



Research Report

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Community Reaction to Older-Age
Parental AIDS Caregivers and Their
Families: Evidence from Cambodia

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Evidence from Cambodia**

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ABSTRACT

Accounts of community reaction to persons with HIV/AIDS and their families typically focus only on negative reactions stemming from stigmatization with little acknowledgement of variation over time and across settings. To usefully guide local interventions, a broader view is needed that also encompasses attitudes and actions stemming from sympathy and friendship. We examine community reaction in Cambodia to families from the perspective of parents of adults who died of AIDS or currently receive antiretroviral therapy. Survey evidence and open-ended interviews reveal a mixture of reactions related to social relations, interactions with local officials, gossip, business patronage, funeral participation, and orphaned grandchildren. Positive support is often dominant and reactions typically improve substantially over time. Misplaced fears of contagion through casual contact underlie most negative reactions. Moral condemnation or blame is not evident as a source of negative reactions. Overall a sufficiently supportive atmosphere likely exists in many localities to facilitate community based efforts to mitigate the epidemic's impact on affected families.

INTRODUCTION

HIV infected persons and their families live their daily lives in localities where they interact with neighbors and other acquaintances, earn their living, buy food and other necessities, and share use of local facilities and services. The reaction of community members and local officials towards them has considerable bearing on their quality of life. Besides infected persons themselves, family members who participate in caregiving, live together with the infected persons, or are their spouses or offspring are most likely to be the subject of reactions by others in the community (Ogden and Nyblade 2005; HAI 2003). Understanding the extent, nature and underlying causes of such reactions is important for designing and implementing programs aimed at impact mitigation, especially those that are community based (Commission on AIDS in Asia 2008, p. 156).¹ Such knowledge is also particularly pertinent for determining the need for education programs to minimize negative reactions and for guiding their content in terms of the issues that need to be addressed (ICRW 2006).

Depictions of community reaction have often been based on assumptions and generalizations that are unduly influenced by anecdotal data and whose validity is largely undetermined (VanLandingham, Im-em & Saengtienchai 2005). In addition, the focus is usually exclusively on negative reactions and their adverse consequences stemming from stigmatization associated with the disease. These are thought to include unfavorable psychological effects, discrimination in employment and health care, delays in seeking treatment, and reluctance to seek welfare benefits or other kinds of formal assistance. More recently efforts are underway to more systematically collect data on stigma and discrimination but there is a notable absence of efforts that investigate the fuller range of reactions (e.g. Nyblade & MacQuire 2006; Ogden & Nyblade 2005; Tanzania stigma-indicators field testing group 2005).

To be useful for guiding the development of local interventions, a broader view of community reaction is needed that encompasses not just negative responses related to stigma but also positive attitudes and actions stemming from sympathy and friendship as well as relatively neutral reactions. Moreover, the situation is likely to vary considerably across settings and over time. The limited focus of research to date detracts from a fuller understanding of the social context of the epidemic. In addition, ignoring the extent to which local communities can provide supportive environments risks underestimating potential opportunities for marshalling community based assistance for persons with HIV/AIDS (PWA) and their families.

Another aspect of the epidemic that is often ignored is the impact on older persons as family members, especially as parents of infected adults, and their contributions to how societies cope with HIV/AIDS. While some attention has focused on older persons as grandparents who raise

young children orphaned by AIDS, far less publicized is the substantial role they play in the care and support of adult family members, particularly their infected adult sons and daughters (Knodel & VanLandingham 2002; Population Reference Bureau 2007). There is mounting evidence that parents often play a prominent role in caregiving for adult PWHA when they become ill, yet little is known if and how this affects relations with others in the community. Even when serious illness and incapacity of PWHA is being reduced or at least delayed as a result of increasing availability of effective treatments, especially anti-retroviral therapy (ART), parents may be taking on new roles assisting with treatment adherence (Williams et al. 2008).

The present study examines community reaction in Cambodia to families in which an adult has either died of an AIDS related illness or is currently being treated for HIV/AIDS with ART. Particular attention is given to reactions related to the older age parents of adult PWHA. We draw primarily on qualitative data from open-ended interviews with parents but also provide quantitative evidence from the 2004 Survey of Elderly in Cambodia and its 2005 supplement. These sources covered positive and negative reactions and thus provide a more complete picture than typically available. In addition, for background information we summarize several relevant findings from the 2000 and 2005 Demographic and Health Surveys (DHS).

BACKGROUND

Country Setting

Cambodia is among the poorest countries in Asia, with development indicators similar to many sub-Saharan African countries that face serious HIV/AIDS epidemics. The majority of the 15 million population live on less than two dollars a day (UNAIDS 2007). Most depend on agriculture and fishing and 80% live in rural areas. Health conditions are generally poor with life expectancy at birth only 62 years (UNAIDS/WHO 2008). War and extensive internal conflict between the 1970s and early 1990s left the country with little infrastructure, minimal government social services, and a dearth of skilled and educated professionals. While these problems are being addressed, they continue to affect the country today (Chan and Ear 2004; Coates 2005).

Although well below the scale of many sub-Saharan African countries, the AIDS epidemic in Cambodia has been one of the worst in Asia. The country's response to the epidemic, however, has been remarkably strong and effective. Collaborative government and NGO prevention efforts succeeded in substantially reducing adult HIV prevalence (Saphonn et al. 2004). Adult HIV prevalence is estimated to be as 0.8% for 2007, down from just over 2% in the late 1990s (UNAIDS/WHO 2008). Voluntary testing and counseling services have expanded rapidly (NCHADS 2007). ART is provided to those who meet eligibility criteria and by 2007 approximately two thirds of persons needing ART were receiving treatment (UNAIDS/WHO

2008). Recipients of ART go to the hospital once a month to pick up their medications and are invited to participate in support-group meetings. Home-based care teams, typically associated with NGOs, visit most recipients to give advice and printed informational materials and sometimes provide various forms of material assistance (NCHADS 2007).

