Low level of awareness among Iranian women concerning cervical cancer and screening: the role of knowledge, risk perceptions and cues to action

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Abstract

Background Iran has a low incidence of, but a higher rate of death from, cervical cancer (CC). The country is in the process of implementing an organized screening program including HPV testing and cytology. Studies show high drop-out in continued testing among eligible women. This qualitative study aimed to explore women’s awareness regarding CC and CC testing, and the role of knowledge, perceived risk and cues to action in this process. Methods We recruited 81 women aged between 25-65 years, who participated in 15 focus group discussions (FGDs) and two in-depth interviews in Tehran, the capital of Iran. Data were acquired through 11 open-ended questions and 32 related probe questions. All interviews were transcribed and independently analyzed by two researchers (Kappa and agreement testing respectively: 0.77, 97.11%). Results Coded texts were categorized under three themes and 13 subthemes. The three thematic areas referred to knowledge, cues to action and perceived risks regarding cervical cancer and screening. Results showed that women had inadequate and unspecified knowledge about cervical cancer and screening, compounded by misconceptions regarding infection and cancer prevention measures. Social and cultural barriers hindered proper communication between health system/providers and clients, and within communities on subjects related to cervical cancer and screening. Perceived risk of getting CC was low due to insufficient knowledge regarding the causes of cancer, difficulty in differentiating between cancer and sexually transmitted infections, and the absence of visible symptoms. Conclusions The results indicate a strong need to invest more efforts to improve health education and communication in the current national health program to promote awareness of the need to screen for CC, through, for example, establishing correct knowledge and risk perceptions among women. In addition, this intervention should address women’s social environment in order to prevent misconceptions being communicated to women.
Background

Cervical cancer (CC) is the fourth most common cancer among women worldwide with a total of some 570,000 new cases and 6.6% of all female cancers in 2018 (1-4). About 86% of CC cases and almost 90% of deaths due to CC occur in low- and middle-income countries (1, 3). High mortality from CC can be reduced significantly by comprehensive health programs for prevention, screening and early detection, effective treatment and care (1, 5). The epidemiology of cervical cancer in Iran, both through the pathology-based cancer registry (ASR 2.2 per 100,000) (2, 6) and the population-based registries (6 per 100,000, 2012) (7, 8), shows a low incidence but a high mortality rate to reported incidence (54%) (2). This means that cervical cancers are a health priority.

CC control guidelines, including the WHO guidelines for cervical cancer control (1), the WHO package of essential NonCommunicable Disease (NCD) interventions for Primary Health Care (PHC) in low resource settings (9) and cohort studies in 13 European countries show that integrated screening sequence modalities including HPV testing, visual inspection with acetic acid (VIA) and cytology testing within an organized testing strategy is the most efficient method for screening and prevention of CC (4, 7, 8, 10, 11), contributing to decreased cancer morbidity and mortality (12, 13). Statistics in central Asian countries show an increasing rate of cervical cancer and related mortality (among generations after 1940-50) in the absence of organized and well-established screening programs (13). In addition to the general phenomenon of changing sexual behavior and risk factors (13, 14), social and cultural challenges regarding sexual education (14, 15) point to the necessity of implementing well-organized screening programs including HPV testing and cytology (16). Combining integrated strategy of sequence of HPV and cytology testing (Papanicolaou test; Pap smear),and HPV vaccination for all girls by age 15, and access to treatment and care for identified CC cases provides an effective and feasible
strategy for eliminating CC (7, 8, 17, 18)

The Islamic Republic of Iran is implementing an opportunistic testing strategy for cervical cancer screening (CCS), integrated in Public Health Care (PHC) services. This CCS program was exclusively cytology-based and testing was recommended every three to five years until the age of 65 years (19). There is no national surveillance system or comprehensive epidemiologic data for CCS in Iran. Based on the results of small surveys (e.g. 2009) in limited populations, the attendance rate for CCS was around 65% for attending at least once, and less than 30% for regular attendance (20). In late 2016, Iran launched the specific health intervention package of combating NCD (21). Consequently, the policy for CCS as part of the NCD strategies was modified to an organized testing strategy including HPV- and cytology-based testing, with an estimated coverage rate in the pilot area of about 10% in 2017 (19). According to an updated national protocol for CCS (not yet implemented countrywide), all women aged between 30 and 59 are eligible for early diagnosis check-ups that include history-taking, and a general examination/observation every five years. A sequence is performed of HPV-testing followed by Pap smear testing in cases where questionable signs are evident, or every 10 years for asymptomatic women. It was every 3-5 years for all women aged 30 to 65 before 2016(22). General examinations will be applied for women after 50 but testing will be voluntary-based (21-23).

