Resolving the Uncertainty Following *Harman v Director of Proceedings*: Should Patients be able to Waive the Right to be Fully Informed about Medical Treatment?

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Introduction

The right of patients to be fully informed in order to make an informed choice and give informed consent is an established and uncontroversial right affirmed in the Code of Health and Disability Services Consumers' Rights ("the Code").[1] Right 7(1) of the Code goes as far as prohibiting healthcare providers from providing treatment to patients without their informed consent, unless an exception applies.

But what if a competent patient does not want to receive full information prior to receiving healthcare services? Does Right 7(1) mean patients will be denied medical treatment if they refuse information relevant to that treatment? This dissertation analyses whether patients should be permitted to waive information relevant to their prospective treatments and be able to receive treatment albeit being less than fully informed. This is a dilemma regularly faced by medical practitioners, yet there is no fully developed analysis on the issue. This dissertation seeks to fill that gap, making normative arguments in favour of recognising a waiver of the right to be fully informed in some circumstances.

Chapter I illustrates the significance of consent for the purposes of the criminal law, and explores the evolution of informed consent in the common law. The Code is New Zealand's preeminent source of law in the healthcare setting, so its adoption is examined, with a focus on the requirements for informed consent established therein. Chapter II analyses how a waiver of the right to be fully informed has been treated at common law, with a particular focus on High Court case *Harman v Director of Proceedings*.[2] In that case, Wild J forfeited the opportunity to determine whether a waiver is recognised at common law, and if so, in what circumstances it may be considered legally valid. Instead, he simply concluded that the position as to whether or not a right to waive information exists at common law is uncertain. Chapter II considers the obiter comments of other Commonwealth courts, and professional standards, suggesting that Wild J came to an incorrect conclusion on the issue and highlighting the inherent uncertainty that has resulted.

[1] Code of Health and Disability Services Consumers' Rights, Right 6(2).
[2] *Harman v Director of Proceedings* HC Auckland CIV-2007-404-3732, 29 May 2009.

Chapter III examines the concepts of medical paternalism and patient autonomy. This chapter outlines various accounts of autonomy in order to determine what sort of autonomy is reflected in New Zealand medical law. Ultimately, it is argued that a waiver of the right to be fully informed enhances patient autonomy by ensuring patients are in a position to control their course of treatment. Support for a waiver can be found in the literature on the right 'not' to know, which is also explored. In concluding that recognising a waiver of the right to be fully informed is desirable, Chapter IV considers criteria for a sufficiently informed and therefore legally valid waiver, and addresses the ways a waiver could be incorporated into the law.

Chapter I: Consent and the Code of Patients' Rights

A Consent Simpliciter

The legal significance of consent was first acknowledged by the British courts in 1767 in *Slater v Baker & Stapleton*[3] after surgery was performed against a patient's wishes.[4] The common law concept of consent is hence the physician's obligation to secure his or her patient's permission prior to medical treatment.[5] Nowadays, consent provides a defence to the crimes of battery and assault. This is provided in s 61A of the Crimes Act 1961, which outlines that those who perform any surgical operation with reasonable care and skill upon any person are protected from criminal responsibility if the consent of that person (or of any person legally entitled to consent on their behalf) is obtained.[6]

The criminal law is hesitant to punish physicians unless it is clear they intended harm. If a physician provides a patient with treatment intended to be beneficial, the physician is unlikely to be criminally charged.[7] The crime of battery is only relevant in limited circumstances where there is an utter failure to obtain consent and the provider has no justifiable defence for treating the patient without consent.[8] Similarly, a physician will not contravene the criminal law of assault when treatment is provided in good faith with the patient's consent, regardless of whether the patient knew about risks and alternatives.[9] Professor Peter Skegg highlights that instead "it is the common law of torts which is of much the greatest significance in relation to consent – be it informed or otherwise – to medical procedures".[10] The torts of battery and negligence are discussed in Part B.

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[3] *Slater v Baker and Stapleton* (1767) 95 ER 860.
[4] Kayvan Shokrollahi "Request for treatment: the evolution of consent" (2010) 92 Ann R Coll Surg Engl 93 at 94.
[5] Dennis J. Mazur "Consent and Informed Consent: Their Ongoing Evolutions in Clinical Care and Research on Humans" (2008) Sociology Compass 253 at 256.
[6] Crimes Act 1961, s 61A.
[7] Edward Richards "Battery – No Consent" (19 April 2009) Public Health Law Map – Beta 5.7 <www.biotech.law.lsu.edu>.
[8] Amardeep Singh Dhadwal, Lwazi Sibanda and Igor R. Blum "Awareness and Understanding of Decision-Making Capacity and Its Relationship to Legally Valid Consent for Older Patients in Dentistry" (2020) 9(3) Prim Dent J 59 at 60.
[9] PDG Skegg "English Medical Law and 'Informed Consent': An Antipodean Assessment and Alternative" (1999) 7(2) Med Law Review 135 at 142.
[10] At 142.

B The Evolution of Informed Consent

1. Distinguishing consent and informed consent

The primary difference between consent simpliciter and 'informed' consent is the patient's knowledge underlying the consent.[11] 'Informed' consent emerged to deal with the issue of how much information patients ought to receive before consenting to medical treatment.[12] The term entered the legal lexicon in 1957 in *Salgo v Leland Standford Jr. University Board of Trustees,*[13] where a California Court of Appeal stated:[14]

> A physician violates his duty to his patient and subjects himself to liability if he withholds any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.

Salgo initiated the long effort to determine the disclosure requirements for physicians before treating patients[15] and addressed that previously physicians' statements had not been sufficient to enable patients to make informed decisions.[16] The amount of information necessary to elevate consent to sufficiently informed consent varies depending on complexity, treatment risks, and the patient's wishes.[17]

Both consent and informed consent relate to the right of self-determination and the need to ensure individuals' autonomy is respected.[18] However, informed consent is a broader concept. Not only do individuals have a right to decide what happens to their bodies, they also need the information necessary to make treatment choices. This enables patients to achieve individual goals, not simply medical goals.[19]

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[11] Christian P Selinger "The right to consent: It is absolute?" (2009) 2(2) BJMP 50 at 50.
[12] Skegg, above n 9, at 138.
[13] *Salgo v Leland Standford Jr. University Board of Trustees* 317 P 2d 170 (Cal 1957).
[14] Alexander Morgan Capron "Where Did Informed Consent for Research Come From?" (2018) 46 J Law Med Ethics 12 at 17.
[15] Ezekiel J Emanuel and Steven Joffe "Informed Consent" in DW Kufe and others (eds) *Holland-Frei Cancer Medicine* (6th ed, BC Decker, Hamilton (ON), 2003).
[16] Capron, above n 14, at 17.
[17] Selinger, above n 11, at 51.
[18] MD Kirby "Informed consent: what does it mean?" (1983) 9 J Med Ethics 69 at 70.
[19] Jessica Berg "The E-Health Revolution and the Necessary Evolution of Informed Consent" 11:2 Indiana Health Law Review 499 at 590.

2. *The torts of battery and negligence*

Skegg highlights that the tort of battery may have a role in situations where it is arguable the patient did not give an adequately informed consent.[20] He goes on, however, to refer to English case *Chatterton v Gerson*,[21] where the Court held that failing to explain risks and implications of treatment would not lead to a patient's consent being 'unreal', therefore ineffective for the purpose of the tort of battery.[22] Skegg finds "there is no likelihood of the tort of battery playing more than a very minor role in matters of informed consent".[23] Where treatment does not involve some kind of bodily touching, "the very basic requirements of the tort of battery … do not apply".[24] Further, most physical contact in ordinary life is not actionable in battery because it is impliedly consented to by those who expose themselves to the risk of bodily contact by moving in society.[25]

Skegg contends that the tort of negligence provides "the greatest potential where there has been a failure to disclose relevant information about a medical procedure".[26] Patients can recover damages in negligence by establishing they were insufficiently informed, despite having had enough information to give a consent that precludes them from recovering damages in battery.[27] In negligence, the plaintiff must prove the physician's failure to disclose caused the patient's harm – if the risk had been disclosed, the patient would have refused treatment.[28]

The Supreme Court of Canada in *Reibl v Hughes* indicated the tort of negligence is preferred over the tort of battery in cases of inadequate information:[29]

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[20] Skegg, above n 9, at 143.
[21] *Chatterton v. Gerson* [1981] QB 432.
[22] Skegg, above n 9, at 143.
[23] At 150.
[24] At 150.
[25] *Collins v Wilcock* [1984] 1 WLR 1172 at 234.
[26] Skegg, above n 9, at 143.
[27] At 139.
[28] Shane S Monks "The Concept of Informed Consent in the United States, Canada, England and Australia: A Comparative Analysis" (1993) 17(2) University of Queensland Law Journal 222 at 226.
[29] *Reibl v Hughes* (1980) 2 SCR 880 at 9.

> Actions of battery … should be confined to cases where surgery or treatment has been performed … to which there has been no consent at all or where, emergency situations aside, surgery or treatment has been performed … beyond that to which there was consent.

The Court found that when the plaintiff has consented to surgery or treatment but attendant risks that should have been disclosed were not, the consent is not vitiated by the failure of disclosure.[30] The surgery or treatment would not become an unconsented to and intentional invasion of the patient's bodily integrity, and failing to disclose attendant risks should go to negligence rather than to tortious battery.[31]

There are additional reasons why the tort of negligence is preferred over the tort of battery in situations where patients proceed with treatment not fully informed. Liability for battery carries a greater social stigma for medical professionals compared to the negligence tort.[32] Further, negligence arguably "places a reasonable limit on liability by restricting it to cases where disclosure would have caused the patient to refuse to undergo the treatment".[33]

3. Summation

The civil law in this area does not have direct application in New Zealand given the unique no-fault compensation scheme for personal injury under the Accident Compensation Act 2001 ("ACC Act").[34] However, references to the common law in the Code mean the civil law still applies in terms of some concepts informing the Code, when the Health and Disability Commissioner is determining complaints, the Health Practitioners Disciplinary Tribunal is hearing disciplinary proceedings, and when cases reach the courts. The introduction of the Code will be explored next.

C New Zealand's Adoption of a Code of Rights

[30] At 10.
[31] At 10.
[32] Monks, above n 28, at 225.
[33] At 226.
[34] Accident Compensation Act 2001, s 20.

1. The Cartwright Inquiry

The Cartwright Inquiry led to significant reforms by affording patient rights the force of law for the first time in history. It signalled a shift towards patient-centred healthcare and facilitated consumer participation in decision-making. The Cartwright Inquiry was a response to publication of the article "An unfortunate experiment at National Women's Hospital" in the magazine *Metro*.[35] The article described a study led by Dr Herbert Green that began in 1966. The article alleged Dr Green was conducting research on women with cervical abnormalities without definitively treating them and without their knowledge or consent.[36]

In June 1987 the Minister of Health appointed Silvia Cartwright to conduct an Inquiry into these allegations.[37] The Inquiry led to scrutiny of various issues relating to how medicine is practiced in New Zealand.[38] It resulted in various findings and recommendations made in *The Report of the Cervical Cancer Inquiry 1988*.[39] These included the identification of significant and sustained failures in physicians' ethical practices in relation to information sharing and obtaining informed consent.[40] Given the no-fault compensation scheme under the ACC Act, the patients could not bring civil proceedings. The recommendations made generated extensive change in law and practice in terms of patient rights.

