

The Family has Cancer: An Interpretive Conflation of Identity, Memory and Ecology

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Abstract

There are more than six million cancer survivors over the age of 65 in the United States. There are many reasons why an increasing number of people are becoming long-term cancer survivors including new screening guidelines, access to genetic testing, early detection, advanced diagnostic tools, and most importantly new innovative treatments. According to the Institute of Medicine (IOM) Report, people diagnosed with the majority of types of cancer have an estimated 64% chance of surviving more than five years.

Even as science transforms a cancer diagnosis into a chronic disease, the diagnosis and treatment must move beyond the individual patient to the family in consideration of an expanded context in which they live. To help the family learn ways to live within their new reality calls upon the healthcare provider to understand not only the innovative treatments, but as importantly, the ways in which a family can live together with their memories and sense of identity set in a particular sociopolitical, cultural ecology. This exploration of the conflation of identity, memory and ecology of a family who has cancer is embedded in interpretive hermeneutics.

Keywords: *Hermeneutics; Health Providers; Family Care; Cancer; Sociopolitical and Cultural Ecology*

Introduction

How we choose to understand anyone's world reflects the choice of our research paradigms, which in the past have most often focused on objective, number-based systems, then qualitative procedures came into the research picture, and more recently, the interpretive, hermeneutic turn. This paper uses an interpretive stance drawing on an on-going case study of a family in which the mother has been diagnosed with leukemia. Three categories that form the boundaries of the larger case study also represent the selected emphases for this paper: identity, memory and ecology. The purpose of this paper is to outline some key principles that could be useful in designing a protocol for healthcare providers to use who work with families living with a member diagnosed with cancer. An introduction to identity from an interpretive stance, the place of memory in creating our present and future worlds, and the place of one's sociopolitical and cultural ecology in this study are presented as the guiding categories. A portrait of a family from El Salvador, whose wife and mother has leukemia, follows the discussion of the categories. Final considerations address possible directives for a protocol that could be used in working with families who have cancer.

The approach

An interpretive, or hermeneutic, approach to research allows the researcher to delve deeper into the worlds of the people under study. This approach calls for the researcher herself to be aware that it is her responsibility to fully realize that only through genuine conversation and trust among all can anything of value emerge from the inquiry. To establish trust takes commitment and time. The cat-

egories guiding this inquiry are actually obvious as reasons for choice. One's identity is critical to telling others about oneself overtime. Everyone has memories and upon reflection we see they are essential for us to make sense of our world, especially when there is a radical shift in our taken-for-granted everyday world. And, each of us can point out the context in which we live and how it affects our lives when shifts in our lives take place; moreover, our sociopolitical and cultural ecological space both informs and influences our identity and memory. Below is further elaboration on the selected categories.

Identity

The identity of anyone is best found out by the story they tell of themselves. Paul Ricoeur ([1]: p.121) provides important ideas about identity when he explains that each of us is made up of three kinds of identity: one is called *ipse* -the idea that there is a part of us that never changes. We can still recognize someone we have not seen for many years. Another part of our identity is called *idem*-that part of us that changes over time even though we are still the same throughout the changes. Both of these take on meaning when we realize that it is the narrative identity or story we tell of ourselves that is our complete identity. It is the narrative that provides coherence for the different aspects of one's identity. Each member of a family will have a different story to tell of him or herself as they experience major and minor shifts in their lives. Each person, for a meaningful life, will need to find coherence for him or herself in understanding their identity. Moreover, each family will need also to establish a familial coherence, which will enable them to move along with their lives in face of shifts and challenges. An individual has the cancer diagnosis, as does the family.

Memory

In Ricoeur's economy of ideas, our imagination and our understanding of events and actions shape and inform our memory. Memory can have a truthful relationship with the past or an untruthful relationship. When we remember, we recollect-it is a kind of knowledge. The relationship between memory and forgetting is an ongoing one mixed with mourning and hope. Forgetting can be one way to bear up under a memory that brings forth pain. Yet as Ricoeur reminds us ([2]: p.445) "...the trauma (of receiving a cancer diagnosis, for example) remains even though it is inaccessible, unavailable," but under certain situations, "entire sections of the reputedly forgotten past can return" (445). The working though of the past, whether it was long ago or in recent times, is a critical aspect of refiguring a possible, more encouraging and positive narrative. This requires imagination. As argued earlier, "Imagination is the wellspring of all human innovation. In order for something to be possible, it must first be imagined" ([3]: p.102). To provide help to both the patient and the family to imagine what their story could be is clearly a constructive step in moving from mourning to hope. The context in which all of these events and efforts are attempted are influenced and shaped by the sociopolitical and cultural ecology of the family. Our memory plays a critical role in how we preserve our identity and how we come to see ourselves in the environment in which we live-present and future.

