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The Heroes' Journey: A Young Couple's Experience with Choriocarcinoma

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Abstract

A 20 year retrospective qualitative case study was conducted to investigate the relational impact of choriocarcinoma (a type of gestational cancer) on a couple of child-bearing age. A unique feature to the study was that the primary investigator was the couple's biological son, initiating the first known auto-case study design. Using holistic content analysis, investigators learned that anticipatory grief played a central part in the couple's ultimate detachment and divorce. While the wife began to refocus her emotional energies on her children, in psychological preparation for her possible death, the husband focused on ways to keep the family finances together in preparation for life after cancer. He perceived her emotional detachment from him as abandonment. In spite of taking separate paths, the two perceived one another as heroes. The conceptual and clinical implications for a young couple battling gestational cancer are discussed.

Keywords

Choriocarcinoma, Couple, Cancer, Case study, Holistic Content Analysis, Gestational

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The Heroes' Journey: A Young Couple's Experience with Choriocarcinoma

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A 20 year retrospective qualitative case study was conducted to investigate the relational impact of choriocarcinoma (a type of gestational cancer) on a couple of child-bearing age. A unique feature to the study was that the primary investigator was the couple's biological son, initiating the first known auto-case study design. Using holistic content analysis, investigators learned that anticipatory grief played a central part in the couple's ultimate detachment and divorce. While the wife began to refocus her emotional energies on her children, in psychological preparation for her possible death, the husband focused on ways to keep the family finances together in preparation for life after cancer. He perceived her emotional detachment from him as abandonment. In spite of taking separate paths, the two perceived one another as heroes. The conceptual and clinical implications for a young couple battling gestational cancer are discussed. Key Words: Choriocarcinoma, Couple, Cancer, Case study, Holistic Content Analysis, and Gestational

Introduction

Shifts in self perception and social posturing begin the moment a cancer diagnosis is made (Lindholm, Rehnsfeld, Arman, & Hamrin, 2002). Much of the stress associated with the psychosocial and somatic challenges of a cancer diagnosis can either be alleviated or exacerbated by perceptions of spousal and familial understanding and support (Lewis & Deal, 1995). However, no amount of societal or familial support can compensate for lackluster support from a patient's significant other (Giese-Davis, Hemanson, Koopman, Weibel, & Spiegel, 2000; Walsh, Manuel, & Avis, 2005).

In fact, couples who reported higher levels of marital satisfaction prior to a cancer diagnosis exhibited better adjustment post-diagnosis (Fang, Manne, & Pape, 2001). The mediating factor in terms of this adjustment seems to be the patient's ability to express their own fears and concerns pertaining to the disease and death (Lindholm et al., 2002). Manne, Ostroff, Sherman, Heyman, Ross, and Fox (2004b) noted that another component of adjustment is the ability for a patient to maintain some assemblance of normalcy in the face of such a life-changing event. If a partner exhibits mental distress in dealing with the diagnosis, a patient's ability to adjust in a beneficial way has been found to be hindered, as well (Sergin, Badger, Sieger, Paula, & Lopez, 2006). For example, in 2005, Walsh et al. found that 12% out of 117 participating couples separated after a breast cancer diagnosis. The patient had initiated the breakup in half of those separations. Patients who had initiated the dissolution felt that they were not receiving emotional support from their partner, and that the diagnosis had brought to light their partner's unsupportive nature. This study lends credence to the idea that perceived support is also

a core component of a patient's adjustment to a cancer diagnosis. However, support received and given by couples may look different at points in time across the lifecycle (Lynch, 1998).

The majority of researchers who have focused on cancer and married women employed samples whose collective age ranges were 29-80 years ($M = 54.5$; e.g., Fang et al., 2001; Giese-Davis et al., 2000; Kuijer, Buunk, Ybema, & Woods, 2002; Lindholm et al., 2002; Manne et al., 2004b; Manne Ostroff, Rini, Fox, Goldstein, & Grana, 2004b). Studies on young couples (one or both partners under age 35) are minimal. Issues for young couples often involve the relative newness and fragility of their relationship, presence of fewer resources and social supports, as well as, limited abilities of their young children to help aid in the ill parent's care (Fitch, Bunston, & Elliot, 1999; Helseth & Ulsaet, 2005). Connell, Patterson, and Newman (2006) and Guinee, Olsson, Moller, Hess, Taylor, Fahey, et al. (1994) found that the majority of couples under age 35 who are parenting young children still think about future pregnancies. While many of the concerns and issues across predominately female cancers (i.e., breast cancer) may parallel those faced by couples of any age; a greater look into young couples' experiences with gynecological cancers is a distinct and understudied area of research.

Researchers have provided a general understanding of issues surrounding communication, marital satisfaction, reciprocal dyadic interactions, parenting, etc. (Giese-Davis et al., 2000; Helseth & Ulsaet, 2005; Kuijer et al., 2002; Manne et al., 2004a, 2004b; Swenson & Fuller, 1992); however, while quite expansive, their research still lacks in description both the depth and complexity of a couple's experience with cancers, gynecological cancers in particular. Existing research can be expanded on and enhanced by the utilization of qualitative research methodologies with attentiveness to detail and breadth of datum (Yin, 1989). The current study was designed to contribute to the knowledge base of how one type of gynecological and gestational cancer, choriocarcinoma, influences one couple's interactions, elucidating how both medical and mental health care providers can intervene to expand the unit of care from the patient to the couple dyad. Another unique component to this design is that the primary investigator is also the biological son of the participating couple. This contemporary approach to research opens up a discussion about auto-case studies and the benefits and limitations of such a design.

Gestational Trophoblastic Cancer

In 2007, more than 78,000 women in the United States were diagnosed with some type of gynecological cancer and of those, 35% were expected to die from the malignancy, co-morbidities, or complications arising from the treatment process (American Cancer Society, 2007). The National Cancer Institute (2004) documented diagnoses given as early as age ten and continuing past age 85.

