



Original Article

Psychosocial interventions for reduction of distress in children with leukemia during bone marrow aspiration and lumbar puncture



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Key Words

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Background: Children with cancer undergo many invasive medical procedures that are often painful and highly distressing, including bone marrow aspiration (BMA) and lumbar puncture (LP). Psychosocial interventions have been demonstrated to reduce children's distress resulting from invasive medical procedures. The aim of the study is to assess the efficacy of psychosocial interventions to reduce distress in children with cancer undergoing BMA and LP in a pediatric cancer center in Taiwan.

Methods: Children with cancer who received treatment between March 2015 and December 2016 at Chang Gung Memorial Hospital, Linkou, Taiwan were eligible for the study. The psychosocial intervention comprised preparation and cognitive behavioral intervention and was provided by a certified child life specialist. The assessment instrument was the revised version of the Observational Scale of Behavioral Distress (OSBD-R). The behavioral distress of patients who underwent psychosocial interventions for BMA and LP was compared with patients without interventions. We also analyzed the difference of behavioral distress in patients' pre- and post-psychosocial intervention for BMA and LP.

Results: Eighteen patients were enrolled into this study. The mean age of diagnosis of leukemia was 6.6 years old (range: 3–11 years). Fifteen patients were diagnosed with acute lymphoblastic leukemia, and 3 were diagnosed with acute myeloid leukemia. The mean of OSBD-R total scores in 7 patients with psychosocial intervention was significantly lower than the mean

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score in 6 patients without intervention (0.65 vs. 4.81, $p = 0.002$). Pre- and post-psychosocial intervention for BMA and LP behavioral distress were evaluated for the remaining 5 patients. Consistently, there was a significant reduction of the OSBD-R score following interventions (3.04 vs. 7.81, $p = 0.025$).

Conclusion: Psychosocial interventions provided by a certified child life specialist have a significant potential to reduce children's distress during BMA and LP in pediatric healthcare settings in Taiwan. Copyright © 2018, Taiwan Pediatric Association. Published by Elsevier Taiwan LLC. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

1. Introduction

The diagnosis of pediatric cancer strongly impacts on the child and his/her family, followed by exhausting procedures such as lumbar puncture, bone marrow aspiration and venipuncture. These diagnostic procedures and treatments are the stressors that are potentially responsible for significant psychological distress, anxiety and depression.¹ It was found that emotional distress, fatigue, nutrition and pain were the symptom areas that caused the most problems for children undergoing cancer treatment.² Pain and distress does not decrease with repeated procedures and may worsen with time if pain is not adequately managed, which results in anticipatory anxiety about subsequent procedures or negative behaviors due to maladaptation.^{3,4} The anxiety and distress resulting from anticipation of these procedures is sometimes so severe that children display symptoms such as nausea, vomiting, insomnia, nightmares and skin rashes.¹ Young children often exhibit their distress in behaviors (kicking, fighting, screaming) to such an extent that physical restraint is necessary and it can be very difficult for medical staff to carry out a procedure.¹

Psychosocial interventions can decrease pediatric patients' pain and anxiety during invasive procedures, and also enhance children's coping capacity.¹ Psychosocial providers, such as psychologists and nurses, have collaborated with pediatric oncologists to treat children with cancer and their families in Taiwan.^{5,6} The policy statement published by American Academy of Pediatrics (AAP) in 2004 indicates that a child life specialist should be included in a multidisciplinary team committed to the care of the child or adolescent with cancer.⁷ However, child life services are still in their infancy in Taiwan.

Non-pharmacologic intervention for pediatric patients with cancer to help relieve the stress from painful medical procedures in healthcare settings has rarely been reported in Taiwan. The purpose of the study is to provide children with preparation and cognitive behavioral intervention to reduce children's fear and anxiety about invasive procedures in a pediatric cancer center in Taiwan.

2. Methods

2.1. Participants

Patients with acute lymphoblastic leukemia (ALL) or acute myeloid leukemia (AML) younger than 18 years old and

receiving treatment at the Department of Pediatric Hematology/Oncology in Chang Gung Memorial Hospital, Linkou, Taiwan were recruited. This study was approved by the Chang Gung Institutional Review Board. Informed consent was obtained from the patients and/or guardians.

