to this was an active medical

⁴⁵⁷ MA Rodwin, "Strains in the Fiduciary Metaphor: Divided Physician Loyalties and Obligations in a Changing Healthcare System." (1995) 21:2/3 Am J Law Med 241; J Shafrin, "Operating on Commission: Analyzing How Physician Financial Incentives affect Surgery Rates" (2010) 19:5 Health Econ 562; M Neumann et al. "The Impact of Financial Incentives on Physician Empathy: A Study from the Perspective of Patients with Private and Statutory Health Insurance" (2011) 84:2 Patient Educ Couns 208; A García-Prado & P González, "Whom Do Physicians Work For? An Analysis of Dual Practice in the Health Sector" (2011) 36:2 J Health Polit Policy Law 265.

⁴⁵⁸ AC Kao et al. "The Relationship between Method of Physician Payment and Patient Trust" (1998) 280:19 JAMA 1708; Hall et al, *supra* note 50.

⁴⁵⁹ RB Saltman, "Patient Choice and Patient Empowerment in Northern European Health Systems: A Conceptual Framework" (1994) 24:2 Int J Health Serv 201.

malpractice environment. Hence, a change occurred in the qualitative nature of PPRs in the USA's consumer-oriented healthcare market, even as 'quality improvement' and 'clinical governance' movements (largely driven by non-physicians) began to strengthen the external governance of medical professionals.⁴⁶⁰

Viewing the patient merely as a consumer of healthcare obviously has several limiting effects within a critical service industry that is based on care-giving and empathy in the face of human suffering — although arguably, doing so may ultimately promote the agency of the patient.⁴⁶¹ Empirical research demonstrates that the type of financial incentivization of physicians has a bearing on the degree of empathy that they display toward patients and their families.⁴⁶² Insurance coverage that provides higher physician compensation has been shown to allow doctors to spend more time with their patient, while a higher contact time can increase patients' perception of the physician's empathy, both directly as well as by improving their appreciation of medical staff stress.⁴⁶³

Clearly, a variety of structural features of the healthcare system have the propensity to impact the nature and quality of the PPR, not the least of which are the financial arrangements in place for physician compensation, in combination with ease of access to services. In the next section I discuss relevant contextual factors of the healthcare system within which my research participants practiced.

6.1.1 (ii) – The Canadian Healthcare System and the Participants' Practice Environment

As my research was conducted in the context of Canada's healthcare system, I make epistemological assumptions based on my interpretation of certain systemic factors most likely to impact the PPR in Canadian society generally. In Canada, the ratio of practicing physicians to population is 2.5 per 1,000, which is below the average of 3.1 per 1,000 for Organization for Economic Co-operation and Development (OECD) countries.⁴⁶⁴

⁴⁶⁰ V Harpwood, *Medicine, Malpractice and Misapprehensions* (New York: Routledge-Cavendish, 2007) at 69-71.

⁴⁶¹ K Rowe & K Moodley, "Patients as Consumers of Healthcare in South Africa: The Ethical and Legal Implications" (2013) 14:1 BMC Med Ethics 15.

⁴⁶² Neumann et al, *supra* note 457.

⁴⁶³ *Ibid.*

⁴⁶⁴ By comparison, the ratios (physicians per 1000 persons) for other countries are: USA 2.5, United Kingdom 2.8, Germany 4.0, Russian Federation 4.9, France 3.3, India 0.7, Brazil 1.8, Italy 4.1. Organisation for Economic Co-operation and Development. "Doctors," *OECD Data* (2016) online: <https://data.oecd.org/healthres/doctors.htm> (accessed 2 March 2017).

Resource limits structure the public's access to services, as well as many of their choices. Although a recent Angus Reid Public Opinion poll indicated that 71% of British Columbians expressed confidence in the healthcare system in general, a quarter of persons identified long wait times as a 'major problem.'⁴⁶⁵ Canadians have indicated their dissatisfaction with the amount of time it takes to see a general practitioner or to obtain an appointment with a specialist, and the wait times in Canada appear to be amongst the longest in industrialized countries.⁴⁶⁶

Locally, the Island Health Authority of Vancouver Island has confirmed that it does not meet the benchmarks it has set for wait times.⁴⁶⁷ I posit here that long wait times are linked to the likelihood of patient compliance with specialist physicians' recommendations, compared to situations where patients are either able to access treatment outside of the system (for example through 'medical tourism'), or where the ratio of doctors to patients is more favourable. Wait times could thus represent more than an inconvenience or a risk factor for delays in diagnosis and treatment, as they may also contribute to the power differentials that inform physicians' approaches to the PPR, as well as the quality of their engagement with patients' families.⁴⁶⁸

6.1.1.(iii) – Regulatory Influences

The participants in my project were all Canadian-trained specialist physicians practising in British Columbia, and hence subject to legal rules and ethical codes that govern their practices. In addition, they receive practice guidance from national and provincial professional regulatory entities and medical malpractice defence organizations.

⁴⁶⁵ Angus-Reid Public Opinion. "Most British Columbians Express Confidence in Health Care System," *For Immediate Release: British Columbia Public Opinion Poll* (25 April 2013) online: http://angusreidglobal.com/wp-content/uploads/2013/04/2013.04.25_Health_BC.pdf (accessed 2 March 2017).

⁴⁶⁶ HCC, *Where You Live Matters: Canadian Views on Healthcare Quality* (Ottawa: Health Council of Canada, 2013) online: https://secure.cihi.ca/free_products/HCC_CMWF_Bulletin_8_Eng.pdf (accessed 2 March 2017). Patient stories currently trending on Twitter (#CanadaWAITS) detail shocking experiences like a four-and-a-half year wait for a neurology referral, and a northern Ontario town that has been without a local physician for twelve years. See: S. Gandhi, "Politicians Ignored Doctors' Calls To Fix Health Care. Will A Hashtag Convince Them?" *HuffPost Canada: The Blog* (6 November 2017), online: http://www.huffingtonpost.ca/sohail-gandhi/politicians-ignored-doctors-calls-to-fix-health-care-will-they-listen-to-a-hashtag_a_23266755/

⁴⁶⁷ Island Health, *supra* note 431.

⁴⁶⁸ J Newman & E Vidler, "Discriminating Customers, Responsible Patients, Empowered Users: Consumerism and the Modernisation of Healthcare" (2006) 35:2 J Soc Policy 193; Adams et al, *supra* note 448; Ackerman, Auer & Gonzales, *supra* note 448.

In this section I discuss the relevance of official rules and guidelines to the nature of physicians' interactions with patients' families, as I describe the ethico-legal frameworks within which such interactions are conducted.

As discussed in the Introduction of the dissertation (p. 11), the law governing medical consent in British Columbia is the *Health Care (Consent) and Care Facility (Admission) Act*⁴⁶⁹ and the portion where family or close others are mentioned explicitly is Section 8, which states:

When seeking an adult's consent to healthcare or deciding whether an adult is incapable of giving, refusing or revoking consent, a healthcare provider (a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and (b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.

Section 8(b) does not explicitly require physicians to recruit the input of family or close others of the patient for the purpose of considering that input in the consent process.⁴⁷⁰ It appears to offer the healthcare provider the discretion to determine the conditions under which family members may be included in discussions.⁴⁷¹

Section 8(b) explicitly indicates that if the healthcare provider 'allows' the identified persons to participate in consent discussions, their role is limited to translation — helping the adult patient “understand or demonstrate an understanding of” information identified in the previous section (7) of the statute. It is silent on the position of the relative or close friend in terms of their being allowed to participate in the actual decision-making

⁴⁶⁹ How incapability is determined: s7 When deciding whether an adult is incapable of giving, refusing or revoking consent to health care, a health care provider must base the decision on whether or not the adult demonstrates that he or she understands (a) the information given by the health care provider under section 6 (e), and (b) that the information applies to the situation of the adult for whom the health care is proposed. Duty to communicate in appropriate manner: s8 When seeking an adult's consent to health care or deciding whether an adult is incapable of giving, refusing or revoking consent, a health care provider (a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and (b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.

⁴⁷⁰ The clause applies to all health care providers but for the purposes of this discussion I will refer to the 'provider' as a physician.

⁴⁷¹ British Columbia's *Interpretation Act*, RSBC 1996, c 238 confirms in s.29 that in an enactment, the word “may” is to be construed as being permissive and empowering.

process that leads up to the patient giving consent. The ‘information’ referred to in the clause is that which is given by a provider to the patient under section 6(e) of the statute.⁴⁷² Included specifically is information that a reasonable person would need in order to make an informed decision — their medical condition, the nature of the intervention recommended (including its risks and benefits), and what the alternative treatment choices are. Persons identified as potentially allowed to participate in the interaction are those who “accompany the adult and offer their assistance.” There is certainly no obligation placed upon the healthcare provider to inquire if anyone had, in fact, accompanied the patient to the visit. There is also no explicit requirement for the provider to inquire whether the patient prefers that a relative or friend be invited to listen to the medical explanations about the treatment, whether or not they had accompanied the patient.

What section 8(b) seems to create (or reinforce) is a discretionary power that allows physicians to control interactions, privileging privacy and independent decision-making by the individual patient within a physician-patient dyad. The physician is given the discretion to judge whether or not the assistance of family members is needed to support the patient’s comprehension of medical information. The discretionary power created by section 8(b) would appear to apply even if the patient indicated a preference for family member participation in the process. My research findings indicate the difficulty when language barriers complicated communications with the patient during triadic interactions. Whenever this happened the participants experienced first-hand how family members’ voices can become intimately intertwined with the patient’s, making it difficult to identify the genuineness or independence of the consent offered by the patient. In such circumstances the participants remained conscious of unique intra-family dynamics and non-verbal signalling. However, possibly due to the limited time in the clinical setting, they were not always able to ensure that the patient had sufficiently appropriate comprehension, and that decision-making was truly unfettered.

⁴⁷² Section 6 (e): the health care provider gives the adult the information a reasonable person would require to understand the proposed health care and to make a decision, including information about (i) the condition for which the health care is proposed, (ii) the nature of the proposed health care, (iii) the risks and benefits of the proposed health care that a reasonable person would expect to be told about, and (iv) alternative courses of health care.

Besides the law of consent in BC, the practices of the participants in my project were governed by ethical codes and guidelines determined by professional associations, as well as by medical indemnity organizations. The development of medical ethics codes in Canada may be traced to the influence of the British centres of medical education in Edinburgh and London in the mid-19th Century.⁴⁷³ During that period, medical institutions were in the process of responding to progressive regulatory intrusion by external parties, such as governmental authorities, into the conduct of what had hitherto been understood as a private, doctor-patient interaction.⁴⁷⁴ Over recent decades, technological advances, immigration, and resultant demographic changes are among the diverse factors that have induced adaptations to ethical codes.⁴⁷⁵ The current version of the Canadian Medical Association's *Code of Ethics*, however, remains relatively silent about how doctors should approach the patient's family. It provides broad advice only once, in s30, stating: "Be considerate of the patient's family and significant others and cooperate with them in the patient's interest."⁴⁷⁶

Along similar lines, the Royal College of Physicians and Surgeons of Canada, which is the national professional association overseeing the medical education of specialists, offers its members an online bioethics curriculum through case studies, primers, and interactive modules.⁴⁷⁷ Broad general advice is offered, advising College members to "Be considerate of the patient's family and significant others and cooperate with them in the patient's interest."⁴⁷⁸ More specifically, the status of family members' participation in decision-making are addressed through case studies in three areas. The first speaks to the matter of decisional capacity of minors, where the legal doctrine of 'mature minors' is considered.⁴⁷⁹ The second is a case study involving the issue of patients and families who

⁴⁷³ H MacDougall & R Langley, *Medical Ethics: Past, Present and Future* (Ottawa: Royal College of Physicians and Surgeons of Canada, nd) online: <http://www.royalcollege.ca/rcsite/bioethics/primers/medical-ethics-past-present-future-e> (accessed 2 February 2015).

⁴⁷⁴ *Ibid.*

⁴⁷⁵ *Ibid.*

⁴⁷⁶ Canadian Medical Association, *supra* note 113.

⁴⁷⁷ Royal College of Physicians and Surgeons of Canada, "Cases" *Bioethics* (2017) online: <http://www.royalcollege.ca/rcsite/bioethics/bioethics-cases-e> (accessed 7 March 2017).

⁴⁷⁸ TS Callanan, "Communication 2.3: Truth Telling" *Bioethics: Cases* (Ottawa: Royal College of Physicians and Surgeons, 2017) online: <http://www.royalcollege.ca/rcsite/bioethics/cases/section-2/truth-telling-e> (accessed 7 March 2017).

⁴⁷⁹ M Jackman & A McRae, "Medical Decision-Making 1.5.2: Medical Decision-Making and Mature Minors" *Bioethics: Cases* (Ottawa: Royal College of Physicians and Surgeons, 2013) online:

demand inappropriate treatment; while the third is titled “Conflict with Patients’ Families’ in the neonatal intensive care unit.”⁴⁸⁰ In the latter case, centred on treatment choice in the context of poor probability of survival of a newborn infant, the College advises physicians:⁴⁸¹

- *Decisions must serve the best interests of the infant.*
- *Parents must be fully informed.*
- *Parents' values, cultural beliefs and religious beliefs must be respected whenever possible.*
- *A family-centred care approach must be utilized.*
- *Whenever possible, consensus must be derived between the parents and the physician/healthcare team directly involved in the care of that infant.*

These three examples, addressing family interests, fall in the realm of conflict management during interactions with family members over commonly encountered emotive and contentious issues wherein the patient does not have capacity to consent. They do not address situations where competent patients choose to make treatment decisions alongside family members, which is the subject of my research.

Another organization involved in issues of professional governance of physicians is the Canadian Medical Protective Association (CMPA), which offers much more detailed advice. The CMPA is a mutual physicians’ not-for-profit organization incorporated by an Act of Parliament. It provides core services of medical liability protection, education about risk reduction, and pertinent professional development programs for its member-physicians.⁴⁸² In its web section on ‘Helping Patient Decision-making,’ it advises physicians to consider a patient’s cultural values, beliefs, and level of health literacy, and

<http://www.royalcollege.ca/rcsite/bioethics/cases/section-1/medical-decision-making-mature-minors-e> (accessed 9 March 2017).

⁴⁸⁰ S Workman, “Physicians, Patients and the Health Care System 7.1.6: Demands for Inappropriate Treatment” *Bioethics: Cases* (Ottawa: Royal College of Physicians and Surgeons, 2017) online: <http://www.royalcollege.ca/rcsite/bioethics/cases/section-7/demands-for-inappropriate-treatment-e> (accessed 9 March 2017).

⁴⁸¹ J Hellmann, “Communication 2.5.2: Conflicts with Patients’ Families in the Neonatal Intensive Care Unit” *Bioethics: Cases* (Ottawa: Royal College of Physicians and Surgeons, 2017) online: <http://www.royalcollege.ca/rcsite/bioethics/cases/section-2/conflicts-with-patients-families-neonatal-intensive-care-unit-e> (accessed 9 March 2017).