Several factors have been found to be associated with low attendance of cervical cancer screening in various countries. Some of these pertain to socio-demographic factors, such as access to services and financial issues (24, 25), lack of advice from a health care provider (HCP) (20, 25, 26), and social and cultural barriers (24, 27, 28). Others are related to women’s knowledge regarding the existence of HPV infection- and cervical cancer screening programs (26, 29-32), factors influencing the awareness of the need to be screened (33, 34), misconceptions about susceptibility to CC (34), and contextual cues
such as cancer in the family (20). Studies have also revealed that factors such as the attitude toward cancer (33), subjective norms (27) and self-efficacy (34, 35) are also associated with women’s attendance in CCS.

The newly established strategy in Iran needs some regulation for developing proper health communication and promotion interventions in order to improve and retain attendance in CCS. A first step is to create awareness among women in Iran concerning the availability and need for CCS, and the efficacy of screening, which appears to be important as studies showed a lack of this awareness (36, 37). Awareness of CC and screening is a prerequisite for motivating attendance and also acknowledged as an essential phase preceding motivation in behavior change models, such as the Integrated-Change Model (I-Change) (38) predicting health behaviors such as participation in screening programs (34). This implies that before women are motivated to participate in CCS, they need to be aware of its existence as well as of their own levels of risk. Hence, knowledge and risk perceptions may not always influence behavior directly, but serve as distal factors influencing for instance motivational factors such as attitudes and self-efficacy beliefs (39, 40).

According to the I-Change model, important determinants of awareness are: (a) having sufficient knowledge about CC and the possibilities for screening; (b) feeling at risk of getting CC; and (c) receiving sufficient cues that prompt a person to think about the need for CCS. In Iran, very limited information exists about these determinants of awareness of CCS (37) – information that is relevant to develop health communication interventions. Consequently, the aim of this study is to explore knowledge, cues to actions and perceived risks of women about cervical cancer screening. As several studies suggest that screening attendance and its determinants may differ per educational level and socio-economic status (41, 42), we will also explore potential differences related to these variables. Results from this study will be most interesting for low-epidemic Islamic
countries, with limited awareness about cervical cancer considering cultural, social and religious sensitivities. In addition these findings will be helpful for developing effective health promoting interventions for Muslim women from Islamic countries living in the western or non-Islamic countries as well in order to provide them culturally tailored information suitable to their background. (43-45).

Methods
This qualitative study was conducted using Focus Group Discussions and In-depth interviews. We have used four-dimension criteria to ensure and explain trustworthiness of the study in all steps from design to implementation, analysis and interpretations. For this purpose we have used “the Four-Dimension Criteria”(46) which was summarized in table1 and explained in details subsequently.

Table 1: Four Dimension Criteria to assess rigor of qualitative study
| Rigor Criteria       | Strategies applied in our study                                                                 |
|---------------------|--------------------------------------------------------------------------------------------------|
| Credibility         | • Seventeen interviews, 60 minutes each, January to May 2015 (six months)                        |
|                     | • Interview protocol, tested in two pilot interviews                                              |
|                     | • Skillful researchers for interview and data analysis                                            |
|                     | • Two moderators for each interview, one as interviewer and one as note-taker                    |
|                     | • Immediate debriefing after interviews                                                          |
|                     | • Double checking transcribed interviews by both researchers and taken notes                     |
| Dependability       | • Prepared study protocol and briefing before interviews                                         |
|                     | • Track record of interviews and detailed information related                                   |
|                     | • Coding accuracy and inter coders’ reliability testing (Kappa agreement testing)                |
|                     | • Using software (NVIVO10) for analysis                                                          |
| Confirmability      | • Immediate descriptive review of transcripts to identify diversities and similarities of data   |
| Transferability     | • Sampling based on Urban HEART results for classifying districts and selecting interviewees from all socio-economic classes |
|                     | • Examining repeated coding after each interview and not arisen new nodes and additional subthemes in final analysis |

The semi structured interview guide for this study was composed of 11 main open-ended questions and 32 related probe questions (annex 1). The interview guide was based on the I-Change model (38) and focused on knowledge about cervical cancer (CC) and Pap smear
testing, perceived susceptibility and severity of CC, cues to action, advantages and
disadvantages of testing, as well as barriers and motivating factors, self-efficacy, and
action plans. For this paper we focused only on awareness factors (pre-motivational
components) and related constructs including knowledge, perceived risk and cues to
action. The interview guide was reviewed by a group of experts and tested in two FGDs
with eligible women (N=12) and it was used in the study after finalization regarding
method and language. The study has received ethical clearance by Tehran University of
Medical Science (TUMS) (reference number 24890, 11/08/2014) and was registered in Iran
Clinical Trials (IRCT2014092918120N1) (47).

