Psychological programs to improve the life quality and psychosocial behavior of pediatric cancer patients

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April 05, 2024

Abstract

Background: Emerging evidence exhibited the importance of life quality of children with pediatric cancers and their parents. The child patients generally have poor life quality and pyschological status under the intensive comprehensive therapies. Procedure: The cultural and psychological program named Ward School Program (WSP) may ease the psychological stress for the child patients. The purpose of this study is to systemically evaluate the impact of the WSP on the quality of life and psychological behavior of children with pediatric cancers. We evaluated the life quality and negative emotions of the children and their parents individually. Results: 46 child patients and their parents have accepted the invitation. compared to the occasional participation group (OP), the WSP has significantly improved the life quality satisfaction, enhanced self-conception, and promoted learning ability and attitude of the In-depth participation group (IDP), while their parents have different opinions. The parents believe that the WSP could significantly improve children's personality problems and relieve children's anxiety, but it has not much help on their learning skills, it indicated that it is necessary to enhance communication between parents and children for better understanding of each other. Conclusion: The WSP have postive effects on the improvement of life quality and pyschosocial behaviors for the children with pediatric cancers.

Introduction

According to the 2014 China Children's Causes of Death Report, malignant tumors rank second among children aged 5-14[1]. With the continuous updating of comprehensive treatment methods and the improvement of treatment programs, the survival rate of children with pediatric cancers has been significantly improved, especially for leukemia, lymphoma, Wilms tumor, etc.[2,3]. However, the children are under the threat of death for a long time, leaving the familiar family environment, being isolated from the school learning environment, and receiving various diagnoses and treatment in unfamiliar hospitals. These are all very strong stresses that will bring different degrees of psychological discomfort and pain, which affect their quality of life[4,5]. Therefore, the life quality and psychological intervention of long-term survivors of pediatric cancers have received more and more attention.

Previous studies have shown that children with pediatric cancers often have a sense of social isolation, and it is difficult to return to the group of children of the same age[6,7]. The reason is partly due to intensive treatments causing growth arrest, body image destruction, fear of tumor recurrence. And more often, it is caused by social problems such as wasted or delayed schoolwork, reduced exercise, and worries about one's health and reproductive ability caused by long-term treatment[8,9]. People are increasingly aware of the importance of the mental health of children with malignant tumors and their families. Psychosocial support teams in the United States and Canada, including social workers, clinical psychologists, and child life specialists, are committed to developing programs that can reduce the psychological burden of children

with cancer and their parents, and provide powerful support for children and their families[10,11]. Psychosocial support can not only improve the psychological problems of children and their families but also improve the compliance of children with treatment and reduce the failure rate of treatment[12].

China lags behind developed countries in terms of children's psychosocial care, but the psychosocial needs of children with pediatric cancers and their families are attracting more and more attention from medical staff in clinical work[13,14]. In recent years, Sun Yat-Sen University Cancer Center has also paid special attention to the psychosocial and humanistic care of children with cancer. In 2020, the Department of Pediatric Oncology of Sun Yat-Sen University's Cancer Center launched a "Ward School Program (WSP)", which aims to provide psychosocial support for long-term hospitalized children with cancer. Educational support and psychological counseling, through online facetime and offline classrooms, each child is assigned a headteacher and a teacher of each subject. According to their learning needs, different subject counseling and emotional accompaniment are provided to solve the problems of lack of educational resources, psychological cognitive barriers, and prone to study weariness. The goal of this study was to comprehensively evaluate the value of WSP for children with pediatric cancers and their parents.

Methods and materials

Ward School Program

The WSP is to provide psychosocial and educational support for children with pediatric cancers who have been hospitalized for a long time. The WSP was launched at early 2020 during the epidemic, and the children who participated in campus learning ranged from kindergarten to high school. There are many different types of subjects, including Chinese, mathematics, English, and others. Besides, WSP and Guangdong Museum of Art jointly launched art classes. The monthly art class teaches painting techniques, focusing on parent-child interaction, and using art as the medium to build parent-child interaction for them. WSP and Dreaming Heart Ball Game Growth Center jointly created a game therapy psychological counseling course. Children can express the true face of their inner world freely, fully, and defenselessly through games.

Participants

All the children with pediatric cancers greater than 6-year-old and their parents enrolled in the WSP program since its inception in March 2020 were eligible to participate. The exclusion criterion was the children with brain tumors or the children and their custodians enrolled in the WSP for refusing to sign the informed consent. 69 children participated in the WSP program. Of these children, 46 agreed to participate (67% participation rate) when 23 declined the invitation. The range of age was from 6 to 18 (median 11), all the children with pediatric cancers were actively treated during this study.

Survey Materials

Questionnaires were widely used for the evaluation of life quality and negative emotions from the perspective of children and their parents, respectively. The Quality of life was assessed according to the Quality of Life Scale for Children and Adolescents (QLSCA), which included 3 categories and 10 subcategories. Negative emotions were assessed by using the Children's Psychological Behavior Questionnaire (PSQ) (for parents) based on the Corners Children's Behavior Scale, it included 5 categories, all the questions were rated ranging from "never happened" (marked as "no") to "always happened" (marked as "a lot of"). The questionnaires generally need 30 to 60 minutes to be finished.

