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Development of a Comprehensive Psycho Social Care and Support Model for Children and Adolescents Living with HIV/AIDS in India

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Abstract

Introduction: Psychosocial care and support for children and adolescents living with HIV is a novel program initiated with an aim to develop and standardize a comprehensive psychosocial care and support model for children and adolescents living with HIV/AIDS (CALHIV) in India.

Methods and Materials: Cross-sectional approach was used to collect the data from different groups. Non-random purposive sampling technique was employed for selecting the subjects for different groups. Structured in-depth interview and focus group discussion were held with children living with HIV/AIDS, their parents/care providers, stakeholders, NGO's peronnels, government officials and policy makers to understand their concerns, needs and psychosocial issues of children infected with HIV/AIDS. The existing programs, polices and gap in delivering services; and training needs were also explored using structured in-depth interview guide and focus group discussion guide.

Results and Conclusion: Based on the need assessments and in triangulation with existing literature a comprehensive psychosocial care and support intervention package and disclosure booklets were prepared and field-tested with counselors from ART centers and NGOs staffs. The paper discusses methodology adopted in developing and standardizing a model and its utility in resource limited settings.

Keywords: Children; Stigma; Disclosure; HIV; Psychosocial care; Support

Introduction

Globally, it was estimated that in the year 2008 there were 33.4 million people living with HIV, out of which children below 15 years constituted 2.1 million [1]. It was estimated that India has an overall prevalence of 0.31%. Approximately 50,000 children below 15 years are infected by HIV every year [2]. The increased access to antiretroviral treatment resulted in increased survival rates among the children infected with HIV/AIDS and also led to the improved quality of life of sero-positive children. This continues to have an increased impact on the mental health of children and adolescents living with HIV. Children with any chronic illness, in general, are found to be at greater risk of psychiatric problems, including depression, anxiety, and feelings of isolation. A major factor that distinguishes HIV/AIDS from other chronic or terminal illness is the stigma. Too often many HIV infected children and their families live in shame associated with AIDS. Illness is often kept as a secret. Parents delay disclosing child's as well as their own HIV/AIDS illness status due to stigma and possible psychological consequences. Internalizing problems such as anxiety, withdrawn behaviour, depression and somatic complaints are more in younger children with HIV and externalizing problems such as rule breaking, aggressive behaviour, and conduct disorders are common among older adolescent living with HIV [3,4,5]. Further, children with HIV/AIDS have additional factors in the complexity of their illness and treatment as well as in the adverse psychological circumstances and poverty in which many live. These children who know about their HIV status live in fear of their disease, and fear of loss of parents with HIV/AIDS. Moreover, given the nature of HIV transmission, if both parents infected with HIV, then many children become 'double orphans'. Children not only have to endure the pain and loss of losing parents, and also have to face stigma and survive without the emotional support of their parents. Following the death of the parents most of these infected children end up in living in orphan homes for long term care and protection. This has immediate as well as longer term emotional consequences [6]. As a result the mental health, needs and concerns of the children and adolescents with HIV infection need to be an essential part of their care even with advancements in HAART. When it comes to the disclosure of HIV/AIDS infection status to the children, there is no clear consensus among the practitioners and parents on when to disclose the HIV positive status to the child. Most of the disclosure guidelines address on illness aspect and treatment adherence and not on addressing the mental health impact of disclosure of HIV status to the child [7]. Once the HIV diagnosis has been disclosed to the infected child, there is a need to monitor in every follow-up visit, the child's level of functioning, behavioural changes, emotional and psychological adjustment by the health care provider. Moreover, health care providers who work directly with HIV infected children are not being trained with adequate skills to handle the psychosocial and mental health issues of children infected with HIV/AIDS [8,9]. This adds to the woes of the children in vulnerable situations and affects their