⁴⁸² CMPA, “Who We Are,” *The Canadian Medical Protective Association* (nd) online: <https://www.cmpa-acpm.ca/en/who-we-are> (accessed 27 October 2014). The *Act of Incorporation for The Canadian Medical Protective Association* was passed by the Canadian House of Commons on February 27, 1913, and assented to on May 16, 1913.

goes on to counsel physicians to ask patients if a family member, friend, or other healthcare provider should participate in the information exchange.⁴⁸³ The CMPA's section on 'Patients and their Families,' however, tends to use defensive language:

*Nevertheless, when a patient's or the family's expectations are not met, they may resort to abusive behaviour or threaten to launch a complaint or go to the news media. Patients and their families may become frustrated and stressed by uncertainty, long wait times, or when a physician denies requests that the physician deems are unreasonable. The latter may occur when, for example, the family requests information about the patient and the doctor denies the request citing lack of patient consent to release such information. Or the patient may be uncertain or may not understand why the doctor is providing a certain treatment or why a request for a narcotics prescription is refused. Difficult as it may be, physicians should continue to follow the standard of care and not be intimidated into providing investigations or treatments they feel are not in the patient's best interest.*⁴⁸⁴

The interests of family members are recognized, in risk management terms, within the CMPA's advice to physicians about how to diffuse tense situations if they arise in interactions with patients. It reminds its members that mutual respect and understanding are important factors that build good physician-patient relationships, and advises that a "considerate attitude, recognition and acknowledgement of the patient's or family member's concerns can help resolve friction."⁴⁸⁵ In the CMPA's section on long-term care, physicians are cautioned that they may be required to "navigate communications with family members (sometimes several of them) or substitute decision-makers. Family

⁴⁸³ CMPA, "Helping Patients Make Informed Decisions," *Duties and Responsibilities: Expectations of Physicians in Practice* (April 2014) online: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/helping-patients-make-informed-decisions> (accessed 22 October 2014).

⁴⁸⁴ CMPA, "When Physicians Feel Bullied: Effective Coping Strategies," *Duties and Responsibilities: Expectations of Physicians in Practice* (March 2014) online: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/when-physicians-feel-bullied-effective-coping-strategies> (accessed 22 October 2014).

⁴⁸⁵ CMPA, "Physician-Patient Communication: Making It Better," *Safety of Care: Improving Patient Safety and Reducing Risks* (December 2010) online: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2010/physician-patient-communication-making-it-better> (accessed 22 October 2014). Family engagement by physicians is also addressed extensively in the CMPA's section on end-of-life care, but the material will not be addressed here as it is beyond the scope of the discussion in this chapter.

members may be easily available, or in a different geographical location, making communication more challenging.”⁴⁸⁶

The various official rules and guidelines governing or influencing the participants’ approach to engaging with patients’ families are incompletely defined and non-standardized. As with consent law in general, the regulatory framework regarding patient engagement views patients individually, and hence does not make explicit provisions for the possibility that an adult patient — although fully competent — may have a critically dependent relationship with their family and/or close others, especially in medical decision-making.

Compared to the obligation to comply strictly with legal requirements, the ethical obligations of physicians to engage with family, as described by The Right Honorable Lord Moulton, have in the past belonged to the realm of “Obedience to the Unenforceable,” as “the obedience of a man to that which he cannot be forced to obey. He is the enforcer of the law upon himself.”⁴⁸⁷ In some countries, the expectation that doctors should engage constructively with family as a form of decisional support for patients during consent processes is explicitly laid out in directives from national regulatory bodies. For example, the guidelines of the General Medical Council of the United Kingdom (GMC, UK) state:

*21. You should check whether the patient needs any additional support to understand information, to communicate their wishes, or to make a decision. You should bear in mind that some barriers to understanding and communication may not be obvious; for example, a patient may have unspoken anxieties, or may be affected by pain or other underlying problems. You must make sure, wherever practical, that arrangements are made to give the patient any necessary support. This might include, for example: using an advocate or interpreter; asking those close to the patient about the patient’s communication needs; or giving the patient a written or audio record of the discussion and any decisions that were made.*⁴⁸⁸

⁴⁸⁶ CMPA, “Long-Term Care: Quality Decisions,” *Safety of Care: Improving Patient Safety and Reducing Risks* (June 2014) online: <https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2014/long-term-care-quality-decisions> (accessed 22 October 2014).

⁴⁸⁷ J Moulton, “Law and Manners” (1924) Jul. Atl Mon 1.

⁴⁸⁸ GMC UK. “Sharing Information” *Consent: Patients and Doctors Making Decisions Together* (London: General Medical Council, 2017) online: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_sharing_information.asp (accessed 10 March 2017).

In fact, the GMC's guidelines clearly address the matter of doctors involving families if the patient so wishes, including helping in the decision-making process:

Consent guidance: Involving families, carers and advocates

22. *You should accommodate a patient's wishes if they want another person, such as a relative, partner, friend, carer or advocate, to be involved in discussions or to help them make decisions. In these circumstances, you should follow the guidance in paragraphs 7–21.*⁴⁸⁹

Given that these are specific recommendations by a national organization responsible for monitoring and regulating the ethics of physicians' practices, I posit that they carry the weight of legal rules in terms of the consequences of any failure of UK physicians to heed them. Currently in Canada, the equivalent national or regional regulatory bodies of the medical profession do not make such explicit recommendations regarding engaging with family, as discussed earlier in this chapter. In other words, the nature and quality of the approaches that physicians in BC may adopt in engaging with their patients' families is, by and large, unregulated. It may be argued that the lack of a systematic professional approach to family of patients, combined with the provisions in BC's consent law, leaves the position of family in medical decision-making vulnerable to interpretation (and control) by physicians and other healthcare providers. Discourses that examine the possible role of the family in decision-making become increasingly pertinent as demographic diversity, multiculturalism, and issues such as physician-assisted death place pressure on the need to clarify the locus of authority in medical decision-making.

6.1.1 (iv) – Medical Education and the Development of Interactive Skills

The education of a physician is generally delivered through a highly structured medical training curriculum, with a focus on biomedicine and associated sciences. In most programs, aspects of the humanities — including bioethics, law, doctor-patient communications, the history and philosophy of medicine, and the sociology of healthcare

⁴⁸⁹ GMC UK. "Involving Families, Carers and Advocates" *Consent: Patients and Doctors Making Decisions Together* (London: General Medical Council, 2017) online: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_involving_families_carers_and_advocates.asp (accessed 10 March 2017).

— are incorporated into the formal or ‘declared’ curriculum.⁴⁹⁰ In addition to this curriculum, there exists a well-recognized and powerful informal ‘hidden curriculum,’ which effectively socializes future physicians, and through which seniors, supervisors, and clinician-educators transmit norms and values.⁴⁹¹ Regrettably, the lessons learned within the informal curriculum often inadvertently undermine the messages of the formal curriculum.⁴⁹² Research demonstrates frequent dissatisfaction amongst medical students about the manner in which the teaching of the humanities is ultimately delivered. In fact, it has been noted that the hidden curriculum inhibits, rather than facilitates, the development of moral reasoning, such that a phenomenon of “ethical erosion”⁴⁹³ occurs as medical students complete their clinical training.⁴⁹⁴ The process of erosion results in damage to their idealism, adoption of a form of ritualized professional identity, an acceptance of hierarchy, and even emotional flattening.⁴⁹⁵

The hidden curriculum is a largely unregulated and widely experienced aspect of medical learning. Unfortunately, it might deliver negative modeling through observance of seniors’ behaviours and attitudes to patients and their accompanying persons. Examples are clinical teachers’ offhand ridiculing of patients’ physical characteristics, their poverty or ethnicity, and their actual disinclination to interact with families of patients wherever possible.⁴⁹⁶ Ironically, medical students are exposed to such forms of negative modelling

⁴⁹⁰ WE Stempsey, “Medical Humanities and Philosophy: Is the Universe Expanding or Contracting?” (2007) 10:4 *Med Healthcare Philos* 373; WE Stempsey, “Medical Humanities: Introduction to the Theme” (2007) 10:4 *Med Healthcare Philos* 359; J Shapiro et al. “Medical Humanities and their Discontents: Definitions, Critiques, and Implications” (2009) 84:2 *Acad Med* 192; L Cordingley et al. “Undergraduate Medical Students’ Exposure to Clinical Ethics: A Challenge to the Development of Professional Behaviours?” (2007) 41:12 *Med Educ* 1202.

⁴⁹¹ Shapiro et al, *supra* note 490; WS Jones, WS, JL Hanson & JL Longacre, “An Intentional Modeling Process to Teach Professional Behavior: Students’ Clinical Observations of Preceptors” (2004) 16:3 *Teach Learn Med* 264; Branch et al, *supra* note 307; WT Branch, “Viewpoint: Teaching Respect for Patients” (2006) 81:5 *Acad Med* 463; Mahood, *supra* note 13.

⁴⁹² FW Hafferty, “Viewpoint: The Elephant in Medical Professionalism’s Kitchen” (2006) 81:10 *Acad Med* 906; Hafferty & Hafler, *supra* note 13; Mahood, *supra* note 13.

⁴⁹³ C Feudtner, DA Christakis & NA Christakis, “Do Clinical Clerks Suffer Ethical Erosion? Students’ Perceptions of their Ethical Environment and Personal Development” (1994) 69:8 *Acad Med J Assoc Am Med Coll* 670 at 675.

⁴⁹⁴ PC Hebert, EM Meslin & EV Dunn, “Measuring the Ethical Sensitivity of Medical Students: A Study at the University of Toronto.” (1992) 18:3 *J Med Ethics* 142; Feudtner, Christakis & Christakis, *supra* note 493; J Patenaude, T Niyonsenga & D Fafard, “Changes in Students’ Moral Development during Medical School: A Cohort Study” (2003) 168:7 *Can Med Assoc J* 840; Mahood, *supra* note 13.

⁴⁹⁵ Lempp & Seale, *supra* note 14.

⁴⁹⁶ Mahood, *supra* note 13.

in hospital wards contemporaneously with medical school classroom instruction on topics such as the ethics of patient engagement and the virtue of cultural sensitivity.⁴⁹⁷ A Foucauldian understanding, that the system of medicine is perhaps best viewed as a ‘discursive practice,’ reinforces the view that the hidden curriculum has significant power to mould the minds of future physicians.⁴⁹⁸ Here, multiple forms of knowledge, including those from disciplines beyond biomedicine itself, are folded into the interactions that physicians have with patients and their families, and manifest themselves with what has come to be known as ‘bedside manners’ and ‘communication skills.’⁴⁹⁹

None of the participants in my study indicated that they were taught explicitly, at any stage of their medical education, about the various competencies that should be employed in communicating with families. They attributed whatever family interaction skills they possessed to the lessons learned as they matured in their individual practices, influenced to a degree by the tacit modeling of professional seniors. Their acknowledgment of the lack of formal training in this specific skill reflects a dilemma identified in medical education and clinical practice: that the role and status of family in the overall care of patients is complex and difficult to clearly define. It remains a subject of examination in medical communications research.⁵⁰⁰

More than the potential to generate satisfaction amongst patients and family members, physicians’ communication skills have been shown to have positive effects on patients’ adherence with treatment.⁵⁰¹ The research findings of my Master’s project demonstrated that, in the aftermath of adverse medical events, aggrieved or frustrated family members need physicians to communicate more than merely the medical facts. They are expected to communicate their empathy — an integral component of the conflict management process.⁵⁰²

⁴⁹⁷ *Ibid.*

⁴⁹⁸ M Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (London & New York: Routledge, 2003) at 118; E van Leeuwen & GK Kimsma, “Philosophy of Medical Practice: A Discursive Approach” 18:1-2 *Theor Med* 99 at 99.

⁴⁹⁹ Van Leeuwen & Kimsma, *supra* note 498.

⁵⁰⁰ Albrecht, TL, S Eggly & JC Ruckdeschel. *Communicating with Relatives/Companions about Cancer Care* (Oxford: Oxford University Press, 2010) at 158-9; Karnieli-Miller et al, *supra* note 293; Greene & Adelman, *supra* note 280; Visser, Deliens & Houttekier, *supra* note 137.

⁵⁰¹ KBH Zolnierek & MR DiMatteo, “Physician Communication and Patient Adherence to Treatment: A Meta-Analysis” (2009) 47:8 *Med Care* 826.

⁵⁰² Veerapen, *supra* note 38.

In the preceding section I discussed various structural, social and educational factors that have a propensity to affect the nature and quality of the relationships that physicians generally develop with their patients, particularly in the context of British Columbia (where my research was conducted). Besides the factors affecting physicians' direct relationships with patients, there are recognizable factors that shape physicians' interactions with patients when family members are present. Influences arising as a result of the overarching legal and bioethical frameworks and discourses under which physicians function must also be taken into account.

6.1.2 – Participants' View of the Role of Family in the Consent Process

Within the clinical practice context of all the participants, the ethico-legal expectation, in common with prevailing thinking in bioethics and consent law, was that decision-making ought to be undertaken only by the individual (competent) patients themselves. These persons must have first demonstrated clear comprehension of the risks and benefits of the proposed intervention. With that understanding, the participants' assumptions of what each family's role (if any) was in decision-making seemed to determine the interest they showed in engaging directly with them, as well as the degree to which they would entertain the interposition of the family's influences during clinical interactions.

All the participants appeared to regard the family's contribution to the consent discussions as being primarily informational. That is to say, family was viewed as a source of historical information that supplemented their patients' narratives and occasionally provided completely new, 'collateral' information. None of the participants indicated that they would encourage family members to directly contribute to the decision-making process, even in situations where family acted as interpreters, and where all appearances suggested that the patient trusted them and appeared to be comfortably dependent on them. All the participants indicated that they would not proceed unless they were sufficiently convinced that there was a degree of comprehension by the patient, and that the patient had made the final decision themselves. In any case, the evidence of full comprehension as a prerequisite for valid consent is intrinsically challenging to achieve or substantiate

objectively because of medical knowledge differentials, and even more so if language barriers complicate the exchange.⁵⁰³

Despite this demand that patients make the final decision themselves, participants were desirous of engaging purposefully with family members for a few reasons. One of them was the intention to fulfill ethical obligations to the family by responding to their concerns, balancing reassurance with sufficient risk warnings. Another reason was to actively recruit influence on the patient's decision-making process by forming a coalition with one or more family members, especially when the patient showed hesitation in agreeing to the recommended treatment. The strategy of aligning with family members was also adopted if there were safety concerns, for example in situations where the patient did not appear reliable enough to comply with medical instructions. Here, family members were recruited essentially to ensure that patients did not return home to an unmonitored environment with potentially unstable medical conditions.

Although all the participants had several clear reasons for interacting with family, when it came to the patients' actual decision-making leading to consent, all of them retained a primary focus on the individual patient's right to decide. The participants' approaches to family members thus evidenced some common practices in terms of privileging the individual, while differences in approach could be attributed to formative training or past experiences. These are addressed in the next section.

6.1.3 – Participants' Understanding of their own Roles and Duties

Although healthcare providers may view families as integral to medical decision-making and care-planning for patients, these persons are also commonly perceived as a burden to the communications process, being unpredictable by virtue of inherent structural complexity and intra-family relational dynamics. In particular, the need to consider the multiple variables that population diversity introduces complicates the design of specific training within medical education curricula. Consequentially, formal training programs are necessarily limited to incorporating lessons that only address broad general principles

⁵⁰³ M Škegro et al. "Improving Comprehension of Informed Consent" (2006) 60:3 Patient Educ Couns 294; AE Crepeau et al, "Prospective Evaluation of Patient Comprehension of Informed Consent" (2011) 93:19 J Bone Jt Surg e114.

related to cultural respect and empathy.⁵⁰⁴ The participants acquired a major component of their learning about interacting with family from a hidden curriculum — which, as we saw earlier, is dependent on individual mentors' behaviours and styles, and is therefore intrinsically difficult to plan for. In addition to the external training they had received, the participants' own personalities, cultural values, and prior work and life experiences contributed to the development of their communication skills. Given the multiple variables and lack of requirement to comply with well-defined ethical or legal guidelines regarding their interactions with patients' families, it is unsurprising that the participants' approach to family engagement was idiosyncratic.

There was a general similarity in the participants' awareness that, even though they would not seek the family members' opinions about choice of treatment (deferring always to the patient themselves), they still had ethical duties to the family. For example, within triadic interactions, they would help the family interpret medical information about the patient, and respond to questions of a technical nature, or engage in discussions about care at home. What became evident, though, was that throughout these triadic conversations, the participants would ultimately privilege the patient's independence and privacy, even if there was clear evidence that the interpersonal relationships between patient and family were trusted and supportive. This practice is discussed in greater detail in the next chapter, where I directly address issues related to patient autonomy.

