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Original Article

Psychological health of young children undergoing treatment for Acute Lymphoblastic Leukaemia: A cross-sectional study

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Abstract

Introduction: Research on the psychological health of children with cancer have tended to focus on older children. In India, studies in paediatric psycho-oncology are scant. This study examined the psychological health of young children undergoing treatment for Acute Lymphoblastic Leukaemia (ALL).

Method: Sample comprised 20 children hospitalized for treatment of ALL, aged 4 to 8 years, and an equal number of gender and age-matched healthy peers, along with their respective mothers. This was a cross-sectional study, employing consecutive sampling, with participants from the lower socioeconomic background. Tools used were (i) Strengths and Difficulties Questionnaire (SDQ) to assess psychiatric disturbances, (ii) Feelings Cards (FC) to examine subjective current emotional state and, (iii) Teddy Bears' Picnic (TBP) to examine personal constructs.

Results: Children with ALL were reported on SDQ to display more behavioral disturbances (total difficulties: $U = 97.50$, $p \leq .01$; conduct problems: $U = 97.50$, $p \leq .01$; peer problems: $U = 88.50$, $p \leq .01$). However, median scores were within the normative range, comparable to the general population. On FC, more children with ALL expressed negative emotional states

(cancer: 50%, healthy: 10%; FEP (1) = 7.62, $p \leq .01$). On TBP, there was lesser self-perceived helplessness in children with ALL ($U = 129.00$, $p < 0.05$).

Conclusion: The psychological health of young children undergoing treatment for ALL is comparable to healthy children, with disturbances being expected responses to a challenging situation. Further research is warranted with larger samples and across stages of child development.

Keywords: Paediatric mental health, Psycho-oncology, Psychological health

Introduction

The psychological health of children with cancer is unique in comparison to their adult counterparts, given the dynamicity of development, which mediates emotional and behavioral health. Recent updates on paediatric psycho-oncology asserted the need to examine the psychological response to cancer across stages of development [1]. Studies have prominently focused on children who are school-aged or older, with adolescence comprising the bulk of psychosocial research in paediatric oncology [2-3]. Very little is known regarding young children, specifically age eight years and younger [2-3]. Development is an ontogenetic process, with early issues impacting subsequent progression. It is necessary to understand the psychological health of young children battling cancer, towards addressing their immediate needs, and subsequently that of older children as well.

Among cancer diagnoses in children, Acute Lymphoblastic Leukaemia (ALL) is the most frequent [4-6]. Common mental health issues noted in childhood cancers are anxiety, depression, behavioral problems, neurocognitive disabilities, substance misuse, and body image disturbances [7]. While findings have varied across studies, there is an emerging consensus that children with cancer do not have elevated levels of psychiatric disturbances in comparison to the general population [8-13]. However, the mere absence of psychopathology

does not suggest sound psychological health [14]. There is a need to examine specific aspects of psychological health such as psychiatric disturbance, subjective emotional state, and thoughts regarding self and others in the context of having cancer.

A recent review of non-pharmacological interventions in paediatric cancer in India documented only 28 studies in a two-decade time period [15]. Studies focused on psychiatric disturbances in family members rather than children [15]. Other reviews have also noted the absence of studies in paediatric psycho-oncology in the country [16-17]. In bridging this lacuna, the present study, which is part of a doctoral dissertation on play therapy in paediatric oncology, examines psychological health of young children undergoing treatment for ALL in India.

Methodology

Participants

The sample comprised 20 children diagnosed with ALL and an equal number of age and gender-matched healthy peers. Mothers of children in both groups were also recruited. Consecutive sampling was employed.

Children diagnosed with ALL were sampled from the paediatric oncology ward at Kidwai Memorial Institute of Oncology (KMIO), Bangalore. A regional cancer center, KMIO caters largely to the lower-income strata of society. Consequently, participants were from lower socioeconomic backgrounds. Mothers resided with children in the ward and were available for participation. Children were recruited within the first month of hospitalization, while in the phase of induction chemotherapy. Healthy peers were drawn from government-run/aided schools in the city, towards matching the socioeconomic background of the cancer group.

