

# UC Irvine

## UC Irvine Previously Published Works

### Title

Perceptions and Health Care Needs of HIV-Positive Mothers in India

### Permalink

<https://escholarship.org/uc/item/1fq9c97z>

### Journal

Progress in Community Health Partnerships Research Education and Action, 3(2)

### ISSN

1557-0541

### Authors

Nyamathi, Adeline  
Thomas, Beena  
Greengold, Barbara  
et al.

### Publication Date

2009

### DOI

10.1353/cpr.0.0060

### Copyright Information

This work is made available under the terms of a Creative Commons Attribution License, available at <https://creativecommons.org/licenses/by/4.0/>

Peer reviewed



PROJECT MUSE®

---

## Perceptions and Health Care Needs of HIV-Positive Mothers in India

Adeline Nyamathi, Beena Thomas, Barbara Greengold, Soumya Swaminathan

Progress in Community Health Partnerships: Research, Education, and Action,  
Volume 3, Issue 2, Summer 2009, pp. 99-108 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/cpr.0.0067>



➔ *For additional information about this article*

<https://muse.jhu.edu/article/265904>

## Perceptions and Health Care Needs of HIV-Positive Mothers in India

Adeline Nyamathi, PhD<sup>1</sup>, Beena Thomas, PhD<sup>2</sup>, Barbara Greengold, PhD<sup>1</sup>, and Soumya Swaminathan, MD<sup>2</sup>

(1) University of California, Los Angeles—School of Nursing; (2) Tuberculosis Research Centre

Submitted 28 June 2008; revised 27 October 2008; accepted 20 November 2008.

### Abstract

**Background:** An estimated 2.5 million Indians live with HIV/AIDS. Spread primarily through heterosexual contact, the epidemic is shifting toward women, 29% of whom are currently infected, with still more cases going unreported. As the primary caregivers for their families, women face many challenges when it comes to accessing care; these include dealing with discrimination from family, community, and health care providers, and a general lack of education, social support, and nutrition guidance and sustenance.

**Objectives:** The purpose of this study was to explore the perceptions and experiences of a group of HIV-positive mothers living in India to learn about the challenges they face in terms of assessing health care services, dealing with mental health stressors, and giving them a voice in designing the structure of a culturally sensitive and tailored intervention for women like themselves.

**Methods:** This study used a qualitative approach using focus groups consisting of a convenience sample of 60 HIV-infected mothers recruited from a large maternity hospital and sexually transmitted disease clinic in Chennai, India. Using a semi-

structured interview guide, information was solicited from participants and qualitative content analysis conducted to determine common themes discussed among the groups.

**Results:** Participants described challenges they face on a day-to-day basis, living with HIV and factors that prevent or help them to seek, obtain, and maintain care. The women also provided recommendations for future intervention plans, to include counseling, nutritional support, psychological support, and educational services for women living with HIV.

**Conclusions:** Findings of this study provided a rich backdrop upon which a community-based AIDS program for HIV-positive mothers in India can now be designed.

### Keywords

Community health research, community-based participatory research, health promotion, HIV/AIDS, women's health preventive health services

In India, there are an estimated 2.5 million people living with HIV/AIDS; of those infected with HIV, about one third are women of childbearing age.<sup>1,2</sup> Injection drug users, men who have sex with men, and female sex workers have long been identified as groups at high risk for the development of HIV/AIDS; however, the rates of infection are increasing among women whose only risk behavior is to engage in sex with their marriage partner.<sup>3,4</sup> HIV/AIDS is transmitted primarily through heterosexual contact (86%), followed by mother-to-child transmission (3%), blood products

(3%), and through injection drug use (2%).<sup>5</sup> Among antenatal women, the HIV prevalence rate has been reported to be more than 1% in many states within India.<sup>6</sup>

In 2004, the National AIDS Control Organization launched a program providing free antiretroviral therapy (ART) to those in need in India, including HIV-positive pregnant women, children up to 15 years of age, and adults with AIDS.<sup>7</sup> Still, HIV-positive persons in India continue to face a number of challenges that deter accessing care, including dealing with discriminatory behaviors by family in the home environment,<sup>8</sup>

as well as by health care and social providers who fear infection from casual contact.<sup>9</sup> Poor health-seeking behavior among HIV-positive women has also been identified as an on-going challenge,<sup>6,7,10</sup> because a greater number of men with HIV often receive care from their relatives, whereas HIV-positive women often overlook their own needs and do not seek or receive care.<sup>11</sup>

