FAMILY RESPONSES TO HIV/AIDS IN MEXICO

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Abstract—This paper presents findings from a qualitative study of household and community responses to HIV/AIDS in Mexico. Fieldwork took place in two contrasting settings: (a) Ciudad Netzahualcóyotl, a socially marginalized urban community and (b) the homosexual community of Mexico City, a sexually marginalized social network. 113 in-depth interviews were conducted with people with HIV/AIDS, their relatives and members of their social networks. This paper describes findings from interviews conducted with family members of persons with AIDS. Four stages of response are identified and characterized within each community: (i) life before AIDS, (ii) life during the discovery of AIDS, (iii) living with a person with AIDS and (iv) surviving those who have died from AIDS. The social marginalization of both communities is central in explaining how families respond to the disease. In Ciudad Netzahualcóyotl, social support derives from a local culture of kinship. In the gay community, on the other hand, solidarity arises out of friendship. Between social support and discrimination, many more "ambivalent" behaviours (neither fully supportive nor discriminating) are displayed by family members and friends. Fear, pre-existing family conflicts and prejudice nurture these negative responses. Family responses and the processes to which they give rise, also differ depending on whether or not a male or female household member is affected. Policy recommendations are made concerning how best to promote positive family and household responses to persons with HIV/AIDS and how to inhibit negative ones. © 1998 Elsevier Science Ltd. All rights reserved.

Key words—AIDS, family, career, social support, solidarity, discrimination, prejudice

INTRODUCTION

A number of authors have highlighted the importance of social research in families where one or more members is affected by HIV and AIDS (e.g. Bonuck, 1993; Danziger, 1994). This call derives both from the need to examine whether family and community care for people with HIV and AIDS is relatively cost effective (Ward and Brown, 1994) and from the importance of understanding the most immediate context, the family, in which for many people HIV-related illness evolves (Bor, 1990). In industrialising countries such as Mexico, it is of crucial importance to examine how "community care" for those affected by AIDS may vary according to factors such as social class, geographical zone or ethnic group.

Recent investigations also highlight the need to explore the limits to the family and community support received by people with HIV and AIDS (Seeley et al., 1993). Evidence from several countries has forced both a re-definition of the concept of family (Levine, 1990) and a deeper exploration of the problems experienced by households in their efforts to respond positively when one or more members is affected with HIV disease. Affected households may face stigmatization (McGrath et al., 1993; Gilmore and Somerville, 1994) which can in turn affect their responses to AIDS (Powell and Brown, 1994). The families of people with HIV and AIDS may also undergo a process of adaptation about which little is currently understood (Barret and Victor, 1994). This adaptation includes both a re-negotiation of the family's identity with the external social environment, in which the families struggle to avoid the stigmatization associated to AIDS and the delimitation of new duties and responsibilities in relation to care (Powell-Cope, 1994). The available literature suggests that these social processes of family adaptation are directly linked to the ways in which families respond to the knowledge that one or more of their members is infected. These "transitions through uncertainty" may be characterized as trajectories with several clearly defined stages (Brown and Powell-Cope, 1991). Other studies have identified specific counseling and psychological support needs in HIV affected households (Lippmann et al., 1993) and have drawn attention to the need to strengthen the family's capacity to offer support.

There has, however, been little investigation of these issues in Mexico, a country in which more
than 38,000 cases of AIDS have been documented (INDRE, 1996). In some publications, the issue of the family is mentioned just marginally (Ponce de León, 1989), whereas in others it is completely absent (e.g. Galván Díaz, 1988; PIEM, 1994; Hernández-Avila et al., 1995). This is true even of some recently published state of the art compilations (Del Río-Chiriboga and Valdespino-Gómez, 1995). Moreover, there have been no systematic investigations of the coping strategies used by families and while casual observation might lead us to surmise that collective reactions towards AIDS and people with AIDS tend to be negative, there may also be positive behaviours of support and solidarity about which very little is known. The systematic study of both types of reactions is of paramount importance from a public health perspective.

This paper presents findings from a study which aimed to describe household and community responses to HIV/AIDS in Mexico, as well as to identify the principal economic, cultural, ideological and societal factors underpinning such response.*

The aim was to identify critical points in the families’ response patterns or trajectories, as a precursor to the development and implementation of educational, materially and emotionally supportive interventions by health institutions and NGOs.

Our analysis is organised around the concepts of “career” and “trajectory”, terms that are used here interchangeably. “Career” was defined by Goffman as “any social strand of any person’s course through life” (Goffman, 1984a). It is a concept that “allows one to move back and forth between the personal and the public, between the self and its significant society” (Goffman, 1984a, p. 133). Other authors have found the related concept of “trajectory” useful in making sense of the work performed by patients and peers in relation to illness and its consequences (Glaser and Strauss, 1968; Strauss et al., 1985). In this paper, we will describe the response “careers” of the families of two contrasting groups of people with AIDS. In doing so, we will examine how structural factors, including economic and sexual marginalisation, mediate the choices available to affected individuals and family members. Our focus will be on the dynamic and changing nature of family responses to HIV and AIDS and on their relationship to broader social and community structures and forces.

