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Research Report

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Advance Care Planning: Training and Providing an Anthropological Critique of Cultural Competence to Health Care Professionals

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Introduction

“Three days of horrible suffering, followed by death. That could happen to me at any moment, he thought...But then right away...the more customary thought came to him that this had happened to Ivan Ilyich and not to him, that this should not and could not happen to him.” Leo Tolstoy wrote this in his 1886 novella *The Death of Ivan Ilyich*. Set in 19th-century Russia, the story traces the suffering of the high court judge, Ivan Ilyich, and details his ultimate death from terminal illness. He never gave thought to his death before having to confront it surprisingly one day.

Even though this novella was written over one-hundred years ago, Tolstoy’s words ring true today with many people in the United States (and around the world) not wanting to discuss death in general and especially not wanting to discuss their own death with loved ones or health care providers. This lack of communication—while not universal—can be due to cultural taboos about death or just a fear of discussing what may not be known. There is a plethora of cultural beliefs and practices that need to be considered when talking about people’s wishes for end-of-life care, as different cultures and communities approach death and dying in a multitude of ways.

With a population that is aging overall, there is little doubt that end-of-life care is an urgent, yet highly sensitive, matter in the United States today. This is in part highlighted by the vast body of literature on the topic, ranging from decision-making (Luce and White 2007) to bereavement (Schulz et al. 2003) to evaluations of end-of-life care in hospitals (Chapple 2010).

In 2010, the Obama administration proposed that Medicare could reimburse medical providers for discussing end-of-life options with their patients. Just a short while later in 2011, end-of-life planning was removed under the Medicare benefit for fear that it would encourage people to use advance directives to reject life-extending measures. We must note that advance directives (such as a living will or a durable power of attorney) are meant to document a patient’s wishes, which means there is a wide range of what they may state, from doing everything possible to stopping all aggressive treatments and providing comfort care to something in-between the two.

Research shows that end-of-life discussions between medical providers and patients do not occur soon enough, often leaving patients unaware of their options (Kaufman 2005, Silveira et al. 2000) or thinking—as in Tolstoy’s account—that death cannot happen to them. One reason why end-of-life conversations may not happen as frequently or as early as they should is because death strikes at the heart of cultural, religious, spiritual, moral, and political beliefs. For some, it can be a difficult topic and emotionally fraught. Given the United States’ population is truly diverse in many different ways, it is reasonable to consider how various communities approach the end-of-life. Even within a single society like the United States, the ways in which death is discussed and end-of-life care is administered can vary and be influenced by cultural and social identities.

Advance Care Planning

This Research Report is focused on a project that we put together and implemented around Advance Care Planning (ACP). ACP is a process in which an individual will plan for future medical care in the event that they are unable to make decisions or speak for themselves (Sudore and Fried 2010). There are many other people besides just the person who is planning for future care involved in this process, such as health care professionals, family members or friends, and/or legal representatives. ACP involves multiple methods, such as conversations, education, and officially documenting wishes for care in advance directives or more formally with an order from a physician, such as Do Not Resuscitate (DNR) (Sabatino 2010). It is important to recognize that legal requirements for documenting wishes can vary from state to state in the United States.

ACP is able to facilitate patient autonomy in end-of-life decision-making and can empower individuals to make their own choices about future medical care. It also allows them to document their wishes before they are unable to do so due to deteriorated physical or mental capacities that have resulted from a specific disease or advanced age. In light of this, ACP is viewed as a key component of care that is person-centered and has been shown to improve satisfaction with health services and reduce anxiety among patients and loved ones (Detering et al. 2010). However, a lack of ACP due to personal, institutional, and/or structural reasons can be an obstacle to providing high-quality end-of-life care and can create tension or worry among staff and surviving loved ones when someone is approaching death (Sudore and Fried 2010).

With support from the Virginia Center on Aging (specifically the Geriatric Training and Education Fund), our objective was to address the general lack of ACP and to help make the overall process a little more transparent by developing and implementing a training session for staff members at Medicare/Medicaid agencies—primarily nursing homes and assisted living facilities—located in Northern Virginia (and the D.C. metro area in general). These staff members are the ones who are mainly responsible for providing information on ACP to residents or clients when they are admitted. There were two main components to the training: 1) clarify the purposes and functions of various types of ACP and 2) enhance the abilities of the staff to communicate with their patients and residents regarding ACP in culturally competent ways. As a multi-disciplinary team comprised of a medical anthropologist (Hughes Rinker), a professor of social work (Inoue), and a physician and professor of public health (Vargas-Jackson), we each brought our own expertise and interests to the table while designing the training, which we ran on three separate occasions between March and May 2017.