Besides being aware of their ethical obligations to patients' families, the participants were uniformly conscious of over-arching legal stipulations governing physicians' interaction with patients and their families, particularly within the informed consent process. Although all indicated a general awareness of such legal obligations, none of them alluded to specific legal rules as being influential to their process of obtaining consent. In fact, two of the participants admitted to having never read the details of BC's consent statute, although they were aware that it existed. The obligations that were predominant in their considerations were ethical rather than legal, relating to the protection of patient privacy and confidentiality, and the requirement to deliver appropriate information and risk warnings to help patients in their decisional process.

⁵⁰⁴ Nelson, *supra* note 198; Hardwig, *supra* note 132; Levine & Zuckerman, *supra* note 279.

6.1.4 – Culture and Language

All the participants identified that there were special challenges that emerged in interactions with non-English speaking patients accompanied by family members acting as interpreters. The combination of cultural specifics and individual families' relational dynamics made it challenging to ensure that the patient's agency was not suppressed and that their final comprehension of their illness and the treatment proposed would meet the criteria for valid consent. Besides precipitating novel legal dilemmas, exchanges that involve interpretation by family members potentially introduce ethico-legal risks, one of them being whether the truth was actually being concealed from the patient, either purposefully or inadvertently.

'Truth-telling'⁵⁰⁵ in medical interactions has been explored in detail, especially in the fields of cancer care and surgery.⁵⁰⁶ Although bioethics discussions have tended to be binary — Western (full disclosure) vs. communitarian (family-controlled disclosure to patient) — research indicates that current practices in communitarian societies may indeed favour keeping the patient fully apprised of their diagnosis, prognosis, and treatment risks.⁵⁰⁷

The candid and individual-focused 'truth-telling' approach favoured in Western medical practice has been viewed as unacceptable in many cultures of medicine around the world, such as in China, parts of the Middle East and Southeast Asia. However,, attitudes appear to be changing.⁵⁰⁸ For example, in Singapore, which is a Westernized Southeast

⁵⁰⁵ Truth-telling, or veracity, can be defined as the avoidance of lying, deception, misrepresentation, and non-disclosure in interactions with patients or relevant to patient care. University of California School of Medicine. "Truth Telling" *Ethics Fast Facts* (2008) online: http://missinglink.ucsf.edu/lm/ethics/content%20pages/fast_fact_truth_telling.htm (accessed 16 March 2017).

⁵⁰⁶ Surbone, *supra* note 441; Hebert et al, *supra* note 441; MD Cantor, "Telling Patients the Truth: A Systems Approach to Disclosing Adverse Events" (2002) 11:1 *Qual Saf Health Care* 7; A Surbone, "Telling the Truth to Patients with Cancer: What Is the Truth?" (2006) 7:11 *Lancet Oncol* 944; DK Sokol, "Truth-Telling in the Doctor-Patient Relationship: A Case Analysis" (2006) 1:3 *Clin Ethics* 130.

⁵⁰⁷ A Surbone, "Truth Telling to the Patient" (1992) 268:13 *Jama* 1661; Surbone, *supra* note 441; C Ells, "The Impact of Culture on the Patient-Surgeon Relationship" (2002) 195:4 *J Am Coll Surg* 520; Surbone, *supra* note 506.

⁵⁰⁸ SM Adib & GN Hamadeh, "Attitudes of the Lebanese Public Regarding Disclosure of Serious Illness" (1999) 25:5 *J Med Ethics* 399; Fan & Li, *supra* note 92; Sokol, *supra* note 506; DK Sokol, "How the Doctor's Nose has Shortened over Time; A Historical Overview of the Truth-Telling Debate in the Doctor-Patient Relationship" (2006) 99:12 *J R Soc Med* 632. N Horikawa et al. "Changes in Disclosure of Information to Cancer Patients in a General Hospital in Japan" (2000) 22:1 *Gen Hosp Psychiatry* 37; Lee & Wu, *supra* note 88; Back & Huak, *supra* note 90; AM Al-Amri, "Attitudes of Saudi Medical Students toward the Disclosure of Information on Cancer in Eastern Saudi Arabia" (2011) 18:2 *J Fam Comm Med* 54. GN

Asian country where families often remain involved in medical decision-making even for legally competent adults, recent research illustrates that the matter remain unresolved. The study, which involved interviews with 78 physicians on truth-telling and end-of-life decision-making, demonstrated tension and confusion amongst doctors when applying Western bioethical and legal doctrines of individual consent.⁵⁰⁹ Uncertainty about interpreting autonomy arose whenever the doctors recognized that a family appeared to have valid cultural, social, and economic reasons for involvement in decision-making about the care of terminal but competent patients. The authors of the report summarized one of the major findings of their study as follows:

*In Singapore, doctors find that they have to involve families in decision-making for most patients, particularly those who are elderly and legal minors, or otherwise dependent on their family for care. Families may expect to be consulted before any information is given to the patient, and often feel protective towards the patient, seeking to hide information or make decisions on the patient's behalf. Doctors say that they have to work with families towards disclosing bad news and involving patients in decisions, and also that there are other factors that affect family decisions apart from consideration of what is best for the patient, such as the welfare of the family, finance and filial piety.*⁵¹⁰

The ethical principles and dilemmas linked with withholding the truth from patients are not uniquely a non-Western cultural experience. As recently as in the mid-1980s, medical students in Italy were required to learn the principles articulated within the Italian Medical Association's *Italian Deontology Code*, which contained this statement: "A serious or lethal prognosis can be hidden from the patient, but not from the family."⁵¹¹ Within Western bioethics practice, which now decries physician paternalism, the recommendation defaults to truth-telling in *all* instances except those specific circumstances where full disclosure carries a serious risk of harm to the patient's well-

Hamadeh & SM Adib, "Changes in Attitudes Regarding Cancer Disclosure among Medical Students at the American University of Beirut" (2001) 27:5 J Med Ethics 354. In this particular report it is perhaps significant to note that the students surveyed were from the American University of Beirut.

⁵⁰⁹ JOA Tan & JJJ Chin, *What Doctors Say about Care of the Dying* (Singapore: The Lien Foundation, 2011).

⁵¹⁰ *Ibid* at 25.

⁵¹¹ Surbone, *supra* note 441.

being.⁵¹² Even when family members insist that the truth be withheld from the patient, physicians are advised to convince them otherwise.⁵¹³ To overcome the ethical challenges arising from language barriers, the use of interpreters has become a common practice in clinical settings.⁵¹⁴ Interpreters' roles may be viewed as those of reporters (who translate content literally), recapitulators (who retain content but reframe it), or responders (who do not translate but instead interact with one of the participants).⁵¹⁵ Given the variability of these roles, it is unsurprising that physician-patient-interpreter encounters are fraught with miscommunication risks that carry potentially serious consequences for patient comprehension within the informed consent process.⁵¹⁶

The participants' experience of working with interpreters in family interactions was complex and associated with a variety of challenges, ranging from attempts by family members to protect the patient from potentially harmful bad news by filtering or tempering information, to the outright blocking of information.⁵¹⁷ In my study, the participants who discussed language challenges in their interactions with family interpreters indicated that they could ultimately proceed with a limited degree of assurance that the patients themselves had sufficient comprehension prior to consenting. In most instances, however, they seemed to defer to the family's control of the exchange. In one case, the participant was satisfied enough to proceed with treatment having obtained only a limited degree of evidence of comprehension by the patient, signalled as head-nodding gestures, all within a mix of communications in two languages.

When the participants depended on the families' participation as sole interpreters, they seemed resigned to compromising their usual standard of ensuring full comprehension by the patient at the level required for legal consent. Triadic-interactive scenarios which

⁵¹² GMC UK, "Reasons for Not Sharing Information with Patients" *Consent: Patients and Doctors Making Decisions Together* (London: General Medical Council, 2017) online: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_reasons_for_not_sharing_information.asp (accessed 3 March 2015).

⁵¹³ CH Braddock III, "Truth-telling and Withholding Information" in *Ethics in Medicine* (Seattle: University of Washington School of Medicine, 1998) online: <https://depts.washington.edu/bioethx/topics/truth.html> (accessed 17 November 2014).

⁵¹⁴ Brisset, Leanza & Laforest, *supra* note 450.

⁵¹⁵ C Wadensjö, *Interpreting as Interaction* (London & New York: Longman, 1998); Greene & Adelman, *supra* note 280.

⁵¹⁶ Greene & Adelman, *supra* note 280 at 8.

⁵¹⁷ Brisset, Leanza & Laforest, *supra* note 450.

involve family translators may, however, be examples of situations where the legal and ethical anxiety around the patient's actual comprehension may be allayed by viewing the patient in relation to their family, rather than individualistically. It is possible to view a patient who trusts family members to translate medical information as a person functioning with sufficient capacity to make medical decisions. The challenge for a clinician, however, is in being able to accurately assess the genuineness of the patient's voluntariness whenever they consent to their family's participation in discussions. The risk of misdiagnosis of the family dynamic is the inadvertent contribution to ongoing social duress, and hence it is critical to be conscious of the possibility that not every family member has the patient's best interests at heart. Limitations of time and resources make it difficult to conduct a reasonable analysis of a family's internal interaction patterns and socialization. To add to the challenge, there is also a need to consider intersections of socio-economics, education, history, gender, culture, and trust in the healthcare system — all of which may qualitatively inform the family's participation in the interaction.

Part of the 'diagnosis' of any family's role in a patient's decision-making is the assessment of the degree of inter-dependence amongst family members.⁵¹⁸ As Cigdem Kağıtçıbaşı claims, the single most important cultural difference in social behaviour is the degree to which persons are characterized, from being individuals who clearly value separateness at one extreme, to those who function effectively through relatedness and interdependence at the other.⁵¹⁹ Economic and emotional bonds exist between patients and their family members, and these are the bases that inform interdependence within the family. Recognition of the salience of these factors in every individual case could arguably contribute to better promotion of a patient's decision-making capacity. Being able to read the family dynamic and respond appropriately in each case is hence a critical skill that belongs to a different paradigm from that applied in traditional, dyadic physician-patient interactions. The importance of such an attribute is illustrated by the accounts of my participants' willingness to depend on family members acting as interpreters during consent discussions with patients.

⁵¹⁸ Kağıtçıbaşı, *Family*, *supra* note 45 at 168.

⁵¹⁹ *Ibid* at 104.

6.1.5 – Control of the Conversations

The research participants' stories illustrated their strategies to retain control of the conversations whenever family participated in interactions with patients. Two of the participants indicated that they had no qualms with denying family members' requests to participate in the discussions, and would readily do so without seeking the patient's agreement. They rationalized their actions on the basis of protecting the patient's privacy or preventing the potential suppression of the patient's voice, especially if they felt that the family member was likely to adversely influence the conversation. Even in situations where they had allowed the family to be present with the patient's consent, they applied conversational manoeuvres that essentially privileged and protected the integrity of their dyadic interaction with the patient. For example, they would address questions or offer advice directly to the patient and not to the family, and in one instance, the participant would physically move to stand behind the patient's seat during the interaction.

Each participant's responses to family members within triadic or multiparty conversations generally followed a pattern similar to the 'convergence' model' described by Terrance Albrecht and his co-workers, based on their empirical research.⁵²⁰ The theoretical basis, here, is that the greater the agreement between physicians, patients, and family members about the cause of the illness and the proposed treatment, the better the clinical outcome of the medical intervention. By retaining control of the tenor of the conversations in their interactions, the participants adapted their approaches to the family by eliciting concerns and expectations from them, seeking a measure of agreement, and in general shoring up support for the participant's own plans. Except for a limited number of instances of discord between the participant and family member (for example, where a daughter disagreed with the decision to move her mother to an institution, or when the out-of-town family member disagreed with the treatment of her relative), in most cases the participants' experiences suggested that they did not have difficulty exerting definitive authority in the decision-making process. They generally ensured that convergence was achieved, even if it entailed actively stopping attempts by family to dominate the conversation. As stated before, no participants indicated that they would encourage or entertain decision-making by family members if the patient was legally competent.

⁵²⁰ Albrecht, Egly & Ruckdeschel, *supra* note 500 at 159.

Conclusion

In this chapter I addressed relevant theoretical considerations, within Canadian medical training and health system structures, which are very likely to have an impact on the nature of relationships between patients and physicians. These factors, combined with the legal and ethical framework within which healthcare is structured, directly or indirectly determine a physician's approach to, and attitude toward, families of patients. The participants acknowledged that the skills they applied in engaging with patients' family members were personally acquired in an unstructured manner, largely through the *ad hoc* observation of seniors and via their practical experience. With the understanding that it was critical to listen for and honour the patient's voice in the presence of family members, the participants' stories indicated their assumptions about what the role of the family ought to be. These assumptions were clearly influenced by broad and general interpretations of their ethical obligations to interact with family, rather than any particular ethico-legal rules. This outcome is in keeping with the relative paucity of rules or guidance from professional organizations, or within Canadian consent law, which would have provided a framework governing physicians' interactions with family of patients during consent processes.

Ultimately, given the understanding that consent decisions by competent persons should only be made by individuals, family members' opinions were excluded or marginalized in decision-making about a patient's treatment. None of the participants felt obliged to consider the family's opinion if the patient had capacity to consent. The participants invited the family's opinion principally when they had an interest in forming a coalition with a family member, so as to influence the patient's final choice. Even in cases where it was obvious that the patient was dependent on family members for their own care and for help in processing medical information, the participants did not appear to acknowledge that the family members' opinions should be influential in the final decision.

The participants assumed they had the privilege to exert overall authority and control of conversations with family members present, even if it meant displacing family members from the interaction if they felt their input was overbearing or in some way unsettling to the comfortable dyadic conversations with patients. The justification here was their deeply held belief that the patient's independence was paramount.

The tilt of power generally in favour of physicians within a public healthcare system may disadvantage patients and families in terms of their being able to determine where the locus of decision-making rests during informed consent processes. Added to that is a referral system that precludes the public's direct access to specialist physicians, limits choice, and produces long wait times. These factors compound the intrinsic power gradients unavoidably caused by existing differentials in medical language and knowledge.

Amongst the more challenging experiences the participants had during family interactions were those that involved patients who were unable to communicate in English and were dependent on family members for translation. Whenever cultural or language differences were significant, the participants appeared to be less capable of exerting their overall control over the environment of the patient's decision-making.

CHAPTER 7: Discussion [B] – Patient Autonomy and Family Interactions

Introduction

In this second discussion chapter I focus on the research findings that illustrate the instances during consent discussions where the participants perceived that their patients' autonomy was challenged by the input of their attending family members. The participants' responses to such challenges offer insight into their understanding of the concept of 'personal autonomy' in the context of medical decision-making. In examining autonomy-related aspects of my research findings my discussion is illuminated by several alternative formulations of informed consent doctrine proposed by bioethicists as well as relational and post-colonial theorists, who promote an interpretation of consent beyond its traditional, individualist paradigm.

From a healthcare professional's perspective, a family's active participation in a legally competent patient's decision-making might provoke the impulse to protect the latter's freedom to be independent. I conclude the chapter in section 7.2, by arguing that in such circumstances, the adoption of a relational perspective of autonomy could enhance the practitioner's appreciation of the variety of influences that promote a patient's decisional capacity.

