

Examining the Effects of Childhood Cancer on the Parental Subsystem: Implications for Parents and Health Care Professionals—Part 3

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Abstract

This article is the third part of a hermeneutic research study examining the impact of childhood cancer experiences on the parental relationship. In Part 1, we offered an exploration of the phenomenon with background literature; a description of the research question, method, and design; and finally a discussion of relationships that survived, thrived, or demised, with an emphasis on the notions of difference and trading. In Part 2, we furthered the interpretations to look at the complexities of issues such as teams, roles, focus, protection, intimacy, grieving, putting relationships on hold, and reclaiming them. In this article, we discuss the advice that the participants offered us and how that advice might have implications for other parents in similar situations and health care professionals working with families experiencing childhood cancer.

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Recognizing that childhood cancer has profound relational impacts on individuals and subsystems in families, we undertook a study to examine the effects of it on the parental relationship. In this hermeneutic study, we conducted 24 interviews with a total of 30 participants consisting of parents who had experienced having a child with cancer. Ethical approval for this study was granted through the University of Calgary Conjoint Health Research Ethics Board. In Part 1 of this research report, we offer the background and literature review of the topic area, and describe the research method and design (Moules, Estefan, McCaffrey, Tapp, & Strother, 2016a). We also examined the data with a lens on the couples who remained together and those who did not. In that article, we particularly speak to interpretations of differences and trading. In Part 2, we extended the interpretations to speak to aspects of teams, roles, focus, protection, intimacy, grieving, and finally putting relationships on hold and then reclaiming them (Moules, Estefan, McCaffrey, Tapp, & Strother, 2016b). In this article (Part 3), we discuss the findings of the study as described in Parts 1 and 2, and offer implications for parents who have a child with cancer and for health care professionals working with families in this area. These implications arise from the parents in this study and our interpretations of the wisdom they imparted to us through their participation in the study.

Discussion: Implications for Other Couples and for Health Care Professionals

In this coming section, we begin to think about how the experiences of participants in this study may be invited into broader conversations about how to understand childhood cancer experience; the experiences of parents of children with cancer; and the ways that health and social care professionals may take up helpful positions upon the landscapes within which parents trade, negotiate, and recalibrate their relationships. In the course of this endeavor, we are reminded that interpretation “offers a plausible and prudent response to something, but it does not offer a final answer” (Moules, McCaffrey, Field, & Laing, 2015, p. 135). This study is thus not an ending, nor a conclusive assertion of what people need.

Hermeneutic research does not presume to speak for the other. Instead, we believe the implications or utility of this research lay in a care-full engagement with the expertise of participants. With this in mind, we asked all of the

participants what they had learned from their experiences that might be of use for other couples to hear. As well, we asked them for advice they might offer to health care professionals for practices that might have been helpful and not so helpful in regard to their own relationships.

Advice for Other Couples

Through hindsight and reflection, participants were quick to identify things that they either had already or would wish to impart to other couples facing an experience of childhood cancer. There were differences and similarities across the interviews, but these were the eight predominant things that arose in this inquiry.

Faith. Many families spoke to us of the need to hold on to their faith in both a higher power and each other, and sometimes even the oncologist.

Any sort of faith, even an agnostic belief that there's a greater power; that life goes on . . . life after death . . . that's a big part of maybe not feeling as much pain . . . that you'll see your loved one again.

Faith . . . no matter what your faith is, no matter what it is, you have to rely on something beyond.

Grab hold of a chaplain.

Don't give up each other.

Put your oncologist in charge. We idolized our oncologist . . . psychologically we had to do that to get through . . . we joked that we were the parents but she (oncologist) was the overriding parent . . . whatever she said goes; she made all the decisions and we just followed. And that took a lot of pressure off of us . . . she had to be the person in charge.

This is an interesting twist. We often assume we should defer to the parents' decision making, but this reminds us that sometimes they want to be able to have permission to let that go and put themselves in the hands of a trusted oncologist (or nurse). Later in this article, we take up this idea in an interpretation of ways that health professionals can respond and engage helpfully with parents.

Counseling. Some families recommended good counseling during and after the experience. They said,

Find someone that connects with you. Just get help . . . like counseling or support . . . make sure you make your relationship not a priority but a focus . . . you can't ignore it; tell each other exactly how you are feeling. Go for counseling to have them check your relationship temperature rather than getting stuck in a vortex.

