

Parenting children with cancer: Impact assessment on quality of life using World Health Organization quality of life tool-BREF tool

Rashi¹, Shibsankar Barman¹, Sujay Pal², Sankha Subhra Ganguly¹, Sumitra Kumar Biswas¹

¹Department of Paediatric Surgery, NRS Medical College and Hospital, Kolkata, West Bengal, India, ²Department of Paediatric Surgery, Institute of Post Graduate Medical Education and Research and S.S.K.M. Hospital, Kolkata, West Bengal, India

Correspondence to: Shibsankar Barman, E-mail: dr.shibsankar@gmail.com

Received: January 02, 2018; Accepted: January 19, 2018

ABSTRACT


Background: The diagnosis of childhood cancer has a devastating effect on parents. It causes a major shift in lifestyle and psychological reality of parents. Treatment of childhood cancer is much more intense, associated with more toxicity and need more supportive care. It is assumed that parents of children with cancer have their quality of life (QOL) deranged in comparison to healthy general population. However, empirical evidence to support this assumption is weak. **Objective:** The objective of the study was to assess the QOL among parents of diagnosed childhood cancer in comparison to parents of children with minor ailments. **Materials and Methods:** It was an observational cross-sectional study carried in a tertiary care centre at Kolkata. We assumed a mean difference of 20 units in QOL, sample size calculated to be 40 participants in each group, i.e., parent of children with cancer versus matched normal healthy population. The World Health Organization QOL-BREF questionnaire (Bangla Version) was used to assess the QOL. Statistical analysis used: Statistical analysis was done using Microsoft Excel 2016. Unpaired *t*-test applied to compare the means. **Results:** The QOL of parents of childhood cancer was found to be significantly impaired in psychological domain (42.3 ± 6.4 vs. 57.4 ± 10.5 , $t = 7.71$, $P < 0.000$), social relationship domain (53.7 ± 8.9 vs. 69.6 ± 7.3 , $t = 8.68$, $P < 0.000$) and environmental domain (48.8 ± 7.3 vs. 62.3 ± 5.8 , $t = 9.01$, $P < 0.000$). Gender, educational qualification, socioeconomic status, and place of residence had shown no significant difference on QOL of participants. **Conclusions:** QOL was found to be deranged in parents of children with cancer. There is a felt need to facilitate crisis intervention strategies that help parents adjust to the stress associated with childhood cancer.

KEY WORDS: Childhood Cancer; Quality of Life; World Health Organization Quality of Life Tool

INTRODUCTION

In India, the estimated incidence of childhood cancer is nearly 40–50,000 cases each year. 70% of them die due to lack of awareness, late detection and late diagnosis, poor facilities, the high cost of treatment and the absence of supportive care.^[1] Childhood cancer requires much parental

participation or supervision in managing day to day illness related issues. Need for a relevant, reliable, and valid assessment tool to measure the childhood illness related parental stress, coping and life quality, always felt. Few tools such as parent-related pediatrics specific measures, parental coping strategies, and parental adaptation to raising a child with a physical disability were developed in the past.^[2] At present, the most frequently used tool in the studies involving quality of life (QOL) in chronic disease is World Health Organization ([WHO] QOL tool-WHOQOL). This tool is useful in epidemiological studies or clinical trials. It is also used to evaluate the effectiveness of treatment and disease control.^[3] Earlier this tool was used to assess QOL among mothers with asthmatic children^[3,4] or QOL in parents

Access this article online	
Website: http://www.ijmsph.com	Quick Response code
DOI: 10.5455/ijmsph.2018.0101619012018	

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of children with anorectal malformations^[5] We postulate that QOL of parents of a child diagnosed with cancer can be impaired. To the best of our knowledge, an assessment of QOL among parents of childhood cancer cases has not done in our setting. It was, therefore, assumed that parents of children with cancer had their QOL deranged in comparison to healthy general population. However, empirical evidence to support this assumption is weak. With this idea in mind, we carried our study with an objective to assess the QOL among parents of diagnosed childhood cancer in comparison to parents of children with minor ailments.

MATERIALS AND METHODS

It was an observational cross-sectional study carried during the month of June to July 2016. The study was carried in oncology and outpatient units of Department of Paediatric Surgery in a tertiary care centre at Kolkata. The study population comprised all the parents of diagnosed case of childhood cancer registered in hospital. All the parents of diagnosed case of childhood cancer registered in the Department of Paediatric Surgery were our study sample. The comparison group composed of parents of follow-up children having minor ailments such as post-incision and drainage, minor burn, minor injuries, and animal bites, who visited the outpatient department. In reference with various other studies, we expected a mean difference of 20 units in QOL between groups. Desired sample size calculated was 40 parents in each group. Parents of children currently undergoing as well as those off treatments were included in this study. Out of 44 registered cases 33 given their consent to participate resulting in 75% participation rate. Lack of interest and inconvenience were the main reason for not participating. Consecutive sampling was done. Age and sex-matched comparison group was taken from outpatient department setting. Informed written consent was taken before interview. WHOQOL-BREF tool: A 26-item instrument consisting of four domain, i.e., physical health (7 items), psychological health (6 items), social relationship (3 items), and environmental health (8 items) was used as a study tool. Cronbach's reliability test applied to access the internal consistency of various domains of QOL. Cronbach's α value for various domains were as, physical (0.832), psychological (0.783), social (0.663), and environmental (0.669). A value of Cronbach's $\alpha > 0.7$ indicated good reliability and a high degree of correlation between items. A Bangla version (local language) of this tool was obtained from WHO with due permission. A face to face interview was carried out with the help of our Medical social worker. Data collected were entered and analyzed using Microsoft Excel student's edition 2016. Frequency with percentage and mean with standard deviation was calculated. Chi-square test and unpaired *t*-test were applied to compare the means. Ethical Approval obtained from Institute Ethical Committee for the study.

