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Taking One for the Team: Examining the Effects of Childhood Cancer on the Parental Subsystem. Part 2

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Abstract

In this Part 2 of a three-part research paper, we further our interpretations from our hermeneutic study examining how having a child who has experienced cancer had an impact on the relationship between the parents. In Part 1, we identified the focus of the study and provided background to the topic. We also described the research question, method, and design before offering an interpretive analysis of couples whose relationships survived, thrived, or demised. In this article, we extend the interpretations under an overarching theme of "taking one for the team." Here, we discuss issues of changes in focus and roles, and the notions of tag teaming, protection, intimacy, and grieving. We examine the phenomenon of putting relationships on hold, then finding reclamation later. In Part 3, we offer implications of these findings for other parents in similar situations and for health care professionals working with these families.

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This hermeneutic study involved 24 interviews with a total of 30 parents who had experienced having a child with cancer. Ethical approval was granted through the University of Calgary Conjoint Health Research Ethics Board. This study is presented in three parts. In Part 1, we offered the background to the study and a description of the research method (Moules, Estefan, McCaffrey, Tapp, & Strother, 2016a). In that paper, we then analyzed the parents' interviews with a lens on the couples who stayed together and those whose relationship ended during or after the cancer experience. Within that examination, we more closely looked at the interpretations that arose around notions of differences and the complexity of trading. In this article (Part 2), we discuss the overarching interpretation of "taking one for the team" as a way to speak to aspects of experiences: the need to change focus in family relationships, tag team, protection, intimacy, grieving, and, finally, 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 (Moules, Estefan, McCaffrey, Tapp, & Strother, 2016b).

Interpretive Findings

As noted, we began the interpretations of the data in Part 1 of our analysis of this study, where ideas of differences and trading were unpacked. We continue the interpretations here with a turn toward some of the other complexities that parents faced and how they understood what they were facing and responded to the demands.

A Necessary Change in Focus

All of the participants spoke of a profound shift of focus in their lives.

> I never did anything except eat, sleep, and breathe cancer.

Cancer became their worlds and, for most, it took their entire focus to get through it. For some, living with cure but long-term side effects, the care of the child continues to be the focus of the family. This change in focus was not offered as apology but in a matter of fact way: the focus on the child was what had to happen and it was recognized not questioned.

> We didn't have the time or energy to even be concerned about our relationship . . . you're so focused on the one that's sick and you should be.

Focusing on the one who is sick necessitates revision to the way life is unfolding within families and relationships. As the focus shifts, be that gradual or sudden after a diagnosis, the felt necessity to focus on the child that was expressed by participants manifests in changes to rhythm and routine in relationships and family life.

Alternating Roles and Tag Teaming

Trading familiar places for new, trading familiar roles for different roles, and trading time were common experiences as participants adapted their life and relationships in the context of childhood cancer. Many of the participants discussed the value of taking on different roles and handling different things. Sometimes they alternated or sometimes it was a very deliberate division, such as one person handling hospital things and the other managing things at home. In many ways, this mirrors the styles of grieving that Doka and Martin (2010) wrote of: intuitive and instrumental—feeling and dealing with the emotions or action oriented, doing things to make everything run smoother or get by.

> I don't think he was to the hospital more than twice while (child) was in . . . and to this day there are moments when I think "creep" . . . but it was difficult for him to be there, watching (child) in that situation, he just couldn't do it . . . he tried his best. The biggest fight we had is that he kept buying me appliances, trying to make my life easier. He bought me a new washer and dryer! Well it came with a fucking video on how to work it! I don't have time to watch a video! (Laughing)

> I did days; he would spend nights.

> We had complementary skills . . . polar opposites but that worked for us.

> We were alternating twenty-four hour shifts in hospital.

Protecting Spouse and Others

A part of being a family often seems to involve protection, and protecting a spouse from harm, hurt, knowledge, or bad news was important to some participants.

> The day we got the diagnosis was the first time I saw him cry . . . a little teary in the car but found out later he went to the garage and had a break down . . . he was worried about how it would impact me . . . upset me and make it worse for me because he's not really a crier.

