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Measuring child awareness for adult symptomatic HIV using a verbal assessment tool: Concordance between adult-child dyads on adult HIV-associated symptoms and illnesses

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Abstract

Objectives—This study assessed children's awareness for adult HIV-associated symptoms and illnesses using a verbal assessment tool by analyzing inter-rater reliability between adult-child dyads. This study also evaluated socio-demographic and household characteristics associated with child awareness of adult symptomatic HIV.

Methods—A cross-sectional survey using a representative community sample of adult-child dyads (N=2,477 dyads) was conducted in KwaZulu-Natal, South Africa. Analyses focused on a subsample (n=673 adult-child dyads) who completed verbal assessment interviews for symptomatic HIV. We used an existing validated verbal autopsy approach, originally designed to determine AIDS related deaths by adult proxy reporters. We adapted this approach for use by child proxy reporters for reporting on HIV-associated symptoms and illnesses among living adults. Analyses assessed whether children could reliably report on adult HIV-associated symptoms and illnesses and adult provisional HIV status.

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Ethics Approval: Ethical review committees at Oxford University, the University of KwaZulu-Natal, the government Department of Health in KwaZulu-Natal and the Department of Basic Education in KwaZulu-Natal approved research protocols.

Competing interest: None

Results—Adult-child pairs concurred above the 65th percentile for nine of the ten HIV-associated symptoms and illnesses with sensitivities ranging from 10%–100% and specificities ranging from 20%–100%. Concordant reporting between adult-child dyads for the adult's provisional HIV status was 72% (sensitivity=68%, specificity=73%). Children were more likely to reliably match adult's reports of provisional HIV status when they lived in households with more household members, and households with more robust socio-economic indicators including access to potable water, food security, and television.

Conclusions—Children demonstrate awareness of HIV-associated symptoms and illnesses experienced by adults in their household. Children in households with greater socio-economic resources and more household members were more likely to reliably report on the adult's provisional HIV status.

Keywords

HIV; South Africa; child; signs and symptoms; awareness

INTRODUCTION

An estimated 6.3 million [6.0 million–6.5 million] people are living with HIV in South Africa.[1] Due to the magnitude of the epidemic, home-based care programs have rapidly expanded in generalized endemic setting to meet the needs of individuals with HIV. Consequently, provision of care for HIV infected adults is increasingly provided by non-medical professionals such as children in the home. Poverty and lack of support services are major factors contributing to children providing care to HIV sick adults.[2] We have a growing understanding of the possible challenges, risks, and benefits associated with children serving as 'young carers.' These young carers describe the challenges of limited knowledge and skills for care tasks.[3] They describe negative consequences including difficulty concentrating on school-related tasks, attendance, and performance;[4] increased burden of domestic chores due to adult illness;[5] and psychological distress.[6] However, they also report positive outcomes including the perception that care has contributed to their maturation,[7] positive self-image, and development of resilience strategies such as building of social networks.[8]

Both quantitative and qualitative studies document involvement of children in intimate care tasks including bathing and dressing HIV sick adults.[9–11] As such, it is not surprising that children might directly observe symptoms of HIV illness. However, few studies explicitly examine children's awareness of adult HIV illness.[12] No studies, to our knowledge, systematically assess the accuracy of children's awareness of adult HIV-associated symptoms and illnesses in their household. Although affordable HIV testing is now widely available, knowledge of how accurately children report on HIV-associated symptoms and illnesses using a standardized tool would be helpful in cases where adults cannot be directly assessed (for example when the adult is absent or not included in studies). Additionally, developing understanding of whether children are aware of adult HIV-associated symptoms and illnesses, and evaluating accuracy of children's awareness, would significantly enhance understanding of children's outcomes. Such knowledge could contribute to our understanding of why some young carers report differential outcomes (either positive or

negative) compared to other young carers. Such knowledge could better contextualize individual and family dynamics of HIV illness including choice of strategies children utilize to support sick adults, implementation of protective strategies to diminish HIV infection risk, choice of who young carers turn to for support, and how family members interact as the HIV-ill adult becomes more symptomatic.

