Using Verbal and Social Autopsies to Explore Health-Seeking Behaviour among HIV-Positive Women in Kenya: A Retrospective Study

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Abstract

Background

There is limited understanding of the factors that influence decisions to seek HIV care and treatment services in community settings. The aim of this study was to explore the socio-cultural and health system factors affecting health-seeking behaviour among women living with HIV (WLHIV) in resource-constrained settings.

Methods

Retrospective data were drawn from verbal/social autopsies administered to caregivers of 218 women who had died of AIDS-related illnesses at the age of 15-49 years. Information was collected on essential elements of the care-seeking process and analyzed using qualitative/quantitative techniques.

Results

Poor women were less likely to access formal health services (OR=0.2; $p<0.01$) compared to non-poor women. Socioeconomic status, poor knowledge and clear understanding of AIDS-related illness, distance to facility and transportation costs, medical pluralism, stigma, low HIV risk perception, lack of family support and health care system barriers emerged as factors contributing to delays/constraints in seeking care.

Conclusion

The findings highlight important issues that have implications for addressing challenges faced by WLHIV, including non-adherence to treatment regimen and late diagnosis of HIV.

Keywords: Verbal autopsy; Social autopsy; HIV; Women; Kenya

Background

At the end of 2010, an estimated 34 million people were living with HIV globally with sub-Saharan Africa (SSA) being disproportionately affected by the epidemic [1]. According to the UNAIDS, the region accounts for about 68% of all people living with HIV worldwide and women are mostly affected accounting for over half (59%) of all people living with HIV [1]. In Kenya, the national HIV prevalence among adults aged 15-49 years was 6.3% as of 2008-2009 [2]. HIV prevalence was twice as high among women compared to men (8% among women and 4% among men). In addition, HIV prevalence is higher in the urban than in the rural areas [3]. Heterosexual intercourse is the predominant mode of HIV transmission in the country with 44% of new infections occurring among regular or steady partners while casual sexual partners account for 20% [4]. Female sex workers and their clients account for 14%, male prisoners for 8%, men who have sex with men for 7% and injecting drug users for 4% of new infections in the country [4].Expansion of access to life-saving antiretroviral therapy (ART) in sub-Saharan Africa has enabled people to lead productive lives. In Kenya, the number of those accessing antiretroviral therapy increased from less than 10,000 in 2003 to over 430,000 in 2010 [5].

Condom use remains low in the country, in particular among married or cohabiting couples (2% women and 3% men), and is significantly lower for women than for men, independent of type of relationship [6]. While men are much more likely than women to engage in high-risk sex, they are also much more likely to use condoms when having such sex (62% of the men compared to 35% of the women) [7]. Socio-economic status is closely tied to vulnerability to HIV infection and access to health services and information: women who have higher levels of wealth and education are much more likely to use contraceptives, have knowledge regarding HIV prevention and access treatment and care services [8] [include citation]. While poverty and socio-economic inequality affects both women and men, women's subordinate status in patriarchal societies implies that they have less access to education and paid employment besides lacking control over financial and productive resources [7].

Evidence on health-seeking behaviour among people living with HIV has primarily focused on their HIV treatment experience in clinical settings [9, 10], on demonstrating the feasibility of HIV treatment in such settings [11-13], monitoring how treatment is delivered and individuals' treatment adherence [14]. A number of factors have been shown to influence health-seeking behaviour of people seeking HIV treatment and care. Previous studies have demonstrated that physical distance and accessibility of services, availability and quality of services, costs-related to services and transportation, availability of commodities and supplies, negative attitudes among health workers, fear of stigma and discrimination, low HIV risk perception and socioeconomic status are important factors that determine utilization of HIV treatment and care services [15-25]. Among people living with HIV, available evidence shows that they seek care from formal (such as government and private health facilities) and informal sources (such as traditional healers, home and over-the-counter) [26].

There has, however, been little emphasis on understanding the factors that influence decisions to seek HIV care and treatment services in community settings. The objective of this paper is to explore the socio-cultural and health system factors affecting health-seeking behaviour among women living with HIV (WLHIV) in resource-constrained settings.