The purpose of this study was to explore the perceptions and experiences of women, and particularly mothers living with HIV/AIDS (MLH) who have children, to learn about the challenges they face in terms of assessing health care services, dealing with mental health stressors, and giving them a voice in designing the structure of a culturally sensitive and tailored intervention for women like themselves. By understanding the social and cultural perspectives and experiences of the mothers to be served, there is a greater potential for creating tailored intervention programs that will lead to realistic and need-based outcomes.<sup>4</sup>

#### IMPACT OF HIV/AIDS ON MLH

As the HIV/AIDS epidemic in India becomes increasingly feminine, appreciating the family and gender-based influences that impact support and care delivery of HIV-infected women is critical to aid clinicians and researchers in the design of culturally sensitive programs.<sup>12</sup> Despite the fact that mothers in India are the primary caregivers for their family, they have little to no power in sexual decision making,<sup>8</sup> and lack basic knowledge of HIV transmission. They are thus prime targets for becoming HIV positive.<sup>11</sup> When living with HIV, MLH often face a series of social, psychological, and economic problems, such as coping with stigma, caring for an ill husband, providing income to the family if the husband is ill or deceased, and caring for children, some of whom may be HIV-infected or have AIDS.<sup>8</sup> As a result, MLH often find themselves with little time to devote to their own health problems and moreover lack information about HIV disease progression. The cumulative negative effects are overwhelming in terms of heavy work demands, poverty, child bearing, and child rearing, increasing MLH's susceptibility to opportunistic diseases and mortality.<sup>13</sup> The psychological pain that these mothers experience in their daily lives is as great as their physical pain.<sup>14</sup> These challenges often lead MLH to exhibit powerlessness, victimization, and anger.<sup>15</sup>

The life of a MLH is, however, improving. In a recent study of 268 women in Hyderabad, Bangalore, and Imphal, findings revealed that almost all the participating women received services from nongovernmental organization-supported Prevention of Parent to Child Transmission programs; most of these women took AZT to prevent transmission to their unborn child, and nearly three fourths utilized replacement feed for their babies.<sup>7</sup> Nearly 80% of the women reportedly received financial and emotional support from husbands and parents; still, stigma and poor access to care were also apparent. As long-term implications of affording or accessing ART become apparent,<sup>6,12</sup> the need for continued sharing of perspectives and experiences from women who can inform and guide the design of programs that meet the needs of all women is critical.<sup>16</sup>

#### COMPREHENSIVE HEALTH SEEKING AND COPING PARADIGM

The Comprehensive Health Seeking and Coping Paradigm (CHSCP)<sup>17</sup> has guided many investigations of impoverished adults at risk for HIV/AIDS or other infectious diseases in Los Angeles<sup>4,18,19</sup> as well as India.<sup>4,20</sup> Originally adapted from Lazarus and Folkman's<sup>21</sup> stress and coping paradigm and Schlotfeldt's<sup>22</sup> health-seeking paradigm, the CHSCP proposes that a number of factors impact health outcomes of vulnerable populations who experience health disparities. These include sociodemographic, situational, and personal factors; physical health and social resources; cognitive appraisal; and coping responses. In this study, sociodemographic factors reflect age, marital status, gender, education, and history of HIV/AIDS. Situational factors encompass environmental facilitators and barriers to successful coping with HIV/AIDS and health-seeking behaviors, such as inadequate transportation or financial resources. Personal resources include mental health and well-being; social factors reflect an important resource for MLH, namely, social support provided by spouse, family, or health care providers. Physical health represents yet another critical resource, whereas cognitive appraisal reflects education about HIV/AIDS diagnosis and treatment. Finally, coping behavior relates to the ways MLH deal with their illness, including seeking health care and requesting information, all of which may impact health outcomes, such as compliance with ART and maintenance of focused goals.