RESULTS

A total of 66 participants were interviewed during the study period. They are divided into two groups. Group A comprised 33 parents of children with cancer while Group B, 33 parents of children with minor ailments. A statistical comparison of various sociodemographic characteristics such as age, education, occupation, and residence was done between both groups [Table 1]. None of them differ significantly across the group. This showed that both groups were comparable.

Out of 26 WHOQOL items, first two were analyzed separately and later 24 were included into four domains. Approximately 50% participants in Group A have very poor or poor, overall QOL in comparison to Group B, where it is 10% [Figure 1].

An assessment of overall health status showed that 50% participants in Group A were either highly dissatisfied or dissatisfied with their health in comparison to Group B, where it is 8% [Figure 2].

A comparison of mean scores of various domains showed that the QOL of parents of childhood cancer was found to be

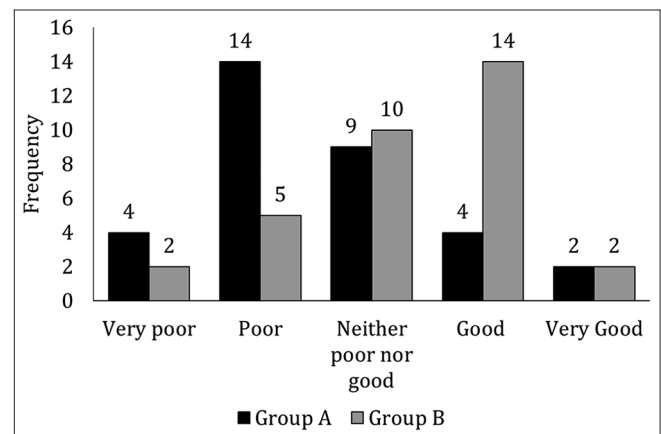


Figure 1: Self-rating of overall quality of life among respondents ($n=33$ in each group)

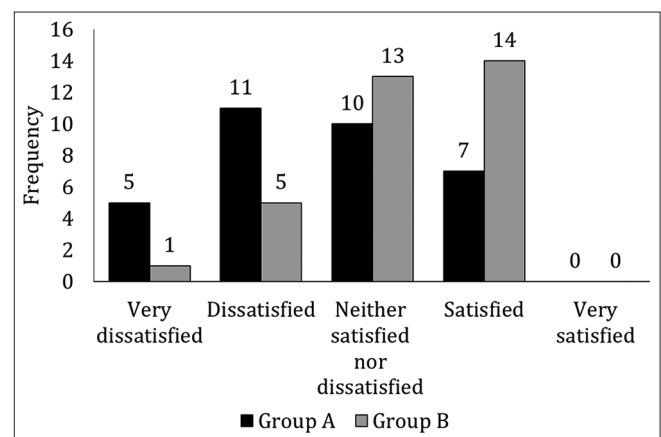


Figure 2: Self-rating of overall health among respondents ($n=33$ in each group)

significantly impaired in psychological domain (42.3 ± 6.4 vs. 57.4 ± 10.5 , $t=7.71$, $P < 0.000$), social relationship domain (53.7 ± 8.9 vs. 69.6 ± 7.3 , $t = 8.68$, $P < 0.000$), and environmental domain (48.8 ± 7.3 vs. 62.3 ± 5.8 , $t = 9.01$, $P < 0.000$) [Table 2]. Gender, educational qualification, socioeconomic status, and place of residence had shown no significant difference on QOL of participants.

Table 3 summarized the correlation matrix between various domains of QOL. It was observed that all the domains had mild to moderate correlation coefficient among themselves. A strong correlation was seen between physical and psychological domains ($r_s = 0.778$), while psychological and social domains had a mild correlation ($r_s = 0.558$).

DISCUSSION

A population-based review of cancer registries in India reported an age-adjusted cancer incidence of 18.6–159.6 per million for boys and 11.3–112.4 per million for girls.