Knowledge and Attitudes Related to AIDS

Knowledge and attitudes concerning AIDS influence the reaction of community members to PWHA and their family members. Misunderstandings about the risks of casual transmission can lead to social avoidance (Ogden & Nyblade 2005). Demographic and Health Surveys taken in 2000 and 2005 provide nationally representative assessments of knowledge and attitudes related to AIDS. The 2000 DHS was limited to women aged 15-49, while in 2005 both women and men in this age group were sampled. As the upper bank of Table 1 indicates, awareness of AIDS among women was extremely high in 2000 and virtually universal by 2005. Knowledge about AIDS improved substantially between the two surveys. By 2005 the vast majority of reproductive age women understood that condoms can prevent HIV and that breast-feeding can transmit it. Just fewer than 70% understood that a healthy looking person can have AIDS representing a very large increase compared to only five years before. Trends in men's knowledge are not available since they were not included in the 2000 sample. However, their awareness of AIDS was virtually universal in 2005 and their knowledge on the items shown is fairly similar to that of prime age women.²

Table 1. AIDS Knowledge and Attitudes, Cambodia

% of women age 15-49 who:	2000	2005
Ever heard of AIDS	94.8%	98.5%
Agree condom can prevent HIV	66.3%	87.4%
Agree a healthy looking person can have AIDS	22.9%	68.6%
Agree breastfeeding can transmit HIV	67.4%	87.1%
% of persons age 15-49 in 2005 who:	Women	Men
Cannot get AIDS from sharing food with PWHA	87.2%	87.3%
Would buy vegetables from PWHA shopkeeper	63.8%	72.7%
Would not conceal that a family member is PWHA	72.4%	52.7%
Are willing to care for PWHA family member in own home	76.5%	83.1%

Source: 2000 and 2005 Demographic and Health Surveys (National Institute of Public Health, National Institute of Statistics [Cambodia] and ORC Macro 2001 and 2006)

The results of several more direct questions related to attitudes towards PWHA included in the 2005 DHS are summarized in the lower bank of Table 1. Vast majorities of both adult men and women in 2005 know that one does not get AIDS from sharing food with an infected person. Although fewer indicated that they would buy vegetables from an infected shopkeeper, still substantial majorities of both men and women appear undeterred to do so. Almost three-fourths of women but only slightly more than half of men indicated they would not conceal that a family member was a PWHA. Thus, according to these results, there is still reluctance on the part of a substantial minority of adult Cambodians in 2005 to be open to the community about HIV/AIDS in their families. Large majorities of both men and women indicated they would be willing to care for a family member with HIV/AIDS in their own home. The 77% of women indicating willingness in this respect represents a considerable increase from the 2000 DHS in which only 54% said they would be willing to do so (data for men is not available for 2000).

Overall the DHS results suggest that much of the adult public in Cambodia is reasonably well-informed about HIV/AIDS. Moreover, attitudes expressed in the survey suggest a reasonable degree of tolerance towards persons with AIDS. Still, considerable minorities appear to have incorrect knowledge and express reluctance to interact with PWHA in ways that they likely (incorrectly) perceive as putting them at risk.

Older Persons and the Epidemic

Although older age persons in Cambodia are much less likely to be infected with HIV than younger adults, they are very much involved with the epidemic through the illness and deaths of their HIV infected adult children. The 2004 Survey of Elderly in Cambodia (described below) revealed that 81% of persons age 60 and over expressed a willingness to provide care to a family member with AIDS. More importantly, many older age Cambodian parents who lost an adult son or daughter to AIDS are closely involved in their fatally ill adult children's lives and deaths. Over 60% co-resided with their child at the terminal stage of AIDS, approximately 80% provided major care, and almost 70% helped pay medical expenses (Knodel et al. 2007). They also often arrange and pay for the funeral. In addition, if young children are left behind, grandparents very commonly take responsibility for the orphaned grandchildren. Thus by fulfilling critical functions, older persons play an important role in helping mitigate the potential burden and adverse consequences that the epidemic poses for society. At the same time, being so intimately associated with the care and living arrangements of PWHA exposes older age parents to potential stigma and negative reactions by other community members.

DATA AND METHODS

Quantitative information on community reaction to PWHA and their older age parents come from the 2004 Survey of Elderly in Cambodia (SEC) and a supplemental companion survey in 2005. The 2004 survey consisted of 1273 interviews with persons aged 60 and over and is representative of Phnom Penh and the five most populous provinces (together constituting over 50 percent of the Cambodian population). The questionnaire contained an extensive section directed at assessing the impact of an adult child's recent death on the parents including a series of questions about potential positive and negative reactions of neighbors in their community. If AIDS was not stated as the cause of death, responses to several "verbal autopsy" questions were used to determine if the child died of AIDS. Since only 113 respondents reported the recent loss of an adult child due to illness, and only 39 of these appear to be due to AIDS, an additional supplemental sample was interviewed in 2005 using the same questionnaire but purposively targeting persons age 50 and older who lost an adult child within the last five years to an illness with an emphasis on deaths due to AIDS. Respondents in the supplemental sample were identified through intermediaries such as local officials combined with snowball sampling yielding an additional 103 respondents of whom 79 lost an adult child presumably to AIDS.³ Thus all together the combined surveys included 118 cases (39 + 79) of parents of adults who recently died presumably of AIDS. Detailed descriptions of the SEC and supplemental surveys as well as the determination of deaths due to AIDS from the verbal autopsy questions are available elsewhere (Knodel et al. 2005 and 2007).

Qualitative information for the present study comes from 25 semi-structured open-ended interviews conducted in Fall 2006 with parents of adults who either died of AIDS (15 cases) or was currently HIV positive and receiving ART (10 cases).⁴ For six of the cases of deceased children, either a surviving grandchild or other household member was currently on or waiting for ART. The two Cambodian coauthors, who are senior researchers at the Royal University of Phnom Penh, conducted the interviews which averaged one and a half hours and were typically conducted in the homes or yards of the interviewees. Efforts were made to ensure privacy. In several cases, the PWHA was also present and invited to participate. Interviews were tape recorded with prior permission and fully transcribed.

