
PARENTAL CAREGIVING OF CHILDREN WITH CANCER AND FAMILY IMPACT, ECONOMIC BURDEN: NURSING PERSPECTIVES

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Pediatric cancer diagnoses affect the entire family: parents, well siblings, the ill child, and others. The objective of this study was to review nursing studies on parental caregiving of children with cancer, family impact, and costs. The study used inclusion/exclusion criteria and family systems theory, self/dependent-care, and symptom management (monitoring, alleviation) concepts. Regarding “levels of evidence,” 3 studies were Level II; 7 were Level IV; 7 were Level VI; 1 review was Level V and the second was Level I. Of 19 studies: 11 were qualitative; 4, quantitative; 2 were mixed methods. Content analysis themes were: Parental caregiving and family impact, economic burden. Conclusions were that (a) qualitative studies are predominant; findings supported quantitative findings; (b) quantitative nursing studies are less common: found one longitudinal, randomized controlled trial (RCT) focused on outcomes of an intervention for well siblings and parents, implemented by Clinical Nurse Specialists, CNSs; (c) few quantitative studies with large samples were found, especially ones with theoretical models of the family system and measures of illness impact on families; and (d) “mixed methods” longitudinal nursing research is illustrated. There is a need for “evidence-based” practice (EBP) nursing studies of interventions focused on parent education/support/assistance; respite care, and increasing family/well sibling knowledge/other information on the child’s illness.

Keywords: Childhood cancer, economic burden, parental caregiving and family impact

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Approximately 10 400 children under the age of 15 were diagnosed with cancer in the United States during 2007 (NCI, 2011). Although the incidence of childhood cancers has increased over the past 20 years, overall survival rates have significantly improved due to advances in treatment (ACS, 2013). These intensive treatments often cause side effects in the ill child (ACS, 2013; Williams et al., 2012a; Williams et al., 2013b). Many of these treatments are given in the outpatient setting, reducing hospital stays. At home, parents are increasingly required to provide care to the ill child. Other family members at home may assist in this care, or otherwise witness the severe manifestations and occurrence of symptoms (side effects), and bear other consequences such as separations during repeated rehospitalizations of the ill child (e.g., Gibbins et al., 2012; Williams, 1997; Williams et al., 2009). Thus, the diagnosis of pediatric cancer and the care required impact the entire family system: parents, ill child, well siblings, and others.

Purpose

The purpose of this review is to describe the nursing literature regarding impact of a pediatric cancer diagnosis on parental caregiving and the family system, and on economic burden.

From the perspective of family systems theory, the family is defined as a small group of closely interrelated and interdependent individuals who are organized into a single unit so as to attain specific purposes, namely, family functions or goals (Freidman, 2003). Family members who live in the household include parents, ill child, siblings, and others. Within this family group are “subsystems” such as parent-child, child-sibling, parent-siblings, parent-parent, etc. A change in any one part results in changes in the entire system (Bronbrenner, 1986; Kaakinen et al., 2010). Such a “change” includes illness occurrence, such as a child’s cancer diagnosis (Freidman, 2003; Stein & Jessop, 1982, 2003; Williams, 1997).

Within families, children are in early stages of human development; therefore, parents care for children and monitor their self-care needs, a process called *dependent care* (Orem, 1995). In families of children with cancer, parents provide care that may include symptom management (monitoring and alleviation), and other dependent care strategies for the child during cancer treatments (Williams P. et al., 2006)—referred to in this review as parental caregiving.

METHOD

PubMed and CINAHL were used to locate studies in the nursing literature that addressed the study purpose. Search terms used

were: pediatric oncology, children's cancer, family impact, costs, parent caregiving, nurse clinician interventions, and outcomes. Of 42 reports found, 19 were included; 2 were reviews. The quantitative, "mixed methods design," and qualitative studies were conducted during diagnosis and treatment of the ill child; these were focused on the parent-child subsystem, child-well siblings system, and/or the child-family system. Each study/review was either conducted by a nurse, and/or published in a nursing journal. Excluded were studies that focused on end-of-life issues, medical procedure-related distress, and on post-traumatic stress in parents. Also excluded were (a) studies/reviews that focused mainly on gender differences in impact (mothers vs. fathers) (da Silva et al., 2010); (b) reviews of interventions focused on siblings alone, not including parents, delivered by non-nurses—focused on measurement tools used (Alderfer et al., 2010; Prchal & Landolt, 2009); and (c) reviews that focused only on parental stress (Klassen et al., 2007; Vrijmoet-Wiersma et al., 2008). The excluded reviews cover the topics well; reviews in b and c were published in non-nursing journals—readers should access those sources as needed. All studies in this review *met the criteria for qualitative and quantitative designs, mixed methods, and reviews* (Polit & Beck, 2012). Thus, for qualitative research reports guide evaluates the title, abstract, introduction (statement of the problem, research questions, literature review, conceptual underpinnings); method (protection of participants/rights, research design/tradition, sample and setting, data collection, procedures, trustworthiness); results (data analysis, findings); discussion (interpretation of findings, recommendations/implications), global issues (Polit & Beck, 2012, pp.115–117). The quantitative research report criteria evaluate similar aspects, with several variations in terms used such as hypotheses, variables, conceptual framework, power analysis, randomization, interventions, standardized instruments/scales, measurement, psychometric properties (reliability, validity), statistical significance (Polit & Beck, 2012, pp. 112–114). In addition, the criteria for evaluating systematic reviews include aspects such the problem, search strategy, the sample, quality appraisal, data extraction and presentation, data analysis (quantitative, qualitative), conclusions (Polit & Beck, 2012, pp. 674–675). In this article, one of the reviews (qualitative) used a guide by Letts et al. (2007); the guide uses criteria that are similar to the criteria above, obtained from Polit and Beck (2012, pp. 115–117).