As such, this study set out with two objectives: 1) to measure child awareness for symptomatic HIV using a verbal assessment tool and, 2) to evaluate factors associated with reliability in children's reports. To develop a better understanding of whether children were aware of HIV-associated symptoms and illnesses when involved in caregiving, or direct observation of sick adults living in their household, we utilized a standardized multi-question tool to assess symptomatic HIV. This tool was based off an existing validated verbal autopsy tool used throughout sub-Saharan Africa to identify AIDS-related deaths, and adapted in this study to assess HIV-associated symptoms and illnesses.[13] We term this adapted tool the verbal assessment tool for symptomatic HIV. To develop an understanding of whether children could accurately report on adult HIV-associated symptoms and illnesses using the verbal assessment tool, we analyzed rates of concordance between adult-child dyads on adult HIV-associated symptoms and illnesses and provisional HIV status.

METHODS

Study Site

The study was conducted in South Africa, the country with the largest HIV epidemic in the world.[14] The study focused on the province with the highest HIV prevalence: KwaZulu-Natal Province, South Africa. Within this province, data collection focused on an urban and rural site, selected based on HIV antenatal prevalence of 30% or higher.[15] The urban site was a township in the eThekwini municipality; the rural site was located in the uMhlabuyalingana municipality. All data collection occurred between August 2009 and December 2010.

Study Sample

Within each study site, Geographical Information Systems (GIS) was used to map census enumeration size areas. Random sampling of geographical areas representing census enumeration size areas was conducted to reduce site selection bias. Within each census enumeration size area, each household was visited to determine eligibility. Eligible adults were primary caregivers of children in the household, 18 years of age or older, and resident in the household at least 4 nights per week. The primary adult caring for the child was defined as the individual responsible for the majority of day-to-day active care. The adult could be related to the child in any way (biological parents, aunts, grandparents, non-relatives). Eligible children were 10–17 years of age, had to reside in the same household for at least 4 nights per week, and concur that the adult interviewed was their caregiver. If more than one eligible adult or child was identified in the household, one was randomly invited for participation. In each household, one adult and one child were interviewed. In total, N=2,477 adult-child dyads were eligible and included in the study.

Study Procedures

Ethical review committees at Oxford University, the University of KwaZulu-Natal, the provincial Department of Health in KwaZulu-Natal and the Department of Basic Education in KwaZulu-Natal approved research protocols. Adults provided voluntary informed consent for their own participation and for the interviewer to seek the assent of the child under their care. Children provided assent for participation in the study. Adults and children were interviewed separately by trained survey enumerators. Respondents completed face-to-face interviews lasting 45–60 minutes in the language of their choice. All questions were shown to respondents and were read aloud by the interviewer. All respondents were provided with detailed information and services relating to HIV testing, care, and support; mental health and substance use services; government services including agencies for accessing social welfare grants; child welfare; and local community organizations providing more general support and services to families. Individuals needing more immediate care were offered referral letters, and with permission from respondents, the study team assisted respondents in linkage to appropriate services.

Creating an HIV Verbal Assessment Tool Based on a Verbal Autopsy Measure

The measure used in this paper was based off of a verbal autopsy approach. Verbal autopsy approaches have been used throughout sub-Saharan Africa where vital registration systems may not accurately capture the cause of death.[16–18] Verbal autopsy approaches obtain information about a deceased person's illness based on the principle that each disease category has a distinct pattern of symptoms that can be recognized, recalled, and reported accurately by medical personnel or lay people.[19] Typically, this approach begins with interviewing a relative, non-relative (e.g., neighbor), primary caregiver, or non-primary caregiver (e.g., community health worker) who act as a proxy when answering questions about the deceased individual's health. During this interview, the proxy reporter describes symptoms observed prior to death of the individual. Then, symptoms reports are reviewed to determine the cause of death.

