

Differences and Trading: Examining the Effects of Childhood Cancer on the Parental Subsystem—Part I

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Abstract

This article is the first of a three-part report of a research study that used hermeneutic inquiry to examine the effects of childhood cancer on the relationship between the parents of the child. In Part 1, we identify the topic of investigation and the relevant literature; describe the research question, method, and design; and begin our interpretations of the data with a focus on the couples who remained together and those who experienced relationship demise. In this analysis, we discovered that issues of difference and trading played a strong role in how the couples fared in their relationships. In Part 2 of this series, we focus on further interpretations, and in Part 3, we discuss the implications of the study for other parents and for health care professionals.

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A child diagnosed with cancer is a *family* experiencing cancer, where no member goes unaffected or unchanged. While natural and biological science research has significantly decreased morbidity in childhood cancer, the experiences of family members and ways in which health care professionals can be most effective in mitigating family and child suffering have received considerably less attention in the research arena.

Caring for a child with cancer obligates health care professionals to care for the multiple systems levels that have the greatest influences on the child. The tone and quality of the parental relationship have profound effects on the physical, emotional, mental, and spiritual health of the child (Becvar, 2006; Becvar & Becvar, 2003; Bond & Burns, 1998; Lavee, 2005; Lavee & Mey-Dan, 2003; Moules, Thirsk, & Bell, 2006). A child's relationship with parents is often the most significant relationship influencing the child's well-being; in fact, this relationship has formative and lasting imprints on a child. In this regard, attending to the parents' relationship in whatever way is possible is indeed primary prevention in caring for the health of the child (Becvar, 2006; Bond & Burns, 1998). This study, examining how parental relationships are affected by the experience of having a child who been diagnosed and treated for cancer, continues to help us understand the human and lived component of pediatric cancer, leading us to exceptional care that is guided by evidence.

This study is presented in three parts. In Part 1, we offer the background to the study and a description of the research method. We then examine the parents' interviews with a lens on the couples that stayed together and those whose relationships ended during or after the cancer experience. Within this examination, we more closely look at the interpretations that arose around notions of differences and the complexity of trading. In Part 2, we discuss the overarching interpretation of "taking one for the team" as a way to speak to experiences of the need to change focus in family relationships, tag teaming, protection, intimacy, and finally examine the attempts at reclaiming the couple relationship. Part 3 concludes this report with a discussion of the implications of the study for other parents and for health care professionals.

Background and Literature Review

Although most studies have focused on the individual, there has been some research since the early 1990s that has examined the effects of childhood cancer on the parental dyad (Bonner, Hardy, Willard, Hutchinson, & Guill,

2008; Dahlquist, Czyzewski, & Jones, 1996; Engel, 2002; Gerhardt et al., 2007; Greenberg & Meadows, 1991; Grootenhuis & Last, 1997; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1998; Lähteenmäki, Sjöblom, Korhonen, & Salmi, 2004; Lavee, 2005; Martinson, McClowry, Davies, & Kuhlenkamp, 1994; Pai et al., 2007; Quittner et al., 1998; Sawyer, Antoniou, Toogood, & Rice, 1997; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 1993; Streisand, Kazak, & Tercyak, 2003; Syse, Loge, & Lyngstad, 2010; Van Dongen-Melman et al., 1995; Vrijmoet-Wiersma, van Klink, Kolk, & Koopman, 2008; Wallander & Varni, 1998; Woodgate & Degner, 2004). The results of these studies are contradictory with some claiming that the parental relationship suffers as a result of enduring the diagnosis and sequelae of childhood cancer, sometimes to the dissolution of the relationship (da Silva, Jacob, & Nascimento, 2010). An almost equal number of studies suggest that the relationship does not suffer, but rather is unchanged or even strengthened as a result of this experience (Bergstrasser, 2007; da Silva et al., 2010; Klassen et al., 2007; Syse et al., 2010; Vrijmoet-Wiersma et al., 2008). There is some suggestion that relationships that falter were those experiencing difficulty pre-diagnosis, and the deleterious effect is less attributed to the cancer than to pre-existing difficulties, exacerbated by stress (Dahlquist et al., 1996; Gerhardt et al., 2007; Grootenhuis & Last, 1997; Quittner et al., 1998; Sawyer et al., 1997). The difference between situations where the child has died or has had long-term effects is unknown (da Silva et al., 2010). Some studies have shown a decrease in the quality of the marital relationship in the first year of treatment, an improvement in the second year, but a continued deterioration after 4 years (Lavee, 2005; Lavee & Mey-Dan, 2003). In some cases, while communication and trust may have improved, there is a marked decline in the quality of the sexual relationship (Lavee & Mey-Dan, 2003). It is unclear what makes some couples able to endure and strengthen, and others dissolve. For example, it is not known whether pre-existing relationship factors or the impact of the cancer influence dissolution or longevity. Similarly, what enables couples to remain together during these life-changing circumstances is a question that remains to be answered (Russell, Coleman, Ganong, & Gayer, 2016).

