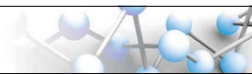


**RESPONSE**

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# Being a burden to others and wishes to die: The importance of the sociopolitical context

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Utrecht, The Netherlands.  
Email: Bernadette.Roest@phd.uvh.nl**Abstract**

All articles in May 2019's special issue of *Bioethics* offer profound insights into the issue of "being a burden to others" in relation to wishes to die, which are highly relevant for ethical debates about end-of-life care and physician-assisted dying. In this reply, we wish to stress the importance of acknowledging and analyzing the sociopolitical context of the phenomenon "being a burden" in relation to wishes to die and we will show how this analysis could benefit from a care ethical approach. As discussions in care ethics have made clear, caring practices are both social and political practices. An empirical and ethical analysis of "being a burden" therefore needs to take institutional and societal norms and structures into account, in addition to first-person experiences and concepts such as caring needs, relational autonomy, and interdependency. Besides the relevance of the sociopolitical context for the phenomenon "being a burden" as such, the sociopolitical context also seems relevant for the investigation of the phenomenon, which we will illustrate by reflecting on "being a burden" in relation to the practice of physician-assisted dying in the Netherlands.

**KEYWORDS**

being a burden, care ethics, physician-assisted dying, sociopolitical context, wish to die

## 1 | INTRODUCTION

"Being a burden to others" in relation to wishes to die is, as the editors of May 2019's special issue of *Bioethics* stated, a highly complex as well as extremely relevant issue with regard to end-of-life care practices and ethics.<sup>1</sup> All contributions to the special issue offer new and very valuable insights. Nevertheless, we think that the influence of the sociopolitical context on both the phenomenon "being a burden" in relation to wishes to die and the empirical study of this phenomenon deserve more attention.

Our view follows from the theoretical background of care ethics, which focuses on care as both a social and political practice, and from our experiences with research on physician-assisted dying in the

Netherlands. The sociopolitical context includes the informal and formal norms as found in institutions or society as a whole and that can be, but do not have to be, laid down in laws, regulations and policies.

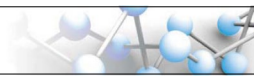
The authors of the special issue already briefly touch on elements of the sociopolitical context that could impinge on the experience of being a burden, such as cultural factors,<sup>2</sup> gender norms<sup>3</sup> and attitudes of healthcare staff.<sup>4</sup> They discuss the possible influence of

<sup>1</sup>Rehmann-Sutter, C., Ohnsorge, K., Onwuteaka-Philipsen, B., & Widdershoven, G. (2019). "Being a burden to others" and wishes to die: An ethically complicated relation. *Bioethics*, 33(4), 409–410.

<sup>2</sup>Rodríguez-Prat, A., Balaguer, A., Crespo, I., & Monforte-Royo, C. (2019). Feeling like a burden to others and the wish to hasten death in patients with advanced illness: A systematic review. *Bioethics*, 33(4), 411–420, p. 419; Gudat, H., Ohnsorge, K., Streeck, N., & Rehmann-Sutter, C. (2019). How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families. *Bioethics*, 33(4), 421–430, p. 428.

<sup>3</sup>Metselaar, S., & Widdershoven, G. (2019). Moral dilemmas in (not) treating patients who feel they are a burden. *Bioethics*, 33(4), 431–438, p. 433.

<sup>4</sup>Gudat et al., op. cit. note 2, p. 429.



home care arrangements and reimbursement systems<sup>5</sup> and legislation concerning assisted dying<sup>6</sup> at more length. Still, we think that these topics require further investigation and that this investigation could benefit from a care ethical approach.<sup>7</sup>

Metselaar and Widdershoven describe how a care ethical approach,<sup>8</sup> in contrast to a principle-based approach, enabled them to offer new perspectives on the phenomenon “being a burden” in a moral case deliberation. The other authors similarly demonstrate how the use of care, relationality and dependency as guiding concepts<sup>9</sup> and the empirical study of lived experiences and care practices<sup>10</sup> are valuable tools when examining the phenomenon “being a burden” in relation to wishes to die. Still, the authors mainly restrict their inquiries to a small-scale context, namely patients, their next-of-kin, the home care setting or clinical encounter.