Moreover, each selected article was examined and the areas of focus were identified using content analysis (Krippendorff, 2004). This was done to identify the main themes of the studies; the number of studies focused on those themes was also identified. In addition, the levels of evidence for evidence-based practice (EBP) in nursing were identified

for each publication included in the review. That is, the seven levels of evidence are: Level I—systematic reviews of RCTs; systematic reviews of nonrandomized trials); Level II—a single RCT, or a single nonrandomized trial; Level III—systematic review of correlational/observational studies; Level IV—single correlational/observational study; Level V—systematic review of descriptive/qualitative/physiologic studies; Level VI—single descriptive/qualitative/physiologic study; Level VII—opinions of authorities, expert committees) (Melnik & Fineout-Overholt, 2011; Polit & Beck, 2012).

FINDINGS

The selected studies are presented in tabular format. As mentioned, all studies in this review met the criteria for qualitative and quantitative designs, mixed methods, and reviews described above. Within the groupings, each study is presented with the author, year, study purposes, and level of evidence (column 1); the methods (sample, setting or location, design type or approach, data collection methods and analysis—column 2); and Findings and conclusions (column 3).

Regarding levels of evidence, the Table shows that 3 studies were Level II; 7 were Level IV; 7 were Level VI; 1 review was Level V; the second was Level I. Nineteen articles were selected for the table: 11 qualitative; 2 “mixed designs”; 4 quantitative studies; 2 were reviews: 1 review, published in a nursing journal, included 28 qualitative studies; 17 of the studies were published in nursing journals (Gibbins et al., 2012)—it is noted that none of the studies in that review were among those chosen for this paper. The second review met Polit & Beck’s (2012) criteria for systematic reviews mentioned above—the review was done by a nurse and published in a nursing journal with a high “impact factor” (Polit & Northam, 2011). The review examined quantitative studies focused on impact of pediatric chronic illness (*cancer comprised 10 studies*) and risk to well siblings, parents, and families (Williams, 1997). Notably, the Williams review of sibling studies *predated 4 excluded* reviews (Alderfer et al. 2010; Klassen et al., 2007; Prchal & Landolt, 2009; Vrijmoet-Wiersma et al., 2008)—but was not cited in any of them. Moreover, the Williams review provided an empirical basis for the advance practice nurse (APN)-delivered interventions in a large, longitudinal RCT (Williams et al., 2003, see Table 1). APNs also are referred to as Clinical Nurse Specialists (CNSs) in this report.

Overall, the table shows that studies using qualitative methods and mixed methods were conducted in various settings and in different countries, and had a wide range of sample sizes (between

Table 1. Qualitative, mixed methods, quantitative studies, and reviews: parental caregiving of children with cancer and family impact, economic burden

Study; Purpose; Level of Evidence ^a	Methods	Findings; Implications
<p>Banjeree et al., 2011. Level VI^a <i>Purpose:</i> Described cultural beliefs and coping strategies of first-generation South Asian immigrant parents of children with cancer.</p>	<p>Part A. Qualitative Studies (11)— Studies below meet criteria for qualitative studies (Polit & Beck, 2012, pp. 115-117), i.e., research approach/design, sample and setting, data collection, analysis, trustworthiness.</p> <p>Qualitative In-depth semi-structured interviews. Constant comparison method. <i>Sample:</i> In Canada, 25 South Asian parents of children diagnosed with cancer served as informants</p>	<p>Central themes: a) cultural belief that cancer is “unspeakable,” incurable, and understood through religion; b) coping strategies were: gaining information; using religious rituals, prayer; obtaining support of other South Asian parents</p>
<p>Branstetter et al., 2008 Level IV^a <i>Purpose:</i> Examine the impact of family communication patterns between well siblings, parents, others within families of children with cancer/other chronic illness.</p>	<p>Naturalistic inquiry, post RCT; recorded interviews; thick descriptions, triangulation. <i>Sample:</i> 30 parent-well sibling dyads; Cancer, with 6 dyads</p>	<p>Major themes: Communications as a reflection of family relationships and roles; Staying connected; Struggling for normalcy; Giving voice</p>
<p>Clarke, 2006 Level VI^a <i>Purpose:</i> Examined how mothers manage one part of their home healthcare labor—the emotion work.</p>	<p>Focus group interviews <i>Sample:</i> Canadian, 10 focus groups; interviews with 49 mothers</p>	<p>An increase in parental responsibilities of caring for a child with cancer is labor- and emotion-intensive</p>
<p>Fletcher, 2010 Level VI^a <i>Purpose:</i> Examined the lived experiences of female caregivers, specifically the various costs associated with caring for a child with cancer.</p>	<p>Phenomenology study; used questionnaires; semi-structured interviews. Content analysis <i>Sample:</i> 9 Canadian mothers of children with cancer were informants</p>	<p>Subthemes identified: a) financial and work issues b) health of family c) upheaval of family d) ‘lost’ life</p>

