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Culture and control in end-of-life planning

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Sister Rita, a Franciscan nun, lived an active life of service, working first as a teacher and later in hospital-based pastoral care until she retired in her early 80s to the Sisters of the Sacred Heart convent, an apostolic order in the Midwestern United States. Even then, she continued to live independently and provide pastoral care to her older peers. She was physically active until her last year, and only began to slow down and show signs of cognitive impairment about a year before she died at 96.

When she retired, Sister Rita was neither ill nor had any chronic conditions. Yet she and each of her peers filled out a set of forms inviting them to plan for the end of their lives. Unlike the advanced care planning forms typically encountered by lay adults, these forms asked few questions about medical care. Such decisions are usually made by physicians, convent nursing care, and convent leadership. Instead, the packet the sisters filled out and updated every few years asked them to describe their wishes for their last few days on Earth. Sister Rita specified that she wanted the room to be quiet, ideally with just one sister by her side. For her funeral, she chose a few people she thought knew her well enough that "they're not going to keep talking" to perform the homily. She wanted to keep it short. She also chose a casket and selected each of the hymns and readings for her funeral mass. When she did die, in March of 2021, the funeral matched the vision she had described over a decade earlier.

Mrs. Richardson, a widow, was politically, socially, and physically active until weeks before her death at the age of 85. A longtime supporter of the Hemlock Society, a right-to-die organization that promotes end-of-life choice, she also volunteered in her Unitarian church and enjoyed gardening and birdwatching. While she did not believe in God, she believed that everyone should be a good person. After being diagnosed with cancer, she decided against treatment. She had lived alone since her husband's death and did not want to be a burden to her three children. According to her daughter, Mrs. Richardson said, "I've lived 85 wonderful years. And this is the end. And I'm okay with that. I'm not willing to go through chemotherapy just to say that I've lived a couple more weeks."

As a Vermont resident, Mrs. Richardson decided to pursue medical aid-in-dying under the state's Patient Choice and Control at End of Life Act. It enabled her to end her life before her health declined significantly, to say goodbye to the people who mattered to her, and to tie up all of her loose ends. She wanted to be in control, to end her life on her terms, to avoid lingering or suffering. Mrs. Richardson invited her children, her sister and brother-in-law, the minister from her church, a hospice nurse, and a neighbor to attend her death. When she woke up from her morning nap, they took turns toasting her with champagne, and her children gave her the vials of medication. Addressing her gathered loved ones, she said, "I've had 85 wonderful years. I have a marriage that lasted 50 years. I raised three great kids. It's been a perfect life." After ingesting the medication, she fell asleep peacefully, and 2 h later, she stopped breathing.

THE CULTURAL MEANINGS OF END-OF-LIFE PLANNING

Our opening vignettes are drawn from our respective ethnographic research with older Catholic nuns (AC) and advocates of medical aid-in-dying (MB). As anthropologists, we are interested in understanding how different cultural contexts can shape end-of-life planning and individuals' experiences. In a largely death avoidant society, Sister Rita and Mrs. Richardson both bucked dominant cultural scripts in planning for death and embracing it head-on.[1,2] However, upon closer inspection, these cases illustrate that cultural practices that appear superficially similar can be motivated by profoundly different values.

Mrs. Richardson's story reflects dominant middle-class American values of autonomy and control. Medical aid-in-dying offers proponents a pathway to maintain self-determination, individual choice, and independence throughout the dying process. In most cases, it is not primarily a means to avoid pain in the terminal trajectory.[3]

While Sister Rita's death planning also reflects an expression of individual choice, she was cooperating with an institutional process involving obedience to convent authorities. In the cultural context of the convent, planning for one's death is one of myriad socialization practices that teaches the sisters to accept that they are not in control of their lives and bodies.[4] When a healthy, active older sister is invited to complete her packet, it is a reminder that she will die and that she is not ultimately in control of how or when she will die—in Catholic terms—when God will call her home. In theological terminology, this is a *kenotic* practice, one (of many) designed to help the sisters let go of their attachments and the illusion of control. As another sister, Sister Theresa, said in an interview, "I am still in control" but "there's gonna come a time when I'll not be able to do that, and that's okay. I'll have to give in." In this sense, choice and control are separated.

When Sister Rita joined the convent as an 18-year-old girl, she learned that expressing personal preferences would contradict her vow of obedience. The end-of-life planning packet may appear at first to flout this commitment to obedience. However, most nuns by middle age have sat with dying peers and each is keenly aware that knowing a dying peer's wishes lightens the burden on her caregivers. Planning one's death and funeral is not only a way to exert individual control but also a way to care for others. Imagining and planning one's death and providing a script for the community are devotional practices in which the sisters practice caring for others and letting go of the illusion of self-determination.

Mrs. Richardson's commitment to planning for death can likewise be seen as an expression of care.[5] She wanted to avoid burdening her children with her care over the period of prolonged decline that typically characterizes the terminal cancer trajectory. Yet in her case—in stark contrast to Sister Rita—the choice for assisted death reflects a dominant middle-class American fear of becoming dependent on others for bodily care and a reluctance to relinquish control of the body.

DISCUSSION: RECOGNIZING MULTIPLICITY

Sister Rita and Mrs. Richardson, both active women who remained self-sufficient well into their 80s, engaged in similar cultural practices: imagining and planning their deaths. However, these practices were shaped by different values in distinct cultural contexts. For Mrs. Richardson, planning for death was an expression of individual control serving the secular American values of individual independence, self-determination, and bodily autonomy. For Sister Rita, on the other hand, planning for death was a religious practice designed to recognize interdependence and facilitate the release of individual control.

Analyzing these cases comparatively underscores the importance of considering end-of-life planning in its cultural context. While both examples reveal forms of death acceptance that belie mainstream societal trends, they reveal how pervasive values like choice may be associated with different cultural meanings. Recognizing the multiplicity of such potential meanings is critical in a multicultural setting like the United States. As we push for more and better advanced care planning, we should interrogate the ends that this planning purports to serve. Personal control may not be a universal goal for all individuals and planning and choice may hold different cultural meanings. For example, as we saw with Sister Rita, planning may be a means of letting go of control. Therefore, as we advocate for advanced care planning, it is important to understand and take into account our patients' cultural values and their goals.

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