You don't know shit . . . go out and find help . . . You can't do it by yourself. You're not equipped to . . . but there's lots and lots of good people who are more qualified, who do research like you guys are doing who can say here's some strategies.

It appeared as though support can also come from other sources.

Get support from organizations. Find an online support network . . . it's huge . . . people I've never met know me better than my husband does.

Faith communities, social media, and support groups were offered as examples, and it was clear that participants felt as if counseling support could come from different places and people. In many ways, the parents suggested that it was important to be able to recognize and accept wise counsel when it comes their way regardless of the source. We noticed that some participants sought out professionals "like ourselves" who can offer parents strategies. In a forthcoming interpretive turn, we consider the qualities and attributes of the professionals who might become privileged insiders in the experiences of parents whose children are diagnosed with and treated for cancer.

Communication. The recommendation of communication was emphatic. Participants said,

Communication before anything else; take time to connect; talk to other people with similar experiences.

If you're coming in with any difficulties or challenges in your marriage, address those early on . . . because you won't have energy or time during.

Go through all of it together and be open about what grief is for you; talk to each other and to others.

Get mentorship from other parents informally, not a support group. Learn to communicate. Don't be afraid to communicate your fears. Don't be afraid to ask for help. Don't be afraid to ask questions. Communication is key.

Communicate; share a journal, email each other, get guidance from someone . . . very often the social workers worry mostly about the cancer and don't want to intrude on your relationship.

Try to be at every important meeting with your oncologist together . . . so you don't have to share that bad news when you get home. You don't have to be the bearer of bad news . . . so sometimes even (child) would say "mom you don't have to tell dad, I will." Talk about the decisions. Talk and talk and talk and be fair with each other. Nobody caused this disease. Be each other's friends and confidantes. Share and trust.

You have to talk to each other. Be each other's best friend.

Expect differences and hard times. Experiencing childhood cancer is hard on families and differences arise; participants offered advice around this. They said,

A lot of parents said to me that they were never in sync with each other . . . don't expect to be . . . but you have to be for the big decisions. But know you're going to grieve differently than each other.

Know your own management style and how you deal with stress as a couple.

Learn how to tag team during it all; if you have other resources like family, get some respite; grandparents! . . . even just go for a coffee and have a break.

Relating to our earlier discussion on naming the difficulty, several parents were very clear that the naming of what they are undergoing was useful.

Advise them to expect that this is a trauma.

In regard to differences in grieving, parents suggested,

Don't judge each other on the quality of each other's grief . . . because now not only did your child die or your child is sick but you're also judging the other person who is the best in trying to deal with it.

Be on the same page. In the midst of differences and hard times, couples discovered that things went smoother when they were on the same page about major decisions and even discipline:

It's a big deal to be on the same page about discipline . . . when we disagree on something, the first thing I do is shut down.

Although this was offered as advice, earlier participant accounts showed how being on the same page did not always happen. Sometimes, differences were tolerated, but at times, these differences were important sources of division. What is important here, we believe, is the aspirational message being conveyed. Being on the same page is not only about agreement but also about trust, support, and confidence in each other. These are important attributes in relationships where difficult and sometimes heartbreaking decisions have to be made.

Steal time for yourselves. In spite of the fact that most of the couples were clear about the fact that their focus was (and needed to be) on the child (see Part 1 and Part 2), some did recommend that some time alone was important. Some offered the advice:

Steal time to be alone for the two of them or the other kids . . .

However, this same mother also stated,

But if someone would have told me in the beginning to try and steal some time away and (child) was staying in hospital and a nurse said “you know what? We’ve got everything handled, you go home.” I would have said “step out of my way! My kid, backseat, girl, I’m staying.” No one would have been able to push me out of the way.

Perhaps it is an issue of timing, of where the family is at in the cancer experience. There was something about children’s cancer camp that allowed parents to let go and attend to their needs. Children’s cancer camp seemed to be a safe and comforting respite for most families, knowing their child was being well cared for and having fun allowed them to take time to themselves without guilt or worry.¹

Have some time alone . . . that’s one of the huge things about kids cancer camp . . . that was the only time we were ever alone . . . and just talk even when it’s the end of the day and the last thing you want to do.

Camp gave many families respite, time with their other children, and time with each other.

Send your kid to camp. Go and play in your own city. Go out for dinner every night. Enjoy a bottle of wine every night because they are looking after your kid in camp. You don’t have to worry.