> I think instinctively we knew that we loved each other and we knew to protect each other as much as we could.

> There were things happening with (child) and they were a big deal a lot of times but when I explained them to (husband), because he was away, I didn't make them a big deal . . . I didn't want him to worry . . . and wanted him to come home safe, not worrying about it . . . I would dumb it down to him about how stressed I was.

This same mother offered many examples of protecting other families from what they were facing. She did it also when asked how many children she had, and she would not include her lost child to protect the receiver from the information.

The first author of this article (and principle investigator) was reminded of being on an airplane en route to a conference on grief:

> I recall sitting beside a woman who had engaged me in conversation. I asked her how many children she had and she said "one" but I noticed something familiar in her look when she said it and I said "one?" Her response was to say, "that is the first time I've ever done that, denying him. Today is the anniversary of my son's suicide 5 years ago. I always say he's my son but I read an article in a magazine that to tell people such things is like 'emotional slutting' and you lay things on innocent bystanders that they don't deserve to get." This open and frank admission allowed me to tell her of the work I do and my beliefs about grief and we spent two hours in a powerful conversation. I asked her permission to tell her story at the conference and thereafter, telling her that it had a poignant effect on me.

The intent to protect, though rooted in good intentions, can sometimes (though not always) be misdirected and not necessary. Discernment about who, when, and why to protect was an interesting negotiation with these participants. It was often an internal negotiation rather than negotiated between partners, a decision based on their somewhat unquestioned beliefs and a decision that often led to a sense of isolation and loneliness.

Couple Time

For some participants, their relationship rhythm altered in a way that meant they either voluntarily or involuntarily reduced the time they spent together as a couple:

> We never really felt the need to . . . didn't want to be away from him too far . . . if someone said "hey go away for the weekend," I don't think either of us would have been comfortable to want to do that . . . we wouldn't have relaxed.

There were stresses on the relationship for all the couples; having a child with cancer is a stress. Some worked it out by putting the focus on what had to be done; some talked it out:

> (Child) was at camp and friends gave us their condo in the mountains for the weekend and said "Go. You two need some down time." And we went and we had a long talk . . . that weekend got us back together (emotionally) and recognizing that—because it did, him not coming to the hospital did bother me. I understood but it still pissed me off . . . we got time to talk.

> It wasn't important to get away . . . mentally we couldn't leave (child). We were given tickets to a hockey game but all we did was talk about (child) the entire time we were gone.

> Every once in a while someone would say we'll watch the kids, go out for dinner and we'd do that but we would end up talking about (child) and the cancer.

Having time away from the hospital, from the immediate practicalities of being present with the child and participating in their care, is one thing. It is possible to create physical "breathing room" and we have heard examples from participants about how they did this by taking shifts, giving each other room to attend to other aspects of family life. When both parents leave, however, the experience seems to be different because the couple are not emphasizing their own needs:

> We weren't focused on our relationship. We were focused on our family. It wouldn't have helped to have time away alone.

Even when alone-time for the couple may be desired, such as in the account offered by a participant below, it may not feel like a comfortable or natural experience:

> It's a very isolating experience and we were lonely for each other but the advice to find time for each other is ridiculous . . . go on a date in the middle of this?

We wonder if alone-time feels, in some way, like an indulgence, particularly when, as one of our participants stated, there is uncertainty about how much time they will get with their child:

> I certainly didn't feel like I needed any time away from the kids . . . not knowing how much time we actually had, we wanted to make the most of everything. It was financial, fatigue but mostly we just didn't want to leave the kids.

For another,

> It wasn't even on my list of priorities . . . no desire to be alone with him

Through most of the discussion about couple time, there were some people who thought it important and they did recommend it as advice for other couples, but there was a sense that cancer is not a particularly good dinner date and when the direction of focus has changed and is in motion, it is hard to take one's eyes off the road directly ahead. We see this creates tension for health care providers who may recognize a couple's need for time together. The idea that couple time is ridiculous sensitizes us to the need to learn about the parental subsystem in such a way as to make suggestions that are welcome, helpful, and sensible rather than that appear ridiculous, strange, and unwelcome.