For both groups, children were recruited if they were (i) between ages of four and eight years, (ii) with no history of global developmental delay, and (iii) were able to verbally communicate in either English or one of four local languages (Hindi, Telugu, Kannada, and Tamil). Criteria specific to ALL group were (i) sole and first-time diagnosis of ALL and (ii) deemed to be

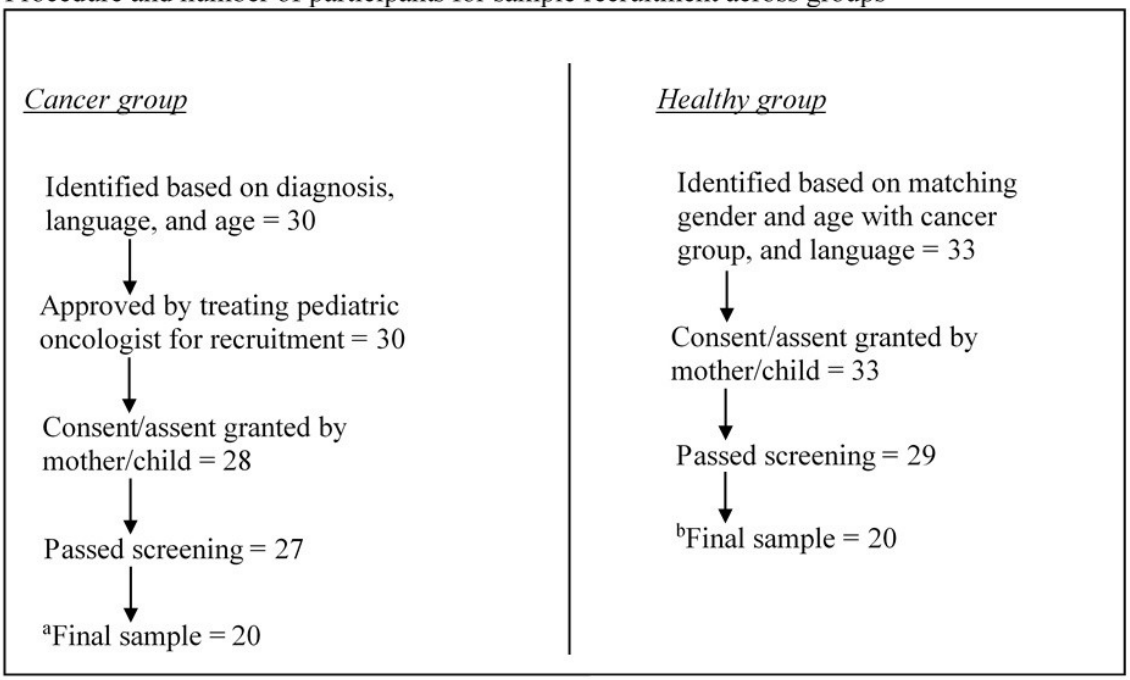
physically fit for the study by the treating paediatric oncologist. Specific criteria specific for the healthy group were (i) school-going children, (ii) with no current or past history of medical/psychiatric illness.

Procedure

The study was approved by Institutional Review Boards at the National Institute of the Mental Health and Neuro Sciences (NIMHANS) and KMIO. The study was designed at NIMHANS, with KMIO being the site for data collection. Written informed consent was sought from managerial heads of KMIO and schools, and mothers. Verbal assent of children was obtained. The participation of the study subjects was voluntary, and no incentives were offered to them.

Figure 1

Procedure and number of participants for sample recruitment across groups



[a]Reasons for dropout post screening
- Lack of cooperation = 3
- Child discharged = 3
- Death of child = 1

[#]Reasons for dropout post screening
- Lack of cooperation = 3
- School space/time constraints = 6

Figure-1 displays the procedure and number of participants for sample recruitment. Children in both groups were screened for global developmental delay on a brief interview schedule

with mothers inquiring into the birth history and developmental milestones. Additionally, children were administered Gesell's Drawing Test [18] and Picture Vocabulary Test [19], which are non-verbal and verbal screening measures of intelligence. Both tests have been used on children in India, and have requisite norms [18-19]. Mothers of healthy children were also inquired regarding the history of major medical/psychiatric illness in their child on the interview schedule. If any issues were noted during screening, appropriate referrals were given.

Measures

Psychological health was indexed on psychiatric disturbance, subjective emotional state, and personal construct. Tools were administered individually with mother or child, as required, in their preferred language. Tool items were asked orally, and responses were noted and clarified.

Psychiatric disturbance: The Strengths and Difficulties Questionnaire (SDQ) [20] was utilized to assess psychiatric disturbance. The parent-report version consisting of 25 items, rated on a three-point scale, was administered on mothers. Scores were computed for total difficulties and subdomains, and categorized on the four-band classification of "close to average", "slightly raised/lowered", "high/low", and "very high/very low". Standardized language versions of SDQ, freely available in the public domain, were utilized.