A key recommendation was that the Human Rights Commission Act 1977 be amended to provide for a statement of patients' rights and to provide for the appointment of a Health Commissioner.[41] This ultimately led to the development of a legislated Code of Patients' Rights, which amongst other things, seeks to ensure patients receive sufficient information to give informed consent and make informed choices.[42] The Code was created by the Health and Disability Commissioner Regulations 1996 under the Health and Disability Commissioner Act 1994 ("the HDCA"). It establishes ten rights of consumers, and the obligations and duties of

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[35] "The Cartwright Inquiry 1988" (2 January 2009) Ministry of Health <www.health.govt.nz>.
[36] "The Cartwright Inquiry" Women's Health Action <www.womens-health.org.nz>.
[37] "The Cartwright Inquiry 1988", above n 35.
[38] "The Cartwright Inquiry", above n 36.
[39] Silvia Cartwright *The Report of the Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters* (The Committee, July 1988).
[40] At 212.
[41] At 214.
[42] Code of Health and Disability Services Consumers' Rights, Right 6(2).

providers to comply with the Code.[43] Section 31 of the HDCA creates a complaints process for those alleging breaches of the Code.

2. Rights relevant to a waiver

The right to be fully informed is affirmed in Right 6. Right 6(2) states:[44]

> Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.

Right 7(1) affirms:[45]

> Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.

D Conclusion

The Code does not expressly permit a waiver of the right to be fully informed. In proceeding to determine whether or not patients can nevertheless waive that right, it is important to keep in mind that the Code was introduced to achieve a rights-centric approach and to challenge medical paternalism.[46] Right 7(1) prohibits proceeding with medical treatment unless informed consent is obtained, but the reference to the common law provides an avenue for a waiver of the right to be fully informed to be recognised in law. There has been some recognition of a waiver in several obiter comments in the common law. This is explored in Chapter II with a particular focus on *Harman v Director of Proceedings*, where the New Zealand High Court was afforded the opportunity to determine whether a waiver of the right to be fully informed is recognised in New Zealand.

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[43] "About the Code" Health and Disability Commissioner <www.hdc.org.nz>.
[44] Code of Health and Disability Services Consumers' Rights, Right 6(2).
[45] Right 7(1).
[46] "The Cartwright Inquiry", above n 36.

Chapter II: The Common Law and the Uncertainty Following Harman

A Common Law Position

1. Harman v Director of Proceedings

In *Harman*, the patient consulted a cosmetic surgeon, Mr Harman, about a breast reduction. Mr Harman explained risks of the procedure, including infection, possible loss of sensitivity to the nipples, and scarring.[47] The patient also raised the possibility of an abdominoplasty. When Mr Harman explained what excisions would be made, the patient told him she did not want to know those sort of "gory details".[48] Mr Harman did not press the patient, so the location of the abdominoplasty incisions were not explained.[49] The possibility of a procedure to reduce the size of the patient's upper arms was also briefly discussed, with Mr Harman saying liposuction would be performed.[50]

The patient raised the possibility of surgery on her chin, but Mr Harman said the three procedures already discussed were "quite enough".[51] The fact that the patient continued to inquire about potential procedures arguably indicates she did not fully understand how significant the procedures she would be receiving actually were. The procedures were performed at the same time and post-surgery the patient experienced complications: infections developed in her right nipple and the umbilical stump.[52] The patient also experienced inflammation requiring antibiotics, eventually lost her right nipple because of infection and also lost sensation in her left nipple, and was left with permanent scarring on her breasts.[53]

The Health and Disability Commissioner's findings resulted in the matter being referred to the Director of Proceedings, who charged Mr Harman pursuant to sections 91 and 100 of the Health Practitioners Competence Assurance Act 2003 ("HPCA Act") for professional misconduct.[54]

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[47] *Harman v Director of Proceedings*, above n 2, at [6].
[48] At [7].
[49] At [7].
[50] At [8].
[51] At [9].
[52] At [16].
[53] At [24].
[54] *Director of Proceedings v Harman* Health Practitioners Disciplinary Tribunal 107/Med06/37D, 31 May 2007 at [40].

The Commissioner only makes such referrals in a very small number of cases,[55] signifying the seriousness of the matter. There were various allegations, including that Mr Harman failed to gain sufficiently informed consent.[56] The Tribunal held Mr Harman failed to ensure the patient understood: the surgical details of each procedure and the associated risks of each; the increased risk of complications and/or adverse outcomes because of the combined procedures; the advantages and disadvantages of having the procedures performed separately; and the increased risk of complications and/or adverse outcomes because of her obesity.[57] The Tribunal found it proved that in failing to adequately inform the patient of the risks involved in the procedures, Mr Harman failed to obtain sufficiently informed consent.[58] The Tribunal also concluded the patient did not want to hear the gory details but was "not pressed on this issue, and should have been".[59] The procedures were significant and the patient needed to fully understand what was involved.[60]

Mr Harman appealed the Tribunal decision. The issues on appeal included whether in holding Mr Harman "failed to ensure" the patient understood the risks associated with the surgical procedures, the Tribunal applied the wrong test for informed consent.[61] Another issue was whether in finding Mr Harman did not obtain informed consent, the Tribunal erred in its treatment of the patient's right not to hear all the information about the proposed surgical procedures.[62]

Wild J held the Tribunal did not apply an incorrect test for informed consent.[63] The Tribunal used the words "failed to ensure" in relation to Mr Harman's provision of information to the patient, not in relation to her understanding of that information.[64] Wild J confirmed that when it came to understanding information provided, the standard for informed consent is not to "ensure", but to "enable" understanding, which involves some level of checking.[65]

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[55] "Complaint Process" Health and Disability Commissioner <www.hdc.org.nz>.
[56] *Harman v Director of Proceedings*, above n 2, at [25].
[57] At [28].
[58] At [28].
[59] *Director of Proceedings v Harman*, above n 54, at [136].
[60] At [136].
[61] *Harman v Director of Proceedings*, above n 2, at [32].
[62] At [32].
[63] At [63].
[64] At [60].
[65] At [62].

On the issue of the patient's right not to hear all the information about the procedures, Wild J identified Right 7(1) of the Code is expressed not as a right, but as a prohibition on proceeding without informed consent unless an exception applies.[66] He proceeded to determine whether the common law recognises an exception for waivers of the right to know.[67] Wild J referred to Canadian decision *Reibl v Hughes* and Australian decision *F v R*.[68] Significantly, obiter comments in both cases indicate patients can waive the right to be fully informed.[69]

2. *Reibl v Hughes*

In *Reibl v Hughes*, the patient underwent surgery to remove an occlusion in the left internal carotid artery, which had prevented a fifteen per cent blood flow through the vessel. During surgery the patient suffered a massive stroke leaving him impotent and paralysed on the right side of his body.[70] The patient had formally consented to the operation, but alleged this was not an 'informed' consent.[71]

The issue for the Supreme Court of Canada was the patient's right to know what risks were involved in undergoing or foregoing certain surgery – a different issue from whether the doctor carried out his professional activities to the level required by applicable professional standards.[72] The Court found that when dealing with the standard of disclosure of risks, the Ontario Court of Appeal had gone too far in saying: "the manner in which the nature and degree of risk is explained to a particular patient is better left to the judgment of the doctor in dealing with [the patient]".[73]

Against this background, the Supreme Court considered the issue of a waiver of information. The Court said in obiter:[74]

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[66] At [81].
[67] At [81].
[68] *F v R* (1983) 33 SASR 189 (SC).
[69] *Harman v Director of Proceedings*, above n 2, at [82].
[70] *Reibl v Hughes*, above n 29, at 1.
[71] At 1.
[72] At 13.
[73] At 12.
[74] At 13.

> It is, of course, possible that a particular patient may waive aside any question of risks and be quite prepared to submit to the surgery or treatment… Such a situation presents no difficulty. Again, it may be the case that a particular patient may, because of emotional factors, be unable to cope with facts relevant to recommended surgery or treatment and the doctor may, in such a case, be justified in withholding or generalising information as to which he would otherwise be required to be more specific.

The Court ultimately concluded the duty of disclosure was breached.[75] There was a failure to disclose the risk, even though the plaintiff himself raised the question of the risks he faced.[76] The plaintiff was told nor understood no more than that he would be better off having the operation than not.[77] However, the Court was prepared to make the obiter comment about a waiver of risks despite the risks being severe with a high likelihood of occurring. The Court found the doctor appreciated this likelihood in view of his own experience that of the 60 to 70 operations he had previously performed, eight to ten resulted in the patient's death. Although the mortality rate was falling, the rate of related sickness or disease rate was still about ten per cent.[78] However, it seems the Court did not restrict a waiver of the right to relevant information to situations where only minor risks are involved.

3. F v R

In *F v R*, a woman had a sterilisation operation and the medical practitioner failed to advise her there was a failure rate of less than 1%.[79] The woman subsequently became pregnant.[80] The Supreme Court of South Australia considered the patient's desire for information is relevant when considering what a responsible doctor would disclose in the circumstances.[81] King CJ stated in obiter:[82]

> The presumption is clearly in favour of disclosure of the information which is relevant to the making of a decision. But a doctor is not required to inflict on his patients information which

[75] At 41.
[76] At 41.
[77] At 39.
[78] At 39.
[79] *F v R*, above n 68, at 189.
[80] At 189.
[81] At 192.
[82] At 193.

> they do not seek and do not want. Many people are prepared to place themselves in the hands of their doctors and to leave all decisions to them. Such people would be burdened unnecessarily and unwillingly with information about the risks involved in contemplated treatment. What is required is reasonable care on the part of the doctor in exercising a judgment as to the real wishes of his patient in relation to receiving information relating to risks. If a reasonable exercise of that judgment is against volunteering information he will not be negligent.

