

SURGICAL INFORMED CONSENT AND RECOGNIZING A PERIOPERATIVE DUTY TO DISCLOSE IN TRANSGENDER HEALTH CARE

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In this article, the author argues that our current medical practices with regard to obtaining informed consent are inadequate. They do not require the systematic disclosure of information which is necessary to prepare for the surgery and what it comes with, but which would not impact the decision to undergo surgery. The article analyzes the two primary processes for obtaining informed consent, namely with and without a referral from a mental health professional, and sketches how both processes fall short of disclosing all relevant information. The author draws on personal experience and community knowledge to argue for an expansion of the notion of informed consent which is better adapted to the needs of patients who are preparing for the surgical process. They highlight how surgeons and mental health professionals are poorly situated to learn and transmit all actionable information and take note of the various barriers patients face in attempting to independently access

Cet article soutient que nos pratiques médicales actuelles par rapport à l'obtention du consentement éclairé sont inadéquates parce qu'elles n'incluent pas la divulgation systématique d'informations nécessaires à la préparation au processus chirurgical si elle n'influencerait pas la décision d'entreprendre la chirurgie. Les deux procédés principaux d'obtention de consentement éclairé, soit avec ou sans lettre de professionnels en santé mentale, sont analysés, et une explication de comment les deux processus échouent à divulguer toutes les informations pertinentes est donnée. S'appuyant sur l'expérience personnelle et sur les connaissances communautaires, l'article suggère une notion de consentement éclairé élargie de sorte à être mieux adaptée aux besoins des patients en préparation au processus chirurgical. L'article souligne comment les chirurgiens et professionnels en santé mentale sont mal situés pour apprendre et transmettre les informa-

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this information. They then foreground the importance of community knowledge and interdisciplinary collaboration as central devices to meet the legal burden born by professionals tasked with obtaining informed consent and facilitating the informed consent process, as well as to improve the well-being of trans individuals who seek transition-related surgeries.

tions utiles aux personnes trans et explique les barrières à l'accès indépendant à cette information par les personnes trans. Enfin, l'article met en évidence l'importance des savoirs communautaires et de la collaboration interdisciplinaire pour rencontrer le fardeau juridique d'obtenir et de faciliter le processus de consentement éclairé ainsi que pour améliorer le bien-être des personnes trans recherchant des interventions liées leur transition.

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INTRODUCTION

Looking at my reflection in the mirror, my vision became blurry and I broke down crying. That was the third time in as many weeks, a highly unusual occurrence for my usual calm self. Though I was surprised by just how easy it was the first time I broke down crying, I quickly came to realize that the ease with which I cried was related to my fluctuating hormone levels. Due to an upcoming surgery, I had to cease taking my hormone replacement therapy.¹ Composed of estradiol and spironolactone, the medication cocktail's effect on blood pressure and clotting was judged too risky by the surgeon – a fact I was informed of roughly one month prior to surgery. I had to stop taking the hormones three weeks before surgery, give or take a few days. I was ill-prepared for this endeavour. Because hormones regulate emotions, amongst many other things, changes in hormonal regimen can have a heavy impact on mood stability and mental health. In my case, the fluctuations were large enough that I had to raise my dosage of antidepressant.

A few months after surgery, my reflection in the mirror elicited an emotional reaction I had not yet grown accustomed to. After over a year on hormone replacement therapy,² my body had changed in ways that finally began feeling comfortable. After decades of discontent, I was finally feeling at home in what I had previously described as a flesh prison. It had only taken a few weeks without hormones to lose what I estimated as six months of progress, noticeable in terms of fat redistribution, breast tissue loss, and changes to sexual functioning.³ The mirror served me a cruel reminder of this loss of self.

¹ Hormone replacement therapy refers to the hormonal medication that many trans people take as part of their medical transition. For transfeminine persons, it is typically composed of oestrogen and an anti-androgen, with the occasional addition of progesterone, although anti-androgens are not always necessary. For transmasculine persons, it is composed of testosterone.

² Hormone replacement therapy has many nicknames among transfeminine people, including titty pills, titty skittles, smartitties, chicklets, anticistamines, mammary mints, life savers, tit tacs, breast mints, femme&m's, antiboyotics, trans-mission fluid, and the Notorious H.R.T.

³ See Eli Coleman et al, "Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People, Version 7" (2012) 13:4 *Intl J Transgenderism* 165 at 188–89; Amy Bourns, *Guidelines and Protocols for Hormone Therapy and Primary Health Care for Trans Clients* (Toronto: Sherbourne Health Center, 2015) at 13. The negative impact of periopera-

Gender dysphoria is a strange beast. One trans person may be dysphoric about a part of their body that another trans person is content with.⁴ Not all trans people are dysphoric about their genitalia – or at all – for instance. Quite the contrary, many trans people rejoice and find pleasure in the genitalia they were born with.⁵ Dysphoria can also be context-sensitive: though my penis filled me with a dread that occasionally morphed into panic attacks in sexual contexts, I found it quite glamorous and provocative bulging through a tight dress. Dysphoria is not always stable over time either. Prior to facial feminization surgery, I had days when looking in the mirror made me happy, whereas other days – which I termed “bad face days” – haunted me with every detail I perceived as masculine, and left me tearing up in front of the mirror. On good days, dysphoria is a muted whisper. On bad days, it is a debilitating shriek that fills me with anxiety and turns my apartment into a prison I cannot escape for days.

I was well aware of the surgical risks when I consented to facial feminization surgery. My surgeon and I had discussed the risk of nerve damage most extensively. It makes sense: nerve damage can be devastating, and the risk is not negligible. We had also discussed a more minor nerve-related consequence which materialized as expected: I lost all sensation in the top of my head. The facial feminization surgery technique I underwent involves cutting the skin at the hairline, which severs the nerves connected to the top of the head. Though perhaps a significant side effect for some, I found it more amusing than anything to not be able to feel myself touching my

tive cessation of hormones is discussed in UCSF Center for Excellence for Transgender Health, *Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People*, 2d ed by Madeline B Deutsch (San Francisco: UCSF Center for Excellence for Transgender Health, 2016) at 43–44 [*UCSF Guidelines*]; Anne A Lawrence, “Patient-Reported Complications and Functional Outcomes of Male-to-Female Sex Reassignment Surgery” (2006) 35:6 *Arch Sex Behav* 717 at 720.

⁴ A person is said to be trans or transgender if their gender identity does not correspond to the gender they were assigned at birth. A trans woman, for example, is a woman who was assigned male at birth. A trans person can be a man, a woman, or a non-binary person. Non-binary people do not identify as completely male or completely female.

⁵ See Sandy E James et al, “The Report of the 2015 U.S. Transgender Survey” (December 2016) at 101ff, online (pdf): *National Center for Transgender Equality* <www.transequality.org/sites/default/files/docs/USTS-Full-Report-FINAL.PDF> [perma.cc/9ASS-EN5S].

scalp. The only annoying aspect was an occasional phantom itch that could not be scratched.

Equally certain and much more worrisome for someone like me who had not taken hormone replacement therapy for a long time – one year out of my then 25 – was the loss of progress. Yet this hormonal re-masculinization of my body was not a side effect that my surgeon mentioned. I suspect that he did not consider it, and that he might not have considered it significant enough to disclose if he had. Since the standard for disclosure is whether the information will weigh in the patient’s decision to have surgery or not, this side effect would not have seemed necessary to disclose. Hormonal change is temporary and would have had no impact on my ultimate decision to undergo surgery.

Whether others might change their mind about undergoing surgery for that reason is uncertain, although my experience in trans communities suggests that it would overwhelmingly not have an impact on one’s decision to undergo surgery. The effects are not visible when clothed, and temporary side effects pale in comparison to the long-term alleviation of gender dysphoria brought on by transition-related surgeries.⁶ However frustrating it may be, temporary hormonal change is a comparatively minor effect, outweighed by the hefty psychological benefits of facial feminization surgery.⁷

Nonetheless, my surgeon’s failure to disclose this side effect robbed me of the ability to adequately prepare for it. I would not have changed my mind about having surgery, it is true, but I could have done more to prepare had I known about the impact of ceasing hormone replacement therapy.

⁶ Gender dysphoria is not the sole reason why trans people undergo surgical procedures: see generally Florence Ashley & Carolyn Ells, “In Favor of Covering Ethically Important Cosmetic Surgeries: Facial Feminization Surgery for Transgender People” (2018) 18:12 Am J Bioethics 23.

⁷ See e.g. Coleman et al, *supra* note 3 at 201; Gail Knudson et al, “Position Statement on Medical Necessity of Treatment, Sex Reassignment, and Insurance Coverage in the U.S.A.” (21 December 2016), online (pdf): *World Professional Association for Transgender Health* <www.wpath.org/policies> [perma.cc/C5CH-DJ8Y]; Jens U Berli et al, “Facial Gender Confirmation Surgery: Review of the Literature and Recommendations for Version 8 of the WPATH *Standards of Care*” (2017) 18:3 Intl J Transgenderism 264 at 266. Trans people who are visibly identifiable as transgender – which facial feminization surgery can alter – face higher rates of harassment, treatment, and violence: see James et al, *supra* note 4 at 209.

Knowing in advance is crucial to psychological preparation and adaptation. Armed with knowledge, I could have scheduled appointments with my therapist, warned my loved ones about my increased need for support and softness, and refrained from in-person commitments. I did the latter two of those for a subsequent surgical procedure.

Throughout this article, I adopt an autoethnographic perspective to supplement legal analysis, drawing on self-reflection and personal experiences as a guide of policy-making. I am positioned in the discussion as a transfeminine individual who has first-hand experiences with many facets of transition-related care, as well as extensive exposure to trans communities in professional, advocacy, and private settings.

First-hand accounts are crucial to improving trans care. The weight of gender dysphoria is difficult to appreciate in abstract terms but can come through a little more clearly in stories. Through experiential narratives such as this one, we can warn prospective patients and practitioners about the diversity of experiences associated with surgeries that might otherwise fall through the cracks. A few days ago – as I wrote this paragraph – I had a postoperative follow-up with my surgeon. However, I was too tired and emotionally vulnerable to share my experiences with the surgeon. Though it may seem like hypocrisy, I think it instead highlights the inappropriateness of surgeon-patient relationships in naturally unearthing first-hand experiences and leading to improvements in health care. If I, an outspoken and confident scholar, do not feel comfortable sharing my experiences with health care providers, then perhaps we need a more systematic approach to building trans health care in a patient-centred way.

Although litigation is rare, academic discussions on the scope of informed consent can prompt culture shifts and amendments to normative documents such as professional standards of care and guidelines. Such documents can have a significant impact on medical practice. Standards of care and guidelines serve crucial roles in pedagogical settings.⁸ They constitute current medical standards, which physicians have a professional duty to respect, and are frequently used as criteria for health insurance coverage. By inviting us to recognize a perioperative duty to disclose within the scope

⁸ See Kinnon R MacKinnon et al, “Protocols as Curriculum? Learning Health Advocacy Skills by Working with Transgender Patients in the Context of Gender-Affirming Medicine” (2019) *Advances in Health Sciences Education*, online: <link.springer.com/article/10.1007%2Fs10459-019-09899-0> [perma.cc/X2PY-AQFH].

of informed consent, I hope to influence medical practice through juridical and normative avenues alike.

