

“Well being among SCH children”- A study report

I am a 4th year medical student at the University of California San Francisco (UCSF) Medical School and was fortunate to have the opportunity of working with Sheeja Perumpil and Dr. Anita Shet of St. John's College as well as Dr. Maria Ekstrand of UCSF to help develop and carry out a project to assess the wellbeing among the children at Sneha Care Home. The overall purpose of our study is to explore and identify factors that correlate with psychosocial and physical wellbeing of children living with HIV, document the impact Sneha Care Home has on quality of life, and identify areas where interventions based on this wellbeing assessment could be made.

Children affected by HIV face multiple risks to their health, education, and psychosocial wellbeing. This increases our need to understand the unique challenges faced by the children of Sneha Care Home. In our study, a Health Related Quality of Life (HRQOL) score was used to measure the perceived physical and mental health over the past month. Perceived physical wellbeing was derived from questions about pain, energy, and difficulty with activities. Psychosocial wellbeing was measured through questions about perceived emotional, social, and academic difficulties. Reports were both from child and caregiver questionnaires. Physical wellbeing was measured by height and weight for each child and health indicators were gathered from medical charts. These included:

- Age and Sex
- CD4 count and clinical stage
- Parental status
- ART status and age of starting ART
- Age of joining Sneha Care Home and years of schooling

Although a full analysis of the data is still in progress, we have identified some interesting initial findings. 67% of the 97 children report it never being difficult to do sports, activity or exercise with about 26% experiencing difficulty some of the time. More than 50% of children reported they felt physical pain or low energy never or almost never within the last month. Most of the children were pro-social with more than 90% of them feeling that other children wanted to be their friend and being able to get along with others at least half of the time. The proportion of children experiencing sadness and fear at least some of the time within the last month is 53% and 48% respectively. Within academics about half of the children perceived that they would forget things at least some of the time but greater than 95% of students felt well enough to attend school and keep up with their school work. Children that reported often or almost always having difficulty within any area have been identified and are being given supportive attention to better understand and help care for the challenges they are experiencing.

These findings suggest that the overall wellbeing of the children at Sneha Care Home is at a high level and that interventions within specific areas may help improve the HRQOL of these children. Further analysis will be useful to understand whether specific demographics and caregiver evaluations are correlated with wellbeing. This work sets the foundation to understand in what ways Sneha Care Home can continue providing an enriching environment. Ultimately this work will be part

of a larger study that seeks to evaluate the wellbeing of children cared for in a home vs. residential values-based institution.

Being part of the community of Sneha Care Home exposed me to the compassionate environment that the children thrive within. Their thoughtfulness and enthusiasm to answer questions and help each other take turns in the study reflected their eagerness to learn and become involved. The results showing an overall high level of wellbeing therefore stood to further underscore the validity of the efforts made by the staff and volunteers. The depth of resiliency, maturity, and curiosity was demonstrated by the children's own questions and actions to overcome difficulty in the setting of life challenges. When asked what they do to live with difficulty the children share names of Sneha staff they trusted to listen and help them think through any problems. My experience carrying out the wellbeing study was filled with meaningful moments listening to the children and being inspired by them. I am confident that the information from this study will increase awareness on the particular needs of each child and will increase the already high level of wellbeing at the Sneha Care Home. It was a privilege to be welcomed into the Sneha family and to know the people that make it possible.

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