The Court in *F v R* require doctors to exercise reasonable care in ascertaining the patient's wishes regarding receiving information relating to risks,[83] whereas the Court in *Reibl v Hughes* accepted that the situation where a patient waives information regarding risks "presents no difficulty".[84] Arguably, the Court in *Reibl v Hughes* affords patients a greater degree of control compared to the Court in *F v R*, who add a standard of reasonableness before recognising a waiver. On the Supreme Court of South Australia's interpretation, the doctor would have the ability to refuse to uphold the waiver if the doctor believed it was inconsistent with the patient's real wishes.[85] However, both courts did not seem concerned with permitting a waiver of relevant information if the patient's health would be negatively affected by the information disclosure.[86]

4. Returning to Harman

After quoting these obiter comments, Wild J referred to Professor Peter Skegg, Lord Scarman and Dr Judy Gutman.[87] Skegg contends that if a consumer "makes it clear he or she does not want to receive information" and is "content to leave the choice of treatment to the provider", the provider will not infringe the consumer's right to receive information by omitting to provide it.[88] Skegg qualifies this, however, claiming "there will be circumstances where a provider would act reasonably in disclosing information, even to a consumer who had no wish to receive it".[89] He gives the example of a back operation that involves a risk of paralysis.[90] Thus, in

[83] At 193.
[84] *Reibl v Hughes*, above n 29, at 13.
[85] *F v R*, above n 68, at 193.
[86] *Reibl v Hughes*, above n 29, at 42; *F v R*, above n 68, at 193.
[87] *Harman v Director of Proceedings*, above n 2, at [84].
[88] Peter Skegg and others *Health Law in New Zealand* (Wellington, Thomson Reuters, 2015) at 270.
[89] At 270.
[90] At 270.

procedures where treatment risks are low, Skegg indicates the right to informed consent can be waived, but not when the risks are significant. Similarly, Lord Scarman has highlighted that "the patient has a right to know, but that is not a right he has to exercise, and he may not wish to know".[91] Lord Scarman explains patients should have the opportunity to hear relevant information, but for their own reasons, choose to refuse it. That means the consent is not informed, but is still a free consent.[92] Gutman also contends "patients should be able to exercise their autonomy by asking doctors not to discuss details of treatment with them".[93]

Despite being aware of the common law recognition in obiter, the acceptance by legal commentators, and the Medical Council's Statement of Information and Consent 2002, which all support a waiver of the right to be fully informed, Wild J concluded the legal position in New Zealand as to a patient's ability to waive the right to know is uncertain.[94] He forfeited a rare opportunity to clarify whether a common law exception for waivers of the right to be fully informed exists in New Zealand. He found "the weight of authority seems to be that the surgeon should insist on the patient listening to sufficient detail, at least where major surgery carrying high risks is proposed".[95] Wild J focussed on the views of medical experts Dr De Chalain and Dr De Geus[96] who gave evidence to the Tribunal they would not have proceeded with the surgery unless the patient had consented to it, listening in reasonable detail to what was involved.[97] However, one expert accepted there was no universal rule.[98] The Tribunal's reliance on these experts is discussed in Part B.

5. *Montgomery v Lanarkshire Health Board*

Six years after *Harman*, the UK Supreme Court (highest UK authority) in obiter recognised a waiver of the right to know in *Montgomery v Lanarkshire Health Board*.[99] Mrs Montgomery's baby was born with severe disabilities due to complications during delivery. She sought

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[91] Lord Scarman "Consent, Communication and Responsibility" (1986) 79 J R Soc Med 697 at 698.
[92] At 698.
[93] Judy Gutman "The Right Not to Know: Patient Autonomy or Medical Paternalism?" (2000) 7(3) J Law Med 286 at 290.
[94] *Harman v Director of Proceedings*, above n 2, at [85].
[95] At [85].
[96] At [86].
[97] At [80].
[98] At [80].
[99] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [2015] AC 1430.

damages, attributing the injuries to negligence on Dr McLellan's part.[100] Mrs Montgomery was not told about a 9-10% risk of shoulder dystocia,[101] and alleged that if she was told, she would have requested a caesarean section.[102]

The Court referred to Lord Templeman's finding in *Sidaway v Board of Governors of the Bethlem Royal Hospital*: "the provision of too much information may prejudice the attainment of the objective of restoring the patient's health".[103] Thus, if optimising the patient's health is an overriding objective, information disclosure to a patient should be regarded as an aspect of medical care with the standards for appropriate disclosure set by the medical profession.[104] The Court continued, however, to find the way providers and recipients of healthcare services view their relationship has changed.[105] Patients are treated as consumers exercising choices and are regarded as persons holding rights, not passive recipients of the medical profession's care.[106] The Court referred to the Human Rights Act 1998 (UK), stating the courts have become "increasingly conscious of the extent to which the common law reflects fundamental values".[107]

These social and legal developments indicate a legal approach that treats patients as adults capable of understanding that medical treatment is uncertain and involves risks, accepting responsibility for taking risks affecting their lives, and living with the consequences.[108] Against this background the Court stated in obiter:[109]

> A person can of course decide that she does not wish to be informed of risks of injury (just as a person may choose to ignore the information leaflet enclosed with her medicine) and a doctor is not obliged to discuss the risks inherent in treatment with a person who makes it clear that she would prefer not to discuss the matter.

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[100] At [1].
[101] At [13].
[102] At [18].
[103] *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871 at 904.
[104] *Montgomery v Lanarkshire Health Board*, above n 99, at [74].
[105] At [75].
[106] At [75].
[107] At [80].
[108] At [81].
[109] At [85].

The UK Supreme Court takes more of a rights-based approach compared to the Commonwealth courts who were previously willing to recognise a waiver of the right to be fully informed. This reflects the notion of patients as bearers of *rights* – the waiver is recognised because of the patient's right to decide. Notably, the UK's most authoritative court was willing to recognise a waiver (although in obiter) even though the medical information in question related to a considerable risk with a 9-10% possibility of occurrence. It is significant that the Court did not restrict the obiter comment to situations of minor risk or where the likelihood of the risk occurring is low.

Ultimately, the Supreme Court gave judgment in Mrs Montgomery's favour.[110] Doctors have a duty to take reasonable care to ensure patients are aware of any material risks involved in recommended treatments. The test of materiality is whether a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware the particular patient would be likely to.[111] Had Dr McLellan advised of the risk of shoulder dystocia, Mrs Montgomery would probably have elected a caesarean section.[112]

6. Summation

Some Commonwealth courts have recognised a waiver of the right to be fully informed, albeit in obiter. It is unusual that Wild J refrained from properly interrogating these obiter comments and the comments of the legal academics he referred to. The UK Supreme Court emphasised individual rights in *Montgomery*, which appears to extend to the right to waive relevant medical information. Although the New Zealand system can be differentiated to that in the UK because there is no equivalent to the Code, the position in both jurisdictions is arguably actually very similar given the Code was introduced to affirm patients' rights.[113] However, Wild J's finding indicates he declined to give this due weight. As Skegg recognises:[114]

> The Code is, after all, a key element in a legislative scheme 'to promote and to protect the rights of health consumers…', not to remove rights they previously had, like that of declining to receive information.

[110] At [106].
[111] At [87].
[112] At [104].
[113] Health and Disability Commissioner, above n 43.
[114] Skegg and others, above n 88, at 270.

Wild J did not rule out a common law waiver, but instead caused significant uncertainty, which is further explored in Part B.

B The Uncertainty and Inconsistency Following *Harman*

1. The High Court's failure to scrutinise the issue

Skegg contends that "*Harman* did not provide a good opportunity to argue that the Code of Rights provides patients with a right to information, but not a duty to receive unwanted information".[115] There were other factors related to Mr Harman's past and present conduct that Skegg states "would have made any judge very reluctant to overturn the disciplinary decisions in their entirety".[116] Presumably, Wild J was not sympathetic to Mr Harman given the serious findings against him. It seems this contributed to the Court's failure to properly consider whether a waiver of the right to be fully informed exists at common law.

This is unfortunate – we expect the judiciary to prioritise the common law in its full sense and not determine legal questions based on the individual in the particular case. In light of Skegg's finding, *Harman* was not an appropriate case to determine the *legal* question of whether a waiver exists. Even if Wild J found a waiver exists in common law, based on the *Harman* facts the question still arises whether the patient actually waived her right to information. Skegg surmises that in refusing the "gory details", the patient was hardly waiving her right to receive information about *risks*.[117] Therefore, the issue of whether a waiver should be permitted on these facts was not sufficiently addressed.

In concluding the position as to whether a waiver is recognised in common law is uncertain, Wild J also created inconsistency when his finding about the standard of informed consent is considered. He held the standard is not to "ensure" understanding but to "enable" understanding, which involves ascertaining whether the information provided has been

[115] At 270.
[116] At 271.
[117] At 271.

understood.[118] But by offering patients the *option* to receive medical information, thereby affording them the chance to refuse hearing it, it is arguable this interpretation constitutes "enabling" understanding. From this perspective, it could be said Wild J's conclusion actually supports recognising a waiver of the right to be fully informed given doctors merely have to provide patients the opportunity to understand.

2. *Professional standards*

Further inconsistency arises from Wild J's conclusion when professional standards are considered. The HPCA Act sets out the Medical Council of New Zealand's role, whose primary purpose is to protect patients and the public.[119] The Council has five main functions, which include setting and promoting standards for doctors before and after they are admitted to the register; and setting programmes to develop doctors' competence.[120] The Council produces policy statements to inform what the Council regards as safe medical practice and which are modified in light of events.[121]

The Council's current statement *Informed Consent: Helping Patients Make Informed Decisions About Their Care* was released in September 2019.[122] It has a section headed "When a patient declines information about treatment" that states:[123]

> If a patient tells you they do not want information about their treatment, you must record their decision in their notes. You should also explore with the patient why they are declining information about their treatment… and record the patient's reasons… You should tell the patient that they can let you know if they change their mind…

This current statement accepts patients can waive information. Arguably it is desirable that the law is consistent with professional practice. Wild J's conclusion creates further discrepancy when considering Right 4(2) of the Code, which affirms that every consumer has the right to

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[118] *Harman v Director of Proceedings*, above n 2, at [62].
[119] "What we do" Medical Council of New Zealand <www.mcnz.org.nz>.
[120] Richard Sainsbury "A History of the Medical Council of New Zealand" (1 July 2015) <mcnz.org.nz> at 9.
[121] At 164.
[122] Medical Council of New Zealand *Informed Consent: Helping patients make informed decisions about their care* (Medical Council of New Zealand, Wellington, September 2019).
[123] At [16].

have services provided that comply with professional standards.[124] There is therefore significant disconnect between the Medical Council statements on informed consent and the overseas expert evidence expressed to the Tribunal, which the Tribunal relied on in concluding the issue, and which Wild J subsequently affirmed.

