

# Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge and behaviour in families of HIV infected children in Kenya

Mary Hamra<sup>1</sup>, Michael W. Ross<sup>2</sup>, Mark Orrs<sup>3</sup> and Angelo D'Agostino<sup>4</sup>

<sup>1</sup> Department of Medicine, Chronic Disease Prevention and Control Research Center, Baylor College of Medicine, Houston, TX, USA

<sup>2</sup> WHO Center for Health Promotion and Prevention Research, University of Texas School of Public Health, Houston, TX, USA

<sup>3</sup> Department of Sociology, Saint Joseph's University, Philadelphia, PA, USA

<sup>4</sup> Nyumbani and Children of God Relief Organizations, Nairobi, Kenya

## Summary

**OBJECTIVES** To quantify expressed stigma in clients of the Kangemi program for HIV+ children, and to characterize the association between stigma and other population characteristics.

**METHODS** By means of a household survey we created a stigma index and indices for other social and knowledge domains that influence HIV-related healthcare. We used  $\chi^2$ , anova, and correlation to identify associations between domains.

**RESULTS** The mean ( $\pm$ SD) expressed stigma on a six points scale (6 = least stigma) was  $3.65 \pm 1.64$ . Composite scores on knowledge about AIDS were skewed toward more knowledge; and analysis of individual knowledge items indicates that most respondents reject erroneous traditional beliefs and myths about the causes and transmission routes of AIDS. Respondents who were younger, had never married, and had less education expressed greater stigma. Differences in stigma were associated with poor knowledge about AIDS and negative attitudes toward testing, but not with gender or tribal affiliation. Condom use at last intercourse, unrelated to stigma, was only 40% ( $n = 218$ ).

**CONCLUSIONS** While this population has good knowledge about AIDS and appraises risks realistically, it fails to reduce these risks. Associations between stigma and other domains can inform interventions that improve HIV care and mitigate spread of HIV.

**keywords** HIV+ orphans, HIV/AIDS stigma, AIDS knowledge, HIV/AIDS outreach programs, Africa

## Introduction

When children orphaned or soon to be orphaned by AIDS are also HIV+, the options for care are limited. Children who remain with family avoid the added burden of disrupted kinship ties. In Eastern Kenya, the Lea Toto Kangemi Program\*, an affiliate of Nyumbani Orphanage, provides medical and social support to families caring for HIV+ children in and around Nairobi, Kenya. Our study examines expressed stigma (a term we have coined to refer to stigmatising beliefs, attitudes and behaviour) in these families. Stigma has usually been studied from either the perspective of the victim or the perpetrator. There are numerous reports, primarily from Western studies, on the demographic, attitudinal and behavioural correlates of stigmatisation in these two groups (Peruga & Celentano

1993; Green 1995; Crocker *et al.* 1998; Malcolm *et al.* 1998; Alubo *et al.* 2002; Herek *et al.* 2002; Parker & Aggleton 2003). It is less common to examine stigmatising beliefs and attitudes in groups that are normally stigmatised. Our focus in the present study is the examination of expressed stigma in a population that is normally the target of stigma.

In Africa, families affected by AIDS are often the target of AIDS-related stigma (Lwihula *et al.* 1993; Muyinda *et al.* 1997; UNAIDS Best Practice Collection 2000; Alubo *et al.* 2002; International Center for Research on Women 2002; Nyblade *et al.* 2003; Sepulveda *et al.* 2003; Rankin *et al.* 2005). Families may lie about the illness or cause of death; they may shield a sick relative from the community for fear of rejection (Lwihula *et al.* 1993). In our population, HIV-infected children at Kangemi's sister program, Nyumbani, were refused admittance to local schools until a court order required school compliance (Lacey 2004).

\* Supported by USAID and children of God Relief Fund.

While we have no specific data on the degree of real or perceived stigmatisation experienced by the Kangemi families, it is probable that some stigmatisation has accompanied their care of the dying/deceased parent and now the child, and possibly accompanies even their association with the Kangemi program. Because the program benefits the entire household in a resource poor community, some victimization of the family may result not only from AIDS-related stigma but from jealous resentment in the community.

Families affected by HIV/AIDS have to deal with stigma on two fronts: the stigma that targets them, and their own feelings of covert or overt stigmatisation. Stigma associated with HIV has been present since the epidemic began (Herek & Glunt 1988; Farmer 1992; Mann *et al.* 1992). AIDS-related stigma is linked to fear, lack of information, and absent or minimal exposure to people living with AIDS (PLWA) (Malcolm *et al.* 1998; Ezedinachi *et al.* 2002; Herek 2002; Herek *et al.* 2002; Brown *et al.* 2003). However, the dimensionality of the latter, that is the continuum of intimacy regarding exposure to PLWA (e.g. from mere acquaintance to friendship/love) has not been adequately explored in the West, let alone in Africa. In addition, while the prevalence of AIDS in Africa suggests that few people are unacquainted with PLWA, the lack of disclosure and denial common in Africa may confound associations between stigma and knowing PLWA. The associations between stigma and AIDS-related information are also complex. While stigma results in part from a lack of information (Malcolm *et al.* 1998; Ezedinachi *et al.* 2002; Herek 2002; Herek *et al.* 2002; Brown *et al.* 2003), studies indicate that providing information about HIV/AIDS may be necessary but not sufficient to decrease stigma (Malcolm *et al.* 1998; Herek 2002; Brown *et al.* 2003).

Stigma has social, political, and economic implications (Parker & Aggleton 2003). An important implication of HIV/AIDS-related stigma is its role in perpetuation of the epidemic. Fear of stigmatisation impedes efforts to increase testing, encourage treatment seeking, and promote prevention and risk reduction (Malcolm *et al.* 1998; Lentine *et al.* 2000; Ezedinachi *et al.* 2002; Herek 2002; Brown *et al.* 2003). Thus, measures that might curb the epidemic or mitigate its effects are often not accessed by those who fear the repercussions of becoming stigmatised.

In June 2003, the Lea Toto Kangemi program conducted a household survey of client families. We examined the survey and found several items that are markers of expressed stigma. We had two aims: (a) to quantify, through use of an AIDS stigma index, the level of expressed stigma in our population and (b) to characterize the association between the respondents' stigma-index scores

and other social, belief and demographic characteristics. We developed several hypotheses about the study population based on previous studies of AIDS-related stigma in other populations. Those hypotheses were that lower expressed stigma is positively associated with (a) more extensive and more accurate knowledge about HIV/AIDS, (b) personal acquaintance of one or more PLWA, (c) less over-estimation of infection risk and (d) positive attitudes toward HIV-testing and the practice of risk-reduction.

Our data provide a unique perspective on AIDS-related stigma in Africa. In this pilot examination of an under-investigated population, we present associations between expressed stigma and various demographic, social and behavioural characteristics.

## Methods

We analysed cross-sectional household survey data conducted among client families of the Lea Toto Kangemi Outreach Program, Nairobi, Kenya. These client families are caring for one or more HIV+ children, though not all members of the household may know the HIV status of the child or of others in the home; some may not admit to HIV in the home. The survey included children in the household irrespective of HIV status or status as orphans/non-orphans. The questionnaire did not query HIV status of either children or caretakers. Our study is a pilot investigation, which examines correlates of expressed stigma in a population for which there are currently no comparable data.

## Sample design

A representative sample of households served by the program was selected. The sampling frame consisted of all six program areas (Ruthimitu, Riruta, Kawangware, Waithaka, Mutuini and Kangemi). The target groups of the program are HIV+ children and their caretakers. Some of the children are orphans (defined as having lost one or both parents to AIDS), though not all. An estimated sample size of 180 households was determined from the following formula:  $n = (t^2 \times p(1-p))/m^2$ , where  $n$  = required sample size,  $t$  = confidence level at 95% (standard value of 1.96),  $p$  = estimated prevalence of AIDS orphans in the project area (computed from national statistics), and  $m$  = margin of error at 5% (standard value of 0.05). This formula generated the number of households necessary to describe household characteristics: income, expenditures, etc. The number of individual respondents was 873. For most of the analyses presented here, the unit of analysis is the individual. However, we have considered that while household members may have differing knowledge of HIV status, they may share stigmatising attitudes and beliefs.