METHODS

Context

The study was conducted in two social settings: Ciudad Netzahualcóyotl (from here on “Netza”) and the “gay community” of Mexico City. Ciudad Netzahualcóyotl was a geographically defined community, being a municipality in the State of Mexico just east of Mexico City. The gay community on the other hand was delimited by the social networks of different groups of men who have sex with men, including both those who considered themselves to be gay and those, who like their counterparts in many Latin American cities, have sex with other men without actively assuming a gay social identity (Carrier, 1989; Schifter Sikora, 1989; Parker and Barbosa, 1996). Both communities were subject to a high degree of marginalization, socioeconomic in the case of Netza and sexual in the case of the gay community.†

Access and initial rapid assessment

An initial rapid assessment (RAP) took place to characterise each community demographically and socio-economically. On the advice of the National Council for AIDS Prevention (CONASIDA), access to respondents and their families was negotiated through NGOs. In the case of Ciudad Netzahualcóyotl, contact was made through the Pro-shelter Association for AIDS victims in Ciudad Netzahualcóyotl (ASPANE). In the case of the gay community, access was negotiated through the well established activist and support group Colectivo Sol. Both organisations were committed to building social solidarity around HIV and AIDS (Daniel and Parker, 1991; Parker, 1994) and both acted as links between the research team and individuals, households and families affected by HIV and AIDS.

Main fieldwork

In a second phase of work, in-depth interviews were conducted with 113 individuals. These included people who were HIV positive, the relatives of people with HIV and AIDS and members of the social networks of people with HIV and AIDS (Table 1). Interviews examined responses to AIDS and sought to identify positive (support, solidarity and help), negative (rejection, prejudice, stigmatisation) and mixed or more ambiguous

*This project was funded by the Social and Behavioural Studies and Support Unit, Division of Research and Intervention Development, Global Programme on AIDS, World Health Organization (WHO) and by the Joint United Nations Programme on AIDS, (UNAIDS). The views expressed here, however, are those of the authors alone and should not necessarily be construed as those of WHO or UNAIDS. CONACYT, from Mexico, also funded this project.

†It is important to recognize that there is no strong, unified homosexual community in Mexico. Instead, there are many homosexual communities, as is the case of Brazil (Scheper-Hughes, 1994). Many of the members of these groups use the English term “gay” to refer to themselves. Therefore, when we talk about the “gay community”, we are in fact referring to a set of overlapping gap groups and communities in Mexico City.
reactions. Through participant observation over a period of 9 months, efforts were made to identify community, family and individual factors associated with each of these different types of responses and to examine the impact of AIDS on the emotional life and family and household dynamics, of interviewees.

Access to respondents was negotiated through the NGOs who further advised on ethical issues. Interviews took place with the informed consent of respondents who were assured of confidentiality and the right to withdraw from the study without explanation at any time. In fact, no respondents took up the opportunity to withdraw from the study, which may perhaps reflect the acceptance of the NGOs by the populations and groups they support. Interviews lasted an average of 90 minutes.

Analysis

Following the completion of each interview, a verbatim transcript was prepared. An initial reading of the data took place to check for completeness of coverage. This was followed by a more in-depth analysis of recurrent themes and issues. Interviews were coded and subjected to preliminary analysis using Ethnograph (Seidel, 1995). They were subsequently analysed in-depth by more than one researcher for the purposes of validation. Emergent findings were discussed and evaluated by the entire team. Information was analysed to the point of theoretical saturation using a grounded theory approach. (Glaser and Strauss, 1967; Glaser, 1978). Analysis made it possible not only to identify family and household responses to HIV/AIDS, but also those of people with HIV and AIDS themselves.

It is important to stress that the two communities studied were chosen for their capacity to illuminate a potentially common set of issues and problems, namely the manner in which household and families respond to HIV and AIDS and the different stages passed through in this response. It should be seen as a strength, therefore, that there exists potential overlap between the two communities studied. Homosexually active men do reside within Ciudad Netzahualcóyotl and some participate in the wider social networks that make up the gay community of Mexico City.

FINDINGS

The two communities

Ciudad Netzahualcóyotl is a 62-km² area inhabited by more than 1,250,000 people. According to the 1990 Census, more than half of the population consists of immigrants from the States of Oaxaca, Puebla, Michoacán and Chiapas who moved to this region in search of better opportunities. Only 44% of the population older than 12 years of age are currently employed. (INEGI, 1991). In the socio-demographic literature, the municipality is characterised as a marginalised zone in which alcoholism, promiscuity, a result of a high population density and public insecurity, prevail (CONAPO, 1993).

The gay community consists of a complex pattern of social networks that coincide with meeting places (including bars, discothèques, coffee shops, public baths, hotels and cinemas) where social and sexual interactions among men take place. A distinctive feature of the homosexual community in Mexico City is its marked socio-economic and cultural heterogeneity. Members vary from those with well defined gay identities through those who consider themselves to be bisexual to those who see themselves as heterosexual but who may occasionally or regularly have sex with other men. Regardless of personal and social identity, however, all members are likely to experience discrimination and stigmatisation, especially when individuals are open about their sexuality and sexual desires.

Despite differences in social and community organisation, the two communities studied showed some similarities in terms of the sequence of responses passed through by family and household members as they sought to cope with the news that one of their members had been diagnosed as having HIV disease. In general, it was possible to identify four principal stages in the career associated with family responses to the person with AIDS: (i) life before AIDS; (ii) discovering AIDS within the family; (iii) living with a person with AIDS and (iv) surviving the person who has died from AIDS.

