

“Bouncing back to life: A perspective of living arrangement among adolescents with HIV”

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Abstract

Background: Most research on adolescent focuses on the risk associated with the illness. Very little research has been carried out on adolescents who have been diagnosed with HIV since birth. With recent advances with ART treatment, life span of these children has increased, and there are lots of protective factors in the environment influencing the resilience. The present study has focused on the resilience among the adolescence with respect to the living arrangement, i.e., in institutionalized care and extended family. **Methodology:** The current study follows an exploratory research design with the aim of comparing resilience among adolescents living in the institutional setup and those living with their families—parents and extended families. Adolescents receiving ART treatment from a tertiary care hospital constitute universe and were selected purposively for the study. Resilience was measured using Child and Youth Resilience Measure. **Results:** The results indicated that 70% of the female and majority of them belong to Hindu religion. For majority, the mode of transmission is mother to child. There is no statistically significant difference between the resilience with respect to the living arrangement. However, respondents are resilient. **Conclusion:** This study has given a space for resilience for different groups of adolescents with respect to the living arrangement.

Key words: Adolescents, HIV/AIDS, living arrangement, resilience

Introduction

The life expectancy of children with prenatally acquired HIV has increased over the period of time and they are entering adolescence and adulthood.^[1] Adolescence is a period where one develops knowledge and learns to manage emotions and relationship, and it is a foundation to assume adult roles.^[2] Specifically, for the adolescent who are born with HIV, it is a turbulent period due to different reasons such as traumatic periods in life, loss of parents, multiple caregivers (institutionalization), prolonged health problems, and hospitalization. Hence, they require specific kind of assistance compared to other adolescents. Their needs are complex in terms of developmental tasks which include physical and sexual maturity. Maturation also brings the need to understand relationship and peer pressure. Economic and psychosocial distresses are one among the pressures for institutionalized adolescents which can heighten the risky behaviors. Hence, without the protective factor of having parents, adolescents are more vulnerable.^[3]

Adolescent living with HIV has increased risk of being victims, exploitation, and neglect. Death of a parent during

childhood has a profound and potentially lasting impact on a child's psychosocial well-being.^[4] There is a difference in the process of grief when children with HIV loss their parents including stigma, disruption of care, and financial hardship institutionalization.^[5] Research findings suggested that children in long-term residential are at high risk of impaired cognitive, behavioral, emotional, and social development.^[1] The social and psychological needs of the adolescent in the institutional care are unmet due to the structure and capacity of the institute.^[6] Furthermore, the institutional care facilities attract the children from poverty-stricken environments and render them more vulnerable to physical and sexual abuse and promote stigma and discrimination.^[7] Hence, adolescents born with HIV/AIDS either residing with extended caregiver or institute have their own difficulties. Hence, there is a need to evaluate the protective factor for them to foster and promote resilience. This helps one to positively deal with the worst or traumatic circumstances. To date, there is very little coordination across research on resilience in adolescents with HIV/AIDS.

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The present study operationalizes resilience as the attainment of desirable social and emotional adjustment, despite risks due to HIV^[8,9] explained that a supportive environment with reciprocity in individuals' need enhances environment and conflicted relationship decreases the level of resilience. Positive aspects of the interpersonal relationship, social support and reciprocity, should lead to resilience and the negative aspect of social support, conflict, should decrease the level of resilience.

This article introduces the concept of resilience among the adolescents born with HIV in institutional care and the one who is residing with the secondary caregiver.

Methodology

The study aims to explore the resilience among adolescents living with HIV and then compare the resilience among the adolescents born with HIV, in an institutional care and with the extended family. The study sample included adolescents from the age group of 13–18 years, from both the genders, and who were receiving ART treatment from the Indira Gandhi Institute of Child Health Hospital, Bengaluru. The exclusion criteria were the adolescents who were residing with both the parents. The study was carried out during January 2016–February 2016. The study was approved by the institute ethics board and followed the ethical guidelines. Informed written permission was obtained from IGICH and NIMHANS and written consent was obtained from the caregivers, respondents, or legal guardians.

Measures

The following two tools were used for gathering data from participants.