**Setting**

The study was carried out in Tehran-Iran, a metropolitan city with 8 million inhabitants.
The municipality of Tehran has categorized its 22 districts (zones) into five categories
using the Urban Health Equity Assessment and Response Tool (Urban HEART) which takes
health and social determinants (48). A reference indicator for this classification was life
expectancy at birth. We recruited our population study from randomly selected districts
from all determined categories as shown in table 2.

| Life expectancy (years) in 2010 | Districts code | Selected districts for FGD |
|--------------------------------|----------------|----------------------------|
| 79.1 to 78.3                   | 1,4,5          | 4 (3FGDs)                  |
| 78.2 to 77.4                   | 2,3,22         | 3 (2 FGDs), 2 (1 FGD)      |
| 77.3 to 76.4                   | 6,15,20,21     | 15(2 FGDs)                 |
| 76.3 to 75.5                   | 7,8,14,18      | 8 (3 FGDs)                 |
| 75.4 to 74.5                   | 9,10,11,12,13,16,17,19 | 13(2 FGDs), 12 (2FGDs) |

**Recruitment of participants**

15 FGD and two in-depth interviews were conducted. The total number of attending
women in the interviews was 79 and two for in-depth interviews. All FGDs were conducted
in nine Public Health Care Centers located in seven selected districts in Tehran. PHC centers were selected based on their availability and cooperation.

All women were invited to the interviews by Public Health Care Centers located in the selected zones of the city (see table 1). Inclusion criteria for the study pertained to residence in the selected zone, being married, age between 25-65 and Farsi-speaking. PHC staff from the Department of Reproductive Health contacted the women by phone (if accessible, by order from family health profiles) or directly (by order of appearance in the health center), to invite them to participate in the study. Due to the low proportion of women with higher education and employment among the interviewees, we decided to conduct one interview (FGD17) at the workplace (for convenience of the interviewees) and two in-depth interviews with employed women with higher education, which were introduced by PHC staff based on a request of the researchers.

**Data collection and analysis**

RTA (MD, MPH) and SZ (PhD in health education), both with good experience in qualitative research design and implementation, moderated all interviews during January to May 2015. Each interview was run by two researchers (always female and male together), one as interviewer/moderator and one as note taker., one as interviewer/moderator and one as note taker.

The interviewers are introduced to interviewees by PHC staff; then they gave a brief introduction of the interview and its objectives. Subsequently, the process and ground rules of the interview (time, role of facilitator and interviewees, respect and confidentiality) were explained and a consent form was read for all. The consent form clearly stated that results would be published for scientific purposes with consideration for confidentiality and anonymity of interviewees. Participants were informed that they could decide to stop and terminate the interview at any time without having to give an
explanation. Before starting the interview, they were asked for consent for audio recording of the whole interview. All women who provided verbal consent continued participation in the interview. Each interview was continued with an introduction and collection of information on demographic characteristics (age, marital status, employment, literacy) and completed in approximately 60 minutes.

After finishing each interview, both the moderator and note taker reviewed the notes taken and consolidated them to be incorporated in the interview text when the audio file was transcribed. All audio files were transcribed literally by a typist and double-checked by the interview team and transcribed data descriptively reviewed to identify variation and similarity of information and expressions between FGDs while interviews were in progress. All names were coded in the interviews and finally transcribed data was used for detailed analysis.

All transcribed interviews were entered in NVIVO 10 and two interviewers applied inductive content analysis. Randomly selected four FGDs (4,5,9,11) were used for extracting a unique list of nodes and comparison of coding by the two interviewers as analyzers. Results for Cohen’s Kappa and agreement testing showed 0.77 and 97.11% respectively. Then researchers coded all interviews and then classified all codes under specified subthemes and themes. Eventually all themes were clustered in accordance with the I-change model.

Inductive content analysis was applied to code all interviews based on developed nodes by free coding. Then all coded texts were categorized based on identified themes. After completing ten FGDs (two in each zone) we have performed a preliminary analysis on the data and then continued with one more interview in each area (including workspace) and two additional individual in-depth interviews. By analyzing them we noticed redundancy in coding and no new node or theme arose which indicated data saturation. For analytic
purposes we reclassified selected districts (zones) for interviews in four socio economic groups (SEG) using socio-economic position (SEP) scoring developed based on Urban HEART data (49) and we have compared summarized expressions and coded texts from each SEG when it was possible.

Results

Characteristics of the sample

Table 3 shows a summary of the demographic characteristics of interview participants. No illiteracy was reported and five out of 81 respondents (6%) reported having completed university education.

