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Barriers to Cervical Cancer Screening among Rural Women in Eastern China: a Qualitative Study

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Barriers to Cervical Cancer Screening among Rural Women in Eastern China: a Qualitative Study

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ABSTRACT

Objectives To explore barriers to cervical cancer screening among rural women in China from the perspective of women, health care providers and women's husbands to provide effective information for policy makers and planners.

Design A qualitative study using semi-structured in-depth interviews, focus group discussions and key informant interviews.

Setting This study was carried out at township level within two counties in Jining Prefecture of eastern China.

Participants Semi-structured in-depth interviews with 21 women eligible for screening aged between 35 and 64 years, and with five cervical cancer screening services providers. These were supplemented by two focus group discussions with nine providers of cervical cancer screening services, and four key informant interviews with husbands of women eligible for screening.

Results Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers including reticence for intimate examinations, (4) influence of close contacts on screening decisions, and (5) inconvenience. These demonstrate key knowledge gaps challenging current community health education. Important service barriers, including with fear of treatment cost, and the time needed for screening were also raised.

Conclusion Our study details important barriers to cervical cancer screening relating to

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3 knowledge gaps, attitudes of fear or embarrassment, and the role of contacts and service
4 models. These provide data for policy and planning to improve the screening that will
5 decrease the incidence and mortality rates of cervical cancer in China.
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10 11 **Article Summary**

12 13 **Strengths and limitations of this study**

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18 ■ The qualitative methods allowed for detailed and deep responses and triangulation
19 across providers, clients and their partners.
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24 ■ The findings have direct relevance to policy makers considering the development of
25 effective interventions to increase uptake rate of cervical cancer screening in China.
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32 ■ The study was carried out in two rural districts and results may not be generalisable to
33 all women. These findings may need to be evaluated larger or different populations.
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INTRODUCTION

Cervical cancer is the second most common cancer in women worldwide.¹ In 2012, 528,000 new cases of cervical cancer were diagnosed and 266,000 women died of cervical cancer, and almost 9 out of every 10 of these, or 231,000 women in total, lived and died in low- or middle-income countries (LMICs).^{2 3} In China, the estimated number of cervical cancer cases was 78,400 in 2010 and is projected to reach 93,500 in 2030.⁴ In recent years, it is set to increase in young women.⁵ The occurrence of cervical cancer poses a serious threat to woman's physical and mental health, and causes severe economic and social burden.^{6 7}

Infection with the human papilloma virus (HPV) is the most significant risk factor for cervical cancer which can be transmitted during sexual intercourse.⁸ The majority of HPV infections resolve spontaneously and do not cause symptoms or disease.¹ However, persistent infection with specific types of HPV (most frequently, types 16 and 18) may lead to precancerous lesions, which, if not treated, can progress to cancer 10 to 20 years later.⁹ Cervical cancer is a preventable and treatable disease, and screening of precancerous lesions can reduce its incidence and mortality.¹⁰ In many high-income countries, the incidence and mortality of cervical cancer have decreased significantly because of the efforts made to detect precancerous lesions early.^{11 12} However, in LMICs, cervical cancer remains the most common cause of cancer-related deaths among women.¹³

Cervical cancer is recognized as a major public health problem in China,¹⁴ both in mortality and morbidity burden, the latter causing protracted economic stress on women, heaviest in rural communities. As part of responses in 2009, a new round of deepening health

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3
4 system reforms intended to integrate the breast cancer and cervical cancer screening
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6 programs in rural areas into broader national public health services.¹⁵ The government's
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8 National Cervical Cancer Screening Program in Rural Areas (NCCSPRA) launched in 221
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10 pilot counties and a total of 11.69 million rural women between 35 and 59 years of age
11
12 accessed this screening program between 2009 and 2011.¹⁶ In one site that is the subject of
13
14 our study, Jining Prefecture, free breast cancer and cervical cancer screening has been
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16 available to rural women over 35 years of age since 2011, with the upper age limit extended
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18 from 59 to 64 years in 2014.¹⁰ Despite this, uptake rate of cervical cancer screening remains
19
20 very low.
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26 In China, a number of studies have been conducted into women's knowledge and attitudes
27
28 toward cervical cancer screening and related factors,¹⁷⁻²⁰ however most data have been
29
30 quantitative in nature, aiming to document the magnitude of demand-side barriers to access.
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32 This leaves gaps in understanding of underlying determinants of care-seeking, including the
33
34 reasons why women do not take up care-seeking, which require more qualitative research
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36 approaches.^{21 22} Therefore, this research aims to use qualitative inquiry to understand the
37
38 barriers to cervical cancer screening uptake among rural women in Jining Prefecture, and to
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40 contribute new policy and practice recommendations that can help reduce cervical cancer
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42 incidence.
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49 **METHODS**

50 **Study setting and design**

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4 This study was conducted in Shandong Province, which is located in eastern China with a
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6 population of more than 100 million.²³ In 2016, the gross regional product of Shandong
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8 Province amounted to CNY6803 billion (US\$1024 billion), ranking it as the third largest
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10 economy within China.²³ Jining Prefecture, located in the southwest of Shandong Province
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12 with a population of 8.35 million and the gross regional product of CNY430 billion (US\$63
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14 billion) in 2016.²⁴

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19 Descriptive phenomenology is used as a qualitative approach in this study. This study was
20
21 carried out at township level within two counties in Jining Prefecture of eastern China. The
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23 qualitative methods included semi-structured in-depth interviews with 21 women eligible for
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25 screening aged between 35 and 64 years, and with five cervical cancer screening services
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27 providers. These were supplemented by two focus group discussions with nine cervical
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29 cancer screening services providers, and four key informant interviews with husbands of
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31 women eligible for screening.
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36 37 **Study participants and sample**