(continued)

Table 1. Continued

Study; Purpose; Level of Evidence ^a	Methods	Findings; Implications
Flury et al., 2011 Level VI ^a Described the experiences of parents taking child home from the hospital for the first time after cancer diagnosis.	Interviews Content analysis. Sample: Swiss parents of 10 children ($n = 9$ mothers and $n = 3$ fathers) newly diagnosed with cancer were informants	Everyday family life is severely affected
James et al., 2002 Level IV ^a Examined parental perceptions of what helps or hinders their caregiving responsibilities and affect their caregiving role when their child has cancer.	Descriptive; "Care of My Child with Cancer" tool. Responses analyzed using semantic content analysis. Sample: 151 American parents of children with cancer were informants	a. Negative physical and emotional health most frequently reported effect; b. Periodic respite from caregiving role desired c. Helpful assistance included education about child's illness and emotional support from family and friends.
Jongudomkarn et al., 2012 Level VI ^a Examined Thai cultural beliefs on the experience of pain, societal expectations on parental behavior to meet their child's acute pain experience, and the parent's "inner struggle" in providing pain care.	Phenomenology; audiotaped interviews with 45 parents of children with cancer. Used the Colaizzi method (thematic analysis, listing emergent themes on parents' methods to manage pain, structural descriptions, and member checking).	Parents preferred to use traditional remedies. They also wanted to provide and secure pain care for their child, but were reticent to approach staff with concerns about their child's care.
Martinson & Yee, 2003 Level VI ^a Identified concepts regarding how parents in Hong Kong restored health in their child with cancer.	Qualitative study; in depth interviews. Content analysis Sample: Parents of 93 children with cancer were informants	Key concepts included (a) providing adequate nutrition, (b) using alternative therapy to supplement Western medicine, and (c) preventing infections.
Moore & Beckwith, 2004 Level IV ^a Examined parental "dependent care" practices and the self-care of children with cancer; identified self-care deficits (Orem), and the nursing interventions needed.	Purposive sample of 9 children and 18 parents were interviewed. Content analysis was done using NVivo qualitative analysis software, and Orem's self-care requisites (universal, developmental, and health-deviation).	Parents often performed self/dependent-care requisites (universal, developmental); and health-deviation self-care practices less often—shows need for educative-supportive nursing interventions.
Sidhu et al., 2005 Level VI ^a Examined parental perceptions about issues for	Focus group; Emergent topics analyzed using content analysis. Sample: 9 Australian	Three major themes found: (a) Losses arising from illness experience; (b) Behavioral

<p>siblings of children with cancer and identify support that is helpful. Williams et al., 2009 Level IV^a <i>Purpose</i>: Identified themes in parents' responses on their perceptions of the effects on well siblings of living at home with brother/sister with cancer or CF.</p>	<p>parents of children with cancer who had one or more siblings Content analysis of baseline qualitative data gathered for an RCT^b with CNS^c-administered interventions for siblings and parents in USA. <i>Sample</i>: 44 parents total— of children with CF^d (<i>n</i> = 15), and of children with Cancer (<i>n</i> = 29).</p>	<p>challenges and adaptations; (c) Parent-sibling communication. Majority of parents reported negative manifestations of increased risk in siblings of children with Cancer and those with CF.</p>
<p>Kerr et al., 2007 Level IV^a <i>Purpose</i>: Assessed supportive care needs of parents of children diagnosed with cancer.</p>	<p>Part B. "Mixed Methods Design" (2)—Studies in this section meet criteria for "mixed design" studies (Polit & Beck, 2012, p. 216) Exploratory, mixed-methods design using standard needs survey and semi-structured interviews. <i>Sample</i>: 15 Canadian parents completed initial survey. Three parents served as key informants in follow up interviews.</p>	<p>Reported needs in 6 categories of the Supportive Care Needs Framework. Informational and emotional needs most frequently found.</p>
<p>Williams P. et al., 2006 Level IV^a <i>Purpose</i>: Examined parents' use of a symptom checklist during pediatric oncology treatments, and the <i>dependent care</i> used by parents to alleviate and monitor symptoms using complementary/integrative care categories.</p>	<p>A "mixed method" research design was used. <i>Sample</i>: 11 cancer in-patients and their parents. Used a precursor of the Therapy-Related Symptom Checklist-Children, TRSC-C. (Note: there is now a calibrated tool that measures symptoms occurrence and severity during pediatric cancer treatment, Williams et al., 2012a, 2013b). Part C. Quantitative Studies (4)— Studies in this section meet criteria for quantitative studies (Polit & Beck, 2012, pp. 112–114), i.e., design, variables, sample, setting, randomization, interventions, standardized</p>	<p>Found (a) occurrence of 12 symptoms, with mean severities of "quite a bit"; (b) to alleviate symptoms reported, methods used were diet/lifestyle modifications; mind/body control; prescribed medications.</p>

