

Cancer in Children and Young People

The Cancer in Children and Young People set of articles is separated into 12 sections, each of which can be individually downloaded. It is a 'work in progress' incorporating new information whenever time permits.

Section 10

Parents, family and GPs of childhood cancer survivors

1. Childhood cancer incidence and types of cancer
2. Genetics and parental exposure
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The needs of parents, family, GPs of childhood cancer survivors and things which may help

Parents of a child with cancer have their own needs which need to be looked at to provide the optimal circumstances for a healthy family life (Mu [2015](#), Sultan [2016](#), McCarthy [2016](#)). These include illness-related factors, parental factors, child characteristics, familial factors, and social factors (Golfenshtein [2015](#)). Families with younger children had a higher level of economic burden of caregiving. Leukaemia required a higher family commitment than any other cancer considered (Pagano [2014](#)). This may be because of the higher number of children with leukaemia compared with other forms of cancer. In times of health service cutbacks, how these are addressed is likely to be a question needing more urgent consideration.

Caregivers of paediatric oncology patients are expected to understand and adhere to a complex medical plan of care while at home; yet little is known about how to assess and evaluate the caregivers' abilities to adequately meet these demands. A brief psychosocial intervention was evaluated for caregivers of Iranian children with cancer. It was found to be an effective strategy to improve the quality of life of primary caregivers. Most child cancer diagnoses were for brain tumours and blood cancers. Significant improvement was found within the intervention group on quality of life including improvements on mental/emotional burden, disruption and positive adaptation (Safarabadi-Farahani [2016](#)). Caregiving demand, caregiver competence, and coping/support factors were associated with parental physical and psychosocial health-related QoL, when controlling for significant background and child characteristics (Quast [2016](#)). A home visit by an expert paediatric oncology nurse assisted the caregiver in transitioning to caring for the child at home. Such programs should be considered when planning transition programs from hospital to home (Branowicki [2016](#)). It is important to help parents understanding of their child's treatment-related symptoms so that they may better help the family coping and communicating style (Di Battista [2016](#)). Crespo ([2016](#)) considered that the way parents perceive formal care, namely as being more or less family-centred, may influence the burden they experience as caregivers of a child with cancer and, indirectly, their adaptation. These findings highlight the relevance of gaining greater understanding of the interaction between the family and the health-care systems in the context of paediatric cancer. However, despite the stress of their child's illness, many female caregivers of survivors of paediatric cancer reported finding benefits associated with their experience (Willard [2016](#)). Use of positive coping strategies by parents could help them to manage the stress associated with the unpredictability of their child's illness. Nurses could assume a more active role in identifying sources and level of parental uncertainty, encouraging parents to stay optimistic (He [2016](#)). The Hospitalization Coping Scale (HCS) can be used by paediatric oncology nurses to assess the effectiveness of family coping during a hospitalisation of their child with cancer and may help paediatric oncology nurses to develop and implement realistic support strategies based on assessments of family coping effectiveness (Lyu [2016](#)).

In a study by Bennett ([2013](#)) 51% of parents of children diagnosed with brain tumours were experiencing clinically significant levels of stress. Results emphasised the importance of ongoing support for parents of children with brain tumours (Ohashi [2015](#)). Intervention might helpfully be centred on strategies to increase parents' internal locus of control. In a study by Schorr ([2016](#)) child loss (for any reason) was associated with a slightly increased risk of mortality in parents, the authors believed was related to psychological stress.

Ångström-Brännström ([2015](#)) reported that cancer and treatment turns people's lives upside down, affecting the entire family. Further, the parents experience the child's suffering and must cope with intense feelings. Gardner ([2015](#)) found that positive spiritual coping, optimism, and the impact the child's illness has on the family predicted the ability to find positives in the experience

for caregivers of childhood cancer survivors. The authors of the study suggest that there are potential avenues for intervention among this population.

These needs include support and supportive care, discussion about parental hopes and expectations, about the child's quality of life and wellbeing, communication and information (Markward [2013](#)). Data were collected from parents who had children being treated for cancer, proving that their needs were complex and changing. There was a need for health professionals to invite conversations about the parents' experience of their child's illness, in order to support them adequately (Bally [2014](#)).

