The Psychosocial Impact of Completing Childhood Cancer Treatment: A Systematic Review of the Literature

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Objective To review the results of any published research study examining the psychosocial functioning of children who have recently completed cancer treatment. **Methods** Five electronic databases were searched (from 1978 to 2008). Of 1,734 identified articles, 19 met all inclusion criteria. Four articles utilized a qualitative methodology, thirteen utilized a quantitative methodology, and two used mixed methods. **Results** Children may experience positive psychosocial outcomes on treatment completion, including high self-worth, good behavioral conduct, and improved mental health and social behavior. However, they may also experience significant negative outcomes, including lower levels of psychological well-being, mood, liveliness, self-esteem, and motor and physical functioning, as well as increased anxiety, problem behaviors, and sleeping difficulties. **Conclusions** Completing treatment can be a psychologically complex time for children as they wait to make the transition from ''cancer patient'' to long-term ''cancer survivor.'' Further high-quality research targeting the needs of these children is warranted.

Key words childhood cancer; leukemia; needs; psychosocial; treatment completion.

Despite the large numbers of children surviving cancer worldwide (Dickerman, 2007), surprisingly little research describes the psychological and social issues of children who have recently completed cancer treatment. In addition, it is a disparate literature varying across disciplines from medicine to nursing and allied health (e.g., psychology and social work). Not only does this make it difficult for clinicians and researchers to quickly appraise the content and quality of the evidence but there are also few guidelines available to support the ever increasing population of children through the first years after treatment. To address this gap, the present paper comprises a systematic review of studies exploring the psychosocial issues faced by children who have *recently* (i.e., within the last 5 years) completed cancer treatment. The review was justified because despite the large and growing bodies of psychosocial research documenting the impact of being on cancer treatment as well as the impact of long-term survival, there appears to be no other published collation of the results of research specifically conducted at this point in the childhood cancer trajectory of care. It is hoped that this review will help to inform the development of appropriate, targeted interventions to support children who have recently completed cancer treatment, but who have not yet reached formal status as long-term cancer survivors.

Multiple studies and reviews have now investigated the longer term psychosocial impact of surviving childhood cancer (Eiser, 2007; Goldsby, Taggart, & Ablin, 2006; Massimo, Zarri, & Caprino, 2005). In part, due to the evidence of negative psychosocial outcomes such as depression, anxiety, and reduced quality of life provided by this research, long-term follow-up clinics have been established in many countries to support and monitor survivors (Bhatia & Meadows, 2006; Landier, Wallace, & Hudson, 2006). There is much variability in the

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enrollment of children into these clinics. However, survivors typically enroll in these clinics once the risk of relapse is significantly lowered, or around 5 years after cancer diagnosis (Oeffinger, Nathan, & Kremer, 2008). This leaves a potential gap of several years during which children who have completed treatment may be waiting to make the transition from ''patient'' to ''survivor.'' While coming off treatment has been acknowledged as a major stress point in the pediatric cancer journey (Chesler & Barbarin, 1987), there is little empirical research describing the experience of children when completing treatment and waiting to attain long-term survivor status.

This time is a well-documented risk period within the adult cancer experience, with up to 30% of adult patients developing ''post-cancer distress'' soon after treatment completion (Alfano & Rowland, 2006). Postcancer distress in adults is characterized by fear of cancer recurrence; difficulty integrating back into normal life; feeling abandoned by health professionals; cognitive changes; body image, sexual health, and functioning difficulties; and distress, anxiety, and depression (Alfano & Rowland, 2006; Hodgkinson et al., 2007). Little research has investigated how the findings from the adult literature might manifest in children. However for childhood cancer patients, the transition from patient to survivor might also be a phase characterized by psychological vulnerability. For example, children may also experience fears of cancer recurrence, difficulty reintegrating back into school or friendship groups, and may also feel abandoned by the team of health professionals who cared for them during their treatment. Children's normal cognitive development may also be affected by their cancer experience, and they may also experience concerns surrounding changes to their physical appearance at treatment completion.

These difficulties may be further compounded by the fact that many children completing cancer treatment also reach, or are approaching, adolescence during this time and are becoming increasingly responsible for personal healthcare (Wilkins & Woodgate, 2006). A healthy adolescence may be a complex life-stage, involving an altered body image, balancing the influences of peers and family, exploring one's sexuality, and preparing for adult responsibilities (Palmer, Mitchell, Thompson, & Sexton, 2007). For adolescents who have had cancer, it may be particularly difficult to receive appropriate care while waiting to become a long-term cancer survivor given the dichotomized (pediatric versus adult) design of many public health systems worldwide (Drybrough, Frid, Vitko, Vlach, & D'Agostino, 2006).

Despite the possibility of the negative outcomes described above, the completion of cancer treatment might also be expected to be a positive time psychologically for children. It is, in fact, a significant milestone on the path to becoming a long-term cancer survivor and can mark the end of invasive treatment regimens with numerous side effects. The disruption to normal family life caused by the cancer and treatment will be reduced and normal social and educational activities may be able to recommence. As such, it may be a time that is celebrated as representing a desired return to life as it was before the child's cancer diagnosis. This review was designed to answer the following question: What is the psychosocial impact (both positive and negative) of completing cancer treatment on children?

Methods

The literature search aimed to identify any research study published in a peer-reviewed journal that examined the psychosocial impact of completing childhood cancer treatment. The target cohort comprised children who had not yet reached long-term survivor status; that is, cancer treatment was completed less than 5 years prior to the child participating in the study. The inclusion criteria for the review were studies where all children in the study: (i) had been diagnosed with a malignant form of childhood cancer, (ii) were younger than 18 years at treatment completion, (iii) had completed cancer treatment less than 5 years prior to study participation, and (iv) were in complete remission at the time of the study.