Potential interviewees were first contacted by intermediaries most of whom were members of NGO affiliated home-based-care teams assigned to visit AIDS affected households in four provinces and Phnom Penh. Due to the extensive role of NGOs within the current Cambodian AIDS program, contact with NGO-administered home-based-care teams is common. Nevertheless, our sample excludes the minority of parents who received no support services

either during their child's illness or following their death. Sample selection was purposively carried out to ensure inclusion of roughly equal shares of rural and urban cases and a broad range of socio-economic levels. All parents interviewed were over age 50 and more than half were over age 60. Consistent with the low educational levels among older Cambodians, over half of those interviewed had no education. Most cases involved daughters (18 of the 25), attributable in part to the greater likelihood that for infected married couples, husbands usually become infected and ill first. Thus while husbands can often be cared for by their wives, by the time wives become ill they are widowed and need to depend on parents for assistance.

Given that the intermediaries had some discretion in identifying families to be interviewed in both the supplemental survey and the qualitative interviews, it is possible that selection biases were introduced. For example, intermediaries likely chose cases that were relatively open about their situation which in turn could be associated with more positive or less negative experiences. It is reassuring that comparisons between the AIDS cases in the SEC, which did not involve the use of intermediaries, and the supplemental sample reveal only very modest differences in the extent of either negative or positive reactions, none of which are even remotely statistically significant. Moreover, the diversity of experiences reported in the open-ended interviews reasonably mirrors the quantitative survey results. Thus while selection effects may influence our results to a modest extent, they are unlikely to seriously distort the overall picture provided.

In accordance with our research interests, for the open-ended interviews we choose parents who gave care to their grown child with HIV/AIDS. Thus our cases intentionally exclude parents who were uninvolved, did not know their child had AIDS, or did not live with or near their HIV infected child at the time of illness. However, as noted above, most parents of adults who died of AIDS in Cambodia gave care and lived with the child at the terminal stage. Thus our cases reflect a very large share of situations of care and treatment of PWHA in the country.

Our findings from the open-ended interviews are based on thematic content analysis of both the original Khmer and translated English transcripts (see Knodel et al. 1993). We constructed overview grids to systematically summarize transcript content regarding issues of interest. This was done independently by each team member and then compared. Differing assessments were resolved through discussion and re-examination of the transcripts. In reporting results, we sometimes cite the number of cases or roughly characterize their frequency to distinguish situations that are more commonly mentioned from those that arose only occasionally. While such information is useful for describing our set of interviews, the nature of case selection and small number of total cases renders it inappropriate for generalizing beyond this limited purpose.

RESULTS

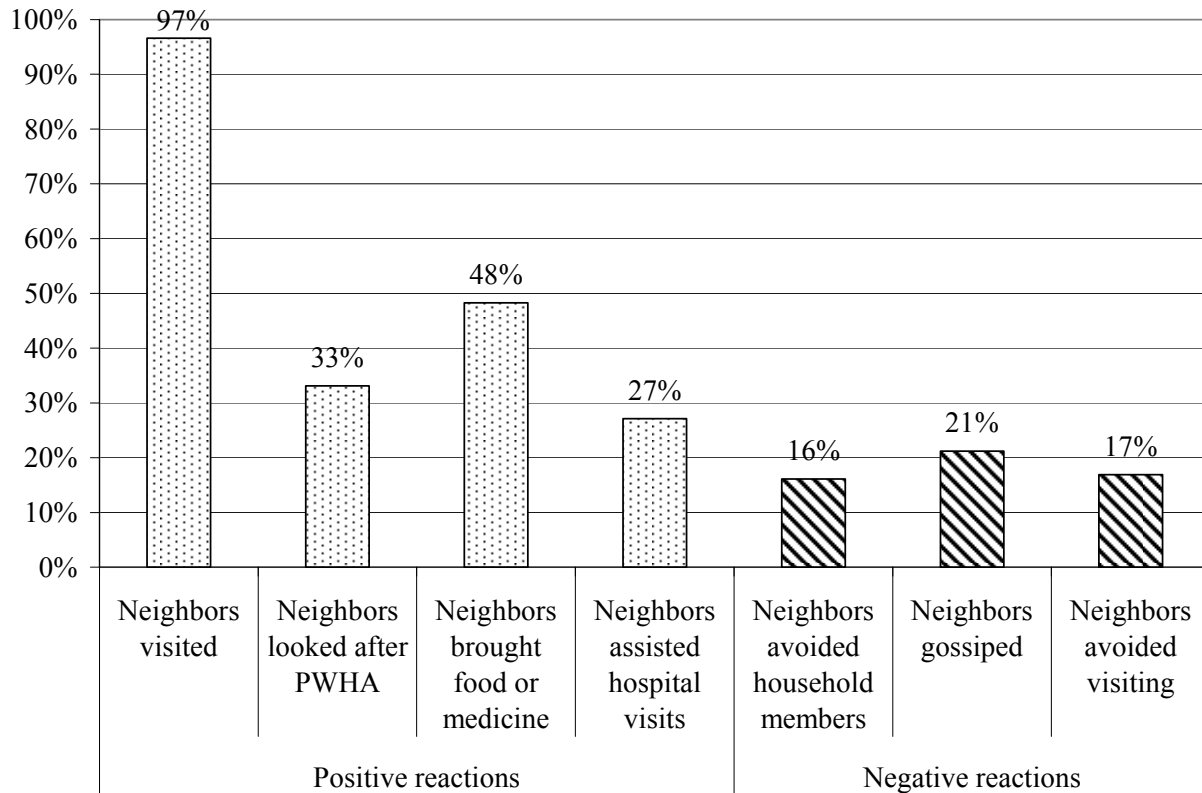
Results based on combined data from the 2004 Survey of Elderly in Cambodia and the 2005 supplemental survey provide an overview of the balance between positive and negative reactions. Analysis of the open-ended interviews provides greater detail on the nature of community responses as well as the reasons underlying them and descriptions of how and why they may have changed. The analysis of the qualitative data covers social relations, interaction with local officials, gossip, business patronage, funeral participation, and the situation of grandchildren.