The needs of the parents will also include information about the effect of the child's treatment on health and education issues. This will enable them to deal better with the challenges that these effects will make on their support for the child and other siblings, in the health & education systems. This section is in addition to Section 9 which deals also with late effects into adult life of the survivor of childhood cancer.

Seven years after the diagnosis of childhood cancer, family members can still feel vulnerable. To varied degrees they still may need support (Sundler [2013](#)).

Discussion of death

In a study by van der Geest ([2015](#)), of the 86 parents of the 56 children who answered questions regarding discussing death with their child, 55 parents of 35 children did not discuss it. The following themes were identified: the parents' inability to discuss it; the parents' desire to protect their child; views regarding talking with children; parents' views of child characteristics; the child's unwillingness to discuss the subject; lack of opportunity to talk; and the child's disability. The parents who did discuss death with their child generally used symbolic and/or religious narratives, or they had brief, direct conversations regarding death. The majority of parents felt positive regarding their decision about whether to talk with their child about his/her impending death. Our findings highlight the sensitive and complex issues surrounding these conversations, indicating that there may be a role for clinicians in supporting parents.

Many bereaved parents experience poor psychological outcomes during bereavement and parents want follow-up and benefit from continued connection with their child's healthcare providers (Lichtenthal [2015](#)).

Caring for a dying child suffering from a brain tumour needs increased awareness of the neurological deterioration. The symptom pattern strongly depends on the tumour localization and type (Kuhlen [2016](#)).

Educational needs

Significant numbers of cancer survivors had educational problems during schooling (Pakakasama [2010](#), Kuehni [2011](#)).

A neurological evaluation of the child's abilities after cancer treatment is very useful, but families need ongoing support and knowledge to implement the test recommendations (Quillen [2011](#)). 46% of a sample of paediatric cancer survivors reported school difficulties (Roberts [2014](#)).

Survivors of CNS tumours and of leukaemia had deficits in numeracy and reading. Survivors were significantly more likely to receive special education. Females and those who had received radiation treatment (particularly cranial radiation) were at increased risk for poor educational outcomes (Lorenzi [2009](#)).

Children treated with platinum chemotherapy subsequently had severe difficulties recognising words in noise, but word recognition in noise improvement markedly with hearing aids (Einar-Jón [2011](#)).

Survivors of infratentorial (cerebellar) tumours performed more poorly on selected measures of more specific cognitive functions and on parent-report of social-emotional functioning relative to survivors of supratentorial tumours (another type of cerebellar tumour). Higher frequency of auditory deficits was noted in the infratentorial tumour group and was associated with lowered academic achievement scores (Patel [2011](#)).

Mabbott ([2011](#)) found a significant decline over time in working memory, processing speed and visual memory in children who had been treated for CNS germ cell tumours.

Risk factors included attention, working memory, processing speed, new learning, visuospatial and visuomotor functioning, executive functioning, and areas of academic achievement (Gragert & Ris [2011](#)). Additional socioemotional and broader quality of life problems have been found in both survivors and their families.

Long-term neuroblastoma survivors, especially those with hearing loss, are at greater risk of having academic learning problems and psychosocial difficulties. This is reflected in the child reporting loss of quality of life, due to the stress this causes (Gurney [2007](#)).

Helms ([2014](#)) emphasised the importance of school re-entry programmes in terms of enhancing academic achievement in children with cancer and lowering their levels of depression.

It was suggested by Darcy ([2016](#)) that health care professionals need to plan for ongoing contact with school services, information and support beyond the treatment period; children had different needs for support, but these could persist for 2 to 3 years after diagnosis.

Neurocognitive effects

Childhood leukaemia survivors performed poorly on measures of attention, girls worse than boys (Jain [2009](#)). Krull ([2011](#)) suggests that attention problems similar to, but not typical of ADHD may be as a result of leukaemia-specific treatment. Survivors who met symptom criteria for ADHD demonstrated greater impairments in IQ and working memory than survivors who did not (Hardy [2015](#)). Parental ratings of attentional symptoms may be a useful way to screen survivors who may be in need of a full neuropsychological assessment.

Paediatric survivors of medulloblastoma were found to have a large decrease in cognitive capacity, including a slower acquisition of functions and knowledge in the domains of verbal comprehension, perceptual organisation, social perception and psychomotor skills (Saury [2011](#)).