In this reply, we adopt a broader perspective and show how a care ethical approach enables us to acknowledge and analyze the sociopolitical context of “being a burden” and wishes to die as well. We will discuss ideas about the position and context of foundational thinkers in care ethics and how these ideas could increase our sensitivity for the sociopolitical context of the phenomenon “being a burden” and the investigation thereof. We will illustrate the latter point by reflecting on “being a burden” in relation to the practice of physician-assisted dying in the Netherlands.

## 2 | THE RELEVANCE OF THE SOCIOPOLITICAL CONTEXT IN CARE ETHICS

In care ethics, care is seen as both a social and a political practice, as caring practices intrinsically contribute to and are determined by the way society is organized.<sup>11</sup> Besides paying attention to relationality, interdependence, caring needs and responsibilities, a care ethical analysis should therefore also include an examination of how care is

organized in a community and how caring activities are being supported or frustrated because of informal and formal norms and organizational structures.

Political scientist Joan Tronto cautions against what she calls “the containment strategy”; that is, the tendency to restrict an ethics of care to the particular or private sphere of family relationships.<sup>12</sup> Through this containment strategy, structural power imbalances and injustices that transcend the private sphere but nevertheless have great impact on caring practices may remain hidden.

Moral philosopher Margaret Urban Walker, another foundational thinker of the care ethical tradition, points to the “intricate mesh of moral and social worlds”.<sup>13</sup> According to Walker, moral understandings are created and sustained in the midst of our daily life and are thus embedded not only in our relationships with next of kin, but also in the cultural, institutional and political dimensions of life.

Moreover, because of this social embeddedness of moral understandings, Walker argues that not everyone is in the same position of power to define beforehand what should be considered morally relevant and what should not. In the same vein, she asks moral philosophers and ethicists to critically look at their own position as “participants in a particular set of institutional arrangements and social practices”<sup>14</sup> and to ask themselves whether this might unwittingly influence their professional undertakings.

How does this care ethical approach that emphasizes the sociopolitical context change our reading of the articles in the latest special issue of *Bioethics*? First, following Tronto's position on containment strategies, we want to stress the importance of looking beyond the private setting of the family or the clinical encounter in the empirical and ethical analyses of “being a burden” in relation to wishes to die. For instance, in the clinical case of Metselaar and Widdershoven<sup>15</sup>, one may ask whether it also involves a clash of professional cultures (say, a more cure-oriented approach by academic medicine versus a more care-oriented approach by general practice) and how this might affect the assessment of and response to the patient's and husband's needs.

Second, the authors of the special issue described self-perceived burden as “based on conflicts of values and moral understandings”<sup>16</sup> and as “a moral emotion.”<sup>17</sup> Walker's ideas direct our attention to how these moral understandings and emotions are not only shaped by intimate personal relationships, but also by the interactions, norms and values in our local and global communities. Similarly, we may ask whether a wish to hasten death is merely an “expression of shared suffering” of patients and their next of kin as Rodríguez-Prat et al. suggest,<sup>18</sup> or that it could also be seen

<sup>5</sup>Seidlein, A.-H., Buchholz, I., Buchholz, M., & Salloch, S. (2019). Relationships and burden: An empirical-ethical investigation of lived experience in home nursing arrangements. *Bioethics*, 33(4), 448–456.

<sup>6</sup>Rodríguez-Prat et al., op. cit. note 2, p. 419; Rehmann-Sutter, C. (2019). Self-perceived burden to others as a moral emotion in wishes to die. A conceptual analysis. *Bioethics*, 33(4), 439–447, p. 447.

<sup>7</sup>Leget, C., van Nistelrooij, I., & Visse, M. (2019). Beyond demarcation: Care ethics as an interdisciplinary field of inquiry. *Nursing Ethics*, 26(1), 17–25. <https://doi.org/10.1177/0969733017707008>. We prefer to speak of care ethics not as an ethical theory, but as an interdisciplinary field of inquiry that is characterized by (a) care as the central theoretical concept; (b) the use of shared sensitizing concepts such as relationality, interdependence and position, among others; (c) empirical investigation into care practices, lived experiences and the connected sociopolitical context; and (d) a “dialectical relation” between empirical research and ethical theory.

<sup>8</sup>Metselaar & Widdershoven, op. cit. note 3, p. 435. The care ethical approach as described here coincides to a large extent with our view on care ethics. Our emphasis is however slightly more on the social and political dimension of care, thereby enabling other questions to emerge.

<sup>9</sup>Rodríguez-Prat et al., op. cit. note 2, pp. 418–420; Rehmann-Sutter, op. cit. note 6, p. 440; Gudat et al., op. cit. note 2, p. 429.

