

RESEARCH ARTICLE

Parents' and Health-Care Providers' Perspectives on Side-Effects of Childhood Cancer Treatment in IndonesiaStefanus Gunawan¹, Emma Wolters², Josephine van Dongen², Peter van de Ven³, Mei Sitaresmi⁴, Anjo Veerman², Max Mantik¹, Gertjan Kaspers², Saskia Mostert^{2*}**Abstract**

Background: Efficacy of childhood cancer treatment in low-income countries may be impacted by parents' and health-care providers' perspectives on chemotherapy-related side-effects. This study explores prevalence and severity of side-effects in childhood cancer, and compares health beliefs about side-effects between parents and health-care providers, and between nurses and doctors in Indonesia. **Materials and Methods:** Semi-structured questionnaires were filled in by 40 parents and 207 health-care providers in an academic hospital. **Results:** Parents expressed a desire to receive more information about side-effects (98%) and worried about this aspect of treatment (90%), although side-effects were less severe than expected (66%). The most frequent was behavior alteration (98%) and the most severe was hair loss. Only 26% of parents consulted doctors about side-effects. More parents, compared to health-care providers, believed that medicines work better when side-effects are more severe ($p<0.001$), and accepted severe side-effects ($p=0.021$). More health-care providers, compared to parents, believed that chemotherapy can be stopped or the dosage altered when there are side-effects ($p=0.011$). More nurses, compared to doctors, stated that side-effects were unbearable ($p=0.004$) and made them doubt efficacy of treatment ($p<0.001$). **Conclusions:** Behavior alteration is the most frequent and hair loss the most severe side-effect. Apparent discrepancies in health beliefs about side-effects exist between parents and health-care providers. A sustainable parental education program about side-effects is recommended. Health-care providers need to update and improve their knowledge and communication skills in order to give appropriate information. Such measures may improve outcome of childhood cancer treatment in low-income countries, where adherence to therapy is a major issue.

Keywords: Childhood cancer - side-effects - low-income countries - adherence to therapy

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Introduction

Childhood cancer survival is lower in low-income countries (<35%) than in high-income countries (80%) (Mostert et al., 2011; 2012; Rohani-Rasaf et al., 2012). Several factors contribute to this discrepancy: death from toxicity, relapse and non-adherence. Treatment abandonment, a severe form of non-adherence and seldom seen in high-income countries, is the most prominent factor. Recently, various studies indicated that non-adherence and abandonment are not merely caused by socio-economic hardships, but also by psychological aspects and side-effects of chemotherapy (Yeh et al., 1999; De Oliveira et al., 2005; Bonilla et al., 2009; Sitaresmi et al., 2010; Wang et al., 2011).

Chemotherapy-related side-effects may deteriorate the child's quality of life and hinder families' acceptance and adherence with prescribed medication (Yeh et al., 1999;

Parsay et al., 2012). Non-adherence with cancer treatment is associated with increased chance of relapse and poor survival (Wang et al., 2011). Health beliefs of doctors and nurses regarding side-effects may influence their attitude and management of side-effects (Sitaresmi et al., 2008). This management subsequently will impact patients' adherence and outcome of treatment.

At Prof Dr RD Kandou Hospital in Indonesia, the most important reason for childhood cancer treatment failure is non-adherence: 48% of patients abandon treatment (Mostert et al., 2012). Insight into parents' and health-care providers' perspectives on chemotherapy-related side-effects are missing. More understanding by health-care providers of the role side-effects play in the lives of their patients, and how their own health beliefs can influence patients' treatment adherence is necessary to better prepare families and control side-effects.

Therefore, we wanted to assess the prevalence and

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severity of chemotherapy-related side-effects in childhood cancer, and compare health beliefs about side-effects between parents, doctors and nurses.

Materials and Methods

Setting

Indonesia's population counts around 238 million citizens, of whom 66 million (27%) citizens are younger than 15 years (Indonesian Statistics Central Body, 2010). A childhood cancer incidence of 102 per million children under 15 years in low-income countries (Howard et al., 2008; Mostert et al., 2012), gives rise to approximately 6.700 new Indonesian childhood cancer patients per annum.

Our study was conducted at Prof Dr RD Kandou Hospital in Manado. This academic hospital serves an estimated 5 million citizens, including 1.4 million children less than 15 years old. Although about 140 childhood cancer patients under 15 are envisaged in its service area, solely 25-30 children are actually diagnosed with cancer at Prof Dr Kandou Hospital per year.

