

## OPEN PEER COMMENTARY

# Commentary to: “Timely dying in dementia: Use patients’ judgments and broaden the concept of suffering.” Timely dying, suffering in dementia, and a role for family and professional caregivers in preventing it

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### Abstract

Broadening the concept of suffering in dementia to five types of suffering including suffering of family caregivers as proposed by Terman et al., may help raise awareness on a need to relieve suffering when living with dementia and adopt a holistic approach. However, as objective criteria in advance care plans for severe enough suffering to stop assisted feeding or other life-sustaining treatment in people with advanced dementia, these still need interpretation in the context of, for example, available treatment, and change in coping. New is the proposal to broaden severe enough suffering to suffering of family, including “bi-directional empathic suffering.” We believe this creates new dilemmas regarding responsibility and may increase feelings of guilt. Quantifying suffering by adding up moderate suffering could further complicate matters. Therefore, we argue that a health care professional should guide the process and assume responsibility over current decisions to follow a person’s previous wishes.

### KEYWORDS

advance care planning, dementia, end of life, ethics, holistic health, life stress, nutritional problems, pain, terminal care, withdrawing care

We appreciate the debate that Dr Terman et al.<sup>1</sup> initiate about gaining control of severe suffering in living with dementia. We recognize palliative care principles in a wish to relieve suffering including anticipated existential suffering of patient and family caregivers. We also appreciate the relational approach he adopts in this, despite the “use patients’ judgments” in the title suggesting otherwise. Four proposed paradigm shifts consider criteria to be adopted in advance care planning to anticipate the moment that five possible types of suffering exceed the limit of what the individual finds tolerable in life. At that moment, to “avoid

prolonged dying with severe suffering,” not offering handfeeding or withholding other life-sustaining treatment would be a way out when lack of capacity does not permit assisted suicide or euthanasia in a United States context.

In evaluating the innovative nature of Terman’s proposal to prevent prolonged suffering with dementia, we focus on the multiple layers of suffering, and on the decision making regarding assisted feeding: who should bear primary responsibility for this decision? Terman et al. aim to counter the complexity and alleviate the heavy responsibility upon

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others by proposing criteria that enable more precise assessment of suffering. In evaluating the criteria, we also draw on insights from the Dutch context.

Of four paradigm shifts proposed, the first recommends that people with dementia to pre-judge and document in an advance directive, as part of advance care planning, the clinical indicators that represent severe enough suffering to guide health care providers in deciding when they should be allowed to die. Family can alert health care providers to this moment. We agree that assessing a range of clinical conditions in advance is helpful as it offers clarity on what a person regards as suffering. However, reaching a recorded severe enough clinical condition should not lead to withholding care automatically or immediately. It is necessary to consider what non-burdensome treatment is available to relieve the suffering in the patient's interest.<sup>2</sup> Focusing on being allowed to die could lead to opportunities to relieve being overlooked, such as stepwise approaches to treat pain and responsive behavior that can diminish suffering and caregiver burden.<sup>3</sup> Some time may be needed to optimize symptom control also in the dying phase, as Dutch specialized elderly care physicians observed more suffering in sudden deaths compared with expected deaths in persons with dementia.<sup>4</sup>

Therefore, in determining whether the documented conditions are met, interpretation of the context remains necessary. This can be extraordinarily complex. It relates to the tension, mentioned at the end of the article, between the then and the actual experience of advanced dementia both for the person and the family. Persons with dementia may cope differently than anticipated with the clinical situations, with suffering, and with the dementia. For example, not undergoing the dementia passively but using emotion-oriented and problem-oriented coping strategies.<sup>5,6</sup> Interpretation of indicators in the context of coping is difficult also because, as Terman et al. cite "it is not the misery people are afraid of. They just do not want years of withering." Rather than particular clinical conditions that can be included in an advance directive, the then-self may dread advanced dementia because of prolonged dwindling.

Paradigm shift 2 argues to broaden a mostly physical concept of suffering to five types of suffering while any of the five can represent severe enough suffering. We acknowledge that causes are not always treatable, and that the detection of physical suffering and its sources can be difficult. For example, behavioral pain observational tool scores hardly correlate with self-reported pain<sup>7</sup> and they overlap to a large extent with tools for observable discomfort from any negative emotional or physical state.<sup>8</sup> Indeed, suffering in silence, for example, from headache or fatigue, cannot be ruled out. Therefore, beyond clinical indicators, and probably superior in addressing what people are afraid of, Terman et al. propose that other types can suffice as criteria for severe enough suffering; suffering in line with Cicely Saunders' concept of "total pain." For example, social suffering, which they refine as "disruption of life narrative." It includes loss of social roles, independence, and dignity while exhausting emotional and financial resources of family caregivers. Such social suffering overlaps with anticipated "existential suffering" through not contributing to others' lives and

society, lack of meaningful communication, or not feeling connected to higher powers, resulting in not feeling at peace.