<sup>10</sup>Seidlein et al., op. cit. note 5; Gudat et al., op. cit. note 2; Rehmann-Sutter, op. cit. note 6, pp. 440–441.

<sup>11</sup>Leget et al., op. cit. note 7.

<sup>12</sup>Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. New York, NY: Routledge, p. 89.

<sup>13</sup>Walker, M. U. (2007). *Moral understandings: A feminist study in ethics* (2nd ed.). New York, NY: Oxford University Press, p. 237.

<sup>14</sup>Ibid: 36.

<sup>15</sup>Metselaar & Widdershoven, op.cit. note 3, p. 437.

<sup>16</sup>Gudat et al., op. cit. note 2, p. 422.

<sup>17</sup>Rehmann-Sutter, op. cit. note 6, p. 439.

<sup>18</sup>Rodríguez-Prat et al., op. cit. note 2, p. 418.



as an expression of the “social suffering” of a certain community.<sup>19</sup>

Furthermore, it seems necessary to further examine the interaction between formal policies and informal norms. Seidlein and colleagues highlight the “mutual dependency in the triangle of care”<sup>20</sup> between care-recipients, informal and professional caregivers and how healthcare policies and reimbursement systems influence the burden perceived by all. The authors also reflect on informal norms, namely the duty to care for one’s parents, and offer the worthwhile suggestion to use the special goods theory as a heuristic in dialogues about which moral duties can be entrusted to professional caregivers.<sup>21</sup> However, we may ask whether not only familial duties, but also other informal norms such as gender expectations might be an issue in home care arrangements. In addition, we may ask how the healthcare policies and reimbursement systems in their turn could reinforce or change familial duties and gender expectations. Interesting in this respect is how Seidlein and colleagues describe how both informal and professional caregivers, while being fully committed to their caring tasks, feel aversion to the idea of burdening their own next-of-kin in the future and prefer other care arrangements and choices at the end of life for themselves.<sup>22</sup>

Third, Walker helps us realize that, while we as academic bioethicists may agree that “being a burden” is an important issue in the normative evaluation of end-of-life care, social circumstances may inhibit others in raising it as a morally relevant issue. One may for example question how the speechlessness of patients about their feelings of being a burden as found in the interview-study by Gudat and colleagues<sup>23</sup>, should be explained. Is it just an individual matter, caused by shame and an internalized societal norm not to burden others? Or might patients and family members be inhibited from raising feelings of being a burden as a relevant issue due to a lack of appropriate language, as Gudat and colleagues suggest<sup>24</sup>, or due to other organizational factors like a lack of time or inadequate counseling skills among the attending medical professionals?

Lastly, Rodríguez-Prat and colleagues<sup>25</sup> and Rehmann-Sutter<sup>26</sup> mention the relationship between “being a burden” and legislation on physician-assisted dying. They stress the importance of legislation that does not undermine caring attitudes or increase feelings of being a burden, as well as the state’s responsibility to install safeguards. However, Walker’s observations about the intricate mesh of moral and social worlds remind us how this may not at all be straightforward. The changeability of policies and social provisions and the intertwining of politics, law, practice, and (empirical) ethics may

deserve more attention, which we will illustrate with an example from the Netherlands.

### 3 | THE RELEVANCE OF THE SOCIOPOLITICAL CONTEXT FOR “BEING A BURDEN” AND PHYSICIAN-ASSISTED DYING IN THE NETHERLANDS

In the following paragraphs, we reflect on the relevance of the socio-political context for the phenomenon “being a burden” in relation to requests for physician-assisted dying (PAD) in the Netherlands.<sup>27</sup> First, we observe that both the practice of PAD and surrounding social policies and healthcare arrangements are changing. However, some of these policies and arrangements were previously seen as safeguards to prevent requests for PAD on account of feelings of being a burden. Second, while further empirical inquiry into the possible relationship between “being a burden” and requests for PAD in the Netherlands is needed, we wonder whether certain implicit societal or professional norms have unintentionally affected this empirical inquiry. Although in-depth investigation is necessary before we can draw any conclusions, we hope that our reflections will indicate how a care ethical approach could help broaden our scope of analysis.