The CHSCP has been tested in a number of studies that

validate the constructs of the model. For example, a causal model of the CHSCP successfully assessed personal, cognitive, behavioral, and demographic predictors of coping responses and health outcomes of HIV testing and return for test results, and having an sexually transmitted disease as outcome variables.<sup>23</sup> Findings revealed that more social support, greater AIDS knowledge, greater perceived risk for AIDS, and more problem-focused coping predicted HIV testing and return for results. In another study, variables of the model related to self-esteem, social support, environmental and substance abuse-related factors, and sociodemographic factors predicted a positive attitude about quitting alcohol or drug use among homeless women.<sup>24</sup> More recently, the CHSCP predicted effectiveness of nurse case managed strategies focused on completion of TB chemoprophylaxis among a sample of homeless adults.<sup>25</sup>

## METHODS

### Design

A qualitative approach utilizing focus groups was conducted with MLH who were offered ART, free of charge, by the Government of India Programs. Fundamental qualitative descriptive methods are sought to develop a description of the life experiences of the HIV-positive women with children and the meanings attributed to their portrayal of events.<sup>26</sup> A total of 11 focus groups, lasting 60 to 75 minutes, were conducted with groups ranging from four to seven women. The study was approved by the Ministry of Health, Government of India, and the University of California, Los Angeles Human Subject Protection Committee.

The design included a strong focus on community-based participatory research, which welcomes the contributions of the community in the design, implementation, and evaluation of research that is designed to prove valuable to populations in need.<sup>27</sup> Empowering the team with knowledge of the social and cultural perspectives and experiences of the target population to be served promotes the potential for successful outcomes of the project and leads to the design of intervention programs that will be realistic and need based.<sup>25</sup>

### Community Advisory Board

Employing community-based participatory research strat-

egies, extensive discussions were conducted with a community advisory board (CAB) composed of 15 members that included medical officers, counselors of the maternity and government hospitals, representatives of non-government organizations working with HIV-infected women, and MLH themselves. All CAB members were intimately involved with the treatment and care provided to MLH and were interested in supporting MLH in receiving improved care; their participation has been an incredible strength in ensuring that the findings are relevant to the population. As a group, the CAB met with the research team on a number of occasions and have provided helpful insights into possible ways to access HIV-positive women, private areas within each site for which the study could be conducted, and a discussion of the needs of the women as perceived by these members.

The CAB was also involved in assessing and refining the questions that were posed to the women, and thus played a major role in formulating the semistructured interview guide to ensure that the content was culturally sensitive and linguistically appropriate for the women. Upon completion of the focus groups, and after the data were transcribed and analyzed, the CAB reviewed the findings and validated the women's perceptions about what the future intervention might include. In terms of dissemination, the CAB have returned to their work sites to discuss the findings of the study and plans for additional meetings are anticipated to finalize the design of a future intervention and seek grant support for funding.

### Participants and Setting

A convenience sample of 60 HIV-infected MLH were recruited from two large maternity hospitals, a large sexually transmitted disease clinic, and an ART clinic in a Government Hospital in Chennai, India. The study inclusion criteria were documented HIV-positive mothers living with one or more children aged 0 to 10 years, age 18 or older, ability to speak in Tamil (the spoken language of the women), and willingness to provide written consent in participating in the study. The women ranged in age from 23 to 42 years, with a mean age 30. Approximately half ( $n = 27$ ) of the women had one child, with two women having three or more children. About one third (30%) of the women were housewives; the remaining women worked in assorted jobs, such as tailors, teachers, or as staff in offices or nongovernmental organizations.

## Procedure

Approved flyers describing the study were posted in the sites where data collection occurred. MLH interested in being a part of the study notified the research staff member who was available at a designated and private room at the site. After information was provided about the study, interested women were read the informed consent and discussion of the consenting process followed. After all questions were answered, women wanting to participate in the study signed the informed consent and were asked questions to determine their eligibility, which included the ability to validate HIV/AIDS status. Those questions asked the women's date of birth, employment status, HIV/AIDS status, marital status, number of children, and age of children. All women who met eligibility criteria were provided with a date and time to join the group.

At the beginning of each focus group, eligible MLH were greeted by the focus group facilitator and a research assistant; both were well trained in methods of qualitative focus group design. A semistructured interview tool (Appendix 1), based on an extensive review of the literature relating to issues of relevance to MLH (e.g., stigma, disclosure, and psychosociocultural factors affecting MLH health-seeking behavior), was used to solicit participant response. This interview tool, used as a guide for each focus group, was developed based on the CHSCP constructs to cover sociodemographic, situational, and social factors; cognitive appraisal; coping responses; and health outcomes as they relate to the challenges MLH face seeking and obtaining care and maintaining their mental health. To capture the interview content, all discussions were recorded with participant permission. One of 11 discussions was not taped owing to audiorecorder malfunction; however, the content was written verbatim by the research assistant during the focus group and reviewed by the research facilitator for accuracy. During the focus group sessions, the research assistant also captured observations such as nonverbal interactions, gestures, and emotional content of the women by means of field notes.