A previous study conducted in Manado found that 80% of diagnoses are hematological malignancies, of which acute lymphoblastic leukemia is by far the most common (68%) (Mostert et al., 2012). Acute lymphoblastic leukemia patients are treated according to Indonesia 2006 ALL protocol. During its induction phase prednisone or dexamethasone, vincristine, L-asparaginase and daunorubicin are administered. During consolidation phase high-dose methotrexate with leucovorin rescue and 6-MP are given. Additional cyclophosphamide is included for high risk patients. Reinduction phase for high risk patients entails cytarabine. During maintenance phase daily 6-MP and weekly methotrexate were given, with a steroid block in between. All patients receive intrathecal methotrexate as prophylaxis against central nervous system leukemia. Whole treatment lasts 110 weeks.

The pediatric department contains 100 beds and is operated by 20 pediatricians. The pediatric hematology-oncology department has 18 beds and is managed by 2 pediatric oncologists. Three different wards are recognized: first, second and third class. With augmenting rank, conditions on ward and quality of delivered food ameliorate and number of children per hospital room declines. Nevertheless, treatment protocols and medical staff are the same for all patients. No information material about cancer, treatment and its side-effects is available. Interns give parental education about cancer and side-effects once a week. Interns take turns every week.

Study design

This was a cross-sectional study using semi-structured questionnaires with parents and health-care providers. The questionnaires were part of a more elaborate investigation on adherence with childhood cancer treatment in Manado, Indonesia. Questionnaires explored perspectives of parents and health-care providers on chemotherapy-related side effects of treatment.

Regarding the parents' questionnaire study, participants were caretakers of childhood cancer patients who

visited the inpatient or outpatient clinic at Prof Dr RD Kandou Hospital between October 2011 and January 2012. Participants were interviewed by an independent interviewer.

Regarding the health-care providers' questionnaire study, all 254 health-care providers working at the pediatric department of Prof Dr RD Kandou Hospital were approached personally and asked to fill in a questionnaire at home or in the clinic. The questionnaire was anonymous and participants were affirmed of the confidential nature of their responses. Respondents self-denoted their professional title as pediatric oncologist, pediatrician, resident, intern or nurse. This was the sole demographic variable assembled.

Parents' questionnaire contained a checklist assessing 16 common symptoms to examine the prevalence and severity of chemotherapy-related side-effects. The severity of symptoms was ranked as mild, moderate or severe. The checklist was established on literature studies and experiences of children diagnosed with cancer. Both questionnaires contained statements that parents and health-care providers could evaluate on 3-5 point rating scales. A group of Dutch and Indonesian doctors and psychologists ensured proper, explicit and coherent statements. Questionnaires were pilot-tested on a separate group of parents and health-care providers for its substance, lucidity of language and cultural sensitivities. Some adjustments were imparted based on the pilot-test. Anonymity and confidentiality were asserted. The Medical Ethics Committee of Prof Dr RD Kandou Hospital authorized the study.

Data analysis

Frequency distributions were calculated. Relationship between prevalence of chemotherapy-related side-effects and socio-demographic characteristics was evaluated by chi-square and Fisher's exact tests. Relationship between severity of side-effects and socio-demographic characteristics was evaluated by Mann-Whitney test. Differences in health beliefs between parents and health-care providers were compared by Mann-Whitney, chi-square and Fisher's exact tests. Data management and analysis were performed with SPSS for Windows version 17.0. A two-sided significance level of 5% was used in all analyses.

Results

Between October 2011 and January 2012, 41 childhood cancer patients attended Prof Dr RD Kandou Hospital. Caretakers of 40 children (98%) were interviewed. Parents of 1 child did not participate because their child died before the interview took place. Interviewees comprised of mothers (80%), fathers (13%), grandmothers (5%) and sister (3%). The patients consisted of 52% boys and 48% girls. Their ages ranged between 1-13 years. Mean age was 7.0 years (SD=3.3) and median age was 6.7 years. Patients had hematological tumors (90%) or solid tumors (10%). Acute lymphoblastic leukemia was by far the most common hematological tumor (86%). During interviews, 95% of children were still undergoing treatment and 5%

Table 1. Health-Care Providers Participating in Questionnaire Study

Health-Care Providers	No. (%)
Pediatric Oncologists	2 100
Pediatricians	14 70
Residents	81 99
Interns	59 98
Nurses	51 78
Total	207 90

