HTLV-1 Related Knowledge, Attitude and Behaviour Patterns among Mothers who Participated in the Jamaica Breastfeeding Intervention Study (1996–2000)

CM Jones Cooper[1], K James[1],RJ Wilks[2]

ABSTRACT

Human T-cell Lymphotropic Virus type-1 (HTLV-1), the first human retrovirus associated with a malignant disease, is endemic in Jamaica. Vertical transmission and sexual intercourse are the major routes of transmission. Women are at greater risk of contracting the virus as it is more efficiently transmitted from male to female than in the reverse. Prevention of transmission is best achieved by health education on safe practices. The study aims to document the knowledge, attitude and behaviour pattern (KABP) of a group of women five years after they had participated in a mother-to-child transmission of HTLV-1 risk reduction study. A cross-sectional study was conducted using a 46-point structured interviewer-administered questionnaire to capture data from 88 mothers. Overall knowledge scores were computed and four rating categories created. There were large deficiencies in the knowledge and practice of women at risk of being infected with HTLV-1. Only 58% knew that HTLV-1 is sexually transmitted.
A minority was aware of HTLV-1 associated diseases: Adult T-cell lymphoma/leukaemia (ATL) –30.7%; Tropical Spastic Paraparesis (TSP) –42%; Infective dermatitis–42%). Ten (11.4%) believed that HTLV-1 infection can cause HIV/AIDS and only 33% knew that there was no cure for the virus. Most women (88.6%) continued to have unprotected sex.
Controlling HTLV-1 spread must be based on interrupting transmission. In Jamaica, donated blood is screened for HTLV-1 and sharing of infected needle is an insignificant mode of transmission. However, although safe practices in breastfeeding and sexual intercourse are proven ways to reduce HTLV-1 transmission, these data show that knowledge and safe practices among those at risk may not be retained and health education will need to be sustained.

Keywords: JBI Study mothers, knowledge, attitude, HTLV-1, transmission, health education

Conocimientos, Actitudes y Patrones de Conducta en Relación con el VLHT-1 entre las Madres que Participaron en el Estudio de Intervención de la Lactancia Materna en Jamaica – JBI (1996-2000)

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RESUMEN

El virus linfotrópico de células T humanas de Tipo 1 (VLHT-1) – el primer retrovirus humano asociado con una enfermedad maligna – es endémico en Jamaica La transmisión vertical y las relaciones sexuales, son las principales vías de transmisión. Las mujeres tienen un mayor riesgo de contraer el virus, ya que este se transmite más eficientemente del varón a la hembra que a la inversa. La prevención de la transmisión se logra mejor por la educación de salud en las prácticas seguras. El estudio tiene por objetivo documentar los conocimientos, actitudes y patrones de conducta (KABP) de un grupo de mujeres cinco años después de haber participado en un estudio de la reducción del riesgo de la transmisión madre a hijo del HTLV. Se llevó a cabo un estudio transversal usando un cuestionario de 46 puntos aplicado por un administrador para recoger datos de 88 madres. Se computaron las

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puntuaciones sobre los conocimientos generales y se crearon cuatro categorías globales y cuatro categorías de clasificación.
Hubo grandes deficiencias de conocimientos y práctica entre las mujeres con riesgo de ser infectadas por HTLV-1. Sólo el 58% sabían que el HTLV-1 se transmite sexualmente. Una minoría tenía conciencia de las enfermedades asociadas con el HTLV-1: leucemia/linfoma de células T de adulto (TSP) LTA-30.7%; paraparesia espástica tropical PET-42%; y dermatitis infecciosa-42%. Diez (11.4%) creían que la infección por HTLV-1 puede causar VIH/SIDA, y solamente el 33% sabía que no hay cura para ese virus. La mayoría de las mujeres (88.6%) continuó teniendo sexo sin protección.

