“Shifting Family Boundaries” After the Diagnosis of Childhood Cancer in Stepfamilies

Katherine Patterson Kelly, PhD, RN1, and Lawrence H. Ganong, PhD2

Abstract

The childhood cancer experiences of stepfamilies have not been described despite the fact that nearly one third of U.S. children will live in a stepfamily household. To describe the impact of diagnosis on parental relationships in stepfamilies, we undertook a secondary analysis of data from a study of parental decision making in structurally diverse families. As described by 13 parents of six stepfamilies, the crisis of a childhood cancer diagnosis immediately changed family dynamics. Parental relationships changed, which shifted family boundaries, creating instability in families who were trying to cope with a very stressful life experience. Through increased understanding of parental relationship changes that occur after the diagnosis of childhood cancer in stepfamilies, clinicians can anticipate these changes and provide supportive interventions to reduce overall family conflict and distress. These distinctive stepfamily responses underscore the need to include structurally diverse families in future trials targeting parental coping in childhood cancer.

1Children’s National Medical Center, Washington, DC
2University of Missouri Sinclair School of Nursing, Columbia

Corresponding Author:
Katherine Patterson Kelly, PhD, RN, Nurse Scientist, Children’s National Medical Center, 1111 Michigan Ave. NW, Washington, DC 20010-2970
Email: kakelly@cnmc.org
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A child’s diagnosis of cancer causes significant distress for parents individually and as a couple (e.g., Brody & Simmons, 2007; Goldbeck, 2001; McCubbin, Balling, Possin, Friedich, & Byrne, 2002). These findings come from research of primarily first marriage families. When childhood cancer affects a stepfamily, distress could be compounded by existing family complexity, resulting in greater conflict and added risk for negative psychosocial outcomes in these structurally diverse families. Stepfamilies, compared to first marriage families, include the potential for more adults to be involved in decision making, the possibility of heightened tension between former partners and/or their subsequent partners, and the challenges of communicating between two households (Ganong & Coleman, 2004).

Background

The few studies that have been reported about the impact of childhood cancer on parental and family coping in structurally diverse families have been limited to single parent families (Brown et al., 2008; Iobst et al., 2009) despite data indicating that nearly one third of all children in the United States will spend some time before they become adults as members of a stepfamily household (U.S. Census Bureau, 2008). Children living in stepparent households have chronic illnesses but little is known about how their parents and stepparents cope with their illnesses. This is unfortunate, because there is little research-based guidance regarding the needs of stepfamilies in these situations (Brown et al., 2008).

Impact of Remarriage and Repartnering on Family Relationships

Parents who remarry or cohabit with someone other than the other parent of their children create stepfamily households. These households are not simply reconfigured nuclear families; instead, they are inherently more complex than nuclear families. Stepfamilies often have more people, family roles, and relationships, thus creating greater demands on problem solving and communication. Complexities of roles, relationships, and structure contribute to stepfamilies being emotionally different from first marriage families (Ganong & Coleman, 2004).
Feelings between stepfamily members vary considerably; some relationships might be emotionally close whereas others might be neutral or hostile. Stepfamily relationships change over time as members unite to become a family (Braithwaite, Olson, Golish, Soukup, & Turman, 2001). The most stressful time is within the first 2 to 4 years of forming the stepfamily (Braithwaite et al., 2001). The distress experienced by all family members after a diagnosis of cancer in a child member likely will impact these evolving relationships, adding to the distress that occurs when there are family transitions such as separation, divorce, and during the early development of stepfamilies (Baum, 2004).

Impact of Childhood Cancer on Parents and Coparental Relationships

A diagnosis of a serious or life-threatening illness in a child immediately thrusts parents into a world of fear and uncertainty (Cohen, 1995). The intensive diagnostic and treatment regimens required to treat a child with cancer fractures the family’s life (Clarke-Steffen, 1993). In the face of this profound emotional distress and often physical separation, parents must make critical treatment decisions (Hinds et al., 2001; Kupst, Patenaude, Walco, & Sterling, 2003; Stewart, Pyke-Grimm, & Kelly, 2005) and provide complex care to their child with cancer throughout the disease trajectory (Klassen et al., 2007). Parents experience a loss of confidence in their parenting abilities and often blame themselves for the child’s illness and express feelings of guilt about not having identified the child’s problem sooner (Young, Dixon-Woods, Findlay, & Heney, 2002). Mothers and fathers often cope with the illness differently from each other, which can cause stress in the marital relationship (Goldbeck, 2001).

Families experience prolonged periods of separation when parents must split time between the ill child at the treatment center and other family members at home. Typically, the mother stays with the child in the hospital or travels with the child to frequent clinic visits while the father either works or cares for the rest of the family. Roles change when the father assumes primary caregiving for other family members (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; McCubbin et al., 2002; McGrath, 2001). Parents report that the separation during the child’s frequent and often extended hospitalizations adds to marital distress—this is most prominent immediately after diagnosis and dissipates over time (Lavee & Mey-Dan, 2003; Norberg & Bowman, 2008). Even though parents experience significant stress and strain, they also report gaining renewed strength and support from their spouses during the child’s illness (Brody & Simons, 2007).
Most families of children with cancer experience initial and recurrent distress, but generally cope and adjust well over time (Kazak et al., 2007). According to Kazak (2006), the impact of the family and its subsystems on the child’s adjustment are primary to understanding the potential for psychosocial difficulties experienced by the child and family after cancer diagnosis. In Kazak’s studies, a marital status of single, separated, or divorced was identified as a higher risk indicator for problems in 26.2% of 107 families who completed a psychosocial screening tool (Kazak et al., 2001).

