A qualitative exploration of parental experiences of stigma while living with HIV in Bangladesh

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Abstract:

With much of the focus on the "risk" groups, families have often been less studied in HIV research. Further, because of a focus on the aetiology and epidemiology of HIV, the social impacts associated with HIV on families and neighbours are sometimes overlooked. This study examined parental experiences of stigma and discrimination while living with HIV within a family context in Bangladesh. A qualitative research design using a grounded theory approach was used for this research. Data was collected through in-depth interviews with 19 HIV positive parents, recruited with the support of two self-help groups of HIV positive people, in two settings namely Khulna and Dhaka in Bangladesh. The findings indicate that HIV-positive parents held the view that they continue to experience significant stigma and their narratives clearly show how this affected them and their children. A range of informal practices were enacted in everyday contexts by extended family and community members to identify, demarcate and limit the social interaction of HIV positive parents. Parents highlighted a number of factors including negative thoughts and behaviours, rejection, isolation and derogatory remarks as manifestations of stigma and discrimination, impacting upon them and their children because of their association with HIV.

Keywords: HIV; family; parents; children, stigma and discrimination; Bangladesh

Introduction

While HIV prevalence is low in Bangladesh (<0.1%), the number of HIV-infected individuals is steadily increasing. For example, recent data indicate that in 2013 there were 370 newly reported HIV cases and 95 newly reported AIDS cases compared to 338 and 103 in 2012 (Shahrin et al., 2014). As a result of this increase, research into the social impacts of HIV/AIDS in Bangladesh has emerged over time. Researchers have focuses mainly on measuring knowledge and recording public attitudes, especially the attitudes of health care workers towards HIV-positive individuals (Hossain & Kippax, 2012; Ullah, 2011), rather than describing the everyday experiences of HIV-positive individuals, such as relations between family members.

There is increasing recognition that HIV stigma may present distinct challenges for HIV-positive parents with children (Islam, Scott, & Minichiello, 2014). Research outside Bangladesh has suggested that parents have to cope with their own stigma, while at the same time dealing with social and personal issues associated with stigma due to living within HIV-infected families (Bogart et al., 2008; Cowgill et al., 2008; Guoping et al, 2007). This study examines parents' experiences of stigma and discrimination while living with HIV within families in Bangladesh.

Methods

A qualitative research design informed by grounded theory was used to describe and understand the everyday experience of stigma. Conceptually, stigma is used in this study as a social construct that uncovers the social processes that mark the lived experience of living with HIV

within a family context. Data were collected through in-depth interviews with 19 HIV-positive parents (either mother or father) who lived with at least one child in a family, recruited with the support of two self-help groups of HIV-positive people, in two settings namely Khulna and Dhaka in Bangladesh.

After confirming the informants' willingness to participate, the first author conducted the interviews at the offices of the self-help organizations. Following consent, the interviews were audio-recorded. The duration of interviews ranged from 35 to 110 minutes. Some interviews were longer because the participants raised more follow up issues as a result of the recursive method of interviewing used. Informants were compensated for their time and their names were replaced by pseudonyms.

The sample consisted of 11 mothers and 8 fathers. Among the informants, 16 were aged between 35 to 44 years, about three quarters had five years of less of education, and more than three quarters were Muslim. The interviews were conducted in Bangla using open-ended questions. The interview guide covered topics like, for example, responses to their diagnosis, relationships and interactions with family, extended family and community members, how HIV/AIDS has affected everyday living.

Data were analysed through Nvivo 9 using a coding system. After creating nodes, the other data were coded into more refined levels that identify or relate to particular theme. For example, in order to understand the meaning of stigma and discrimination clusters of themes

such as negative perceptions, exclusion, rejection, and isolation, contagiousness, and breakdown of relationship were developed for this study.

Results and discussion

From the findings, it is asserted that extended family members and community members held prejudicial stereotypes that were used to devalue HIV-positive parents in the community. The reaction from others towards them as HIV persons indicates a shift from self-identification as "normal" to being identified and categorized by others as "deviant" (Parker and Aggleton, 2002). As people held many misconceptions about HIV contraction, the notion that HIV occurred only through extramarital sexual relations had much currency in the community. Most of the parents (16 out of 19) interviewed were presumed by others to be sexually promiscuous and perceived as "the other", a person of less value in their community, and sometimes in the family unit.

