

The Potential Role of Benefit and Burden Finding in School Engagement of Young Leukemia Survivors: An Exploratory Study

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Abstract

Childhood cancer may radically change the daily lives of young survivors, particularly in school. Depending on the sense they derive from the experience of illness, survivors may go through profound transformations in the way they approach life. Using a mixed methods approach, this exploratory study reports on school engagement of cancer survivors by examining their perceptions of benefits and burdens in relation to their illness. Forty-nine young Quebecers, previously diagnosed and treated for leukemia, completed a questionnaire measuring their school engagement and participated in an interview focusing on the impact of cancer on their lives. Perceptions with regard to the presence and types of benefits and burdens were described and examined in light of participants' characteristics. An analysis of variance explored if the presence/absence of benefits and burdens were associated with participants' scores regarding school engagement. Most participants mentioned benefits from having had cancer, and in particular benefits at an interpersonal level. Half of the participants mentioned burdens, mainly of a physical and psychological nature. Significant correlations indicated that 1) the older survivors were, the more likely they were to report benefits in terms of qualities and strengths of character, and 2) the more time had elapsed since their diagnosis, the more survivors were likely to report psychological types of burdens. A main effect indicated that school engagement was greater for survivors who perceived the presence of benefits. An interaction effect revealed that the perception of both benefits and burdens predicts the highest scores of school engagement. While the results reveal the promising potential that an optimistic yet realistic disposition has in regard to school engagement, more research is necessary to further our understanding of such a disposition, as well as its potential to contribute to the adaptation of young cancer survivors within the various spheres of their lives.

Keywords: Pediatric Oncology; Leukemia; Psychosocial Aspects of Cancer Survivorship; Positive Psychology; Benefit Finding Or growth; Realistic Optimism; School Engagement.

Introduction

Nowadays, pediatric cancer is considered a curable disease. Up to 82% of youngsters diagnosed with cancer are still alive five years after their initial diagnosis [9]. As survival rates have improved, the majority of survivors are able to resume with their normal lives, although many will experience late effects of treatments [47, 52]. The proportion of childhood cancer survivors being in constant rise, it becomes imperative to ensure their quality of life and the restoration of their health in its physical, psychological and social domains [68].

Childhood cancer may radically change the daily lives of young survivors, particularly in school [58], which stands out as an essential component. As Tadmor and Weyl Ben Arush [72] have reported, 3 out of 4 survivors feel that their illness has affected their education. In comparison to their peers, young survivors are more likely to report underachievement [8, 26], a higher number of school absences [77], to attend learning-disability or special-education programs [5, 39, 46] and to repeat a year [5, 25]. Also, they are less likely to pursue higher education [6, 46, 47].

Paradoxically, the majority of young survivors show signs of a good psychological adaptation to their illness [43, 50, 55, 56]. In order to

explain such positive consequences, researchers and clinicians are suggesting more and more to focus on the potential for growth rather than on the impairment brought on when facing a potentially lethal illness [2, 4, 53, 79-81]. One hypothesis points to the presence of a phenomenon of posttraumatic growth which stems from the profound psychological transformations that the experience of a traumatizing event may provoke and pushes survivors to reconstruct certain aspects of their lives more positively than how they were before [73-75].

In a meta-analytic review of 87 cross-sectional studies, Helgeson and colleagues [27] found that growth or benefit finding, defined in terms of positive effects that result from a traumatic event, was positively related to indicators of psychological health such as better subjective well-being (positive affect, self-esteem, satisfaction toward life). To date, results that associate benefit finding to positive long-term adaptation to cancer, both physically (e.g., improved immune function, lower fatigue and pain) and psychologically (e.g., lower distress and depression), come from studies involving survivors of adult cancers [7, 10, 14, 35]. Nevertheless, recent research initiatives have attempted to examine this phenomenon in the everyday lives of young cancer survivors [4, 11, 44, 57]. These initiatives take their inspiration within the field of positive psychology, which aims to « catalyze a change in the focus of psychology from preoccupation only with repairing the worst things in life to also building positive qualities » [69]. Also seen as a quest for actions that lead to well-being, to positive individuals, and to thriving communities, positive psychology focuses on discovering and reinforcing what is positive in the human being, while

acknowledging the coexistence and independence of positive and negative emotions [3].

