Education and End-of-Life Options: Hawaii's Our Care, Our Choice Act

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In 1993, the Medical School Hotline was founded by Satoru Izutsu PhD (former vice-dean UH JABSOM), it is a monthly column from the University of Hawai'i John A. Burns School of Medicine and is edited by Kathleen Kihmm Connolly PhD; HJH&SW Contributing Editor.

On April 5, 2018, Governor David Ige signed the Hawai'i Our Care, Our Choice Act. This legislation allows eligible terminally ill adults to request medical aid-in-dying (MAID). MAID is defined as "A safe and trusted medical practice in which a terminally ill, mentally capable adult with a prognosis of six months or less to live may request from his or her doctor a prescription for medication, which she or he can choose to self-administer to bring about a peaceful death."[1] MAID has also been referred to as physician-assisted suicide, or physician-assisted death. On January 1, 2019, Hawai'i became the eighth US jurisdiction (preceded by California, Colorado, Montana, Oregon, Vermont, Washington state, and Washington, D.C) to implement the law authorizing MAID.

Oregon was the first state to legalize MAID in 1997, and was used as a model in creating MAID bills, including the Hawai'i Our Care, Our Choice Act. Hawaii's law is the most restrictive in safeguards of all the eight US jurisdictions. It deviates from the model in two major areas: an increased minimum waiting time, from 15 to 22 days between the patient's initial MAID request to their physician and receiving the prescription; and the requirement of an additional mental health screening beyond that of the attending physician.[2] These safeguards create more complexity with the intention of greater safety for patients and physicians. Understanding the process and having open discussions are vital to a patient's success in ensuring quality end-of-life care free of undue influence in making decisions, such as the option to pursue MAID.

The Hawai'i Our Care, Our Choice Act authorizes, but does not require, physicians to support MAID for their patients. It is up to the physician to decide whether they will participate in MAID, unless they are restricted by their employment, as may be the case with some institutions. Physicians may face ethical or moral questions, such as the time honored principle to "do no harm." Thus, physician support of MAID may present a grey area in caring for terminally ill patients who may be vulnerable and influenced to make unwitting emotional decisions. Physicians must also be able to discuss the availability of hospice services where careful attention to pain control, symptom management, and compassionate counseling services have greatly alleviated pain and suffering at the end of life. Hospice services provide skilled counseling and support services for patients and families. Many of the painful negative experiences described by supporters testifying in favor of MAID occurred before hospice services were available or widespread.

Most of Hawaii's hospitals and clinics are taking a neutral stance on MAID, but are not currently allowing patients to intentionally end their lives in their facilities. Kaiser Permanente Hospitals, for example, will arrange for the patient to be transferred home or to another appropriate location for such actions to take place. This is in keeping with the policies of facilities in other states, such as Oregon, where MAID-like laws have existed for many years, and where most patients who choose to end their lives do so in their own homes surrounded by supportive friends and loving families. Physicians may make an individual decision to support their patient's requests for MAID directly, or to make the necessary arrangements for transfers to other physicians' care and to other appropriate locations. Education and training will potentially help physicians understand both the law and how to approach end-of-life options to provide better comprehensive care for patients.

Education on End-of-Life Options for Medical Students

The first cohort of the John A. Burns School of Medicine (JABSOM) medical school graduates since the passage of MAID will enter training programs in Hawai'i in 2019. At some time in their careers, regardless of specialty, they will face end-of-life situations. Training to assist the students in providing end-of-life care is broader than training in MAID, although a discussion of the pros and cons of this option is appropriate. Education on end-of-life issues in medical school have improved students' comfort level, preparedness, and self-efficacy in discussions on end-of-life issues including MAID.[3] In several studies, medical students felt that training in end-of-life care would be beneficial in medical school. This training would incorporate pain and symptom management, patient and caregiver coun-

seling, multidisciplinary approaches, hospice services, and end-of-life options.[3-5]