Gestational Trophoblastic Cancer (GTC) is a sub-type of gynecological malignancy, and the parent group, to which the cancer being studied here, choriocarcinoma, belongs. Once thought to be fatal, advances in both detection and treatment have made GTCs one of the most treatable and responsive of all gynecological malignancies (Hancock, Newlands, & Berkowitz, 1997). Accounting for less than 1% of

all gynecological cancers, a woman developing a GTC during pregnancy is rare (See, Freedman, Kudelka, Kavanaugh, 2006).

Choriocarcinoma. Choriocarcinomas occur in one out of every 20,000 pregnancies (See et al., 2006). While more than 50% of choriocarcinomas develop from complete molar pregnancies, the likelihood of developing this type of cancer after a full term pregnancy is one in 120,000. Although uncommon, choriocarcinomas preceding live births are known to be extremely aggressive, which creates an issue diagnosing and treating the tumor prior to metastasis to the vagina, lungs, brain, or liver (Hancock et al., 1997; See et al.).

The preferred modality of treatment for choriocarcinomas is chemotherapy. Patients who exhibit resistance to normative chemotherapy trials are recommended for surgical extraction of the cancerous chemotherapy-resistant tissue (Hancock et al., 1997; See et al., 2006). While the etiology, somatic issues, and treatment of the disease is known, little may be found on how to prepare women and their support systems for the psychosocial changes and experiences following diagnosis. Issues surrounding communication about the disease, as well as, fears pertaining to death; are often concerns at the forefront of most individuals' minds when they or their spouses are faced with a diagnosis of cancer (e.g., Chapman & Pepler, 1998; Giese-Davis et al., 2000; Lindholm et al., 2002; Swenson & Fuller, 1992).

Background of Investigator

The period of my mother's experience with cancer has always been a time of great angst and emotional turmoil. Even though the event transpired when I was four years old, the reverberations of such an experience carry on even to this day. As an adult, I am able to recall things from my early childhood, even events that I experienced at the age of two years that can still be recalled with complete clarity. However, the entire period of my mother's dealings with cancer, a nine month ordeal, can be summed up with one memory: Me sitting on the orange shag carpet stairs of our old home with my father just walking in the door. I looked at my father and asked, "When is mommy coming home," to which he replied, "I do not know if she ever is son." That one sentence has stuck with me from then to now, and held many differing implications for both my father and myself at that particular time. Although the questions posed within this study have always been in my mind, they have continuously eluded me to a degree throughout both my childhood and adolescence. It was not until I became older that I was able to articulate clearly the questions that gave birth to this present research endeavor. How did this one event impact my parents? Did it drive them closer together or was it the catalyst for their decision to part? This study strikes at the heart of very personal and sought after childhood questions; however, in answering those questions for myself, and quite possibly for my parents, the answers found may very well speak to larger and more encompassing relational issues regarding a cancer diagnosis. As a researcher it is my aim that this study will shed light not only on my understanding of my parents' experience with cancer, but will construct an understanding found useful by other young couples facing potential fatal diagnoses. However, as a son, it is my hope that I am able to

present an objective, to as much of a degree as one can, account of the event, and still be able to honor the familial relationships I have held so dear my entire life.

Method

Mode of Qualitative Inquiry

Individuals are storytellers by nature, and it is this inherent skill that allows some experiences to be recalled with lucidity while allowing others to fall into incertitude (Lieblich, Tuval-Mashiach, & Zilber, 1998). It is along with this “selective” recall that this narrative inclination facilitates the collection of large quantities of datum by the investigator, providing for both the breadth and depth of information needed during the data collection process (Lieblich et al.; Yin, 1989). A case study design allows for an in depth, exhaustive description of the event itself and the rich experiences of the individuals engrossed in it (Yin). Qualitative methods emphasize the notion of “voice,” or the experience of those immersed within an event, even if the subject experiencing the event and the researcher are one and the same. Methodologies such as autoethnography and narrative inquiry utilize the experiences of the researcher as the subject under study (Ellis, 2004; Riessman, 1993). To date, no known studies have been done utilizing the auto- case study design where the child of the case study participant(s) is helping the data to emerge using his or her relational rapport to create a safe structure for openness to occur.

This study followed Yin’s (1989) philosophical groundwork on case study design, Merriam’s (1988, 1998) methodological perspective, and McCaslin and Scott’s (2003) discourse on question construction and interview typology. The data was analyzed using Lieblich et al.’s (1998) specifications for holistic-content analysis. The purpose of this rigorous methodology was to take a retrospective look at one young couple’s experience with choriocarcinoma and to address the following research question, “What are the couple and parenting dynamics found among a married dyad who experienced a diagnosis of choriocarcinoma?” The method of qualitative inquiry was chosen in order to adequately capture the entirety of the experience, which was thought to emerge through the emphasis on depth and complexity inherent in a case study design (Yin). Lieblich et al.’s holistic content analysis was the preferred analytic strategy since it emphasized the viewing of the narrative as whole with intertwined themes. This was analytical method was best thought to align with the ideology of a case study in that it promotes understanding of “parts” of the story only in relationship to the whole of the narrative.

Since the primary investigator is the biological son of the participants, his role within the study was carefully monitored according to qualitative verification techniques (discussed later) that are designed to increase trustworthiness (Lincoln & Guba, 1985) of the findings. This study received Institutional Review Board approval prior to participant recruitment and the obtainment of informed consent.