Intimacy and Sex

A recent qualitative study conducted in Brazil suggested that intimacy and sexuality can be negatively affected by childhood cancer (Silva-Rodrigues, Pan, Sposito, de Andrade Alvarenga, & Nascimento, 2016). Issues of intimacy can be uncomfortable for couples to articulate and address. Intimacy can be equally difficult for health and social care professionals to raise amid competing care demands. Although a sensitive question to ask, we felt obligated in this study to inquire into how the experience had affected or still is affecting participants' relationship intimacy. Intimacy was termed as emotional, spiritual, and physical, allowing the participants to answer with what fit for them. One couple told us,

> It certainly was not on my list of priorities . . . it wasn't convenient . . . so tired . . . just let me sleep (wife stated this but husband stated) . . . probably a diminished interest, but not totally gone . . . but not a point of contention.

When asked if there had been noticeable shifts in intimacy, they said,

> we were rarely home together and when we were, we quite often had her in the middle with us . . . that got shelved too. We became roommates not romantics. There was none . . . you didn't focus on the relationship . . . we were always hugging and we liked to dance but sexually, pretty well nothing . . . it just fell off or you're so exhausted.

One family became pregnant while their child was in hospital. They had discussed their lack of intimacy in counseling and they made the effort, but it *was* an effort:

> I just went egh . . . I was in survival mode and nothing was big on the scale except (child)

The mother was very upset finding herself pregnant but father knew it was

> a blessing. I knew it would help break her mind thought of (child) . . . because no matter what, eventually she was going to have to start worrying about herself right?

The mother had to stop being present at X-rays and CT scans but she also started going to her own ultrasounds and eating properly. When the new baby was born, what happened to this family was powerful. The sick child who they anticipated might resent having a new baby

> loved him so much; I still remember the look in his face and I looked at (child) as a big brother now instead of my sick little baby . . . it was a flip mentally for me.

The lack of intimacy led one family to a near marriage breakup. The man wanted more intimacy, sex, but not just intercourse—hugging, kissing. He said,

> I quite honestly felt if we did make love it was because she had to, certainly not because she wanted to. I lay in bed many, many nights just turned over going "maybe tonight's the night she's going to touch me, she's going to instigate something" and every night it didn't happen . . . she didn't feel any romance.

This led the couple to a counselor who they attribute as saving their marriage after two visits. He advised them to make time for each other, set goals, schedule sex, but not to force it during times of the cancer crisis (at this point the child was past treatment but still requiring major care because of ongoing disabilities). They reported that he helped them not only find each other again but also find themselves as individuals.

Discussions of intimacy and sex reveal how, amid childhood cancer experiences, aspects of family and couple's lives become something a performance, reduced to routine in order to get the job done and save focus for their child. In many dimensions of couple's lives, this seems to work to different degrees. Sex and intimacy draw our attention to the instability and tenuousness created

and sustained by the performance. Parents need to respond to the directions they are given: be at the X-ray on cue, be sure to hit the mark, stand in the right place, take the role of lead actor for their child, and play supporting cast for physicians and nurses.

> The last thing you want is sex . . . like oh are you kidding me?

In these circumstances, it is easy to see how a person may lose a sense of integrity as a parent and as a person. Intimacy suffers when a sense of self is called into question and spontaneity of intimate and sexual expression gives way to having to perform. In private, once the script falls away, perhaps couples do not recognize their cues to enact and sustain intimacy.

We have already been clear that trading requires a space that supports the transaction between people. A couple's bed is an important space in which the emotional and sexual bonds of a relationship are exchanged. Having children and making a transition from a "marital" bed to sharing a family bed can begin to shift how sexual intimacy is experienced. Another family spoke of how their decision for a family bed interfered with their sexual intimacy. The father found himself feeling rejected,

> especially when they were very young and breastfeeding . . . I felt I was being sort of separated and sexual activity wasn't available because of the kids . . . but we were both disconnected about the amount of sex we weren't having and unable to work out what to do about it . . . and then there was a kid with cancer between us . . . it felt like she was kind of substituting (child's) easy and plentiful physical affection for the possibility of any physical affection between the two of us . . . and we haven't had such a very happy reconciliation . . . I still have sexual stirrings but they don't often go in her direction.

