

## Article

# Impact of after completion therapy assistance on pediatric oncology patients: A study from a tertiary care center from Jammu & Kashmir

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**Abstract: Background:** Advances in all fields of oncology have resulted in five-year survival rate approaching 80% among pediatric /AYA survivors which has led to increased focus on psychosocial relationship care, identification of late effects and improving quality of life. For this growing population of cancer survivors with a whole life ahead of them, more concrete support structures have been directed towards the evaluation and improvement of post-treatment care. Medical care complemented with non-medical (psychosocial relationship) care increases awareness with respect to many psychosocial relationship aspects such as educational, employment, post treatment distress and coping which need to be addressed for the survivor to lead a normal productive life. Recent studies have shown that regular psychosocial relationship follow ups have resulted in timely identification of late effects followed by appropriate rehabilitation services being provided to survivors.

**Method:** The study is based on project PICASSO (partnership in cancer survivorship optimization) initiated by Indian Cancer Society which aims at providing holistic care for childhood cancer survivors. The qualitative analysis was performed by using the quality-of-life scale (WHOQoL-BREF). Non probability purpose sampling pediatric/AYA oncology survivors were taken from the act clinic and potential survivors participated who have completed the treatment till June 2022. (n=100).

**Results:** The Significant difference is seen between ACT and non-ACT survivors as far as psychological well-being health and physical health domain is considered and insignificant difference is seen as far as social relationship and environment wellbeing is considered.

**Conclusion:** The Study revealed that ACT survivors have good psychological well-being and physical health then non-ACT survivor.

**Keywords:** Oncology; physical health; Cancer.

## 1. Introduction

**C**ancer is a rare disease in children, affecting 1 in 300 below 16 years of age [1]. Over the last 50 years, it has changed from an inevitably fatal condition to one that is potentially curable, with overall survival rates approaching 75% [2], and possibly 90% for acute lymphoblastic leukemia [3]. As survival rates have improved, a proportion of survivors experience late-effects as a consequence of the disease itself or the treatment needed. Late-effects are adverse side effects of cancer and its treatment and can occur many months or years after completion of treatment. With this it is important about how best to inform patients about the potential risks to their future health, how frequently they should be monitored for these late-effects and the kind of follow-up they should be offered. For service providers, provision of follow up should be compulsory to increase survival and improve their quality of life by providing different kind of assistance. These include educational funding, counselling, and late effect funding and other assistance for improving quality of life among survivors. In addition, the wide range of late-effects requires a multi-disciplinary approach to care.

## QOL

Health-related QOL refers specifically to the impact of health and illness and is usually distinguished from broader concepts of general well-being. Health-related QOL is recognized to be a multidimensional concept comprising a number of domains [4]. Core domains include physical health, social relationship, emotional, and cognitive functioning. Additional domains thought to be especially pertinent for young adults (body image, autonomy) have also been proposed.

Challenges to assessment of QOL in survivors include those that are common to all assessment, such as establishing reliability and validity [5]. Others are specific to child cancer survivors. Critically, QOL reflects the views of the individual and not those of proxy caregivers [6]. This importance on the individual outlook has proven a challenge to measurement, especially where the patient is too young, disabled, from economically weaker section with little education. Disease-specific measures are more suitable where the question is about how the illness and its treatment impact on the patient's life. These are considered essential when evaluating outcomes in clinical trials. However, currently available measures [7] are more appropriate for early stages of treatment, as they include questions about the impact of physical health symptoms or medical procedures on QOL. These issues are not likely to be of concern to survivors. Furthermore, on-treatment measures tend to focus on issues relevant to young children. Measures for survivors therefore need to include issues of relevance to young adults, such as gaining independence from their families and establishing intimate relationships, and perhaps less emphasis on school progress or social relationship relationships in the classroom. At the same time, measures for adults may also be limited, in that the concerns of older adults with established employment and families are not necessarily the same as those for young adults making their way in life, and contemplating their futures. Measurement of QOL for young adult survivors therefore poses special challenge than QOL in children or older adults following cancer.

## 2. Objectives of the study

The objectives of our study include:

- Assessing the QOL among the pediatric/AYA cancer survivors receiving the ACT assistance.
- Assessing the QOL among the pediatric/AYA cancer survivors not receiving the ACT assistance.