Humor, connection, and kindness. There is something very powerful about the connection that both humor and kindness brings us. Humor is hermeneutic in its truest sense; what we find funny is about recognition and kinship, finding ourselves and each other very present in human conditions that call forth laughter and tears in the same breath. There is a kindness in this. This is a balance that for many sustains us. In the worst imaginable situations, it is often humor that grounds us and connects us to each other. There is other evidence, from biological research, that suggests that laughter can release endorphins that reduce physical stress and increase pain thresholds, as well as confer various psychological benefits (Bennett, Zeller, Rosenberg, & McCann, 2003; Dunbar et al., 2012; Mahrer & Gervaise, 1984).

Acknowledge this is going to be stressful. Be kind to each other. Stick together. Do some gestures of small pampering. Don't expect that you are your only friends . . . that kind of expectation is dangerous . . . utilize other people. Keep your sense of humor. It's easy to look at another couple and to be able to say "they're going to be okay because they know how to laugh."

You really have to talk and be willing to talk about the dark, scary places; be forgiving of each other; keep your sense of humor. Be each other's best friend.

Someone once asked me if I still loved him and I don't think I love him as a husband anymore, granted he's a person, he's the father of my children . . . he's a funny guy, he still makes me laugh. He made me laugh the first night I met him and he still makes me laugh. Don't lose your sense of humor; remember how to laugh. Just talk to one another; realize you have to take on different roles . . . no two people are going to do it exactly the same way; just try to be there for each other as much as you can because it's a lonely, lonely place.

There are going to be days when one of you is not going to have a good day . . . respect that, don't hold it over them or blame them . . . just help them get through it and be kind about it. Stay in the day and don't think too much ahead; take time for yourself; it's going to help you take care of your marriage.

Be gentle with each other . . . use counseling when it's appropriate . . . maybe have a date night . . . don't get psyched out by what you're told. The numbers psyched me out big time.

Intimacy. Intimacy, in its many forms, was seen as important advice to offer. For some, this intimacy meant sex:

Schedule sex. Having sex brings you closer to your partner . . . it's the last thing you want to have and it's probably the first thing you should because it brings you closer and you can communicate better.

For others, intimacy was not just sexual. As we discussed in Part 2, there were changes in intimacy and new kinds of intimacy evolved. Some of the advice to other couples included,

Something as simple as holding the other person's hand can mean the world, sitting and crying together.

One insightful couple suggested the idea of taking off the pressure of the changed forms of intimacy and perhaps the temporary changes in sexual intimacy. This study led us to consider a dialectic of a sexless intimacy and the ways that health professionals can help couples to explore the experience, rewards, and limitations of changes to their expressions of intimacy:

One of our former oncologist was always worried about intimacy . . . you know the idea of having sex . . . Like how could you have sex when your child was that sick? It's like blasphemy . . . so my advice to other couples: don't feel bad about not having sex!

Advice for Health Care 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.

As powerful as this quote is, we offer that the people who work in pediatric oncology are not usually "stray." They are known and unknown persons who know something and are there for a purpose. They strode into this field in many cases intentionally, and although they may feel "stray" to the children and family, they are, for the most part, there purposefully. What is interesting in this participant's quote is the realization that it was the relationships with the health care professionals that was the "only thing that tethers them." This sense of being tethered, grounded, and taken care of by the health care professionals has been explored in other studies such as Robinson's (1996) study on families' experiences of nurses being "mirrors for family strengths, compassionate strangers, nonjudgmental collaborators, and curious listeners" (p. 152). Moules wrote of the role of listening to suffering as acts of compassion that allow health care professionals to "hear the cries of the wounded"

(Moules, 2002, p. 106) and to “suffer together” (Moules, 1999, p. 257). A study in Australia examined the desire of oncologists and oncology nurses to involve families in cancer consultations and a belief in the benefit of family involvement (Laidsaar-Powell, Bulow, Bu, Fisher, & Juraskova, 2016).

In the interviews in our study, we asked each participant what kinds of advice they would offer health care professionals in terms of guiding them toward useful practices with respect to attention to their couple relationship. We received the following kinds of advice, much of which was echoed by almost every participant.

No one inquired about our relationship with the exception of our family physician who would often ask how things were going with us relationally . . . our grief. When we said we were waiting for the pain to go away and the doctor said “do you really want it to go away?” That was profound and I realized I just wanted to fix things but you can’t . . . and grieving him . . . those painful experiences from time to time, I really revise my love for him, how much I loved him and it makes him real again.