El control de la propagación del HTVL-1 tiene que basarse en acciones encaminadas a interrumpir su transmisión. En Jamaica, la sangre obtenida mediante donaciones es sometida a examen en busca del HTLV-1 y el compartir una aguja infectada es un modo insignificante de transmisión. Sin embargo, aunque las prácticas seguras en la lactancia materna y las relaciones sexuales son formas probadas de reducir la transmisión de HTLV-1, estos datos muestran que la atención para garantizar el conocimiento y las prácticas seguras entre aquéllos en riesgo no pueden ser interrumpida, y es por ello necesario mantener la educación para la salud.

Palabras claves: Madres del estudio JBI, conocimientos, actitudes, HTLV-1, transmisión, educación para la salud

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INTRODUCTION

Human T-cell Lymphotropic Virus type-1 (HTLV-1) is a type C retrovirus, estimated to infect approximately 20 million people worldwide. The virus is endemic in the Caribbean, Southern Japan, parts of Africa, South America, Melanesia and Papua, New Guinea (1). Population based studies have shown that HTLV-1 seroprevalence ranges from 3–6% in Jamaica, Trinidad and Tobago, and other Caribbean islands to 30% in rural Miyazaki, Southern Japan (1). Seroprevalence in other Caribbean islands is less than in Jamaica (2).

HTLV-1 was the first human retrovirus to be associated with a malignant disease. The virus causes the highly aggressive adult T-cell leukaemia/lymphoma (ATL), tropical spastic paraparesis (TSP), a degenerative myelopathy, infective dermatitis, a chronic relapsing inflammation of the skin in children, and a variety of other chronic inflammatory syndromes (3).

Transmission occurs during unprotected sexual contact with an infected person, from mother to child – through breast-feeding, receiving transfused infected cellular blood products and the sharing of infected needles (2). Some transmission may take place *in utero* or at delivery as infection occurs in approximately 5% of children, born to infected mothers, who were not breastfed (2, 4). There is no effective vaccine against the virus and no satisfactory treatment for either the malignancy or the inflammatory syndromes (3).

The prevalence of HTLV-1 infection, its modes of transmission and the diseases that are associated with the infection are well documented (1, 2, 3). Approximately, 5–10% of infected individuals will develop ATL or TSP (5, 6). However, from reviewing the literature, there seems to be insufficient data regarding the knowledge, attitude and behaviour pattern of the persons infected and those at risk for infection by the virus. This is important since with no known cure for this disease, prevention is of paramount importance for its control. Valid and timely information on the knowledge, attitude and practice of those at risk is important to the design of appropriate interventions.

This study documents the knowledge, attitude and behaviour of the mothers, with regards to HTLV-1, five years after they had participated in the Jamaica Breast Feeding Intervention (JBI) study (unpublished). The JBI mothers were counselled on entering that study and this study now seeks to find out to what extent they understood the advice given and to what extent their current knowledge and behaviour conforms with the information provided during that study.

SUBJECTS AND METHODS

STUDY POPULATION

The study participants were a group of 194 women in the child-bearing age who were recruited from the Victoria Jubilee Maternity Hospital antenatal clinic and from other HTLV-1 studies to be enrolled in the Jamaica Breast Feeding Intervention study (JBI). The study was conducted in two phases from 1996–2000 to determine the effect of bottle feeding on the maternal-infant transmission of HTLV-1 infection in Jamaica. The babies were followed from six weeks to 2 years of age. Mothers were counselled and encouraged not to breast feed for longer than six months. Milk substitute was provided for all babies from 6 months to 1 year of age.

Study Design

A cross-sectional study using both quantitative and qualitative research methods was conducted. Focus group discussions and a 46-point structured questionnaire was used to capture data from 91 mothers. We attempted to enroll all

available mothers. The mothers were informed that participation in the study was voluntary and those who participated could withdraw at anytime. There was no sanction for non-participation or withdrawal. Written informed consent was obtained from all participants. The proposal was reviewed and approved by the University of the West Indies, Faculty of Medical Sciences/ University Hospital of the West Indies Ethics Committee.