First, I will explain the two primary paths to obtaining informed consent for transition-related surgeries in Québec. Second, I will argue that the current distribution of informational duties between surgeons and mental health professionals is ill-adapted to the needs of trans communities because it relies on overly narrow conceptions of informed consent and underestimates the role that communal knowledge should play in health care. Third, I will argue for the legal recognition of a perioperative duty to disclose, highlighting the central role of community organizations as creators and communicators of medical knowledge.

I. ALL YOU NEED TO KNOW: HOW CONSENT IS OBTAINED

There are two leading approaches to obtaining informed consent to transition-related surgeries. Under the first approach, the surgeon is the sole bearer of the duty to inform patients and to obtain their consent. This approach is only applicable when the interventions are not subjected to the World Professional Association for Transgender Health (WPATH) Standards of Care (SOC7), which must be satisfied to obtain insurance coverage in Québec.⁹ Under the second approach, the responsibility to inform patients and obtain their consent is shared between the surgeon and mental health professionals. This approach, which is delineated in the SOC7, applies to surgeries that are covered by Québec public insurance.

The surgery I underwent, facial feminization surgery, is considered cosmetic by the Québec government.¹⁰ Thus, it is not covered by insurance despite its significant impact on safety and psychological well-being. Breast

⁹ See Coleman et al, *supra* note 3.

¹⁰ Although the Régie de l'assurance maladie du Québec (RAMQ) typically administers health insurance in Québec, transition-related surgeries are covered under a special agreement with the Ministry of Health: see Center for Gender Advocacy, News Release, "Important Changes to Sex Reassignment Surgery in Quebec" (21 January 2010), online: <genderadvocacy.org/2010/01/21/changements-importants-dans-la-maniere-daccéder-aux-chirurgie-de-reassignation-sexuelle-au-quebec-bulletin-du-reseau-sante-trans-du-quebec/> [perma.cc/F2MW-NA7U].

augmentation for trans women also falls in the same category.¹¹ Since these services are not covered by public health insurance, the process through which informed consent is obtained is determined by the surgeon.

Medical care is provided subject to the informed consent of patients. Article 10 of the *Civil Code of Québec* protects the fundamental principle of the integrity of the person, declaring that “no one may interfere with [the] person without [their] free and enlightened consent.” The requirement to obtain free and enlightened consent is repeated in various other legal provisions. Most significant for the present discussion is in article 28 of the *Code of Ethics of Physicians*,¹² which governs medical practitioners in Québec: “A physician must, except in an emergency, obtain free and enlightened consent from the patient or [their] legal representative before undertaking an examination, investigation, treatment or research.”

Article 29 details what physicians must disclose in order for consent to be enlightened:

A physician must ensure that the patient or [their] legal representative receives explanations pertinent to [their] understanding of the nature, purpose and possible consequences of the examination, investigation, treatment or research which [they] plans to carry out. [The physician] must facilitate the patient’s decision-making and respect it.

In Ontario, the *Health Care Consent Act*¹³ adopts a similar understanding of informed consent:

11(2) A consent to treatment is informed if, before giving it,

(a) the person received the information about the matters set out in subsection (3) that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and

¹¹ Facial hair removal by laser or electrolysis also falls under the same category. Although it could potentially be covered under a diagnosis of hirsutism, it would have to be practiced by a physician or under a physician’s supervision. Physician or physician-supervised laser and electrolysis is not offered in Québec, to my knowledge.

¹² CQLR c M-9, r 17.

¹³ SO 1996, c 2, Schedule A.

(b) the person received responses to his or her requests for additional information about those matters.

11(3) The matters referred to in subsection (2) are:

1. The nature of the treatment.
2. The expected benefits of the treatment.
3. The material risks of the treatment.
4. The material side effects of the treatment.
5. Alternative courses of action.
6. The likely consequences of not having the treatment.

Québec and Ontario both set out similar lists of information that must be disclosed to the patient before valid consent can be obtained. The most relevant categories are “purpose” and “possible consequences” in Québec law, and “expected benefits,” “material risks,” and “material side effects” in Ontario law. A parallel may be drawn between purpose and expected benefits, and between possible consequences and the categories of material risks and side effects.

Many other jurisdictions appear to share substantially similar conceptions of informed consent. In the US context, Mark Gorney sets out five similar elements of informed consent for surgical procedures:

1. The diagnosis or suspected diagnosis. In cosmetic surgery, this typically is straightforward.
2. The nature and purpose of the proposed treatment or procedure, as well as its anticipated benefits.
3. The risks, complications, or side effects of the treatment.
4. The probability of success, based on the patient’s condition.
5. Reasonable available alternatives to the proposed treatment or procedure.¹⁴

¹⁴ Mark Gorney, “Professional and Legal Considerations in Cosmetic Surgery” in

Both the limitations and risks of transition-related surgeries are central to decision-making. The leading guidelines for medical transition, the WPATH's SOC7,¹⁵ set out that surgeons should explain the different available surgical techniques, the limitations of surgery in achieving ideal results—an explanation that should be tailored to the patient's history and rationales or seeking surgery—as well as potential risks and complications.¹⁶ These explanations aim at supporting patients' decision-making and ensuring realistic expectations. Otherwise, consent may be vitiated. Although the degree of detail varies from law to law and document to document, the core of informed consent seems shared by all sources.

How informed consent is obtained depends on the surgery and the jurisdiction. In Québec, surgeries deemed medically necessary by the government are publicly covered on the condition that the criteria for surgery set out by WPATH are met.¹⁷ Vaginoplasties, phalloplasties, and metoidio-

David D Sarwer et al, eds, *Psychological Aspects of Reconstructive and Cosmetic Plastic Surgery: Clinical, Empirical, and Ethical Perspectives* (Philadelphia: Lippincott Williams & Wilkins, 2005) at 321–22. For a discussion on whether surgeries like facial feminization surgery should be considered cosmetic, see Ashley & Ells, *supra* note 5.

¹⁵ See Coleman et al, *supra* note 3. According to the American Psychological Association Task force on Gender Identity and Gender Variance, the WPATH Standards of Care are “widely recognised” and reflect “the consensus in expert opinion among professionals in this field on the basis of their collective clinical experience as well as a large body of outcome research”: see American Psychological Association, Task Force on Gender Identity and Gender Variance, *Report of the APA Task Force on Gender Identity and Gender Variance* (Washington, DC: American Psychological Association, 2009) at 32, online (pdf): <www.apa.org/pi/lgbt/resources/policy/gender-identity-report.pdf> [perma.cc/35PZ-KPLB].

¹⁶ Coleman et al, *supra* note 3 at 200.

¹⁷ As Dr. Pierre Brassard of GRS Montréal has reported:

GRS Montréal is pleased to announce that following initiatives taken with the Ministère de la Santé et des Services sociaux, the requirements for access to gender reassignment surgery for transsexual, transgender, and gender non-conforming clients have been updated. GRS Montréal can confirm that the MSSS's requirements will now be based on the most recent version of WPATH's Standards of Care (Version 7) (Press Release, “Changes to the MSSS's requirements for gender reassignment surgery” (10 November 2016)).

plasties (surgeries commonly known as genital reassignment surgery) are publicly covered, as are orchiectomies, hysterectomies, and mastectomies with chest masculinization.¹⁸ Canadian residents rarely elect to pay out-of-pocket for these procedures since they cost between five thousand and tens of thousands of dollars each.¹⁹ As a result, the majority of those paying out-of-pocket likely reside in other countries and come to Canada for surgery.²⁰ Immigrants to Canada who have not yet obtained their permanent residency, disproportionately people of colour, are likely a smaller portion of out-of-pocket payers given their economic precarity.²¹

¹⁸ See Louise Leduc, “Personnes transgenres: les demandes de soins explosent”, *La Presse* (4 December 2017), online: <plus.lapresse.ca/screens/ce9d3fe7-dca5-46ca-8b2c-b1bc2617ee68__7C__0.html> [perma.cc/N7KX-HW6F]. Until recently, only the Montréal clinic offered genital reassignment surgeries in Canada. The inability to effectively choose a surgeon and surgical technique impoverishes the quality of consent. It is also worth noting that while insurance coverage is extensive for transmasculine individuals, transfeminine individuals must pay out of pocket for commonly desired treatments such as facial hair removal, facial feminization surgery, and breast augmentation surgery.

¹⁹ Out-of-pocket payment for surgeries was not uncommon among sex workers a few decades ago. Gender identity clinics held a monopoly over referrals for surgery and did not consider sex work to adequately satisfy the real life test: see Viviane K Namaste, *Invisible Lives: The Erasure of Transsexual and Transgendered People* (Chicago: University of Chicago Press, 2000) at 206ff. The increased availability of referrals as well as a loosening of the real life test has made it considerably less difficult for trans sex workers to obtain public coverage for genital reassignment surgery, although significant barriers to access remain.

²⁰ The majority of Canadian provinces and territories cover some transition-related surgeries: see United Food and Commercial Workers Canada & Canadian Professional Association for Transgender Health Care, “Publicly Funded Transition-Related Medical Care in Canada” (11 September 2015), online (pdf): *CPATH* <www.cpath.ca/wp-content/uploads/2016/02/Publicly-Funded-Transition-Related-Medical-Care-in-Canada_poster8x11_EN.pdf> [perma.cc/Y56T-3WWP].

²¹ Public insurance coverage in Québec requires Canadian citizenship, permanent residence, or refugee status: see *Health Insurance Act*, CQLR c A-29, s 5. Given the positive impact of health coverage on community well-being, the unavailability of genital reassignment surgery coverage across the globe, and the wide racial disparities created by residence requirements for health care

While non-covered surgeries are subject to the will of surgeons, who often do not require referrals from mental health professionals, patients must follow the requirements set out in WPATH's SOC7 if they wish to obtain public coverage in Québec. Though the SOC7 is not directly applicable as a matter of law, public insurance policy makes them the *de facto* authoritative standards for many surgeries, such as genital reassignment surgery.²² Under the SOC7, the responsibility of disclosing all information necessary for patients to make an informed decision is shared between the surgeon and referring mental health professionals.²³ Patients must obtain a referral letter from one or two qualified mental health professionals,²⁴ depending on the surgical procedure, attesting that the patient satisfies the SOC7 criteria for surgery. The surgeon bears the ultimate responsibility of obtaining written consent.

As the referral letters must state that informed consent was obtained from the patient, the SOC7 duplicates (or triplicates, in the case of surgeries requiring two letters) the informed consent processes.²⁵ The requirement of assessing gender dysphoria and psychosocial adjustment has been criticized by members of trans communities and health care professionals specializing in transgender health.²⁶ While I have serious ethical qualms about these

coverage, provincial governments should consider extending public insurance coverage to everyone domiciled in Canada.