Table 3: Demographic characteristics of participants in FGDs

| Characteristics                  | Frequency | Percentage (%) |
|----------------------------------|-----------|----------------|
| **Age**                          |           |                |
| Mean=39.3 (SD=10.8)              |           |                |
| 25-34                            | 32        | 38.6           |
| 35-44                            | 26        | 31.3           |
| 45-54                            | 14        | 16.9           |
| >54                              | 9         | 10.8           |
| **Socio-economic groups (SEG)**  |           |                |
| High                             | 14        | 17.3           |
| Upper-Middle                     | 36        | 45.7           |
| Lower-Middle                     | 20        | 24.7           |
| Low                              | 10        | 12.3           |
| **Occupation**                   |           |                |
| Employed                         | 5         | 6              |
| Housewife                        | 76        | 94             |

The results of the study focus on three main components of the pre-motivational stage of the I-Change model (38): knowledge, cues to action and perceived risks. Each component or theme contains subthemes accordingly as follows.

Knowledge about cervical cancer and cervical cancer screening

The results of the interviews revealed that women’s knowledge and information about
cervical cancer, the signs and symptoms of disease, as well as cervical cancer testing, was neither specific nor explicit. Tacit knowledge is embedded in practical experiences, not achieved through systematic or formal trainings, and not from standard documents, and it is nonspecific. By contrast, explicit knowledge is evidence-based, specific and precise knowledge which could be articulated and communicated systematically (50).

The results revealed different subthemes for this area, which are discussed below.

**Lack of explicit knowledge on cervical cancer**

Most of the women had heard about cervical cancer in general, but had not specifically mentioned the exact name of cervical cancer in the discussion. According to participants, older women have less knowledge than the younger generation. The majority of interviewees were also unable to differentiate between cervical cancer and other genital cancers (e.g. uterine cancer) and did not know the affected organ.

“We don’t know anything about this (cervical cancer), we just know that a test is taken every six months or every year to see if a woman has uterine cancer or not.” (participant 1, 56 yrs.)

Half of the participants (almost equally distributed over the socio-economic classes) referred to cervical cancer using nonspecific terms, mainly “women cancer” or “uterine cancer” without differentiating uterine and cervix.

“...among the general population, I don’t hear anyone say cervical cancer, it is called uterine cancer.” (participant 13, 56 yrs.).

Participants from low and lower-middle socio-economic groups (SEGs) reported the least accurate and explicit knowledge about cervical cancer in general, while inaccurate knowledge (content and frequency) was almost the same among all SEGs.

**Limited knowledge about signs and symptoms**

Most women did not recognize signs and symptoms of CC specifically and explicitly. They did not differentiate between CC and sexually transmitted infections (STIs), nor their signs
and symptoms.

“I think this cancer is very silent and the one that is affected does not see any symptom and cannot identify the disease herself.” (participant 55, 50 yrs.).

Several women stated hemorrhage (vaginal bleeding) and vaginal discharge (extensive and smelly) as hallmark symptoms.

“...it starts from the inner uterus and extends to the abdomen. One of our relatives was affected and within six months, when in hospital, her uterus was removed but it was rooted in her abdomen... I guess the first symptom is severe bleeding.” (participant 4, 33 yrs.).

Others, however, referred to a lack of pain or symptoms.

“...cervical ulcer does not have any specific pain sometimes, no consequence and symptoms, and if any symptom exists it could be foul-smelling vaginal discharge, for example.” participant 55, 50 yrs.).

Occasionally interviewees mentioned other signs such as abdominal pain, genital burning and irritation. A few women mentioned warts as a sign of cancer and some others disagreed.

“In my opinion (vaginal) irritation, itching, abnormal and smelly discharge can be a sign of having cervical cancer.” (participant 67, 44 yrs.).

Women in the upper and lower-middle SEGs expressed more accurate knowledge about signs and symptoms than the high and low SEGs. Inaccurately assigned STI-related signs and symptoms to cervical cancer were very frequent among all groups.

**Lack of specific knowledge on testing purpose, frequency and timing**

The majority of women knew about cervical cancer testing but their knowledge in most of the cases was nonspecific and inaccurate concerning the purpose and frequency (timing) of testing.
They did not differentiate between testing for cervical cancer screening (CCS) and testing for sexually transmitted infections (STIs).

The cervical cancer screening test was referred to by different names: Pap smear, cancer testing, women testing. It was very frequently stated that this test (Pap smear testing) diagnoses sexually transmitted infections and cancer (not specifically cervical cancer).

“...this test (Pap smear) in fact shows infections in the body of women or disease inside of the uterus.” (participant 61, 40 yrs.).

Almost all women who had previously taken the test stated that the first time they had undergone testing was when they visited their health care provider (physician, gynecologist or midwife) for reproductive health reasons after marriage, during pregnancy or after giving birth. In addition, most of the women stated that they performed the test whenever their health care provider (HCP) advised to do so.