The measure used in this study – which we term the verbal assessment tool for symptomatic HIV was based off of an existing validated verbal autopsy measure from two studies by Lopman et al.,[20, 21] which inquired about ten signs and symptoms of HIV illness including: weight loss, wasting, jaundice, herpes zoster, sores or abscesses, oral candidiasis, acute respiratory tract infection, vaginal tumors, tuberculosis (TB) and diarrhoea. Lopman's 2006 study, conducted in Zimbabwe, found a sensitivity of 66% and a specificity of 76% for predicting death due to AIDS when using a rule-based algorithm to minimize false positives. [20] Lopman et al.'s subsequent 2010 study, used sites in Tanzania and Zimbabwe to retest the algorithm. This study found a sensitivity of 79% and specificity of 79% from Zimbabwe phase 1, sensitivity of 83% and specificity of 75% from Zimbabwe phase 2 and sensitivity of 75%, specificity of 74% from Tanzania for deaths in 15–44 year olds.[21]

In our study, the verbal assessment tool for symptomatic HIV, was translated and back-translated from English into isiZulu and piloted to ensure coherency and cultural validity. Data were collected by a team of trained research assistants fluent in isiZulu. Each medical term was accompanied by a layman's description which was composed with the assistance

of the South African nurse who worked directly with HIV infected individuals and extensively pre-tested. Questions on the child version of the verbal assessment tool were adapted from the original verbal assessment tool to use more child-friendly language, as demonstrated in Table 1, and were pre-piloted with the study's Teen Advisory Group of 14 AIDS-affected children.

Analysis Approach

All statistical analyses were conducted using STATA version 10.[22] Our analyses focused on a subset of the main study sample, consisting of n=673 children and n=673 adults who answered questions on the verbal assessment tool for symptomatic HIV. Since our analyses focused on measuring child awareness and accuracy on adult HIV-associated symptoms and illnesses through concurrency assessment, the following criteria had to be met to be included in analyses of the sub-sample: 1) adult self-reported on illness, and answered the verbal assessment tool for their own HIV-associated symptoms and illnesses and; 2) child reported on adult HIV-associated symptoms and illnesses using the verbal assessment tool.

We assessed child awareness and accuracy of adult HIV-associated symptoms and illnesses by examining concurrency between adult-child dyads for each HIV symptom and illness. Then, an adult provisional HIV status was made by tallying responses on symptoms and illnesses reports based on the following algorithm calculation: 1) any combination of three or more symptoms or illnesses of acute respiratory tract infection, jaundice, sores/abscesses, vaginal cancer, wasting, weight loss, constant diarrhoea, herpes zoster, oral candidiasis, and TB or 2) any two symptoms or illnesses that are hyper-indicative of HIV/AIDS which included constant diarrhoea, herpes zoster, oral candidiasis or TB. Bivariate statistical tests were conducted to assess whether differences in children's socio-demographic and household characteristics might explain differential accuracy in reporting. We also conducted logistic regression analysis to examine which socio-demographic variables were predictors of concurrency between adult-child dyads on adult provisional HIV status.

RESULTS

We achieved a high response rate of 99.9% for the urban site and 99.7% for the rural site. Response rate was based off of eligible households (both adult and children had to meet inclusion criteria for a household to be deemed eligible) and consenting and assenting dyads. Adult respondents were primarily female (94%), first-language isiZulu-speaking (95%), from the urban study site (62%) and had a mean age of 44 years old. Child respondents also primarily spoke isiZulu (96%). Approximately half of the child respondents were female (53%), and the mean age for the children was 14 years old. More child respondents lived in the urban study site (62%), lived in formal housing (68%) defined as buildings made with brick, concrete, etc. and had access to potable water (93%) defined as water sourced from a house or community tap opposed to non-potable water which is sourced from a river or stream. Slightly more children lived in households that were food secure (68%) defined as being "never hungry", had a household size of 6 people or smaller (68%), had access to radio (76%) and access to TV (68%).

Results summarizing child awareness of adult HIV-associated symptoms and illnesses using the verbal assessment tool are found in Table 2. We assumed that adults would be aware of their own symptoms and illnesses. Adult-child pairs concurred above the 65th percentile for nine of the ten HIV-associated symptoms and illnesses with sensitivities ranging from 10%–100% and specificities ranging from 20%–100%. Vaginal cancer had the highest concurrency (99%), sensitivity (100%) and specificity (100%) while constant diarrhoea had the lowest concurrency (29%) and specificity (20%) but a relatively high sensitivity (80%). The dyad agreement on adult provisional HIV status can be found in Table 2 as well. In total, 484 adult-child dyads concurred on adult provisional HIV status, resulting in an overall concurrency of 72% (sensitivity=68%, specificity=73%).

We describe whether socio-demographic and household characteristics, age, gender, site location, household type, potable water, household food security, household size, access to radio and access to TV, of children respondents were significantly related to adult-child concurrence in Table 3.