In order to address concerns about independence with regard to expressed stigma, we performed additional analyses described in the Data Analysis section. Children were included in the demographic profile of the study population (Table 1). However, we excluded children under 12 years in the subsequent analyses about stigma and its correlates because we could not be sure that young children understood certain questions sufficiently to provide meaningful data.

The questionnaire was designed with various modules, or groupings of questions that fall into a similar domain. Children and adults in the household who wanted to participate in the survey were interviewed. Not every individual answered every question in all domains; and some individuals skipped whole domains either by choice or because, based on age or previous responses, they were not eligible to answer every series of questions. For example, those who were not sexually active would not have answered questions about sex behaviour and condom use; those who had not been tested for AIDS would not have answered the question about returning to get HIV test results. Thus, we present data for subsets of the overall sample population. Where we created indices for various domains, the *n* represents the number of respondents for whom we had answers to all items of the index. Where cross-tabulations were performed, the *n* reflects those individuals for whom we had responses on both items. In every analysis, our number was sufficient to report our findings with statistical confidence.

### Questionnaire development

The survey of Lea Toto Kangemi clients was conducted to establish certain demographic, social, belief and behavioural characteristics of the clients served. Focus groups, selected through a non-random purposive sampling method, were interviewed to explore domains for inclusion in the household questionnaire. The groups included self-help community groups, youth groups, religious leaders, community owned resource persons, groups of HIV+ children, and client caregivers. The focus groups were qualitative and followed an open-ended format of directed questions. Responses from the focus groups, in conjunction with performance questions and indicators determined by the Program's stakeholders, were used to inform the design of the household survey. The questionnaire was pilot-tested and refined prior to use in the sample population.

### Data collection teams and methods

The survey consultant and the Lea Toto Kangemi Program Director supervised the data collection team of enumera-

tors and enumeration supervisors. Field-team training of the data collection team included the following: the purpose of each method, data collection and analysis; understanding the questions and accurate recording of answers; facilitation techniques (including discussion methods, role plays, use of flip charts and analogies); ways of recording information from each of the methods used; and if necessary, translation of the questionnaire into the preferred/suitable language. Data from filled questionnaires were entered into an SPSS statistical software spreadsheet.

### Data preparation and measures

All data preparation and subsequent analysis was performed using SPSS 11.5 and 12.0 software<sup>†</sup>.

Survey items often used to assess AIDS-related stigma fall into four broad categories: (a) support for coercive AIDS-related policies, (b) attributions of blame and responsibility to the victim, (c) negative feelings toward the victim and (d) avoidance and discomfort. These are the same categories delineated by Herek *et al.* in their creation of AIDS-related stigma scales (Herek & Capitanio 1992,1993; Herek *et al.* 2002). In addition, secrecy and denial are both causes and products of stigma (Malcolm *et al.* 1998; Rankin *et al.* 2005). We were limited in that the Lea Toto survey did not include items that reflect all of these domains. However, there were six items on the survey that are associated with expressed stigma. Stigma items were derived from themes that emerged in the focus groups in response to probes about HIV-related stigma.

These items and the rationale for including them in our stigma scale are as follows:

- If married, have you ever talked with your spouse/the woman or man you are living with about getting the virus that causes AIDS?
- Would you buy fresh vegetables from a vendor who has the AIDS virus?
- If a member of your family got infected with the virus that causes AIDS, would you want it to remain a secret or not?
- If a relative of yours became sick with the virus that causes AIDS, would you be willing to care for her or him in your household?
- If a teacher has the AIDS virus, should she/he be allowed to continue teaching in school?

<sup>†</sup> Prior to analysis, we determined that there were two cases of miscoding in the data files. In those cases, the same identification number was used for two different respondents in one of the data subsets. We deleted the second respondent with the identical ID number. We had no demographic data on two of the respondents.

M. Hamra *et al.* Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge**Table 1** Description of sample; demographic characteristics and stigma scores (SS) ( $n = 871$ )

Variables	Frequencies	%	SS, $n^{\dagger}$
Division			
Westlands	132	15.2	$4.00 \pm 1.66, n = 71^*$
Dagoreti	739	84.8	$3.53 \pm 1.62, n = 221$
Location			
Kangemi	132	15.2	$4.00 \pm 1.66, n = 71$
Kawagware	133	15.3	$3.93 \pm 1.66, n = 30$
Riruta	125	14.4	$3.76 \pm 1.60, n = 33$
Waithaka	154	17.7	$3.84 \pm 1.10, n = 51$
Mutuini	151	17.3	$2.80 \pm 1.77, n = 46^{**}$
Ruthimitu	176	20.2	$3.51 \pm 1.71, n = 61$
Sex			
Male	420	48.2	$3.79 \pm 1.59, n = 136$
Female	451	51.8	$3.53 \pm 1.67, n = 156$
Age category			
0–15	273	31.3	See categories below
16–30	332	38.1	
31–45	136	15.6	
46–60	102	11.7	
61–75	17	2.0	
76–90	9	1.0	
91–100	2	0.2	
Age category for Stigma			
12–20	55	19.0	$2.55 \pm 1.65, n = 55^{***}$
21–35	130	44.5	$3.91 \pm 1.59, n = 130$
36–50	70	24.0	$3.97 \pm 1.37, n = 70$
51–75	37	12.7	$3.76 \pm 1.61, n = 37$
Marital status			
Never married	512	58.8	$2.98 \pm 1.73, n = 99^{****}$
Married	284	32.6	$4.13 \pm 1.39, n = 152$
Divorced	15	1.7	$3.0 \pm 1.77, n = 8$
Widowed	19	2.2	$2.64 \pm 1.63, n = 11$
Separated	22	2.5	$4.55 \pm 0.82, n = 11$
Don't know	19	2.2	$3.54 \pm 1.86, n = 11$
How long respondent has lived in village (years)?			
0–10	129	14.8	See categories below
11–20	14	1.6	
21–30	17	2.0	
31–40	4	0.5	
Always	626	71.9	
Visitor	43	4.9	
Missing or don't know	38	4.4	
Duration of residence for Stigma (years)			
0–15	36	12.3	$4.33 \pm 1.35, n = 36$
16–30	9	3.0	$4.56 \pm 0.73, n = 9$
Always	219	75.0	$3.62 \pm 1.61, n = 219$
Visitor	23	7.9	$2.52 \pm 1.83, n = 23^{*****}$
Don't know	5	1.7	$3.60 \pm 2.19, n = 5$
Religion			
Catholic	295	33.9	$4.19 \pm 1.37, n = 96^{*****}$
Protestant	460	52.8	$3.39 \pm 1.72, n = 166$
Muslim	7	0.8	$3.33 \pm 2.08, n = 3$
Atheist	7	0.8	$4.0, n = 1$
Others	102	11.7	$3.31 \pm 1.59, n = 26$
Tribe			
Kikuyu	512	58.8	$3.56 \pm 1.61, n = 178$
Luyha	153	17.6	$3.86 \pm 1.63, n = 51$

