

## **Psychosocial issues of HIV-positive children in Mangalore, Karnataka (India)**

Tanguy Borgeaud dit Avocat, Julie Möckli, Claire Stoppa, Maelle Zürcher

### *Introduction*

In India, around 2 million people were infected with HIV in 2016 (1), of which children accounted for 6,54% of all cases (2). According to the *Park's Textbook of Preventive and Social Medicine* (2017), Karnataka is one of the 6 high HIV prevalence states, meaning that the prevalence is higher than 5% in high-risk groups and than 1% in antenatal women (3). Literature underlines the presence of psychosocial issues that HIV-positive children might face. Those include: stigmatisation, social isolation, depression, and so on (4)(5). As part of the Indian National Aids Control Plan (NACP-IV), psychosocial support and counselling are provided by Anti-Retroviral Treatment (ART) centres (6)(7). Experts also point out the importance of these interventions as well as of awareness programs to reduce stigma (5). One of the significant benefits of their wellbeing is a better treatment compliance (8). Despite that, there is still little literature on how to take care of the psychosocial aspects of HIV-positive children.

### *Method*

The objectives of this study are to identify 1) the potential psychosocial issues of HIV-positive children, 2) the involved professionals in their caring and, 3) the means to prevent psychosocial issues and to support HIV-positive children.

This study is based on a qualitative design. Before arriving in Mangalore (India), literature on the subject was reviewed. A Swiss nurse and physician both specialized in infectious diseases and especially in HIV were encountered, in order to understand the stakes of the subject in Switzerland. The protocol of this study was approved by the Father Muller Institutional Ethic Committee (FMIEC). Once in India, local literature was reviewed. Furthermore, comprehensive semi-structured interviews (9) were conducted in the following places : Father Muller Charitable Institutions (1 paediatrician, 2 nurses, 1 psychiatrist), a governmental Integrated Counselling and Testing Centre (1 counsellor), a Christian school (1 headmistress, 3 teachers) and 2 NGOs : a centre located in Mangalore (the director and the project manager) and a Christian centre located near Mangalore (2 nurses [Christian father and sister], 1 counsellor). Interviews were realised in duos nursing-medical students. They were conducted in English and, when needed, translated by a teacher from Father Muller Charitable Institution. Confidentiality and ethic requested in research were respected. Then, partial retranscription and analysis of the data by themes using a grid based on the Transcultural Nursing theory of Madeleine Leininger (10) were done. The analysis was firstly realised individually, in order to obtain inter-subjectivity and then shared with the group. This, in addition to the formulation of some hypotheses, allowed us to answer the research question.

### *Results*

According to the professionals interviewed, psychosocial issues start around the age of 10 as before this age there is no systematic disclosure or children do not understand the implications of the infection. Because of family neglect or orphan status, children are often sent to foster homes. People interviewed are almost only in contact with this population of infected children.

All professionals agreed that stigma is the biggest issue, which could be due to sexual connotations of HIV and misconceptions about its way of transmission. The main problems that respondents related to stigma are isolation, anxiety and depressive state. Some children were also reported to have insecurity regarding their future (studies, job and marriage) which was associated to neglect by family and/or society. This insecurity was reported by the psychiatrist to be linked to mental stress and substance abuse. Some issues underlined such as attention seeking behaviours, depressive state and sadness were said to be a result of their orphan status more than of their HIV infection. Non Governmental Organizations (NGOs) representatives and teachers also evoked issues due to children's physical health which lead to mental stress, anxiety and fear. In addition, divergent opinions were collected on whether infection affected school attendance. Although a lot of issues were reported, all interviewees agreed that nowadays there are fewer. Regarding the professionals involved, counsellors were spontaneously presented by all interlocutors as the main reference person for children having psychosocial issues. Other actors like social workers, NGO manager and director, priest, psychologist, nurses and on-call doctor were also underlined. Among the teachers interviewed, none of them declared having a relationship with these children allowing them to open up about their issues.