Subjective emotional state: The Feelings Cards (FC) was prepared for study purposes, towards eliciting children's subjective emotional state. A similar approach has been used in other studies in paediatric oncology [21-23].

In preparing this tool, previous studies and child mental health professionals were consulted. Four emotions of anger, sadness, joy, fear, and a neutral facial representation (okay/fine) were concluded as being easily identifiable by children of the sample age range. Pictorial representations of chosen emotions were drawn on separate cards. These cards were shown to a child mental health professional and deemed to represent specific emotion states adequately.

Once finalized, cards were pilot-tested independently by two clinical psychologists on a sample of ten children. FC was noted to have adequate face and content validity.

During administration with participants, it was first established that the child appropriately identified emotions depicted on each of the cards. Following this, the child was asked to point to the card depicting the emotion he/she was currently feeling. In the final analysis, emotions were coded as being negative or positive. Anger, sadness, and fear were coded as negative, while joy and the neutral facial expression were coded as positive.

Personal construct: The Teddy Bears' Picnic (TBP) [24] is a semi-projective test that assesses children's personal constructs (thoughts regarding self and others). Using a family of toy bears, children complete stories initiated by the examiner. The narrative proposed by the child is coded for positive and negative codes such as the Main Character (MC) valuing/devaluing others, others valuing/devaluing MC, helplessness in MC and others, etc. TBP has adequate convergent validity with Pre-school Behaviour Checklist [24] and is applicable to children in India [25].

In this study, five of the original nine narratives on TBP were used. In addition to the codes already provided on the tool, new codes were introduced, bearing in mind the unique context of participants, as noted in a small pilot study with four children. These included positive/negative sibling relationships, sado-morbidity (sadistic and/or morbidity towards self/others), and positive/unresolved endings. Each completed narrative was examined for the presence of content reflective of each of the codes. Each code was scored as being present or absent in a given narrative. The frequency of individual codes and totally positive and negative codes were computed. To ensure appropriate coding, satisfactory inter-rater reliability was established on 25 narratives between the first and second authors.

Statistical Analysis: Data was entered and analysed on Statistical Package for Social Sciences, Version 20. Given the small sample size, non-parametric statistics were employed.

Result

Sample Characteristics

Of the total sample of 40, girls and boys were 12 (six in each group) and 28 (14 in each group) in number, respectively. The mean age of the sample was 58.13 months (SD = 9.856). There was no significant difference in age across gender (median age in months: girls = 58.5, boys = 57; U = 152.5) or group (median age in months: healthy = 56, ALL = 58; U = 156.5). Children across both groups were in pre-school academically. Parents were minimally educated, and most fathers were daily-wage earners (%^{ge} in both groups = 75%)

Psychological Health

Psychiatric disturbance: On SDQ, there were significant differences between groups on total difficulties, conduct, and peer problems (table 1). Children with ALL demonstrated more disruptive behaviours and peer problems than healthy children. However, median scores were in the "close to average" (normative) range.

Table-1: Mann-Whitney Test Comparing Median Scores on SDQ

SDQ Domain	Group[#]	Median[$]	Range		Mean Rank	U	p-value
			Min	Max			
Total Difficulties	Healthy	5.50	0.00	12.00	15.38	97.50**	.005
	ALL	9.00	0.00	18.00	25.63		
Emotional Problems	Healthy	1.50	0.00	4.00	18.38	157.50	.253
	ALL	2.00	0.00	7.00	22.63		
Conduct Problems	Healthy	0.50	0.00	3.00	15.38	97.50**	.005
	ALL	2.00	0.00	5.00	25.63		
Hyperactivity	Healthy	2.00	0.00	6.00	20.10	192.00	.841
	ALL	2.50	0.00	8.00	20.90		
Peer Problems	Healthy	0.00	0.00	2.00	14.93	88.50**	.002
	ALL	1.50	0.00	5.00	26.08		
Pro-Social	Healthy	8.50	5.00	10.00	21.58	178.50	.565
	ALL	7.00	2.00	10.00	19.43		

** $p \leq .01$; [#]Sample number in each group = 20

[$]Close to Average scores – total difficulties: 0-13, emotional problems: 0-3, conduct problems: 0-2, hyperactivity: 0-5, peer problems: 0-2, pro-social: 8-10

Emotional state: On FC, significantly more percent of children with ALL (50%) reported subjective state of negative emotion in comparison to healthy children (10%) (F.E.P.(1) = 7.62; $p \leq .01$).