Poverty, migration and crisis are closely related in the day-to-day lives of the inhabitants of Netza. Together, they help constitute a culture of emergency in which the unexpected is lived as the “normal” and pervades all aspects of life. Central to the community orientation of residents, however, is a culture of kinship which ensures that support is available when needed.
offered in times of crisis, even though the means to provide this support may not always be adequate. As one respondent explained (M/brother of a person who died of HIV/AIDS/29):*

*For reasons of confidentiality, respondents are identified by the sex of the informant ("M" male, "F" female), the informant’s relationship to the HIV positive person, and the age of the interviewee.

... Yes, they just arrived. Do you see the kids? It was more than 25 years (ago) that I last saw my sister... they were on a vacation, but they ran out of money and then her husband started to look for a job and told me: “Why don’t you give me a hand while we recover?”... And here they are all with me now... and there’s no way I can say no... I can’t turn my back on them...

Prevaling gender relations and expectations determine decision making and survival strategies. Women in particular are destined from an early age to provide services and support to others; an orientation that, as we will see, is decisive in explaining how HIV and AIDS is managed within the family. Framed by a value system that strongly differentiates men from women, sexual activity is encouraged among young men and restricted among women. Linked to the expression of such strongly defined gender roles is an open rejection of homosexuality and of any sexual practice that does not conform to the hegemonic model.

Family conflict and rupture is the normal course of events if a family member is discovered to have homosexual preferences or behaviours (F/mother of a person who died of HIV/AIDS/44):†

† Parker (1991) among others has highlighted the importance of patriarchy as a key element structuring the sexual order in Latin American countries.

... When my husband found out about that, he evicted him. He told him to get out and he left. He then used to live with many of those who were very obvious, you see. He used to live just around the corner...

It cannot be emphasised too strongly how central the daily experience of poverty and associated uncertainty and precariousness are in explaining how families in Netza cope with and respond to HIV and AIDS. These factors constitute the social backcloth against which increasing numbers of families live with the knowledge that one or more of their members is directly affected by the epidemic.

Images of HIV and AIDS and dominant cultural values also influenced the way in which the families of gay men reacted to the news that a son has HIV disease. Of particular importance in determining the form of such responses was the way in which the family had previously reacted to the news that one (or more) of their sons was homosexual. Such responses were closely linked to the behaviors the same family displayed later regarding the second coming out as HIV positive or as a person living with AIDS. Given the hegemonic character of heterosexuality, the presence of one or more homosexual men in the family is an event that demands an important series of “adjustments”. These adjustments can range from repressive attempts at control to open acceptance. The latter responses were, however, more usually seen after a period of learning and awareness raising, or a “family career” in which the subject of homosexuality has figured strongly.

Initial suspicions about a son being homosexual were reported as leading to a variety of family responses. Frequently, the family went through a phase of bewilderment. This was sometimes compounded by the coping strategies used by the son. Some men, for example, reported asking female friends to play the role of girlfriend. Additionally, parents attempted to “normalize” the homosexuality of sons through marginalization or by denying their sexual preferences. After confirming the homosexuality of one of its members, families may enter into a phase of conciliation. This can be a long process in which family members have to review many of their previous convictions about homosexuality. In both Netza and the gay community, the eventual outcome of this process was often determined by gender. Women, for example, tended to be more accepting than men when it came to acknowledging a son’s homosexuality. As one respondent explained (M/brother of a person who died of HIV/AIDS/40):

...The response in the family has been as in other families. There are some who have taken it quite calmly, it doesn’t generate a problem for them. This is true for my sisters, but for my brothers there was always an attitude. It was not really an aggressive one but a mistrustful one, see?

Not infrequently, the degree of tolerance shown towards a homosexual family member is the outcome of a more or less tacit agreement. A person will be accepted so long as he does not create “problems” for the family. Not creating problems requires faking, covering up or denying the issue of sexual preference. This cover up, however, requires considerable self-repression against the backdrop of an overarching rule that says “repress yourself or we’ll repress you” (F/mother of a person who died of HIV/AIDS/51):

...For example, if Mario had behaved with vulgarity [we wouldn’t have accepted him]. I told him “Please, don’t you ever behave vulgarly, please never go too far. If you are like this, we’ll accept it and that’s it. If you have already accepted it and have your own lifestyle, well go ahead, but take it easy, try to... if you are going to do something, try to... try to, if you like, pretend. Try to pretend (...) so that it is not apparent at first sight”...

Upon occasion, however, these rules were applied so rigorously that there was simply no space left for the homosexual member to share his sexual preference with the rest of his family. In this kind of situation, HIV and AIDS presupposes a drastic double coming out: both as homosexual and as a person living with HIV disease.
In order to receive support and care from the family, an individual needs to let them know about his or her HIV status. Given the stigma associated with HIV and AIDS, it was not uncommon for those affected to want to keep their serostatus a secret. The difficulty families had in explaining to themselves and to others the problems of having an HIV positive member, was directly associated to the interest that people with HIV have in controlling the information flow about their own status. This dilemma, to tell or not to tell, forces people with HIV to resort to often complex information control strategies (Goffman, 1984b). Great care is taken in deciding who to inform first and how the news is to be broken. Based on the initial alliance established between the person living with HIV and the selected relative, a gradual opening up of communication may ensue which involves other family members coming to know about the individual’s HIV status (F/sister of a person who died of HIV/AIDS/29):

...He used to say: “How are we going to let them know?” and he always had the idea of letting people know without affecting them, you see. Because my mother is a diabetic, then... very discreetly there was information on TV, and just as discreetly we told her, see? We started breaking the news, and my mother accepted it quite calmly because we chose the right moment to tell her, see? And then we told my father, and then my brothers and relatives...

