

Medical Assistance in Dying for Multiple Chemical Sensitivities: A System Failure?

Sebastian Straube, Charl Els et Xiangning Fan

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Résumé de l'article

Nous avons été étonnés de lire un article de presse récent concernant une femme de 51 ans de l'Ontario qui s'est vu proposer et a accepté l'aide médicale à mourir (AMM) parce qu'elle souffrait de polysensibilité chimique, également connue sous son terme diagnostique préféré, intolérance environnementale idiopathique (IEI). Il semblerait qu'elle n'ait pas pu accéder à un logement approprié. Nous trouvons cela préoccupant, car le fait de fournir une MAID à des personnes présentant des symptômes réfractaires d'IEI sur la base de l'indisponibilité du logement implique qu'il n'y avait pas de meilleures options de gestion disponibles. Ce cas devrait susciter une réflexion éthique sur la question de savoir si les aides que nous apportons aux plus vulnérables leur permettent de conserver leur dignité humaine de base, et si une action systémique de la société par d'autres moyens pourrait mieux soutenir les personnes atteintes d'une IEI.



LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

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Sebastian Straube^a, Charl Els^b, Xiangning Fan^a

Résumé

Nous avons été étonnés de lire un article de presse récent concernant une femme de 51 ans de l'Ontario qui s'est vu proposer et a accepté l'aide médicale à mourir (AMM) parce qu'elle souffrait de polysensibilité chimique, également connue sous son terme diagnostique préféré, intolérance environnementale idiopathique (IEI). Il semblerait qu'elle n'ait pas pu accéder à un logement approprié. Nous trouvons cela préoccupant, car le fait de fournir une MAID à des personnes présentant des symptômes réfractaires d'IEI sur la base de l'indisponibilité du logement implique qu'il n'y avait pas de meilleures options de gestion disponibles. Ce cas devrait susciter une réflexion éthique sur la question de savoir si les aides que nous apportons aux plus vulnérables leur permettent de conserver leur dignité humaine de base, et si une action systémique de la société par d'autres moyens pourrait mieux soutenir les personnes atteintes d'une IEI.

Mots-clés

assistance médicale à mourir, AMM, sensibilités chimiques, intolérance environnementale idiopathique, système de soins de santé, services sociaux

Abstract

We were astonished to read a recent media news item about a 51-year-old woman in Ontario who was offered and accepted medical assistance in dying (MAID) because she was experiencing multiple chemical sensitivities, also known by its preferred diagnostic term, idiopathic environmental intolerance (IEI). Reportedly, she could not access appropriate housing. We find this concerning, as providing MAID to individuals with refractory IEI symptoms on the basis of housing unavailability implies that there were no better management options available. This case should prompt ethical reflection on whether our supports for the most vulnerable enable them to maintain basic human dignity, and whether systemic societal action in other ways could better support people with IEI.

Keywords

medical assistance in dying, MAID, chemical sensitivities, idiopathic environmental intolerance, healthcare system, social services

Affiliations

^a Department of Medicine, University of Alberta, Edmonton, Canada

^b John Dossetor Health Ethics Centre, University of Alberta, Edmonton, Canada

Correspondance / Correspondence: Sebastian Straube, straube@ualberta.ca

As specialists working in Occupational Medicine, Psychiatry, and Ethics, we have provided care for a number of individuals affected by multiple chemical sensitivities – otherwise known as idiopathic environmental intolerance (IEI), the preferred diagnostic term. This condition involves diverse chronic symptoms of unclear etiology manifesting in response to environmental stimuli. Without evidence of an underlying organic disease (1), this condition can undoubtedly be challenging to manage and to live with. However, we were astonished to read a recent media news item about a 51-year-old woman in Ontario who was offered and accepted medical assistance in dying (MAID) because she was experiencing multiple chemical sensitivities and reportedly could not access appropriate housing (2).

It is worth noting that IEI is a diagnosis of exclusion. Sometimes there are other, well established, medical conditions that can present with the same symptoms as IEI, such as olfactory-induced migraines (where migraine abortive treatment or prophylaxis may yield significant benefit) or asthma worsened by exposure to irritant cleaning chemicals (where, in addition to avoidance of triggers, optimization of asthma management may help considerably). For chemical sensitivities without identifiable organic cause, avoidance of the offending triggers to the extent possible, psychoeducation and psychotherapy should be considered as preferred management options. There may be underlying, undiagnosed mental health conditions that are amenable to treatment, while psychotherapy may enhance coping skills. Although symptoms may improve with care and treatment, in our experience they rarely remit altogether, and the degree of disability experienced by many with IEI remains high.

People affected by IEI who feel that conventional medical practice has little to offer them may seek alternative management options, which often involve costly, non-evidence-based investigations (such as experimental blood tests not used in routine clinical care) and treatments (such as extensive renovations of the home to remove supposedly causative chemicals). In our clinical experience, these alternative interventions do not leave individuals with IEI significantly better off and may in fact significantly burden them with out-of-pocket expenses. Providing MAID to individuals with refractory IEI symptoms seems like a further giant leap in the wrong direction, not least because this action implies that there were no better management options available. That the condition in the reported case was not irremediable is evident – if the woman with IEI had been able to access housing that met her reported needs, i.e., the ability to avoid the offending environmental exposures, it is likely that she would not have sought medical assistance to end her own life.

We do not question the quality of the care received by the individual whose case has been reported in the news, and there may well have been other co-morbid conditions or considerations justifying the decision to access MAID. However, the way

the case has been portrayed in the media certainly raises the question of whether MAID is in fact a reasonable option available to someone with IEI. Whether or not she had a verifiable alternate medical diagnosis, her quality of life was undoubtedly poor. Her case should prompt ethical reflection on whether our supports for the most vulnerable enable them to maintain basic human dignity, and whether systemic societal action in other ways could better support people with IEI.

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