RESEARCH ARTICLE

Exploring health seeking behaviour among incidentally diagnosed HIV cases in Rawalpindi, Pakistan: A qualitative perspective

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Abstract

Objective: To identify the determinants of health-seeking behaviour among incidentally diagnosed cases of HIV and to explore the patterns of care seeking behaviour among these HIV infected persons.

Method: The qualitative study based on the grounded theory was conducted from February to September 2019 at the Armed Forces Institute of Transfusion, Rawalpindi, Pakistan, and comprised incidentally diagnosed new cases of human immunodeficiency virus. Data was collected using in-depth interviews to understand how local environments and settings impact healthcare-seeking behaviour. Data was analysed using the constant comparison method.

Results: Of the 12 patients, 10(83.3%) were male, 1(8.3%) female and 1(8.3%) transgender. The mean age of the sample was 31±5 years. Of the total, 10(83.3%) patients were receiving free antiretroviral treatment from government hospitals in Rawalpindi/Islamabad, while 2 (16.7%) opted for some alternative form of healthcare. Ten (80%) were married and were carrying the diagnosis for >6 months. Processing of human immunodeficiency virus status, value placed in one's own health, experiences with healthcare provider and medication-related factors were the main themes that emerged from the data. Better counselling services, free-of-cost medication, positive patient-provider relationship and social support were the key players, while non-disclosure due to fear of stigma and beliefs about the disease were the main stumbling blocks.

Conclusion: Value placed in one's own healthcare and thus the need for healthcare services, regardless of social norms, cultural reservations and personal beliefs, was the most important factor affecting the healthcare-seeking behaviour of human immunodeficiency virus patients.

Keywords: Grounded theory, Health-seeking behaviour, Human immunodeficiency virus, HIV. (JPMA 72: 2453; 2022)

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Introduction

Early human immunodeficiency virus (HIV) treatment is important for newly-diagnosed patients because delays lead to worse clinical outcomes.[1] The majority of people living with HIV (PLHIV) in developing countries do not start or continue their antiretroviral treatment (ART), leading to transmission of the disease in the general population.[2]

While the national HIV prevalence is 0.1%, the Pakistan HIV epidemic has been concentrated, with more than 5% prevalence among one or more important key populations,[3,4] as it is in other parts of Asia. Although healthcare-seeking behaviour (HSB) has been studied widely, there is paucity of literature on the subject in Pakistan, especially on the HSB of newly-diagnosed HIV patients due to stigma as well as the cultural and religious concepts about the disease being related to immoral set of behaviours. Existing evidence from the developed world is not directly applicable to Southeast Asia's resource-limited and culturally diverse environments. It is alarming that treatment initiation and adherence to HIV treatment in Pakistani PLHIVs is among the lowest in Asia.[5] A study conducted in Pakistan in 2016 also showed an increase in seroprevalence of HIV in blood donors.[6] Understanding why patients start or fail to start treatment and care needs an explanation and understanding of complicated HIV-related healthcare-seeking actions affected by multi-level factors.[7] In this context, a qualitative study design provides rich contextual data to explain and better define social patterns associated with behaviour and the manner in which individuals and communities have adapted to HIV in their lives.[8] The current study was planned to understand the HSB and what treatment options the newly-diagnosed patients opt for once they receive the news of being HIV-positive.

Subjects and Methods

The qualitative study was conducted from February to September 2019 at the Armed Forces Institute of Transfusion (AFIT), Rawalpindi, Pakistan, and comprised

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incidentally diagnosed new cases of human immunodeficiency virus. Approval was obtained from the ethics review board of AFIT which is the largest blood transfusion centre in Rawalpindi-Islamabad region. The sample was raised using purposive sampling technique from among those who came to AFIT for replacement blood donation. Those included were individuals regardless of gender aged >18 years who were positive on nucleic acid amplification testing (NAT) as per the World Health Organisation (WHO) guidelines,[9] and had been diagnosed within the preceding one year. Those who were unapproachable, in denial of their disease and having advanced disease were excluded. After taking written informed consent from each subject, data was collected using in-depth interviews to understand how local environments and settings impact HSB.