Boundary Ambiguity in Stepfamilies and Chronic Illness

Family systems theory defines family as a group of interrelated individuals organized as units to attain family functions or goals (Friedman, Bowden, & Jones, 2003). Any change in one part of the family affects the entire system. Family systems theory identifies the external family boundary as integral to adapting to outside demands and internal family needs (Friedman et al., 2003). In stepfamilies, coparenting often involves adults and children in two households, stretching and diffusing household boundaries. When families lack clarity regarding family membership or role expectations, boundary ambiguity can occur (Boss, 1999). There are two dimensions of boundary ambiguity, membership and role ambiguity (Berge & Holm, 2007).

Boundary ambiguity has been associated with increased family and individual distress in multiple studies conducted in different family contexts (e.g., death, divorce, remarriage, health concerns)(Carroll, Olson, & Buckmiller, 2007). Stepfamilies’ complex relationships contribute to boundary ambiguity (Bray & Kelly, 1998). For instance, ambiguity about whether or not nonresidential parents are family members, (i.e., they may be psychologically present but physically absent in children’s lives), or role ambiguity issues such as whether stepparents are expected to function as parents or not, contribute to interpersonal stress and reduce couple relationship satisfaction. As a result, couple formation and coparenting can be negatively impacted (Carroll et al., 2007; Stewart, 2005).

In families of children with chronic and acute illnesses, role ambiguity is the lack of clarity regarding parental roles in the family and membership ambiguity involves perceptions about whether the ill child is psychologically included in the family (Berge & Holm, 2007). Studies have been conducted in children with chronic illnesses such as epilepsy and childhood cancer in Chinese families (Mu, Kuo, & Chang, 2005; Mu, Ma, et al., 2001; Mu, Wong, Chang, & Kwan, 2001) and in acute illnesses such as admission to the pediatric intensive care unit (Mu & Tomlinson, 1997; Tomlinson & Harbaugh, 2004;
Turner, Tomlinson, & Harbaugh, 1990). In studies of chronic childhood illnesses, parents’ uncertainty about the child’s condition and overall boundary ambiguity were related to parental depression and anxiety (Mu et al., 2005; Mu, Ma, et al., 2001; Mu, Wong, et al., 2001). In acute care settings, parents experienced role ambiguity in intensive care units because intensive nursing care left parents not knowing how to care for their critically ill child (Tomlinson & Harbaugh, 2004).

Although a recent study demonstrated positive outcomes associated with clinical intervention directed to reducing boundary ambiguity in parents of children with epilepsy (Mu & Chang, 2010), much more research is needed to fully explain the effect boundary ambiguity has on parent outcomes in pediatric illnesses. As boundary ambiguity has been studied primarily in other family contexts (Boss, 1999, 2002), this construct should be targeted for future research in pediatric illnesses. For stepfamilies affected by childhood cancer, lingering boundary ambiguity from a previous divorce or remarriage (McBroom, in press) combined with boundary ambiguity after diagnosis of a life-threatening illness in a child (Mu et al., 2005; Mu, Ma, et al., 2001; Mu, Wong, et al., 2001) could contribute to parental distress.

**Coparenting**

Coparenting involves the coordination of the care and upbringing of children (McHale, Kuersten-Hogan, & Rao, 2004). The core features of coparenting include support, solidarity, and the degree of conflict between parents, and parents’ engagement with their child (McHale et al., 2004). Coparenting dynamics in first marriage families differ from coparenting after separation or divorce because of changed living and child custody arrangements, an often lower standard of living for both parents, and conflict between parents (McBroom, in press). Preseparation communication and decision-making styles between parents are predictive of coparental relationships after divorce (Coysh, Johnston, Tschann, Wallerstein, & Kline, 1989). Parents who experienced long and conflicted legal proceedings, who were not satisfied with financial or custody agreements, or who could not forgive their former partners experience more conflicted coparenting relationships (Baum, 2004; Bonach, 2005). In general, women are more affected by postdivorce family issues, tensions, and conflicts than are men (Fine, Ganong, & Demo, 2005). The stress of a child’s serious illness, coupled with lingering hostility from the dissolution of prior unions, and the added demands of a new partner could adversely affect coparents’ ability to work together to care for their child with cancer.
Impact of Chronic Illness in Structurally Diverse Families

Only a few studies about the effects of childhood chronic illness, including cancer, on families have included structurally diverse families (Kelly & Ganong, 2010; Ganong, Doty, & Gayer, 2003; Gayer & Ganong, 2006). In a qualitative study of 13 divorced mothers who were primary caregivers of children with cystic fibrosis, researchers found that after divorce, the fathers’ involvement with their children lessened over time (Ganong et al., 2003). These fathers knew little about their child’s illness and would often return the child to the mother if the child became ill during scheduled visitation. Mothers reported little support, and extreme time and financial pressures as they sought to balance work and child care. For these mothers, respite from caregiving was limited to hospitalization of the child for an acute exacerbation of the illness. Mothers who repartnered (via marriage or cohabitation) anticipated help with their ill child from the new husband/partner but instead often found themselves with added responsibilities of caring for stepchildren. Conflicts arose between these mothers and their stepchildren and stepfathers regarding discipline of the ill child. When the ill child’s father remarried, biological mothers increased their vigilance for the sick child during visits to their new stepfamily (Ganong et al., 2003). These family dynamics have not been studied among childhood cancer populations.

In another study, differences in mother’s caregiving experiences were examined in diverse family structures (Gayer & Ganong, 2006). Compared to married and repartnered mothers, single mothers reported receiving significantly less help caring for their ill children. Married mothers got more help from fathers than did separated or divorced mothers. Stepfathers provided more assistance than did nonresidential fathers, but not as much as married fathers.