Whether childhood cancer experiences strengthen or challenge relationships between parents depends on many factors and particulars of context. Each family brings a history of interactions, problems, strengths, and issues that are at play prior to diagnosis and treatment. It was not, then, the intent of this study to determine “once and for all” whether childhood cancer experiences strengthen or challenge the relationships between parents. Rather, we sought to arrive at an understanding of how the childhood cancer experience may have affected the relationship. To our knowledge, there have been no

hermeneutic studies in this area, and past research has focused on the treatment period; there are few studies examining the long-term impact on the parental relationship (Bergstrasser, 2007; da Silva et al., 2010; Klassen et al., 2007). This research is novel in its attention to interpretation of the effect after at least 3 years post treatment and in its focus to discover ways that pediatric cancer care can assist couples in mitigating the effects that having a child with cancer can have on their relationship.

Research Question

Our research question in this study was: **How might we understand the influences and effects that childhood cancer can have on parents' relationships with each other?** This research received ethical approval by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary. The proposed research adhered to the principles of the "Tri-Council Policy Statement: Ethical conduct for Research Involving Humans" and to the Alberta "Health Information Act." Families of children who have or have had cancer might be considered a vulnerable population and, thus, experienced members of the research team conducted all of the interviews.

Research Method and Design

This study employed a sophisticated method of research well documented under the umbrella of phenomenological studies: Hermeneutics. Hermeneutic inquiry is described as the philosophy, practice, and theory of interpretation and understanding in human contexts (Moules, McCaffrey, Field, & Laing, 2015). Hermeneutics, as a research method, invokes us to make sense of the particulars of families' experiences and arrive at deeper understandings of how families experience the angst, fortitude, and capacity to learn to live alongside life events that call forth the unimaginable (Gadamer, 1960/1989; Koch, 1996; Moules, 2002; Moules et al., 2015; Smits, 1997). Unlike some qualitative methods, hermeneutics does not result in thematic reduction, semantic codes, constructs, or theories, nor is it focused on explanation—rather, it is focused on understanding (Moules et al., 2015).

Recruitment of Participants and Data Collection

Twenty-four interviews (in person or by telephone) were conducted with a total of 30 participants across Canada and the United States. Six interviews

were conducted with the parental couple together; 18 were conducted individually (15 mothers, 3 fathers). Participants chose whether to be interviewed individually or as couples. For purposes of reflection, we required the parents to have had some time since the cessation of treatment (either through cure, termination of treatment, or death); therefore, we only interviewed parents who were at least 3 years post cessation. Participants fit into one of three categories: (a) parents of children who have died from cancer; (b) parents of children who have survived cancer, considered fully “cured,” and are living with no complications from the cancer or treatments; and (c) parents whose children have survived but live with life altering consequences of their treatments. Two thirds of children have at least one complication from treatment and one third have severe and long-term complications requiring specialized and even constant care (National Cancer Institute, 2009). The most relevant demographics for this study are as follows: The participant sample comprised of 12 families whose child died, six families where the child was still alive but with severe side effects/disabilities, and six families where the child was treated and in remission with little to no side effects. Four of the couples were separated or divorced during or after the cancer experience and/or death experience. Nineteen were still married and one father was widowed after the child’s cancer experience. All of the couples that volunteered were heterosexual. Demographic details around diagnosis, length of treatment, ages of parents, how long they were married, socioeconomic status, and specific other factors were not collected and cannot be reported because our intent was not to create a typology of experience. Some of the demographic details (such as diagnosis) often emerged in the interviews, however, and were considered if they were relevant to the analysis.

Participants self-selected in response to advertising that occurred through the network of the Kids Cancer Care Foundation of Alberta. Of interest, as a result of a media release of the study, the news of it “went viral” on social networks, and within 1 week, we had more than 100 emails from Canada and the United States inquiring about the study. It seemed to us that a story had not been, and needed to be, told. We interviewed every person who volunteered and responded to a follow-up email. The majority who made the initial inquiry did not respond to the follow-up email.

The number and distribution of participants in this type of study is not validated by quantitative measures of “power” or specifications of random sampling; rather, in hermeneutics, researchers aim for a richness of data through exemplars of experience, otherwise known as purposive sampling (Koch, 1996; Morse & Field, 1995; Moules, 2002; Moules et al., 2015; Sandelowski, 1995). Put more simply, the best informants are purposefully sought. The number of participants required for interpretive inquiry is

difficult to predict prior to the beginning of the study, but typically 10 to 15 participants (individuals or couples) would provide sufficient data for analysis. In this study, the research team felt obligated to continue interviews for couples who had volunteered and responded to follow-up emails, resulting in 24 interviews. The interviews were open-ended, conducted in person or by phone by three of the researchers, and audiotaped for transcription purposes (Kvale & Brinkmann, 2009). Often research assistants conduct interviews, but as stated above, due to the sensitive nature of the topic, we believed that they required the expertise of seasoned researchers, and in this case, the three researchers all have family and mental health backgrounds. An interview guide was not used; rather interviews in hermeneutic studies take on a more conversational tone. They are purposeful but not scripted and involve deep listening and responsiveness (see Moules et al., 2015, for a deeper description of the nature of conducting interviews in hermeneutic research).