Participants

My mother emigrated from Italy in 1956 with her parents, older sister, and younger brother. My father grew up a United States citizen from an intact home with one older sister and younger brother. Both obtained college educations from a local university where they met and dated for two years. They married in the summer of 1981. I was born in the fall of 1982, with my sister following in the spring of 1986. My mother was diagnosed with choriocarcinoma eight weeks after my sister's birth, resulting in six months of chemotherapy and a full hysterectomy. Thankfully, her cancer went into complete and sustained remission. In 1995, my parents began divorce proceedings. It was finalized in the spring of 1997. This study took place in the fall of 2007, 20 years after being diagnosed with choriocarcinoma and 11 years after their divorce. Recruitment for the study came in the form of a conversation in person with my mother, and over the phone with my father since he lives out of state. The conversation itself surrounded the presentation of the idea of the study, the perceived benefit of conducting the study, explanation of the process of data collection, confidentiality, as well as, answering any questions either had regarding any of the aforementioned topics.

Role of Investigators

Prior to collecting data, and to help reduce the influence of known biases, my triangulated investigator and I recorded bias statements holding us accountable to interpretations grounded in data. These statements included our prior experiences with choriocarcinoma and any anticipated findings. The greatest bias I held was that I am the participants' son, and thus, had a much larger context to draw from in terms of data analysis. This relationship put me at an increased risk of making analytic assumptions based on my own experiences. Since my parents' marriage ended in divorce 10 years after the cancer went into remission, I had to make sure the interviews were research driven and not driven by my curiosity. My triangulated investigator's experience with chronic illness was also a source of potential bias that too could have influenced his analysis of the data.

Investigator #1: Bias Statement

With this being the case, it is enough for me to acknowledge some degree of personal bias. It also becomes important at this juncture to touch on some of my research expectations that influence my bias as well. The relative youth of both my parents, coupled with the stress of having to care for two young children, in my mind, can only serve as exacerbations to the stress inherent in the experience of a chronic illness. The ideology that the psychological detachment generated and fostered by the anticipatory grief process only continued after my mother's cancer's remission, which continued to shift focus away from the "couple" to the "family," is also a thematic result that I may uncover as well.

Investigator #2: Bias Statement

Despite the lack of immediate exposure to a crippling disease such as cancer, I have found myself reminded of profound experiences that my own mother has gone through suffering a chronic illness. I recall when I was a young adolescent considering the possibility of being raised by just my dad if my mom happened to pass away. Through this and other similar experiences, I wanted desperately to find a way to ameliorate my mother's situation. This study delves into the recesses of my past experiences with my family and what it was like for my family to cope with my mother's situation. From this, there is a potential to blur the situation of my family with the situation of the principal investigator's family.

Procedures

Written interview. Data collection began with the triangulated investigator sending packets to each participant, which included a letter stating the study's purpose, the informed consent, a form containing directions for the written narrative, the questions directing the written narrative, and a pre-paid return envelope. After they read and filled out the informed consent, and recorded their narrative accounts, the packets were mailed back to the triangulated investigator. These written accounts were thought of as a way of obtaining the most "direct" answers to the questions posed. Since the participants would be answering these questions alone and in the place of their choosing, any perceived pressure to respond in a certain way due to the interaction with the researcher or tone of the conversation in context, was thought to be minimized. Neither my triangulated investigator nor I read these written accounts until after all face-to-face interviews were conducted to minimize bias. There were opportunities later in the analysis to member check the data and clarify inconsistencies.

Face-to-face interviews. Face to face interviews were conducted with each parent separately. These interviews were conducted in order to having a "living" account of their experience as they remembered it, and later juxtapose that experience with their written account to obtain a more holistic and complete picture noting both similarities and differences. The initial plan was to interview them conjointly about their individually recorded experiences. However, the thought of being interviewed together proved to be too emotionally difficult for both of them, even 20 years after the diagnosis. Instead of a final conjoint interview, my parents agreed to read and reflect on each other's transcribed face to face interviews. I was present for this and recorded their verbal and non-verbal reactions. This change in the data collection procedure was thought to not only substitute for the inability to conduct a joint interview, but yield a different kind of interview experience for my parents. Instead of adjusting their answers to each other's presence during the joint interview, both of my parents were able to see the thoughts and feelings of the other "as is." This produced a certain degree of earnestness and truthfulness that may have been lacking had both my parents been interviewed together.

Question construction. Written and face-to-face individual interviews consisted of a set of open-ended questions. McCaslin and Scott's (2003) discourse on question construction and interview typology was used to formulate the interview process, helping to create a basis for the kinds of questions asked. Within the face to face interviews, my parents had the flexibility to expand on each question as they told their respective stories. The following questions were adopted:

Grand Tour: What changes, if any, did you notice in your marriage to {insert name} and within yourself throughout the cancer experience?

Mini-Tour: (a) How was your relationship impacted due to the illness? (b) How did the illness influence your outlook on life, and your relationship? (c) Describe what you thought your roles were during that time? (d) How did this diagnosis impact your parenting philosophy and approach?

Sub-Tour: (a) Describe the emotional and physical closeness of your relationship before/during/and after your illness experience? (b) How did this experience influence your thoughts on death and loved ones? (c) What was the toughest issue to deal with during this time and why? (d) Given the reflective nature of the interview, do you think you would have answered any questions differently had they been asked immediately following this experience?

Data Analysis

Narrative analysis (Lieblich et al., 1998) guided the process of searching for, tracking, and recording thematic expressions. Lieblich et al.'s work was used to identify the specificities of the overall analytic process and the holistic-content analysis steps. Although Lieblich et al. recommended a more comprehensive analytic extrapolation of primary global themes into thematic categories; we followed Merriam's (1988, 1998) instruction on how to determine categorical construction, with reference back to Lieblich et al. for the final analysis of the categories themselves. This analytic process was utilized for the written, initial face to face, and reaction interviews, all three of which served as the data collected for the study. The following steps were adopted from Lieblich et al.:

(a) Read the material several times until a pattern emerges, usually in the form of foci of the entire story. Read or listen carefully, empathetically, and with an open mind, (b) Put your initial and global impression of the case into writing. Note exceptions to the general impression as well as unusual features of the story such as contradictions or unfinished descriptions, (c) Decide on special foci of content or themes that you want to follow in the story as it evolves from the beginning to end, (d) Using colored markers, mark the various themes in the story, reading separately and repeatedly for each one, and (e) Be aware of where a theme appears

for the first and last times, the transitions between themes, the context for each one, and their relative salience in the text. (pp. 62-63)

Example. The following statement by my father was echoed repeatedly by both he and my mother, in some form or fashion, throughout all of their interviews, which in turn lead to the creation of the over-arching impression *The Heroes' Journey*. The overall plot or theme cannot be derived from one or two utterances, but as a confluence of the narratives in their entirety:

I felt more alone now than ever and plowed my way through each day as if my life had become a novel and I was a character. I knew my character was destined to win and bring his family to the end of the book but I didn't know how or why.