²² Surgeons' inclination to use the same approach for all their patients may explain why they also follow the SOC7 with patients paying out-of-pocket if they typically use the SOC7 for public coverage purposes.

²³ See Coleman et al, *supra* note 3 at 182–83, 200.

²⁴ A mental health professional will be considered competent for the purposes of SOC7 if they have a master's degree from a clinical behavioural science field, training in psychotherapy or counselling as well as working knowledge of the assessment and treatment of gender dysphoria. For a full list of minimum credentials, see *ibid* at 179.

²⁵ See *ibid* at 183.

²⁶ While some of the critiques have focused on referral requirements for hormonal therapy, the arguments apply *mutatis mutandis* to gender dysphoria assessments for surgery: see generally C Jacob Hale, "Ethical Problems with the Mental Health Evaluation Standards of Care for Adult Gender Variant Prospective Patients" (2007) 50:4 *Perspect Biol Med* 491; Timothy Cavanaugh, Ruben Hopwood & Ceil Lambert, "Informed Consent in the Medical Care of Transgender and Gender-Nonconforming Patients" (2016) 18:11 *AMA J Eth-*

requirements, criticizing the SOC7 letter requirements is beyond the scope of this paper.

Given the chronological distance between drafting letters and undergoing surgical procedures, the role of mental health professionals in obtaining informed consent is diminished. Although mental health professionals are given the responsibility to “encourage, guide, and assist clients with making fully informed decisions and becoming adequately prepared,”²⁷ the ultimate duty to obtain written consent lies with the surgeon. The mental health professional's role with regard to preparedness is understood both in psychological terms – ensuring the patient has realistic expectations, is ready to undertake the treatment plan, has an adequate support system, etc. – and practical terms – ensuring the patient has arranged aftercare, is able to take time off work, has chosen a surgeon, etc.²⁸

For surgeries subject to the SOC7, mental health professionals play a complementary role to surgeons in assessing eligibility and readiness for surgery and in ensuring patients' preparedness. Given this distribution of roles, the perioperative disclosure of side effects which may be managed and prepared for, but which would not impact the decision to undergo surgery, would primarily fall under the responsibility of mental health professionals. However, they often fail to provide all the relevant information.

II. I NEEDED TO KNOW MORE: THE LIMITATIONS OF INFORMED CONSENT

Current informed consent practices have significant limitations. Clinicians and surgeons appear to rarely engage in perioperative disclosure of

ics 1147; Florence Ashley, “Gatekeeping Hormone Replacement Therapy for Transgender Patients is Dehumanising” (2019) 45:7 *J Med Ethics* 480 [Ashley, “Gatekeeping Hormone Replacement Therapy”]; Sarah L Schulz, “The Informed Consent Model of Transgender Care: an Alternative to the Diagnosis of Gender Dysphoria” (2018) 58:1 *J Humanist Psychol* 72; Phyllis Randolph Frye, ed, “Health Law Standards of Care for Transsexualism” in *Proceedings from The Second International Conference on Transgender Law and Employment Policy* (Houston, TX: Phyllis Randolph Frye, 1993) 4; Florence Ashley, “The Informed Consent Model of Transgender Health and Detransitioners: Friends, not Foes” (2019) [unpublished] [Ashley, “Friends, not Foes”].

²⁷ Coleman et al, *supra* note 3 at 181.

²⁸ See *ibid* at 182.

information that would not impact decision-making, but which is necessary for adequate psychological and practical preparation in relation to surgery. This failure to disclose can have significant impacts on the well-being of patients and their postoperative success. The limits of current approaches to informed consent emerge from the legal conceptions of informed consent, the situated knowledge of surgeons and mental health professionals, and patients' limited access to information. I will consider each of these in turn.

A. Legal responsibility and the narrow conception of information

In this Sub-Part, I will explore how current discussions of legal responsibility for obtaining informed consent are narrowly focussed on the disclosure of information necessary to make an informed decision on whether to undergo surgery. This narrow conception of information that must be disclosed excludes large swaths of information that is actionable and subjectively relevant to the patient.

After over 35 years, *Hopp v Lepp* and *Reibl v Hughes*, remain two of the leading Canadian cases on medical liability for failure to adequately inform a patient prior to obtaining consent.²⁹ *Hopp* sets out that the probable risks of surgery must be disclosed, with due consideration for the gravity of the consequences and their likelihood of occurring. The risk of death must be disclosed if it is a mere possibility, whereas minor consequences must be much likelier to require disclosure.³⁰ Sufficiently trivial consequences may not have to be disclosed at all. The guiding principle, borrowed from US law, is that patients have a right to decide “what, if anything, should be done with [their] body.”³¹ Thus, probable risks are risks that, were patients informed of them, “would reasonably be expected to affect the patient’s decision to submit or not submit to a proposed operation or treatment.”³² *Hopp* stands for the patient’s right to choose.

²⁹ See [1980] 2 SCR 192, 112 DLR (3d) 67 [*Hopp*]; [1980] 2 SCR 880, 114 DLR (3d) 1 [*Reibl*]. See also Suzanne Philips-Nootens, Robert P Kouri & Pauline Lesage-Jarjoura, *Éléments de responsabilité civile médicale: le droit dans le quotidien de la médecine*, 4th ed (Montréal: Yvons Blais, 2016) at paras 184, 189ff.

³⁰ See *Hopp*, *supra* note 29 at 209.

³¹ *Ibid* at 196.

³² *Ibid* at 208.

Reibl, which followed in the same year of the Supreme Court of Canada's jurisprudence, sets out that the duty to disclose must be evaluated objectively by asking: "Can it be said that a reasonable person in the patient's position, to whom proper disclosure of attendant risks has been made, would decide against the surgery, that is, against the surgeon's recommendation that it be undergone?"³³ Although the objective test goes to causation, a related test was formulated with regards to fault: "What the doctor knows or should know that the particular patient deems relevant to a decision whether to undergo prescribed treatment goes equally to [their] duty of disclosure as do the material risks recognized as a matter of required medical knowledge."³⁴ The potential impact on decision-making relates to fault, whereas constructive impact on the decision goes to causation.

Although *Hopp* and *Reibl* have been applied in Québec, their applicability has been controversial.³⁵ The main point of contention among both courts and doctrinal authors relates to the objective test of causation, based on the reasonable patient.³⁶ According to Robert P Kouri, the objective test for causation was initially applied in Québec, but was subsequently replaced by a subjective one, grounded in the actual patient rather than the idealized "reasonable patient."³⁷ Some judgments have attempted to reconcile the objective and subjective tests by referring to the patient's reasonable responses.³⁸

Despite the debate on whether causation must be appreciated objectively or subjectively, Québec courts have largely applied *Hopp* and *Reibl*. The duty to disclose is mandated for all information that may impact patient decision-making.³⁹ Physicians must disclose all information that a reasonably prudent and diligent physician would disclose, which includes risks

³³ *Reibl*, *supra* note 29 at 898.

³⁴ *Ibid* at 894.

³⁵ See Philips-Nootens, Kouri & Lesage-Jarjoura, *supra* note 29 at para 188.

³⁶ See *ibid* at para 193.

³⁷ See Robert P Kouri, "L'obligation de renseignement en matière de responsabilité médicale et la «subjectivité rationnelle»: mariage de convenance ou mésalliance?" (1994) 24 RDUS 345 at 355–57.

³⁸ See e.g. *Lalonde c Tessier*, 2011 QCCS 3935 at paras 297–99.

³⁹ See *ibid*.

that could alter the patient's decision.⁴⁰ The notion of the "reasonable doctor" is found in both common law and Québec law.⁴¹ The spirit of informed consent jurisprudence underlies the patient's right to choose. The duty to disclose must be understood in this light, extending to all information central to deciding whether to undergo surgery.

We find prefaced in *Hopp*, and set out more explicitly in *Reibl*, the crux of the problem. Medical liability for breach of informed consent addresses the wrongful imposition of surgeries, not the harm of side effects per se. Omissions and lies may fundamentally threaten the autonomy of the patients, may be psychologically harmful, and may cause tangible difficulties, but the existing law of informed consent provides little comfort unless these omissions and lies caused the decision to undergo surgery.

Medical liability is concerned with an entirely different type of harm than the perioperative duty to disclose I seek to unearth. If bodily changes and psychological distress from pausing hormone replacement therapy may have changed my ultimate decision to undergo surgery, then the failure to disclose these side effects can give rise to liability. But if I merely wanted to know that these changes may occur so that I might better prepare for them, psychologically and practically, the current law of medical liability is silent and offers no aid. It is not surprising that the law lags behind patients' needs here. The law of medical liability evolves through lawsuits, and I would opine that few trans people would spend tens of thousands of dollars pursuing minimal damages on an uncertain legal case.

Professional responsibility under codes of ethics offers a possible alternative recourse for patients – one that is promising since it dispenses with proof of causality. Unlike medical liability under *Hopp* and *Reibl*, proof of causality need not be established in disciplinary proceedings. In *Médecins (Ordre professionnel des) c Nguyen*⁴², the physician was disciplined regardless of whether the patient would have refused surgery had she been adequately informed. It sufficed, for the disciplinary complaint to succeed, that the patient was not given all the information needed to make an enlightened decision on whether to undergo surgery.

⁴⁰ See Jean-Louis Baudouin, Patrice Deslauriers & Benoît Moore, *La responsabilité civile*, 8th ed (Cowansville, QC: Yvon Blais, 2014) vol 2 at paras 2–50.

⁴¹ Compare for e.g. *ibid* with *Reibl*, *supra* note 29 at 894.

⁴² 2013 CanLII 25807 (QC CDCM) [*Nguyen*].

Unfortunately, the current interpretations of professional obligations under the *Code of Ethics of Physicians* suffer from the same limitations as medical liability law. In *Nguyen*, the disciplinary council framed informed consent as a function of the patient's decision to have surgery or not,⁴³ relying on the *Code of Ethics of Physicians*, which states that "[the physician] must facilitate the patient's decision-making and respect it."⁴⁴ The disciplinary council retained the same conception of necessary information, namely information necessary for the patient to make a decision about whether to have surgery. This framing of informed consent did not make room for a perioperative duty to disclose information that, though unnecessary to make a decision, is actionable.

Some may argue that any suffering brought on by the surgeon's failure to prepare the patient could be litigated. Medical liability could be sought outside of the boundaries of informed consent under the more general law of medical negligence, for instance. It is true, and I will later argue that we can and should expand our understanding of informed consent to recognize a perioperative duty to disclose information that helps patients prepare psychologically and materially for the surgery or its side effects. However, the recognition of a perioperative duty to disclose relies on judges and administrative decision makers' willingness to go beyond the boundaries delineated by *Hopp*, *Reibl*, and *Nguyen*. Potential complaints and lawsuits are tempered by the current state of the law: there is no strong indication that courts or administrative decisionmakers would hold professionals liable in the circumstances contemplated here.

