

Voices of the Women: Feedback from Women of Child-bearing Age who are Living with HIV can help Improve Efficacy of Psychosocial Interventions

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ABSTRACT

Background: We hypothesized that voluntary counselling and testing during pregnancy are necessary but not sufficient to provide the holistic psychosocial support needed by Jamaican women living with HIV and/or AIDS. Based on this hypothesis, we investigated a range of coping methods and support systems used by HIV-infected women and a group of their HIV-negative counterparts before, during and immediately after their pregnancies.

Methods: Women attending obstetric clinics in urban Jamaica completed a quantitative survey aimed at discovering coping behaviours, social and spiritual support systems. Pre-survey focus group studies and key informant interviews contributed to the design of the questionnaire while post-survey focus groups were used to probe the validity of the data gleaned from the questionnaire survey. Survey data were analyzed using non-parametric tests for trend with independent univariate tests.

Results: Fifty-five HIV-infected women and 51 HIV-negative women completed the survey. Compared with HIV-negative women, more HIV-infected women reported both feeling depressed ($p = 0.07$) and having difficulty concentrating ($p = 0.05$) during the month immediately prior to the study. Other statistically significant differences included: HIV-infected women were more likely to pray, to sleep and to change eating habits in response to worry and stress ($p = 0.001$ in each instance). Although several women declared religious faith, significantly fewer HIV-infected women were willing to talk to a religious leader about their problems compared to their HIV-negative counterparts ($p < 0.001$).

Conclusions: Participation of HIV-infected women in post-survey focus groups augmented the survey findings. Many of the women reported negative emotions and some indicated serious challenges in accessing social support. The results point to the need for systematic documentation of psychosocial profiles as part of the approach to caring for these women. In addition, in the Jamaican sociocultural context, we recommend improved training of religious leaders and healthcare providers in psychosocial issues.

Voces de Mujeres: la Retroalimentación de Mujeres en Edad de Parir Viviendo con VIH Puede Ayudar a Mejorar la Eficacia de las Intervenciones Psicosociales

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RESUMEN

Antecedentes: Planteamos la hipótesis de que someterse al asesoramiento y prueba voluntarios durante el embarazo es necesario, pero no suficiente para el apoyo psicosocial holístico que necesitan las mujeres jamaicanas que viven con VIH y/o SIDA. Sobre la base de esta hipótesis, investigamos una serie de métodos de afrontamiento y sistemas de apoyo usados por las mujeres infectadas por el VIH y un grupo de sus contrapartes VIH negativas antes, durante e inmediatamente después de sus embarazos.

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Métodos: Mujeres que asistían a clínicas obstétricas en áreas urbanas de Jamaica, completaron una encuesta cuantitativa, encaminada a descubrir conductas de afrontamiento, y sistemas de apoyo social y espiritual. Estudios de grupos focales mediante encuestas y entrevistas a informantes claves, contribuyeron al diseño del cuestionario, mientras que grupos focales de post-encuesta fueron usados para investigar la validez de los datos recogidos de la encuesta-cuestionario. Los datos de la encuesta fueron analizados usando tests no paramétricos para tendencia con tests univariados independientes.

Resultados: Cincuenta y cinco de las mujeres infectadas con VIH y 51 de las mujeres VIH negativas, completaron la encuesta. En comparación con las mujeres VIH negativas, más mujeres infectadas con VIH reportaron sentirse deprimidas ($p = 0.07$) y tener dificultades con la concentración ($p = 0.05$) durante el mes inmediatamente anterior al estudio. Otras diferencias estadísticamente significativas fueron las siguientes: las mujeres infectadas con el VIH mostraron una mayor tendencia a orar, dormir y cambiar sus hábitos alimentarios en respuesta a la preocupación y el estrés ($p = 0.001$ en cada caso). Aunque varias mujeres declararon tener fe religiosa, significativamente pocas mujeres infectadas con VIH estuvieron dispuestas a hablar a un líder religioso acerca de sus problemas, en comparación con sus contrapartes VIH negativas ($p < 0.001$).