I would be so offended if someone told me at the initial diagnosis of our child to get our marital affairs in order, and hopefully your marriage can handle this . . . who the heck are you to tell me this?

If you were to tell me that day “you better get your shit together as a couple because you have a sick child,” I would have been “what do I need to get together? I have a sick child.”

At one point, (husband visiting in hospital) he reacted to something and security guards got called . . . the next time a social worker spoke to me asking if I was okay and if he was okay with me at home . . . I didn’t mind being asked . . . I think he had a flag or file at the hospital and they just wanted to know if I was safe.

They’d ask how you’re doing individually, but almost a social question but we didn’t want to be asked . . . we would have gotten defensive and said “no we’re good.”

If health care professionals warn about anything . . . make sure your individual health, mental health is maintained, stay stable and don’t misdirect your feelings . . . couple time is not practical.

Our social worker asked how we were doing . . . he’s a family member now. He didn’t tell us that we were in risk of losing our marriage, I would have found that offensive and negative; he just supported us. Doesn’t help telling people

“you’re doomed, say goodbye now” . . . just an acknowledgment that “this is hard.”

There should be massage therapists for the parents at the hospital. Maybe massage therapy students supervised; it’s these informal caregiving kinds of things. Not formal things. It’s uncomfortable to sit in a group and force the conversation.

This family was strongly against using a formal group as it did not fit with their style and they would have felt pressured if they had been encouraged to attend one. We think the message in this is that differences in family style and preferences have to be weighed and health care professional preferences need to take a back seat to this assessment.

We knew we in trouble as a couple and we didn’t try to hide it and the person who asked us about it was like a grad student in the social work department . . . he was terrific, giving us really great attention but he wasn’t going to solve our marriage crisis.

We were warned by a health care professional that the public is gonna perceive us differently. Just cause we have no other kids; we’ll no longer be a family; we’ll be a couple . . . She was right. No other person asked how things were going between us and that would have useful. Ask about the relationship and don’t just ask once . . . that’s often what happens . . . it might never come to the attention of a social worker until a family is having real problems.

It seems as though asking was important but perhaps not in the way we address in the next section.

It would have been nice if they had asked how we were doing . . . they asked about groceries and parking but not us . . . never even got a condolence card from our social worker . . . that was pretty awful.

One particular nurse would check in with the mother about how things were going in the relationship; the family described her as an older nurse.

. . . she was brave, she would ask . . . and I think it takes somebody brave to ask that . . . she’d say “how are you and (husband) doing?”

We do see this inquiry as brave and also caring. Health care professionals need to be brave and take thoughtful risks, while being prepared to respond differently to different families.

Never asked by anyone about our relationship but we didn't have any issues so didn't matter.

We went to get grief counseling . . . but counselor said, "I don't think you are grieving. I think that you both are doing a yucky dance and I'm going to teach you how to behave so that you treat each other better" . . . it was drastically better, amazing.

Don't give us stats about marriages . . . that alone can lead down a road of disaster . . . best to say "there are no statistics."

It would have helped me immensely if someone had explained that there are different styles of coping, like what you just said about instrumental and intuitive.

Families suggested that it was helpful when health care professionals "took the worry off them" by promising alerts; there is a freeing to this, saying the vigilance is not yours alone:

(Child) was going through first round of infections and I was standing outside her door and I couldn't stop crying because I said "what's happening . . . why is (child) so sick . . . what's going on?" . . . they were checking her vitals and the doctor called me outside and said "we're trying to decide if (child) should to ICU or not . . . I don't want you to panic . . . we send kids to ICU all the time." And (doctor) took my hands and she said to me "if you can go back into that room and just breathe and be beside your child, I promise you I'll let you know when you need to worry."

The flip side of this is dismissing the parents' intuition and assessment:

I'd say there's something wrong and I was completely dismissed as an over-vigilant mother . . . not feeling heard . . . my daughter's dying nobody is listening to me.

Someone should have explained to me that there is a syndrome called post-traumatic stress disorder . . . nobody ever used the word trauma . . . that parents are being exposed to trauma . . . this trauma parent is the part that nobody talks about for the parents . . . I'm not kidding you . . . I think it's imperative to help parents.