Sociopolitical and cultural ecology

Interactions of a family and its environment play heavily in understanding the place a family has come from and the place they believe they currently live in. Taking into consideration the cultural and sociopolitical ecology of a family will portray many details that can effect how the family sees themselves, past and future. In looking at place as an environment, we see the importance of country, home, culture, history, society and politics. When any of these elements are radically or forcefully changed, such actions will affect and influence identity and memory of both individuals and families. Parallel changes take form in anguish, fear and hope for families depending on the family's sociopolitical and cultural ecology. Gessler and Kearns [4] established links among culture, place and health in their book with the same title. As researchers they argue, "seeing implies a vantage point, a social and literal place in which we position ourselves to observe and be part of the world" ([4]: p.36). In this paper, it is argued that the social and literal place of a family, or the place from where they come, is an important element in how they see themselves in their future, and how they view their prospects for good health and a good life. The conflation of identity, memory and ecology finds a prominent position in many families faced with particular challenges, particularly those compounded with health challenges. The family drawn from the larger case study referred to above is described below and highlights the relevance of ecology, or place, in consideration of a realistic understanding of how life is for one family who has cancer.

A family who has cancer

This family, for present purposes, is named the Rivera family. The Rivera family has a father, mother, a son, age 22, a first daughter, age 18 and a second daughter, age 10. They arrived to the United States from El Salvador eleven years ago (2009) without documents. The two oldest children are part of the Deferred Action for Childhood Arrivals (DACA) program while the youngest daughter was born in the U.S.

Their son will transfer in the fall of 2020 from a community college to a university to study computer engineering. The oldest daughter is in high school. The youngest daughter is in elementary school. The father works in the construction industry as does their son to help support his own education since neither the federal or state government provide any financial help. Students who are green card holders or are citizens receive considerable financial aid. DACA students receive virtually no aid. The mother works as a waitress. Due to the work restrictions imposed by the California governor in attempts to curb the Covid 19 virus, both the father and mother's work hours have been severely reduced. For some periods of time, there was no work for the father, the mother or the son. A year and a half ago, the mother was diagnosed with leukemia. She is under treatment at this time, but still goes into work when she is given some employment hours.

In 2009, the year the Rivera family made it into the U.S., there was a historic presidential election campaign with a leftist and right-wing candidate each promising a change for El Salvador. Poverty was entrenched, and the people of El Salvador were barely recuperating from a 13-year civil war. Even though the civil war ended 17 years previously to the departure of the Rivera family, violence, drugs and a weak economy made life almost as unbearable as it was during the civil war. Gangs and drug lords primarily controlled the country. Half of the population of El Salvador lived in poverty. About 1,200 families, who used to live in the capital city of San Salvador, but who could no longer pay rent, moved into the Gerardo Barrios squatter camp. Here they stood in line for hours early in the morning and later afternoon to fill their cans from one of the four water taps. They waited in lines for churches and other agencies to hand out blankets and food [5]. The Rivera family was one of the families who lived in this camp. Today, conditions in El Salvador remain extremely dire and dangerous for anyone trying to live there. As one can certainly understand, the Rivera family hopes to stay in the U.S.

The situation looks bleak for this family. They left a place that held no promise for them. They moved to a place that held hope for themselves and for their children. But they would question who they are since they are here without papers, and know that the identity they carried with them from their home land holds little relevance at this point. Their primary memories are of fear, anguish, and despair having had no way to make a living wage in El Salvador and the treatment for this family at this point is the specific treatment for the wife and mother. There is no treatment for the family. However, this entire family is living with cancer, a condition that is made even more difficult by their past and present sociopolitical and cultural ecology.