As my triangulated investigator and I began to discuss the elements composing the overall story structure certain features began to stand out as globally constituting the overall structure/feature of the story itself, one of them being Maintenance of the Status Quo:

You almost pretend and try to making things as status quo as possible, meaning that nothings really changed other then its uh...where it's a cold or...something that is going to go away....something that is going to be okay when you get up in the morning.

Finally, through continual conversation my triangulated investigator and I indicated themes that we saw as imbedded within the over-arching story, as well as, its components, one of which was Abandonment:

I [my mother] understood that it was something rare...that they didn't know, but it was how they...where they even left me in the hospital afterwards...you know, where he didn't...he came and did the dilation and curettage (DNC) procedure in his little tennis outfit then went on vacation, didn't tell the office that I was there, didn't tell the office that he had done any surgery on me...so I'm in this hospital thinking I'm going home and being released, and no doctor was coming to see me, and I started crying to the nurses because the baby wouldn't take any milk unless I was home.

Verification Strategies

In qualitative methodology, investigators work to uphold the credibility, transferability, dependability, and confirmability of the study's findings (Lincoln & Guba, 1985). For this study, Lincoln and Guba's recommended use of a triangulated researcher, peer debriefer, reflexive journal, audit trial, and member checking procedure were employed. A triangulated investigator was used as a confirming source in the creation of themes, and the placement of datum into those themes. Interrater consensus was reached through conferences where both investigators presented interpretations,

grounded them in actual data not biases, and together they revisited the interpretation until consensus was achieved. Only when both investigators were able to reach complete agreement were particular dialogic sequences grouped into themes. The peer debriefer helped confirm that the findings were grounded in the data by reading the raw data in question, listening to the perspectives of both investigators, monitoring for investigator biases, re-reading the raw data, and extending an interpretation for consideration. A reflexive journal and audit trail were kept by the primary investigator to track emerging themes, biases, and document modifications to the data collection or analytic process. To further ensure that the results were grounded in the actual data and experiences of the participants, member checking occurred at both the transcript proofing and results stages.

Data Organization

A holistic-content analysis is used to analyze different facets of each participant's story within the context of their complete narrative (Lieblich et al., 1998). Results from this study are organized into the following subsections: (a) investigators' impressions of the data, (b) the generalized-global impression, (c) three components of the global impression, (d) exceptions to the global impression and unusual features, and (e) five specific themes that served to facilitate the induction of conclusions about the participants' experience with choriocarcinoma. Each content area is connected directly to interview and written data, as well as, narratives recorded by the investigators in their reflexive journals regarding their impressions of the data.

Results

Investigators' Impressions of the Interview Experiences

Across all interview experiences (i.e., written and face to face), my triangulated investigator and I noticed that my father's responses to the questions occurred at a deeper level of psychosocial introspection than my mother's. My mother made reference to the fact that she remembered very little about her illness experience. This limited degree of cognitive and affective recall may be attributed to the toxic cancer treatments and intense psychosocial shifts (from well to sick; from caregiver to care recipient) she endured for six months. Seeing that difference, my triangulated investigator and I worked to construct a balanced perspective drawing from my mother's generally communicated memories paired with my father's detailed narrative account. Adding to the ability to construct a balanced perspective was the use of both written responses, as well as, face-to-face interviews. The written responses appeared to lack a degree of depth regarding content, but included powerful emotional undertones. The face-to-face interviews helped to draw out their responses. The themes exhibited in the written responses were consistent with those in the face-to-face interviews.

Knowing that my bias as their son may influence the data collection and analysis process, several methods were employed to help ensure the trustworthiness of the data. Use of peer evaluation allowed me to share my personal reactions in an appropriate place and the evaluator held me accountable to staying true to the interview method. Reflexive journals allowed me to further examine my own experiences while conducting the

interviews, as well as, further process how the triangulated researcher and I analyzed the data. Here I was able to separate my thoughts and feelings as a son from those as an investigator. The triangulated researcher reviewed my reflections and helped to confirm the findings. Audit trails sequenced the course of data collection to analysis. Ultimately I wanted the re-telling of their story to benefit them, the research, as well as, translate information to those who shared their diagnosis.

Global Impression

According to Lieblich et al. (1998), a global impression emerges from reading and analyzing all data. This global impression is used to form a singular “plot” or story line. In this study, the global impression formed was, “the heroes’ journey.” This notion of “the heroes’ journey” grew out of the repeated utterance of words such as *fight*, *struggle*, and *journey* by both my parents, and the word *character* used by my dad repeatedly in his initial written narrative. This in turn lead my triangulated investigator and myself to begin viewing parallels between my own parents’ struggle and the struggle of the archetypal “hero” in Joseph Campbell’s (1961) seminal work *The Hero with a Thousand Faces*. In his work, Campbell outlined the journey of the “hero” in literary works from the place of the commoner to the procurement of some great self/universal truth or achievement (known as a “boon”) that in turn sets them apart from the rest of humankind.

