
ESSAY/PERSONAL REFLECTIONS

Personal reflections on legacy making

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Previous research on legacy making includes Chochinov et al.'s (2005) work on dignity therapy, during which older adults with end-stage malignancies discussed issues that mattered most to them or that they most wanted remembered about themselves. Coyle (2006) reported that adults living with advanced cancer were concerned about how they would be remembered, and the creation of a legacy was universal to all participants. Bereaved parents and siblings reported that children living with cancer created legacies that were both intentional and serendipitous in nature (Foster et al., 2009). These studies suggest that it is important for many dying individuals to create a legacy and know they will be remembered.

As a nursing scientist studying continuing bonds and legacy making at the end-of-life since 2004, I found that this phenomenon appeared very different to me after it recently and suddenly became a very personal part of my own life. A 33-year-old loved one was diagnosed with squamous cell oral cancer, quickly deteriorated, and died just 6 months later. I was suddenly living within my own research phenomenon of interest and observing legacy making through a different lens. During the last few weeks of Henry's life (real name not used to maintain privacy), it struck me that I should write about my observations, and he agreed for me to write and share this small part of his life and death. This article reflects what I wrote in the waiting room just weeks before his death.

When first diagnosed, Henry created a blog to "relieve some stress and keep family and friends updated." As his weak, emaciated body was pushed in a wheelchair through the hospital halls, I observed that he smiled and asked everyone he encountered, "Are you a Christian? Do you know Jesus?" Friends and family in the waiting room recollected positive

memories of the past and commented that he had already created a legacy prior to his illness. Everyone's reminiscing always came back to Henry's compassion for others' personal relationship with Jesus. Although he did not seem to create an intentional legacy to be remembered, a serendipitous legacy evolved from his love for Christ and concern for others. He wanted others to know Jesus: "Oh, if everyone could understand and believe just how real and wonderful He is." When facing death, he seemed to gain an eternal perspective that "It's all about Jesus—everything, always." The legacy making I witnessed was similar to legacy making activities reported in a study of bereaved parents and siblings who lost a child to cancer (Foster et al., 2009). Participants reported that children living with advanced cancer did specific things to be remembered, such as making crafts for others, willing things away, writing letters to loved ones, and giving special gifts. A few children, particularly those who were very ill or died unexpectedly, did not do or say things to be remembered. Children's legacies included family members remembering qualities of the deceased child, the child's concern for family, and his/her beliefs about afterlife. Cancer inspired children to prepare for their own deaths while leaving an enduring impact on others. Ill children's advice about how to live life inspired family members to live differently.

Although Henry's legacy began to evolve long before he was diagnosed with cancer, it was magnified when he learned that cure was not possible. His legacy was not purposely created, but evolved through maintaining faith, trust, and hope in God, even during life's most difficult of circumstances. Henry did not seem to feel like he was called to be remembered, but he felt called by God to share Christ with others and to succumb to God's will rather than his own: "Not my will, but His be done." Henry did not seem concerned with being remembered, but only seemed concerned about things with eternal value: "What God says is what interests me. . . . He is where my focus must be stayed . . . I want us all to focus on

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Him and all the miracles of which He is capable.” Henry believed that life’s purpose was not about him or his illness. The meaning of cancer, to Henry, seemed to be about revealing God’s glory to others:

We are taught in scripture that our purpose on earth is to glorify God and enjoy Him forever. Instead of spending time asking why this happened to me, let’s spend our time praying that God will be glorified to the fullest degree through my illness. I want to be healed, and I do pray that you will ask the Father boldly for complete healing, but most of all, I want His will to be accomplished. I want lives to be changed. I ask you to pray boldly that many, who are without a personal relationship with our Lord, . . . will be drawn into such a relationship as a result of my earthly struggle. Do you realize that if one soul is saved from eternal separation from God—hell—that it is worth all the cancer treatment that can be thrown my way?! . . . I also pray that God makes a difference in His kingdom as He reveals His glory in my trials. I pray that many will come to experience the balm of relationship with the creator of the universe as they watch Him soothe me during these days.

While Henry desired to be healed from cancer, his greater desire was to glorify God:

You know that I want to be healed from this disease, but I desire that God be glorified no matter what His ultimate plan reveals. One of the easiest ways to glorify Him is to tell of the great things He has done for us—to share Him with others. . . . We are simply charged with telling the world that He waits with open arms to accept all those who desire an eternal relationship with Him. . . . Remember, it is all about Him; . . . it is all about the person of Jesus Christ!

Henry also perceived that we are not promised fairness in life. His hope was in clinging to God’s promise of being with him:

I’ll admit, there are days when I want to scream, “This isn’t fair! I want my taste buds back! I want these sores gone! Get this mucus out of my mouth! Get this growth off my neck! Get this tube out of my stomach! I want pizza, I want Cokes, I want ice cream and cookies and cheeseburgers—this isn’t fair!” I’ll probably have a few more of those days. I hope, however, that I (we) will be able to stop looking for fair in all circumstances. Rather, I pray that complete trust will replace tantrums. Our precious Father is good, and He will not leave us.

Even in the midst of cancer and potential death, Henry found joy in God and advised others to do the same:

Eternal life does not begin when you die. . . . You get to be with the loving-kind creator of the universe for the remainder of your existence on earth and forever and ever and ever! Your time with Him will never cease—don’t let the joy of this truth escape you until Heaven. . . . You have a Father who loves you and is with you wherever you go and whatever you face. So, go about your day glorifying Him with your decisions and enjoying his unfathomable goodness—it truly is everywhere, even in the midst of earthly confusion, especially in the midst of earthly confusion!

Henry counted his cancer trial as a test of faith and embraced the exhortation of James: “Consider it pure joy, my brothers, whenever you face trials of many kinds, because you know that the testing of your faith develops perseverance. Perseverance must finish its work so that you may be mature and complete, not lacking anything” (The Holy Bible, James 1:2–4, New International Version). Henry created a legacy by maintaining his hope in Christ, even in the midst of a great trial: “Though he slay me, yet will I hope in him” (The Holy Bible, Job 13:15, New International Version).

Many individuals with life-threatening illnesses create legacies. Some people are concerned with being remembered if death occurs, and others do not seem concerned. My observations of Henry’s legacy support that legacy making can be intentional or serendipitous, as noted in another study (Foster et al., 2009). Henry’s legacy making was not on doing or saying things so that he would be remembered. His spotlight was on doing or saying things so that others would first and foremost remember Christ. For that, his legacy is great, and he will always be remembered.

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