(continued)

Table 1. Continued

Study; Purpose; Level of Evidence ^a	Methods	Findings; Implications
Svavarsdottir, 2005 Level IV ^a <i>Purpose:</i> Parents of children with cancer were evaluated on caregiving demands, parental well-being, and perceptions on health status of child.	instruments/scales, measurement, psychometric properties (reliability, validity), analysis including model testing, statistical significance. Longitudinal, three time points over 18 months measured; observations and standardized questionnaires. <i>Sample:</i> Icelandic parents of 26 children under 18 years of age with cancer.	Emotional support the most time consuming and difficult caregiving activity Long term impact on families of a child with cancer found.
Williams et al., 2006a Level II ^a <i>Purpose:</i> Using a structural equation (SEM) model, examined interrelationships among variables affecting parents and well siblings when a child lives at home with cancer/other chronic illness.	Multivariate analysis using SEM ^c with baseline data of an RCT. Standardized scales with strong psychometric properties used. <i>Sample:</i> 252 parents and well siblings of children living at home with a brother/sister with chronic illness including cancer.	Consistent with hypotheses: (a) family cohesion and SES ^f were significantly related to sibling behavior problems; (b) SES affected maternal mood, which in turn affected family cohesion; (c) well sibling knowledge of the illness was related to other sibling variables (attitude toward the illness, mood, self-esteem, feelings of social support); in turn, all these were related to well sibling behavior problems
Williams et al., 2006a Level II ^a <i>Purpose:</i> Examined the validity and reliability of Stein's 15-item, revised Impact on Family (IOF) scale.	Secondary analysis of IOF ^g data in the RCT. <i>Sample:</i> 252 parents who completed the IOF in the RCT sibling study. ¹ . Confirmatory factor analysis (CFA), Item Response Theory (IRT), and related analyses done	The IOF has strong psychometric properties. Construct validity evidences: Significant relationships found between parent IOF scores and 4 variables (parent mood, illness severity, sibling behavior problems, and SES or socioeconomic status).
Williams et al., 2003 Level II ^a <i>Purpose:</i> Examined effects of an intervention for siblings (and parents) of children with chronic illness	RCT: large randomized, three-group repeated measures design, with one year follow-up. <i>Sample:</i> USA; 3 groups of	<i>Dose-response relationship to intervention</i> was found; treatment gains (knowledge, attitude towards illness, mood, self-esteem,

<p>(including cancer). In addition to sibling activities at a residential camp, CNSs also provided the key well sibling interventions (knowledge of illness; discussion of family issues).</p>	<p>siblings: 79 (cancer, 6) received <i>full</i> intervention; 71 (cancer, 9) had <i>partial</i> intervention; 102 (cancer,7), waiting list <i>control</i> group. Follow-up, ‘booster’ interventions (for siblings and parents), at a medical center. Part D. Reviews (2)</p>	<p>perceptions of social support, less behavior problems) sustained over 12 month period: Full >partial > control group.</p>
<p>Gibbins et al., 2012 Level V^a <i>Purpose</i>: Reviewed qualitative studies on experiences of mothers and fathers, from different countries and cultures, whose child is diagnosed with cancer.</p>	<p>Reviewed 28 <i>qualitative studies</i>, identified themes found in the studies; 17 studies were published in nursing journals. Studies included in the review met criteria from the guidelines for qualitative studies by Letts et al. (2007), and Polit & Beck, 2012, pp. 674–675 and 115–117.</p>	<p>The common themes from the studies were: Parents felt a need to have control, had to adjust to unpredictable nature of cancer treatment, learning to cope, valuing emotional and practical support; cultural differences exist.</p>
<p>Williams, 1997 Level I^a <i>Purpose</i>: Reviewed studies on the extent and nature of risks to siblings and parents of children with chronic illnesses (including cancer), and the factors related to these risks.</p>	<p>Over 40 <i>quantitative studies (10 of them on pediatric cancer)</i>, published between 1970 and 1995, were reviewed. Studies included in the review met criteria for quantitative studies (Polit & Beck, 2012, pp. 112–114); and review criteria (pp. 674–675), i.e., problem, search strategy, research quality appraisal (design, sample, standardized instruments, measurement, data collection, data analysis.</p>	<p>60% of all the studies reported increase in sibling risk. 9 of the 10 cancer studies, found increased risk for negative outcomes to siblings and family.</p>
<p>^aLevels of evidence of the study/review: Level I—systematic reviews of RCTs; systematic reviews of nonrandomized trials); Level II—a single RCT, or a single nonrandomized trial; Level III—systematic review of correlational/observational studies; Level IV—single correlational/observational study; Level V—systematic review of descriptive/qualitative/physiologic studies; Level VI—single descriptive/qualitative/physiologic study; Level VII—opinions of authorities, expert committees) (Melnik & Fineout-Overholt, 2011; Polit & Beck, 2012).</p> <p>^bRCT, randomized controlled trial</p> <p>^cCNS, Clinical Nurse Specialist</p> <p>^dCF, Cystic Fibrosis</p> <p>^eSEM, Structural Equations Model</p> <p>^fSES, socioeconomic status</p> <p>^gIOF, Impact on Family scale</p>		