According to Campbell (1961), the journey begins with the presence of the herald; “The herald, or announcer of the adventure is often dark, loathly or terrifying, and judged evil by the world,” (p. 53) may call the character to adventure simply by the crisis of his (its) appearance. This “herald” could be equated to the cancer diagnosis for both of my parents’ as it marked the “starting point” of their new journey. As the hero sets out to achieve the “boon” or the goal of the journey, they may enlist the help of others along the way, but ultimately must face the final challenge and receive the boon alone (Campbell). This also parallels my own parents’ illness narratives in that both felt as though they were fighting the cancer in isolation; my mother engaged in a physical battle for survival, and my father engaged in a battle for the fiscal survival for his family. Neither my mother nor father felt as though they could rely on the other for emotional support due to the fear of only exacerbating any psychosocial turmoil the other was experiencing. This in turn created a thematic dissonance so great that while my mother felt as though my father was there for her helping her “battle” the cancer, my father felt as though he a “was a little boy running as fast as [he] could to escape.”

This dissonance, or incongruence, translated even further into what each perceived their “boon” or ultimate goal of their journey with cancer (Saldinger & Cain, 2004); for my mother it was about making sure her children were okay, “...if something happened to me I knew that dad would find somebody else, that he would be happy...but I knew that it would be devastating to...you and your sister...” While my mother’s focus had shifted to making sure that both my sister and I did not suffer emotionally (re-orienting of relational priorities indicative of anticipatory grief), my father’s boon could be interpreted as maintaining the highest level of pre-diagnosis “normalcy” possible, or what my father referred to as “an even keel.” Given the individualistic and perceptually isolated paths that both my parents took with cancer, neither were truly able to battle the diagnosis together. Perhaps had they been able to equate their battle with that of a hydra,

a creature with one body but many heads, their journey would have been one they felt that they undertook together. The following quote from my father's narrative seemed to set the tone for the story's structure, "...[I] [husband] plowed my way through each day as if my life had become a novel and I was a character...my character was destined to win and bring his family to the end of the book."

The next part of Lieblich et al.'s (1998) analysis protocol included analyzing the global impression and extracting components that presented themselves as being the portal through which "the heroes' journey" emerged. These three components included: (a) maintenance of status quo, (b) denial, and (c) isolation. Each component will be discussed below in greater detail.

While both parents' journeys centered on a vested interest in *maintenance of the status quo*, it was this component that appeared to be my father's main purpose. For him, success or failure of this journey was predicated on maintaining the maximum amount of normalcy, or prior functioning, for both his wife and his children. Overall, his ability to fight the somatic facets of the cancer were non-existent, so in turn he was forced to focus his attention on managing the financial and social aspects of the disease in an attempt to keep the system at a pre-diagnosis state.

You almost pretend and try to make things as status quo as possible, meaning that nothings really changed... What I've tried to do is maintain for my family, and especially for your mother, is an even keel...

For my mother, her illness story centered on how cancer threatened her ability to respond to and meet actual and perceived familial demands thereby maintaining the status quo, "...I'm a good person, why is this happening... I was just angry a little bit because I wasn't able to take care of my family."

While my father plunged headlong into his work, hoping to buffer the effects of the illness through both fiscal and social means; my mother gravitated inward, focusing her physical and psychological energies toward combating the disease itself and the physical effects of its treatment. However, both parents utilized one coping tool above all others to maintain the status quo: denial. Whether it was from feelings of abandonment or the fear of death, denial allowed both my parents to feel as though they were somehow protecting the other from the psychological pain that they carried and dealt with on a daily basis. Denial manifested as two distinct types: *denial about the disease* and *denial of self*.

My father used the euphemism of "blindness" to demonstrate his *denial about the disease* and its possible outcome, "I could squeeze it [his purpose] down to it being about taking care of my family, and making sure they have a mother." He never acknowledged that my mother could die. For him it was about how quickly he could move our family through this time with as "few scars as possible." However, while my father's blindness excluded the possibility of death, it was a very real possibility in my mother's mind, "...he [her husband] was so sure I wasn't going to die, but I wasn't."

My father's denial about death as an outcome of my mother's battle with cancer hindered his ability to begin psychologically preparing himself for his possible loss; in effect negating his ability to detach himself psychologically from my mother. However, my mother had accepted this outcome as a possibility, and thusly was able to begin

preparing for this undesired result, which manifested as detachment. This process of both patients and loved ones anticipating death as a possible end result of chronic illness, and the subsequent psychological preparation for that death; namely the psychological detachment of themselves, a process known as anticipatory grief (Fulton, 2003; Lindemann, 1944), played a part in how my parents' experienced feelings of isolation or connectedness during that time.

Just as my father's denial about the disease caused frustration for her, her denial in not wearing a wig was a source of frustration for him. He noted, "...that would make me [husband] upset because I knew there was a way to counteract that [hair loss], and she refused to do it and she would never explain to me why. Her response to this was, "... you don't want to believe that you're losing your hair...and that was the biggest thing." My mother's experience with denial served the same as my father's in terms of avoiding powerful subjects about what may come.

Denial of self speaks to the notion that each denied themselves certain behaviors to protect the family from psychological angst. What they shared in common with denial was that both refused to talk with one another about the cancer.

Well it's almost like that I [wife] wanted to talk about it, but I didn't want to hurt other people around me...it made me feel bad not being able to talk...

I [husband] can tell you there were plenty of times I wanted to talk about it...and you sure can't talk about it when your [wife] head's in the toilet...

Both types of denial, although done with the intention of protecting the other, instilled in my parents the next component of the heroes' journey: feelings of isolation.

In the attempt to maintain the status quo through the use of denial, a sense of *isolation* manifested for both of my parents. Phrases included: "I [husband] felt more alone now than ever" and "[wife] you are kind of in a class by yourself... people who have cancer and people who don't." Interestingly enough, my mother's sense of isolation seemed to be buffered by the fact that she felt taken care of by her family throughout the entire experience. She repeatedly used the word "cherish" to describe my father in all three interview phases.

