

Abstract

In life, we are expected to maintain a certain level of dignity. In fact, the NASW code of ethics maintains "Dignity and Worth of the Person" as a core tenet. However, in most of the USA, when someone is given a terminal diagnosis with little hope for remission, the options are either go through with expensive, rigorous treatments that may not help, or to let the disease take its natural course, with all the pain and suffering it entails. In some nations, people with certain diagnoses are able to get their affairs in order, book an appointment, and celebrate their life how they wish and simply go. So why is it, in most of the USA, we do not offer this level of choice in something as personal as end of life? What can we do to ensure that people have the choice to give themselves the "easy out" if they so choose, and how can we make sure that when people are faced with a terminal diagnosis, they choose the option that is truly the best for themselves and their morals and needs, rather than to alleviate perceived burden? In order to tackle these issues, one must understand who may be most impacted by the availability of medical euthanasia, the history of use and acceptance of medical assistance in dying (MAiD) here and abroad, why MAiD is controversial, and issues of justice within the scope of access to medical care and MAiD.

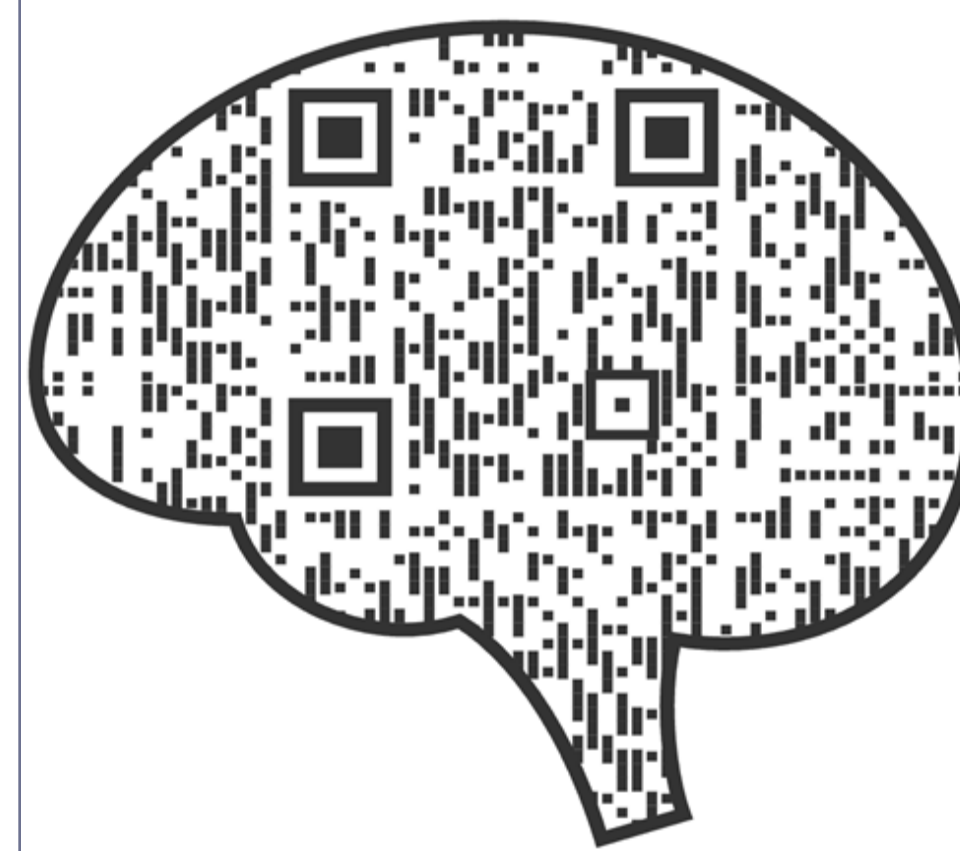
General Issues

In order to understand why someone may choose this for themselves, we need to start with issues that generally plague the terminally ill. The first thing that most likely first comes to mind is the sheer cost of healthcare. \$4.5 trillion, or 17.3% of USA GDP, was spent on healthcare in 2022, with 21% of that spent by Medicare patients. (NHE Fact Sheet 2022). Those that spend the most spending with Medicare is the 5% of patients experiencing their last year of life, making up 25% of Medicare spending (Einav et al 2018). If my math is correct, 5% of that original \$4.5 trillion in expenditure is done by terminal Medicare patients - not accounting for spending done by patients out of pocket, or on private insurance. Looking at cancer care as a whole, the National Cancer Institute reports in 2019 that oncological care cost \$208 billion, with \$20.9 billion of that being spent on prescriptions alone.

Another issue that largely affects anyone facing terminal illness is pain management. Pain management can be tricky as disease progresses, but stigma born from the opioid epidemic has become a barrier in proper treatment of pain. One review reveals that 41% of radiotherapists report staff hesitancy to prescribe opiates, with 70% of doctors stating concern about cancer patients developing non-medical dependence on opioids. The same review also shows that self-stigma serves as another barrier to effective pain management and patients tend to underutilize opioid prescriptions at a rate of 40% (Harsanyi et al., 2023).

Methods and Materials

Research was conducted through literature and study review. All references can be found via the QR Code.