When physical intimacy starts to diminish, it can be an effort to return to a mutually satisfying sexual relationship. Sex becomes a demand, another aspect of the relationship that needs to be performed and, as such, a chore. Rather than being a means to reconnect, to comfort, and to experience bonding, physical release, and playfulness, sex becomes something to be avoided:

> Physical exhaustion, you're not even friends with each other . . . I told him to stay away and that I deserved a bit of down time.

Other couples thought about this differently, and spoke in ways that revealed a sense of loss of the sexual side of their relationship:

> We hardly slept in the same bed together . . . that was really difficult, not spending quality time together . . . weren't able to be intimate very often . . . it

> was something we accepted . . . and we knew it wouldn't be forever . . . we would talk about I miss not having you at home, I miss being with you in bed and even just saying that was a good thing . . . to let the partner know we did miss not being intimate with each other.

Perhaps just knowing someone wants to be intimate with you is as meaningful as actually being intimate (Basson, 2001):

> Because even now with three kids, it's not often that you find the time . . . so we say we really need to get naked soon . . . let's make this happen.

One relationship had been having trouble, and intimacy had decreased prior to the death of their child. After the child died, all physical intimacy ended:

> We were intimate inside the hospital . . . a bathroom . . . found ways but after she died and I have PTSD, I'm on medication so the physical intimacy never really came back up because it decreased my libido . . . really scared of having another child who could have cancer.

Similar to our discussion about shifts in couples' foci, many couples reported that their sexual relationship changed since having children and continued into the cancer experience. One mother recognized that although she did not have the desire, her partner did. She said,

> Sex is a way that he feels connected to me and he feels closer to me . . . but it's kind of remained on that same sort of pattern before the cancer after we had children. I had sex to try to keep things as normal as possible for everybody. Lack of intimacy didn't start because of (child) getting sick—it probably started with having children.

A husband in another couple told us,

> There's no physical contact; you kinda see each other, like a kiss and go sort of thing as one goes out the door the other's coming in. She viewed the physical relationship during it all as weird and for a long time after (child) died, sex was a fearful thing for my wife because she thought she might get pregnant again and have another child that would die . . . so from the sexual perspective, it just kind of all went away . . . it's improved over time but it's still an issue.

The tie of biology sometimes overshadowed the enjoyment of sex: Sex begets children and children can get cancer.

Another aspect to consider is that much of sexual attraction is based on the realization that someone desires you (Giles, 2015). For sex, attraction is often

sufficient for short-term physical engagement and release. For a longer-term, more committed sexual relationship, that attraction is sustained by feeling desired and wanted:

> She just was not into it and I think OK, she's not into it, then I guess I'm not either. It was almost like a guilt . . . we're gonna have fun? We can't have fun with all these terrible things that are going on. You feel guilty.

Even though the space is a private one, the couple are, once again, on a stage. The mood of this particular scene is more muted, subdued, and disconnected. For many families, guilt seemed to play a major part in the diminishment of intimacy. When a child is suffering, dying or has died, the pleasure attached to sex can produce guilt. The experience of pleasure may also imply to a couple that they must not care for or love their child enough because if they did, they would not be experiencing joy. This is consistent with the grief research we have conducted, with guilt arising as the handmaiden to grief (Moules & Amundson, 1997).

Taking one for the team. A provocative expression from one participant, although offered in a joking way, really spoke to us in this research. She said,

> It's affected me and nothing affects his (sexual desire) . . . but we still . . . I'll take one for the team (both laughing). We still have sex once a week.

On paper, it sounds uncomfortable and raises issues of power, control, and other gendered nuances, however, in the actual interview, it was said and received with much mirth and teasing, even affection. It had obviously become a joke between them that may not have accurately reflected their actual sexual relationship. However, although this couple was talking about intimacy and sex, we found that many of our findings in this study were, in different ways, about family members taking one (or more) for the team. They compromised, protected, sacrificed, and put relationships and personal needs on hold. The family, as a team, required this kind of sacrifice and giving.

