

#### REVIEW



# SCHOOL DIFFICULTIES in Children Cancer Survivors: A Narrative Review and a Teacher Point-of-View

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## ABSTRACT

School difficulties are common in children cancer survivors and may be prognostic for the success of the patient social reintegration after the disease. Here, we carry out a narrative review of the literature from 2001 to 2022 to assess the school difficulties of these patients, the predictive factors of these difficulties, and the possible long-term consequences. We punctuate this review the practical point-of-view of a teacher dedicated to our hospital, who works with children with chronic diseases such as cancer. Therefore, we expose possible barriers and solutions to improve the scholar reintegration and limit the impact of cancer on the academic achievement.

## **KEYWORDS**

Cancer; children; school

## Introduction

The French incidence of pediatric cancer is well described at 156.6 per million children aged 0-14 years per year, and increases to 231.9 cases per million person-years in children aged 15-19 years [1,2]. An improvement in long-term survival rates of pediatric cancers has been achieved over time [3]. Therefore, the post-treatment period remains a challenge, with the main objective of optimizing social reintegration. Therefore, the return to school remains fundamental, attending school leads to improved emotional regulation and social and intellectual stimulation [4]. Time out of school has detrimental effects on children's mental health, well-being and educational outcomes, and this time has to be limited as much as possible when a child is absent due to illness, such as in the context of cancer [5]. However, during the post-treatment period, children can present with sequalae induced both by the cancer itself or the treatments

(chemotherapy, surgery, radiotherapy). All of this may compromise the success of the patient's school reintegration and its quality of life (QOL) [6-8]. Difficulties in school performance are described during and after the cancer period, with an impact on long-term career achievement with disparities in employment in comparison with the general population [6,7]. Some children are at risk of these school difficulties, notably children with central nervous system (CNS) tumors, with cranial radiotherapy and at a young age at diagnosis [8-12]. Some additional factors may also contribute to these difficulties, such as the household's socio-economic status (SES) [6,8,13-15]. Nowadays, the patient QOL is a fundamental objective of all cancer management. Therefore, in France, QOL is one of the priorities of the national cancer strategy, with the importance of the maintenance of schools in children with cancer [16]. This strategy suggests some keys for this specific schooling (flexible school program, contributions of



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teachers at hospital and home, development of numeric tools ...) [16].

In this narrative review of the literature, we focused on the description of the school difficulties in children with cancer, notably during the post-cancer period. These difficulties are plural and can be generalized to every situation likely to induce a feeling of malaise at school. In the literature, these difficulties are described, but the solutions and barriers to dealing with these situations in real life are not well known. Therefore, we associate with our review a qualitative point-of-view of a teacher to better understand these difficulties in real life and suggest solutions to better integrate childhood cancer survivors (CCSs) at school.

#### Materials and Methods

We carried out a narrative review by selecting papers from the PubMed database. The research equations proposed were: (i) (education [MeSH Terms]) AND (childhood cancer) (ii) (academic [MeSH Terms]) AND (childhood cancer) (iii) (socioeconomic factors [MeSH Terms]) AND (education [MeSH Terms]) AND (childhood cancer), from the year 2001 to the year 2022.

The teacher that we chose to give a practical point-ofview is working in our hospital. This teacher is in charge of supporting and maintaining schooling despite a cancer history, for all children of the pediatric oncology unit. In addition, this teacher has frequent contact with the current teachers of the patient's school, even after the cancer postperiod. Therefore, she can bring different perspectives to this scientific review by adding her experience in everyday practice.

### Results

#### Description of school difficulties

School difficulties in CCSs are plural and induce a real impact on their QOL [8]. These difficulties remain frequent in CCSs, with a higher prevalence than children with chronic diseases [13,11,17]. The prevalence of these difficulties varies between studies and countries, and such a variation can be explained by the differences in the national educational systems of each country [9]. Nevertheless, from 22% to 41% of CCSs reported school difficulties [18–20].

In the context of childhood cancer, intensive treatments are needed to obtain remission. These treatments are carried out in a hospital, with repeated periods of hospitalization lasting several days. In addition, treatments induce physical health problems, notably asthenia and discomfort [19]. These consequences remove the child from school during active treatment, and absenteeism is reported as the most important problem associated with school difficulties [11,18,20–22]. This absenteeism represents a significant loss of time in school, and may be increased in case of severe diseases or relapses, which require longer and more intensive treatments in hospital [23,24].

## The teacher's point of view

In France, children aged from 3 to 18 years at a cancer diagnosis are eligible to a scholar support called APADHE (Accompagnement Pédagogique A Domicile, à l'Hôpital ou à l'Ecole). APADHE consists of teachers at home. I insist on this help for children from the age of four (second year of school in France), in order to limit the occurrence of school difficulties. Indeed, the rules of school life, oral expression and good posture are important skills to acquire as soon as possible. In France, children aged from three to five may receive two hours of support, from six to eleven four hours, from twelve to fifteen six hours, and from sixteen to eighteen eight hours.

