Review

Psychosocial adjustment of siblings of children with cancer: a systematic review

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Abstract

Objectives: To promote a broader understanding of the psychosocial impact of childhood cancer on siblings, a systematic review was undertaken. Directions for future research are proposed and clinical strategies are suggested for addressing the needs of these children.

Methods: Searches of Medline, PsycINFO and CINAHL revealed 65 relevant qualitative, quantitative, or mixed methods’ papers published between 1997 and 2008. These papers were rated for scientific merit and findings were extracted for summary.

Results: Siblings of children with cancer do not experience elevated mean rates of psychiatric disorders, but a significant subset experiences post-traumatic stress symptoms, negative emotional reactions (e.g. shock, fear, worry, sadness, helplessness, anger, and guilt), and poor quality of life in emotional, family, and social domains. In general, distress is greater closer to time of diagnosis. School difficulties are also evident within 2 years of diagnosis. Qualitative studies reveal family-level themes such as loss of attention and status as well as positive outcomes including increased sibling maturity and empathy.

Conclusions: Research regarding siblings of children with cancer continues to be methodologically limited. The conclusions of qualitative and quantitative studies differ considerably. We propose a research agenda to propel this field forward including greater attention to alterations in normative development (as opposed to psychiatric conditions), development of more appropriate quantitative measures, examination of potential moderators of adaptation, and use of prospective longitudinal designs. Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services.

Keywords: siblings; childhood cancer; oncology; psychosocial adjustment; systematic review

Pediatric cancers affect approximately 14 000 children in the United States each year [1]. Increasingly complex and intensive treatments have led to five-year survival rates just over 80% across cancer types [1]. Being cured of childhood cancer, however, has long been defined as extending beyond biological/physical outcomes to include health within social, emotional, and psychological domains [2]. We have made great strides toward that goal. Children with cancer experience few long-term psychosocial difficulties [3]. We argue, however, in accordance with a recent Institute of Medicine Report [4] that this biopsychosocial definition of cure should be extended to all members of the families of children with cancer [5].

Psychosocial effects of childhood cancer are beginning to be understood for parents. Reviews of this literature [6,7] indicate that parents show increased distress (symptoms of anxiety, depression, and traumatic stress) and some marital conflict within the year after diagnosis and that strong social support, open communication, external attributions about cause rather than self-blame, and lack of additional stressors are associated with better psychological adaptation. Despite growing knowledge about the effects of childhood cancer on parents, the impact of childhood cancer on healthy siblings within these families is less clear [8].

It is not difficult to understand why siblings of children with cancer may experience social and...
emotional consequences of their brother's or sister's illness. The need for at least one parent to attend to the ill child at the hospital or at home, plus increased levels of parental distress, may make parents physically and emotionally unavailable. Changes in family routines and roles may disrupt day-to-day functioning of siblings, with some siblings assuming more household chores and responsibilities. These changes may, in turn, curtail after-school and other social activities. Plus, these challenges occur while siblings are witnessing physical changes in their brother or sister and worrying he or she will die.

In 1999, two reviews of the sibling literature were published [9,10]. Across these reviews, 45 unique studies published between 1956 and 1997 were identified. Both reviews concluded that siblings of children with cancer experience emotional distress and some behavioral problems but typically not at clinical levels. Positive effects of the cancer experience, such as increased maturity, responsibility, independence, and empathy, were also documented. Both reviews agreed, however, that these conclusions were tempered by frequently conflicting findings, possibly related to methodological weaknesses (e.g. small, heterogeneous samples; cross-sectional designs; absence of appropriate control groups).

In 2005, a review of the qualitative research regarding siblings of children with cancer [11] summarized 27 studies published between 1979 and 2004, 16 of which were not included in the reviews discussed above. Three themes emerged: (a) tremendous change within the lives of siblings, including losses (e.g. losses of parental attention, normal family roles, sense of self) and gains (e.g. increased family closeness, independence, maturity, empathy); (b) intense feelings (e.g. sadness, loneliness, rejection, anxiety, anger, jealousy, guilt); and (c) unmet sibling needs (e.g. needs for open communication, more information and involvement in the treatment process, and greater support maintaining personal interests and activities). The authors noted that findings were diffuse and methodological shortcomings were common such as failure to specify constructs a priori and choose and adhere to specific qualitative research designs and methods.

These past reviews called for more rigorous research methodology, increased utilization of qualitative methods as a means of providing a rich account of the sibling's perspective of cancer, development of standardized quantitative instruments that are sensitive to the experiences of siblings, and attention to the effects of stage of treatment and developmental factors on adjustment. In an effort to build upon these past reviews, assess whether the recommendations have been followed, and propel research regarding siblings of children with cancer forward, we have undertaken a new systematic review of the sibling literature published since 1996.

The present review includes empirical work from several disciplines, including medicine, psychology, and nursing. It integrates findings from qualitative and quantitative studies to ensure comprehensiveness and to deepen our understanding of the sibling experience. Given our desire to be inclusive and explore nuances in the available research, we chose not to pursue meta-analytic techniques; however, the scientific merit of each study was assessed and considered when integrating findings. Five broad topic areas related to the psychosocial adjustment of siblings emerged from the literature and are summarized in this review: (a) psychological adjustment, (b) family functioning, (c) social/school functioning, (d) somatic issues, and (e) resilience/growth. We also attempt to examine the relationships of adjustment and time since diagnosis, developmental level of the sibling, and gender. Finally, we identify remaining limitations of the current empirical-base, propose specific ways to advance this field of research, and summarize clinical implications.

**Method**

To guarantee comprehensiveness in our review, minimize our biases, and ensure reliability of our conclusions, we adhered to the strict scientific methodology of systematic reviews [12–14]. This methodology includes careful planning of the scope of the review, upfront specification of research questions, thorough literature searching and data extraction, evaluation of research quality, synthesis of findings, and distillation of implications.

**Literature search**

Both computerized and manual searches were undertaken to identify potentially relevant articles. PsycINFO, MEDLINE/PubMed, and the Cumulative Index to Nursing & Allied Health Literature (CINAHL) were searched using the following terms: (sibling * or sister or brother or twin or family), (cancer or malignancy or tumor or oncolog * ) and (pediatric or child * ). Searches were completed on June 30, 2008. Reference lists of all manuscripts chosen for full-text review were manually searched for additional potentially relevant papers. To build upon past reviews, searches were limited to manuscripts published in English and appearing after 1996.