## Data Analysis

Transcripts from the groups were analyzed manually and using computer methods. NVivo,<sup>28</sup> a qualitative software program, was used to store and organize the focus group interview data. Data were summarized to determine the challenges MLH face living with HIV/AIDS, the factors that

related to these challenges, and the format they recommended with respect to the actual delivery of the intervention program. Content analysis was carried out by two researchers trained in qualitative analysis once the transcripts were summarized. This was performed by selecting several units of analysis and then quantifying participant response around each category. Content analysis was used to evaluate the number of separate examples elicited from focus group participants' responses.

## RESULTS

Data from the transcribed focus groups revealed a number of issues related to the delivery of care to MLH. Consistent with the CHSCP theoretical framework, we discovered a number of health-related problems MLH experienced in dealing with HIV; institutional and financial barriers experienced; factors facilitating care seeking; strategies health care providers could employ to provide better care for MLH; and ideas relating to the structure of an intervention designed by MLH.

### Health-Related Problems of MLH in Dealing With HIV

Women identified the following health-related problems that led them to seek medical care: headache, fever, diarrhea, pain, herpes infection, vaginal infection or discharge, sore throat, fluid in the lungs, tuberculosis, back and neck swelling, fatigue, and nausea and vomiting. The most common symptoms for which they sought care included headache and fever. Most of the women said that only when symptoms were severe did they seek health care, in part because of challenges they sought in seeking care, such as discrimination resulting from stigma from family and health care providers. Fear of being discovered as being HIV positive was also experienced as a barrier. For example, one MLH recounts, "I do not go when I have guests at home. I cannot tell them I am going to the hospital and so avoid going."

### Institutional and Financial Barriers Faced by MLH

Delay in surgery was a challenge experienced by these women. Many reported experiencing delays in childbirth-related services or delays in medical interventions, caused by HIV status disclosure. As one woman commented, "We would like programs which do not delay us in the clinic. When we have to go to the counselor, then the doctor, then to get the drugs, there is delay. Sometimes it takes even two hours.

We need to go back home and cook. We become so tired.” Another participant said that “private hospitals do not think well of us once they know our HIV status”; this perception was echoed by another MLH who said that “if we need surgery, the surgery is unnecessarily postponed.” As one woman reported, “I was admitted to the hospital for 1 month and they refused to even do the sterilization for me, when I said I did not want a child. They told me to wait till 15 others had [the surgery] completed.” Another woman who needed an operation reported the doctors were delaying her surgery for more than one month and she was subjected to unnecessary and repeated investigations.

Inability to seek care was also a result of lack of finances for traveling to the provider, or having someone to care for their children. However, they sought care immediately when their children were sick. One participant mentioned that she had no one to take care of her or her children, making it all the more difficult to live with HIV. Difficulties of caring for children while feeling ill was cited by many as an ongoing challenge for MLH, particularly as it related to who would care for the children, pay for their education, and employ them.

#### Factors MLH Perceive as Facilitating Care Seeking

Types of care women desired included counseling, HIV testing, and symptomatic treatment by a concerned physician with minimal delay. As one participant reported, the availability of counseling services had motivated her to seek care. The majority of participants agreed that “caring health care providers” were the key ingredient motivating them to seek and receive care. Several women said that it was also important to have loving, supportive care offered to their children.

Additional facilitators included “knowing other women will be there that are also HIV infected,” knowing benefit will be gained by the mother and child/ren, and the importance of receiving information about nutrition, about ARV treatments, and how to cope with life’s problems encountered as a mother and a woman. They also valued information about seeking legal aid.

#### Strategies Health Care Providers Can Employ to Provide Better Care for MLH

Basic education about HIV/AIDS was expressed as one of the most important needs that the women had. The needs

related to dealing with the psychological impact of their own illness. As one woman revealed,

When I heard about the disease, I worried that I will die soon. After going for counseling, I was able to understand better. The experiences in the hospital also helped me develop a more positive attitude.