The APADHE support is particularly efficient for young children. Teachers from the child's school are frequently volunteers to teach at home. But in some areas, particularly the most deprived, we are faced with a lack of teachers, and volunteers are rarer. In these cases, the situation is difficult and the permanent help of a parent may be key to ensure that schooling continues. For these children, the combination of APADHE with the school at the hospital is efficient and children do not present difficulties upon reintegration into school.

For children over twelve years, volunteers are rare because children attend different classes with different teachers for each one, and we can understand that not all of the teachers can be available to provide full schooling support at home.

To compensate for the absenteeism, video conferencing and connected robots are available. Therefore, a child can attend a virtual class at the same time as peers. However, in real life, the installation of these robots is not easy. It requires time and investment from the school to ensure a good connection. Plus, an important financial contribution is required from the academy, and limits the number of robots available.

Whatever the age of the child, motivation is key for the success of the scholar achievement, particularly in this challenging situation.

CCSs with cancer suffer from a lack of socialization due to absenteeism and with important loss of time with peers [23,25]. Borrescio-Higa et al. described up to 80% of children with blood disorders with difficulties meeting with friends or carrying out hobbies or sports because of the cancer during the treatment in hospital [25]. When CCSs are back to school, 22% of them suffered from a lack of friends with difficulties in inclusion at school [19,23]. Barrera et al. described 19% of CCSs with no close friends, and these children are 58% less likely to use friends as confidants [18]. CCSs are at risk of mental conditionsanxiety and depression-sometimes occurring several years after the cancer diagnosis and treatment [7,22,26]. Poor social experiences may potentiate these psychological difficulties and may alert educational staff to detect symptoms.

The teacher's point-of-view:

The absenteeism may increase the risk of rupture of the social link with the peers. This lack of socialization is one of the limits of the school at home.

For the youngest, a link is frequently maintained between the child and his class (letters, drawings, videos for the child). Frequently, the teacher who helps with the schooling at home is the one of the child's class, which facilitates the link with the school of "outside".

On request by a child or its parents, and with the agreement of both parties, I and one of the nurses of the

pediatric oncology unit can propose interventions in classes to explain the absenteeism of the child, and its disease, and anticipate a return. Therefore, the child keeps his place in class, and is awaited by his peers... so the return is quite easy!

However, things are more complicated in high school and college. Indeed, a lot of children do not have contact with their peers, and teachers who come at home are not necessarily attached to the child's school... Social media can help to keep the link with peers. The Majority of adolescents use this tool, but the best option remains real contact with the other children. Therefore, pediatricians can authorize occasional returns to school, depending on the child's physical condition.

Consequences of these difficulties can occur, and CCSs are at risk of repeated grades and have lower academic marks resulting from impairments in verbal learning and physical [10,13,18,19,21]. Rates of repeated grades vary between countries, but a high rate was noted up to 21% in the Canadian population [10,13,21]. Exclusion from sportive activities proposed at school can occur secondary to physical sequelae induced by cancer or its treatment, notably surgery [27,28]. Indeed, these types of sequelae can be frequent, reported in 67% of patients with osteosarcoma in a cohort of 694 tumor bone survivors [28]. Impaired motor functions can also be seen in children with CNS tumors who are three times more likely than siblings to report physical performance limitations [27,29]. Overall, CCSs reported 18% of deficits in physical performance, resulting in weakness, decreasing activity and fatigue during intensive treatment, which can persist and become a long-term problem [18,27].

#### Risk factors of school difficulties

Assessing children's scholarly difficulties prior to diagnosis is important, because children who are already facing difficulties are particularly vulnerable to scholarly consequences during the post-cancer period [23].

Children with CNS tumors represent the population most at risk of school difficulties with significantly lower levels of QOL [8,10,29,30]. Even before diagnosis, the symptoms caused by a CNS tumor can be severe, and potential neurological dysfunctions can affect the continuation of schooling. Indeed, visual symptoms, headache, irritability, and motor impairments can be noted [31-33]. During the post-treatment period, major learning disabilities are noted, with delays in passing grade exams, significant difficulties in numeracy and reading, and an impact on physical education [6,19,34]. Plus, a meta-analysis conducted by Wang et al. in 2022 reported a higher rate of attention problems, emotional difficulties and psychosocial problems in pediatric brain tumor survivors [35]. Indeed, social inclusion with pairs remains a challenge for CCSs with CNS tumors, who are likely to have no close friends and therefore, can suffer from psychological distress [18,36]. These difficulties can be potentiated by absenteeism, CCSs with CNS tumors miss significantly more school than survivors with other tumors do [11,19]. In this population, young age at diagnosis may be a prognosis [6,10,30], and age thresholds from six to nine years have been proposed as predictive factors for cognitive impairment [10,20,30]. In the long term, the risk of unemployment in adulthood is important, CCSs with CNS tumors are five times more likely to be unemployed [11,36,37].