**Inclusion assessment**

After redundant citations were eliminated, titles and abstracts of each identified paper were independently screened by two reviewers. Reviewers
included five doctoral level professionals with expertise in psychology, nursing, and epidemiology and a psychology graduate student. To ensure comprehensiveness, full-text versions were collected for any manuscript suggested by at least one reviewer to be potentially relevant to our review. Included manuscripts needed to meet these criteria: (a) be empirical (i.e. commentaries, practice guidelines, reviews, etc. were excluded); (b) examine siblings of children with cancer (i.e. not adults with cancer and not siblings of children with other disorders); (c) include interpretable data (e.g. quantitative scores were compared to norms or control groups); and (d) report outcomes relevant to psychosocial adjustment. Papers exclusively concerning bereaved siblings were excluded, as bereaved siblings confront different challenges than nonbereaved siblings. For a paper to be excluded, two members of our team needed to agree that the manuscript did not meet inclusion criteria after independent screenings.

Scientific merit appraisal

Specific criteria based upon a range of published recommendations [15–20] were developed to appraise the scientific quality of the studies selected for review (Table 1). Quantitative studies were rated on 9 criteria and qualitative studies were rated on 11 criteria. Studies using mixed qualitative–quantitative designs were rated on the 16 criteria for review (Table 1). Quantitative studies were praised the scientific quality of the studies selected for review. Recommendations [15–20] were developed to apply specific criteria based upon a range of published materials and reference lists of selected studies revealed 278 potentially relevant manuscripts. Of these, 86 (31%) were not empirical, and 127 (46%) did not include data regarding siblings; included samples extending beyond childhood.

<table>
<thead>
<tr>
<th>Table 1. Criteria for scientific merit ratings</th>
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<tbody>
<tr>
<td><strong>Quantitative criteria</strong></td>
</tr>
<tr>
<td>(1) Explicit scientific context and purpose: clear rationale for the study, theoretically and/or empirically based questions/predictions, specified purpose</td>
</tr>
<tr>
<td>(2) Methods: design and analysis are appropriate to the question(s) posed; methods are described adequately, allowing for replication of the procedure</td>
</tr>
<tr>
<td>(3) Measurement reliability and statistics: variables are measured reliably; proper (adequate, even if not best) statistical methods are used; statistical results are appropriately interpreted</td>
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<tr>
<td>(4) Internal validity</td>
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<tr>
<td>If two groups are compared, groups are comparable in all aspects except the IV or appropriate steps are taken to equate participant characteristics</td>
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<td>If groups are examined over time, only the passage of time occurred between assessments</td>
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<tr>
<td>If correlations (e.g., X → Y) are examined, the reverse relationship is not feasible and a third variable could not be causing both X and Y</td>
</tr>
<tr>
<td>(6) Measurement validity and generalizability of constructs: variables are appropriately operationalized and measured; results would be the same if other measures were used</td>
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<td>(7) External validity: The findings are generalizable to the target population, real world, and across time periods</td>
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<td>(8) or (10) Appropriate discussion: Limitations noted; conclusion appropriate to data gathered</td>
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<tr>
<td>(9) or (11) Contribution to knowledge: contributing something new or validating past results</td>
</tr>
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</table>

Results

Literature search and selection of relevant studies

A total of 2107 unique titles and abstracts were distilled from the electronic searches. Screening these materials and reference lists of selected studies revealed 278 potentially relevant manuscripts. Of these, 86 (31%) were not empirical, and 127 (46%) did not include data regarding siblings; included samples extending beyond childhood.
cancer, did not include data related to psychosocial functioning or did not provide a context in which to interpret scores (i.e., norms or comparison groups). The remaining 65 papers were rated and findings extracted.

Characteristics of studies included in the review
The majority of the papers reviewed (n = 37, 57%) were quantitative [21–57]. One-third used qualitative methods (n = 22, 34%) [58–79], and a few used mixed-methods designs (n = 6, 9%) [80–85]. The overwhelming majority of studies (n = 56, 86%) were descriptive, with the remaining nine reporting on interventions but providing information relevant to this review [22,23,35,38,47,50,52,83,84]. Most studies (n = 50, 77%) collected data from siblings, with half (n = 32; 49%) involving multiple family members. Sample sizes ranged from one to 3899 siblings; fifty-eight percent of studies (n = 38) had sample sizes below 50. Approximately half (n = 36, 55%) used self-report questionnaires with normative data either alone or in combination with other data collection methods. Six (9%) descriptive studies included peer comparison groups [21,25,27,28,40,41]. Six studies (9%) were longitudinal [33,36,41,51,60,76]. This summary illustrates continued methodological weaknesses in this research.

Overall, a broad age range of siblings was studied, including preschoolers through adults. Across studies, time since cancer diagnosis ranged from a few weeks to 30 years post-treatment, but was not reported in 11 (17%) studies. Ten studies (15%) specifically examined siblings of children currently on cancer treatment, 14 (22%) included only siblings of children who had completed cancer treatment, 11 (17%) involved mixed samples and the remaining 30 (46%) did not specify treatment status. Important demographic information was missing from many manuscripts; almost half had no racial or ethnic information (n = 30, 46%), and a similar percentage (n = 31, 48%) did not report socioeconomic status. Time since diagnosis, gender, and/or age was explored in relation to adjustment in 14 (22%) studies. Race, ethnicity, and socioeconomic status were not examined as moderators of adjustment in any of the studies seemingly due to oversight of these variables, small sample sizes, or homogeneity of samples.

Half (n = 33, 51%) of the reports originated within the United States, with six originating in Canada (9%), six (9%) in the Netherlands, and four (6%) in Australia. Three or fewer manuscripts originated from each of the following countries: Sweden, United Kingdom, Israel, Finland, Hong Kong, Iceland, India, Italy, Mexico, Taiwan, and Thailand. Thus, a broad sampling of cultures was represented.

Scientific merit of reviewed studies
Scientific merit ratings of the studies almost spanned the full range of the scale (1.22–3.00) with an overall mean of 2.35 (SD = 0.44). Quantitative (M = 2.40, SD = 0.47), qualitative (M = 2.37, SD = 0.40), and mixed designs (M = 2.02, SD = 0.23) did not differ significantly in terms of scientific merit (F[2,62] = 2.03, p = 0.14). To help ‘weight’ studies by their scientific merit during synthesis, studies scoring more than one standard deviation below the mean (rating < 1.91) were classified as ‘Low’ in scientific merit (n = 11, 17%). These studies had deficits across multiple domains, scoring a 1 (Low) on numerous criteria. They are identified in the text and their findings are reported with caution.