Three search strategies were employed. First, the electronic databases from MEDLINE, PreMedline, PsychInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Social Work Abstracts were searched from January 1978 to September 2008, limited to studies using the ''English language'', ''humans'', or ''human.'' The search was restricted to studies published since 1977 due to the limited availability of searchable electronic records prior to 1978. As well, the substantial medical and social changes that have occurred in the last 30 years would have limited the relevance of studies published prior to 1978 (Dickerman, 2007). The following free-text search terms were entered individually: ''child$'', ''adolescen$'', ''paediatric,'' and ''pediatric.'' These terms were then grouped to form the first stem group. The second stem group used the terms, ''oncology'', ''cancer'', ''leukemia'', ''leukaemia'', ''tumour,'' and ''tumor.'' The third stem group used the terms ''post-treatment'', ''off treatment,'' and ''surviv$.'' The fourth

stem included the search terms ''psych$'' and ''needs''. These four stem groups were then combined and de-duplicated, yielding 1,734 articles meeting the search algorithm.

The remaining abstracts were screened by two researchers (J.M. and C.W.) and studies not fitting the inclusion criteria were discarded. The agreement rate between authors was 98.5%, with 22 articles being coded differently between the two raters. Full-text versions of these 22 studies, plus another 160 studies in which the abstract did not provide sufficient data with which to exclude studies, were obtained. Of this group of 188 studies, the two searching authors remained unclear about the eligibility of eight studies (primarily due to inclusion criteria (iii) above). The authors of these eight studies were contacted directly to obtain further demographic and clinical data on their participants before a final inclusion decision was made in consultation with the multidisciplinary team, which included a behavioral scientist, two psychologists, a pediatric oncology social worker, a clinical oncologist, and a biostatistician.

Only 19 (1.1%) of the electronically identified studies met all inclusion criteria. The majority of studies were excluded based on the study reference period, because either the child had not yet completed cancer treatment or they had completed cancer treatment more than 5 years prior to participating in the study ($n = 738$) or because the sample was not pediatric (i.e., not all participants were under 18 years) ($n = 280$). The appendix lists all reasons for excluding studies. The large number of excluded studies highlight the difficulties caused by differences in the nomenclature used to describe this cohort across studies. As children in this group were variously called ''survivors,'' ''surviving children,'' ''patients,'' ''children off-treatment,'' and ''children in remission,'' it was impossible to develop more specific search criteria without missing pertinent studies for the review. Thus, we opted for wider ranging original search terms with a more thorough manual review of each abstract with two investigators. In order to reduce confusion with the body of literature concerning *long-term* survivors of cancer, this review uses the term ''off-treatment children'' to describe the children participating in the included studies.

Each included study was then assessed for quality by two authors (C.W. and J.M.) using the criteria outlined in Table I [based on the validated tools described in Harden and Thomas (2005), Jackson, Cheater, and Reid (2008), and Long and Godfrey (2004)]. Studies were assessed as meeting each criterion (yes, no, or unclear). All criteria were equally weighted. The assessing authors completed the assessment separately and the interrater reliability was 95.81%, with only 13 discrepancies across 286 assessment criteria. The criterion with the least agreement was assessing whether a study had clearly reported using a theoretical framework, with 4 out of 19 discrepancies between assessors in this category. All discrepancies were discussed with the larger team before a consensus was reached for each criterion. Studies were not excluded from the review on the basis of quality; however, methodological quality is discussed below.

Inclusion of Both Qualitative and Quantitative Studies in the Review

Given the dearth of literature specifically addressing the research questions for the review, and calls to strengthen systematic reviews by incorporating the results of qualitative studies (Harden & Thomas, 2005; Weed, 2008), studies using either or both qualitative and quantitative methodologies were included, although the results are summarized separately. The methods described in Noblit and Hare (1988) and the meta-ethnography techniques described in Tong, Lowe, Sainsbury, & Craig (2008) guided analysis of the qualitative findings (Noblit & Hare, 1988; Tong, Lowe, Sainsbury, & Craig, 2008).

Briefly, meta-ethnography involves systematically identifying key concepts arising from each study (using original quotations from participants, as well as the themes described by the researchers). Common and differing themes within and across the included studies can be analyzed and synthesized to create a coherent summary of the literature (Noblit & Hare, 1988). The synthesis was started using the most recent article in the review, which was Ortiz and Lima (2007). Starting with this article, we listed all the themes described by the authors, and then compared these with the themes identified by subsequent studies, listing the number of other studies that reported the same themes and adding additional themes as they arose in the articles until all themes were included on the list (Tong, Lowe, Sainsbury, & Craig, 2008). The techniques described in Oxman (1995) guided analysis of findings from the quantitative studies (Oxman, 1995). It was not possible to conduct a formal meta-analysis because few utilized consistent measures enabling direct comparison (see Tables III and IV for the extensive range of measures used); however, where studies included a healthy control group, we calculated Cohen's effect sizes for all reported findings (Thalheimer & Cook, 2002).

Results

From a total of 1,734 articles identified by the search algorithm, 19 met all inclusion criteria. Of these, 4 studies

utilized a qualitative methodology, 13 utilized a quantitative methodology, and 2 used mixed methods. The majority of articles originated from the United States ($n = 12$).