If an overly optimistic view of reality may sometimes lead to deleterious consequences [76], results from previous studies suggest that more realistic perceptions toward illness, showing evidence for both its bright and dark sides, may lead to better outcomes in a survivor's adaptation to daily life [66]. In short, the studies suggest that the experience of illness may provoke profound transformations in the way that survivors approach life and the world that surrounds them, depending on the sense (positive, negative, or balanced) they derive from this experience. Yet, no study has explored the relevance of this phenomenon as to the way young survivors approach their academic experience.

The current study proposes a preliminary exploration of the association between the perceptions young survivors hold of the impact of their illness and their academic experience. To achieve this, the study focuses on the concept of school engagement which proves to be a promising variable in understanding academic success or dropping out [21]. Among the many variants that exist, the definition proposed by the National Research Council in conjunction with the Institute of Medicine [48] appears to be the most inclusive, involving an ensemble of behaviours and of psychological dispositions towards school that are influenced by the perceptions of the student towards his or her competence and control (I can), his or her goals and personal values (I want), and his or her social relations (I belong). If there remains a lack of consensus regarding the definition of school engagement, many researchers agree however on its multidimensional and variable nature. A two-, three- or four-part conceptualization is generally suggested, reflecting the students' behaviours, (behavioral or academic engagement), the emotions they associate to school (emotional or psychological engagement) and the cognitions that they invest in school (cognitive engagement). School engagement is also an evolving process that may very well vary in intensity according to the interactions that take place between the student and his environment. Based on the principal theoretical models behind this concept [13, 19, 22], the student plays an active role regarding his/her school engagement, by way of his/her personal characteristics and interpretation of the events.

The present study's aims are as follows: 1) To describe the study participants' perspective regarding the benefits and burdens of their illness, with a focus on the presence and various types of these aspects ('aim 1'); 2) To examine the associations between the demographic and medical characteristics of the study participants and the latter's perceptions regarding the presence and types of benefits and burdens related to their illness ('aim 2'); 3) To explore the relationship between young cancer survivors' school engagement and their perceptions regarding the presence/absence of benefits and burdens of their illness ('aim 3').

Methods

Participants and recruitment procedures

Participants were recruited in collaboration with Leucan, a non-profit organization that offers an array of services to families living with childhood cancer in the province of Quebec: information, awareness-raising in schools, financial assistance, support groups, hosting and support in playrooms, massage therapy, etc. [38]. Inclusion criteria were as follows: having completed treatments for leukemia for

at least a year, attending primary or high school regularly for at least a month, speaking French fluently and having neither incapacity nor deficit likely to impede communication.

According to the organization's databases as of November 2005, a member of Leucan's personnel posted an invitation to families that have a child that responds to the given criteria. This posting included an explanatory leaflet that sought to inform the child and his or her parent of the goals of the study and its process, as well as the expected impact of the study's results. The posting also included a participation form for the parent to fill out and send by mail to the research laboratory in a stamped envelope that had been supplied. Upon receiving each participation form, a member of the research team contacted the family to confirm its eligibility to the study and to set up a meeting. This recruitment strategy led to the formation of a convenience sample of 49 leukemia survivors, all of which were members of families that had responded to the invitation. We are aware, however, that this represents but a small sampling of the families that currently benefit from Leucan's services. For ethical purposes, the number and the characteristics of the cancer survivors and their families who refused to participate in the study remain undisclosed.

Data collection

This study uses a concurrent embedded strategy of mixed methods involving the simultaneous collection of quantitative (core component) and qualitative (supplemental component) data [15]. The first author of the study met participants individually, at home, between January and June 2006. At the beginning of the meeting, participants were reminded of the goal of the study, namely to obtain their views on what helps young people who have received cancer treatments be happy at school. During each meeting, which lasted between 20 and 40 minutes, the participants first completed a paper and pencil questionnaire and then participated in a semi-structured interview with open-ended questions. To ensure confidentiality and the quality of the interview recordings, participants were met in a closed room of their choice. The questionnaire items and the interview questions were asked in the same order for all participants. The questionnaire items were presented in the presence of the interviewer, and the presentation of these items was done by way of thumbnail images that illustrated the possible answers and allowed to collect the participants' answers in writing. When necessary, the interviewer helped the younger participants to read the questionnaire items. Subsidiary questions had been prepared in advance if there was a need to further explain or clarify the interview questions. The conduct of the meeting, the questionnaire items and the interview questions had all been tested previously by way of individual meetings held with two young survivors of pediatric cancer.