2.2. Intervention procedures

At our Pediatric Hematology/Oncology ward, we used the combination of intravenous midazolam (0.1 mg/kg) and ketamine (1 mg/kg) sedation before invasive procedures as routine practice.⁸ In this study, patients received psychosocial interventions delivered by a certified child life specialist (CCLS). The intervention was initiated before the patients received invasive procedures, bone marrow aspiration (BMA) and lumbar puncture (LP). The psychosocial interventions in this study included preparation and cognitive behavioral intervention (CBI). Preparation is a generic term for a number of techniques and procedures, the central component of which is provision of information to children and their parents concerning the necessity, nature and various phases of the impending medical procedure.¹ CBI in this study focuses on the development of personal coping strategies that target solving current problems and changing unhelpful patterns in cognitions, behaviors, and emotional regulation.⁹ Coping strategies included distraction, storytelling, breathing exercise, and guided imagery.

For children aged 3–6 years, the CCLS provided a 1-h session with the goal of establishing a relationship with the child and family 2 days before their first scheduled BMA or LP. The child's past medical experiences, behavioral patterns and the understanding of BMA or LP of the child and family were explored during this session. In the next 1-h session one day before the procedure, medical play was provided as preparation to help the child understand the procedure and anticipatory sensory information, and to discuss activities that the child could engage in to obtain a sense of control before sedation. The tools of medical play included a demonstration doll, doctor's kits and medical materials such as tape, gauze, syringes, etc. The goal of medical play is to help children gain a sense of control, understand age-appropriate information and become familiarized with medical supplies during demonstration. Parents accompanied their child during the intervention sessions and were encouraged to coach their child during the medical procedures. On the day of scheduled BMA or LP, the CCLS accompanied the child to the treatment room.

Distraction as CBI strategy was provided to divert the child's attention from anticipatory anxiety before sedation was given, such as counting, blowing bubbles, story reading, etc. On the next day of scheduled BMA or LP, the CCLS visited the child and family, reviewing with the child their feelings throughout the procedure and providing emotional support to the child and family.

For children aged 7–13 years, the CCLS provided two 1-h sessions 3 days before their first BMA or LP. The first session was to build relationship with the child and family. The second session included preparation, in which the child's concerns were explored. The development of individual coping strategies, such as breathing exercises, talking, guided imagery, etc., was also fostered in this session. On the day of scheduled BMA or LP, the CCLS accompanied the child to the treatment room and guided the child to apply their coping strategies. The aim of interacting with the child in the treatment room was to decrease anxiety and maintain stable emotional state before sedation was given. Just as for the younger children, the CCLS visited the child and family on the next day of scheduled BMA or LP.

2.3. Assessment instrument and observation procedures

The revised version of Observational Scale of Behavioral Distress (OSBD-R)¹⁰ was administered in this study to document behavioral distress of children prior to and during BMA or LP. Briefly, the OSBD-R consists of eight behavioral categories which are indicative of anxiety and/or pain.¹⁰ The behavioral categories include information seeking, crying, screaming, restraint, verbal resistance, requesting emotional support, verbal expression of pain and flailing.¹⁰ Patients' behaviors were continuously recorded on the OSBD-R forms in 15-sec intervals. The 15-s intervals were indicated on a timer during the entire procedure. If any behaviors were displayed, even during the sedation, patients' behaviors were recorded based on the eight categories. Phase 1 consisted of the first 3 min in the treatment room (measurement of anticipatory anxiety). Phase 2 began with the given sedation and ended with phase 3. Phase 3

began with the cleansing of the procedure site and included the actual procedure. Phase 4 began with the removal of the needle and lasted for one and one-half minutes (measurement of post-procedure recovery). Higher OSBD-R scores indicated more behavioral distress of the patients. Differences in the comparisons were tested using Mann–Whitney U test and Wilcoxon Rank Signed test.

3. Results

This study was conducted between March 2015 and December 2016. Totally, 18 patients participated in this study, including 15 patients with ALL, and 3 patients with AML. The mean age of the 18 participants was 6.6 ± 2.5 years (range = 3–11 years). The participants consisted of 8 boys and 10 girls. The behavioral and emotional responses of 18 patients were recorded during BMA or LP. All the procedures of lumbar puncture were followed by intrathecal chemotherapy. The clinical features of the 18 patients, including age, gender, diagnosis, treatment phase, numbers of invasive procedures experienced, and recorded procedures are described in Table 1 and Table 2.