In the Netherlands, a persistent wish to die can be granted through the performance of physician-assisted dying, i.e., the active termination of a patient’s life on their request (euthanasia) or physician-assisted suicide. PAD was legalized in 2002 and physicians are not persecuted for performing PAD if patients have a voluntary, well-considered request to end their life and if there is unbearable and lasting suffering.<sup>28</sup> According to the Dutch legislation, the criterion of unbearable suffering is not restricted to a certain underlying disease or life-expectancy, although the majority of cases so far concerns patients with incurable cancer.

In the 80s and 90s, when legislation on PAD was being developed in the Netherlands, the concern that societal pressure and feelings of being a burden could lead to requests for PAD was already being discussed.<sup>29</sup> However, from 1985 onward, physician-assisted

<sup>19</sup>Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York, NY: Basic Books.

<sup>20</sup>Seidlein et al., op. cit. note 5, p. 456.

<sup>21</sup>Seidlein et al., op. cit. note 5, p. 454.

<sup>22</sup>Seidlein et al., op. cit. note 5, p. 453.

<sup>23</sup>Gudat et al., op. cit. note 2, p. 426.

<sup>24</sup>Gudat et al., op. cit. note 2, p. 429.

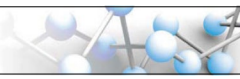
<sup>25</sup>Rodríguez-Prat et al., op. cit. note 2, p. 419.

<sup>26</sup>Rehmann-Sutter, op. cit. note 6, p. 447.

<sup>27</sup>We realize that wishes to die and requests for PAD are not necessarily the same thing. Wishes to die could reflect different motivations and intentions that do not always overlap with an explicit request to hasten death, as Ohnsorge et al. (2014, 2019) have shown. These subtle differences between wishes to die and explicit requests for PAD may be something worth exploring further in the Dutch practice of PAD. Ohnsorge, K., Gudat, H., & Rehmann-Sutter, C. (2014). What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care*, 13(38). Available at: <http://www.biomedcentral.com/1472-684X/13/38>; Ohnsorge, K., Rehmann-Sutter, C., Streeck, N., & Gudat, H. (2019). Wishes to die at the end of life and subjective experience of four different typical dying trajectories. A qualitative interview study. *PLoS one*, 14(1), e0210784. <https://doi.org/10.1371/journal.pone.0210784>

<sup>28</sup>Government of the Netherlands. *Euthanasia*. Available at [www.government.nl/topics/euthanasia](http://www.government.nl/topics/euthanasia) [accessed Jul 17, 2019] and Regional Euthanasia Review Committees *Due care criteria*. Available at [english.euthanasiecommissie.nl/due-care-criteria](http://english.euthanasiecommissie.nl/due-care-criteria) [accessed Jul 17, 2019].

<sup>29</sup>Kennedy, J. (2002). *Een weloverwogen dood: Euthanasie in Nederland*. Amsterdam, the Netherlands: Bert Bakker; Weyers, H. (2004). *Euthanasie: Het proces van rechtsverandering*. Amsterdam, the Netherlands: Amsterdam University Press.



dying was explicitly defined as medical aid in dying after a *voluntary* request, in a situation of unbearable suffering.<sup>30</sup> In addition, the existence of a generous welfare state assured that everyone, regardless of private financial resources, had access to high quality curative and supportive care as well as easy access to institutional care.<sup>31</sup> Furthermore, PAD was very much a general practitioners' affair. General practitioners (GPs) often had a long-term relationship with both patients and their next-of-kin and knew their individual and shared histories. Therefore, they would be able to establish the voluntary nature of a euthanasia request; requests based on feelings of being a burden or due to pressure exerted by others would be recognized as such and ruled out. Due to the existence of these safeguards, concerns about "being a burden" or societal pressure were no longer seen as reasons to reject legalizing PAD.<sup>32</sup>

However, since the enactment of the Dutch Euthanasia law in 2002, practices, healthcare arrangements and social policies have changed. Although the absolute number of cases of PAD is still relatively low (4.4% of annual deaths in 2017<sup>33</sup>), the number has been rising.<sup>34</sup> According to a recent government-commissioned inquiry<sup>35</sup>, a combination of different factors may contribute to this rise. The authors describe as possible contributing factors an increased acceptance of PAD among the general public, an increased willingness of GPs to be involved or to refer patients, an increased mortality due to cancer compared to cardiovascular diseases, and the ageing of the population. The ageing population seems to contribute not only because the absolute number of elderly is rising, but also because elderly people are requesting and receiving PAD relatively more often than before.<sup>36</sup>