In the only study reported to date of structurally diverse families of children with cancer, single and repartnered parents and stepparents thought that treatment decision making was the responsibility of the child’s biological parents (Kelly & Ganong, 2010). In this grounded theory study, stepparents provided support to their partners but did not participate in treatment decision making for the stepchild with cancer. Parent participation in treatment decision making was influenced by the parent’s position in the family (custodial parent, nonresidential coparent, or stepparent), perceptions of family dynamics prior to the diagnosis, and length of time since diagnosis. These adults moved toward or were moved away from treatment decision making by the actions of stepping up (biological parent’s purposeful involvement in treatment decision making), stepping back (parent’s, coparent’s, or stepparent’s
purposeful nonparticipation), being pushed (biological parent’s purposeful exclusion of a coparent or stepparent), and stepping away (parent’s, coparent’s, or stepparent’s purposeful removal of themselves). In this study, we also identified a number of codes and categories that reflected another psychosocial process—how the cancer diagnosis and treatment process affected parental relationships. We believed that this parental relationship impact served as background to the decision-making process, so we set aside analysis of the relationship effects to complete the analysis for the primary focus on treatment decision making (Kelly & Ganong, 2010). We returned to the data a year later to conduct a secondary analysis focusing on the effects of childhood cancer diagnosis and treatment on parental relationships in stepfamilies.

**Method**

In the original study, we sampled 15 parents who no longer lived with the child’s other parent; children were patients at a large metropolitan children’s hospital. Both the original study and this secondary analysis were approved by the hospital institutional review board (IRB). Prior to the audiotaped interviews in the original study, all participants gave informed consent that included permission for subsequent analyses.

In the original study, parents were interviewed at a time and setting of their choosing (three telephone and 12 face-to-face interviews). Interviews were divided into information about the following: (a) the circumstances of the separation/divorce, which was facilitated by constructing a family genogram, (b) the child’s disease and treatment, and (c) recent treatment decision-making experiences. Interviews lasted 45 to 90 min. Audiotapes were transcribed verbatim and imported into ATLAS.ti (2004) for analyses.

We applied secondary analytic parameters as described by Hinds, Vogel, & Clarke-Steffen (1997) and Thorne (1994) to focus on a new question that was not explored in detail in the original analysis. Based on extensive analyses of the original data set, we knew there was adequate fit between the original data set and this reanalysis (Hinds et al., 1997), which was designed to answer the question, “How does a childhood cancer diagnosis affect parental relationships in stepfamilies?”

Strauss and Corbin (1998) advocated theoretically sampling data to identify variations of relevant situations to analyze further. They admitted that although categories may have less densely described properties and dimensions, typically there were “ample variation within cases to enable the researcher to compare concepts for similarities and differences” (Strauss & Corbin, 1998, p. 288). We began the analysis for this study by initially examining the coded data.
from all adults \( (n = 15) \) from the original data set. In the original study sample, two mothers were single (unpartnered) parents and the children’s biological fathers were not involved in the child’s treatment or care. As these mothers’ experiences were dissimilar from the other parents, we excluded them from the sample for this secondary study. The data for the analyses described here were taken from interviews of ten biological parents and three stepparents of six children with cancer from the original sample of 15 adults. Demographic information is listed in Table 1 and a representative genogram is depicted in Figure 1.

Using constant comparison, we reanalyzed all 13 interview transcriptions, adding a number of new codes to the relationship impact codes identified in the original study. We considered limiting this report to data from the three stepfamilies in which we had interviewed all of the adults (both biological

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**Figure 1. Genogram for family A**

- - - - - - Cohabitating relationship

/ Separation

// Divorce

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>○</td>
<td>Mother/girl child</td>
</tr>
<tr>
<td>□</td>
<td>Father/boy child</td>
</tr>
<tr>
<td>⠽⠴⠴</td>
<td>Non-custodial family for child with cancer</td>
</tr>
<tr>
<td>⠽⠴⠴</td>
<td>Extended stepfamily of child with cancer</td>
</tr>
<tr>
<td>⠻⠻⠻</td>
<td>Custodial family for child with cancer</td>
</tr>
</tbody>
</table>
Table 1. Child Disease and Family Structure

<table>
<thead>
<tr>
<th>Family ID</th>
<th>Diagnosis</th>
<th>Divorce/ separation circumstances</th>
<th>Time since divorce/ separation</th>
<th>Current marital status: Mother/ father</th>
<th>Custody arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Acute lymphoblastic leukemia (n = 3 parents)</td>
<td>Lived together—now separated</td>
<td>10 years</td>
<td>M—Repartnered, living together F—Single</td>
<td>Maternal primary custody during diagnosis Joint currently Mutually agreed on</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Father never established legal rights</td>
</tr>
<tr>
<td>B</td>
<td>Neuroblastoma</td>
<td>Never married</td>
<td>N/A</td>
<td>M—Single, has boyfriend F—Living with another person</td>
<td>Maternal full custody</td>
</tr>
<tr>
<td>C</td>
<td>Brain tumor (n = 2 parents)</td>
<td>Lived together—now separated</td>
<td>2 years</td>
<td>M—Single F—Remarried</td>
<td>Maternal primary custody Recent legal proceedings to establish custody arrangements</td>
</tr>
<tr>
<td>D</td>
<td>Hodgkins lymphoma (n = 1 parent)</td>
<td>Never married</td>
<td>15 years</td>
<td>M—Single F—Remarried, currently separated</td>
<td>Maternal full custody prior to diagnosis with limited visitation by father Father legally obtained decision-making authority shortly after diagnosis. Child currently lives with father.</td>
</tr>
<tr>
<td>E</td>
<td>Acute lymphoblastic leukemia (n = 3 parents)</td>
<td>Married—divorce pending</td>
<td>1 year</td>
<td>M—Single F—Repartnered, living together</td>
<td>Maternal primary custody Legally mandated with separation agreement</td>
</tr>
<tr>
<td>Family ID</td>
<td>Diagnosis</td>
<td>Divorce/separation circumstances</td>
<td>Time since divorce/separation</td>
<td>Current marital status: Mother/father</td>
<td>Custody arrangements</td>
</tr>
<tr>
<td>-----------</td>
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<td>-------------------------------</td>
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</tr>
<tr>
<td>F</td>
<td>Acute lymphoblastic leukemia (n = 1 parent)</td>
<td>Married—now separated</td>
<td>8 months</td>
<td>M—Single, F—Repartnered, living together</td>
<td>Maternal primary custody, Legal proceedings on hold due to financial issues, Mutually agreed on</td>
</tr>
<tr>
<td>G³</td>
<td>Brain tumor</td>
<td>Never married</td>
<td>N/A</td>
<td>M—Single, has boyfriend, F—Single</td>
<td>Maternal full custody, Father pursuing legal rights before diagnosis</td>
</tr>
<tr>
<td>H</td>
<td>Hodgkins lymphoma (n = 3 parents)</td>
<td>Divorced</td>
<td>5 years</td>
<td>M—Remarried, F—Single</td>
<td>Joint custody, Legally determined with divorce decree</td>
</tr>
</tbody>
</table>