Quality Assessment

The quality of studies varied significantly (see Table I). The mean quality scores ranged from 74.90% (qualitative studies) to 82.2% (quantitative studies). All studies provided a clear description of their aims and objectives, the setting for the study, and used an appropriate sampling procedure. All qualitative studies demonstrated critical reflection of their results, and all quantitative studies utilized at least one valid and reliable assessment tool (although many also used purposely created unvalidated tools as well). However, no studies reported using a consumer representative in the research process, and only 68% explicitly reported using a theoretical framework to guide their research. As well, only 60% of quantitative studies provided attrition data and only 73.7% of all studies discussed the strengths and limitations of their research.

Qualitative Results

Table II summarizes the findings of the qualitative studies admitted to the review.

Several consistent themes were identified. These included the positive and negative emotional impact of finishing cancer treatment plus the impact on children's school experiences. Two studies reported that off-treatment children experience a wide spectrum of emotions when completing cancer treatment, ranging from ''relief,'' ''joy,'' and ''elation'' to ''abandonment'' and ''isolation,'' as well as cognitive impacts such as having to redefine what was normal in life (Duffey-Lind et al., 2006; Ortiz & Lima, 2007). Some children felt that they received less attention once treatment ended, while others felt that there were not any big life adjustments after completing treatment (Duffey-Lind et al., 2006). Some adolescents have described completing treatment as a time of emotional exhaustion, coupled with uncertainty about whether to relax and enjoy life again (McGrath, Suppiah, & Patton, 2005). They also felt that other people did not understand that while treatment was over, the cancer experience remained ongoing (Duffey-Lind et al., 2006). One Brazilian study reported that while children celebrated discharge from hospital, they also felt threatened by the absence of the hospital structure and concerned about not being monitored as often by doctors (Ortiz & Lima, 2007).

The completion of cancer treatment also appears to have a strong impact on children's school experiences, with studies reporting that returning to school provides a sense of normality (even if this was a slightly changed sense of ''normal'') (Bessell, 2001; McGrath, Suppiah, & Patton, 2005). Indeed, many children have reported positive

Table I. Percentage of Studies Scoring a ''Yes'' for Quality Assessment Criteria (Based on Jackson, Cheater, & Reid, 2008)

	All	Percentage	Quantitative ($n = 13$)	Qualitative ($n = 4$)	Mixed ($n = 2$)
Explicit theoretical framework identified/literature review	13	68.4[a]	8	4	1
Clear aims and objectives	19	100.0[a]	13	4	2
Clear description of setting	19	100.0[a]	13	4	2
Clear description of sample	17	70.6[a]	12	3	2
Appropriate sampling procedure	15	100.0[b]	13	–	2
Clear description of data collection	18	94.7[a]	12	4	2
Clear description of data analysis	16	84.2[a]	11	3	2
Evidence of critical reflection	6	100.0[c]	–	4	2
Provision of recruitment data	13	86.7[b]	11	–	2
Provision of attrition data	9	60.0[b]	8	–	1
Valid and reliable outcomes	15	100.0[b]	13	–	2
Findings reported for each outcome	13	86.7[b]	11	–	2
Description of validity/reliability of results	4	66.7[c]	–	2	2
Sufficient original data	5	83.3[c]	–	4	1
Evidence of consumer involvement	0	0.0[a]	0	0	0
Strengths and limitations stated	14	73.7[a]	12	1	1
Mean percentage of maximum possible score			82.2	74.9	84.4

[a]Percentage of all 19 studies.

[b]Percentage of the 15 studies that utilized quantitative methods (13 quantitative plus 2 mixed methods).

[c]Percentage of the 6 studies that utilized qualitative methods (4 qualitative plus 2 mixed methods).

Table II. Summary of Qualitative Studies Reporting the Experiences of Children after Recent Cancer Treatment Completion

Study authors, year	Study origin	Sample size	Gender M (%)	Mean age at diagnosis (range)	Mean age at time of study (range)	Mean time since treatment completion	Emergent themes
Stuber et al., 1991	USA	6	50	4.9 years (3–6)	5.9 years (4–7)	1 year	PTSD symptoms after BMT, e.g., intrusive thoughts, denial, avoidance. No evidence of hypervigilance, attention problems, obsessions, or compulsions. Maintained interest in activities, closeness to loved ones, and career and family plans.
Davies, 1992	USA	1	100	3 years (n.a)	4.8 years (n.a.)	6 months	Previously vivacious child became serious, quiet, inhibited, physically cautious, ability to play delayed relative to peers, less social. No symptoms of psychopathology.
Bessell, 2001	USA	51	55	7.3 years (NR)	12.7 years (8–17)	3.6 years	School provided normality. Less than 50% reported school as good and 45% identified as good students. 30% reported teacher was sensitive to their needs, while 30% reported teacher was poor. 47% had positive friendships. Those repeating a grade reported more issues with peers.
McGrath et al., 2005	Australia	2	0	12 years (0–16)	13 years (1–17)	1 year	Embraced re-entry to school, felt well supported by friends. No evidence of self-esteem problems. Some eager to forget and move on.
Duffey-Lind et al., 2006	USA	4	50	NR	NR (14–18)	2 years	Describe relief and adjusting to new definition of ''normal''. Most concerned about school re-entry and being different from peers. Less inclined toward risky behaviors, reluctant to talk of potential relapse or late effects.
Ortiz and Lima, 2007	Brazil	10	NR	NR	NR	NR	Reported not only joy at treatment completion but also concerns related to physical condition and future adaptation. Discharge celebrated as well as feeling threatened by the absence of hospital plus own capacity to be responsible for medical care.