Participants are not individually described or identified as connected to the quotes as the intent is not to represent them as individuals or conserve their stories. Instead, hermeneutics attends closely to a topic or phenomenon that is informed by participants' experiences. As such, "the participants in the study are not the topic but are chosen to bring their knowledge about, and to, the topic and expand our understanding of the phenomenon" (Moules et al., 2015, p. 123).

Data Analysis

Analysis in hermeneutics is synonymous with interpretation, which occurs in the complex dialectic of research interviews with participants and interpretive memos written by researchers based on the transcripts of the interviews (Moules et al., 2015). The dialectical movement between transcripts and memos opens new understandings. We did not use qualitative research software because interpretation is not based on repetition of themes but on particular expansion of data that furthers understanding of the topic. Software data analysis is unable to recognize the particular and the hermeneutic interpretation of the valuing of the individual "case" (Moules, Jardine, McCaffrey, & Brown, 2013). We arrive at interpretations through a careful read of the data, looking for instances that resonate and offer portals to understanding the topic better. In the vernacular, we look for statements that "have grab" in that they catch our attention and invite reflection and consideration. They may at times appear to be themes if they appear across the interviews, but it is the work then of hermeneutics to "dive" into the themes and deconstruct and unpack them, arriving at an interpretation of a theme.

The initial individual interpretations of the researchers were moved to another level of interpretive analysis in the research team's conversations through in-depth, rigorous reflexive, and communal attention to the data. The developing interpretations were further deepened through the practice of interpretive writing (Moules et al., 2015). Hermeneutic analysis is recursive. A dynamic and evolving interaction between the whole and parts of data characterizes analytic and interpretive movement toward an understanding that opens up possibilities. Attending to the relationship between whole and part involves extensive readings, re-readings, reflection, dialogue, and challenging taken-for-granted assumptions (Moules, 2002; Moules et al., 2015). "The art of interpretation . . . involves the process of moving past the initial descriptive themes into the depth and richness of interpretation" (Moules et al., 2015, p. 119). Because the interpretation lies with the researchers, the method does not involve what is known in some other qualitative methods as "member checking." In other words, it does not need to be validated by the participants but rather the researcher "thinks with the data" (Steeves, 2000, p. 98), making it possible to fulfill the "obligation of the researcher to go beyond his or her data, but not in the sense of reaching conclusions unrelated to the data or unjustified by the data" (Steeves, 2000, p. 97). Put another way, the truthfulness of hermeneutic research does not rely on the nod of agreement from informants but rather on its capacity to open up and extend the landscape of understanding.

Interpretive Findings

In this section, we present the findings of the study. The findings are presented in interpretations that weave the voices of participants with the interpretive reach of hermeneutics. Interpretations extend from and return to participants' experiences in a way that acknowledges, reveals, and extends how we might understand the influences and effects that childhood cancer can have on parents' relationships with each other. Participant quotes are presented verbatim and appear in italics. Line spacing between them indicate a different participant and ellipses indicate that a part of what was spoken was not included as it was not relevant to the interpretation.

The Shape of the Relationship Prior: Couples Still Together

One of the speculations we arrived at in conceptualizing the study and in the review of the literature was that the state of the parental relationship prior to the cancer experience might have some impact on how the couples responded to the experience. Therefore, we intentionally asked the

participants about this. Couples that stayed in the relationship spoke of their experience in this way:

We wouldn't be where we are today had we not gone through that . . . his short life really has enriched ours . . . made us focus on our priorities . . . we are completely different people.

This family claimed the experience of cancer and death of their child strengthened their relationship and enriched their life as a couple. For another couple, this enrichment, expressed as a kind of “bonding,” was one also reached through the death of their child.

We grew up as high school sweethearts, been together over 30 years . . . him and I are the only two that can share the bond of (child) . . . birth, living . . . I think it is the strongest bond I have with him.

This couple's experience was one of intimacy. Together, they were the only ones who shared memories of the birth of their child. These memories helped to sustain the marital relationship. Importantly, other participants showed how the intimacy and everyday-ness of parental relationships are also ordinary and even practical:

We made an agreement when we first got married if we have an argument, it's over before we go to bed . . . like all marriages there were good and bad day . . . but it was usually over or circling around something about the kids . . . but not serious . . . a regular marriage . . .