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40 Two townships (Tangma and Xingcun) were randomly selected from within the two mainly
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42 rural areas of Sishui and Yutai Counties in Jining Prefecture. A convenience sample of 21 (10
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44 from Xingcun, 11 from Tangma) women were recruited to participate in interviews in
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46 collaboration with township community partners. The selection criteria included: women
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48 aged between 35 and 64 years, resident in the study townships, and women who had either
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50 never been screened or who had been screened once but failed to attend follow-up. Fourteen
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52 health care providers (seven from Xingcun, seven from Tangma) whose responsibilities
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3 included cervical cancer screening service provision, were purposefully selected for
4 interviews and focus group discussions. Five providers were invited to participate in
5 semi-structured in-depth interviews and nine in focus group discussions (four in the first and
6 five in the second group). Four key informant interviews (2 from Xingcun, 2 from Tangma)
7 were conducted with screening-eligible women's husbands. The numbers of interviews and
8 focus group discussions were intended to enable a theoretical saturation of qualitative
9 themes.
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22 **Data collection**

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24 All interviews and discussions were conducted over a one-week period in November 2017
25 by four researchers from Shandong University who had extensive knowledge of cervical
26 cancer, screening and HPV, and were trained in conducting qualitative research. Women
27 participants were interviewed in private rooms identified by community partners. Before
28 interviews, a short questionnaire assessed women participants' knowledge of general cancer
29 risk factors, symptoms of cancer, and screening techniques. The semi-structured in-depth
30 interviews with women included questions on sociodemographic characteristics and health
31 status, screening experience, beliefs about cervical cancer risk factors, perception of barriers
32 to screening uptake, the impact of a service providers' gender on cervical cancer screening
33 behavior, and a husband's reaction to her screening uptake and related topics. Interviews
34 lasted approximately 30 minutes.
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52 In-depth interviews and focus group discussions with providers were conducted close to
53 the work place and lasted approximately 30 and 45 minutes, respectively. The in-depth
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3 interviews and focus group discussions guide explored providers' perception of barriers to
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6 cervical cancer screening uptake for women. Key informant interviews with
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8 screening-eligible women's husbands were conducted in their home. Interviews guide
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11 included questions on their knowledge about cervical cancer, and attitudes towards screening
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13 for cervical cancer and potential barriers to uptake.

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16 Verbal informed consent using a standard script was obtained from all participants prior to
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18 interviews. All interviews and focus group discussions were digitally recorded.
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20 Confidentiality was ensured through using code numbers rather than names. Researchers
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22 took care to identify and reflect on any bias relating to differential status between themselves
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24 and interviewees, aiming to minimize this effect during the interview process. Each
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26 participant was given a vacuum beverage cup to compensate for their time commitment to
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29 the study.
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35 **Data analysis**

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38 All interviews and focus group discussions were transcribed verbatim and subjected to
39
40 thematic analysis. The transcripts were systematically read several times by two researchers
41
42 to identify both pre-determined and emerging themes relevant to barriers to cervical cancer
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44 screening, which were then elaborated as a coding list through consensus discussion among
45
46 three authors (YH, SL, QC). Codes were then used to identify themes that could be
47
48 consolidated into larger categories. Investigators then discussed and agreed on a standard
49
50 interpretation for each category of coded group of viewpoints. All analyses were performed
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53 in Chinese and the final results were translated into English.
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Ethical approval

This study was approved by the Medical Ethics Committee of Medical School, Shandong University (LL-201401048), and conforms to the ethics guidelines of the Declaration of Helsinki.

RESULTS

Sociodemographic characteristics of participants

Twenty-one rural women were included in this study. The mean age of participants was 48.7 \pm 6.4 years, with a range from 37 to 60 years, with more than half (57.1%) aged between 46 and 55 years. Most participants (95.2%) were married and most (90.5%) had an education level of primary school or below. About half of the participants (52.4%) had previously been screened once for cervical cancer. Table 1 shows details of the characteristics of participants.

Table 1 Sociodemographic characteristics of women interviewees, n (%).

Characteristics	Sishui(n = 10)	Yutai(n =11)	Total(n = 21)
Age (years)			
35~45	6(60.0)	0(0.0)	6(28.6)
46~55	3(30.0)	9(81.8)	12(57.1)
56~64	1(10.0)	2(18.2)	3(14.3)
Educational level			
No school	3(30.0)	5(45.5)	8(38.1)
Primary school	6(60.0)	5(45.5)	11(52.4)

Middle school or above	1(10.0)	1(9.0)	2(9.5)
Marital status			
Married	9(90.0)	11(100.0)	20(95.2)
Divorced or widowed	1(10.0)	0(0.0)	1(4.8)
Ever screened for cervical cancer			
Yes	7(70.0)	4(36.4)	11(52.4)
No	3(30.0)	7(63.6)	10(47.6)

Among the 14 health care providers, the mean age was 42.6 ± 9.0 years and most (64.2%) were aged between 41 and 50 years. They had an education level of junior college and above. Most providers were medical practitioners (50.0%). The mean age of four husbands who undertook key informant interviews was 50.7 ± 6.3 years, and all of them were small-hold farmers.

Key themes

Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers, (4) influence of close contacts, and (5) inconvenience. Each of these is elaborated below, including quotations from participants with their identification number and age.

Gaps in knowledge of cervical cancer and health awareness

Knowledge gaps and lack of access to reliable information on cervical cancer is reported as a major barrier to women's participation in cervical cancer screening. Most women indicated that they had heard about cervical cancer from their friends or television, however, almost none knew that HPV infection was the cause. Some cited inaccurate information and most

1
2
3 reported that their knowledge, especially about causes and symptoms, was speculative. For
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5
6 example, one reported misconception was that “cervical cancer will never happen after
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9 menopause”. Limited knowledge seemed linked to lack of awareness of being at any
10
11
12 personal risk of cervical cancer happening. When asked why she had not participated in
13
14
15 cervical cancer screening, one woman stated:

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17 *I think my health is in a good condition. I've never had anything serious, or any*
18
19 *symptoms. No symptoms, no examination. We only go to the hospital when we are*
20
21 *uncomfortable or feel sick.* (Woman 11, 53 years)

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23
24 One of the health provider focus groups also mentioned:

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28 *Cervix is a dumb organ. There are no symptoms nor is it typical in the early stage. It*
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30 *doesn't affect their work or daily life; there is even no bleeding. No symptoms, nothing at*
31
32 *all. They don't think they are infected, so there is no need to go through the screening.*

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35 (FGD 2, provider 05, 41 years)

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38 Gaps in health knowledge specific to disease prevention, as well as limited knowledge of
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41 the process, cycle, purpose and importance of screening. The importance of early screening
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44 prior to symptoms showing, was poorly recognized. These factors were reported to limit
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47 women's acceptance of or commitment to screening; hindering or postponing their
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50 participation in cervical cancer screening.