Notes. NR: not reported in article; PTSD: posttraumatic stress disorder; BMT: bone marrow transplant.

school experiences, as well as an eagerness to return to school after treatment (McGrath, Suppiah, & Patton, 2005). Bessell, for example, asked 51 off-treatment children about their school experiences and reported that more than half described their school experiences as ''good'' (Bessell, 2001). Some studies also report nervousness in children surrounding school re-entry due to a lower sense of confidence (McGrath, Suppiah, & Patton, 2005) and feeling different from peers (Duffey-Lind et al., 2006). Indeed, while Bessell (2001) reported that many off-treatment children had positive friendships at school, other studies have reported that they may prefer to not discuss their illness with peers (Duffey-Lind et al., 2006) and may feel eager to forget their experiences and move on with life (McGrath, Suppiah, & Patton, 2005).

Quantitative Results

Tables III and IV summarize the findings of the quantitative studies admitted to the review.

Several studies have described positive psychosocial outcomes for children who have recently completed treatment. For example, Bessell (2001) reported that children who had recently completed treatment have high levels of global self-worth and good behavioral conduct. As well, they demonstrated that overall psychosocial adjustment in their sample was similar to the general population (Bessell, 2001). Similarly, Reiter-Purtill et al. reported that children exhibited ''considerable psychosocial hardiness'' and argued that completing cancer treatment had impacted minimally on children's social functioning and social acceptance (Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003). In this study, off-treatment children were perceived as more pro-social and less aggressive by their teachers when compared with their peers (although their peers viewed them as more ill, tired, and absent from school) (Reiter-Purtill et al., 2003). Another study showed that off-treatment children may engage in less health-related risk taking and may show more interest

Table III. Summary of Quantitative Studies of the Psychosocial Impact of Recent Childhood Cancer Treatment Completion

Study author, year	Study origin	Sample size	Gender M (%)	Mean age at diagnosis (range)	Mean age at time of study (range)	Mean time since treatment completion (range)	Comparison group/s	Scales used
LeBaron et al., 1988	USA	15	53%	8.3 years (9–15)	10.8 years (6–17)	1.7 years	None	CBCL, WISC-R, PIAT
Assessed children with posterior fossa tumors. One-third showed behavior and adjustment problems warranting clinical intervention. Social relationships and school functioning were perceived by parents as areas of weakness.								
Stuber et al., 1991	USA	6	50%	4.9 years (3–6)	5.9 years (4–7 years)	1 year	None	PTSD-RI, PPS
12 months after bone marrow transplantation, 3/6 children met criteria for PTSD. Play performance remained within the normal range.								
Sawyer et al., 1998	Australia	38	53%	3.5 years (NR)	5.5 years (NR)	2 years	None	CBCL, GHQ, FAD
Psychological adjustment consistent with norms; however, mother's distress at diagnosis predicted externalizing and internalizing behavior in the child.								
Sawyer et al., 1999	Australia	46	53%	NR	13.6 years (10–18)	4.8 years since diagnosis	232 healthy, 24 on treatment	CHQ, FSQ, IFS
Positive findings[a]: role social–behavioral ($d = 0.40$; medium), mental health ($d = 0.28$; small), behavior ($d = 0.23$; small), role/social–emotional ($d = 0.17$; small), bodily pain ($d = 0.16$; small). Negative findings: general health perceptions ($d = 0.39$; small), self-esteem ($d = 0.35$; small). No difference: physical functioning ($d = 0.07$), role/social–physical ($d = 0.03$). Parents also reported the following: *Negative:* general health perceptions ($d = 1.06$; large), physical functioning ($d = 0.84$; large), role/social–physical ($d = 0.69$; medium), parental impact–emotional ($d = 0.68$; medium), role/social–emotional ($d = 0.60$; medium), family activities ($d = 0.54$; medium), self-esteem ($d = 0.38$; small), bodily pain ($d = 0.22$; small), family cohesion ($d = 0.18$; small). *No difference:* parental impact–time, mental health, behavior. Children living with both parents had better outcomes.								
Kazak et al., 1999	USA	19	68%	NR	13.3 years (10–17)	At least 1 year	None	IES, PTSD-RI, STAI, RCMS, FLS
Assessed impact of intervention for families completing treatment. Provide useful data on preintervention measures of intrusion, avoidance, PTSD, anxiety, and family functioning.								
von Essen et al., 2000	Sweden	35	51%	9.3 years (6–17)	12.6 years (8–18)	39.4 months	Norms and 16 on treatment	ITIA, CDI, RCMAS
Negative findings[a]: psychological well-being ($d = 0.90$; large), physical components ($d = 0.76$; large), self-esteem (10–18 years; $d = 0.65$; medium). No difference: depression, anxiety, skills, relations to parents/family, relation to others, self-esteem (8–9 years). Children living with two parents had best outcomes.								
Bessell, 2001	USA	51	55%	7.3 years (NR)	12.7 years (8–17)	3.6 years	None	SASC-R, SAS-A, SPP, MPQOL
Overall psychosocial adjustment similar to general pop. Primary school-aged children more anxious than secondary school children. 42% clinically significant social anxiety scores. High global self-worth and behavioral conduct, but low athletic competence.								
Grootenhuis and Last, 2001	The Netherlands	43	51%	8.9 years (NR)	12.9 years (8–18)	3.1 years	43 relapsed children	DQC, TRAIT, DESC, CCSS-C
No differences between OTC and relapsed children on measures of control, defensiveness, anxiety, or depression. Time since diagnosis and survival perspective do not explain variance in depressive symptomatology and anxiety.								
Carpentieri et al., 2003	USA	31OTC, 32 parents, 32 teachers	56%	8.8 years (2–15)	14.5 years (12–18)	4.1 years	Norms for general population	BASC
Mean scores within normal range compared to norms on all 13 child-report, 11 parent-report, and 13 teacher-report subscales. However, when percentage of OTC with "at-risk" scores was compared to the percentage of individuals in the population who had "at-risk" scores, teachers reported that OTC experienced greater somatization and learning problems. Parents also reported greater somatization, attention, and leadership problems.								