3. The Tribunal's reliance on expert opinion in Harman

On the issue of the patient's right not to hear all the information about proposed surgical procedures, counsel for Mr Harman submitted that as with the right to decline treatment in the Bill of Rights Act 1990, patients have the right not to know risks and details of the surgical procedure.[125] However, the Tribunal accepted the expert opinions given to it that a patient's statement that they do not want to hear details does not obviate the surgeon's obligation to properly inform.[126]

Dr De Chalain trained and had experience as a general surgeon and a plastic surgeon *overseas* before practicing in New Zealand. Neither the Tribunal nor the High Court questioned whether overseas expert professional guidance is different to that in New Zealand. This is particularly noteworthy in light of Dr De Geus accepting there is no universal rule in the circumstance under which a surgeon must operate where a patient does not want to hear about the surgical procedure.[127]

Despite concluding the issue based on the expert witnesses' views, the Tribunal referred to various case law when discussing what it deemed "the appropriate standard".[128] The Tribunal looked at *B v Medical Council of New Zealand*, where Elias J stated:[129]

> … usual professional practice, while significant, may not always be determinative: the reasonableness of the standards applied must ultimately be for the Court to determine, taking into account all the circumstances including not only usual practice but also patient interests and community expectations …

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[124] Code of Health and Disability Services Consumers' Rights, Right 4(2).
[125] *Harman v Director of Proceedings*, above n 2, at [73].
[126] *Director of Proceedings v Harman*, above n 54, at [136].
[127] *Harman v Director of Proceedings*, above n 2, at [75].
[128] *Director of Proceedings v Harman*, above n 54, at [80].
[129] *B v Medical Council* [2005] 3 NZLR 810 at 811.

Elias J also stated, "In the case of adequacy of communication of information to the patient … wider considerations are relevant.[130] This supports considering factors beyond experts' views when determining what constitutes usual practice in terms of the standard of care required. However, the Tribunal also referred to *F v Medical Practitioners Disciplinary Tribunal*, where the Court of Appeal held evidence of accepted practice would be "highly relevant",[131] and relying on *Lake v Medical Council of New Zealand*[132] the Tribunal in *Harman* concluded it "cannot substitute its own views, however expert, for the views of any expert called in the case".[133]

The Tribunal was aware of the 2002 Medical Council statement, referring to it as a source giving rise to a medical practitioner's duty to obtain a patient's informed consent.[134] Wild J went further, confirming the 2002 statement states a patient may waive the right to discuss details of the procedure.[135] The Tribunal, however, instead chose to "carefully consider" the principles in the cases outlined above.[136] The Tribunal made no reference to *Reibl v Hughes* or *F v R*. In affirming the Tribunal's finding Wild J disregarded the authority supporting a waiver, making the decision based on the expert opinions.

This is disappointing – despite a waiver having been recognised only in obiter thus far, we expect the judiciary to decide cases having adequately considered the full breadth of authority available to it. Instead, the Tribunal and the High Court omitted to consider how a waiver of the right to be fully informed has been recognised in obiter and seemingly placed disproportionate emphasis on the views of the expert witnesses. The conclusion also conflicts with certain rights in the Code.

4. Tension with the Code of Patients' Rights

[130] At 812.
[131] *F v Medical Practitioners Disciplinary Tribunal* [2005] 3 NZLR 774 at 795.
[132] *Lake v Medical Council of New Zealand* HC Auckland 123-96, 23 January 1998.
[133] *Director of Proceedings v Harman*, above n 54, at [82].
[134] At [87].
[135] *Harman v Director of Proceedings*, above n 2, at [84].
[136] *Director of Proceedings v Harman*, above n 54, at 84.

There is tension between some of the rights in the Code and Wild J's position on a waiver of the right to be fully informed. Right 1(1) affirms the right to be treated with respect.[137] Sometimes medical news is extremely distressing.[138] Arguably, compliance with Right 1(1) involves respecting people's wishes not to hear information if they have a good reason for not wanting to know it. A similar argument could be made in light of Right 4(3), which outlines the right for every consumer "to have services provided in a manner consistent with his or her needs".[139] It is difficult to reconcile Right 7(1) expressed as a prohibition with Right 1(1) and Right 4(3), particularly when one recalls the Code was introduced to provide patients with rights and healthcare providers with obligations.[140]

Right 5 of the Code affirms the right to "effective communication in a form, language, and manner that *enables* the consumer to understand the information provided".[141] This supports the proposition that the standard does not go beyond providing the consumer the opportunity to fulfil his or her right, leaving it to the consumer to decide whether or not to realise it. Further, Wild J did not fully draw on the Code. In choosing to place sole emphasis on Right 7(1) he seemingly decided the case being unaware of Clause 3 of the Code, which states:[142]

> A provider is not in breach of the Code if that provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in the Code.

Skegg recognises Clause 3 could have a role where a patient purports to waive the right to know.[143] This will be explored further in Chapter IV.

C Conclusion

The common law may be reflected in the Code via the Right 7(1) exception. In *Harman*, Wild J was presented with the opportunity to incorporate a waiver of the right to be fully informed in law. However, he arguably neglected to interrogate the obiter comments of other

[137] Code of Health and Disability Services Consumers' Rights, Right 1(1).
[138] Ben Davies "The right not to know and the obligation to know" (2020) 46 J Med Ethics 300 at 300.
[139] Code of Health and Disability Services Consumers' Rights, Right 4(3).
[140] Health and Disability Commissioner, above n 43.
[141] Code of Health and Disability Services Consumers' Rights, Right 5(1).
[142] Clause 3(1).
[143] Skegg and others, above n 88, at 270.

Commonwealth courts and the findings of renowned academics, all of which support recognising a waiver. In relying on expert evidence heard in the Tribunal, Wild J reached a conclusion that is inconsistent with the Medical Council statement, which reflects professional standards, and with some of the rights affirmed in the Code.

Given the rights-centric approach adopted by the UK Supreme Court in *Montgomery*, it would be interesting to know whether Wild J would have considered the issue in more detail had *Harman* been heard after *Montgomery*. Interrogating the comments of the Court in *Montgomery* may have had Wild J align the approach of that Court with the underlying reasons for adopting a Code in New Zealand. Perhaps Wild J would have been more willing to recognise a waiver, which would have led him to outline the sort of situation where a waiver would apply.

Chapter III: Conceptions of Autonomy and the Right 'Not' to Know

A Introduction

The analysis in Chapter II demonstrates there is scope to recognise a waiver. However, this needs to be considered in light of arguments that patients who waive the right to be fully informed are failing to act autonomously. Chapter III analyses accounts of autonomy to determine whether recognising a waiver is desirable in terms of whether it would enhance or infringe patient autonomy. Exploring the ethical perspectives of autonomy and paternalism enable the nature of the doctor-patient relationship to be analysed. Literature on the 'right' not to know is discussed to examine how such a right supports recognising a waiver of the right to be fully informed.

B Medical Paternalism Versus Patient Autonomy

1. The emergence of patient autonomy

Medical paternalism is a longstanding concept that originated in the Hippocratic Oath.[144] Traditionally, the doctor's role was all-powerful and paternalistic – patients had a submissive role. The elevated status of doctors meant the medical decisions they made were almost always accepted and rarely challenged.[145] The Hippocratic doctors considered it an ethical requirement to follow 'the criterion of beneficence' where the doctor's role involved acting in the patient's best medical interests.[146] Focus on the patient's welfare led to beneficence becoming a central justification for the notion of paternalism.[147] It was often assumed the patient's welfare was primarily defined by what doctors thought to be the correct choice, rather than what patients

[144] Veikko Pelto-Piri, Karin Engström and Ingemar Engström "Paternalism, autonomy and reciprocity: ethical perspectives in encounters with patients in psychiatric in-patient care" (2013) 14 BMC Med Ethics at 2.
[145] Gutman, above n 93, at 287.
[146] R Kaba and P Sooriakumaran "The evolution of the doctor-patient relationship" (2007) 5 International Journal of Surgery 57 at 59.
[147] Sheila AM McLean *Autonomy, Consent and the Law* (Routledge-Cavendish, Oxon, 2010) at 9.

themselves wanted.[148] Paternalistic doctors believe "patients often need to be guided firmly through the decision making process as they do not always know what is best for them".[149]

During World War II some physicians used the concept of paternalism to justify conducting treatments that amounted to violations of patients' dignity and human rights.[150] Experimental studies were often carried out on volunteers without their consent. Dr Herbert Green's study at the National Women's Hospital, which became the subject of the Cartwright Inquiry, is an example of research being conducted and justified on the basis of medical paternalism. Studies like this sit at the extreme end of the spectrum, but throughout the 1900s doctors would often direct patients to have treatment that involved unpleasant side effects even when patients tried to decline. Doctors would justify treatment based on the long term interests of patients being better served.[151]

Discussion on medical ethics after the war contributed to the strengthening of patient rights with the concept of autonomy coming into focus as a trump value.[152] A breadth of research was conducted which led to various findings like the psychoanalytical and psychological theories proposed by Breuer and Freud, which constitute the patient as a person whom it is important to listen to.[153] This contributed to the traditional reliance on the physician shifting; patients began to be recognised as having legitimate interests and viewpoints, with the right to be engaged in treatment decisions.[154]

Hence, the concept of patient autonomy gradually replaced medical paternalism as the fundamental principle of the doctor-patient relationship.[155] This idea of autonomy was reflected in the first version of the International World Medical Association Code of Medical Ethics in 1949. The code outlines that physicians are obliged to respect competent and well-informed

[148] At 9.
[149] Brian McKinstry "Paternalism and the doctor-patient relationship in general practice" (1992) 42 British Journal of General Practice 340 at 340.
[150] Pelto-Piri, Engström and Engström, above n 144, at 2.
[151] McKinstry, above n 149, at 340.
[152] Pelto-Piri, Engström and Engström, above n 144, at 2.
[153] Kaba and Sooriakumaran, above n 146, at 59.
[154] McLean, above n 147, at 6.
[155] Jennifer K Walter and Laine Friedman Ross "Relational Autonomy: Moving Beyond the Limits of Isolated Individualism" (2014) 133 Pediatrics S16 at S17.

patients' right to accept or refuse treatment.[156] Informed consent litigation also contributed to the growing recognition of patient autonomy. *Schloendorff v Society of New York Hospital*[157] was a pivotal case that has been "widely quoted as legal recognition of the patient's right of autonomy, or of self-determination".[158] The plaintiff had consented to being examined to determine if a diagnosed fibroid tumour was malignant, but not to its removal. The physician, however, removed the tumour after finding it malignant.[159] Justice Cardozo held that "every human being of adult years and sound mind has a right to determine what shall be done with his own body".[160] This was ground-breaking in terms of strengthening the concept of patient autonomy.