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52 A woman who had been notified to attend cervical cancer screening said:

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55 *I was told to do the screening yesterday. Well, I didn't want to. I thought I always have a*
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4 *good appetite and never feel uncomfortable. There's no point doing it. (Woman 04, 48*
5
6 *years)*

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9 Another woman who participated in cervical cancer screening only once stated:

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12 *I did the examination once and the doctor said I was good. So I never came back. Why*
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14 *bother when I'm good? (Woman 15, 55 years)*

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17 Health care provider viewpoints echoed this:

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21 *These women have low health care awareness. They wouldn't go to the hospital even if*
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23 *they have other common diseases. All they care about is if they could still do the*
24
25 *housework. They don't have much understanding of medicine, so they couldn't know the*
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27 *significance of early screening if they got the disease. (FGD 1, provider 03, 52 years)*
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30 31 **Fear of cancer and screening outcomes**

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35 The majority of women in the interviews expressed a deep fear of cancer. Some did not want
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37 to know if they had cervical cancer; a common reason provided for why they were unwilling
38
39 to attend the screening was that they did not want to learn the results. This fear extended to
40
41 any form of cancer terminology. Women wanted to avoid the anxiety and distress that would
42
43 be associated with being told of a cancer-related lesion:
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48 *It's a terrible disease. I'm afraid something bad might show. If I don't do the screening I*
49
50 *wouldn't know if I had it, I will at least have a good appetite. If the results were bad, I*
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52 *wouldn't feel comfortable knowing that. Appetites and good sleep would be gone for sure. I*
53
54 *would have more years to live freely if I didn't know it. (Woman 01, 37 years)*
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4 *People become upset whenever they talk about cancer. In the first 2 years of the*
5 *screening campaign, we couldn't put 'cancer screening' on the banner and used 'health*
6 *examination' instead. People couldn't take it if they saw the word 'cancer'. (FGD 2,*
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11 provider 01, 47 years)

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14 A husband also mentioned, during key informant interview:

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17 *They were all afraid they might have it. Older women would say 'why do the screening?*
18 *I would be upset if I knew I had it'. (Husband 02, 63 years)*
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23 Fear of a positive screening test was also related to the financial implications. Some women
24 with fewer economic resources reported avoiding screening because they were worried they
25 would not have the money for treatment if they were diagnosed with the cancer, noting that
26 at present, while screening is free of charge, treatment is not. This suggests that family
27 finances are likely to influence their participation, with families weighing up the impact of
28 debt against that of the disease:
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38 *We wouldn't afford the treatment even if we found out we had it, so it's better we don't*
39 *do it at all. Adults need money and so do children. The money would be wasted if we went*
40 *through the treatment and not cured. No need to spend money on a disease that can't be*
41 *cured. We don't want to add burden to the family. (Woman 10, 54 years)*
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48 Two focus groups also noticed this:

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51 *People only see nearly 100,000 yuan for the surgery and it's a very heavy burden. The*
52 *disease would drag the already poor family into debt. They can't take it. (FGD 1, provider*
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02, 44 years)

There are indeed financial problems, especially for rural families. They think they don't feel anything right now, if they find out they are infected after the screening they have to go through the treatment and spend money. So it's better not to do the screening at all.

(FGD 2, provider 03, 41 years)

Cultural barriers

A common report, especially among older women, was a reluctance to remove clothing or allow genital examination, especially being exposed in front of non-family members. It was mentioned by nearly all women that they felt embarrassed about this step. Informants related this to cultural norms in their rural setting, and among Chinese women more generally.

Felt like a very private part and I don't want other people to see it. That's the thought. Yes it's embarrassing. I'm too old. Don't want to be a joke. So ashamed. (Woman 09, 55 years)

When I went to the gynecology for the screening, I went inside and the doctor told me to take off my pants, and I suddenly didn't want to do the screening. (Woman 02, 48 years)

Participants were specifically asked about willingness to accept screening by male doctors. For some participants, the gender of the service provider seemed a barrier; nearly half indicated that they would not undertake screening if performed by a male doctor.

I wouldn't go if a man was doing the examination. It's less acceptable than a woman. It's so private and men are so improper for that. (Woman 14, 41 years)

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3 A female service provider mentioned:
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6 *They are very conservative. Some women with vaginitis go to the clinic. We tell them to*
7 *take off the pants and they are embarrassed. Some even put up with the disease until they*
8 *can't. So they would be more uncomfortable if male doctors are here. (Provider 01, 63*
9 *years)*
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16 **Influence of close contacts**

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18 It was found that close contacts (such as mothers, sisters or neighbors) were an important
19
20 factor influencing women's participation in cervical cancer screening. Knowing other people
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22 who had been screened or who had been diagnosed with cervical cancer and undertaken
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24 treatment was reported to increase participation in screening. The converse was also true,
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26 with reports that if close contacts were not willing to participate, this reduced affected
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28 women's acceptance of screening. This was also reported to generate clusters of women who
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30 would refuse screening.
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38 *I wouldn't know it if they (the neighbors) asked me to come along. If the others (the*
39 *neighbors) don't come, I wouldn't either. It's good to have someone with you. I wouldn't*
40 *come by myself. (Woman 05, 55 years)*
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46 *I would for sure not come by myself. (Woman 06, 48 years)*
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49 A service provider mentioned a similar situation during the screening campaign:
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52 *We met this situation once when we were doing the screening in a town. Several women*
53 *came together and they learned they need to take off the pants. One said 'This is what it is.*
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4 *Forget it. Let's go'. And all of them felt reluctant and left together. It's a group mentality.*

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6 (Provider 03, 43 years)

7 8 9 **Inconvenience**

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Difficulty in scheduling, or otherwise allocating time for screening was considered to be a significant barrier to women's participation. Many women eligible for screening work in disparate locations throughout the year and may and only return home at the time of Spring Festival. Such holidays are busy with limited time available for activities such as routine health checks. One working woman stated that leave is only feasible for actual illness.