Conclusiones: La participación de mujeres infectadas con VIH en grupos focales de post-encuesta aumento marcadamente los hallazgos de la encuesta. Muchas de las mujeres reportaron emociones negativas y algunas indicaron serios desafíos en cuanto a tener acceso a algún apoyo social. Los resultados apuntan a la necesidad de poseer una documentación sistemática de los perfiles psicosociales como parte del abordaje del cuidado a estas mujeres. Además, en el contexto sociocultural de Jamaica, recomendamos mejorar el entrenamiento de los líderes religiosos y los proveedores de salud en cuanto a las problemáticas psicosociales.

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INTRODUCTION

Data from 2006 indicate that at least 3000 children were born to mothers infected with the human immunodeficiency virus (HIV) each year in the Caribbean (1). It is known that without the benefit of preventive interventions approximately 25–35% of HIV-infected pregnant women will transmit HIV to their newborns (1–4). So, it could be predicted that, without such intervention, approximately 1000 children would be infected every year in the Caribbean if HIV-infected mothers did not receive antiretroviral drugs during pregnancy and at the time of delivery. In fact, it is estimated that the transmission of HIV from an HIV-infected mother-to-child in 2006 was 10% compared to 25% in 2002, prior to the introduction of antiretroviral medication for prevention of mother-to-child transmission (5).

In Jamaica, it has been estimated that as many as 1.5–2% of antenatal clinic attendants are HIV-infected (2, 3). Before programmes for prevention of mother-to-child transmission (pMTCT) of HIV were well established, this form of transmission accounted for 7% of all reported AIDS cases in the country, reflecting the substantial contribution of women to the Jamaican epidemic (3). Among HIV-infected women, MTCT occurred in approximately 25% of such cases, either during pregnancy, through exchange of blood or during labour and delivery or through breastfeeding (3).

Within the past three years, several Caribbean countries, including Jamaica, have accelerated their pMTCT programmes (5, 6). We now know that with appropriate interventions, this form of transmission can be reduced to below 5% in infants born to HIV-infected mothers (2–4).

Given the relatively high incidence of HIV infection among pregnant women in Jamaica and the knowledge that appropriate psychosocial support will ameliorate the effects of HIV/AIDS (7), the authors decided to investigate how some of these women have coped with life before and during their pregnancies, how they are adjusting to living with HIV and/or AIDS and how they anticipate the future.

The main aim of the study was to identify patterns of psychological functioning among pregnant HIV-positive women attending antenatal clinics with a view to helping this group of persons to: a) reduce their risk in relation to further exposure to HIV and other sexually transmitted infections; b) increase their ability to cope with the psychological and social stresses commonly associated with HIV, and c) improve their parenting behaviour.

At the time of the study, a comprehensive voluntary counselling and HIV testing (VCT) programme had been initiated in Jamaica and standardized manuals and training programmes were being used in an effort to improve the quality of VCT provided (8, 9).

In embarking on the study, the desire was that publication of data related to the psychosocial needs and care of HIV-infected women would be beneficial to the women themselves as well as to persons involved in their care, treatment and support (7, 10). We anticipate that the results of the study will improve the ability of members of the healthcare team to provide more pertinent referrals for services, particularly when psychosocial interventions are required.

As far as we are aware, this is the first study of its kind to be undertaken in the English-speaking Caribbean. We trust that

it will prompt similar work in other parts of the region and elsewhere.

SUBJECTS AND METHODS

Objectives

- * To examine a range of psychosocial factors (including emotional well-being, self-esteem, self-efficacy, life stressors and coping strategies, religious beliefs and practices, real and perceived social support, attitude and practice with respect to healthcare, freedom to disclose HIV status and perception of victimization) associated with risk reduction and with adherence to treatment protocols.
- * To compare the issues and psychological profiles of HIV-positive women attending antenatal and postnatal clinics with those of women at the clinic who are not HIV-infected.

Hypothesis

At the beginning of the study, it was hypothesized that voluntary counselling and testing for HIV as currently prescribed and practised is not sufficient to allow pregnant women to adjust to the realities of a diagnosis of HIV infection and to improve their coping with its implications or to guarantee safe behaviour among HIV-negative women. In the context of the present study, we proposed that certain additional psychosocial factors would improve the efficacy of current models of VCT and provider-initiated testing and counselling. We sought to test these ideas by interviewing groups of women who were either attending antenatal clinics or were in the immediate postnatal period.

