COMMENT: RELATIONAL AUTONOMY AND THE REPORT OF THE CANADIAN COUNCIL OF ACADEMIES ON THE STATE OF KNOWLEDGE ON ADVANCE REQUESTS FOR MEDICAL ASSISTANCE IN DYING

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Abstract

Following the introduction of the Canadian Criminal Code amendment to allow medical assistance in dying (MAID) in limited and specific circumstances, a panel of experts formed to study MAID in several contexts. This paper will focus on the findings from that panel in relation to relational autonomy in the context of advanced requests for MAID. The first part of this comment introduces the case law leading up to the amendment, the MAID legislation, and relevant theories on the nature of autonomy. The comment goes on to apply the theory of relational autonomy to MAID and discuss how a patient's social and personal relationships can both enhance and detract from decision making autonomy. The comment then considers how social contexts and other social factors can enhance and detract from a patient's decision making autonomy. The comment concludes by noting that, while the panel explores many issues, it convincingly explains the benefits that a relational approach brings to understanding autonomy in the context of MAID.

I INTRODUCTION

In 2015, the Supreme Court of Canada released its unanimous decision in *Carter v Canada* that a complete prohibition on medically assisted death was not justified under Section 7 of the *Canadian Charter of Rights and Freedoms*.[1] Section 7 states that '[e]veryone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.'[2] The ruling in *Carter* declared the blanket prohibition on medically assisted dying in the *Criminal Code* in violation of this Charter provision and gave the Federal Government one year to amend the legislation.[3] In 2014 the Government introduced Bill C-14 which amended the *Criminal Code* to allow for Medical Assistance in Death (MAID) under limited and specific circumstances.[4]

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[1] *Carter v Canada (Attorney General)* (2015) SCC 5 127 [*Carter*].

[2] *Canadian Charter of Rights and Freedoms*, s 7, Part 1 of the *Constitution Act, 1982*, being Schedule B to the Canada Act 1982 (UK), 1982, c 11

[3] Ibid.

[4] Bill C-14, *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, 1st Sess, 42nd Parl, 2016, (as passed by the House of Commons 17 of June 2016) [Bill C-14].

The preamble to Bill C-14 outlines its legislative objective which seeks to strike a balance between the autonomy of persons who desire medical assistance in dying and the interests of vulnerable persons who need protection from coercion and despair.[5] The preamble further describes the legislative objective which is meant to provide an exemption to the *Criminal Code* provision for health care professionals aiding and abetting a person to end their own life.[6] The preamble also refers to"'robust safeguards' which are the specific eligibility criteria aimed at protecting vulnerable individuals from being induced to end their lives prematurely.[7]

Eligibility Criteria for MAID:[8]

> s 241.2 (1)(a) they are …eligible for health services funded by a government in Canada;
> (b) they are at least 18 years of age and capable of making decisions with respect to their health;
> (c) they have a grievous and irremediable medical condition;
> (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
> (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

The legislation further defines the third criteria and outlines what it means for a person to have a grievous and irremediable medical condition. To meet this requirement, the patient must have a serious and incurable disease and be in an advanced state of irreversible decline, the illness must be causing intolerable physical or psychological suffering, and their death must be reasonably foreseeable.[9] If a patient has a grievous and irremediable medical condition causing intolerable suffering, MAID can enable these individuals to have a planned and peaceful medically assisted death.

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[5] Ibid.
[6] Ibid.
[7] Ibid.
[8] *Criminal Code*, RSC 1985, c C-46, s 241.2(1).
[9] Ibid s 241.2(2).