Justice Issues

In a perfect world, end-of-life issues would affect everyone of all walks of life equally. Unfortunately, we do not occupy a perfect world. As mentioned previously, general healthcare accounts for much of American spending. When seeing a doctor for a regular check up is a financial burden, you get checked for certain cancers less. If you cannot afford regular screening, then it is more likely that when you do, not only are you more likely to find cancer, but it is also much more likely to be at a later stage or a worse prognosis. Race also plays a role in screening rates, and survival rates. A study on men with testicular cancer shows that African Americans who occupy a lower socioeconomic status are predisposed to late-stage diagnosis, and had higher mortality rates than their White counterparts of any socioeconomic status (Sun et al., 2011). Even as overall diagnosis rates among Black people decline, they still have the highest mortality rates (Tong 2022). One factor affecting this is a sense of distrust towards healthcare institutions present in communities of color. One study conducted in California shows that those identified as African American are 73% more likely to report medical distrust compared to Whites, with personal experience with discrimination making respondents 25% more likely to report distrust in medical institutions (Barzagan et al., 2021). The medical institutions in this country have done little to fix this reputation. Physicians are proven to underestimate the pain being felt and experienced by Black patients regardless of personal attitudes and biases, due in part to misconceptions about the Black body being fundamentally different from the White body (Hoffman et al, 2016). Taking this into account, with information regarding the effects of opioid stigma, one can extrapolate that to be a terminal patient of color, you are further stigmatized in seeking pain management - if the amount of pain you are experiencing is affirmed by doctors to begin with. As a result of many of these factors, people of lower economic status, especially those of color, are much more likely to opt to do end of life care at home with and by loved ones (Born et al, 2004).

Another concern as the practice becomes more widespread is concerns relating to eugenics. In a UN disability expert Catalina Devandas reported in a 2020 press release on many new medical developments that serve to categorize certain characteristics as desirable, or undesirable. She states specifically, "If assisted dying is made available for persons with health conditions or impairments, but who are not terminally ill, a social assumption could be made that it is better to be dead than to live with a disability... We cannot accept that people choose to end their lives because of social stigma...or lack of access to personal assistance or disability-related services." (OHCHR 2020). One thing that is consistently expressed across literature is how understudied the impact of terminal issues and MAiD availability affects all of these vulnerable populations.



Current Legislation

Worldwide, MAiD legislation continues to be adopted. The earliest legal adoptions were in the Netherlands and Belgium in 2002, but was practiced informally throughout Europe prior to legalization. Legislation and decriminalization of the act of MAiD continues to be popular in primarily Western countries and cultures. Interestingly, in Switzerland, "suicide tourism" is occurring, where people will travel there to receive MAiD (Mroz et al 2021). Focusing on the USA specifically, the Death with Dignity movement gained traction in Oregon in the 90s, with legislation first passed there in 1994, and implemented in 1997. According to 2018 data published by the Oregon Health Authority, the reasons that people opt for MAiD since 1998 include losing autonomy (90.6%), inability to engage in enjoyable activity (89.1%), loss of dignity (74.4%), loss of control over bodily function (44.3%), burdening caregivers (44.8%), with pain control only being a primary concern in 25.7% of cases, and financial burden of treatment only a concern in 3.9% of cases. This is especially interesting, considering that 66.9% of those opting for MAiD in 2018 were Medicare or Medicaid patients. While there are some variances, most places implementing MAiD include many checks before approval for the procedure - including age minimums, multiple physician opinions and health assessments, mandatory waiting periods, and record keeping (Mroz et al 2021). There are currently laws allowing physician-assisted death in 10 states, with many more currently reviewing and enacting legislation. New Jersey has been one of those states since 2019, but in January 2024, Assemblyman Robert Auth sponsored A407, a bill that would repeal the legality of this practice in NJ.

Conclusions

There are innumerable difficulties to being a patient of a terminal diagnosis. First, there are the obvious, physical issues that come with being a patient, and the pain involved with the treatment and natural course of many diseases. There is also the financial stress and burden we place upon patients within the American healthcare system, that then compounds when you are reliant on the system in the way some terminal patients are with continuous treatments and prescriptions. This, on top of the stigma associated with the medications used to manage pain, can add a lot of unnecessary hardship. The situation compounds if you are of low economic status and/or POC, with additional tangible and intangible difficulties by way of worse prognosis and additional stigma when seeking care. While I have express interest in MAiD as a means of pain alleviation, I fear there may be injustice present in widespread implementation, as marginalized people with these diagnoses will either be pushed to opt for it at higher rates by healthcare professionals based on pre existing trends of bias, as well as just being more likely to be in the circumstances that lead one to consider MAiD. There are also implications of wider acceptance of death as an alternative to facing the realities that come with many diagnoses, and what that can mean for people with long-term illness or disability that may not be terminal. Even with these factors, I believe in the right to choose in decisions regarding personal and bodily autonomy when faced with difficult situations, ranging from less consequential choices like choosing an antidepressant, to ones like abortion and MAiD. I do not think we should limit the availability of MAiD to those that can be helped by it, because there are those who may be coerced or be circumstantially disadvantaged. All people should have all facts and options available to them for any choice they may have to consider, and this goes doubly for those facing end of life choices.

Justice Impact Factors