All aggressions of the cerebral tissue are at risk of cognitive consequences, and this explains the risk associated with CNSdirected therapies [7,13,20,21,36]. Cranial radiation therapy is well known to be dangerous on cognition, but also growth, sensorial and endocrine functions, notably for young children [38–41]. Plus, clinicians need to be careful with neurotoxic chemotherapy. Indeed, the use of intrathecal methotrexate may induce acute and chronic leukoencephalopathy, and pseudo-stroke syndrome [42–46]. Intrathecal chemotherapy with methotrexate and aracytine can also induce a cytotoxic action on the medullar cord, which can induce para or tetraplegia [47–51]. In the context of leukemia, de-escalation for children with CNS involvement cranial is promoted with a limitation of cranial irradiation in favor of intrathecal chemotherapy which presents rarer late effects [52].

CCSs with hemopathy seem less impacted by neurocognitive sequalae, but they remain at risk of difficulties in their educational achievement [6,7,10]. Indeed, CCSs with non-Hodgkin lymphoma presented with the risk of not graduating high school [7]. Intensification by hematopoietic stem cell transplantation (HSCT) increases the risk of school difficulties, 24% of children with HSCT did not graduate high school and 17% underwent emotional performance limitations [21,24]. Indeed, HSCT is an intensive treatment and requires protective confinement because of the high infectious risk for the child. Therefore, HSCT potentiates the absenteeism of the child.

Socio-economic status (SES) of the CCSs' household influences the occurrence of school difficulties [6,8,13–15]. A strong link between SES and academic achievement is already known [53]. On a geographical scale evaluated by a deprivation score, the probability of presenting with school difficulties during the post-cancer period was significantly associated with social deprivation, an observation also retrieved in the CNS-tumors group [20,54]. At the individual scale, school difficulties are associated with the parental level of education, the family structure and ethnicity [13–15]. Higher parenting knowledge is associated with higher school QOL, and is therefore prognosis in global QOL in CCSs [8]. Plus, household SES impacts how the family is able to make up for the child's absence from school [22]. Individual scholar support is available, but it requires financial contributions from families [23]. Families in deprived situations cannot access this support, and prevent the occurrence of difficulties [22]. Indeed, in the study published by Delehaye et al., learning difficulties were significantly associated with greater social deprivation, but the probability of benefitting from academic support was not [20]. Therefore, academic support seems to be equally shared between children according to a deprivation score, whereas there are higher needs in deprived areas. Besides, SES negatively moderates the relationship between school socialization and academics, and may compromise psychological well-being and academic achievement [55].

## The teacher's point-of-view:

For some parents during the intensive care period, school is not a priority and the care is the only subject of interest. In some cases, they can be reticent about the maintain of schooling during the intensive care period. This is the case for parents who have experienced difficulties in school themselves. This attitude is frequently observed in the context of poor social environment, and can compromise the child's success and accentuate its difficulties to get out of it.

For example, I knew a child who presented already with academic difficulties in a deprived social context, and parents who strongly limited the support to school in favor of rest periods.

In these situations, we are more vigilant about the child's academic continuation, and we insist on the school in hospital for compensation. However, these situations remain complex and can reflect the limits of the support we can offer during cancer.

Lack of adherence to a rigorous APADHE or similar helps by the family clearly increases the risk of scholar difficulties. Therefore, the child's motivation to the scholar support seems influenced by their parents and socio-economic background.

#### Long term-consequences of school difficulties

Long-term consequences in CCSs vary between studies, but an impact on graduation and employment seems notable [9]. In a meta-analysis published in 2019, CCSs are less likely than controls to graduate from high school or university, but these results remained not significant when children with CNS tumors were excluded from analyses [56,57]. Even if CCSs present similar high school graduation rates to their siblings, the way to achieve graduation is harder, and the recourse to special education services is frequently noted [21,36]. Age at diagnosis can be important, cancer prior to adolescence may reduce the likelihood of graduating high school, but not university [57].

The risk of unemployment in adulthood is described in CCSs. Surprisingly, a rather positive employment rate can be noted [58,59]. However, CCSs are older when starting their first occupation with difficulties in accessing a steady job [58–60]. Factors such as younger age at cancer diagnosis, a CNS tumor, and a higher number of late effects put survivors at higher risk for unstable employment. Besides, it may compromise access to employment in which a good physical condition is required [59–61]. In a qualitative study published in 2022 by Ingrand et al., 30% of CCSs believe that their difficulties in obtaining a first occupation are related to their medical history [60]. To access employment, 23% of CCSs do not work in their initial file of study, being more likely to accept compromises in their job offers [60].