2. Autonomy in healthcare

There are multiple reasons for valuing autonomy. Legal philosopher Gerald Dworkin highlights that autonomy is used in an "exceedingly broad fashion".[161] He says that "it is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge".[162] However, autonomy has a particularly significant role in healthcare because one's body is irreplaceable and inescapable.[163] Dworkin highlights this by identifying that if an architect does not listen to his clients, resulting in a house they do not like, the clients can always move – there are options to resolve the issue. However, people can never move from their bodies.[164] Thus, failing to respect an individual's wishes concerning his or her body is an "insulting denial of autonomy".[165]

Critics of the modern dominance of autonomy express concern that it may negatively affect patient care due to the influence of medical advice on patients' decisions being reduced,

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[156] Pelto-Piri, Engström and Engström, above n 144, at 2.
[157] *Schloendorff v Society of New York Hospital* 211 NY 125 (1914).
[158] Monks, above n 28, at 223.
[159] Stephen Bolsin and Kym Saunders "Informed consent in medical practice" (2012) Trends in Urology & Men's Health 34 at 34.
[160] *Schloendorff v Society of New York Hospital*, above n 157, at 129.
[161] Gerald Dworkin *The Theory and Practice of Autonomy* (Cambridge University Press, Cambridge; New York, 2007) at 6.
[162] At 6.
[163] At 113.
[164] At 113.
[165] At 113.

causing the relationship between the healthcare professional and patient to become sterile.[166] Dworkin recognises intrinsic value lies not necessarily in having choices, but in being recognised as someone capable of making choices. However, just because it is intrinsically better to be someone that makes choices does not mean it is preferable to have more.[167]

This idea can be applied in the healthcare setting – sometimes patients expect and even urge their doctors to be paternalistic, especially when medical news is distressing or where patients cannot decide. If denying autonomy is justified to promote benefit to an individual's health, then paternalism has a strong claim in the medical context.[168] However, Sheila McLean recognises that what makes us generally prefer the concept of autonomy over paternalism is that although we consult doctors precisely because they have expertise in health matters, neither their knowledge nor their recommendations define our 'best interests'.[169] Our 'best interests' will be derived from more than clinical diagnosis – they come from our hopes, fears, and aspirations, for example – factors unique to each person.[170]

3. Summation

Despite having opposing viewpoints, the objective of both patient autonomy and medical paternalism is the good of the patient: while the former sees the patient as best placed to know what is in their best interests, the latter considers doctors know best. However, there is uncertainty around whether recognising a waiver of the right to be fully informed enhances autonomy, or undermines it *because* of the idea patients have a duty to exercise their autonomy. Is permitting a waiver violating patient autonomy given it means patients are deprived of information relevant to their treatment? Or is permitting a waiver an enhancement of patient autonomy because decisions to refuse information are respected? The lack of clarity around what it means to respect patients' autonomy is arguably a result of the various ways the concept of autonomy can be understood.[171]

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[166] McLean, above n 147, at 14.
[167] Dworkin, above n 161, at 80.
[168] At 113.
[169] McLean, above n 147, at 11.
[170] At 11.
[171] Walter and Ross, above n 155, at S17.

C Various Accounts of Autonomy

1. Introduction

There are differing accounts of autonomy proffered by philosophers and academics, which rely on various ethical and philosophical traditions.[172] McLean states, "autonomy rules, but its precise meaning is far from agreed".[173] Dworkin contends that sometimes autonomy is used "as an equivalent of liberty, sometimes as equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will".[174] Dworkin finds there is "no single conception of autonomy … we have one concept and many conceptions of autonomy"[175].

Part C sets out the dominant accounts of autonomy expressed by renowned legal philosophers. The notions of individualistic autonomy and relational autonomy are also discussed. This involves looking at how the conceptions of autonomy apply in situations where patients waive their right to be fully informed. Part C draws conclusions on what sort of autonomy should inform medical treatment in general, considering the issue of the right to waive information in particular.

2. Kantian account

Kant's view of autonomy is that "a rational will must be regarded as autonomous, or free, in the sense of being the author of the law that binds it".[176] For Kant, being autonomous is not being able to do what one desires, but having the capacity for rational self-governance.[177] Kant considered that "every rational being should be regarded as an autonomous legislator in a kingdom of ends", meaning self-legislation must also be capable of being willed as universal.[178] Therefore, people are obliged to act upon principles that a community of rational agents would

[172] McLean, above n 147, at 14.
[173] At 7.
[174] Dworkin, above n 161, at 6.
[175] At 9.
[176] Robert Johnson and Adam Cureton "Kant's Moral Philosophy" in Edward N Zalta (ed) *The Stanford Encyclopedia of Philosophy* (Spring 2019 ed, Metaphysics Research Lab; Stanford University, 2019).
[177] McLean, above n 147, at 15.
[178] Alasdair Maclean *Autonomy, Informed Consent and Medical Law: A Relational Challenge* (Cambridge University Press, 2009) at 15.

accept as laws. However, autonomy ensures the source of the authority of the binding principles is a person's own will.[179]

Kant's conception of autonomy has been criticised for overlooking the role relationships and emotion play in our decisions. In particular, premising autonomy on a strict adherence to impartial and abstract principles is implausible because of factors like emotion and partiality.[180] Alasdair Maclean contends that consuming ourselves in the individual's right to determine his or her own good enables a "moral vacuum and underplays the importance of a person's social relationships".[181] Beasley and Graber question whether so fully rational an approach to life is desirable, contending that such an approach requires people to make decisions based on an articulated set of life goals, leaving no room for choices based on whims of the moment, for example.[182]

Applying a Kantian approach to autonomy, patients who waive relevant medical information would not be fully rational, therefore not fully autonomous. This approach requires high standards of autonomous decision-making that are arguably unreasonable in the healthcare setting. Even if informed of risks, patients will never be *fully* informed about surgery or treatment they plan to undergo – they will rarely be expert in the particular procedure. McLean questions whether we are asking for standards of autonomy in healthcare we do not expect in other areas of life. Other decisions are seldom subject to the same level of scrutiny, despite also being decisions of importance.[183]

We do not apply a Kantian account of autonomy in the law generally. For example, Kant might say individuals should not be allowed to make advance directives given they are decisions that bind or constrain the treatment of consumers in the future. Yet Right 7(5) of the Code enables consumers to use an advance directive in accordance with the common law.[184] Therefore, Kant's approach to autonomy does not fit well with the approach taken in law. It is not a legal

[179] Johnson and Cureton, above n 176.
[180] McLean, above n 147, at 15.
[181] Maclean, above n 178, at 16.
[182] Alfred D Beasley and Glenn C Graber "The Range of Autonomy: Informed Consent in Medicine" (1984) 5 Theoretical Medicine 31 at 33.
[183] McLean, above n 147, at 62.
[184] Code of Health and Disability Services Consumers' Rights, Right 7(5).

conception of autonomy, but a philosophical way of how to live the ideal life that is neither practical nor realistic.

3. Millian account

John Stuart Mill advanced a different conceptualisation of autonomy, while rarely using the term itself.[185] Mill links autonomy to control, emphasising liberty and freedom from external constraint. He argued that these prevent interference with our personal decisions so we can be free to choose to live our lives how we wish. Thus, private behaviour with no negative consequences for others should lie beyond the reach of state intervention.[186] This is subject to the "harm principle", however, which is the idea that harm to third parties can justify interference with individual liberty.[187] Under a Millian account of autonomy, patients should control their course of treatment according to their point of view.[188] Mill conceives that personal autonomy is intrinsically beneficial to a person – a constituent part of his or her well-being or happiness.[189] Mill argued that each person's self-knowledge is usually better than other-regarding knowledge. Therefore, competent persons should be afforded the liberty to make decisions for themselves about issues affecting their own lives.[190] Individuals are seen as supreme and entitled to decide based on their own interests, subject only to the harm principle.[191]

This account of autonomy would likely support a waiver of the right to be fully informed. In choosing to waive information the individual is exercising freedom to make a choice and is not harming others in the process. However, Ben Davies argues that in some cases, patients who refuse relevant medical information may make their health issues worse and more expensive to treat.[192] If such patients live in a society that provides publicly funded healthcare, by refusing information they increase the overall costs to society.[193] It could be argued this satisfies the

[185] McLean, above n 147, at 15.
[186] At 17.
[187] At 17.
[188] Muhammad Hammami and others "Patients' perceived purpose of clinical informed consent Mill's individual autonomy model is preferred" (2014) 15 BMC Med Ethics.
[189] Stephen Darwall "The Value of Autonomy and Autonomy of the Will" (2006) 116 Ethics 263 at 266.
[190] Maclean, above n 178, at 27.
[191] McLean, above n 147, at 20.
[192] Davies, above n 138, at 301.
[193] At 301.

harm principle, meaning on a Millian account doctors could require patients who refuse relevant medical information to hear it should they wish to proceed with treatment. However, Davies accepts that although patients who do not wish to hear information may be unreasonably imposing burdens on others, this does not mean such patients can be forced to hear relevant information.[194]

4. Individualistic autonomy

Mill's idea of self-determination led to the development of the individualistic notion of autonomy.[195] This conception of autonomy characterises autonomous agents as highly individualistic, prioritising the rational over the emotional.[196] The emphasis is on self-reliance meaning individuals should not be overly influenced by others in decision-making to ensure they are not swayed from putting their personal preferences into action.[197] Because the individualistic account involves an element of rationality it seems this "in-control" agent account of autonomy demands patients be given full information about their diagnosis and treatment options.[198] On this interpretation, the individualistic account could see a patient who waives information as irrational and senseless.[199]

However, as recognised by legal academics Manson and O'Neill, it is "difficult to base justifications for informed consent requirements on conceptions of rational autonomy"[200] because rational autonomy "is more cognitively demanding than a minimal conception of autonomy as mere, sheer choice".[201] McLean finds "this individualistic model of autonomy is largely unconcerned with what the decision is; rather it is interested in the right to make it".[202] Philosopher Anita Ho also recognises that an important aspect of this model is the focus on

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[194] At 301.
[195] Edward S Dove and others "Beyond individualism: Is there a place for relational autonomy in clinical practice and research?" (2017) 12(3) Clin Ethics 150 at 151.
[196] Walter and Ross, above n 155, at S17.
[197] At S18.
[198] At S17.
[199] At S18.
[200] Neil C Manson and Onora O'Neill *Rethinking Informed Consent in Bioethics* (Cambridge University Press, 2007) at 21.
[201] At 21.
[202] McLean, above n 147, at 20.

"the making of autonomous *choice*, or the actual governance itself".[203] She finds that "autonomy consists of ensuring that a subordinate agent is not being in the power of a dominant agent who directly imposes choices on him/her".[204] Similar to a Millian account, this would allow patients to determine the extent of information they receive if an individualistic notion of autonomy is adopted.