Patel ([2013](#)) found health-related quality of life (HRQoL) was significantly lower in children with neurocognitive and behavioural dysfunction following therapies directed at the central nervous system; younger age at diagnosis predicted dysfunction in inattention, learning problems and hyperactivity/impulsivity.

Margelisch ([2015](#)) highlights the need for cognitive interventions early in the treatment process in order to minimize or prevent academic difficulties as patients return to school.

Health & Development

Parents of children with cancer report higher levels of concern about their child's health and development than comparison parents (Long [2014](#)). Parents often accompany adolescent and young adult (AYA) paediatric cancer survivors to follow-up oncology clinic visits and remain involved in their care, although little is known about their reasons for doing so. Mothers accompany AYAs to survivorship clinic for both maternal/family-focused and survivor-focused reasons that can be incorporated in survivorship and transition care to reflect ongoing communications among survivors, parents, and health care teams (Doshi [2014](#)).

It is important to inform childhood cancer survivors regarding their increased risk of secondary cancers, as only a relatively small percentage are aware of this. Cherven ([2014](#)) found that the perceived likelihood of developing a late effect is an important factor in the individuals' ability to learn about their risk and should be addressed before initiation of education. Since most of these people first report their symptoms to their GP, all GPs should be aware of the increased risk, particularly because this concerns cancer at a younger age than would be normally expected (Berendsen [2013](#)).

Neutrophil oxidative capacity was significantly depressed in the ALL group, however, it increased after exercise and stimulation (Ladha [2006](#)). Shore & Shepard ([1999](#)) had suggested exercise was beneficial but care had to be taken to tailor any programme individually, due to variable effects on immune response.

Health care professionals, especially nurses, who look after the needs of paediatric patients, should develop the ability of encouraging play activities and therefore, to promote this aspect of care that promotes childhood development (da Silva & Cabral [2015](#)). In sessions of play with 9-12 year-old children with cancer 9 themes were identified: (a) expressing good memories, (b) control, (c) problem-solving ability, (d) relations, (e) aggressive behaviours, (f) regression, (g) good-bad, (h) trauma, and (i) anxiety. It was suggested that the self-concept of the school-age child needs to be supported in addressing these themes (Manav & Ocakci [2016](#)).

During hospitalization, play either in the form of therapeutic play, or as in the form of play therapy, is proven to be of high therapeutic value for ill children, thus contributing to both their physical and emotional well-being and to their recovery. It helps to investigate issues related to the child's experiences in the hospital and reduce the intensity of negative feelings accompanying a child's admission to hospital and hospitalization (Koukourikos [2015](#)).

Parents' handling of their children's fear was equivalent with caring in the best interests of the child (Anderzén-Carlsson [2010](#)). This included striving for the security and well-being of the child up to a certain point where the parents instead used their authority to maintain the child's physical health rather than trying to prevent or relieve the child's fear.

Parents and providers agreed that changes in the child's psychosocial, environmental, and biological processes affect sleep during cancer treatment. Parents were most interested in interventions targeting difficulty falling asleep (Daniel [2016](#)). In a study by McCarthy ([2016](#)) parents of children with ALL reported significantly more lax parenting practices and strategies associated with their child's sleep including co-sleeping, comforting activities, and offering food and drink in the bedroom. After controlling for illness status, parent-child co-sleeping was significantly associated with child sleep difficulties.

Despite recommendations, only a proportion of long-term childhood cancer survivors attend follow-up care (Vetsch [2016](#)). Most survivors saw paediatric oncologists (79%), followed by endocrinologists (17%) and GPs (16%). Most parents (92%) reported being involved in follow-up.

Educating survivors and their parents on the importance and effectiveness of follow-up care might increase attendance in the longer term.

Endocrine disorders

Endocrine disorders are frequently seen within the first 5 years after diagnosis of a childhood brain tumour (Clement [2014](#)).

Hearing problems

Hearing loss is common following chemotherapy for children with medulloblastoma (Moeller [2011](#)).