## 3. Material and methods

The samples were collected using random sampling wherein every 3rd patient was included in the study. Among 100 survivors, 50 were taken from ACT (after completion therapy) clinic established at SKIMS medical oncology department under the project PICASSO (under tutelage of ICS)

A comparative study was made between two groups of cancer survivors, who had completed two years of treatment and were considered disease free. First group comprised of 50 patients registered within ACT clinic of the hospital. The survivors received various kind of functional assistance, besides regular counseling sessions and follow ups. The other mentioned non-ACT group did not receive any kind of assistance. The identity of the study subjects was not revealed. The survivors (n=100) were administered WHOQoL-BREF questionnaire.

WHO Quality of life scale brief has been used to check the quality of life, it is subset of 26 items taken from the WHOQOL-100, and Scoring is based on four domains

1. Overall quality of life and general health.
2. Physical health.
3. Psychological well-being health.
4. Social relationship relationships.

The questionnaire was validated and was available in 19 different languages which include Hindi and English. The English Language version is used in this study, which has been validated and has good reliability and internal consistency. (Mention internal consistency for current study)

### 4. Data analysis

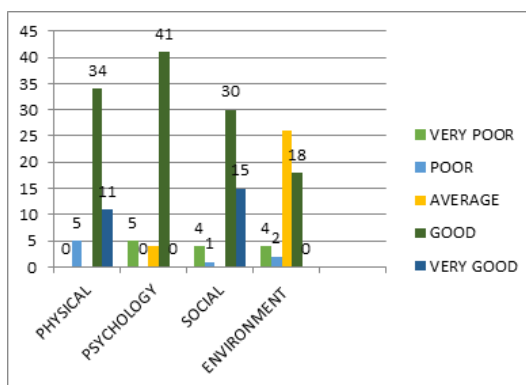
The data was entered in excel sheet and analyzed using specific software. The data was represented using descriptive statistics and graphical methods. Independent sample t -test was used. The level of statistical significance was set to be less than 0.05.

### 5. Results

Age group of 8-25 years was included in the study. Pediatric age group, i.e.,  $\geq 14$  years were 59%. AYA group, i.e.,  $< 14$  years were 41 % (Table 1). The mean age of cancer survivors across the study group was 13.75 years. 61% of cancer survivors were males and 39% were females (Table 2).

**Table 1.** Socio-demographic profile of the study participants

Domain	Items	ACT (n=50)	Non-ACT(n=50)
Physical health	very poor	0%	0%
	Poor	10%	12%
	Average	0%	44%
	Good	68%	4%
	very good	22%	40%
Psychology well being	very poor	10%	0%
	Poor	0%	50%
	Average	8%	42%
	Good	82	8%
	very good	0%	0%
Social relationship	very poor	8%	0%
	Poor	2%	4%
	Average	0%	4%
	Good	60%	48%
	very good	30%	44%
Environmental health	very poor	8%	0%
	Poor	2(4%)	26(52%)
	Average	26(52%)	2(4%)
	Good	18(36%)	22(44%)
	very good	0(0%)	0(0%)



**Figure 1.** Item wise score of domains of ACT survivors

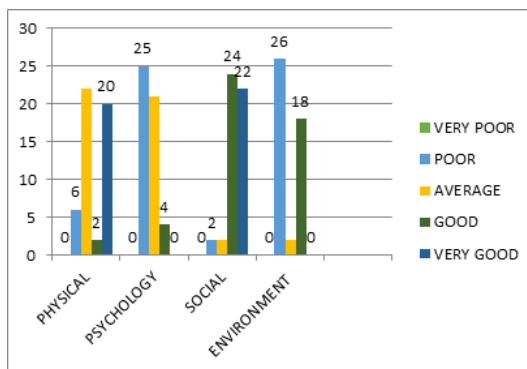


Figure 2. Item wise score of domains of non- ACT survivors

Table 2. Percentage of domains in groups

Domains	Non-ACT(n=50)	ACT(n=50)	Total (n=100)
	Mean ±SD	Mean± SD	Mean± SD
Physical health.	69.35* ±18.03	77.64*±12.36	73.5±15.94
Psychological well-being.	58.33* ±10.06	70.33*±14.89	64.33±14.00
Social relationship	79.00±9.25	77.00±19.12	78.57±15.94
Environment health.	59.12±14.11	63.87±12.09	61.5±13.29

Scoring of each domain was done with scale WHOQOL-BREF (0-100) where 16 were lowest and 100 were considered highest score. Higher the score, higher is the quality of life [8]. Scores were interpreted with range

- 16-33(Very poor),
- 33-50 (Poor),
- 50- 67 (neither poor nor Good),
- 67-83(Good) and
- 83-100 (very good).