Narrative summary of reviewed studies
In each of the following sections, the numbers of qualitative, quantitative, and mixed design studies relevant to the topic area are provided. Then, the themes developed from qualitative and mixed methods’ studies are reviewed, followed by the findings of the quantitative studies. Studies reporting mixed findings within a single sample are reported in some detail to best convey potential moderators of outcomes. Finally, a brief summary is given in each section. Tables 2–6 provide definitions of each of these topic areas, lists the ways in which the reviewed papers operationalized these topics, and summarizes the findings across studies.

Psychological functioning of siblings of children with cancer
The majority (n = 51, 78%) of the identified studies provided data regarding psychological functioning of siblings (Table 2). These studies assessed clinical levels of emotional and behavioral maladjustment, anxiety, depression, symptoms of post-traumatic stress, quality of life, and emotional functioning. Three studies (6%) were classified as low in scientific merit [22,31,63].

Emotional intensity and vulnerability [66,68,76], chronic intrusive worry [70,75], and enduring sadness [78] were evident across the 18 studies reporting qualitative data in this domain. Feelings of loss, anxiety, fear, grief, shock, disbelieve, helplessness, insecurity, loneliness, abandonment, jealousy, anger, and guilt were also reported [58,62–68,70,74–76,80,85].

Quantitative data on psychological functioning was reported in 35 studies. Sixteen examined general emotional and behavioral problems. Three [53,55,57] found adult siblings of long-term childhood cancer survivors to have means better than controls on the Behavioral Symptom Index. Ten
Table 2. Summary of studies regarding psychological functioning

<table>
<thead>
<tr>
<th>Area of functioning</th>
<th>Number/type of studies</th>
<th>Primary methods/measures used across studies</th>
<th>Summary of findings</th>
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</thead>
<tbody>
<tr>
<td>Psychological functioning: Clinical and subclinical levels of emotional and behavioral maladjustment problems, specific symptoms of anxiety, depression, and cancer-related posttraumatic stress. Also, quality of life and general emotional functioning</td>
<td>Sixteen qualitative⁵</td>
<td>Semi-structured interviews; Focus groups; Written narratives; Non-standardized measures (5 studies); BASC; CBCL; YSR; FTBA; BS; Conners'; RCMAS; STAIC; CDI; Self Perception Profile for Children; PedsQL; DucatQoL; TacQoL; POMS; IES-R; PTSD-RI; Rosenberg; Children's Self-Esteem Scale</td>
<td>Themes of emotional intensity and vulnerability, chronic intrusive worry, and enduring sadness. Feelings of loss, anxiety, fear, grief, anger, helplessness, and guilt. Mean levels of behavioral adjustment are no different from controls and norms. Some evidence of increased rates of adjustment problems (3 studies). Eighty-seven percent of studies (13 of 15) show no increased risk for depression among siblings compared to control or norms. Seventy-eight percent of studies (14 of 18) show no increased risk for anxiety among siblings compared to controls or norms. Across 5 studies 29–38% of siblings report moderate to severe cancer-related posttraumatic stress. Eighty-six percent of studies (6 of 7) show decrements in siblings' Quality of Life. Distress is more common within 2 years of diagnosis.</td>
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</table>

BASC = Behavioral Assessment Scale for Children; CBCL = Child Behavioral Checklist; YSR = Youth Self Report Form; FTBA = Finnish Test for Behavioral Assessment; BS = Brief Symptom Inventory; Conners' = Conners' Parent and Teacher Rating Scales; RCMAS = Revised Child Manifest Anxiety Scale; STAIC = State Trait Anxiety Inventory for Children; CDI = Children's Depression Inventory; PedsQL = Pediatric Quality of Life Scale; DucatQoL = Dutch Children's AZL/NQO Quality of Life Questionnaire; TacQoL = TNO AZL Children's Quality of Life Questionnaire; POMS = Profile of Mood States; IES-R = Impact of Event Scale-Revised; PTSD-RI = Posttraumatic Stress Disorder Reaction Index.

⁵Citations include: [58,62–68,70–72,74–76,78,79].

⁶Citations include: [21–25,27–39,41,44,46–50,52–57].

⁷Citations include: [80,82–85].
**Table 3. Summary of studies regarding family functioning**

<table>
<thead>
<tr>
<th>Area of functioning</th>
<th>Number/type of studies</th>
<th>Primary methods/measures used across studies</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family functioning:</td>
<td>Nineteen qualitative&lt;sup&gt;a&lt;/sup&gt;</td>
<td>Semi-structured interviews; Focus groups; Non-standardized measures (5 studies); DucatQoL; SRQ</td>
<td>Themes of sibling loss of attention, feelings of neglect, parents report difficulty attend to siblings' needs.</td>
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<tr>
<td>Topics related to the functioning of the family as a whole and the quality of the relationships between family members</td>
<td>Seven quantitative&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
<td>Themes of increased closeness, but also conflict and resentment.</td>
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<tr>
<td></td>
<td>Two mixed&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td>Themes of loss of normalcy, predictability and security within the family.</td>
</tr>
</tbody>
</table>

<sup>a</sup>Citations include: [58-62,64-67,70-79].
<sup>b</sup>Citations include: [26,31–33,42,48,51].
<sup>c</sup>Citations include: [81,85].

DucatQoL = Dutch Children's AZL/TNO Quality of Life Questionnaire; SRQ = Sibling Relationship Questionnaire.

**Table 4. Summary of studies regarding school and social functioning**

<table>
<thead>
<tr>
<th>Area of functioning</th>
<th>Number/type of studies</th>
<th>Primary methods/measures used across studies</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>School/social functioning:</td>
<td>Seven qualitative&lt;sup&gt;d&lt;/sup&gt;</td>
<td>Semi-structured interviews; Focus groups; Written responses; Non-standardized measures (7 studies); BASC; CBCL; Conners’; PedsQL; Medical Outcomes Short Form-36; FTBA; DucatQoL; TacQoL.</td>
<td>Themes of disruptions in school performance and behavior; the need to be more independent with schoolwork.</td>
</tr>
<tr>
<td>School performance and school problems including troubles with concentration, memory, learning and achievement. Social functioning includes problems with social behavior (e.g. withdrawal, aggression, poor social skills, fewer social activities) and social acceptance (e.g. having fewer friends, being bullied)</td>
<td>Fifteen quantitative&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
<td>No differences in rates of repeated grades or teacher reported performance.</td>
</tr>
<tr>
<td></td>
<td>Two mixed&lt;sup&gt;f&lt;/sup&gt;</td>
<td></td>
<td>Mixed findings on parent and self-reported indices of concentration, memory and learning.</td>
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<td></td>
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<td></td>
<td>School problems more likely during first 2 years post-diagnosis.</td>
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<td></td>
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<td></td>
<td>Themes of decreased opportunities for social activities and increased need for support in getting to activities.</td>
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<td></td>
<td></td>
<td></td>
<td>Sixty-four percent of quantitative studies found no evidence of social problems for siblings.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>When social problems were noted, they were within 2 years of diagnosis.</td>
</tr>
</tbody>
</table>