...some people would flee or take off... he [husband] was always very cherishing of me, so I knew that he loved me regardless of what we went through.

My father's isolation took the form of not feeling emotionally and physically supported by others. His family of origin was 200 miles away; dealing with his own father's losing battle with lung cancer. He reported not having a close relationship with my mother's family of origin.

A lot of that loneliness draped into me [husband] because... I was alienated from my sister, I uh didn't really have a close relationship with my in-laws, my [father] was sick, my mom was only thinking of herself

For my father, isolation seemed to be the predominant path of his particular journey: A direct consequence of his ability (or perceived inability) to maintain the “status quo” through partial use of denial, “The purpose that I [husband] had was more so to make everything normal again... with nothing more, [than] a blip in our whole history of being a family.”

Exceptions to the Global Impression

The second stage of a holistic content analysis requires that the researcher look for times where this general impression is contradicted (Lieblich et al., 1998). This notion of “the heroes’ journey” is seemingly absent when my father made the statement that “I hope they [his family] will forgive me and understand I am only a man and not a hero.” He saw himself not as a champion or hero for his family, but rather, simply a man with all the fragility that entails. My mother’s narrative lacked the contradictory statements found in my father’s narrative (his reference to himself as a “hero” at times and “only a man” at others), which in and of itself could be considered an unusual feature of her story.

Unusual Features

Lieblich et al. (1998) stated that a researcher must also pay attention to any aspects of the story that seem out of place or ill fit; and for this reason unusual features of the narrative are also presented. The very way in which my parents answered the interview questions can be construed as an unusual feature. While my father’s answers were much more specific and wrought with intense emotion, my mother’s tended to be more general and devoid of these intense emotional undertones. Although both of my parents seemed to display frustration in the telling of similar experiences, my father’s portrayal was much more introspective and interwoven than my mother’s.

Major Themes

As the journey was broken down even further beyond its three varying components, five themes began to emerge consistently throughout all six narratives: (a) *role reversal*, (b) *loss of control*, (c) *guilt*, (d) *abandonment*, and (e) *incongruence*.

Theme 1: Role reversal. For my mother, her inability to provide physically for her family and having to allow others to take care of her seemed to be a source of much frustration and anger. She struggled to assume this new role of being “cared for” instead of caring for others. She shared, “We had a complete role reversal. [My husband] was now the caregiver and I felt that I was an invalid.” Having lost time as a mother angered her; especially time bonding with her newborn daughter. My father’s issue did not seem to be with the reversal of roles, but with the exhaustion, both physically and mentally that came with having to assume all aspects of providing care for his family. He recounted, “it’s such a feeling of helplessness...you have these two children and you don’t know what to do...”

Theme 2: Loss of control. Feeling a lack of agency was derived from their perceived inability to adequately buffer the effects of the cancer; physically for my mother and psychosocially for my father. This feeling of helplessness is exemplified in this account,

I [husband] remember one night [my wife] was at the hospital because the chemo was too much. [My son] and [my daughter] lay in bed with me and it was raining outside. This was the first house we had ever bought and it was putting a strain on us financially. When the rain started I could hear the sound of a leak in the roof dripping in my bedroom. [My son] and [my daughter] were both sleeping and I remember crying myself to sleep wondering how I was going to get through tomorrow and how was I going to afford to fix the leak. The sound of that leak of water I can still hear today....no matter where I patched that roof the leak always found it's way through.

No matter how he tried to maintain that ever-elusive sense of normalcy (patching the roof), the cancer (the leak) always managed to get through, further damaging his home (status quo). The inability to mediate the somatic effects of the cancer and its treatment were also an experience for my father that exacerbated this sense of helplessness. He reported,

...you just want to be able to reach in and touch her [wife] and take the pain...you never want to experience when somebody hurts like that...if I could take it all I'll take it, but you can't...even if you tried...

My mother's struggle with loss of control was portrayed again through her inability to care for her family, or her role reversal from caregiver to care receiver. It was magnified in her interactions with the medical community. She recalled having to push for answers that many times were inadequate. She remembered, "I kept calling, they kept saying, you know, "You're doing too much, put your feet up." They were typical men... who were thinking it was mostly in my head."

While within the context of the medical system my mother struggled to retain her sense of agency and influence, it was here that my father was able to once again don the role of the protector "hero" with a renewed sense of fervor.

You just instantly start to put that aura in the room that this is not a piece of meat; this is your wife, this is the person you love, and [the doctors] are going to make sure it's all there, and the first thing you do is grab the hand that she [wife] can't feel and you're telling her I [husband] can feel it and it's there...and I'm standing there and there's no way I'm leaving till this is all fixed and it's alright...

My father felt that often times he was left to pick up the pieces of her physicians' handling of emotionally sensitive situations, and effectively had to "undo" everything that they had done "because of what they said to her and how they said it."

Theme 3: Abandonment. Throughout my mother's illness story she recounted how her family was always there in some capacity to care for her and her children. However, she perceived her other support systems as lacking in terms of their presence, "Friends kind of just didn't show up... I think they thought it was catching...if they came too close to me, maybe they were going to get cancer too..."

My father experienced abandonment quite differently. He felt abandoned by those around him, especially by my mother, with regard to her "turning inwards" and becoming more "introspective." Upon reading my mother's interview transcript this became solidified.

[husband]...there's not a single sentence in there [her transcript] that says that "I wanted to survive, live old, and die with my husband"... everything came before me, and that her whole reason for survival and living was not about spending the rest of her life with me...

My father referred to his coming last in my mother's life as being the "fourth child," and went on to further describe this idea. He stated, "Her relationship with me became, what I call, the fourth child...and the reason was because she had the relationship with you, your sister, the disease, then me... I was after the disease."

