Exchanging Non-Medical Service Needs of Women Living With HIV/AIDS

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[to cite]:


[url]:

http://www.acrwebsite.org/volumes/13323/volumes/v35/NA-35

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ABSTRACT
This exploratory study examines non-medical support services for HIV-positive women in Australia, with the aim of understanding their long term consumption needs. Interviews were conducted with three HIV-positive women, eight medical practitioners who specialize in treating HIV/AIDS, and four HIV-positive women advocates. Analysis of the data provided three key themes that are vital in the design and delivery of non-medical support services: counseling, sexual orientation and peer support. Findings reveal agreement about the increasing importance of non-medical support services to the well-being of HIV-positive women.

INTRODUCTION
The academic community has increasingly identified the need for transformative consumer research that attempts to alleviate the stress and suffering of vulnerable consumers in the modern world (Mick, 2006). Topics with the ultimate goal of enhancing consumer welfare are considered imperative in the field of consumer research. As Sheth and Sisodia (2006) state:

“Marketers should think of themselves as “healers;” after all, their job is to meet the functional and psychological needs of their customers, and leave them satisfied and even delighted. They should adopt this perspective at the individual as well as the societal level”.

One particularly vulnerable market segment consists of individuals suffering from HIV/AIDS. Due to recent medical advancements, people living with HIV/AIDS (PLWHA) are managing to continue working, have relationships, and start families; in effect they are maintaining aspects of a pre-HIV life. This gives rise to a new segment of consumer whose needs are not fully met through traditional medical avenues and who, instead, require support services that provide both medical and non-medical assistance. To date, little investigation has been conducted on this emerging segment of consumers, and none has focused attention on the needs of women living with HIV/AIDS (Ciambrone, 2001).

Thus, this exploratory study was initiated to address the following research objectives:

- to determine the unmet needs of HIV-positive women;
- to determine the perceptions and attitudes of other key stakeholders towards existing support services (medical practitioners and HIV-positive women advocates);
- to identify the perceived barriers to HIV-positive women consuming non-medical support services.

Theoretically, this study is grounded in the emerging marketing paradigm known as the ‘service-centered model of exchange’ (Vargo and Lusch, 2004) and specifically applies the approach to the context of HIV-positive women. At its root, the conceptual foundation of this theoretical position is to promote the importance of taking into account all relational interactions (Vargo and Lusch, 2004) in the exchange transactions associated with non-medical support services delivery to these women.

Greater effectiveness in reaching the growing number of Australian women with HIV/AIDS will assist in maximizing good health for longer periods, minimizing discrimination and reducing the stigma associated with HIV/AIDS, thereby enhancing the well-being of people living with the debilitating condition.

BACKGROUND OF THE STUDY
An increasing proportion of people living with HIV in Australia are heterosexual females. A significant rise in new HIV notifications among women occurred between 1999 and 2004 with the latest available figures revealing approximately 2000 registered HIV-positive women in Australia (NCHECR, 2004). Significantly, however, infections among women do not pertain to an identifiable age or risk group (NCHECR, 2004) and consequently, the specific needs of individual women vary considerably. The main issues that affect the quality of life of HIV-positive people can be examined from three different perspectives.

1: Living with HIV and adherence to HAART (Highly Active Antiretroviral Therapy)

The success of antiretroviral treatments has transformed HIV from being a fatal illness to a permanent but manageable health condition (Kennedy et al., 2004). Indeed, one of the main challenges for PLWHA is adhering to the strict antiretroviral drugs regime.

Previous research has indicated that an individual’s psychological state can have a significant effect on their adherence to this treatment regime. Alfonso et al (2006) demonstrated that distressing emotions impacted significantly on a large number of participants’ decision to take HAART, and a survey conducted by the Australian Federation of AIDS Organizations (AFAO) in 2006 revealed that women are less likely than men to take antiretroviral or prophylactic (preventative) treatments for HIV. Similarly, research conducted by Cook et al. (2006) revealed that women struggling to cope with high levels of depressive symptoms are less likely to initiate or continue treatment using HAART.