Relationships in general involve many different kinds of sacrifice, but there seems to be a difference in the kind of sacrifice that happens when cancer is present. Perhaps, it is a sacrifice people start making without consciously agreeing to it, or working it through first. Indeed, cancer and the resultant treatment trajectory does not wait for people to "figure out" what they are going to do, negotiate their game plan, and make sure everyone is on the "same page": sometimes, there just is not the time. In this case, sacrifice

is an emergent and almost pernicious experience. It is another hostile guest that demands hospitality.[1]

A New and Different Intimacy

This research has led us to challenge the notion of intimacy as something that exists between a couple in emotional and sexual ways—for many of these couples, intimacy was relocated in the new focus on an intimate commitment to do well by the child and family.

> Finding time for each other . . . in the midst of what you are going through seems ridiculous . . . are we actually going to go out on a date in the midst of it? Our goal was that she was never alone . . . we were both very unselfish when it came to her, like she was number one and we did everything we had to do for that whole year and sacrificed whatever we needed to, especially when it came to emotional intimacy.

There is even a new intimacy with strangers such as other parents:

> I found you have this oddly intimate relationship with strangers because they understand your cancer journey in a way that your friends and family never can. These are people who really know about what's happening in your heart, but they're probably not going to ever come to your house. It's strange, but it's often necessary, I think.

For some, new kinds of intimacies were also formed with health professionals:

> For parents, it's being thrown into a vortex that they had no anticipation was coming and that sometimes the only thing that tethers them are the relationships they have with the hospital staff . . . the stray people through whose hands we pass.

The importance of being aware of intimacy and the way intimate relationships can shift in abject experiences such as childhood cancer is emphasized in this quote from one participant:

> (Husband) was like a stranger . . . all my people in my life were the nurses and to a certain degree the doctors . . . when I moved back home after a year I felt really shy of him; it was unnerving to be with him; awkward and shy; weird to live with a man . . . he was my husband and I knew I was meant to love him and I knew who he was but it was like a form of him . . . I couldn't believe I'm expected to sleep in the same bed with this man.

It is important for those in helping relationships with parents who have sick children to recognize that intimacy is an effect. Our perceptions of intimacy and our desire to act on feelings of intimacy are directed toward those who are the most important to us. Those whom you allow to touch your face, for example, are often those who share your table at Thanksgiving and your bed at night. Those with the power to care for and cure a child occupy deeply intimate space for parents. Knowing this reminds us that while we care and cure, we may also need to name our presence in ways that make intimacy available, a possibility for the parents of the child.

Up to now, we have discussed intimacy and sex, but intimacy is not reduced only to sexual relations between couples. Participants in this study were clear that being able to sit and cry together or to hold hands is a different but important kind of intimacy. They said,

> I don't care what we do as long as I get to hold your hand.

> We became more mentally intimate through this process but we became much less physically intimate . . . in fact physical intimacy went away for a least 6 months . . . we attempted it but doesn't work when you're never at home . . . No actual intercourse happening but there was lots of touching . . . like I'd rub her feet for an hour . . . just touch her.

In a recent study of grandparents' experiences of childhood cancer, grandparent talked about how they adapted to a new normal (Moules, Laing, McCaffrey, Tapp, & Strother, 2012) and this idea of a new normal was also discussed by West, Bell, Woodgate, and Moules (2015). We see something of a new normal for intimacy in the above example. In this way, intimacy is not lost, sacrificed, or an indulgent burden. For the couple above, intimacy just happened differently. Another couple said,

> The new normal came around with new routines. We were a family separated physically but not emotionally. No sexual intimacy but we were pretty tight.

Many parents indicated that having a child experience cancer or, in some cases, having a child die was the most intimate thing they had ever experienced as a couple. This is an exquisite and painful intimacy that makes possible different understandings of why some couples may survive and even thrive following childhood cancer experiences and why others may struggle and end.