First, we compared the behavioral distress between patients with and without psychosocial interventions for the invasive procedures. The mean OSBD-R scores from 7 patients receiving psychosocial interventions by CCLS for BMA or LP (defined as the experimental group) were compared with 6 patients who did not receive psychosocial interventions (defined as the control group). Mann–Whitney U test was conducted for comparison between the experimental and control group. During the phase 1 of procedure, the mean OSBD-R score in the experimental group was 0.23 compared to 1.95 in the control group ($p = 0.022$). Although the mean OSBD-R scores in the experimental group were lower than the scores in the control group during phase 2, 3, and 4, the difference did not reach statistical significance. For the total phases, the mean OSBD-R score in the experimental group was 0.65 compared to 4.81 in the control group ($p = 0.001$) (Table 3).

Table 1 Demographic characteristics of patients in the experimental group and control group.

	Patient No.	Age	Gender	Diagnosis	Treatment phase	No. of procedures experienced	Recorded procedure by OSBD-R
Experimental group	1	6	M	ALL	Induction	0	BMA
	2	9	F	AML	Induction	0	BMA
	3	7	F	ALL	Induction	0	TIT
	4	11	F	AML	Induction	0	BMA
	5	6	F	ALL	Induction	0	TIT
	6	5	M	AML	Induction	0	TIT
	7	8	M	ALL	Induction	0	TIT
Control group	8	11	M	ALL	Continuation	18	TIT
	9	3	F	ALL	Continuation	9	TIT
	10	7	F	ALL	Consolidation	4	TIT
	11	5	M	ALL	Consolidation	3	TIT
	12	6	M	ALL	Induction	0	BMA + TIT
	13	5	F	ALL	Induction	0	BMA + TIT

Abbreviations: ALL: acute lymphoblastic leukemia; AML: acute myeloid leukemia; BMA: bone marrow aspiration; TIT: triple intrathecal chemotherapy.

Table 2 Demographic characteristics of patients recorded pre-and post intervention.

Patient No.	Age	Gender	Diagnose	Treatment phase	No. of procedures experienced before intervention	Recorded procedure by OSBD-R before intervention	Recorded procedure by OSBD-R after intervention
14	10	F	ALL	continuation	10	TIT	TIT
15	6	F	ALL	continuation	7	TIT	TIT
16	3	M	ALL	continuation	11	TIT	TIT
17	3	M	ALL	continuation	13	TIT	TIT
18	7	F	ALL	continuation	11	TIT	TIT

Abbreviations: ALL: acute lymphoblastic leukemia; TIT: triple intrathecal chemotherapy; OSBD-R: Observational Scale of Behavioral Distress-Revised.

Table 3 Comparison of OSBD-R scores between experimental and control groups.

Recording phases	OSBD-R score of experimental group (mean ± SD) (n = 7)	OSBD-R score of control group (mean ± SD) (n = 6)	<i>p</i> ^a
Phase 1	0.23 ± 0.26	1.95 ± 1.66	0.022
Phase 2	0.23 ± 0.33	1.25 ± 1.75	0.445
Phase 3	0 ± 0	0.61 ± 0.97	0.138
Phase 4	0.19 ± 0.32	1.00 ± 0.97	0.101
Total phases	0.65 ± 0.27	4.81 ± 2.75	0.001

Abbreviations: OSBD-R: Observational Scale of Behavioral Distress-Revised; SD: standard deviation.

^a Mann–Whitney U test

We further compared the inpatient differences of behavioral distress pre- and post-psychosocial interventions for the invasive procedures. Five patients had OSBD-R scores evaluated for BMA or LP without psychosocial intervention, and the pre-intervention mean OSBD-R scores for the total phases were 7.81 (range 3–13) (Table 4). Five patients received psychosocial intervention for the next BMA or LP, and the post-intervention mean OSBD-R scores for the total phases were 3.04 (range 0–5.28). All 5 patients demonstrated a reduction in distress following intervention (Table 4).

Finally, we analyzed the difference of behavioral distress during each phase of the 5 patients by Wilcoxon Rank Signed test. Before psychosocial interventions for the invasive procedures, the mean OSBD-R scores of phase 1, 2, 3, and 4 were 4.11, 1.37, 1.27, and 1.45, respectively. After the psychosocial interventions were provided, the mean OSBD-R scores of phase 1, 2, 3, and 4 were 1.17, 0.87, 0.27, and 0.73, respectively. Behavioral distress during each

phase was reduced. As revealed in Table 5, there was a significant difference of behavioral distress in phase 1 (*p* = 0.043) as well as the total phases (*p* = 0.043).