Table 2. C Prevalence and Severity of Chemotherapy-Related Side-Effects in 40 Childhood Cancer Patients According to Their Parents

Symptoms:	Prevalence		Severity			Mean severity score*
	N	(%)	N	(%)		Mean±SD
Behavior alteration	39 (98)	14 (36)	13 (33)	12 (31)		2.0±0.8
Mouth ulceration	33 (83)	16 (49)	9 (27)	8 (24)		1.8±0.8
Infection	33 (83)	20 (61)	7 (21)	6 (18)		1.6±0.8
Nausea	33 (83)	26 (79)	7 (21)	0 (0)		1.6±0.4
Decreased appetite	33 (83)	21 (64)	9 (27)	3 (9)		1.5±0.7
Fatigue	33 (83)	22 (67)	8 (24)	3 (9)		1.4±0.7
Increased appetite	32 (80)	13 (41)	13 (41)	6 (19)		1.8±0.8
Pain	32 (80)	18 (56)	11 (34)	3 (9)		1.5±0.7
Abdominal pain	32 (80)	23 (72)	7 (22)	2 (6)		1.3±0.6
Loss of hair	30 (75)	3 (10)	2 (7)	25 (83)		2.7±0.6
Adipositas	29 (73)	12 (41)	10 (35)	7 (24)		1.8±0.8
Vomiting	29 (73)	20 (69)	5 (17)	4 (14)		1.4±0.7
Leg weakness	26 (65)	16 (62)	4 (15)	6 (23)		1.6±0.9
Diarrhea	21 (53)	16 (76)	4 (19)	1 (5)		1.3±0.6
Constipation	18 (45)	12 (67)	3 (17)	3 (17)		1.5±0.8
Spontaneous bleeding	15 (38)	7 (47)	3 (20)	5 (33)		1.9±0.9

*Mean severity score; rank 1 (mild); rank 2 (moderate); rank 3 (severe)

of children had accomplished treatment.

Between July and November 2011, the 229 health-care providers working at pediatric department were inquired to participate in our study. A total of 207 health-care providers (response rate of 90%) participated and yielded questionnaires (Table 1).

Parents' perspectives on chemotherapy-related side-effects

Although some explanation about chemotherapy-related side-effects at diagnosis had been received by 90% of parents, 98% of parents stated that they would like to receive more information about the side-effects of treatment. All parents (100%) mentioned that their child had suffered from side-effects. Compared to what parents expected before the start of treatment, side-effects were: more severe (13%), less severe (66%), as expected (21%). Parents (90%) stated that they paid much attention to and worried about side-effects in their child.

Table 2 illustrates the prevalence and mean severity score of chemotherapy-related side-effects, as indicated by the parents. The most frequent side-effect was behavior alteration (98%). Becoming angry was the predominant behavior alteration. The mean (±SD) number of symptoms per patient was 11.7±2.7 (range 4-15). The most severe side-effect was loss of hair, which was cited as a severe symptom by 63% of parents. The second most severe side-effect was behavior alteration, which was reported as a severe symptom by 30% of parents. No significant differences in children were found regarding

either prevalence or severity of side-effects by socio-demographic characteristics (gender, age).

Chemotherapy-related side-effects hindered daily activities of their child according to 83% of parents. The most common hindered daily activity was attending school. In total 70% of patients were of school-going age at time of diagnosis. School attendance decreased in 72% of children: 10% of these children stopped attending school due to the disease and the other 90% missed classes. Other common hindered activities were difficulties in eating and drinking (44%), playing (22%) and sleeping (20%).

Parents' primary coping strategy with chemotherapy-related side-effects was: consulting doctors about side-effects (26%), using symptomatic medication (23%), mouthwash against mouth ulceration (13%), praying (2%), resting (2%), special diet (2%), vitamins (2%) and adjusting the dosage of chemotherapeutic drugs (2%). The rest (28%) took no action.

Comparing parents' and health-care providers' perspectives on chemotherapy-related side-effects

Table 3 compares health beliefs about chemotherapy-related side-effects between parents and health-care providers. Parents, compared to health-care providers, more strongly believed that prescribed medicines work better when side-effects are more severe ($p<0.001$). Health-care providers, compared to parents, more strongly answered that side-effects were unbearable ($p=0.002$). Parents, compared to health-care providers, more strongly accepted severe side-effects ($p=0.021$) and more strongly believed that most side-effects will disappear when full cancer treatment is accomplished ($p<0.001$).