Quantitative Overview

Respondents who experienced the recent loss of an adult child were asked a series of questions about potential positive and negative reactions of neighbors in their community. Figure 1 shows the results for respondents who were judged to have lost an adult child to AIDS. Positive reactions were considerably more likely to be reported than negative reactions. Overall almost all respondents who lost a son or daughter to AIDS reported that neighbors visited and many reported other positive responses with almost half saying that neighbors brought food or medicine.⁵ In contrast, far fewer reported negative reactions, the most common of which was gossip reported by just under one-fourth. Less than one in six reported that neighbors avoided talking with them or avoided visiting.

Table 2 provides summary measures of community reactions according to selected characteristics of the adult child who died and of the parents who provided the information. Since negative reactions were relatively uncommon, a single summary measure is provided indicating the percent who reported any of the three potential negative reactions asked about in the questionnaire. To summarize positive reactions, two measures are shown: the mean number of four potential positive reactions reported and the percent who reported at least three of the four positive reactions. These measures are presented in relation to how AIDS deaths were identified, the year of death, the gender of the deceased child, and the type of area of residence and current economic status of the respondent (i.e. parent). Economic status was estimated from housing characteristics and household possessions.⁶ Because of the small number of cases involved, few of the differentials reach statistical significance even at the .10 level and thus are more appropriately considered suggestive rather than firmly established.

Figure 1. Community reactions to persons with AIDS and parents as reported by older-age parents who lost a grown child to AIDS, Cambodia, 2004-05



Source: 2004 Survey of Elderly in Cambodia and 2005 Supplemental Survey

Overall, 22% reported at least one of the three potential negative reactions. With regards to the four potential positive reactions, respondents reported experiencing an average of just over two. As noted above, almost everyone reported that neighbors visited; thus on average they reported one of the other three positive reactions. In addition, a third of respondents reported at least three of the four positive reactions.

Negative reactions were more common in cases when AIDS was directly stated as the cause of death than when an AIDS death was inferred from symptoms. There are several possible explanations for this. The latter group is more likely to include cases erroneously attributed to AIDS and less likely that actual AIDS cases to be subject to negative experiences. Also directly reporting AIDS as the cause of death may be associated with wider disclosure to others and more community members would be aware and react negatively. Still, even those who directly stated that the cause of death was AIDS were far more likely to report positive than negative reactions.

Table 2. Summary measures of community reaction as reported by parents of adult children who died of AIDS related illnesses, Cambodia 2004-2005

	Number of cases	% reporting any of 3 <i>negative</i> reactions	Mean number reported of 4 <i>positive</i> reactions	% reporting at least 3 of 4 <i>positive</i> reactions
Total	118	22.0	2.05	33.9
Cause of death		(p=.100)	(p=.098)	(p=.258)
stated AIDS	90	25.6	2.14	36.7
suspected AIDS	28	10.7	1.75	25.0
Year of death		(p=.453)	(p=.437)	(p=.623)
1999-2000	30	30.0	1.83	26.7
2001-02	43	20.9	2.16	37.2
2003-05	45	17.8	2.09	35.6
Gender of deceased child		(p=.839)	(p=.081)	(p=.190)
son	66	22.7	1.89	28.8
daughter	52	21.2	2.25	40.4
Type of area		(p=.204)	(p=.347)	(p=.211)
Phnom Penh center	29	10.3	2.14	44.8
Phnom Penh periphery	17	29.4	2.35	41.2
Rural	72	25.0	1.94	27.8
Residence of deceased child at terminal stage		(p=.886)	(p=.736)	(p=.582)
with respondent	92	21.7	2.03	32.6
not with respondent	26	23.1	2.12	38.5
Current economic status		(p=.095)	(p=.875)	(p=.896)
poor	60	28.3	2.03	33.3
non poor	58	15.5	2.07	34.5

2004 Survey of Elderly in Cambodia and 2005 Supplemental Survey

Parents of adults who died of AIDS more recently were less likely to report negative reactions than when the death occurred earlier. This suggests a decline in negative reaction over time. No consistent trend in positive reactions is evident although fewer are reported in cases with the earliest deaths than for cases in which the death occurred in either of the two latter periods. Little difference in negative reactions is associated with the gender of the deceased child. Positive reactions appear more common in situations of deceased daughters than sons. Negative reactions are less commonly reported by respondents in Phnom Penh than elsewhere while positive reactions are less common in rural areas compared to central or peripheral areas of Phnom Penh. There is little association between both negative or positive reactions and whether or not the

deceased child lived with the parent at the terminal stage of illness. Poorer respondents report more negative reactions than those who are better off but socioeconomic status shows little association with positive reactions.

Social Relations

We now turn to results from our open-ended interviews. They contain considerable information on how social relations with others in the community were affected by the presence of an adult household member becoming ill and in many cases dying of AIDS. Consistent with the survey results presented above, our open-ended interviews with parents of PWHA indicated in most cases that at least some neighbors still visited their home during the period of their child's illness even if others avoided doing so. Only rarely did the interviewee say no one visited.

In a sizeable majority of the interviews the parents either simply mentioned that neighbors visited the family normally (11 cases) or that most people visited normally with only a few avoiding visiting (6 cases). In several cases, parents stressed that neighbors ate with the PWHA and in one case that they massaged the PWHA. On the other hand, in three interviews parents indicated that neighbors visited but avoided eating with or touching the PWHA.

"Yes, they liked [my daughter] very much when she was alive. They also visited her frequently when she was sick, bringing her some food and fruit. I just thanked them when they came and told them that they did not have to bring something along."
(Mother of daughter, deceased 2005)

"They did not behave strangely. They came to visit us and the house was full [with many people]. No one avoided talking with us because at that time [my son's] body looked like our bodies. He only became skinny when he was in the hospital. There were a few people who avoided meeting us or gossiped." (Mother of son, deceased 2004)

In some cases visits by other community members may have been largely out of curiosity but many parents mentioned positive motivations including to socialize, to bring food, and to express sympathy for the PWHA. Material assistance from others to the PWHA and their family was fairly common, especially food brought by neighbors. Overall, about a third of our cases stated that they had received food, money, or clothes from community members. Some were quite poor and neighbors provided food that they were not able to afford themselves. Even if the parents were able to provide food to their ill child, neighbors brought food as a gift and token of support.

