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Article:

Irving, A.D. orcid.org/0000-0002-1175-716X (2018) Important Patient and Public (PPI) perspectives on addiction as a reason for performing euthanasia. Addiction. ISSN 0965-2140

https://doi.org/10.1111/add.14193

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Running Head: Commentary on Hall & Parker

Commentary on Hall & Parker: Important Patient and Public (PPI) perspectives on addiction as a reason for performing euthanasia.

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Word count: 862

Declaration of interests

None.

"Addiction is already a fate worse than death" (Jen, ShARRP member)

The Dutch case highlighted by Hall and Parker [1] has prompted debate amongst academics, clinicians and law makers. The commentary below comes from the Sheffield Addiction Recovery Research Panel (ShARRP): a patient and public involvement (PPI) research group whose members all have personal and familial lived experience of addiction. In providing this commentary, ShARRP use three illustrative characters; 'Joe', 'Phoebe' and 'Jen' to offer a different and often unheard perspective which aims to help those engaging in this debate to ground themselves in the individual and family psychological and physical suffering which surrounds addiction.

The quote above from a ShARRP member reveals the extent of suffering experienced by those living with addiction and is further captured in the story of Joe, a street drinker whose life is littered with unresolved childhood trauma, violence, physical and mental illness and entrenched drug and alcohol use. There are many marginalised and stigmatised people like Joe on high streets in big urban centres across the world and the problems they experience are well known and highly visible. In his later years, Joe became wholly incapable of his own personal care, was doubly incontinent and suffered a level of physical and emotional pain unimaginable to most. At this point, fellow street drinkers kept 'watering him' (providing alcohol) in a paradoxical bid to keep him alive and help ease his inevitable shuffle towards death. While ShARRP believe that hope and recovery from addiction is always possible, Joe's case highlights how his fellow drinkers enacted their own form of slow assisted suicide. Despite the compassion, kindness, commitment and camaraderie of his fellow street drinkers, Joe's case also paints the picture of, to use an Alcoholic Anonymous phrase, an 'unfortunate soul' [2]. Joe's suffering seems quite different to the social and economic context of the Dutch man [1] whose family, education and social circumstances appear to have afforded him the privilege of a painless physician assisted suicide. In addition to the question of whether to allow euthanasia for addiction, important issues around fairness and accessibility to euthanasia need careful consideration. The sad truth is that social and economic barriers apply in life as much as in death.

Sharp understand that addiction can be as much a collective disorder of the whole family as it is an individual disorder. Here we describe two family circumstances which raise important questions around an individuals' decision to request euthanasia on the grounds of intractable addiction.

Phoebe and her husband were in their 50s and she described the torment of living with someone whose health was in serious decline and whose alcohol use felt selfish and hurtful. Hall and Parker [1] note the risk of euthanasia decisions being made to reduce the burden on family members however; Phoebe does not fit this concern. She would not have wanted the legal option to request assisted suicide available because: "there was always hope".

Jen has a different perspective. ShARRP members describe how a sort of indentation of drug dependence is left behind when a person first enters recovery. If this void left behind by drug or alcohol use is not filled by e.g. meaningful pro-social activity and adequate support this can leave a person in almost unbearable and constant fear of relapse. Jen noted that, during bouts of 'white knuckling' abstinence, the fear of seemingly inevitable relapse was palpable in her family. In much the same way as people with terminal degenerative diseases can plan for their own death through euthanasia, she would have wanted this 'option on the table'. Jen imagined pre-programming a request for euthanasia which would be triggered by a relapse. This would limit the trauma that her

return to drinking would cause her partner and children and therefore give her peace of mind. We would urge those considering euthanasia requests relating to addiction to respect 'addicts' in scenarios like Jen's as having potential agency. Contrary to stigmatising notions of 'selfish addicts', such requests may show a level of courage and selflessness; characteristics seldom attributed to people who experience drug and alcohol dependence.

A final consideration relates to treatment provision. Physicians assessing euthanasia requests need to be assured that all current treatment options have been explored. However, what if those treatment options do not fit a person's needs? In the absence of a well-funded, diverse, evidenced based treatment system which is not compounded by societal shame and stigma, euthanasia could appear a more appealing solution for individuals and their families. This demands the question; to what extent are health systems willing to provide assisted suicide also willing to address systemic failures to adequately support individuals and families living with addiction?

The author and ShARRP contributors are not arguing in favour or against euthanasia in general or specifically related to addiction. Instead, our perspective rooted in lived experiences, illustrates underrepresented positive characteristics of people in 'addiction'. Given the tendency to underrepresent such perspectives, we recommend that those with lived experience of dependent drug and alcohol use be included in any legal or policy developments in this area and also in the decision making process when reviewing applications for euthanasia on the grounds of addiction.

Acknowledgements

We thank the editors for the invitation to produce this commentary. We also thank the ShARRP members as who contributed their experiences and comments on this commentary.

References

- 1. Hall W., Parker M. The need to exercise caution in accepting addiction as a reason for performing euthanasia. Addiction 2017; https://doi.org/10.1111/add.14025
- 2. Alcoholics Anonymous: The Story of How Many Thousands of Men and Women Have Recovered from Alcoholism, William G. Wilson, Alcoholics Anonymous World Services, 1939