Attempts to control the flow of information were often limited by the physical signs and symptoms of AIDS. These, family members gradually transform into “certainties” about the condition that is affecting one of their members.

In other cases, however, family members and not the person directly affected, were the first to learn about the HIV status of one of their relatives. This could happen, for example, when a health care worker decided to communicate the news directly to the family. This not infrequent response violated individual rights to confidentiality and created further dilemmas for the family, whether or not to tell the truth to the affected member directly and what might be the consequences of his or her knowing (F/sister of a person who died of HIV/AIDS/36):

...And when they told me it was... well I really got frightened and I didn’t know what to do. I didn’t know if I should tell him or not, and when. Or if he would take it badly or would want to commit suicide...

Within the families of men drawn from the gay community, learning about AIDS was a process which had some distinctive features. In some cases, the news had to be broken within the context of ongoing family “adaptation” to the homosexuality of one of its members. In other cases, however, HIV disease came as an unexpected revelation - a double reality that required both the homosexuality and the HIV status of a family member to be confronted. In these latter circumstances, the person concerned (and his family) might have to face up to a double coming out. In the context of widespread intolerance towards homosexuality, the stresses associated with this were considerable and presupposing discretion and preparedness. As the mother of a gay man already deceased explained (F/mother of a person who died of HIV/AIDS/50):

...From the very day I arrived... now I realize, right? That he was always trying to prepare me. Initially he told me about his condition, and (then) about his (sexual) preference...

Be it a simple or double coming out, knowing that a family member is HIV positive places an enormous burden of pain and despair on relatives (F/mother of a person who died of HIV/AIDS/51):

...It was something like feeling that I was losing my son, that my son was going to die...

Reactions to HIV/AIDS were influenced by fears and anxieties about the epidemic as well as by the distress of needing to communicate this new information to selected members of the family. Age and experience were key factors taken into account when deciding whether or not to inform other family members about an affected family member (F/sister-in-law of a person who died of HIV/AIDS/36):

...What happened is that we (asked ourselves): “What are we going to do? What are we going to tell the kids and teenagers in the family? How are the children going to be kept away? (How are they going to learn) how it is transmitted and how it is not transmitted?”...

During the phase of acknowledging that HIV/AIDS has affected one of its members, family members not infrequently blamed one another. The form that this blaming took often mirrored that which had earlier occurred in relation to the discovery of the homosexuality of a member. Processes of blaming involved a search for clues to “explain” the events that have come to pass. In extreme cases, the affected individual blamed not only himself but other family members (M/brother of a person who died of HIV/AIDS/40):

...The first attitude he had was to (...) blame the family, to blame our mother: “You never took care of me, if you had looked after me I would have never been like this!” There was a moment when my mother didn’t understand, and she said: “Well, how was I supposed to look after in you? How didn’t I take care of you?” (And he said): “But, didn’t you ever notice that Juan and I were homosexuals and that we had sex with our friends?”... he said: “And you are responsible for my death, and you’re going to stay with that remorse...”

In Netza, HIV infection was part of that set of undifferentiated risks, of pain and disgrace that characterize daily life. Several years ago, some of those interviewed had been professional blood donors, selling their blood in order to survive. Then, it had not been uncommon to sell blood perhaps twice a week to different banks in order to obtain money. Families referred back to these
events in order to explain why one or more of their members should have been affected (F/mother of a person who died of HIV/AIDS/53):

...Alice only went twice, but that was enough for her misfortune. She used to do washing, ironing, house cleaning, but through those two times (she visited the blood bank) she lost her life...

Popular beliefs about HIV and AIDS were much influenced by the suspicion that the person concerned may have been leading a “censorable” life, at least from the point of view of the family (F/sister of a person who died of HIV/AIDS/35):

...Well, I think he was leading a bad life. (...) He used to drink and he used to run off, I think he went to... Sometimes I say to my husband: “Sometimes I wonder, who knows if he didn’t get infected by other men. Maybe he got it because he went around with faggots”..."

In summary, families’ discovery that one of their members was HIV positive was most usually followed by a period of shock and adjustment. This involved a search for explanations that would make the situation more manageable. This quest varied in difficulty depending on whether family members were dealing with the problems posed by the HIV status of their relative alone, or whether they had to witness the double coming out of the affected individual. The moment of initial crisis is often characterized by a high degree of conflict during which the quest for explanation may pass through several stages of intra-familiar blaming. This is a temporary but serious situation that can severely undermine the foundations of family solidarity.

**Living with a person with AIDS**

Family coping with chronic illness has been widely explored in the socio-medical literature (see, for example, Bury, 1982; Charmaz, 1990). In both Ciudad Netza and the gay community, beyond what is already known (i.e. that family rejection is associated with stigma and prejudice), it is valuable to distinguish more clearly the types of discrimination and solidarity affected people receive, as well as the social processes associated with these. We will begin by characterizing some of the social factors and processes associated with solidarity and support, before looking at those factors linked to rejection. Between these two extremes, we will offer an analysis of factors that hinder outright discrimination but which are not associated with support and of factors that make support difficult but which do not lead to the outright rejection of family members. We do this in order to emphasize that neither solidarity nor discriminatory responses are, strictly speaking, “pure” responses. Instead, they are often intermixed and intertwined, the precise balance between them being influenced by the characteristics of the actors involved and the social structures that generate them. At this in their career, family response trajectories in Netza and among members of the gay community largely converge. We will therefore analyse them alongside one another, highlighting differences between them only where appropriate.