Data Management And Analysis

Data collected from questionnaires were entered and analysed using the SPSS statistical software, version 11.5. The questions were pre-coded before entry into the SPSS programme to facilitate a more efficient analysis of data. Data validity checks were done by running frequency and normal distribution checks and checking for miscoded and missing data. Data were analyzed to show demographic and socio-economic status, knowledge, attitude and behaviour of the JBI study mothers. Questions regarding knowledge were assigned responses *yes* = 1, *no* = 2 and *don't know* = 9. Age groups were coded as 20–29-year = 1, 30–39- year = 2 and 40–50-year = 3. An overall knowledge score was computed and four rating categories created (0–3). Chi-square tests, correlations coefficients and regression analyses were used to identify associations between outcome and explanatory variables**.** Factors contributing to knowledge were also investigated in bivariate and multivariate regression. Statistical significance was reported at $p < 0.05$.

RESULTS

STUDY SUBJECTS

The JBI study conducted from1996–2000 included 194 mothers. Eighty were lost to follow-up prior to this study. We received contact information from the HTLV-1 Research Project at the Department of Pathology, the University of the West Indies, Mona, Jamaica for 114 mothers. Of these mothers, 23 were unable to participate for the following reasons: ten had changed addresses without leaving contact information, eight migrated and five who lived in volatile areas were not visited. Of the 91 available, 3 took part in the focus group discussions and were not included in the quantitative aspect of the study, leaving 88 eligible mothers (Fig. 1).

Demographic and Socio-economic Characteristics

All 88 mothers who were contacted, consented to participate. Their ages ranged from 22 to 50 years with the age range 40–50 years accounting for 43%. Median age was 37.5 years. In terms of union status, visiting relationships were most common among the group (37.5%), common-law (27.3%), married (22.7%) and 12.5% reported no relationship. There were 32 (36 .4 %) mothers reporting a high of more than nine years duration in a stable relationship while only 8 (9.1%) were in relationships less than a year. As much as 70 (80%) mothers stated that their partner contributed financially to

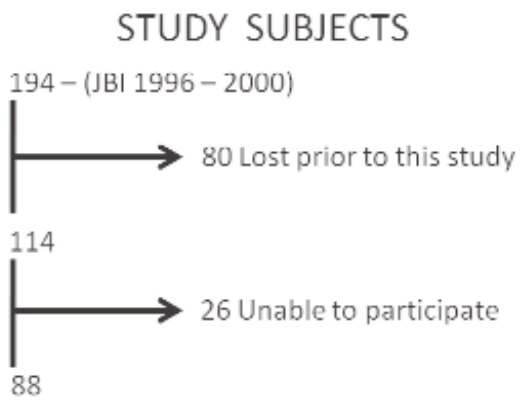

Fig.1: Recruitment of Study Participants

their home. The number of children born to these mothers ranged from 1–8 with the largest proportion of mothers having 2 children (25%). The number of dependents also ranged from 1–8 and only 22 (25%) mothers reported having adult dependents (Table 1).

Educational levels were low with secondary education most frequent (44%), followed by those with vocational training (27%). A large number (36) of the mothers were unemployed representing 41% of those studied. 'Domestic helper' was the main occupation at 8%. The majority of mothers (73%) either had no income or earned less than $15 000.00 monthly. Family monthly income was also low and less than $10 000.00 monthly was reported by 17 (19.3%) mothers (Table 1).

Mothers Knowledge of HTLV-1

Knowledge was estimated by responses to 25 equally rated questions and these were used to create a rating scale of 1–4, higher scores reflecting greater knowledge. The mean knowledge-rating was 1.58 ± 0.93 and 56.8% achieved ratings of 2–3 and correlation of age category and rating scale showed that older mothers were more knowledgeable ($r = 0.263$; $p = 0.013$). In response to the question "how is HTLV-1 transmitted", the majority recognized the role of blood transfusion (86.4%) and mother-to-child transmission (96.6%). However, only 50–60% recognized the role of sexual transmission and the sharing of infected needles for injections. A few (9.1%) harboured the myth that transmission occurs *via* sharing of toilet. Thirty-seven (42%) were unaware that the virus is a sexually transmitted disease (Table 2).