“...we don’t know more, we only heard the name (of the test for cancer) and we only perform tests which are advised here (in the Public Health Center).” (participant 2, 31 yrs.).

A few women were aware of the correct frequency of testing as recommended in the national program for CCS. They expressed broad knowledge about timing and frequency of testing, including twice a year, annually, every three years, etc., and the majority named annual testing

“As far as I know we should perform this test every year; if three consecutive tests are negative then there is no need to do it annually anymore, and we can do it every three years. When we have passed reproductive age and after aging, it (testing) also needs to be done, and likewise after surgery (hysterectomy) which I had, after extraction of my uterus. I mean when you don’t have ovaries or a uterus this test still needs to be done.” (participant 55, 50 yrs.).
In addition, interviewees mentioned different ages and circumstances as starting time for testing, including after marriage, before pregnancy, after giving birth (delivery), after turning 30 years old, from age 20 to 60 years, and after the menopause. Several women indicated that women should be examined and tested for disease (i.e. STIs) after marriage.

“….after marriage, some problems (STIs) happen...when a woman feels that her discharge smells or is discolored, she should consult a physician.” (participant 69, 26 yrs.).

Most women believed that samples are taken from vaginal discharges and did not differentiate between CC and STIs regarding care and management. The majority of interviewed women explained the testing as taking samples on slides and a few of them talked about taking samples in liquid mediums. A few participants noted that there are several ways to diagnose cervical cancer, and mentioned biopsy and diagnostic curettage as additional options. Only one interviewee specified HPV testing.

“...I know that a sample (for CC testing) is taken from (vaginal) discharges of women and sent to the laboratory for examination.... If the result of the test is suspicious then the test should be repeated and in the case of an infection, it is cured with pills and medicine. It is important for women to be tested every six months and sometimes every year.” (participant 4, 33 yrs.).

While the high SEG had least knowledge about testing in general, most women in all groups expressed inaccurate knowledge about frequency, purpose of testing and type of specimens taken, and did not differentiate between STIs and cancer.

**Deficit in knowledge about risk factors and causes**

Most women wrongly mentioned cervical cancer as a consequence of STIs, more specifically prolonged/chronic infections, and also described family history as a main risk factor for CC. In addition, they listed other risk factors, including multiple partnerships,
ignoring personal hygiene (cleaning and washing the genital organs, daily changing of underwear), unhealthy nutrition (e.g. high intake of fast food), air pollution, stress, and wearing tight underwear. Only two participants mentioned smoking tobacco and alcohol use as possible risk factors.

“...an unmarried person may be affected by this disease (cervical cancer) because of hereditary reasons.” (participant 63, 26 yrs.).

The majority of women mentioned chronic and untreated STIs as the underlying cause for cervical cancer.

Women very frequently used terms of hereditary and genetic (more than 48 times) causes, and infections (STIs in general, more than 85 times) as being a cause of cervical cancer. Almost none of the women differentiated between cleanliness and hygiene in their statements and expressed an implicit understanding of hygiene to control risks.

“I do believe that cervical cancer and other women cancers (related to genital organs) are caused by simple infections which are caused by our negligence such as neglected personal hygiene. We should be concerned about our sexual relations a lot, also about our underwear which I think is highly important.” (participant 72, 27 yrs.).

Awareness of CC risk factors was highest among the high SEG, but most importantly, inaccurate knowledge about the main cause of cervical cancer (believed to be heredity) and misconceptions about hygienic measures for self-protection were highly stressed by almost all women.

**Appropriate knowledge on conditions/ requirements for testing**

The majority of women were aware of practical preparatory measures and recommended considerations required before attending CC testing. They stated practical terms and conditions for testing including sexual abstinence, avoiding the use of vaginal douche and vaginal treatments (gel and cream), and recommended scheduling testing when not the
menstruating.

“In general no (vaginal) discharge should exist (at the time of testing) to avoid incorrect results of the test and a week should have passed after menstruation. Additionally, sexual intercourse should not have taken place in the previous 24 hours (before testing) and (vaginal) ointments should not be used during the previous 48 hours.” (participant 74, 26 yrs.).

All groups excluding the high SEG elaborated on in detail the required preparedness before testing.

**Limited and unspecified knowledge on preventive measures, care and treatment**

Almost all women indicated not knowing how to prevent cervical cancer; they indicated that they were simply advised to perform the test.

“In fact, we don’t know what to do or not to do, to avoid facing the problem (of getting cervical cancer) we do not know anything in this regard at all, we only know that a test is being taken, every six months or year, to identify if uterine cancer exists or not.” (participant 1, 56 yrs.).

Most women understood that CC testing was a way to detect STIs early (without mentioning HPV) and they believed that STI prevention was essential in cervical cancer prevention. A few participants mentioned condom use as a preventive method. Only two women mentioned the availability of a vaccine and its preventive role; both women were highly educated.