We performed a multivariate logistic regression of n=670 child respondents (3 children omitted due to missing data for household size) assessing significance of socio-demographic and household characteristics to correctly matching adult provisional HIV status (Table 4). Children were more likely to accurately report adult provisional HIV status if they lived in households of larger size, by nearly a factor and a half (OR= 1.49, 95% CI 1.0 to 2.2, $p < 0.05$). Children were more likely to accurately report adult provisional HIV status if they lived in a household with more robust socio-economic indicators including access to potable water (OR=.49, 95% CI .25 to .95, $p < 0.04$), a television (OR 1.7, 95% CI 1.04 to 2.76, $p < 0.04$), and food security (OR= .36, 95% CI .25 to .53, $p < 0.001$).

DISCUSSION

This study systematically assessed child awareness of adult HIV-associated symptoms and illnesses using a verbal assessment tool. Concurrency rates showed that for six symptoms and illnesses - vaginal cancer, jaundice, oral candidiasis, herpes zoster, TB and wasting - children concurred with the adult self-report at rates between 75–100%. Although vaginal cancer had almost perfect concordance, the low number of adult cases (n=5) and high number of non-applicable responses (n=410) suggest we should interpret with caution. For three symptoms and illnesses - sores/abscesses, weight loss and respiratory tract infection - concurrency rates ranged between 50–75%. Finally, only one symptom - diarrhoea for 3 or more days - had a concurrency rate below 50%. The low concurrency in reports for diarrhoea may relate to the difficulty of children accurately recalling the number of days another was affected by diarrhoea, especially since this symptom of HIV may be less likely to be observed than the other symptoms and illnesses included in the assessment tool. A 2010 study conducted in Kenya highlighted this issue of poor recall for diarrhoea finding that diarrhoeal recall should not extend back >3 days for children and >4 days for adults to achieve 80% accuracy.[23] Therefore, it may have proved difficult for child respondents to remember a consecutive ≥3-day event that had happened in the past. Sensitivity analysis for the symptoms and illnesses varied widely from 10% for jaundice to 100% for vaginal cancer. Specificity analysis proved mostly better outcomes with the majority of symptom

ranging from 70–100%. Constant diarrhoea was an exception with specificity at 20%. Along with the low number of cases for vaginal cancer its perfect sensitivity and specificity may be due to its ‘diagnostic’ characteristic namely that a person must be told by a medical professional (or told by someone privy to this information) that they have cancer. The variations in sensitivity and specificity may be partly explained by how ‘observable’ a symptom or illness is on the human body. The adult provisional HIV status had a concurrency of 72%, sensitivity of 68% and specificity of 73%. These findings were consistent with outcomes for the individual symptom or illness analyses. Children’s ability to reliably match adult provisional HIV status was associated with socio-economic indicators including access to potable water, food security and access to TV. This may be related to factors that influence the spread of information regarding HIV and public health, such as the ability to understand information provided in English, access to books, TV and media, and the number of HIV campaigns. Children’s ability to reliably match adult provisional HIV status was also associated with households with above median household size, a possible proxy for household crowding where children would be in frequent observable contact with the ill adult.

Our study benefited from a large sample size and a high response rate (>99%). We also recognize several study limitations. For example, we assume the adults are familiar with their own symptoms and illnesses and can accurately report on them. This assumption is the basis of our comparison between child and adult reports of HIV-associated symptoms and illnesses and adult provisional HIV status. Another limitation includes the possibility that our results may not generalize to other contexts and that concordance rates may differ when the adult being assessed is male as the vast majority of adults in our sample were female. Other South African studies have shown that men are less likely to report HIV status compared to women,[24] and this difference may affect behaviour in the home in such a way that the child’s ability to observe adult HIV-associated symptoms and illnesses is also affected. Finally, our logistic regression may suffer from unmeasured confounding. Despite these limitations, we believe our findings are novel due to our study design of measuring child awareness of adult HIV-associated symptoms and illnesses using a verbal assessment tool modeled after a validated verbal autopsy measure. Overall, findings reveal that children were seemingly aware of a broad range of HIV-associated symptoms and illnesses affecting adults in their household, as demonstrated by high concurrency with adults self-reports of HIV-associated symptoms and illnesses. Children’s awareness of the adult HIV-associated symptoms and illnesses may be a result of children’s increasing involvement in the provision of medical and intimate care for HIV positive adults within their household, especially in HIV endemic settings.[6, 25, 26]