Metabolic syndrome

Childhood cancer survivors should have a thorough metabolic evaluation including the measurement of body fat percentage even if they are not obese. It has been suggested (Sohn [2011](#)) that a better understanding of the determinants of the metabolic syndrome during adolescence might provide preventive interventions for improving health outcomes in adulthood.

Nutritional needs

Poor nutrition during treatment for ALL can be a problem especially for those children receiving steroid treatment. Williams ([2015](#)) suggests that parenting interventions, specifically targeting behaviours such as assertive discipline, may help promote better nutrition amongst this vulnerable group.

Psychological and Social Effects

During adolescence, survivors demonstrated higher rates of attention deficits, emotional problems, externalising behaviour and social withdrawal (Krull [2010](#)).

In the years following participation in childhood cancer camps, these continue to play an important role in adults surviving childhood cancers, providing them with ongoing social and emotional support and access to resources (Beckwitt [2014](#)).

The intense grief associated with the loss of a child creates shared experiences in an American paediatric hospice but Spanish- and English-speaking parents describe their experiences in different ways. Additional studies in paediatric hospice care are warranted to improve the care we provide to children at the end of life (Thienpravoon [2016](#)). In a Swiss study (Zimmermann [2016](#)), parents of a child with cancer rated their experiences highest when compared with the deaths of children with a cardiac or neurological condition and reported the highest satisfaction with care.

Parents and caregivers of children with cancer are both resilient and deeply affected by the child's cancer. Parent distress increases around diagnosis, then it returns to normal levels and post-traumatic symptoms are common. Distress may be impairing for vulnerable parents and may impact a child's coping and adjustment. Parents and caregivers should receive early and ongoing assessment of their mental health needs with access to appropriate interventions facilitated to optimize parent, child, and family well being (Kearney [2015](#)).

Nam (2016) found that caregiver stress levels were associated with various socioeconomic factors. Caregivers with household incomes of less than \$40,000 reported higher distress scores than those with higher incomes; those who did not attend or infrequently attended religious services; those whose child was diagnosed at a younger age, or with AML were also associated with higher stress. Caregivers with a child currently receiving therapy reported higher overall stress levels compared to those off therapy.

Quality of care

Caregivers' reactions to having a child with cancer are characterised by the existential threat of cancer, the shattering of notions of control and certainty in their capacity to protect their child's well-being and reliance on medical intervention. A study by Cox (2016) acknowledges these issues and highlights the care, advocacy and pseudo-nursing contributions that caregivers bring to the paediatric oncology setting.

Caregivers of adolescents and young adults (AYA) with complex medical conditions, including brain tumour survivors, have protracted and often complex roles, yet a gap exists in understanding their perceived competence. Family functioning and the health of survivors are both important as to how caregivers of AYA are evaluated (Deatrick 2014). In a questionnaire and interview study (Kaal 2016), parents were satisfied with the emotional care they themselves received and the medical care that their child received. The GPs were very satisfied with the cooperation with the palliative team. Gaps are present in the areas of symptom control, communication between hospital professionals and parents, aftercare, and transition between hospital and GP.

Nielson (2015) highlighted some of the difficulties of getting care from GPs and the disparities existing between surgeries. Time pressures influence GP working practices. Enhanced communication and collaboration between the GP and regional childhood cancer centre may help address identified GP challenges, such as learning deficits, and promote more time-efficient working practices through role clarity. Parents need greater awareness of their GP's wide-ranging role; one that transcends palliative care incorporating bereavement support and on-going medical care for family members.

In interviews conducted in Swiss hospitals (Wangmo 2016) participants reported being very content with the care they received. Aspects that contributed to satisfaction were the friendliness and responsive nature of healthcare staff; helpful communication; and professionals going beyond their duties to care for the family. In spite of mainly being pleased with the care they received, participants underlined several issues that made their experiences at times difficult. These included frequent change of physician or receiving care from another unit, which for them represented lack of continuity of care; language problems; and challenges with reproductive health issues of the child.

Quality of Life

30% of survivors reported poor physical and/or mental HRQOL. Race/ethnicity, education, and head/neck disfigurement were significantly associated with poor mental HRQOL, while sex, age, household income, obesity, alkylating agents, pelvic radiation, head/neck or limb disfigurement, and walking with a limp were associated with poor physical HRQOL. Identification of high-risk adolescent cancer patients may facilitate timely intervention to attempt to minimize the impact of cancer and treatment on subsequent quality of life (Nolan 2014).