a. Information corresponds to the lone parents from the original study who were not included in this analysis.
Table 2. Code Definitions

<table>
<thead>
<tr>
<th>Codes from secondary analysis</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shifting family boundaries</td>
<td>Biological family relationships are reinforced after diagnosis of childhood cancer pushing stepparents away from previously established parenting relationships with the ill child.</td>
</tr>
<tr>
<td>Diagnosis of childhood cancer</td>
<td>Time period that begins when the child is first suspected to have childhood cancer.</td>
</tr>
<tr>
<td>Structurally diverse families</td>
<td>Family structures existing after the dissolution of a first marriage or partnership that include biological and step children.</td>
</tr>
<tr>
<td>Focus on the ill child</td>
<td>Parents place child at the center of their attention thereby ignoring previous family conflicts.</td>
</tr>
<tr>
<td>Time</td>
<td>Phase that begins with diagnosis or recurrence of cancer and extending beyond into later phases of treatment. Greater time since diagnosis corresponded to an improvement in the child’s medical condition.</td>
</tr>
<tr>
<td>Increased contact</td>
<td>After a child’s diagnosis, biological parents must spend large amounts of time together caring for and coparenting the ill child.</td>
</tr>
<tr>
<td>Coparental responses</td>
<td>Biological parents are able to provide support for or identify positive qualities in each other in response to caring for their ill child.</td>
</tr>
<tr>
<td>Brought us a little closer</td>
<td>Parents verbalize their confidence in their former partner’s ability to care for child.</td>
</tr>
<tr>
<td>(in support)</td>
<td>Biological parents described a genuine affection and concern for one another.</td>
</tr>
<tr>
<td>Respects the other</td>
<td>Parents describe the pain they experience when faced with increased interactions with their ex-partner after the child’s diagnosis.</td>
</tr>
<tr>
<td>as a parent</td>
<td>Distress experienced when biological parent must interact with former partner’s current mate.</td>
</tr>
<tr>
<td>Parent still cares for the</td>
<td>After the child’s cancer diagnosis, biological parents work closely together to care for and make treatment decisions for their ill child.</td>
</tr>
<tr>
<td>other</td>
<td>Biological and stepparents acknowledge that knowing the experience of having a child with cancer rests with the biological parent alone.</td>
</tr>
<tr>
<td>Hard to be together</td>
<td>Parent’s privileged understanding of their child because the child is their flesh and blood.</td>
</tr>
<tr>
<td>Confronted with the other</td>
<td>Biological and stepparents acknowledge that knowing the experience of having a child with cancer rests with the biological parent alone.</td>
</tr>
<tr>
<td>person</td>
<td>After the child’s cancer diagnosis, biological parents work closely together to care for and make treatment decisions for their ill child.</td>
</tr>
<tr>
<td>Reinforced biological family</td>
<td>Biological and stepparents acknowledge that knowing the experience of having a child with cancer rests with the biological parent alone.</td>
</tr>
<tr>
<td>You can’t understand</td>
<td>Parent’s privileged understanding of their child because the child is their flesh and blood.</td>
</tr>
<tr>
<td>You don’t know my child</td>
<td>Parent’s privileged understanding of their child because the child is their flesh and blood.</td>
</tr>
</tbody>
</table>

(continued)
Table 2. (continued)

<table>
<thead>
<tr>
<th>Codes from secondary analysis</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclude stepparent from TDM&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Stepparent not allowed to participate in TDM</td>
</tr>
<tr>
<td>Hoarding the ill child&lt;sup&gt;b&lt;/sup&gt;</td>
<td>A parent, most commonly the mother, keeps the ill child with them ignoring previously agreed on custody arrangements. As the child’s condition improves, the parent relinquishes this control.</td>
</tr>
<tr>
<td>Stepparent responses</td>
<td></td>
</tr>
<tr>
<td>Overstepping boundaries</td>
<td>Stepparents and biological parents are mindful of how stepparent actions may cross over an unspoken family (biological) border in regards to interacting with and caring for the ill child.</td>
</tr>
<tr>
<td>Support of biological parent&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Stepparent shores up their partner during TDM</td>
</tr>
<tr>
<td>Keeping the home fires burning</td>
<td>Stepparents provide instrumental support to biological parent by ensuring household and other family members are taken care of</td>
</tr>
<tr>
<td>Stepping back (from the conflict)&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Parents purposefully adapt their responses in potentially controversial situations in service of reducing overall interparental conflict.</td>
</tr>
<tr>
<td>Jealous of the time together</td>
<td>When confronted with their current partner’s increased interaction with their former partner, stepparents display a range of emotions from no to severe jealousy.</td>
</tr>
<tr>
<td>Pulled by both families&lt;sup&gt;a,b&lt;/sup&gt;</td>
<td>Descriptions of biological parent’s stresses related to trying to balance the needs of his or her two families.</td>
</tr>
<tr>
<td>Don’t have it to give to relationship</td>
<td>Biological parent’s focus on the ill child leaves little time or energy to devote to their current partner.</td>
</tr>
<tr>
<td>Relationship shut down</td>
<td>Biological parent unable to invest any energy or other work on their relationship with stepparent due to stress of the situation and their focus on the ill child.</td>
</tr>
<tr>
<td>Walk away (from relationship)&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Parent thinks about or actually ends relationship with their partner.</td>
</tr>
<tr>
<td>Stronger in the end</td>
<td>Strengthening of the step—bio parent relationship as a result of the childhood cancer experience</td>
</tr>
<tr>
<td>No impact on parent relationship&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Child’s diagnosis of cancer does not change the overall quality of parental rapport (relationship) with one another.</td>
</tr>
</tbody>
</table>