BASC = Behavioral Assessment Scale for Children; CBCL = Child Behavioral Checklist; Conners’ = Conners’ Parent and Teacher Rating Scales; PedsQL = Pediatric Quality of Life Scale; FTBA = Finnish Test for Behavioral Assessment; DucatQoL = Dutch Children's AZL/TNO Quality of Life Questionnaire; TacQoL = TNO AZL Children's Quality of Life Questionnaire.

<sup>d</sup>Citations include: [62,67,69,70,71,75,76].
<sup>e</sup>Citations include: [25,28,29,31–34,39–41,43,46–48,57].
<sup>f</sup>Citations include: [83,85].
### Table 5. Summary of studies regarding somatic symptoms

<table>
<thead>
<tr>
<th>Area of functioning</th>
<th>Number/type of studies</th>
<th>Primary methods/measures used across studies</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somatic symptoms:</td>
<td>Four qualitative(^a)</td>
<td>Semi-structured interviews; Written narratives; Non-standardized measures (3 studies); Conners'; FTBA; BASC; CBCL; BSI; PedsQL; DucatQoL; TacQoL</td>
<td>Siblings worry about their health. Seventy percent of quantitative studies find no differences or better functioning in siblings compared to controls or norms. Four quantitative studies had mixed findings with regard to age, suggesting that 8–12 year olds may be at greater risk for somatic problems than younger or older siblings. When somatic symptoms are elevated, this seems to happen within 2 years of diagnosis.</td>
</tr>
<tr>
<td>Physical complaints and general physical functioning</td>
<td>Fourteen quantitative(^b)</td>
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<tr>
<td>One mixed(^c)</td>
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</table>

\(^a\)Citations include: [62,63,74,76].
\(^b\)Citations include: [25,27,28,31–34,41,46,47,53,55–57].
\(^c\)Citations include: [83].

### Table 6. Summary of studies regarding resiliency/positive outcomes

<table>
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<tr>
<th>Area of functioning</th>
<th>Number/type of studies</th>
<th>Primary methods/measures used across studies</th>
<th>Summary of findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resiliency/positive outcomes: Reports or evidence of perceived benefits, skills gained or improved self-concept</td>
<td>Five qualitative(^a)</td>
<td>Semi-structured interviews; Focus groups; Written narratives Non-standardized measures (3 studies) Personal Attribute Inventory for Children Rosenberg/Children's Self Esteem Scale; The Self Perception Profile for Children</td>
<td>Increased responsibility, independence, maturity Increased empathy, sensitivity, and compassion Mixed findings on self-esteem</td>
</tr>
<tr>
<td></td>
<td>Six quantitative(^b)</td>
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<td></td>
<td>One mixed(^c)</td>
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\(^a\)Citations include: [62,68,75–77].
\(^b\)Citations include: [26,31,45–47,50].
\(^c\)Citations include: [85].

Conners’ = Conners’ Parent and Teacher Rating Scales; FTBA = Finnish Test for Behavioral Assessment; BASC = Behavioral Assessment Scale for Children; CBCL = Child Behavioral Checklist; BSI = Brief Symptom Inventory; PedsQL = Pediatric Quality of Life Scale; DucatQoL = Dutch Children's AZL/TNO Quality of Life Questionnaire; TacQoL = TNO AZL Children's Quality of Life Questionnaire.
studies, investigating a range of ages and times since diagnosis, revealed siblings’ means on measures such as the Youth Self Report Form, Child Behavioral Checklist, and Behavioral Assessment Scale for Children were no different than controls [22–25,28,32,33,36,39,46]. Two of these studies did, however, show significantly elevated percentages of siblings in clinical ranges [23,32]. One additional study did not examine means but found elevated rates of internalizing problems for siblings compared to the general population [50].

The final two studies [33,41] had mixed findings dependent upon time since diagnosis, developmental stage, and gender, but their subgroups were small; thus, these results are reported with caution. The first study [41] found preschool siblings (3–7 year olds; n = 12) to have elevations in general behavioral problems compared to a control group at 3, but not 12 months post-diagnosis, while school-aged siblings (8–15 year olds; n = 20) had elevations at both time points. The second study [33] found at 1 month post-diagnosis, adolescent (12 to 18-year-old) girls (n = 21) but not boys (n = 19) had mean internalizing scores and rates of at-risk/clinical impairment significantly greater than norms but no elevations for externalizing or total behavioral problems. By 6 months post-diagnosis, these girls (n = 17) were no longer showing the internalizing difference, and boys (n = 15) were performing better than norms for externalizing and total behavioral problems. Overall, these studies show general adjustment to be within normal limits, with some elevations shortly after cancer diagnosis.

Fifteen quantitative studies assessed depression. Ten (67%) found no differences between siblings’ scores and norms or no elevations in the percentage scoring in the clinical range [22–25,28,41,46,52,54,56]. Three reports indicated that siblings endorsed less depression than norms [53,55,57], and two indicated increased depression compared to community controls [27,44]. The majority of the research indicates siblings of children with cancer do not show elevated levels of depression.

With regard to anxiety, 18 quantitative studies used standardized measures with most (n = 14, 78%) finding that siblings’ mean scores were no different from or better than norms [21–23,25,28,30,32,35,46,47,53,55–57]. Only one study indicated increased risk for anxiety among siblings compared to community controls [27]. Three studies [33,35,41] had mixed results depending upon gender, time since diagnosis, and reporter, but again these subgroups were small and the findings are reported with caution. One study [35] demonstrated elevated anxiety among school-aged (7 to 11-year-old) boys and girls and adolescent (12 to 18-year-old) boys (but not girls), but group sizes were small (n = 4–9) and the sample had been referred for services. A second study by the same authors [33] found adolescent (12 to 18-year-old) girls, but not boys nor school age (7 to 11-year-old) girls and boys, had mean anxiety levels greater than norms at 1 month post-diagnosis, but were no different from norms by 6 months post-diagnosis. The final study [41] found school age children (aged 8–15; n = 20) had elevated self-reported anxiety levels compared to norms at 3, but not 12 months post-diagnosis, and parent-reports of sibling anxiety were no different from norms at either time point. In sum, most of these studies find no elevations in clinical anxiety among siblings of children with cancer.