Informed consent forms were signed by participants and, when required, by their parents. The socio-demographic and medical data regarding the participants was collected by way of a questionnaire given to their parents. Approval of the study was previously obtained by the institutional review board of Université du Québec à Montréal. Finally, an advisory committee composed of school and hospital professionals, Leucan representatives and a volunteer parent offered advice and suggestions throughout the entire process of the study.

Measure of school engagement

A new questionnaire was developed in order to measure school engagement by following a global approach, with items thereby addressing the four dimensions most retained in research on the concept: 1) academic achievement and effort (behavioral dimension), 2) interest in school; school climate (emotional dimension), 3) sense of belonging and support for learning (psychological dimension), 4) perception of competence and valuing school (cognitive dimension) [1, 23, 28]. The questionnaire contained 14 multiple-choice items (e.g., I like school ; Doing well in school is a very important part of my life ; I know I can do well in school ; I do things to make sure school goes well for me), most of which used a Likert-type scale with verbal anchors, such as 1 = totally false, 2 = somewhat false, 3 = somewhat true, 4 = totally true. Each answer was associated to a numerical value that indicated some degree of school engagement (e.g., 1 = low vs. 4 = high). With numerical values for the items appearing on different scales (ranging between 2 and 4 choices), each participant answer to each item were transformed into standardized scores (or Z scores). Standardized scores to each of the 14 items were then compiled for each participant in order to determine their summary score of school engagement. Summary scores varied from -18.74 to 12.15 (SD = 6.65) and the measure of school engagement showed satisfactory internal consistency ($\alpha = .74$).

Perceptions of benefits and burdens

The present study distinguishes itself from the trend that consists of examining the adjustment or adaptation to childhood cancer by collecting the respective points of view of cancer survivors by way of a list of items established beforehand by researchers [33, 36, 42] : the present study examines the discourse used by young survivors. To achieve this, a semi-structured interview grid was put together using the method developed by the second author in the course of various studies on the conception of health and well-being of children and families [29-32].

During a 20-minute interview on various aspects of the participants' experience of cancer and life at school, two questions were asked in order to investigate the impact of their illness from the perspective of both the presence and the types of benefits and burdens:

1) Did cancer bring something good into your life? (presence of benefits),

[If answer is Yes] What ? (types of benefits);

2) Did cancer bring something you don't like into your life? (presence of burdens),

[If answer is Yes] What ? (types of burdens).

These questions were asked in the last part of the interview in order to allow the participant to feel at ease with providing the interviewer with details of the more difficult aspects of his or her life.

Data analysis

This study involved an exploratory descriptive design that employed mixing methods at the analytical stage in order to put perceptions of benefits and burdens in relation with summary scores of school engagement. To describe the perceptions young survivors have of the presence and the types of benefits and burdens associated with their illness (aim 1), participants' answers to the interview were first transcribed verbatim and entered into a File Maker Pro® database for

classical content analysis [37]. With the help of two independent coders, answers were broken down into distinct units of information that were then given a code in accordance with the closest corresponding category of a grid. Taking root in the studies of Jutras et al. [29, 30], this coding grid was adapted in light of relevant scientific literature, the aims of the present study, and half of the participants' responses to each interview question. In order to avoid giving more weight to answers containing many synonyms, and to thus prevent the occurrence of any possible biases from more verbal individuals, a single code was attributed to all the information units relating to the same category of the grid for a given answer. The reliability of the coding procedure was determined by percent agreement. Coders' choices proved to be congruent for 71 % of the units analyzed. In other cases, coders achieved agreement following a thorough discussion in the presence of the research coordinator. Statistical analysis was based on the sum of the frequencies, followed by the calculation of the proportions, of the categories of coded responses for each question. A threshold criterion of 10 % (n = 5) was established in order to retain only the types of benefits and burdens most frequently mentioned by the participants.