Table 4 compares health beliefs about the influence of chemotherapy-related side-effects on treatment adherence between parents and health-care providers. Health-care providers, compared to parents, more strongly believed that chemotherapy can be stopped or dosage altered on the initiative of parents when there are side-effects ($p=0.011$). A larger proportion of health-care providers, compared to parents, stated that side-effects make parents not give prescribed medicines to their child ($p<0.001$). In fact asking parents if side-effects make them not give prescribed medicines was almost always done by 2% of health-care providers. A larger proportion of health-care providers, compared to parents, stated that side-effects make parents alter the dosage of prescribed medicines ($p<0.001$). Actually asking parents if side-effects make them alter the dosage of prescribed medicines was almost always done by 0.5% of health-care providers.

Comparing nurses' and doctors' perspectives on chemotherapy-related side-effects

Explanation about the side-effects of treatment at diagnosis had been provided by 100% of nurses and 94% of doctors.

Table 3 compares health beliefs about chemotherapy-related side-effects between nurses and doctors. Nurses, compared to doctors, more strongly believed that prescribed medicines work less good when side-effects are more severe ($p<0.001$). Nurses, compared to doctors, more strongly answered that side-effects were unbearable

Table 3. Health Beliefs About Chemotherapy-Related Side-Effects of Parents (n=40) Versus Health-Care Providers (n=207), and Nurses (n=51) Versus Doctors (n=156)

Statements	Parents		Hcp		p*	Nurses		Doctors		p*
	Total	Count	Total	Count		Total	Count	Total	Count	
When side-effects are more severe, prescribed medicines work:										
Better	27	19 (70%)	155	55 (35%)	<0,001	39	8 (21%)	116	47 (41%)	<0,001
The same	7	(26%)		53 (34%)		8 (21%)	45 (39%)			
Less good	1	(4%)		47 (30%)		23 (59%)	24 (21%)			
Side-effects make me doubt efficacy of treatment										
Agree	40	10 (25%)	205	22 (11%)	ns	49	10 (20%)	156	12 (8%)	<0,001
Uncertain	4	(10%)		48 (23%)		21 (43%)	27 (17%)			
Disagree	26	(65%)		135 (66%)		18 (37%)	117 (75%)			
Chemotherapy makes children only sicker and therefore cannot cure cancer										
Agree	39	3 (8%)	207	16 (8%)	ns	51	8 (16%)	156	8 (5%)	
Uncertain	1	(3%)		20 (10%)		10 (20%)	10 (6%)			
Disagree	35	(90%)		171 (83%)		33 (65%)	138 (88%)			
Side-effects are unbearable										
Agree	39	2 (5%)	205	41 (20%)	0,002	50	16 (32%)	155	25 (16%)	0,004
Uncertain	5	(13%)		49 (24%)		14 (28%)	35 (23%)			
Disagree	32	(82%)		115 (56%)		20 (40%)	95 (61%)			
I accept that a severe disease requires strong treatment and causes severe side-effects										
Agree	39	23 (59%)	207	89 (43%)	0,021	51	30 (59%)	156	59 (38%)	ns
Uncertain	9	(23%)		38 (18%)		4 (8%)	34 (22%)			
Disagree	7	(18%)		80 (39%)		17 (33%)	63 (40%)			
Most side-effects will disappear when treatment is completed										
Agree	39	37 (95%)	206	138 (67%)	<0,001	50	35 (70%)	156	103 (66%)	ns
Uncertain	2	(5%)		40 (19%)		7 (14%)	33 (21%)			
Disagree	0	(0%)		28 (14%)		8 (16%)	20 (13%)			

*Mann-whitney test

Table 4. Health Beliefs About Influence of Chemotherapy-Related Side-Effects on Treatment Adherence of Parents (n=40) Versus Health-Care Providers (n=207), and Nurses (n=51) Versus Doctors (n=156)

Statements	Parents		Hcp		p*	Nurses		Doctors		p*
	Total	Count	Total	Count		Total	Count	Total	Count	
Chemotherapy can be stopped or dosage altered on initiative of parents when there are side-effects										
Agree	39	2 (5%)	207	39 (19%)	0,011*	51	9 (18%)	156	30 (19%)	ns*
Uncertain	1	(3%)		16 (8%)		5 (10%)	11 (7%)			
Disagree	36	(92%)		152 (73%)		37 (73%)	115 (74%)			
Side-effects make me/parents not give prescribed medicines										
Yes	40	3 (8%)	195	167 (86%)	<0,001**	51	40 (78%)	144	127 (88%)	ns***
No	37	(93%)		28 (14%)		11 (22%)	17 (12%)			
Side-effects make me/ parents alter dosage prescribed medicines										
Yes	40	3 (8%)	207	120 (58%)	<0,001**	51	24 (47%)	156	96 (62%)	ns***
No	37	(93%)		87 (42%)		27 (53%)	60 (38%)			

*mann-whitney test; **fisher's exact test; ***chi-square test

(p=0.004) and that side-effects made them doubt the efficacy of treatment (p<0.001).