HIV programme managers have assumed that a standardized approach to pre- and post-test counselling, namely voluntary counselling and testing for HIV, would be sufficient to allow pregnant women to adjust to the realities of a diagnosis of HIV infection and to improve their coping with its implications.

Study Design

This study was a collaborative effort between the Kingston Paediatric and Perinatal HIV/AIDS Programme (KPAIDS), the Ministry of Health, Jamaica, and the University of the West Indies HIV/AIDS Response Programme (UWI HARP).

The participants in all phases of the study were attending health services affiliated to the KPAIDS programme in the parishes of Kingston, St Andrew and St Catherine (see below). The majority of the women were therefore from urban or semi-urban residential settings.

Ethical permission for conducting the study was obtained from the Joint Ethics Committee of the UWI Faculty of Medical Sciences and the University Hospital of the West Indies as well as the Ethics Committee of the Ministry of Health, Jamaica. As part of the ethical review that occurred prior to the study, the Ethics committee approved the text of an informed consent form. In carrying out the fieldwork, this

informed consent form was read to each prospective participant and those who agreed to participate signed their agreement with the content of the form; this was done at each stage of the study. A minority of prospective participants declined to take part in the study. Their reasons for declining were not recorded.

Phase 1 – Initial qualitative research

The first phase of the study consisted of (a) focus group interviews with two groups of HIV-infected women and one group of HIV-negative women and (b) ten key informant interviews with the following persons: (i) seven AIDS/ pMTCT service providers within Governmental and Non-Governmental agencies, (ii) two HIV-infected patients and one HIV-negative patient. The women who participated in the focus groups and the patients who were interviewed individually were recruited voluntarily from the antenatal clinic at the University Hospital of the West Indies.

Phase 2 – Design and pre-testing of questionnaire

Data from focus groups and key informant interviews were used in the design and modification of a structured questionnaire which was pre-tested before being administered in the second phase of the study.

Phase 3 – Questionnaire survey

Participants were recruited from among women who were attending antenatal and postnatal clinics at the Spanish Town Hospital and at three Kingston locations, namely, the Victoria Jubilee Hospital, the Government Comprehensive Health Centre and the University Hospital of the West Indies (4, 10). Convenience samples were chosen as follows: (a) women who were known to be HIV-infected and who knew their HIV serostatus and who were part of the Kingston Perinatal and Paediatric AIDS (KPAIDS) programme and (b) women who were HIV-negative at the time that they were tested during pregnancy and who reported that they were still HIV-negative at the time of the study. The patients' medical records were reviewed to provide information on demographic variables and to verify the HIV status of prospective participants prior to their recruitment. The relatively small size of the patient population (sampling frame) and the sensitivity of the subject caused the authors to avoid random sampling.

The questionnaire was administered to the respondents by a small team of pre-trained Research Assistants. An explanation of the study was read to each prospective participant and each person then signed consent to take part. The questionnaire, based on a review of the literature, consisted of over 300 questions, designed to assess psychosocial and other variables including: depression, anxiety, life stress, social support, coping skills and religious beliefs/practices (7, 11–15). At the end of the interview, a small gift package and a set of Health Promotion brochures were given to each participant as a token of appreciation. Where important

psychological or social needs were identified during interviews, participants were given advice and/or referrals at the discretion and initiative of the interviewers or the lead researcher.

In the quantitative arm of the study, emotional well-being was measured using a modified well-being question set, a 13-item tool asking participants to rate their levels of various negative emotions on a 4-point scale (not at all, a little, sometimes, a lot). Participants were classified as experiencing important levels of each emotion if they reported the emotion sometimes or a lot. The proportions experiencing each emotion were compared among HIV-negative and HIV-infected women, using the Chi-square test, unadjusted for multiple testing.

Phase 4 – Second qualitative phase

This phase consisted of four focus group interviews to probe information derived from the questionnaire survey. The informants were again recruited voluntarily.