7.1. – Alternate Interpretations of Patient Autonomy in Informed Consent

As argued in Chapters 2 and 6, early formulations of bioethical doctrines linked autonomy with individuality, while making various assumptions of universal applicability despite wide differences in healthcare systems and relationships between the public and healthcare providers.⁵²¹ Indeed, critics of the dominant, 'conventional' interpretation of patient autonomy within bioethics and legal theory point to traditional liberalism's atomistic view of individuals that often fails to recognize the inherently social nature of human beings. Writers such as Jennifer Nedelsky claim that what needs to be developed is a *relational* conception of autonomy, in order to "distinguish genuinely autonomous

⁵²¹ J Harris, "Consent and End of Life Decisions" (2003) 29:1 J Med Ethics 10; Gilbar, *supra* note 279.

behaviour from acts of mere rational agency.”⁵²² In fact, many societies do not construct the individual or their capacity for autonomy in terms of opposition to the collective. Instead, autonomy may be seen as a capacity that is made possible by constructive relationships, through which dependence on others for a social world enables persons to develop core capabilities.⁵²³ In the context of medical decision-making, dependence on close others is precipitated (often urgently) by the prospect of a relative stranger, in the form of a health professional, interfering physically with one’s body. It may be argued that consent doctrine could better serve its goals of protecting patient dignity and security if it were to incorporate awareness of where the person sits within their structure of relations (i.e., those others with whom they choose or need to interact).⁵²⁴ In what follows, I discuss my participants’ responses to situations where they felt that their patients’ freedom to be autonomous was compromised, to illustrate the wariness that the participants generally had to the participation of family members in consent discussions. I then discuss how a relational model could help improve the participants’ disposition to family participation. The discussion herein is organized in alignment with the general framework that was used to present the research findings in Chapter 5.⁵²⁵ ,

7.1.1 – Family Members as Interpreters

As mentioned in the previous chapter, ‘patient comprehension’ of risks during consent processes being a critical component of consent doctrine necessitates a preliminary discussion of the role of interpreters: family members, professionals, or staff volunteers.⁵²⁶ It was understandably challenging for the participants to gauge how well a non-English speaking patient understood medical information presented, especially if they were from

⁵²² S Sherwin, *The Politics of Women’s Health: Exploring Agency and Autonomy* (Philadelphia: Temple University Press, 1998) at 33; Nedelsky, *supra* note 33 at 63.

⁵²³ Nedelsky, *supra* note 33 at 5, 18.

⁵²⁴ *Ibid* at 374.

⁵²⁵ a) Culture, language and truth-telling, b) waivers of privacy and the right to decide, c) undue influences of family member/s, d) respecting autonomous patient choice against family’s wishes, e) strategies and manoeuvres to protect patient autonomy.

⁵²⁶ MK Mayberry & JF Mayberry, “Consent with Understanding: A Movement towards Informed Decisions” (2002) 2:6 *Clin Med* 523; LM Hunt & KB de Voogd, “Are Good Intentions Good Enough? Informed Consent without Trained Interpreters” (2007) 22:5 *J Gen Intern Med* 598; B Gray, J Hilder & H Donaldson, “Why do We Not Use Trained Interpreters for All Patients with Limited English Proficiency? Is There a Place for Using Family Members?” (2011) 17:3 *Aust J Prim Health* 240; Miola et al., *supra* note 25.

cultures with collective decision-making practices.⁵²⁷ Besides the problematic filtering of information by family interpreters, there are the risks of clinical error from mistranslation, breaches of confidentiality and privacy, and threats to family or community harmony caused by revelation of details of an individual's illness and prognosis. Additional challenges to the patient's autonomy arise from family interpreters' imposition of their own agendas or opinions, whether inadvertently or intentionally.⁵²⁸

There is a significant difference in results between the use of a professional interpreter and a family interpreter in clinical interactions. The differences are observed in the type, motivation, and frequency of interruptions by the interpreter, and also in the degree of trust that develops or exists between the physician and interpreter.⁵²⁹ Partly because of cost and limited availability of trained interpreters, stand-in interpreters are often a necessity — with significant variation in their strengths and weaknesses quickly becoming problematic. These substitutes are commonly adult family members, minor children, healthcare staff, institutional non-professional employees, strangers in waiting rooms, or volunteers from community organizations.⁵³⁰

Ensuring the patient's comprehension during risk disclosure remains the legal responsibility of the professional obtaining consent. A physician who depends on family members for interpretation must therefore be fully confident in the quality of communication and this demands an accurate reading of the family's cultural characteristics, as well as their internal, relational dynamics.⁵³¹ Three of the participants in my research pointed out that the difficulty in obtaining formal interpreter services in their institutions often makes them depend on family members or accompanying persons, or any available institutional staff. They were fully aware of the risks that this dependence created

⁵²⁷ F Meddings & M Haith-Cooper, "Culture and Communication in Ethically Appropriate Care" (2008) 15:1 *Nurs Ethics* 52; J McCarthy et al. "Conversations through Barriers of Language and Interpretation" (2013) 22:6 *Br J Nurs* 335.

⁵²⁸ G Flores, "The Impact of Medical Interpreter Services on the Quality of Healthcare: A Systematic Review" (2005) 62:3 *Med Care Res Rev* 255; Ho, *supra* note 40; Gray, Hilder & Donaldson, *supra* note 526.

⁵²⁹ E Hsieh, H Ju & H Kong, "Dimensions of Trust: The Tensions and Challenges in Provider-Interpreter Trust" (2009) 20:2 *Qual Health Res* 171; Y Leanza, I Boivin & E Rosenberg, "Interruptions and Resistance: A Comparison of Medical Consultations with Family and Trained Interpreters" (2010) 70:12 *Soc Sci Med* 1888.

⁵³⁰ L Haffner, "Translation is Not Enough: Interpreting in a Medical Setting" (1992) 157:3 *West J Med* 255; Seidelman & Bachner, *supra* note 450; Gray, Hilder & Donaldson, *supra* note 526.

⁵³¹ MM Hammoud, CB White & MD Fetters, "Opening Cultural Doors: Providing Culturally Sensitive Healthcare to Arab American and American Muslim Patients" (2005) 193:4 *Am J Obstet Gynecol* 1307.

in terms of the patient's comprehension, and the extent to which the full truth was being transmitted. Communication of information to the patient being viewed by the participants as critically important, the availability of accompanying relatives offering to act as interpreters was one of the few situations where they were positively disposed to the presence of family members during clinical interactions.

7.1.2 – Culture, Language, and Truth-Telling

As I discussed earlier, several writers from countries with communitarian cultures have put forward alternative, 'relational' conceptions of patient autonomy, arguing that a 'Western' bioethical conceptualization of the patient as an atomistic individual does not align with the defining view of patients in the moral systems of large parts of the world.⁵³² More recently, there have been calls for reconceptualization of the doctrine of medical consent itself, noting that the law generally does not recognize the possibility of positive influences of family members in consent processes.⁵³³ Alternatives to the Western, individual-focused approach to consent are exemplified in debates over telling the patient the full truth about their medical condition.

As discussed in Chapter 6, truth-telling to patients has come to be regarded as a universal communicative virtue; hence, healthcare workers are expected to meet the ethical standard of full disclosure despite concerns that this practice may extinguish hope for some patients.⁵³⁴ The manner in which my participants approached truth-telling was reflective of a blended approach, given their focus on protecting their patients' rights while exhibiting a measure of sensitivity to the cultural norms of the family. The approach prioritized patient consent, but participants did not demand overt expressions or other evidence of independent or 'autonomous' actions of the patient, and all the participants appeared flexible and adaptive in their communications during multi-party encounters.⁵³⁵ Further,

⁵³² Fan, *supra* note 237; Takala, *supra* note 178; Kagiticbasi, "Autonomy," *supra* note 45; Barth-Rogers & Jotkowitz, *supra* note 189.

⁵³³ O'Donovan & Gilbar, *supra* note 285; Gilbar, *supra* note 279; Manson & O'Neill, *supra* note 9 at chapter 4.

⁵³⁴ P Pergert & K Lutzen, "Balancing Truth-Telling in the Preservation of Hope: A Relational Ethics Approach" (2011) 19:1 *Nurs Ethics* 21; RE Wells & TJ Kaptchuk, "To Tell the Truth, the Whole Truth, May Do Patients Harm: The Problem of the Nocebo Effect for Informed Consent" (2012) 12:3 *Am J Bioeth* 22.

⁵³⁵ Hammoud, White & Fetters, *supra* note 531; DF Tsai, "Personhood and Autonomy in Multicultural Healthcare Settings" (2008) 10:3 *Virtual Mentor* 171; Meddings & Haith-Cooper, *supra* note 527; Pergert & Lutzen, *supra* note 534; G Siegal, RJ Bonnie & PS Appelbaum, "Personalized Disclosure by Information-on-

despite their sensitivity to the influence of culture on family members' relationships, and respect for decision-making practices, the participants ultimately paid attention to whether their patients appeared to understand the need for or risks of treatment, especially where language was a constraint. They were conscious of the patients' and families' sensitivity to unspoken messaging through their body language and tone of speech, especially where family were attempting to shield the patient from bad news.⁵³⁶ All the participants were aware that any dissonance between their verbal and non-verbal messages risked breaking the trust their patients had in them. For example, an act of reassuring or comforting the patient directly, whilst arranging for a private conversation with family members, could easily be construed by the patient as being physician-family collusion, aimed at concealing the truth.

The challenge involved in truth-telling to patients may be related to the degree to which the participants equated 'autonomy' with 'independence,' particularly when engaging with families from non-Western cultures (where identifying the family's decisional dynamics was intrinsically difficult) under time constraints. I posit that whenever a family's decision-making process produces anxiety in the observer because it appears to deny independence, adopting a relational view of autonomy could offer a useful way to better understand the patient's actual need for information. In most instances, families are more likely than a physician to know how harmful being told the truth would be to one of their members. One proviso, however, is that a patient's decision-making preferences should be explicitly determined in every instance, lest encouraging them to comply with collective decision-making actually compound habitual suppression of the individual's autonomy by family members. A patient's deference to their family's input could be a genuine and voluntary waiver of their right to make a decision, but it may also be an illustration of traditional social oppression.⁵³⁷ Despite instances of language difficulty, the participants were confident that they were able to identify when a patient

Demand: Attending to Patients' Needs in the Informed Consent Process" (2012) 40:2 J Law Med Ethics 359; Tsai, *supra* note 246; J Tamin, "Can Informed Consent Apply to Information Disclosure? Moral and Practical Implications" (2014) 9:1 Clin Ethics 1.

⁵³⁶ P Pergert, *Façading in Transcultural Caring Relationships: Healthcare Staff and Foreign-Born Parents in Childhood Cancer Care* (PhD in Women's and Children's Health, Karolinska Universitetssjukhuset/Solna, 2008) [unpublished].

⁵³⁷ Hyun, *supra* note 40; Hyun, *supra* note 43; Ho, *supra* note 40.

was being kept in the dark and coerced by family members, and would intervene accordingly.

The dilemma faced by the participants in achieving a legal standard of risk warning while ensuring comprehension exemplifies one of the shortcomings of the informed consent doctrine in practice. As argued by Manson and O'Neill, the process has become a uni-directional transfer of information from the knowledge expert (conduit) to a patient (container), the focus remaining on what is communicated rather than the act of communicating.⁵³⁸ Unfortunately, such an approach risks underestimating the importance of other complex determinants of medical decision-making, such as cultural understandings of illness, degree of fear or trust, and the ability to rationalize well.⁵³⁹ Family members are able to contribute complementary dimensions of decision-making but these are often tacit, unpredictable, and difficult for outsiders to identify. The family can thus be viewed positively as an organic component of an individual's supportive decisional matrix. The participants' stories, however, indicated that the visible level of interconnectedness between patient and family did not shift their attention from ensuring that the patient had been allowed at least a basic understanding of the issues, and was consequently offering consent with a measure of independence.

Balancing respect for cultural norms with legal and ethical obligations can be a dilemma for healthcare professionals working with families in triadic encounters. Truth-telling in healthcare presents an archetypal decision-making challenge where several critical moral and legal considerations converge. One factor is the physicians' own position on ensuring full transparency with patients, an attribute informed by their own ideological 'baggage.' Other influences include their moral education prior to medical training, their medical education itself (which would have introduced principles of normative and procedural bioethics), and importantly, their overall experience of other cultures.⁵⁴⁰ All of these factors potentially inform the position that full disclosure to the patient trumps other

⁵³⁸ Manson & O'Neill *supra* note 9 at 35-49

⁵³⁹ Kleinman, *supra* note 287; KW Bowman, "What are the Limits of Bioethics in a Culturally Pluralistic Society?" (2004) 32:4 J Law Med Ethics 664.

⁵⁴⁰ KL Ulrey & P Amason, "Intercultural Communication between Patients and Healthcare Providers: An Exploration of Intercultural Communication Effectiveness, Cultural Sensitivity, Stress, and Anxiety" (2001) 13:4 Health Commun 449; A Fernandez et al. "Physician Language Ability and Cultural Competence" (2004) 19:2 J Gen Intern Med 167; R Johnson et al. "Racial and Ethnic Differences in Patient Perceptions of Bias and Cultural Competence in Healthcare" (2004) 19:2 J Gen Intern Med 101; Chettih, *supra* note 37.

moral considerations, and influence a physician's skill in balancing truth-telling's harms against its benefits.

7.1.3 – Patients' Waivers of Rights to Privacy and Independence in Decision-Making

The participants were uniformly willing to consider patient requests to have family members present during their interactions, but all explicitly indicated that they would retain final authority over who was present and the extent to which family would be allowed to participate. The reason for retaining such control appeared to be grounded in their understanding that a patient should never be sidelined or excluded from the conversation, be it due to language difficulty or the dominance of a family member. Another reason for excluding family members would be if there were risks of compromising the accuracy or completeness of the history volunteered by the patient because of fear or embarrassment.

The issue of privacy of a patient during medical decision-making is a source of tension between two opposing viewpoints. One view is that healthcare workers should reformulate their views of patient autonomy to allow for a less individualistic approach, encouraging the family to be involved in aspects of decision-making under appropriate conditions.⁵⁴¹ To induce this change, it becomes necessary to improve the understanding amongst healthcare professionals about the relevance of relational autonomy — such a reformulated approach is discussed further in the next section. The opposing view on privacy of patients suggests that the nature of social relations and intra-family dynamics is generally far too complex and therefore healthcare workers risk perpetuating habituated or culturally traditional forms of suppression of an individual by family members. A seemingly voluntary waiver by a patient of their right to private decisions may hence be inauthentic. Hence it is critical for physicians to ensure that the person's autonomy is not adversely influenced by decision-making values which are presented as being their own, but which are in fact acquired as a result of “wholesale indoctrination or manipulation” by their socio-cultural circumstances.⁵⁴²

⁵⁴¹ Gilbar, *supra* note 285.

⁵⁴² Hyun, *supra* note 40 at 16.

7.1.4 – Undue Influences of Family Members

All the participants alluded to a degree of wariness about encroachment on the patient's autonomy during triadic conversations, even in situations where they had allowed the family member(s) to participate with agreement of the patient. If the undue influence of the family (as subjectively evaluated by the participant) on the patient's decision-making was palpable, the participants uniformly took measures to isolate the patient before continuing their discussions. They indicated that they needed to remain continuously vigilant to the possibility of coercion of the patient by heeding the family's form of communication and the broader socio-cultural dynamic. In one case, the participant had no qualms about insisting that the family member physically leave the room when such a situation occurred. Another method of intervention included steering the conversation to focus on the patient, in an attempt to ensure that decision-making was not proceeding under duress. No matter how closely dependent the relationship between the patient and their family appeared to be, none of the participants would look to the family for a final decision *per se*. This position seemed to apply even when the participants relied on family members to provide interpretation.

In summary, an important consideration was the interpretation and application of informed consent doctrine itself, the participants' narratives indicating a common understanding that legal and ethical rules place the family outside of the medical decision-making matrix.⁵⁴³ Such an arguably narrow interpretation persists amongst healthcare practitioners despite professional organizations' directives about the advisability of doctors communicating with family members, both from an ethical as well as a risk management perspective. As the participants acknowledged, formal medical education offers very little in terms of how to engage with family members constructively. The complexity of individual patients' relationships with their families, together with inherent difficulty in gauging what their cultural and moral values are like during brief clinical encounters, make it difficult to develop rules around appropriate family engagement during consent processes. Arguably, the paucity of rules and explicit guidelines governing physicians' interactions with family explains the idiosyncratic nature of the approaches they adopt. The

⁵⁴³ J Herring, "Where Are the Carers in Healthcare Law and Ethics" (2007) 27 Leg Stud 51; Chan, Peart & Chin, *supra* note 88.

participants acknowledged that the skills they apply when engaging with family are acquired in an *ad hoc* manner, during the course of their clinical practices. As they had been trained to, they approached informed consent primarily by presenting the patient with what they had decided was sufficient information to make an informed decision, while looking for evidence of comprehension. The participants would accommodate the family members' requests for clarifications or more information, but their opinion would not be sought for a treatment decision even when they showed evidence of being a well-connected and resourceful social unit for decision-making. The participants would only be satisfied if they had been convinced that the decision was being made by the patient themselves.

