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Choosing to Thrive: An Autoethnographic Journey of Cancer, Companionship, and Carrots

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Abstract

In this autoethnography, I explore the companionship experience of someone supporting a cancer patient who is endeavoring to thrive in the face of this disease. A wide range of studies has been conducted on the emotional and social issues relating to cancer and specifically to breast cancer. Appropriately, most of the research relating to the personal narrative focuses on the stories of the person who has been diagnosed with cancer, and limited research has highlighted the perspective and experiences of their companions. My primary goals for this autoethnographic research are to: (1) Begin to answer the question: What role do we take when cancer becomes a reality and how do we provide helpful companionship? (2) Provide a template for personal narratives for companions, and (3) Share a path toward transformation for those that want to thrive. Autoethnography was selected as the qualitative inquiry method to gain meaning and understanding of the role of a companion to a person experiencing cancer. Most qualitative research methodologies are directed toward the study of others; however, in this case the primary focus of the research design is on self. This autoethnographic account of my experience as a companion to someone with cancer highlights the importance, both for you and the one you are supporting, of using your voice, owning your space, writing your story, and building a sense of community.

Keywords

cancer, companionship, thriving, autoethnography

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Choosing to Thrive: An Autoethnographic Journey of Cancer, Companionship, and Carrots

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In this autoethnography, I explore the companionship experience of someone supporting a cancer patient who is endeavoring to thrive in the face of this disease. A wide range of studies has been conducted on the emotional and social issues relating to cancer and specifically to breast cancer. Appropriately, most of the research relating to the personal narrative focuses on the stories of the person who has been diagnosed with cancer, and limited research has highlighted the perspective and experiences of their companions. My primary goals for this autoethnographic research are to: (1) Begin to answer the question: What role do we take when cancer becomes a reality and how do we provide helpful companionship? (2) Provide a template for personal narratives for companions, and (3) Share a path toward transformation for those that want to thrive. Autoethnography was selected as the qualitative inquiry method to gain meaning and understanding of the role of a companion to a person experiencing cancer. Most qualitative research methodologies are directed toward the study of others; however, in this case the primary focus of the research design is on self. This autoethnographic account of my experience as a companion to someone with cancer highlights the importance, both for you and the one you are supporting, of using your voice, owning your space, writing your story, and building a sense of community.

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Introduction/Literature Review

Life is fragile and each of us likely lives far closer to disruption than we imagine. The space between our comfortable existence and living in the margins (for whatever reason) may be far smaller than we know. The intended audience for this research is everyone who may face disruption, is facing disruption, or has faced disruption, whether that be from breast cancer or for any other reason. In line with Chang's (2008) observation that, "Doing, sharing, and reading autoethnography can also help transform researchers and readers (listeners) in the process" (p. 53), my hope is that this research will provide a story that may lead to reflection and transformation in the life of a reader, just as it has provided reflection and transformation to me, the researcher.

A wide range of studies has been conducted on the emotional and social issues relating to cancer and specifically to breast cancer. These studies have utilized several methodologies including case study (Denmon, 2013; Haas et al., 2016), phenomenology (Froude et al., 2017), linguistic inquiry (Smith et al., 2005), narrative inquiry (Martino & Freda, 2016; Martino et al., 2019), personal narrative (Sealy, 2012b), and autoethnography (Greenhalgh, 2017; Sealy, 2012a; Wessner, 2018). In some cases, the researcher has focused on their own experience relating to cancer, either as the person who has been diagnosed with cancer (Greenhalgh, 2017; Sealy, 2012a, 2012b) or from the perspective of a family member (Denmon, 2013; Wessner,

2018). In each of these studies, the research highlights the emotional and social issues, and in most cases, a desire of the patient and family member to take action, find meaning, and generate growth.