2: HIV and stigma

People who acquire HIV differ significantly from people with other chronic or terminal illnesses in terms of how they cope with medical, social, economic and personal pressures. Feelings of guilt at becoming infected and fear of disclosing their status due to the perceived risks of being stigmatized and marginalized in society are unique for PLWHA and influence almost every aspect of their lives (Molassiotis et al., 2002).

Gender difference also plays a significant role in relation to stigma felt by PLWHA. For example, women are inclined to feel victimized if the infection is caused by unprotected sex with men who did not divulge their HIV status (Lichtenstein et al., 2002).

3: HIV and Support Services

Increased rates of life expectancy (following initial HIV-positive diagnosis) mean that those infected are now facing a different set of challenges that centre on how to live with HIV. In particular, the health care system, community care networks or
other agencies, now need to develop strategies to provide adequate assistance for people with an HIV-positive diagnosis in order to help them maintain good mental health and remain independent and productive members of the community for as long as possible. These circumstances raise questions as to the accessibility and relevance of available support services, which have been primarily designed for homosexually active men and injecting drug users.

In the peak years of the HIV/AIDS epidemic, it was the gay community that was predominantly afflicted. The spread of HIV/AIDS to other groups, however, has necessitated some urgency in establishing organizations that accommodate the needs of a more demographically diverse population. People outside of the gay community and other cultural groups identified in the earlier stages of the epidemic (e.g., needle users, sex workers) often lack the various forms of emotional, economic and political support that are required to promote resilient attitudes. They also tend to be susceptible to a higher degree of isolation, stigma and marginalization.

Women, in particular, are marginalized within the Australian HIV population and have few support resources available to them en masse. This is because the specific needs of women vary considerably depending on their current health condition, family status, financial situation and their degree of emotional fulfillment.

A substantial body of research in mental health provides evidence that use of social support services has the potential to reduce levels of stress and risk behavior (Bruce et al., 2002, Waddell and Messeri, 2006). Findings from Tsunekawa et al. (2004) demonstrate that positive attitude changes occur when PLWHA encounter others who share the same burden. However, while many studies emphasize that peer support and participation in social groups enables HIV-positive people to reinforce their coping skills, restore emotional balance and increase self-esteem (Molassiotis et al., 2002, Bruce et al., 2002), only one study conducted in the United States pointed out that many people diagnosed with HIV do not receive regular support (Uphold and Mkanta, 2005).

Within Australia, there is only one non-governmental HIV group that currently targets women’s needs. ‘Positive Women,’ which is based in Victoria, is the only organization with a mission to solely address the needs of HIV-positive women. The organization offers a limited range of information resources and services, such as a drop-in service, hospital and home visits, access to funding for personal development, and food vouchers.

In summary, an overview of academic and practitioner literature in the area of HIV support services leads us to conclude that, to date, there are no well grounded programs or soundly designed strategies for tailoring support services to HIV-positive people in general and women in particular.

**RESEARCH METHOD**

This project has discovery-oriented goals and employs a qualitative approach for the data collection process. The sensitive nature of this study, the ability to guarantee confidentiality to respondents and the desire to make the research as participatory as possible require a face-to-face, individual approach from the researcher. For this purpose our research methodology adopts a grounded theory approach (Strauss and Corbin, 1998) embedded within a constructivist paradigm (Denzin and Lincoln, 2005) in which the data collection method is informal, based on semi-structured in-depth interviews (Strauss and Corbin, 1998) and complemented by observation and recording of field notes (Marshall and Rossman, 1999). The research employs the purposive (or judgment) sampling techniques (Albright, 2002). Interviewing the three groups of primary stakeholders (Wheeler and Sillanpää, 1997)—HIV-positive women, medical practitioners and women advocates—allows us to build a more holistic picture and gain greater appreciation of various perspectives on designing non-medical support services for HIV-positive women.