Lack of guidance leads to tangible failures. Although the boundaries delineated by *Hopp*, *Reibl* and *Nguyen* do not preclude recognizing a perioperative duty to disclose, the fact that they do not expressly make room for it impedes professionals' impetus towards disclosure. Actions are less guided by an abstract, idealized notion of what the law may be than by the guidance found in decisions and written opinions.

Whether in professional responsibility under codes of ethics or in civil liability, preparation for surgery writ large does not fall within the courts and decisionmakers' conception of informed consent. Instead, they structure the duty to disclose around a view of surgery as a momentary event that is validly chosen or not. This view of surgery stands in stark contrast to the

⁴³ See *Nguyen*, supra note 41 at paras 178–79.

⁴⁴ *Code of Ethics of Physicians*, supra note 12, s 29.

one I am proposing, which frames surgery as a complex process that we navigate, manage, and prepare for over the course of months or years. It is unsurprising, then, that the current legal conception of informed consent fails to account for the diversity of patients' informational needs.

B. The situated knowledge of physicians and mental health professionals

In this Sub-Part, I will explore how the situatedness of physicians' and mental health professionals' knowledge explains why they currently fail to provide patients with all the information they need to prepare for surgery, and why improving professional practices requires collaboration with trans communities.

Everyone is uniquely situated in relation to the surrounding world. As someone who is well-educated and trans, I do not navigate the world in the same way that a well-educated cis person⁴⁵ or uneducated trans person would.⁴⁶ Being white and a Canadian citizen, I do not experience a range of difficulties that migrants and people of colour, especially those who are Black or Indigenous, disproportionately face: poverty, lack of education, racial discrimination, and lack of insurance coverage. Access to education and financial resources facilitates access to transition-related care, as the process of obtaining referral letters and insurance coverage can be complex and expensive.⁴⁷

As I navigate the world and it reacts to my presence, I collect knowledge and perspectives that are responsive to how I am situated. This situated knowledge impacts my behaviour: I would know better than to cen-

⁴⁵ A person is cisgender or cis if their gender identity corresponds to the gender they were assigned at birth.

⁴⁶ Level of education is strongly correlated with mental health, with 58% of trans people who did not finish high school currently experiencing serious psychological distress compared to 30% of those who have a bachelor's degree: see James et al, *supra* note 4 at 107.

⁴⁷ Lack of coverage for transition-related care maintains racial and class hierarchies: see generally Pooja S Gehi & Gabriel Arkles, "Unraveling Injustice: Race and Class Impact of Medicaid Exclusions of Transgender Health Care for Transgender People" (2007) 4:4 Sex Res Soc Policy 7. Similarly, albeit to a lesser extent, barriers to insurance coverage, such as requiring difficult to find and expensive letters of referral, contribute to racial and class disparities within trans communities in Canada.

tre mirrored surfaces when doing interior design for a trans homeowner, whereas a cis interior designer may not think of the fact that trans people can have a tense relationship to their reflection.⁴⁸ I am also able to readily access extensive documentation on the technical aspects and approval process for transition-related surgeries because of my institutional access to scholarly resources, which would not be the case for someone unable to attend or work in university.

Most providers of trans health care are cisgender. This not only reflects the prevalence of cis people in the general population, but also barriers to professionalization faced by trans people due to harassment, discrimination, and violence in education, employment, and other spheres of life.⁴⁹ Cis practitioners do not have direct access to the experiences of trans people and must instead rely on second-hand knowledge. Unless patients who undergo surgery tell them about the physiological and psychological impacts of hormone cessation, cis practitioners are unlikely to be capable of fully appreciating them. And even when told, the magnitude and minute details of the problem are lost in translation. Many bodily changes cannot be isolated but only grasped holistically. For instance, I may notice that my body looks

⁴⁸ The mirror is a recurring theme in trans narratives. As Matt Fournier explains,

[g]ender dysphoria is [a] moment of leakage, when the face you see in the mirror is not a face for you anymore, when a supposedly familiar landscape is blurred by the transposition of gender-signifying marks from one milieu to another, when the socially determined coordinates of familiarity-identity-gender no longer add up to a legible (legitimate) pattern, when materiality itself escapes the frame of representation, because this frame is built on gender binarism (M Fournier, “Lines of Flight” (2014) 1:1–2 *Transgender Studies Quarterly* 121 at 121).

Jay Prosser, “Mirror Images: Transsexuality and Autobiography” in Jay Prosser, ed, *Second Skins: The Body Narratives of Transsexuality* (New York: Columbia University Press, 1998) 99 at 100 also speaks of the mirror in negative terms: “The mirror misrepresents who I know myself really to be: at an angle to Lacan’s mirror phase, the look in the mirror allows the transsexual only dis-identification, not a jubilant integration of body but an anguishing shattering of the felt already formed imaginary body—that sensory body of the body ‘image.’”

⁴⁹ For a general portrait of trans realities, see James et al, *supra* note 4. In the Canadian context, the Trans PULSE Project also unearthed a wealth of information regarding the lives of trans people: “What was Trans PULSE”, online: *Trans PULSE* <transpulseproject.ca> [perma.cc/XD6U-BG5A].

“more masculine,” but have trouble pinpointing exactly which features have changed and how. I say that I feel “awful” or “absolutely horrendous,” yet the clinician will have to translate these words into their own emotional language. The minutia of emotions is ineffable, and the words we use to convey them may hold slightly different meanings for each of us. It is all too easy to inadvertently underestimate the suffering of others when all we hear are words detached from the context that behind them. This is why I began my article with a vivid description: it elicits sympathy and better captures the emotional landscape of the experience than a short, disembodied statement.

Besides influencing the contours of our experiences, our situatedness also determines whom we are most likely to associate with. Trans communities take form in our shared need to relate, to be accepted, to be understood. Most of my friends are trans because I easily get along with trans people, without the friction of cisnormativity, and because my activism places me in constant proximity to them. Since most of my friends are trans, I have had the opportunity to hear about their experiences in informal contexts and to absorb a wealth of communal knowledge about the diversity of trans lives. When I discuss health policy just as when I contemplate whether to undergo surgery, I bring this knowledge along with me. My therapist, however knowledgeable about psychology and assessing gender dysphoria, is unlikely to be aware of just how pervasive fears regarding genital surgeries are, or the seething hatred many transfeminine people have for dilations.⁵⁰

Mental health professionals are ill equipped to guide patients through the surgical preparation process. As Dr. Madeline B Deutsch explains, “while the [SOC7] provides detail on how to assess patients for gender dysphoria and consent for surgery, it does not provide specific guidance on performing a psychosocial assessment of housing, social support, or functional status.”⁵¹ Trans people are often concerned that voicing their fears might lead to being denied surgery. Because of the gatekeeping dynamic between clinicians and patients, patients often downplay their doubts or concerns to avoid being denied care.⁵² Gatekeeping undermines the quality of informed

⁵⁰ Dilations involve inserting a dildo, typically made of hard plastic, into the neovagina to stretch the internal muscles and avoid vaginal stenosis.

⁵¹ Madeline B Deutsch, “Gender-affirming Surgeries in the Era of Insurance Coverage: Developing a Framework for Psychosocial Support and Care Navigation in the Perioperative Period” (2016) 27:2 *J Health Care Poor Underserved* 386 at 388.

⁵² See Dean Spade, “Mutilating Gender” in Susan Stryker & Stephen Whittle,

consent, since asking questions freely and honestly is integral to the process.⁵³

Surgeons are even more ill equipped to guide patients through preparation. Because of the opportunity cost of consultations, surgeons spend little face time with patients prior to surgery. Psychological preparations are not among their usual concerns. In our overspecialized medical profession, surgeons live in an environment that speaks in terms of scalpels, anesthesia, bone, skin, nerve, blood clot, medical liability, complication rates, inherent risks, adverse events. As Dr. Barry D Silverman reminds us, “[s]tudents are taught bedside skills, the art of medicine, by our senior, most experienced clinicians. However, in the past 20 years, more of these professors are laboratory scientists, often deficient or unpracticed in their bedside skills.”⁵⁴ Unsurprisingly, most resources available on transition-related surgeries foreground adverse outcomes such as pain, infection, hemorrhage, nerve damage, and dissatisfaction with the results.⁵⁵

With the focus starkly placed on the anatomy, it can be easy to forget that trans patients seeking transition-related surgeries have a complicated relationship with their bodies and frequent mental health issues – especially

eds, *The Transgender Studies Reader* (New York: Routledge, 2006) 315 at 326 [Spade, “Mutilating Gender”].

⁵³ See Veronica Pimenoff & Friedemann Pfäfflin, “Transsexualism: Treatment Outcome of Compliant and Noncompliant Patients” (2011) 13:1 Intl J Transgenderism 37 at 43; Cavanaugh, Hopwood & Lambert, *supra* note 26 at 1149; Ashley, “Friends, not Foes”, *supra* note 26.

⁵⁴ Barry D 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 at 58. Despite attempts at improvements, discussions of doctors’ poor bedside manners and relationship to their patients abound. See e.g. Lorianna De Giorgio, “Is Bad Bedside Manner a Conscious Decision on the Doctor’s Part?”, *The Star* (12 May 2012), online: <www.thestar.com/news/world/2012/05/12/is_bad_bedside_manner_a_conscious_decision_on_the_doctors_part.html> [perma.cc/U2CB-UXXF]; Cheryl Lewis, *Bedside Manners: The Myth of Doctor-Patient Relationship* (Bloomington, Ind: Authorhouse, 2003).

⁵⁵ See e.g. Cameron Bowman & Joshua M Goldberg, “Care of the Patient Undergoing Sex Reassignment Surgery” (2006) 9:3–4 Intl J Transgenderism 135 at 144–46, 156–60; UCSF Guidelines, *supra* note 3 at 129ff. For an example of literature that takes into account patient readiness and psychological needs, see Deutsch, *supra* note 50 at 386.

anxiety and depression.⁵⁶ Once out of the operating room and barring any complications, patients are left to their own devices during the recovery process, with but a few postoperative appointments punctuating the ensuing period. During my postoperative experience, I had to remind my surgeon – on two separate occasions – which surgeries he had performed on me. It is hard to imagine him putting much thought into my healing and mental well-being, if he had not even been able to remember the procedures he performed on me.

Adopting a situated knowledge analysis, we would expect a surgeon's positionality to bias their disclosure of information. Well-intentioned surgeons may overemphasize risks that could give rise to medical liability and forget or ignore the potential emotional weight of recovery. Risks may also be viewed through the lens of what society understands as normal, desirable human functioning, overlooking concerns peculiar to trans communities.

Mental health professionals are better equipped to attend to the patient's overall well-being and integrate concerns of psychological and practical preparedness into their interactions with patients. Their world is replete with references to mental health, emotions, coping, management, support, interpersonal relationships, and resilience. The requisite qualifications in the SOC7 require knowledge of the clinical needs of trans people in addition to training in psychiatry, psychology, or social work. The expertise of mental health professionals complements that of surgeons' and they are tasked with assessing and supporting trans patients partly for that reason.