9 and 150). A wide range of qualitative approaches were used including phenomenology, and data collection methods such as focus groups, semi-structured interviews, written responses to questionnaires, needs survey; and various analysis methods including content analysis, descriptive analysis, constant comparison method, thematic analysis, and so forth. The studies met Polit & Becks' (2012) criteria for qualitative studies. The quantitative studies used standardized data collection tools with good psychometric properties, trained data collectors, large samples, randomization to groups, standardized interventions provided by APNs, use of powerful statistical analysis methods, including model "testing." The studies met Polit & Becks' (2012) criteria for quantitative studies; moreover, the studies were published in journals with "high impact factor."

In the next section, added to the information provided in the Table, the themes found from content analysis of the studies are grouped into: Parental caregiving and family impact, and economic burden. For each topic, the themes from the qualitative and mixed method studies are presented together, followed by the quantitative studies.

Parental caregiving and family impact

James et al. (2002), with 151 U. S. parents, used content analysis of responses to a tool called the "Care of My Child with Cancer." The two most common responses to the question on what would help them most were respite from caregiving and receiving emotional support. Parents also cited education from health care professionals and receiving accurate information about their child's disease as the most helpful aspects in providing care for their child.

Kerr et al. (2007) used a mixed methods design to examine these issues. They developed a framework based on the literature regarding the supportive care needs of 15 Canadian parents when their child was diagnosed with cancer, through the treatment period. They found that parents' highest need was for information about the disease, treatment, and how to best care for their child, which offered a way for parents to feel more in control. Physical needs were described in terms of their child's physical symptoms. Emotional needs were met by family, friends, support groups, nurses and other parents who had a child with cancer. Practical needs included financial support, daily activities (i.e., cleaning, cooking), and respite from caregiving. Likewise, using 10 focus groups, and interviews with 49 Canadian mothers, Clarke (2006) also described the mothers' experiences providing care to their child at home. The amount of time the mothers spent caring for their ill child consumed their lives which left little time for spouses, healthy children, work, or themselves.

In Iceland, over an 18-month period, Svavarsdottir (2005) identified and observed time consuming and difficult caregiving tasks when caring for a child with cancer. The most time consuming tasks for 26 mothers was providing emotional support for the ill child as well as other children in the family and coordinating daily activities. Emotional support was provided by their spouses.

Using a mixed methods design, Williams et al. (2006) focused on the use of a symptom checklist during oncology treatments and reported the occurrence of 12 symptoms, with mean severities of “quite a bit.” U.S. parents also reported their symptom management methods (monitoring and alleviation) in the context of “dependent care.” That study used a precursor of the Therapy-Related Symptom Checklist for Children, TRSC-C (a newly calibrated tool that measures pediatric cancer symptoms had been developed by Williams et al., 2012a, 2013b). As described, other studies in this review described the ill child’s physical needs and symptoms manifested (Fletcher, 2010; James et al., 2002; Kerr et al., 2007).

Other qualitative studies in this review show that parental caregiving is influenced by culture. Jongudomkarn et al. (2012) interviewed Thai parents of children with cancer; they reported that parents wanted to provide and secure pain care for their child, but were reticent to approach staff with concerns about their child’s care. Banjeree et al. (2011) also interviewed South Asian immigrant parents who had a child with cancer and found as most helpful: obtaining information about the child’s cancer, trusting in the health care professionals, prayer and practicing religious rituals and obtaining support from other South Asian parents. In Hong Kong, parents’ caregiving focused on restoring their child’s health through adequate nutrition, use of alternative therapies, planning rehabilitative activities, and preventing infections (Martinson & Yee, 2003). Gibbins et al.’s review (2012) recommends that individualizing care for patients with respect to the different coping styles of different cultures should be done by health care providers.

Finally, a qualitative study (Moore & Beckwitt, 2004) with 18 parents of 9 children with cancer examined Orem’s concepts of self-care. They found that parents most often performed dependent care requisites (universal, developmental) practices with their ill child. However, less often, they performed care practices related to “health-deviation requisites;” they stated that they were less comfortable in doing these—suggesting the need for “educative-supportive nursing interventions.” The current review and the discussion show studies focused on symptom management (monitoring and alleviation) that may offer ideas for such educational, supportive nursing interventions (Geiseking et al.

2012; Gonzalez et al., 2012; Kelly et al. 2012; Williams et al. 2012a, 2013b).