Subsequently, the categories coded in the responses to the questions on the presence and types of benefits and burdens were examined by taking into account the socio-demographic and medical characteristics of the participants (aim 2). Fisher's exact p-value and Pearson's r value were calculated to test the differences in proportion and the presence of associations within the categories of responses. When the analysis of the responses of a given question revealed an effect on a pair of correlated variables, partial correlations were made in order to control their potential influence. Finally, associations between the presence/absence of benefits and burdens and participants' scores of school engagement (aim 3) were tested through inferential analysis such as ANOVA. All statistical analysis were done using the Statistical Package for the Social Sciences (SPSS 17.0) [71].

Results

Participant characteristics

The 49 participants of this study comprised 22 girls and 27 boys. On average, participants were 12 years old (M = 11.6, SD = 2.6) and had been diagnosed 6 years prior to the study (M = 5.8, SD = 2.6). At the time of diagnosis, 51.0 % of participants were attending school. At the time of the study, participants attended either elementary (59.2 %) or high school (40.8 %). All had undergone chemotherapy and almost two-thirds of the participants had received radiation therapy (61.2 %). A small percentage of the participants (12.2 %) had also received transplants, in addition to chemotherapy and radiation treatments. Most participants lived in a two-parent family (75.6 %) and the median household income was between CAD \$60,000 and CAD \$75,000, which is similar to that of Quebec families with children between 0 and 17 years of age during this same period [45].

Presence and types of benefits and burdens

To the question targeting perceptions regarding the presence of benefits, 3 out of 4 participants (75.5 %) answered that cancer had brought something good into their lives (see Table 1). Regarding the types of benefits mentioned by these participants, more than 1 in 4 (26.5 %) referred to the support (for the most part emotional and material) they had received from their relatives during the acute period of the illness (e.g., I received gifts; I got to play often with my mother;

My godfather came to see me every evening to make me laugh; I liked the food at the hospital). An almost equivalent number of participants (24.5 %) identified qualities and strengths of character they believe they have developed as a result of the illness: courage (e.g., It toughens you; I feel stronger), self-control (e.g., It made me calmer because I used to be very agitated), confidence (e.g., You don't care about what people say about you), an appreciation for life (e.g., I see life differently, It teaches you to enjoy life). Establishment of positive relationships with family and friends is also mentioned by 1 in 5 participants (20.4 %): It created strong bonds between members of my family; I made friends. Other benefits are mentioned by a smaller proportion of participants, namely personal fulfillment through participation in social or recreational activities (12.2 %): I collected money for the telethon; I had time to draw a lot; I went to Walt Disney World; I really like Leucan and its summer camp program.

To the question targeting perceived presence of burdens (see Table 2), half of the participants (51.0 %) answered that cancer brought something they dislike into their lives. Types of burdens mentioned

appear to vary greatly from one participant to the other, but most of them relate to physical (22.4 %) and psychological aspects (11.3 %) of the participants' development. As regards the physical aspects, the participants mentioned certain manifestations regarding their physical appearance (e.g., I'm smaller than the others; My face is still a little bit puffy; My hair used to be thicker, now it's thin) and their physical abilities (e.g., I can't walk very fast; I've lost a lot of muscle mass). With respect to the psychological aspects, the participants mentioned their worries (e.g., My friends often tell me to trust myself; I'm afraid that, in the future, I won't have any teeth), their negative thoughts (e.g., I have nightmares; I have mood swings), as well as the memories they have of the difficult moments they endured during the time of their illness (e.g., the needles; going to the hospital).

Associations with demographic and medical characteristics

Participants' perceptions of the presence of benefits did not differ by any of the demographic or medical factors assessed in the study (see Table 1).