Appropriately, most of the research relating to the personal narrative focuses on the stories of the person who has been diagnosed with cancer and limited research has highlighted the perspective and experiences of their companions. Ellis points to some of the related issues of the companion when she says, “Through living and writing about my experiences, I learned directly about power dynamics and gender roles in relationships, and their potential reversal when one person is ill” (Bochner & Ellis, 2016, p. 28). A deeper understanding of the challenges of the companion is necessary to fill the gap in the research. My primary goals for this autoethnographic research are

1. Begin to answer the question: What role do we take when cancer becomes a reality and how do we provide helpful companionship?
2. Provide a template for personal narratives for companions.
3. Share a path toward transformation for those that want to thrive.

Methods

Autoethnography was selected as the qualitative inquiry method to gain meaning and understanding of the role of a companion to a person experiencing cancer. Most qualitative research methodologies are directed toward the study of others; however, in this case the primary focus of the research design is on self. Because of the iterative, reflexive, and self-representative aspects of autoethnography, this is a particularly appropriate methodology to implement in the current study.

Bochner and Ellis (2016) identify 1975 as the first time the word *autoethnography* was used. As the focus on self-reflection and self-representation in research gained momentum through the 1980s and 1990s, autoethnography began to find a place and fill a need in the research options, even though it experienced mixed acceptance in the research community.

Many definitions of autoethnography have been offered (Adams et al., 2015; Chang, 2008; Denzin, 2014; Ellis & Bochner, 2000; Reed-Danahay, 1997), and they all coalesce around the idea that an autoethnography is a self-narrative in a cultural context. Bochner and Ellis (2016) further explain that “Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural” (p. 65). Chang (2008) adds: “Autoethnography shares the storytelling feature with other genres of self-narrative but transcends mere narration of self to engage in cultural analysis and interpretation” (p. 43). Each of these elements can be found in the word *autoethnography* itself – *auto* refers to the self-narrative, *ethno* refers to the cultural-element, and *graphy* refers to analysis and interpretation. Ellis and Bochner (2000) point out that, “Autoethnographers vary in their emphasis on the research process (*graphy*), on culture (*ethnos*), and on self (*auto*)” (p. 740).

In this particular autoethnography, all elements are represented; however, the research presentation is weighted toward an emphasis on the *auto* in the story itself. In addition to this approach to categorization, there are other frameworks and approaches to segmentation of autoethnographic studies. For example, Denzin (2014) describes an epiphany as “interactional moments and experiences which leave marks on people’s lives” (p. 52). Denzin further segments epiphanies into four categories: major events, representational events, minor epiphanies, and reliving. This situation that is the focus of this study could be considered a major epiphany. Another example of segmentation is Chang’s (2008) typologies of autoethnographic writings: descriptive-realistic writing, confessional-emotive writing,

analytical interpretive writing, and imaginative-creative writing. Within this framework, the presentation of this study aligns with the confessional-emotive approach. Additionally, evocative autoethnography is sometimes considered to be a category, whereas Bochner and Ellis (2016) describe all autoethnographies as evocative.

Often due to the evocative nature of this type of research, a significant challenge of developing an autoethnography is that it is vulnerable writing (Bochner & Ellis, 2016, p. 80). In fact, Adams et al. (2015, p. 39) identify vulnerability as a goal of an autoethnography. In this vulnerability, it is important for the writer to reflect on where to set the boundaries on what to share and how vulnerable they are willing to be. The simple fact of reflecting on one's thoughts and feelings and committing them to paper can be scary. Additionally, sharing with an unknown reader is both easier and far more difficult than sharing with a friend who is sitting there in the present. And yet, it is in this vulnerability that we are able to share and make a connection with story (Bochner & Ellis, 2016, p. 247).

Participants

The primary participant of the study is oneself. The focus of the research design was to highlight the voice and reflection in an iterative manner and utilize the insider knowledge available in the study of oneself in the context of one's own culture (Adams et al., 2015). However, it is fully recognized that the research of self does not happen in a vacuum – "Autoethnographers research themselves in relation to others" (Boylorn & Orbe, 2014, p. 17). Denzin (2014) adds that autoethnographies are presented "with an 'other' in mind" (p. 7) and Chang (2008) describes the "self" as "part of the cultural community" (p. 26). Based on this highlighted relationship between the self and the other, there is a related relational ethic (Adams et al., 2015) that should be applied in the development of the research.