A semi-structured interview guide with open-ended questions was used. The main questions were; After getting diagnosed with HIV, how did you decide about your treatment options/referrals? What did you do? Did you go to the referral centre? If not, where did you go/what did you do? After how many days? Each interview lasted 40-50 minutes and all interviews were audio-recorded. The recorded interviews were transcribed verbatim, and then translated into English. A 10% back-translation was done for quality control. The transcribed data was read and reviewed to ensure understanding and was then compared with the original audio-records for accuracy. All transcripts were analysed manually and coded. Data analysis was conducted manually using a constant comparative method of grounded theory approach, with three levels of open, axial and selective coding.[10] New codes were added as necessary. Once the themes were established, the transcripts were re-read to ensure that the themes appropriately reflected the content of the data.

To ensure methodological rigour, the interview transcripts were initially analysed by two researchers independently to establish patterns and descriptive codes from the participants' responses and to reduce the possible bias. Peer debriefing was undertaken with Western-based team members to enhance transferability and credibility. The members observed both data and theory from an outsider's viewpoint and offered their observations and perceptions based on their experiences. Standards for Reporting Qualitative Research (SRQR)[11] guidelines were used to express the findings.

Results

Of the 12 patients, 10(83.3%) were male, 1(8.3%) female and 1(8.3%) transgender. The mean age of the sample was 31±5 years. Of the total, 10(83.3%) patients were receiving free antiretroviral treatment from government hospitals in Rawalpindi/Islamabad, while 2(16.7%) opted for some alternative form of healthcare. Most of them were married and were carrying the diagnosis for >6 months.

Interrelated concepts were integrated to develop laws of general understanding by deciding what, why and how patients chose treatment and how individuals, families and community support was needed (Figure). The core category identified from data analysis of all the interviews was "Realising the value of health". Value placed in one's own healthcare and thus the need for healthcare services regardless of social norms, cultural reservations, and personal beliefs, was the most important factor affecting the HSB. The main themes that emerged were internalisation of HIV status, value placed in one's own healthcare, experiences with healthcare provider (HCP) and system and medication-related factors. Sub-themes were also developed (Table).

The first theme was internalising the HIV-positive status. Interviews indicated that psychological issues, such as negative emotions, including fear after diagnosis, shame along with stigma, were important factors in processing the information of being positive and ultimately deciding about the initiation of treatment. Non-acceptance was an obstacle to disclosure of HIV status since disbelief, perceived stigma, and fear of adverse judgment may force PLHIVs to conceal their positive status. The majority of participants 11(91.6%) expressed their fears and worries about being stigmatised.

P2, M: "People generally do not know much, neither understand the disease."

Table: Themes and subthemes emerging from study data.

Themes	Sub Themes
Internalisation of an HIV positive status	• Stigma and non-disclosure
	• Shame /guilt
	• Depression
	• Feeling of helplessness
	• Lack of symptoms
	• Family responsibilities
Value placed in one's own health and care	• Spirituality and self-care
	• Beliefs and misbeliefs about disease
	• Social support
	• Alternative Medicine preference
Experiences with Health care Provider and system	• Positive Attitude and counselling by health care provider
	• Satisfaction with HCP and services provided
Medication Related Factors	• Side-effects of ART
	• Improvement of health

HIV: Human immunodeficiency virus, HCP: Healthcare provider, ART: Antiretroviral treatment.