Statistical analysis

The SPSS software version 22.0 (IBM, Chicago, IL) was applied for statistical analysis, the Fisher's tests or chi-squared were applied for the analysis of categorical variables, and student's t-tests were applied to analyzing the differences between different groups. P-value less than 0.05 was considered as statistical significance.

Result

Patient characteristics

In 2020, during the epidemic, the ward school enrolled a total of 69 children, each child participated in the WSP ranging from 1 to 18 times (median 3), in the sum of 183 times (Table 1). 46 child patients (25 male versus 21 female) and their families accepted the questionnaire invitation. Almost 47% of enrolled children were diagnosed with sarcoma, and 22% with lymphoma. The rest of them with various solid tumors. The children with pediatric cancers were categorized into 2 groups as occasional participation (OP group, 1-2 times) and in-depth participation (IDP group, greater than 3 times) based on the numbers of participation, and the median time is 3 for all of the child patients participated in WSP. The children who participated in campus learning ranged from elementary school to high school. The main subjects of this program are Chinese, mathematics, English, and other subjects. Through questionnaire surveys and interviews, this project exhibits an overall good effect. Through tests, we found that the children have improved their subject knowledge. In addition to the teacher-student relationship between the children and the volunteers, It also establishes its friendship, volunteers can easily communicate with them and relieve their stress. At the same time, for children who are afraid of injections and uncooperative treatment, this program is used as an important treatment medium to help children regain the courage and strength to face and solve difficulties and ultimately relieve and eliminate the psychological symptoms that trouble children.

WSP can improve the life quality satisfaction and enhance the social and mental functions of the child patients in the perspective of themselves

In the perspective of children with pediatric cancers, the QLSCA form was applied to evaluate the effect of WSP. This questionnaire could be categorized into 3 sections, including life quality satisfaction, social mental function, and physical and mental health, each section has varying amounts of subcategories. Based on the results of QLSCA form from the children with pediatric cancers, compared to the OP group, the WSP has significantly improved the overall life quality satisfaction of the IDP group (p=0.045) but has no significant effect on either self-satisfaction (p=0.086) or life satisfaction (p=0.123) (Table 2). Besides, compared to the OP group, the WSP also has enhanced IDP group's social and mental functions (p=0.021), including self-conception (p=0.01) and learning ability and attitude (p=0.005), but it has not much help on the relationships, including companionship (p=0.2), teacher-student relationship (p=0.248), and parent-child relationship (p=0.088). Additionally, the WSP has no effect on physical and mentor health either on IDP or OP groups (p=0.331). These results demonstrated appropriate psychological intervention support can improve children's satisfaction with the quality of life, enhance the children's social and mental functions, especially in terms of self-conception, learning ability, and attitude. But The WSP has not much help on the relationship improvement, it suggested that the child patients are unwilling to open up their hearts to communicate further with those around them, including their parents, it may be because their physical and mental health was heavily traumatized due to the intensive comprehensive anti-cancer therapies, it also indicated that the children with pediatric cancers need professional psychotherapy to fix up their psychological trauma.

WSP can improve children's personality problems and relieve the anxiety from the perspective of their parents

Parents have different opinions on the effect of the WSP project. In the perspective of parents, the Corners Parental Meter form was applied to evaluate the effect of WSP. We also evaluated the psychological effect and negative emotions by interviewing their parents, and they considered the WSP as a positive regulator for their children. Compared to the OP group, The WSP could significantly improve the character issues (P=0.047) and relieve the anxiety (p=0.02) of the IDP groups (Table 3), but it does not improve the learning problems, mental disorders, and impulsion, which differs from the opinion of the child patient themselves, while they believe the WSP has a positive effect on their learning skills (Table 2), it may suggest that the parents have higher expectation on the learning part. These results demonstrated that appropriate psychological intervention and support can improve children's character issues and relieve anxiety. Also, the child patients and their parents have different views on learning issues, it indicated that the parent-child relationship between the child and the parent has not been significantly improved, and it also further shows

there is a lack of communication with each other.

Discussion

In recent years, the requirements for the quality of life of child patients have increased and the development of modern tumor theories has led to great changes in the principles and concepts of treatment of pediatric cancers[15]. The purpose of treatment can not only be satisfied with the improvement of survival rate but also requires improvement of the quality of life.

However, in clinical practice, there are still many problems and challenges in the actual situation of children's psychological status, which seriously affects their life quality. A study from the United States surveyed online pediatric oncologists (n=99), psychosocial leaders (n=132), and pediatric oncology managers (n=58) from 144 training programs in 44 states and the Columbia region. The results showed that most of the participants indicated that the psychosocial care provided by their centers met the relevant standards based on evidence-based medicine. However, only half of the pediatric oncologists (55.6%) and psychosocial leaders (45.6%) believed that their psychosocial and social care is comprehensive and advanced, but it is usually provided when children have mental problems[16]. A study in South Korea in 2018 showed that 20% to 25% of pediatric cancer survivors had no friends after returning to school, 41% had learning difficulties, and 53% had lower academic performance than before, suggesting that education support should be provided for children with pediatric cancers to return to school[17].