In addition to the self and the other, the reader is also recognized as a participant and stakeholder in this narrative research through the nature of a story. Denzin (2014) explains:

A story that is told is never the same story that is heard. Each teller speaks from a biographical position that is unique and, in a sense, unshareable. Each hearer of a story hears from a similarly unshareable position. But these two versions of the story merge and run together into a collective, group version of the story that was told. (p. 55)

The potential for transformation through the shared story and through the entire research process extends to all the stakeholders (those who affect and are affected by the experience) of the research. In fact, it is the overt hope of this researcher that this shared story may lead to transformation in the self, the other, the reader, and any other stakeholder.

Data Collection

Most research involves the researcher speaking for others, whereas autoethnography involves the researcher using their own voice. Adams et al. (2015) propose that this leads to a "crisis of representation" (p. 22). In accordance with Chang's (2008) statement that data collection for an autoethnography involves self-reflection and self-observation, both methods were included in this research. The data collection included the use of external artifacts (appointment notices, etc.), note taking, personal conversation, and self-reflection. For example, I performed a review of emails from the medical facilities, friends, the adoption agency, and others to establish or confirm timelines as well as to trigger thoughts and emotions. This was an iterative process that occurred before, during, and after the development of the

story. These efforts were part of what Bochner and Ellis refer to as “(1) memory work and (2) story-making work” (p. 252).

Data Analysis

In an effort to make sense of the data using the autoethnography method, the researcher used analysis and interpretation (Chang, 2008; Creswell, 1998). The iterative nature of autoethnographic research also allows the researcher to both reflect by writing and use the writings for reflection, or, as Ellis (2004) phrases it, “thinking with a story and thinking about a story” (p. 197). Indeed, one of the many powerful aspects of a story is that it can be theoretical and analytical (Ellis, 2004). To be clear, development of the story in autoethnographic research is not an end in itself. “What makes autoethnography ethnographic is its intent of gaining a cultural understanding” (Chang, 2008, p. 125). Throughout this research, the iterative aspect was implemented as the data was analyzed and interpreted and as the story was written and used for further reflection.

Rigor and Trustworthiness

Although there is a tension between social science and interpretive inquiry of autoethnography (Bochner & Ellis, 2016), there are established criteria for evaluating autoethnographies and self-narratives (Adams et al., 2015; Bochner, 2000, Clough, 2000; Ellis, 2000; Richardson, 2000; Roberts, 2002). General criteria of reliability and validity (Denzin, 2014), factuality (Bochner & Ellis, 2016), ethicality (Roberts, 2002), and a standard of fairness for all stakeholders (Ellis, 2004) are appropriate evaluative marks. Additionally, in alignment with the criteria presented by Bochner (2000), Richardson (2000) identifies five key criteria: substantive contribution, aesthetic merit, reflexivity, impact, and lived experience. Similarly, Adams et al. (2015) identifies the following criteria:

- Making contributions to knowledge
- Valuing the personal and experiential
- Demonstrating the power, craft, and responsibilities of stories and storytelling
- Taking a relationally responsible approach to research practice and representation. (p. 102)

In addition to reviewing these criteria before and after the story was developed, I also shared the story with my wife for feedback. Additionally, the autoethnographic story was originally presented at the TQR 2019 Conference (Lilyea, 2019) where additional feedback was received, and the research presentation was validated based on the factors listed above.

The next section presents the story that is a central part of the autoethnographic research and includes actual segments of conversation that are interspersed into the narrative. This story is a result of the iterative process of analysis and interpretation, and hopefully the reader will find that this research presentation aligns with the evaluative criteria listed above.

