

Reflections: A Daughter's Experience of Parental Cancer and the Beginnings of

Un Abrazo Para La Familia

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Abstract

The author describes her impetus and journey in developing *Un Abrazo Para La Familia*[™] [Embracing the Family] (Abrazo), three hours of cancer information presented in an educational and modular format and designed for low-income informal caregivers who are co-survivors of cancer. A rehabilitation-informed preventive intervention, Abrazo reflects the importance of family, culture, and socioeconomic background in its approach.

Keywords: Cancer; Caregivers; Cancer Knowledge; Poverty; Self-efficacy; Vulnerable and Underserved Populations

INTRODUCTION

*Un Abrazo Para la Familia*TM (Abrazo) was developed as a face-to-face intervention to address the cancer knowledge and self-efficacy needs of low-income caregiving co-survivors of cancer [1], understanding co-survivors to be those affected by the cancer diagnosis of a loved one [2]. The term caregiver applies to family members and friends who provide a range of support services in caring for an individual with an acute or chronic illness [3]. Informal caregivers are predominately female [4] and experience stress at levels that can harm them physically and psychologically [5-7].

While the role of the family in cancer care and the stress associated with a cancer diagnosis has been extensively summarized and documented over the past two decades [6], consensus exists that we still need to better understand the cultural needs of and differences among caregivers [5]. Abrazo was developed with cultural context and other social determinates of health factors in mind [8]. Abrazo is a psychoeducational evidenced-based intervention that has demonstrated significant outcomes in cancer knowledge and self-efficacy [2, 9-11] for low-income caregiving co-survivors of cancer, as well as for survivors or care recipients [12].

A DAUGHTER'S EXPERIENCE: PARENTAL CANCER

Using autoethnography, I first reflected on the role of the family in cancer and within the context of culture and socioeconomic status—my motivation being my experience as a daughter of a man with prostate cancer [13]. My caregiving roles had included a) helping my father understand and make treatment options, b) seeking second opinions through a review of medical records and in-person assessment by a specialist, and c) driving him multiple times from our home in Georgia to treatments provided by specialists at the University of Virginia (956 miles round trip) and the University of South Florida (1148 miles round trip). As with too many other

low-income folks [8], my father had been diagnosed with a late-stage cancer and died two and half years afterward. I certainly felt that for all my efforts, my “caregiving” was too little, too late.

Subsequent to his death in 2000, and given my professional background in rehabilitation research, I applied for and was accepted to a one year fellowship program beginning in January 2002 with the Cancer, Culture and Literacy (CCL) Institute [14] at the H. Lee Moffitt Cancer Center and Research Institute. According to Meade, “the goal of the Institute was to improve care across the continuum of cancer control by enhancing the skills of researchers responsible for creating multicultural, multilingual, and literacy sensitive interventions and communications for a demographically changing population” (p.4)[14].

A Caregiving Experience and the Abrazo Model

I learned through the CCL Institute that when family members are called upon to participate in making treatment decisions, multiple factors may influence their ability to fully participate. Family members may find that they do not have the health literacy (i.e., cancer-related vocabulary and knowledge), problem-solving, or communication skills to most effectively support their relative, or to address the overarching family challenges that cancer can present. This was my case and may be particularly true of those of us from low-income backgrounds [8, 15]. Specifically, we struggle with:

1. Health literacy. Words we know may have different meanings in an oncology context—one example from my personal experience as my dad’s caregiver—I was told to expect a “bleeding event.” I truly had no idea what to expect—an ebola-type bleeding? We may not know how to pronounce words, even common terminology used in oncology—a barrier to asking questions for information or clarification. We

- may not know how to spell terminology related to cancer treatment so note-taking is a problem.
2. **Problem-solving.** Low-income people can be very proud people and not accept “handouts” or feel inclined to sit with a social worker to complete applications for free or reduced-price medicines. Working with siblings to determine “who pays” when a low-income parent has cancer can be difficult. Even if a family agrees that a second opinion may be warranted, again, the question of “who pays” can pose a problem—there are not only physician costs but potentially travel costs as well if a specialist is not available locally.
 3. **Communication skills.** As mentioned earlier, speaking in “oncology” can present a unique set of communication circumstances from pronunciation to spelling to comprehension of basic terms. And this is assuming the oncologist and the caregiver speak the same language. Apart from terminology, my experience was that communication was not always appropriate—from an oncologist asking my father in my presence about his sexual function to then suggesting a physical exam before I could scramble out of the room. What might be fine for a wife to hear or see might not be appropriate for a daughter who has accompanied her father to his oncology appointment. Communication may need to be improved not only from the family perspective but from the practitioner perspective as well. Indeed, the diagnosing urologist told me he had a great deal of difficulty giving a cancer diagnosis to his patients.
 4. **Overarching family challenges.** The challenges my family faced were many and, as I learned later, reflective of other low-income families—perhaps especially those

uninsured families whose first encounter with the medical establishment brings along a cancer diagnosis. A few of those challenges:

- a. My mother was a passive, fearful person and did not accompany my father to any of his medical, and later, oncology appointments—it was left to me, a daughter, and my two sisters to go with him.
- b. My sisters typically did not agree on a way forward with my father's treatment—this included whether or not to take him by ambulance to the hospital on the day he died. My older sister, a nurse, wanted my father to die at home—he did.
- c. Processing information about cancer, its causes and its possible treatments, were the ultimate challenge. My mother internalized the cancer prevention message that what you eat might cause cancer—she said once, “I prepared the food—everything he ate for 50 years.” My father searched the internet to find information about power lines causing prostate cancer—he had been convinced that the power lines crossing our property had caused his cancer. Whether or not to have chemotherapy in advance of radiation? Whether or not to have brachytherapy? Whether or not or how to pay for expensive medications? Shortly after my father was diagnosed with cancer he told me that the doctor only spent 10 minutes with him[13]. We needed more time than that.