In addition to examining psychological disorders among siblings of children with cancer, some researchers have examined cancer-related post-traumatic stress, quality of life, and mood states. Five quantitative studies examined post-traumatic stress reactions in siblings [21,38,46,47,82] and reported that 29–38% exhibited moderate to severe post-traumatic stress (i.e. intrusive thoughts about cancer, a desire to avoid anything cancer-related, physiological reactivity, hypervigilance). In Alderfer et al. [21] siblings endorsed more symptoms of cancer-related post-traumatic stress than a comparison group of children with no experience of childhood cancer within their families. Seven manuscripts reported quantitative data on quality of life of siblings of children with cancer. Six revealed sample means indicative of significantly poorer quality of life and emotional functioning compared to norms [32–34,36,47,83]. In one series of studies, emotional quality of life was significantly below norms at 1 month post-diagnosis with 57% of siblings indicating a relative absence of positive feelings including happiness, joy, satisfaction, relaxation, enthusiasm, and cheerfulness, and 37% endorsing feelings of jealousy, anger, aggression, sadness, worry, gloominess, fear, and depression [34]. Quality of life continued to be impaired at 6 and 12 months post-diagnosis but was found to be within normal limits by 2 years post-diagnosis [36] with some variability related to sibling age and measure used [32,33]. Data from one study of mood states indicated adult siblings of childhood cancer survivors had less tension and anger than norms [56].

In summary, siblings of children with cancer do not experience elevated mean levels of psychiatric symptoms such as behavioral problems, anxiety disorders, or depression. However, the percentage of siblings falling into at risk/clinical ranges on these indices is elevated in some samples typically soon after diagnosis. Furthermore, a significant subset experiences negative emotional reactions, an absence of positive emotions, and cancer-related post-traumatic stress.

Family functioning related to siblings of children with cancer

Twenty-eight studies addressing the family context of siblings of children with cancer were identified
(Table 3). Most were qualitative (n = 19) and provided rich accounts of the family experience of siblings of children with cancer; one of these studies was rated low in scientific merit [61]. The most common theme across these studies (and one mixed methods study) was sibling loss of attention, cited in 14 studies [59,61,62,66,67,70–73,75,76,78,79,85]. Siblings reported spending less time with parents and feeling neglected, ignored, isolated, ‘uncared for’, and lonely within their families. In one longitudinal study [76], over 50% of the sample reported loss of attention and status within the family at 6 months post-diagnosis; this decreased to one-third of the sample by 18 months post-diagnosis. Across studies, parents reported difficulty attending to needs of both their sick and healthy children [61,66,67,72,73,75,78]. In one study, one-third of parents reported neglecting siblings [73]. Parents reported guilt for not being there for siblings and worry about the effect it would have on them [75].

Ten studies reported themes related to family roles and relationships; one was rated low in scientific merit [77]. Increased cohesion, closeness, or a strengthening of bonds between family members was frequently reported [64,65,71,73,74,77]; yet, reports of sibling rivalry, conflict, jealousy, and resentment also emerged [59,66,67,72,73,76,85]. Loss of normalcy and sense of security within the family was another frequent theme [58,60,66,74–76,78]; examples included disrupted routines, lack of predictability, and role changes. Fathers were noted to assume more caretaking responsibilities for siblings, and siblings, especially older ones, were noted to take on more chores. In the longitudinal study mentioned above [76], 80% of siblings reported a loss of routines at 6 months post-diagnosis with 40% reporting similar disruptions at 18 months. Less frequent but repeated themes included overprotection by parents including restrictions in communication [60,62,73,79] and siblings hiding their feelings to protect parents [78,79].

Seven quantitative and one mixed design study addressed family functioning through written indices; three were rated low in scientific merit [26,31,48]. One series of studies found siblings’ reports of family functioning (home-based quality of life) did not differ from norms at 1, 6, 12, or 24 months post-diagnosis [32,33]. In one study, children with cancer reported average levels of conflict with their siblings [42]. Using suggested cut-scores for the Spinetta scoring system of the Kinetic Family Drawing—Revised, one study [81] found one-third of their sample of siblings had minimal family support. In one final descriptive quantitative analysis [51], parents reported that providing siblings with emotional support ranked among the hardest and most time-consuming tasks related to the childhood cancer experience.

In summary, findings of qualitative studies converge to reveal important family-level themes relevant to siblings’ experience of childhood cancer including loss of attention and status within the family, changes in family roles and relationships, and disruptions in normalcy and the sense of security a family typically provides. Quantitative studies regarding this topic are scant and do not provide enough information to determine if siblings of children with cancer experience family environments and relationships that diverge from the general population.

School and social functioning of siblings of children with cancer

Twenty-four studies addressed school and social functioning of siblings (Table 4). Across four qualitative [62,67,70,71] and one mixed-design study [85], two primary themes emerged regarding school: (a) disruptions in school performance and behavior due to changes in routine, fatigue, worry, a parent-assumed desire for attention, and sibling-reported conflicts in loyalty (wanting to be with the child with cancer instead of at school); and, (b) a need to be more independent and responsible regarding schoolwork. Thirteen quantitative studies addressed the topic of school performance. Eleven compared siblings to norms and/or control groups; one was of lower scientific merit [40]. Five of these studies reported no differences in rates of repeating grades (school and self-report); teacher-reported school performance, attention, learning problems and study skills; parent-reported attention; or self-reported concentration, memory, and learning [25,28,32,41,46]. Five studies indicated that siblings experienced more difficulties than norms/controls on measures of parent-reported and self-reported school functioning, including concentration, memory, and learning [34,39,41,47,83]. The remaining study reported that siblings, once reaching adulthood (age 18 and older), had higher rates of high school and college completion than the general population [43]. Overall, studies showing school problems had samples 1–24 months post-diagnosis [34,39,41], and those showing no school difficulties were typically farther from diagnosis [25,32,43,46].