Data Analysis

Data from the initial focus group and key informant interviews were analyzed manually for significant themes and patterns and these were incorporated into the structured questionnaire. Data from the questionnaire survey were analyzed by computer using Stata Statistical Software: Release 8 for performing Chi-square and Student's *t*-tests, where necessary. Data from the final set of four focus groups were analyzed manually for significant themes and patterns in a similar way to the analysis of the earlier focus group data.

RESULTS

In the present paper, the results of analysis of qualitative and some quantitative data are reported. In some instances, information from the three operative phases of the study is reported together. Unique findings are reported separately.

Demographics

The median age of 51 participants without a known HIV diagnosis was 25 years (interquartile range 21 to 32, range 14 to 40) and in 55 HIV-infected participants, it was 27 years (interquartile range 24 to 31, range 15 to 41). This age difference between HIV-infected and HIV-negative participants was not statistically significant ($p = 0.41$).

The majority of the women reported that they were currently either in common-law relationships or had visiting partners (82% HIV-negative and 69% HIV-infected women).

There were proportionately more married women in the HIV-negative group. One quarter of HIV-negative women reported having no regular partner.

Most of the women were educated to secondary school level with a larger proportion of HIV-infected women only educated to primary level. There were fewer HIV-infected women who were educated at tertiary level.

Emotional well-being

Statements from some HIV-infected women:

"I thought about death a lotmy mother had to hide the knives and scissors...it is only because of family why I don't kill myself..."

"I am scared to die but I can't see a reason for living..."

"Ask yourself 'what did I do?'"

"...when you die the children ... nobody will take care of them like you"

Statistically significant differences were noted for 'feeling tense' and for 'guilt' with a larger proportion of HIV-infected women reporting these experiences. We also noted an increased rate of self-reported depression among HIV-infected women ($p = 0.02$) compared to their HIV-negative counterparts. In addition, a greater proportion of HIV-infected women reported difficulty concentrating ($p = 0.05$).

In this relatively small sample of respondents, none of the 51 HIV-negative women and four of 55 HIV-infected women reported using alcohol ($p = 0.12$, using Fisher's exact test, two-tailed) (16). None of the HIV-negative women reported using tobacco or "other drugs" compared to five of 55 HIV-infected women ($p = 0.058$, using Fisher's exact test, two-tailed).

With respect to possible coping strategies for 'worry and stress' adopted by the study participants, important differences between HIV-negative and HIV-infected women were noted. Specifically, HIV-infected women were more likely to pray, to sleep and to change their eating habits in response to worry and stress ($p = 0.001$ in all cases).

Knowledge about where to go for help

The voice of one HIV-infected woman:

"If only I could talk to somebody at night!"

Both HIV-infected and HIV-negative women (43% HIV-negative, 36% HIV-infected) reported that they did not know where to go for advice about HIV/AIDS. Although the majority of women had telephone access (90% of HIV-negative and 82% of HIV-infected women), many were not aware of the services offered by the national AIDS/STD Helpline telephone counselling and referral service (35% HIV-negative, 40% HIV-infected). However, the participants in the final focus groups felt that most HIV-positive women should know where to go but probably do not trust the system to maintain confidentiality.

Social support

The voices of HIV-infected women:

"I was longing for this (group session) ... sometimes you feel so alone"

"It brings a lot of guilt... lying to people you love"

The support networks of friends and family are important determinants of quality of life. We asked a series of questions about theoretical and practical support offered by friends and family members.

Across both groups of women, on average, family members were more likely to provide support than friends (family 78%, friends 70%). HIV-infected women were a little more likely to receive support (HIV-infected 77%, HIV-negative 71%). Significantly higher proportions of HIV-infected women reported ease at asking friends or family to take care of children during absence or illness. Families were more likely to provide help without payment to their HIV-infected female relatives compared to HIV-negative women.

When the women were asked theoretical questions about support provided by family and friends, on average, they anticipated more support from family members. HIV-infected women believed that they were less likely to expect support. These differences were not statistically significant except in two instances: (a) significantly fewer HIV-infected women believed that friends understood their problems, and (b) significantly fewer HIV-infected women believed that they could get advice from family compared to their HIV-negative counterparts.