**Interview schedule**

The interview schedule was developed using an adaptation of the service-centered model (Vargo and Lusch, 2004) as a framework and employed a semi-structured approach.

The semi-structured interviews lasted around one hour and were conducted at a place selected as convenient for the informants. All interviews were audio taped after written consent was granted.

Data analysis was performed in two stages employing the hermeneutic (idiographic) approach (Thompson et al., 1994, Packer, 1985, Fournier, 1998). The first stage involved reading the verbatim transcript with the goal of gaining insight to the personal hardships of being diagnosed with HIV in which psychological tendencies were revealed as well as an understanding of how women utilized available support services. The second stage involved comparative analysis of the responses of each interviewee. This stage was directed at finding any similarities or specific differences within and across the three informants groups, as well as an assessment of what is lacking in addressing women’s needs.

**Sample**

*Women living with HIV/AIDS;* The researchers approached the Positive Women Organization in Australia to seek its assistance with recruitment. The director of this organization was provided with an explanatory note of the study. She then approached the clients of this organisation via email and this resulted in three women being self-selected.

The key informants of this research were women living with HIV/AIDS (R1–R3). The three respondents were Caucasian women who live in Melbourne, speak English as their first language and all between 25 and 50 years of age. The time lapse since diagnosis of these women was over 14 years (R1), approximately 16 years (R2), and 9 years (R3). Two of the three informants (R2 & R3) have children, and at time of interview R3 had a new born baby and therefore was not working. Only respondent R3 is married. R2 has a PhD degree and worked in a consulting business, while R1 was enrolled to study her Diploma of Social Welfare and worked part-time. Overall, there was sufficient variation in the life circumstances of these women to reflect some diversity of lived experiences and life perspectives.

*Medical practitioners (Physicians);* This group comprised medical practitioners specializing in the health of women living with HIV/AIDS. Eight doctors (D1–D8) from Melbourne and Sydney clinics specializing in HIV/AIDS treatment were interviewed. This respondent group was selected on the basis that doctors are recognized as the first real contact that a woman makes when diagnosed with HIV/AIDS and that, by virtue of the chronic and stigmatizing nature of the illness, an enduring doctor-patient relationship often ensues.

*Women advocates;* This group of informants were four women (WA1–WA4) living with HIV/AIDS who are also actively involved in national advocacy roles and in support services such as peer support at the community level. They have all publicly disclosed their HIV status and serve to support, represent, and advocate for the needs of all women living with HIV/AIDS in Australia at a state and national level. The participants were from four Australian state capital cities (Adelaide, Sydney, Melbourne and Brisbane) and reflect varied life experience, ethnicity and family circumstances. They were all first diagnosed HIV-positive over ten years ago.
FINDINGS

In accordance with the service-centered model of exchange (Vargo and Lusch, 2004), the interviews focused on the relational aspects of the exchanges that the women experienced during the period of their diagnosis, the subsequent commencement of treatment, and the management of their condition. This approach elicited three key themes that emerged during the data analysis—counseling, orientation of support services, and peer support.

Before presenting these main findings it is important to understand the profile of the female Australian HIV-positive population. One medical practitioner, who deals with PLHWA on a daily basis, claims that an increase in the global epidemic directly affects this population.

It’s not home grown transmissions…They are certainly there, but those figures aren’t going up. It tends to be going up with people who are coming to Australia, migrating to Australia and they’ve acquired HIV from overseas…or Anglo women who’ve gone overseas and had sex with a local and acquired it in that way… [D1]

This gives us an insight into a population who may have significant economic, social, cultural and religious differences, and offers both an understanding of and impetus for the examination of HIV support services. Both the responses from the interviewees and the surveillance data jointly support the contention that it is extremely difficult to identify any commonality across the female HIV-positive population. As another medical practitioner states:

Women are very, very different. There are some who are injecting drug users, there are some who’ve acquired it from their partners who are HIV positive and heterosexual, …young women who are students and occasionally older women who have had it for a while and are diagnosed in their sixties only recently because their husbands were bisexual and positive and didn’t know about it. [D2]

Counseling; Diagnosis of HIV is obviously a shocking experience and all respondents revealed that, at the initial stage of diagnosis with HIV, it felt like a death sentence. The psychological trauma of one of the respondents was intensified by the doctor’s reaction.

