VIEWPOINTS Ethics of paediatric Medical Assistance in Dying ANGELA DONG¹, AARON WEN² EDITED BY MATTHEW LYNN & JAMES YU

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INTRODUCTION

Medical assistance in dying (MAID) -formerly known as euthanasia- is sought after by terminally ill individuals to relieve their pain and suffering. In the 2015 Carter vs Canada ruling, the Canadian Parliament invalidated prohibitions on MAID in the Canadian Charter of Rights and Freedoms. Although adult MAID is now permitted, MAID for minors is still up for debate.1

Over the past few years, the discussion of MAID has become increasingly prevalent amongst children and teens. In a Canadian Paediatric Surveillance Program survey of 1050 paediatricians, 118 indicated that over the course of one year, they had "[MAID] discussions with over 419 patients."2 These results have the potential to alter current MAID laws and reform the arguments between an individual's right to autonomy and society's responsibility to protect the most vulnerable. To date, only two countries allow MAID for minors: the Netherlands and Belgium.

This Viewpoints piece will provide two opposing opinions on the legalization of paediatric MAID in congruence with the enacted MAID laws within Canada.

FOR PAEDIATRIC MAID

"Do not go gentle into that good night," we used to say on the subject of dying. However, death comes for us all in the end, and in recent times, dialogue has shifted towards leaving with dignity into the great beyond.³

Current methods of end-of-life care for minors center around palliative care, where opioids are prescribed in increasing dosages to relieve pain and counteract long-term tolerance. However, providing increasing doses of opioids may still end in death, just like other widespread passive measures of letting the patient die, such as "pulling the plug" or stopping treatment. Opponents of MAID argue that palliative care's existence should preclude the use of MAID as it achieves the same effect passively, something presumably more moral than an active decision. However, from a utilitarian point of view, both seek the same result of relieving pain and causing death, and are therefore equivalently moral. One could even argue that palliative care ---the terminally ill languishing for weeks, minds addled with opioids, while the family waits with bated breath for the tragic, unpredictably-timed conclusion- is less

humane as it prolongs the suffering of everyone involved. One must also remember that patients are often those who have lost almost all control of their lives -to deny them one more opportunity for autonomy would be against their best interests psychologically.⁴

Upon establishing the necessity of MAID even in the age of palliative care, the line in the sand between MAID and paediatric MAID, autonomy, must be addressed. For mature minors and incompetent minors seeking MAID, one current legal caveat unjustifiably limits their access to relief: the arbitrariness of the age limit. In the Netherlands, only mature minors aged 12 to 18 or infants under 1 year old (Groningen Protocol) are eligible.⁵ Such strict age limits fail to consider vast differences in maturity uncorrelated with biological age and undermine case-based evaluation, an approach more thoroughly considerate of complex situational factors. Opponents of paediatric MAID argue that minors should not be trusted with such decisions, citing immaturity. However, due to the highly unique medical histories of MAID-requesting youth, no one else can understand the impact of the disease on their life as much as they do. One can even argue that they grasp the gravitas of their choice moreso than adult patients, as many paediatric patients with lifelong conditions have grown used to confronting their mortality, while adult patients often face shocking lifestyle changes overnight, potentially skewing their perspective.⁵

In the case of incompetent minors where parental determination comes into play, there is a societal right for parents to raise offspring as they see fit. Compared to hours of doctors' visits, a parent's experience with their child extends into months and years. Not only do they know the full story and what their child might want, but there is also a higher likelihood of compatible values between parent and child than child and doctor —they are the primary caregivers.⁶ In cases of terminally-ill neonates, parents will be toiling long after intensive care discharge, an oftentimes fruitless and life-altering endeavour especially deleterious to disadvantaged parents. Some may say that parental determination opens the door to abuse. However, safety measures exist to prevent policy abuse such as strict regulations and evaluations on eligibility after opting-in, and intervention by courts and physicians if ulterior motives are suspected.³ Similarly, if opponents cite systemic abuse incentives ---such as claiming that corporate hospitals will pressure for MAID to cut costs- there is no telling that this does not currently exist on a more opaque level. To

- Baum K. Children, teens, parents asking Canadian pediatricians about assisted dying [Internet]. 2018 [Accessed 2018 Oct 26]. Available from: https://www.theglobeandmail.com/news/national/pediatricians-across canada-report-fielding-questions-on-assisted-dying-survey/article36723278/. 2
 - Davies D. Medical assistance in dying: A paediatric perspective. Paediatr Child Health. 2018;23(2):125-130. Available from: doi:10.1093/pch/pxx181 З.

- Brouwer M, Kaczor C, Battin M, Maeckelberghe E, Lantos J, Verhagen E. Should pediatric euthanasia be legalized?. Pediatrics. 2018;141(2):e20171343. Available from: doi:10.1542/peds.2017-1343 5.
- Bovens L. Child euthanasia: Should we just not talk about it?. J Med Ethics. 2015;41(8):630-634. Available from: doi:10.1136/medethics-2014-10232 6

Health Canada. Medical assistance in dying [Internet]. 2018 [Accessed 2018 Oct 26]. Available from: https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html.

Wakefield D, Bayly J, Selman L, Firth A, Higginson I, Murtagh F. Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. Palliat Med. 2018;32(8):1288-1304. Available from: doi:10.1177/0269216318783919. 4