This idea of trauma and even the use of the diagnosis of "post-traumatic stress disorder" was mentioned in only two interviews, but the people who brought it up felt strongly that it was a very real part of their experience. They

also believed that it would have been helpful at the time to have someone name it and tell them to expect it even after the treatment was over. The power of naming something was apparently important for these people as a way of recognizing and understanding what they were experiencing; for them, it was not enough to say it is going to be a hard experience, as they wanted it recognized as a traumatic experience, an unfathomable trauma. This, however, is not necessarily what is best said to all families. In much the same way that families did not want to be told that this could have ill effects on their couple relationship, perhaps labeling the experience *a trauma* or assigning a disorder diagnosis term to it would not be in the best interest of many.

All of the focus is on the child . . . we had to fend for ourselves . . . I had to go outside and find interventions. They greatly discouraged you even talking to another parent at that time.

I'd like a little more control over who visits when . . . of course you understand that the doctors and nurses are going to come freely and you welcome that; they're taking care of your child. But the auxiliary people, the religious people that would come and want to talk or the counselors . . . maybe a little more on my terms . . . I didn't always welcome the visitors . . . But the nurses are incredible. And they were my friends, I loved it when they would come and talk to me, make me tea . . . so lovely.

Similar to the earlier comments about the social worker becoming family, there is something very humanizing about this that challenges conventional notions of professional distance and boundaries.

The (specific health care professional) knew about programs but tended to avoid worst-case scenarios . . . not very well versed in dealing with the people side of it. They gave this recliner chair to those people whose kids they thought were gonna die. And everybody on the whole floor knew it so if you walked by a room and you saw the comfortable chair in it, you'd say "Ok, their kids gonna die" . . . But we got to know the nurses really well obviously 'cause we were there for a long time . . . some of the older nurses had such great bedside manner . . . "you two people, I'm looking after your kid, get the hell of the hospital. Go have a nice dinner somewhere. Go hold hands in the park." And that was good advice. We needed that permission from someone in a uniform, an authority so I could step out of the hospital and look at her and say "now I remember what you look like."

Boundaries are sustained, in part, by the belief that the professional takes up a position in relation to the parent. To do this, the boundary around professional

and parent needs to be clear. Participants in this study have rendered clear boundaries problematic. Despite professional conduct, we sometimes cannot control how we are experienced by others. With this in mind, we venture into questions about professional practice when we discuss implications of our findings.

Receiving bad advice. Repeatedly throughout the interviews, we heard a recounting of one particular message from health care professionals that, without exception, couples found to be particularly unhelpful, if not devastating: the prediction and even likelihood of the demise of the relationship because of the cancer experience.

We were told there's like an 80, 85% chance of a divorce and when it comes to actually losing a child, it's even higher, like 90, 95 or more . . . so we made a pact right there that no matter what, we were going to stay together. We weren't going to let this tear our family apart . . . When you have something tragic happen in life, it really puts a strain on marriage and the instances are quite a bit higher and if you have something as devastating, which most people say is the worst thing they can think of is losing a child, that it's just, it really accelerates . . . marriages maybe they don't break up but they're very strained, they live totally separate lives, or they do end up actually breaking up the family (child died).

This family talked very early on and decided on two things: (a) The marriage would not break up, and (b)

Bitter or better, we have to choose the vowel . . . and by the grace of God, we'll chose better before bitter if we can.

Another family stated,

The reason I was interested in participating in your study is because I can very clearly remember on the day after (child's) diagnosis, we were in hospital with him, and someone said to us "be very careful or be very aware that a lot of marriages don't make it through this."

When asked how she responded to hearing this, she said all she felt was

fear . . . yet another element of fear, something to worry about . . . but honestly we did see people whose marriages did not make it so that added to the stress.

Statistics were not helpful to another family:

I do remember when (child) was diagnosed, the social worker kept coming in and saying, how are you finding time for the two of you, you know the divorce rates are 80% . . . 80% is the magic number that keeps being thrown at us every time we get a new diagnosis . . . That's not useful . . . in midst of this, you need to find time for each other? It's like our child is dying every day here and we need to be not number one on the list right now . . . Statistics weren't helpful for us.

Nor were they helpful to another family:

Don't give us those 85%-95% stats . . . that is just dis-compassionate.

Not only is it dis-compassionate, but it angered some families:

(Health care professional) told us divorce rate is much higher than for normal population . . . pissed us off . . . I walked out of that room said to him "oh great . . . not only is our child going to struggle; we're probably going to end up divorced." . . . it was devastating to hear.