Despite complementary expertise, knowledge about the needs of trans people gets lost in the cracks. Though mental health professionals are better able to infer the psychological impact of interventions than surgeons, they are not always aware of all the particular medical aspects of surgical interventions – a knowledge that lies squarely within the expertise of surgeons. Outside of multidisciplinary teams, which primarily exist in community health centres that do not offer surgeries, direct interaction between surgeons and mental health professionals is limited. Time is a limited and expensive resource, and surgeons may not always know what information is most useful for mental health professionals seeking to support trans patients. Surgeons may also inadequately disclose information to mental health professionals, constraining the latter's ability to give patients all information needed to adequately prepare.

⁵⁶ See Cecilia Dhejne et al, "Mental Health and Gender Dysphoria: A Review of the Literature" (2016) 28:1 *Intl Rev Psychiatry* 44 at 52–53.

Existing literature and guidelines, written primarily by cis professionals, fail to fill the gap. As Dr. Madeline B Deutsch reminds us, the SOC7 provide little information about the needs of trans patients and the difficulties they may experience, including:

How will a transgender woman be able to perform the necessary vaginal dilation three to four times daily after vaginoplasty, if she is living in a homeless shelter with no private quarters? How will a transgender man be able to replenish his supply of bandages for his chest wounds after mastectomy if he has no car and no social support system? Surgeons who perform gender-affirming procedures and who participate in insurance networks or Medicaid are limited to several large cities. How will a transgender person with low health care literacy, who has met the current surgical criteria, react to sudden bleeding at 3 a.m. in their home city which may be far from (and in some cases in a different state from) the city where the procedure was performed, and how will they navigate the local emergency department? Furthermore, long waiting lists can exist for surgeries, sometimes exceeding one year. [The SOC7 lack] recommendations on reassessing patients who may have undergone a surgical assessment one year or more in the past, and whose psychosocial, housing, or mental health status may have changed from since the time of the original assessment.⁵⁷

Professionals could fill this gap by interacting with trans communities. However, the relationship between health care providers and trans communities is fraught, marked by gatekeeping and mistrust. Trans communities are suspicious of and resentful towards the all-powerful psychologists and psychiatrists on whom access to transition-related care depends.⁵⁸ Rampant trans-antagonistic attitudes pervade some clinical and scientific circles,⁵⁹

⁵⁷ Deutsch, *supra* note 50 at 388.

⁵⁸ See Susan Stryker, *Transgender History* (Berkeley: Seal Press, 2008) at 36ff, 97; Namaste, *supra* note 19 at 157ff; Spade, “Mutilating Gender”, *supra* note 51; Ashley, “Friends, not Foes”, *supra* note 26.

⁵⁹ See Jemma Tosh, ““Zuck Off”! A Commentary on the Protest Against Ken Zucker and his ‘Treatment’ of Childhood Gender Identity Disorder” (2011) 13:1 *Psychology Women Section Rev* 10; Jemma Tosh, *Perverse Psychology: The Pathologization of Sexual Violence and Transgenderism* (New York: Routledge, 2015) at 13–14; Julia M Serano, “The Case Against Autogynephilia”

and it can be difficult to predict if a clinician is trans-affirmative. Though a wider range of practitioners is available, trans individuals continue to fear being denied a referral for hormones or surgery should they express doubts, fears, and anxieties with regard to the treatment. As a result, the relationship between trans patients and health care professionals remains fraught and fearful, despite significant progress towards trans-affirmative care.⁶⁰

By making mental health professionals the arbiters of gender dysphoria, assessments become guided less by the subjective experiences of trans people and more by a clinical programme set by cis researchers, many of whom consider transitude – being trans – to be fundamentally undesirable.⁶¹ If I say I am trans, then shouldn't my relationship to my body be integrated into our understanding of gender dysphoria instead of being invalidated because it does not fit clinical preconceptions?⁶² It is no surprise that patients prefer sanitizing their stories and silencing any doubts they may develop for fear of having to go through the assessment all over again, including paying for the sessions, or worse, being denied access to desired surgeries altogether. Due to the incentive structure created by mental health referral requirements, mental health professionals' knowledge is obfuscated by the lies and omissions of their patients.

(2010) 12:3 Intl J Transgenderism 176 at 178–79; Julia Serano, “Psychology, Sexualization and Trans-Invalidations” (Keynote lecture presented at the 8th Annual Philadelphia Trans-Health Conference, 12 June 2009) at 1–2, online (pdf): <www.juliaserano.com/av/Serano-TransInvalidations.pdf> [perma.cc/AW5X-4G6C].

⁶⁰ See Gemma Applegarth & John Nuttall, “The lived experience of transgender people of talking therapies” (2016) 17:2 Intl J Transgenderism 66. For more on trans-affirmative care, see Sand C Chang, Anneliese A Singh & Lore M Dickey, *A Clinician's Guide to Gender-Affirming Care: Working with Transgender & Gender-Nonconforming Clients* (Oakland, Cal: Context Press, 2018); Schulz, *supra* note 26; Ashley, “Gatekeeping Hormone Replacement Therapy”, *supra* note 26; Cristan Williams, “#DiscoSexology Part I: Dr. Zucker, CAMH, & Conversion Therapy” (18 January 2017), online: *TransAdvocate* <www.transadvocate.com/part-i-the-rise-and-fall-of-discosexology-dr-zucker-camh-conversion-therapy_n_19556.htm> [perma.cc/9YFE-9BGD].

⁶¹ See Y Gavriel Ansara & Peter Hegarty, “Cisgenderism in Psychology: Pathologising and Misgendering Children from 1999 to 2008” (2012) 3:2 Psych & Sex 137.

⁶² See Ashley, “Gatekeeping Hormone Replacement Therapy”, *supra* note 26 at 481; Ashley & Ells, *supra* note 5 at 24.

The pragmatic context of assessment also gives rise to knowledge constraints. Therapy is expensive and few mental health professionals are qualified to provide referrals for transition-related interventions. Patients are generally motivated to minimize cost, opting for the shortest and fewest appointments possible, while therapists are motivated to see as many patients as possible to ensure that all of them may access needed interventions despite the scarcity of providers. Besides trans people's general dislike for long and arguably dehumanizing assessments,⁶³ both the patient and the mental health professional are incentivized to minimize the length of the assessment. Unless they have an ongoing therapeutic relationship to the patient, referring professionals come into mistrustful and rushed patients' lives long before the day of surgical operation; they are therefore poorly situated to learn from the mouth of patients the difficulties that surgeries bring about and for which they could have better prepared.

Even in cases where clinicians have been in a therapeutic relationship with the patient for a long time before surgery and continue seeing them afterwards, anecdotal observation coming from individual patients is of limited reliability. To be reliable, clinical experience must build upon a large number of observations that are adequately and systematically documented. And though anecdotal evidence may highlight the experiences of some patients, it cannot provide a reliable estimate of frequency nor guarantee that all important experiences are accounted for. The story I opened with might tell you that some patients' dysphoria is exacerbated by the surgery, but it does not tell you whether some patients experience postoperative itching so severe it prevents them from sleeping.

Since honest and thorough patient reports are rare outside of therapy and since therapy is financially inaccessible, clinical observations will primarily reflect the perspectives of wealthier and more privileged trans individuals. Even when surgeries are covered by public insurance, paying for referrals and psychotherapy and being out of work for two to three months are significant barriers to access. This introduces a class and racial bias and downplays the impact of sustained postoperative support which may be lacking among poorer patients, whose loved ones may not be able to afford taking time off to care for them. Careful and widespread gathering of qualitative data is needed to compensate for the limitations of anecdotal evidence.

Positioned in the world as cisgender professionals, many health care professionals are poorly situated to understand the range of information that

⁶³ See Ashley, "Gatekeeping Hormone Replacement Therapy", *supra* note 26.

trans patients may need to figure out how to best prepare for surgery, including following the postoperative treatment plan and managing side effects. Limited by their perspectives, the knowledge of professionals fails to empower patients by adequately preparing them for surgery.

C. The know-it-all patient and access to information

Practitioners' inability to fully inform patients would be inconsequential if patients were independently aware of all useful information. In this Sub-Part, I will explain why many patients do not and cannot independently obtain this information from other sources. As a result, it is necessary to review our informed consent practices to ensure that all useful information is granted to patients who have limited access to information.

Readers of this article will be surprised to know that I am what most people would consider a "know-it-all." I came to my surgical consultations and psychological assessments having read the SOC7 and surveyed the academic literature on the surgical process. For people outside of health care fields and trans activism, the assessment process is often a nebulous maze. For them, the Internet is a primary tool for navigating the uncharted territories of transition-related surgeries. The most invaluable source of information is those who have already undergone the same surgery, and many support groups and websites dedicated to transition-related surgeries can be found online.

Since finding people who have first-hand information about surgeries can be daunting, integration within trans communities is a major factor of access to information. For those with many trans friends and acquaintances, surgeries are likely devoid of big surprises. After hearing about how annoying dilations are for the fifth time, it is hard to forget that they are an integral part of postoperative care. Finding referrals is also simplified as patients can contact therapists suggested by other trans people. Trans community organizations also maintain lists of vetted practitioners and readily answer questions about medical transition.

For a wide variety of reasons, many trans people are not well connected to trans communities. Outside of major urban centres, trans people are sparsely distributed. Within major urban centres, many trans people opt not to surround themselves with other trans people out of anxiety or fear of being recognized as trans in public, because it triggers dysphoric feelings, or because they have little interest in foregrounding their trans identity in their social relations. Because trans community groups and organizations are

often dominated by white people both at the level of staffing and membership, intersecting identities can also impact people's ability to integrate into them. Trans people of colour often experience racism in trans communities. Among those who are not well connected to trans communities, the availability and comprehensiveness of written information is a sizable determinant of surgery-related knowledge and, consequently, of their preparedness for surgery.

The SOC7 is a valuable compendium of information about obtaining referrals and commencing on the road to surgery. However, the jargon-filled document can prove indecipherable to trans people who are not well educated, especially those without university-level education. Though trans people are more educated than the average, only 47% of trans people in the United States have a college degree or higher and many return to school later in life at a time when they may have already completed their desired medical transition.⁶⁴ As a result, most trans people seeking surgery may have difficulties reading technical documents. Other readily available sources of information such as the Guidelines of the Center of Excellence for Transgender Health at the University of California, San Francisco are equally difficult to read, having been written with health care professionals in mind.⁶⁵ Vetted information not contained in these publicly-available documents is difficult to access, requiring institutional access and a working knowledge of academic databases. The WPATH-affiliated *International Journal of Transgenderism* and the previously-cited article by Dr. Madeline B Deutsch sit behind a paywall.⁶⁶ Even previous versions of the SOC7 are only available to paying members of WPATH.

Information on surgeries is available as previously described. However, the quality and availability of information vary significantly. Many publicly accessible sources are dated and of questionable value. Since surgical techniques vary by surgeon, the information may also not be applicable – some-

⁶⁴ See Jaime M Grant et al, *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey* (Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force, 2011) at 39, 41.