Ordinary and practical dimensions of parenting and family life exert stressors upon couples in different ways. Some participants told us that, despite differences and challenges, features of relationships such as communication and decision making were very important in the context of the cancer experience.

We're inherently a couple who has never been in sync in how we deal with things and that works for us . . . but we are for the hard decisions. I think personally if you are struggling when your child got cancer, you might not make it . . . but if you're doing good when your child gets cancer, you'll probably come out of it okay.

This sense of being “in good shape,” spoken of in different ways by participants, says something about the relationship qualities that participants thought were necessary for their relationship to survive the cancer

experience. For one couple, this recognition extended into a commitment to help others who were having difficulties in their relationship and family life:

We could see other families struggling so we talked about recommitting in our marriage . . . we became mentors for other families.

Another family stayed together and their child who was affected by cancer survived. Sadly, they lost another child in an accident in later years and were dealing with grief of the death of that child. The mother sought out counseling whereas the father hesitated. She told us,

And I finally said to him, we've lost enough; I don't want to lose the marriage . . . He did attend grief counseling and the marriage was strengthened as a result.

Relationships that survive are subject to losses and gains. For some, the loss is the child, whereas for others, they lose intimacy, communication, privacy, and the normalcy of a family life that, even in the best of circumstances, is rarely to be considered "normal." For some, the losses were accompanied by gains such as intimacy and purpose, for example.

Losses and gains are relative, contextual, and the sense of loss and gain shifts over time. What strikes us, though, is the way participants' experiences call upon us to think about the things that people in this relationship context learn about themselves, about each other, and about their limitations and capacities as people and within the parental context. Their words suggest areas of sensitivities that health and social care professionals might require as they work with parents of children affected by cancer.

Differences and trading out. Some couples talked about experiences that involved "trading" in some way. Historically, to trade has been to take a path. In other words, to trade one has to go somewhere. Trading does not sit still, nor does a trader turn in herself or himself. The evolved meaning of trade is important too: The center of trading is the trade, which requires a willingness to trade and the assumption of mutual advantage (even if one side or both ends up feeling cheated later). Trading is related to the "manner of life" and, as such, implies transaction between people. We are, then, focused upon the material of life, upon the conditions that lead to, sustain, and complicate trading. One couple attributed their survival as a couple to their ability to deal with stress by taking turns and "trading out."

Even before . . . one of the reasons our marriage has survived is because we have a really great way of dealing with stress in our marriage. So inevitably

one of us will kind of take charge and deal with everything and the other kind of falls apart. And then when the other one is finished falling apart, they can take charge and it's the other person's turn to fall apart for a little while. She termed this behavior as a habit of functioning . . . taking turns freaking out . . . I'm a ruminator; he doesn't worry; I think we balance each other out. And so we would trade, literally traded . . . for three and a half to four years of treatment, we were just constantly fine-tuning the way we dealt with it. I never worried if we were going to make it . . . we always been very committed to staying together no matter what.

If trading involves action and implies going somewhere, this couple began to illuminate a path that involved traveling “within” as well as “without.” When trading in a childhood cancer context, one question then becomes, not “with whom do you trade,” but rather, “where do you go?” Participants in this study traded physical spaces and places, taking turns being present for difficult or stressful situations. They also went to different identity places, trading taking charge for decisions to following the lead of a partner.

This type of trading is a complex dialectic within which notions of identity, parenting practices, sacrifice, and benefit seem to work in interesting ways. For some couples, their trading was dynamic. For one mother in our study, the trading was an internal experience, working out her path in relation to her husband's. This couple recognized that they came from very different backgrounds and had different natures; these continued during the cancer experience with the mother scheduling everything and making sure the father did not have to worry about things. Again, it was the differences in style that assisted this family:

He's the fun parent; I'm the structured, the whole good cop, bad cop thing . . . that's just the dynamic of our relationship.

As well as trading places between hospital and home, a sick child, and other responsibilities, couples also engaged in trading on and with past and present relationship dynamics. The couple above further elaborated,

so we went into this saying, we have something to prove . . . we're staying together no matter what. Even if he had died, I don't think it would have broken up our marriage . . . we'd just have to figure out a new way to live.

Whether it seemed like a hand they had been dealt, or simply what they had to work with now, some couples made the best of the hand they had to trade.

Sometimes different styles worked and sometimes their different styles were amplified and made for difficulties.

I didn't have a friend in my husband because we couldn't talk about the diagnosis because he knew statistics and I refused to hear them. He was a lot more negative, had less hope that all things would turn out okay . . . moms and dads handle a crisis like that a lot differently; it was that way with us . . . with our personalities . . . we couldn't talk about it when we were going through this awful hell . . . we couldn't talk to the person we were closest to.