However, when broadening the concept of suffering, the same cautions apply as for clinical indicators of severe enough suffering. For example, current coping style may or may not exacerbate emotional or existential suffering, and persons with advanced dementia may not appreciate or contemplate the suffering in the same way. Dutch physicians find it hard to judge whether persons with dementia experience suffering as unbearable and if nursing home admission as assessed in advance represents actual unbearable suffering and a good enough reason to honor a previous request to die.<sup>9</sup> As such, although highly valuable, a holistic perspective on life and suffering defined in advance does not offer the immediate solution to prevent prolonged dying.

A new aspect is detailed in the third proposed paradigm shift to broaden the concept of suffering. It regards the status of "loved ones' suffering" including from feelings of guilt or witnessing (anticipated) suffering, to bear equal weight as the person's suffering. The literature has described the layered phenomenon of coping with anticipatory grief and suffering from loss of aspects of relationships and connection; for example, in ethnographic fieldwork by Lemos Dekker<sup>10</sup> and blog posts by family.<sup>11</sup> We value the new expression coined by Terman et al.: "bi-directional empathic suffering." This second form of suffering puts the finger on the complex interactions of (anticipated) suffering for the sake of the other.

In The Netherlands, such suffering may be addressed in trustful relationships between family and physicians. Unlike physicians in the United States, Dutch physicians are inclined to advocate for quality of life in the now patient, if needed, against family wishes.<sup>12</sup> In the Dutch context, when deciding on treatment for persons with advanced dementia, less value is attached to advance directives than in the United States.<sup>13</sup> Research in The Netherlands shows that reluctance to provide euthanasia based on an advance directive is particularly high among certified elderly care physicians, a relatively large specialty caring for nursing home residents with advanced dementia.<sup>14</sup> The focus, usually shared with family, is on withholding burdensome life-prolonging or futile treatments including artificial feeding to allow dying from the underlying disease as soon as there is an opportunity for a peaceful, comfortable death.<sup>15</sup>

Paradigm shift 4 proposes to additionally define the moment of severe suffering as the sum of moderate forms of suffering. This could be moderate suffering of the persons with dementia, or moderate suffering of at least two of their loved ones. However, putting the ultimate decision of the "when" in the hands of more loved ones raises practical ethical concerns. For example, a dilemma on how to weigh their input if two children experience suffering and two do not. Does it depend on the quality of the relationship or the amount of time and money they spent on care? Does the suffering of a spouse weigh more heavily than that of a child or cousin? Autonomy should be in place also for family to opt out or reject the strong moral appeal to advocate for the advance directive. In addition, caregivers should be allowed to refuse to cease assisted feeding for the sake of their own autonomy and feelings of guilt, which may also affect grief.

There is another important difference in the U.S. context compared to the situation in The Netherlands. In the latter, nursing homes are publicly financed. In the United States, family having to sell their house or not being able to study at good schools can increase the sense of (anticipated) burden that people with dementia and their families experience. These factors may guide their advance directive as well and add pressure on family to state that the suffering is severe enough. Solutions may lie in enhancing financial security rather than dying earlier.

We suggest that the ultimate decision to discontinue any life-sustaining interventions including stopping assisted feeding rests with a physician preferably in light of an advance directive or advance decision, considering the narrative of a person's life after extensive consultation with the family. This might seem paternalizing in the eyes of some but in our view a shared autonomy between all parties does more justice to the complexity of suffering than the individual autonomy of the person, their family, or the professional caregiver. The calculation of clinical conditions and the broadening of forms of suffering to which Terman et al. point expose the complexity of suffering rather than resolving the uncertainty of health care providers in assessing whether it is severe enough. This complexity is a reality in caring for persons with dementia. We would, therefore, rather focus on not abandoning and better professional support and guidance for persons with dementia and their families in considering such uncertainty and complexity.

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## CONFLICT OF INTEREST STATEMENT

The authors report no conflict of interest. (None of the authors has anything to disclose.) Consent of human subjects was not necessary.

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