"My neighbors told me about how to care for my daughter and what food I should give her. But I did not have money, so how could I provide her with good food? ... Sometimes when I had money, I bought rice soup for her, or my neighbors gave money to her to buy something to eat when she was hungry. My neighbors had a lot of pity for her. Sometimes they provided her with food or money, especially in the final stage of her illness." (Mother of daughter, deceased 2003)

Expressions of sympathy were both in response to understanding the difficult situation that the family was in and because neighbors felt that the PWHAs were generally good people. Several parents indicated that as a result of this sympathy, their neighbors refrained from gossiping and discrimination.

"My relatives and neighbors come to see and visit my son normally. They do not discriminate against him. Some have sympathy for him because he is well behaved and never did bad things to other people since he was young. When he was seriously sick they were very worried because they feared he would die." (Mother of son on ART)

Avoidance of social contact with the PWHAs and their families, largely because of fears of infection, was also often mentioned although only in six cases did interviewees explicitly state that no one or only a few people in the community visited their family. In many cases, neighbors avoided social contact only with the PWHAs. However, a few respondents mentioned that neighbors were also afraid of becoming infected from other family members who had close contact with the PWHAs. They would thus avoid contact with the parents, siblings or children of the PWHAs. Social contact outside the home could also be hampered or unpleasant because of fears of contagion. In two cases, parents described how a shop owner was very cautious and did not allow them to touch the food they wanted to buy. Only in one case, however, was it stated that there were lasting problems of social contact with other community members even after the PWHAs died.

"Sometimes, the villagers and my neighbors were afraid and scorned my daughter and my family. For instance, they did not sit on places where we had sat. Furthermore, when her youngest sister wore her clothes, villagers said, "You are wearing the clothes of your sister who has AIDS, so you will be infected too". (Mother of daughter on ART)

"Nobody entered my house because they were afraid of transmission of AIDS. When I bought corn they did not allow me to choose with my hands (touch the corn) and they said that "Do not choose because we are afraid of AIDS". Some villagers said, "Mothers who look after sons with AIDS will get infected with AIDS too... Only I looked after him

and no one helped with care because they were so afraid of my son. If someone dared to visit, they only stood outside of the door to talk with him or me and then they returned back to their homes." (Mother of son deceased 2004)

Several interviewees mentioned that avoidance was greater when the PWHAs had visible symptoms or wounds. Similarly, a few linked a lack of problems with respect to social contact to the lack of visible symptoms (for example after the PWHAs had started ART) or to the cleanliness of the PWHAs. On the other hand, in some cases, neighbors came to visit even when the PWHAs were visibly ill. Our interviews also revealed that improved knowledge about the disease and modes of transmission largely assuaged fears of infection and improved social contact with the community. In four cases, interviewees explicitly stated that there were no problems once people understood more about the disease.

"Now [after starting ART] they do not discriminate so much because they see my son as a normal person. His skin doesn't have wounds or itches. Before, when he was seriously ill, a lot of people avoided him. But now it is okay, they contact us normally. (Mother of daughter on ART)

Daughter: "At the beginning of my AIDS infection, villagers discriminated against my family. However, when some NGOs came and repeatedly explained to the villagers about this disease at their houses, their discrimination to my family melted away."

Mother: "Previously, they didn't eat with us, even when we went somewhere they didn't allow us to walk with them... There is no problem now. Everyone changed their attitude, and they allow us to walk with them and eat with them because they understand that AIDS is not transmitted by walking or eating together with a PWHAs." (PWHAs-daughter on ART)

Local Officials

At the local level, provincial areas are divided into communes and then villages with their equivalents in municipalities being sectors and wards. Discussions in the interviews about reactions of local officials thus refer to the heads of these administrative units. For simplicity we will use the term commune chief and village headman for both provincial and equivalent municipal local officials. Unlike with neighbors whom daily or frequent interaction would be normal, contact with village heads and especially commune chiefs would be uncommon for most families. Indeed, most parents indicated that local officials ignored their situation and sometimes mentioned that AIDS was of little interest to them. In some cases, interviewees sounded disappointed or even bitter about the lack of concern showed by local officials but others seemed to accept it as something outside the officials' duty and thus to be expected.

"Neither the head of the village nor the commune ever came to visit my son and me. They know about his illness. When they met me along the road I told them. But they have not paid any attention to my family. They are very busy with their work and their businesses." (Mother of son on ART)

At the same time, some parents explicitly mentioned that local officials, more often village heads than commune chiefs, had visited during the period of illness and in others their comments implied such visits likely occurred. Visits by local officials may have served as a show of public support for the PWHA and their family and thus had an added significance beyond just social contact. In some cases, besides visiting, local officials were proactive in assisting with referrals to organizations that could provide services, helping to raise or provide community funds for the household, or assisting with the funeral. One village head organized a meeting to educate the community about AIDS to lessen fears of contagion and thus helped eliminate negative reactions. In some cases these activities were linked to the fact that the official was a volunteer or participant in organizations dealing with AIDS.

"[The village chief and head of the commune] came to visit my home one or two times during her illness. Sometimes when the head of commune came to visit my daughter, he gave one or two dollars and when she died he contributed \$20 US to her funeral." (Mother of daughter, deceased 2003)

Overall favorable reactions by at least one local official were reported in a third of the cases. Only in a couple of cases did it appear that a local official showed signs of avoiding contact because of his own concern about contagion. In addition, favorable reactions were more commonly reported for the cases in which the adult child was currently on ART than those where the child had died earlier, possibly reflecting an improving involvement by local officials.

Gossip

Among the most common negative reactions, reported in almost half of the interviews, was the knowledge or belief that others in the community were gossiping about their infected adult child or members of their family in relation to this. In a number of other cases it was implicit that word of their situation had spread, possibly also reflecting gossip beyond simply neutral reporting of local news. However, most of those who reported gossip in their communities also indicated that the gossip was not extensive. In addition, even when interviewees mentioned that some neighbors gossiped, they sometimes also mentioned that others did not.