I work elsewhere and only ask for leave when they have an emergency or special occasions at home. It's hard to ask for leave and I lose some salary for that. Usually I come home once a year for only 5 or 6 days. It's not enough. (Woman 21, 40 years)

Many rural people go to other places to work and don't come home often. We call them to come back but they can't. They don't get paid if they ask for leave and it's too expensive on the road. So they don't want to come back. (Provider 02, 44 years)

Women who do not travel for work also report many demands on their time including family business, child-care, housework and farming duties that are often seasonal. Lack of time for routine health care is reported as a barrier to cervical cancer screening either. When asked why not attend the screening, a woman who had never gone through the examination said:

I'm always busy with the kids going to school every day and housework never seems to

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4 *end. Family and housework are the most important for me. So I somehow forget about it*
5
6 *(the screening). (Woman 08, 46 years)*
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9 *I tell you we farmers are pretty busy. When we are not, we want to do some small*
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11 *business to make money. So no time for examinations. (Woman 19, 56 years)*
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14 15 16 **DISCUSSION**

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19 This study used standard qualitative tools to explore the barriers to attending cervical cancer
20 screening among rural women in Jining Prefecture of Shandong province in eastern China.
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22 Such in-depth assessments have rarely been reported in Chinese literature. Our study
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24 identified gaps in knowledge of cervical cancer and health awareness, fear of cancer and
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26 screening outcomes, cultural barriers, the influence of close contacts, and inconvenience as
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28 frequently cited barriers.
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35 Our findings on gaps in knowledge or awareness are echoed in studies from other
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37 resource-constrained settings, with specific misconceptions and poor awareness of the
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39 benefits of routine health checks reported from diverse settings including Burkina Faso,
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41 ²⁵Iran, ²⁶Malawi, ^{27 28}Nigeria²⁹ and elsewhere. Reluctance to seek care in the absence of
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43 symptoms is a common theme, seen also in high-income settings such as Norway, ³⁰and this
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45 was one of the most important constraints identified in our study. Our finding that there is
46
47 very low awareness of the risks posed by cervical cancer is seen elsewhere in China.^{31 32}
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53 Fear poses a significant psychological barrier to care-seeking for cervical cancer screening.
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55 This includes the general fear of “cancer” as a vicious and intractable class of disease,³³ and
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4 the fear that it would not be possible to emotionally cope with a diagnosis, seen in relation to
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6 cervical cancer in our findings and in other high- middle- and low-income settings.^{34 35 36} A
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8 study among Mexican women shows that women reported not attending cervical cancer
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10 screening because of fear of ‘knowing,’ that is, prefer to live with hopeful doubts instead of
11
12 facing the possibility of an unfavorable result.³⁷ This poses a key knowledge challenge to
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14 community health education efforts; they must find ways to not only build knowledge of the
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16 risks of an asymptomatic disease, but also address the misconceptions and emotions aroused
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18 by cancer more generally, in order to build trust that timely screening can render cervical
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20 cancer treatable.
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26 The influence of women’s close contacts risks generating clusters of mutually-reinforcing
27
28 resistance to screening,³⁸ with partners playing a key role.^{39 40} This suggests some education
29
30 initiatives will need to address whole communities and possibly include peer-education
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32 approaches that encourage positive health discussions among friends.
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36 In our study, like other resource-constrained settings²⁸ fears of financial catastrophe
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38 generated by high treatment costs also posed a barrier to screening. In our context this
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40 emphasizes the need for health planners to understand the pragmatic choices families make
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42 when health care costs are seen as unaffordable. Making treatment financially accessible, for
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44 cervical cancer and many other protracted diseases, is a key challenge facing China’s public
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46 health system reformers.
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51 We found culturally based embarrassment to be a key barrier. Such associations with
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53 concepts of conservatism and modesty obstruct access to reproductive health in general and
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4 cervical cancer screening in particular in our and many other settings,^{31 41-43} especially when
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6 providers are male,^{44 45} or women are older.⁴⁶ For such communities in China and Asian
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8 populations elsewhere,⁴⁷ this requires providers of screening to have high levels of cultural
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10 competence, and planners to ensure sufficient numbers of female providers.
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14 Inconvenient screening services, in terms of timing and location also posed a major barrier
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16 for the rural women in our study. This applies to those who must relocate for paid work and
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18 those whose family care duties leave little time for health screening, and findings were seen
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20 in a wide range of settings.^{34 48 49} Delivering services at times, even holiday times, and in
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22 places where women already congregate, perhaps through mobile services, may help
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24 overcome this barrier in China, and elsewhere.⁴⁷
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30 These findings have several implications for practice, as noted above in relation to each
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32 key theme. In addition, new methods for screening⁵⁰ using automated nucleic acid
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34 amplification tests may help overcome timing and location constraints by allowing more
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36 rapid screening, and may help overcome cultural constraints by allowing women to
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38 self-collect vaginal swab samples.
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43 Our study acknowledges the usual limitations of qualitative research, with our findings
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45 immediately generalizable only to our sample of women from rural area of Jining were
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47 characterized by low educational levels. However, this is, unusually for China, an in-depth
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49 assessment of women, providers and husbands, which we believe will be useful across a
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51 wide range of settings where uptake is poor, and provide a basis for future research.
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CONCLUSION

In summary, our study details important barriers to cervical cancer screening in terms of gaps in knowledge, fear of cancer and screening outcomes, cultural embarrassment, the influence of close contacts, and inconvenience. We hope policy makers and planners can make use of these findings to improve education and service delivery for screening that will decrease the incidence and mortality rates of cervical cancer in China.