Disclosure

To family

The voice of one HIV-infected woman:

“Family ... too much stress ... they speak too freely...”

Half of all HIV-infected women had told family members about their illness. Among women who had yet to inform a relative, 58% did not feel able to tell any family members about their illness and 76% were not interested in referral to someone who could help them to prepare to tell a relative.

To Friends

One-quarter of all HIV-infected women had told one or more friends about their illness. Among women who had yet to inform a friend, 89% did not feel able to tell any friends about their illness and 90% were not interested in referral to someone who could help them to prepare to tell a relative.

Almost all of the women said that they knew who would take care of their children in a crisis (96% HIV-negative and 85% HIV-infected). More than three-quarters identified a relative (85% HIV-negative and 87% HIV-infected) and one-quarter identified a friend (28% HIV-negative and 29% HIV-infected). Fewer HIV-infected women said that the father would take care of the child [83% HIV-negative and 52% HIV-infected] ($p = 0.002$). However, less than half of the women had contacted the father (50% HIV-negative and 30% HIV-infected), the friend (15% HIV-negative and 18% HIV-infected) or the relative (54% HIV-negative and 41% HIV-infected) about this care.

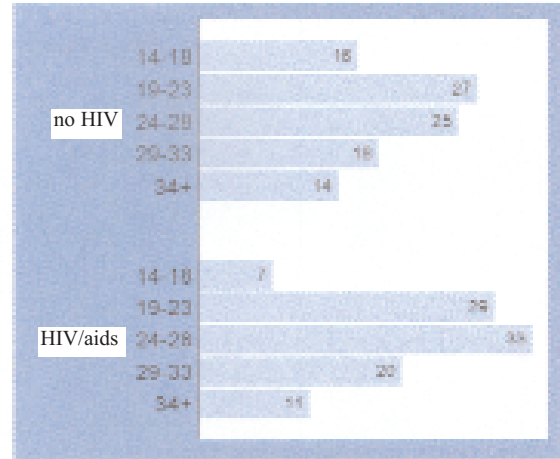
Religious beliefs/practices

The voices of HIV-infected women:

“Paid \$7000 to go to a science healer ... gave me dirty water to drink”

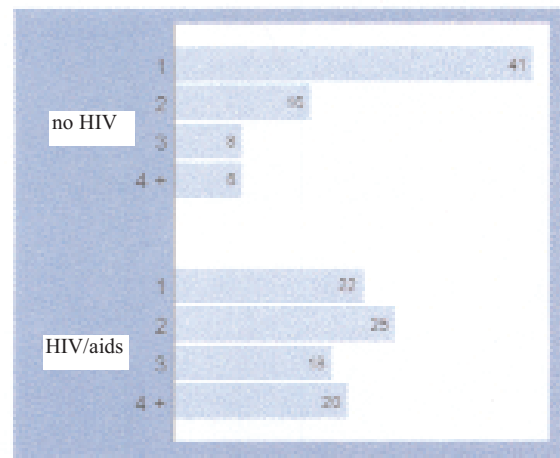
“prayed all daybelieved in miracles...”

Spirituality was noted to play a central part in the responses of many women. Some said that they prayed and believed that their faith helped them to deal with stress. Many believed that their faith, even without medication,



Note: Data expressed as percentages.

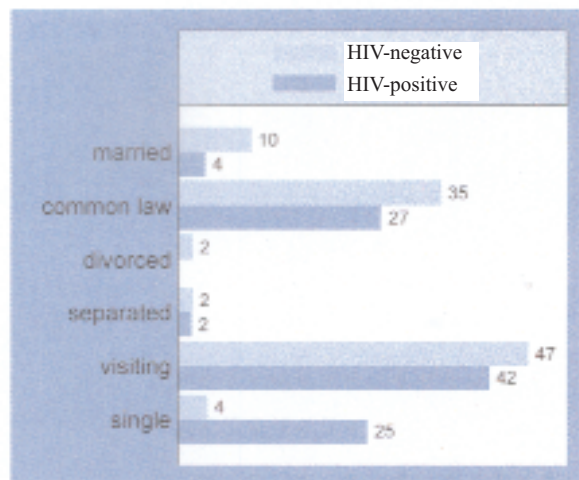
Fig. 1: Age distribution of 106 study participants (55 HIV-infected; 51 HIV-negative).