#### Discussion

In this review, we can see that children who underwent a cancer history are at risk of scholarly difficulties. These difficulties can be plural, and increased in case of CNS involvement. Based on the literature and the teacher's point of view, motivation seems to be key to avoiding the occurrence of scholarly difficulties. Indeed, some challenges (absenteeism, psychological isolation) make difficult a serene continuation of the usual school calendar, and a real investment of the child and its parents can make a difference.

We can propose some keys for improvement. If required, access to special education seems fundamental. Some CCSs

are already involved in these programs, more frequently than children who did not experience cancer [6,7,21,36]. In literature, rates around 20% of CCSs benefited from special education, notably children with CNS tumors, leukemias, aged under six years at diagnosis, female gender, and treatment by cranial radiotherapy [7,18,36]. In France, this help for education can take varied forms. A regular educational program can be followed for children with moderate learning difficulties. In these cases, an additional person (called in France AVS "auxillaire de vie scolaire") assists the child in class, and acts as individual support: this AVS can write the lessons, take supplementary time to explain new notions... In case of severe difficulties, children can benefit from classes specially geared to their needs, in a small teaching environment with dedicated teachers. Then, in cases of important physical and/or intellectual disabilities, medico-educational institutes can be proposed.

#### The teacher's point-of-view:

In CCSs, I know children for whom the disease has induced important consequences, and these children had to switch to specific structures, such as medico-educational institutes. These structures are rare, with long waiting lists. Sometimes, the school registration procedure is never completed... and children who require specialized education stay in ordinary establishments under the guise of inclusion, which clearly accentuates the difference with peers.

During cancer, an alternative to the classic school process is proposed "School in Hospital". However, the child's adherence to this program varies with its health conditions, and some lessons may be canceled. Outside the APADHE dispositive, contact with other students and teachers of the school is possible but requires a long time for coordination.

Individual academic support may be key to limiting a delay when the school reintegration occurs, but all children cannot benefit from this help [23]. Financial help to families to generalize this support to every child can be key to optimizing reintegration.

Return to school has to be anticipated, for both parents and CCSs. Indeed, the neurocognitive deficits possibly associated with post-cancer sequelae may compromise the successful return to school. Therefore, parents need information to anticipate the return to school dealing with the academic difficulties of their child. However, up to half of the parents reported to fell inadequately prepared for such a return [62]. Besides, a global evaluation of the child's ability seems necessary. A neuropsychological profile can be helpful to predict the academic difficulties [63]. However, such a type of skills assessment is not usual, and the successful return to school occult can be compromise by not anticipating some difficulties. The after-effects and difficulties detected must be known by the educational school council, and adaptations must be proposed to improve reintegration.

#### *The teacher's point of view:*

Some establishments offer at the child return adaptations of the timetable, the working conditions and some adaptations for the exams (for example: computer equipment to compensate for the slowness of graphic gestures...).

However, sometimes, the return is not so easy... School reintegration is a challenge for the child, but also for the

teachers. Indeed, they need to assess the child's academic level in each competence to ensure a good continuation of the teaching, and also a good reintegration with the peers. All of this requires particular attention and a specific time dedicated to the child. Therefore, some establishments do not adhere to the concept of adaptations, "if the child comes back, he must be able to do like the others!". There, it is very complicated, with a permanent fight between the school, parents, and the school hospital teacher to explain the child's difficulties and justify the need for adaptations.

Sometimes schools force CCS parents to go through administrative procedures to finally access academic accommodations, but these procedures are complicated and the time frame for implementing the measures is long...

## Conclusion

School difficulties are common in CCSs, notably for children with CNS tumors. These difficulties are plural and include educational and relational aspects. Multiple actors are needed for the success of the school reintegration, and clinicians, teachers, children, and their families are important. Therefore, the "International Late Effects of Childhood Cancer Guideline Harmonization Group" recommends a regular screening for educational and employment outcomes among CCSs to adapt as soon as possible to the educational program and support and minimize the burden of disease and treatment-related late adverse effects [64].

Implementation of the school in hospitals is fundamental to ensure the continuation of scholarly achievement despite cancer. Plus, these specific teachers have contact with families and schools and can anticipate the reintegration based on the potential sequelae of the child. Financial help for deprived families can be a clue to promote academic support and therefore, limit the impact of the SES. More investigations, notably specific sociological analyses such proposed by Rollin Z and al. are important to better understand children and facilitate their scholarly reintegration [65,66].

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