HIV/AIDS education was also critical for MLH as they desperately sought health care for their spouses. For one woman, knowing more about HIV when her husband was alive would have been very helpful:

I did not know about my husband’s HIV status till one week after his death. At that time, I was told there was no medicine for this disease. If I only knew about the drugs available that I got, my husband could also have been treated.

Thus, improved knowledge about HIV/AIDS could have positively impacted the way these women were able to deal with HIV/AIDS.

Twelve percent of the MLH also recommended that interventions be offered free of charge, and that ART should be available on a life-long basis, because lack of resources to purchase ART was a definite barrier for these women to keep healthy. Some MLH recommended that ART should be provided in more centers, but most agreed that it was more important that therapy be offered close to their homes. One woman said that “everything should be provided under one roof.” Having more health care workers and better availability of medication was recommended.

Another woman reported a facilitator for her would be a hospital close to her residence. She commented, “I will go there since I come from a village and have to come so far. Access to service close by our residence will be helpful.” However, another MLH felt that if the center was too close to the residence, others would recognize them.

Social support was seen as another critical resource for MLH. For example, one woman appreciated it when the field investigator visited the home as “I feel so good—I feel there is so much concern.” The majority of mothers (65%) requested compassionate care for themselves and their children, and for quality care to be delivered with respect and concern.

Nutrition was a critical element for many women (61%), because the drugs were difficult to take without proper nutri-

tion. Many women were unable to purchase nutritious food owing to a lack of income; all the women recommended that nutritional services be provided in conjunction with intervention and counseling. In particular, nutrition demonstration programs that presented cost-effective and tasty meals that could be made easily and quickly were requested. The provision of nutrition in the form of Kanji, pulses, dates, sakhimao, and dried fruits would be highly desired because these foods were not easily afforded by many women. However, the powdered nutrition packets were not liked by many women. They were reportedly more difficult to store, and led to insect infestation. One woman reported the powder to be indigestible. Another woman was concerned that the nutritious packets they were currently receiving might disclose their HIV status.

We need programs which would provide us with nutrition supplements like Horlicks instead of the sathumavu [nutritious flower] we are given now. These packets have the HIV symbol [red ribbon] and we need to hide it. It would be good if they are given to us in small quantities and we refill when we need to. The problem is with big quantities in that storage becomes difficult and the amount is more than we require. Each patient should be asked for his/her requirements and the packet given according to their need.

Small acts of consideration and thoughtfulness were suggested by another woman who thought “maybe a cup of tea when we enter since we reach the hospital so tired.” Another mother recommended that the government involve MLH without jobs in preparing nutritious food and distributing to others impacted with HIV/AIDS.

#### Structure of an Intervention Designed by MLH

The participants suggested that the intervention sessions be offered at the ART delivery sites. Although a few participants said that families and children should not be included in the actual intervention sessions, most of the women (71%) said it was important for their spouses to be invited to education sessions targeted for the men in the form of support groups. Several women were clear that they did not want programs for men and women together.

For other women, having caregivers present was important to them so that care at home could be improved. As one woman expressed, “it is better to also include those at

home who give us care so that they will understand about the disease.” Other women were adamant that those who they felt would stigmatize them should be included in the education session. Approximately 5% of the participants recommended that physicians should receive educational interventions. Other women stated that physicians should meet with patients in support groups. The women were very clear that doctors need to be better informed about the impact negative care has on them and that HIV-positive women should share their experiences with their doctors.

Specific content MLH requested included information about positive ways of living with HIV/AIDS, nutritional counseling and nutritional supplements, emotional counseling, the provision of loving care, and support groups. For one sixth of the women, counseling on sexuality was important. For half the women, information on how to disclose their HIV status to their children and their family was very important. As one woman revealed,

We do not know what to do, when to tell our children about our status, and for those who have positive children, they need to be told on how to disclose the child’s status to them.

Peer-led intervention was mentioned by one woman and a group format was recommended by five others. However, the MLH cautioned that newly HIV-diagnosed mothers should not be exposed to group sessions immediately; rather, they should meet another HIV-positive mothers one on one to feel more comfortable. Group sessions were recommended for MLH who feel comfortable with their status. In addition, role playing (skits) was considered as helpful and entertaining. Four women thought that television serials would be a good way to educate the community about HIV, and for one woman, having a well-known actor present positive aspects about HIV/AIDS was important.