**Table 1** (Continued)

Variables	Frequencies	%	SS, <i>n</i> †
Luo	68	7.8	4.00 ± 1.78, <i>n</i> = 23
Others	138	15.8	3.58 ± 1.68, <i>n</i> = 40
Attended school			
Yes	560	64.3	3.68 ± 1.62, <i>n</i> = 269
No	302	34.7	3.24 ± 1.86, <i>n</i> = 17
Don't know	9	1.0	3.17 ± 1.94, <i>n</i> = 6
Highest level of school			
Nursery	40	7.1	4.13 ± 1.25, <i>n</i> = 8
Primary	244	43.6	3.23 ± 1.71, <i>n</i> = 99
Vocational	14	2.5	3.67 ± 1.03, <i>n</i> = 6
Secondary	182	32.5	3.82 ± 1.53, <i>n</i> = 101
College‡	62	11.1	4.05 ± 1.45, <i>n</i> = 44
University	18	3.2	4.73 ± 1.74, <i>n</i> = 11
(note: 311 missing)			
Occupation			
Owner/farmer	13	1.5	3.9 ± 1.29, <i>n</i> = 10
Own business	87	10.0	3.86 ± 1.42, <i>n</i> = 62
Casual	71	8.2	3.91 ± 1.43, <i>n</i> = 45
Permanent employee	62	7.1	4.0 ± 1.70, <i>n</i> = 43
Unemployed	83	9.5	3.45 ± 1.77, <i>n</i> = 31
Housewife	72	8.3	4.05 ± 1.19, <i>n</i> = 43
Student	162	18.6	2.44 ± 1.80, <i>n</i> = 39*****
Other	321	36.9	3.26 ± 2.00, <i>n</i> = 19
Total household income (KSHS)			
0–180, 833	672	78.2	3.58 ± 1.53, <i>n</i> = 208
180,834–361,666	132	15.4	3.50 ± 2.00, <i>n</i> = 60
361,667–542,499	23	2.7	4.75 ± 0.46, <i>n</i> = 8
542,500–723,332	12	1.4	3.50 ± 2.12, <i>n</i> = 2
723,333–904,165	8	0.9	5.00 ± 0.82, <i>n</i> = 4
904,166–1085,000	12	1.4	4.14 ± 1.57, <i>n</i> = 7

SS, stigma scores.

† Number of stigma scores available per category.

‡ In Kenya, this represents technical or trade school.

\*  $P = 0.037$  Westlands *vs.* Dagoreti.

\*\*  $P = 0.001$  (Mutuini *vs.* Kangemi);  $P = 0.043$  (Mutuini *vs.* Kawagware);  $P = 0.023$  (Mutuini *vs.* Waithaka).

\*\*\*  $P < 0.004$  compared to all other age categories.

\*\*\*\*  $P = 0.000$  compared to married.

\*\*\*\*\*  $P = 0.001$  (visitor *vs.* 0–15 years);  $P = 0.034$  (visitor *vs.* 16–30 years);  $P = 0.045$  (visitor *vs.* always).

\*\*\*\*\*  $P = 0.002$  Catholic *vs.* Protestant.

\*\*\*\*\*  $P = 0.008$  (student *vs.* own business);  $P = 0.012$  (student *vs.* casual);  $P = 0.005$  (student *vs.* permanent employee);  $P = 0.004$  (student *vs.* housewife).

- Should children aged 12–14 be taught about using condoms to avoid AIDS?

The questions used for the stigma index reflect several documented aspects of expressed stigma (note: some questions express more than one aspect): (a) the desire to be secretive regarding HIV/AIDS (1, 3, 4, 6), (b) fear and avoidance (2, 4, 5), overestimation of risk (2, 4, 5) and (c) restrictive measures (5). Denial of HIV (1, 3, 6), although more subtle, is also part of the process of stigmatisation (Malcolm *et al.* 1998). While it might be

argued that reluctance to discuss issues surrounding sex (items 1 and 6) may instead reflect a cultural taboo, it is also true that secrecy and denial about AIDS, both of which are reflected in items 1 and 6, are classic examples of stigma manifestations.

The questions used were a series of 'Yes/No' response items. The most liberal response (the response expressing the least stigma) was assigned a value of 1; the more stigmatising response, a value of 2. For each respondent, items with a 1 score were counted. A summary stigma

score was computed as the sum of least stigmatising responses. Thus, each respondent had a SS of 0–6, with six representing the least expressed stigma. Cronbach's alpha for this scale was 0.6.

Because many of the social, belief, and behavioural questions of interest required a 'Yes/No (occasionally, Don't know)' response, we organized the Stigma Index so that cross-tabulations and  $\chi^2$  analyses appropriate for categorical data could be performed. We created a dichotomised stigma index DichotStigma Index (DSI) based on the findings of the six-item stigma index. In this pilot project, we were looking for gross differences, not fine distinctions. The DSI organized the data into two groups: group 1, SS scores below the mean; group 2, SS scores above the mean.

Using the same methods as those described for the Stigma Index and the Dichotomised Stigma Index, additional indices were created for 'General AIDS knowledge'. A composite AIDS knowledge index was constructed from 21 questionnaire items that reflect general AIDS knowledge, including items about cause, treatment, and prevention. (Survey items used in the index appear in Appendix 1). The composite score was calculated as the sum of the 'more knowledgeable' responses on the 21 questionnaire items. Thus, a score of 21 represents the most AIDS knowledge; and a score of 0, the least AIDS knowledge. Scores on the composite AIDS knowledge scale were then dichotomised above and below the mean to form two groups DichotKnowledge Index (DKI). Group 1 contained respondent with scores of 0–15 (less AIDS knowledge); group 2, respondents with scores of 16–20 (more AIDS knowledge; includes the median).

We assessed attitudes toward HIV testing with the following four survey items:

- Have you ever been tested to see if you have the AIDS virus?
- When was the last time you were tested?
- Did you get the results of the test?
- Would you want to be tested for the AIDS virus?

Responses regarding the timing of testing fell into three groups: less than 12 months ago, 12–23 months ago, and two or more years ago. These responses were grouped such that group 1 represented recent testing (<12-month ago), and group 2 represented more distant testing ( $\geq 12$  months ago). This dichotomised index was then cross-tabulated with the DSI (see Table 4, second question).

Finally, two domains were explored with one question each. Acquaintance with PLWA was assessed with the question: 'Do you know someone personally who has the

virus that causes AIDS?' Practice of risk reduction was assessed with one question about condom use: 'Did you use a condom the last time you had sexual intercourse?'

In most cases, we have presented analyses of responses for both individual items in a category as well as that for the composite, dichotomised responses for the category.

### Data analysis

Summary statistics were performed on all survey items. For continuous data response items, we determined the range, the mean, the median and the standard deviation on all items. For categorical data, we determined the frequency and percentage for each response.

To explore relationships between SS (stigma scores, reflection of expressed stigma) and other demographic, social and belief characteristics, we performed cross-tabulations between the DSI and selected response items representing each of these domains. Most of our data are discrete, categorical data that are represented in  $2 \times 2$  contingency tables. We tested the alternative hypothesis that an association exists between two discrete variables. The chi square goodness-of-fit test statistic (two-sided) was used to test for association.

Four categories of cross-tabulations are listed below. One or more representative questions were explored in each category. We predicted that these analyses would provide important information about our population regarding factors associated with stigmatising beliefs/attitudes. Categories of cross-tabulations were:

- DichotStigma Index  $\times$  general AIDS knowledge,
- DichotStigma index  $\times$  respondent's contact with PLWA,
- DichotStigma index  $\times$  practice of risk-reduction,
- DichotStigma index  $\times$  attitudes toward testing.

Cross-tabulations 1 and 2 were chosen for exploration in order to verify or refute the current literature on AIDS-related stigma in our population. Most studies indicate that expressed AIDS-related stigma is less when the respondent has contact with people who have AIDS (Herek *et al.* 1998; Herek 2002) (thus, tabulation 2); in addition, it is diminished, though not eliminated, when the level of AIDS knowledge is higher (Malcolm *et al.* 1998; Ezedinachi *et al.* 2002; Herek 2002; Brown *et al.* 2003) (thus, tabulation 1); 3) there is usually a high correlation between expressed stigma and overestimation of risk of infection (Herek & Capitanio 1993; Herek *et al.* 2002) (several items in tabulation no. 1 address risk assessment). We wanted to explore these relationships, previously confirmed primarily in Western studies, in our population.

Cross-tabulations 1 and 2 explore associations between the DSI and factors known to influence expressed stigma. Cross-tabulations 3 and 4 explore variables that are believed to be a product of AIDS-related stigma. Fear of stigmatisation often leads to negative attitudes toward testing or the practice of risk reduction (Malcolm *et al.* 1998; Lentine *et al.* 2000; Ezedinachi *et al.* 2002; Herek 2002; Brown *et al.* 2003). Since it is probable that expressed stigma in our population reflects our respondents' perception of stigmatisation in the community (vis à vis the tendency to project onto others one's own perceptions), we wanted to explore the relationships between expressed stigma and these two known consequences of fear of stigmatisation.