1. Sociodemographic data sheet: Prepared by the researcher, which includes age, sex, domicile, and education
2. Child and youth resilience measure [Table 1]: Self-report instrument. Items are rated on a 5-point scale from 1 = does not describe me at all to 5 = describes me a lot. Higher scores indicate higher levels of resilience.

Data analysis

Quantitative data were coded and analyzed using the Statistical package for the social sciences (SPSS) Version 22.00 (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp.). Frequency distributions, percentage analysis, mean, and standard deviation were the descriptive statistics that were used. Independent *t*-test and Mann Whitney U-test were used to find significant differences between the means of variables.

Results

Table 2 represents the sociodemographic details of the respondents. A total of 60 adolescents participated in the study [Table 2]. They were aged 13–18 years, and majority of them follows Hindu religion. Table 2 also gives us the overview about the mode of transmission in the respondents that is from mother to child. Regarding the knowledge about the illness and Anti Retroviral T therapy, 47 have knowledge of HIV/AIDS and 59 have knowledge about the ART.

Table 3 represents the living arrangement of the respondents where 30 of them are in residential care and the rest are residing with the extended family members.

Table 4 represents a statistically significant difference which was observed between the respondents who are residing in institution and with the secondary caregiver in terms of the subdomain spirituality.

Discussion

The present study evaluated the difference between the resilience among the two groups of the respondents. However, it can be inferred from the results that majority of the respondents are either institutionalized or staying with extended caregivers. (Brief *et al.*, 2004)^[10] pointed out that many children are usually incorporated into the extended families that act as a safety net. However, the shrinking number of caregivers and the considerable strain on families mean that children are much more vulnerable to economic and social hardships such as malnutrition, poverty, child labor, homelessness, and reduced access to education and health care.^[10] Thus, the results of the present study also indicate that due to the reduced number of caregivers, the adolescents are receiving institutional care.

In general, the study revealed partial knowledge about HIV/AIDS among adolescents. Most of the research findings in India and abroad have pointed out that people between 15 and 24 years have adequate knowledge about HIV/AIDS,^[11] and people still harbor several misconceptions about this infection.^[12] In the present study, of 60 respondents, 59 have knowledge about ART, whereas 47 respondents have knowledge about HIV/AIDS.

Around 98% of the adolescents in the research group have prenatally acquired HIV/AIDS. Adolescents with perinatally acquired HIV have been prescribed antiretroviral therapy from an early age; they are likely to have some resistant strains of HIV.^[13] Mother-to-child transmission accounts

Table 1: Child and Youth Resilience Measure

1. Do you have people you look up to?
2. Do you cooperate with people around you?
3. Is getting an education important to you?
4. Do you know how to behave in different social situations?
5. Do you feel that your parent(s) watch you closely?
6. Do you feel that your parent(s) know a lot about you?
7. Do you eat enough most days?
8. Do you strive to finish what you start?
9. Do you strive to finish what you start?
10. Are spiritual beliefs a source of strength for you?
11. Are you proud of your ethnic background?
12. Do people think you are fun to be with?
13. Do you talk to your family about how you feel?
14. Are you able to solve problems without using illegal drugs and/or alcohol?
15. Do you feel supported by your friends?
16. Do you know where to go in your community to get help?
17. Do you feel you belong at your school?
18. Do you think your family will always stand by you during difficult times?
19. Are you treated fairly in your community?
20. Do you have opportunities to show others that you are becoming an adult?
21. Are you aware of your own strengths?
22. Do you participate in organized religious activities?
23. Do you think it is important to serve your community?
24. Do you feel safe when you are with your family?
25. Do you have opportunities to develop job skills that will be useful later in life?
26. Do you enjoy your family's traditions?
27. Do you enjoy your community's traditions?
28. Are you proud to be (Nationality: _____)?