Even with these recent legislative amendments, the issues underlying MAID are still a subject of public, legal and moral debate. To better understand the debate and effects of MAID, the Federal Government asked the Council of Canadian Academies to study three specific issues concerning MAID; the application for mature minors, where a mental disorder is the sole underlying medical condition and the use of advance requests. A panel of experts (the Panel) formed to study these issues through an independent, evidence-based review. The panel does not necessarily provide recommendations or evaluate the current legislation or legal arguments, they only collect and assess the evidence concerning the three specific areas of mature minors, advance requests and mental disorders and the clinical, legal, cultural, ethical, and historical context in Canada.[10]

The Panel's report is quite extensive considering many topics influencing the discussion on MAID. The report explicitly considers the relationship between advance requests and decision making autonomy from both an individualist and a relational perspective. This piece will focus on those findings particularly relational autonomy in the context of advance requests. More specifically, how an individual's relationships and their social context can strengthen relational autonomy and thereby support the autonomous decision making of a patient considering MAID.

II TERMINOLOGY, DETAILS, AND BACKGROUND

The Panel defines advance requests (AR) as a request for MAID, documented before the patient loses decision-making capacity and are to be acted on under the specific circumstances outlined in the patient's request.[11] Outside the context of MAID, advanced planning is available for other health care situations; such as an advanced directive which gives a patient advanced consent or refusal for specific health care treatments. However, the Panel claims that an AR for MAID would be far more complicated to draft, interpret and administer than its health care counterparts.[12] This complexity comes primarily from the need for a third party to be involved

[10] Council of Canadian Academies, 2018. *The State of Knowledge on Advance Requests for Medical Assistance in Dying*. Ottawa (ON): The Expert Panel Working Group on Advance Requests for MAID, Council of Canadian Academies at 4 [The Panel].
[11] Ibid 35.
[12] Ibid 39.

with the AR to determine the exact timing and the precise circumstances that the patient is suffering intolerably, thereby activating the AR.[13] Any AR for MAID would, therefore, require precise details, specifically, when and how to tell that a patient's suffering is so subjectively unbearable that the third party should activate the AR.

Preserving and supporting the patient's decision making autonomy is a primary objective of the MAID legislation.[14] The Panel starts from a position that autonomy is a critical issue in MAID; however, there is no consistent meaning for autonomy, and there are different ways of understanding it. The Panel recognizes individualistic and relational autonomy as two approaches to understanding decision making autonomy for MAID and acknowledges how they are distinct in this context and how autonomy can be enhanced or reduced.

Individualistic autonomy may be considered as the fundamental concept of autonomy in MAID and this conceptualization of autonomy is about the right of the individual to make their self-determining decisions without interference by others.[15] This notion is grounded in the concept of free will with its roots in traditional liberal theory and it is this conception of the autonomous person that is indeed evident in the preamble to Bill C-14 emphasizing self-determination and non-interference. The individualistic approach is also present in the *Carter* decision where the court stated that 'denying the right to request MAID impinges on a person's liberty and security, specifically on their ability to make decisions concerning their bodily integrity and medical care'.[16] The individualistic understanding of autonomy plays a principal role in legal theory and decision making and is perhaps the leading understanding of autonomy in modern society.

The Panel discusses individualistic autonomy at some length and even extends the discussion to Dworkin's individualistic concept of precedent autonomy. Dworkin agrees with the individualistic take on autonomy but looks more specifically at the autonomy of the capable

[13] The Panel (n 10).
[14] Bill C-14 (n 4}.
[15] S Sherwin, 'A Relational Approach to Autonomy in Health Care' in Sherwin, ed, *The Politics of Women's Health: Exploring Agency and Autonomy* (Philadelphia: Temple University Press, 1998).
[16] *Carter* (2015) SCC 5 127 66.

person, which he believes, should outlast their decision-making capacity.[17] What Dworkin is suggesting is that what is articulated in an AR is the last expression of the patient's preferences for MAID, and the law should protect that previous autonomous self by validating and following those wishes.[18] If this theory is operable, a capable person's interests for their future self would take precedence over the interests of one's future incapacitated self. The Panel claims this would create a significant moral grey area for anyone interpreting the AR, particularly if a patient is still visibly content but unable to communicate.[19]

Dresser criticized Dworkin's concept of precedent autonomy on the ground that it suggests that only those with decision-making capacity can be autonomous and that the previous version of the self is the only version worth protecting.[20] Despite this critical response from Dresser, Dworkin's model could reduce the interpretive grey area of an AR with an objective measure by confirming the accuracy of the last statement, the patients last documented preferences.[21] However, if a patient is continuing to express contentment with their situation, but a previously written AR is calling for MAID, it may become an ethical and a moral challenge for a third party decision maker. The decision maker must either follow the express preferences in the AR or import an interpretation on the patients suffering and delay the provision, possibly against what would have been the patient's wishes.