Results

Vulnerability is often an overlooked, but significant, aspect of an autoethnography. For 3 years after writing this story and originally sharing some of this as a conference presentation, I have looked for the courage to submit my story in the form of a journal article. I have continued to work through the sense-making iterations that are part of any highly personal story, realizing that the story is not just evocative for the reader, but also evocative for the

storyteller. I have finally made peace with the essential elements and now offer the following account of my experience as a companion to someone with cancer with you, the reader. In the middle of the initial whirlwind of this crisis, I remember thinking: “This would make a great autoethnography!” and then the thought was quickly dismissed as too overwhelming. However, the qualitative researcher within me eventually emerged and six months later I penned the following words:

We were heading back to China! This would be our third international adoption. We committed to the special needs program, but not a big issue because everyone in our family has special needs and no one greater than mine. In reality, we all have special needs, don’t we? Paperwork – so much paperwork – followed by fees, fees, and more fees. But we were headed back to China and that picture of our gorgeous little soon-to-be daughter! All four of us were planning to travel – it was the first time either one of our two daughters would return to the country where they were born. A wide variety of emotions, curiosity, and a whole lot of feelings, mostly positive, filled all of us. All the interviews, the physicals, the paperwork, and nearly everything else in the process was done, we were just waiting to get our travel plans and in just over a month we would be on a plane.

I remember that my wife had mentioned a follow up doctor’s appointment, but in all of the demands of life I hadn’t thought any more about it than if she had mentioned going to the dentist, until she called, and life stopped.

“The test results came back.”

“It’s cancer.”

“Yes.”

“No, I’ll get them Monday, but it doesn’t matter.”

“Oh.”

“Are they sure?”

“Did they give you any details?”

I knew what she meant. The adoption was done – it wouldn’t happen. We had just celebrated our 25th wedding anniversary; she was my college sweetheart, and my best friend for over 30 years. Now I was facing the loss of a daughter that I had never met and the possible loss of my spouse that I had known for most of my life. Emotions seemed to disappear, and I could barely breathe. I didn’t know how to react or what to do. The Serenity prayer that had hung in my grandmother’s kitchen and I had always thought of as pithy now became almost a mantra for the next few weeks – “God, grant me the serenity to accept the things that I cannot change, the courage to change the things that I can, and the wisdom to know the difference.” I couldn’t change the adoption, but I could care for my wife and daughters.

Meanwhile, there were the comments – “I’m praying for you, “you’ll be in our thoughts and prayers,” and other similar comments. I remember thinking, “What? You pray? When did that happen? That seems so out of character!” Or other comments like, “Be strong,” and other show-no-pain encouragements. Not showing weakness didn’t seem to be the best tactic right now and my mind was filled with thoughts like, “Did I take a class that covered death and dying? I don’t remember. I probably should have paid more attention. I don’t know what to do right now.” I have never paid attention to cancer, never really had a reason to. I had heard the term and knew people that had cancer – some recovered, and some didn’t. I had heard about different stages and knew that stage 4 was really bad, and smaller numbers weren’t quite as bad, but cancer was never good. Now here we were, with my wife in the prime of life with

stage 2 cancer - or was it stage 3? I heard both numbers and when I asked for clarification, I got so much additional information that I was overwhelmed. I remember hearing about gram-positive, H-something-or-other, and the words “very fast-growing”. My wife seemed to understand the details, so I followed her lead. We plodded forward in a haze and were handed a process. The waterfall of doctors’ appointments, tests, donated pillows, more appointments, shared meals, and eventually, to the first chemo session, that all just continued forward in a well-choreographed, one-size-fits-all way that we just followed...until we didn’t.

We were told that after the first chemo session, she would be tired for a few days and most people scheduled it on a Thursday so they could go back to work on the following Monday. That may be normal, but that wasn’t our reality. When she later described the aftermath of the first chemo session, she said that she “felt nonhuman for three weeks.” With her sitting in a living room chair for nearly twenty-four hours a day surrounded by pillows, hushed tones, low lights, stacks of medicine bottles, and funny smells, our daughter bluntly, but accurately said, “It was like having your great-grandmother move in.”