In spite of this, this couple never considered separation and attributed it to the fact that neither had family nearby for support, and they were able to reclaim a friendship once the child was cancer free. *I think we were both just really, really scared and so it came out as anger towards each other.* After some advice from her father that he was concerned about their marriage, they repaired the tone of fighting by putting their focus on the kids.

The qualities of surviving relationships. Values, kindness, respect, partnership, and friendship were features of the relationships of couples that had stayed together through and following the cancer experience. One couple said,

We grew stronger as a couple over the course of (child's) diagnosis to now . . . we've seen many families ripped apart by this disease and I'm not sure we ever made an explicit promise to one another but we wanted to make sure that we as a couple and as a family didn't lose one another . . . a very conscious decision . . . even from the beginning we have a very strong partnership and relationship and love and respect for one another but we have certainly grown over time and with each everything we experienced, it just made us stronger and more of a unit than we could have ever imagined and maybe even more than we would have had this hadn't happened . . . From the beginning, we both had very common values in life, we both want similar things, we both believe in treating people with kindness and being good to one another and respect one another . . . we simply really love one another . . . a partnership.

Another couple put more emphasis on friendship, saying,

We were best friends before we started dating. We always had a pretty good marriage . . . ups and downs like everybody . . . but I think we were drifting apart a little . . . interests were changing, doing more things separately . . . no serious rift or anything, just drifting apart a bit and the cancer pulled us back together and made us stronger. Petty issues disappeared; you had to recommit to what you married in the first place. I think we were probably better

friends than we were husband and wife . . . I think our marriage was sustained because we were friends.

Recommitment strikes us as a concerted doing, as action that is taken as part of the path toward trading what used to be in the relationship to that which is sought or desired. To recommit is a conscious decision that can lead to unconscious outcomes, like discovery. We are reminded that not all outcomes of a determined action like recommitting (or even therapy) can be foreseen. In these most precarious of moments, care and sensitivity toward each other are called for.

One couple in our study was comprised of a biological mother and her new partner. The biological father of the child with cancer was only peripherally involved. At the time of diagnosis, the mother feared it might end her newer relationship and, for a period of time, it did change it. However, it was the cancer experience itself that helped to bond the new partner to the child. As they went through this experience and the death of the child, they grew stronger as a couple and had children together.

Another family had a good relationship, characterizing it as “absolutely strong” before but also believed the experience strengthened their relationship and increased their respect for and confidence in themselves and each other.

We were strong going in; we stronger coming out. You certainly wouldn't want to be going into it and being already antagonistic in any way to each other.

It occurred to us some of these conscious decisions and commitments become a sustaining foundation on which couples can stand. As nurses, therapists, and physicians, we cannot escape the implications of this insight: As existing relationships and family units are shifting, being modified, and even falling apart, new foundations are also being built. It is incumbent, then, upon health and social care professionals to attend to helping families to build foundations as they work to repair that which feels damaged, broken, and now incomplete.

The hermeneutic twist: It is not as simple as it seems. Not all couples that stayed together were made stronger by the experience of cancer. Nor were all couples taxed during the cancer experience. One family described their relationship as good before their child was diagnosed:

We met at work and fell in love, madly in love, got married and started a life . . . she was very young . . . I thought our marriage was great and there were just

some problems but all marriages have problems . . . but when I look back, we went into vicious circles . . . we are not fighters, not yellers and screamers . . . but we had heated discussions . . . and then (child) got cancer . . .

When they spoke about the time during the cancer experience, they said,

We grew apart very quickly . . . very quickly . . . her 100% focus was (child) . . . I had to remind her she had another child . . . distance was massive between them and me and her but I put that part aside.

The father in this marriage said that the day his wife told him she did not know if their marriage worked,

was devastating . . . the most devastating thing in my life, the thought of losing her. For her, it was the thought of losing (child). [It was] not necessarily turbulent . . . we'd been through turbulence in our younger years, then settled down period, then kids and not a lot of time for a relationship . . . we didn't have a strong relationship at that point. Nothing bad was happening, no one was doing anything outside of the relationship . . . just a lack of warmth and love . . . I wondered if we would split when kids grew up . . . just kind of a neutral place; not a fantastic marriage but not a horrible one.

In this context, there is something resonant about endurance, about just carrying on. For this family, the path had led to a neutral place that seemed, in many respects to be able to hold, to support the endurance needed to sit with a not-fantastic-not-horrible marriage. Another family stayed together after their child died, but explained,

there was a lot of blame . . . and we had big discussions, like should we stay together? . . . divorce was definitely on the radar screen . . . staying married is too hard of a thing to do and there's guilt and there's blame and financial things . . . we exited life for three months and then said "Oh, things aren't very good between us" because we hadn't paid attention to each other.