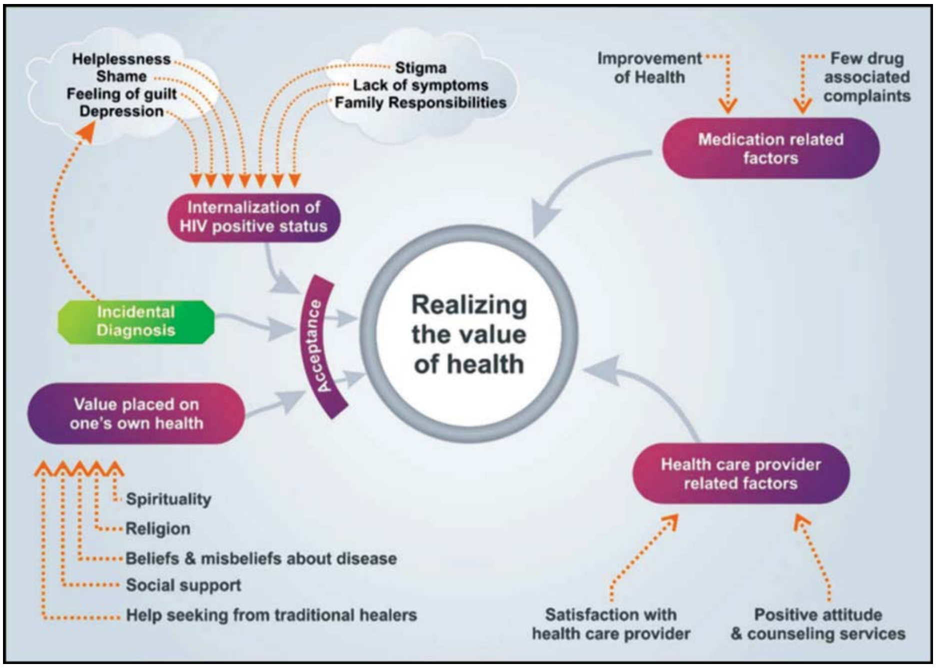

Figure: Grounded theory of healthcare-seeking behaviour.

It was difficult to distinguish whether respondent's fears and emotions were based on their past experiences or general perceptions of how others affected by HIV were treated in the community.

Disclosure was an important factor with respect to stigma and HSB. Participants were careful in revealing their status as they were afraid of being stigmatised. They recognised stigma in the form of being rejected or disliked by their parents, family members, friends or other members of society.

Because of this nondisclosure, it was difficult for patients to start treatment and visit healthcare centres for getting the required medication.

P7, SM: "I don't want to be seen by anybody at the health centre clinic for HIV. If any of my acquaintances sees me there, they will doubt that something is wrong even if I deny it to them. What will they think of me?"

The perceived need for and faith in healthcare benefits was influencing whether or not people decided to opt for professional care. This was especially obvious where people did not feel unwell, had no symptoms associated with HIV and did not recognise their HIV status as they were apparently healthy. Almost all 11(92%) of the interviewed patients were asymptomatic. They were not having any complaints or symptoms which can be related to HIV infection.

P3, M: "I feel perfectly fine at this time and have felt fine also when I was diagnosed 9 months ago. This was a shock for me as I didn't feel anything physically wrong with me."

Majority 10 (80%) of participants had little interest in knowing more about the disease apart from what the doctors told them. This was probably due to the perceived feeling of helplessness after being diagnosed with a chronic stigmatised disease requiring lifelong medication. Many of them 8 (66.6%) had only heard the name of HIV and knew nothing about the disease other than its sexual transmission.

P9, M: "I just trust Allah. He will forgive me for my sins. I just pray to Allah and ask for His forgiveness. What good will it do to know more about the disease? I am already taking medicines so what use is the knowledge about it?"

The second theme was value placed in one's own health and care. After the processing of HIV status, the participants initiated ART, but the therapy also included spirituality and self-care, dependence on social support, beliefs and misbeliefs about the disease, and included preference for alternative medicine in case of 2(16.7%) patients.

Many of the participants 5(41.7%) believed that the disease was from Allah. They believed that regular prayers and some religious rituals will cure the disease. Patients also believed in the power of Holy Scriptures to cure the disease.

It was evident that sociocultural factors had a strong impact on HSB, especially regarding the beliefs and misbeliefs about the disease. One of the patients believed he was a victim of black magic.

P10, M: "I know that my sister-in-law is jealous of me and my mother, and that is why she has sought help from a peer and done black magic on me with the help of her father who is also a relative of mine. This was her father's disease which has been transferred to me by black magic. I know with 100% surety because I am a strong and stout man and have never fallen ill before."

Another patient believed that the disease cannot be transmitted by human contact and will be cured by itself. Only 2(16.7%) patients accepted that the disease had been a result of their lifestyle and had no misbeliefs about the mode of transmission or cure of the disease.

Many of the participants 5(41.7%) believed that the disease is given by Allah and it was Allah's will for them to have this disease. They believed that if they regularly said their prayers, especially the late-night Tahajjud, and performed some religious rituals, like Wazeefas, they will be cured of the disease, though they intended to continue medication as well. This was identified as an HSB facilitator.

P5, F: "Me and my husband both get up late in the night and say our Tahajjud prayers and then recite Surah Rehman from the Quran every day. We will keep on doing this for 40 days, just as we have been told to, and pray to Allah to cure us of this infection. We are hopeful that we both will be cured eventually."