Findings from qualitative studies (n = 4) addressing social issues among siblings of children with cancer were consistent, suggesting decreased opportunities for social activities and increased need for instrumental support (e.g. transportation) to maintain friendships and social pursuits [62,69,75,76]. Eleven quantitative studies investigated siblings’ social functioning. Seven [25,28,40,46,47,57,83] found no differences between siblings and norms/controls across measures of parent-reported social functioning (e.g. social problems, withdrawal, aggression), teacher-reported social
functioning (e.g., social skills, withdrawal, antisocial behavior), or self-reported social functioning (e.g., social quality of life, being bullied, having friends). One [34] found no differences between mean levels of social functioning in siblings and norms but reported a greater than expected percentage of siblings falling into the clinical range for social problems. Another [39] found siblings to have poorer social functioning than norms as measured by parent report of social activities and relationships. The remaining three [32,33,41] reported some evidence of social problems for some subgroups within their samples, but not for all siblings.

Among those studies with inconsistent findings within their samples, one [41] found preschoolers (aged 3–7) displayed some social difficulties at 3 months post-diagnosis compared to controls but rebounded to normal levels by 12 months. The other two studies [32,33] reported social quality of life was poorer than norms for siblings at 1 month post-diagnosis on one measure, but not a second measure. On the measure where means were not significantly different from norms, the percentage falling into the borderline/clinical range (33%) was greater than that expected in the general population. At 6 months post-diagnosis, adolescents (12–18 year olds) continued to show poorer social quality of life, but younger children’s (7–11 year olds) scores rebounded to normative levels. At 2 years post-diagnosis, means for all siblings were within normal limits on both measures, but an elevated percentage of younger children (7–11 year olds) fell into the borderline/clinical range on one of two measures [32]. In sum, social problems were rarely reported, but when evident, occurred closer to diagnosis.

Somatic complaints of siblings of children with cancer

Nineteen studies examined somatic complaints of siblings (see Table 5). Four qualitative studies, one rated low in scientific merit [63], revealed a common theme of siblings worrying about their own health [62,63,74,76]. Similarly, a quantitative study [27] showed that siblings worry about their health significantly more than community controls. Fourteen additional quantitative studies investigated siblings’ somatic complaints or physical quality of life with one [31] of low scientific merit. Nine (69%) found no differences or better sibling functioning in these realms compared to norms/control groups [25,28,46,47,53,55–57,83].

Four studies had mixed results depending upon developmental stage and time since diagnosis [32–34,41] One study [41] found no differences in somatic and psychosomatic symptoms for preschool siblings (3–7 year olds) compared to controls at 3 or 12 months post-diagnosis, but marginally more psychosomatic problems for school age siblings (8–15 year olds) at 3 months and significantly more symptoms at 12 months post-diagnosis compared to a control group. In a series of studies [32–34], adolescent siblings (13–18 year olds) showed no significant differences from norms on measures of physical quality of life at 1, 6, or 24 months post-diagnosis; but younger children (7–12 year olds) showed poorer physical quality of life compared to norms on one of two administered measures at some, but not all, time points. In sum, somatic complaints and physical functioning do not seem to be poorer for most siblings; however, siblings in early childhood may be at some risk for somatic distress within 2 years of diagnosis.

Resiliency and positive outcomes of cancer for siblings

Twelve reports investigated self-esteem, self-concept, or positive outcomes of childhood cancer for siblings (Table 6). Four of these reports were rated low in scientific merit [26,31,45,77] but had results similar to higher quality studies, thus are summarized here where relevant. Five studies investigating positive outcomes were qualitative designs, six were quantitative, and one was mixed. Two general themes were revealed across studies: (a) increased responsibility, independence, and maturity of siblings; and, (b) increased empathy, sensitivity, and compassion [26,31,62,68,76,85]. Two studies reported 60–72% of siblings in their samples indicated gains or positive outcomes of cancer [76,77]. Only one quantitative report used a standardized measure of adaptive behavior (i.e., levels of leadership) and found that siblings of children with cancer were no different from norms [46]. Three studies examined self-concept or self-esteem with one finding moderate levels of self-esteem [47], one finding no differences between mean self-concept scores of siblings and norms [45], and one finding better than average sibling self-concept [50] compared to a normative sample. Given that qualitative studies find positive outcomes as a theme, more quantitative and targeted qualitative research in this area is needed to better understand potential positive outcomes of the cancer experience over time.

Patterns of adjustment and time since diagnosis, developmental stage, and gender

Fourteen studies examined relationships between adjustment and time since diagnosis, developmental stage, and/or gender. Two of the five studies exploring time since diagnosis utilized correlations; one [30] found a negative relationship between time since diagnosis and anxiety, and the other [39] found no significant association between time since
diagnosis and behavioral problems. The remaining longitudinal studies [33,36,41], discussed in some depth above, suggest sibling adjustment is more likely to be discrepant from norms and control groups within 2 years of diagnosis than further out, but findings are mixed.

Five studies explored developmental stage or age and adjustment. One [30] comparing 9–13 year olds and 14–18 year olds found no differences in anxiety but greater reports of loneliness for adolescents. Across a series of publications investigating 7–18 year olds [32,33,36], older age was associated with more anxiety, poorer quality of life, and more negative emotions; however, younger children (7–12 year olds) manifested poorer physical quality of life compared to norms on some measures and at some but not all points in time from diagnosis. A final study [41] suggested preschoolers (3–7 year olds) showed fewer problems in adjustment than school age siblings (8–15 year olds) and rebounded to normative levels more quickly. Overall, results of cross-sectional studies suggest better than normative functioning among adult siblings (age 18 and over) [53–56] greater vulnerability to psychosocial adjustment problems for adolescent siblings, and some risk for somatic distress among younger school age children. However, given mixed findings in the literature and variation in the definition of ‘school age’ and ‘adolescence’ across studies, these preliminary conclusions are made with caution.

Eight studies investigated gender and adjustment. Three of these found female siblings reported greater levels of post-traumatic stress, anxiety, and social problems than males [21,34,36]. Two found no differences between female and male siblings on anxiety or loneliness [24,30]. The remaining three studies examined gender as a predictor of outcomes across siblings and cancer survivors and found female gender to be a significant predictor of poorer adjustment [53–55] These studies suggest that when differences are found, females report more distress than males.

Discussion

This systematic review provides an updated examination of the qualitative and quantitative literature regarding five domains of adjustment of siblings of children with cancer: psychological adaptation, family adjustment, school and social functioning, somatic distress, and growth/resilience. Sixty-five studies published between 1997 and 2008 were included, their scientific merit rated, and their findings summarized. Results of this review allow us to summarize the literature, comment upon its quality, propose suggestions to advance this field, and suggest ways to address the needs of siblings of children with cancer.