After my father's death from prostate cancer, reflecting upon these factors were the impetus that led me, as a researcher, to ask if these experiences were indeed uniquely my own. Did others from low-income families experience the same stress and distress due to their lack of

preparedness when facing the cancer diagnosis of a loved one? I wanted to use my rehabilitation research skills, coupled with my personal experience as daughter of a man with prostate cancer, to understand if other low-income families experienced a cancer diagnosis as my family had.

I received, a NIH NCI-sponsored Ruth L. Kirschstein National Research Service Award (NRSA) for Individual Senior Fellowship during 2007-2009. The NRSA allowed me to obtain the data needed to develop a psychoeducational, skill-building, and tailored intervention designed to increase the quality of life, including well-being and productivity, of low-income female family members who were providing socioemotional and/or financial support to a cancer survivor relative who had either cervical or breast cancer—this intervention became *Abrazo* [2, 9-12]. By first researching the needs of local low-income families facing cancer, irrespective of stage, *Abrazo* was then developed to meet the specific needs of these family members who had reported that they (1) needed more information about cancer, (2) had trouble communicating with their provider and (3) needed information regarding resources available to them [1].

Having obtained my doctorate in rehabilitation at The University of Arizona (UA) in Tucson in 1985 [13], I returned to UA in 2007 via the NRSA to conduct the research leading to the development of *Abrazo*. I envisioned *Abrazo*, as a rehabilitation-informed intervention, as a platform for developing psychosocial oncology evidence-based interventions for families affected by cancer that would also serve as community outreach strategies for low-income and underserved populations [8]. “Over the years the philosophy of rehabilitation has remained focused on the belief that all people are unique and possess dignity and worth” (p.192) [16]. Rehabilitation philosophy embraces the importance of involving family when coping with a chronic illness and utilizing group methods for psychoeducational interventions [13].

Rehabilitation principles acknowledge the importance of education, skills-teaching, and strength-based psychosocial support as components of interventions [17].

BENEFIT THROUGH ABRAZO

While rehabilitation informed, Abrazo is conceptualized as a preventive intervention [2]. We use the term preventive intervention in line with literature that indicates that informational approaches can prevent the stress, and clinical depression and anxiety associated with the distress of a cancer diagnosis among families facing cancer [18]. The needs that Abrazo addresses include not only providing knowledge and basic understanding about cancer, but also skill development for use of supportive services, using tools needed to understand cancer stage, and skills to address site-specific issues with their oncology team.

Abrazo participants are typically informal family caregiving co-survivors of cancer who provide a range of services [3]. For instance, a caregiver might provide a loved one with support for bathing, eating, preparing meals, and grocery shopping. Further, as per my personal example, a caregiver may provide support by making and driving a loved one to appointments, paying bills, or keeping records.

In chronic illnesses such as cancer, family caregivers are often involved in shared decision-making regarding treatment. Recognition of this shared decision making requires strategies for upholding the autonomy of the patient while recognizing and respecting family input and contributions [19]. Given the two decades since the turmoil of my father's diagnosis from prostate cancer, and his subsequent death from the disease, it is my lasting hope that Abrazo can continue to benefit others, ensuring everyone's needs are being met in the family touched by cancer [20]. As stated earlier, Abrazo draws from a rehabilitation perspective, to include positive psychology [21, 22]. We leave pathology to the cancer and do not search for it

among the dynamics impacting family members facing a loved one with cancer.

CONCLUSION

In the 20 years since I began to process my father's death, three areas of overlapping clinical, educational, and research advances that inform the continued work of Abrazo: 1) Progress toward meeting the needs of low-income people within the context of high-cost cancer treatment, 2) Continued understanding of co-survivor impact on survivor wellbeing, and 3) The ubiquity of technology utilized by families and telemedicine.

The Affordable Care Act (ACA) arrived with the hope of preventive and wellness health care to all [23]. My personal hope became that a cancer diagnosis was then not the first encounter for a low-income family with a health care team. While ACA has now been in place for a decade, we still see that the intersection of race and ethnicity with income status requires focused attention to eliminate disparities [24]. Some would argue that the economic implications of cancer may well trump all other concerns [25]. Financial toxicity is now being discussed in regard to cancer treatment [26, 27].

We have understood that social support can impact survivor outcomes [28]. Researchers continue to look at the implications of social support, for instance, caregiver psychological states upon survivor outcomes—recently adding the dynamic of SES-related stress and finding that caregiver stress would indeed predict depression and anxiety in the survivor [29].

In 2006 we wrote of the promise of telemedicine to allow the underserved, especially those in rural and remote areas, access to health care advocates and to specialized medical knowledge [30]. Importantly, we also noted that telemedicine could be a conduit for providing cultural expertise in an intervention as well. Now, 14 years later, telemedicine is no longer a promise nor is the technology associated with it. In 2020 most folks have smartphones and are savvy, for instance, with FaceTime, WhatsApp, and Zoom. Families can connect readily through

technology. This was not the case in 1998 when my father was diagnosed with prostate cancer. We were concerned with the cost of long-distance calls. Seeing each other meant a flight.

Telehealth has become far more common than we might like during the time of COVID-19. Our comfort in using, and our need to use, the tools available to telemedicine will have forever changed the way we provide information, education, and support. The digitization of Abrazo is underway so that families may access the intervention online if face-to-face is not an option. Thus, whether Abrazo is delivered in person or via some form of telehealth, an embrace, a virtual hug for the low-income family facing cancer, continues to be relevant and needed.

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