Purpose and Context of the Training

One of our aims for the training was to help the participants build their skills and confidence so they can effectively engage in ACP with their residents, clients, or patients. We advertised the training to and designed the training for primarily staff at nursing homes and assisted living facilities in the region. Since these are Medicare and Medicaid funded institutions, they are required to give their residents or clients written information about Advance Directives when they enroll; this is in accordance with the Patient Self-Determination Act (PSDA) of 1990. Given this requirement, we wanted to provide staff with tools and skills they could use when having discussions about end-of-life care with residents or clients and with resources that could aid in the process of documenting medical wishes.

Northern Virginia, which typically refers to the counties surrounding Washington, D.C., such as Arlington, Fairfax, Loudon, and Prince William, has an extremely diverse population on many different levels. For example, we conducted one of the three training sessions at a nursing home and assisted living facility in May 2017 in Prince William County. This county's population has increased 43% between 2000 and 2010, and this is in part due to migrant growth. Over half of the residents of the county identify as African American, Hispanic, Asian, or another minority race/ethnicity. The county's Hispanic population is roughly 22%, which is higher than the state of Virginia and the United States in general. In addition, nearly one-third of the population in Prince William County speaks a second language besides English.

Similar demographic trends can be found in other counties in Northern Virginia too. In Fairfax County, where George Mason University is located, approximately 40% of the 1.1 million county residents who are over the age of five speak a language other than English at home, with the most popular language being Spanish (13.2%). Those who identify as Asian/Pacific Islander (not Hispanic) make up the second largest ethnic group in the county after those who identify as White (not Hispanic). The counties in Northern Virginia have higher than average Median Household incomes, as compared to the United States, with Loudon and Fairfax counties being two of the counties with the highest in the whole country. However, as economists and anthropologists both have already illustrated, wealth is not always distributed equally in many communities (Farmer 2003); some people reap a majority of the benefits and have increased access to resources, while others are excluded—this also holds true for the region.

Given the diversity of the population, it is critical that local health care professionals at Medicare and Medicaid funded agencies, as well as at other types of care facilities, are aware that there are many different perspectives on issues related to ACP. These perspectives are molded by people's unique cultural and social backgrounds. This does not just mean race, ethnicity, and language must be accounted for, but also education, religion, family dynamics, and economics, among other factors. We designed this training with the intention of helping the staff develop their abilities to communicate with residents and clients, as well as with families or loved ones, in sensitive ways that are attune to both cultural differences and similarities.

Training Structure

Together, the three of us developed a training that drew on literature in anthropology, public health, social work, medicine, and the social sciences relating to issues of ACP, but would be relevant to a professional (not particularly academic) audience. We attempted to make scholarly research and theoretical concepts from within these fields applicable to everyday health care practices, but without losing sight of their rigor or significance.

The training was multi-disciplinary in that we each facilitated one section of it given our areas of expertise: Inoue discussed the purposes and benefits of ACP and the different types of documents involved, such as advance directives, DNR, and Physicians Orders for Scope of Treatment (POST), and also presented some of the challenges that have been documented in having these completed. Vargas-Jackson discussed health literacy and the need for care that meets residents or clients where they are as well as stigma in health care. And finally, Hughes Rinker presented ethnographic examples from her own research as well as anthropology that related to culturally competent care at the end-of-life. Combined the three sections made up the three-hour training. We facilitated three identical sessions, two of which took place at George Mason University with attendees coming to campus. The third session took place at the facility in Prince William County that was discussed in the previous section.