Qualitative studies have focused on well siblings. Fletcher (2010) noted that healthy siblings are significantly affected by upheavals from normalcy during a diagnosis of cancer. The sibling is often physically separated from their parents as well as the ill child. Well siblings generally experience a lack of attention. Flury et al. (2011) of Swiss parents, described the family as being divided into two groups—the sick child and the healthy siblings; the needs of each can be vastly different, which can create difficulties for parents. Parents also described needing grandparents or family friends to do many things for the healthy siblings that they would normally do themselves. Done in Australia, a study of 9 parents of children with cancer reported the emotional difficulties of well siblings, similar to the literature, “maladaptive behaviors” were described such as attention seeking, somatization, feelings of jealousy, anger, guilt and resentment (Sidhu et al., 2005). Williams’ (1997) review of quantitative studies in many countries focused on the impact of pediatric chronic illness (including cancer) on the healthy sibling; it described behavioral problems, decreased grades in school, lower social functioning and emotional problems such as depression, anxiety, and anger. Recent qualitative findings from the baseline data of an RCT also have reported these behaviors (Williams et al., 2009). Moreover, family communication was found by Branstetter et al. (2008) to be an important factor in maintaining family functioning in a qualitative study of 30 parent-child dyads during Phase 2 of the RCT study (Williams et al., 2003).

In contrast, based on baseline quantitative data from the large RCT study (phase 1), Williams A. et al. (2006) found excellent psychometric properties of the Impact on Family (IOF) scale. Stein & Jessop (1982, 2003) developed the scale, based on decades of clinical and research experiences in the care of children and families with chronic or long-term conditions and illnesses. The IOF measures the impact of chronic illnesses including cancer on the entire family system (ill child, parents, well siblings, others). Answered on a 4-point scale, sample items included: “Family gives up things”; “Fatigue is a problem”; “No time for family members”; “Travel to the hospital is a strain.”

Likewise, “model testing” based on baseline quantitative data from the RCT study and using a structural equation (SEM) model, Williams et al. (2002) examined interrelationships among psychosocial variables affecting parents and well siblings when a child lives at home with a chronic illness or disability. The sample included 252 parents and well siblings living at home with brothers or sisters with a chronic illness/disability. Standardized scales with strong psychometric properties were

used in this study. Consistent with hypotheses based on family systems theory, SEM results showed that (a) family cohesion and socioeconomic status (SES) were significantly related to sibling behavior problems; (b) SES affected maternal mood, which in turn affected family cohesion; and (c) well sibling knowledge of the illness was related to other sibling variables (attitude toward the illness, mood, self-esteem, feelings of social support); in turn, all these were related to well sibling behavior problems. SEM results suggest potential interventions including economic assistance and boosting the knowledge about the illness of well siblings.

The large randomized controlled trial (RCT) examining the effects of a *nurse clinician-delivered intervention for siblings and parents* of children with chronic illness (including cancer) was found (Williams et al., 2003). The RCT ($N=252$) done by a research team including advanced practice nurses. Based on the 1997 review by Williams, the RCT intervention was developed for siblings and parents of children with chronic illness including 22 who had cancer; each diagnostic group had a specific lesson plan for that diagnosis. Examined were the effects of the intervention using a randomized, three-arm repeated measures design, with 1 year follow-up. Clinical Nurse Specialists, CNSs provided the interventions; *these CNSs themselves were the health care providers at clinics attended by the ill children (brothers and sisters of the well children)*. As described, the educational interventions specific to the respective diagnoses were provided in a residential camp setting. That is, the siblings of children with cancer were taught medical information about cancer; and, discussed family issues in group sessions led by CNSs. Three groups of siblings were studied: 79 (6 in the cancer group) received *full* intervention (educational and psychosocial sessions, and attended a 5-day sibling camp); 71 (9 in the cancer group) received *partial* intervention (or a 5-day camp attendance only); and 102 (7 in the cancer group) comprised the waiting list *control* group. Williams et al. fully describe the interventions and the standardized instruments used. Results showed a “dose-response relationship” to intervention. That is, intervention gains (knowledge, attitude towards illness, mood, self-esteem, perceptions of social support, less behavior problems) were sustained over 12 months of follow-up. The full intervention group significantly had the most gains on the six outcomes measured; next, the partial intervention group; and last, the control group (Williams et al., 2003).

As mentioned in Methods, two reviews on siblings were found. One was on interventions done by non-nurses, focused on siblings alone, not including parents. That review had *explicitly* excluded the above RCT (Prchal & Landolt, 2009): the reason given was that the intervention was

“not specific to the diagnosis.” This is incorrect, given the above descriptions of the RCT intervention to siblings and parents, stated clearly in the report, including an *Appendix* of the intervention provided to siblings and parents; the pediatric cancer clinic affiliations of nurse-authors also were identified. Likewise, the review on “sibling adjustment” by Alderfer et al. (2010) also did not include the Williams review (1997) although they included other reviews and studies since 1994. The two reviews were published in non-nursing journals.

Economic burden

Two qualitative nursing studies reported on economic strain. In a study by James et al. (2002), parents often reported economic losses such as paid employment, income, vacation time, and other benefits. These economic issues provoked anxiety in parents and added to the difficulty in caring for a child with cancer. Lost wages due to missing work, disputes with insurance companies, and incurring costs associated with their child’s treatment were items contributing to financial stressors. In Fletcher’s study (2010) one mother described how she was fired from her job when her child became sick and another mother reported cuts to part-time work in order to care for her child. In both instances, significant financial losses were incurred. Traveling back and forth to the treatment center, buying food during the child’s treatment, and supportive care medications are examples of extra expenses that all add up quickly. The child requires close monitoring due to the multiple side effects of treatment, leading to time lost from work or complete loss of employment for one or both parents.

