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Feeling like a burden to others and the wish to hasten death in patients with advanced illness: A systematic review

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Short summary

This article provides a systematic review of the reasoning behind patients' expressed wishes to hasten death (WTHD). The analysis presented in this paper reveals both personal and social dimensions that may trigger patients' feeling of being a burden. An understanding of these dimensions and how they influence the individual patients' lives is crucial to clinical policies that focus on the moral duty to provide humane care to all patients.

Background and Method

According to the Oregon Death with Dignity Act report from 2017, nearly half of the people who opted for assisted suicide up until January 2016 identified the feeling of being a burden to others as a concern that came into play in end-of-life decisions. This has given rise to the question of whether the feeling of being a burden to others justifies patient requests for physician assisted suicide. The concern is that the frequently expressed feeling of being a burden to others may cover over a general lack of care for people who are vulnerable.

Previous studies have shown that the feeling of being a burden to others causes distress and suffering and that it may trigger WTHD in some patients. This article reports on a meta-ethnographic study of patients' WTHD. 1729 articles were retrieved, of which 16 articles met the eligibility criteria and were included in the final analysis. After analyzing the data the authors categorized the findings under two interrelated dimensions: the personal dimension and the social dimension of the feeling of being a burden.

Key findings

The Personal Dimension refers to the patient's experience of the illness i.e. the emotional and psychological effects of living with an advanced illness and its impact on their personal state and sense of identity. Many patients with advanced illness experience a loss of independence

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and inability to carry out daily activities which they associate with their normal life. The transition towards being dependent is experienced as a loss of control, and many patients living with a life-threatening illness describe it as a loss of personal dignity. In some patients, the self-perception of being a burden to others triggers a WTHD to alleviate this feeling.

The Social Dimension: According to the authors the WTHD can also be a way of expressing certain care needs. The feeling of making loved ones suffer or the fear of being seen as vulnerable and not being treated with respect may lead to a patient's WTHD. These patients may not have an actual desire to die sooner if their needs could be met without them feeling that they've become a burden on family members or care givers.

The personal and the social dimension are closely intertwined and the feeling of being a burden affects both patients and their families. The authors highlight the clinical importance of feeling like a burden, and argue that it is necessary to make a greater effort to analyze the underlying reasons behind patients' feelings of being a burden, and to increase awareness among clinicians about the significant impact that living with a life-threatening disease can have on patients. Some suggested strategies to help alleviate the personal feeling of being a burden include involving patients more in treatment-related decisions and having them prepare advanced care plans and advance directives, which may increase the experience of maximal control.

Limitations

This review only includes studies conducted among patients with advanced diseases who have explicitly expressed WTHD. Analyzing a broader range of studies for example around assisted suicide may contribute more in depth to the findings in this review. Another limitation mentioned is that two of the 16 included studies are based on the same fieldwork.

Conclusion:

The feeling of being a burden to others is clinically important because it causes distress to patients and can impact their quality of life negatively. A better understanding of the dimensions of patients' lives that may lead them to feel like a burden to others is essential to alleviate suffering and to inform clinical policies based on the moral obligation to provide adequate care for the individual patient.