SUMMARY 2: STIGMATIZATION, DISCRIMINATION IN THE CONTEXT OF CARE

Introduction

We have come to the end of the second theme in our structured discussion, Stigmatization, discrimination in the context of care. This theme started on 17 September and concludes today, 16 October.

The discussions commenced by stating that HIV/AIDS-related stigma seriously impedes and poses a barrier to effective care and support programmes. We know that stigma within or directed toward the affected family often poses one of the greatest challenges for those living with HIV and AIDS, as it is the most subtle and debilitating form of stigma and the hardest to address. HCC programmes provide a unique and important opportunity to devise and apply strategies to make an impact within families and help reduce stigma at this level

The Advocacy for Action on Stigma and HIV/AIDS in Africa compiled at the Regional Consultation Meeting on Stigma and HIV/AIDS in Africa from the 4 - 6 June 2001 in Dar-es-Salaam was posted to the forum. The session concluded with this statement. "All those with understanding and authority about HIV and AIDS have a responsibility, individually and collectively, to act to reduce stigma within their spheres of influence. Doing nothing contributes to the growing death toll, as well as to distress and poor quality of life for many of those directly affected. Promoting hope and acceptance is a key element in responding to stigma at all levels of society."

Moderator questions:

Prof. Shalini Bharat introduced Theme 2 and posed the following Moderator questions to the forum members:

- How does stigma impact on Home and Community Care?
- What can we do to reduce stigma in the Home and the Community?

It was stated that fear of AIDS stigma and related discrimination, first of all lead to extraordinary levels of secrecy and non-disclosure on the part of HIV positive individuals rendering the epidemic faceless and socially invisible. This compromises the ability and inclination of HIV positive persons to access care, support and treatment within their homes, in hospitals and in their community.

Prof. Bharat said that stigma associated with AIDs leads to anger and a sense of shame at the diagnosis of HIV in a family member. This in turn leads to both covert and overt forms of discrimination. The fear of contagion is heightened during illness episodes, as also the demand on the care providers' time and financial resources. At this time the home care providers also experience tremendous amount of stress because of the efforts required to maintain secrecy about the disease in their community. Fear of contagion and prejudice towards HIV positive people are the prime driving forces behind AIDS related stigma and discrimination.

Theme 2: Discussion Summary

Stigma was described a silent epidemic which occurs in different contexts and at different levels. It was said that there is stigma that is very obvious and the subtle type, sometimes clothed in 'love' where the perpetrator does not even recognize or accept that their action is stigmatizing. (Florence Mhonie, Kenya/Botswana)

The experiences of the HDN KC Team, Botswana relating to stigma were examined. It was found that stigma came up in almost every session at the Gaborone Conference on community based care. The complexity of stigma and the many levels at which it operates was raised.

Roberto Gutierrez González, Costa Rica cited that stigma occurs due to ignorance, which results due to lack of commitment of Governments in many countries to HIV/AIDS.

Certain participants felt that people with HIV/AIDS can be hypersensitive. As a result, they would note stigma where it does not exist or amplify it where little exists. It was said that people in our society stigmatize themselves (David Chipanta, Zambia and Rachel Kiguli, Uganda) It was conceded however that stigma exists in the health care system. This was re enforced by Mary Ellen of Taiwan who cited several incidents of health care worker related stigma. It was suggested that in order to understand the impact of stigma and discrimination on home and community care we need to hear what PLWHA are saying. It was found that schools refused to admit their children, or that the children were treated insensitively by teachers at the school. Acute discrimination was experienced when accessing healthcare services. PLWHA need to be included the provision of services The presence of PLWHA, serves as a block to the development of attitudes that allow fear and stigma to flourish. (Patrick McGee, India)

Orphans and stigma: The problems experienced by orphans were raised. It was stated that older girls are often believed to have become sex workers and boys are accused of stealing in order to survive. (Rev Alfred G Nyirenda, Zambia)

Traditions and Customs and Stigma: Nenet L. Ortega stated that in the Phillipines the issue on stigma is very rampant and very societal. In fact deviations from the traditional customs and beliefs are regarded as a disgrace to that society, thus stigmatization happens, and this is part of culture.

In response to this Dan Rutz indicated that it is very convenient for people to hide behind culture or tradition as a basis for not merely misunderstanding other people, but more importantly for dismissing or even hating them and Chuck.Kevghas, USA felt that individual cultures need to be recognized and one must work within those cultures but until public health measures are instituted that identify those infected and prevent the virus in them from infecting other, the numbers will continue to grow, and more people that we proclaim to want to protect will continue to die.

Masimba Kumashi Biriwasha, Zimbabwe mentioned that there is no specific word for stigma in many African languages and that this, in itself, presents a major stumbling in dealing with the problem of stigma.

Concern about stigma in the work places was raised .It was stated that supervisors make HIV positive people redundant by making sure they frustrate them. (Milpha Kangootui, Botswana)

Gender and Stigma: Florence Mhonie, Key Resource Person, Botswana posed the following moderator question to the forum:

* How does stigma impact on gender in the context of HCC?