The answers has to be marked from (1=Not at all; 2=A little; 3=Somewhat; 4=Quite a bit; and 5=A lot)

for the majority (80%–90%) of pediatric HIV-1 infections around the world.^[14]

One objective of the present study was to compare resilience in adolescent who are residing with extended caregiver and institutional care. The mean score of resilience for both the groups is 112 and 107, respectively. It does not indicate any significance difference. Both the groups share commonality status of prenatally acquired HIV. The results support the existing literature available on resilience among the children born with HIV/AIDS.^[15]

Table 2: Sociodemographic data

Variable	Frequency (%)
Age (years)	
13-15	35 (58)
16-18	25 (42)
Gender	
Male	18 (30)
Female	42 (70)
Religion	
Hindu	40 (67)
Islam	4 (7)
Christian	16 (26)
Education	
Primary	7 (12)
Secondary	42 (70)
Senior secondary	11 (18)
Mode of transmission	
Mother to child	56 (93)
Unknown	4 (7)
Knowledge about illness	
Yes	47 (78)
No	13 (22)
Knowledge about ART	
Yes	59 (98)
No	1 (2)

Table 3: Living arrangement

Variable	Frequency (%)
A	17 (28)
B	13 (22)
Extended family members-paternal	1 (2)
Only father	8 (13)
Only mother	6 (10)
Extended family member-maternal	15 (25)
Total	60 (100.0)

Table 4: Comparison of means of resilience and domains

Independent <i>t</i> -test	Mean±SD		<i>t</i>	<i>P</i>
	Family	Institutions		
Resilience	107.00±12.18	112.07±11.32	1.669	0.100
Cultural context	19.03±2.77	20.13±2.801	1.529	0.132
Psychological care giving	19.6±3.39	19.10±2.96	-0.608	0.545
Individual personal skills	20±2.15	20.9±2.22	1.596	0.116
Individual social skills	12.6±2.63	13.77±3.19	1.544	0.128
Mann-Whitney U-test	Median±IQR		Test statistics	<i>P</i>
	Family	Institutions		
Education	9±3	8.50±2.50	409.5	0.536
Spirituality	11.50±4	14±3	261.000	0.004*
Physical care giving	8±2	9±2	340.000	0.095
Individual peer support	8±3	8±3.25	443.00	0.915

*Statistically significant according to *t*-value. SD: Standard deviation, IQR: Interquartile range

Research on exposure to adversities in childhood and range of developmental and social adaptation difficulties in childhood and adulthood are well established.^[16] It also indicates the risk for social adaptation difficulties in parallel with focus in identifying resources that facilitate the occurrence of positive outcomes and avoidance of negative outcomes in the face of adversity.^[17] Resources in the individual, family, and community-organizational domains facilitate positive outcomes by either promoting effective adaptation processes or by reducing the child's exposure to adversities.^[18] This is in converse with the finding by Hong *et al.*, 2011^[19] that reveals that double orphans in community-based group homes have better psychosocial well-being as compared to their counterparts in orphanages and kinship care. The reason is community-based homes provide support preserving the family style.

The only difference was in terms of spirituality where mean was 11.50 and 14 for the respondents residing with the family and institution, respectively. Even though the difference was very small, it shows that the institutionalized adolescents have more spirituality as compared to their counterparts residing with the extended family. Activities in institutions are more structured than in home when it comes to spirituality. It is a key factor for fostering resilience as it encompasses existing and shared inner strengths, as well as interpersonal and problem-solving skills, such as hope and morality.^[20]

Limitation and Implication

There are limitations of the current study that should be noted. It can also be considered as guidelines for the future research. First, the number of respondents who participated in the study was limited; the results cannot be generalized to a larger population. Second, the relation between the duration of stay in the institutional care has not been into consideration while measuring resilience. Third, the data regarding when orphan hood was established are not elicited which is also one factor in determining resilience. Further research on qualitative exploration about resilience among adolescent with HIV/AIDS will capture the richness of the data regarding the positive experiences in a traumatic environment. Another limitation of the study is that the impact of malnutrition, poverty, child labor, homelessness, and reduced access to education and health care on resilience in the two groups was not analyzed.

The findings of the study also have some important implication for HIV education among the adolescents. Culturally, appropriate education strategies are needed that should also include other family members.

Conclusion

This study concluded that one's capacity to bounce back toward life lies in the situational protective factors which can be at individual, family, or community level. Adolescents with chronic illness conditions like living with HIV, do have acceptance of their illness, are bouncing back in their life, coping with the day-to-day demands, and meeting the expectation. It is required to consider their resilience level and help them with appropriate psychosocial interventions so that they can bounce back when ever their chronic condition limits their functioning.

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Conflicts of interest

There are no conflicts of interest.

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