Adjustment of siblings of children with cancer

Siblings of children with cancer do not typically have elevated scores on measures of behavioral problems, anxiety, or depression, though some studies report an increased percentage of siblings falling into at risk or clinical ranges on these indices compared to normative samples. Siblings commonly report negative emotional reactions, an absence of positive emotions, impaired quality of life, and cancer-related post-traumatic stress symptoms. Common themes in qualitative studies include siblings’ loss of attention and status within the family, changes in family relationships, and disruptions in normalcy and security, but quantitative studies addressing these issues are scant.

School difficulties were documented in half of the studies investigating this issue, those collecting data within 2 years of diagnosis. Social problems were rarely documented but when apparent, reflected the need for instrumental support during treatment. Siblings in middle childhood may be at increased risk for somatic complaints and poorer physical functioning based on comparisons with norms. Qualitative studies also noted increased responsibility, independence, and maturity of siblings; and increased empathy, sensitivity, and compassion.

Few studies examined potential moderators of adjustment, and those that did provided conflicting data. Generally, it seems sibling outcomes are more likely to differ from norms/controls closer to the time of diagnosis, with less distress shown over time. With regard to developmental stage, adolescent siblings seem to show the poorest adjustment compared to adults, school age, and preschool children. Finally, females may exhibit more distress than males. Owing to the small number of studies investigating these factors, the lack of prospective designs, and small samples unable to compare subgroups while controlling for confounding variables, these findings should be interpreted with caution.

Quality of the current research

Past reviews published approximately 10 years ago called for more rigorous research regarding siblings of children with cancer. These calls have not been answered. Quantitative studies continue to utilize small, heterogeneous samples and to rely on cross-sectional designs. Qualitative studies often fail to specify a theoretical approach to data analysis or to articulate possible biases of investigators. Data regarding potential moderating factors of adjustment (e.g. race/ethnicity, socioeconomic status) are scant. The past 10 years have shown few improvements in research design in this topic area.

It is quite striking that the past decade of research regarding siblings of children with cancer continues to display the same limitations that have
plagued this field since its inception. Some progress is evident with regard to research attention given to siblings of children with cancer. Indeed, the number of studies regarding siblings of children with cancer published in the past 10 years is greater than that of the preceding 40 years. This is progress, but methodologically the research has not advanced.

There are many potential reasons for this lack of methodological advancement. First, childhood cancers are relatively rare compared to the cancers of adults, and thus, receive less research attention. Second, the majority of government and foundation research dollars are devoted to issues of cure. Psychosocial issues have only recently been highlighted as an important component of family-wide cancer care [4]. Third, psychosocial research regarding children with cancer has typically focused on patients and parents. In the studies we reviewed, siblings were sometimes used as a control group to understand more about the patients themselves [53–57], or mentioned as an aside or secondary aim in studies designed for other purposes (e.g. understanding the parent experience) [38,61]. Such research does not have the same level of scientific rigor as studies specifically designed to understand the experience of siblings.

Practical reasons also make it difficult to produce high-quality sibling research. University-based researchers may have great difficulty identifying families of children with cancer without hospital-based research partners. Even for hospital-based researchers, siblings are difficult to access as they may not come to the hospital regularly and parents may resist agreeing to research that adds the burden of bringing siblings to the hospital. Conducting home visits to collect data can be expensive, and relying upon families to complete and return data packets by mail may result in poor response rates and biased samples. Appropriate control groups (e.g. children with no cancer experience of similar demographic make-up) may be even more difficult for hospital-based researchers to access. Furthermore, single site samples may be small, given the low base rate of pediatric cancers within the population, coupled with the fact that not all children with cancer have siblings. When restrictions are placed on the age of the sibling, the type of cancer diagnosis, or time since diagnosis, these samples become even smaller. These barriers, and failures to surmount them, are hampering advancement of this field.

Observations of the research findings

There is a striking lack of convergence of findings across qualitative and quantitative designs. Qualitative investigations offer rich descriptions of the psychological experience of siblings in the months following their brother’s or sister’s cancer diagnosis. In contrast, the majority of quantitative studies conclude siblings are no different from norms or comparison groups with regard to symptoms of depression, anxiety, or problem behaviors. The one area in which quantitative and qualitative data agree is in themes and outcomes related to post-traumatic stress, quality of life, and emotional states. This pattern of results suggests that many quantitative studies may not be assessing constructs pertinent to siblings’ experiences of cancer. In other words, they may be asking the wrong questions. Although we, along with others [9,10], have established that most siblings do not exhibit elevated levels of psychopathology, qualitative descriptions indicate a pattern of adjustment that differs from normative developmental processes. These qualitative descriptions, along with elevations in post-traumatic stress and negative mood states and lower scores on quality of life measures, indicate that the sibling experience is unique and worthy of further investigation. Future research in this area should select or develop outcome measures more appropriate to this population.

It should also be noted that this literature reports both positive and negative outcomes for siblings. Given the considerable threat associated with cancer in a brother or sister, one might assume siblings’ reactions would be uniformly negative. However, some studies indicated that siblings report increased maturity, resiliency, and empathy in the face of cancer. Furthermore, positive and negative outcomes may be reported by the same siblings. These findings suggest that siblings’ adjustment is complex and multidimensional. The same precipitating factor, having a brother or sister with cancer, can lead to widely variable outcomes across siblings, within siblings across time or developmental stage, or even within a single sibling at a certain time. Future research should attempt to explore the complexity of factors that may influence various adjustment trajectories and outcomes across time and over development.

Recommendations for researchers

Our review suggests that continued investigation into the unique experiences of siblings of children with cancer is an important component to understanding the psychosocial impact of childhood cancer on families. However, there are many opportunities to improve upon the quality and direction of the research such as grounding research in theoretical models, improving research design and methodology, broadening the range of topics investigated, and implementing studies that inform intervention. These topics are explored in detail below.
Use of theoretical models

Efforts to advance this field must take a more focused and detailed view of the cancer experience of siblings. The best way to do this systematically is for researchers to adopt and adhere to specific theoretical models in their research. No one model seems adequate to capture the complexity of the sibling cancer experience. Our research endeavors are guided by three primary models. First, we find a post-traumatic stress framework useful in understanding the nature of both cancer-related distress and growth. This framework accepts that cancer-related distress is a normal reaction to a potentially life threatening stressor. It recognizes feelings of fear, horror and helplessness; and symptoms such as intrusive thoughts, avoidance of anything cancer-related, and episodes of physiological arousal [21]. Furthermore, a traumatic stress model provides a context in which to understand positive reactions and growth after cancer. We also embrace a family/systems model that considers the adjustment of the sibling in the context of the family turmoil that the diagnosis and treatment of cancer causes [5]. We have also found that a developmental social ecology model is useful [86]. This model holds that characteristics of the child (e.g. gender, biological predispositions) partially determine the way in which he or she develops, but specific events occurring in his or her life and the social contexts in which he or she lives, such as the family, peer group, school, community, and broader culture, also shape development and adjustment. This model has spurred us specifically to consider the social context of siblings in ongoing research examining their adjustment.

