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Original Article

Fertility Desire in Iranian Women with HIV: A Qualitative Study

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Abstract

Background: Childbearing is a cause of concern for women living with HIV. To improve reproductive right of women with HIV and prevent the spread of HIV; it is needed to understand fertility experiences of infected women with HIV. The aim of this study was to explore fertility intentions and experiences of HIV-infected women in Iran.

Methods: Totally, 15 in–depth interviews were conducted with HIV- infected women who were at reproductive age and had referred to Imam Khomeini Hospital Consultation Center for Clients with Risky Behaviors in Tehran, Iran. Data were analyzed using the conventional content analysis method in MAXQDA 10.

Results: Analysis of the meaning units of interviews showed themes in describing of fertility desires of HIV women as follows: 1) Motherhood as a way for stability of life; 2) Uncertainties about the future; and 3) Unpleasant experience of pregnancy and delivery. This theme has three sub-themes as stigma, discrimination and weakness in health care system.

Conclusion: Health care provider and community should respect the right of infected women and inform them on sexual and reproductive health.

Keywords: Fertility, Desire, HIV, Qualitative study, Iran

Introduction

Childbearing is a cause of concern for women living with HIV, due to the risk of HIV transmission to children and sexual partners (1-5). With the introduction of HAART (Highly Active Antiretroviral Therapy) in 1995, two prominent concerns about childbearing have been significantly decreased; mother-to-child transmission of HIV (MTCT); and concern about not living long enough to grow up and develop a child by mother. With HAART, mother to child transmission rates could be reduced from 25% to only 1% to 2% (6). Having enjoyable sexual relationship and growing up children are among the rights of people living with HIV. However, there are still some debates on making informed decision on the sexual and reproductive health of infected people and it is even ignored in some parts of world (7, 8). Many health care workers do not recommend childbearing for women living with HIV (3). Understanding fertility desire in infected women is significant because we provide fertility counselling, family planning to protect fetus, partners and their own health; and, support children born from infected people (9). The reproductive decisions made by HIV-infected women have long-term consequences for the survival and wellbeing of their families and society (10).

Number of people living with HIV in Iran according to registered persons was 28600 that 70% of the patients are men and 30% were women.

45.8% of infected people were in the age group 25 to 34 years and were sexually active. Causes of infection were 45.7% from injection drugs, 37.9% from sexual transmission, 3% from mother to child transmission and 13.5% transmission ways are unknown (11). In Iran, most of prevention programs focused on injection drug users and less attention is given to reproductive needs of people living with HIV. Recent data reveal increasing sexual transmission. It is important to understand the fertility desires and intentions of HIV-positive women in order to develop programs to support them and their current and future participants in planning safer pregnancies that protect the health of the women, their partners and their children. To improve reproductive rights of women with HIV and prevent the spread of HIV, it is needed to explore and describe experiences of fertility desire of women with HIV within their local context. Given that few studies were conducted on this issue, we decided to carry out qualitative research to understand women's desire with HIV for childbearing.

Methods

This was a qualitative study, based on a content analysis approach. We conducted in-depth, semi-structured interviews. The intent of the interviews was to obtain narratives describing how participants had experienced fertility. Participants shared their understanding of situations about fertility desire that they had countered during their infection with HIV.

Sample/Participant

This study included 15 in- depth interviews taken from women with HIV in the age of fertility who were referred to Imam Khomeini Hospital Consultation Center for Clients with Risky Behaviors in Tehran, Iran. Data collection started in November 2013 and ended in March 2014. These women were selected in consultation with midwife of behavioral Counselling Centre.

The criteria of women to be included in this study were: 1) Age between 15-49 yr 2) HIV Positive 3) Have sexual relation with partner 4) lack of infertility problems.

Data Collection

Approval of Ethics Committee was received from Tehran University of Medical Science in 2 February 2014 with NO: 92/د/130/2639. All participants were informed about the purposes and the methods of this study. Informed consent from all respondent was an important aspect of this research project and those who agreed to participate in the study provided signed written consent. Before interviews, they were informed that they had a right to refuse to participate in the interview and this right could be exercised at any time without having any negative impact on the services delivered to them.

The data were collected by semi-structured, open-ended interviews. Participants were selected by purposeful sampling with maximum variation. Initially, first interview was conducted by first and corresponding authors, after approval by the other members of the research team next interviews were conducted. Interviews continued until saturation of the data was reached and the researcher was no longer obtaining any new data. All women were interviewed in a private room in the positive club in the Iranian Research Center for HIV. Only interviewer and participant present in place of interview. Interviews with women with HIV took from 45–90 min on average.