Through questionnaire surveys and interviews, we learned that the WSP has an overall good effect on the child patients. In the perspective of children, the WSP has a positive effect on their life quality and social mental functions, especially on the aspects of self-conception and learning skills. In terms of quality of life, the IDP group believed they are more energetic, happier in life, and better in memory than the OP group. At the same time, the children of the IDP group are more satisfied with their health and sleep quality. In terms of learning skills, the specific performance is that learning ability can be more persistent, easier to remember knowledge points, and willing to do other things besides homework for the children of IDP group. However, this project did not improve the relationship between children and their friends, teachers, and parents. They still feel nervous and scared from time to time, worry about doing something wrong, which indicated the child patients may need further psychological assistance and psychosocial care during the clinical treatment.

Besides, This WSP has greatly improved the children's character problems and relieved their anxiety from the perspective of their parents. In terms of character, the children of the IDP group became more polite to the elders, their tempers became better, more honest, and more disciplined compared to the children of the OP group. Furthermore, the parents found that this project alleviated children's anxiety. The children of the IDP group became less shy, no longer afraid of strangers and new environments, and no longer worried about bad things such as loneliness, illness, and death. In addition, the parents found that the WSP alleviated children's anxiety. But they also found that children are still more sensitive and impulsive, and often feel headaches, stomachache, and other discomforts. In addition, contrary to the opinions of the children, the parents still found that the children have difficulty in learning, lack concentration during the learning process, and are easily distracted and discouraged. These results suggested that the parents have high expectations for their children's learning, and it also demonstrated the child patients and their parents need more communication to promote mutual understanding and deepen the parent-child relationship.

Of note, this pilot project could guide us to respond promptly to the quality of life and psychological changes of children with pediatric cancers during the clinical treatment, and it also allows us to provide psychological intervention and psychosocial support for them as early as possible. Although our sample size was limited, all of the participants endorsed the WSP as a meaningful and valuable project of psychological intervention support during the treatment.

The WSP developed by our team uses cultural subjects and psychological counseling courses to improve the scientific knowledge of children with pediatric cancers so that the children will be easier to return and adopt the school life after treatment. Campus life also improves the quality of life of children and reduces their feelings of social isolation. This program has clinical value in improving the quality of life and psychosocial

issues of child patients. Therefore, based on the preliminary work of this study, we will develop a prospective study to further explore the impact of the WSP on the quality of life and psychosocial behavior of children with pediatric cancers.

Table 1. Characteristics of Children with pediatric cancers.

Characteristic	No.
Gender (n%)	
Male	25(56%)
Female	20(44%)
Age(years)	
Median	11
Range	6-18
Tumor types(n%)	
sarcoma	21(46.7%)
lymphoma	10(22.2%)
others	14(31.1%)
Participation times	
Occasional participation (1-2 times)	19(42.2%)
In-depth participation ([?]3 times)	26(57.8%)
Median	3

Table 2. The program evaluation of WSP in the perspective of child patients.

	Occasional participation (X±2SD)	**In-depth participation (X±2SD)**	**In-depth participation (X±2SD)**	**p value**
Life quality satisfaction	22.38±6.46	22.38±6.46	24.42±5.1	0.045
Self-satisfaction	17.23±6.18	17.23±6.18	18.79±5.16	0.086
Life satisfaction	5.15±1.92	5.15±1.92	5.63±2.12	0.123
Social mental function	57.68±14.5	57.68±14.5	63.38±13.32	0.021
Companionship	14.95±4.32	14.95±4.32	15.77±5.72	0.200
Teacher-student relationship	15.42±5.14	15.42±5.14	16.08±4.9	0.248
Parent-child relationship	11±5.26	11±5.26	12.12±3.48	0.088
Self-conception	9.16±3.7	9.16±3.7	10.73±3.04	0.010
Learning ability and attitude	7.16±3.1	7.16±3.1	8.69±3.08	0.005
Physical and mental health	34.26±9.18	34.26±9.18	33.58±6.54	0.331
Homework attitude	9±2.32	9±2.32	8.65±2.44	0.226
Negative emotions	11.11±3.42	11.11±3.42	10.92±4.02	0.402
Somatosensory	14.16±6.22	14.16±6.22	14±3.54	0.436

Table 3. The program evaluation of WSP in the perspective of parents.

	Occasional participation (X±2SD)	In-depth participation (X±2SD)	p value
Character issues	18.75±9.2	16.16±3.18	0.047
Learning issues	7.55±4.12	6.76±2.9	0.132
Mental disorder	7.4±2.28	6.72±2.68	0.074
Impulsion	5.85±2.9	5.48±2.02	0.267
Anxiety	6.4±3.36	5.4±1.86	0.020

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