Methods

Retrospective data were drawn from verbal and social autopsies administered to caregivers of 218 women who had died of AIDS-related illnesses at the age of 15-49 years. Verbal and social autopsies have been used to provide data on social, behavioural, and health systems contributors to maternal and child deaths and to provide evidence for informing health care programmers and policymakers in designing and implementing initiatives for improving maternal and child health [27]. The study was part of a project conducted by the Population Council whose aim was to evaluate the effect of the output-based aid (OBA) program being implemented in five districts in Kenya on reproductive health behaviors and outcomes. Information was collected on essential elements of the care-seeking process such as recognition of the illness, whether adequate care was provided, whether and what type of outside-the-home care was sought (informal, formal, or both), delays to formal healthcare-seeking and related constraints (e.g., lack of knowledge of danger signs of illness, seeking traditional care, lack of transportation, costs) and the quality of health care provided (from the client’s perspective). For quantitative data, descriptive statistics were used to describe the study sample, including primary caregiver’s relationship, place where care was sought, number of contacts with formal health services, place of death, household socioeconomic status, marital status, education and age. Quantitative data were analyzed using STATA ® version 10. For the bivariate analysis, Chi-square and Fisher’s Exact tests were used to test the associations between key variables of interest. Multivariate logistic regression analysis was conducted to examine the relationship between having contact with formal health services and socioeconomic status after controlling for confounding factors. Qualitative interviews were tape recorded, transcribed verbatim, translated to English and analyzed using QSR NVivo 9 Software © (International Pty 2007, Australia). Analysis of the data was guided by the pathway to survival model [28, 29] and three-delay framework [30].

Results

Quantitative analysis results

The background characteristics of the study sample are described in Table 1. The median age of the women at the time of death was 34 years (results not shown). The majority of them had primary or lower levels of education, were divorced, separated or widowed, and were from non-poor households. In addition, for the majority of the women, information was provided by their parents. With respect to access to medical care, a similar proportion of women sought care from over-the-counter (pharmacy or drug stores) and government health facilities while more than a third of the women sought care from private health facilities. Nearly two-thirds of the women had made contact with formal health services 1 to 2 times a month prior death while most died at home.

[Insert Table 1 here]

The results from bivariate analysis examining the association between the place where a woman sought treatment and socioeconomic status (poor vs. non-poor) are presented in Figure 1. Women from poor households were more likely than non-poor women to seek care from informal sources, including over-the-counter (54.2% vs. 42.4%; p=0.121), home (45.9% vs. 24.0%; p=0.002) and traditional medicine (23.0% vs. 15.0%; p=0.167). Majority of the women from poor and non-poor households sought care from government health facilities (95.5% and 90.3%; p=0.151). Besides, a similar proportion of women from both socio-economic groups sought care from private health facilities. A significantly higher proportion of women from non-poor households compared to those from poor households (9.7% vs. 1.6%; p=0.044) sought care from health facilities managed by faith-based organizations (FBO). Further analysis was also conducted to examine the association between socioeconomic status and whether a woman had any contact with formal health services one month prior to death. On average, non-poor women had contact with formal health services 2.3 times (standard deviation=3.6) compared to 1.8 times (standard deviation=2.1) among poor women (p=0.3833). A higher proportion of poor women did not have any contact with formal health services compared to non-poor women in the month before death (22.4% vs. 6.3%; p=0.001). In the multivariate logistic regression analysis, poor women were significantly less likely to have contact with formal health services (OR=0.2; p<0.01) compared to women from non-poor households (results not shown). Education, marital status and age were not significant predictors of contact with formal health services.

[Insert Figure 1 here]

Qualitative analysis results

Qualitative findings showed that a number of factors were responsible for delays and constraints to formal health care seeking.

Poor understanding of HIV-related opportunistic infections

There was poor knowledge and understanding of signs and symptoms of severe illnesses associated with HIV/AIDS among the women as reported by caregivers. Many people interpreted AIDS-related conditions as malaria prompting them to seek over-the-counter malaria medications. This often resulted in multiple uses of different types of anti-malaria drugs even in areas with low prevalence of malaria. Due to poor knowledge and lack of understanding of symptoms associated with HIV-related illnesses, it emerged that in some cases HIV/AIDS was associated with witchcraft and evil spirits. The findings showed that women sought treatment in three ways namely; (i) going to a witchdoctor or traditional medicine man, (ii) taking home-made remedies believing that it is a mild illness that will go away, and (iii) going to a health facility.