Note: TDM = treatment decision making.

a. Codes that were also included in the paradigm model, Moving to Place, from the original study.

b. Codes that were incompletely saturated in stepfamily triads data set.
parents and a stepparent) as all codes were represented in these three stepfamilies. However, when we compared codes from the three families for whom we had not been able to interview all of the adults to the three families for whom we had stepfamily parent triads, we found that responses from adults from the nontriadic families provided additional descriptions to more fully saturate six codes that represented coparental conflict issues (Table 2). It is possible that some adults in these stepfamilies were not willing to be in the original study because of coparental conflicts. Therefore, we believed that reporting data from all stepfamily adults would yield a more comprehensive answer to the research question.

Increased interpretive bias is a potential concern in secondary qualitative analyses (Hinds et al., 1997; Thorne, 1994). By using constant comparative analytic techniques and returning to the data to validate emergent findings, the proposed category definitions were grounded in parents’ descriptions. We also consulted with a known expert in secondary qualitative analysis—the first author met regularly with this expert throughout the study to discuss emergent findings and to review the authors’ audit trail (P. Hinds, personal communication, January–August 2010).

Results

In this report of how the diagnosis of childhood cancer impacted adult relationships in stepfamilies, we purposefully overlapped common elements of the psychosocial process of Shifting Family Boundaries1 with the original treatment decision making process model, Moving to Place (Kelly & Ganong, 2010). In Table 2, we provide code definitions for the current model, highlighting the common elements to help delineate overlap and distinction between the two processes.

Increased Coparental Contact

When a child who lives in a stepfamily was diagnosed with cancer, multiple households and their members were affected, as illustrated in Figure 1. Immediately after the stepchild’s diagnosis, a marked focus on the ill child consumed parents’ lives. The biological parents came to the experience of having their child diagnosed with cancer with their past relationship histories, which ranged from amicable to hostile. The parents needed to spend time together to attend to their ill child and to make decisions about treatments. Parents had varied reactions to this increased coparental contact. When the separation had been relatively recent, parents found it hard to be together. The pain of the separation was still present and, depending on the
circumstances of the breakup, parents were confronted with the other person who was the cause of the relationship demise (i.e., the new stepparent).

As parents observed their former partners in a new role of parenting a seriously ill child, they were able to acknowledge their old emotions in the new context. Parents talked about how they still cared for the former partner; not romantically, but caring that resulted from their shared experience of raising children together (parent still cares for the other, brought us a little closer).

Um, it may have brought us a little bit closer [pause] again. Not in a romantic way but in a support for each other way. Ah, our arms have been around each other in support, just it makes me cry, just because we are the only two parents she has [tearful]. And he is the only one who knows how I feel.

Biological parents were also able to see past interpersonal animosity and to see the former partner as a good parent (respects the other as a parent).

I guess it helped in that [long pause] it gave us an understanding what we really cared about was (child with cancer) and you know, my feelings or (biological mother’s) feelings, it really didn’t matter, it was we just focused on (child with cancer). I think, you know, given that I think that helped us because it took our mind off of, you know, our selfishness I guess you could say.

Reinforced Biological Family Boundary
Leading to Stepfamily Boundary Changes

Throughout the illness experience, changes occurred to stepfamily boundaries that existed prior to the diagnosis (shifting family boundaries). The crisis of diagnosis and resulting focus on the ill child reinforced the biological family boundary as the biological parents rallied to care for and make treatment decisions. Previous family boundaries between the biological parental households became more diffuse as they came together to care for their ill child. Whether the previous parental relationship was amicable or conflicted, biological parents’ focus on their ill child helped them to more effectively coparent during this crisis period. One parent stated, “It’s a blood and family thing.” The fear and uncertainty surrounding the child’s illness, future treatment, and possibility of death brought the biological parents together to support, care, and make treatment decisions for their child. Reinforcing or reestablishing boundaries surrounding the ill child and his or her biological parents created emotional
and sometimes physical separation between the biological parents and their current partners (reinforced biological family boundary). In some relationships, the increased contact between biological parents sparked jealous reactions (jealous of the time together) in a stepparent. In other relationships, biological parents expressed resentment about intrusions of the stepparent into this parenting circle surrounding the ill child because they felt that no one but the biological parents could understand the pain they were enduring (you can’t understand).

These reinforced boundaries around the original family underscored the primacy of biological parents’ roles. They believed that only biological parents knew the child well enough (you don’t know my child) to make critical treatment decisions. Despite previously negotiated childrearing relationships with the stepparent, biological parents now viewed a limited, support-only role for the stepparent. Intrusions over this genetic family boundary by the stepparent created conflict with a biological parent (overstepping boundaries).

A particularly sensitive time during the diagnostic period was when the diagnosis was first heard. Some biological parents viewed this event as a sacred time and space only to be occupied by biological parents. This mother recounted her distress when the stepmother was present in the room when the diagnosis was delivered, [Stepmother] “was right there in the room and I needed that to be a very private moment between, this choking up [some tears], between the doctor and her dad and I. Not somebody who doesn’t belong there.”