5. *Relational autonomy*

An individualistic account of autonomy has been critiqued for viewing people as distinct from their communities[205] and for making autonomy inconsistent with other values.[206] Critics of the individualistic account have argued that autonomy should accommodate the fact individuals are rarely, if ever, fully independent.[207] These critiques have caused some philosophers to reconceptualise autonomy in relational terms.[208] On a relational account, the autonomous person recognises his or her inter-relationship with society and acknowledges that his or her choices have consequences for the community.[209] This conception of autonomy recognises that the ability to choose as one desires needs to be weighed against the claims of other values including equality, justice, happiness, and public order.[210] Individuals exist in relation to others, therefore self-realisation is only achieved relationally.[211]

Following a relational approach, it is not unreasonable for patients to defer decisions to those close to them if they believe their well-being and identity are intrinsically linked to those people.[212] Nor is it unreasonable to ask for help from family members, friends, or health professionals.[213] The professional role of providers includes sharing in the responsibility of

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[203] Anita Ho "The Individualist Model of Autonomy and the Challenge of Disability" (2008) 5 Bioethical Inquiry 193 at 195.
[204] At 195.
[205] McLean, above n 147, at 20.
[206] At 21.
[207] Dove and others, above n 195, at 151.
[208] Carlos Gómez-Vírseda, Yves de Maeseneer and Chris Gastmans "Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature" (2019) 20 BMC Med Ethics.
[209] McLean, above n 147, at 21.
[210] At 28.
[211] Walter and Ross, above n 155, at S19.
[212] At S21.
[213] At S21.

decision-making in ways not acceptable under an individualistic account. The provider's role is not just to provide facts but also to care for the emotional needs of patients.[214]

Legal academic Alasdair Maclean is an advocate for relational autonomy.[215] Maclean argues that patients can always decide to put the decision in another's hands if they are concerned their own impulsiveness or irrationality will be harmful.[216] He identifies that respecting decisions of autonomous individuals does not mean they should be abandoned to make choices alone.[217] Instead, healthcare professionals should support their patients' autonomy, which may involve attempting to persuade patients their choices are mistaken.[218] Maclean argues that so long as healthcare professionals do not undermine patients' autonomy by withholding relevant information, for example, they will better respect patient autonomy than if they merely accept their patients' decisions regardless of how meritorious those decisions are.[219] His extensive account purports that ultimately, doctors have an obligation to their patients, who must be informed.

A relational account of autonomy is perhaps desirable when patients make non-disclosure requests regarding genetic information or results. Genetic information is shared and emblematic of people's relations to others,[220] but in some cases patients expressly refuse to inform family members or to allow physicians to.[221] A relational approach would not have clinicians retain all information confidential to the individual patient out of fear of violating that patient's autonomy. Healthcare providers would instead be mandated to encourage their patients to consider the interests of their family members and share information relevant to them.[222]

The position is different when the medical information in question concerns treatment risks. It is difficult to see how others are affected by an individual's choice to waive the right to be fully informed. In contrast, sometimes knowing the risks associated with treatment or surgery may

[214] At S21.
[215] Maclean, above n 178.
[216] At 53.
[217] At 55.
[218] At 55.
[219] At 55.
[220] Dove and others, above n 195, at 155.
[221] At 156.
[222] At 160.

cause a patient to refuse to go ahead with it. If the patient's condition worsens or if death ensues due to not having treatment or surgery, family members and friends of the patient will be affected. Would a relational account thereby support a waiver of information? The relational account requires individuals to be seen as socially situated people whose choices are influenced by, and have consequences for, others.[223]

However, a relational conception of autonomy sees the individual as emotional, embodied *and* rational.[224] Further, McLean contends that endorsing a relational account amounts to accepting that merely being able to make a decision is not adequate to establish the individual is behaving autonomously, or to validate that decision.[225] These points reject recognising a waiver of the right to be fully informed if a relational conception of autonomy is adopted.

6. Summation

It seems that recognising a waiver is best supported by a more Millian, individualistic account of autonomy. This is further explored in Part D to determine which conception of autonomy is reflected in the law. This involves considering the views of Dworkin, which are particularly relevant given he has specifically considered whether or not a waiver infringes patient autonomy. Part D also questions which account of autonomy was being applied by the courts that have recognised a waiver in obiter thus far and which model of autonomy is reflected in the Code.

D Autonomy and a Waiver

1. Dworkin's recognition of a waiver

Legal philosopher Gerald Dworkin recognises tension exists between autonomy as a formal notion (where what one decides can have any content), and autonomy as a substantive notion (where only some decisions amount to maintaining autonomy and others amount to forfeiting it).[226] This tension is present when questioning whether waiving the right to know relevant

[223] McLean, above n 147, at 23.
[224] Walter and Ross, above n 155, at S19.
[225] McLean, above n 147, at 23.
[226] Dworkin, above n 161, at 12.

medical information is a decision where autonomy is retained or not. McLean also highlights that it is not clear whether the sheer existence of legal decision-making capacity is enough to demand respect for decisions of competent persons.[227]

Dworkin argues that autonomy functions as a moral, political, and social ideal.[228] In all three areas there is a notion of the self as independent and self-determining. However, Dworkin questions how we can have this self-determination when we have a history, develop socially, and are heavily influenced by those around us.[229] In all of the moral, political, and social dimensions he argues there is "value attached to how things are viewed through the reasons, values, and desires of the individual and how those elements are shaped and formed".[230] Dworkin therefore appears to harmonise the individualistic and relational models of autonomy in offering this rounded description.[231]

Dworkin contends that for individuals to be treated paternalistically, there must be a violation of their autonomy.[232] He characterises this as "a usurpation of decision-making, either by preventing people from doing what they have decided or by interfering with the way in which they arrive at their decisions".[233] However, Dworkin argues that the potential to justify some paternalistic intervention sometimes arises. This is because in some situations individuals will want their autonomy denied – what is in people's interests is not always equivalent to what satisfies their current desires, and the relation between the good of individuals and what they want is not simple.[234]

Dworkin is happy to find that someone who does whatever the doctor advises is as autonomous as someone who evaluates that advice for him or herself.[235] He opines that accepting as final the commands of another person does not amount to forfeiting autonomy, as that would mean values like "loyalty, objectivity, commitment, and love are inconsistent with being

[227] McLean, above n 147, at 7.
[228] Dworkin, above n 161, at 10.
[229] At 12.
[230] At 10.
[231] McLean, above n 147, at 29.
[232] Dworkin, above n 161, at 123.
[233] At 123.
[234] At 124.
[235] At 109.

autonomous".[236] Dworkin therefore does not think respect for autonomy is, or ought to be, absolute.[237] In his monograph on autonomy, he sets out possible exceptions to respecting patients' autonomy which encompass emergency, incompetence, waiver, and therapeutic privilege.[238] Dworkin finds that in a waiver situation, the patient determines that particular information will be harmful or cause distress so it is better not to know it. Significantly, he argues that:[239]

> If a patient has knowingly and freely requested of the doctor that he not be informed or consulted about his course of treatment then to seek to obtain informed consent would itself be a violation of autonomy.

2. The common law, the Code, and the autonomous patient

It is necessary to determine whether the account of autonomy reflected in the law supports a waiver of the right to be fully informed. This involves analysing the Code and looking at the approach to autonomy taken by the common law courts who have considered a waiver. In setting out individual patient rights, the Code at the outset appears individualistic. Some rights in particular guarantee patients the right to be self-determining. For example, Right 3 affirms the right to have services provided in a manner that respects the dignity and independence of the individual.[240] Right 6 in asserting the right to be fully informed and Right 7 in affirming the right to make an informed choice and give informed consent places the individual in a position of control. This evidences a deliberate shift from a tradition of medical paternalism towards a more patient-focused approach.

In *Rogers v Whitaker*, the High Court of Australia instrumentally formulated a test for determining what is required of medical practitioners when it comes to informing patients. This is particularly relevant given the right to informed consent affirmed in the Code is derived from this common law formulation – it has been adopted via Right 6(2). The High Court in that case held:[241]

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[236] At 109.
[237] At 114.
[238] At 115.
[239] At 118.
[240] Code of Health and Disability Services Consumers' Rights, Right 3.
[241] *Rogers v Whitaker* (1992) 175 CLR 479 (HCA) at 490.

> A risk is material if, in the circumstances of a particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient if warned would be likely to attach significance to it.

The test adopted in the Code is thus centred on the information a reasonable person in the patient's circumstances would expect to receive. Skegg highlights that the Code has incorporated only the first element of the High Court's formulation – notably absent in the test is the duty to warn if the practitioner "is or should reasonably be aware that *the particular patient,* if warned of the risk, would be likely to attach significance to it".[242] Skegg argues that Right 6 merely affords patients the information a 'reasonable consumer' in that consumer's circumstances would expect or need, with there being:[243]

> … no duty to disclose information that this (arguably unreasonable) consumer would consider significant, even if the provider knew (or ought to have known) that this consumer would have considered the information significant.

Despite Skegg warning healthcare providers they "would be unwise to use this as a reason for withholding information" they know or suspect particular consumers to consider significant,[244] this provides leeway to argue there is no requirement for providers to impose information on patients who do not want it. Further, Right 6 is about what the particular patient would expect. Consequently, if a person's characteristics cause him or her to not want to receive information, there are strong grounds to argue Right 6 requires us to take that person as they are, rather than apply a generic standard. This supports adopting an individualistic account of autonomy, focussed on the particular person and recognising we are all different from each other.

Reflecting on the cases discussed in Chapter II where a waiver of the right to be fully informed was recognised in obiter, it seems the waiver described by those Commonwealth courts goes to the *individual* deciding how much information he or she wants to know. For example, in *F v R* King CJ said that "a doctor is not required to inflict on his patients information which they

[242] Skegg and others, above n 88, at 271.
[243] At 271.
[244] At 271.

do not seek and do not want".[245] This aligns with Skegg's claim that the absence in Right 6 of the Code of the latter part of the *Rogers v Whitaker* formulation means there is no duty to disclose information even if the patient would consider that information significant. Further support is found in the Court's comment in *Reibl v Hughes* that in the situation where a patient waives information about risks, "the doctor may… be justified in withholding or generalising information as to which he would otherwise be required to be more specific".[246] Adopting Skegg's finding leads to the corollary that the standard of informed consent reflected in Right 6(2) actually aligns with the approach the courts have taken to recognising a waiver of the right to be fully informed thus far.

There are aspects to the Code, however, that have it reflect more of a rich relational autonomy model. Right 4(3) affirms the right for every consumer to have services provided in a manner consistent with his or her needs.[247] Right 8 affirms the right to have support persons present.[248] Right 6(3)(b) goes further, affording consumers the right to honest and accurate answers to questions relating to services, including the provider's recommendation.[249] This evidences that healthcare has evolved so that shared decision-making occurs – the Code does not purely reflect an individualistic account of autonomy where doctors provide information and patients do what they please with it. Even at a professional guidance level, doctors are encouraged to be invested in their patients' decision-making. In the situation when a patient declines treatment information, the Medical Council statement requires doctors to explore with patients why they are declining such information.[250]

However, it must be remembered that the Code provides people with rights, which do not have to be exercised. There is no obligation on patients to involve others in their decision-making. Just because patients have the right to be fully informed does not mean we expect them to hear all relevant information. Thus, the Code is not a true reflection of relational autonomy – it remains patient-centric. This dissertation therefore asserts that the account of autonomy informing medical law in New Zealand is individualistic, but not solely individualistic. It is not an account that abandons patients to decision-making. There is a role for others to play, but

[245] *F v R*, above n 68, at 193.
[246] *Reibl v Hughes*, above n 29, at 13.
[247] Code of Health and Disability Services Consumers' Rights, Right 4(3).
[248] Right 8.
[249] Right 6(3)(b).
[250] Medical Council of New Zealand, above n 122, at [16].

rights accrue to patients who are in a position to dictate. This is an approach informed by the views of Dworkin. In seemingly reconciling the individualistic and relational accounts, Dworkin appears to reject the part of the individualistic account that assumes patients are completely self-contained, making decisions without being influenced by their healthcare providers' opinions.