Note: Data expressed as percentages.

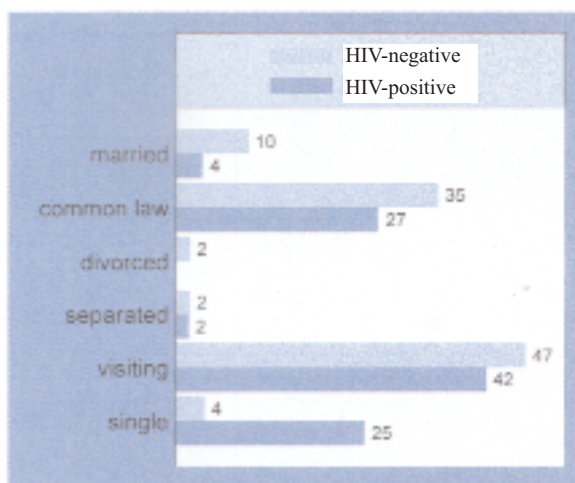
Fig. 2: Numbers of previous births reported by 55 HIV-infected and 51 HIV-negative women.

could lead to healing. Almost a quarter of the HIV-infected women had sought advice from a traditional faith healer. On the other hand, several of the HIV-infected women interviewed were less likely than their HIV-negative counterparts to feel comfortable talking about their problems with a conventional religious leader.



Note: Data expressed as percentages.

Fig. 3: Union status reported by 55 HIV-infected and 51 HIV-negative study participants.



Note: Data expressed as percentages

Fig. 4: Educational status reported by 55 HIV-infected and 51 HIV-negative study participants.

Real or perceived victimization

The voice of an HIV-infected woman:

"Can't deal with so much people ...don't want to go there ... they see you and point you out later."

One-fifth of HIV-infected women ($n = 10$) reported feeling victimized or taken advantage of because of their HIV status. Of these victimized women, five reported victimization by a healthcare worker, two by a family member, three by a neighbour or community member and two by a friend.

DISCUSSION

This study provided data regarding some of the psychosocial processes influencing the behaviour of women of child-

Table 1: Proportion of HIV-negative and HIV-infected women reporting thirteen negative emotions

Variable	HIV-negative (%) $n = 51$	HIV-infected (%) $n = 55$	Prob ¹
Nervousness	8	15	0.28
Sadness	47	55	0.44
Fearfulness	16	27	0.15
Loneliness	25	40	0.11
No interest	29	42	0.18
Hopelessness	20	29	0.26
Feeling tense	31	51	0.04
Panic	10	15	0.46
Restlessness	33	20	0.12
Worthlessness	14	20	0.39
No sleep	47	29	0.06
Eating (too much)	53	55	0.87
Guilt	27	47	0.04

¹Proportions compared using the Chi-square test

Table 2: Proportion of HIV-negative and HIV-infected women who reported that it was easy to get friends or family to provide selected support

Type of Support	HIV-negative (%) $n = 51$	HIV-infected (%) $n = 55$	Prob ¹
Friends			
Watch my home	67	71	0.64
Care for my children	49	71	0.02
Do something I couldn't do	73	67	0.55
Social / party	80	71	0.26
Help, without payment	78	75	0.64
Family			
Watch home	74	82	0.36
Care for children	56	89	<0.001
Do something I couldn't do	80	78	0.78
Social/party	73	80	0.37
Help, without payment	76	91	0.04

¹Proportions compared using the Chi-square test

bearing age who are living with HIV. As has been found elsewhere, many of these HIV-positive women were experiencing negative emotional experiences and were attempting to cope with them in the best ways they could (12). A larger percentage of them were depressed, less satisfied with their lives and less optimistic compared with their HIV-negative counterparts (7, 13, 14).