To address concerns about independence of individual respondents regarding expressed stigma and its correlates, we had two considerations. First, of the respondents for each of the indices created for this research (Hamra *et al.* 2005), 40%–42% were the sole persons in the household for whom we had an index score. Second, we performed an additional analysis, one which created an average of scores in households with more than one respondent in order to generate a single household value. Using this procedure, which statistically obviates non-independence, we performed a correlation analysis between the indices (for example, the correlation between the stigma scores and the knowledge scores) using one value per household, either that for the one member for whom we had a score or the mean of the group (household mean correlation). We performed the same correlations using the whole sample of individual data for comparison.

For the demographic indices, we used single factor analysis of variance to examine the relationship between expressed stigma and demographic characteristics. Where significance was found, we made post-hoc comparisons using the method of Scheffé.

## Results

The survey included 873 respondents from 180 households. The mean and median household size was  $5 \pm 2$  and five persons, respectively. Demographic data are presented in Table 1. The population is skewed toward the younger age groups, with 69.4% of respondents ages 0–30 years. Of the 273 children (0–15 years), 39 (14.3%) either had a deceased mother or didn't know if she was alive; and 74 (27.1%) had a deceased father (or didn't know). Only 25 children were double orphans (including those who didn't know parental status). Most respondents (91.3%) fell into two marital categories: never married or married. The majorities of respondents were Catholic or Protestant, and most were of the Kikuyu tribe. Though there is pervasive

poverty in this population and school fees were only rescinded in 2003 in Kenya, most respondents had completed primary (43.6%) or secondary school (32.5%).

Stigma Index Scores, determined for a subset of 292 respondents (and excluding children under 12 years), represented the sum of the least stigmatising responses on six questionnaire items (see Methods). Thus, a score of six represents the least expressed stigma. The mean ( $\pm$ SD) and median stigma scores were  $3.65 \pm 1.64$  and 4.0, respectively. When the index was dichotomised DSI, group 1 had scores of 0–3; and group 2 had scores of 4–6. Thus, group 2 represents the least expressed stigma and includes the median score.

Stigma scores, and the number ( $n$ ) per category for whom we had scores, are presented in the right hand column of Table 1 (note: Table 1 has additional collapsed categories for age and duration of residence so that enough stigma scores were available per category for meaningful analysis). We found significant differences within some, but not all, categories. Adolescents 12–20-years old had significantly lower SS (more expressed stigma) than any other age group ( $F_{(df,3)} = 11.51, P = 0.000$ ); the mean differences from the other age groups were, respectively: 21–35 years,  $-1.36$  (CI:  $-2.07$  to  $-0.6594$ ); 36–50 years,  $-1.43$  (CI:  $-2.21$  to  $-0.6387$ ); 51–75 years,  $-1.21$  (CI:  $-2.14$  to  $-0.2823$ ). There were no significant gender differences ( $F_{(df,1)} = 1.86, P = 0.174$ ), and no differences associated with tribal affiliation ( $F_{(df,3)} = 0.860, P = 0.462$ ). Dagoreti respondents had significantly lower SS (more expressed stigma) than those in the Westlands ( $F_{(df,1)} = 4.41, P = 0.037$ ). Within divisions, SS differed among locations ( $F_{(df,5)} = 3.72, P = 0.003$ ). Mutuini had lower SS than Kangemi [mean difference  $-1.20$  (CI:  $-2.09$  to  $-0.2999$ )], Kawagware [mean difference  $-1.13$  (CI:  $-2.24$  to  $-0.0183$ )], and Waithaka [mean difference  $-1.04$  (CI:  $-2.00$  to  $-0.0764$ )]. Most respondents (72%) had always lived in their respective locations. Visitors had lower SS (more expressed stigma) ( $F_{(df,4)} = 5.32, P = 0.000$ ) than all other residents; mean differences between visitors and others were: 'Always',  $-1.10$  (CI:  $-2.18$  to  $-0.02$ ); 0–15 year residents,  $-1.81$  (CI:  $-3.13$  to  $-0.50$ ); 16–30 year residents,  $-2.03$  (CI:  $-3.97$  to  $-0.10$ ).

There were significant differences in stigma scores per marital status ( $F_{(df,5)} = 8.75, P = .000$ ) with never married persons having lower SS (more expressed stigma) than married persons; the mean difference was  $-1.15$  (CI:  $-1.82$  to  $-0.49$ ).

The numbers of Muslims and atheists in our sample were small; and for atheists there was only one stigma score (thus, the stigma analysis was performed without the Atheist subset). The difference in SS among religions was significant ( $F_{(df,3)} = 5.48, P = 0.001$ ), with Catholics

M. Hamra *et al.* Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge

having higher SS (less expressed stigma) than Protestants (mean difference = 0.80 (CI: 0.22–1.37). We found no differences in SS based on whether or not school had been attended ( $F_{(df,2)} = 0.87, P = 0.422$ ). However, when stigma is examined only for those who have attended school, there is a significant relationship between level of education attained and expressed stigma ( $F_{(df,5)} = 3.31, P = 0.007$ ). While the more conservative test of Scheffé did not identify significant differences between groups, a Bonferroni comparison identified lower SS (more expressed stigma) in those with a primary education compared to those who attended University; the mean difference was  $-1.50$  (CI:  $-2.99$  to  $-0.01$ ). Occupation was also associated with a difference in SS ( $F_{(df,7)} = 4.68, P = 0.000$ ), with students showing significantly lower SS (more expressed stigma) than those who owned their own business, casual workers, permanent employees and housewives; mean differences for these were: owned business,  $-1.42$  (CI:  $-2.63$  to  $-0.21$ ); casual workers,  $-1.48$  (CI:  $-2.77$  to  $-0.18$ ); permanent employees,  $-1.59$  (CI:  $-2.90$  to  $-0.28$ ); housewives,  $-1.61$  (CI:  $-2.92$  to  $-0.30$ ). Finally, we found no significant difference in SS across income categories ( $F_{(df,5)} = 1.60, P = 0.161$ ).

Factors that influence expressed stigma: We explored the relationship between expressed stigma in our population and several factors reported to influence expressed stigma in other populations. The relationships between these factors and expressed stigma in our population were consistent with those previously reported with one exception, that for overestimation of risk.

**General AIDS knowledge.** In the general AIDS knowledge index (see Methods), whose score represents the sum of the 'most knowledgeable responses', a score of 21 represents the most AIDS knowledge; a score of 0, the least AIDS knowledge. The mean  $\pm$  SD and median general knowledge scores for our population subset ( $n = 303$ ) were  $15.38 \pm 2.65$  and 16, respectively. Thus, composite AIDS knowledge scores were skewed toward more knowledge.

Cross-tabulation of the DKI and the DSI is presented in Table 2. General AIDS knowledge and expressed stigma are not independent ( $\chi^2_{(df,1)} = 4.59, P = 0.032$ ). The frequencies/percentages suggest that respondents with more general AIDS knowledge have less expressed stigma, compared to those with less AIDS knowledge. The correlation between stigma and general AIDS knowledge, using one value per household, was 0.224 (CI: 0.081–0.358,  $n = 180, P = 0.01$ ); this, coupled with a similar correlation for the whole sample, 0.238 (CI: 0.126–0.344,  $n = 292, P = 0.01$ ) verifies our results.

**Table 2** Composite dichotomized general AIDS knowledge index (DichotKnowledge) cross-tabulation with DichotStigma index: DichotKnowledge  $\times$  DichotStigma\* ( $n = 283$ )

	Less knowledgeable	More knowledgeable
More stigma	52 52.0%	48 48.0%
Less stigma	71 38.8%	112 61.2%

\* % = Percentage of within DichotStigma.

$\chi^2_{(df=1)} = 4.59, P = 0.032$ .