I felt that the GP [physician] was really angry with me for having exposed him to the virus. [R1]

Another respondent had a more favorable first experience:

I was probably very fortunate that I went to the [clinic] for my diagnosis and that’s where I still go for my HIV doctor related appointments basically because I think they are a really compassionate and understanding service [R2]

These two contrasting situations reveal a critical stage where support services begin; namely, with the advice and counseling from initial consultation with a General Practitioner and their compassion and understanding of the client’s situation.

The HIV specialist or diagnosing general practitioner is often the sole source of information about medical treatments and the non-medical support services available for women when newly diagnosed. While it is perceived as obvious that counseling for HIV-positive people is of utmost importance to assist them in normalizing their lives, there is a serious frustration in regards to the provision and delivery of these services. As one of the respondents commented:

the counseling I think is something that’s really under resourced. There’s very little of it about, and that’s the thing, like, where do you find out where ongoing counseling is unless you go to Positive Women or the AIDS Council which most women feel intimidated by. [R2]

This was also supported by medical practitioners, who indicated that psychological and psychiatric services are traditionally underfunded, which ultimately inhibits the necessary support that women need through their diagnosis.

The experience of the women interviewed, in terms of receiving counseling support, varied considerably. One respondent stated that, at the time she was diagnosed, there was:

… no counseling whatsoever. As I said, I didn’t go for an HIV test, I went because I was sick, and then when I got the test results. [R1]

Another respondent sought help from her circle of friends:

I had a good friend around the corner, [Name], and he actually used to work as a counselor.….so he sort of gave me quite a bit of support. [R3]

She then shared her experience of finding support from a counselor in the hospital:

Somewhere around the ‘90s I met a counselor who was working at [Name] Hospital, and he offered to have sessions with me, and I probably ended up seeing him for about two years and he was a psychotherapist, and that was great and that was probably-ultimately it was probably the best. [R3]

Adequate levels of counseling support are considered to consist of more than merely a few post-diagnosis sessions. Counseling must be an ongoing process to address various needs as they emerge over time and the availability of ongoing counseling has a crucial impact on personal well-being.

From these findings it is apparent that counseling services have to be designed and widely available to enable HIV-positive women to adapt to their new life, provide psychological support and additional information services specifically related to the HIV disease. In addition, HIV-positive people require on-going counseling.

Orientation of support services: A number of community-based organizations provide support for people infected by HIV/AIDS. However, the specific sexual orientation of their activities poses significant constraints on the consumption of such services by women. For example, two major organizations, the AIDS Council and NAPWA (National Association of People living with HIV/AIDS) were described as follows:

…largely gay men oriented...I do know that a lot of women do feel uncomfortable and have a lot of concerns about the gayness of these places. [R1]

One woman advocate supported this perception.

A lot of women don’t feel that welcome walking in there when 90% of it’s gay men [WA4]
A comment by one of the respondents indicates that, unlike the HIV-positive gay society, women often find themselves with no emotional attachment to other HIV-positive women.

...in terms of community, the gay men in Australia have got the numbers, so they do have quite a community whereas ... The women in Australia, we don’t live near each other, we’re spread out. We don’t have that extra being homosexual in common to bind us. [R1]

While an essential objective of non-medical support services is to challenge the isolation experienced by many women diagnosed with HIV, the image of Positive Women often does not reflect a sense of community. This is in line with comments that the population of HIV-positive women is very diverse, and that makes it difficult to create an image of an organization that will appeal to various segments of the female population. Despite a relatively small HIV-positive female population in Australia it is evident that having one organization to address all women’s needs is not sufficient.