The second chemo session was pushed back until her body could recover and I was left trying to understand what was happening. Friends came to sit with her during the day and our kids helped out around the house where they could, but mostly, I took on a massive additional workload and added exhaustion to my confusion. The sleepless nights spent wondering about a future without my wife didn’t help and as I tried to understand this foreign new world. I discovered how many others had skipped chemo, quit chemo early, or were turned into shells of themselves and just tried to survive. My wife had always been a strong, resilient woman with an easy laugh, but the person that I was now caring for hardly resembled that woman that I had spent most of my life with. I rarely push back and overtly challenge her, but I am goal-oriented and I wanted a solution. When she started the conversation, I decided I wasn’t going to let it go. Whether it was an off-handed comment or was actually meant to be the start of a conversation, I’m still not sure; however, it became another pivotal moment for me.

“I’m not doing it anymore.”

“What does that mean?”

“I’m done with chemo.”

“Wait. What?”

“I’m done with chemo.”

There was no emotion, just a factual statement from her. My head was spinning...this isn’t us...we don’t just give up.

[Nothing]

“Please tell me you’re not giving up!”

“I’m not giving up. I don’t want to just survive. I want to thrive. I’m done with chemo.”

“I need you to tell me you’re not giving up!”

These are not new concepts. These are my concepts – “use your voice,” “own your space,” “write your own story,” “thrive” – all parts of my personal ethos that I have shared with her many times. Now they are being handed back to me with a firm resolve. I’m confused. I

mean, you can't just walk away from chemo. Can you? She explains that she's been reading and wants to explore a holistic approach. I asked for specifics, and she didn't have the details. Not convinced at all, scared for her, for our children, and for myself, and not knowing what else to say, I asked for her to develop a plan. In a few days, after meeting with a medical doctor who specialized in alternate cancer treatments she came back with a plan – vitamin C IV infusions, massive amounts of carrot juice, 100% vegetables, mostly raw. This was yogi-in-the-desert stuff, not real medicine, and certainly not a space that I was comfortable with. It was fine for other people, but was this really how we were going to deal with cancer? Yet, I found myself saying, "If you are going to do this, I need to know that you are going to be all in, full commitment. I am not going to hound you but I need you to keep me in the loop so I can know what is going on with your health." As we talked through what it looks like to thrive, we also developed a plan for us and agreed that as her strength came back, she would focus on the kids first and then get back to her online kids, where she teaches them to speak English. We agreed that we could find someone to take care of everything else (and yes, I realized that much of this would be me). Then, when she was able, she could take those things back over. Most importantly, this meant that she would write her own story and I would need to figure out my role as a companion.

Through this time, I began to appreciate the vital role of community – some people encouraged, some challenged, but a strong community surrounded us. I had always viewed Facebook as a waste of time, but her network of friends were significant and wonderful resources for everything from headscarves to where to find sunflower seed butter and many, many other details we didn't even know to ask, as well as overwhelming support and encouragement. In fact, if it weren't for her headscarves, no one would have known that she was dealing with cancer after the initial effects of chemo faded. In another interaction, a blunt and caring friend, who is a medical doctor, pulled me aside and told me that he had never seen a case where someone with my wife's type of cancer chose a holistic approach and had survived. I responded that my role was to support her, but the magnitude of this decision started to set in. Although my wife continued to carry herself with amazing poise and her quick and pleasant smile returned, this was not an easy time for me. In addition to taking on cleaning, laundry, dishwashing, and other household chores, I was also attempting to feed my family and helping to provide general care for my wife and children.