An interview questions was developed during interview and research team opinions (Table 1). Interviews were tape recorded with permission. The interviewer took field notes immediately after each interview. During interview each participant responds to questions about age, education, marital status, job, and husband/partner HIV status, children, time of diagnosis, transmission, and family income.

Data Analysis

First, we listened to each recorded interview and transcribed the content. Then we checked this process by listening to a random selection of interviews, comparing what she heard to the transcribed document, thus checking for accuracy.

Table 1: Sample of interview questions

Can you please tell me about your diagnosis experience?
Please describe what fertility means to you?
Do you want to have a child/ more children in the future?
How do you think the experience of being diagnosed with HIV has impact their fertility desire?

Data were analyzed using the method of Data analysis performed on guide by Graneheim and Lundman (12); the following steps were taken to analyze the collected data:

1- Transcribing the interviews verbatim and reading through several times to get a general sense of the material.
2- Dividing the text into meaning units, which are key phrases in the text.
3- Abstracting the condensed meaning units and outlining with codes.
4- Grouping codes into sub-categories and categories based on comparisons regarding their similarities and differences.
5- Re-organizing and merging into subthemes and overarching themes as the expression of the latent content of the text Participant. Data were analyzed with MaxQDA 10 software**.**

Rigor

In this study, various aspects of trustworthiness have been observed. Credibility was established through member checking, peer checking, and prolonged engagement. Member checking was done by asking the respondents to approve the transcripts and emerging codes from the interviews. Research teams consulted with each other to deal with any ambiguities in the coding process, categories and themes. In areas where the two researchers did not agree, definitions were clarified and discussion continued until consensus was reached. For addressing transferability, the complete set of data analysis documents are on file and available upon request.

Results

Participant demographic information is summarized in Table 2.

Table 2: Characteristics of the study population

Age (yr)	
22-27	6
28-33	3
34-39	5
40-45	1
Marital Status	
single	1
Married	12
Divorced	2
Education	
Primary or less	2
Secondary	4
Diploma	7
University	2
Job	
House keeper	11
Employee	2
Unemployed	1
Informal Job	1
Transmission	
Out of marriage sexual relationship	3
Infected husband	9
Unknown	3
Time Of Diagnosis	
<1	1
1-5	8
6-10	3
11-15	2
Partner/Husband Status	
Negative	5
Positive	10
Currently Living Children	
0	5
1	6
2	3
3	1
Infected Child	
0	11
1	4
Family Income	
Good	3
Average	8
Bad	4
Fertility Desire	
Yes	3
No	12

Analysis of the meaning units showed the following themes in describing of fertility intentions of HIV women.

1- Motherhood as a way for stability of life
2- Uncertainties about the future
3- Unpleasant experience of pregnancy and delivery. This theme has three sub themes 1) stigma 2) discrimination 3) weakness in health care system (Table 3).

Table 3: Summary of the Themes, Sub-Themes and codes

Themes	Subthemes	Codes
Uncertainty about the future	-	Fearing to growing up as an orphan
		Fear of pregnancy intolerance
		Fearing that the child to be infected
		husband's fearing that the child to be infected
		Fearing that the mother's disease will be disclosed to child
		Fearing that the child to be stigmatized for his/her illness
		Economic problems in the providing the child expenditures
		Contractive behaviors in health providers
Unpleasant experience of pregnancy and delivery	Stigma	Pregnancy with stress
		Feeling guilty to become pregnant
		Blame hospitals staff because of being pregnant
		Bad behaviors of doctors with HIV$^+$ pregnant women.
		Consider HIV$^+$ pregnant women as prostitute
	Discrimination	Lack of attention to the patient in the hospital.
		Ignoring the rights of patients.
	Weakness in health care system	Not staying confidential of disease in small cities
		Weakness in advising for HIV screening before the marriage and pregnancy
		The problem of travelling from small city to big city for keeping secret the illness
Motherhood as a way for stability of life	-	Husband's willingness to have child
		Having Belief that a child can be real supporter for mother
		Family insistence to have child
		Childbearing improve the relationship with women and husband
		A better life with baby

Motherhood as a way for stability of life

Most of participants mentioned instability in their life. They experienced violence by husbands especially women that husbands were negative for HIV. Women that were infected by husband feel that they are victim and they do not like to continue their life with husband but they have to live, because of fear of divorce stigma and family rejection. Some women accuse their partner to be unfaithful. Women that did not have any child and families did not know about their status encouraged them to have a child and threaten them to divorce. In this study, three women desired to have more children for stability of life.