Peer support: Siegel and Lekas (2002) observed that there are two dominant reactions by women to a diagnosis of HIV: to either engage with the HIV community or to continue with the pre-illness self, which results in social and/or emotional isolation. This isolation can be reduced by encouraging women to engage with the community based organizations through peer support workers. As it was observed by medical practitioners, significant barriers exist that prevent women from wanting to engage with support services as a consequence of the HIV/AIDS diagnosis.

I have several patients who do not use any support services. They come and talk only to me. Sometimes I feel that I am GP, psychiatrist and social worker all rolled into one but, of course, I feel that I don’t do these [psychiatrist and social worker] very well. They need to talk to other professionals ... but when I advise them to use these other services they appear offended, as though I am trying to pass them off to others [D5]

When asked ‘what sort of things would stop someone using a service?’ one HIV specialist remarked:

For many women it is all related to confidentiality, the fear of disclosure, who to disclose to and not having that support network that you talk about being often so good at getting together. [D2]

Despite issues relating to confidentiality, peer support services were consistently identified by the women interviewed as one of the most valued support services, particularly in the early stage of diagnosis. This importance is acknowledged by one advocate, who speaks from her experience.

It’s just that relief that you can actually pick up the phone and know you’re speaking to another woman who’s been through what [you have been through]. [WA1]

It is important to note that the most effective support-providers may be similar others; that is, individuals who themselves have successfully faced the same stressful circumstances that are currently experienced by the subject (Thoits, 1995). The importance of peer support is strongly emphasized by women in our study and, in general, respondents seek more communication with other HIV-positive women— to share information and experience, to maintain social contact and for emotional support.

...even now in Australia I kind of crave for some-to talk to other HIV-positive people with a similar perspective to mine, and there are very, very few people. There’s a guy in Sydney that I ring up, and he’s probably my best peer support, which is crazy. There’s one in Melbourne and there’s a few women in Melbourne I like and get on with but... it’s a lonely journey... I know for me I want to spend more social time with other women who are positive, and yet I can’t find them; I can’t get to them and I don’t know where they are. Positive Women doesn’t supply that need to me [R2]

Coupled with this are concerns about the evolving nature of the support services, with many current health care workers not being HIV-positive and thus not perceived as ‘similar others’.

All the peer support positions are being turned into health promotion positions, and it’s as though it’s not cool to be a peer support worker. You’re not bringing enough to the position, you’ve got to be, you know, highly qualified. [WA1]

This reflects trends across Australia, where the role of the peer support worker is subsumed by the position of a trained health worker and is inconsistent with the nature of desired service provision. This trend changes the nature of the peer support service which provides empathy from an experienced perspective in understanding the nature of the challenges that the women face.

These narratives illustrate the evolving and dynamic nature of support services needed for women through the evolution of HIV/AIDS from the pre-treatment era to the current situation where there are widely available antiretroviral treatments. Of particular importance is evidence for the need of counselling and non-medical support services following the commencement and balancing of antiretroviral treatments.

**IMPLICATIONS FOR CONSUMER THEORY:**

**RESEARCH IN HIV AREA**

This study has introduced the contemporary issues relating to support services for people with HIV in Australia and specifically highlights the dearth of information relating to women as a minority group within this population. By adopting a more flexible approach to the marketing viewpoint underscoring the design of the study, a contribution has been made to better understanding (1) consumer needs, and (2) the design and marketing of appropriately oriented non-medical services to heterosexual women with HIV/AIDS.

The results reported in this paper challenge the current understanding of services marketing; that the effect of support services depends not only on the range and variety of specific services that people receive but on more specialised features within the context of the service transaction. It is apparent that HIV-positive people, and women in particular, engage with only limited service providers.