(continued)

Table III. Continued

Study author, year	Study origin	Sample size	Gender M (%)	Mean age at diagnosis (range)	Mean age at time of study (range)	Mean time since treatment completion (range)	Comparison group/s	Scales used
Reiter-Purtill et al., 2003	USA	69	61%	5–16 years (NR)	NR (9–17)	16.7 months	77 comparison peers	RCP
Positive findings[a]: OTC perceived themselves as more prosocial ($d = 0.42$; medium), teachers perceived OTC as less aggressive ($d = 0.43$; medium), and more prosocial ($d = 0.34$; small), and peers perceived OTC as less aggressive ($d = 0.37$; small). Negative findings: OTC perceived themselves as less popular/leader-like ($d = 0.18$; small), peers nominated them less as best friends ($d = 0.18$; small) and perceived them as more ill ($d = 0.82$; large), absent ($d = 0.70$; medium), tired ($d = 0.56$; medium), and sensitive isolated ($d = 0.15$; small). No difference: OTC described themselves as similar to peers in aggressive disruptiveness and sensitive isolated. No difference on popular leadership and prosocial scales (teacher and peer report), no difference on liking ratings, and reciprocated friendship scales (peer report).								
Tercyak et al., 2004	USA	28	50%	10.1 years (NR)	15.4 years (NR)	3.4 years	Norms from NLSAH	Test battery: adapted items from previous studies.
79% of OTC rated health as good/excellent (93% in norms); 57% think about illness ''a fair amount, or a lot''; 57% interested in cancer screening; 75% never experimented with smoking (43% in norms).								
Vannatta et al., 2007	USA	82	60%	9.9 years (NR)	13.5 years (9–17)	NR	None	RCP
Children with more CNS-directed treatment had lower peer acceptance ratings, were less likely to be identified as a friend by peers, more likely to be perceived as sensitive and isolated, and less likely to be perceived as a leader. These associations were significant for boys and younger children.								
Wolfe-Christensen et al., 2007	USA	21	62%	7.2 years (3–15)	9.8 years (6–17)	13.1 months	None	CBCL, CRS
Compared with children who did not develop Posterior Fossa Syndrome (PFS), those with PFS were more likely to exhibit obsessive–compulsive type symptoms, withdrawal behaviors, social problems, and internalizing behaviors.								
Butler et al., 2008	USA	161	65%	5.1 years (NR)	10.9 years (6–17)	NR	108 in intervention, 53 waitlisted	WRAT-3, WJTA-R, PIAT-R, WISC–III, CMS, RAVLT, SCWT, TMT, ROCFT, SAM, CTRS, CFSEI
Academic achievement significantly improved for children with attention deficits receiving intervention. Parents reported fewer cognitive and attention problems.								
Maurice-Stam et al., 2008	The Netherlands	53	49%	2.6 years (<1–5)	3.9 years (1–5)	2 months, 1, 2 & 3 years	Norms for population	TAPQOL, GHQ
Negative findings[a]: 2 months off treatment—motor functioning ($d = 3.6$; huge), anxiety ($d = 1.3$; very large), liveliness ($d = 1.1$; very large), positive mood ($d = 0.90$; large), sleeping ($d = 0.90$; large), and problem behavior ($d = 0.70$; medium). No difference: communication. One year off treatment—all scales normalized, except motor functioning ($d = 2.60$; huge) and anxiety ($d = 0.40$; small), which remained worse until 2–3 years off treatment. Longer treatment, poor prognosis, and greater parental distress related to lower physical scores.								

Notes. NR: not reported in article; NA: not applicable; OTC: off-treatment children; NLSAH: National Longitudinal Study of Adolescent Health; BDI: Beck Depression Inventory; CBCL: Child Behavior Checklist; CCSS-c: Cognitive Control Strategy for Children; CDI: Children's Depression Inventory; CFSEI: Culture-Free Self-Esteem Inventory; CMS: Children's Memory Scale; CRS: Conner's Rating Scale; CSS: Control Strategy Scale; CTRS: Conners' Teacher Rating Scale; DCQ: Depression Questionnaire for Children; DESC: Defense Scale for Children; FAD: Family Assessment Device; FLS: Family Life Scales; GHQ: General Health Questionnaire; IES: Impact of Events Scale; MPQOLQ: Miami Pediatric Quality of Life Questionnaire; PIAT-R: Peabody Individual Achievement Test; PPS: Play Performance Scale; PTSD-RI: Post-Traumatic Stress Disorder Reaction Index; RAVLT: Rey Auditory Verbal Learning Test; RCMS: Revised Children's Manifest Anxiety Scale; RCP: Revised Class Play Instrument; ROCFT: Rey–Osterrieth Complex Figure Test; SAM: Strategies Assessment Measure; SAS-A: Social Anxiety Scale for Adolescents; SASC-R: Social Anxiety Scale for Children Revised; SCWT: Stroop Color–Word Test; SPP: Self-Perception Profile for Children; SSERQ: Situation Specific Emotional Reaction Questionnaire; STAI: State-Trait Anxiety Inventory; TMT: Trail Making Test B; TRAIT: Trait Anxiety Inventory; WISC–III/R: Wechsler Intelligence Scale for Children—Revised; WJTA-R: Woodcock–Johnson Tests of Achievement; WRAT-3: Wide Range Achievement Test.