Table 4 illustrates that nurses and doctors had similar health beliefs about the influence of chemotherapy-related side-effects on treatment adherence.

Discussion

This study accentuates the need of parents to receive better explanation about side-effects of chemotherapy in their children. Almost all parents indicated that they worried about side-effects and would like to receive more information. Encountered side-effects were ultimately less severe than expected beforehand. This makes clear that there are gaps between what has been explained and what really happened. In Manado, interns have a scheduled task to give information about cancer and side-effects of treatment once a week. However, interns lack both experience in the field of pediatric oncology and knowledge about side-effects. In addition, interns turn every week and have no opportunity to gain experience

in providing parental education. As a consequence, the information given may not be accurate, inconsistent and too frightening. This might contribute to the high rates of abandonment, especially during induction (Mostert et al., 2012). The unmet needs of parents towards information provided by health-care providers were also reported elsewhere (Patistea et al., 2003; Poder et al., 2009; Demirbag et al., 2013). Moreover, the majority of parents assumed that treatment efficacy ameliorates when more severe side-effects occur. A similar parental health belief was reported in Malawi, Africa (Israels et al., 2008). In reality, parents in Manado faced less severe side-effects than expected. This discrepancy might cause parents to doubt treatment efficacy and could lead to non-adherence or abandonment. Therefore, an experienced health-care provider should be responsible for providing structured information about side-effects, rather than those least experienced.

Only a quarter of parents consulted doctors regarding problems with side-effects. This is not in accordance with medical advices. It is of great importance to manage side-

effects effectively in order to improve the child's quality of life. Prescribing medications, such as anti-emetics for nausea, may minimize the occurrence of side-effects and increase treatment adherence and outcome. Parents therefore should be well guided how to prevent or control symptoms (Hedstrom et al., 2003; William et al., 2006; Poder et al., 2010). Previous studies in Indonesia illustrated that differences in status and social hierarchical structures between doctors and parents hindered communication, particularly toward poor families (Mostert et al., 2008). This barrier should be eliminated. Health-care providers need to realize that families often are too shy to ask help for management of side-effects and therefore a proactive role of health-care providers is required. Doctors should routinely ask parents for the occurrence of side-effects and act to this (Hinds et al., 2008).

The most severe side-effect was unanimously hair loss. Remarkably hair loss was not considered a severe side-effect by parents in another academic hospital in Yogyakarta, Indonesia (Sitaresmi et al., 2009). This deviation might be due to different socio-cultural and religious backgrounds between the populations in Manado and Yogyakarta. Inside Indonesia, mundane seaside Manado has a reputation for its fashion and style. Maybe people in this region therefore attribute extra attention to physical appearances. Another explanation might be that Manado has a Christian population, in contrast to the rest of Indonesia. One could imagine that girls in Muslim Yogyakarta can camouflage their baldness unnoticed by wearing a scarf. A few studies concerning hair loss in pediatric cancer populations were done. In certain studies being bald was considered a distressing symptom (William et al., 2006), but not in others (Collins et al., 2000; Hedstrom et al., 2003; Poder et al., 2010). In adult cancer populations hair loss has been identified as a severe side-effect (Carelle et al., 2002). In a recent Korean study, most breast cancer patients stated that alopecia was the most traumatizing experience. They had not received adequate information about alopecia and subsequently were not well prepared how to cope with it. Patients lost self-esteem and felt stigmatized. Wearing wigs, hats or scarves meant an extra financial burden. Alopecia forced them to reduce outside daily activities to conceal it. Patients were worried that hair might not grow back (Kim et al., 2012). Although losing hair usually will recover over time, a report of adult survivors of childhood cancer documented that in fact 10% of survivors were affected by prolonged alopecia after treatment completion (Kinahan et al., 2009). Future studies exploring specific challenges families face when their child has chemotherapy-induced alopecia would be of benefit to better understand the needs of parents and patients. The gained insights could be implemented in a parental education program aimed at better preparing families how to manage and cope with alopecia and other side-effects.

