VOLUNTARY ASSISTED DYING FOR CHILDREN

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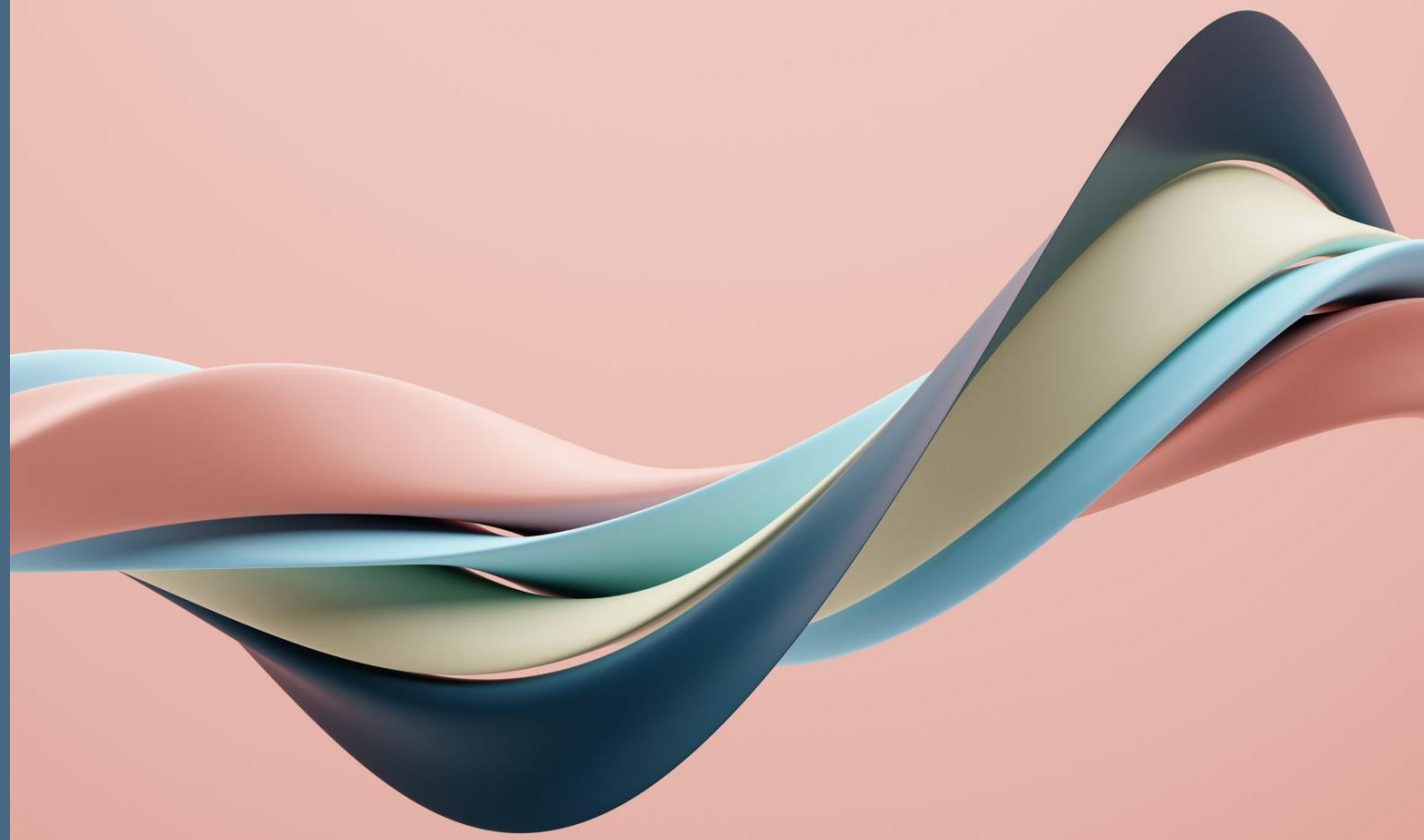

JUST A QUICK BIT OF CONTEXT

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Creating a safer and better functioning system: Lessons to be learned from the Netherlands for an ethical defence of an autonomy-only approach to assisted dying

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Abstract

The proposal to allow assisted dying for people who are not severely ill reignited the Dutch end-of-life debate when it was submitted in 2016. A key criticism of this proposal is that it is too radical a departure from the safe and well-functioning system the Netherlands already has. The goal of this article is to respond to this criticism and question whether the Dutch system really can be described as safe and well functioning. I will reconsider the usefulness of the suffering criterion, and I will ultimately argue this criterion should be rejected altogether. Instead, we should consider moving towards an autonomy-only approach to assisted dying. This would resolve some significant issues occurring under the current system of assisted dying in the Netherlands and ultimately make the process safer and better functioning. I will then consider some possible objections to adopting an autonomy-only approach and provide some preliminary responses to these also. I will finally highlight some potential areas where further research may be necessary, namely, how to mitigate the effect of external factors such as poverty or other life aspects that may have the potential to distort the individual's ability to make autonomous decisions. I will also consider some possible international lessons that can be taken from both current as well as the proposed practice in the Netherlands.

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THE CURRENT SITUATION

- Assisted dying options are available in the Netherlands for
  - Neonates (up to 1 year of age)
  - Children 12 and up (with parents' consent)
  - Children 16 and up (without parents' consent)
- Paediatricians' attitudes
  - Discomfort about lack of options between 1-12 years of age (NVK, 2020)
  - Emphasis placed on suffering (Bolt et al., 2017)

PAEDIATRIC SUFFERING

- Paediatricians' argument but… what is it?
- The new futility? (Salter, 2020)
- Mirage (Tate, 2020)
- Reflects responsibilities and experiences of adult stakeholders (de Weerd et al., 2015)
- Even more unstable as a concept than in adult care
- So, what might be a better way of centring children's **autonomy** in end-of-life decision-making?

PREFERENCES AND ACTIVE CHILD PARTICIPATION

- Willing, capable, and legally entitled to active participation (Schalkers et al., 2015)
- Research on children's participation in end-of-life decisions is limited and with varied results (Ruhe et al., 2014)
  - Can lead to conflict/children being overwhelmed
  - Interested in decisions about how they are treated and remembered
  - Children instinctually indicate their desired level of involvement
- Important to accurately gauge willingness and ability to engage and where possible discuss reasons for disengagement

BEST INTERESTS

- "Best interests" standard is the predominant approach (Kopelman, 2010)
- Problematic for a number of reasons
  - Ill-defined, unreasonably narrow, and does not respect the family (Salter, 2012)
  - Contains ableist conceptions of 'a good life' (Janvier, 2011)
  - Bogs down discussion and focuses on the wrong thing (Gillam, 2016)
- Harm principle
  - State can only intervene if child is at significant risk of serious harm (Diekema, 2009)
  - Zone of parental discretion (Gillam, 2016)

VAD ONLY AS A RESPONSE TO HARM

- Response to paediatricians concerns about suffering

- Consider this set of questions
  1. What are the reasons for considering assisted dying for this child?
  2. Will the child's basic needs be compromised if assisted dying is refused?
  3. Are there alternatives for these needs to still be met in other ways?
  4. Would the child's death be predictably uncomfortable, stressful, or scary if assisted dying is refused?

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THANK YOU FOR YOUR TIME!

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