Most participants 10(83.3%) did not believe in treatment by traditional healers. However, 2(16.7%) respondents preferred the use of alternative treatment. As one respondent put it, P4,M: ''I am not really too much interested in treatment with allopathic medicine." The respondent had not started the treatment in the first place. Besides, 1(8.3%) patient had discontinued ART after a month. Interestingly, 2(16.7%) other patients had gone to spiritual healers, but were disappointed to know that the healers had never heard of HIV.

P10, M: "I know that this disease cannot be cured by medication. Only my spiritual leader, my peer sahib (faith-healer) can cure it. So I went to him and he recited some holy verses on me and I felt as if I am in the air. He has asked me to come to him every two days for 40 days and that I need no tablets to get rid of this infection."

The third theme was experiences with HCPs and the system. HSB was affected by HCP-related factors, including attitude towards the patients, counselling and patients' satisfaction with their respective HCPs. Counselled patients with focus of education on early initiation led to the initiation of treatment as soon as on the same day of being diagnosed.

P6, M: "When I came to know that my blood is positive for HIV infection, I became worried, but then the doctor called me and started telling me about the disease. He told me everything there is to know about it and counselled me about its treatment as well. He answered all of my questions very patiently and offered his help to me any time I wanted. His words relieved my tension a lot."

P9, M: "I am very satisfied with the doctor in the HIV clinic. I believe that he is guiding me right, and doing whatever he can in his professional capacity to treat me. He also informs me of the latest updates in HIV treatment whenever I go to him."

Gender difference in doctors' attitude was also observed by the patients, with male doctors being more considerate and understanding than the female doctors.

The final major theme emerging from the data was medication-related factors. Many patients 7(59%) experienced side-effects after starting treatment, which settled after a few days. Among the patients, 1(8.3%) discontinued the treatment after experiencing side-effects and opted for alternative healthcare options, while 1(8.3%) patient also complained of side-effects, but did not stop medication.

Discussion

Findings showed the complicated interrelationship involving personal, social, cultural, psychological and economic variables that affected the HSB of the respondents. Almost all the patients struggled in accepting the diagnosis, especially those who were symptom-free. The responses were similar to what has been reported in a study done in Africa[12] in which patients reported a state of disbelief and distrust after getting diagnosed.

Although not directly recognised and explicitly acknowledged, many participants encountered an internal battle, citing stigma as a disincentive to treatment initiation. Many studies have highlighted stigma as the most important factor affecting the HSB of PLHIVs.[13,14] Besides damaging individual's family, personal and financial life, the HIV stigma is quoted as a significant obstacle to access to prevention and treatment facilities.[15] Stigma as a presumed obstacle to HSB is compatible with results from other research involving identification and discrimination against PLHIVs as an obstacle to HIV care.[14,16]

Internalised stigma and shame can be correlated more closely with affective and behavioural health and wellbeing. This leads to feeling of helplessness in patients as evident from the current findings. This helplessness was also found to be correlated with low health literacy about the disease. Studies have shown that people with low health education have less awareness of HIV-related diseases,[17] are less likely to take[18] and adhere to ART.[19] In the current study also, patients were not interested in getting more knowledge as they had the feeling that knowing more about the disease will do them no good. These findings emphasise the importance of health literacy in the management of such diseases as poor health literacy has been called a "silent epidemic" that threatens the functioning of health systems worldwide.[20]

In the current study, the health status at the time of diagnosis was not found to be correlated with the decision to start medication. A number of studies have identified the patient's health status at the time of diagnosis as leading to the patient's decision to seek treatment.[21] Fox et al. found that after diagnosis, "feeling great'' was associated with lower care contact levels.[22] The reason for these contradictory results is that the treatment for PLHIVs is provided free of cost in Pakistan, and, secondly, almost all the patients were counselled by their physicians which might have motivated them to start treatment despite having no physical symptoms of the disease.

A particularly worrying false belief among the participants was that spiritual healers can cure HIV infection with prayers, hampering treatment initiation. Similar results were obtained in a study done in South Africa where patients believed in taking both traditional medicines and ART concurrently.[23] These results are contradictory to the results of studies conducted in Southeast Asian countries in which about 31-78% of PLHIVs used alternative medicines.[24]

There was an average level of discriminatory attitudes among HCPs in many surveys.[25] However, study participants stated that health workers were friendly with them. The assumption is that HCPs gain more experience and familiarity with HIV and allied complications by collaborating with PLHIVs and thus develop a greater ability to provide good care for patients. This finding was similar to that of an Indian study.[26]

The feeling of being better than before while on ART was also reported as a facilitator of compliance and adherence to ART by the participants of the current study, which has been reported earlier as well.[27] Side-effects have been quoted to be a reason for discontinuing treatment in HIV patient in other studies.[28] This may be due to the psychological impact after taking medicines or probably due to decreased cluster of differentiation 4 (CD4) count after the treatment.