HIV-associated symptom and illness awareness is important to study in contexts where care of HIV-ill adults in the household becomes more and more common. Such knowledge contributes to the dearth of current research on culturally constructed forms of biological knowledge available to children in this context.[27] Moreover, assessing the accuracy of children’s reports on adult HIV-associated symptoms and illnesses can provide important information on a range of outcomes for both young carers and family members. For example, infection control can be a challenge in home-based care settings.[28] Findings from a large multi-community sample demonstrated a thirteen-fold increase in severe

tuberculosis symptomology associated with family AIDS and children's provision of medical care, exacerbated by socio-economic vulnerability.[29] Also, a study in Kenya found that most caregivers (85%) were unaware of the risks they are exposed to when handling patients with AIDS related infections and many caregivers (65%) used their bare hands when handling body fluids of patients.[30] Awareness and accuracy of HIV-associated symptoms and illnesses might help explain why some young carers implement protective procedures to prevent against infection while others do not.

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Key messages

- Adult-child pairs concurred above the 65th percentile for nine of the ten HIV-associated symptoms and illnesses and at 72% for adult provisional HIV status.
- Children were more likely to reliably match adult's reports of adult provisional HIV status when they lived in households with more robust socio-economic indicators.
- Children were more likely to reliably match adult's reports of adult provisional HIV status in households with above median household size (>6 people).

Table 1

Items in the verbal assessment tool for symptomatic HIV

HIV-ASSOCIATED SYMPTOM/ILLNESS	ADULT SURVEY	CHILD SURVEY
Acute respiratory infection	Have you had trouble breathing, or a cough for more than 2 days with a fever?	Have they had trouble breathing, or a cough for more than 2 days with a fever?
Jaundice	Have you had jaundice where the whites of your eyes are yellow with no history of alcohol abuse?	Have their eyes been yellow, and they've had a fever? Or itching?
Sores/Abscesses	Have you had abscesses or sores on your body?	Have they had sores on their body?
Vaginal cancer	Do you have cancer? Where is the cancer?..... OR Do you have vaginal tumors where there was a vaginal tumor for at least one month with or without bleeding?	Do they have cancer? Where is the cancer?.....
Wasting	Have you had wasting which is moderate or severe weight loss with at least four of the following symptoms: paleness, changing hair color, swelling of legs, burning feelings in feet, or dry scaly skin?	Have they had any of these things:' very pale, or hair changing color, or legs swelling up, or burning feelings in their feet, or has their skin been very dry?
Weight loss	Have you had moderate or severe weight loss?	Have they lost weight and become very thin?
*__Constant diarrhoea__	Have you had constant diarrhoea or a runny tummy? AND How many days has this lasted?	Have they had diarrhoea or a runny tummy for 3 or more days?
*__Herpes zoster__	Have you had shingles or a rash on one side of your body that is like a belt?	Have they had shingles or a rash on their skin?
*__Oral Candidasis__	Have you had oral candidiasis where you have two or three of the following: ulcers in your mouth, difficulty swallowing, or white patches in your mouth?	Have they had ulcers or white patches in their mouth, or problems swallowing food?
*__TB__	Have you had TB in past 2 years?	Have they had TB is last 5 years?

* indicates a hyper-indicative symptom

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Table 2

Child awareness of adult HIV-associated symptoms and illnesses using the verbal assessment tool (n=673 dyads)