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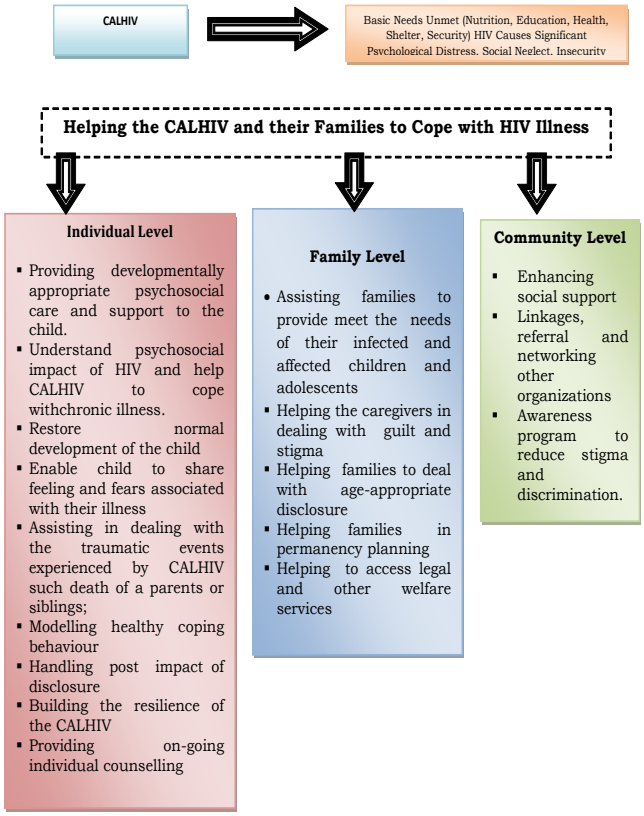


Figure 1: Psychosocial Care and Support Model for CALHIV and their Families.

overall development. The existing counselling programs in India do not address the psychological and mental health issues of children either infected or affected with HIV/AIDS. The existing services in the ART centers in India are more generic than specific needs of infected children and adolescents. There is a lacuna in providing counselling and therapeutic psycho social services to children and adolescents and their families living HIV/AIDS. Some of the existing psychosocial models such as PEPFARmodel based on ecological approach deals with AIDS affected children to promote their resilience and psychological well-being [9] whereas Psychosocial Support (PSS) Model address, age appropriate intervention at emotional, spiritual, cognitive and social domains of HIV infected children through interactions with their surroundings [10]. Few of these models are of western context may not be applicable to the cultural context of Indian setting. There is still limited evidence demonstrating which interventions have positive effects on the well-being of HIV infected children in resource limited settings [11,12]. The present research was aimed towards developing and standardizing a comprehensive psychosocial care model for Children and Adolescents Living with HIV/AIDS (CALHIV) in India. The specific objectives were: to understand the psychosocial and mental health needs of children and adolescents infected with HIV/AID, understand the issues, concerns, training needs of health care service providers working with CALHIV; to develop culturally sensitive comprehensive psychosocial care modules for CALHIV. Towards these ends, we also intended to test the model by training health care service providers in the use of the modules.

Methods and Study Design

The study design was an explorative study using both qualitative methods. It was a cross-sectional research. The use of qualitative methods in a study of this nature would be beneficial as the purpose was to understand the complexity of the participants' situation and experiences in a comprehensive manner. For the current study non-random purposive sampling technique was used to select participants from different groups for data collection. The methodologies adopted for qualitative data collections were In-depth Key Interviews (IDKIs) and Focus Group Discussion Methods. Twenty IDKIs were conducted with CALHIV. A total of four Focus Group Discussion (FGDs) each one with CALHIV and their parents/caregivers; heath care professionals (such as counselors, community care providers, medical officers, pediatricians, and policy makers), and Staffs of Non-Governmental Organizations (NGOs) which provide shelter and care to HIV infected orphan children and adolescents in Bengaluru. Three Phases of the research are given in the flow chart-1.

Results

Phase I: Need assessment

We conducted a needs assessment with children and adolescents living with HIV/AIDS, their parents, heath care providers (includes counselors, community care workers, medical officers, Pediatricians, policy makers and NGO's peronnels, to understand their concerns and mental health needs/problems of children living with HIV/AIDS. The existing programs, polices and gap in delivering services; and training needs were also assessed. The compilation of needs and concerns of different groups is shown in Table 1. The needs of the CALHIV and their parents were varied with health service providers and policy makers. CALHIV expressed concerns related handling stigma both internalized and externalized; handling school related issues, how to face parental and sibling's loss; and living and coping with chronic conditions. Their parents focused on disclosure related issues, difficulty in helping infected child to follow strict treatment regime, permanency planning, and adolescent sexuality and marriage related issues. Health care service providers; medical professionals and policy makers stressed on importance for developing indigenous psychosocial care programs to address issues related to handling psychosocial issues of CALHIV, treatment adherence aspects, how to counsel infected and affected children to deal with multiple loss, dealing with chronic conditions and palliative care. They also expressed the need for training in addressing the issues related to marriage, high risk sexual behaviour, transitional care issues and relationship issues of young adolescents living with HIV/AIDS. Another important concern expressed by them were need for developing age appropriate HIV disclosure booklets for parents/caregivers as it is unavailable in the ART centers and also training on how to address post psychological impact of HIV status disclosure on CALHIV.