One thing I started doing (and am still doing) is juicing carrots. Every other night, no matter the time or how I feel, I wash and prep the carrots, get out the juicer, juice the carrots, and then clean up the mess. Initially, it was one more activity in the whirling confusion of care that was largely fueled by fear and adrenaline. But somehow, in the middle of this time, juicing carrots became cathartic. Early in the process, I remember that there were times when tears were pouring down my face so much that I needed to take a break so they wouldn't fall into the juice. The pain of the failed adoption, the confusion, and the fear of losing my wife was nearly overwhelming. As my wife began to regain her strength and resume her activities, I threw myself into a large home renovation project. The added physical demands did nothing to help my exhaustion but did help to numb my emotions. But the carrots were still there, they still needed to be juiced, and I plodded forward because that's what you do. At some point as I continued the regular process with carrots, I realized that my wife was thriving and my consistency in juicing carrots for her was representational of all of my efforts to be the companion that she needed.

Please understand that throughout this narrative, I am not suggesting that anyone should avoid chemotherapy (although I suspect my wife may feel differently) and I am not advocating for a holistic approach to cancer treatment; I am merely attempting to share my lessons in companionship throughout her illness. Six months into the process, the oncologist was recommending a double mastectomy, and my now emboldened wife continued to write her

story and insisted on additional testing. When the results showed that her cancer was reduced to a speck, the recommendation changed to an outpatient lumpectomy. For now, she is waiting on the surgery and continuing her holistic treatments. My feelings are still mixed: I still want her file to be marked cancer-free, but for now she still has cancer, I am getting better in my role as a companion, and I am still juicing carrots.

Discussion

As I have reflected on my own story and compared it to the research findings of the literature, I have found many similarities. The research by Froude et al. (2017), Martino et al. (2019), Wessner (2018) all point to the essentiality of having a voice, and Denmon (2013), Greenhalgh (2017), and Seely (2012a) all illustrated the importance of writing your own story – both integral elements of this autoethnography. However, as Haas et al. (2016) highlighted, this was not an individual experience and community was important – which includes the importance of both community support and community boundaries. The observation from Smith et al. (2005) about the importance of owning your space and of the benefits of the effects of journaling aligns with my activity and reflection that occurred while juicing carrots.

Through this experience, I both witnessed and learned the importance of being willing to be agile and reflexive with relationship roles and dynamics (Adams et al., 2015, p. 29). Similarly, the concepts of growth and renewal, which were highlighted by Martino and Freda (2016) and Sealy (2012b), were part of my personal narrative as both my wife and I learned to thrive, even in the middle of the cancer experience. I have worked to make sense of my world where cancer became a reality and to understand how to provide helpful companionship in that space. This aligns with the emphasis that many researchers have put on sense-making (Boylorn & Orbe, 2014, Denzin, 2014, Weick, 1995) and especially the way that Adams et al., (2015) highlight that “autoethnographers provide a perspective that others can use to make sense of similar experiences” (p. 27).

One element of my story that was not overtly seen in the literature was the tension between my emotional pain related to my wife’s cancer and other emotional pain that may or may not be directly part of the same experience – in my case, I am specifically referring to the emotional pain related to loss of a child. Additionally, another element that did not appear to be directly addressed in the literature was how to simultaneously feel emotional pain and thrive during the cancer experience. I believe that further research is needed on what it means to thrive in all situations and what it means to thrive while being a companion to someone that is experiencing a significant illness.

Navigating boundaries relating to vulnerability and choosing to push past them (but not too far) was more challenging than I anticipated. For example, I alluded to my pain related to the loss of the adoption but didn’t fully explore that aspect in the presented story. There was, and still is, tension between the emotional pains relating to my wife’s cancer that was recognized by others and the unacknowledged emotional pains relating to the child that will never join our family. Additionally, I continue to pursue a deeper understanding of what it means to thrive in every situation, and my path of discovery continues. These concepts that I was passionate about – using your voice, owning your space, writing your story, and building a sense of community – all took on fuller meaning as I experienced and reflected on this situation throughout the research process.

From one perspective, the findings represent my story and have limited generalizability by themselves. However, many of the themes that emerge from this autoethnography may well resonate with others and prompt reflexivity and additional stories of transformations. This autoethnography is a tile in the larger mosaic and a story in the overarching meta-narrative. At

some point when enough similar stories are written that can be braided into a meta-narrative, the results will have a greater sense of generalizability and even greater impact.

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