Health-related quality of life scores were significantly lower in patients with acute lymphoblastic leukaemia than in healthy controls in a study by Bulut (2015). It is thought that determination of

the psychosocial as well as the physical impacts of the disease on the child will positively influence the treatment given by improving the quality of life of both the child and the family.

Radiation

In Nigeria, it was found (Famurewa [2014](#)) that paediatrician's knowledge about the basic principle of radiation protection ALARA and the doses that children receive during some common radiological procedures is poor. More training on radiation hazards and protection is needed.

Reproductive effects

It has been suggested (Levine [2011](#)) that sperm banking for postpubertal males prior to gonadotoxic therapy should be considered as a matter of course. Postpubertal females receiving highly gonadotoxic therapy that places them at risk of acute ovarian failure should consider embryo or oocyte cryopreservation prior to the initiation of therapy.

In a Dutch study (Overbeek [2014](#)) fertility issues were discussed with patients and/or parents by 97% of the paediatric oncologists in the study. Of those taking part, half to $\frac{3}{4}$ were aware of the possibilities for fertility preservation though less than 25% reported a moderate or high confidence in their knowledge of these techniques.

Resilience factors

Parents of children surviving acute lymphoblastic leukaemia showed significantly lower levels of resilience than parents of healthy children, but no significant difference was found for mental health. Certain resilience factors were positively associated with mental health, especially for mothers, such as family cohesion, good perception of self and being able to plan their future (Eilertsen [2015](#)).

Thyroid disorders

Radiation therapy for cancer increases the risk of developing subsequent thyroid cancer up to 14 or more times, depending on the therapeutic dose, sex (girls have a higher risk), age at exposure (the younger the child receiving the radiation, the higher the risk), and time since exposure (Bhatti [2010](#)). Demirkaya ([2011](#)) reported that radiation-induced thyroid disorders may develop in paediatric Hodgkin's lymphoma patients in complete remission starting as early as the first year after treatment, and they are dose-dependent.

Children treated for medulloblastoma have a high risk of developing hypothyroidism resulting from the treatment (Sobol [2011](#)).

Total body irradiation (TBI)

In a study by Felicetti ([2011](#)), 34% of patients receiving TBI showed growth hormone deficiency.

Weight problems

Obesity is one of the more common after effects of treatment, sometimes depending on gender, or type of cancer treated (Gurney [2003](#), Armstrong [2010](#), Pakakasama [2010](#), Breene [2011](#), Love [2011](#),

Kohler [2011](#)), especially in females. 50% of children who have undergone craniopharyngioma surgery have a substantially reduced quality of life, notably extreme obesity owing to hypothalamic involvement and/or surgical- or radiation-induced lesions (Müller [2011](#)).

Optimal nutritional status is important in children with cancer, as it can influence clinical outcomes. In low income and middle-income countries (LMIC), nutritional information could be improved. Murphy ([2014](#)) suggested that priority areas for improving the nutritional management in LMIC include the following: (1) improved nutrition education and assessment tools for doctors and nurses; (2) increased availability of nutrition education resources for families and patients.

Other physical effects

Can include a need for medical induction of puberty (Ryan & Kay [2011](#)).

Nerve conduction abnormalities, including peripheral neuropathy were seen in nearly one third of children who had finished treatment for ALL more than 2 years previously (Ramchandren [2009](#)).

Parental experience

Substantial numbers of parents of children diagnosed with cancer experienced posttraumatic stress symptoms (PTSS) (Woolf [2015](#)), including depression and anxiety, during the first 6 months of treatment and after any relapse (Dunn [2011](#)). 35% of survivors and 29% of their parents reported severe levels of PTSS (Bruce [2011](#)). The death of a child, the parent's perception of child psychological distress and total symptom burden predicted higher levels of PTSS (Lindahl Norberg [2012](#)).

Parents express both negative and positive experiences as they re-evaluate the meaning and purpose of life, seek to redefine themselves, often in terms of priorities, relationships, sense of community and achieving degrees of optimism and altruism (Schweitzer [2011](#)).