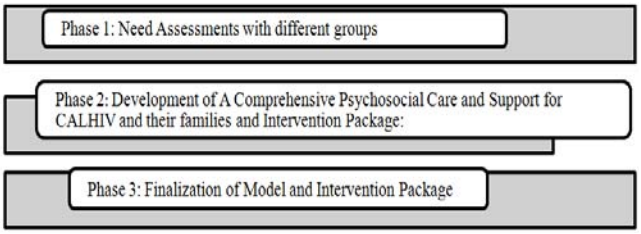
Phase 2: Development of a comprehensive psychosocial care and support model for CALHIV and their families and intervention package

Based on the information collected through the analysis of qualitative data and in triangulation with existing literature [9,10,12,-15] a comprehensive psychosocial care support model was derived. The psychosocial care and support model for the CALHIV and their

Table 1: Compilation of needs and concerns of CALHIV identified by different groups.

HIV Illness and Treatment Related Issues	Psychosocial Issues	Training, Resource Materials and Policy Related Issues
• How to make children to understand HIV illness • Medication adherence • Handling side effects of ART and explaining same to caregivers as well as child • Education about positive prevention • Handling co-morbid medical conditions	• Coping with chronic illness • Dealing with stigma and social ostracism • Dealing with multiple loss and death • Handling fear of death • Preparing for disclosure and how to handle post disclosure impact (difficulties in coming to terms with knowledge of HIV status and coping with emotions (e.g. grief, sadness, fear, guilt, anger, helpless). • Addressing developmental issues • Addressing academic related difficulties such memory problems, attention and concentration problems, and poor academic performance • Handling fear and uncertainty about the future (e.g. fear of one's own death and loved ones, fear of ill health, and uncertainty about future relationships) • How to deal with fear, loneliness, depression, anxiety, and feeling of insecurity • Addressing the adjustmental issues of institutionalized single orphan and double orphan children and adolescents.	• Lack of intensive training in counselling of CALHIV • Lack of information and culturally appropriate materials on how to disclose HIV status to infected children and how to deal with post impact mental health disclosure issues. No formal protocol guidelines for disclosing HIV status to infected children. • Need for comprehensive manual to address the psychosocial issues and mental health issues of children infected with HIV • Integration of life skills training to enhance psychosocial competencies and resilience of CALHIV. • Need of an intensive training of the health care service providers in assessment of psychosocial and mental health issues of CALHIV. • Need for guidelines in addressing the issues related to marriage, sexual behaviour, relationship issues of young adolescent living with HIV as HIV is no longer considered as fatal illness. • Training and guidelines on transitional care from pediatric ART to adult ART care

families is not only restricted to provide care, support and meeting the physical needs. It covers the multifaceted nature of interventions at individual, family and community level. The spectrum of psychosocial care and support includes the multifaceted nature of child's development, building upon the close interplay of the psychological and social aspects of cognitive and emotional growth. Children's psychological development includes the capacity to perceive, analyze, learn, and experience emotions. Social development includes the ability to form attachments to caregivers and peers, maintain social relationships, and learn the social codes of behaviour of one's own culture. Psychosocial care and support interventions recognizes on-going connection between a child's feelings, thoughts, perceptions, and the development of the child as a social being within his/her social environment. The emphasis of psychosocial care and support is that it should be integrated holistically for strengthening social environments that nurtures child's healthy psychosocial development at various levels - individual, family and community level. Psychosocial care and support model aimed towards restoring the normal flow of development of CALHIV; addressing children and adolescent issues and needs in a holistic manner; helping CALHIV to cope with chronic illness; enhancing their psychological well-being; enhancing the capacity of families to care for their infected and affected children; and enabling CALHIV to better and adjust to the community by strengthening the social support and network (Figure 1). Based on the derived model, the comprehensive psychosocial care and support intervention package (manual) was developed which covered various aspects children, and adolescents living with HIV in India, Understanding Psychosocial Needs and Issues of Children and Adolescent Living with HIV, Mental Health Issues among Children and Adolescents Living with HIV, Disclosure of HIV Status and Counselling Support, Adherence Counselling and Support, Dealing with Adolescents Issues including Sexual and Reproductive Health, Grief and Bereavement Counseling, Palliative Care and Caring for the Professional Caregiver. Apart from this developmentally appropriate two supportive HIV disclosure booklets titled "Keeping Healthy and Strong" for the age group of 05-11 years old children and "Knowing about Myself " for the age group 12-16 years old adolescents to facilitative disclosure process using the parents/caregivers HIV