Supportive responses were closely associated with kinship and gender. Men who provided support did so mainly through the resources they obtained from their jobs (i.e. money, access to health services, etc). Women, on the other hand, provided support by taking care of the sick at home. It was within this basic division of labour that any reorganization of the domestic unit in response to the presence of a family member with HIV disease usually took place (F/mother of a person who died of HIV/AIDS/60):

...My son told me “You will have to stay and take care of her, because, what are we going to do? Who else will look after her?”..." And I had to stay in the house and they told me “We’ll help you... don’t worry about that... we’ll help you as much as we can”..."

Gender determinants, in turn, were moulded by other interests related to the care of the sick. For example, “segregating” processes were used by some women to establish their right (over others) to care for affected family members. These processes pursued a double objective: they legitimated the right to care and they conferred the right to different benefits derived from this care. Such processes were often seen in situations where there was conflict about whether care should be offered, what care should be offered and who should provide it.*

The outcome was the separation of the sick person from those members opposed to the provision of care. This allowed those providing care to better conceal the real motives behind their actions. It also eliminated potential contenders in a drive to retain control over the possessions of the person with AIDS. In the course of the fieldwork, numerous testimonies demonstrated how this “adoption” of an HIV affected person was associated with intra-family struggles over property (F/mother of a person who died of HIV/AIDS/53):

...My son left me the deeds to some land as well as his television set. The week he felt worse, he was barely able to tell me that the television set was for me. Then, just recently, his wife called round and asked me if she could take the television. So she was in no doubt, I told her: “Look, my son told me that I could keep the television”. And, yes, she did get very upset...

In the case of families of men from the gay community, previous acceptance of a son’s or brother’s homosexuality influenced subsequent responses to

*These challenges normally refer to the subjective assessment that some women made over the quality of the care provided by others. For instance, several testimonies suggested that a wife who does not demonstrate the expected degree of affiliation and sorrow as a result of having a HIV positive husband can face moral disqualification from the women who surround her.
HIV and AIDS. Other factors too were capable of transforming fear and rejection into family support. In the following example, the affected person himself played a key role in this respect (F/mother of a person who died of HIV/AIDS/30):

...And he explained it to me through drawings and he used to tell me: “Look, mother, the virus entered this way and started growing this way and the other”... everything... he told me everything...

There were also cases where the family learning occurred thanks to the support and counselling received from health institutions and NGOs (F/mother of a person who died of HIV/AIDS/50):

...Here (in Mexico), before he arrived, we had been to CONASIDA and to Ser Humano (an NGO). There we were welcomed by a very humane person, a doctor... and he told us: “Keep calm, the first thing to do is to bring all the family for therapy with a psychologist...”

Family acceptance of homosexuality and HIV/AIDS often involves a process of re-education whereby the family gradually moves from discrimination to greater understanding. Gay social networks sometimes played a critical role in this process. The parents of one man with AIDS described how they perceived the information provided to them by one of his friends (F/mother of a person who died of HIV/AIDS/49):

...He explained to us that everything is happening because of this and that affecting him... and he made us aware of what was happening and that the end was near...

In both communities, however, supportive behaviour was often undermined by time and the physical and emotional exhaustion of providing care, leading to near burn out in some cases. The tiredness that comes from having to provide near constant home care to people with HIV and AIDS had consequences for the family’s own rhythm of life. New activities had to be accomplished without neglecting other daily chores (F/mother of a person who died of HIV/AIDS/49):

...He used to say, “Mum, I am vomiting now”, or “This diarrhoea just won’t go away” or “Massage my back”. He used to ask for things at three in the morning, and I had to get up at seven to send the kids to school and leave at eight thirty, and (I was) alone, alone. For me, that was quite (time) consuming...

During the provision of terminal care, the health of the relatives of people with HIV and AIDS could also suffer. Not infrequently, as in the following example, such health problems were directly associated with the emotional burden of providing care (F/mother of a person who died of HIV/AIDS/51):

...And even the doctors have told me (so), because I suffer of hypertension, and sometimes my pressure goes up very high and they tell me that it’s probably because I am always anxious...

An additional source of wearing out comes from frustration with the bureaucratic attitude of certain health institutions, as well as the limitations of some doctors. Emotional exhaustion also derives from the fact that silence is assumed to be a sign of strength. This can provoke great damage in the lives of those close to the person with AIDS (F/mother of a person who died of HIV/AIDS/50):

...Somehow (AIDS) hit us really hard, see? But none of us wanted the others to see that we were suffering so much...

In summary, in both communities family support for persons living with AIDS was delivered through existing kinship structures and gender relations and was modelled according to the diverse agendas and interests of family members. For gay men, positive responses were premised on family acceptance of their homosexuality and a willingness to accept the support that might be offered by gay friends and wider social networks.