[a]Cohen's *d* and effect size: relative size of Cohen's *d* is reported as negligible effect ($\geq -.15$ and $<.15$), small effect ($\geq.15$ and $<.40$), medium effect ($\geq.40$ and $<.75$), large effect ($\geq.75$ and <1.10), very large effect (≥1.10 and <1.45), and huge effect (>1.45) as outlined in Thalheimer and Cook (2002).

Table IV. Summary of Possible Positive and Negative Psychosocial Outcomes That Can Be Expected for Children on Cancer Treatment Completion (Child Assessment/Report Only)

Type of evidence available	Possible positive outcomes	Possible negative outcomes
Large effect with healthy comparison group	Nil reported	Lower psychological wellbeing (von Essen et al., 2000) Physical components (von Essen et al., 2000) Reduced motor functioning (short and medium term) (Maurice-Stam et al., 2008) Increased anxiety (short and medium term) (Maurice-Stam et al., 2008) Reduced liveliness (short term) (Maurice-Stam et al., 2008) Reduced positive mood (short term) (Maurice-Stam et al., 2008) Sleeping problems (short term) (Maurice-Stam et al., 2008) Problem behaviors (short term) (Maurice-Stam et al., 2008)
Medium effect with healthy comparison or sample size	Improved social/behavioral roles (Sawyer et al., 1999) Felt more prosocial (Reiter-Purtill et al., 2003)	Reduced self esteem (von Essen et al., 2000)
Small effect with healthy comparison or smaller sample size	Improved mental health (Sawyer et al., 1999) Improved behavior (Bessell, 2001; Sawyer et al., 1999) Improved social/emotional roles (Sawyer et al., 1999) Reduced bodily pain (Sawyer et al., 1999) Improved global self worth (Bessell, 2001) Interested in cancer screening (Tercyak et al., 2004) Less risky health behaviors (Tercyak et al., 2004)	Behavior/adjustment problems (LeBaron et al., 1988) Posttraumatic stress disorder-like symptoms (Stuber et al., 1991) Lower general health perceptions (Sawyer et al., 1999) Reduced self esteem (Sawyer et al., 1999) Increased anxiety (Bessell, 2001) Lower athletic competence (Bessell, 2001) Felt less popular/leader-like (Reiter-Purtill et al., 2003)

in cancer screening than children without a cancer diagnosis (Tercyak et al., 2004). Finally, Sawyer et al. reported that adolescents in their study had improved mental health and social behavior compared to adolescents in the general community (Sawyer, Antoniou, Toogood, & Rice, 1999). As well, Carpentieri et al. reported that off-treatment children had no significant negative outcomes in behavioral and psychosocial functioning (Carpentieri et al., 2003) and Maurice-Stam et al. showed that health-related quality of life had normalized in a group of 52 children by 2–3 years after treatment completion (Maurice-Stam et al., 2008).

However, when compared with healthy children (either population norms or control children with no chronic health problems), off-treatment children have also been reported to experience worse outcomes in anxiety (Bessell, 2001; Maurice-Stam et al., 2008; von Essen, Enskar, Kreuger, Larsson, & Sjoden, 2000), depression (von Essen et al., 2000), social competence (Bessell, 2001), self-esteem (Sawyer, Antoniou, Toogood, & Rice, 1999; von Essen et al., 2000), emotional stability (Bessell, 2001), health-related quality of life (Maurice-Stam et al., 2008; Sawyer, Antoniou, Toogood, & Rice, 1999), somatization (parent and teacher report only) (Carpentieri et al., 2003), attention problems (parent report only) (Butler et al., 2008; Carpentieri et al., 2003), lack of leadership (parent report only) (Carpentieri et al., 2003), learning difficulties (Bessell, 2001; Carpentieri et al., 2003), and externalizing and internalizing behaviors (Sawyer, Streiner, Antoniou, Toogood, & Rice, 1998). It must be noted, however, that the sizes of the effects of these comparisons is generally small (see Table IV). Negative findings that had a medium or large effect were reported for motor/physical functioning (Maurice-Stam et al., 2008; Sawyer, Antoniou, Toogood, & Rice, 1999; von Essen et al., 2000), anxiety (only at 2 months off-treatment), liveliness, positive mood, sleeping difficulties, problem behavior (Maurice-Stam et al., 2008), and self-esteem (von Essen et al., 2000). Several studies have also found that off-treatment children report experiencing more symptoms similar to posttraumatic stress disorder, such as intrusion and avoidance, than would be expected in children from the general population, although it was not possible to calculate the size of the effects reported in these studies (Kazak et al., 1999; Sawyer, Antoniou, Toogood, & Rice, 1999; Stuber et al., 1991).

When compared to children currently *on* treatment, the data are less equivocal. For example, while von Essen et al. reported that off-treatment children had similar levels of anxiety, depression, and self-esteem to children on treatment (von Essen et al., 2000), Sawyer et al. reported that 66 off-treatment children had a better health-related quality of life than 24 children on treatment (Sawyer, Antoniou, Toogood, & Rice, 1999). Finally, two

studies compared the psychosocial functioning of children who had completed treatment with those who had relapsed (Grootenhuis & Last, 2001; von Essen et al., 2000). Despite a considerably worse prognosis for relapsed patients, no significant differences were found between the groups in anxiety or depression (Grootenhuis & Last, 2001; von Essen et al., 2000) or defensiveness or feelings of control (Grootenhuis & Last, 2001).