When the child was hospitalized, residential biological parents saw the hospital room as an extension of home and resented the nonresidential stepparent’s presence. The stepparent, new partner to the residential parent’s former spouse, was not usually welcome in the home of the residential parent, but now they had to spend time in close proximity in a hospital room. This typically occurred early in the diagnosis period when the focus was sharply maintained on the ill child and dissipated over time as the child’s condition improved and the family reverted back to more familiar interactions. One biological mother stated, “This initial hospitalization was extremely difficult because she wanted to be there to support him and therefore was in my space constantly when I was dealing with the worst thing I have ever dealt with in my entire life.”

Another manifestation of the reinforced biological family boundary that occurred in several families was the residential mother’s unwillingness to allow the ill child to go on previously established visitations with the nonresidential father (hoarding the ill child). Usually the nonresidential father granted the mother time to gain comfort in letting the child go by altering their patterns
of visitation. If this hoarding period was extended, conflict resulted. In one family, this behavior prompted the nonresidential father’s threat to return to court to enforce the prediagnosis visitation schedule, “and so finally I said well, you know, if you’re not going to let me be involved, we will have to go back to court. You know, and then finally she did.” One family maintained strict adherence to the visitation schedule, however, which caused distress to the mother when the child was ill in the father’s home after treatments.

When the treatment team identified that a stepparent’s presence caused a biological parent distress, either based on their observations or biological parent’s report, clinicians recommended limited visits by stepparents, “[The social worker] talked to his girlfriend and asked her to give me some space and to back off and to limit her visits.” Biological family boundaries were explicitly set by parents or health care providers, who excluded stepparents from medical procedures, discussions, and treatment decision making (exclude stepparent from TDM). Stepparents voiced their understanding of these situations but the purposeful exclusion caused them personal distress. There were no times that stepparents described instances of relationship conflict occurring because of their purposeful exclusion.

I (stepfather) got upset, I was asked to leave the room by one of the nurses there . . . It’s like you know, that really made me feel weird. I mean I’ve been here supporting this all the way through and then all of a sudden (the biological father) shows up and I need to leave the room. I honestly didn’t like that very much.

Boundaries were implicitly understood by stepparents and were reinforced by biological parents’ behaviors. Any action taken by the stepparent that was construed as a parental function for the ill child potentially caused conflict (e.g., signing forms). One mother drew this clear boundary, “She [the stepmother] needs to just love my children and not try to raise my children.”

Stepparents were usually aware of these explicit and implicit boundaries (overstepping boundaries): “… but it’s not about me, you know this is about her and her son and you know, this kept me going forward.” Stepparents provided important instrumental and emotional support to their partners (support of biological parent), the ill child, other children in the family, and to a lesser degree the other biological parent, but received little support themselves. Stepparents made numerous sacrifices to maintain their homes and the other children’s lives (keep the home fires burning).

Stepparents wanted and needed to support their partners going through this crisis, but found that sometimes their presence represented crossing a
boundary drawn by the current partner’s former spouse and as a result they needed to step back. One stepfather recounted, “I really couldn’t because that was his child so, you know, that’s one instance that I needed to step back.” Stepparents stepped back because they acknowledged that the biological parents’ feelings took priority over their own during the crisis (stepping back—from the conflict). They wanted to support their stepchild, but again found this action sometimes crossed a biological family boundary. “I needed to connect with her (child with cancer) and I felt like I couldn’t touch her, I couldn’t be with her and stuff because I didn’t want to make (the biological mother) feel bad.” Stepparents took care not to express opinions regarding treatment, mindful of these boundaries, even if they disagreed with the biological parent’s decisions.

He’s your son and I might have a conversation and say I’ll support that is your son but he lives with me and I provide support to him—both financially and every other way and I will abide by what your wishes are; he’s your son.

It was particularly difficult for stepparents to step back when the child was ill and the stepparent was worried about the child’s condition. Depending on stepparents’ judgment of the seriousness of the condition, they sometimes risked overstepping boundaries to ensure the ill child’s medical needs were met. Stepparents also recognized the importance of the previous family connections during this medical crisis and removed themselves from the hospital room to allow for family time in support of the ill child and the entire family.

You know, it was kind of painful a little bit but you know, you got to realize that this child and their child whether they be here together as a family or whatever, I had to let them be together for a family cause maybe at one point and time they was a family.

Because of the rapid shift in the parental subsystem boundary caused by the sudden illness and initiation of intense treatments, stepparents were uncertain of what roles they should assume in the situation, which added to their distress. They described feeling like an outsider:

I’m like, well what role was I playing here? I didn’t know what role I played in there, I was just trying to be the man that was supposed to be your husband and I was trying to be there for you and it was so difficult doing that.
Consequences of Reinforced Biological Family Boundaries

As a result of reinforced biological family boundaries, the biological parent who was repartnered experienced being pulled by both families (pulled by both families). Their primary allegiance was to the ill child and biological family in the early disease period. Managing two families led to emotional and physical exhaustion that resulted in little energy left for the new partners. In addition, stepparents were worn down by providing support for the ill children and their partners, trying to maintain relationships with their own biological children, and managing the reconfigured relationship boundaries in the two families. Both biological parents and stepparents felt that they could not offer any more of themselves (don’t have it to give) to their own interpersonal relationships. This sometimes led to relationship shut down and for one couple from the original sample, walking away from the relationship.

It’s going to come to you because it’s going to be times where you want to just walk away. You just want to walk away, you say that ain’t my child, that ain’t my girlfriend, you know, that ain’t my family or whatever the case may be.

Normalization of Family Boundaries

As the crisis of the diagnosis passed and focus on the ill child lessened, biological family boundaries returned to near prediagnosis configurations. Previously strained coparenting relationships that had improved after the diagnosis often reverted to their prediagnosis patterns (no impact on parent relationship). “When everything was going on with (child with cancer) he would answer his cell phone when I called but now he’s not answering his cell phone again and so . . .” Sometimes the biological family boundary remained stronger than before the child’s diagnosis (stronger in the end). Some biological and stepparent parental relationships were strengthened by the experience. One stepcouple relationship did not survive.