Personal construct: On TBP, there was a significant difference between groups only on the code of helplessness in self (median – ALL: 1.00, healthy: 1.00; mean rank – ALL: 16.95, Healthy: 24.05; U = 129.00; $p < 0.05$). Children with ALL perceived lesser helplessness in self.

Discussion

The psychological health of young children with cancer (undergoing treatment for ALL) was examined in comparison to age and gender-matched healthy peers. Although children with ALL had more behavioural disturbances than healthy peers, it was comparable to general population norms. Concomitantly, there were more peer problems; again, however, comparable to general population norms. Children with ALL reported experience of more negative emotional states than healthy peers. Conversely, they perceived themselves as less helpless. Findings suggest that overall, the psychological health of children with ALL is comparable to the general population. However, there are variations across specific domains. Similar findings were noted in a recent retrospective chart-review study on the psychosocial functioning of young children treated for cancer [3].

Study findings are explicable based on the current living situation of children with ALL. Being deprived of regular life experiences such as schooling, while simultaneously subjected to painful medical procedures, is likely to contribute to negative emotional states – a natural response to an unnatural situation. Behavioural disturbances are possible corollaries of negative emotional states. Interpersonal relations among children with similar emotional and behavioural issues are likely to be difficult, contributing to peer problems among hospitalized children. Personal constructs are belief related to cognitive phenomena, which are relatively stable and impervious to spontaneous change. The absence of a significant difference in this

domain between groups suggests that the experience of undergoing ALL treatment did not impact children to the extent of causing changes at the level of beliefs regarding self and others. These include constructs such as others devaluing the child and/or child devaluing others, resourcefulness in self/others, impaired sibling relationships, and sadistic/morbid thoughts regarding self/others. However, the finding of lesser helplessness in self in the ALL group is intriguing, considering that they were subjected to stressors of illness and treatment, which were beyond their personal control.

As mentioned earlier, mothers stayed with their children throughout the duration of inpatient care. It is proposed that in the context of children having to undergo such unnatural distress at a young age, mothers were extraordinarily attentive and involved in their children's daily lives than for healthy peers. This is especially likely for this sample. Being from lower socioeconomic backgrounds, the hassles of daily life are likely to have been significant for mothers of healthy children. In contrast, it is likely that mothers in the ALL group were exclusively focused on their child's wellbeing. Thus, it is probable that these children experienced being more catered to than healthy peers, thereby contributing lesser self-perceived helplessness. Indeed, research suggests that parents' presence during medical procedures and active care-taking by parents for hospitalized children is adaptive [26-27]. Also, Noll and Kupst [28] assert hardiness as a core trait in children with cancer. It is probable that this was true for this sample, additionally contributing to lesser helplessness in self vis-à-vis healthy peers.

Resilience is the capacity to adapt successfully to significant challenges that threaten functioning, viability, or development [29]. It is promoted by factors within a child and in the outside environment. It is proposed that children with ALL demonstrated resilience by maintaining adequate psychological health in the face of battling a life-threatening illness. Disturbances in behavioural and emotional domains did not preclude normative functioning;

and children also perceived themselves as less helpless than comparable healthy peers. It is likely that the hypothesized external factor of maternal attention and involvement, and the internal factor of hardiness promoted resilience.

Implications

This study addresses the lacunae in paediatric psycho-oncology research in the country. The sample comprised children from lower socioeconomic strata, which encompasses a large segment of India's population [30]; making it relevant from a public health perspective. This is one of the few studies carried out on young children with cancer; thus, contributing to the global need for understanding psychological health in this population.

Findings suggest that the psychological health of young children undergoing treatment for ALL is relatively well-preserved with capacities for resilience. This implicates a need for promotive mental health interventions within a positive psychology framework, enhancing inherent strengths and strengthening the use of external support systems. Since mothers' reports indicated problem behaviours, resources in the nature of parent support groups may be considered in paediatric-oncology settings. The experience of negative emotional states by children is an expected response. Activities with children that facilitate emotional expression such as art, play, etc., may be beneficial. Suggestions of parent support groups and emotional, expressive activities are feasible with minimal resources, and thus possible to incorporate into hospital policies. Healing environments have become crucial aspects of medical care, and pertinence of these for younger children is noted [31].