Emotional support and counselling were reported to be the main tools to take care of these issues. At school, children were selected for counselling when psychosocial issues were identified by stakeholders or when they opted for it themselves. In centres, there was provision for daily counselling. Besides, both centres paid special attention to provide a good and healthy environment by encouraging sports, healthy food, organising relaxing activities and providing a family-like environment. In order to inspire children, they also presented examples of people that lived in the centre and succeeded in life. All respondents emphasised that awareness through education among the general population is the best way to prevent the emergence of all these issues and that it is effective in Mangalore.

### Discussion

This research showed that psychosocial issues in the studied population start around the age of 10 and is related to awareness of their HIV status. In order to obtain information about a sufficient amount of children, this research focused on children under 18. This study results are in agreement with the recent literature on psychosocial issues of HIV-positive children in India. Notably, stigma is one of the most important issues. Social isolation, depression and anxiety are also pointed out. By analysing the results using the Transcultural Nursing theory of Madeleine Leininger, it appeared that most of the psychosocial issues are due to multiple factors. The most important are: educational, social, economical and cultural factors. However, this research showed that Mangalore is a city with a high level of education and that psychosocial issues in HIV-positive children population are decreasing. This was confirmed by the psychiatrist interviewed, who mentioned that these issues are more frequent in small villages with a lower education level. This leads to the hypothesis that education and awareness could be the key solution to decrease the prevalence of these problems, partly through stigma reduction. One point that could support this hypothesis is that the respondents noticed lower prevalence of psychosocial issues when school and home environment are both non-stigmatising (such as in the centre and school visited). Therefore, efforts have to be maintained in order to remove stigmatisation.

This research has some limits. One of them is that people interviewed were mostly in contact with orphans or single parents' children living in foster homes. Unfortunately, the ART centre declined the interview so information about children living with their family could not be collected. Results of this study can thus only point out issues faced by children living in foster homes and cannot be generalised to the ones living with their families. In addition, collected data shows that some psychosocial issues are more related to their orphan status than to their HIV infection. One avenue to disentangle this aspect would be a comparative study between infected and non-infected children living in foster homes.

To conclude, even though literature shows psychosocial issues of HIV positive children, fewer are noticed in Mangalore, thanks to the increased awareness among general population.

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**Key words :** HIV ; Children ; Psychosocial issues ; Mangalore ; India