Participant number ten said:" My husband is negative for HIV and wants us have more children. Having more children can stable my life more than before, I know that if I take medicine and my husband washes his semen and I deliver my child with cesarean surgery and don't breastfeed my child, the baby will not be infected. "(Have one child)

Another participant said:" My husband is very bad tempered; he beats me, he wants that we have more children, but I do not personally want another child. Only for getting my husband's support, I just like to have another child." (Have two children- negative husbands for HIV)

Participant number one said: "I have not any children; I want a child for getting rid of loneliness. A child will be entertain and recover our life." (Without child)

Another participant who divorced from first husband said:" I remarried; my new husband has one daughter from his previous marriage. My husband is a good man, I want to have child because I think that it makes my life better. When our families understood that we were infected with HIV, they rejected us; I think that I can make better relation with my family when I have a child. "(Without child)

Uncertainty about the future

Living with HIV for women is accompanied with intellectual apprehension and fear of the future. In spite of participant's knowledge about mother to child transmission,

Most of them were in fear and anxiety about virus transmission and child's future. They were thoughtful about HIV stigma for child and worried about how to reveal this disease to children in the future. In addition, they fear that they cannot tolerate the pregnancy and childbirth. Most participants expressed concerns about body's weakness and risk of premature death.

One of participant was infected by husband and her husband was infected due to out of marriage sex. She suffered from 16 years infertility.

"Doctors recommended me that I should have cesarean surgery. This surgery was not fearful for me. Something that feared me was bleeding and not touching me by hospital staff due to my illness. If I died, my child would become orphan. "(Have one child)

Another participant said:" I became pregnant two times and aborted them. I feared that my baby was infected. By the grace of God, one child is infected another one don't. One doctor said became pregnant another said don't become pregnant. I am fearful because I may bear an infected child or die under the surgery." (Without child)

Unpleasant experience of pregnancy and delivery

Most of women perceived stress and anxiety during previous pregnancy and they encounter with many problems in antenatal care, delivery room and postpartum period. These problems have adversely effect on women's intention on fertility.

Ten participants in this study have children and three participants didn't know about their disease and they found out it after delivery. Their babies have been infected during pregnancy and delivery. One woman during pregnancy found about her status and her daughter did not infect. Six women became pregnant while they knew about their illness and one of them have infected baby. These themes had three sub themes as follows: 1) stigma 2) discrimination 3) Weakness in health care system.

Stigma

HIV related stigmatization affects women's lives, most of women did not disclose their status because of it .childbearing opened the way to stigmatization and discrimination for women but when women referred to hospital for delivery, their disease is revealed and they were isolated .Most of physicians, nurses and other hospital staff blamed them because of their decision making for child bearing. Stigma resulting from illness impacts their next intention on fertility.

One of the participants said: "Hospital staff annoyed me and asked me why do you ever get pregnant? How did you get pregnant? Do you have husband? I did not say anything. If I was healthy, I wouldn't let anyone to talk with me like that. "(Have one child)

Another participant said: "staff asked me why you got pregnant, I answered I did not know that I am infected. They reproached me what will be the child's future? Do you ever know how many days are left of your life? I don't like to hear these types of words again. After my daughter's birth, I got pregnant two times and I aborted them each two times." (Have one child)

Discrimination

Some participants experienced type of discrimination about their disease. Seven women that were aware of their disease before pregnancy had complained about discrimination in hospital during delivery.

Participant number four said that: "they connected me urine bag in delivery room, the bag was full and nobody emptied it. Furthermore, date of my delivery was in holiday and I had only two section gloves, they said me: "we need six section gloves surgeries, so, we cannot operate you". I waited until next day at 17:30. I asked staff why do not operate me? They answered, you do not speak, you are infected with HIV and you should be operated as the last person because we must sterilize the room. I do not want to experience this issue again, so I don't want to have another child" (Have one child)

Another participant said: "Hospital staff behaved badly and they wrote above my bed was "isolated" and everyone understood that I am HIV+". (Have one child)

Weakness in health care system

Most of participants were infected by their husbands and also *they unfortunately* infected their children .They did not consult about HIV before marriage and pregnancy .They stated that lack of information was main reason for their infection and their child's infection**.** Some of participants in this study were living in other cities and they said if they had referred to consultation center in their cities, their disease would not kept confidential and therefore they came to Tehran to refer Consultation Center for clients with risky behaviors so that their illness will not be disclosed to other people in their city. Having infected child and having problem with monthly travel to receive drugs and care during pregnancy were factors that effect on intention of fertility in women with HIV.

Participant number six said:" I live in the small city and people refer to health center regularly, if I go to health center of our city, everyone understands my status, and therefore I am forced to refer to these centers in Tehran. When I was in 36 th week of pregnancy, my blood sugar was increased and I needed special care. I was permitted by the security office of hospital to sleep in the yard of hospital inside my car. I did not fear from this situation but I felt loneliness, I fought with my family not accompany me to Tehran because I did not want them became informed from my illness. This was very bad. I do not want another child."