7.2 – Viewing a Patient's Autonomy Relationally

The liberal individualist model of the rational self, embraced in bioethics and law in regard to medical decision-making for consent, is wary of the influence of intimates on individuals. In fact, in most reports on the role of family in medical decision-making, the focus has largely been restricted to the issue of surrogate decision-making for minors or for adults with diminished capacity.⁵⁴⁴ The proposal that an individual can, indeed, remain a competent decision-maker even when they have allowed another person to exert significant influence over their decisions raises concerns about true voluntariness, or even of the person's actual capacity to decide. As the discussion above demonstrates, this general disposition towards family members of general circumspection rather than acceptance, expresses the essential approach adopted by my participants to family of their patients. A relational model of autonomy would, however, counter this circumspect orientation by incorporating a wider range of levels and types of "decisional authority-shifting."⁵⁴⁵

Medical consent interactions offer a pertinent illustration of the uneven negotiating power between powerful physicians, *de facto* gatekeepers in a public healthcare system, and ill persons who have become dependent on care offered by others.⁵⁴⁶ Although ethico-legal doctrines of informed consent were developed primarily to promote patient

⁵⁴⁴ O'Connor et al, *supra* note 157; MB Kapp, "Patient Autonomy in the Age of Consumer-Driven Healthcare: Informed Consent and Informed Choice" (2007) 28:1 J Leg Med 91.

⁵⁴⁵ Downie & Llewellyn, *supra* note 107 at 202.

⁵⁴⁶ Kaufert & O'Neil, *supra* note 46 at 41.

autonomy, the philosophical notion of autonomy is not a phenomenologically accurate depiction of the condition of anyone who has been rendered dependent because of an illness and is now seeking help.⁵⁴⁷ In any case, the capacity for functioning autonomously may be fluid and contextual, and persons often lean on their connections to develop core decisional capabilities — especially when faced with the demands of medical decision-making and confronted by their own mortality.⁵⁴⁸

Respect for the autonomy of persons is considered essential to moral relationships and ethical conduct, and it remains central to the discussion of bioethics even though concerns about patient autonomy *per se* may not be the utmost priority for busy clinicians and seriously ill patients. A philosophical focus on patient autonomy, however, is understandably prominent because of the political power and social standing of physicians as a class, together with the propensity for medical research and interventions to cause injury even though the intent may primarily be to heal.⁵⁴⁹

Institutionally executed versions of ‘patient autonomy’ (if simply interpreted as *independent* actions of the individual) may risk excluding a patient’s voluntarily chosen decisional supports from consent discussions, paradoxically denying patients the right of autonomous choice in the process. In adopting a wider view of autonomy, one can imagine how the relations of a patient can be more constructively treated as their means of self-realization. This self-realization flourishes if the patient is allowed to choose the family members they would prefer be involved.⁵⁵⁰ Unfortunately, traditional liberalism’s understanding of atomistic individuals as the basic units of political and legal theory has failed to recognize the inherently social nature of human beings. Such an understanding is problematic if the prevailing institutional view of the individual restricts healthcare workers’ freedom to foster decision-making capacity by ignoring the strengths that can be derived from positive relationships.⁵⁵¹

⁵⁴⁷ WD White, “Informed Consent: Ambiguity in Theory and Practice” (1983) 8:1 J Health Polit Policy Law 99.

⁵⁴⁸ Nedelsky, *supra* note 33 at 45.

⁵⁴⁹ White, *supra* note 547.

⁵⁵⁰ F Tuoldo, “Ethics of Responsibility in a Multicultural Context” (2010) 53:2 Perspect Biol Med 174.

⁵⁵¹ Mackenzie & Stoljar, *supra* note 76; Donchin, *supra* note 217; Christman, *supra* note 77; EF Kittay, B Jennings & AA Wasunna, “Dependency, Difference and the Global Ethic of Longterm Care” (2005) 13:4 J Polit Philos 443; Downie & Llewellyn, *supra* note 107; Nedelsky, *supra* note 33; JK Walter & LF Ross, “Relational Autonomy: Moving Beyond the Limits of Isolated Individualism” (2014) 133:supp Pediatrics S16; Wardrope, *supra* note 203.

Identifying the difference between an individual's perception of being autonomous (free and independent) and their actual and genuinely autonomous actions can be demanding for anyone, let alone a healthcare worker who has had relatively brief contact with the patient and family. A decision may mistakenly be judged as having been made autonomously simply because the process was viewed with a restricted evaluation of 'autonomy' that ignored feelings of powerlessness and helplessness. Persons and families faced with inescapable dependence on doctors' special expertise for access to and delivery of medical care often "learn to 'play the game' effectively, do what is wanted of them, and to confidently predict and reap the rewards handed out for compliance."⁵⁵² Clearly, such actions of compliance do not constitute expressions of genuine autonomy.

Since patients may feel most capable of being autonomous when supported by trusted persons, isolating them from their decisional supports could undermine key legal and ethical goals of informed consent doctrine. The experiences of my research participants in interacting with family members gives us an understanding of the way adherence to bioethical rules and institutional consent protocols can affect the tone and outcome of patient-family-physician interactions. In conflating 'independence' with 'autonomy,' potentially constructive patient-family relationships can be dismissed as stereotypically adverse external influences on a competent person's decision-making.

I have argued that a narrowly applied and individual-focused ethico-legal consent doctrine may negate positive aspects of a family's contribution to medical decision-making processes. The issue of decision-making in healthcare may be better understood through the perspectives of population-based practices or group identities, and through contemporary understandings of socially constructed vulnerability or power.⁵⁵³ If institutional informed consent processes have both theoretically and practically always existed as a coercive norm, given the intrinsic power imbalances between actors, it must be asked whether a patient can ever actually be autonomous in complying with such a norm.⁵⁵⁴ This would appear to be a valid justification for adopting a broader view of a person's ability to act autonomously.

⁵⁵² Nedelsky, *supra* note 33 at 135.

⁵⁵³ LS Parker, "Bioethics as Activism" in Lisa A Eckenwiler & Felicia Cohn, eds, *The Ethics of Bioethics: Mapping the Moral Landscape* (Baltimore: Johns Hopkins University Press, 2007) 144 at 151.

⁵⁵⁴ Nedelsky, *supra* note 33 at 44.

To apply a wider and more inclusive interpretation of patient autonomy in practice, it becomes critical to take heed of an individual patient's unique location within their web of relations. What may be at stake during physicians' discussions with family, especially about matters of risk to life and limb, may be the family's sense of solidarity, their spirit of cooperation, and their ability to demonstrate a capacity to love.⁵⁵⁵ At times like these, the autonomous rights of the individual patient, which physicians are primarily concerned about, may not be the most important consideration for the family.

When the collective is able to demonstrate convincingly that it does indeed promote, rather than threaten, an individual member's autonomy, adopting a relational view of autonomy in healthcare will likely not risk subordinating the individual patient's will to the collective. This is where anxiety can arise amongst healthcare workers, because of understandably limited appreciation of the normative practices within some cultures and societies.⁵⁵⁶ Taking an inclusive perspective makes it possible to understand why the promotion of autonomy is not always achieved by rigid protection against intrusion by any others. Constructive understanding of the relationships between a patient and their close ones should become a prerequisite to developing a useful form of autonomy promotion.⁵⁵⁷ As Nedelsky argues, a "stripped down image of the 'rational agent'" is a constrictive abstraction in law and political theory.⁵⁵⁸ Such a version of a person translated to a healthcare context is particularly detrimental, as it does not reflect the fact that the capacity for autonomy is informed by diverse factors.⁵⁵⁹

As my research findings have shown, the participants intervened actively to isolate the patient from their family whenever they recognized an 'undue' influence from intimates on the patient's decision-making process. This raises the question of how and when the influences of family ought to be considered excessive. Assuming voluntariness and legal competence, an individual's free choice to defer to others' decision-making authority over their choices is an idea that can be comfortably embraced by applying a relational view of the individual. In the traditional bioethical model, however, a patient's preference for

⁵⁵⁵ R Tong, *Feminist Approaches to Bioethics: Theoretical Reflections and Practical Applications* (Boulder: Westview Press, 1997) at 4.

⁵⁵⁶ Hyun, *supra* note 40; Nedelsky, *supra* note 33; Ho, *supra* note 40.

⁵⁵⁷ Nedelsky, *supra* note 33 at 77-99.

⁵⁵⁸ *Ibid* at 159.

⁵⁵⁹ *Ibid* at 283.

influences of the collective may even be considered an indication of incompetence to provide valid consent. Thus it is now pertinent to ask if law and consent policy have created limits on the exercise of autonomy in clinical settings, especially where patients are considering high-risk procedures.⁵⁶⁰

Nedelsky asserts that, “[l]aw is an important way through which power is exercised, shaped and justified.”⁵⁶¹ Accordingly, she argues that relationships shaped and structured by law have the propensity to hide power and hide the role of the state in that power, law also being a source of norms and a significant influence on how values are shaped. Overarching legal rules contribute to defining relationships and dynamics in medical practice, those between physicians and their patients’ families during consent processes being an example. We have seen how the legal rules governing consent give the physician discretion to control the degree to which family is allowed to participate in triadic interactions. Triadic interactions may thus be subject to a form of physician paternalism reminiscent of consent processes in an era when physicians’ unilateral control of information disclosure to patients was widely accepted. This practice has been supplanted by principles of shared decision-making, applied in varying degrees and contingent, to some extent, on the level of confidence that patients have in their own understanding of the medical details.

Self-trust, a factor that influences a sense of one’s being autonomous, is put at risk when illness and dependence force an individual to enter an environment within which they have very little power to control events. Consequently, if a patient becomes wary of their own judgments and loses confidence in their ability to act on their decisions, their ability to act autonomously is impeded. In such situations it is possible to imagine how the support of family members can be critical in reinforcing or encouraging self-trust. Healthcare professionals should recognize this prospect in order to avoid exacerbating the disadvantaged position of such patients.⁵⁶² Therefore, a deliberate assessment of a patient’s relationship with their family is of value in harnessing the latter’s contribution to the

⁵⁶⁰ Downie & Llewellyn, *supra* note 107.

⁵⁶¹ Nedelsky, *supra* note 33 at 72.

⁵⁶² C McLeod & S Sherwin, “Relational Autonomy, Self-Trust, and Healthcare for Patients Who Are Oppressed” in C Mackenzie & N Stoljar, eds, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York: OUP, 2000) 259 at 267.

patient's own decision-making capacity. From my research participants' perspective, however, there seemed to be a wariness of the possibility that family influence could be positive rather than coercive, especially if they sensed dysfunctional intra-family dynamics. Given their authority over the consent process and the absence of a defined ethical or legal protocol for interactions with patients' families, it is unsurprising that the participants adopted an interpretation of autonomy based on the individual patient's demonstration of independence.

The environment of medicine can be viewed as a reified universe of science, which operates according to scientific rules and procedures and gives rise to scientific knowledge. The lay public, however, lives in what social psychologist Serge Moscovici describes as a universe of 'social representation'⁵⁶³ in which persons are consensually free to elaborate and circulate forms of knowledge that come to constitute the content of common sense.⁵⁶⁴ I posit that in the context of my study, the construction of norms and communications codes within the system of medicine lies in opposition to a lay, commonsensical understanding of the concept of autonomous behaviours. As Nedelsky asserts, 'primal fears' seem to be stirred up by efforts to loosen the grip of control of dominant understandings of autonomy.⁵⁶⁵ This is probably more noticeable in settings where the picture of 'autonomy' needs to be released from its position of being tied to a sense of control and independence (and thus domination).⁵⁶⁶ It is possible to imagine, therefore, that law has the potential to contribute to a 'cultural reconstruction' of the understanding of autonomy in healthcare.⁵⁶⁷

7.2.1 – Consent Law and Patient Autonomy

I have argued that the customary application of consent law replicates an individual-focused philosophical notion of the self. Moreover, despite its intention of protecting patient autonomy, in practice consent processes that aim to comply with the content of the law may not always deliver the emancipation that the doctrine of consent aims to ensure. The process is biased towards ensuring cognitive rationality and

⁵⁶³ Social representation: A code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history. S Moscovici, "Foreword" in C Herzlich, ed, *Health and Illness: A Social Psychological Analysis* (London: Academic Press, 1973) vii.

⁵⁶⁴ S Moscovici, "Notes towards a Description of Social Representations" (1988) 18:3 Eur J Soc Psychol 211.

⁵⁶⁵ Nedelsky, *supra* note 33 at 298.

⁵⁶⁶ *Ibid* at 299.

⁵⁶⁷ *Ibid* at 298-301.

psychological competence, overlooking the diversity of factors that inform decisional competence (such as emotional states informed by fear and anxiety, physical weakness, or abruptly emergent dependence upon close others). Consent law does not explicitly require healthcare practitioners to take steps to enhance a person's capacity to consent, for example through their voluntary recruitment of decisional supports. Through the development of the doctrine of informed consent, law intervened effectively to protect the public from excesses of medical paternalism — but the question remains whether it went far enough.

Philosophically normative thinking about a person's autonomy, in terms of individuality and independence from external influences, has been translated into norms, laws, and institutional rules. These are exemplified by the silence of consent law regarding the role and status of the family of legally competent persons. Hence, a paradox emerges — the rigid application of the legal doctrine of informed consent may effectively be detrimental to the agency of the patient who thrives in nested relationships.⁵⁶⁸

Another paradoxical outcome of an individualistic application of consent rules may be the enabling of neo-paternalism in clinical practice. Here, having been given the discretion to include or exclude family members from the decisional process,⁵⁶⁹ the clinician is vested with the authority to determine what constitutes autonomous agency of the patient.⁵⁷⁰ This appears to run contrary to the goals of shared decision-making in medicine.⁵⁷¹ Additionally (as discussed in my Introduction chapter, p. 24), Western bioethics has had a far-reaching impact on non-Western, collectivist healthcare environments, resulting in a dissonance in the practical application of consent doctrines, and in the ethical training of medical professionals on this topic. This is a pertinent illustration of the epistemic dominance that the Western philosophical underpinnings of

⁵⁶⁸ *Ibid* at 85.

⁵⁶⁹ Institutional policies reflect the law's penchant for individualism. They also typically represent attempts to protect autonomy by reducing it to sets of rules which ensure factors such as the patient's capacity to consent, adequate risk warnings, and accurate identification of the practitioner and medical procedure. These procedural rules, however, remain blind to the patient's relationships, which (as argued above) have the potential to promote genuinely autonomous decision-making. Pursuing the goal of justice, these policies are primarily grounded in established bioethical norms rather than virtues, and do not generally provide for the consideration of aspects of caring within relationships.

⁵⁷⁰ See my discussion on Section 8 of British Columbia's *Health Care (Consent) and Care Facility (Admission) Act*, in my Introduction chapter.