A study surveying first through fourth year medical students from Australian medical schools (n=373) reported 90% of the students believed that they should be involved in end-of-life discussions. And approximately 51% of the students agreed that, as future physicians, they should be active participants in the end-of-life decisions.[4] Other studies have similar results with approximately 50%-60% of medical students in favor of assisting in the end-of-life process.[3,5] Specific to MAID, a study surveying Canadian medical students showed that comfort levels in discussing issues surrounding MAID with patients and the likelihood to provide MAID significantly increased after training or clinical experiences. The majority of students surveyed desired training in areas that include legal, communication, and technical issues of MAID.[5]

Studies have also shown that medical students have an interest in learning more on the topic of the end of life, and that they are aware of the importance of the issue. This is especially relevant in situations when personal, ethical, and/or moral beliefs may come to play on their decisions regarding options at the end of life. Gaining knowledge and skills to cope with personal values versus patients' wishes could help mitigate any potential ethical dilemmas. Skills to manage conflicts can also help provide care with both cultural and emotional sensitivity, without compromising their own beliefs or the patients' well-being.[4] Similar results were demonstrated with residents-in-training. In a study surveying medical residents across disciplines, education on end-of-life care was associated with a higher comfort level in discussing end-of-life care with patients. Being open to discussions, which include intentions and consequences, and training on options can lead to improved care for terminally ill patients.[6]

To better address the aging population and the need for education on both healthy aging and end-of-life care, JABSOM has incorporated a required clerkship in geriatric medicine and palliative care in the fourth year of medical school. Though the US aging population is recognized as an important issue, only a few medical schools require geriatric or palliative medicine clerkships in medical education, although the curriculum in geriatrics is expanding. The American Association of Medical Colleges (AAMC) has pointed out that a primary driver in increased demand for healthcare is the aging US population of those 65 and older.[7] As such, they strongly recommend required training in geriatric medicine. JABSOM is a recognized and early leader in implementing these recommendations. The Institute of Medicine of the National Academies identifies the lack of education in palliative care as one of the greatest challenges in providing quality end-of-life care and recommends expanding educational opportunities in both educational and professional organizations.[8] As Hawai'i enters the first year of legalized MAID, the geriatric medicine and palliative care education that JABSOM students experience will help our future JABSOM physicians be prepared to handle end-of-life issues, including a terminally ill patient's request for MAID.

JABSOM Students Training in Geriatric Medicine and Palliative Care

Since 2005, all fourth-year JABSOM students have a required four-week clerkship in geriatric medicine and palliative care. This clerkship provides medical students with an overview of geriatric medicine and palliative medicine in the outpatient, inpatient, home care, and/or nursing home settings. A variety of instructional methods are utilized, including clinical experiences and didactic and seminar sessions. In addition to a range of clinical settings and patient experiences, this rotation also involves a range of interdisciplinary teachers such as nurses, social workers, rehab specialists and chaplains. Teaching and learning across disciplines are key components of both geriatric and palliative medicine.

The Department of Geriatric Medicine also offers a geriatric medicine research elective to medical students where students develop a research project in the field of aging. Basic principles of epidemiology and statistics are demonstrated so that the student is better able to critically assess the medical literature. Other elective course options include a geriatric and palliative medicine clinical experience in outpatient, inpatient, home care, and nursing home settings, and an introduction to clinical, research, and academic experiences in geriatric medicine.

In graduate medical education, JABSOM's Geriatric Medicine Fellowship Program is one of the four largest fellowship programs in the United States, accredited by the Accreditation Council for Graduate Medical Education (ACGME). To date, there are approximately 191 fellowship graduates, with three additional set to graduate in 2019. All graduates of the program are certified or eligible for specialty board certification in Geriatric Medicine. The program has an excellent geriatric board examination pass rate, many with scores well surpassing the national average. Among the geriatricians practicing in Hawai'i, it is estimated that over 90% received their training from this program.

For more information on JABSOM's Department of Geriatric Medicine, visit their website at http://geriatrics.jabsom.hawaii.edu.

