HIV Status Non-disclosure in HIV-infected Families

We read with interest the recent article by Dwivedi, *et al.* [1] on HIV disclosure. The article comprehensively discusses disclosure from the perspective of an HIV-infected individual and his/her family, especially children. However, there is another facet of disclosure that is probably unique to our settings which has not been included in this write-up. It is the strange problem of hesitation in revelation of their HIV status by the individuals (or their family members) who are positive, to the doctors. Sometimes the non-disclosure of a positive-HIV status may not harm others but intentionally not revealing the information creates a situation of potential harm to others.

It becomes difficult to ascertain whether 'voluntary disclosure' is the responsibility of the parents or non-disclosure of their (or their ward's) HIV status, an unquestionable right to their privacy. Such scenarios are not very uncommon in our country, given the social stigma associated with HIV/AIDS. Parents also fear that revealing the seropositive status to the doctor would put them at risk of discrimination by the healthcare providers within the hospital or by others in the society. Though the stigma is understandable, failure to disclose the seropositive status to the treating physician puts the entire team of healthcare professionals at risk. Universal precautions have been devised precisely for such situations but the ground realities in resource-limited settings are far from ideal. It is also true that non-disclosure puts the child's life at-risk by delaying appropriate diagnosis and prompt treatment.

Worldwide, many countries have invoked legal provisions to tackle this problem by making non-disclosure a criminal offence [2]. According to the Indian Penal Code (IPC), acts likely to spread infection to cause any disease dangerous to life, are punishable [3]. Laws criminalizing HIV transmission may be applicable when there is "intentional [and] malicious" transmission [4,5], but only drafting laws may not solve this problem, as the real solution lies in changing the societal perception. There is need to work with individuals as well as in the society, to make every one understand the importance of disclosing their HIV status to physicians to ensure faster diagnosis, appropriate treatment as well as the safety of treating team of healthcare-providers.

This peculiar aspect of HIV non-disclosure needs to be highlighted on a global platform for creating awareness and seeking solutions. Empowering the society at large with the right knowledge and attitude is the way forward.

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HIV Status Non-disclosure: Author's Reply

HIV disclosure is still a challenge that is faced by Committed Communities Development Trust (CCDT) and other non-governmental organizations (NGOs) throughout the country. Due to stigma and discrimination associated with the illness, it is difficult for families to initiate illness-related discussions with loved ones. While conducting interviews with participants, many parents preferred meeting away from their homes, talked in lower voices, and did not want the neighbors to know about their

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affiliation with an HIV/AIDS organization. The study conducted with CCDT specifically included a cohort that has gone through a full disclosure process with family members, and received the appropriate medical treatment. Though initially there were uncertainties with illness disclosure, over time parents understood the importance of talking about the illness and included children in the discussions. The aim of our study was to focus on CCDT's disclosure practices and learn about the process from parents' and children's perspective. In order to keep the study objective concise, there was no mention of the national level non-disclosure gaps.

The argument you have made in your letter is a sincere concern for India. Even though with the available resources and free treatment, non-disclosure is still a detrimental public health issue for the country. Families are in constant fear of the stigma associated with the illness. In order to address this further, more qualitative and quantitative data need to be generated. There are numerous HIV/AIDS NGOs working independently on this issue; yet there is a lack of collaboration on effective programming and valuable practices. Without stable infrastructure, laws are not sufficient to encourage disclosure. There is a great need of direct ground level efforts, and collaboration between NGOs and providers to tackle this challenge. This is feasible through stricter government policies, increased countrywide discussions to destigmatize the illness, and continuous efforts from health providers and NGOs to educate infected families on the importance of disclosure.

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Trisomy 8 Mosaicism in a Boy with Dysmorphic Features

Trisomy 8 mosaicism is a rare condition with prevalence estimates in the range of 1:25000-1:50,000 births. It is a rare genetic disorder and clinically heterogeneous condition associated with a spectrum of developmental abnormalities, including intellectual disability, congenital heart defects and agenesis of corpus callosum [1,2]. Approximately 50% of these patients present with renal abnormalities [3]. We report a boy with dysmorphic features and delayed development.

A 10-year-old boy with delayed development and dysmorphic features was referred to us for cytogenetic analysis. The proband was first born child to consanguineous parents. He had short stature (height 121 cm, US: LS=0.86), dolicocephaly, broad nose with anteverted nostrils, flat tip pinnae, bilateral limited extension of elbow, restricted joint movements, bilateral comptodactyly, bilateral radial head subluxation, bilateral femoral neck coxa valga, squint, tongue tie, webbed neck and agenesis of corpus callosum. He had vestibular hypersensitivity, and fear of swings, heights and climbing of ladder. Psychological examination showed moderate sub-normality in social functioning. Radiological examination showed generalized osteopenia; electroencephalography (EEG) and thyroid function tests were normal. The cytogenetic analysis using GTG banding revealed mosaic trisomy 8 in 25% of metaphases scored. Fluorescence in situ hybridization (FISH) analysis using Vysis centromeric probe for chromosome 8 showed 59% cells with trisomy 8, and the karyotype was determined as mosaic trisomy 8 (46,XY/46,XY+8).

Trisomy 8 mosaicism occurs due to non-disjunction of chromosome 8 during mitosis in the zygote phase of fetal development. This condition is clinically heterogeneous, and it is associated with wide range of clinical abnormalities [1-4]. Our patient had additional clinical features: restricted joint movements, bilateral comptodactyly, bilateral radial head subluxation, bilateral femoral neck coxa valga, squint, tongue tie and webbed neck. Correlation of genetic abnormalities with clinical phenotype is always important to establish the syndromic diagnosis. The follow-up of mosaic trisomy 8 is essential, as it is more commonly seen in patients with acute myeloid leukemia and myelodysplastic syndrome.

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