⁵⁷¹ Christman, *supra* note 216; A Coulter, *The Autonomous Patient: Ending Paternalism in Medical Care* (London: Nuffield Trust, 2012); Barry & Edgman-Levitan, *supra* note 48.

bioethics theory have had in societies where healthcare workers may not subscribe to the notion that a legally competent patient should be regarded in isolation from their family members.⁵⁷²

Appropriate inclusion of the family may be a valid means of improving the patient's comprehension through collective processing of medical information, and the weighing of factors beyond logic or rationality. For example, for patients from communitarian cultures, the family members' ability to enhance trust in the physician or health system, or to reassure them about the families' ability to pool resources, may be significant factors that can influence decision-making confidence. However, in order to fully appreciate the potential value of the connected family's role in these situations, it is necessary to be reminded that the relational theory (as articulated by Nedelsky and other authorities on the topic) remains a liberal formulation — or reformulation — that still conceives the individual as a basic unit. Such a view of the person may not satisfy communitarian cultural needs. Besides the culturally relevant benefits of recognizing the role of the family, the judicious incorporation of the family's input in decision-making can also be instrumental in addressing the risk of insufficient comprehension, which itself undermines capacity to consent.⁵⁷³

Remembering that consent doctrine progressively evolved as a reflection of societal values upholding a patient's right to autonomous choice, we must now ask how this right operates in terms of the patient's freedom to choose and to control the decision-making environment during interactions with physicians.⁵⁷⁴ As Nedelsky argues, common law systems reflect a combination of the application of general principles and precedent with the particularity of a case. Thus the question arises whether law should then be expected to pay attention to a particular patient's means of acting autonomously during consent processes.⁵⁷⁵ Given the relationships of power within a public healthcare system, what may now be warranted is a review of the limitations to the protection of patient autonomy being produced by applying current versions of legal and ethical consent doctrines.

⁵⁷² M Fricker, "Epistemic Oppression and Epistemic Privilege" (1999) 29:sup1 Can J Philos 1911; J Go, "For a Postcolonial Sociology" (2012) 42:1 Theory Soc 25.

⁵⁷³ Coggon, *supra* note 203; Coggon & Miola, *supra* note 25.

⁵⁷⁴ Nedelsky, *supra* note 33 at 238, 240.

⁵⁷⁵ *Ibid* at 301.

In summary, due consideration of alternate and less individualistic interpretations of autonomy in medical decision-making may enlarge our grasp of the possibilities for family participation in clinical consent discussions. An expanded understanding of how a patient's ability and capacity to act autonomously can be safeguarded may allay fears of compromising that patient's right to self-determination. Adopting a relational approach to individual interactions whenever the protection of patient autonomy is a critical goal may be a means of genuinely protecting autonomy. This calls for a systematized reframing of healthcare workers' approach to patient care such that the position of the family in medical decision-making is viewed more inclusively, wherever appropriate and relevant. A relational analysis is capable of uncovering what is truly at stake in every situation where the family participates in a patient's care.⁵⁷⁶

⁵⁷⁶ *Ibid* at 372.

CHAPTER 8: Conclusions and Implications

Reflecting on ‘A Bruising Personal Experience’

The introduction to this work began with a story — a story I conclude here. After I heard that Sophia’s husband had threatened to harm my wife should Sophia not survive, and having gained a vivid sense of his social network’s membership during their visits to the hospital, my anxiety became more pronounced. This report compounded my sense of disappointment and depression — the sort that physicians often experience in the aftermath of an adverse treatment outcome. Such a response is, in part, the result of reflecting on decisions made during the treatment, combined with a real fear of being sued by aggrieved family members. I had yet to face the disappointment and anger of many more persons, with most of whom I had no opportunity to build a relationship before undertaking Sophia’s treatment. I rescheduled non-urgent surgery, suspended my call duties for three weeks, and temporarily stopped accepting new referrals in my clinic. The hospital did not have a formal physicians’ support system in place; however, I received commiserations from physician colleagues and nurses who, themselves, were aghast when my story made the rounds.

Of course, my spouse, also a physician, was herself deeply troubled at my state of mind, and suggested I speak with a good friend and senior colleague: an anaesthesiologist with whom I had worked closely at a different hospital. He came over to our home late one evening and spent a few hours with me, listening to my narration of the events and to my concerns. He reassured me that I had tried my professional best to help the patient, given the nature of her advanced tumour.

I soon realized that I had an ongoing responsibility, to my current and future patients, to be at my best professionally. Patients (and their families) are rarely aware of the turmoil their physician may be undergoing from the outcomes of other cases — and quite rightly, since their concerns are justifiably with *their* own illnesses and whether that physician is able to focus on helping solve *their* problems. This is particularly so when the medical condition at hand, such as brain or spine tumour, demands hours of physically intricate and mentally demanding surgery. I realized that I needed to pull myself together

as quickly as possible, to be able to get on with my professional work without compromising my current patients' quality of care.

I remembered the words of the late Dr. Brian Cummins, my teacher and neurosurgical mentor, twenty years earlier, after we had struggled unsuccessfully, far into the early hours of the morning, to save a young man who had experienced a massive brain haemorrhage from a congenital vascular malformation. When we reviewed the patient's post-operative findings in the CAT scan room at about 3 a.m., he placed his hand around my shoulder and said, "Go home, and get some rest — you must accept that we can't always save patients with such conditions. There are other patients who will need you tomorrow." Although these words comforted and motivated me, they should not have been my only resource.

Nothing in my physician's training had prepared me for the intensity and form of this encounter; I had been equipped with no formal skills with which to navigate such a high-magnitude emotional and professional challenge to my confidence. Instead, a 'hidden curriculum' had informed my professional conduct at the time of my triadic interactions with the patient and her family; and even though I had fortuitous mentorship to draw on, that same curriculum was nearly mute post-fact, offering me little help in the aftermath of the tragic treatment outcome. Like my peers, I had little awareness of how families' interests and considerations intersect with the procedural aspects of informed consent. Neither had I been able to look to regulatory obligations, institutional policies, or explicit professional guidelines for guidance. So unaided, I was years away from realizing that adequately engaged and informed families are more likely to constructively contribute to the holistic care of the individual patient, while becoming better prepared for any adverse treatment outcomes. Accordingly, my standard understanding of autonomy and consent had been properly deployed and all relevant procedural, legal, and ethical standards and considerations had been satisfied, yet the missed opportunity for more — for the building of trust relationships with close others of the patient — had profound consequences.

8.1 – Physician-Patient Interactions: An Evolving Model, a Training Gap

Patients' families become involved in pre-consent discussions with healthcare professionals for a number of reasons. They may insist on participating alongside the patient to allay their anxieties, for example, or to satisfy cultural expectations in a given clinical context. They may also be in attendance at the explicit behest of the patient themselves, motivated by a range of factors, from surmounting language barriers, to increasing the patient's decision-making confidence in the face of the sense of vulnerability triggered by illness. Such triadic interactions unsettle the traditional physician-patient dyad, which has enjoyed worldwide pre-eminence as the universal model for at least a generation. Clearly, patient autonomy, confidentiality, and privacy which the tight, physician-patient unit is seen to safeguard, are serious and valid concerns. Therefore, in attempting to embrace a relational model when viewing patient-family-physician interactions in medical decision-making, profound challenges remain: ensuring lack of coercion, understanding consensus, and safeguarding against inadvertent perpetuation of any pre-existing oppression of the patient by family members. Yet triadic, physician-patient-family interactions are only likely to increase as powerful demographic and social forces — deepening cultural diversity globally; growing recognition of paternalism, Western biases, and problems with power asymmetries in dyadic consultations; and increasing acknowledgment of the social embeddedness of the individual — continue to converge upon a new norm of *shared* decision-making. That norm calls for constructive engagement with all the parties involved.⁵⁷⁷

The importance of good relationships between healthcare providers and patients' families, who are validly invested in the medical care of their loved ones, cannot be underestimated.⁵⁷⁸ Accordingly, it is critical that relevant clinical systems and professional training curricula reflect an acknowledgement that family members are persons with whom trusting relationships should be built, rather than parties who complicate physician-patient interactions. A high trust level between providers and families offers the benefit of improved long term care planning and better patient compliance with treatment

⁵⁷⁷ Charles et al, *supra* note 4; Barry & Edgman-Levitan, *supra* note 48; Epstein, *supra* note 134.

⁵⁷⁸ Blustein, *supra* note 200.

recommendations.⁵⁷⁹ Consequently, the training of doctors to engage skilfully with patients' families should be approached with the consideration assigned to education in biomedical skills. Inadequately managed conflict with the families of patients is potentially costly to physicians personally, as well as to institutions.⁵⁸⁰

The ascendancy of shared decision-making has spurred serious reconsideration, in the literature, of reigning conceptions of patient autonomy, particularly around informed consent. I recognize that the main approaches to conceptualizing patient autonomy reveal a divergence between individualistic principlism and accounts stressing the interrelatedness of decision-makers. However, I found a fruitful consonance between the relational views of a competent patient proposed by Western communitarian and feminist thinkers, and those of non-Western ethicists who consider the patient in relationship to their family during consent.⁵⁸¹ Using that consonance as a foundation, I then reconciled principlist and relational views of patient autonomy via recasting autonomy as both nested and variable (drawing on Jennifer Nedelsky⁵⁸²), and inherently complexifiable and contextual (using Raanan Gillon⁵⁸³). Such a reformulation takes into consideration the relevant constitutive factors of autonomy, rendering ostensibly individualistic notions compatible with alternative accounts of volition and duty, and non-dominant expressions of virtues and ideals. Further, this reconciliation validates the radical notion that the patient's autonomy may well be compromised by ignoring the value of familial influence, which simultaneously suppresses the agency of the family and restricts the patient's own freedom of choice. These were important theoretical developments that situated my subsequent fieldwork in a hitherto-unexplored space, as the application of relational autonomy presents a significant clinical challenge thanks to incomplete knowledge of how medical practitioners should interpret their patients' ability to be autonomous during consent discussions in the presence of family members.

⁵⁷⁹ Kim, Kaplowitz & Johnston, *supra* note 49; Epstein et al, *supra* note 98.

⁵⁸⁰ Krause, Bremerich & Rustemeyer, *supra* note 119; SC Charles, "Psychological Reactions to Medical Malpractice Suits and the Development of Support Groups as a Response" (1988) 37 Instr Course Lect 289; SC Charles, "Coping with a Medical Malpractice Suit" (2001) 174:1 West J Med 55; JP Lavery, "The Physician's Reaction to a Malpractice Suit" (1988) 71:1 Obstet Gynecol 138.

⁵⁸¹ Gillon *supra* note 256.

⁵⁸² Nedelsky, *supra* note 32; Nedelsky, *supra* note 33 at 82.

⁵⁸³ Gillon *supra* note 256.

Literature that examines the position and role of family in pre-consent physician-patient interactions contains largely theoretical or ethnographic analyses of the effects of third parties, within the ethical and legal frameworks of informed consent doctrine.⁵⁸⁴ It does not tell us about physicians' personal experiences of engaging with family members during such discussions, especially in situations when they sense that the family's input challenges their patient's autonomy or appears to be coercive. The absence of explicit analyses of these experiences implies that the development of physicians' skills in handling these important interactions may be left largely to chance, learned through an informal training system euphemistically recognized as the 'tacit' or 'hidden curriculum.'

In order to reveal and address this theoretical and empirical omission, having felt the profound effect of the 'tacit curriculum' firsthand, I recruited nine Canadian specialist physicians who worked in high-risk fields to interview about interactions with the families of their competent patients during pre-consent discussions. I chose these individuals because the nature of their interactions with patients and their families around consent are informed by different priorities, compared to the sort experienced by physicians in relatively low-risk fields. The latter are mostly able to, or need to develop longitudinal relationships with their patients, for example in the course of managing chronic illnesses.

My overarching objective was to better understand how the physician-participants interpreted their ethico-legal obligations to promote and protect their patients' autonomy in situations where significant others could potentially influence the decision-making process. To this end, I conducted a qualitative study using the interpretative phenomenological analysis (IPA) methodology, collecting data by conducting in-depth individual interviews. My findings contribute to our understanding of the various factors physicians consider as they attempt to balance their ethical obligations to family members with the responsibility to protect their patients' right to make free and informed choices. Moreover, my findings provide useful insights into physicians' interpretations of 'patient autonomy' in a clinical context where the presence of close others influences communications dynamics.

⁵⁸⁴ K Crow, L Matheson & A Steed, "Informed Consent and Truth-Telling: Cultural Directions for Healthcare Providers" (2000) 30:3 J Nurs Adm 148.

Many non-Western patients in a Western context prefer to involve different decision-makers, and are comfortable with decisional influences of trusted persons during clinical encounters — but this is an option that is often beyond what medical providers typically permit. My findings are of relevance in the application of consent doctrines as these are applied not just to non-Western group members in multicultural contexts, but also to members of majority groups in both collectivist and individualist cultural settings. Hence, my research demonstrates that whenever family members from *any* cultural group participate alongside the patient in medical decision-making, useful pointers for practitioners may be gained by examining an alternative — and broader — relational view of autonomy. I review these findings below, grouping them into three cross-cutting observations that emerged from my data.

8.2 – Review of the Main Research Findings

In this section I present three key findings of my research and these pertain to the phenomena of the research participants' experiences of simultaneous, 'triadic' interactions with patients and family members, as well as the actions they took in response to a variety of challenges that arose during such encounters.

8.2.1 – Finding A

Engaging with family of patients during pre-consent discussions presented complex demands and unsettled the familiar physician-patient (dyadic) dynamic. Despite the additional voices in the physician-patient encounter, the participants retained their focus on seeking evidence of the patient's own comprehension and agency.

The presence of family members during pre-consent discussions with patients provoked a variety of communications challenges. This was, in part, because the participants sought to ensure that their patients were offered the protections usually assumed within conventional frameworks of a private, 'dyadic' physician-patient interaction. The participants privileged the dyad even if the patient had explicitly welcomed the presence of their family members, and even where the participants clearly depended upon family members for language translation. The role of family members was viewed as primarily to provide additional information, rather than to help the patient make a decision.

Hence the participants did not turn to the families to obtain their opinions, unless they wished to form a coalition with one or more family members in order to convince the patient to make a particular choice. Whatever the scenario, the participants ultimately sought to hear the patient's voice no matter how faint it had become during triadic interactions.

8.2.2 – Finding B

The participants retained overall authority and control of the consent discourse when family was present, interpreting autonomy in individualistic terms.

The participants controlled the degree to which family members were allowed to influence pre-consent discussions, assuming that the physician had a duty (and thus the authority) to protect the patients' autonomy. Narrowly equating autonomy with independence, the participants curtailed the family's influence whenever it appeared to suppress their patient's voice, even when the patient and their family were ostensibly accustomed to making decisions collectively. This interpretation of 'patient autonomy' is aligned with the individualistic version of autonomy integral to formal ethico-legal principles of informed consent doctrine. Additionally, it is grounded in the participant's general understanding of ethical principles, rather than specific rules defined by the law governing consent in British Columbia.

An individualistic approach to patient autonomy discounts the possibility that decision-making can be autonomous even when it occurs during contemporaneous involvement of trusted others. It also fails to consider that decision-making supported by close ones may indeed strengthen an individual's decisional capacity. This is especially pertinent when a patient faces the burden of considering medical interventions that carry major risks. Additionally, a family member's illness calls attention to the complexity of families and human relationships.⁵⁸⁵ Any evidence of a patient's intersubjective reliance on family to help process complex information when making a serious decision could, therefore, widen the interpretation of 'patient autonomy' in healthcare settings.

⁵⁸⁵ Schäfer et al, *supra* note 44.

A relational interpretation could, however, be problematic. Intersubjectivity between members is unique to individual families, and it may well be unreasonable to expect a physician (or any outsider) to easily recognize its qualities in a clinical context. That said, exerting authority to disallow valuable decisional supports for the patient, based on a subjective interpretation of a potential threat to autonomy, is paradoxically paternalistic.

Often in clinical practice, family members are communicated with separately from the patient, typically at scheduled family conferences. Arranging for these separate discussions or instructing the patient to communicate relevant information to their close ones effectively denies the family the opportunity to participate in critical stages of decision-making. Although such a disconnected approach may fulfil a physician's ethical obligation to keep family members informed, it detracts from the prospects of healthcare professionals choosing to interpret the patient's autonomy relationally — an interpretation which arguably respects the key goals of medical consent in a more holistic fashion. The participants' stories indicated that their routine method of obtaining consent was aligned closely with the dictates of bioethics and law, within which neither the patient nor their family are given the opportunity to indicate their preference for decision-making.