The Panel also considers relational autonomy as an alternative to the individualistic approach for understanding autonomous decision making for MAID.[22] In fact, some research points to MAID being an 'inherently relational act'.[23] The Panel's research even suggests that a decision to pursue MAID is a result of a patient's interpersonal relationships and their social context. This claim counters the individualistic approach which concentrates on a person's intrinsic characteristics

[17] The Panel (n 10) 51
[18] Ibid
[19] Ibid.
[20] Ibid.
[21] Ronald Dworkin, *Life's Dominon: An Argument About Abortion, Euthanasia, and Individual Freedom* (New York (NY), Knopf, 1993) 51.
[22] The Panel (n 10) 49.
[23] Ibid.

and instead suggests that autonomy is supported and even enabled by the specific context a person is situated within and the social and relational components that form that context.[24] Scholars like Nedelski are also suggesting that the relationships we have with others guide, shape and influence our lives and will improve our autonomous decision.[25] This relational approach is not decreasing an individual's autonomous decision making, instead what it does is bring emphasis to and the involvement of the patients context and social relationships when making important healthcare decisions. Relational Autonomy for MAID is then supported by the social context which ensures there are reasonable treatment alternatives available, and by the intimate relationships that enable a person to acknowledge and articulate their sincere wishes about MAID.

III RELATIONAL AUTONOMY AND MAID

The relationship forged between a patient and a physician can develop the patient's decision-making autonomy. In fact, in *Carter* the court refers to MAID as physician-assisted death, suggesting an interaction between the physician and patient is a necessary component of MAID. The Panel identified three ways a physician can help develop a patient's autonomy: by ensuring access and accurate information to reasonable treatment alternatives, by helping the patient understand the trajectory of their illness and by pursuing an understanding of the patient's motivations and fears to provide treatment solutions in a way that supports the patient's dignity and autonomy.[26]

The Panel found that a physician is often the patient's first point of contact when making an inquiry for MAID and the physician-patient relationship will often continue to develop through the approval process.[27] If a physician has a strong relationship with the patient, there will be a

[24] Ibid 139.
[25] The Panel (n 10).
[26] Ibid 34.
[27] Ibid.

deep understanding of the patient's personal circumstances, and a physician will be better suited to discuss MAID, how it will be administered and how it may feel. A physician is also the one who is best positioned to suggest alternatives to MAID, such as long term or palliative care.[28] Doing all these things will build the patients decision making autonomy by helping them to understand MAID, the options available and their implications. Without this real understanding of MAID and alternative options, a patient's decision will not be truly autonomous.

The Panel researched how MAID operates in other countries, particularly concerning an AR, and found that physicians who were completely compliant with the specific legal requirements for administering MAID were the ones who were most familiar with the patient and their specific circumstances.[29] Physicians in Canada have the burden to ensure that the legal requirements for MAID are met (such as unbearable suffering) and by taking the time to develop their relationship with the patient, the physician will be better able to understand when those criteria are met, provide quality care, and avoid the risk of criminal liability.[30] A relational approach to autonomy between a patient and physician builds the patients decision making autonomy; The Panel also suggests that it develops the physician's decision making autonomy to ensure that the legal criteria are satisfied for each MAID request.[31]