> *"The time when she was sick she stayed here at home and we brought for her the drugs. She also could buy drugs from the chemists. We thought it was normal chest complications, but it was the critical chest complications that killed her"*
>
> *"I went to see her but on asking her what the problem was she told me she had stomach ache and headache. But on telling her that I take her to hospital she refused."*
>
> *"Before she died, I messed up, as I got late in intervening as she had severe diarrhea and within that week she died, I could have taken her on Monday but I did not think it was serious. I got late and took her to the hospital on a Friday."*

Medical pluralism

Caregivers reported that the majority of women living with HIV first opted for home treatment, then purchased over-the-counter drugs, then sought care from a traditional healer, then visited a health facility before going back to a traditional healer. Perception of HIV risk and severity of illnesses determined the type of treatment sought by the women. Women in stable relationships often believed they were not infected and, therefore, sought over-the-counter medication. However, when the illnesses were severe and the other treatment options had failed then the women resorted to seeking treatment at health facilities. HIV-related stigma was also a key factor in the utilization of care and treatment. Home and traditional healers were mostly preferred by the women due to fear of stigmatization.

> *"My wife began to have body pain, then I bought for her medicine from the shop, but she never got better. I took her to xxxx Health Centre where she was treated and we came back home, but for one month, she never got well. She was rushed to xxxx district hospital and given medicine. She came back home and stayed for about 3months, and she did not get well; the stomach started swelling again. When it was swollen, instead of taking her back to the hospital, we took her to witch doctors. But one of the ladies told me to take her back to the hospital, and I took her back to xxxx district hospital, and she was tested. She came and told me she had been found with a virus."*

> *"You know in this area, when a person becomes sick, our first thought is to see a witchdoctor. So for this illness, we used to mix medical doctor, witch doctor for the first 5 years, but when she went to xxxx Hospital, it was found out she has typhoid."*
>
> *"There are the witchdoctors here who cheat people that is where she was taken. Also she could be brought a witchdoctor at home, who could tell her it is this place that is the cause. Then it was realized that is not the cause."*

Non-disclosure of HIV status

Many caregivers reported that non-disclosure of HIV status was a problem as many of them learned about the women's status from the health care providers. Besides stigma, non-disclosure of HIV status among women infected with HIV is related to what they perceive as the impact of the illness to their family. Many women did not want to burden the family financially and, therefore, opted not to seek care and treatment despite the fact that some caregivers reported that they suspected the women had HIV/AIDS. Others were psychologically affected by the likely impact the illness would have on their children and who would care for them. Most caregivers mentioned the reason for fear of the unknown for the children as the main reason women did not disclose their HIV status to their children. Women further declined hospital admission in order to take care of children.

> *"Sometimes I feel that if she was open and had said early enough, she could be alive. This is because we have another cousin who is also HIV positive and goes to hospital at xxx and has given my phone number there, so that if she is in any sort of need and I am contacted, she can be assisted immediately. But xxxx was quiet and did not disclose her problem."*
>
> *She went to the hospital and was given drugs to help her. She was also tested for HIV and told she has but she said she does not want to be admitted as she has children who will suffer and the mother is old to take care of the children.*
>
> *"She was seriously sick but could go to work while sick and after coming home she could tell me that the work was bad until I told her to leave the job and stay with us here at home. She was refusing to go to the hospital because of fear of being tested and to be told her status. But I talked to her until she agreed to go to the hospital four months later."*

Access to health services

Distance to facility coupled with transportation costs and challenges emerged as major barriers to accessing care. Caregivers reported that in some areas only a few health facilities provided HIV treatment. Due to lack of confidentiality in handling client information by facilities that were nearby, women preferred to seek care in health facilities that were further away from their homes.

> *I came home and explained to her about the illness, and told her we should begin the clinic, which we began in February 2006, and she even began going for clinics alone, but we felt it was far, because of the bus fare and the bills."*
>
> *"There are no vehicles in the area so we had to stay home."*
>
> *"So she told me to take her to the hospital, but insisted I take her to another hospital at xxxx. So we travelled on a Friday, but we found it difficult to get to the facility. It had rained badly, so the place was swampy, and we could not pass since I was using a bicycle to transport her. It was impassable; we discussed and decided to go to another facility xxxx. But we went to this other facility on a Sunday"*

Health system factors such as poor referral systems, lack of care before referral, perceived lack of providers, equipment/drugs, discrimination by providers especially towards poor clients and perceived poor quality of care were cited as reasons for low utilization of HIV-related health care services as exemplified by the following quotes:

> *"When she took the medication, she started to diarrhoea a lot, and we had been told to take her for other tests, but we did not take her. When we went there, we found there was no doctor"*
>
> *"She was given Malaria medicines as they did not have equipment to examine her"*
>
> *"The patient was referred to xxxx District Hospital because the hospital did not have supply of drugs"*
>
> *"For her the illness bothered her so much because she had no money for her treatment and at the hospital they expected money plus for the drugs. When she went to the hospital she was told to first look for money and then come back. She was ill and could not get the drugs, when she came home she could become sick and got seriously sick."*

Low HIV risk perception and other barriers to testing

Majority of the caregivers reported that low HIV risk perception in the community was responsible for women's reluctance to HIV testing. This observation was particularly common among women with only one sexual partner. Another factor that emerged as a barrier to seeking HIV testing was lack of awareness about facilities that can be trusted to maintain confidentiality of a client's HIV status. Caregivers reported a general fear in the community about a person knowing about their status. Further, women who died while pregnant due to HIV-related complications did not attend antenatal care (ANC) clinic due to fear of coercive HIV testing.

According to the caregivers, the women felt that health care providers at the ANC clinics would deny them their right to informed consent and confidentiality, hence exposing them to HIV-related stigma.

> *"My friend had a problem of coughing and back ache and her chest had pains so I used to advise her to know her HIV status, I used to tell her 'the way I see you coughing, your cough is too deep and let me take you to xxxx health facility so that you can know your status maybe its TB'[tuberculosis] but she was tough headed she didn't go. She said she is not ill, that illness is only malaria so I let her be and she got worse, so for some time she avoided me because she knew I would take her there (xxxx health facility). She wanted to go to xxxx and xxxx Health facilities and the one who took her is another lady called Florence (fictitious name).*
>
> *You know the first time she was told she was HIV positive she denied saying she is not positive; she denied up to the last moment when she died. Later there was one hospital sister who informed my brother's wife that she was HIV positive."*
>
> *"When I took her to xxxx hospital she was counselled then I took her for testing, her blood was tested when I was with her and I was told she is HIV positive after she was told she is HIV positive and by then she was severely ill she was shocked from the time she got to know her status. After being told by the provider she did not stay for long. I even had to force her to take the medicines though she would refuse."*
>
> *"I told her she was to take the medicine as the times we are in today are bad times as she is not the only one who is infected with HIV but others too have HIV but she still insisted she will not take the medicines. All the same, we took the medicine with us at home but she could take some medicine and hide others. So I spoke with her again, told her 'you know I am your mother so instead of dying and leaving your children to die, take this medicine' but she said she will not take as she knows it's her husband who has infected her with the HIV virus so her condition became worse."*

Discussion

The objective of this study was to explore the socio-cultural and health system factors affecting health-seeking behaviour among women living with HIV (WLHIV) in resource-constrained settings. Similar to previous studies [31-34], our study findings showed that the majority of caregivers are family members. This demonstrates that families play a major role of caring and supporting persons living with HIV/AIDS. Socioeconomic status was found to be a significant determinant of utilization of health care services. In particular, a higher proportion of poor women did not have any contact with formal health services one month prior death compared to women from non-poor households. These findings corroborate evidence from previous studies which found that poverty is one of the key barriers to utilization of health services [17, 19, 22].

Although the Kenya government has over the past years introduced various cost-reduction measures such as the introduction of waiver and exemption systems for HIV-related diseases, malaria and tuberculosis treatment and drugs, the implementation has been less successful. It is common for users to encounter some kind of fees for maternal and HIV and AIDS related health services and medication [35]

The findings further show that long distance and unaffordable travel costs were key barriers to clinic attendance and accessing care. Studies on barriers to utilization of HIV-related services also found that distance to facility and transportation costs were critical barriers to accessing treatment [16, 20, 21, 23]. In addition, lack of knowledge and clear understanding of signs and symptoms of AIDS-related illnesses were barriers to clinic attendance. Many of the women interpreted the symptoms as malaria-related and, therefore, sought over-the-counter malaria medications. It also emerged that in some cases HIV/AIDS was associated with witchcraft and evil spirits. This led to delays in seeking care which can have negative effect on clinical outcomes among women living with HIV. It was also evident that women who perceived themselves as having low HIV risk were reported as having not sought HIV treatment.