Behavior alteration was the most frequent and second most severe side-effect. This change in behavior may be due to prednisone or dexamethasone administration. Parents complained that becoming angry predominated. Although this finding is in line with reports from Yogyakarta (Sitaresmi et al., 2009), becoming angry is not

mentioned as exceptionally bothersome in Western reports (Collins et al., 2000; Hedstrom et al., 2003; Poder et al., 2010; Atay et al., 2012). This might partly be attributed to differences in Asian and Western cultures. In Asia harmony in relationships and society is strived for and children who act angry and disturb social harmony may be less tolerated. Taiwanese teachers reported more behavior problems in school-aged children with cancer, such as hyperactive, impulsive, rule-breaking and aggressive behavior, compared to healthy peers (Liang et al., 2008). This finding should be taken into account since parents in our study mentioned that the most commonly hindered daily activity was attending school and the majority of patients were of school-going age upon diagnosis. Health-care providers may need to extend their professional services to school settings and provide psychosocial care for patients who are able to return to school (Moore et al., 2009).

Infections are the most common cause of treatment-related death in low-income countries, where supportive care is often limited (Howard et al., 2004). Remarkably, parents reported that infections in their children were in general mild to moderate. This stands in contrast to our previous finding that 10% of cancer patients in Manado died due to infections (Mostert et al., 2012).

Significant discrepancies between parents' and health-care providers' health beliefs about side-effects and its impact on treatment adherence were found. Parents seemed to better accept severe side-effects and were more confident that most side-effects would vanish once cancer treatment is completed. Many health-care providers believed that parents stopped or altered prescribed medicines due to side-effects. Surprisingly, only very few health-care providers routinely asked parents if medication was indeed stopped or altered. This figure indicates that health-care providers need to be more alert and proactively check if side-effects prevent parents to fully adhere with prescribed medication (Sitaresmi et al., 2008).

A quarter of health-care providers agreed that parents can or could stop or alter the dosage of chemotherapy on their own initiative when side-effects occur. These health beliefs differed significantly from those of parents, who were more convinced that protocol needs to be followed stringently. These bothersome findings reveal a non-optimal knowledge of health-care providers that may negatively impact cancer treatment if left untreated. Health-care providers need to learn more about side-effects and realize that their own attitudes and adherence to protocol guidelines correlates with patients' treatment outcome (Sitaresmi et al., 2008).

Significant differences between nurses' and doctors' health beliefs about chemotherapy-related side-effects were found. More nurses than doctors perceived side-effects to be unbearable. This could be due to the fact that nurses spend more time with patients and parents, especially in Manado, where the turnover of residents and interns is high.

No significant discrepancies between nurses' and doctors' health beliefs about the impact of side-effects on treatment adherence were found. Our findings are in harmony with earlier adult cancer studies, revealing that

overall agreement between cancer patients and medical professionals was rather poor while agreement between nurses and doctors was more considerable (Liau et al., 2005; Mulders et al., 2008; Sikorskii et al., 2012).

A limitation of this study is that respondents, both parents and health-care providers, may have given falsely positive answers since Indonesian culture decrees that it is impolite and unethical to criticize. Another constraint is that only parents of children who came to clinic were interviewed. Parents of children who had abandoned treatment were not interviewed. Although the children of interviewees are still at risk to abandon treatment, this may mean that more adherent caretakers participated.

The following arrangements are advocated: *i*) Comprehensive and sustainable parental education program about side-effects and its management. This program first need to be scheduled at diagnosis to properly prepare families and afterwards needs to be repeated throughout treatment. The information should be complemented with audio-visual or reading materials at a level appropriate for families to understand. Health-care providers experienced in the field of pediatric oncology should be responsible for this task; *ii*) Education program for health-care providers about prevention and control of side-effects and the necessity to adhere to prescribed medication dosages and protocol guidelines; *iii*) Communication training for health-care providers tailored to meet parents' and patients' needs. Health-care providers should learn to proactively ask families about encountered side-effects and check its impact on medication intake and adherence; *iv*) Psychosocial care for patients who are able to return to school. Teachers need to be actively informed about the expected behavior alteration induced by chemotherapy.

These arrangements plausibly will improve side-effects management by health-care providers. Consequently, a better quality of life for children and their families may be achieved. Ultimately, this may lead to enhanced childhood cancer treatment adherence and outcome.

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