In addition, while the majority of PAD cases still concerns patients with cancer, the number of cases of PAD for other conditions is increasing.<sup>37</sup> And while GPs still make up the majority of physicians who perform PAD, this no longer necessarily goes hand in hand with a long-lasting treatment relationship.<sup>38</sup> The necessity of the long-lasting relationship is being challenged in public and

professional debates, patients can request another physician to discuss a request for PAD<sup>39</sup> and the constellation of GP practices in general is changing.<sup>40</sup>

Lastly, legislative changes in 2007 and 2015 have put the Netherlands on a path toward what is generally called a "participation society", which resembles the Big Society developed by then prime minister David Cameron in the UK in 2010. The participation society entails a shift from publicly funded care in institutions to informal family care and to the voluntary civil society.<sup>41</sup> Chronically ill people and their next of kin are now expected to first cope with caring needs and responsibilities through their informal social networks. These changes could potentially affect the perceived burden of giving and receiving informal care among patients and next-of-kin.<sup>42</sup>

The combination of all these developments have caused the theme "being a burden" to resurface in public and professional debates about PAD in the Netherlands. The question is raised whether feelings of being a burden or societal pressure might be a reason for patients to request PAD and whether that would be related to any of the developments mentioned above, either positively or negatively. These aren't easy questions to answer and they require a thorough empirical investigation from multiple methodological perspectives.

Meanwhile, we wonder whether the sociopolitical context, i.e., the existence of implicit assumptions or informal norms, inadvertently influences the empirical investigation of the phenomenon "being a burden" in relation to requests for PAD as well. This question came up while reflecting upon the results of our systematic mixed studies review about the involvement of family members in the Dutch practice of PAD.<sup>43</sup>

In this systematic review, the theme "feelings of being a burden" in connection to a request for PAD did emerge, although it seemed to be of minor importance, especially in quantitative survey research conducted among physicians about reasons for PAD.<sup>44</sup> This surprised us, in light of the close connection between self-perceived burden and

<sup>30</sup>Weyers, op. cit. note 29.

<sup>31</sup>Weyers, H. (2006). Explaining the emergence of euthanasia law in the Netherlands: How the sociology of law can help the sociology of bioethics. *Sociology of Health & Illness*, 28(6), 802-816.

<sup>32</sup>Weyers, op. cit. note 29; Kennedy, op. cit. note 29.

<sup>33</sup>Regional Euthanasia Review Committees (2018). *Annual report 2017*. Available at: <https://english.euthanasiecommissie.nl/the-committees/annual-reports> [accessed Jul 30, 2019].

<sup>34</sup>Heins, M., Donker, G., Versteeg, S., & Korevaar, J. (2019). *Ontwikkelingen in het aantal euthanasiegevallen en achterliggende factoren*. Utrecht, the Netherlands: Nivel, pp.1-48. Available at: <https://www.nivel.nl/nl/publicatie/ontwikkelingen-het-aantal-euthanasiegevallen-en-achterliggende-factoren> [accessed Jul 17, 2019]. The number of annual cases of PAD rose from around 2000 in the year 2003 to 6585 in 2017. In 2018, there was a slight decrease in the number, for the first time; something that can only be interpreted over the course of the coming years.

<sup>35</sup>Ibid.

<sup>36</sup>Ibid: 6.

<sup>37</sup>Regional Euthanasia Review Committees, op. cit. note 33. The percentage of PAD cases with cancer as the underlying disorder decreased from 87% in 2004 to 64% in 2017.

<sup>38</sup>Ibid. Annual reports of the Euthanasia Review Committees do mention the notifying physicians, but there is no information available about the duration or nature of the treatment relationship.

<sup>39</sup>Ibid: 15. Physicians affiliated with the specialized End-of-Life clinic (among them also GPs) accounted for 751 of 6,585 cases of PAD in 2017 (11.4%). Patients can approach the clinic directly or GPs can refer patients to it.

<sup>40</sup>Van der Velden, L. F. J., & Batenburg, R. S. (2017) *Aantal huisartsen en aantal FTE van huisartsen vanaf 2007 tot en met 2016: werken er nu meer of minder huisartsen dan 10 jaar geleden en werken zij nu meer of minder FTE?* Available at: <https://www.nivel.nl/sites/default/files/speciale-uitgave-10-jaar-cijfers-uit-de-registratie-van-huisartsen.pdf> [accessed Jul 17, 2019]. Over the last 10 years, a trend has been seen in the Netherlands towards more GPs working part-time, more female GPs and more GPs working as locum GPs in different clinics for a longer time.