One of the most poignant and powerful statements offered by another family in regard to this "bad" advice was as follows:

We were told you need to work on your relationship because there's a big, big lack of success here in marriages surviving these things . . . that did a lot of damage . . . it made me feel that I don't have a hope. We already have weak marriage so this is sealing the deal . . . but it went the other way for us. That's the message I want to share today . . . you won't necessarily lose your marriage . . . because of that dumb statistic. Because we had a really messed up marriage. You don't have to have a fantastic marriage going in to have any hope . . . we had a very real marriage, a messed up, immature marriage . . . don't be afraid that the writing's on the wall, that the dice have been thrown and you're going to lose your marriage.

It is possible that this message may be delivered in a different way that can be heard, not a prediction or warning but out of concern and caring for the couple. Simply asking them about how they are doing as a couple rather offering a statistic seems to be what the couples were telling us in this study. We would offer it as a more compassionate act. We are reminded of the words of John Caputo as he commented on a research transcript he read in Moules et al. (2015):

Compassion inscribes a zone of respect around the mystery, is sensitive to the abyss that stirs beneath the cool clinical words "pediatric oncology." The interviewer eases into the delicacy of a situation of unimaginable pain with

“questions” that do not interrogate or objectify but create a space in which an unbearable suffering, an unspeakable pain, may find words. The words exchanged are gentle, sometimes hardly articulate, words that do not propose or defend theses, words from the heart, from broken hearts. As opposed to the cruelty of introducing a “statistic” about the divorce rate of parents who undergo this nightmare, a shattering number which threatens to crush the spirits of these courageous parents. In this interview we see what the philosophers call the “hermeneutic situation” in the concrete, glowing white hot and jumping off the pages of the philosophy books. (Caputo, in Moules et al., 2015, p. xi)

On Trading Partners and Compassionate Companions

Caputo’s description of a researcher begins to bring into focus the characteristics that participants in this study have foregrounded as important both within each other as individuals and couples, and among the professionals they encounter. The need to create space for talk; for pain, healing, absence, and escape; and for togetherness and separation—and for both to be okay—is important. Facilitating these processes and spaces does not involve interrogation, benchmarking experience with statistics, or objectifying that experience. We have heard parents describe a different relationship quality with their most intimate companions.

A companion is defined as “one who accompanies another,” or who “keeps company with another” (Companion, n.d.). Etymologically, companion comes from 12th-century French *compagnon* meaning fellows, mates, partners, and friends and from the late Latin *companionem* or “bread fellow.” The word companion is also related to two words with origins in 1600s biblical translation. The first is *helpmeet* taken to mean “a helper like himself” and the other is *playmate* meaning a “companion or playfellow” (Helpmeet, n.d.; Playmate, n.d.).

The way this companionship is lived out among couples has been strongly evoked by participants. It has been their similarities, differences, keeping company with each other, and accompanying of each other that has shaped their experiences. We have offered interpretations in this study that consider these experiences as different kinds of trading. Alongside the qualities of the marital or couple relationship, participants also had relationships with health care providers that were sometimes helpful and enriching and sometimes troubled and unsettling.

It is at this point that we wonder about the ways that companionship might offer something to the practices of nurses, social workers, psychologists, physicians, and oncologists. We do not suggest that professional practice is reducible to simple companionship, but neither do we argue that the dynamics of

companionship are simplistic. Instead, we see value in considering the characteristics of a companionable relationship alongside the practices and interactions of professional practice.

This subtle shift toward notions of companionship is useful to help health care professionals think about the qualities of practice. The bread fellow is encountered in moments where sustenance and nourishment are being taken. We wonder whether thinking about whether a practice, conversation, or comment sustains or feeds a couple's relationship might positively alter an interaction. That we may need to, metaphorically, sit and eat at the same table as those for whom we care implies a reduced distance between parents and professionals, and it alters the quality of the interaction.

Health professionals practice in dynamic environments, balance competing demands, and are sometimes overwhelmed with both the practical and emotional work involved in practice. Although we are not parents of children with cancer, we work intimately with parents and with their children who have cancer. If a companion is a "helper like himself," then professionals in pediatric oncology are eminently suitable companions. Finding helpful ways to convey and cultivate companionable relationships is an answer to questions such as, "who the hell are you to tell me this?" Similarly, recommendations to "find time for each other" or to "take time to go for a meal together" perhaps make more sense when they are offered by an insightful companion.