⁶⁵ See *UCSF Guidelines*, *supra* note 3. Other available documents include “TRS Surgical Summary Sheets” (24 May 2019), online: *Rainbow Health Ontario* <www.rainbowhealthontario.ca/resources/transition-related-surgery-surgical-summary-sheets/> [perma.cc/KZL5-F3C5], which are also intended for use by primary care providers.

⁶⁶ See Deutsch, *supra* note 50.

thing not everyone realizes. Friends of mine have shared their frustrating experiences of community members sharing misleading information, which added unnecessary delays and costs to their transition. It can be difficult to separate good from bad information.

Even when useful information is relayed by a health care professional, patients are not always able to adequately understand it. Surgeons speak in a technical register of language in their practice, and technical vocabulary seeps into their explanations to patients and the mental health professionals they train. According to Mark Gorney, “studies indicate that physicians often overestimate the patient’s ability to understand the risks associated with cosmetic surgery.”⁶⁷ The concern that patients may not understand the information they are given is shared by others in the scholarly literature and was mentioned in *Nguyen*.⁶⁸ Here too, the patient’s educational level mediates the quality of disclosure as it shapes how the information is understood.

Access to information is constrained by access to trans communities, access to paywalled scholarly writing, and ability to understand documents intended for clinicians. Since not all trans people are able to independently access information on how to adequately prepare for surgery, it is necessary to improve our current informed consent practices by incorporating a perioperative duty to disclose all useful, actionable information.

III. MOVING FORWARD: PROPOSED IMPROVEMENTS TO THE INFORMED CONSENT MODEL

Informed consent is a puzzle. Patients cannot get all the pieces without the help of health care professionals. Yet, as we have seen, professionals do not hold all the missing pieces. In this Part, I will outline how we can ensure that patients undergoing transition-related surgeries have all the information they need, not only to make a choice about whether to undergo surgery but also to prepare for the surgical process. I argue that we must rethink the scope of information that is included in informed consent and recognize a

⁶⁷ Gorney, *supra* note 14 at 323.

⁶⁸ See e.g. Alice M Laneader & Paul Root Wolpe, “Ethical Considerations in Cosmetic Surgery” in D Sarwer et al, eds, *Psychological Aspects of Reconstructive and Cosmetic Plastic Surgery: Clinical, Empirical, and Ethical Perspectives* (Philadelphia: Lippincott Williams & Wilkins, 2006) at 305; *Nguyen*, *supra* note 42 at para 178.

perioperative duty to disclose. To adequately meet this duty, we must centre trans knowledges on informational needs and promote open and collaborative dialogue between the health care professionals and trans communities.

A. Completing the puzzle: What information?

The missing information is information that patients would like to know. We might even say that they *need* to know it, insofar as the information is actionable and can have a positive impact on their well-being and postoperative success. To support this claim, I am afraid I have little more than personal and community experiences to offer, but that should be plenty: I do not take this premise of my argument to be controversial. People thirst for knowledge. People are interested in pursuing their own well-being. In this Sub-Part, I will clarify what should be considered useful, actionable information that must be offered pursuant to a perioperative duty to disclose.

How ought we qualify the scope of information that should be given to the patient prior to surgery? I propose that we think of informed consent as including all information that is relevant to deciding whether *and how* to go through the surgical process. Patients ought to know all information necessary to decide whether to undergo surgery – a fact already captured by the narrow conception of informed consent – as well as all information that can be acted upon in preparing for it.

The latter category of information may be considered relevant or useful rather than necessary, since knowledge of this sort would not change the mind of a reasonable patient regarding surgery. Going back to the opening example, I would not have changed my mind about whether to undergo facial feminization surgery because of a few months of heightened gender dysphoria from pausing hormones. It was not, strictly speaking, necessary information for my decision to pursue surgery and later consent to it. It is not information “but for” which I would not have consented: a reasonable trans patient would have elected to have the surgery regardless of whether they were given that information. The gender dysphoria it gave me was short-lived compared to the more intense and ongoing dysphoria of not having had facial feminization surgery. Nevertheless, I believe it is information that most trans patients would like to have. Armed with this piece of knowledge, I could have better prepared for the few weeks prior to surgery and the few months following it.

Information subject to the perioperative duty to disclose, then, includes all actionable information that may help someone prepare for the surgical

process. The surgical process must be understood broadly, as including both the surgery and its accessories. Accessories include direct and indirect by-products of the choice of pursuing a surgery: timeline, treatment plan, need for family or therapeutic support, side effects, etc. In my opening example, both the bodily changes due to stopping hormone replacement therapy as well as the additional emotional difficulties and mental health needs that arose from the bodily changes are accessories to surgery because they are foreseeable consequences of opting to undergo surgery. The relevant link between the surgery and its accessories is that consent to the accessories of surgery is presumed from consent to the surgery itself. One cannot typically consent to the surgery but not the accessories: I could not tell my surgeon, for example, that I consent to the surgery without going off hormone replacement therapy. If I did, he might refuse to operate on me.

The perioperative duty to disclose shifts the frame of consideration from the event of surgery itself to the entire surgical process. The corresponding expansion to informed consent is more responsive to the perspective and needs of patients. A surgery is not a momentary event that marks the boundary between pre-surgical and post-surgical reality, but rather a long process that people explore, navigate, and manage.⁶⁹ Surgeons' involvement with patients might be largely confined to the few hours of surgery during which patients' well-being is in their hands, but, for patients, the surgical process stretches far back in the past, passing through the operating table, and continuing toward the future. For weeks, months, and perhaps even years, the patient's attention will be captured by preoperative preparation and postoperative care. With vaginoplasties, postoperative care puts a significant strain on time management, demanding one to four dilations a day for a year. Dilations have a much more tangible impact on my present life than the moment of surgery did. If the moment of surgery is such a big deal, how come I slept through it?⁷⁰

⁶⁹ For a critique of narratives of genital reassignment surgeries as a fundamental, momentary change marked by rebirth, see Amy Billingsley, "Technology and Narratives of Continuity in Transgender Experiences" (2015) 1:1 *Feminist Philosophy Q 1* (now publishing as Amy Marvin).

⁷⁰ Unlike facial feminization surgery, I was awake through part of my vaginoplasty, and it was awesome.

B. The juridicalization of information

Proposing an expanded conception of informed consent is unlikely to have a concrete impact on practice if the proposal is not translated into normative documents. Laws, regulations, professional codes, guidelines, and policy statement all contribute to medical practices by setting out a clear and authoritative standard of practice. In this Sub-Part, I argue that a perioperative duty to disclose information that is necessary to adequately prepare for the surgical process can be recognized in law.

Two duties to disclose are currently recognized in Québec: the preoperative duty to disclose and the postoperative duty to disclose. The preoperative duty to disclose, which we discussed previously, flows from the duty to obtain informed consent and seeks to ensure that patients can make an enlightened decision about whether to undergo a medical intervention.⁷¹ Unlike the preoperative duty to disclose, the postoperative duty to disclose is not grounded in informed consent, but rather in the duty to follow-up with patients. It aims to prevent adverse events by giving patients information about likely complications, which signs to look out for, and what should be done if these signs manifest.⁷² The underlying goal is to reduce the likelihood and gravity of adverse events.

The proposed perioperative duty to disclose, like the preoperative duty to disclose, would take its roots in informed consent. The perioperative duty to disclose, as discussed in the previous Sub-Part, would include all information necessary to adequately prepare for the surgical process. Information is necessary to adequately prepare for the surgical process if having that information would enable a patient to reduce or avoid inconvenience, distress, harm, injury, suffering, etc. In other words, it refers to actionable information. The goal of the perioperative duty to disclose is to give patients the necessary tools to fend off unwelcome physical and psychological consequences of the surgical process.

I selected the word “perioperative” for three reasons. First, it distinguishes the duty to disclose from the preoperative duty and highlights that the perioperative duty to disclose may not be discharged at the same time

⁷¹ See *Paterson c Rubinovich*, [2000] RRA 26, JE 2000-184 at para 12 [*Paterson*].

⁷² See *ibid* at paras 12–14. See also *Camden-Bourgault c Brochu*, [2001] RRA 295, 106 ACWS (3d) 759 at para 39.

as the preoperative duty to disclose, so long as the information is given sufficiently ahead of time to adequately prepare. Second, the notion of “surrounding” or “around” implicit in the word “perioperative” harmonizes well with the expansive notion of the surgical process. Third, the cessation of hormone replacement therapy for surgery is termed “perioperative.”⁷³ It seems fitting to apply the same term to the proposed duty to disclose since it was the initial experience that inspired this article.

A perioperative duty to disclose can be derived from the duty to obtain informed consent. To see how this is the case, we consider the function of informed consent in relation to autonomy and bodily integrity through the lens of general ethics. Informed consent is about responsibility. When I consent to an intervention, I become the proximate source of that action. I take responsibility for it and may no longer complain that it was done any more than if I had done it myself.⁷⁴ By consenting to a procedure, I take responsibility and relieve my doctor from liability for performing surgery on me. I may, of course, complain of negligence if negligence occurred, but I may not complain that I experienced any of the foreseeable consequences of undergoing surgery at the hand of a reasonably skilled surgeon. Providing informed consent shifts the moral source of the action from the surgeon to me.

In terms of the preoperative duty to disclose, I was sufficiently informed when I consented to cease hormone replacement therapy since further information would not have altered my decision to submit to my surgeon’s request. Yet, it does not seem that I was given enough information to become, in a meaningful sense, the source of my subsequent gender dysphoria and psychological distress. Had I been told sufficiently ahead of time that pausing hormones would lead to dysphoria and distress, I could have prepared for it and taken mitigating steps. Without a perioperative duty to disclose, there is no shift in responsibility for the consequences of ceasing hormones. Although I undertook some responsibility for ceasing hormones, I did not take responsibility for those additional consequences that I could have avoided by psychologically preparing and taking mitigating steps. Since I did not get to choose whether to prepare or take mitigating steps, I am not responsible for the consequences of my inaction—as I would have been

⁷³ See e.g. UCSF Guidelines, *supra* note 3 at 43; Deutsch, *supra* note 50.

⁷⁴ See Heather Draper & Tom Sorell, “Patients’ Responsibilities in Medical Ethics” (2002) 16:4 *Bioethics* 335 at 338.

given all actionable information surrounding consenting to cease hormone replacement therapy.

The perioperative duty to disclose upholds the promise of the duty to obtain informed consent by filling the gap between preoperative disclosure and responsibility for the consequences of the surgical process. Without a perioperative duty to disclose, informed consent can be present without re-locating the moral source of the act to the patient. If people can give valid informed consent without taking responsibility for the consequences, then the relationship between informed consent, autonomy, and bodily integrity is also undermined.

The perioperative duty to disclose is compatible with Québec law. As I detailed previously, the bedrock of medical liability in relation to informed consent can be found in the *Civil Code of Québec* and the *Code of Ethics of Physicians*.⁷⁵ For ease of reading, I reproduce a few of the most relevant provisions:

Art 10 CCQ: Every person is inviolable and is entitled to the integrity of his person. Except in cases provided for by law, no one may interfere with his person without his free and enlightened consent.