Acknowledgments

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Author Contributions

Huan Yang completed the data collection and analyses, and wrote the manuscript. Shunping Li designed the study, collected the data, and edited the manuscript. Qing Chen designed the study and collected the data. Chris Morgan helped design the study, supported interpretation of findings, and edited the manuscript. All authors have read and approved the final manuscript.

Competing Interests

The authors declare no conflict of interest.

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4 This work was supported by China Medical Board Open Competition Grant [Grant number
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6 CMB14-195]. Responsibility for any remaining errors lies solely with the authors.
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9 **Ethics approval**

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12 The study was approved by the Medical Ethics Committee of Medical School, Shandong
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14 University (LL-201401048).
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17 **Data sharing**

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20 No additional data are available.
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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	2
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5
Purpose or research question	#4 Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	6
Researcher characteristics and reflexivity	#6 Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or	7-8

1		presuppositions; potential or actual interaction between	
2		researchers' characteristics and the research questions,	
3		approach, methods, results and / or transferability	
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6	Context	#7 Setting / site and salient contextual factors; rationale	5-6
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9	Sampling strategy	#8 How and why research participants, documents, or events	6-7
10		were selected; criteria for deciding when no further sampling	
11		was necessary (e.g. sampling saturation); rationale	
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15	Ethical issues	#9 Documentation of approval by an appropriate ethics review	8-9
16	pertaining to human	board and participant consent, or explanation for lack thereof;	
17	subjects	other confidentiality and data security issues	
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21	Data collection	#10 Types of data collected; details of data collection procedures	7-8
22	methods	including (as appropriate) start and stop dates of data	
23		collection and analysis, iterative process, triangulation of	
24		sources / methods, and modification of procedures in	
25		response to evolving study findings; rationale	
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31	Data collection	#11 Description of instruments (e.g. interview guides,	7-8
32	instruments and	questionnaires) and devices (e.g. audio recorders) used for	
33	technologies	data collection; if / how the instruments(s) changed over the	
34		course of the study	
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38	Units of study	#12 Number and relevant characteristics of participants,	9-10
39		documents, or events included in the study; level of	
40		participation (could be reported in results)	
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44	Data processing	#13 Methods for processing data prior to and during analysis,	8
45		including transcription, data entry, data management and	
46		security, verification of data integrity, data coding, and	
47		anonymisation / deidentification of excerpts	
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52	Data analysis	#14 Process by which inferences, themes, etc. were identified and	8
53		developed, including the researchers involved in data	
54		analysis; usually references a specific paradigm or approach;	
55		rationale	
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1	Techniques to	#15	Techniques to enhance trustworthiness and credibility of data	8
2	enhance		analysis (e.g. member checking, audit trail, triangulation);	
3	trustworthiness		rationale	
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7	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and themes);	10
8	interpretation		might include development of a theory or model, or integration	
9			with prior research or theory	
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13	Links to empirical	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs)	10-16
14	data		to substantiate analytic findings	
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18	Intergration with	#18	Short summary of main findings; explanation of how findings	16-18
19	prior work,		and conclusions connect to, support, elaborate on, or	
20	implications,		challenge conclusions of earlier scholarship; discussion of	
21	transferability and		scope of application / generalizability; identification of unique	
22	contribution(s) to the		contributions(s) to scholarship in a discipline or field	
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28	Limitations	#19	Trustworthiness and limitations of findings	18-19
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32	Conflicts of interest	#20	Potential sources of influence of perceived influence on study	19
33			conduct and conclusions; how these were managed	
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36	Funding	#21	Sources of funding and other support; role of funders in data	19-20
37			collection, interpretation and reporting	
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The SRQR checklist is distributed with permission of Wolters Kluwer © 2014 by the Association of American Medical Colleges. This checklist was completed on 29. August 2018 using <http://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)

BMJ Open

Barriers to Cervical Cancer Screening among Rural Women in Eastern China: a Qualitative Study

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Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health, Health policy, Health services research
Keywords:	barriers, cervical cancer, cancer screening, China

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Manuscripts

Barriers to Cervical Cancer Screening among Rural Women in Eastern China: a Qualitative Study

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Keywords barriers; cervical cancer; cancer screening; China

Word count 4363

ABSTRACT

Objectives To explore barriers to free cervical cancer screening among rural women in China from the perspective of women, healthcare providers and women's husbands to inform intervention planning.

Design A qualitative study framed around potential policy and practice options, drawing on the concepts of descriptive phenomenology and implementation research.

Setting This study was carried out at township level within two counties in Jining Prefecture of eastern China.

Participants and data collection Semi-structured in-depth interviews with 21 women and five healthcare providers, focus group discussions with nine healthcare providers, and key informant interviews with 4 husbands of women eligible for screening.

Results Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers including reticence for intimate examinations, (4) influence of close contacts on screening decisions, and (5) inconvenience. These demonstrate key knowledge gaps challenging current community health education. Important service barriers, including with fear of treatment cost, and the time needed for screening were also raised.

Conclusion Our study details important barriers to cervical cancer screening relating to knowledge gaps, attitudes of fear or embarrassment, and the role of contacts and service models. These provide data for policy and planning to improve the screening that will

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4 decrease the incidence and mortality rates of cervical cancer in China.
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7 **Article Summary**

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10 **Strengths and limitations of this study**

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- 14 ■ The qualitative methods allowed for detailed and deep responses and triangulation
15 across providers, clients and their partners.
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- 18 ■ The findings have direct relevance to policy makers considering the development of
19 interventions to increase uptake rate of cervical cancer screening in our setting.
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- 22 ■ Our purposive sampling may bias our findings to those representative of women with
23 lower educational levels and low uptake of services.
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- 26 ■ Some social acceptability bias may have influenced focus group discussion findings,
27 which we attempted to counter-balance with individual interview data.
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- 30 ■ As a qualitative study, there are limits to generalizability beyond our setting.
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INTRODUCTION