There was, however, another mode of response in which solidarity and rejection intersected. Marked instability was the quality that characterised the behaviours concerned. Such behaviours seem generated by ambivalence at two different levels: the individual level (the same person may simultaneously provide support and express rejection) and the family level (where there exist both support and rejection within a given family). Such responses aimed, on the one hand, to provide material support (e.g. help with medical expenses, or partially taking care of the sick) and, on the other, to express moral rejection and stigmatization (M/friend of a person who died of HIV/AIDS/35):

...I knew this friend who was HIV positive, a guy with a lot of money. He started getting sick and... he is completely destroyed because... he confessed in his house that he was gay and they rejected him completely. To get rid of him, his mother set up an apartment for him. She pays for the apartment and for everything else. He revealed to me that they told him: “It was the result of your bad behaviour. You have to work it out, here’s your house, here’s the money”. And he has everything, but he’s morally destroyed...

A remarkable aspect of family responses was the propensity of relatives to categorize people with AIDS according to the way the former believed the latter were infected. When AIDS was associated with sexual behaviours considered as unacceptable within the family, the basis for a double standard determining how different actors will respond was established. As reported in the wider literature regarding the interactional quality of medical care (Roth, 1986), when relatives judged that one of the family members became infected “accidentally” or via a blood transfusion, they usually responded with greater solidarity and provided more support than when they considered that infection was a consequence of “deviant” or “immoral” behaviour. When the latter judgment was made, some family members may reconstruct the patient’s biography and identity retrospectively, taking his or her HIV positive status as the point of departure. Many indi-
individuals are thus “labelled” homosexual, independent of the true origins of their condition.

It was also possible to identify certain factors which even though they were not related to the direct promotion of support, at least restrained or inhibited the development of directly discriminatory behaviours. The partial or total concealment of HIV infection or AIDS within the family was one of the most common means both of avoiding discrimination and building solidarity around the person concerned. Chronic and degenerative disorders such as leukaemia and cancer often serve as a mask to disguise the physical deterioration caused by HIV and thus avoid discrimination.

The struggle to avoid discrimination was part of the broader agenda subscribed to by all family members and not just people with HIV and AIDS. This explained the frequent existence of a family “deal” with the affected person whereby support is provided within the family circle so long as outside the family the individual’s HIV status remains concealed or disguised.

Sometimes, family solidarity was hindered by objective factors and an absence of support should not necessarily be taken as implying overt discrimination. For example, on several occasions it was observed that family members stopped visiting one of their members in hospital, or providing care, because of lack of money or because of the time needed to reach the health centre. Sometimes priorities had to be given to other survival activities, such as going to work in order to make money to support children and to take care of them.

Added to the above, the natural progress of AIDS can lead to deterioration in the affected person’s condition which may frustrate efforts to provide care and which may cause relatives to become emotionally affected and not know what to do practically. The impact on family members severely drains their will to provide support and confronts them with dilemmas of whether or not to provide support, how and to what extent (F/sister of a person who died of HIV/AIDS/47):

...He was all bones, believe me, it was horrible bathing someone like that. It was like crying, as if you wanted to scream out because of what you feel, of what you see; then, I used to take a drink, or two in order to have the courage to take him, undress him, bathe him and shave him.

Within the families of respondents drawn from the gay community, ambiguous behaviours occurred within an environment that hindered the open exchange of information. In a world of assumptions and implicit agreements, it could be important to hide the truth and pretend not to know (F/mother of a person who died of HIV/AIDS/51):

...When we have a (family) meeting, or a birthday party, he’s always there and nobody, absolutely nobody, mentions his problem or the like. Of course, (we try to ensure) that he lives peacefully...

Another form of ambiguous behaviour has to do with the process of information control in order to ensure someone else’s provision of support for the person with AIDS. In the course of the study, several cases where identified where the family assigned a domestic worker to look after a person with HIV/AIDS. However, the worker was not always fully informed about condition of the person she was caring for (F/sister-in-law of a person who died of HIV/AIDS/36):

...She’s been here for a long time, she came here as a girl. She helped a lot, but I think that she never knew what he had... We only informed her of the things she had to do with him, so she didn’t incur any high risk practices. (We emphasized she should) avoid cutting herself... I don’t know, things like that...

An additional kind of ambiguous family behaviour which was particularly common among the gay men studied, involved delegating responsibility for care to the individual’s network of friends while maintaining a minimal physical presence and avoiding acknowledging the rejection which in fact was taking place.

In summary, ambiguous behaviour (involving varying degrees of support and rejection) within families of people with HIV and AIDS in Netza was closely related to the conditions of material and financial hardship under which they live, as well as to the need for emotional support of family members themselves and the obligation to adapt to a social environment that is likely to stigmatize not only the sick person but also his or her entire family. In the case of the families of men from the gay community, general intolerance towards homosexuality gave rise to often ambiguous family responses. These ambiguous behaviours were neither classifiable as forms of support nor as forms of rejection, precisely because they share aspects of both of these more direct modes of response. They are behaviours that can be interpreted as forms of “adjustment” that relatives undergo as they respond to the knowledge that one of their members has HIV disease.

A constant presence in the families interviewed in Netza was reference to the course of events that had supposedly led to one of their members becoming infected. Often these accounts stimulated conflict, especially when they implied criticism of the lifestyle of the affected individual and when they had far reaching consequences for the family as a whole. Blaming frequently took place and family members exchanged accusations with one another as a way of freeing themselves from the obligation to take care of the sick (F/cousin of a person who died of HIV/AIDS/34):

...Well, she said it was our obligation, because she said my brother-in-law had infected her and that she was not going to carry the blame. And with his expenses, because he infected her and all that, she said that we had to pay because we had the money...
Fear was another element shaping family reactions and its effects often appeared in the form of discrimination. For the purposes of this analysis, however, it is useful to distinguish between the avoidance that results from fear and other forms of rejection. Here, fear was most often associated with an unwillingness to be close to the patient and with the taking of extreme safety measures (M/brother of a person who died of HIV/AIDS/29):

...I think my wife did feel a certain fear, even though there was no reason for it. In a kind of way she wanted to reprimand the children for communicating with him... But then I explained to the children that there was no reason to be afraid of their uncle, that he was sick but he wasn’t contagious and that they could talk to him and be near him... Later she understood and everything went back to normal...