A minority of women were aware of HTLV-1 associated diseases (Adult T-cell lymphoma/leukaemia – 30.7%; infective dermatitis – 42%; tropical spastic paraparesis – 42%). Ten (11.4%) mothers believed that HTLV-1 infection can cause HIV/AIDS and only twenty-nine (33%) knew that there was no cure for the HTLV-1 infection (Fig. 2**)**.

When asked what advice should be given to HTLV-1 positive breastfeeding mothers, the majority (63%)

Table 1: Demographic and socio-economic characteristics

Variables	Proportion (%)	Variables	Proportion (%)
Age (years)		**Employment Status**	
20 – 29	25.0	Yes	59.0
30 – 39	31.8	No	41.0
40 – 50	43.2	**Occupational Categories**	
Union Status		Professional	4.5
Married	22.7	Skilled	19.3
Common Law	27.3	Semi-skilled	23.9
Visiting	37.5	Un-skilled	11.4
None	12.5	Unemployed	40.9
Duration of Relationships		**Educational Status**	
< 1 year	9.1	Primary School	9.1
1 – 3 years	17.0	Secondary School	44.3
4 – 6 years	12.5	High School	14.8
7 – 9 years	11.4	Vocational	27.3
> 9 years	36.4	Tertiary	4.5
None	13.6	**Mothers Monthly Income**	
Parity		No Income	40.9
1	12.5	< $15000	31.9
2	25.0	$15 000 – $24 999	20.4
3	20.5	$25 000 – $34 999	4.5
4	14.8	Don't Know	2.3
≥ 5	27.2	**Family Monthly Income**	
Partner's Financial Contribution		< $10 000	19.3
Yes	79.0	$10 000 – $34 999	61.4
No	8.0	> $35 000	10.2
No Partner	13.0	Don't Know	9.1
Children dependent on Mothers			
1	23.9		
2	35.2		
3	22.7		
4	11.4		
5	6.8		

Table 2: Knowledge of transmission of HTLV-1

Questions	Responses (n = 88) n (%)		
	Yes	No	Don't Know
How is HTLV-1 transmitted?			
Sharing of infected needle for injections	46 (52.3)	25 (28.4)	17 (19.3)
Hugging someone who has the virus	0 (0)	87 (98.9)	1 (1.1)
Sharing toilet with someone who has the virus	8 (9.1)	69 (78.4)	11 (12.5)
Receiving blood infected with the virus	76 (86.4)	7 (8.0)	5 (5.6)
A HTLV-1 positive mother breastfeeding	85 (96.6)	2 (2.3)	1 (1.1)
Having sex with someone who has the virus	57 (64.8)	21 (23.9)	10 (11.3)
Other*	4 (4.5)	33 (37.5)	51 (58.0)
Is HTLV-1 a sexually transmitted disease?	51 (58.0)	13 (14.7)	24 (27.3)

* Kissing

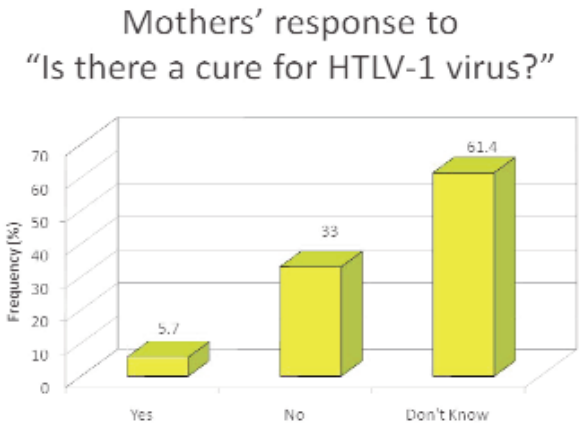

Fig. 2: Mothers' knowledge of the HTLV1

recommended the current standard: to breast-feed for less than 6 months but as much as 24% recommended not to breastfeed at all while 13% suggested breastfeeding for three months.