In India cancer is the 9th most common cause of death among children between 5 and 14 years of age. There is an increasing trend in the incidence of childhood cancer in India.^[6] Literature search showed that most of the research on QOL for childhood cancer was based on an assessment of children itself. An evaluation of QOL of a parent with childhood cancer has never been explored. One study on QOL in parents with an ARM showed that parents do have difficulties in coping with the implications of the disorder and express a need for support.^[7] A review study on parental psychological stress in pediatric cancer patients more stress at the time of diagnosis, with mother reporting more stress than father. Few parents report continuing stress for years.^[8]

In the present study, QOL of parents of children with cancer was found to be deranged in psychological, social relationship, and environmental domain in comparison to a reference value. Out of 33 childhood cancer patients, 22 had diagnosed cancer for more than 1 year. These values for various domains of WHOQOL were obtained from a control group. This control group comprises parents of children with

Table 1: Sociodemographic characteristic of respondents (n=66)

Variable	Category	Group A (n=33)	Group B (n=33)	Test of significance
Age (years) (Mean±SD)		28.5 (±5.9)	29.0 (±4.9)	$t=0.338$, $df=64$, $P>0.05$
Gender	Female	26 (78.8)	26 (78.8)	
	Male	07 (21.2)	07 (21.2)	
Education	Illiterate	16 (48.5)	10 (30.3)	$\chi^2=2.28$, $P>0.05$
	Literate	17 (51.5)	23 (69.7)	
Occupation	Employed	15 (45.5)	19 (57.6)	$\chi^2=0.971$, $P>0.05$
	Unemployed	18 (54.5)	14 (42.2)	
Religion	Hindu	16 (48.5)	14 (42.4)	$\chi^2=2.13$, $P>0.05$
	Muslim	17 (51.5)	17 (51.5)	
	Others	00 (0.0)	02 (6.1)	
Residence	Rural	25 (75.8)	22 (66.7)	$\chi^2=0.665$, $P>0.05$
	Urban	08 (24.2)	11 (33.3)	

SD: Standard deviation

Table 2: Comparison of mean (±SD) value of various domain (n=66)

Domains	Group A (n=33)	Group B (n=33)	Unpaired t test
Physical health	58.3 (±4.4)	59.7 (±5.3)	$t=3.71$, $P>0.05$
Psychological health	42.3 (±6.4)	57.4 (±10.5)	$t=7.71$, $P<0.000$
Social relationship	53.7 (±8.9)	69.6 (±7.3)	$t=8.68$, $P<0.000$
Environmental health	48.8 (±7.3)	62.3 (±5.8)	$t=9.01$, $P<0.000$

SD: Standard deviation

Table 3: Correlation matrix of various domains of QOL

Domains	Physical health	Psychological health	Social relationship	Environmental health
Physical health	1	0.756	0.614	0.627
Psychological health	0.756	1	0.558	0.690
Social relationship	0.614	0.558	1	0.645
Environmental health	0.627	0.690	0.645	1

QOL: Quality of life

other minor ailments. Control group was comparable to study group across various sociodemographic variables. In a study Witvliet *et al.*,^[5] used WHOQOL-BREF tool on parents of children with an anorectal malformation or Hirschsprung disease. Author reported a higher score in psychological, social, and environmental domains in both parents. Author also assessed the changes in these domains over a time of 1 year. This could not be achieved in the present study due to time and resource constraint.

Recently, few studies were done on QOL of parents of children with a different chronic condition such as asthma, diabetes, epilepsy, and obesity.^[3,9] Roncada *et al.*^[3] in their study showed that parents of children with asthma had deranged QOL in all four domains using WHOQOL-BREF tool. While Silva *et al.*^[9] found a significant higher score in social domain only, in similar study population. Gau *et al.*^[4] in a similar study found derangement of physical and psychological health in caregivers of asthmatic children. Parents of children with the different chronic condition tend to keep a closer social relationship. This is useful for their support and coping skill.^[3] First two questions of WHOQOL-BREF were related to self-rating of overall health and self-rating of overall QOL among respondents. For both, level of dissatisfaction was higher in parents with childhood cancer. Raw scores obtained in all domains were transformed to 0–100 scores. WHO-QOL transformation chart used for this purpose physical domains score ranged (43–68), psychological (38–62), social (45–71), and environmental (30–68).

This study had some limitations. Parents with childhood cancer admitted to another department could not be interviewed. Those who were interviewed have their children in various stages of cancer. There were more female participants as they are mainly allowed as an attendant in children ward.

CONCLUSION

QOL was found to be deranged in the parent of children with cancer. There is a felt need to facilitate crisis intervention strategies that help parents adjust to the stress associated with childhood cancer. An experimental study is needed to assess the effect of the active intervention at various stage of the disease process.

ACKNOWLEDGMENT

We would like to acknowledge Mrs. Durga Jha, Medical Social worker (CANKIDS) and Mr Sujit Majumdar, outpatient department attendant, who made the entire process very smooth.

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How to cite this article: Rashi, Barman S, Pal S, Ganguly SS, Biswas SK. Parenting children with cancer: Impact assessment on quality of life using World Health Organization quality of life tool-BREF tool. *Int J Med Sci Public Health* 2018;7(3):225-228.

Source of Support: Nil, **Conflict of Interest:** None declared.