#### DISCUSSION

The purpose of this study was to explore, via focus group analysis, the perceptions of MLH with respect to the challenges they face living with HIV/AIDS, the factors that facilitate or impede health-seeking behavior, and the format and the structure of a future intervention program. The findings indicate that a number of factors were revealed that were centered



around the CHSCP variables, including sociodemographic, social, and resource variables, as well as cognitive appraisal, and coping, were mentioned by MLH as factors related to seeking and accessing health care.

As a critical resource, physical health ailments and personal factors, such as perceived stigma, were the greatest challenges facing MLH. Physical ailments led MLH to seek care, but stigmatization resulted in fear, which simultaneously prevented them from seeking care.

Personal factors such as mental health status was perceived by the women as also important. Because depression can interfere with medication adherence, treating depression in people living with HIV, in advance of or concurrently with ART, has been suggested.<sup>29</sup> Our findings show that MLH are aware of the psychological challenges of living with HIV/AIDS, and they recommend that psychological and counseling services be included in the intervention.

The findings also indicate that it is of paramount importance to MLH to have access to caring health care providers and having easily accessible interventions. In addition to having more accessible and involved practitioners, MLH recommend that services be provided at locations that are close to the home, and that everything should be offered in one place. They also believe that services should be available at minimal or no cost. Our findings are also in accord with other studies demonstrating that affordable health care is important to those living with HIV.<sup>6,9</sup> However, access to HIV-related care is in a state of flux, and there are many obstacles that still need to be overcome to make antiretrovirals accessible.<sup>30</sup> However, the Government of India is promoting strategies to target improving the education of health care providers and promoting delivery of interventions for HIV-positive persons in a more accessible and cost-effective manner.<sup>31</sup>

A number of other situational barriers, however, existed, besides access, that impacted the women's receipt of services. Another included the attitude and behaviors of the physicians; often times seen by the women as uncaring and stigmatizing. The participants believed that physicians should become more familiar with individual cases, and should be a part of the educational and counseling services offered to MLH. One of the suggestions offered by the participants was to reduce HIV-related stigmatization by providing physicians with education about the disease. Providing education to health service providers is

considered to be crucial in changing attitudes and reducing stigmatization.<sup>32</sup> These findings are consistent with findings from other focus group studies where HIV-positive adults expressed concerns about HIV-related stigmatization.<sup>12,18</sup>

Finally, cognitive appraisal was another critical component identified by the MLH. Lack of awareness and knowledge of HIV transmission has been associated with increased risk of HIV/AIDS infection.<sup>16</sup> Our study demonstrates that MLH would welcome receiving more education, and would like education to be a part of the intervention. They suggest that the educational process be provided informally, in counseling sessions and support groups. They also want education to be made available to their families and to the community. It has been noted that one way to reduce HIV-related stigmatization is to provide better community-wide education<sup>32</sup> and our findings show that MLH believe this as well.

Based on the perspectives of these MLH, the ideal for these women would be programs that would attend to the concerns of physical health, mental health, family support, and social networking in a way that would be culturally sensitive and adaptable, particularly for mothers who have young children. Although these findings are appropriate for all women with HIV, the fact that mothers with HIV expressed concerns regarding care giving issues and lack of care givers as one factor impacting accessing health care regularly. In addition, concerns of adequately caring for children while ill is a concern that needs to be addressed.

Within the community wherein these MLH reside, future interventions need to be targeted so that greater awareness of HIV/AIDS and how it impacts the lives of all those who are positive or live with those who are positive is understood. The need for the provision of services free of cost at government hospitals and the need to treat people living with HIV/AIDS without discrimination is critical. There is also need for more training for health care providers and technical staff who deliver care to MLH and other persons in a way that addresses compassionate care and delivery of care without stigma and discrimination, which continue to pose an impediment to MLH's quality of care.

## CONCLUSION

As a result of a longstanding partnership with researchers in India and with the leadership of their medical officers

and counselors of the maternity hospitals, representatives of non-government organizations working with women and MLH themselves, knowledge of facilitators and barriers MLH experience has led to preliminary discussions of the design of an intervention that will need to be tested for efficacy. As demonstrated by the CHSCP, a number of issues are experienced by MLH. Two major issues are living with HIV-related morbidity and stigmatization by health care providers and community dwellers. Other issues that MLH have to face, include access to care, financial challenges, and an inability to take care of themselves, their children, and their families (secondary to their ill-health). The MLH in this study have shared their perceptions of what life living with HIV is like, and have offered suggestions with respect to how future interventions can help them to live better lives.