Code of Ethics of Physicians, s 3: A physician's paramount duty is to protect and promote the health and well-being of the persons he attends to, both individually and collectively.

Code of Ethics of Physicians, s 28: A physician must, except in an emergency, obtain free and enlightened consent from the patient or his legal representative before undertaking an examination, investigation, treatment or research.

Code of Ethics of Physicians, s 29: A physician must ensure that the patient or his legal representative receives explanations pertinent to his understanding of the nature, purpose and possible consequences of the examination, investigation, treatment or research which he plans to carry out. He must facilitate the patient's decision-making and respect it.

Unlike Ontario's *Health Care Consent Act* which confines itself to information "that a reasonable person in the same circumstances would require

⁷⁵ See *Code of Ethics of Physicians*, *supra* note 12.

in order to make a decision about the treatment,”⁷⁶ the Québec law speaks only of free and enlightened consent. This provides us with the flexibility necessary to reinterpret informed consent in a broader manner that includes a perioperative duty to disclose. Because the word “enlightened” speaks to an elevated state of knowledge that goes beyond “informed,” it is easier to defend a perioperative duty in Québec.⁷⁷

A holistic reading of the *Code of Ethics of Physicians* also allows for a perioperative duty to disclose. The paramount duty of physicians is to promote the health and well-being of patients, a duty that is best fulfilled in the context of obtaining informed consent by disclosing all information which could reasonably impact the patient’s well-being. Because perioperative disclosure is grounded in the patient’s well-being, it coheres with section 3 of the *Code of Ethics of Physicians*.⁷⁸

It could be argued that a perioperative duty to disclose is precluded by section 29 of the *Code of Ethics of Physicians*. Under this reading, section 29 defines the scope of the duty to disclose and restricts it to the decision of undergoing surgery or not. I disagree with this interpretation for three reasons.

First, the words “facilitate the patient’s decision-making” are not incompatible with a perioperative duty to disclose. How to prepare for surgery and its accessories is also a decision, and section 29 does not specify that the decision-making under consideration must be the decision of whether to consent to the intervention.

Second, section 29 may be read as a separate duty from the duty to obtain free and enlightened consent under section 28. Unlike section 28, section 29 does not include the words “except in an emergency” and would encompass the duty to inform patients *following* an emergency intervention as well. While section 29 may clarify the scope of section 28, it does not define it.

⁷⁶ *Health Care Consent Act*, *supra* note 13, s 11(2).

⁷⁷ While I focus on Québec, I believe that a perioperative duty to disclose could be equally recognised in Ontario for the reasons set out in this Sub-Part.

⁷⁸ *Code of Ethics of Physicians*, *supra* note 12, s 3.

Third, according to the *Interpretation Act*, statutes must be given a “fair, large and liberal construction as will ensure the attainment of its object.”⁷⁹ If the object of the duty to obtain free and enlightened consent is to shift moral responsibility for the acts on patients and grant them the ability to avoid negative consequences, then it must include a perioperative duty to disclose. Similarly, the act also states that provisions must be “construed by one another, ascribing to each provision the meaning which results from the whole” statute.⁸⁰ Interpreting section 28 as including a perioperative duty to disclose gives it a meaning that fulfils the promise of the “paramount duty is to protect and promote the health and well-being of the persons” in section 3.⁸¹ A broad interpretation of free and enlightened consent, which includes a perioperative duty to disclose, best fulfils the spirit of well-being and autonomy that underpin the *Code of Ethics of Physicians*.

A perioperative duty to disclose is compatible with the *Civil Code of Québec*, which governs medical liability, and the *Code of Ethics of Physicians* which governs disciplinary procedures. The recognition of a perioperative duty to disclose requires going beyond the current legal framework set by *Hopp, Reibl*, and *Nguyen*.⁸² The situations in these cases can be distinguished from those involving a breach of perioperative duty to disclose. It is open to courts to declare that past cases only set precedent or *jurisprudence constante* with regards to the preoperative duty to disclose, and not the entirety of informed consent.

The fact that transition-related surgeries are elective rather than emergency surgeries removes barriers that might otherwise exist in expanding the scope of legally mandated disclosure. According to *Reibl*, the scope of the duty to disclose is larger in the absence of emergency, as there is more time to engage in careful and detailed disclosure without negative impacts on the patient’s health.⁸³ Many months often lapse between scheduling surgery and performing it, giving physicians ample time to disclose information useful to the patient’s preparation.

⁷⁹ *Interpretation Act*, CQLR c I-16, s 41.

⁸⁰ *Ibid*, s 41.1.

⁸¹ *Code of Ethics of Physicians*, *supra* note 12, ss 3, 28.

⁸² See *Hopp*, *supra* note 29; *Reibl*, *supra* note 29; *Nguyen*, *supra* note 42.

⁸³ See *Reibl*, *supra* note 29 at 886–87. See also Kouri, *supra* note 37 at 361–62; Baudouin, Deslauriers & Moore, *supra* note 40 at § 2–59; *Soltani c Desnoyers*, 2010 QCCA 2257 at para 30.

Although not grounded in informed consent, the potential importance of preparation is recognized through the postoperative duty to disclose. This duty, which flows from the duty to follow-up, seeks to inform patients of the precautions they may and should take.⁸⁴ Although the proposed perioperative duty to disclose flows from the duty to obtain free and enlightened consent rather than the duty to follow-up, I see no reason why the importance of preparations and precautions could not be transposed in the perioperative context, since its value is already recognized.

Although it is important, information covered by the perioperative duty to disclose is rarely of such importance that it may motivate a professional complaint or lawsuit. Disciplinary processes are long and do not entitle complainants to compensation.⁸⁵ The cost of lawyers is prohibitive and the cost of enforcement often outweighs expected benefits.⁸⁶ Patients may be further discouraged from making an official complaint if they believe that the professional was acting in respect of established but inadequate professional standards and is therefore not to blame for failing to disclose on an individual level. If all professionals fail to provide full preparatory information to patients, it is a culture problem and seeking vindication in a legal forum may be an uphill battle. Recognizing a perioperative duty to disclose sends the message to patients that legal recourse is an appropriate means of enforcement and sends the message to professionals that their current informed consent processes may fall short of their legal duties.

Considering the limits of legal enforcement, the proposed recognition of a perioperative duty to disclose should be implemented through governmental documents, professional regulation, and policy statements rather than judicial and quasi-judicial processes. The government should amend professional codes of ethics such as the *Code of Ethics of Physicians*. The SOC7 should also be revised to explicitly include a perioperative duty to disclose that would supply patients with all information necessary to prepare for the surgical process. The SOC7 are not only well-recognized and

⁸⁴ See *Paterson*, *supra* note 70 at para 14. See also *Camden-Bourgault c Brochu*, *supra* note 71 at para 39.

⁸⁵ The *Professional Code* only provides for compensation where funds or property entrusted to a professional were improperly used: see *Professional Code*, CQLR c C-26, ss 89.1, 156.

⁸⁶ Even though disciplinary proceedings are free of charge, representation by a lawyer is often desirable, especially on appeal.

respected in transgender health,⁸⁷ but they shape legal duties since physicians must practice their profession in accordance “with the highest possible current medical standards.”⁸⁸ Mental health professionals are subject to similar requirements.⁸⁹ Even if the SOC7 are not directly enforceable as law, they are influential in law and hold great promise for changing professional culture.

C. *Distributing the informational burden*

Without help, patients only gain the information they needed to prepare for surgery once they have already had it. By the time they turn to writing bitter academic articles on the issue, it is already too late. Can we harness this experiential knowledge to enhance informed consent practices in trans health? I believe so. In this Sub-Part, I will argue that trans communities can and should be directly included as creators of medico-legal knowledge regarding informed consent and the perioperative duty to disclose.

As explained earlier, surgeons and mental health professionals do not typically have knowledge of all information that may be needed to prepare and adapt to the surgical process. By expanding our legal frameworks through the recognition of a perioperative duty to disclose, we create a need for professionals to educate themselves further on the experiences of trans patients undergoing transition-related surgeries. Since this information can only come from trans people, whether directly or indirectly, a separation of the informational burden occurs. Whereas the legal burden rests firmly in the hands of professionals, the *de facto* burden of knowledge creation and knowledge dissemination is shared with trans communities. Collaboration with trans individuals ensures that professionals can discharge their legal burden and can foster a more horizontal relationship with trans people by

⁸⁷ With the addenda that some aspects of it, such as referral letter requirements, are archaic and increasingly abandoned by practitioners in favour of more progressive models of trans health.

⁸⁸ *Code of Ethics of Physicians*, *supra* note 12, s 44.

⁸⁹ Psychiatrists are governed by the *Code of Ethics of Physicians*, *supra* note 12. For the codes of ethics governing other mental health professionals, see e.g. *Code of Ethics of Psychologists*, CQLR c C-26, r 212, s 5; *Code of Ethics of the Members of the Ordre Professionnel des Travailleurs Sociaux et des Thérapeutes Conjugaux et Familiaux du Québec*, CQLR c C-26, r 286, s 3.01.07.

positioning them as active participants in transgender health rather than passive recipients of medical services.

The *de facto* burden can be discharged in two main ways: by placing trans individuals and community organizations in a counselling role, and by pursuing collaborative scientific research on the experiences of trans people with surgeries.⁹⁰ Peer counselling and collaborative scientific research each have their advantages and disadvantages, and an optional approach to meeting the *de facto* burden would wed both approaches. Engaging both community leaders and members-at-large of trans communities best draws on the diversity of expertise to be found among trans people.

The value of community knowledge for trans people is indisputable. Community organizations hold regular support meetings, community dinners, and legal clinics. They also create invaluable informational documents and maintain lists of vetted health care professionals. By-and-for services are generally trusted by trans people and exceptionally well positioned to encourage honest and forthcoming participation in research, especially as it relates to doubts, worries, and upsets trans people may otherwise be reluctant to share with cis professionals – so long as their trust can be obtained. Some existing support groups focus on surgery and could readily be adapted to fulfil a peer counselling role.

Welcoming trans people as active participants in the surgical process fosters the recognition of obscured problems and difficulties, creating a space wherein they can be brought to light. Examples of information not adequately captured under the current approaches to informed consent include dysphoria arising from hormone replacement therapy cessation, phantom itches and pains which may impact sleep quality, the strain the surgical pro-

⁹⁰ The tense relationship between trans communities and health care professionals that I have previously highlighted suggests the need for a community-based participatory research approach to ensure full, quality information and contribute to the mending of the relationship between trans people and the health-care world. See generally Annie Pullen Sansfaçon & Kimberley Ens Manning, “Maximising Research Outcomes for Trans Children and their Families in Canada: Using Social Action and other Participatory Methods of Inquiry” in Julie Fish & Kate Karban, eds, *Lesbian, Gay, Bisexual and Trans Health Inequalities: International Perspectives in Social Work* (Bristol, UK: Policy Press, 2015) 223; Sabra L Katz-Wise et al, “Lessons from a Community-based Participatory Research Study with Transgender and Gender Nonconforming Youth and their Families” (2019) 17:2 *Action Research* 186.

cess puts on interpersonal relationships, and the experience of adapting to a new image of the embodied self, to name a few.