Infection with the human papilloma virus (HPV) is the most significant risk factor for cervical cancer which can be transmitted during sexual intercourse.¹ The majority of HPV infections resolve spontaneously and do not cause symptoms or disease.² However, persistent infection with specific types of HPV (most frequently, types 16 and 18) may lead to precancerous lesions, which, if not treated, can progress to cancer 10 to 20 years later.³ Cervical cancer is a preventable and treatable disease, and screening of precancerous lesions can reduce its incidence and mortality.⁴ In many high-income countries, the incidence and mortality of cervical cancer have decreased significantly because of the efforts made to detect precancerous lesions early.^{5 6} However, in low- or middle-income countries, cervical cancer remains the most common cause of cancer-related deaths among women.⁷

Cervical cancer is recognized as a major public health problem in China,⁸ both in mortality and morbidity burden, the latter causing protracted economic stress on women, heaviest in rural communities. As part of responses in 2009, a new round of deepening health system reforms intended to integrate the breast cancer and cervical cancer screening programs in rural areas into broader national public health services.⁹ The government's National Cervical Cancer Screening Program in Rural Areas (NCCSPRA) launched in 221 pilot counties and a total of 11.69 million rural women between 35 and 59 years of age accessed this screening program between 2009 and 2011.¹⁰ In one site that is the subject of our study, Jining Prefecture, free breast cancer and cervical cancer screening has been available to rural women over 35 years of age since 2011, with the upper age limit extended

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4 from 59 to 64 years in 2014, with three free screens available to women up until November
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6 2017.⁴ However uptake rate of the free service remains very low.⁴
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10 In China, a number of studies have been conducted into women's knowledge and attitudes
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12 toward cervical cancer screening and related factors,¹¹⁻¹⁴ however most data have been
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14 quantitative in nature.¹²⁻¹⁴ This leaves gaps in understanding of underlying determinants of
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16 care-seeking, including the reasons why women do not take up free care-seeking, which
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18 require more qualitative research approaches.^{15 16} Therefore, this research aimed to gain a
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20 deeper understanding of the nature of barriers to uptake of free cervical cancer screening by
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22 rural women in Jining Prefecture, using a design that can suggest new policy and practice
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24 approaches that may be able to increase future uptake and reduce the burden of cervical
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26 cancer.
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34 **METHODS**

35 **Study setting and design**

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38 This study was conducted in Shandong Province, which is located in eastern China with a
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40 population of more than 100 million.¹⁷ In 2016, the gross regional product of Shandong
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42 Province amounted to CNY6803 billion (US\$1024 billion), ranking it as the third largest
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44 economy within China.¹⁷ Jining Prefecture, located in the southwest of Shandong Province
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46 with a population of 8.35 million and the gross regional product of CNY430 billion (US\$63
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48 billion) in 2016.¹⁸
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58 Our study design drew on descriptive phenomenology,¹⁹ concepts of acceptability and
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4 appropriateness in health implementation research,²⁰ and was framed by options for change
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6 in policy or practice, as identified by local health managers and experts. These helped
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8 identify qualitative tools, and categories of inquiry, deemed useful to understand knowledge
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10 and attitudes affecting women's and family's decision-making in relation to screening. The
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12 qualitative data collection methods included semi-structured in-depth interviews with 21
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14 women eligible for free screening aged between 35 and 64 years, and with five healthcare
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16 providers. These were supplemented by focus group discussions with healthcare providers of
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18 varying disciplines (described below) aiming to use discussion to elicit contrasting
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20 disciplinary perspectives. To gain a partner perspective, key informant interviews were
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22 conducted with husbands of women eligible for screening.
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31 **Study participants and sample**

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34 Two townships (Tangma and Xingcun) were randomly selected from within the mainly rural
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36 areas of Sishui and Yutai Counties in Jining Prefecture in eastern China. Purposive sampling
37
38 was used to focus research on those were representative of women as less likely to take up
39
40 screening, identified by local health managers. The selection criteria included: women aged
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42 between 35 and 64 years (those eligible for free screening and at higher risk), resident in the
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44 study townships, not in formal employment, and those who had either never been screened
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46 or who had failed to attend a second or third follow-up screening. Twenty-one women (10
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48 from Xingcun, 11 from Tangma) were recruited in collaboration with township community
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50 partners. One third had never been screened, one third screened once, and one third screened
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52 twice. Fourteen health care providers (7 from Xingcun, 7 from Tangma) including hospital
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4 managers, public health directors and medical practitioners whose responsibilities included
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6 contact, recording and managing data for screening and screening service provision, were
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8 purposefully selected by discipline mix. Five providers took part in semi-structured in-depth
9
10 interviews and nine in two focus group discussions (four in the first and five in the second
11
12 group). Four key informant interviews (2 from Xingcun, 2 from Tangma) were conducted
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14 with screening-eligible women's husbands who were purposefully selected and weren't
15
16 related to the women participants. The numbers of interviews and focus group discussions
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18 were designed to enable a theoretical saturation of qualitative themes, and data collection
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20 ceased when no new information was being obtained.
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28 **Data collection**

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31 All interviews and discussions were conducted over a one-week period in November 2017
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33 by four researchers from Shandong University who had extensive knowledge of cervical
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35 cancer, and were trained in conducting qualitative research and interviews on sensitive
36
37 topics. Women participants were interviewed in healthcare institutions identified by
38
39 community partners. Individual interviews in private rooms gave participants the opportunity
40
41 to speak freely and comfortably. Before interviews, a short questionnaire⁴ including 17 items
42
43 was used to assess knowledge on cervical cancer, risk factors, symptoms, and the objectives
44
45 and processes of cervical cancer screening. Consistent with earlier studies, responses were
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47 scored as correct (one point), incorrect or "do not know" (zero points), with numbers of
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49 correct scores used to categorize respondents into 2 groups: "high level of knowledge"
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51 (score 9 to 17) or "low level of knowledge" (score 0-8).^{21 22} The semi-structured in-depth
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interviews with women used open questions in categories informed by our design, with detailed probes to deepen responses (Table 1). Topics covered included sociodemographic characteristics, screening experience, purpose of cervical cancer screening, perception of barriers to screening uptake and suggestions for overcoming barriers.