The promise for understanding of exquisite pain is revealed in such notions as "the worse the breakup, the better the ballad." The word exquisite has a

Latin root and pertains to that which is carefully sought out. Exquisite pain is, then, a distillation. The exquisite and painful intimacy of experiencing a child's death holds within it something vital about human experience. Its emergence is a deeply hermeneutic moment, both a reaching out and a meeting that creates powerful connections and moments of understanding that can become a very uncommon bond between couples.

Reclaiming the Relationship

> We are a grieving, surviving family

Throughout most of, if not all, of the interviews, it was clear that the couples very consciously put their relationships on hold, but with a sense of trust that the relationship had enough strength to survive and there would be opportunity to reclaim it. Although for some couples there were lasting changes to the ways they experienced their relationships, for others there was a sense of need to return to a relationship that was familiar, knowable, and workable. Whatever the outcome for these families related to the cancer experience, there was a point where the couple relationship came back into focus and this often was not without some form of a recalibration. Some relationships found the reclamation difficult:

> the after effects are whatever they are, but about a year and a half ago we were seriously considering divorce . . . an utter and complete shock to me (father). We thought everything was okay because he was alive . . . but really the break that put between us was something we didn't see for years to come . . . a rupture that wasn't repaired (mother) . . . neither of us even saw it as a rupture at the time . . . we didn't see it until years after the fact, when I was getting attention from somebody else . . . it wasn't the person but the attention.

This couple went to counseling and realized that

> we're good at talking to each other but we didn't realize we weren't good at listening.

Again, differences arose in the couples around their timing and pacing of the reclamation. Sometimes the reclamation of the relationship happened simultaneously with the family as a whole, returning to a state of normal or new normal (Moules et al., 2012; West et al., 2015).

> Coming home was hard . . . I remember not wanting to leave the hospital . . . you get in that habit right? It's like Stockholm syndrome . . . you don't want to

> leave your prisoner . . . but we started to do things as a family . . . be more adventurous.

> We needed to withdraw a little and then come back. Heal yourself, then you have to heal the relationship.

After a disengagement and dissent during the cancer experience, one couple was able to reclaim their relationship:

> He's one of the good ones . . . the whole relief helped us to relax a lot and we could breathe a little. We got through it. That's what parents do, they get through it one way or another. I shut down emotionally . . . but he becomes a doer. He'll do anything for me; he's not a great talker, but he will do anything for me. Which is pretty awesome. Since the funeral, I find that we're stronger than ever. We're still together . . . he appreciates me more for being involved in the kids and I appreciate him more for understanding . . . he says sorry a lot more . . . apologizes for not going to meetings with doctors . . . he's more open to me, cries a lot more.

For many of the families, the reclamation involved a simultaneous living with grieving.

Grieving

These accounts serve to remind us that grief is a part of the landscape of childhood cancer, whether or not the child dies. Families grieve for their lost children, and they grieve for the loss of their children as they were prior to the cancer experience. The families who lost their children, however, tended to focus more on discussing grief in the interviews than the families who did not. Some of the participants said,

> We did grieve at different times and it seems like usually I'm sad at a different time than he's sad, so it kinda works out that the other person's just there to hug and hold you.

> We grieve differently and he said if you're not over it in ten years, we will have problems

> The one thing you're going to find out is that everyone grieves differently . . . I had to be very mindful of how I was dealing with it and how it differed from how he was dealing with it and how the girls dealt with it . . . He would zig and I would zag, so we never both had a really bad day at the same time . . . took

> turns with bad days . . . One would be up, one would be down . . . it was a kind of conscious decision off the start (child died).

> If (child) had died, if I lost her I don't think I would have cared about my marriage, about anything.

> We've created a huge amount of resentment and bitterness . . . we didn't talk to each other for about a year, even though we lived together . . . we said "we should split up" but we went to a counselor who saw it as a grief issue . . . but that counselor didn't really help.

> You're going to grieve differently . . . it's like skating on ice . . . you can function above the water on the ice when it's solid by skating around and every once in a while you can sort of get up to your ankles when you run into a soft spot in the ice and it's slushy and every once in a while you break through and fall in.