The majority of women considered cervical cancer as a treatable disease if diagnosed early, by extraction of the uterus and chemo- or radiotherapy, before metastasis to other organs.

“I think it is curable if diagnosed at an early stage, chemo- and radiotherapies exist,
eventually treatment is available, in the past they may not have been able to diagnose it but now I see people who had problems which have been solved.” (participant 27, 53 yrs.).

Low and upper-middle SEGs demonstrated more correct knowledge of preventive measures than the low and high SEGs; however, the frequent referral (>95 times) to personal hygiene and cleanliness (in general terms) as a preventive measure was notable among all SEGs.

**Inaccurate perceived risk of cervical cancer and screening**

In general, the proportion of women who very frequently cited their lack of perceived risk were almost the same in all SEGs. There was an overall low perceived susceptibility and high perceived severity among participants regarding cervical cancer. Most women believed that CC was a curable disease. However, extended social and cultural consequences of cervical cancer seem to lead to an increased perception of the severity of CC, causing some fear.

This theme was categorized under two subthemes which explain three main factors related to risk perception: misperception of cause, misconception about STIs and cervical cancer, and avoidance of negative thinking.

**Low perceived susceptibility to CC due to misconceptions**

Insufficient knowledge about the cause of cervical cancer resulted in misconceptions regarding vulnerability to cervical cancer. Overestimation of the role of heredity of cervical cancer was an important misconception among women; most women considered themselves not at risk because there was no (known) history of cervical cancer in their family. They specified insufficient hygiene as an important risk factor for CC and perceived an association between STIs and cervical cancer. As a majority of women evaluated their personal hygiene measures as being sufficient to prevent infections, they
did not consider their CC risk as high. Those measures (e.g. changing underwear, washing themselves after sexual intercourse, not using toilet paper) pertain to cleanliness rather than specific hygienic measures.

“I don’t think (I will get cervical cancer) because I observe hygiene always and we didn’t have such a thing (cancer) in our family.” (participant 40, 45 yrs.).

A common social belief in Iran says that when you think of something it eventually happens to you, and this scares people away from exploring their concerns like cancer.

“Thinking about (cervical cancer) is very bad, I don’t like to think about it... when you are exploring more (about a disease) it seems that the disease grips you more, it (testing) is a useless cost and I should not consider it (cervical cancer) as important anymore.” (participant 27, 53 yrs.).

**Aggravated severity due to social and cultural misperceptions**

Most women reported a high perceived severity of cervical cancer; severe consequences also included disruption of family life and social image.

“... (women are) concerned that when it is known that they have cervical cancer, their life will be disrupted.” (participant 58, 43 yrs.).

**Lack of perceived cues to action regarding cervical cancer**

Most women reported few cues to action from their environment, also due to an existing stigma on CC in their community, and discrimination against women. Two different types of cues were mentioned, external cues and internal cues.

**External cues:**

*Culturally limited interpersonal and public communication about cervical cancer*

All women strongly emphasized the need for health communication and education on cervical cancer and CC testing. Most women indicated that talking about issues related to the sexual organs including cervical cancer and testing is stigmatized according to cultural and social norms.
“Cervical cancer is not an issue which you expect an affected woman to talk about with her friends and relatives and to open up about it. Usually she keeps it secret, like breast cancer; she does not like others to know about her disease. For this reason, we don’t know how many of our relatives are affected, there is no communication about it, and we know cancer in general but not specifically.” (participant 10, 26 yrs.).

In comparison to other groups, the low SEG indicated a lack of communication about cervical cancer more frequently as a barrier to awareness. Different information sources were listed, including HCPs, television, peers (relatives and volunteers) and others (internet, publications). Face-to-face counseling by public health services and health care providers (HCP) including physicians, midwives and others, was mostly preferred by women, as these consultations were mentioned as being transparent, and provided the opportunity to pose questions. The lack of interaction (i.e. posing questions and receiving answers) was regarded as the main disadvantage of health education through the public media (e.g. television).

“The Public Health Center is credible (for health education); when I am in a Public Health Center I feel comfortable because I can ask my questions to doctors here, but in that case (TV education) I cannot ask questions to anybody.” (participant 47, 35 yrs.).

Women indicated being confident about having the comprehensive knowledge about HCPs (particularly doctors) and trusting them. They were concerned that senior professionals spend less time with patients for health education.

“Doctors do not open the discussion and don’t have time... when you ask more questions, doctors get upset.” (participant 36, 48 yrs.).

A need for health education was commonly expressed among all SEGs, with a higher frequency among high and upper-middle SEGs with the above-mentioned preference scheme.
Health Care Provider (HCP) as main external prompt

Being advised to go for screening by HCPs appears to be a very important cue encouraging attendance. Most of the women stated that they only participated in tests when their HCP advised them to do so; otherwise, they would not go for tests unless they had symptoms that might point to an STI.