Table 1 Overview of question categories in semi-structured in-depth interviews

Knowledge of cervical cancer screening
Have you heard about cervical cancer screening?
What do you understand cervical cancer screening?
Why cervical cancer screening is done?
Barriers to cervical cancer screening
Why don't you take free cervical cancer screening?
Why do you think other women don't take free cervical cancer screening?
Suggestions for overcoming barriers
How do you think these barriers could be overcome?

In-depth interviews and focus group discussions with providers were conducted close to the work place and lasted approximately 30 and 45 minutes, respectively. The in-depth interviews and focus group discussions guide (Table 2) explored providers' experiences in providing screening services, perception of barriers to cervical cancer screening uptake for women, and suggestions for overcoming barriers. Key informant interviews with husbands were conducted in their home. Interviews guide included questions on their knowledge about cervical cancer, and attitudes towards screening for cervical cancer and potential barriers to uptake for women.

Table 2 Overview of discussion/question categories for focus groups and provider interviews

Experience in providing screening services
How long have you provided screening services?
What are your responsibilities for screening services?
Barriers to cervical cancer screening
Why do you think women don't take free cervical cancer screening?
Suggestions for overcoming barriers
How do you think these barriers could be overcome?

Verbal informed consent using a standard script was obtained from all participants prior to interviews. All interviews and focus group discussions were digitally recorded. Confidentiality was ensured through using code numbers rather than names. Researchers took care to identify and reflect on any bias relating to differential status between themselves and interviewees, using introductory explanations on themselves their neutrality and the study purpose, ensuring simple comprehensible language, and maintaining careful non-judgmental listening, in order to minimize bias during the interview process. Each participant was given a vacuum beverage cup to compensate for their time commitment to the study.

Data analysis

All interviews and focus group discussions were transcribed verbatim and subjected to thematic analysis.²³ We analyzed the data across all stakeholder groups collectively. HY collated interview and questionnaire data across all sites, ensuring consistency supervised by

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4 SL for data integrity. HY and SL jointly read all transcripts and developed themes (both
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6 pre-determined by our design and emerging), a topic index and code structure. HY, SL and
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8 QC undertook coding and thematic consolidation, with any differences discussed and
9
10 resolved through consensus. These analyses were performed in Chinese and then translated
11
12 into English by HY for further review by SL, QC and CM. Care was taken to ensure data
13
14 validity in the translation of dialect and colloquialisms.
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21 **Ethical approval**

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24 This study was approved by the Medical Ethics Committee of Medical School, Shandong
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26 University (LL-201401048), and conforms to the ethics guidelines of the Declaration of
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28 Helsinki.
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33 **Patient and public involvement**

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36 Participants were not involved in the study design and conduct, but their experiences and
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38 preferences will inform the development of the research questions to generate major themes
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40 for analysis. Public involvement including community partners were involved in the
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42 recruitment process. A policy brief containing findings and implications will be provided to
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44 local policy makers and managers, and to community leaders for dissemination to study
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46 participants.
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53 **RESULTS**

54 **Sociodemographic characteristics of participants**

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There were no refusals of consent or drop-outs during participation, with a total of twenty-one rural women participating. The mean age of participants was 48.7 ± 6.4 years, with a range from 37 to 60 years, with more than half (57.1%) aged between 46 and 55 years. Most participants (95.2%) were married and most (90.5%) had an education level of primary school or below. About half of the participants (52.4%) had previously been screened once for cervical cancer. Table 3 shows details of the characteristics of participants. The mean knowledge scores were 4.4 ± 2.3 (range from 0 to 10).

Table 3 Sociodemographic characteristics of women interviewees, n (%).

Characteristics	Sishui(n = 10)	Yutai(n =11)	Total(n = 21)
Age (years)			
35~45	6(60.0)	0(0.0)	6(28.6)
46~55	3(30.0)	9(81.8)	12(57.1)
56~64	1(10.0)	2(18.2)	3(14.3)
Educational level			
No school	3(30.0)	5(45.5)	8(38.1)
Primary school	6(60.0)	5(45.5)	11(52.4)
Middle school or above	1(10.0)	1(9.0)	2(9.5)
Marital status			
Married	9(90.0)	11(100.0)	20(95.2)
Divorced or widowed	1(10.0)	0(0.0)	1(4.8)
Ever screened for cervical cancer			
Yes	7(70.0)	4(36.4)	11(52.4)
No	3(30.0)	7(63.6)	10(47.6)

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4 Among the 14 health care providers, the mean age was 42.6 ± 9.0 years and most (64.2%)
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6 were aged between 41 and 50 years. They had an education level of junior college and
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8 above. Most providers were medical practitioners (50.0%). The mean age of four husbands
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10 who undertook key informant interviews was 50.7 ± 6.3 years, and all of them were
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12 small-hold farmers.
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16 17 18 **Key themes**

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21 Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer
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23 and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers, (4)
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25 influence of close contacts, and (5) inconvenience. Each of these is elaborated below,
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27 including quotations from participants with their identification number and age.
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32 33 **Gaps in knowledge of cervical cancer and health awareness**

