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Legacy in palliative care: Legacy that is lived

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Legacy

Philip Bialowitz, at the age of 90, died on August 6, 2016. He had spent much of his final year in a hospital with progressive congestive heart failure. Philip (Fizel) Bialowitz was the last living Polish Jewish survivor of Sobibór, the infamous Nazi death camp located some 55 miles from his birthplace in eastern Poland. Like Elie Wiesel, who died several weeks before him, Mr. Bialowitz felt that having survived the Holocaust death camps obligated him to dedicate his life to be a “witness” to the lives of those who did not. He wrote a memoir of his ordeal aided by his son. He testified at the 2010 trial, in Germany, of John Demjanjuk, who was later convicted of being a collaborating guard at Sobibór. One can imagine that during his medical/palliative care over the last months of his life Mr. Bialowitz had the opportunity to talk about his rich “legacy.” His son Joseph recalled his father's legacy as a lesson in the value of survivorship and the importance of witnessing the suffering of all human beings. Through his survival, his life story, his memoir, and his actions, Mr. Bialowitz lived a life of “significance.” There was a “sign” that he had lived. He had an impact on the world that others took notice of, as best evidenced by his full-page obituary in *The New York Times*.

We often use the term “legacy” to refer to what a person leaves behind—how a person will be remembered and what they will be remembered for (good and bad). In other words, the “legacy that we leave behind.” The term “legacy” and its clinical use in psychosocial interventions had not been widely adopted in the palliative care literature until recently, perhaps because it is such a complex concept. Dictionary definitions and the etymology of “legacy” aren't that particularly helpful. Some root terms of “legacy” suggest that it is “property left by will” or a “gift left by will.” Other root terms of the term suggest that it is derived from “legate,” implying a designated deputy, ambassador, envoy, or perhaps “messenger.” Examining these etymologic terms suggests to me that “legacy” in fact plays the most vital of roles as the medium by which we transmit vital information, values, traditions, and wisdom to the next generation. Legacy is in fact spiritual and cultural DNA.

Conceiving “legacy” as a mode of transmission of vital spiritual and cultural information and wisdom suggests that it is an ever-evolving continuum. There is thus the “legacy that we are given” and receive from our ancestors (e.g., grandparents, parents), and the “legacy that we give” to the next generation. The legacy that we are given shapes us in ways that are often apparent (sometimes less so) in how we live our lives: the values, virtues, traditions, and attitudes we either choose to adopt or reject. It helps shape “who” and “what” we

become in life. Growing up as a child of Holocaust survivors myself, I was profoundly shaped by that legacy, which provided the historical context of what gave meaning to who and what I became in this world. The Holocaust is a dramatic legacy, but all of us, and all of our patients, inherit legacies (no matter how mundane) that have profound influence in their lives. Such legacies can be burdens that destroy, or distract, from living a truly authentic life, or they can be burdens that inspire transcendence and provide a mission and purpose that leads to authentic and full lives.

For most of our patients, “legacy” is understood as “what I leave behind after I die” or “how will I be remembered after I die.” In meaning-centered psychotherapy (MCP) (Breitbart & Poppito, 2014), we identify one of the sources of meaning in life as the “historical sources of meaning.” Meaning exists in a historical context, and so, in MCP, the sessions on historical sources of meaning focus on the “legacy that has been given, legacy that one lives, and will give.”

In doing some 10 years worth of randomized clinical trials with MCP and treating scores of patients, several issues related to legacy as a tool for clinical intervention have become clearer to me. The concept that there is a legacy that we are given is somewhat new to patients, but it is understood and resonates quite clearly in almost universal fashion. What became clear early on in MCP was that legacy isn't always composed of noble, loving, wise, constructive elements. Sometimes a legacy given is an example of “exactly how NOT to live one's life.” Another perspective on legacies of loss and violence and abandonment was the concept of transcendence. We are all given a set of circumstances, genetics, environment, time, context, etc., that we are born with or into. The challenge in life thus becomes to live to one's fullest potential and to perhaps even surpass or transcend the limitations of genetics, context, and environment.

The notion of legacy as “How will I be remembered?” or “What will I leave behind?” after death is one that is most readily available to patients in the palliative care setting. What became challenging in MCP is the realization that some patients will say, “I don't care if I'm remembered or not.” The concept of the importance of being remembered is irrelevant to some. I recall the first time I heard such a response. I was a bit shocked, but perhaps the psychiatrist in me just really didn't believe it. I felt perhaps it was a defense against the fear or sadness that the patient felt that in fact they would not be remembered. After exploring this possibility, it was clear that there were some who in fact felt this way, but that there were others who really did not care, primarily because they felt they would never know if they were remembered or not, and because it was not an idea they wanted to be an influence on their freedom to live authentically. They objected to being judged, especially by others. Perhaps only their own judgment of how they lived their lives was the only judgment that mattered. In the course of conducting MCP clinical trials, it also became clear that there were patients who “had no one to remember them.” There was no one to leave their legacy to. There was no one who had been a witness to their lives and who would then survive them and thus remember them.

Legacy that is Lived: Significance. A Life Witnessed

It was through working with just such patients who had no one to remember them or bear witness to their lives that I stumbled on the importance of the “legacy that is lived.”

The idea of “the legacy that one lives” did not readily resonate with patients. In fact, it was a bit unclear to most MCP therapists. I think we all understood that if you are to have a legacy to leave behind you have to live a life in which that legacy is created. That seemed to be an element of the legacy that one lives. Additionally, there were individuals so profoundly aware of the legacy that they were given that they lived this given legacy every day of their own lives. They are vibrant and shining living examples of the human spirit and their unique cultures: the fourth generation of physicians in a family dedicated to serving others through care and healing. Yet, these two aspects of a legacy that one lives didn't seem to be quite complete or distinct enough for me— until I worked with several patients who “had no one to leave a legacy to,” “no one to remember them,” no one who had been a witness to their lives who would survive them to remember them: no Philip Bialowitz, no Elie Wiesel.

What is clear is that we human beings need to have our lives witnessed. Viktor Frankl wrote, “The only thing worse than suffering is suffering that goes unwitnessed” (Frankl, 1955/1986). This need for our lives to be witnessed, I believe, is related to the concept of “significance.” The question of significance is an essential one. “Did it matter that I lived?” “Did I leave some mark in this world?” “Did I have some impact on this world or on someone?” Was there a “sign” that I was here? The idea of having a life witnessed relates to the question of whether someone else in this world noticed me and ultimately judged the value of my life. It is as if one were a playwright and wrote a script that only you performed but was never viewed by an audience or reviewed by a theater critic. Were you a playwright? Was the play a work of art? A work of great significance?

What I have come to believe is that the “legacy that one lives” refers to the life that is witnessed NOT primarily by others, but the life primarily witnessed by your “self.” We are never completely alone. Our observing “self” or ego is our constant companion—that constant voice, commentator, judge, critic, witness to our lives. In living a truly authentic life, the only judge or critic who really matters is us, our observing self. So as you live, you are creating your legacy through witnessing and striving toward a life of significance. The legacy you live does not require remembrance after death—it is a legacy lived unto death.

References

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