While the Khmer term for gossip ('Niyey Dem') generally has a negative connotation, not all of the gossip reported was necessarily maliciously intended. Our interviewees reported a range of perceived intent about the neighborhood gossip. Several described it in ways that suggested they viewed this as primarily a matter of spreading news without necessarily implying a negative intent. In this sense spreading the information could actually benefit the family as it spared them needing to explain their situation themselves. In addition, learning of another's misfortune by others in the community can have positive or negative outcomes, depending on how community members react.

"They only said or pointed out that this house had a child infected with AIDS. But they still have normal relationships with us. Also there are a few people who talk less with us." (Mother of son, deceased 2004)

On the other hand, some interviewees reported gossip that was clearly negatively intended. Of these, most indicated that they felt the gossip was motivated by a fear of infection. Only a few parents stated or seemed to imply that there was any overtone of moral condemnation in what others said about their child with AIDS or the family. Even among these, in one case the condemnation towards the infected daughter seems aimed at the burden she placed on her parents rather than at behavior through which she contracted HIV/AIDS. Rather than mentioning that others criticized the moral character of the child who had AIDS, parents frequently made the opposite point describing their child as a good or kind person and one who had good relations with neighbors or others in the community, was well liked, and well thought of by others in the community.

"I only heard many words of blame about my daughter like, 'She left her mom and family for years, and then she returned home with AIDS making it hard for them to care for her.'" (Mother of daughter, deceased 2003)

"She was a pleasant and kind person. She had a good relationship with the villagers and other people... My neighbors were very sad for her, because she faced this disease, because my youngest daughter was a very beautiful girl ... and she was very pleasant." (Mother of daughter, deceased 2003).

Interviewees also described how they responded to the gossip they experienced, ranging from those who were resentful and angry to those who just let it pass. Only in two interviews did parents mention feeling badly as a result of these negative reactions. Alternately it was more common that respondents responded to gossip with a striking amount of strength and continued to have relations with their neighbors. This is particularly notable, given that our interviewees are especially vulnerable at this time of their lives and in their specific situation.

"Yes, a few people [gossiped]. They said that my daughter had the AIDS infection, it was so awful. They looked down on my daughter and gossiped, but they didn't dare to speak loudly. I heard them but I didn't reply because people have bodies, so they will have sickness and also they will have sadness too. As a result, I didn't get angry with them." (Father of daughter, deceased 2002)

Business Patronage

Many persons in Cambodia earn or supplement their living by selling things from home, at the market, as mobile vendors or some combination of these. Often they sell snacks that they make or vegetables that they grow. Parents of PWHA who earned money this way could have difficulties if people avoid buying their products out of fear of getting infected, especially if the parent was selling food products. For just over half of the cases we interviewed (13 out of 25), parents had small shops or sold items by vending during the child's illness. In nine of these cases, interviewees explicitly mentioned the effect of having an HIV infected child on business patronage. Although we can not be sure of what happened in the four cases where impact on patronage was not mentioned, it seems probable that there was little dramatic impact or the interviewee would have commented on it. Under this assumption, cases involving parents who ran a business and at the same time gave care to an infected child were about evenly split between those who mentioned problems of losing customers or needing to cease business and those who did not seem to have such problems. In some cases, the main problem was that caregiving demands interfered with business activities rather than loss of patronage due to intentional avoidance by customers.

Most of the nine cases that explicitly discussed reactions in relation to patronage sold some sort of food. In three cases, there appears to have been no avoidance of buying from the parents. The rest mentioned the loss of customers who did not want to buy from them because of their association with AIDS. For some, the problem may have arisen because they were receiving assistance from their infected child when carrying out business. Among those parents who faced difficulties in their business, all but one explained that only some customers were deterred from buying or that the situation subsequently improved and currently their business was back to normal. Interestingly, most of the latter are parents of children on ART. In two cases the child on ART was currently helping parents sell goods at the market. Most of those whose business returned to normal or who did not suffer a loss of customers agreed it was because knowledge about AIDS improved and people now realize that there is no risk in buying food or other items from someone who is infected or is a caregiver to a PWHA.

"Yes before they were some people who avoided buying vegetables (from us), but now they don't avoid doing so any more. It is normal. My daughter can sell everything in my store and the customers come as usual... I asked her to help me to sell the desserts but at that time she was disappointed because only a few customers would buy. But now they stopped discriminating..., it's like that because the village leader gathered all the villagers to a meeting about the HIV/AIDS epidemic..., after the meeting there were no more problems." (Mother of daughter on ART)

Funeral Participation

In Cambodia, as in many societies, funerals are important social events typically involving widespread participation of community members. Together with related ceremonies, typically performed on the 7th and 100th day following the death of a person, funerals are also imbued with considerable religious significance for the deceased person. As a result providing a proper funeral for a deceased adult child is an important responsibility for the parents, often involving substantial expenses relative to their material resources. To ease this burden, community members, friends and relatives customarily make monetary contributions and assist in other ways. Given the social nature of the event, the extent to which community members participate in the funeral and provide assistance is a telling reflection of the nature of community reaction when the deceased person is known to have died of HIV/AIDS.

Among the 15 interviews concerning adults who died of AIDS, the parents were virtually always the key persons who arranged the funeral and thus are likely to be particularly affected by avoidance or lack of assistance in relation to the funeral. Those parents who lost a child to AIDS most commonly reported that community members and relatives attended the funeral and gave contributions. A number specifically mentioned that the fact their child died of AIDS did not deter others from attending the funeral. In several cases, interviewees mentioned that community leaders or their wives also attended the funeral, contributed money or helped with arrangements.

“Many neighbors joined (the funeral)... They helped with organizing and cleaning her corpse and ate food as normal. They were not afraid and they didn’t say anything else. They said they felt sad for her; she died because she got AIDS from her husband and she was their neighbor. They didn’t discriminate against her and they also came to contribute as much money as they could.” (Father of daughter, deceased 2001)

Contributions and assistance at the funeral were very common. The level and type of contribution varied. Some people brought only rice and candles, some gave money, some offered general help cooking during the ceremonies, and some made a combination of contributions. This not only helped parents cover funeral expenses but in some cases also enabled them to arrange additional religious ceremonies for the child after the funeral.