Content of answers	N (%)	Variations (Fisher exact test and correlations)											
		Sex		Age	1-2 parent family		Family income		In school at Dx		Radiation Tx		Time since Dx
		F	M	Pearson r	1	2	-	+	No	Yes	No	Yes	Pearson r
		22	27		12	37	22	25	24	25	19	30	
Did cancer bring something good into your life?													
Yes	37 (75.5)	17	20	0.24	10	27	15	21	16	21	13	24	0.02
Support from relatives	13 (26.5)	6	7	0.05	2	11	5	7	7	6	5	8	0.09
Qualities and strength of character	12 (24.5)	5	7	.59*	6	6	7	5	2	10	4	8	0.08
Positive relationships	10 (20.4)	3	7	0.17	5	5	1	9	2	8	3	7	-0.25
Social and recreational activities	6 (12.2)	1	5	0.03	4	2	5	1	2	4	2	4	-0.04
* p < .01													

Table 1: Participants' answers with regard to presence and types of benefits

Analysis of the types of benefits mentioned by the participants reveals a significant correlation: the older the participant were, the more participant were likely to mention their own qualities and strengths as being benefits stemming from illness ($r(49) = .59, p < .01$ ($r^2 = .35$). Participants' perceptions of the presence of burdens did not differ by any of the demographic or medical factors assessed (see Table

2). However, analysis of the types of burdens mentioned by the participants revealed a significant correlation: the more time had elapsed since the initial diagnosis of cancer, the more likely participants were to mention psychological burdens, ($r(49) = .37, p < .01$ ($r^2 = .14$).

Content of answers	N (%)	Variations (Fisher exact test and correlations)											
		Sex		Age	1-2 parent family		Family income		In school at Dx		Radiation Tx		Time since Dx
		F	M	Pearson r	1	2	-	+	No	Yes	No	Yes	Pearson r

		22	27		12	31	22	25	24	25	19	30	
Question: Did cancer bring something you don't like into your life?													
Presence	25 (51.0)	12	13	0.11	7	18	12	12	9	16	10	15	0.07
Physical aspects	11 (22.4)	3	8	0.18	2	9	7	4	3	8	3	8	0.06
Psychological aspects	6 (11.3)	5	1	0.23	3	3	3	2	3	3	3	3	.37*
* p < .01													

Table 2: Participants' answers with regard to presence and types of burdens

Relations to school engagement

An analysis of the variance of school engagement was performed, taking into account perceptions of the presence/absence of benefits and burdens (see Tables 3 & 4). This analysis revealed a significant main effect, $F(1, 48) = 8.42, p = .01 (\eta^2 = .14)$, indicating that the mean score on school engagement was greater for survivors who perceived the presence of benefits to their illness compared to those who did not. Results also showed a significant interaction effect, $F(1, 48) = 4.63, p = .04 (\eta^2 = .08)$, indicating that perceiving the presence of both benefits and burdens predicts the highest scores of school engagement ($M = 2.71, SD = 4.90$). However, survivors who perceive only the presence of burdens are the least engaged in school ($M = -6.33, SD = 5.56$).

	Presence of benefits			Absence of benefits		
	M	SD	N	M	SD	N
Presence of burdens	2.71	4.9	19	-6.33	5.56	6
Absence of burdens	1.18	5.62	18	-0.16	6.01	6

Table 3: Perceptions of presence/absence of benefits and burdens

Source	SS	df	F	η^2	p
Between subjects					
Presence of benefits	243.99	1	8.42	0.14	0.01
Presence of burdens	48.65	1	1.68	0.03	0.2
Benefits X Burdens	134.38	1	4.63	0.08	0.04
Within-group error	1304.71	45	(28.99)†		
†Values enclosed in parentheses represent mean square error.					

Table 4: Analysis of variance for school engagement

Discussion

Looking at young survivors' perceptions of the impact of cancer on their lives (aim 1), this study first underlines the possible coexistence of

benefits and burdens stemming from a difficult experience, which concurs with the orientations of positive psychology [3, 69]. Regarding this, the present study reaches conclusions similar to those of Mattsson et al. [41] and Engvall et al. [20], which illustrate the perceptions of the consequences (both positive and negative) of cancer held by adolescent cancer survivors who were diagnosed with cancer, collected through telephone interviews, within an average period of two, three and four years. The present study adds that these perceptions were observed equally with younger participants. As for the types of benefits mentioned by the participants, all are reflected in the results found by previous studies in pediatric oncology: better self-esteem [40], improved relationships with family and friends [51], and greater appreciation for life and satisfaction with life [34]. These results may be explained by the phenomenon of posttraumatic growth which, according to Tedeschi and Calhoun [75], brings about three major categories of positive change within individuals who experience a traumatic event: self-perception, interpersonal relationships, philosophy of life. This phenomenon could also explain the fact that young cancer survivors were more prone to note the presence of benefits (75,0%) than the presence of burdens (51,0%) in this study.