<sup>41</sup>Newman, J., & Tonkens, E. (2011). *Participation, responsibility and choice: Summoning the active citizen in western European welfare states*. Amsterdam, the Netherlands: Amsterdam University Press.

<sup>42</sup>Van Den Broek, T., Dykstra, P. A., & Van Der Veen, R. J. (2019). Adult children stepping in? Long-term care reforms and trends in children's provision of household support to impaired parents in the Netherlands. *Ageing and Society*, 39(1), 112-137; Grootegoed, E., & Van Dijk, D. (2012). The return of the family? Welfare state retrenchment and client autonomy in long-term care. *Journal of Social Policy*, 41(4), 677-694; Grootegoed, E., Bröer, C., & Duyvendak, J. W. (2013). Too ashamed to complain: Cuts to publicly financed care and clients' waiving of their right to appeal. *Social Policy and Society*, 12(3), 475-486.

<sup>43</sup>Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: A systematic mixed studies review. *BMC Medical Ethics*, 20(1), 1-21.

<sup>44</sup>Ibid: 11, 16.

wishes to die as described in earlier research<sup>45</sup> and in the articles of the special issue. Still, this could have been a consequence of the scope and method of our review or of the primary studies included in it.

However, other results surprised us as well. We found that there is no standardized registration of the people who make up the inner-circle social network of patients requesting and receiving PAD, and of which informal or professional caregivers are involved.<sup>46</sup> Additionally, we found an underrepresentation of family members as study participants in empirical studies on PAD, leaving caveats in our knowledge about their needs and perceived burden due to informal caregiving responsibilities at times when decisions about PAD are being made.

As “being a burden” has been shown to be a relational phenomenon, information about care arrangements and the perspectives of next-of-kin seem essential to investigate the phenomenon “being a burden” in relation to PAD practices, in addition to detailed accounts of patients’ perspectives. We wonder why these aspects appear to have received little attention so far, especially with the previously described changes in practices and policies in mind.<sup>47</sup> We do not have the impression, nor want to suggest, that there are political or ideological reasons behind this. But with Tronto’s and Walker’s ideas on containment strategies and intertwined moral and social worlds as a heuristic in mind, we pose the following questions.

Could empirical inquiries into the Dutch practice of PAD inadvertently restrict their focus to the physician-patient dyad, leaving out the family or broader social context, when the inquiries too closely follow the legislative framework that focuses on this dyad only? Might certain norms have formed unintentionally about what count as appropriate research questions and methods for empirical inquiry into the Dutch practice of PAD? Or have informal norms developed in Dutch society about how feelings of being a burden are to be discussed in relation to requests for PAD, whether it is in a clinical setting or in research interviews?<sup>48</sup> Or, perhaps more likely, is there is a combination of several factors at play? We hope to further explore these issues in future research.

## 4 | CONCLUSION

In this article, we argued that the sociopolitical context of the phenomenon “being a burden to others” deserves more attention and

that this includes an awareness of how the empirical study of the phenomenon could be influenced by the sociopolitical context as well. A care ethical approach that sees care as both a social and political practice helps to increase our awareness of these aspects and to analyze the broader context that stretches beyond the private sphere of the family and the clinical encounter. Although sensitivity for the sociopolitical context is not exclusive to a care ethical approach, we have shown how a care ethical approach could help broaden the scope of analysis of the phenomenon “being a burden” in relation to both a wish to die and practices of physician-assisted dying.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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<sup>45</sup>McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine*, 21(2), 115–128. <https://doi.org/10.1177/0269216307076345>.

<sup>46</sup>Roest et al., op. cit. note 43, p. 16.

<sup>47</sup>Other scholars have suggested a standardized registration of family involvement and the social context in order to more closely monitor the practice of PAD. See Emanuel, E. J., Onwuteaka-Philipsen, B. D., Urwin, J. W., & Cohen, J. (2016). Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA*, 316(1), 79–90. p. 87.

<sup>48</sup>Already in 2008, Dutch ethicists published a satirical piece in the weekly journal of the Royal Dutch Medical Association to draw attention to the informal norms that physicians seemed to have created around the practice of PAD. The authors suggested, among other things, that patients risked having their request for PAD rejected if they spoke too explicitly about feelings of being a burden. See Van Tol, D. G., van de Vathorst, S., & Keizer, A. A. (2008). Euthanasie voor beginners. *Medisch Contact*, 63, 140–142.

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