In ACT group, most of the domain mean score fell in the range of 67-83, i.e., good. Maximum mean score was observed for psychological well-being (70.33±14.89) and minimum mean score was observed for environmental health (63.87±12.09). In the non-ACT group, most of the domain mean score fell in the range of 33-50, i.e., poor. Maximum score was observed for social relationships (79.00±9.25)

Table 3. Mean values of the domains of QoL in survivors two groups

Domains	Non-ACT(n=50)	ACT(n=50)	Total (n=100)
	Mean ±SD	Mean± SD	Mean± SD
Physical health.	69.35* ±18.03	77.64*±12.36	73.5±15.94
Psychological well-being.	58.33* ±10.06	70.33*±14.89	64.33±14.00
Social relationship	79.00±9.25	77.00±19.12	78.57±15.94
Environment health.	59.12±14.11	63.87±12.09	61.5±13.29

\*Represents significant difference.

Table 3 shows the comparison between the mean score of four domains of the quality of life among the ACT and non -ACT survivors in the groups revealed that the mean score of the physical health, psychological well-being domains was significantly higher among the ACT group as it can be due to assistance extended by ACT clinic as survivors are in continuous follow up at same clinic with time-to-time counseling and other assistance like educational scholarship, late effect funding has been provided.

The mean value of physical health and psychological well-being domains of quality of life in ACT patients were

(77.64±12.36) and (70.33±14.89) respectively these values were significantly higher as compared to non-act survivors were in the values stood at (69.35±18.03) and (58.3310.06) respectively

## 6. Discussion

In ACT group, most of the domain mean score fell in the range of 67-83, i.e., good. Maximum mean score was observed for psychological well-being. This may be due to assistance provided by ACT leading to improved psychological well-being. This also depends on TSD (time since diagnosis). The relevant study was conducted by [9] where it was observed that TSD was associated with greater physical health functioning. In the non- ACT group, most of the domain mean score fell in the range of 33-50, i.e., poor. Maximum score was observed for social relationships. This can be due to good relationships with family and peer groups. Besides, minimum score was observed for psychological well-being considering there was no assistance provided to this group. Besides, time since diagnosis was also less, Hence, fear of relapse and hopelessness towards life was mostly found. Average score was observed in physical health and most of the physical health was affected by pain and discomfort. The relevant study was conducted [10] where it was revealed that pain and discomfort affected their physical health. Improved psycho social functioning was observed in act survivors rather than non-act survivors the relevant study was conducted by [11] were analysis show large and clinically relevant improvements in functioning and symptoms among survivors of childhood cancer undergoing multidisciplinary inpatient rehabilitation. This indicates that family-oriented Oncological rehabilitation can effectively improve the bio-psycho-social health of pediatric cancer survivors, and may help to reduce long-term effects of cancer and its treatment and thus facilitate re-integration into daily life. The performance score led to substantially better agreement with regard to change assessment between children and parents, and should thus be integrated in future studies.

Social functioning was seen good in ACT survivors rather than non-act survivors on quality of life scale the relevant study by [12] were findings indicate a significant association between quality of life and social adjustment, posttraumatic growth, health consequences and posttraumatic stress disorder. Regression analysis showed that posttraumatic growth, social functioning and treatment consequences are significant predictors of quality of life in pediatric cancer survivors.

## 7. Conclusion

The management of cancer is a critical issue. After treatment how the QOL of survivors needs to be improved is a major concern. Healthcare professionals must ensure that the patients receive timely and appropriate education and care. There is a need to develop measures for effective management of symptoms and to improve the QOL. A well-established rehabilitation center is needed such that during and after treatment, focus should be on the overall well-being of the survivors. Strategies that will empower the patients to have a better sense of control over their illness and treatment should be promoted.

## 8. Limitations of the study

- The study findings cannot be generalized to nationwide as the study was confined to a single hospital
- Cancer patients who gave consent only were interviewed
- As with any cross-sectional study, recall bias needs to be addressed,

**Ethical considerations:** The objectives of the study were informed to the cancer survivor, and informed consent was obtained. Administrative permission was obtained from the SKIMS who granted permission for data collection.

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All authors contributed equally to the writing of this paper. All authors read and approved the final manuscript.

**Conflicts of Interest:** "Authors declare no conflict of interests."

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