Very few studies have examined the predictors of psychosocial outcomes in children after recent treatment completion. One study reported a significant positive correlation between maternal distress at diagnosis and poor psychological adjustment of the child after treatment completion (Sawyer et al., 1998). Similarly, Maurice-Stam et al. found that the greater the psychological distress the parents experienced, the worse health-related quality of life they reported in their child (Maurice-Stam et al., 2008). Two studies also reported that psychosocial outcomes were better for children who lived with both parents, rather than only one (Sawyer, Antoniou, Toogood, & Rice, 1999; von Essen et al., 2000).

Discussion

This review of original studies on psychosocial issues affecting children who have recently completed cancer treatment published between 1978 and 2008 identified 19 relevant articles from six countries. The review revealed a lack of relevant, methodologically rigorous studies in the area. Several studies used unvalidated questionnaires, did not perform multivariate statistical analysis, lacked a control group, and used only small sample sizes. Furthermore, most studies focused on identifying evidence of maladjustment or distress, rather than examining evidence of resilience or coping in these children. This may lead to a potential bias toward identifying negative outcomes in childhood cancer survivorship research, with a lack of acknowledgment of the more positive outcomes that can be associated with cancer treatment completion. Similarly, most studies focused on identifying significant differences between off-treatment children and healthy norms, yet failed to recognize that measures which yielded that no difference may reflect clinically positive outcomes of resiliency and successful readjustment in this population. The majority of studies also originated in the United States, which may limit the broader generalizability of these findings to children cared for in different health systems and cultural contexts. There are not enough non-US studies available to be able to compare the results of studies across countries.

Not surprisingly, the largest negative impact of treatment completion appears to be more physical in nature, with off-treatment children scoring significantly lower than healthy children on measures of motor and physical functioning and liveliness (Maurice-Stam et al., 2008; Sawyer, Antoniou, Toogood, & Rice, 1999; von Essen et al., 2000). Related to this, peers of off-treatment children are more likely to identify them as being more ill, absent, and tired than the other children in their class (Reiter-Purtill et al., 2003). Of the psychological domains, the only medium-to-large effects that were reported were for decreased positive mood and self-esteem (von Essen et al., 2000), as well as increased sleeping difficulties and problem behavior (LeBaron, Zeltzer, Zeltzer, Scott, & Marlin, 1988; Maurice-Stam et al., 2008). Off-treatment children have also been found to experience more anxiety than healthy children; however, this effect appears to diminish with time (by 2–3 years posttreatment completion anxiety appears to normalize) (Maurice-Stam et al., 2008). Other smaller effects have been reported for depression (von Essen et al., 2000), PTSD-like symptoms (Kazak et al., 1999; Sawyer, Antoniou, Toogood, & Rice, 1999; Stuber et al., 1991), learning difficulties (Bessell, 2001; Carpentieri et al., 2003), emotional stability (Bessell, 2001), and health-related quality of life (Sawyer, Antoniou, Toogood, & Rice, 1999).

Reflecting the multifaceted nature of the cancer experience, however, positive outcomes in children have also been reported after recent treatment completion, including high levels of global self-worth (Bessell, 2001), good behavioral conduct (Bessell, 2001; Tercyak et al., 2004), and considerable ''psychosocial hardiness'' (Reiter-Purtill et al., 2003). One study also reported that completing treatment had a minimal impact on children's social functioning and social acceptance (Reiter-Purtill et al., 2003). The available quantitative studies have, however, generally failed to capture the complexity of the experience of completing cancer treatment. Indeed, the themes identified in the qualitative studies revealed that the experience of treatment completion is a complex time psychologically. Children do report some very strong positive emotions at this time, using terms such as ''joy'' and ''relief,'' but these are tempered by posttreatment exhaustion and concerns about cancer recurrence and late effects (Duffey-Lind et al., 2006; Ortiz & Lima, 2007). Further research, using both qualitative and quantitative methodologies, to assess the implications of experiencing these potentially conflicting emotions would be valuable.

With regard to predictors of outcomes in these children, this review also highlighted the importance of

the family in children's ability to cope with cancer and recovery. Parental distress at diagnosis appears to be significantly correlated with the psychological adjustment of the child after treatment completion (Maurice-Stam et al., 2008; Sawyer et al., 1998), and children from single parent families are more likely to experience negative outcomes than those living with both parents (Sawyer, Antoniou, Toogood, & Rice, 1999; von Essen et al., 2000). These results suggest that it is important to identify and support distressed families as early as possible in the childhood cancer journey (i.e., at diagnosis and while on treatment) in order to obtain the best possible outcome for patients who go on to complete treatment (Sawyer et al., 1998).

Limitations of Studies Reviewed

Some studies in the review relied heavily on parent or teacher report of children's psychological functioning. However, parent and teacher reports have been shown to provide low interrater reliability, especially with adolescent populations (Chang & Yeh, 2005; Russell, Hudson, Long, & Phipps, 2006). As well, none of the included studies utilized a consumer representative. There is increasing recognition that the involvement of consumers in the research process can have an important impact on not only the processes but also the outcomes of research (Wyatt et al., 2008).

Furthermore, much of the available literature lacks a strong theoretical foundation with which to develop hypotheses, choose measures, and assess outcomes. Indeed, the studies included in this review used a multitude of measures providing no consistency or potential comparison between studies. It is very difficult to compare the results of different studies using no, or a variety of, theoretical frameworks.