ATTITUDE AND BEHAVIOUR

With regards to knowledge of their serostatus, 52% had failed to collect their HTLV-1 test result during the JBI study and were unaware of their serostatus. Similar percentages (23.9%) knew of their seropositive and seronegative status.

Of the seropositive mothers, as much as 47.6% had not revealed their status to anyone and 2 (9.5%) were pregnant at the time of this study.

Most women (88.6%) continued to have unprotected sex. The use of the female condom was infrequently reported among the group with only 3 (3.4%) reporting that they ever used it. A majority (92%) reported that their partner regularly used the male condom. In respect of frequency and consistency of use, 8% never used condom and only 11.4% used condom all the time (Table 2**).**

We investigated the number of mothers who donated blood since the JBI study, 5 (5.7%) reported having done so (the serostatus of these mothers was unknown).

The contribution of age and education to knowledge was explored and both explained 8% of the variation in scores. Both age and highest educational level attained were associated with increased knowledge. However, younger persons were also more educated than older persons. In a regression model with both factors included simultaneously neither variable was statistically significant with regard to knowledge score, although age came closer to achieving conventional levels of statistical significance and was probably the larger contributor to the variance (p = 0.057] (Table 3).

Table 3: Condom use

Questions	Responses (n = 88) Yes	No
Ever Used		
Female condom	3 (3.4%)	85 (96.6%)
Male condom	81 (92.0%)	7 (8.0%)
Frequency Of Use		
All the Time	10 (11.4%)	78 (88.6%)
Most of the Time	14 (15.9%)	74 (84.1%)
Sometimes	34 (38.6%)	54 (61.4%)
Rarely	23 (26.1%)	65 (73.9%)
Never	7 (8.0%)	81 (92.0%)

Table 4: Multivariate regression of mother's age and highest educational level attained on total knowledge score

Variables	B ± SE	P
Age	0.12 ± 0.06	0.057
Highest Educational Level Attained	-1.69 ± 1.28	0.191

r^2 = 0.088

DISCUSSION

As far as we are aware, this is the only study which has attempted to quantify the KAB of a sample of women with regards to HTLV-1. The findings indicate that most of the mothers were of low socio-economic status. These findings are in keeping with other studies reporting that indicators of lower socio-economic status, such as having fewer years of schooling are associated with HTLV-1 infection (7). Overall, the knowledge levels about the possible modes of transmission of HTLV-1 were fairly good. Transmission *via* breastfeeding (96.6%) is still an unacceptable figure as it would have been expected that having participated in the JBI study all mothers would have known that the virus can be vertically transmitted. Transmission from mother to child is an important public health concern, because infection early in life is associated with the subsequent risk of ATL, a uniformly fatal condition.

Knowledge of transmission of the virus by receiving blood infected with the virus (86.4%) probably reflects the higher levels of knowledge regarding the diagnosis of the virus where blood is involved. Blood transfusion-transmission of the contaminated blood is perhaps the most efficient mode of infection by the virus with the probability of seroconversion in a recipient being 40–60% (1). In Jamaica, screening of all blood donated has greatly reduced the possibility of infection through transfusion. It is however unfortunate that at present, pregnant women are not routinely screened for HTLV-1, as preventing perinatal infection would probably have the most significant impact on preventing HTLV-1 associated diseases (8). The limited knowledge that the sharing of infected needles is a mode of transmission (52.3%) may indicate limited discussion regarding transmission *via* injection needles which has rarely been reported in Jamaica (9). It has been reported that in Jamaica and other Caribbean Islands except for Bermuda and Puerto Rico, injecting drug use is responsible for only a very small proportion of HIV infections (10). Of particular concern, was the low proportion of mothers having knowledge regarding the diseases caused by HTLV-1 and whether there is a cure for the virus. This lack of knowledge may result in careless and unsafe practices, increasing transmission of the virus which will negatively impact on the prevalence of the virus in the Jamaican population in the future. This study suggests that women continue to practice unsafe sex (88.6%). Lack of independence and their limited perception of their own vulnerability to contracting the virus may be reasons. It should be noted that male to female transmission is about four times as frequent as female to male transmission (3).