SYMPTOM/ILLNESS	CHILD RESPONSE	ADULT RESPONSE			CONCURRENCY	SENSITIVITY	SPECIFICITY
Vaginal Cancer		No	Yes	Total	99%	100%	100%
	No	258	0	258			
	Yes	2	3	5			
	Not applicable[†]	410	0	410			
	TOTAL	670	3	673			
Jaundice	**No**	576	49	625	86%	10%	90%
	Yes	42	6	48			
	TOTAL	618	55	673			
Oral Candidacies	**No**	555	21	576	85%	40%	90%
	Yes	83	14	97			
	TOTAL	638	35	673			
Herpes Zoster	**No**	537	21	558	84%	60%	90%
	Yes	86	29	115			
	TOTAL	623	50	673			
TB	**No**	501	51	552	82%	50%	90%
	Yes	73	48	121			
	TOTAL	574	99	673			
Wasting	**No**	471	42	513	79%	60%	80%
	Yes	101	59	160			
	TOTAL	572	101	673			
Sores/Abscesses	**No**	472	46	518	74%	40%	80%
	Yes	126	29	155			
	TOTAL	598	75	673			
Weight Loss	**No**	329	50	379	69%	70%	70%
	Yes	158	136	294			
	TOTAL	487	186	673			

SYMPTOM/ILLNESS	CHILD RESPONSE	ADULT RESPONSE			CONCURRENCY	SENSITIVITY	SPECIFICITY
Acute Respiratory Tract Infection	**No**	414	59	473	69%	40%	70%
	Yes	152	48	200			
	TOTAL	566	107	673			
Constant Diarrhoea	**No**	20	7	27	29%	80%	20%
	Yes	97	22	119			
	Not applicable†	527	0	527			
	TOTAL	644	29	673			
ADULT PROVISIONAL HIV STATUS	**No**	407	37	444	72%	68%	73%
	Yes	152	77	229			
	Total	559	114	673			

†These symptoms or diagnoses included a screening question, which resulted in individuals being ineligible for analysis

Table 3

Socio-demographic and household characteristics of child respondents

Characteristic	Child concur on adult provisional HIV status (n=484)	Child did not concur on adult provisional HIV status (n=189)	p-value[i]
Age (M, SD)	13.578 (2.337)	13.751 (2.242)	0.710
Gender (%)			0.926
Male	226 (47%)	89 (47%)	
Female	258 (53%)	100 (53%)	
Site Location (%)			0.000
Urban	321 (66%)	95 (50%)	
Rural	163 (34%)	94 (50%)	
Household Type (%)[2]			0.003
Formal	346 (71%)	113 (60%)	
Informal	138 (29%)	76 (40%)	
Potable water (%)[3]			0.003
Potable Water	459 (95%)	167 (88%)	
Non potable water	25 (5%)	22 (12%)	
Household Food Security (%)[4]			0.000
Food Secure	388 (80%)	110 (58%)	
Food Insecure	96 (20%)	79 (42%)	
Household Size(%)[5]			0.209
Median household size or smaller	322 (67%)	136 (72%)	
Above median household size	159 (33%)	53 (28%)	
Access to Radio (%)			0.213
Yes	373 (77%)	137 (72%)	
No	111 (23%)	52 (28%)	
Access to TV (%)			0.000
Yes	356 (74%)	104 (55%)	
No	128 (26%)	85 (45%)	

[i] P-values are associated with t-test or chi-square test

[2] Formal housing was defined as buildings composed of brick, concrete, etc.

[3] Potable water is sourced from a house or community tap opposed to non-potable water which is sourced from a river or stream

[4] Household food security was assessed by asking how often the household went hungry (never, seldom, sometimes, often). Food security was defined as respondents reporting that their household was “never hungry.”

[5] Coded dichotomous variable based on median of household size (6 people)

Table 4

Multivariate logistic regression testing factors associated with accuracy of child respondents

Characteristic	OR (95% CI)	p-value
Age[1]	.97 [.90–1.05]	.48
Gender[2]	1.03 [.72–1.47]	.89
Site location[3]	.73 [.46–1.17]	.19
Household type[4]	.78 [.53–1.16]	.23
Potable water[5]	.49 [.25–.95]	.04
Household food security[5]	.36 [.25–.53]	.00
Household size[6]	1.5 [1.01–2.22]	.05
Access to radio[7]	.69 [.44–1.09]	.12
Access to TV[7]	1.7 [1.04–2.76]	.03

[1] Dichotomous variable calculated based on mean value; higher values reflect higher age

[2] 1=female, 0=male

[3] 1=urban, 0=rural

[4] 1=informal dwelling, 0=formal dwelling

[5] 1=no, 0=yes

[6] Dichotomous variable calculated based on mean value; higher values reflect more household members; 1= above median (>6 people), 0=equal or below median (≤ 6 people)

[7] 1=yes, 0=no