Flow Chart-1: Three Phases of the Project.

infected children and adolescents were also developed. The two booklets provide developmentally appropriate disclosure information to the children and adolescents living with HIV/AIDS.

The intervention package was field tested with 25 counsellors of ART Centers and NGO's in the three days intervention program. Majority (60%) of the participants had PG education. 40% had 12 years of experience as counselors in ART centers; and 60% of participants were female counselors with no prior training in counseling. Majority 80% of the participants reported lack of available training manuals to address the psychosocial issues of children and adolescents living with HIV/AIDS in their respective settings. Most of the counselors reported lack of disclosure materials and guidelines, difficulties in disclosing parental HIV status to either HIV infected or affected children, lack of counselling materials to address psychosocial issues and mental health issues, difficulties in handling children who are suicidal, lack of training in addressing sexuality issues, information on palliative care and counselling related adolescents' issues. In the intervention program the participatory methodology adopted in the training program. Each module was tested out using participatory methodology such as role play, brainstorming, activities, quiz and group discussions. The sharing of their experiences in each session helped them to understand the concepts in each session clearly from Day one till the third day. More stress was given to counselling skills and also handling psycho social issues of children living with HIV/AIDS and their families in their respective settings. The researchers also facilitated the group discussion, presentation, analysis, explanations, conceptualizations and summing of each session.

Apart from this all the chapters of the manual were revived by the participants' every day. The participants reviewed each of the chapter using the following parameters such as: content of the manual, relevance of chapter, number of pages, language used, style followed, illustrations-case illustrations, general presenting of the text, themes reflected and overall satisfaction. The feedback from the participants it was found of that the model is acceptable and feasible. Few participants suggested add more case vignettes related to mental and behavioural problems of children and adolescents living with HIV.

Phase 3: Finalization of model and the intervention package

The intervention package and disclosure booklets were given to the experts with extensive experience in working with children and adolescents. Their opinion and comments were sought to further refine intervention modules and disclosure booklets. The modules were edited for language, grammar and uniformity. Pictures were added in the beginning of each of the modules to break the monotony and modified where necessary. Information related transitional care from pediatric care to adult care guidelines were included. Final version of the intervention package and disclosure booklets was printed and it was circulated to all the health care service providers of ART centers and shelter homes counselors.

Discussion and Conclusion

This research is the first comprehensive study in Indian context which developed and standardized psychosocial care and support model for children and adolescents living with HIV and their families using health care providers of ART centers. The needs and concerns of the participants of the current study were similar with previous studies. Stigma, behavioural disorders, depression, rule breaking behaviour; delayed disclosure due to stigma by parents about the child's HIV status; dealing with multiple loss, grief, family neglect and poor treatment adherence are some of the consequences of HIV on children and their families living with HIV/AIDS [16-18]. Hence, health care service providers should work in multi-disciplinary team towards enhancing adaptive coping mechanisms and resilience in children living with HIV/AIDS.

Sariah [19] studied experiences of health care providers in relation to disclosure of HIV status of infected children where the authors found out that most health care provider felt disclosure is complex process and need for national guidelines. They viewed that parents lack need skills and training in disclosing child's HIV status and also stigma is another factor that delay disclosure by parents. Chronic depression, suicide, heightened risk of post-traumatic stress following traumatic events were common among HIV infected children and adolescents [19]. The current psychosocial care and support model is the only model in the country which addresses all these issues holistically to help the children and adolescents living with HIV in adaptive ways with the help of multi-disciplinary health care team in ART centers. The model developed by the NIMHANS team need to be integrated into existing programs in all the ART centers in the country to find out the effects and utility in addressing the complex issues of children living with HIV/AIDS on the various aspects of mental health, disclosure related issues, psychosocial well-being, quality of life and adjustment. The disclosure booklets developed by the research team of NIMHANS needs to be translated into various regional languages and made available at all the ART centers.

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