He felt as though the reason for my mother's survival was to be a parent to her children. In the interviews when my father discussed the notion of family he would describe my sister, my mother, and I; however, when my mother discussed the notion of family she referred only to my sister and me. This could be for any number of reasons, but does play into the ideation of my father seeing himself as being the fourth child; "She says right here in this [her transcript] that she understands how I was put on the back burner...and how it was about the kids."

Abandonment was not only felt in my parents' marriage and with others but also with the medical professionals. They felt treated like a "number" and placed on the "back burner," which was exemplified in my mother's account of her DNC.

He [the physician] came and did the DNC in his little tennis outfit then went on vacation... didn't tell the office that he had done any surgery on me...so I'm [wife] in this hospital thinking I'm going home and being released, and no doctor was coming to see me, and I started crying to the nurses because the baby wouldn't take any milk unless I was home... so they called the office and then my doctor apologized profusely because he didn't even know I was in the hospital.

My father's perception of this dehumanization was that "...they talk as if the person's not there...they talk as if the person...is something that's come in that doesn't have a soul, a spirit, a mind." My mother wanted the medical professionals to remember that she was a woman with a family, with a husband, with a four-year-old and seven-week-old at home waiting for her. However, she also expressed apprehension at the physicians becoming too involved with the emotional and psychosocial aspects of her care, believing that it may compromise their ability to provide her the best medical care.

Theme 4: Guilt. Another theme that emerged was the guilt exhibited by my mother and father in regards to their own culpability in the cancer's appearance. For my father this guilt manifested as a consequence of his inability to protect his wife from developing cancer, manage the psychosocial and financial consequences of it, and absorb the knowledge imparted by some [medical professionals] that he was in fact the cause of it. He recalled one nurse who commented to his wife that, "...There's a 90% [chance] that this is his fault, that he gave this to you." Up until then his sense of purpose and role had been predicated on the notion of protection and "making sure everything was okay."

My mother questioned how her own actions contributed to cancer's emergence. "I [wife] had a lot of guilt ... I felt that I probably did something during my pregnancy to cause me to get cancer." This notion of self-blame and the guilt were concisely expressed by my mother, "Neither of us blamed the other one, but it didn't stop us from blaming ourselves."

It is this guilt that my father and mother claim that after 20 years drive many of their actions today. My father expressed regret from feeling torn between the desires to be physically present with my mother for her medical care and needing to earn money, as well as, the comfort he felt when away. My mother reported feeling guilty that during this time my father was placed on the "back burner" and left to care for everyone without being cared for himself.

Theme 5: Incongruence. My parents' perceptions of physical and emotional availability differed greatly depending on who was speaking. When my mother felt that he was there my father felt that he was "a little boy running as fast as [he] could to escape." When my father felt that he never shared in my mother's illness experience, but was merely out on the periphery looking in, my mother thought "[they] fought [her] cancer together;" and when my mother felt as though my father was her strength, a quality found in someone who is heroic, my father could only "hope [she] will forgive me and understand I am only a man and not a hero." The incongruence of their reported experiences made sense under the greater context of needing to be a hero in the face of their greatest marital and personal challenges.

Discussion

In attempting to understand and treat the psychosocial impacts of cancer, one must be able to draw on both generalities, as well as, the issues specific to particular neoplastic manifestations such as choriocarcinoma. Grounded in a holistic-content analysis process, my parents' experience with choriocarcinoma resulted in five themes supported in the available literature on cancers common to women, mainly in the area of breast cancer. Following the themes presented are the studies to which they share a common thread: (a) *Role reversal* (Billhult & Segesten, 2003; Fang et al., 2001; Fitch et al., 1999; Helseth & Ulfsest, 2005; Sergin et al., 2006), (b) *Loss of control* (Lindholm et al., 2002; Manne et al., 2004a), (c) *Abandonment* (Giese-Davis et al., 2000; Lewis & Deal, 1995; Walsh et al., 2005), (d) *Guilt* (Chen, Chu, & Chen, 2004; Giese-Davis et al.; Lindholm et al.), and (e) *Incongruence* (Fang et al.; Giese-Davis et al.; Harkness-Hodgson, Shields, & Rousseau, 2003; Lindholm et al.). For my parents, the need for *role reversals* created a relational shift and helplessness that both expressed as a *loss of*

control and an *abandoning* of one another in their greatest time of need, which for both of them produced very intense feelings of *guilt*. *Incongruence* between their stories demonstrated how each worked so hard to perform well in their hero role, even though done in different and sometimes competing ways.

Connecting these five themes to the global impression of a heroes' journey are three central components. These three components are also found across the age range in the available literature on women and cancer: (a) *maintenance of status quo* (Lindholm et al., 2002; Manne et al., 2004b), (b) *denial* (Giese-Davis et al., 2000; Lindholm et al.), and (c) *isolation* (Giese-Davis et al.; Lindholm et al.; Manne et al., 2004a, 2004b). My parents' efforts to be heroes for one another and their children had painful consequences. Their attempt to maintain the illusion of *status quo* through use of *denial* led them to a place of *isolation*, which both felt led to their eventual divorce. Since my mother reported feeling rejected by her peers during this time, and not wanting to dump on my father emotionally, she felt limited in what she could disclose to my father about the biopsychosocial pain she was experiencing. Knowing that she was fighting for her survival and feeling abandoned by her friends, my father also felt like he could not share his raw emotions with her in effort to "protect" her. This mutual lack of disclosure, and desire to protect created a distance that inevitably left him feeling abandoned emotionally; and my mother mistaking his silence for positive adjustment.

As reported above, although commonalities exist across the age range with cancers diagnosed in women, there was something found in this study that separated out this young couple from the older couples reported on in the literature. While my mother was painfully aware that her journey with cancer may end in death, my father would not acknowledge it as a possible outcome. As a result, my mother experienced an extra-relational shift and turned attention off of my father and onto her two small children. My father, who denied the possibility of her death, was never able to begin the process of psychologically detaching himself from my mother and in fact never reported shifting his relationally focused priorities; if anything he became hyper-focused on her. The relational re-orienting of my mother contributed heavily to his report of feeling emotionally abandoned by her. This psychological distancing expressed by both is explainable by anticipatory grief; a theory of individual coping in regards to the impending or perceived death of a loved one (see Fulton, 2003; Lindemann, 1944).