Mixed Support for MAID

With Hawai'i becoming the eighth US jurisdiction to pass a MAID law, general support across the United States for MAID is growing; in a Gallup poll, approximately 68% of US adults surveyed agreed that physicians should assist in MAID. This is increased from previous years.[9] Physician support of MAID is mixed. In October 2018, the American Academy of Family Physicians (AAFP), the second largest medical association with

over 130,000 members adopted an official stance of "engaged neutrality." This means the AAFP supports the physician's choice to assist patients who request MAID. Other national organizations such as the Academy of Hospice and Palliative Medicine have taken a stance of "studied neutrality", whereby they encourage members to strive for the best care to alleviate suffering. The American Medical Student Association (AMSA) openly supports aid-in-dying legislation.[10]

As medical students graduate and gain experience in medicine, many become less certain about the need and morality of assisting patients to intentionally end their lives. Thus, several organizations actively oppose MAID. The largest US medical organization, the American Medical Association firmly opposes MAID stating "Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."[11] The National Hospice & Palliative Care Organization, the largest US organization representing hospice and palliative care, also does not support MAID, stating that their goal remains to focus on improving access to high quality end-of-life care. The organization respects the patient's choice for self-determination, but does not support the legalization of physician assisted suicide.[12]

Healthcare organizations have also shown mixed support for MAID. Most health organizations in Hawai'i have taken a neutral stance regarding MAID. No hospitals in Hawai'i will allow MAID to occur in the facility, in part due to the complicated nature of the process. Hawaii's law requires that the patient self-administer the end-of-life medication; the physician or healthcare worker cannot take any part in the patient's ingestion of the lethal medication. Leaving medications at the bedside for patients to self-administer, but where others might also access it, presents unique and unacceptable risks. Uniquely, Kaiser Permanente of Hawai'i (KPH) is taking a proactive approach and assembled a special team to help patients who request MAID. KPH has designated a MAID attending physician who will serve as a mentor on compassionate end-of-life medical practice for KPH's patients. KPH also contracted with a psychologist to make available a mental health consultation, as required by law.[4]

KPH's support for MAID comes from experience. Data from Kaiser Permanente Southern California (over 4.5 million members) revealed that within the first year of California End of Life Option Act, 379 patients inquired about the option, of those, 176 patients (46%) were eligible to proceed in their first request to their attending physician. Of those who proceeded, 92 (54%) received the end-of-life prescription, and 68 (74%) of those ingested the medication. At each step of the way, approximately half discontinued the process, with many dying due to their illness.[13] As these statistics show, less than 20% of those that initially enquired about MAID actually completed the process. It takes great perseverance for patients to navigate through both safety requirements of the process while dealing with a terminal illness. Many of these patients only want the comfort in knowing that if their suffering becomes intolerable that they will have the choice to end their lives.

Conclusion

Several grey areas regarding MAID must be discussed and explored. This includes institutional workplace policies, which are likely to impact the ability to allow MAID at inpatient facilities. Financial issues may also be a concern, as the significant cost of MAID medications is not covered by federal dollars funded via Medicare, Medicaid, or the Veterans Administration. Additionally, understanding the motivations and desires at the end of life, such as caregiver support, or patients' desire to not want to be a burden on loved ones, may lead to hasty decisions in requesting MAID. Terminally ill patients also need to understand the need for a strong caregiver support to help facilitate the process of MAID since the process is fundamentally patient-led and occurs outside of a healthcare setting.[14]

Training in geriatric medicine, hospice services, and palliative care will lead to a better understanding of end-of-life care, and hence better care for patients. This includes a thorough understanding of end-of-life options, which may include MAID if requested, as well as, understanding the availability of skilled hospice services and palliative care that are covered by insurance. For many people, hospice services will replace the fear or motivation that leads to a request for MAID.

As more terminally ill patients become aware of and inquire about the Hawai'i Our Care, Our Choice Act, Hawaii's physicians should be prepared to discuss this option or to refer a knowledgeable consultant. They should help patients make informed choices, while navigating their own personal beliefs and ethical values. Overall it is the goal of physicians and healthcare workers to provide the best care at end of life, as this can be a significant time in one's life that can be a period to reflect and reconnect with loved ones. Hawaii's MAID law now provides an option for self-determination; however, this choice must be an educated and unbiased choice by the terminally ill patient, knowing palliative care options are available to provide comfort at the end of life.

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