# Children and HIV: what about psychosocial issues ?

## (Study done in Mangalore, Karnataka, India)

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### Introduction

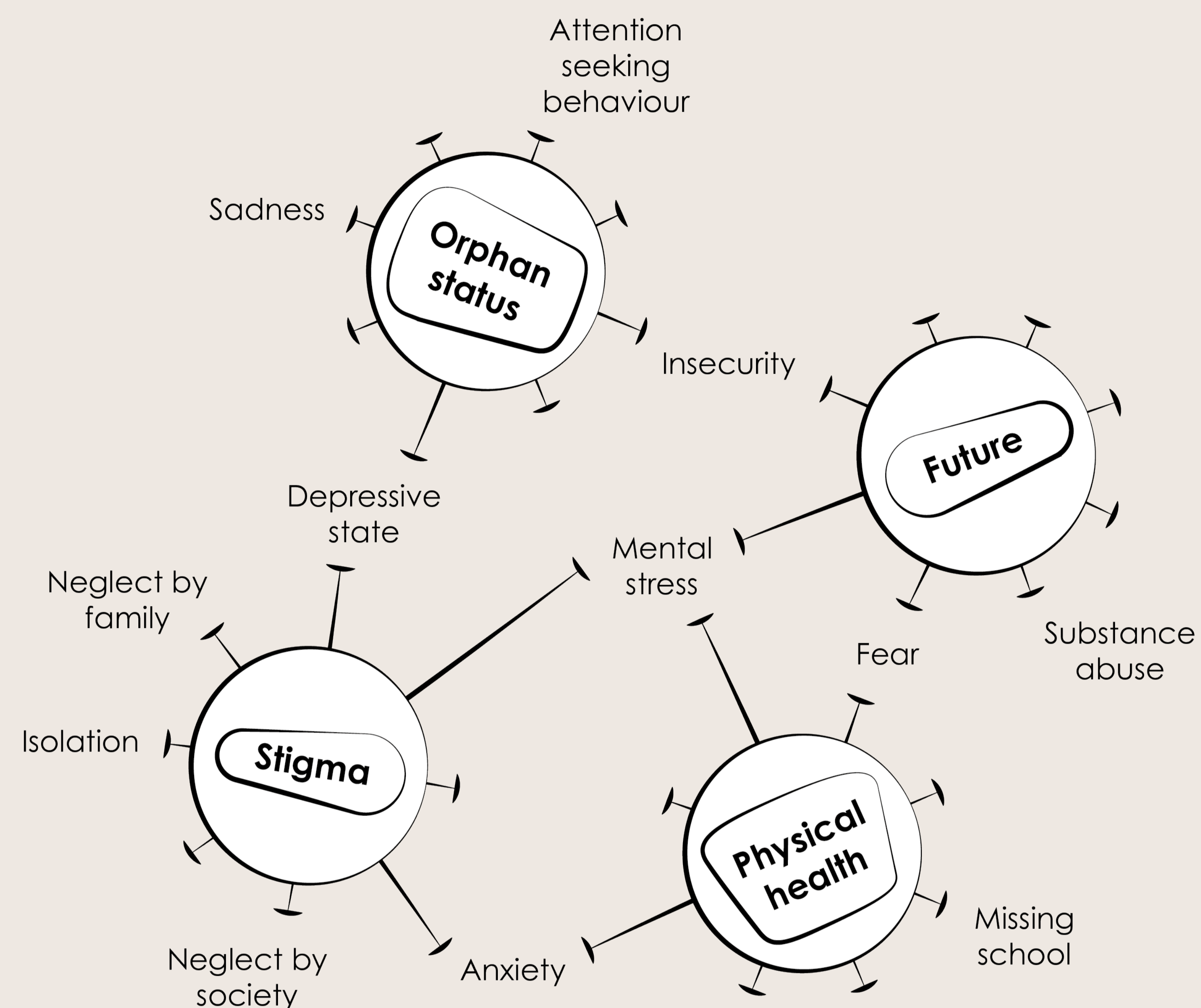
In 2016, India comprised around 2 million people infected with HIV<sup>1</sup>, of which 6,54% were children<sup>2</sup>. Those children can face psychosocial issues such as stigmatisation, social isolation, depression, aso<sup>3,4</sup>. Government treatment centres offer psychosocial support and counselling. Plus, awareness programs help to reduce stigma<sup>5,6</sup>. One of the significant benefits of their wellbeing is a better treatment compliance<sup>7</sup>. The purpose of our work is to better understand their issues and the way they are taken care of.

### Facts

- Free Anti Retroviral Therapy is provided by the government in India
- Most children infection happen through mother to child transmission
- Karnatana is one of the 6 high prevalence states (= prevalence higher than 5% in high risk groups and higher than 1% in antenatal women)

### Results

#### Psychosocial issues identified



#### Professionals identified



#### Principal means identified



### Objectives

- Discern and understand the psychosocial issues faced by HIV positive children in Mangalore
- Identify and meet the different health professionals, teachers and other stakeholders who are in contact with these children
- Identify the tools and the means used to approach these psychosocial issues in HIV positives children and the existing resources to prevent them

### Method

- Literature review (in Switzerland and in India)
- Comprehensive semi-structured interviews<sup>8</sup>
  - Health professionals (3)
  - NGOs representatives (5)
  - Education professionals (4)
  - Counsellor (1)
  - Psychiatrist (1)
- Individual analysis using a grid based on the Transcultural Theory of nursing of M. Leininger
- Results shared in group to obtain intersubjectivity

### Discussion and limits

#### Discussion

- According to the people interviewed, psychosocial issues start around the age of 10. It could be explained by:
  - disclosure at this age
  - understanding of HIV implications
- Psychosocial issues underlined by this study are similar to those found in literature
- There is no convergent opinion about missing school because of the infection
- Nowaday in Mangalore, fewer issues are perceived
  - interlocutors attribute this to better education that enabled increased awareness among the general population

#### Limits

- Respondents are only in contact with children living in foster homes
  - some issues could be related to their orphan status more than to their infection
- Translation biais is possible

### Conclusion

- Fewer issues in Mangalore, thanks to an efficient system and to increased awareness among the general population
- Key reference person = counsellor
- Key solution = education

### References and acknowledgements

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