8.2.3. – Finding C

In the absence of any institutional protocols to guide their interactions with family members, the participants proceeded intuitively in every unique instance.

Not having the benefit of professional or institutional practice guidelines to steer their participation in triadic or multi-party discussions, the participants responded to each interactive dynamic and its challenges as they saw fit. Their communications were impacted by factors such as prior modeling by their seniors, their lack of formal training in specific skills aimed at family interactions, together with their cultural awareness, all underpinned by personal values. Skills that develop a physician's 'bedside manners' is a relatively neglected area in medical education, partly because the field has unfortunately become technology-focused, which oftentimes sidelines the attention paid to developing

good communications practices.⁵⁸⁶ Indeed, several of the stories illustrated situations where conflict arose during interactions with family, with suboptimal outcomes (from the participant's perspective).

8.3 – Limitations of the Research

My research was qualitative by design and aimed primarily at gaining a deeper understanding of a specific clinical experience of a purposefully selected category of medical specialist. Therefore I did not expect that my findings would allow me to make more broadly generalizable recommendations. I anticipate that my suggestions will be pertinent to a limited set of physicians in specialist practice (or in training) who regularly find themselves in situations where family members wish to be involved in medical decision-making alongside the patient.

The fact that I personally conducted the in-depth interviews may also have had an influence on participants' responses. Each interviewee was aware of my professional background, my academic qualifications and interests, and my lived familiarity with the practice of obtaining informed consent in clinical settings. Thus some participants may have circumscribed their comments — for example, due to anxiety about appearing unfamiliar or inarticulate about every ethical or legal expectation related to the application of consent doctrine. It was also difficult to remain constantly aware of my own biases, or to keep them in check, especially when my conversations with participants touched on the types of family interactions with which I had personally encountered difficulties. I realize that another researcher would have dwelt on a different spectrum of communications challenges or ethical dilemmas.

My impressions of how the participants interpreted the concept of 'patient autonomy' were only gleaned from reflecting on their stories of navigating risks to their patients' privacy. I did not administer any research tool that focused on eliciting answers to explicit questions about participants' understanding of patient autonomy, or the actions that they would take to protect it when family was present. In retrospect, such a method may have been a useful component of the research process.

⁵⁸⁶ Silverman, *supra* note 98.

In the interpretation of the idiographic data, it is likely that epistemic influences (including my educational, cultural and professional background) had a bearing on the conclusions I drew. The perspectives and capacity of a single researcher are necessarily restricted, even when they are aware of the risks of personal bias or blind spots, and despite these realizations spurring cautious reflexivity throughout the entire research process.

In my study there was a preponderance of male participants. It is reasonable to speculate that different data may have arisen if there were more female physician participants, and I have discussed this possible limitation earlier, in section 3.12.2 (page 107). Relatedly, the choice of participants from a less senior, or more ethnically diverse selection of specialist doctors, may have produced qualitatively different results. My participants all practiced in urban, tertiary hospital settings, whereas physicians practicing in smaller towns or centres may have had different experiences of engaging with family members, owing to the maintenance of professional reputations in less anonymous community settings. A corresponding limitation could be identified in terms of the research orientation to particular types of patient-family-physician encounters.

The focus of my study was on specific situations where the issues being discussed involved decision-making about high-risk procedures. Hence, the reference was to conversations that were likely charged by fear of complications or conflict over the choice of alternative treatments. Doctors, however, commonly engage in a wide variety of conversations with family members of their patients, thus significantly different experiences could be expected to arise from discussions involving a less emotive range of issues.

Within a public healthcare system affording limited choice of either institution or provider, knowledge and authority gradients between physicians and their patients and families can be steep.⁵⁸⁷ In settings where power differentials are less pronounced — for example, in a highly competitive private medicine context, with similar ethico-legal frameworks — my research may have yielded results that reflected a consumer-focused ethos. Here it is plausible that physicians in the private sector would accommodate the

⁵⁸⁷ MW Calnan & E Sanford. “Public Trust in Healthcare: The System or the Doctor?” (2004) 13:2 *Qual Saf Healthcare* 92; SYS Wong et al. “Comparison of Primary Care Experiences among Adults in General Outpatient Clinics and Private General Practice Clinics in Hong Kong” (2010) 10:1 *BMC Public Health* 397; Neumann et al, *supra* note 457.

family's interests more inclusively, particularly if family members also took responsibility for the cost of treatment.

8.4 – Research Implications

The findings of my research are relevant to three fields of practice and study in Canada: medical education, medico-legal policy in healthcare institutions, and sociological research. I address the implications for each of these fields in turn.

8.4.1 – Implications for Medical Education

Given the empowering access to medical information on the Internet and increasing cultural diversity, physicians will be expected to engage competently with family members who wish to participate in treatment decision-making. The role of family in consent for legally competent patients is not specifically addressed in ethico-legal education; and most medical curricula do not explicitly seek to develop the communication skills for constructive engagement with patients' family members, within the frameworks of ethics and law. Yet these facilities are far too important to be left to *ad hoc* training methods delivered primarily through fortuitous mentorship within a 'hidden' curriculum. As with many other skills in medical practice, systematic study is required to develop vital dyadic and triadic communication techniques. There is much to be gained from a better understanding of the skills that experienced physicians apply in navigating the challenges family interactions when patient autonomy is at risk, and to incorporate these lessons into formal training for doctors at all stages of their careers.

8.4.2 – Implications for Medico-Legal Policy in Healthcare Institutions

Currently there are no regulatory obligations or explicit professional guidelines requiring Canadian healthcare providers to engage with family members of competent patients during pre-consent discussions. Treatment risks are commonly viewed as a 'thing' that physicians are required to disclose to competent patients — that, too, on an individual basis.⁵⁸⁸ Hence, risk disclosure during pre-consent discussions is by and large delivered in the context of a legally-orientated institutional policy of information transfer, ostensibly

⁵⁸⁸ Manson & O'Neill, *supra* note 9 at 36-7.

with the patient's autonomous decision-making in mind. Associated to some extent with medical education, my research findings are relevant to the formulation of institutional policies governing informed consent processes, as well as the laws on which these are based. Other countries have recognized the value in considering the needs of family members during pre-consent discussions — and not only countries with collectivist cultures. Policies that facilitate safe and appropriate inclusion of family members in decision-making are highly likely to contribute to trust-building with the public and reduce the potential for conflict (see Chapter 2.3). If a relational view of patient autonomy can be integrated into the principles underlying informed consent protocols, whilst providing adequate protections against coercion and oppression, a more constructive appreciation of the role and status of family in the process will have been achieved.

I have argued that by giving healthcare professionals the discretion to determine family members' role(s) in the informed consent process, the law of healthcare consent in British Columbia exacerbates their power over lay persons. This provision is ostensibly aimed at giving the professional maximal ability to protect patient autonomy in the face of potential duress or coercion by close others. While the basis for this rule can be appreciated — not all family members or close others may have the patient's best interests at heart (see Chapter 6.2.3) — it seems to deny the possibility that there are situations wherein a person's selfhood and autonomy may validly or preferably be interpreted relationally.

Relevant sections of consent legislation could be amended to allow for a wider interpretation of the concept of patient autonomy to include relationality, and such an interpretation could also inform institutional practice guidelines. Sections 6-8 of the law of consent in British Columbia⁵⁸⁹ are the areas where I would propose changes:

Elements of consent

- 6.** *An adult consents to healthcare if*
- (a) the consent relates to the proposed healthcare,*
 - (b) the consent is given voluntarily,*
 - (c) the consent is not obtained by fraud or misrepresentation,*
 - (d) the adult is capable of making a decision about whether to give or refuse consent to the proposed healthcare,*

⁵⁸⁹ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181.

- (e) the healthcare provider gives the adult the information a reasonable person would require to understand the proposed healthcare and to make a decision, including information about*
- (i) the condition for which the healthcare is proposed,*
 - (ii) the nature of the proposed healthcare,*
 - (iii) the risks and benefits of the proposed healthcare that a reasonable person would expect to be told about, and*
 - (iv) alternative courses of healthcare, and*
- (f) the adult has an opportunity to ask questions and receive answers about the proposed healthcare.*

How incapability is determined

- 7. When deciding whether an adult is incapable of giving, refusing or revoking consent to healthcare, a healthcare provider must base the decision on whether or not the adult demonstrates that he or she understands***
- (a) the information given by the healthcare provider under section 6 (e), and*
 - (b) that the information applies to the situation of the adult for whom the healthcare is proposed.*

Duty to communicate in appropriate manner

- 8. When seeking an adult's consent to healthcare or deciding whether an adult is incapable of giving, refusing or revoking consent, a healthcare provider***
- (a) must communicate with the adult in a manner appropriate to the adult's skills and abilities, and*
 - (b) may allow the adult's spouse, or any near relatives or close friends, who accompany the adult and offer their assistance, to help the adult to understand or to demonstrate an understanding of the matters mentioned in section 7.*

Section 8(b) explicitly gives the healthcare professional sole discretion to make determinations about who can be present during pre-consent interactions, in a role limited to helping the patient's comprehension. Authorizing the professional to make this determination unilaterally arguably represents a narrow and individualistic interpretation of patient autonomy. It additionally fosters a version of paternalism that runs contrary to modern healthcare principles, which instead encourage patient participation and collaboration in medical decision-making.

If subsection 8(b) instead required the person obtaining consent to *privately* enquire of every patient whether they preferred to have the company of a particular person or persons of their choosing during pre-consent discussions, it would offer the patient the

opportunity to determine the form of decisional supports they require.⁵⁹⁰ Such a statutory requirement could promote self-determination, effectively instituting an expanded interpretation of personal autonomy that is better aligned to the primary goals of informed consent doctrine, namely the protection of a patient's dignity, security, and agency. The relevant clause could hence be framed in this manner, to replace subsection 8(b):

Must privately inquire whether the adult requires the assistance of any person or persons of their choice to help them understand the communications of the healthcare provider and to provide the patient support in coming to a decision whether to agree to consent to the proposed intervention.

Although such a regulation would not fully extinguish the risk of coercion from family members who are aware that such a procedural option exists, it may nonetheless help some categories of patients who are not at risk of coercion and whose decisional confidence can thus be enhanced. Further, in situations where a coercion risk has been identified, regulations could be structured to provide adequate safeguards.

One safeguard could be to establish a routine practice where the person obtaining consent is expected to consult with other members of the inter-disciplinary patient care team, to uncover concerns about the risk of coercion. This would allow for recruiting wider insights into the patient's social environment, including the patient's decision-making style and capacity, and an appreciation of the quality of relationships between the patient and individual family members. In a hospital setting, evening/night nursing and other staff often have the greatest opportunity to interact with family members or to observe family-patient interactions, making them a useful resource in attempting to make a 'social diagnosis' of the patient.

Where language is a barrier, and especially where a coercion risk has been identified, the use of professional interpreters could be made mandatory. My research participants' stories indicate that family members are commonly recruited because of resource shortfalls, and this severely compromises the physician's ability to ensure

⁵⁹⁰ Crow, Matheson & Steed, *supra* note 584.

uncoerced decision-making by the patient.⁵⁹¹ Professional interpreters could be trained to identify potential suppression of the patient's voice during these conversations and to ensure that that voice is allowed to emerge.

Apart from a single signed consent form, evidence of the patient's own grasp of disclosed treatment risks (or lack thereof) can be documented explicitly by treatment team members in counselling and pre-consent discussions involving family. Collectively, such documentation serves to record the patient's understanding while also providing signals to the primary, consent-seeking caregiver that additional measures are required to ensure the level of comprehension necessary for valid consent.

8.4.3 – Implications for Sociological Research

My project was restricted to the experiences of physicians in the context of triadic or multi-party interactions, while the corresponding experiences and perspectives of patients and their families clearly merit further investigation. Knowledge obtained from such research would contribute to better understanding, on the part of healthcare institutions and professionals, about satisfying those families with an interest in participating in the medical decisions that affect their close ones. Relative to the context in each situation, adequately engaged and informed families are more likely to constructively contribute to the holistic care of the individual patient, while becoming better prepared for any adverse treatment outcomes.

In pre-consent clinical encounters, the experiences of the family members themselves were not the focus of my study; thus I can only speculate about how satisfied they might have been. It is conceivable that restricting family members' input in the name of protecting the patient's independence can risk alienating the former, particularly if they are accustomed to participating fully in major decision-making processes. Such alienation undermines trust and potentially impacts the quality of the family's support of (and in) the care plan. On a systemic scale, conflict with individual families during clinical interactions

⁵⁹¹ In *Eldridge v. British Columbia (Attorney General)*, [1997] 3 SCR 624 the Supreme Court of Canada ruled that, where necessary to ensure effective communication, interpreters must be provided in the delivery of medical services. In that case, the appellants (Robin Susan Eldridge, John Henry Warren and Linda Jane Warren) were born deaf, and argued that the absence of sign language interpretation impeded their communication with health care providers, risking misdiagnosis and ineffective medical treatment.

impacts public trust in the medical profession in general; this, in turn, has a bearing on the overall risk of malpractice litigation.

Of similar value would be research aimed at developing formal practice protocols and training to help healthcare workers identify and recruit decisional supports (family members or others trusted by the patient). This would benefit individual patients from all cultures, not only those from non-Western groups. Patient and family-oriented research that avoids cultural stereotyping could also help healthcare workers discern intra-family dynamics and identify indicators of patient coercion.

Conclusion

Physician-patient-family interactions and informed consent for medical interventions are of topical interest. As we follow debates in Canada on the withdrawal of treatment for cases deemed medically futile (*Cuthbertson v. Rasouli*)⁵⁹² and physician assisted death (*Carter v. Canada*)⁵⁹³ it becomes evident how families' interests and considerations intersect with the procedural aspects of informed consent.⁵⁹⁴ The deliberations in these cases illustrate the shift from medical paternalism to the sharing of authority for healthcare decision-making between professionals, the patient, and the patient's family and close others.

Guided by philosophical insights drawn from law, bioethics, and feminist and postcolonial theory, my research maintains that in most cases constructive engagement with patients' families materially contributes to the building of harmonious healthcare relationships.⁵⁹⁵ The stories and reflections of my research participants provide insight into the practical intricacies involved in pragmatically balancing ethico-legal obligations to protect patient autonomy with empathetic consideration of the valid interests of family members. It is critical that we widen the focus of pre-consent discussions and decision-making to judiciously include the voice(s) of the family, carefully discerning the plurality

⁵⁹² *Cuthbertson v. Rasouli* 2013 SCC 53, [2013] 3 SCR 341.

⁵⁹³ *Carter v. Canada* (Attorney General), 2015 SCC 5, [2015]

⁵⁹⁴ H Young, "Why Withdrawing Life-Sustaining Treatment should Not Require 'Rasouli Consent'" 6 McGill J.L. & Health 54.

⁵⁹⁵ X Chen & R Fan, "The Family and Harmonious Medical Decision Making: Cherishing an Appropriate Confucian Moral Balance" (2010) 35:5 J Med Philos 573; DE Weissman, TE Quill & RM Arnold, "The Family Meeting: Causes of Conflict" (2010) 13:3 J Palliat Med 328.

of values besides autonomy that inform the determination of the patient's best interests. Hence, a clearer understanding of the multifaceted and nuanced dynamics of patient-family-physician interactions in clinical practice is not only timely, but urgent. Healthcare professionals, who are the face of the healthcare system, could be trained to become as competent at engaging with families as they are with managing the complexities of their patients' illnesses.