Similar to other couples, they described their relationship prior to the cancer as

very normal . . . we were always very close, from the moment that we first started talking to each other; we had a very deep connection . . . not to say we didn't argue or fight but we always had ways to solve our differences . . . very good strategies and were both the type of people that we like to be around each other. A lot of listening; we never went to bed angry, always been very flexible with each other. However, when you go through this and you lose a child you

really change as a person, a fundamental characteristic change because of what you had to do . . . and I think you maybe look at the other person differently, like you don't know the other person anymore . . . you have no idea who she is . . . a whole different person and she is looking at me the same.

It is here that we begin to see the idea of trading identity come forth in a different way. Whereas other couples traded identities or a sense of who they are as a way to navigate pragmatic considerations of family, care, and treatment, these participants seemed to describe trading out in a different way. This was a final trade of sorts, the sense of being fundamentally a different person because of conscious decisions that had been made in relation to navigating the cancer experience.

Some trades were more difficult than others, and in instances where a partner emerged from the cancer experience as a “new” person, there were examples when they were not recognizable to, or even liked by, their partner. Even where there did exist relationship tensions, transactions between couples became more uncertain and concerns and worries, whether real or imagined, arose. One family who stayed together described their prior relationship as very happy and content (although they admitted to some communication problems) for a period of time but then worries about infidelity had entered even before the diagnosis. After the death of their child, they were struggling very much and the decision to stay together seemed to be very much under question at the time of the interview.

She wasn't the same person after . . . before she was extremely capable, outgoing, happy . . . after (child) died, everything's game right? I see him (husband) just trying to cope with me . . . living life by the skin of his teeth, trying to keep all our shit together, looking after family, cleaning house, cooking dinner and he's working because I was not functional.

Even couples that stayed together were not necessarily happy:

We were—we are yellers . . . The social worker took us out of the room and asked if everything was okay . . . told us point blank that 50% of marriages end . . . if the marriage is crappy going into, it's going to get crappier and even happy marriages have a hard time surviving this and we decided at that point we couldn't worry about that . . . if our marriage fell apart, it fell apart but we had a child to save . . . Our relationship was rocky to begin with prior to diagnosis; I don't even know what a perfect marriage is anymore but I know we don't have it . . . so we just clash and it wasn't a good thing to start off with . . . lot of communication issues; didn't talk about problems; not very good compromisers; constantly knocking heads; we fight a lot about stupid stuff . . .

just wasn't a really good marriage . . . we don't talk to each other; we yell at each other . . . but our family survived and we're not pretty by any means . . . we live in the same house . . . we put the "dys" in dysfunctional. Did file for a divorce but cancelled it . . . some laziness thrown in there . . . too tired to do that.

Another couple was still together but, in the interview with the father alone, he predicted that their "troubled and fractured" relationship would not continue, and that is the trouble with a trade. Trading, or walking path, implies improvement or development. One walks from Point A to Point B presumably because Point B contains something that Point A does not, or Point B enables some form of necessary action that cannot be completed at Point A. Trading also involves attending to the manner of life, and life is not linear in the sense of walking a path. Life's path is, instead, convoluted, folds back on itself, and sometimes presents us with Point B before we know our Point A. However, it should be noted that the well-worn path can just get deeper going back to the same place all the time.

There is something instructive in this view for health and social care professionals. The manner or material of life, unpredictable and unknowable as it may be, renders the metaphor of a health professional as guide somewhat redundant. Certain clinical models can predict disease progression, but they cannot foresee other material and relational complexities that occur within families where cancer is present.

The Shape of the Relationship Prior: Relationships That Ended

Four of the parental relationships interviewed ended their relationship at some point during or after the immediate experience of cancer diagnosis and treatment. Where the relationship had ended, participants were, in each case, interviewed individually and were asked about the state of their relationship prior to cancer. For different couples, different experiences had impact on their relationships. For some, it was the big moment that was influential, and for others, smaller events eroded their relationship.

It was the death, not the cancer. One participant spoke powerfully of the experience of the death of her child. She said,

We were starting to feel the effects of growing differently by this point in our life, different goals, we were really great for the first few (young) years . . . but as we got older, our directions . . . we were clearly different. We weren't fighters; we just grew apart.

The child's diagnosis became a reason for the family to pull together, even causing them to wonder if it was a sign to keep them together. According to this participant, they did pull together and were a united front during the course of treatments:

We had great communication skills, together we talk things through, we were always both there, we rotated out . . . (child) never spent a night in hospital without us, so if I wasn't there, he slept there . . . we were like the poster family in a lot of ways . . . shelved all of the relationship stuff . . . it didn't even come into the equation, the only thing that mattered was to get through treatment and make sure the other kids remained stable . . . I never even thought of us and our problems.

However, it was the death of the child that ended the relationship.

Our relationship probably changed drastically the day after (child) died . . . I needed, wanted someone to hold me . . . crying in the bedroom and he wouldn't come near me . . . in hallway in a fetal position and he stepped over me and went downstairs . . . and I'm like, we're done.