As stepfamily boundaries normalized and the ill child returned to prediagnosis visitation patterns, all adults needed to develop strategies to communicate important treatment information as the child moved between the two households. In cooperative coparenting relationships, parents developed effective strategies to share treatment information, such as calendars for medication administration or using email to communicate with the treatment team. In more conflicted coparenting relationships, parents withheld information such as timing of clinic visits or diagnostic test results, “I think in the third
week I was really shut out, you know, I didn’t know when he was going . . . I didn’t get the results, you know, I wanted more results at the time.” Adults worried about whether they were getting critical information from the treatment team. Effective communication between health professionals and stepfamily adults was not consistently found.

Discussion

Shifting stepfamily boundaries after a diagnosis of cancer in a child resulted in changes to the stepfamily’s coparental relationships. The crisis of childhood cancer created changes in stepfamily dynamics that led to relational instability among the adults during what most parents described as the most stressful thing they had ever experienced. Because of the sudden onset of childhood cancer, family boundaries abruptly shifted, leading to ambiguities in coparental relationships and roles. Biological parents who had conflicting coparenting relationships prior to the diagnosis found themselves having to interact frequently on behalf of their ill child. In some families, coparenting relationships improved rapidly with those more cooperative interactions being sustained after the focus on the ill child lessened, but in other families, parents returned to their previous conflicting coparental pattern after the initial focus on the ill child lessened.

Parents and stepparents confronting childhood cancer reported both membership and role boundary ambiguities. After the child’s diagnosis, parents spent many hours in the company of the person from whom they had previously separated or divorced. Parents who had amicable coparenting relationships did not experience the same level of discomfort as parents who had conflicted coparenting relationships. Similarly, parents whose separation or divorce occurred recently experienced more difficulty being together than those whose separation or divorce occurred years previously. Researchers have found that establishing clear boundaries between spousal and parental roles contributes to positive emotional outcomes for divorced parents (Madden-Derdich & Arditti, 1999) and higher levels of boundary ambiguity were associated with greater coparental conflict (Madden-Derdich, Leonard, & Christopher, 1999). The newly reestablished biological family boundary that occurred after the child’s diagnosis blurred previously established physical and emotional boundaries between separated or divorced biological parents.

Stepparents, who either had established relational roles with the ill child or were in the process of defining their roles, were confronted with abrupt changes in family dynamics in response to the medical crisis. Through the purposeful action of stepping back, stepparents allowed biological parents room to
navigate the dangerous waters of childhood cancer diagnosis and treatment. Stepparents stepped back out of respect for the biological parents’ primacy for caring for their own children. By being able to understand this primacy and stepping back, stepparents provided important support to a child’s parents during the cancer experience. Their own needs for support were largely unmet, however. Stepparents had little direct access to the clinical team. They balanced supporting the ill child, supporting their partner, supporting their own biological children, and negotiating uncharted waters in coping with their own childhood cancer experience. They faced role ambiguity, not knowing how or when to act. One stepmother said, “I know there were other stepfamilies up there and I think we are all kind of floundering because the rules are not defined.”

Such uncertainty and confusion about one’s place in a seriously ill stepchild’s life is not unique to the cancer experience. Stepfamily members often cannot agree on what role a stepparent should assume; stepparents are often uncertain about their family roles (Ganong & Coleman, 2004). However, the research reported in the literature to date has focused on everyday family functioning, not the extraordinary family experiences associated with diagnosis of childhood cancer. Boundary ambiguity is more prevalent in stepfamilies than in first marriage families and is negatively associated with the couple relationship quality (Stewart, 2005). Families’ inability to either tolerate or reduce boundary ambiguity is postulated to lead to depression and anxiety (Boss, 1999). As boundary ambiguity may be a psychosocial risk factor for parents of children with chronic illness and stepfamilies (Berge & Holm, 2007; Carroll et al., 2007), the expanded understanding of the meaning of boundary ambiguity as it related to the stepfamily responses reported in our study will provide important evidence to inform family interventions.

There are limitations to conducting a qualitative secondary analysis that must be considered in interpreting our findings. The original participants were not available to us to validate the new findings, representing a key limitation to this secondary analysis. Several parents from potentially conflicted families \( (n = 3 \text{ families}) \) did not participate in the study. Therefore, information about relationship impact in some stepfamilies was reported by only a single reporter, who might either inflate or minimize their experiences in regards to familial or relationship conflict. Another limitation is the potential for increased interpretive bias inherent to secondary analyses (Hinds et al., 1997; Thorne, 1994). We accounted for the influence of the original study findings on this analysis by indexing categories similar to both processes. We admitted upfront that we believed that parental relationship impact was background to the treatment decision-making process of parents in structurally diverse families (Kelly &
and that we purposefully set aside these data for secondary analysis after completion of the primary analysis. As we did not focus on this background phenomenon in data collection for the original study, we may have missed important elements to this description of how a diagnosis of cancer impacts parent relationships in structurally diverse families. Despite these limitations, we believe that our findings are compelling and provide some preliminary evidence to consider for practice interventions and future research.

**Implications for Practice and Research**

Interventions such as providing anticipatory guidance about how family boundaries may shift after the child’s diagnosis and during treatment could possibly help all parents understand and cope with each others’ responses and ultimately reduce their distress. Given that parents report needing assistance to provide optimal support for their partners (Svavarsdottir, 2005) and that parent distress usually decreases over time (Norberg & Bowman, 2008), focusing interventions in the immediate postdiagnosis period might produce the most long-lasting impact. Effective assessment of stepfamily structure, understanding the impact of shifting boundaries, and interpreting this process to stepfamily members could provide support to help stepfamilies cope with their childhood cancer experience.