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Appendix I: Research Ethics Approval



Office of Research Services | Human Research Ethics Board
 Michael Williams Building Rm B202 PO Box 1700 STN CSC Victoria BC V8W 2Y2 Canada
 T 250-472-4545 | F 250-721-8960 | ethics@uvic.ca | uvic.ca/research |

Certificate of Renewed Approval

PRINCIPAL INVESTIGATOR:	Richard Veerapen	ETHICS PROTOCOL NUMBER:	13-160
UVic STATUS:	Ph.D. Student	Minimal Risk Review - Delegated	
UVic DEPARTMENT:	LAWF	ORIGINAL APPROVAL DATE:	05-Jun-13
SUPERVISOR:	Dr. Maneesha Deckha	RENEWED ON:	18-May-17
		APPROVAL EXPIRY DATE:	04-Jun-18

PROJECT TITLE: Physician Engagement with Family and Close Others of Patients During the Informed Consent Process

RESEARCH TEAM MEMBER None

DECLARED PROJECT FUNDING: None

CONDITIONS OF APPROVAL

This Certificate of Approval is valid for the above term provided there is no change in the protocol.

Modifications

To make any changes to the approved research procedures in your study, please submit a "Request for Modification" form. You must receive ethics approval before proceeding with your modified protocol.

Renewals

Your ethics approval must be current for the period during which you are recruiting participants or collecting data. To renew your protocol, please submit a "Request for Renewal" form before the expiry date on your certificate. You will be sent an emailed reminder prompting you to renew your protocol about six weeks before your expiry date.

Project Closures

When you have completed all data collection activities and will have no further contact with participants, please notify the Human Research Ethics Board by submitting a "Notice of Project Completion" form.

Certification

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

Dr. Rachael Scarth
 Associate Vice-President Research Operations

Certificate Issued On: 18-May-17

13-160
 Veerapen, Richard



Appendix II: External Transcription Non-Disclosure / Confidentiality Agreement

CONFIDENTIALITY AGREEMENT Transcription Services

Project Title: "PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS"

I, _____, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentation received from Richard Veerapen related to his doctoral study, "PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS."

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;
2. To not disclose, publish or otherwise reveal any of the confidential information received from Richard Veerapen, to any other party whatsoever;
3. To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Richard Veerapen;
4. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession;
5. To return all audiotapes and study-related documents to Richard Veerapen in a complete and timely manner within ten (10) days of his requesting them. This includes all material received in written or tangible form, including copies, or reproductions or other media containing any confidential information;
6. To destroy any copies of confidential documents or other media developed by me and remaining in my possession after the completion of the transcription work;
7. To provide a written certificate to Richard Veerapen regarding the destruction of relevant material within ten (10) days of completion of the destruction;
8. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) _____

Transcriber's signature _____

Date _____

Appendix III: Letter of Invitation to Participants

Date:

Name and Address

Dear Dr.

Re: Request For Your Participation In My Doctoral Research Project

I am a doctoral candidate in the Ph.D. (Law and Society) program at the Faculty of Law, University of Victoria. I would be most grateful if you would consider being interviewed as a participant in my research project, which has been detailed in Appendix A of this letter. Appendix B contains my brief resume and Appendix C contains sample interview questions.

Your involvement in my research project will entail the following:

1. Participation in an in-depth interview conducted by the researcher personally. This will take an estimated time of 1.5 to 2 hours and may be held at a time and location of your choice. Your participation will be as a private individual and not as an employee or representative of a healthcare organization. Please inform me if your participation in this project will still require clearance from any regulatory body, so that the appropriate permission is obtained ahead of the interview.
2. Signing of a consent form, as drafted below in Appendix A of this document. This form will be presented to you for your signature immediately prior to the commencement of the interview.
3. Reviewing of the transcript of the conversation from the interview session, with a view to correcting misinterpretations or adding clarifications or other comments.

Should you require further clarifications regarding my project kindly contact me directly at the numbers or addresses below.

I shall look forward to hearing from you.

Thank you.

Yours truly,

Dr. Richard J. Veerapen MB,BS

Ph.D. Candidate (Law and Society)
Graduate Program
Faculty of Law, University of Victoria
PO Box 1700, STN CSC
Victoria, V8W 2Y2, British Columbia

Appendix A to Letter of Invitation: Project Information and Consent Form

[Department letterhead]

Project Information and Consent Form

Project Title : PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS

You are invited to participate in a study entitled “PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS”, that is being conducted by Richard Veerapen.

Richard Veerapen is a Ph.D. candidate in the Faculty of Law, University of Victoria and you may contact him if you have further questions.

As a graduate student Richard Veerapen is required to conduct research as part of the requirements for a Ph.D. (Law and Society). It is being conducted under the supervision of Prof. Maneesha Deckha. You may contact his supervisor at 250. 721 8175.

Purpose and Objectives

This qualitative research using Interpretative Phenomenological Analysis (IPA), aims to explore and understand the experiences of a group purposefully selected physicians, with regard to their engagement with the family (and/or close others) of their patients during the informed consent process. It aims to understand how these physicians interpret their ethico-legal obligations to promote and protect their patients’ autonomy in the context of simultaneous family involvement during the process obtaining informed consent.

Additionally it will aim to discover the rationale that physicians apply if they recommend the recruitment of family input during risk discussions, and to discover how the social role of a patient’s family is viewed in shared decision-making, bearing in mind the multicultural nature of Canadian society. Another objective is to discover how Canadian-trained physicians learn the skills of engaging with family of patients, and whether they feel there is value of incorporating relevant training within medical school curricula.

Importance of this Research

Research of this type is important because the legal and biomedically rooted approaches to informed consent have inadequately dealt with the tensions that arise when language and other communication difficulties occur in the physician-patient-family triad. Many minority patients in a N. American context *want* to involve different decision-makers and welcome input from more sources than medical providers typically allow. There appears to be a paucity of literature describing the position of family and close others in the medicolegal consent process amongst non-ethnic minority families and persons of aboriginal descent in Canada. Being able to widen the traditional ethico-legal view of consent by adding a socio-political perspective rooted in the social sciences is therefore critical. The findings of my research may be used to inform the content of ethico-legal curricula for training of healthcare providers in an era where the patients (and their families) are increasingly being viewed as partners in decision-making rather than passive recipients of physician advice. Satisfaction amongst patients and family members is more likely

when all interested parties are apprised of the risks of an intervention, and are able to sense that their influence in the decision-making was appropriately valued. This logically has bearing on the quality of trust in patient-provider relationships and also on cost savings via reduction of the risk of future conflict.

Participant Selection

You are being asked to participate in this study because of your experience in practising in a 'high-risk' medical field in Victoria or Vancouver, British Columbia. The researcher has chosen to invite medical specialists from these fields because their routine care of patients with high-risk conditions or who are asked to undergo high-risk procedures, increases the likelihood of their engagement with family members or close others of their patients. This is particularly true if the latter bear some responsibility for the care of the patient in the long term. This purposeful choice of participants is expected to provide richer data compared to researching physicians who practice in low-risk fields where they likely do not have as much need to be in contact with family members.

Family physicians are excluded because the drivers for their engagement with family are fundamentally different from that of specialist physicians, who largely interact with patients and their family as relative strangers. Family doctors are expected to have longer-term relationships with their patients and their families and the relational nature of that form of doctor-patient-family triad is qualitatively different, and not the focus of this study. The other group of physicians who will be excluded will be those who work in fields where the legal and ethical principles governing physician-patient-family interactions have clearly defined considerations, for example paediatrics, geriatrics, intensive care and organ transplantation surgery

What is involved

If you agree to voluntarily participate in this research, your participation will include an interview by Richard Veerapen, who will use this framework of questions:

- Please could you tell me about an interaction with family members (or close others) of a patient that you recall as being challenging, or in other ways significant, during the course of explaining an intervention and disclosing its risks while obtaining informed consent?
- How does the law of consent influence your engagement with family during the process of obtaining informed consent?
- Could you please tell me how you learned the skills of interacting with family or close others of your patients? What was the nature of the training for such skills that you received in medical school? If you think these skills are important for any reason, what can be done to improve physicians' preparedness for such interactions?
- Probing and prompting questions will be used to follow your story, such as:
 1. *“Please tell me a bit more about the situation you just described”*
 2. *“What made you uncomfortable about that patient’s parent’s attitude to you during your discussion?”*

It is estimated that the interview process will take approximately 1.5 to 2 hours. Dr. Veerapen will record the interview on voice recording systems [analogue and digital].

Venue of interview: a location of your choice not within a hospital or other institutional facility.

You will be free to introduce and discuss areas not covered in the researcher's questions which you think are important to address.

If at any time you wish to terminate the interview for any reason, you will be free to do so.

The transcript of the interview will be sent to you for review and for your comments and additions, if any.

You should not feel pressured or obliged to participate in this study because you may have been recommended as a potential participant by a colleague of yours or because the researcher has a background as a specialist surgeon.

If you have had a previous professional or personal affiliation with the researcher and for this reason will feel uncomfortable or find your freedom to discuss conflict fettered in any way, you should decline the invitation to be a candidate in this research project.

Candidates for this project will all be specialist physicians with at least 5 years of independent practice. Stringent measures will be taken to protect the identity of participants and confidentiality of recorded interviews as outlined in the section on confidentiality below.

In spite of these measures there is a very small possibility that you may still be identified because of relatively small numbers of specialist physicians who practice in your field in Victoria and Vancouver, BC.

Inconvenience

Participation in this study may cause some inconvenience to you, including the dedication of time for the interview and a provocation of recall of conflict experiences that you may be uncomfortable or unwilling to discuss. You will be free at all times to steer the conversation to the next or other topic in the event that you are uncomfortable with any aspect of the interview.

Risks

There are no known or anticipated risks to you by participating in this research.

Benefits

The potential benefits of your participation in this research include an opportunity to describe with confidentiality, the nature of your experiences as a practising clinician, to a researcher with a specialist medical background who uses an academic and qualitative approach to the analysis of the stories you share with him.

By analyzing the experiences of your engagement with family and close others of your patients using an established research methodology, Richard Veerapen hopes to contribute to the understanding skills applied in this particularly important area of clinical practice.

This information has important applications in interactive, communication and ethico-legal skills training at medical undergraduate as well as residency level.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used and will be destroyed.

Anonymity

In terms of protecting your anonymity, any identifying information regarding you personally, your patients, your employing or affiliated institution will not appear in the results of the research.

Confidentiality

Participants will be assigned a pseudonym and only the researcher will hold the master-list of pseudonyms electronically in his personal computer. The master list will be destroyed at completion of the data analysis.

Analogue voice recordings made as a back-up will be erased once the digital recordings are successfully uploaded onto the researcher's computer and password protected. The files on the digital recording device will then also be deleted.

The password protected digital voice recordings will be transcribed and the transcriptions returned to the researcher coded with all identifying features removed.

All audio files will be kept under lock and key. This includes the securely stored and password-protected back-up files and coding list, which will then be deleted from the researcher's computer and the back-up location.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways:

- Richard Veerapen's Ph.D. dissertation
- Publication in peer-reviewed journals.
- Papers presented at scholarly meetings.
- Articles in the media *e.g. newspaper or periodical*

Disposal of Data

- Deletion of electronic data and shredding of notes and other material if any, on hard copy.
- Data from this study will remain in electronic form, under the control of Richard Veerapen and will not be stored in an institutional or electronic storage system with public access.

Contacts

Individuals that may be contacted regarding this study are the researcher as well as his supervisor as detailed above at the beginning of this form.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature on the Participant Consent Section on the next page indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Participant's Consent

I _____ (*Participant to fill name*) consent to participate in the project titled "Physician Engagement With Family and Close Others Of Patients During The Informed Consent Process" conducted by *Richard Veerapen*. I understand the nature of this project, have had the opportunity to have my questions answered by the researcher, and wish to participate.

I am aware that research data may be used by the researcher in a journal article, for academic presentations or in a media article.

I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature
Participant

Date

Signature
Richard Veerapen

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix B to Letter of Invitation: Researcher's Resume

BRIEF RESUME OF RESEARCHER [RICHARD VEERAPEN]

Richard is a UK-trained neurosurgeon who retired from clinical practice after a 28-year career in medicine in the UK and Malaysia, when he moved with his family to Victoria in 2004.

He holds the following qualifications:

Medical:

1. Bachelor of Medicine and Surgery (MB,BS). Panjab University, India 1976
2. Qualified: Fellowship of the Royal College of Surgeons of Edinburgh 1981
3. Qualified: Fellowship of the Royal College of Surgeons of Edinburgh in Surgical Neurology) 1985

Legal:

1. LL.B (Hons) University of Wolverhampton, UK (1999)
2. Masters of Law, (LL.M, Medical Law) Northumbria University, UK (2003)

Dispute Resolution:

MA in Dispute Resolution, University of Victoria, BC (2010)

Thesis: *The experience of Malaysian neurosurgeons with physician-patient conflict in the aftermath of adverse medical events: A heuristic study* is available online.

He currently holds the following positions:

- Affiliate Honorary Lecturer in the University of British Columbia Faculty of Medicine, MD Undergraduate Program
- Tutor, Doctor, Patient and Society Course (DPAS420), UBC-Island Medical Program, University of Victoria
- Tutor, Centre for State and Legal Studies, Athabasca University (Healthcare Law, and Risk Management & Safety in Health Services)

Career highlights:

- President, Malaysian Society of Neurosciences (1994-1998)
- Founding Director and Deputy Chairman, Medical Defence Malaysia, Ltd. (www.mdm.org)
- Qualified by Supreme Court of British Columbia, Canada, as expert witness in Neurosurgery (Dec 2010)
- Former Council member, BC Coastal Canadian Red Cross

Appendix C to Letter of Invitation: Sample Interview Questions

SAMPLE INTERVIEW QUESTIONS

Richard Veerapen

Ph.D. (Law and Society) Research Project

1. Please could you tell me about an interaction with family members (or close others) of a patient that you recall as being significant, during the course of explaining an intervention and disclosing its risks while obtaining informed consent?
2. How does the law of consent influence your engagement with family during the process of obtaining informed consent?
3. Could you please tell me how you learned the skills of interacting with family or close others of your patients?
4. What was the nature of the training for such skills that you received in medical school?
5. What knowledge/skills have you learned in the field or through professional development during the course of your career so far? If you think these skills are important for any reason, what can be done to improve physicians' preparedness for such interactions?
6. Probing and prompting questions will be used to follow your story, such as:
 - a. *"Please tell me a bit more about the situation you just described"*
 - b. *"What made you uncomfortable about that patient's/parent's attitude to you during your discussion?"*

Appendix D to Letter of Invitation: Withdrawal Form

WITHDRAWAL FORM

A) WITHDRAWAL WITH REMOVAL OF DATA FROM ANALYSIS

I WISH TO WITHDRAW FROM THE STUDY TITLED “PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS”, BEING CONDUCTED BY RICHARD VEERAPEN.

I DO NOT WANT ANY DATA COLLECTED FROM ME TO BE INCLUDED IN THIS STUDY AND UNDERSTAND THAT IT WILL BE REMOVED FROM THE DATA SET AND DESTROYED.

SIGNATURE:

NAME:

DATE:

B) WITHDRAWAL WITH PERMISSION TO USE DATA COLLECTED

I WISH TO WITHDRAW FROM THE STUDY TITLED “PHYSICIAN ENGAGEMENT WITH FAMILY AND CLOSE OTHERS OF PATIENTS DURING THE INFORMED CONSENT PROCESS”, BEING CONDUCTED BY RICHARD VEERAPEN.

I GIVE MY PERMISSION FOR INCLUSION OF THE DATA COLLECTED BY ME SO FAR, IN THE STUDY.

SIGNATURE:

NAME:

DATE:

NOTE: PLEASE RETURN THE SIGNED FORM TO RICHARD VEERAPEN BY POST AT THIS ADDRESS:

C/O GRADUATE PROGRAM
FACULTY OF LAW, UNIVERSITY OF VICTORIA
PO BOX 1700, STN CSC VICTORIA, BRITISH COLUMBIA
CANADA V8W 2Y2