Table 3 shows the responses and  $\chi^2$  analysis for individual items used in the composite scale. In general, the analyses of individual AIDS knowledge questions were consistent with the findings for the composite DKI  $\times$  DSI: where the groups differed, those with less expressed AIDS-related stigma had more AIDS knowledge. For several of the AIDS-cause and AIDS-treatment items, the  $\chi^2$  analyses was not valid (see NA) due to cell size minimum requirements; however,  $\geq 94\%$  in both stigma groups responded with the more knowledgeable answer for those items. Interestingly, given a population defined by the presence of an HIV+ child, large numbers in both groups did not know that mother-to-child transmission is a cause of infection.

**Acquaintance with PLWA.** Responses to the question about knowing someone with the virus that causes AIDS were cross-tabulated with the DSI ( $n = 283$ ). Of those with the most expressed stigma, 51/100 (51%) said they knew someone with HIV; of those with the least expressed stigma, 118/183 (64.5%) knew someone with HIV ( $\chi^2_{(df,2)} = 11.34, P = 0.003$ ). Thus, in our population as in others, personal acquaintance with PLWA is associated with less expressed stigma.

**Overestimation of risk.** Four of the survey items presented in the AIDS knowledge index (Table 3) can be used as indicators of over-estimation of risk of acquiring HIV (specifically, the risk associated with touching, sharing food, mosquito bites and sharing utensils). There was little overestimation of risk in this population subset. Most respondents, regardless of stigma group, demonstrated accurate knowledge about risk. Accurate knowledge about the risk of sharing utensils was expressed by 88% (of  $n = 283$ ), for mosquito bite transmission, 87% (of  $n = 283$ ), for risk associated with touching/greeting an HIV+ person, 98% (of  $n = 266$ ), and for risk associated with sharing food, 97% (of  $n = 266$ ). Only the risk associated with mosquito bites was associated with stigma; less stigma was related to



**Table 3** DichotStigma Index  $\times$  individual AIDS knowledge response items

Question*	Yes	No	$\chi^2$ ; <i>P</i> value	
Have you heard of AIDS? ( <i>n</i> = 283)				
More stigma	93 (93.0%)	7 (7.0%)	$\chi^2 = 0.270$ ; <i>P</i> = 0.603	
Less stigma	173 (94.5%)	10 (5.5%)		
Is blood transfusion one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	40 (43.0%)	53 (57.0%)	$\chi^2 = 0.910$ ; <i>p</i> = 0.340	
Less stigma	85 (49.1%)	88 (50.9%)		
Is witchcraft one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	5 (5.4%)	88 (94.6%)	$\chi^2 = 0.246$ ; <i>P</i> = 0.620	
Less stigma	12 (6.9%)	161 (93.1%)		
Is mother-to-child transmission one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	13 (14.0%)	80 (86.0%)	$\chi^2 = 3.91$ ; <i>P</i> = 0.048	
Less stigma	42 (24.3%)	131 (75.7%)		
Is punishment from God one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	0 (0.0%)	93 (100%)	NA	
Less stigma	4 (2.3%)	169 (97.7%)		
Is touching [or] greeting a person with AIDS one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	2 (2.2%)	91 (97.8%)	NA	
Less stigma	4 (2.3%)	169 (97.7%)		
Is sexual contact one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	75 (80.6%)	18 (19.4%)	$\chi^2 = 4.81$ ; <i>P</i> = 0.028	
Less stigma	156 (90.2%)	17 (9.8%)		
Is sharing food with a person with AIDS one of the causes of AIDS? ( <i>n</i> = 266)				
More stigma	3 (3.2%)	90 (96.8%)	$\chi^2 = 0.023$ ; <i>P</i> = 0.879	
Less stigma	5 (2.9%)	168 (97.1%)		
Is there anything a person can do to avoid getting the virus that causes AIDS? ( <i>n</i> = 283)				
More stigma	91 (91.0%)	9 (9.0%)	$\chi^2 = 4.22$ ; <i>P</i> = 0.040	
Less stigma	177 (96.7%)	6 (3.3%)		
Can people reduce their chances of getting the virus that causes AIDS by having just one sex partner who has no other partner? ( <i>n</i> = 283)				
More stigma	58 (58.0%)	42 (42.0%)	$\chi^2 = 18.06$ ; <i>P</i> = 0.000	
Less stigma	149 (81.4%)	34 (18.6%)		
Can people reduce their chances of getting the virus that causes AIDS by always using a condom? ( <i>n</i> = 283)				
More stigma	46 (46.0%)	54 (54.0%)	$\chi^2 = 2.46$ ; <i>P</i> = 0.117	
Less stigma	102 (55.7%)	81 (44.3%)		
Can people reduce their chances of getting the virus that causes AIDS by not having sex at all? ( <i>n</i> = 283)				
More stigma	33 (33.0%)	67 (67.0%)	$\chi^2 = 4.81$ ; <i>P</i> = 0.028	
Less stigma	85 (46.4%)	98 (53.6%)		
	Yes	No	Don't know	( $\chi^2$ ; <i>P</i> value)
Can people get the AIDS virus from mosquito or other insect bites? ( <i>n</i> = 283)				
More stigma	5 (5.0%)	82 (82.0%)	13 (13.0%)	$\chi^2 = 11.83$ ; <i>P</i> = 0.003
Less stigma	14 (7.7%)	164 (89.6%)	5 (2.7%)	
Can people get the AIDS virus from sharing utensils? ( <i>n</i> = 283)				
More stigma	11 (11.0%)	83 (83.0%)	6 (6.0%)	$\chi^2 = 4.35$ ; <i>P</i> = 0.114
Less stigma	11 (6.0%)	167 (91.3%)	5 (2.7%)	
Is it possible for a healthy looking person to have the AIDS virus? ( <i>n</i> = 283)				
More stigma	81 (81.0%)	10 (10.0%)	9 (9.0%)	$\chi^2 = 19.08$ ; <i>P</i> = 0.000
Less stigma	172 (94.0%)	11 (6.0%)	0 (0.0%)	
	Yes	No		( $\chi^2$ ; <i>P</i> value)
What do you think the treatment of AIDS is? ( <i>n</i> = 283 for all) No treatment?				
More stigma	76 (76.0%)	24 (24.0%)		$\chi^2 = 2.82$ ; <i>P</i> = 0.093
Less stigma	154 (84.2%)	29 (15.8%)		
Medication?				
More stigma	11 (11.0%)	89 (89.0%)		$\chi^2 = 0.095$ ; <i>P</i> = 0.758
Less stigma	18 (9.8%)	165 (90.2%)		

**Table 3** (Continued)

Question*	Yes	No	$\chi^2$ ; <i>P</i> value
Bleeding?			
More stigma	1 (1.0%)	99 (99.0%)	NA
Less stigma	6 (3.3%)	177 (96.7%)	
Chasing the person away?			
More stigma	1 (1.0%)	99 (99.0%)	NA
Less stigma	4 (2.2%)	179 (97.8%)	
Herbalist?			
More stigma	0 (0.0%)	100 (100.0%)	NA
Less stigma	11 (6.0%)	172 (94.0%)	
Witchcraft?			
More stigma	0 (0.0%)	100 (100%)	NA
Less stigma	2 (1.1%)	181 (98.9%)	

\* All percentage are within DichotStigma Scale;  $\chi^2_{(df)} = 1$  except for questions about mosquitoes, utensils, and healthy-looking AIDS patients where  $\chi^2_{(df)} = 2$ ; NA, not analysed: cell size requirement not met.

more accurate knowledge about this vector. Variables associated with expressed stigma were: (1) practicing risk reduction: respondents (ages 14–66 years,  $n = 218$ ) were asked about condom use during the last intercourse. Of those with more expressed stigma ( $n = 55$ ), 49.1% said 'Yes', 50.9% said 'No'; of those with less expressed stigma ( $n = 163$ ), 36.8% said 'Yes', 63.2% said 'No' ( $\chi^2_{(df,1)} = 2.59$ ,  $P = 0.108$ ). Thus, we found no association between expressed stigma and condom use; (2) attitudes/behaviour toward HIV testing: we assessed attitude toward testing with four items (see Methods). The (Yes/No) responses were cross-tabulated with the DSI (Table 4). Three of the four analyses show an association between indicators of testing attitude/behaviour and expressed stigma. More expressed stigma

is associated with less testing, less recent testing and less willingness to be tested.