“Whenever my doctor advises me to go for a test I go otherwise I would never go by myself, unless I had complaints.” (Participant 39, 50 yrs.).

The advice of a health care provider was mentioned more often as the main motivation for testing among women in the upper-middle SEG than among women in the other SEGs

Internal cues:

Socially imposed self-deprioritization and misinterpretation of symptoms

There was a general lack of perceived cues to initiate CC testing (apart from HCP advice); for most women, CC testing, and more generally personal health care, was not a main priority. Many women indicated that Iranian women prioritize family and household as a social value and criticize caring about personal health. Limited awareness of symptoms of CC is causing a misinterpretation of being healthy in the absence of visible symptoms, and neglecting routine examination and testing as follow-up.

“Usually the last thing Iranian women have on their mind is (taking care of) themselves and their priority is thinking about other issues.” (Participant 1, 56 yrs.).

All groups very frequently expressed discrimination against women, self-deprioritization and misinterpretations of symptoms as barriers to participation in cervical cancer testing, with a slight dominance among high SEG.

A summary list for each main theme and related subthemes is provided in table 4.

Table 4: Themes and subthemes of women’s awareness of cervical cancer and screening
### Theme

| Tacit/Implicit knowledge about cervical cancer and screening | Sub-theme |
|-----------------------------------------------------------|-----------|
| Lack of explicit knowledge on cervical cancer            |           |
| - Limited knowledge about signs and symptoms of cervical cancer |
| - Lack of specific knowledge on cervical cancer testing, its frequency and timing |
| - Deficit in knowledge about risk factors and causes of cervical cancer |
| - Appropriate knowledge on conditions/requirements for cervical cancer testing |
| - Limited and unspecified knowledge on preventive measures, care and treatment concerning cervical cancer |

| Inaccurate perceived risk of cervical cancer and screening | Sub-theme |
|----------------------------------------------------------|-----------|
| Low perceived susceptibility to CC due to misconceptions |
| - Aggravated severity due to social and cultural misperceptions |

| Perceived cues to action regarding cervical cancer and barriers to action | Sub-theme |
|---------------------------------------------------------------------------|-----------|
| External cues:                                                            |           |
| - Limited interpersonal and public communications about cervical cancer due to cultural considerations |
| - Health provider advice as powerful external prompt                      |
| Lack of internal cues:                                                    |           |
| - Socially imposed self-deprioritization, lack of symptoms and misinterpretation of symptoms |

### Discussion

The aim of this study was to explore relevant factors determining women’s awareness of cervical cancer, awareness of cervical cancer screening programs and their perceived need to participate. Findings were summarized under three main themes including knowledge, perceived risk and perceived cues to act.

Firstly, with regard to knowledge, our results revealed that a vast majority of women had general knowledge about cervical cancer and screening but their information was implicit rather than explicit. They did not differentiate between cervical cancer and other genitourinary cancers, mainly uterine cancer. Most of the women did not explicitly name
cervical cancer and they did not anatomically distinguish the cervix from the uterus. In addition, women did not specifically differentiate cervical cancer from STIs, demonstrated by a lack of knowledge about signs and symptoms and causes, and the relation between STIs, cancer and CC testing. Differences between STI and cervical cancer management measures and interventions were not clear for women. Other national and international studies also reported a lack of sufficient knowledge about CC, a gap in identifying risk factors and causes of cancer, a lack of recognizing the cervix, and differentiating between STIs and cervical cancer (27, 36, 51). In addition to comprehensiveness of data and corroborating previous findings regarding women’s knowledge of CC and CC testing, the current study sheds light on the importance of establishing explicit knowledge and the role of detailed health education. Our results also showed that women’s knowledge about timing and regulations for CC testing was inaccurate and implicit, and mainly reflected their experiences rather than accurate knowledge. Lack of knowledge and unconfident answers by women regarding timing, frequency and procedures was also reported in other studies (33, 52). However, women had detailed, accurate and practical knowledge about terms and conditions for attending CC tests which was not previously explored in other studies. This may reveal women’s attention for and interest in personal health issues and a potential capacity for learning from instructions. It shows a shortfall in the health system lacking systematic health education and uniform practices (51).

Secondly, our results revealed that many women held inaccurate risk perceptions concerning CC. The women in our sample overestimated the role of heredity; similar to findings in other studies in Iran (27, 36) and other countries (52-54), which is challenging, since the role of genetic causes of CC is still not clear (55). The vast majority of women reported low perceived risk and susceptibility regarding CC, findings also reported in other studies (33, 34, 37, 52). We found that women regarded themselves at risk concerning
STIs; however, they had poor understanding of the purpose of CCS. In concurrence with other studies, our respondents considered CCS as an intervention for STI management (27, 56-58). A misconception was found concerning the role of cleanliness and hygiene to prevent STIs (HPV infection specifically) and cervical cancer, and similar findings have been reported by other studies (33, 52). However, the absence of STI symptoms did not make women feel a need to go for screening.