The purpose of highlighting the wide range of information unaccounted for under current practices is not to erect new barriers to surgery, but rather to call on professionals and institutional actors to adequately serve the needs of trans communities.⁹¹ Critiques of inadequate surgical competency, poor informed consent, and inappropriate or unethical behaviours on the part of surgeons have largely come from trans scholars and advocates whose bona fides regarding access to transition-related care without gatekeeping are no longer in doubt.⁹² Commitment to an informed consent model, without gatekeeping, does not mean that informed consent should be treated lightly or that less than optimal disclosure is acceptable. In the words of Dr. Madeline B Deutsch, “educational and resource needs [should] be arranged for and provided during the weeks or months between the referral to the surgeon and the actual surgical date.”⁹³

By relying on community organizations and research participants and providing them with remuneration for their contribution, the solution I propose avoids significantly increasing the human and financial barriers to surgery. Other solutions such as increasing the length of therapy required to obtain a referral – besides being inadequate given the situated knowledge of clinicians – would put an unjustifiable financial strain on trans people, who frequently cannot afford therapy beyond the few sessions required for referral letters. The reliance on community knowledge also plays a supporting role in the movement for lessening or removing referral letter requirements, since it enhances the informed consent process and thus ensures higher qual-

⁹¹ See Deutsch, *supra* note 50 at 388.

⁹² See Gaines Blasdel et al, “Genital Surgery Open Letter” (4 April 2018), online: *WPATH Open Letter* <wpathopenletter.wordpress.com> [perma.cc/5D67-GHDJ]; Noah Adams, “Unethical Trans Doc Exposed” (5 March 2019), online: *TransAdvocate* <www.transadvocate.com/unethical-trans-doc-exposed_n_26683.htm> [perma.cc/5TQN-2CAY]. For my own work regarding gatekeeping, see Ashley, “Friends, not Foes”, *supra* note 26; Ashley, “Gatekeeping Hormone Replacement Therapy”, *supra* note 26; Florence Ashley, “Thinking an Ethics of Gender Exploration: Against Delaying Transition for Transgender and Gender Creative Youth” (2019) 24:2 *Clinical Child Psychology & Psychiatry* 223 at 232; Florence Ashley, “Reply to ‘Hormone Replacement Therapy: Informed Consent Without Assessment?’” (2019) *J Medical Ethics* [published online ahead of print].

⁹³ Deutsch, *supra* note 50 at 389.

ity decision-making even without gatekeeping. Foregrounding community organizations' role in knowledge production and knowledge transmission can bolster arguments against referral letters.

The information could be presented through information pamphlets building upon community consultations and through group meetings and peer learning. Detailed and well-written information pamphlets are essential to those who cannot reasonably attend meetings due to time constraints, distance, mental health issues such as social anxiety, or simply because they have no desire to attend meetings of this kind. A variety of mediums for information dissemination should be available, and the choice between them best left to individual patients.

Since group meetings and peer learning operate outside of the professional-patient relationship, patients' concerns that care could be withheld if they express doubts or ask probing questions should be lessened. Although attending meetings and peer pairing events can involve considerable time commitment, they are more accessible than psychotherapy and remain optional. Patients could always opt for written information. Professionals wishing to confirm the fulfilment of their legal duties could request written details on the content of the sessions and confirmation that the patient attended them.⁹⁴ Those written reports could serve the additional purpose of educating the professional, enabling them to integrate what they have learned into their practices.

I do not believe that my proposed solution would be an undue burden on community organizations, provided that adequate compensation is provided for their added role. Community organizations unwilling to take on the additional work are free to decline, of course, but this additional function can serve as a pivot towards new sources of funding insofar as it opens the door to sources of funding dedicated to health care and health-related services. Surgical centres and mental health professionals could also provide direct funding to these organizations for their services. Since there is a dearth of operational funding for community organizations, with funding being primarily project-based, the suggestion of collaborative projects between health care professionals and community organizations is likely to be welcomed.

⁹⁴ See *Code of Ethics of Physicians*, *supra* note 12, s 9: "A physician must not allow other persons to perform, in his name, acts which, if performed by himself, would place him in contravention of this Code, the Medical Act (chapter M-9), the Professional Code (chapter C-26) and the regulations ensuing therefrom."

Qualitative research into surgery-related informational needs should be led at the local and international levels. Engaging in local, grassroots research recognizes the diversity of trans populations and the sociocultural determinants of health care needs. Social, cultural, legal, and administrative differences can have a tangible impact on the surgical process. Large-scale national and international research contemplates the limitations of local research, since trans communities are often too small outside of large urban centres to nourish an adequate research sample. Yet suburban and rural communities' perspectives need to be reflected in qualitative research. Large-scale research allows for integrating concerns specific to rural communities without threatening data saturation – the point in qualitative research where additional data collection is unlikely to reveal new insights.

Supporting research initiatives falls squarely within the professional role of physicians, who have a duty to “promote measures of education and information in the field in which” they practise.⁹⁵ At the international level, WPATH and its members are uniquely well situated to promote community-based scientific inquiries into the informational needs of trans people regarding the surgical process.⁹⁶ By amending the SOC7 to promote a broad conception of surgical process preparedness in relation to informed consent to care, while at the same time conducting the research necessary to meet the perioperative duty to disclose, WPATH can ensure that recognizing a perioperative duty to disclose does not create any additional access to care barriers. Presentations at trans health conferences, which play a crucial role in clinical and policy education, are often framed in relation to the SOC7, rightly or wrongly. By promoting new, community-driven research and approaches to informed consent, WPATH could encourage trans-affirmative, collaborative developments in trans health studies that engage trans communities as co-creators of medical knowledge.

⁹⁵ *Ibid*, s 14.

⁹⁶ I say this with significant reservations given the rapport that the WPATH executive and board have entertained with trans communities and its unfortunate and inflammatory dismissal of serious concerns raised by community members: see Florence Ashley et al, “Open Letter to WPATH Opposing the Undemocratic Election Process for Officers” (12 September 2018), online: *Change.org* <www.change.org/p/world-professional-association-for-transgender-health-open-letter-to-wpath-opposing-the-undemocratic-election-process-for-officers> [perma.cc/Y8EN-77M6]; World Professional Association for Transgender Health, “WPATH Response to Change.Org Petition” (23 October 2018), online: <[drive.google.com/file/d/1pZTWE0LDEYpi9oOov1Kd6_lwyTF1iSmx](https://drive.google.com/file/d/1pZTWE0LDEYpi9oOov1Kd6_lwyTF1iSmx/view)> [perma.cc/ZNY6-488V].

Informed consent recognizes and operationalizes the foundational principles of autonomy and self-determination. By integrating health care and trans-led support services, and by engaging in horizontal dialogue with trans communities, surgeons and mental health professionals can acknowledge the communal aspects of autonomy and self-determination. Respecting the autonomy and self-determination of the patient means not only enabling the patient's decision-making but also appreciating the significance of uniquely trans experiences and knowledges. The flourishing and the thriving of social justice depends on community empowerment. Perhaps even more so than policy reform, direct services, or cultural changes, "achieving autonomous community power through building a base and developing leadership" lies at the heart of social justice.⁹⁷ With community power, reforms, services, and culture can't but follow.

A narrow understandings of informed consent deforms informed consent by turning it into an issue of medical liability, shrinking autonomy into a threshold for avoiding medical errors. Accompanied by an emphasis on community autonomy and self-determination and through an ethos of care by and for trans people, expanding informed consent to include a perioperative duty to disclose better honours its spirit and holds great promise for the well-being of trans people.

MY HEAD STILL ITCHES: CLOSING REMARKS ON HEALTH POLICY

There is something cathartic in writing about upsetting experiences. For many marginalized writers, writing serves as a form of therapy and of asserting our autonomy in the face of an uncaring or hostile world. By inserting ourselves into academic work, we refuse to be mere objects of study and assert ourselves as creators of our own realities. Harm can spoil the seeds of well-being. Or it can be a transformational moment, blooming into resistance and the refusal to be governed from outside.⁹⁸

⁹⁷ Rickke Mananzala & Dean Spade, "The Nonprofit Industrial Complex and Trans Resistance" (2008) 5:1 *Sex Res Soc Policy* 53 at 61.

⁹⁸ Moments of transantagonism have a long history of forging long-lasting community relationships and infused lifelong resistance, whether we think of the direct police violence at Compton's Cafeteria or Stonewall Inn, or the publication of texts vehemently criticized as anti-trans, such as Janice Raymond's *The Transsexual Empire* or J Michael Bailey's *The Man Who Would Be Queen*. Many scholars and activists who made their mark during those pivotal moments of trans history have gone on to live long, beloved lives of militancy that have far outlasted those of their opponents.

With the growing public and academic interest in trans lives, it is essential to reflect on how the way we treat trans people may disenfranchise rather than empower and support them. The sociomedical institution of informed consent to surgery offers fertile grounds to initiate the discussion of how trans people ought to be treated in medical care given the long paternalistic rapport it has entertained with trans communities and given its close relationship to autonomy.

We embark on the surgical process and must be given the tools necessary to adequately prepare for it. The current understanding of informed consent in law and in medicine is inadequate, requiring only information but for which we may not have consented to the procedure. To be sure, the preoperative duty to disclose is of central importance. But so is the perioperative one.

Legislation may be unnecessary to recognize the perioperative duty to disclose. As I have shown, contextualizing the duty to obtain free and enlightened consent in relation to responsibility and liability allows us to derive a perioperative duty to disclose quite naturally. By consenting while adequately informed, patients become the moral source of the foreseeable consequences of the surgical process. A perioperative duty to disclose is needed to bridge the gap between informed consent and undertaking responsibility, since patients are not the source of consequences which they were unable to prevent due to omissions by health care professionals.

Translating the perioperative duty to disclose into trans health practices will require extensive collaboration between surgeons, mental health professionals, and trans communities. No one knows someone's needs and desires better than themselves. New research must be conducted. Efforts must be made to ensure representation of all trans people, and not merely those privileged trans people who have the greatest access to resources and research participation.

However vulnerable trans people may be, however mistreated they may have been by medical institutions, many others have also had their autonomy undermined and robbed by the medical system. Although I have primarily concerned myself with trans communities and with my experiences as a trans scholar, a perioperative duty to disclose is bound to have a positive impact on many other marginalized groups. Informed consent is not solely within the purview of trans people. Far from it. I can only hope that legislators, surgeons, and mental health professionals will heed the call.

As for myself, I can only hope that my body will be back to normal by the time this article is published.⁹⁹

⁹⁹ It took a long time, but it is. And though I subsequently underwent another major transition-related surgery, I was much better prepared for it.