Among the types of benefits that were mentioned, aspects related to young cancer survivors' interpersonal relationships appear to be predominant: support from relatives, positive relationships, social and recreational activities. On one hand, these perceptions could reflect the central role that family and friends played after the illness, as well as the positive influence family and friends had during the young cancer survivor's development and adaptation to his/her illness [17, 62, 78]. On the other hand, these perceptions may reflect the gratitude that young cancer survivors feel towards family and friends. In fact, following cancer treatments, it has been demonstrated that certain young cancer survivors develop and express a greater sensitivity towards others [34, 51]. To explain this process of "changed relatedness", Newman [49] proposes the theory of "Health as Expanding Consciousness" which posits that the experience of illness produces a greater sense of self-consciousness as well as an increased openness to interactions within one's social environment.

As for burdens, the young cancer survivors surveyed mentioned both physical and psychological aspects of their development. These negative consequences of childhood cancer have also been reported openly by young survivors in other studies: poor body image [59], the presence of concerns [54], difficult memories related to the experience of cancer [41, 51]. Surprisingly, a significant number of participants did not mention interpersonal relationships as a burden stemming from their illness. This despite the fact that numerous studies have established that the interpersonal relationships of young cancer

survivors are indeed somehow adversely affected, compared to those of their peers: isolation [18, 77], difficulty getting along with others [67], fewer close friends [60] and a lower tendency to confide in friends [5]. However, certain studies have established that young cancer survivors demonstrate better social functioning skills than their peers [60, 63], which would explain why almost all participants of the present study did not mention relationship-related aspects when asked about burdens stemming from their illness.

The analysis of associations between the participants' perceptions and their socio-demographic and medical characteristics (aim 2) reveal two significant correlations. Firstly, though Currier et al. [16] established on the basis of a questionnaire that older children were more prone than their younger peers to derive benefits from their experience with cancer, the present study adds that this difference could be greater regarding certain aspects of young cancer survivors' personal development, namely their qualities and strengths. While the present study does not offer an explanation for these observations, it does suggest that the more advanced cognitive maturity manifested by teenagers could be a factor. Furthermore, the greater tendency showed by participants to mention burdens of a psychological nature when more time had elapsed since their initial diagnosis of cancer suggests that additional life experiences might help survivor better define the ways in which cancer has both positively and negatively impacted their lives.

Inferential analysis of the study (aim 3) indicates that young survivors who are aware of benefits stemming from their illness seem to be more engaged in school compared to those who perceive no benefit. Studies on posttraumatic growth indicate that the capacity of young survivors to derive benefits from their experience of illness is strongly associated with their disposition for optimism [11, 44, 57], which consists of holding favourable expectations for the future [65]. Optimism is thought to promote physiological as well as psychological benefits on different spheres of the lives of individuals, principally as a result of a better capacity to cope with stressors and tackle challenges [64]. Therefore, it is possible to posit that keeping a positive outlook on the experience of cancer may coincide with the capability of survivors to see their respective lives under a more favourable light. This study adds that this phenomenon may also have an impact on the academic lives of cancer survivors.