Similar to other studies, family and societal barriers were also cited as impediments to utilization of health services [15, 25]. Stigma was blamed for non-disclosure of HIV status and this resulted in the women delaying seeking care and treatment. Many caregivers reported that they learned about the women's status from the health care providers. These findings were also observed in studies conducted in Zimbabwe, South Africa and Tanzania, where it was noted that there was need to consider the social context of HIV status disclosure, since the social context shapes the process of status disclosure [36-38] . HIV status disclosure is important, especially for expectant women since it can inform the provision of prevention of mother-to-child transmission (PMTCT) of HIV services. Disclosure is also important for psychosocial support, treatment adherence and stigma reduction [39, 40]. Lack of family support particularly among men who forced their spouses to decline hospital admission in order to look after the children was also a barrier to accessing treatment. This finding is consistent with evidence from previous studies, which demonstrated that male involvement is an important factor in facilitating women's access to HIV-related services [41].

Socio-cultural norms and values provide the foundation upon which unequal power relations between men and women are constructed. Given the social control such norms exert over individual behaviour, including sexual and health seeking behaviour, any attempt to prevent the spread of HIV and enhance access to available treatment and care services must recognize and address harmful gender norms. Several anthropological and sociological studies have focused on understanding the cultural setting in which behaviour related to HIV/AIDS takes place [42-44]. Unequal power relations between men and women and structural violence such as poverty often transform into personal risks. The delay to seek medical care in women within the study context was largely influenced by lack of recourses and the socially constructed role of women and the only caregivers; women, therefore, prefer attending to socially constructed roles to seeking medical care. The findings show that the individual risk of women and health seeking behaviours are influenced by wider contextual factors such as poverty, sexism and structural violence especially in rural Kenya where women are disproportionally affected in wealth and power

Health care system barriers including negative experiences with health care providers, poor referral systems, perceived lack of providers, drugs and equipment and perceived poor quality of care were mentioned by caregivers as factors that discouraged the women from seeking care from public health facilities. These factors have been cited by previous studies as contributors to irregular or delayed utilization of HIV-related services [15, 16, 18, 20, 23-25].

Although HIV testing is critical in HIV prevention programming, only a small proportion of those infected with HIV in Kenya are aware of their status (16%), significantly limiting opportunities for prevention, treatment and care [6]. However, there has been an enormous expansion of HIV testing and counselling (HTC) services in the country: the number of Voluntary Counselling and Testing (VCT) sites, for instance, increased from 3 in 2000 to 960 in 2007 [6]. The increased integration of provider-initiated testing and counselling (PITC) into antenatal care services has resulted in more women being tested for HIV. While integration of HIV testing into antenatal care is an important way to enhance access and ensure that HIV-positive women can fully exercise their reproductive rights, it is important that testing is accompanied by adequate counselling and respect for clients' right to informed consent and confidentiality. As reported by caregivers in our study, coercive testing not only alienates women from the health system, but also creates social distances between the women and the local community, despite the fact that the community is an important social capital required by the women. A national health workers survey conducted in Kenya in 2005 showed that 20% of health workers found it acceptable to test patients without their knowledge [45]. This calls for proper training of health workers on HIV testing and counselling guidelines and procedures.

The findings also showed that medical pluralism was a common practice among the women living with HIV. The majority of women living with HIV first opted for home treatment, then purchased over-the-counter drugs, then sought care from a traditional healer, then visited a health facility before going back to a traditional healer. Evidence from previous studies also showed a similar pattern [26]. Key determinants of medical pluralism were level of perceived risk of HIV infection and severity of illnesses.

This study had some limitations. Due to the fact that the respondents were the main caregivers of the deceased women, it was possible that the data may have been affected by different types of biases, including recall bias of past events and likelihood of providing socially desirable answers to sensitive questions.

Conclusion

Universal access to HIV services is a key agenda in the global and national debate in the fight against HIV/AIDS that seeks, among other things, to reduce HIV-related illnesses and deaths through universal access to treatment for people living with HIV [46, 47]. The findings of this paper highlight important issues that have implications for addressing challenges faced by women living with HIV, including non-adherence to treatment regimen and late diagnosis of HIV. Being poor, poor knowledge and lack of understanding of AIDS-related illness, long distance to facility and transportation costs, medical pluralism, stigma, perceived low risk of HIV infection, lack of family support and health care system barriers emerged as factors contributing to delays/constraints in seeking care. These factors have negative consequences for patient outcomes and may, overall affect the effectiveness of national HIV care and treatment programs. HIV programs need to find ways of addressing these barriers in order to increase utilization of appropriate services. Health planners and policymakers need to adopt multi-pronged approaches when designing policies and programs for improving access and utilization of HIV-related services. For example, provision of subsidies as part of the national social safety-net strategy can help in addressing financial constraints associated with transportation costs. Proper training for health care providers and adequate supply of drugs, supplies and equipment in the public health systems is critical in addressing some of the challenges that were highlighted in the paper.