“The day when she died, my neighbors helped me. I had no money, not even one Riel. My neighbors bought materials and some helped cook rice. For the 7 days ceremony, her husband sold a pig for 100,000 Riel and bought everything but the money was not enough to cover expenses. So, we used the money contributed by neighbors to buy the food and materials for this ceremony.” (Mother of daughter, deceased 2004)

There were several exceptions to the lack of problems associated with funerals. In some cases persons attending the funeral gossiped about the fact that the deceased had died of AIDS. However, even in the few cases where people were said to avoid the funeral, numbers who did so appear to be modest. The main reason for not attending in these cases seems to have been fear of infection perhaps related to the custom to provide a meal for funeral guests. Still, no one we interviewed explicitly said this was their experience. Generally when eating at the funeral was mentioned, the interviewees stressed that everyone who attended ate normally.

“My neighbors came (to the funeral) and we ate meals all together. Even his friends came to participate and also ate together. Rarely someone did not come back. It seems nobody discriminated towards him or my family. I saw everyone come, it seems they actively participated (in the funeral).” (Mother of son, deceased 2004)

In brief, participation in the funerals of those who died of AIDS largely indicates a positive reaction from community members to the parents after the death of an adult child due to AIDS. The extensive practice of making contributions in cash and kind by relatives, neighbors, and friends to help cover expenses remained very much in tact in almost all cases, serving as a show of collective belonging among people in the same community. This likely also provided comfort to the parents at a time they were experiencing the grief of losing a child. Money, material and labor contributed by other people at the funeral were of considerable help to the parents and in some cases crucial for the process. Manifestations of negative feelings towards the person who died of AIDS and fear of getting infected by joining the funeral was not entirely absent but appears to have been minimal. The less frequent avoidance of funerals compared to home visits during the period of illness may reflect a reduction in fear of contagion after the infected person is dead. It may also reflect that funerals are seen as a time for conciliation given the passing of the deceased person or a reduction in fear of contagion since the PWHA was dead.

Grandchildren

Among family members potentially subject to stigma and adverse community reactions, the young children of adults who are living with HIV/AIDS or who have died of the disease are often mentioned as being particularly vulnerable (UNICEF 2006). In cases where the young children are also HIV infected, the situation is likely to be particularly serious although even those who are not infected may be discriminated against and mistakenly thought to be carriers of the virus. Caring for these children, especially when orphaned, typically falls on older generation family members, particularly grandparents. This is the aspect most frequently highlighted when discussing older persons in reference to the epidemic (HAI & HIV/AIDS Alliance 2003). Considerable anecdotal data has been publicized concerning refusal to allow children of PWHA to attend school although systematic evidence on the extent of such situations is largely lacking.

Most of the adult PWHA (16 of 25 cases) who were the focus of our interviews had children of their own. The grandchildren generally lived with or nearby the interviewee. The experiences are quite mixed. Most interviewees reported relatively minor or no negative reactions from community members towards their grandchildren or said that the situation had improved considerably after initial difficulties. The main two problems mentioned involved neighbors who prohibited their children from playing with children whose parents had AIDS and other children ridiculing or talking badly to or about them, especially when they were at school.

The main reason that neighbors wanted their own children to avoid those of persons who had died of or were living with AIDS appears to be fear of contagion. Typically only some neighbors felt this way while others were not concerned. In one case, even though neighbors did not allow their children to play with those of a PWHA, they bought cookies from the child and the grandmother. The HIV status of the grandchild could also affect reactions of neighbors. In at least one case, the situation changed once the child of the PWHA was tested and the result was negative. In another, however, the interviewee stressed that even though her grandchildren were not HIV positive, neighbors still did not want their own children playing with those of a PWHA.

“Some neighbors did not let their children play with my grandchildren... When my grandchildren have arguments with their children, they curse them saying ‘Damn orphan, your parents died of AIDS.’ So I have to ask them to play inside the house with their siblings only. But most people in this community are okay.” (Mother of daughter, deceased 2004)

“Some neighbors ... didn’t let their children play with my grandsons. Some said to my grandchildren that ‘your mom had AIDS’... Now everything is better because villagers understand much better. They are well informed about AIDS and how it passes to others.” (Mother of daughter, deceased 2003)

Positive reactions to grandchildren were also reported. Some community members feel pity for young orphans who lost their parents to AIDS. One case reported that their grandchildren even seem to get favorable treatment from neighbors as a result. In another, the teachers no longer asked for the customary monetary ‘contributions’ to attend school when they learned that the children were orphaned and the responsibility of the grandparents. In over half of the cases where grandchildren were being cared for, the grandparents mentioned that their own children, i.e. aunts and uncles of the grandchildren, or other relatives helped with paying school expenses or providing school uniforms.

“(Neighbors) did not look down on or discriminate against my grandchildren. Some let my grandchildren buy cakes and candy on credit when they do not have money. They do not think about the fact that my grandchildren have a mother who has AIDS. My grandchildren have good and normal relationships with other children. They go to play with them every day.” (Mother of daughter on ART)

No one reported that the local schools prevented the children of PWHA from attending, even when the children themselves were HIV positive. However several interviewees mentioned that their grandchildren did not want to go to school at first because they were ashamed or afraid of being verbally abused or socially shunned. Nevertheless all of them eventually did attend school. Some of these problems seem to arise from fear of contagion on the part of other children undoubtedly reflecting misinformation imparted by their parents. However much of it may have been more routine bullying or teasing behavior characteristic of school-age children, although again such actions could reflect what the offending children heard from their parents at home.

“Before, my grandchildren did not want to go to school because other children discriminated against them and were afraid of them. They said ‘Oh, children of an HIV patient do not play with them, do not sit near them because we can get infected with the AIDS viruses. (Their mother) was so unhappy when her children told her that she went to tell the school director and teachers about the discrimination against her children. Now it is different and all of the students know a lot about AIDS and consider it a normal thing.” (Mother of daughter on ART)

Clearly there is evidence of discrimination and negative reactions towards the grandchildren of our interviewees and whose parents had either died of AIDS or were currently on ART. Nevertheless, the more common situation seems to be one in which most if not all community members treat these children relatively normally, even when the child is HIV infected. Moreover, stigma and community reaction to the children of PWHA can change over time, particularly in response to better understanding about the epidemic and efforts associated with improving understanding among the community in general, including parents of children who were previously forbidden to associate with those of persons who died of or was living with AIDS.