### Discussion

We have described the relationship between expressed stigma and other population characteristics in clients of the Kangemi Outreach program in Nairobi, Kenya, a program that serves HIV+ children and their caretakers. There are limitations to our study. First, these data are cross-sectional data. Therefore, we cannot infer directionality (cause versus effect) from the results. However, our analyses do show significant associations between markers of expressed stigma and other demographic, belief/knowledge, and behavioural indicators in this population. Second, there are

**Table 4** DichotStigma Index  $\times$  attitudes toward HIV-testing

Question*	Yes	No	$(\chi^2; P \text{ value})$	
Have you ever been tested to see if you have the AIDS virus? ( $n = 270$ )				
More stigma	17 (18.7%)	74 (81.3%)	$\chi^2 = 5.66; P = 0.017$	
Less stigma	58 (32.4%)	121 (67.6%)		
When was the last time you were tested? ( $n = 75$ )				
More stigma	4 (23.5%)	Recent test 13 (76.5%)	$\chi^2 = 5.27; P = 0.022$	
Less stigma	32 (55.2%)	Not recent test 26 (44.8%)		
Did you get the results of the test? ( $n = 75$ )				
More stigma	13 (76.5%)	4 (23.5%)	$\chi^2 = 3.82; P = 0.051$	
Less stigma	54 (93.1%)	4 (6.9%)		
	Yes	No	Don't know	$\chi^2; (P \text{ value})$
Would you want to be tested for the AIDS virus? ( $n = 270$ )				
More stigma	30 (33.0%)	47 (51.6%)	14 (15.4%)	$\chi^2 = 8.34; P = 0.015$
Less stigma	91 (50.8%)	72 (40.2%)	16 (8.9%)	

\* All percentage are within DichotStigma Scale;  $\chi^2_{(df)} = 1$  except for last question about wanting to be tested where  $\chi^2_{(df)} = 2$ .

limitations to our stigma measures: (a) the six questions used do not cover all of the theoretical domains of stigma (for example, attributions of blame), though they do cover most; (b) some questions, while often used as measures of stigma, may also measure certain cultural norms, e.g., discussion of sex, that confound their measure of stigma; (c) there is always the potential for social desirability bias in respondent answers, especially about stigma; we have no way to assess the degree of the latter. Another limitation concerns the study population. Our population is unique; it represents families living with HIV. The participants do not represent a cross-section of Kenya. The respondents' beliefs and perceptions are most certainly influenced by their unique association with the AIDS epidemic. Subpopulations in a given society will vary in their response to stigma (Herek *et al.* 1998). Thus, without a control study population, we cannot assume that the associations we have documented apply to the larger society in the districts surveyed.

#### Demographic characteristics and expressed stigma

We found more expressed stigma in the very young (12–20 years), in the 'Never Married', in Protestants (compared to Catholics), among those with less education, among students, and in visitors. Our finding that expressed stigma was more apparent in the young and in groups typically populated by the young ('Never Marrieds' and Students) is dissimilar from previous Western studies where AIDS-related stigma is more common in older persons (Green 1995; Herek 2002). However, AIDS-related stigma in the West is often intertwined with anti-gay sentiment (Herek & Glunt 1988; Price & Hsu 1992; Herek & Capitanio 1997; Herek *et al.* 1998; Herek 2002), a sentiment more often found in older persons (Herek 1984; Price & Hsu 1992). In Africa, HIV/AIDS is primarily a heterosexual disease. In a recent study from Botswana (Letamo 2003), it was also young people who had discriminatory attitudes toward PLWA.

#### Factors associated with expressed stigma

There are encouraging indicators in this population. General AIDS knowledge is good; and the composite score of expressed stigma is slightly skewed toward lesser stigma. However, AIDS-related education and behavioural change are still needed. Stigma remains a significant problem; knowledge about risk reduction is often inaccurate; and practices that reduce risk are too often not followed. Our data are consistent with a number of studies in Africa, which indicate that, while AIDS knowledge is often fairly high (Baggaley *et al.* 1997; Peltzer *et al.* 2000; Odujinrin

& Adebajo 2001; Takyi 2001; James *et al.* 2004), even among those infected with HIV (Nachega *et al.* 2005), misinformation about transmission modes and prevention measures still persist.

Our findings about general AIDS knowledge, including prevention, cause and treatment, were mixed. Composite AIDS knowledge scores were skewed toward more knowledge. In addition, analysis of the individual knowledge items (Table 3) indicates that the majority of our respondents reject erroneous beliefs about traditional causes of AIDS (e.g. witchcraft, punishment from God) and traditional treatments (e.g. bleeding, witchcraft, herbalist and chasing the person away). Similarly encouraging, most respondents have discarded the myths about routes of HIV transmission (e.g. touching, sharing food with an AIDS patient, sharing utensils and mosquito transmission). We believe these latter findings are especially important. For a household that lives intimately with an HIV+ child, the absence of unrealistic fears about transmission improves the quality of life for all. By comparison, a recent study from the United States cited at least some contact avoidance between HIV-infected parents and their children in 36% of the sample due to fears of transmission via unrealistic modes (Schuster *et al.* 2005).

From a prevention perspective, the greatest concern is related to those questions about reducing risk of exposure. While the group with less expressed stigma had more knowledge regarding reducing exposure risk, the percentages in both groups who still did not know that having sex with one partner who has no other partners, that abstinence, and that condom use are important ways to reduce chances of acquiring AIDS were large. Regarding treatment for AIDS, a similar continuum of accurate knowledge was demonstrated. While the majority in both groups understood that the traditional treatments for AIDS were ineffective (bleeding, chasing the person away, herbalist witchcraft), many still believe that there is no treatment for AIDS and that medications are not a treatment option. The latter may reflect economic realities in this environment rather than misinformation.

The tendency toward lesser expressed stigma in this population is interestingly different. AIDS-related stigma in most African societies is high (UNAIDS Best Practice Collection 2000; Alubo *et al.* 2002; Ezedinachi *et al.* 2002; Letamo 2003; Sepulveda *et al.* 2003). However, there are no comparable examinations of expressed stigma in normally stigmatised groups. The difference in this population may be related to its perspective. These families live with HIV. Studies indicate that knowing someone with HIV/AIDS decreases stigmatising beliefs/attitudes (Herek & Capitanio 1997; Gerbert *et al.* 1991; Herek 2002). Our own exploration of the association between expressed

stigma and acquaintance with PLWA has verified this relationship in our population.

Many studies have documented an association between misinformation (or lack of knowledge) and stigmatising attitudes and beliefs (Price & Hsu 1992; Peruga & Celentano 1993; Malcolm *et al.* 1998; Ezedinachi *et al.* 2002; Herek *et al.* 2002). We have verified this association in this population (Table 2). Thus, dissemination of accurate information in this population may be important not only for increasing AIDS-related knowledge, but for fostering reduced expressed stigma as well. Alternatively, the association between greater information and reduced expressed stigma may instead indicate that individuals with less expressed stigma tend to seek more knowledge. It should be noted that information alone is not sufficient to eliminate stigmatising attitudes and behaviours (Malcolm *et al.* 1998; Herek 2002; Brown *et al.* 2003).

Risk reduction, by condom use for example, and being tested for HIV are behaviours necessary to containing the AIDS epidemic. AIDS-related stigma negatively impacts the practice of risk reduction and attitudes toward testing (see Malcolm *et al.* 1998; Chesney & Smith 1999; Herek 1999, 2002; Brown *et al.* 2003; Kalichman & Simbayi 2003). We did not find an association between condom use and expressed stigma; we did find an association between positive testing attitudes and less expressed stigma (Table 4).