Several frameworks might provide useful structures for future research in the area. For example, given the continued possibility of cancer relapse and the unpredictable nature of the late effects of childhood cancer and its treatment, the Uncertainty in Illness framework (Mishel, 1988) may help to guide the design of future studies. The primary psychological approach to uncertainty in cancer survivorship has been derived from the stress-deficit paradigm, whereby uncertainty is expected to have multiple adverse psychological effects (Lazarus and Folkman, 1984). However the Uncertainty in Illness Theory also acknowledges the potential for uncertainty to have positive impacts on well-being, although this has not yet been extensively empirically examined (Mishel, 1990). Similarly, the Positive Psychology framework may provide a useful structure for future research looking to identify predictors of positive and negative outcomes emerging from the childhood cancer experience (Phipps, 2007). Other potentially useful frameworks include the Children's Health Belief Model, which may help to explain some of the more positive health behavior outcomes in childhood cancer survivors (Ionotti & Bush, 1993), and some transition models might be useful in understanding the impact on children transitioning from ''patient'' status to ''survivor'' status along the cancer journey (Konsler & Jones, 1993).

Importantly, theoretical frameworks such as these allow for the investigation of many cognitive processes and coping strategies which may predict the onset of psychological distress in off-treatment children and their families. These frameworks might improve consistency across studies and provide a platform for the development of valid and reliable assessment and screening tools for this population. Given the large numbers of children that appear to be coping relatively well after cancer treatment completion, accurate identification of vulnerable families and the development of targeted, evidence-based interventions are likely to be the most cost-effective methods of reducing the levels of distress experienced by some children at this time. Proactive psychosocial intervention with the families of these children before treatment completion may prevent the development of negative psychological outcomes after cancer treatment completion.

Limitations of This Study

This systematic review included only studies assessing the psychosocial impact of cancer treatment completion of children. The impact of treatment completion is likely to be significant on the wider range of individuals caring for and interacting with the affected child, including their parents, siblings, and extended family and friends. Also, the search terms utilized for the review were extremely broad. While this strategy allowed the review to capture a large number of potentially eligible studies, it meant that a very large proportion of studies identified electronically were later excluded manually. Finally, it is difficult to differentiate between the final psychosocial outcomes of cancer treatment completion and the other well-known consequences of receiving cancer treatment, such as changes in motor function, inattention, and learning problems (Dickerman, 2007), all of which are likely to interact with the psychosocial well-being of the child.

Future Directions

Few studies to date have included an effective comparison or reference group such as a group of children with other chronic illnesses, which is essential in order to be able to

accurately quantify the effects reported. Also, given the rarity of the different types of childhood cancers and associated small sample sizes, very few studies have attempted to elucidate the psychological impact of completing treatment for children with different cancer types and treatment protocols and other moderators such as the child's gender and age. As might be expected, data suggest that the intensity of the child's treatment protocol directly impacts on the ability of the family to cope on treatment completion (Maurice-Stam et al., 2008; Reiter-Purtill et al., 2003; Vannatta, Gerhardt, Wells, & Noll et al., 2007; Wolfe-Christensen, Mullins, Scott, & McNall-Knapp, 2007). Further research examining the variability in the psychological impact of different types of cancer treatments (e.g., chemotherapy, radiotherapy, types of medications administered) and the location and the severity of the cancer is essential in order to develop appropriately tailored strategies to prepare families for treatment completion.

There is also insufficient data on healthcare professionals' perspectives on the treatment completion stage for children. Their input into the development and evaluation of effective interventions to support distressed families at this time is critical for documenting the cost–benefit analyses of interventions developed for this cohort of families. The implementation of any interventions developed may add pressure to demanding work schedules, in which caring for patients undergoing active treatment will usually need to take priority for professionals. It may also be prudent to investigate the large range of interventions already evaluated for newly diagnosed patients and their families, as many of these may be modifiable for use in families approaching treatment completion [for example, see the psychosocial intervention developed by Kazak et al. (2005)]. Finally, more discussion is needed on the nomenclature used to describe this cohort. Currently, there is little consistency in the terminology used to describe cancer patients who have recently completed treatment and are awaiting transition to long-term survivor status. Consensus is needed on how to define and label this cohort. Indeed, a lack of a distinctive identity at this point in the cancer journey could be testimony to the lack of formal guidelines for the care of patients and their families at this time.

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Appendix. Exclusion Criteria[a]

Exclusion criteria	No. of studies rejected on exclusion criteria
Data collection period prior to treatment completion or beyond 5 years posttreatment completion	738
Sample population aged >18 years at cancer diagnosis	280
Other primary conditions, e.g., child's reaction to adult cancer, noncancer trauma survivor, transplants, informed consent issues	73
Validity study of measurement tool	43
Epidemiological study	34
Drug trial	49
Biomedical study	62
Case study	15
Review	95
Editorial comment/letter, book chapter	127
No assessment of psychological factors	62
Other, e.g., no abstract in database, obituary, author's reply, unpublished dissertation, animal study[b]	135
Study not able to be classified: could not obtain and inconclusive abstract	2
Number of studies	1,734
Number of studies excluded	1,715
Number of studies included	19

[a]When a study met two or more exclusion criteria, each excluded study was coded by its first, or main, exclusion reason so that each study was only included in the table once.

[b]Although ''human/humans'' was included as an original search limit, some animal studies circumvented this as reference was made to the human implications of the study.

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