Physicians have tremendous responsibility moving through a patients request for MAID, but a request for MAID may not always align with the individual physician's ethics, morals or beliefs. Physicians are not required by law to fulfil a patient's request for MAID. They may follow their individual conscious and choose to reject to provide MAID.[32] The Panel found that those physicians who do accept a patients MAID request must possess strong interpersonal skills to be able to navigate all the complexities of a request for MAID.[33] The physician's interpersonal skills will create a stronger and more supportive relationship with the patient and strengthen the

[28] Ibid.
[29] Ibid 132.
[30] Ibid.
[31] Ibid 155.
[32] Ibid.
[33] Ibid.

relational autonomy of both parties by fostering a healthy relationship and a mutual understanding of the patient's wishes.[34]

However, it is not the responsibility of a physician to pursue MAID on behalf of a patient. The patient makes the request, but their relational autonomy will be enhanced when physicians'[show] empathy, were clear about their boundaries, and helped patients organize their thoughts and feelings.'[35] As a result of a patient/physician relationship developing through conversations about MAID, its implications and alternatives, the patient's decision making autonomy builds as reasonable alternatives are available, and because the patient has the resources and knowledge to make a truly autonomous decision.

Interpersonal relationships outside of the doctor- patient parameters will also impact a patient's ability to make an autonomous decision for MAID. A patient's close relationships have the power to make a patient feel like a burden on others (and actively pursue MAID as a result), or to make a patient feel cared for and pursue MAID willingly with support through all the stages. Sherwin suggests that intimate and close 'relationships define who we are and what we value in a way that makes individualism impossible.'[36] These relationships are integral to our decision making in many aspects of life, and the Panel claims that the involvement of close relationships in decision making can be a way to "foster, not detract from autonomy."[37]

These interpersonal relationships can be integral to supporting the autonomous decision making of patients pursuing an AR. Patients would not only draft the AR with relational support but could express their more profound wishes beyond the written words in the AR. With this dialogue, the patient's family and friends should have a stronger understanding of the circumstances and reasons that a patient wishes to die, and therefore, be able to understand and support those wishes. With more accurate and detailed information, they can make a more informed decision for the patient's death when the circumstances in the AR are reached.[38] This

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[34] M K Dees et al, 'Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands' (2013) 27(1) *Palliative Medicine* 155, 27–37.
[35] Ibid.
[36] Above (n 15}.
[37] The Panel (n 10) 49.
[38] Ibid 83.

understanding should remove challenges for family members when trying to interpret a patient's AR, particularly if the patient is no longer able to communicate effectively. The patient's family members would better understand the patient's wishes and therefore be more decisive with any unplanned circumstance or complexity that the disease may present, thereby continuing to exercise the patient's decision making autonomy.[39]

While the Panel indicates that interpersonal relationships should strengthen a patient's decision-making autonomy, family members may also detract from it. Patients may be at risk of subtle and often unintentional influences from the family members who are helping them. For example, an adult child expressing the time commitment or expense to care for their parent may motivate the parent to pursue MAID as to avoid becoming a burden on their family. The Panel found that many patients feel they can actually 'provide for their loved ones by ending their life early' and in doing so, reduce the perceived burden on family and caregivers by requesting MAID.[40] So while some patients may fixate on their individualized loss of dignity and personal suffering, other patients may be more worried about the impact of their decline on their close relationships and family which the Panel suggests would detract from a truly autonomous decision.[41] The close and intimate relations that a patient has can either enhance or detract from a patient exercising their decision making autonomy. Because of this, The Panel discusses the inclusion of safeguards to promote autonomous decision making such as the direct involvement of a doctor or counsellor trained to detect undue influence.[42] Safeguards like this may allow family members to be active and supportive without any unintentional coercion. The ultimate goal of the MAID legislation is for patients to make the most autonomous decision they can and the Panel's report suggests that close relationships can play a vital, but delicate role.[43]

IV SOCIAL CONTEXT

[39] Ibid 157.
[40] Ibid 145.
[41] Ibid.
[42] Ibid 149.
[43] Ibid 150.