There are still specific limitations to these models and other models may be appropriately and usefully applied to the study of siblings of children with cancer. Models of attachment, risk and resilience during childhood, along with general models of stress and coping or child development may all be useful. At this point, the specificity afforded in research designs by the adoption of and adherence to a specific model or framework is far more important to the field than the specific model adopted. In fact, research emanating from a range of models would greatly enhance understanding of the sibling cancer experience. Our research endeavors need to be made to reach out to families of various races, ethnicities, and socioeconomic status in both qualitative and quantitative studies. Research would also benefit from consideration of factors likely to impact adjustment including: (a) demographic variables; and (b) disease factors (e.g. diagnosis, time since diagnosis, treatment intensity or difficulty of cancer course, treatment status [on versus off treatment]). A surprising percentage of published studies did not include important demographic information regarding their samples.

In addition to improving sampling we need to improve the way in which we assess variables of interest. In qualitative studies, constructs of interest should be specified in advance and the efforts undertaken to ensure the reliability and validity of coding needs to be reported. Quantitative studies typically rely solely on questionnaire data either reported by the siblings themselves or by a parent regarding the sibling. These methods are useful and appropriate for some constructs (e.g. personal beliefs) when questionnaires are carefully developed and psychometric properties are proven to be adequate, however scientific rigor would be improved by the use of multiple respondents within the family when assessing observable behavioral outcomes or shared experiences, such as the perceived severity of the cancer course or family functioning. Using well-validated observational coding systems or assessing the opinions and observations of people outside the family, such as teachers or classroom peers, may shed further light on the adjustment of siblings.

Finally, research designs need to be improved. Qualitative studies need to adhere more closely to their specified data analytic strategies. Quantitative studies need to include appropriate control groups and have designs with sufficient power to assess and compare subgroups of participants. Large cross-sectional samples may provide some clarity regarding questions to be addressed in prospective studies and therefore may be considered a first step, but prospective longitudinal studies are sorely needed to yield information about trajectories of adjustment and potential moderators of outcome.

Important topic areas to be investigated

A greater effort should be placed on studies that shift away from measures of psychopathology and toward variations in normal development, quality of life, emotional reactions and functional outcomes. A first step in this research may be the careful development of measures appropriate for and sensitive to the experiences of siblings of pediatric cancer patients. Additional developmentally sensitive qualitative investigation may further our understanding of the processes underlying sibling adjustment and guide the construction of appropriate quantitative measures. Any studies of...
psychopathology in siblings should be reserved for large-scale, representative national samples capable of accurately assessing these rare phenomena.

Future research, using both qualitative and quantitative designs, should also focus on possible moderators of adjustment, including developmental stage or age (at time of diagnosis and data collection), gender, time since diagnosis, ethnicity, and socioeconomic status. Parental distress, family functioning, and the specific course of cancer treatment (e.g., number of days in the hospital, severity of side effects, etc.) may also influence sibling adjustment and should be examined in this regard.

Additionally, certain subgroups of siblings and some important outcomes seem to be overlooked in most of the current research. Young siblings, those below the age of 7 or 8, are rarely investigated but are probably greatly impacted by the changes that occur in the family system and the shifts in parental attention. Bereaved siblings and those who are bone marrow or stem cell donors should receive more attention. Additionally, the health behaviors of siblings and their involvement in risky behaviors such as drug and alcohol use require more attention [87].

Keep intervention in mind

An overarching recommendation is to design research that can inform intervention development. Intervention is important for siblings, particularly those deemed high-risk. More research attention should be devoted to identifying subgroups of siblings at risk for future psychosocial and adjustment difficulties based upon their patterns or trajectories of adjustment. Identifying the basic characteristics of those most at risk and the situations that are more likely to lead to difficulties for siblings will help identify those most in need of intervention. Examination of modifiable factors that distinguish well functioning and more poorly functioning subgroups (e.g., cancer-related beliefs, family communication) would directly lead to targets of interventions for siblings of children with cancer.

Clinical considerations

While siblings of children with cancer do not consistently show elevated rates of psychopathology, they do have psychosocial needs that should be recognized and addressed by professionals. While definitive empirically validated interventions are not yet available, reviews of the literature regarding sibling interventions [88] and specific guidelines for sibling care are emerging [89,90]. From our review of the literature, we know siblings often experience a loss of needed attention and a threatened sense of security within the family. The demands of caring for a child with cancer often limit parents’ physical and emotional availability to attend fully to the needs of healthy children within their family. It is recommended that extended family, the oncology-care team (oncologists, nurses, psychosocial staff), the siblings’ primary-care physician, the siblings’ school staff (teachers, coaches, guidance counselors), and relevant community members (clergy, neighbors) consider the unique needs of siblings in addition to the needs of the family generally and the health of the child with cancer.

Minimal gestures such as asking healthy sibling how they are doing (instead of asking about the child with cancer) or providing them with individual attention concerning their interests may be beneficial and appreciated. Members of the oncology team should consider including siblings in the treatment of the child with cancer, as appropriate (e.g., giving tours of the hospital ward; explaining tests, procedures, and treatments) as this may help siblings feel more included and less isolated. Community members (e.g., neighbors, friends) might consider offering siblings transportation to activities or ensuring they have their favorite meals to help normalize routines. Referring siblings to national support organizations such as SuperSibs! (www.Supersibs.org) will provide them with additional supportive care. This website also provides clinicians and community members with further recommendations.

Although most siblings respond well with minimal support, some siblings will display significant distress and should be referred for evaluation and treatment by mental health-care specialists. Based upon the research, higher levels of distress may be more common within 2 years after diagnosis. However, in our clinical experience, we have seen patterns of late onset distress (e.g., after treatment ends) or distress associated with developmental transitions (e.g., movement through cognitive stages and greater awareness of the meaning of cancer). Whenever distress emerges, it should be appropriately addressed. It is our hope that the research recommendations in this review advance the field such that more specific clinical recommendation can be provided in the future for the care of siblings.

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