When HIV/AIDS affected more than one person in a household, a couple for example, it could trigger a conjugal crisis in which husband and wife engaged in mutual recrimination (F/mother of a person who died of HIV/AIDS/46):

...She came one day, when he was already sick, she took her clothes and she told me: “Here’s your son’s clothes... I have no more use for him.” She said my son was useless as a husband. Then my son told her “If I was never good as a husband, you, as a woman, you were never a wife to me, that’s why I am as I am”. These were Miguel’s words... she didn’t say anything. She just turned around and walked out. She went to her house and that was it. My son was begging her, he used to go and knock at her door. You should see, he caused me so much pain, he used to knock and they didn’t open...

In this kind of atmosphere family conflicts deepen, giving rise to even more negative responses supported by legitimizing discourses. When commenting on the reasons she had to send her sick child to the hospital, one women said (F/sister of a person who died of HIV/AIDS/30):

...For example, you have this chicken in the chicken house with all the rest of them, all robust and healthy, and you have this chicken that’s dying, so what do you do? You take her out, don’t you? You take her out so she doesn’t ruin the rest of the chickens. Then the sick person has a place where he belongs...

Family rejection towards people with AIDS occurred to variable degrees. In some cases, mainly within the families of men drawn from the gay community, this rejection could be selective and was focussed on only some aspects of the patient’s biography; the person was accepted and responded to as he was before assuming his homosexuality (M/former partner of a person who died of HIV/AIDS/25):

...And when Enrique decided to share it with his family, the first reaction (his mother had) was “poor little son of mine”, and the memories were totally around his childhood. I mean, she didn’t make any reference to the 36-year-old Enrique, with his history of work around AIDS and gay work. Instead, they rather (thought) of that child they took care of, who was very pretty and very studious... They never approached Enrique to ask him “What do you need or how can we help you?...”

In other cases, the rejection could be more outright (M/friend of a person who died of HIV/AIDS/35):

...There was a moment when his mother went and left him in a hospital in Cuernavaca, and she came back, as if she wanted to leave him there; and he got very angry and didn’t want to be there and he left (the hospital) and he came back all the way back from Cuernavaca with the drip still attached to (his arm)...

Occasionally, rejection could reach the point where patients were abandoned in a public welfare hospital or evicted from their apartments, condemned not only by their relatives but by the rest of society to die in the most extreme loneliness (M/friend of a person who died of HIV/AIDS/35):

...And finally poor Javier, came to die here at the General Hospital, utterly alone, completely abandoned by everybody...

Finally, for some gay men, prior estrangement from the family could be so profound that in some cases relatives did not know anything about the infected individual and, for this reason, did not experience the issue of HIV as a family problem. During fieldwork it was possible to collect indirect testimonies from several people who had been abandoned in this way and who, because of this, could not count on their families to provide support.

Surviving people who have died from AIDS

Intra-familial processes triggered by the death of a family member not infrequently persisted afterwards. Several different kinds of consequences could be distinguished: emotional effects, fear of stigma, the consequences of debts and worry for those who survived the patient, especially when these were children.

In the case of the families of men from the gay community, after the death of the individual concerned relatives usually decided to discontinue contact with his friends. Additionally, they might prevent friends of the deceased from attending his wake and sometimes his funeral, either because of fear and shame, or because of rancour as a consequence of the family’s belief that his gay friends had been responsible for his infection and death. Gay respondents usually interpreted these negative responses as an attempt by families to “close a chapter” in their lives and to avoid social censorship.

Even in those families that displayed solidarity with the ill person, emotional consequences remained. HIV and AIDS often had a lasting impact within the family which modified, in a variety of ways, the individual careers of its members (F/mother of a person who died of HIV/AIDS/50):

...Yes, I think so, you see, the youngest one stopped going to university, he couldn’t continue. And my daughter gave up her plan to start a new job. Once Guillermo passed away, she didn’t join (her new job)...
Surviving family members reported emotional sequelae of various types (M/brother of a person who died of HIV/AIDS/38):

...Before this happened, we were a very united family... When any of us had a problem, we used to talk it over, we shared it... This doesn’t happen now, problems make us fall out again, and that happened to him. I mean, he had problems and instead, let’s say, of helping each other, we seemed to end up sort of repelling each other...

Such conflicts often led family bonds to disintegrate, sometimes irreversibly. In the case of families from Netza, unpaid bills could impose a heavy burden which slowed down recovery from the setbacks an illness like AIDS produces. This situation was even more critical when the person who died of AIDS had been the family’s main source of economic support (M/father of a person who died of HIV/AIDS/53):

...He always provided everything, he took care of all the expenses. Then, our situation really collapsed, and up to this day we are deeply in debt...

Stigma remained attached to those who were closest to the person affected by HIV and AIDS and this could have serious longer term consequences (F/mother of a person who died of HIV/AIDS/48):

...But I dislike a lot young people’s lack of understanding, because, you see, they start saying, “Your brother died of this, or perhaps you also have it... or you’re from a family of sidosos* and I don’t want that for my children...”