Relational Autonomy is more than just interpersonal relationships; the Panel also examined the 'socio-political contexts that healthcare is delivered and its effects on autonomous decision making.' The social context will support a patient's relational autonomy by having a reasonable range of alternative treatments available that the patient can contemplate while in their decision-making process.[44] For a range of diseases, options from the Canadian healthcare system may include acute care, home care, long-term care, and palliative care.

The Panel describes autonomy in the social context which is influenced by how society 'creates laws and policies that respect autonomous decision-making and how those laws and policies are put into practice by clinicians, care teams, family, and friends.'[45] That means that the policies governing the accessibility of services and treatment alternatives will determine whether there are actually alternatives available for a patient.

Situational factors will also influence the availability of treatment options such as the patient's location and proximity to specific treatment options, whether the alternative options are affordable, and whether the patient's interpersonal relationships (physician and family) support it. The Panel presented two examples; one where a gentleman with ALS (a progressive neurodegenerative disease) chose MAID because he was suffering unbearably and he claimed the staff at the care home could not look after him.[46] Another example presented by the Panel was an ongoing lawsuit where an individual claims that a health centre failed to provide a care option that would relieve his suffering and instead referred him for MAID.[47]

These examples demonstrate circumstances without sufficient access to alternative health care options which leads to decision making for MAID not being autonomous. To achieve decision making autonomy, the social context needs to provide a patient with reasonable alternatives, at which point the patient's interpersonal support team may then contribute their part to the patient's autonomous decision making.

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[44] Ibid 49.
[45] Ibid.
[46] Ibid 147.
[47] Ibid 148.

The Panel identifies that the patients social context is also influenced by their“ [f]amily, ethnicity, religion, workplace, education and cultural experiences.”[48] These factors may influence how a patient views themselves as a patient, how they view physicians, how they view health care generally and more particularly, how they view end of life care. So “[w]hile discussions on medical options to prolong life may be appropriate and desirable for some patients, others may view them as an interference in the natural passage of life.”[49] The patient's perception of these extrinsic factors influences their relational autonomy, which may either strengthen or detract from their autonomous decision making.

A patient’s feeling of being a social burden or being discriminated against as a vulnerable individual may also be prevalent in their social context and can reduce their decision making autonomy. Some patients may request MAID out of what they consider to be a moral duty, to avoid becoming a burden on their family and society and to avoid the perception and discrimination they believe is inevitable with societies perspective on their disease.[50] An international report highlighted by the Panel found that 'the risk of being discriminated against by society can motivate elderly people to draft an advance euthanasia directive.’[51] Safeguards could be introduced at the procedural level to address this risk and to ensure patients are aware of and adequately understand the alternatives that are available. Social workers and counselling care should also be introduced to help patients feel valued by society. These methods could help to identify both positive and negative perceptions of society and to effectively be an oversight to ensure patients are not coerced by their social context.

Relational autonomy is more than the patient's interpersonal relationships. A patient's social context also determines the healthcare options available and the relevant presumptions around

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[48] Ibid 29.
[49] P R Coolen, ‘Cultural Relevance in End-of-Life Care’ (01 May 2012) Ethno Med at 29, online: *Ethno Med* <ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care/>.
[50] The Panel (n 10) 147.
[51] Ibid.

healthcare and end of life procedures. Relational autonomy brings our attention to these social factors in influencing a patients decision making autonomy.[52]

V CONCLUSION

The Panel discusses in great depth other pressing issues related to MAID such as intolerable suffering, consent, access to MAID and how one might draft and interpret an AR.

The MAID legislation is still new, and the Canadian government accepts there are opportunities for the law to develop and become more inclusive. The Panel has found there are challenges inherent in MAID, never mind the addition of advanced requests. The Panel's discussion and application of relational autonomy to MAID has exposed some of those weaknesses but more importantly, discussed the benefits that a relational approach can bring to understanding autonomy and promoting the decision making autonomy of the patient.

[52] Ibid 49.