In summary, (a) qualitative nursing studies in this review (Part A of the table) and the Gibbins et al. (2012) review show that qualitative studies are predominant, and that findings supported the quantitative findings; (b) quantitative nursing studies (Part C of the table) are less common: one large RCT with a one-year follow-up was found; it focused on outcomes of an intervention for well siblings and parents *implemented by Clinical Nurse Specialists, CNSs*; (c) few quantitative studies with large samples also were found, especially studies that used and tested theoretical models of the family system and measures of illness impact on families; and (d) mixed methods research (Polit & Beck, 2012) is illustrated also.

DISCUSSION

The review findings reflect family systems theory and the effects of children’s cancer diagnoses on the family system—parents, well

siblings, and others. The parent-ill child subsystem was the focus of many studies, as presented above in the section on parental caregiving. A large part of parental caregiving (also called dependent care, in Orem's terms) includes symptom monitoring and alleviation, and related care, as reported in recent research presentations of one research program (Geiseking et al., 2012; Gonzalez et al., 2012; Kelly et al., 2012; Williams et al., 2012b, 2013b), and others (Li et al., 2012). Studies on the ill child-well sibling subsystem and the parent-well-child subsystem were the focus of the section on *family impact*. This focus was seen in two large quantitative studies (the RCT and the SEM—Williams et al., 2002, 2003; Williams & Williams, 2005). The economic impact of pediatric cancer on the family also was a part of the model tested by the SEM. The SEM results showed that sibling and parent outcomes and family variables are significantly interrelated. Past research (Williams & Williams, 1997) also illustrate the use of multivariate research designs and analyses, and the testing of a family theoretical model. The RCT intervention was provided to well siblings and to parents, and outcomes were measured four times during one year following the residential camp interventions for siblings. Compared to those who attended camp only (partial intervention) and the waiting list control group, the best outcomes (immediate and over 12 months) were found with the siblings who received the full intervention at camp (information on the ill brother or sister's illness, as well as discussions of family issues with nurse researcher-health caregivers) (Williams et al., 2002, 2003, 2009). Similar findings were reported by Packman et al. (2005) in a pre-post sibling camp study, reported in a non-nursing journal; the authors did not cite the RCT nor the related publications.

Help with financial expenses arising from illness have been recommended also in studies done by nurses in this review. Likewise, the broader literature on costs conducted by non-nurses support these findings. Thus, quantitative studies conducted in Scandinavian countries, where social insurance covers most health care costs, parents still reported financial strain. Employment rates of Norwegian parents of children diagnosed with cancer were compared to those of the general population, and found that mothers were much more likely to experience a reduction in earnings than fathers (Sykes et al., 2011). A Canadian study found that mothers were more likely than fathers to leave their jobs when a child was diagnosed with cancer, and a loss of income for these families meant a higher reliance on social assistance (Limburg et al., 2008). Similarly, families in the United Kingdom report a parent (usually the mother) giving up outside employment in order to care for the ill child, often a significant financial blow (Eiser & Upton, 2007).

Similar quantitative studies on costs to American families were not found in this review.

Other family theories may help explain present findings, including family role theory. Family roles are reciprocal, and any significant change in one role (parent, brother, sister) alters other role patterns. These patterns often change when a child is diagnosed with a chronic illness like cancer (Freidman, 2003; Kaakinen et al., 2010; Williams et al., 1993, 2009). That is, the caregiving demands and other needs of the ill child have the potential to cause family or individual disruptions, manifested in negative outcomes as reported. Family communication is vital to family functioning. That is, the RCT intervention received from CNSs was described by parents and siblings as having enabled them to practice and understand the importance of (a) communication as a reflection family relationships and roles; (b) being available to communicate and “stay connected”; (c) the siblings’ ability to “give voice”; (d) the use of anticipatory and responsive communication; (e) the use of problem-solving communication and “creative strategies” (Branstetter et al., 2008).

Caregiving demands or parental caregiving for children with cancer was a key theme of studies in this review. Parents, often mothers, were the primary caregivers of the ill child in most families. The studies described the child’s physical and other needs. One study reported on symptom management (monitoring and alleviation) done by mothers (Williams P. et al., 2006). Recent replications have reported that (a) in 40% or more of the sampled pediatric oncology patients, the range of symptom occurrence reported by parents was 15–19 symptoms, with average severities of “quite a bit”; and, (b) for the alleviation of each symptom, parental caregiving included the use of ‘complementary care’ methods such as diet modifications, mind/body control, lifestyle changes, and prescribed medications (Geiseking et al., 2012; Kelly et al. 2012; Williams et al., 2013b). Mothers in Hong Kong reported some of these methods also (Martinson & Yee, 2003); likewise, with mothers in Thailand (Williams et al., 2012b), and in Puerto Rico (Gonzalez et al., 2012).