Parents' experienced increased distress with the physician's first suspicion that something was seriously wrong. Distress was ameliorated when they arrived at a specialty treatment centre but increased as they tackled treatment decisions. Stress was higher for single marital status and the ill child being the mother's only child (Sulkers [2015](#)). Distress decreased again after they consented to enucleation but increased after hospital discharge (Hamama-Raz [2012](#)).

A study looking at parental psychological distress up to 2 years post treatment (Barrera [2011](#)) found that depression and anxiety scores significantly decreased by 2 years for mothers and fathers. Mothers reported significantly more depression symptoms than did fathers, but reported comparable symptoms of anxiety.

Parental stress was a predictor of overall functional impairment in survivors at least 2 years postdiagnosis (Hile [2014](#)).

Parents were asked, 1 year after their child's diagnosis, about the oncologists' role in emotional support. They overwhelmingly told us that they did not want to discuss their feelings with oncologists. They wanted to preserve the oncologists' focus on their child's clinical care, deprecated anything that diverted from this and spoke of the value of boundaries in the parent-oncologist relationship (Young [2013](#)).

In the first year after the death of a child, parents regulated their intense feelings of grief through loss-oriented, restoration-oriented, and/or meaning reconstruction strategies. Often, parents' relationships with others and many of the bereavement follow-up and support services helped them in this regard (Stevenson [2016](#)).

Parents reported significant worsening of all their own health behaviours, including poorer diet and nutrition, decreased physical activity, and less time spent engaged in enjoyable activities 6 to 18 months following their child's diagnosis. More partnered parents found support from friends increased or stayed the same since their child's diagnosis, whereas a higher proportion of lone parents reported relationships with friends getting worse. More lone parents reported that the quality of their relationship with the ill child's siblings had gotten worse since their child's diagnosis (Wiener [2016](#)).

The employment rate of women has increased in recent years, and support for working mothers with children diagnosed with cancer is needed. Women who continued to work during the treatment period reported financial reasons. Okada ([2015](#)) suggested that nurses confirm mothers' willingness to take a long leave of absence from work and give relevant advice about seeking financial assistance. Mothers of survivors were more often not employed (Mader [2016](#)), whereas fathers of survivors were more often employed full-time. Among parents of survivors, mothers with tertiary education were more likely to be employed. Having a migration background increased the likelihood of being full-time employed in mothers of survivors. Less likely to be employed were mothers of survivors diagnosed with lymphoma and with more than 2 children; and fathers of survivors who had had a relapse.

Employment situation of parents of long-term survivors reflected the more traditional parenting roles. Specific support for parents with low education, additional children, and whose child had a more severe cancer disease could improve their long-term employment situation.

Siblings

Siblings of long-term childhood cancer survivors are psychologically healthy in general. There are, however, small subgroups of siblings at risk for long-term psychological impairment (Buchbinder [2011](#)).

The parental perceptions of siblings' bereavement after childhood cancer deaths were investigated by Barrera ([2013](#)). The themes that emerged were:- (a) expression of grief missing deceased child; (b) what helps siblings grief moving on; (c) relationship with parents improved for most siblings; and (d) bond with deceased sibling.

When caring for a child diagnosed with cancer, nurses need to include siblings in the assessment of a family unit's adaptation to cancer distress and provide appropriate interventions to promote their psychosocial well-being (Zegaczewski [2016](#)).

In a survey of 174 bereaved siblings of children with cancer (Lövgren [2016](#)), the most common advice, suggested by 56% of siblings, related to their own support. One third suggested giving better medical information to siblings. Some siblings wanted to be more practically involved in their brother's/sister's care and suggested that health care professionals (HCPs) should give parents guidance on how to involve siblings. Other common advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted.

Things which may help

One time acupressure may reduce the intensity of fatigue suffered by children with leukaemia receiving chemotherapy at 1 h post-treatment. Therefore, acupressure could be recommended as an effective, non-pharmacologic method for some cancer-related fatigue (CRF) control. Applying one time acupressure did not have a long-term effect (Bastani [2015](#)).

Forty-three percent of all parents with a child receiving palliative care reported complementary and alternative medicine (CAM) use (Schütze [2016](#)). The most common types of CAM used were homeopathy and treatment with mistletoe preparations.