Globally, with regard to research, there is an emphasis on examining factors across disease, individual, family, and context in evaluating adjustment to paediatric illnesses [32]. This study offers two hypothesized factors of maternal presence and involvement and trait of hardiness as research possibilities.

There are several limitations of index study: The sample size, along with dropout of participants, is a limitation in generalizing findings. Another limitation is the tools utilized, with regard to the lack of standardization. These issues are universal to paediatric psycho-oncology research [33-34]. Thus, it is hoped that study findings are given due regard despite these limitations.

To conclude, the psychological health of young children from lower socioeconomic backgrounds undergoing treatment for ALL in India is comparable to healthy children. Experience of negative emotions is expected, given the travails of treatment. There is lesser perceived helplessness in self among children with ALL. Put together, findings suggest that children with ALL demonstrate resilience. The clinical, research and public health implications of study findings may be examined through research involving larger samples across varied socioeconomic brackets, stages of development, and cancer diagnoses.

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Conflict of interest: None declared

References

1. Mavrides N, Pao M. Updates in pediatric psycho-oncology. Int Rev Psychiatry 2014, 26: 63-73. doi: 10.3109/09540261.2013.870537.
2. Eiser C. Children with cancer: The quality of life. Marwah, NJ: Lawrence Erlbaum Associates, Inc; 2004.

3. Cox LE, Kenney AE, Harman JL, Jurbergs N, Molnar Jr AE, Willard VW. Psychosocial functioning of young children treated for cancer: findings from a clinical sample. J Pediatr Oncol Nurs 2019, 36: 17-23. doi: 10.1177/1043454218813905.
4. Arora RS, Eden TOB, Kapoor G. Epidemiology of childhood cancer in India. Indian J Cancer 2009, 46:264-73. doi: 10.4103/0019-509X.55546.
5. Stiller CA. Epidemiology and genetics of childhood cancer. Oncogene 2004, 23: 6429-6444. doi: 10.1038/sj.onc.1207717.
6. Hunger SP, Mullighan CG. Acute Lymphoblastic Leukemia in children. N Engl J Med 2015, 373:1541-52. doi: 10.1056/NEJMra1400972.
7. The Datta SS, Cardona L, Mahanta P, Younus S, Lax-Pericall MT. Pediatric psycho-oncology: Supporting children with cancer In: Joseph MR, ed. JM Rey's IACAPAP e-textbook of child and adolescent mental health 2015 edition [book on the internet]. Geneva: International Association for Child and Adolescent Psychiatry and Allied Professions 2015.
8. Barlow JH, Ellard DR. The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. Child Care Health Dev 2006, 32: 19-31. doi: 10.1111/j.1365-2214.2006.00591.x.
9. Noll RB, Kupst MJ. Commentary: The psychological impact of pediatric cancer: hardiness, the exception or the rule? J Pediatr Psychol 2007, 32: 1089-98. doi: 10.1093/jpepsy/jsm049.
10. Phipps S, Jurbergs N, Long A. Symptoms of post-traumatic stress in children with cancer: Does personality trump health status? Psycho-Oncol 2009, 18: 992-1002. doi: 10.1002/pon.1496.
11. Chao C, Chen S, Wang C, Wu Y, Yeh C. Psychosocial adjustment among pediatric cancer patients and their parents. Psychiatry Clin Neurosci 2003, 57: 75–81.
12. Tillery R, Willard VW, Long A, Phipps S. Posttraumatic stress in young children with cancer: risk factors and comparison with healthy peers. Peadtr Blood Cancer 2019, 66: e27775. doi: 10.1002/pbc.27775.
13. Patenaude AF, Kupst MJ. Psychosocial Functioning in Pediatric Cancer. J Pediatr Psychol 2005, 30: 9-27. doi: 10.1093/jpepsy/jsi012.
14. United Nations. Constitution of the World Health Organization. New York, 1946. (htt p://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf, accessed 4 January 2011).