E The 'Right' Not to Know

There is significant literature regarding the 'right' not to know, albeit largely in relation to genetics, but which may be helpful when considering the normative arguments in favour of, or against, recognising a waiver of the right to be fully informed. The right embodies an entitlement to choose whether or not to be informed. There is much debate about whether a 'right' not to know exists, and this largely depends on which view of autonomy is adopted.

1. Objections to the 'right' not to know

Those that object to the 'right' not to know make the argument it is inconsistent or incoherent, so is therefore harmful to the concept of autonomy. Ost has examined the work of Robert M Veatch and also Beauchamp and Childress.[251] Ost highlights that Veatch opines that physicians are restrained from imposing information on unwilling patients because of patient freedom, not because of a moral obligation to respect a patient's 'right' not to know.[252] In contrast, Beauchamp and Childress recognise patients have the right to refuse information, but doctors may be justified in infringing that right to 'promote' autonomy.[253] This could be on the basis of non-maleficence, for example. Ost agrees with Veatch, arguing that there cannot be a right not to be informed.[254] He contends that individuals are instead obliged to exercise the right to be informed because its mandatory aspect is bound up with the concept of an autonomous agent.[255] Individuals cannot waive the foundation of their rights – their status as autonomous agents.[256] Thus, Ost seems to pursue a Kantian account of autonomy.

[251] D Ost "The 'right' not to know" (1984) 9(3) J Med Philos 301.
[252] At 302.
[253] At 302.
[254] At 303.
[255] At 307.
[256] At 309.

2. *Support for the 'right' not to know*

The 'right' not to know can be defended by grounding it in an appeal to the right to respect autonomy.[257] Knowledge can be inimical to autonomous decision-making because it can be highly distressing to patients, so can impinge on the conditions of autonomy required to make choices.[258] Some have expressed concern that the right to know can lead to the conclusion that one *should* be informed.[259] Such reasoning may support a version of paternalism where not telling individuals for their own good is replaced by obliging patients to know for the good of their autonomy.[260]

In the context of genetic information, Davies outlines that two central arguments for a 'right' not to know are the appeal to harm and the appeal to autonomy. In terms of harm, he argues that medical news can be distressing and may lead to discrimination or social stigma. With respect to autonomy, information should not be forced on individuals who do not want to receive it because that would mean that they are not directing their own lives.[261] Davies suggests in a pluralistic, liberal society, individuals should have freedom to pursue the life they want and this pursuit should not be constrained by their own welfare or the assumed irrationality of their values.[262] This rejects a Kantian approach to autonomy, taking a more Millian stance.

Herring and Foster also argue that in many situations withholding information can increase a person's autonomy.[263] One case is when an individual will become so distressed upon learning what will be done during treatment that they would not consent to it. Another case is where the patient requests to be ignorant of medical information or delegates the decision to his or her doctor. In Herring and Foster's view, this is a "perfectly acceptable use of autonomy" because ensuring there is a 'right' not to know is an essential part of having the freedom to decide how

[257] Jane Wilson "To Know or Not to Know? Genetic Ignorance, Autonomy and Paternalism" (2005) 19 Bioethics 492 at 500.
[258] At 502.
[259] At 502.
[260] At 502.
[261] Davies, above n 138, at 300.
[262] At 301.
[263] Jonathan Herring and Charles Foster ""Please Don't Tell Me" The Right Not to Know" (2012) 21 Cambridge Quarterly of Healthcare Ethics 20 at 21.

to live our lives.[264] They argue that in maintaining that patients need information because without it they are acting irrationally, "autonomy becomes tyrannous" because autonomy removes the right to delegate one's autonomy.[265] They suggest that professional bodies and the courts should identify that in some situations it is appropriate not to provide information to patients.[266]

3. Summation

Clearly, there is uncertainty around whether a 'right' not to know exists. On a Kantian account of autonomy, the information being waived by patients is relevant to a rational appraisal of deciding whether to proceed with treatment. Ost therefore argues that decisions that refuse to recognise information as relevant are ones that are irrational.[267] Conversely, there are strong grounds to argue that waiving information about risks of medical treatment is not acting irrationally. Indeed, disclosing information might upset patients so much that they cannot rationally involve themselves in decisions about treatment options.[268] Ost references Beauchamp and Childress who consider it difficult to create a moral argument for the conclusion that a deeply committed Jehovah's Witness who informs the doctor to do everything possible must be told transfusions will be employed.[269]

The 'right' not to know has been recognised at an international level, having been acknowledged in at least two important international legal instruments.[270] The UNESCO Universal Declaration of the Human Genome and Human Rights (1997)[271] and the Council of Europe Oviedo Convention on Human Rights and Biomedicine (1997)[272] characterise the 'right' not to know as an aspect of personal autonomy. This promotes recognition of a 'right' not to know, and certainly favours affording patients the option to waive information regarding risks of medical treatment during the consent process.

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[264] At 22.
[265] At 22.
[266] At 28.
[267] Ost, above n 251, at 305.
[268] Alan JD Meisel and Mark Kuczewski "Legal and Ethical Myths about Informed Consent" (1996) 156(22) Arch Intern Med 2521 at 2526.
[269] Ost, above n 251, at 301.
[270] Graeme Laurie "Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications" (2014) J Law Med Ethics 53 at 53.
[271] UNESCO Universal Declaration of the Human Genome and Human Rights (1997), Article 5c.
[272] Council of Europe Oviedo Convention on Human Rights and Biomedicine (1997), Article 10(2).

F Conclusion

Chapter III discusses the concepts of patient autonomy and medical paternalism, illustrating how patient autonomy has gained prevalence over time and how it has such a significant role in healthcare. Competing accounts of autonomy have been summarised to analyse whether a waiver of the right to be fully informed would be supported or rejected by these accounts. The position taken in this chapter is that upholding a waiver of the right to be fully informed in law best emulates an individualistic account of autonomy, which is centred on the individual's right to make choices, not being dominated by others. This account therefore supports recognising a waiver in law.

Medical law in New Zealand appears to reject the part of the individualistic account that prevents others from being involved in patient decision-making. The Code makes it clear that doctors should be engaged in the process of informed consent, but this chapter demonstrates this does not encumber patients from being in control of their decisions and does not preclude a waiver from being upheld. The common law cases that have recognised a waiver of the right to know in obiter also take a patient-centric approach, and indicate doctors are not obliged to impose information on patients unwilling to receive it.

Although the right 'not' to know is predominantly analysed in the context of genetics, the arguments in favour of upholding this right support recognition of a waiver of the right to be fully informed in law. International acknowledgment of the right 'not' to know also promotes affording patients the option to refuse relevant medical information in certain circumstances. Chapter IV addresses the circumstances in which a waiver ought to apply, outlining that it is desirable to have minimum requirements for a legally valid waiver, should one be implemented in law. Chapter IV illustrates that there are various ways for this analysis on a waiver to be incorporated into law, policy, and practice in New Zealand, drawing together the normative arguments made in this dissertation to highlight that it is expedient to recognise a waiver of the right to be fully informed.

Chapter IV: Recognising a Waiver

A Introduction

The exploration in Chapters II and III illustrate strong arguments in favour of recognising a waiver of the right to be fully informed in the law. Permitting such a waiver would resolve the uncertainty that exists post-*Harman*, better aligning the law with obiter comments of the Commonwealth courts referred to in Chapter II and with the standards reflected by the medical profession. As highlighted in Chapter III, there is room to uphold a waiver in the law given that medical law in New Zealand is arguably informed by an individualistic, Millian account of autonomy that places the patient in control. Having established the answer to the normative question of whether there should be a waiver of the right to be fully informed is "yes", the question becomes: how would a waiver work in practice?

This chapter illustrates that the particular circumstances in which patients seek to waive their right to be fully informed are extremely relevant in determining whether a waiver should be upheld. Risks vary both in magnitude and likelihood. For example, risks may be serious with a low likelihood of ensuing, or moderately serious with a high likelihood of occurring. We would expect patients exercising waivers to be informed to different extents depending on such factors. To address this, this chapter proposes that a 'legally valid' waiver is one that is 'sufficiently informed', exploring how a scale or spectrum of waivers of the right to be fully informed could be useful. This chapter also explores how a waiver could be incorporated in the law.

B 'Sufficiently Informed' Waiver

1. Legally valid waiver

Should a waiver of the right to be fully informed be recognised in law, it is desirable to provide guidance to determine whether the patient's waiver is one that should be negotiated in practice. There is a vast difference between a patient waiving relevant medical information having an idea of the nature of the information being refused, and waiving being completely unaware

risks even exist. Therefore, it is essential some minimum requirements are satisfied before a patient's waiver is deemed valid.

The idea of validity in law exists already, not only in relation to informed consent. For example, the common law creates criteria for valid advance directives. The principles in *Re T (Adult: Refusal of Treatment)*[273] inform the conditions for validity at common law.[274] The person must have had capacity when he or she made the directive, it must have been intended to apply to the particular circumstances in question, the directive can be vitiated by the undue influence of others, and there must be an appropriate standard of evidence to substantiate the validity of the directive.[275] In the context of waivers of information, the criteria for a valid waiver could include the waiver being 'sufficiently informed', and to ensure certainty, that doctors document their patients' waivers and have them sign.

2. Spectrum of waivers

When patients exercise a waiver, the sort of information being waived varies significantly between patients depending on the treatment in question. The patient's own health and/or circumstances are also relevant. For example, the patient in *Harman* was obese and was having multiple procedures, which compounded the risks. Thus, the information about the treatment or procedure being performed is specific to the patient's clinical situation. This variation in patient circumstances could be addressed by implementing a scale, or spectrum of waivers, where the minimum requirements for the waiver to be valid differ depending on the seriousness of the risks in question, or the likelihood they will result. Therefore, one patient might receive less information than another about the treatment or procedure being performed, but still satisfy the requirements for a sufficiently informed waiver.

This would involve escalating the seriousness of the waiver. However, different medical procedures involve inherently different risks which adds uncertainty around when a more informed waiver is required. Some procedures are low risk with a high likelihood of

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[273] *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, [1992] 3 WLR 782.
[274] Ron Paterson and PDG Skegg "The Code of Patients' Rights" in PDG Skegg and Ron Paterson (eds) *Medical Law in New Zealand* (Brookers, Wellington, 2006) 23 at 45.
[275] Jane Goodwin and Nick Laing "Advance Care Planning – Issues for Lawyers" (New Zealand Law Society webinar, 2019) at 9.

occurrence, others are high risk with a low likelihood of occurrence. In some situations the information being waived is so significant that the provider would be uncomfortable performing the treatment without the patient being fully informed. If a waiver was recognised in this situation, it could amount to a *duty* on providers to perform treatment, which may have them providing services that are not of an appropriate standard according to their own professional ethic.