It was stated that the burden of caring for orphans often times falls onto the grandmothers who themselves are in need of care.Charlene Smith, South Africa quoted Nozipho Bhengu who said: "Sometimes stigma is what we allow. We have to make it uncomfortable for people to discriminate. We have to educate." It was felt that stigma is gender oppressive. Men who do not want to reveal their status to anyone in the family for fear of being stigmatized, keep having sexual relationship with their women partners or wives, infecting them without basic ethics, love or concern. (Daisy Dharmaraj, India)

The HDN KC Team, Botswana session coverage on Gender, Culture, Stigma and CHBC was revisited. The issue of who cares for HIV positive women? Was raised. It was stated that gender norms complicate home care provision and that young girls suffer an immense burden of providing care particularly for their sick mothers. Involving men in HCC was deemed extremely difficult and to date, unsuccessful.

Joy Kalyebara, Uganda raised the difficulties experienced by those who are doubly stigmatized. Most sex workers face stigma and persecution because of their work as well as additional health problems related to their work such as stress and exposure to opportunistic infections. Other HIV+ people, counselors and carers who are not sex workers sometimes believe that sex workers are to blame for their HIV. They may also sometimes face disapproval from other sex workers. So they too are in need care and community support.

The impact of stigma on female-headed households when either the head of the household, or a member suffers from HIV/AIDS was discussed. (H.A.Akinsola, Botswana)

Religion and Stigma: Dr Ian Campbell, London addressed the moderator question:

* How does religion impact on stigma in the context of Home and Community Care?

He felt that simply by respecting capacity for personal faith of people who are confronting HIV/AIDS, support organizations, both secular and religious, at no financial cost, will concretely scale up response.

Susan Paxton, Key Resource Person, Australia posed the final of moderator question to forum members:

* What strategies can be utilized to address stigma and discrimination in the context of Home and Community care?

Susan felt that it is difficult to know how much we self-impose AIDS-related stigma. Very few of us are openly "out" about our status. Most who are have taken years to get to the point of accepting it and using our experience to educate others about the realities of HIV. Yet, most people who disclose their HIV-status, either to family, to friends or to an anonymous group of strangers find the experience very rewarding and thus openness in itself it a strategy to address stigma and discrimination

Aurapin Pochanapring and Udom Likhitwonnawut, Thailand said that people say that they don't have any problems or objection towards PHAs, because it is a politically correct thing to say. The formation of self-help groups has proved to be a successful strategy in addressing stigma.

Joyce Djaelani Gordon, Indonesia works in a recovery center (Yayasan Kita). And said that many of the addicts are found to be HIV positive. Counseling is a very crucial part at all stages for both, the person infected, or the family members.Hannes van der Walt, Mailula and de la Porte, South Africa described a unique project which aims to aims in care to persons living with HIV/AIDS should be to keep them economically active for as long as possible.The comprehensive programme which Mildmay Centre has implemented to address stigma was discussed (Molly Tumusiime, Uganda)

Zeb O. Waturuocha, India explained that the SUMANA (AIDS Awareness Campaign Programme) Mysore prevent stigmatisation of HIV/AIDS patients by not focusing only on HIV/AIDS The counseling centre is named as "Center for Emotional and Stress Control" rather than counseling centre for HIV/AIDS patients and their relatives - the later would carry its own stigma.

Finally the discussion concluded with the following words from Etambuyu Imasiku "Care for those with HIV/AIDS is too complicated. No one reacts in the way another would. Love, patience and understanding are virtues a caregiver needs to develop. No matter how difficult the patient is he will melt under love."

Analysis:

The discussion consisted of responses and commentaries from all over the world. The continents were represented as follows:

- Africa 24 (60%).
- Asia 9 (23%)
- Australia 1 (2.5%)
- Europe 2 (5%)
- South America 1(2.5%)
- USA 2 (5%)
- Unspecified 1 (2%)
- Total 40 (100%)

The following countries were represented:

- India 5
- Indonesia 1
- Philippines 1

Taiwan	1	
Thailand	1	
Australia	1	
Costa Rica	1	
Africa	1	(Unspecified)
Botswana	7	
Ethiopia	1	
Kenya	1	
Nigeria	2	
South Africa	2	
Uganda	5	
Zambia	4	
Zimbabwe	1	
USA	2	
UK	2	
No country	1	
Total:	40	

- Project represented included:

PREPARE	India
Indian Network for People living with HIV/AIDS (INP+)	India
Yayasan Kita	Indonesia
CARE Thailand / Raks Thai Foundation	Thailand
Asia Pacific Network of People living with HIV/AIDS(APN+)	Australia)
The STH Consortium Tshwane/Pretoria,	South Africa
Mildmay Centre	Uganda
TASO community	Uganda
In-Community Care For Orphans (I-CCO)	Zambia

Thank you once more for your interesting and insightful contributions, which are ensuring the success of this structured discussion. We look forward to your continued support and active participation as we move through Theme, Enabling, empowering environment so as to support care.

With best wishes

Insight Initiative Team, Thailand
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Fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS Chiang Mai, Thailand - 17-20 December 2001 Web site: http://www.hiv2001.com

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