The MLH have made the following suggestions as to the structure and format of the future intervention:

- better HIV education should be provided to physicians and other health care providers;
- HIV education should be available for MLH, their families and friends;
- educational sessions should be incorporated into support groups;
- nutritional support should be available;
- support groups should be offered;
- medication and other services should be easily accessible and provided at low, or no cost;
- health care providers should assist MLH with respect to disclosure issues;
- and all health care services should be available in a central setting.

As demonstrated by the CHSCP, a number of challenges are experienced by MLH. Two major issues are living with HIV-related morbidity and stigmatization by health care providers and community dwellers. Other issues that MLH have to face, include access to free or low-cost care, financial challenges, and an inability to take care of their children and families (secondary to their ill-health). The MLH in this study have been able to share their perceptions of what life living with HIV is like, and have offered suggestions with respect to how future interventions can help them to live better lives.

## REFERENCES

1. UNAIDS. 25 million people in India living with HIV, according to new estimates. Press release. Geneva: United Nations; July 6, 2007.
2. National AIDS Control Organization (NACO). HIV Sentinel Surveillance and HIV estimate. New Delhi (India): NACO; 2006.
3. Newmann S, Sarin P, Kumarasamy N, Amalraj E, Rogers M, Madhivanan P, et al. Marriage, monogamy, and HIV: A profile of HIV-infected women in south India. *Int J STD AIDS*. 2000;11:25–253.
4. Nyamathi AM, Suhadev M, Swaminathan S, Fahey JL. Perceptions of a community sample about participation in future HIV vaccine trials in South India. *AIDS Behav*. 2007;11:619–27.
5. National AIDS Control Organization. Prevalence of HIV/AIDS in India. New Delhi (India): NACO; 2004.
6. Mawar N, Joshi P, Sahay S, Bagul RD, Paranjape RS. Concerns and experiences of women participating in a short-term AZT intervention feasibility study for prevention of HIV transmission from mother-to-child. *Cult Health Sex*. 2007;9:199–207.
7. Mahendra V, Mudoi R, Oinam A, Pakkela V, Sarna A. et al. Continuum of care for HIV-positive women accessing programs to prevent mother-to-child-transmission. Findings from India. Washington (DC): USAID; 2007.
8. Thomas B, Rehman F, Suyanarayanan D, Josephine K, Dilip M, Dorairaj VBS, et al. How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals in Chennai, South India. *AIDS Care*. 2005;17:795–801.
9. Tarakeshwar N, Krishnan AK, Johnson S, Solomon S, Sikkema K, Merson M. Living with HIV infection: Perceptions of patients with access to care at a non-governmental organization in Chennai, India. *Cult Health Sex*. 2006;8:407–21.
10. Mitra P, Schaffer T. Strategy for the second wave: Learning from India's experience with HIV/AIDS. Washington (DC): Center for Strategic and International Studies; 2004.
11. D'Cruz P. In sickness and in health: The family experience of HIV/AIDS in India. Kolkata: STREE; 2003.
12. Tarakeshwar N, Srikrishnan AK, Johnson S, Vasu C, Solomon S, Merson M, et al. A social cognitive model of health for HIV-Positive adults receiving care in India. *AIDS Behav*. 2007;11:491–504.
13. UNAIDS. AIDS epidemic update. Geneva: The United Nations; 2002
14. Ingram D, Hutchinson SA. Defensive mothering in HIV-positive mothers. *Qual Health Res*. 1999;9:243–58.
15. Chandra PS, Deepthivarma S, Jairam KR, Thomas T. Relationship of psychological morbidity and quality of life to illness-related disclosure among HIV-infected persons. *J Psychosom Res*. 2003;54:199–203.
16. Morrow M, Arunkumar MC, Pearce E, Dawson H. Fostering disability-inclusive HIV/AIDS programs in northeast India: a participatory study. *BMC Public Health*. 2007;7:125–35.
17. Nyamathi A. Comprehensive health seeking and coping paradigm. *J Adv Nurs*. 1989;14:281–90.
18. Nyamathi A, Singh VP, Lowe A, Khurana A, Taneja D, George S, et al. Knowledge and attitudes about HIV/AIDS among homeopathic practitioners and educators in India. *Evid Based Complement Alternat Med*. 2008;5:221–5.
19. Nyamathi A, Nahid P, Berg J, Burrage J, Christiani A, Aqtash S, et al. Efficacy of nurse case-managed intervention for latent tuberculosis among homeless subsamples. *Nursing Res*. 2008;57:33–9.
20. Suhadev M, Nyamathi A, Swaminathan S, Venkatesan P, Sakthivel R, Shenbagavalli A, et al. A pilot study on willingness to participate in future preventative HIV vaccine trials. *Indian J Med Res*. 2006;124:631–40.
21. Lazarus R, Folkman S. *Stress, appraisal and coping*. New York: Springer Publishing Co.; 1984. p. 117–80.
22. Schlotfeldt R. Nursing in the future. *Nurs Outlook*. 1981;29:295–301.
23. Nyamathi A, Stein J, Swanson J. Personal, cognitive, behavioral and demographic predictors of HIV testing and STDs in homeless women. *J Behav Med*. 2000;23:123–47.
24. Nyamathi AM, Stein JA, Dixon E, Longshore D, Galaif E. Predicting positive attitudes about quitting drug and alcohol use among homeless women. *Psychol Addict Behav*. 2003;17:32–41.
25. Nyamathi A, Stein JA, Schumann A, Tyler D. Latent variable assessment of outcomes in a nurse case managed intervention to increase latent tuberculosis treatment completion in homeless adults. *Health Psychol*. 2007;26:68–76.
26. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23:334–40.
27. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19:173–202.
28. NVivo software Version 7. Doncaster (Victoria, Australia): QSR International Pty Ltd.; 2006
29. Kalichman SC, Graham J, Luke W, Austin J. Perceptions of health care among persons living with HIV/AIDS who are not receiving antiretroviral medications. *AIDS Patient Care STDs*. 2002;16:233–40.
30. MacQueen KM, Namey D, Chilongozi A, Mtweve SP, Mlingo M, Morar N, et al. Community perspectives on care options for HIV prevention trial participants. *AIDS Care*. 2007;19:554–60.
31. National AIDS Control Organization (NACO). When it comes to AIDS silence means death. A newsletter of the National AIDS Control Organization. (Vol 4–5). New Delhi (India): NACO; 2005.
32. Mawar N, Sahay S, Pandit A, Mahajan U. The third phase of HIV pandemic: Social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian J Med Res*. 2005;122:471–84.