The wish to forget often became the need to start a new chapter in life (F/mother of a person who died of HIV/AIDS/54):

...I’d better look for a smaller house where I can go live, this is not my house, it belongs to my older son, but I’ve told him I want to sell it... I’ve always felt (ashamed)... I can’t help it...

However, according to accounts elicited in both communities, lingering doubts about the vulnerability of survivors were common, as was the convenience of “forgetting” about the whole matter (M/brother of a person who died of HIV/AIDS/40):

...When José’s (status) became known, my mother also talked about it with me, she said: “Listen Miguel, do you take care of yourself? Yes, you see what I mean?” And I told her: “C’mon, it’s the first time we talk(ed) about that!”. She said to me “The thing is, please take care of yourself, take care of yourself...”

In summary, family responses towards a person with AIDS did not end with the death of the affected person. Financial and emotional consequences lived on among family members and it was often only with time and adjustment that remaining family members could overcome the shock and normalize, where possible, their lives.

*Sidóso, derived from the Spanish word for AIDS—SIDA—is a pejorative work used to describe people with AIDS.

CONCLUSIONS AND RECOMMENDATIONS

Given the pervasive social stigma associated with HIV and AIDS, information management was central to the responses of affected individuals and their families in both studied communities. In each case, infected persons preferred to hide their HIV seropositivity, or chose selectively with whom to share this information. Again, in both communities, family members who were aware of the problem tended to cover it up, making sure the information did not travel outside the family unit. The two communities studied differed from one another, however, in relation to the “motives” underpinning the information management process. While the family members of gay men in Mexico City tried hard to hide the fact that one of their members was homosexual, families in Netza showed greater concern to conceal the fact that one of their members was HIV positive. If actions in the former case were motivated by fear of loss of social status, at least in relation to prevailing moral and sexual standards; actions in the latter seemed triggered by fear of violent reaction from the broader community which in more than one case had ousted the infected individual from the neighbourhood.

In both communities, specific responses to HIV and AIDS depended very much on pre-existing family dynamics. Families with a history of family conflict tended to experience conflict with respect to AIDS, whereas families that were more adept at communication and conflict resolution tended to react more constructively. Support and solidarity behaviours in both communities also had different origins. In Netza, support derived primarily from a culture of kinship, while in the families of gay men, kinship bonds (and the supportive responses to which they are capable of giving rise) seemed to have been weakened by the conflict that being homosexual creates. In a few cases, however the ethics of kinship prevailed, allowing the individual to return home, often with the support of his social network.

Both Netza and the gay community studied are environments that have a strong community-orientation. This underpins many of their responses to social and health crises. This characteristic explains why in times of difficulty individuals turn to their family for support. It also explains why families tend to judge and in some cases control, the sexuality of their members. Both intolerance towards homosexuality and family support derive from kinship ties and obligations and are nurtured by the same cultural matrix, the community-oriented base of these groups.

In Netza, the death of a person with AIDS was often followed by irreconcilable conflicts indicative of factionalism in family relations. For gay men on the other hand, conflict was more prevalent between family members and the friends of the infected indi-
In the first case, conflict is a destabilising factor. In the second case, conflict between family and friends creates cohesion within the family.

The struggle for the possessions of the infected person is of central importance in explaining the kind of support given to people with AIDS. In Netza, immediate family members tended to keep the possessions of the infected member after his or her death. The partners of gay men on the other hand cannot inherit the possessions of the deceased because in Mexico the law currently does not acknowledge the rights of homosexual couples. In this case, family members tended to keep the possessions of the deceased, even though family ties beforehand may have been minimal.

Family responses towards people affected by AIDS therefore varied along a continuum ranging from openly supportive behaviours to crudely discriminating ones. In between, there were more ambiguous behaviours which constituted the majority of the responses described and which showed both supportive and discriminatory characteristics.

Since economic and sexual marginalisation were the main factors influencing solidarity and rejection towards people with AIDS, these factors should be the main focus of public policy interventions. Efforts to reduce such marginalisation and to promote greater tolerance and acceptance of homosexuality should be encouraged. More specifically, better counselling and psychological support services are needed to allow affected people and their families to cope better with the news of being seropositive. Inhibiting blaming is essential, since this constitutes a real obstacle for the expression of subsequent supportive behaviours. It is also urgent to develop intervention and communication programmes which work with more inclusive definitions of “family support”. Only this way can all members of the family be encouraged to participate in the provision of care and support to people with HIV and AIDS. And only this way can prevailing gender inequalities be challenged.

Another difficulty which families face in supporting people with AIDS derives from their lack of knowledge about treatment options and about how best to provide for, and live with, a family member who has AIDS. It is of the utmost importance, therefore, to develop educational programmes that provide guidance on ways of caring for people with AIDS at home. These educational programmes must contain information on diet, medicines, hygiene and the physical care of the affected person. After the death of the person with AIDS, there remain issues to be attended to by the family. Institutional support programmes need to be offered to help families overcome the emotional conflicts that remain once a person with AIDS has died.

Finally, invisibility, fear and stigma are deterrents to prevention and care for HIV positive gay men. Greater support is needed by NGOs working directly with homosexual men to establish outreach programmes for those as yet uninfected and to provide better access to counselling and care in an enabling and friendly environment.

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