In this example, we notice how the couple traded places, they "rotated out" to ensure care for the child and, presumably, some respite and relief for the parent. They struggled to trade in other ways, resulting in emotional and relationship tensions. There are different styles of grieving but not acknowledging each other's pain—closing off to each other—is not healthy. Perhaps the trade here is within a dialectic of acknowledgment/expression and containment of emotion.

Although it may not be healthy for the relationship, containing one's path into emotional territory may be the safest, most containable option individually. The woman participant from this couple said,

He shut it up, closed it, hard, rigid, that's how I describe it. He didn't talk about it . . . He would say it's over, it's in the past; I'm dealing with it, don't worry about it.

The words speak to us of the containment of emotion, but they also simultaneously betray it. The closed up, hard, rigid "dealing with it" is not an absence of emotion; it is a glut of it that sits between the couple, incompletely and unsatisfactorily expressed, perhaps obscuring the path, perhaps in some way further shaping it. The trading shifted in this case, trading sharing for silence, and it was a trade-off that ended the relationship. After the death of their child, they stopped communicating:

we weren't nice to each other anymore . . . we lost the business and I didn't even know about it as he wasn't confiding in me anyone . . . he shut down when (child) died.

When asked how much the cancer experience contributed to their relationship demise, the participant said,

I think if (child) had survived and we made it through that, we would have been closer . . . it was (child's) dying that we couldn't survive . . . He died the day (child) died . . . Our marriage was in the right position to come to an end . . . as a result of her death . . . not because of the cancer . . . if anything the cancer made us stronger.

The metaphorical trade that we speak of is a complex dialectical movement between where a person is and where they want (or need) to be. Similarly, it is a tension between the needs of self, other, and relationship. As with other ways of trading, this dialectical tension is mediated, at least in part, by questions of “what is it worth?” We have seen this question lived out in previous examples of the value of communicating versus staying silent, sticking at it versus leaving and calling it a day, “sticking to your guns” versus giving in, and consciously choosing to love each other when the relationship was the last thing on a couple’s mind. For this most recent participant in our discussion, she left her husband first in her mind, in part because she wanted to model a “healthy” relationship to the remaining children—that was worth more than failed attempts at therapy, no intimacy, and ongoing financial struggles as a couple.

Differences that divide. In the last description of couples that stayed together, we offered examples of how differences worked well together toward balancing and trading off. However, sometimes differences are so extreme or meaningful that balance is hard to find, and no trading space can be created or sustained. This was often the case when grief was involved. One participant offered,

Grief ebbs and flows . . . you never know what will bring on this wave of sadness . . . everyone deals differently . . . I tried to be constructive in my grief and grow in my life, do something that was positive to make what (child) went through to mean something to the rest of the world . . . I have a strong faith and rely on that a lot but my husband has gotten very angry . . . angry at diagnosis and multiplied when (child) passed away . . . I became the target of his anger . . . so I moved out two weeks ago (after a 25 year marriage).

Earlier in their relationship, this participant had noticed her husband was a reactive angry person. During the cancer experience and death of the child, this trait was hugely amplified, such that other people including his family had removed themselves from him. He had previously only occasionally used marijuana and alcohol and this became a daily behavior. Although this couple started counseling a few months after (child) died, it was not successful in helping them reclaim the marriage.

Prior to the cancer experience, in spite of recognizing some anger issues, the mother would have predicted theirs was a marriage that would last but the demands of parenting a child dying of cancer seemed too great. She said,

We really struggled; we processed information differently . . . he did it without emotion . . . and I'd start to cry and I'm thinking, I don't get this. Are we sitting with the same child? . . . really took a toll after a while. We were so exhausted . . . didn't have the energy . . . He was devastated but I was having a hard time seeing that we were ever on the same page. We were a family fractured . . . living apart . . . and we fought a lot throughout the hospital . . . and he didn't want to see his child die . . . I didn't get that luxury of not. We fought through it all . . . same with (child's) funeral. I was mad at him for not sitting there, supporting me . . . I remember screaming at him telling him he was a piece of shit and him telling me I was a bitch . . . for a couple of months after diagnosis, it was just chaos.

Even though this couple recognized their differences and fractures, they did not talk about them. We are reminded of the earlier words of other participants who told us they did not know what a perfect marriage was, but they knew they did not have one. For the couple described above, they forecast for themselves not a perfect marriage, but one that would last. Images of perfect, or even lasting, marriages do not contain the unchecked trading of insults, resentment, and contempt. We wonder about the qualities of helpful intervention, assistance, or companionship when a couple does not know what their relationship should look like. Couples struggle to discover what they need to give in exchange with each other as they trade and look for the enduring, resilient, or even salvageable parts of their relationship.

