

Embracing Life with Faith, Hope and Love: Death is Part of Life's Journey

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Healthcare Professional - First Prize

Life is a journey; an inevitable part of that journey is dealing with death and dying. If one is to fully embrace life with love, faith, and hope, then one must learn to cope with end-of-life issues. This essay will share glimpses of my transformation as a person, as a family member, and as a registered nurse as I tackle life and death issues of close family members.

My journey in death and dying started in 2009 when my father passed away. Life had given me a lot of opportunity to prepare for his death because my dad lived for 15 years after he was diagnosed with a terminal illness. One might say that I had plenty of time to prepare myself; however, the passing of time and my trainings in Theology, Psychology, and Nursing did not fully equip me with the intricacies of dealing with my father's dying and death. The extent of my conversation with my dad was that he did not want to be cremated so I buried him in our family plot. "You can wrap me in a mat and throw my body in the river, but don't ever burn my body" my Dad used to say jokingly. After his death, majority of other decisions like who will take custody of my minor siblings, disposition of his business, belongings and properties, funeral arrangements, etc. fell on my lap being his oldest son. In the Filipino culture, death and dying is not something that we openly discussed. Therefore, most of the decisions I made were what I thought my dad would have wanted. Trying to guess what my dad would have done if he were still alive was a very difficult task during a very stressful time.

As fate would have it, I was given the opportunity to redeem myself in 2018 when my aunt designated me as her fiduciary trustee and surrogate medical decision-maker after she was diagnosed with cancer. It was an opportune time as part of my job as a nurse project manager at Santa Clara Valley Medical Center (SCVMC) was to promote completion of Advance Directives. As part of my self-enrichment, I found myself playing cards in the Heart to Heart Cafe facilitated by the Chinese American Coalition for Compassionate Care (CACCC) where I learned how to start the conversation on advance care planning (ACP). What I learned there I applied to myself by completing my own advance directive; then, I used that experience to find out my aunt's wishes regarding areas of medical, financial, familial, religious, psychosocial, and personal preferences. In the five months prior to her death, I had full understanding, verbally and in writing, how she wanted to be treated before, during, and after her death.

Now, as a subject matter expert in the field of Advance Care Planning (ACP) and a registered nurse at the Quality Incentive Program (QIP) at SCVMC, and in partnership with CACCC in training the trainers to advance the cause of ACP, I was given another opportunity to advocate for improving quality of life and promoting self-dignity and respect for a dying patient. On June 15, 2022, I buried my uncle, but not without any complications. Complete with an Advance Directive, Durable Power of Attorney, Physician Order for Life Sustaining Treatment (POLST),

medical consents, and a full understanding of my uncle's wishes, I found myself fighting for my uncle's rights for self determination, respect, and dignity as a hospice patient. When my family and I could no longer care for my uncle at home, we agreed to hospitalize him in a nursing home with all the COVID-19 restrictions. However, the nursing home where my uncle was hospitalized for the last 66 days of his life wanted him to conform to the stereotype of a dying patient confined to his death bed waiting to take his last breath. Instead, my uncle thrived and started living his life. He started ambulating on his own and wanting to engage in activities fit for the living. When my uncle started driving his scooter to go shopping and dining out, the nursing home confiscated his scooter key without his consent. When he wanted to spend time with his pet dog, the nursing home threatened to call animal control stating that animals are not permitted. When he wanted live plants by his bedside, they said that plants are not allowed in patient's rooms. When he managed his pain with THC, they accused him of using drugs. The nursing home tried to discharge my uncle without notice with a 5-day motel voucher, 14 days before he died, telling him that he no longer meets hospice criteria. Needless to say, as a caring family member and a fully informed healthcare provider, I was able to advocate for my uncle enlisting the assistance of the Ombudsman, licensing department, and Patient's Rights advocate. In the end, my uncle died with respect and dignity and was laid to rest in our family plot as he wished.

My metamorphosis as an Advance Care Planning expert would not be complete if not for my affiliation with the County of Santa Clara Health System (CSCHS). CSCHS has an interest in increasing the occurrence and effectiveness of ACP activities within our system and affiliated primary care practice settings. ACP is also a project under QIP and the California Department of Health Care Services. CSCHS aims to engage their primary care providers and educate support staff in ACP so that conversations with patients and completion of documents occur on a regular basis for target groups. CSCHS, in partnership with CACCC, provides ACP education, skills training, and support to the enterprise providers and staff with the goal of increasing their ACP knowledge, expertise, and conversation skills for ACP discussions. This education and training will increase the likelihood that the conversations occur with greater regularity and earlier in the course of a patient's care.

My personal transformation, and my metamorphosis from novice to expert in the field of ACP came because of my life's circumstances, and professional affiliation; however, the same can happen by design. There are educational programs provided by organizations like SCVMC and the CACCC that aim to equip people with knowledge and tools on ACP. Studies have shown that higher levels of participation in ACP will benefit patients, families, and providers by clarifying goals, improving end of life care and increasing patient and family satisfaction and reducing stress, anxiety, and depression in surviving relatives (Detering, et. al, 2010). Additionally, ACP will promote care concordant with patient wishes and will reduce the costs associated with expensive or intensive care that is not in alignment with patient wishes. My challenge to anyone reading this essay is to fully embrace life with love, hope and faith by accepting that death and dying is part of life's journey. Embark on your personal journey to equip yourself with knowledge on ACP and start advocating for someone. You never know that someone may be yourself or someone very dear to you...

Detering, K, Hancock, A, Reade, M, and Silvester, W; The impact of advance care planning on end-of-life care in elderly patients: randomized control trial: BMJ, March 24, 2010: 340:c1345. [The impact of advance care planning on end-of-life care in elderly patients: randomised controlled trial | The BMJ](#)