4. Discussion

Overall, the results of this study provide support for the efficacy of psychosocial interventions in ameliorating children’s distress associated with receiving BMA or LP. The mean OSBD-R scores of the experimental group in phase 1 and total scores were significantly different from the mean OSBD-R scores in the control group. Phase 1 of the recording process is defined as the 3 min before the child was given sedation, when the medical procedure was prepared and the child and parent were waiting for the procedure.^{11,12} This was the phase in which the significant difference of children’s behavioral distress was noted, which indicated the existence of anticipatory anxiety. Phase 1 was also the only period in which children had clear memories during the entire procedure of BMA or LP. Therefore, the psychosocial interventions provided by the CCLS during this phase guided the patients to employ coping strategies instead of anxiously watching the procedural preparation by medical staff, to help children maintain stable emotion before being sedated. It is particularly crucial to decrease fear and anxiety for newly diagnosed children with leukemia due to the necessary BMAs and LPs in the following treatment. In terms of the phases after the patients received sedation, there are different levels and depths of sedation. Patients who receive sedative medications can still have verbal and emotional behaviors according to the state of sedation. Research found that preprocedural anxiety was inversely associated with the success of sedation in children.¹³ In

Table 4 Pre- and post intervention OSBD-R score of total phase of 5 patients who underwent invasive procedures.

Patient No.	OSBD-R scores (pre-intervention)	OSBD-R scores (post-intervention)
1	4.22	0
2	10.81	5.28
3	13	4.12
4	8.04	3.19
5	3	2.63
Mean OSBD-R scores	7.81	3.04

Abbreviations: OSBD-R: Observational Scale of Behavioral Distress-Revised.

Table 5 Comparison of pre- and post intervention OSBD-R score of each phase of 5 patients who underwent invasive procedures.

Recording phases	OSBD-R scores (pre-intervention) (mean \pm SD)	OSBD-R scores (post-intervention) (mean \pm SD)	p^a
Phase 1	4.11 \pm 1.75	1.17 \pm 1.06	0.043
Phase 2	1.37 \pm 1.13	0.87 \pm 0.84	0.144
Phase 3	1.27 \pm 1.80	0.27 \pm 0.47	0.180
Phase 4	1.45 \pm 1.13	0.73 \pm 0.68	0.273
Total phases	7.81 \pm 4.24	3.04 \pm 1.98	0.043

Abbreviations: OSBD-R: Observational Scale of Behavioral Distress-Revised; SD: standard deviation.

^a Wilcoxon Rank Signed test.

their study, children with greater anxiety demonstrated less comfort and more movement during sedation for procedures.¹² In our current study, patients in the control group during sedation tended to display the behaviors that fit in the OSBD-R categories of crying, needing restraint and requesting emotional support. These phenomena were in agreement with the previous study that the level of a child's preprocedural anxiety and the success of the sedation were correlated. Therefore, the success of sedation for an invasive procedure would benefit from the maintenance of stable emotion before the procedure.

The fear of medical procedures might arise from negative experiences that have accumulated since the beginning of the long-term treatment for children with cancer.⁴ Making first procedures as comfortable as possible may prevent a learned response and the related ongoing distress.¹⁴ AAP suggests that the non-pharmacologic and pharmacologic interventions should be integrated to control pain and anxiety, particularly for children with cancer during first diagnostic procedures and treatment.^{4,15} Research indicated that children who undergo systematic preparation, rehearsal and supportive care respond best before, during and after the procedure.^{1,4,15}

In the comparison of the behavioral distress of the same group of participants without and with the psychosocial interventions for the invasive procedures, the patients were recruited due to the high level of emotional and behavioral distress during previous BMAs or LPs. The results indicate significant difference in pre- and post-psychosocial interventions, which meant that children's response to stressful medical procedures could be changed through effective interventions. Earlier psychosocial interventions are provided to help children establish coping strategies, lower children's fear level when confronting invasive procedures is observed. A patient's cognitions determine their stress reactions; therefore, modifying negative and maladaptive cognitions is one way to reduce distress.¹ One of the guidelines for psychosocial services in pediatric oncology includes routine provision of a basic level of psychosocial support from the time that a child's cancer diagnosis is first given.¹⁶ The results of this study are similar to previous studies that investigated preparatory information and psychological interventions for patients receiving bone marrow aspiration and lumbar puncture in pediatric cancer.^{4,9,10,14,17}