Using Boss’ (2002) boundary ambiguity framework as a guide, family interventions could be undertaken to help parents cope. Preliminary research using interventions informed by this framework in parents of children with epilepsy provide encouraging results (Mu & Chang, 2010). In this study, interventions were directed to enhancing family boundary integrity by constructing the meaning of the situation, including awareness of family membership and needs; enhancing mastery of both coping and activation of resources; and reconstructing family identity including role clarification. Results demonstrated reduction of family boundary ambiguity and maternal depression in this sample of 78 Chinese parents (Mu & Chang, 2010). Although this study employed a weak experimental design that did not include a control group, results indicate promise for this type of family intervention and could be adapted for use in a future study.

In this study, as in previous work by others (Ow, 2003), we identified that parents were usually able to set aside their interpersonal difficulties to focus on their ill child’s treatment. It is possible that crisis events such as having a child diagnosed with cancer could possibly motivate parents to abandon old patterns of behavior and adapt new ones with support from informed health care providers. Bonach (2005) identified coparental forgiveness as an important mediator
of effective coparental relationships after divorce. In this study, we found that biological parents were able to see each other as good parents after the diagnosis. Perhaps the opportunity to see each other coping with their child’s diagnosis and treatment, and to help each other cope, opened a window for improved coparenting. Indeed, some fathers helped the mother’s need to keep the ill child close by changing established visitation schedules. The addition of specific interventions designed to target forgiveness during a time when parents might be reconsidering life’s priorities could promote healing of the trauma associated with the relationship breakup and lead to improved coparenting outcomes (Talbot & McHale, 2004) that could be sustained after the crisis of diagnosis and early treatment passed.

Clinicians may not have an appreciation of the complexities within stepfamilies. If the diagnosis occurs within a few years of separation or there is substantial coparental conflict, the family potentially will be at risk for increased distress. Clinicians must recognize that during this time, stepfamily relationships are still developing and coparents may not have established a stable alliance (Baum, 2004; Braithwaite et al., 2001). A diagnosis of cancer might result in the biological parents abandoning established boundaries and patterns of behavior and adapting new ones. As we experienced during data collection for the original study, using a family genogram with the child with cancer as the focal/starting point is an efficient method to characterize the complexity of stepfamilies and can provide critical insight into family needs in regards to the child with cancer’s ongoing care coordination throughout treatment (Kelly, 2010; Wright & Leahey, 2009). Armed with information from a child-centered genogram, nurses could purposefully plan interventions to mediate stressors for these families rather than reacting to the problems that might arise after diagnosis.

Stepparents and stepsiblings need to be included in support interventions at diagnosis and throughout the course of treatment. However, clinicians must be mindful of the potential distress a stepparent’s presence could cause to their current partner’s ex-spouse or partner. Careful assessment of the nature of family and parental relationships at diagnosis will assist clinicians to provide effective interventions for all family members. Stepparents will need to be included in education and training regarding the child’s treatment as they will ultimately be involved in the child’s care. If clinicians approach stepfamilies armed with information about the potential stressors and intervene accordingly, they can help to see that all parents are equipped to provide maximal support and care of the child with cancer and other family members. Duplicate teaching sessions or follow-up calls may be necessary. In the original study, families identified email as an effective method to provide this duplicate communication (Kelly & Ganong, 2010).
Kazak and colleagues (2001) identified single, separated, or divorced parents as representing higher risk for psychosocial distress after cancer diagnosis. Stepfamilies may also be at risk. Researchers must incorporate more detailed descriptions of family structure in future studies to allow better interpretation of findings for structurally diverse families, including stepfamilies.

These families in this study provided unique descriptions of coping with childhood cancer that is absent in the literature. Stepfamilies are affected by the childhood cancer experience but they are separated from the typical supports made available to biological family members. Studies of stepfamily responses to childhood chronic illness will be needed to further define the unique challenges and interventions needed to improve these families’ adaptation to childhood illness.

Even though there are many stepfamilies, their experiences in childhood illnesses have not been adequately described in the scientific literature (Zarelli, 2009). Through this study, we contribute to a greater understanding of the impact of childhood cancer in stepfamilies. To move this science forward, family nursing researchers must thoroughly describe family demographics and examine the possible influences of structural diversity in family coping in childhood chronic illness. Through increased understanding of the possible shifts in family boundaries that occur after diagnosis of cancer in stepfamilies, supportive interventions can be developed to reduce distress and conflict and promote positive coping.

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1Italicized phrases correspond to code names as listed in Table 2.

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Bios

Katherine Patterson Kelly, PhD RN, is a nurse scientist in the Department of Nursing Research and Quality Outcomes at the Children’s National Medical Center in Washington D.C. Longstanding clinical involvement with children and families affected by cancer led to her research program focused on childhood cancer treatment decision making in families. Relevant publications include “Moving to Place: Childhood Cancer Treatment Decision-Making in Single Parent and Re-Partnered Family Structures” appearing in Qualitative Health Research (with L. Ganong), “Helping Parents Make and Survive End-of-Life Decisions for Their Seriously Ill Child” appearing in Nursing Clinics of North America (with P. S. Hinds), and “Parent Treatment Decision Making in Pediatric Oncology” appearing in Seminars in Oncology Nursing (with J. L. Stewart, and K. Pyke-Grimm).

Lawrence H. Ganong, PhD, is a professor of Nursing and co-chair and professor of Human Development and Family Studies at the University of Missouri. He has conducted numerous workshops for stepfamily members and for professionals working with stepfamilies. He has coauthored seven books and numerous articles and book chapters on postdivorce families and stepfamilies. Relevant publications include “Mothers in Postdivorce Families Caring for a Child With Cystic Fibrosis” appearing in Journal of Pediatric Nursing (with M. E. Doty & D. Gayer) and “Family Structure and Mothers’ Caregiving of Children With Cystic Fibrosis” appearing in Journal of Family Nursing (with D. Gayer).