Parents stated that education from health care providers including accurate information about the child’s disease and treatment helped them provide care to their child; it helped them feel more “in control” (Branstetter et al., 2008; Gibbins et al., 2012; James et al., 2002; Kerr et al., 2007). Consistent findings of recent studies have been reported, on symptom monitoring and alleviation by parents that allow parents to discover methods most useful or effective in the care of the ill child (Geiseking et al. 2012; Gonzalez et al., 2012; Williams et al., 2012b, 2013b). Nevertheless, these studies also articulated parents’ expressed

needs for respite from relentless, intensive caregiving. The need for emotional support from families, friends, healthcare providers also were voiced by parents in many studies. The need for help from family with daily activities such as cleaning, cooking, care of the well children, was often expressed by parents. The combined effects of pediatric chronic illness on the family are measured by the Impact on Family (IOF) scale. This scale has been shown to be a valid and reliable measure of many aspects of life within a family that is impacted by illness (Stein & Jessop, 1982, 2003; Williams A. et al., 2006). Crisis intervention strategies when caring for families of children with cancer have been described clearly by nurses (Hendricks-Ferguson, 2000). Active participation in children's camps (for siblings and for ill children) have been done by nurses for many years, and well described (Hancock, 2011), as well as the development of a respite program for caregivers of pediatric oncology patients and their siblings (Carter & Mandrell, 2013).

Some studies in this review illustrate mixed methods nursing research on a broad scale, including the planning of two phases, implementation, and reporting over time (Branstetter et al., 2008; Williams, 1997, Williams et al., 2002, 2003, 2006, 2009; Williams & Williams, 2005). Conn & Groves (2011) alert researchers and others to protect the power of interventions through proper reporting. The importance of clinical nursing research also is emphasized (Hastings et al., 2012). The use of EBP interventions are needed, such as ones done by *advanced practice registered nurses (APRNs)* with adult oncology patients (Williams et al., 2011, 2013a).

CONCLUSIONS

Several areas need more study in this important aspect of pediatric oncology. There is a need for larger studies including RCT of nurse-delivered interventions and the use of "mixed methods" designs as illustrated by studies in this review. One large RCT with a 1-year follow-up was found. Few quantitative studies with larger samples exist, especially ones that use theoretical models of the family system and measure the impact on the family of pediatric cancer. There is need for studies that include in their theoretical models the variable illness severity, measured using robust calibrated instruments based upon symptom occurrence, severity, and/or other constructs (Williams et al., 2012a, 2013b). Symptoms during outpatient treatments need to be monitored and alleviated. Studies of the economic impact on the family of a pediatric cancer diagnosis are scarce and much needed.

Clinical/practice implications

As mentioned, parents stated that education from health care providers including accurate information about the child's disease and treatment helped them provide care to their child; it helped them feel more "in control." An important aspect of parental caregiving at home involves symptom monitoring and alleviation of those symptoms with familiar methods including diet/nutrition, lifestyle modifications, mind/body control, in addition to prescribed medications. Thus, counseling on the use of parental care methods to alleviate symptoms (both traditional comfort measures as well as use of prescribed medications, including medications to stop nausea and vomiting, pain, etc.), and hydration (monitoring fluid intake) are helpful. For example, traditional comfort measures used by parents in the U.S. and across cultures (as related to diet/nutrition) include methods such as adding flavoring to food items, changing the variety of foods, providing small frequent meals, and offering soft or liquid diets. Other comfort measures parents/caregivers provide (as related to mind/body control) include talking, reassurance, drawing, playing, singing, watching a favorite show with family, allowing/assisting child with his/her computer games and other electronic tools, use of body massage, bathing, cold compresses on the forehead, etc. Reinforcing these parental caregiving methods by providers is basic.

Other practice implications include: crisis intervention strategies by nurses caring for families of children with cancer; active participation in children's camps by siblings (and perhaps the ill children also); as well as the development of a respite program for caregivers of pediatric oncology patients. Moreover, pediatric oncology health care provider awareness of the importance of and continuing support for family communications is important. It is a reflection of family relationships and roles, their attempts at staying connected, their daily struggles for "normalcy"; their need to allow family members to "give voice." Fundamentally, providers need to constantly use anticipatory and responsive communication, especially the use of problem-solving communication. In addition, cultural aspects of coping strategies need consideration as needed, such as involvement of the entire family (nuclear and extended), use of religious rituals, prayer; and need to obtain support of similar parents within the culture group.

Overall, there is a need for more "evidence-based practice" (EBP) *nursing* interventions on the special population represented in this review, with measurements of outcomes including symptom management (monitoring and alleviation). Possible helpful interventions include parent education, support, and/or assistance with (a) symptom

management (monitoring and alleviation) during the treatments of the child, for example, with the use of a checklist such as the TRSC-C, Therapy-Related Symptom Checklist for Children, and (b) increasing parent and sibling knowledge of the child's illness. Respite care and financial assistance to families would also help lessen interpersonal strain.

DECLARATION OF INTEREST

The authors have no conflicts of interest to disclose.

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