The current study has its limitations. The responses of the patients may have been affected by their feeling of social desirability. Though no significant differences were found based on gender, the study results are limited by underrepresentation of females due to low prevalence and stigma. Besides, this was a single-centre study which may also restrict its generalisability.

The current study can help the national and international communities understand the challenges of implementing ART in developing countries. Better plans and policies can be formulated together to ensure that ART is available and is started in a timely manner throughout Pakistan as well as in other developing countries.

Conclusion

The themes illustrated the complex domains controlling and affecting HSBs among newly-diagnosed HIV cases. Better treatment facilities, free medication, positive patient-provider relationship and counselling were identified as key players for a better HSB. Non-disclosure due to fear of stigma and beliefs about the disease were the stumbling blocks for healthcare seeking.

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References

1. Robertson M, Wei SC, Beer L, Adedinsewo D, Stockwell S, Dombrowski JC, et al. Delayed entry into HIV medical care in a nationally representative sample of HIV-infected adults receiving medical care in the USA. AIDS care 2016;28:325-33. doi: 10.1080/09540121.2015.1096891.
2. Koirala S, Deuba K, Nampaisan O, Marrone G, Ekström AM. Facilitators and barriers for retention in HIV care between testing and treatment in Asia—A study in Bangladesh, Indonesia, Lao, Nepal, Pakistan, Philippines and Vietnam. PLoS One 2017;12:e0176914. doi: 10.1371/journal.pone.0176914.
3. NACP. Integrated Biological & Behavioral Surveillance in Pakistan 2016-17. [Online] 2019 [cited 2019 September 25]. Available from URL: https://nacp.gov.pk/repository/whatwedo/surveillance/Final%20IBBS%20Report%20Round%205.pdf
4. UNAIDS. The Gap Report. Geneva, Switzerland. UNAIDS, 2014. [Online] 2014 [Cited 2019 December 16]. Available from URL: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_Gap_report_en.pdf
5. National Aids Control Program Pakistan. Homepage. [Online] 2019 [Cited 2019 November 7]. Available from URL: https://nacp.gov.pk
6. Ghani E, Rathore MA, Khan SA. Trends in human immunodeficiency virus seroprevalence in blood donors in northern Pakistan. Public Health 2016;131:71-4. doi : 10.1016/j.puhe.2015.10.010.
7. Kaufman MR, Cornish F, Zimmerman RS, Johnson BT. Health behaviour change models for HIV prevention and AIDS care: practical recommendations for a multi-level approach. J Acquir Immune Defic Syndr 2014;66(Suppl 3):s250-8. doi: 10.1097/QAI.0000000000000236.
8. Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review-a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy 2005;10(Suppl 1):s21-34. doi: 10.1258/1355819054308530.
9. WHO. Consolidated guidelines on HIV testing services. [Online] 2015 [Cited 2019 February 13]. Available from URL: https://www.who.int/publications/i/item/9789241508926
10. Glaser BG, Strauss AL. The Discovery of grounded theory:

Strategies for Qualitative Research, 1st ed. New York, USA: Routledge; 2017.