HIV-infected post-natal mothers were worried about their own health and the concomitant financial burdens. Yet they were not seen to be engaging in 'unhealthy coping behaviours' any more than the HIV-negative women. In fact, according to our data, stress was more likely to lead to more 'acceptable' behaviours like sleeping and praying. In addition, with regard to healthcare, the HIV-infected women were also more likely to be watching their diet, taking medication

Table 3: Proportion of HIV-negative and HIV-infected women who reported positively on aspects of support

Type of support	HIV negative n = 51	HIV infected n = 55	Prob ¹
Friends			
Can depend on	82	69	0.11
Can turn to	67	53	0.14
Will come to help	82	84	0.86
Can get advice	71	58	0.18
Understands	78	56	0.02
Want these friends	75	65	0.31
Family			
Can depend on	90	85	0.46
Can turn to	76	67	0.29
Will come to help	98	95	0.35
Can get advice	86	69	0.04
Understands	75	64	0.23
Want this family	71	71	0.97

¹Proportions compared using the Chi-square test

but not exercising – an area of selfcare worthy of more promotion.

The large proportion of respondents who practised religion at a personal level was striking. This reinforced the importance of understanding the spiritual focus of these individuals (7, 14). It was not as simple as saying that if we find that someone was religious we should refer her to a pastor. This may be true and certainly a referral mechanism to spiritual advisors should be part of the armamentarium of any AIDS service provider. However, a full appreciation of the implications of these spiritual beliefs may make all the difference in facilitating uptake of and adherence to medical regimens. It should be noted that there was clearly a need for more work to be done to educate religious leaders to the needs of HIV-infected women and to ensure that the perception of their availability as appropriate counsellors and confidants improved.

As would be expected, social support was an important factor in the lives of the women (7, 11, 13, 15, 17). However, the experience of support, whether from family or friends, appeared to be limited to help with practical problems *eg* in child care and was less likely to include emotional support and empathy with the challenges of living with HIV.

Of the women who had not disclosed their HIV status, the majority did not want to explore ways to share this information either with friends or family. While the issues of disclosure, stigma and discrimination continued to be barriers to accessing the necessary emotional support, there was increasing need to provide additional support systems that were available, when needed (7, 12, 17). In this context, it was also noteworthy that most of the persons interviewed said that they did not know where to go to for advice about HIV/AIDS. This is eminently solvable by the national health authorities.

It was commendable that the majority of the women had allegedly made plans for the care of their children in a crisis should they be unable to play this role and that most of them had identified a relative to play the role of caretaker. However, fewer of the HIV-infected women included the father as an option. These plans were mostly in the minds of the women as less than half of them had contacted the identified caregiver about their roles *vis-à-vis* the children. There were a number of possible reasons for this lack of communication, ranging from the “superstitious” to the matter of reluctance to disclose HIV status. Whatever the reasons, this was another area worthy of investigation, guidance and support both in the interest of the welfare of the children and for the emotional well-being of the mothers (17).

As we have reviewed some of the more actionable results, it was clear that an appreciation of these potentially complex yet important psychosocial variables could provide insights that were to improve the efficacy of our interventions. Yet the complexity of these behavioural factors may sometimes seem intimidating especially for those who felt that they were not adequately trained to intervene at this level. We need to revisit our paradigm for comprehensive care in order to ensure that the best use is made of all the data available and that all potential providers are appropriately equipped to play necessary roles.

Implications for training of providers included a greater focus on a teamwork approach, psychosocial assessment, creation of an effective referral network, use of material suitable to the literacy level of the client, public education and continuing in-service education (7, 18, 19). The provider must be seen as not only a provider of medication/clinical services but also a sensor who assessed broad needs, a gatekeeper who provided direction to other service providers, a sentinel who identified trends and patterns and a supporter during the entire process.

There must be modifications of curricula in professional schools *eg* schools of medicine, nursing, pharmacy, psychology, counselling and social work (18, 19). Provider competencies must include: communication skills, counselling skills, proficiency in patient education, ability to assess psychosocial needs, current knowledge about drug regimens, knowledge of appropriate referral processes and sources, willingness to refer when necessary and supervision skills (19).

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