We are unable to escape the idea that companionship is also related in some way to playfulness. Perhaps it is because the idea of playfulness in the context of childhood cancer is a difficult one that we feel is drawn to acknowledge it and wonder about its possibilities for understanding. To be clear, playfulness is not about trivializing experience or infantilizing. To be playful is also to be experimental. Playfulness in the context of, for example, our notion of exquisite and painful intimacy is a state of wonder and openness that is both deeply existential and a pragmatic recognition of contingency. In such situations, there are rarely right answers, single courses of action to be taken, or logical and knowable outcomes. In this context, companionship is a piece of solid ground from which to venture out into unfamiliar territory and it is a necessary soft landing when some of those ventures test us in unforeseen ways.

Playfulness is also a way to reach out that helps us to get to know each other better. Lugones (1995) referred to this as world traveling. Although professionals and parents live in different worlds, we gather around a sick child in a way that necessitates a knowing of each other that goes beyond arrogant perceptions, the sense that we already know the experience of the other. Being open, experimental, and playful makes possible moments of connection that begin to answer the "who are you (to . . .)" questions, and builds and develops practical and personal resources that parents may need.

On Hospitals, Hospitality, and Hostility

In many of the accounts of the participants, we began to hear a tone of transience. Referring to our discussion of relationships that stayed together and those that did not, we noted that the ways that the cancer experience led to changes that were already coming seemed to accelerate a relationship breakdown. In some cases, they were unforeseen and there was a discovery, or even resignation, that the relationship was not going to work or survive either the cancer or the death. In many regards, the hospital was the site where this realization or shift happened.

The word hospital is connected to the word hospitality, where people are invited to be guests. Being a guest implies on one hand that a service is offered. On the other hand, it assumes that the guest will return to where they came from, no longer a guest but also not entirely transformed or changed by the period of hospitality. Kearney and Caputo write about this as hospitality—as a word that has roots of hostile and hospice. Hospitality means to say “come in” to what is calling, and what is calling may not always be a good thing. There are dangers, risks, and wagers of “hospitality.” Caputo reminds us that hospitality is not inviting our best friends over for a meal or opening our home to family for the holidays. Hospitality as Caputo articulates it, following Derrida, is about saying “yes” and saying “come” to the unknown stranger who is seeking shelter. “If you already know who is on the other side of the door, it is not hospitality. Or, only half” (Caputo, 2013, p. 39).

Richard Kearney (2015) wrote in *Hospitality: Possible or Impossible*,

My theme is the wager between hospitality and hostility. When faced with the stranger do we open the door or close it? Do we reach for a weapon or extend a hand? . . . I will suggest that hosting the stranger is not just some abstract virtue but a living existential struggle with crucial contemporary implications. The ethos of hospitality is never guaranteed. It is always shadowed by its twin: hostility. In this sense, hosting others—aliens and foreigners, immigrants and refugees—is an ongoing task; never a *fait accompli*. (p. 173)

Hospitality, then, in this study surfaced in two ways: first, as the uninvited and mostly hostile guest of cancer arriving at the door, and families not knowing what was on the other side of a door that they had no choice but to open. Cancer became an unwelcomed guest, and families, too, became guests in an environment that made efforts to be hospitable in the face of a hostile situation. Second, hospitality emerges within the encounter between the health professional and the expected but never really known family who seeks care. We offer that a part of our work is understanding what it may mean to provide hospitable care to families affected by the cancer.

Summary: On Being Compassionate Companions

In this hermeneutic study involving 30 participants in Canada and the United States, we examined experiences of parents of a child with cancer in terms of the impact on their couple relationship. In this Part 3 of our research study, we are called to listen to the words of the participants of this study, offering that, although cancer is an uninvited guest to the family, there are things that parents and health care professionals can do to foster a healthy response to an unnatural life event. This event asked much of the entire family and perhaps, one could argue, asked the most of the parents of the child with cancer, sometimes even to the demise of their relationship, or sometimes to the nurturing of it. As health care professionals, we need to recognize the sacrifices, changes, challenges, and compromises that parents are faced with and endure and recognize our role as potential “compassionate companions” in an unpredictable journey.

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Note

1. The work of Dr. Catherine Laing on children’s cancer camps speaks to this issue.

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