Characteristics of support service providers, service recipients and transpired relationships, are all important elements within service delivery and have an impact upon access and use of support as well as effectiveness of such exchanges. This study demonstrates a paradox in the model of services designed for HIV-positive people. While the majority of service initiatives are developed and funded to provide various forms of emotional and instrumental support for PLWHA, there is no fit between service providers and service recipients, with clients often rejecting the value propositions made by the service provider. The customer is not a co-producer; she remains an operand resource.

The medical community is in a unique position to redress the imbalance in the provision and utilization of support services as they have privileged access to women, particularly those newly diagnosed with HIV/AIDS, who are in need of counseling, Coun-
counseling is of great importance in the earlier stages of diagnosis as it helps individuals not only accept the first exposure to the illness but also to plan their future life. Over the years counseling gives way to communication networks with HIV-positive people who have similar problems and share an understanding of the requirements and concerns of people with comparable debilitating conditions.

Engagement with a supportive HIV community was more closely oriented to women’s particular needs was found to be of great importance. However, in reality it is not so straightforward. Firstly, the population of HIV-positive women in Australia is very heterogeneous, and while women want to communicate with similar others, the diversity of the group means that they may not share any aspects of their identity beyond their HIV status. The second issue is that women perceive that they have little in common with the majority of community members, given that the support networks have been largely organized by and on behalf of the gay male community.

In general, the support services which exist are in their infancy. There is no theoretical or practical guidance on how to treat emerging support services, and it is correspondingly difficult to measure and evaluate the efficacy of those organizations.

The strategies employed by peer-support organizations require extreme flexibility and adaptability in dealing with the diverse population of HIV-positive women. HIV support organizations are, by their very nature, limited and tend to operate in a similar way to each other rather than offering distinctive services to their clients. There is no competitive incentive to sharpen the quality of services available and women who use these services do not have many options from which to choose. Some of the key aspects mentioned in this study suggest the need for further development of marketing strategies and service-centered social marketing approaches to satisfy the needs of HIV-positive women.

This highlights the paradox which marketers have to address. On one hand so many academic and practical advances have been accumulated in the theories of service and consumer research. However, when society faces the challenge of providing support services for people with terminal illnesses, it is evident that new factors posited by the environment have to be incorporated into the services model to address the needs of a new segment of consumers. This exploratory study demonstrates that the “marketplace has more to teach the scholars than scholars have to teach the marketplace” (Deighton and Narayandas, 2004, p. 20).

The problems associated with HIV/AIDS are too readily perceived as relating purely to the domain of physical health. However, the contribution that can be made from the services marketing paradigm is to overcome this major ‘short-circuit’ in the design and promotion of health care services caused by the failure to take into account consumer variables such as individual personality, socioeconomic status, existing knowledge and interests, mass media habits, and interpersonal communication networks (Bratic et al., 1981). We must add gender to this list, as it has been long overlooked. As this study reveals, such an approach will improve the design of support services and facilitate the development of gender-sensitive marketing strategies to enhance the consumption of support services by HIV-positive women.

LIMITATIONS AND DIRECTIONS FOR FUTURE RESEARCH

The process of data collection was marked by objective difficulties in recruiting women with HIV/AIDS who were willing to participate in this study. The major obstacle was that women consider their privacy to be a high priority and they were therefore reluctant to disclose their HIV status. Subsequently, the number of respondents selected to participate in this study was constrained by the scope of the project and the closed nature of the target community. However, even though the number of respondents was small, their comments and responses reveal high levels of consistency, which is important for new research directions.

Future studies could also investigate the needs of women who are caring for HIV-positive partners or children, individuals from cultural and diverse backgrounds, or on a growing elderly population who are affected by HIV/AIDS. Finally, similar research could examine the consumption practices of the heterosexual male community who, like their female counterparts, suffer from being a minority within a minority.

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