A cultural difference was evident mainly in the communication regarding diagnosis between the patients

and their parents in this study. Some parents approached in this study tended to limit the information about illness that they passed on to their child. In a literature review, early studies examining Taiwanese, Chinese, and Japanese populations found that the majority of parents elected not to tell the child of his or her diagnosis.¹⁸ Although a study conducted in Hong Kong suggests that this practice has been declining,¹⁹ the recent literature review indicated that Caucasian-American parents engaged in active strategies to prepare their child psychologically for upcoming medical procedures, whereas Chinese parents limited anticipatory verbal communication and focused more on helping their children by being present during the procedures and providing comfort.¹⁸ The factors that contribute to the levels of disclosure of diagnosis to the child from parents include (1) information overload and emotional turmoil, (2) lack of knowledge and skills with disclosing the diagnosis, and (3) assumptions about burdening the child when discussing cancer.²⁰ The different levels of disclosure of diagnosis to the child from parents influence the ways and timing that child life specialists discuss the illness with the child. Therefore, more time and resources for psychosocial support are needed for parents in Taiwan to help them to cope with cancer diagnosis and enable them subsequently to speak openly to their child.

Psychosocial interventions were provided by a CCLS in this study. Although nurses are the major support professionals involved with pediatric patients and their families, nurses are requested to be more focused on the process of medical procedures.³ In addition, psychosocial care is strongly recommended to be provided by professionals trained in psychological techniques.³ A literature review indicates that child life specialists have been essential as primary providers of procedural preparation using many of the approaches developed and tested by psychologists.¹⁴ Psychologists and psychiatrists may be appropriate referrals for additional assistance when routine preparation and intervention have been ineffective.¹⁴ Furthermore, a study exploring the number, type and availability of multidisciplinary psychosocial staff at U.S. pediatric oncology treatment programs indicated that over 90% of programs had social workers and child life specialists who provided care to children with cancer and their families.²¹ Child life specialists are equipped with an understanding of children of all ages and their family as well as developmental assessment expertise.²² They recognize the developmental issues specifically related to illness and

health care experiences and understand how to mitigate fears, fantasies, and concerns through adaptive role play, education, and behavior-management techniques.²² Therefore, a multidisciplinary team including medical and psychosocial providers is needed to deliver sustainable psychosocial care to children with cancer and their families.

The results of this study have provided a positive step toward ameliorating children's distress associated with BMA or LP. However, there are limitations with regard to this research. First, although there were significant differences between the experimental group and the control group, these results were derived from a small sample size. Second, the outcomes of sedation are likely influenced by many factors such as skills and judgment of medical staff, environment for procedures, presence of family members, patients' cooperation, etc. Therefore, the OSBD-R scores of phase 2 and phase 3 should be interpreted with caution. Third, some patients in the control group experienced invasive procedures several times. Conversely, no patients in the experimental group had undergone invasive procedures. The stress intensity before procedures among two groups could be sufficiently different as to render our results questionable. Further studies that employ the sample size with statistical power and in a well-controlled fashion are needed to examine the outcomes of psychosocial care for children with cancer undergoing invasive procedures to establish the cultural adaptation of psychosocial interventions in Taiwan. It would be useful to conduct longitudinal research on the same subjects to investigate if there is continuity of the efficacy of psychosocial interventions and if children's coping strategies could be of lasting use. Furthermore, since a child's adaptability is directly related to the parent's emotional state, it would be necessary to explore parents' perception of their child's emotion and behavior undergoing BMA or LP. With the understanding of the association between children's emotional state and parents' perception, recommended coping strategies could be provided to newly diagnosed children with cancer and their families.

The results of this study suggest that the psychosocial interventions provided by a CCLS have a significant potential to reduce children's distress during BMAs and LPs. This is the first formal research in Taiwan to investigate the influence of child life specialists when children encounter invasive medical procedures for cancer treatment, and to have shown positive efficacy on the psychosocial interventions. The outcomes of this study could serve as evidence-based suggestions to improve the quality of pediatric health care in Taiwan, and to emphasize the role of child life services in the future.

Conflict of interests

The authors declare no competing interests.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.pedneo.2018.07.004>.