With regards to the result obtained from the multivariate regression where highest educational level attained reflects a negative relationship between age and education; we believe this may need to be further examined as it may be affected by an interaction between age and educational level on the knowledge outcome.

LIMITATIONS

The approach taken in this study was influenced by time constraints and its limitations are acknowledged. We were unable to contact 23 mothers and were unable to compare participants' knowledge, attitude and behaviour (KAB) at the time of the JBI study five years before, as a KAB survey was never done.

CONCLUSION

We conclude that there are deficiencies in the knowledge and practice of women at risk of HTLV-1 infection and who had previously received education on the subject, with respect to safe practices in breastfeeding and sexual intercourse. These data suggest that as knowledge may not be retained, health education needs to be sustained.

RECOMMENDATIONS

1. Implement a public educational campaign on the HTLV-1 virus which could be similar to the approach used for HIV.
2. Make available information on the HTLV-1 virus so that it can be easily accessed by individuals
3. Make available and easily accessible condoms and infant formula for HTLV-1 positive mothers.
4. Prenatal screening, including pre- and post-test counselling, for HTLV-1 virus should be considered
5. Further studies should be done to evaluate the effectiveness of this programme.

It is hoped that the information from this study will be utilized for further research and that the recommendations be implemented.

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REFERENCES

1. Manns A, Hisada M, La Grenade L. Human T-lymphotropic virus type 1 infection. Lancet 1999; **353:** 1951–7.
2. Wilks RJ, Figueroa JP. The Epidemiology of HTLV-1 and risk of disease and outcome-Jamaica. Postgraduate Doctor Caribbean 1996; **12:** 185–192.
3. Bangham CRM. HTLV-1 infections. Journal of Clinical Pathology 2000; 53: 581–586. Available: http://jcp.bmjjournals.com/cgi/content/full/53/8/581 March 31, 2005.
4. Khabbaz RF, Fukuda K, Kaplin JE, Bianco C, Blattner W, Busch M et al. Guidelines for Counseling Persons Infected with Human T-Lymphotropic Virus Type 1 (HTLV-1) and Type 11 (HTLV-11). Annals of Internal Medicine 1993; **118:** 448–54.
5. Barmak K, Harhaj E, Grant C, Alefantis T, Wigdahl B. Human T Cell leukemia virus type 1-Induced disease: pathways to cancer and neurodegeneration. Minireview/Virology 2003; 308: 1–12. Available: www.sciencedirect.com.
6. Gallo RC. Human retrovirus after 20 years: a perspective from the past and prospects for their future control. Immunol Rev 2002; **185:** 236–65.
7. Proietti FA, Carneiro-Proietti ABF. HTLV in the Americas. J Public Health 2006; **19:** 7–8.
8. Poiesz BJ, Poiesz MJ, Choi D. The Human T-cell lymphoma/leukemia viruses. Cancer Invest 2003; **21:** 253–77.
9. Carneiro-Proietti ABF, Catalan-Soares BC, Castro-Costa CM, Murphy EL, Sabino EC, Hisada M et al. HTLV in the Americas: challenges and perspectives. Rev Panam Salud Publica. 2006: **19:** 44–53.
10. UNAIDS. Uniting the world against AIDS – Caribbean. Available: http://www.unaids.org/en/Regions_Countries/Regions/Caribbean.asp, April 21, 2006.