15. Satapathy S, Kaushal T, Bakshi S, Chadda RK. Non-pharmacological interventions for pediatric cancer patients: a comparative review and emerging needs in India. Indian Pediatr 2018, 55: 225-32. doi: https://doi.org/10.1007/s13312-018-1323-3
16. Arora B, Banavali SD. Paediatric oncology in India: Past, present, and future. Indian J Med Paediatr Oncol 2009, 30: 121-3. doi:10.4103/0971-5851.65333.
17. Mehrotra S. Psycho-oncology research in India: Current status and future directions. J Indian Acad Appl Psychol 2008, 34: 7-18. Retrieved from medind.nic.in/jak/t08/i1/jakt08i1p7.pdf.
18. Venkatesan S. Extension and validation of gessell's drawing test of intelligence in a group of children with communication handicaps. Indian J Clin Psychol 2002, 29: 173 -77.
19. Verma SK. Index of cognitive development. In: Channabasavanna, SM, Varghese M, Chandra PS (eds.). Indicators of mental health – A multi centered ICMR study: report of the study and manual for family interventions by the health worker. 1995; New Delhi: ICMR.
20. Goodman R. The strengths and difficulties questionnaire [Internet]. 2005 [cited 2019 Dec 02]. Available from http://www.sdqinfo.com/py/sdqinfo/b3.py?language=Englishqz(UK); 2005.
21. Robb SL, Haase JE, Perkins SM, Haut PR, Henley AK, Knafl KA, Tong Y. Pilot randomized trial of active music engagement intervention parent delivery for young children with cancer. J Peadtr Psychol 2017, 42: 208-19. doi: 10.1093/jpepsy/jsw050.
22. Kaminski M, Pellino T, Wish J. Play and pets: the physical and emotional impact of child-life and pet therapy on hospitalized children. Child Health Care 2002, 31: 321–35. doi: 10.1207/S15326888CHC3104_5.
23. Gariépy N, Howe N. The therapeutic power of play: Examining the play of young children with leukaemia. Child Care Health Dev 2003, 29: 523–37. doi: 10.1046/j.1365-2214.2003.00372.x.
24. Mueller N. The Teddy Bear's Picnic: Four year old children's personal constructs in relation to behavioural problems and to teacher global concern. J Child Psychol Psychiatry 1996, 37: 381-89. doi: 10.1111/j.1469-7610.1996.tb01419.x.
25. Janveja V. Teddy Bears' Picnic: Personal constructs as revealed in play of children with behavior problems [dissertation]. Bangalore, India: National Institute of Mental Health and Neuro Sciences; 1999.

26. Al-Eissa M, Saleheen H, Yousif A, Al-Manea S, Al-Hijali B, Khan A. Parental presence during resuscitation and invasive procedures in the emergency department: Saudi parents' perspective. J Nurs Care 2015, 4:278-82. doi:10.4172/2167-1168.1000278.
27. Powers KS, Rubenstein JS. Family presence during invasive procedures in the pediatric intensive care unit. Arch Pediatr Adolesc Med 1999, 153:955-8. doi:10.26634/jnur.4.1.2624.
28. Noll RB, Kupst MJ. Commentary: The Psychological Impact of Pediatric Cancer Hardiness, the Exception or the Rule? J Pediatr Psychol 2007, 32: 1089–98. doi: 10.1093/jpepsy/jsm049
29. Masten AS. Resilience theory and research on children and families: past, present, and promise. J Fam Theory Rev 2018, 10: 12-31. doi: 10.1111/jftr.12255.
30. Gupta R, Sankhe S, Dobbs R, Woetzel J, Madgavkar A, Hasyagar A. India's path from poverty to empowerment [Internet]. McKinsey Global Institute; 2014. Available from https://www.mckinsey.com/featured-insights/asia-pacific/indias-path-from-poverty-to-empowerment.
31. Woo J, Lin Y. Kids' perception towards children's ward healing environments: A case study of Taiwan university children's hospital. J Health Eng 2016, vol.2016(Article ID 8184653):10 pages. doi:10.1155/2016/8184653.
32. Kazak AE, Kassam-Adams N, Schneider S, Zelikovsky N, Alderfer MA, Rourke M. An integrative model of paediatric traumatic stress. J Pediatr Psychol 2006, 31, 343-55. doi:10.1093/jpepsy/jsj054.
33. Matza LS, Swensen AR, Flood EM, Secnik K, Leidy NK. Assessment of health related quality of life in children: A review of conceptual, methodological, and regulatory issues. Value Health 2004, 7:79-92. doi:10.1111/j.1524-4733.2004.71273.x.
34. Palermo TM, Long AC, Lewandowski AS, Drotar D, Quittner AL, Walker LS. Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology. J Pediatr Psychol 2008, 33:983-96. doi:10.1093/jpepsy/jsn038.

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