In regards to anticipatory grief with chronic illness and couples, Swenson and Fuller (1992) found that when a spouse is diagnosed with cancer and the perception of mortality for that spouse exists, a shift occurs from the interpersonal relationship to its extra-relational extensions (i.e., family, children, mutual friends, etc.); a shift which my mother seemed to experience and my father did not. This re-orienting response can only manifest if death is accepted as a possible outcome (a fact that the concept of anticipatory grief is predicated on), and can be retarded or altogether halted if intense and persistent denial is used to better shoulder the burden of coping with the diagnosis. Saldinger and Cain (2004) found this to be common amongst caregivers. The process of anticipatory grief has been studied in older couples where death was a more accepted prognosis (Chapman & Pepler, 1998), within children (both younger and middle-aged) in regards to the impending death of a parent (Saldinger, Cain, Kalter, & Lohens, 1999; Smith, 2005), and with parents in regards to the impending death of a child (Weiner, Theut, Steinberg, Riekert, & Pizzo, 1994). However, the researchers referenced above only studied this

phenomenon when death was imminent. No researcher has explicated the consequences of this detachment process on patients who survived their battle with cancer/death. The current study's finding of how the inability to experience this detachment phenomena together, as well as, the re-orientation of relational focus indicative of the process, can manifest as feelings of abandonment and isolation on the part of the non-detached spouse, can be considered a unique addition to the understanding of anticipatory grief as a relational rather than individual coping process.

Limitations

Although generalization was not the intent of the study, a methodology that includes a small sample size must be acknowledged. Another limitation is that the principle investigator is related to both participants as their biological son. This limitation is further compounded by the qualitative methodology employed to study their cancer experience since the researcher is the instrument through which data collection and analysis occurs (Lincoln & Guba, 1985). Although many devices were utilized to ensure the trustworthiness of the data (triangulated investigator, audit trail, reflexive journal, member checking, etc.), the subjectiveness associated with qualitative methodology, as well as, the personal connection with the participants is a limitation that must be acknowledged. Lastly, one could assume a limitation that retrospective study of an illness experience 20 years later may not produce the same results. However, according to the respondents, they did not believe their stories would have been any different. This couple is a good example of what happens when a couple endures a cancer diagnosis and treatment without psychosocial intervention or support as part of their treatment plan. The long term implications of their naturally occurring relational processes are revealed giving insight and idea to future researchers and interventionists.

Future Research

More attention in contemporary literature is needed on the role anticipatory grief plays, if any, in both patient as well as healthy family members coping with cancer. Few researchers have dealt with the power that anticipatory grief has when it comes to cancer exclusively. Not only does the specificity of this phenomenon in relation to cancer require more psycho-oncological consideration, but also the impact of anticipatory grief; especially in terms of its proliferation of psychological detachment in the face of patient survival. The relational re-orientation (i.e., the focusing on extra-relational elements; kids, the family system itself, etc.) that seems to be indicative with anticipatory grief needs to be better understood in regards to how this shift is and or can be relationally experienced by the patient, their spouse, and the family in general. Perhaps if it is not occurring naturally for both partners, this would be a good place for professional intervention and study on the long term implications of that work.

This process of coping, up until now, has only been studied on an individual level, along with how this process manifests outward through individual behavior. However, given the fact that an individual's acceptance of death as a possible outcome serves as a precursor to this reorienting process, a systemic, relational re-conceptualization of anticipatory grief deserves further consideration to better understand how co-existing

grief and couple processes may exacerbate or hinder this adjustment process of a couple/family to a diagnosis of cancer, rather than simply an individual's adjustment.

Also requiring more attention in psycho-oncology literature is the role that "protective" posturing plays in the creation and exacerbation of distress in couples who are facing not just cancer, but chronic illness in general. Contemporary research has focused on the communication patterns, namely the silence and withdrawal that chronic illness promotes, but few researchers have focused exclusively on how the desire to protect possibly sets this wheel into motion.

Recommendations

Cancer is not a monolithic issue, but rather a systemic one with varying impacts affecting all facets of a couple's life together. We recommend that providers and clinicians be cognizant of patients' ambivalence in discussing topics such as death not only with mental and biomedical health care providers, but especially with those closest to them. Mental health care providers must also be mindful to promote conversations between patients' and their loved ones about death, as well as, any fears stemming from this possible outcome. In doing so, patients are able to align themselves with their loved ones in fighting the impacts of cancer in a collective and cohesive manner. These types of conversations also help facilitate grief processes, such as anticipatory grief, so they can be experienced in tandem rather than in isolation, which will lead to greater solidarity in a time of great tumultuousness.

Also recommended is the highlighting of changes that a couple may potentially see as a result of diagnosis and treatment. In discussing the changes that each partner expects and fears, mental health and biomedical health care providers can better help couples to express their frustration and begin to relinquish, to a degree, each one's protective posture. Through the easing of this protective stance, couples will be able to rely on the emotional support each needs from one another so desperately during this time, but often times goes unasked for due to their desire to shield one another from their own emotional pain.

The therapeutic utility of the retrospective account used to collect the participants' stories cannot be overlooked as a powerful clinical tool to aid couples in synthesizing their individual experiences, releasing years of assumptions and unknowns. Not only helpful for the participants, but in this case, the researcher as well. This semi-autobiographical study allowed me to better understand my parents' fears and concerns about cancer, as well as, the situations that lead up to their eventual divorce. We recommend that while this method of study poses certain limitations, the therapeutic contributions are threefold: the field of study, the participants, and the researcher

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