11. O Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. Acad Med 2014;89:1245-51. doi: 10.1097/ACM.0000000000000388.
12. Saki M, Kermanshahi SM, Mohammadi E, Mohraz M. Perception of patients with HIV/AIDS from stigma and discrimination. Iran Red Crescent Med J 2015;17:e23638. doi: 10.5812/ircmj.23638v2.
13. Horter S, Thabede Z, Dlamini V, Bernays S, Stringer B, Mazibuko S, et al. "Life is so easy on ART, once you accept it": Acceptance, denial and linkage to HIV care in Shiselweni, Swaziland. Soc Sci Med 2017;176:52-9. doi: 10.1016/j.socscimed.2017.01.006.
14. Chan BT, Tsai AC. HIV stigma trends in the general population during antiretroviral treatment expansion: analysis of 31 countries in sub-Saharan Africa, 2003-2013. J Acquir Immune Defic Syndr 2016;72:558-64. doi: 10.1097/QAI.0000000000001011.
15. Nakigozi G, Atuyambe L, Kamya M, Makumbi FE, Chang LW, Nakyanjo N, et al. A qualitative study of barriers to enrollment into free HIV care: perspectives of never-in-care HIV-positive patients and providers in Rakai, Uganda. Biomed Res Int 2013;2013:470245. doi: 10.1155/2013/470245.
16. Rathore MA, Rashid Z, Khushk IA, Rathore MA, Mashhadi SF, Ramzan N. Factors Affecting Health Care Seeking Behaviour among Newly Diagnosed HIV Cases in Rawalpindi, Pakistan. Ann King Edw Med Univ 2021;27:269-275. doi: 10.21649/akemu.v27i2.4572
17. Khan R, Bilal A, Siddiqui shakira H. Knowledge about hiv and discriminatory attitudes toward people living with HIV in Pakistan. Pak J Public Health 2019;9:37-41. doi: 10.32413/pjph.v9i1.237
18. Rathore M, Rashid Z, Mashhadi S, Rathore M, Sharif I. Health care seeking behaviour among newly diagnosed human immunodeficiency virus cases in Rawalpindi. Pak Armed Forces Med J 2020;70:1522-7.
19. Wawrzyniak AJ, Ownby RL, McCoy K, Waldrop-Valverde D. Health literacy: impact on the health of HIV-infected individuals. Curr HIV/AIDS Rep 2013;10:295-304. doi: 10.1007/s11904-013-0178-4.
20. Marcus EN. The silent epidemic–the health effects of illiteracy. N Engl J Med 2006;355:339–41. doi: 10.1056/NEJMp058328.
21. Sanga ES, Mukumbang FC, Mushi AK, Lerebo W, Zarowsky C. Understanding factors influencing linkage to HIV care in a rural setting, Mbeya, Tanzania: qualitative findings of a mixed methods study. BMC Public Health 2019;19:383. doi: 10.1186/s12889-019-6691-7.
22. Fox MP, Mazimba A, Seidenberg P, Crooks D, Sikateyo B, Rosen S. Barriers to initiation of antiretroviral treatment in rural and urban areas of Zambia: a cross-sectional study of cost, stigma, and perceptions about ART. J Int AIDS Soc 2010;13:8. doi: 10.1186/1758-2652-13-8.
23. Appelbaum Belisle H, Hennink M, Ordóñez CE, John S, Ngubane-Joye E, Hampton J, et al. Concurrent use of traditional medicine and ART: Perspectives of patients, providers and traditional healers in Durban, South Africa. Glob Public Health. 2015;10:71-87. doi: 10.1080/17441692.2014.967709
24. Peltzer K, Pengpid S. Utilization and practice of traditional/complementary/alternative medicine (T/CAM) in Southeast Asian nations (ASEAN) member states. Stud Ethno-Med 2015;9:209-18. doi: 10.1080/09735070.2015.11905437
25. Harapan H, Khalilullah SA, Anwar S, Putra RP, Zia M, Novianty F, et al. HIV-related stigmatized attitudes among health care providers in Aceh, Indonesia: The findings from a very low HIV case-load region. Polish Ann Med 2015;22:74-81. doi: 10.1016/j.poamed.2015.05.003
26. Maheshwari P, Sunny M. A Prospective Study on the Knowledge, Attitude and Perception on HIV/AIDS among the Nursing and other Healthcare Professionals. Res J Pharm Technol 2016;9:1403-6. doi: 10.5958/0974-360X.2016.00271.7
27. Bezabhe WM, Chalmers L, Bereznicki LR, Peterson GM, Bimirew MA, Kassie DM. Barriers and facilitators of adherence to antiretroviral drug therapy and retention in care among adult HIV-positive patients: a qualitative study from Ethiopia. PLoS One 2014;9:e97353. doi: 10.1371/journal.pone.0097353.
28. Moradi A, Alavi SM, Fahimfar N, Haghighizadeh MH, Mirzaei B. Study of determinants of adherence to antiretroviral treatment among HIV patients covered by Ahwaz Jundishapur University of Medical Sciences. Int J Med Res Health Sci 2016;5:477-84.