Participant number seven said:" I did not know about my illness .if I understood this issue and was screened for HIV during pregnancy, I would not breastfeed my boy .and considering that I had cesarean surgery, the baby is not infected with HIV. Infected child has his special problems, his immunity system is weak and the drugs for curing this disease are expensive. I think this child is enough for all my life. (Have one child)

Discussion

Our findings indicated that fertility intentions in Iranian women with HIV are complex and are influenced by several factors as follows: Possibility of pregnancy intolerance and premature death, stigma, discrimination, previous pregnancy's experiences, infected child, disclose of HIV status, health care system and economic situation. The results of qualitative study in South Carolina showed factors influencing the pregnancy intentions of HIV-positive women, these include: i) concerns surrounding the potential to transmit the virus to the infant (ii), financial instability (iii), single relationship status (v), age, and (iv) previous Childbearing and/or childrearing experience (13).

Most participants in this study were infected by their husbands. Their husbands were not screened for HIV before marriage .Some women found out their status after delivery and were not screened during pregnancy. These factors affect life stability and sense of motherhood. HIV testing is seen as part of a comprehensive package of universal prevention, treatment and care is not enough because it is a gateway to treatment and provision of prevention messages (14) routine testing of antenatal attendees is necessary to diagnose affected mothers so that they receive PMTCT to prevent verti-

cal transmission of HIV. Nearly 1.4 million women require PMTCT services throughout the world every year (15). Only 6% of pregnant women were tested for HIV and 79% of those who perceived were at risk of HIV infection had never been tested (16).

In UK approximately one third of the 450 women that participated in study were diagnosed with HIV when they sought antenatal care (17). Based on our study and in line with the studies mentioned above screening HIV in antenatal visit is essential for preventive of mother to child transmission. Iranian health care provider do not conduct HIV screening test accurately. Although this test is done free of charge in Iran, but most of people do not take it.

Health concerns about self and child were common among women with HIV. Themes that emerged of other studies on fertility desire in HIV women supported this theme (18-22).

Result of study in UK showed some of the concerns of HIV women include others reaction toward them or their children if their disease was revealed, sadness at possibly not seeing their children grow up and concerns about future (23).

Result of our study indicated women who had previous pregnancy with diagnosis of HIV did not want to repeat these experiences again due to the stigma and discrimination. These experiences effect on fertility desire. Women living with HIV Like another woman have fertility rights including number, spacing and timing of pregnancy and use of contraceptive methods (24, 25).

Today women with HIV receive conflicting advice, one that anti-retroviral therapy reduces vertical transmission to the fetus and due to it women hope to become pregnant and to conceive a healthy baby unlike the stigma is an opposite effect (26) although the stigma towards HIV/AIDS emerges differently in all communities, each community has its own particular circumstances. The stigma leads to differences among people with HIV/AIDS to access and receive different levels of health services (27). Nyblade and others describe discrimination as the result of stigmatization or enacted stigma (28). Stigma and discrimination on the part of health providers and the community make power imbalances between health care providers and patients and these factors lead to missing opportunities to fulfill the desires of sexual and reproductive health and in some cases, resulting violating the rights of individual (29). HIV women whose infection was diagnosed during pregnancy or became pregnant while they knew about their infection stated contrast between society's theory about female reproductive rights and negative judgmental behaviors about HIV positive women who became pregnant (30). HIV-positive women who become pregnant are essentially caught in difficult situation; they are stigmatized regardless of their pregnancy outcome likely due to the root of the stigma being based in disapproval of HIV-positive women becoming pregnant (31).

Most of women mentioned that they did not afford for child expenditure. Infection with HIV can escalate the economic situation of individual and result in increased poverty and inequality (32). Confidentiality was a concern to the participants and most of them did not disclose their disease during pregnancy and in other situation have more problems.

As for limitations of this study, it was performed on a small sample size. The nature of the study limits the ability to generalize the results. However, as with all qualitative studies, results are not intended to be generalized. Nevertheless, we used maximum variation in sampling.

Conclusion

Health care provider and community should respect the right of infected individuals and inform them on sexual and reproductive health. Communities should financially support women with HIV and empower women with HIV. They should educate discourse and problem solving skills to HIV women for stability of their life; they should provide health care without stigma, discrimination and fear of disclosing the illness. Health care provider is expected to test all women regularly so that the spread of disease is limited and emergence of new case of HIV is prevented.

Ethical considerations

Ethical issues (Including plagiarism, informed consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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