## APPENDIX 1. Focus Group Questionnaire (Translated from the Tamil language)

Please tell us what health services you have sought in the last few years.

If you ever had a time when you had a health-related problem but did not seek care for it, what stopped you, or got in your way?

What, if anything, has helped you to seek and receive care when you have needed it?

Where do you, or your family, typically go to seek this care?

What kinds of HIV/AIDS programs would you like to access or feel you need?

What are the barriers you experience when you request such care?

What has helped you seek out and receive this care?

What do you think might be reasons you, or your family, might not get treatment for HIV/AIDS?

What do you think has helped persons like yourself in accessing HIV/AIDS treatment or what do you think would help?

Do you think you, or people like yourself, would be willing to receive HIV/AIDS assistance at your maternity clinic?

We would like you to tell us your thoughts about how you would like care to be delivered.

- What format would you like the care to be delivered?
- Whom would you like to be included in the education sessions?
- What are your thoughts about integrating this strategy within a clinic setting?
- What might be some strategies you might suggest to clinic directors who might like to integrate your approaches within this clinic?
- How can the director and staff of your clinic better enable you to access these services?
- How can the clinic directors encourage their clients who have HIV/AIDS to seek such services within their clinic sites?

Did you have any problems with regard to disclosure of your HIV status?

Do you have any concerns about disclosing your status/spouse's status to your children?

Do you plan to disclose? If so, when?

Do you have any concerns about disclosing your child's HIV positive status? If so, please elaborate.

Do you need help in disclosing your HIV status or your child's HIV status to your child or to others in the family? What help might you need in this regard?

Have you experienced any discrimination on account of the illness?

Do you think mothers living with HIV and their families need additional nutrition to cope with illness?

Are you a member of a self-help group? Do you think self-help groups can be involved in any intervention program?