The lack of association between condom use and expressed stigma is not consistent with previous data (Malcolm *et al.* 1998; Herek 2002; Brown *et al.* 2003). This discrepancy may be due to confounders. The social context of sexual encounters in many cultures impacts condom use. For women, requesting the use of condoms requires equal negotiating power; and for both men and women, suggesting the use of condoms may impart inferences about one's or one's partner's HIV status, an inference that many may choose to avoid. Associations with stigma aside, an important observation in the present study is the large percentage of respondents who report not using a condom during last intercourse (especially given the large number of 'Not Marrieds'). This finding is congruent with the fairly large percentage of respondents who answered 'No' to the question about the utility of condom use in reducing one's chances of acquiring AIDS (Table 3).

Stigma is inversely related to HIV-testing, in this and in previous studies (Malcolm *et al.* 1998; Lentine *et al.* 2000; Ezedinachi *et al.* 2002; Herek 2002; Brown *et al.* 2003; Kalichman & Simbayi 2003). While we have emphasized the difference between groups in our analysis of expressed stigma, it is important to note that there were still large percentages in both groups who had not been tested and did not want to be tested. This finding, coupled with that

regarding condom use, does not bode well for prevention of the spread of HIV in this population. It is yet more evidence that targeting stigma is an important prevention measure.

Our description of demographic factors, beliefs and knowledge, as well as behavioural characteristics in this population of families in Kenya living with HIV verified associations between general AIDS knowledge and expressed stigma, between knowing someone with AIDS and expressed stigma, and between some aspects of prevention and expressed stigma. While these are pilot data, which are cross-sectional, and therefore cannot be used to infer directionality, the clear and consistent associations presented should be explored further in this and in similar populations since many of these associations may impact both prevention and care.

### Acknowledgements

Our collaborators in Kenya have made this work possible. Father D'Agostino, founder and medical director of Nyumbani, invited us to visit Kenya and gave us tremendous access to his programs for HIV+ AIDS orphans. Mr. Kamu Karuri made a significant contribution during the data collection process. The administrators and managers of Nyumbani and of the Lea Toto programs, Protus Lumiti and Nicholas Makau, facilitated the access we needed and contributed significantly to the direction of the study. We thank them. Finally, we would like to thank John Atkinson, DrPH for his assistance in structuring the data files for easy and efficient analysis.

### References

- Alubo O, Swandor A, Jolayemi T & Omudu E (2002) Acceptance and stigmatization of PLWA in Nigeria. *AIDS Care* **14**, 117–126.
- Baggaley R, Drobniewski F, Pozniak A, Chipant D, Tembo M & Godfrey-Faussett P (1997) Knowledge and attitudes to HIV and AIDS and sexual practices among university students in Lusaka, Zambia, and London, England: are they so different? *Journal of the Royal Society of Health* **117**, 88–94.
- Brown L, Macintyre K & Trujillo L (2003) Interventions to reduce HIV/AIDS stigma: what have we learned? *AIDS Education and Prevention* **15**, 49–69.
- Chesney MA & Smith AW (1999) Critical delays in HIV testing and care: the potential role of stigma. *The American Behavioral Scientist* **42**, 1162–1174.
- Crocker J, Major B & Steele C (1998) Social stigma. In: *The Handbook of Social Psychology*, 4th Edn (eds DT Gilbert, ST Fiske & G Lindzey) McGraw-Hill, New York, USA, pp. 504–553.
- Ezedinachi ENU, Ross MW, Meremiku M *et al.* (2002) The impact of an intervention to change health workers' HIV/AIDS

M. Hamra *et al.* Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge

- attitudes and knowledge in Nigeria: a controlled trial. *Public Health* 116, 106–112.
- Farmer P (1992) *AIDS and Accusation: Haiti and the geography of blame*. University of California Press, Berkeley.
- Gerbert B, Sumser J & Maguire BT (1991) The impact of who you know and where you live on opinions about AIDS and Health Care. *Social Science & Medicine* 32, 677–681.
- Green G (1995) Attitudes towards people with HIV: are they as stigmatizing as people with HIV perceive them to be? *Social Science & Medicine* 41, 557–568.
- Hamra M, Ross MW, Karuri K, Orrs M & D'Agostino A (2005) Relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV infected children in Kenya. *AIDS Care* 17, 911–922.
- Herek GM (1984) Beyond “homophobia”: a social psychological perspective on attitudes toward lesbians and gay men. *Journal of Homosexuality* 10, 1–21.
- Herek GM (1999) AIDS and stigma. *The American Behavioral Scientist* 42, 1106–1116.
- Herek GM (2002) Thinking about AIDS and stigma: a psychologist's perspective. *Journal of Law, Medicine & Ethics* 30, 594–607.
- Herek GM & Capitanio JP (1992) *A Second Decade of Stigma: Public Reactions to AIDS in the United States 1990–91*. Retrieved 12/14/03 from [http://psychology.ucdavis.edu/rainbos/heml/aids\\_stigma\\_paper.html](http://psychology.ucdavis.edu/rainbos/heml/aids_stigma_paper.html).
- Herek GM & Capitanio JP (1993) Public reactions to AIDS in the United States: a second decade of stigma. *American Journal of Public Health* 83, 574–577.
- Herek GM & Capitanio JP (1997) AIDS stigma and contact with persons with AIDS: the effects of personal and vicarious contact. *Journal of Applied Social Psychology* 27, 1–36.
- Herek GM & Glunt EK (1988) An epidemic of stigma: public reactions to AIDS. *American Psychology* 43, 886–891.
- Herek GM, Mitnick L, Burriss S *et al.* (1998) Workshop report: AIDS and stigma: a conceptual framework and research agenda. *AIDS & Public Policy Journal* 13, 36–47.
- Herek GM, Capitani JP & Widaman KF (2002) HIV-related stigma and knowledge in the United States: prevalence and trends 1991–1999. *American Journal of Public Health* 92, 371–377.
- International Center for Research on Women (2002) *Understanding HIV-related stigma and resulting discrimination in Sub-Saharan Africa: Emerging themes from early data collection in Ethiopia, Tanzania and Zambia*. ICRW Res Update. Available: [http://www.icrw.org/docs/Stigma\\_Research\\_Update\\_062502.pdf](http://www.icrw.org/docs/Stigma_Research_Update_062502.pdf). Accessed March 25 2005.
- James S, Reddy SP, Taylor M & Jinabhai CC (2004) Young people, HIV/AIDS/STIs and sexuality in South Africa: the gap between awareness and behaviour. *Acta Paediatrica* 93, 264–269.
- Kalichman SC & Simbayi LC (2003) HIV testing attitudes, AIDS stigma, and voluntary HIV counseling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections* 79, 442–447.
- Lacey M (2004) Court allows Kenyan pupils with HIV into schools. *New York Times* 153, A5.
- Lentine DA, Hersey JD, Iannacchione VG, Laird GH, McClamroch K & Thalji L (2000) HIV-related knowledge and stigma—United States 2000. *MMWR. Morbidity and Mortality Weekly Report* 49, 1062–1064.
- Letamo G (2003) Prevalence of, and factors associated with HIV/AIDS-related stigma and discriminatory attitudes in Botswana. *Journal of Health Population and Nutrition* 21, 347–357.
- Lwihula G, Dahlgren I, Killewo J & Sandstrom A (1993) AIDS epidemic in Kagera Region, Tanzania: the experience of local people. *AIDS Care* 5, 347–357.
- Malcolm A, Aggleton P, Bronfman M, Galvão J, Mane P & Verrall J (1998) HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health* 8, 347–370.
- Mann JM, Tarantola DJM & Netter TW (eds) (1992) *AIDS in the World*. Harvard University Press Cambridge, Mass.
- Muyinda H, Seeley J, Pickering H & Barton T (1997) Social aspect of AIDS-related stigma in rural Uganda. *Health Place* 3, 143–147.
- Nachega JB, Lehman D, Hlatshwayo D, Mothopeng R, Chaisson RE & Karstaedt AS (2005) HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs, and practices in HIV-infected adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndrome* 38, 196–201.
- Nyblade L, Pande R, Mathur S, MacQuarrie K, Kidd R *et al.* (2003) *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. International Center for Research on Women, Washington, DC, USA, p. 53.
- Odujinrin MT & Adebajo SB (2001) Social characteristics, HIV/AIDS knowledge, preventive practices and risk factors elicitation among prisoners in Lagos, Nigeria. *West African Journal of Medicine* 20, 191–198.
- Parker R & Aggleton P (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine* 57, 13–24.
- Peltzer K, Cheria L & Cheria VI (2000) Knowledge, self-efficacy and behavioral intent towards AIDS prevention behaviors among culturally diverse secondary school pupils in South Africa. *East African Medical Journal* 77, 279–282.
- Peruga A & Celentano DD (1993) Correlates of AIDS knowledge in samples of the general population. *Social Science & Medicine* 36, 509–524.
- Price V & Hsu M (1992) Public opinion about AIDS policies: the role of misinformation and attitudes toward homosexuals. *Public Opinion Quarterly* 56, 29–52.
- Rankin WW, Brennan S, Schell E, Laviwa J & Rankin SH (2005) The stigma of being HIV positive in Africa. *PLoS Medicine* 2, e247.
- Schuster MA, Beckett MK, Corona R & Zhou AJ (2005) Hugs and kisses: HIV-infected parents' fears about contagion and the effects on parent-child interaction in a nationally representative sample. *Archives of Pediatric & Adolescent Medicine* 159, 173–179.
- Sepulveda D, Habiymbere V, Amandua J *et al.* (2003) Quality care at the end of life in Africa. *British Medical Journal* 327, 209–212.