Considerations for a cancer family protocol

By protocol, I mean a general guideline for understanding and working with families who have cancer or any other life-threatening condition. There are no set actions, questions or answers in such a protocol. There are ideas and constructs to take into consideration when working with families. Ultimately and idealistically, such a family would not simply be identified as a "cancer family." Rather, a capable family, a family that sees justice in their lives, or a family who learns how to live with disruption and uses it to hone in on their ability remember the past, learn to forgive, figure out a new narrative that tells who they are and to see themselves as capable-unique, valuable, and contributing to each other and to their community. This entire scenario changes our ideas of disease as a deficit to a condition experienced by a capable person who knows who she is and values herself and her memories along with her family. The following points are offered as considerations in the development of such a protocol:

1. Identity, both personal and collective, is not static, but changes over time because of the two aspects of *idem* and *ipse*. We can more clearly understand the permanent aspect of our self as well as the innovative and temporal quality when we tell our story. This dynamic and temporal character of humans gives us the opportunity to reimagine our lives in light of the pres-

ent circumstances. All families are embedded in a culture, a set of norms and values, along with ideals and their own heroes through which we recognize who we are. When these elements in our lives change, story changes encompassing the changes in each of us. When a patient and her family understand what makes up a person, that is, their own identity, they come to recognize that one's identity is moored by integrity ([1]: p.122), which is tried and tested against new events in our lives as well as other people in our experiences. How one maintains his or her integrity, draws upon memories, which, in turn, relies on our imagination for refiguring our lives.

2. Our memories are always with us. It may be an abuse to simply try to forget the pain memories can bring. This effort often simply pushes the painful memories further from our awareness and our need to do something about them doesn't allow us to mourn. Our memories can have a truthful relationship with the past or an untruthful relationship. Abusing our memories, forgetting too much springs forth melancholia. Ricoeur provides insight into an important difference between mourning and melancholia by explaining that mourning is reconciliation with the loss of someone or something. What is preserved in mourning and lost in melancholy is self-esteem or the sense of one's self. This is the case because in melancholy there is despair and a longing to be reconciled with the loved object (one's health, one's country, one's ability to earn a living, one's freedom, a civil war, etc.), which is lost without the hope of reconciliation.
3. Reconciliation with a loss, whatever it may be, can be a difficult journey. At the heart of reconciliation is the act of forgiveness. Ricoeur ([6]: p.11) posits, "we can forgive only when there is no forgetting;" and "forgiveness requires enduring patience." We have to be prepared to receive a negative response. However, if the request for forgiveness is real, it does not matter whether the request is accepted or not. The act of requesting forgiveness shows self-esteem and it also shows we esteem others as we do our self. Forgiving others, as well as ourselves, liberates us from painful events and persons in our lives. Our imagination steps in and allows us to refigure our own narrative identity, allowing us to live in freedom from remembering abuses fostered upon us. This liberating act, a remembrance, refiguration and reconciliation with the past, is available to both individuals and families.
4. Our ecology can be influenced by a civil war or a pandemic, a disease or the loss of a job or a civic identity; each person has a story-a narrative identity that contains either forgiveness or unforgiveness towards the circumstances. This identity contains all the requisites for remembering and refiguring new worlds and possible ways of being, of forgiving others, and for identifying one's self-esteem in relationships to others. Although we cannot change the sociopolitical and cultural ecological boundaries in which we move, live, or escape, we can imagine ourselves in a different relationship to the boundaries. This imagination provides the bridge to move from melancholia to mourning to a liberating re-imagining and re-construction of our lives.

Conclusion

In summary, our identity, memory and environment are, for the most part, those very aspects of our lives that allow us to live fuller lives when we recognize how capable we are in liberating ourselves from restraints found in our health, our selves, history and present lives. There is no set questions and "right" answers that could become part of a protocol for work with individuals and family who are experiencing life's immense challenges, especially for those who through no fault of their own face injustice. Were a protocol developed using the capabilities each of us has, these constructs could provide the very conditions for an esteemed life. We do not yet know what research and technology will bring to the physical healing and prevention of cancer. But perhaps we know what can liberate all families with cancer from living a life bound by melancholia, despair and unforgiveness, those very elements that are far more constraining in our efforts to lead a full life than any physical diagnosis. The conflation of our identity, memory and ecology is the very essence of a human, which provides the means to live through and with life's challenges; those very conditions that provide the medium in which an individual and her family can appropriate a liberating life.

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