We offer that, in skating, especially learning how to skate, one is also moving faster than normal, only ever partially in control, always looking ahead, and conscious of if not preoccupied with technique. Adding to this sense of things happening a little faster than normal, one couple said:

> We don't grieve at the same times; you're never in the same place at the same time

For one family that was struggling, it was the death of their child that brought them together.

> Death is not that unlike birth. Death is a kind of an event that should be honored and he and I nailed that one really well. Together . . . I feel like our marriage is so much more wonderful and stronger now; we're pretty nuts about each other . . . is so surprising for me when the kids were little, I would never have thought we'd make it. I've always been absolutely enthralled, in love with my husband and that's never wavered. I think my sadness is that I felt he didn't love me . . . I think very differently now. I think he loves and appreciates me very much.

This participant's sentiments resonate for us with the idea of exquisite and painful intimacy. The honoring of the death of child, thinking of it as an event akin to birth and feeling though, as a couple, they "nailed" that experience enlivens and celebrates the hermeneutic possibility of this tension filled, but generative, dialectic. Other participants show us that this experience is not transcendental, but more likely the result of considerable effort and more than just a little trial and error:

> It was almost like going through a dating process all over again . . . going to quiet places where the two of us could be together and try to talk about stuff as much as possible . . . like getting to know each other again . . . getting to know how our new personalities with each other were again . . . and then planning a life without (child). Our lives are never ever going to be the same and in a way, it's almost a gift now cause our relationship is so strong now . . . but the dates that we went on was having to hash all of that out . . . you know what are your likes and dislikes, where do you wanna go, what do you wannabe, what kind of work do you want, how are we gonna make money, where are we going to live? We had to recover the relationship after (child) died. I can't imagine my life without you cause you're the only person that knew (child) the way that I did. She's the only person that has gone through that experience and understands life that way that it is now going forward . . . and the memories and being able to look at the pictures and the context behind the pictures . . . without each other, (child) dies all over again.

Dating after death or after the experience offers one view of what recalibration might look like. It is not just returning to what was previously seen as normal but also recognition that each are changed in some way that necessitates getting to know each other again. This reminds us that, in the cancer experience, the people you know and are closest to can so quickly become strangers.

Grief is a complex private, relational, and communal experience. It is beyond the scope of this study to review all of the literature and research on the grief experience.[2] What is remarkable here is the emphasis on recognizing and accepting different styles of grieving and different patterns, timings, and expressions of it. Doka and Martin (2010) have aptly shifted from a gendered view of grieving (female/male) to one of recognizing that individuals lean toward particular styles of grieving and, within the leaning, can shift from one to the other. These styles are named "instrumental" and "intuitive" and are characterized by working through grief by attending to things to be done (instrumental) and feeling grief at a deeply emotional level (intuitive). These authors also pointed to the idea that most people are capable of moving between the two and existing somewhere in between them. The difficulty at a relational level can come when the styles between individuals create misunderstanding and even conflict.

Summary

Parents described different styles of coping, which led to the interpretation "taking one for the team," with implications of common cause, sacrifice, and mutual recognition shifting in response to changing needs. These elements emerged across a temporal arc from having to abruptly reconfigure roles

within the relationship in the light of a child's cancer diagnosis, to reclaiming the relationship following resolution of the cancer episode (whether by complete recovery, complicated recovery, or death). Along the way, the parental "team" distributed responsibilities in ways that were driven by economic necessity and schedules, as well as personal values and priorities. Where relationships survived, parents often appeared to have had a high degree of mutual understanding of each other's contributions and sacrifices to the team effort. Intimacy, sex, and couple time were all areas that at times called for "taking one for the team." Another area of reciprocal understanding was allowing the other partner her or his own way of expressing emotion, at times seeking protection, or accepting different ways and times of grieving.

Teamwork, interpreted as a sensitive, dynamic interaction of coming forward and holding back in response to changing needs, may be an interpretation that is of value to health care providers as well as parents. In Part 3 of this research section, we discuss the implications of this study for other parents and for health care professionals.

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Notes

1. See Part 3 for a deeper discussion on the ideas of hospitality, hostility, host, and hospitals.
2. See, for example, the work of Attig, Doka, Moules, and Neimeyer.

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