Thirdly, with regard to cues to action, our respondents disliked discussing and thinking about cervical cancer and their existing symptoms, due to local beliefs about the consequences of such thinking and discussions, a finding reported in other studies (24, 27, 52, 59). Consequently, receiving a cue to act as a result of discussions with others is rare in Iran. HCP advice on performing a CC test was found to be a crucial factor – if not the most crucial – for undergoing screening. Women emphasized that despite all existing barriers and lack of awareness regarding cervical cancer and testing, they attended CC screening when their physician advised them to do so. Other studies also reported this positive influence (20, 60, 61).

Previous local studies showed a positive correlation between health literacy for cervical cancer and income level (62), a higher concentration of cervical cancer among lower socio-economic groups in Tehran (63), and delayed diagnosis of CC among lower SEG (64). However, our findings did not indicate a constant pattern and do not suggest differences in awareness, knowledge and risk perceptions between participants with different socio-economic backgrounds. Health education and communication interventions are therefore suggested in all SEGs while further quantitative studies are recommended.

To our knowledge, this was the first comprehensive qualitative population study on this subject in Tehran conducted with the participation of a large number of participants from diverse SEGs (spread over the city). Moderating interviews by two experts of both genders
and the openness shown by interviewees were other positive points of this study. The results of this study provide a wide range of comprehensive data on the above-mentioned thematic areas and advocate the development of health communication interventions to promote adequate uptake of cervical cancer testing in Iran. However, the status of socio-cognitive factors related to CCS adherence should be further investigated to broaden understanding on this subject. In addition, quantitative studies are needed to identify statistical differences between groups and to identify which variables are most important for the realization of awareness of CC and CCS, and to explore the association of individuals’ characteristics and identified factors with outcomes. Although there is now a vaccine against cervical cancer, this is not yet available in Iran. Future preventive actions could entail making this vaccine available and to provide information about this, a strategy which is advocated by the WHO suggesting to achieve a high coverage with both vaccine and a very sensitive screening test like a HPV test(18).

Conclusions

The results of our study indicate low and implicit knowledge about CC and the preventive role of cervical cancer testing. In addition, women reported a low level of perceived susceptibility along with misconceptions influencing their uptake of preventive measures. Health communication campaigns, preferably using face-to-face methods in Public Health Centers, should therefore stress correctness, explicitness of knowledge and the importance of preventive measures and possible consequences of CC screening ignorance and late detection. Campaigns should emphasize that a negative family history of CC is no guarantee for not getting CC, as hereditary factors only play a minor role. HCPs and, more specifically, physicians were mentioned as trusted and preferred sources of education and their advice is one of the most influential factors for attendance, indicating that they can play a vital role in the success of health communication campaigns for CCS in Iran.
Abbreviations

CC: Cervical cancer; CCS: Cervical cancer screening; HPV: Human Papilloma virus; FGD: Focus group discussions; ASR: Age-standardized rate; WHO: World Health Organization; NCD: NonCommunicable Disease; PHC: Primary Health Care; VIA: Visual Inspection with Acetic Acid; HCP: Health care provider; I-change: Integrated-Change; TUMS: Tehran University of Medical Science; IRC: Iran Clinical Trials; Urban HEART: Urban Health Equity Assessment and Response Tool; SEP: Socio-economic position; SEG: Socio-economic groups; STI: Sexually transmitted infections

Declarations

**Ethics approval and consent to participate**
The ethics committee of Tehran University of Medical Science (TUMS) (reference number 24890, 11/08/2014) approved this project and it was registered in Iran Clinical Trials (IRCT2014092918120N1). All data and records were stored confidentially. Consent to participate (verbal) has been taken with standard forms.

**Consent to Publish**
Not applicable.

**Availability of data and materials**
The datasets used and/or analyzed during the study will be made available by the corresponding author following a reasonable request.

**Competing interests**
The authors declare that they have no competing interests.

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Authors' Contributions
RTA, HDV, NDV, LVO, KZ and MS designed the study, supervised the project, data abstraction, and data analysis; and FZ has contributed in data collection, abstraction and analysis. They prepared the initial draft and finalized it based on internal reviews and discussions among authors. All authors reviewed each manuscript draft, participated in interpreting the results, and approved the final version.

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Supplementary Files

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FGD interview guide CCS Iran.docx
FGD interview guide CCS IRAN.pdf