Integrating a Critique of Cultural Competence into Training Design and Implementation

Anthropologists have already masterfully demonstrated that cultural competence is not easy to define and have pointed out that there is an overall lack of a standard definition in medical education—even though it is a key concept in contemporary American medicine. Baker and Beagon (2014) observe it is often reduced to referencing ethnic and racial minorities, which leaves out other cultural and social forces and excludes certain populations who may need other considerations or have different types of needs. Furthermore, it denies the fact that people “belong to multiple cultures, but those cultures are neither coherent, static, nor do they always join together seamlessly” (Baker and Beagon 2014, 581). Arthur Kleinman and Peter Benson write, “One major problem with the idea of cultural competency is that it suggests culture can be reduced to a technical skill for which clinicians can be trained to develop expertise” (2006, 1673). This critique of cultural competence was a theme that wove together all of our presentations in the training. We were able to unfold this critique to participants by offering examples from our research projects, the literature, and even our own personal experiences with ACP and end-of-life care.

For example, Hughes Rinker, whose latest study is on the diverse experiences of Sunni Muslim patients and families in the D.C. area during serious illness and end-of-life care, pulled two particular examples from her interviews that were contradictory. In one, the Muslim Middle Eastern son of a dying patient was much appreciative of the opportunity to speak with a Muslim physician at the hospital about his father’s condition, and gave his medical opinion more credence than the other non-Muslim providers. In the other, a daughter was happy to find out that the attending physician at the hospital was Muslim, like her and her elderly mother, who was originally from East Africa and was actively dying. She was going to be transferred to hospice soon after the interview. But then, after meeting with this physician several times and discussing her mother’s condition, she said, “I realized he’s not Muslim like me. Then we had [another physician] who is not Muslim and we liked him a lot more. He was more in line of what we wanted for our mom.” Just within the two examples from Hughes Rinker’s project, the attendees were able to see that cultural competence does not always mean matching patients and families with providers who may identify in a similar way, but there are many other dynamics and beliefs that must also be taken into consideration. They also demonstrated the complex relationship between religion and culture that is not cut-and-dry. These examples, and the discussion among participants that ensued in the training after they were presented, may also point to the narrowness of cultural competence as it is usually applied in medical practice—as Baker and Beagon (2014) call our attention to in their work.

At the same time, we had to balance this critique of cultural competence with emphasizing the actual importance of providing health care that is attentive to various social and cultural factors. Culturally competent care is regularly described as part of offering high quality health care in the United States (Saha, Beach, and Cooper 2008). Such care is also viewed as patient-centered and as treating the whole-person, rather than isolating health and the physical from their social and cultural contexts. Anthropologists have previously shown that the physical and the cultural cannot be separated and frequently work together to create unique illness experiences (Kleinman 1988, Shapiro 2011).

One aim of the training was to encourage participants to think more about how individuals (and even themselves) interact with the U.S. health care system and how ACP unfolds across different spaces, times, and relationships. We also considered some of the individual and institutional challenges that ACP involves. While in our presentations, we stressed the need to offer culturally competent care—particularly in a diverse region like Northern Virginia—we also wanted to caution against stereotyping or assuming that because a resident or client identifies in a particular way culturally, socially, or demographically, they will hold a particular set of beliefs or want particular types of services (Kleinman and Benson 2006). At one of the trainings, a participant, who helped coordinate the session and advertised it to her staff, made the comment that this was one of the most salient parts of the training. She said that in health care, it is important to understand that even though a patient population may identify in a similar way (whether it be first-language or ethnicity, for instance), this does not mean that there is complete homogeneity among them and they have the same health needs or wants.

Final Thoughts

Overall, the 34 participants who attended one of the three trainings were receptive to our multi-disciplinary approach. Through the examples that they shared during our discussions, it was evident that the cultural critique resonated with their experiences with ACP in their daily work. There was little disagreement among the participants that cultural beliefs and practices are key to how their residents or clients made decisions about end-of-life care and how they approached ACP in general, but yet they also saw how other factors played an equally important role in their decision-making, such as financial resources or religious beliefs. We believe that the multi-disciplinary training was able to provide these health care professionals with a more holistic view of cultural competence and a better understanding of the vast diversity within particular patient populations—as Kleinman and Benson (2006) note, there is no “typical” patient within any racial or ethnic group. Additionally, after we completed facilitating all three training sessions, we found that participants had better recognition that cultural competence is in fact a collaborative and learning process between providers and patients or families, and one of the first steps necessary is just being open to listening and learning from others and accepting that there are multiple ways to view the body, care, and death.

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