It appears as though as much as differences are inevitable, there are some that serve the experience well in allowing for trading off and taking turns and balancing out divergent roles, needs, functions, and emotions. Then there are other differences that are too antithetical, that perhaps violate values and beliefs, or that call into question the integrity of the other person. Not all differences can (or should) be overcome.

Not the cancer but doomed to end. The state of the relationship prior may not always be a definitive predictor but there were signs that convinced some that it would not have lasted even if cancer had not entered the picture. One participant stated,

things were pissy already, not bad but he was not a healthy person . . . emotionally . . . a suffering martyr.

The couple married when she was very young. They considered it a good marriage in the first few years, but it began to fall apart with another pregnancy and the relationship declined further with the cancer diagnosis and treatment. Problems amplified after the child died:

. . . he would badger me and try to break my spirit so hard, this was just weeks after (child) died . . . knock me down mentally . . . a mental abuser.

When the mother began a successful career, more distance was created between them; the financial situation slowed the separation but it eventually ended in divorce. She did not believe though that it was the cancer experience that ended the marriage; she believed that it would not have lasted in any situation:

I would have outgrown him . . . our marriage would have ended anyways, probably at a different time, a different place. It may have been sooner . . . may have been later but I can assure you we would not be together today.

Several philosophers and anthropologists have taken up the idea of difference and its significance. Pragmatist William James wrote extensively on difference, maintaining that differences are inevitable but they do make a difference somewhere (James, 1907/1978).

There is very little difference between one man and another; but what little there is, is very important . . . it is not only the size of the difference which concerns the philosopher, but also its place and its kind. (James, 1896/1931, p. 257)

James went on to say,

The individual has a stock of old opinions already, but he meets a new experience that puts them to a strain. Somebody contradicts them; or in a reflective moment he discovers that they contradict each other; or he hears of facts with which they are incompatible; or desires arise in him which they cease

to satisfy. The result is an inward trouble to which his mind till then had been a stranger. (James, 1907/1978, pp. 34-35)

James's words remind us again of the pragmatic potential of trading spaces. Difference has the capacity to trouble us, to construct barriers, and to build tensions that are not only inwardly troubling but also catalytic. Trouble is energetic and calls upon us to act in ways that confront, reduce, and even "play" with it. At times, this energy can be chaotic and unpredictable, meaning that in the context of childhood cancer, couples may require particular types of support as they balance or trade within dialectics of expression and containment, and loving and being "on hold."

Anthropologist Gregory Bateson understood difference to be something that is not considered until it reaches a threshold of an extreme to make the difference noticeable (Bateson, 1979). Childhood cancer is an extreme that pushes thresholds. Differences that might have been below notice tend to surface and sometimes couples are caught off guard and metaphorically "get boiled."

Similarly, it is very difficult for us to perceive changes in our own social affairs, in the ecology around us . . . it is a nontrivial matter that we are almost always unaware of trends in our changes of state. There is a quasi-scientific fable that if you can get a frog to sit quietly in a saucepan of cold water, and if you then raise the temperature of the water very slowly and smoothly so that there is no moment marked to be the moment at which the frog would jump, he will never jump. He will get boiled. (Bateson, 1979, p. 98)

John Caputo, a contemporary philosopher, embraced difference as something akin to a commitment to recognize the other—to notice the difference and find a way to accept the other not just despite of but because of the difference (Caputo, 1993). He suggested that we can embrace difference "without setting foot in the dialectical trap, without springing the door of 'opposition'" (Caputo, 1993, p. 44). Perhaps it is here where we see why some couples used difference to complement and sustain, while others faced it as a divisive force that indicated opposition—a hospitality that admitted a monster rather than a friend (Kearney & Semonovitch, 2011).¹

Summary

Differences can complement and divide; friendships can ebb and flow; values can shift and change; and love does not always sustain the momentum that is required in the difficult work of relationship maintenance. Within this

context, couples are engaged in different kinds of trading that sustain the various matters of life as it is lived in the context of childhood cancer and its treatment. Factoring in then the experience of a cancer diagnosis for one's child and, in some cases, the loss of a child, the complexity of the relationship is layered with things that are at times insurmountable. Some relationships survive and strengthen and some just survive. Other relationships struggle and dissolve.

As stated, it was not the intent of this study to determine which couples would remain in relationship or not, nor was it to determine what factors either predicted relationships sustaining themselves or dissolving. Rather, it was an effort to examine the complexity of how parents were affected and how they may have understood the strengths and challenges of their relationship prior to the cancer experience, during it, and after it. Differences are inevitable and the concept of trading presented as complex and varied. It is a concept, however, that offers insight into the ways in which parents are not only affected but how they respond to the life-changing event of having a child with cancer. In Part 2 of this study, we further our analysis with other interpretations that offer greater understanding, recognizing that hermeneutics is concerned with understanding, not explanation (Moules et al., 2015).

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Note

1. See Part 3 for a discussion of the idea of hospitality in the context of this topic.

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