DISCUSSION AND CONCLUSIONS

Characterizations of how others in their community react to PWHA and their families typically focus on discrimination and stigmatization with little recognition that neighbors, acquaintances and local leaders may react with sympathy and support. Nor is there sufficient

acknowledgement that the mixture of positive and negative reactions is likely to vary across settings and improve over time. The lack of adequate evidence, however, has not hindered sweeping one-sided generalizations.

For example, the recent report of the Commission on AIDS in Asia (2008, p. xii) asserts that for “people living with HIV, and their families ... infection did not elicit compassion but condemnation and rejection”. The research on the situation in Cambodia presented in this study shows that community reaction is often complex and subject to transformation over time. Contrary to the common portrayals that emphasize negative aspects, our results reveal not only that there is typically a mixture of positive and negative reactions present but that positive support from others in the community is often dominant and that negative reactions appear to be declining over time.

Two root causes of stigma and discrimination that lie at the core of negative reactions are widely believed to be fear of contagion through casual contact and moral disapproval of the behaviors that are assumed to lead to HIV infection (ICRW 2006; Nyblade & MacQuire 2006; Ogden & Nyblade 2005). Our findings in Cambodia clearly indicate the critical role of the former in driving negative reactions by community members due to inadequate knowledge about HIV and incorrect understanding of modes of its transmission. Both survey evidence from the DHS and narrative evidence from our in-depth interviews indicate that negative attitudes are decreasing as correct knowledge becomes more common amongst the general population. On a policy level, this underscores the important role that education can play (and has played in Cambodia) in reducing stigma and discrimination.

At the same time, we find little evidence that moral condemnation of the behaviors that may have contributed to HIV infection or that blame of the PWHA is a major factor fueling negative community reactions. In fact, our interviews indicate that positive moral judgments of the PWHA’s general character are more common and often elicit concern, sympathy, and support. In part, this likely stems from the fact that many of the cases we studied involve women who were infected through marital intercourse with an infected husband, a mode of transmission that is unlikely to be subject to ‘blaming the victim’ in most contexts (Ogden & Nyblade 2005). However, a lack of strong negative moral judgment may extend to a considerable extent to men as well because the use of commercial sex, which in Cambodia is a main route of infection of men, is common and, at least prior to its role in spreading HIV, considered relatively normal behavior. These findings for Cambodia are quite similar to those for neighboring Thailand, whose cultural context is also rooted in Theravada Buddhism (VanLandingham et al. 2005). That the religion emphasizes norms of detachment and individual responsibility may also underlie the social tolerance and condition how community reaction to HIV/AIDS has been evolving in these two societies (Little and Twiss 1978).⁷

At a more general level, this study underscores the importance of the cultural setting in conditioning the nature and trajectory of reactions by others in the community to those who are infected with HIV/AIDS and their families. While there may be considerable similarity in the ways stigma is manifested, there is also likely to be substantial variation in the prevalence of stigma as well as the extent to which it is counterbalanced by supportive attitudes and actions of others in the community. Moreover, our results strongly suggest that negative reactions decline over time as knowledge about how HIV is transmitted improves and the occurrence of AIDS becomes more routine. This underscores the need not only to examine the full range of reactions but also to incorporate temporal variation into discussions related to community reaction.

An important danger in over emphasizing stigmatization, discrimination and negative community reaction towards persons with AIDS and their families is that it likely results in underestimating the potential for community-based efforts to assist in mitigating the impact of the epidemic. The fact that supportive reactions may be common and even prevail over negative ones suggests that there are compassionate sentiments and favorable attitudes among many in the community towards helping those who are infected or have a family member who is. This in turn bodes well for drawing on local resources to assist efforts to help families with infected members or who have suffered the loss of a member cope with their situations.

Endnotes

¹ In this study, we use the term community to refer to persons linked together by living in the same locality. We note that in the AIDS literature, community can also refer to groups of persons who have a common sense of identity and belonging due to sharing common circumstances or experiences, e.g. persons living with HIV/AIDS, being gay or being a commercial sex worker (Commission on AIDS in Asia 2008, p. 153-54).

² Among men aged 15-49, 99% had heard of AIDS, 91% agreed condoms can prevent HIV, 60% agreed a healthy looking person can have AIDS, and 84% agreed breast-feeding can transmit HIV.

³ The supplemental cases resided in Phnom Penh and all but one of the five provinces covered in the original survey.

⁴ In five interviews both parents participated and in the remaining 20 only one parent served as respondent.

⁵ Some visits could be motivated by curiosity and associated with subsequent gossip in which case the visits would not necessarily represent a positive reaction (Ogden & Nyblade 2005). It is not possible from the brief survey question to know the reasons for reported visits from others. However, our open ended interviews suggest that respondents overwhelmingly viewed visits in a positive light and rarely mentioned those of a voyeuristic nature.

⁶ A summary measure was created using principal-component analysis with results converted into a percentile score (Filmer & Pritchett 2001). A dichotomous measure is formed by regrouping the scores according to whether they fall in the upper or lower half.

⁷ HelpAge International (no date) conducted a study in 2003 under the auspices of the Cambodia Country Office that presents findings at considerable variance with those of the present study. According to the HAI report, "Older carers face exclusion and discrimination, which often results in isolation, and leaves carers without adequate and reactive community support networks" (p.2) and "There was also a common perception among many of the older people interviewed that HIV/AIDS infection is due to 'immoral' and 'sinful' behaviour." (p.11). The research is described as "an informal qualitative study" (p.4) conducted in 15 villages in Battambang province. The difference could be attributable to differences in sample sites, data collection methodology, analytical strategies, and time period, especially since the several case studies presented referred to deaths between 1995 and 2000. The study gives no consideration to potentially positive aspects of community reaction. In contrast, a recent report issued by HAI based on focus groups and interviews conducted in Cambodia, Thailand and Vietnam, notes that many who participated said that discrimination had decreased and some emphasized the valuable support received from community members (Orbach 2007).

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