Inferential analysis of the study indicates also that results revealing a significant interaction between the presence of benefits and burdens to explain school engagement point toward the promising potential that an optimistic yet realistic outlook may hold in regard to adapting to a traumatic event. While a realistic approach promotes the successful negotiation by an individual of his/her environment, realistic optimism refers to the individual's holding of favourable expectations within the constraints brought on by said environment [66]. Hence, realistic optimism suggests maintaining aspirations while considering and accepting the limits imposed by one's situation. Although uncertainty remains a factor, as is often the case for school success after cancer, realistic optimism involves engaging in efforts toward the achievement of goals, without however claiming any particular result. Reaching a goal is thus experienced as an enjoyable process that, while triggering positive emotions (also known as flow), promotes the active engagement of the person [61, 70]. A similar process could explain the fact that young survivors who see themselves as being more engaged in school are also those who appear to be the most balanced (reporting both pros and cons) in regard to the impact their illnesses have on their lives. In sum, young survivors give evidence of their capacity to

take advantage of their experiences as well as to accept the limits these experiences involve.

Implications for research and practice

Current knowledge in the area of psychosocial interventions with young survivors remains mostly limited to issues relating to periods of diagnosis and treatments: fatigue, pain, distress, social isolation. In line with the guidelines for survivorship care [12], the present study's results suggest to go beyond traditional interventions and focus on difficulties that are likely to manifest themselves and endure in the longer term, even up to almost six years after the end of treatment. These guidelines underline educational issues among others, these being, post-illness, at the core of young cancer survivors' psychosocial adaptation. Since the difficulties associated with cancer can appear to increase with time, it would also be relevant to conduct longitudinal studies in order to verify if the trajectory of school engagement of survivors varies according to their adaptation to the different stages of their illness (diagnosis; treatment; remission; cure) and in the longer term as they reach and go through young adulthood. While the results reveal the promising potential that an optimistic yet realistic disposition has in regard to school engagement, it would be necessary to further our understanding of such a disposition, as well as its potential to contribute to the development and adaptation of young cancer survivors within the various spheres of their lives.

On the clinical front, the results of the present study invite practitioners to provide adequate support and guidance to young survivors in their attempts to fulfill a personal exercise, which consists in the development of a more balanced outlook on their experience of illness, recognizing both pros and cons. Through various modalities, such as peer support groups, social skill building and problem solving training, as well as education in regard to illness and treatments, psychosocial interventions may help survivors make sense of their experiences. Late effects and long-term survivorship clinics, which are strongly encouraged by the Children's Oncology Group, could represent a convenient environment in which to offer such support to survivors. Typically, after-treatment psychosocial care is delivered by a multidisciplinary team that provides services to address the psychological implications of cancer for survivors and their families as well as to assist them with transition, educational and employment issues [24]. In addition, guidelines for after-treatment care suggest classroom strategies that might bear on promoting school engagement for survivors with difficulties, such as "preferential seating in classroom, use of computer keyboards instead of handwriting, use of calculators for math, modification of test requirements (extra time, oral instead of written exams), extra help with math, spelling, reading, and organizational skills, assignment of a classroom aide" [12].

Strengths and limitations of the study

The present study is one of the few studies to examine the phenomenon of school engagement among young people with health problems, and it certainly is the first to do so in the field of pediatric oncology. The study also has the merit of examining a population that, up to now, has not been the subject of many studies, namely young cancer survivors for whom the acute phase of illness appears to be well and truly over. Among the strengths of the procedures used, participants were met in their homes, which avoided a potential confound of the hospital context. Also, the number of items ($n = 14$) making up the school engagement measure is greater than that of the majority of studies reviewed on the subject [23, 28] and thus offers the

advantage of covering the concept in its broadest sense. Finally, the study should also be credited with highlighting young survivors' statements on both positive and negative aspects of their experience, which is rather rare in studies examining subjects' post-illness adaptation.

The study's main limits concern its exploratory nature, its small sample size and the use of measures that have not yet been examined psychometrically. The lack of multiple informants and multiple measures, as well as the use of a sample that crosses two developmental levels, may also have had the effect of limiting the precision of the results and their interpretation. Also, characteristics of non-participants remained unknown as a result of the recruitment process that was used. Since participation was purely voluntary, it is possible that the process may have resulted in the self-selection of young cancer survivors who had adapted well to the illness, who suffered fewer effects associated with treatment, and whose school experience was a more positive one. Therefore, participants' representativeness cannot be assured and limits the possibility to generalize the results to the entire population of young leukemia survivors, such a goal being well beyond that of an exploratory study.

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