A procedure where *both* the magnitude and the likelihood of the risks occurring are high, or when the risk involved is death, are perhaps examples of situations where a waiver should not be permitted. If a provider thought a patient would choose not to proceed with treatment if he or she was fully informed, that likely constitutes a situation where a wavier should not be respected. This is supported by Maclean, who responds to Mill's argument that we should be allowed to make mistakes given this is the best way to learn. Maclean surmises that Mill's argument would not apply when the consequences are catastrophic.[276] In these circumstances, many providers would refuse to provide treatment to patients because doing so would put the providers at risk of having complaints made about them. Other providers will resist treating patients who waive if they believe proceeding would not be in the patient's best interests. There are also situations where a waiver *cannot* be permitted. For example, s 11(2) of the End of Life Choice Act 2019 states medical practitioners *must*, among other things, give persons exercising the option of receiving assisted dying certain information and communicate with them about their illness.[277]

The validity of the waiver may differ depending on the circumstances. Providers are likely to be more willing to accept waivers in situations where patients have no choice but to proceed – that is, no treatment will result in death. Rejecting the waiver would be harmful, so at a professional ethics level providers would likely be acting reasonably in respecting these patients' waivers. In contrast, where the surgery is *elective* and involves serious risks, a provider who accepts a waiver of information would arguably not be discharging his or her obligations to the patient. This could constitute a situation where the waiver, if challenged, may not be upheld as valid.

[276] Maclean, above n 178, at 38.
[277] End of Life Choice Act 2019, s 11(2).

Therefore, there are situations in which a waiver cannot and/or should not apply. However, a large portion of medical treatments and procedures do not carry catastrophic risks with high chances of occurring. In such situations, to deny patients treatment because their doctors disagree with them proceeding without being fully informed almost seems punitive. It reflects a more Kantian account of autonomy where patients are denied the ability to make choices about their healthcare because their doctors believe their decisions are irrational. This goes against the individualistic account of autonomy described in Chapter III, which places the patient in control.

Returning to a spectrum of waivers, circumstances where *either* the magnitude or the likelihood of risks ensuing is high could constitute a situation where a more informed waiver is required. At the serious end of the spectrum, patients should have to be more informed about what they are waiving before the waiver is 'sufficient', therefore valid, therefore upheld. To illustrate this, it is helpful to return to *Harman* to consider what would be required for a legally valid waiver in similar circumstances.

3. Revisiting Harman

It is highly doubtful that in refusing the "gory details" the patient said enough to satisfy a sufficiently informed waiver, especially given it seems the patient was waiving information about excisions rather than risks. Adopting the analysis in this chapter, a sufficiently informed waiver in *Harman* would require the patient to know the risks of proceeding were compounded because of her weight and the number of procedures being performed. It was also an elective surgery – had she been provided the opportunity to exercise a more informed waiver, she may have chosen no surgery or to have them performed separately.

4. Patient autonomy

The concept of a sufficiently informed waiver reflects the individualistic account of autonomy described in Chapter III as informing medical law in New Zealand. This is because it ensures patients retain their status as autonomous agents, but does not completely deny them the ability to involve their healthcare providers. This means healthcare providers are afforded the ability to assure themselves their patients are exercising waivers with a general idea of the nature of the information being waived. The Code and professional standards urge doctors to be involved

in patients' decision-making. Before upholding a waiver of the right to be fully informed, the law seems to require that waivers be exercised only when patients have reached a sufficient level of understanding, with providers probing them about reasons for their decision, and responding appropriately. A sufficiently informed waiver might also require patients to outline the reasons why they do not want to receive the relevant medical information. It may be the patient has blind trust in the clinician, or is willing to receive information about some treatment risks but not others.

5. *What might a waiver look like?*

A waiver at the lower end of the spectrum could involve patients acknowledging:

> "I have been informed that by exercising this waiver, I am proceeding with [treatment/procedure] foregoing relevant information regarding risks."

If the healthcare provider has greater concerns about the patient proceeding without being fully informed or if doing so is contrary to the provider's advice, patients could be required to acknowledge:

> "Against medical advice, I am waiving the right to know relevant information regarding the risks of proceeding with [treatment/procedure]."

Alternatively:

> "I have been informed that by exercising this waiver, I am proceeding with [treatment/procedure] foregoing relevant information regarding major risks."

Despite the common law and the Medical Council statements described in Chapter II recognising a waiver, there has been no attempt to formulate a specific waiver. These could provide a starting point in terms of being potential ways to frame a waiver.

6. *Hypothetical scenario*

The hypothetical scenario of a cancer patient choosing to undertake chemotherapy but not wanting to know information about possible side effects demonstrates how a sufficiently informed waiver could work in practice. This could constitute a situation where a waiver of some information is accepted, but the provider will refuse to provide treatment if certain risks are not conveyed. For example, providers may refuse to proceed with chemotherapy if the patient is uninformed of the particular risk of sterility. Providing treatment to patients who are unaware of the risk of sterility would likely constitute providers failing to discharge their obligations to their patients given the information relates to the ability to have children. If informed, patients in this position could undergo fertility preserving procedures. However, the particular circumstances of the patient are relevant. Whether the doctor accepts or rejects the part of the waiver going to information about the risk of sterility would also depend on the patient's age and whether the patient had indicated a desire to have children, for example.

Despite refusing to proceed without the patient being informed of the risk of sterility, providers may be willing to provide treatment when the patient waives *other* risks associated with chemotherapy. For example, the patient acknowledging that:

> "In refusing to hear information about risks other than the risk of sterility, I am waiving information about probable risks of unpleasant side effects associated with chemotherapy."

The patient could then proceed with treatment not knowing specifics – for example, side effects like hair loss, infection, and fatigue. Given the unpleasant and presumptive risks of side effects associated with chemotherapy, the patient's waiver would need to satisfy the requirements at the more serious end of the spectrum.

C Recognising this Analysis in the Law

A waiver could be incorporated into New Zealand law in various ways.

1. Common law

Right 7(1) of the Code outlines that the common law may provide an exception to proceeding only when the patient has made an informed choice and given informed consent. Therefore,

there is an avenue for a waiver to enter the law. If a case with *Harman*-type facts arises again, the courts may be willing to build on the obiter comments of the Commonwealth courts regarding a waiver of the right to be fully informed. A problem with leaving the issue to be determined by the common law is that New Zealand's no-fault compensation scheme under the ACC Act means there is no guarantee a case with suitable facts will come before the New Zealand courts again. In only a very small number of cases does the Director of Proceedings lay charges, and fewer again are appealed to the High Court.

2. Express a waiver in the Code

A waiver could be recognised in the law if the Commissioner, upon reviewing the Code, outlined in another provision of the Code that a sufficiently informed waiver of the right to be fully informed can provide an exception to Right 7(1). A 'sufficiently informed' waiver could be defined in Clause 4. The content of a 'sufficiently informed' definition may be informed by the analysis in Part B of this chapter. For example, it could outline that healthcare providers must assess the seriousness of risks or the likelihood they will ensue when determining how informed patients' waivers must be. It could also outline that a waiver will only be sufficiently informed once in writing and signed by the patient. Guidance could be provided on the rare cases where waivers should not be permitted, as explained in Part B.

3. Guidance from the Commissioner

A waiver could enter the law indirectly through the Commissioner, in the course of making an opinion following a complaint, providing specific guidance on how a waiver could constitute a Clause 3 defence to a breach of Right 7(1). The subject matter of the defence (what amounts to a sufficiently informed, therefore, legally valid waiver) could be informed by the analysis in Part B. This would enable the Commissioner to endorse this approach without having to expressly include a waiver in the Code. Incorporating a waiver in this way would require healthcare providers to assess on a case-by-case basis whether the waiver being exercised reflected that the patient had a sufficient understanding of the nature of the information being waived. The danger in framing a waiver as a defence is that in an effort to ensure they are not breaching the Code, providers may cause the waiver to become more informed than it needs to be. In low risk situations, requiring an overly informed waiver could be a violation of patients'

rights. It would be imperative that the Commissioner's guidance on how a Clause 3 defence would operate is direct and unambiguous.

4. Updated Medical Council statement

Another option is for the Medical Council to elaborate on the situation where a patient declines information in an updated Medical Council statement. The current statement appears to recognise a waiver of the right to be fully informed, indicating professional guidance on the issue is patient-centric. If the statement was more direct on what providers should do when patients decline information, providers would be more willing to uphold patient waivers, thereby respecting patients' rights. A clear statement on a waiver could inform professional practice by becoming a legal standard by virtue of Right 4(2) of the Code.

D Conclusion

A potential complication with expressly including a waiver of the right to be fully informed in the Code, or with setting out guidance on how such a waiver should apply, is that it is difficult to outline an approach to encompass the wide array of circumstances in which patients wish to waive information. No two patient cases are ever the same. How a sufficiently informed waiver could provide for these varying circumstances has been explained in this chapter. What is important is that the normative arguments in the prior chapters support recognising a waiver in the law. On an individualistic account of autonomy, a waiver would enhance patient autonomy and respect patients' rights. Given the Code, the common law, and professional standards all seek to achieve these purposes, the means in which a waiver is recognised is therefore subordinate to the fact one is upheld to begin with.

Conclusion

Wild J left the question of whether a waiver of the right to be fully informed is recognised in the common law unanswered in *Harman*. The uncertainty and inconsistency this finding has caused has been analysed, arguing that the High Court failed to reach a conclusion that aligns with the fundamentals of the Code, which is rights-based and patient-centric. In placing emphasis on the medical experts' opinions heard in the Tribunal rather than giving due weight to the authorities available, all of which indicate support for recognising a waiver of the right to be fully informed, it appears that Wild J erred. However, Wild J has not precluded the recognition of a waiver in the law. The analysis in Chapter II conveys there is scope to uphold a waiver, and strong arguments for doing so.

In building on the analysis that supports a waiver of the right to be fully informed, it is important to consider whether a waiver would infringe or enhance patient autonomy. This depends on how autonomy is conceptualised. Chapter III highlights that the account of autonomy reflected in the Code is not one that deserts patients to make their decisions alone, but one that supports them to involve others, including healthcare providers. However, given the rights-based approach the Code takes, the account of autonomy reflected in New Zealand medical law is more of an individualistic account that ensures patients retain their status as autonomous agents. The account of autonomy described in Chapter III therefore supports recognising a waiver of the right to be fully informed in law.

Chapter IV explores a legally valid waiver by setting out some relevant criteria before upholding waivers of the right to be fully informed. The various ways a waiver could be incorporated in the law are also examined. What is important is that the arguments in favour of recognising a waiver made in this dissertation are addressed, regardless of how a waiver actually enters the law. Permitting a waiver of the right to be fully informed would enable healthcare providers to discharge their obligations under the Code whilst simultaneously ensuring their patients' autonomy and therefore respecting patients' rights.

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