Author's contribution

RN: Involved in the conceptual design of the study, data collection, data analysis, drafting, re-organizing and overall revision of the manuscript

JK: Involved in data analysis, drafting, re-organizing and overall revision of the manuscript

FO: Involved in the revision of the manuscript

CW: Conceptual design of the study and revision of the manuscript

All authors read and approved the final manuscript.

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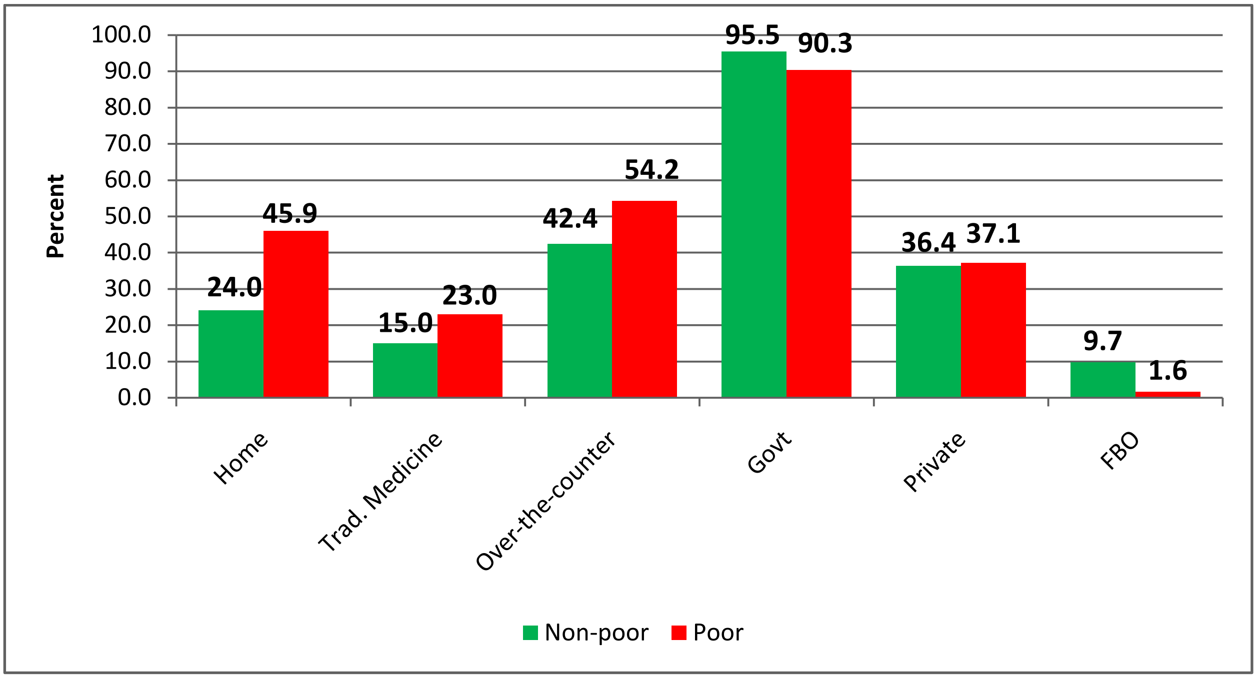
Table 1: Descriptive statistics of study sample

Variable	Women (N=218)	
	N	%
Age		
19-29 years	67	31.0
30-39 years	103	47.7
40+ years	46	21.3
Education		
Primary and below	166	77.9
Secondary and higher	47	22.1
Marital status		
Single	66	30.3
Married	57	26.2
Divorced/separated/widowed	95	43.6
Household socioeconomic status		
Poor	62	28.7
Non-poor	154	71.3
Relationship of primary caregiver		
Parent	109	50.0
Spouse	27	12.4
Brother/sister	54	24.8
Children	12	5.5
Other relative	11	5.1
Not related	5	2.3
Place where care was sought[a]		
Home	66	30.4
Traditional healer	37	17.1
Over-the-counter	97	45.8
Government health facility	96	45.3
Private health facility	80	36.7
Faith-based facility	16	7.3
Number of contacts with formal health services a month prior to death		
None	22	10.8
1-2 times	132	65.0
3 and above times	49	24.1
Place of death		
Home	130	60.5
Health facility	80	37.2
Other place	5	2.3

[a] multiple responses

Figure 1: Type of care sought by socioeconomic status



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