M. Hamra *et al.* **Relationship between expressed HIV/AIDS-related stigma and HIV-beliefs/knowledge**

Takyi BK (2001) Correlates of HIV/AIDS-related knowledge and preventive behavior of men in Africa. *Journal of Health and Human Services Administration* 24, 234–257.

UNAIDS Best Practice Collection (2000) *HIV and AIDS-related stigmatization, discrimination and denial: forms, contexts and*

*determinants*. Research studies from Uganda and India. Electronic document, retrieved 3/16/04 from <http://www.unaids.org/publications/documents/human/law/ugandaindiabb.pdf>.

**Corresponding Author** Mary Hamra, Department of Medicine, Center for Chronic Diseases, Baylor College of Medicine, 1709 Dryden, Houston, Texas 77030, USA. Tel.: +1-713-7984614; Fax: +1-713-7983990; E-mail: mhamra@bcm.tmc.edu

**Relations entre l'expression des stigmas liés au VIH/SIDA et aux connaissances/croyances VIH avec le comportement dans les familles d'enfants infectés par le VIH au Kenya**

**OBJECTIFS** Quantifier les stigmas exprimés chez les participants au programme de Kangemi pour les enfants VIH+ et caractériser l'association entre stigmas et autres caractéristiques de la population.

**MÉTHODES** Au moyen d'un suivi des familles, nous avons créé un index de stigmas et des indices pour d'autres domaines sociaux et de connaissances qui influencent les soins de santé liés au VIH. Nous avons utilisé Chi carré, ANOVA et la corrélation pour identifier les associations entre les domaines.

**RÉSULTATS** La moyenne de stigmas a été exprimée sur une échelle de six points (6 étant la plus faible valeur de stigma) était de  $3,65 \pm 1,64$ . Les scores composés sur les connaissances à propos du SIDA étaient orientés vers plus de connaissances, et l'analyse des éléments de connaissance individuelle indique que la plupart des répondants rejettent les croyances et mythes traditionnels sur les causes et les voies de transmission du SIDA. Les répondants jeunes, non mariés et ayant le plus faible niveau d'éducation exprimaient le plus de stigmas. Les différences dans les stigmas étaient associées avec une connaissance faible à propos du SIDA et des attitudes négatives par rapport au dépistage, mais n'étaient pas associées au sexe ou à la tribu. L'utilisation de préservatif au dernier rapport sexuel, indépendamment des stigmas, était seulement de 40% ( $n = 218$ ).

**CONCLUSIONS** Bien que la population étudiée a une bonne connaissance sur le SIDA et sait évaluer les risques de façon réaliste, elle n'arrive pas à éviter ces risques. Les associations entre stigmas et autres domaines peuvent informer les interventions pour l'amélioration des soins et la propagation mitigée du VIH.

**mots clés** orphelins HIV+, stigma VIH/SIDA, connaissance du SIDA, programmes VIH/SIDA, Afrique

**Relación entre el estigma expresado por VIH/SIDA y los conocimientos/creencias sobre el VIH/SIDA en el comportamiento de familias con niños infectados por VIH en Kenia**

**OBJETIVOS** Cuantificar el estigma expresado en clientes del programa Kangemi para niños HIV+ y caracterizar la asociación entre el estigma y otras características poblacionales.

**MÉTODOS** Por medio de encuestas domiciliarias se creó un índice de estigmatización así como índices para otros dominios sociales y de conocimiento que tienen influencia en los cuidados de salud relacionados con el VIH. Utilizamos el  $\chi^2$ , ANOVA, y la correlación para identificar las asociaciones entre los diferentes dominios.

**RESULTADOS** La media ( $\pm$ SD) del estigma expresado en una escala de seis puntos (6 = menor estigma) fue de  $3.65 \pm 1.64$ . Los puntajes compuestos sobre conocimiento del SIDA estaban inclinados hacia un mayor conocimiento, mientras que el análisis de ítems de conocimiento individuales indica que la mayoría de los encuestados rechazan los conocimientos tradicionales y los mitos erróneos sobre las causas y las rutas de transmisión del SIDA. Los encuestados más jóvenes, que nunca habían estado casados y tenían un menor nivel de educación, expresaban también un mayor estigma. Las diferencias en estigma estaban asociadas a un menor nivel de conocimiento sobre el SIDA y a actitudes negativas con respecto al aconsejamiento y prueba voluntaria, pero no con el género o la afiliación tribal. El uso del preservativo en la última relación sexual no estaba relacionado con el estigma y fue solo del 40% ( $n = 218$ ).

**CONCLUSIONES** Mientras que en esta población hay un buen conocimiento sobre el SIDA y evalúan los riesgos de forma realista, fallan en reducirlo. Asociaciones entre estigma y otros dominios pueden ayudar a intervenciones que mejoren el cuidado y disminuyan la expansión del VIH.

**palabras clave** VIH + huérfanos, estigma VIH/SIDA, conocimiento SIDA, programas ayuda VIH/SIDA, África

**Appendix I** Response items used for creation of general AIDS knowledge index (note: response choices were Yes (Y), No (N), and in some cases, Don't know (DK))

1. Have you heard of an illness called AIDS?	Y/N
2. If yes, what do you think are the causes of AIDS?	
a. Blood transfusion?	Y/N
b. Witchcraft?	Y/N
c. Mother-to-child transmission?	Y/N
d. Punishment from God?	Y/N
e. Touching/greeting a person with AIDS?	Y/N
f. Sexual contact?	Y/N
g. Sharing of food with a person with AIDS?	
3. *Is there anything a person can do to avoid getting the virus that causes AIDS?	Y/N/DK
4. How can people reduce their chances of getting the virus that causes AIDS?	
a. Having just one sex partner who has no other partner?	Y/N
*b. Always using a condom?	Y/N/DK
c. Not having sex at all?	Y/N
5. Can people get the AIDS virus from mosquito or other insect bites?	Y/N/DK
6. Can people get the AIDS virus from sharing utensils?	Y/N/DK
7. Is it possible for a healthy looking person to have the AIDS virus?	Y/N/DK
8. What do you think the treatment of AIDS is?	
a. No treatment?	Y/N
b. Medication?	Y/N
c. Bleeding?	Y/N
d. Chasing the person away?	Y/N
e. Herbalist?	Y/N
f. Witchcraft?	Y/N

\* 'Don't know' responses were combined with 'No' responses for analysis since both represent poor or uncertain knowledge in this scale and  $\chi^2$  cell size minimums for these questions required a combination of categories.