It was therefore not surprising to hear stories of how, people referred to parents living with HIV using derogatory terms, which reinforced humiliation, rejection, isolation and social discrimination experienced by those living with HIV. These local terms included: 1) *kharapkaj* (bad practices); 2) *kharaplok* (bad person); 3) *kharaprog* (bad disease); and, 4) *kharapkotha* (bad words). These terms situated HIV within a moral and normative framework and inferred that those who had contracted HIV had, to use Goffman's (1963) concept, a spoilt identity. For example, *kharapkaj* has many meanings in Bangladesh and is used as a broad term to describe behaviours, beliefs, attitudes and social norms, values and standards that an individual transgresses.

In spite of having several meanings, parents perceived that when others referred to the cause of their HIV status as "bad practices" they specifically implied sexual promiscuity or, more particularly, that the parents had extramarital relations with sex workers. Likewise, in spite of having several connotations, a total 13 parents perceived that when community members referred to them (or their husbands in case of female parents) as "bad person" they specifically meant someone who had extramarital relations with female sex workers. Similarly, all the interviewed parents perceived that when community members referred to their HIV status as "bad disease", they specifically meant that the parents had contracted it via extramarital sexual relations with sex workers. For instance, *Sattar* indicated that community members believed that he contracted HIV after having sex with female sex workers; and that he visited different *kharapjaiga* ("bad places", e.g. brothels) to meet with *kharapmohila* ("bad women", e.g., female sex workers) and suffering with HIV was the outcome of his "bad practices". *Sattar* comments:

> When the status of my disease was disclosed everyone blamed me. They said "*okamkoreci tai vugteci"* (I was suffering from this disease by doing "bad practices"). People regarded me as a "bad person". They said that I had contracted this "bad disease" by visiting different "bad places" and meeting with "bad women". (Male)

These narratives indicate that the stigma associated with HIV/AIDS often made established communal and extended familial relationships vulnerable. Extended family members feared being associated with HIV-positive family members, lest they were also perceived as HIV-positive or labelled as having low moral standards for maintaining relationships with HIV-positive individuals (see, for example, Herek et al., 2002). For instance, *Abul* reported that his

brothers cut ties with him as they feared that, by proxy, they also may suffer stigma and discrimination. While they wanted to maintain the honour of families by distancing themselves from *Abul*, this only perpetuated and exacerbated the stigma and discrimination he experienced from others. *Abul* observed:

> My family has stopped loving me because of my disease. They thought if they loved me other people would hate them. They felt embarrassed to introduce me as their brother. (Male)

Due to the stigma associated with HIV, not only were the parents discriminated against but also were immediate family members, especially children. All the interviewed parents noted that the prevalence of rumours that HIV is transmitted through casual contact and interaction isolated them and their children from community participation. In a study Surkan and colleagues (2010) also reported that children were discriminated against simply for living within an HIV-affected family. Parents were distressed to report that their children were sometimes accused by others of having HIV. *Rahim* described how one of his children was humiliated and rejected by their peers for being associated with a HIV-affected family. *Rahim* recalled:

> One day my elder son went to play with other children. They quarrelled and bullied my son cruelly. They told my son that your father is suffering from AIDS and you are also infected with that disease. You will not play with us because if you come to us we will also be infected. (Male)

Conclusion

Having HIV is generally believed to be an indication of impurity in Bangladesh, and HIV contraction is considered to be an outcome of having committed “a sin” (Ullah, 2011). In this way, HIV is considered highly polluting and threatens not only public health, but the extant social order. The findings from this study support the strong sense of sexual “morality” in Bangladeshi society in which premarital and extramarital sexual relations are strictly prohibited, with real consequences for individuals and families (Ullah, 2011).

The data reveal that the experiences of stigma and discrimination of HIV-positive parents, are heavily influenced by the socio-cultural meanings of HIV that are constructed through interactions with families, extended families, and community members. Almost all the parents in this study reported that other people often reacted negatively towards them because of their HIV status. Perhaps, this is because they present a greater threat to the existing social order than those already situated outside of it as “others”, such as gay men and sex workers. Having acquired a new status, the social order has to react visibly and swiftly to create a new deviant identity for these people and often this process places them outside of the community with real everyday consequences for their ability to interact socially.

In spite of having several limitations being a qualitative research i.e., samples were purposively collected from two self-help groups, this pioneer study provides a picture of the extent of stigma and discrimination in the context of Bangladeshi society. Within the context of the findings, we argue that it is essential to formulate culturally appropriate intervention programs to educate

people about the modes of HIV transmission and minimize irrational fears about HIV and AIDS. It is important for future research to better describe the consequence of how family and community tension negatively influences people living with HIV and their children.

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