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36 Knowledge gaps and lack of access to reliable information on cervical cancer is reported as a
37
38 major barrier to women's participation in cervical cancer screening. The results of this
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40 questionnaires showed that the majority of women participants had a low level of cervical
41
42 cancer knowledge. Most women indicated that they had heard about cervical cancer from
43
44 their friends or television, however, almost none knew that HPV infection was the cause.
45
46 Some cited inaccurate information and most reported that their knowledge, especially about
47
48 causes and symptoms, was speculative. For example, one reported misconception was that
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50 "cervical cancer will never happen after menopause". Limited knowledge seemed linked to
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52 lack of awareness of being at any personal risk of cervical cancer happening. When asked
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54 why she had not participated in cervical cancer screening, one woman stated:
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4 *I think my health is in a good condition. I've never had anything serious, or any*
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6 *symptoms. No symptoms, no examination. We only go to the hospital when we are*
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8 *uncomfortable or feel sick. (Woman 11, 53 years)*
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12 One of the health provider focus groups also mentioned:
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16 *Cervix is a dumb organ. There are no symptoms nor is it typical in the early stage. It*
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18 *doesn't affect their work or daily life; there is even no bleeding. No symptoms, nothing at*
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20 *all. They don't think they are infected, so there is no need to go through the screening.*
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22 (FGD 2, provider 05, 41 years)
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27 Gaps in health knowledge specific to disease prevention, as well as limited knowledge of
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29 the process, cycle, purpose and importance of screening. The importance of early screening
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31 prior to symptoms showing, was poorly recognized. These factors were reported to limit
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33 women's acceptance of or commitment to screening, hindering or postponing their
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35 participation in cervical cancer screening.
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40 A woman who had been notified to attend cervical cancer screening said:
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44 *I was told to do the screening yesterday. Well, I didn't want to. I thought I always have*
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46 *a good appetite and never feel uncomfortable. There's no point doing it. (Woman 04, 48*
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48 *years)*
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52 Another woman who participated in cervical cancer screening only once stated:
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56 *I did the examination once and the doctor said I was good. So I never came back. Why*
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58 *bother when I'm good? (Woman 15, 55 years)*
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4 Health care provider viewpoints echoed this:
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7 *These women have low health care awareness. They wouldn't go to the hospital even if*
8 *they have other common diseases. All they care about is if they could still do the*
9 *housework. They don't have much understanding of medicine, so they couldn't know the*
10 *significance of early screening if they got the disease. (FGD 1, provider 03, 52 years)*
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15 16 17 18 **Fear of cancer and screening outcomes** 19

20 The majority of women in the interviews expressed a deep fear of cancer. Some did not want
21 to know if they had cervical cancer, a common reason provided for why they were unwilling
22 to attend the screening was that they did not want to learn the results. This fear extended to
23 any form of cancer terminology. Women wanted to avoid the anxiety and distress that would
24 be associated with being told of a cancer-related lesion:
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36 *It's a terrible disease. I'm afraid something bad might show. If I don't do the screening*
37 *I wouldn't know if I had it, I will at least have a good appetite. If the results were bad, I*
38 *wouldn't feel comfortable knowing that. Appetites and good sleep would be gone for sure.*
39 *I would have more years to live freely if I didn't know it. (Woman 01, 37 years)*
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47 *People become upset whenever they talk about cancer. In the first 2 years of the*
48 *screening campaign, we couldn't put 'cancer screening' on the banner and used 'health*
49 *examination' instead. People couldn't take it if they saw the word 'cancer'. (FGD 2,*
50 *provider 01, 47 years)*
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58 A husband also mentioned, during key informant interview:
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4 *They were all afraid they might have it. Older women would say 'why do the screening?*

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7 *I would be upset if I knew I had it' .(Husband 02, 63 years)*

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10 Fear of a positive screening test was also related to the financial implications. Some women
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12 with fewer economic resources reported avoiding screening because they were worried they
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14 would not have the money for treatment if they were diagnosed with the cancer, noting that
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16 at present, while screening is free of charge, treatment is not. This suggests that family
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18 finances are likely to influence their participation, with families weighing up the impact of
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20 debt against that of the disease:
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26 *We wouldn't afford the treatment even if we found out we had it, so it's better we don't*
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28 *do it at all. Adults need money and so do children. The money would be wasted if we went*
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30 *through the treatment and not cured. No need to spend money on a disease that can't be*
31
32 *cured. We don't want to add burden to the family. (Woman 10, 54 years)*
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37 Two focus groups also noticed this:

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41 *People only see nearly 100,000 yuan for the surgery and it's a very heavy burden. The*
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43 *disease would drag the already poor family into debt. They can't take it. (FGD 1, provider*
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45 *02, 44 years)*

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49 *There are indeed financial problems, especially for rural families. They think they don't*
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51 *feel anything right now, if they find out they are infected after the screening they have to*
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53 *go through the treatment and spend money. So it's better not to do the screening at all.*
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57 (FGD 2, provider 03, 41 years)
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Cultural barriers

A common report, especially among older women, was a reluctance to remove clothing or allow genital examination, especially being exposed in front of non-family members. It was mentioned by nearly all women that they felt embarrassed about this step. Informants related this to cultural norms in their rural setting, and among Chinese women more generally.

Felt like a very private part and I don't want other people to see it. That's the thought. Yes it's embarrassing. I'm too old. Don't want to be a joke. So ashamed. (Woman 09, 55 years)

When I went to the gynecology for the screening, I went inside and the doctor told me to take off my pants, and I suddenly didn't want to do the screening. (Woman 02, 48 years)

Participants were specifically asked about willingness to accept screening by male doctors. For some participants, the gender of the service provider seemed a barrier; nearly half indicated that they would not undertake screening if performed by a male doctor.

I wouldn't go if a man was doing the examination. It's less acceptable than a woman. It's so private and men are so improper for that. (Woman 14, 41 years)

A female service provider mentioned:

They are very conservative. Some women with vaginitis go to the clinic. We tell them to take off the pants and they are embarrassed. Some even put up with the disease until they can't. So they would be more uncomfortable if male doctors are here. (Provider 01, 63 years)

Influence of close contacts

It was found that close contacts (such as mothers, sisters or neighbors) were an important factor influencing women's participation in cervical cancer screening. Knowing other people who had been screened or who had been diagnosed with cervical cancer and undertaken treatment was reported to increase participation in screening. The converse was also true, with reports that if close contacts were not willing to participate, this reduced affected women's acceptance of screening. This was also reported to generate clusters of women who would refuse screening.

I wouldn't know it if they (the neighbors) asked me to come along. If the others (the neighbors) don't come, I wouldn't either. It's good to have someone with you. I wouldn't come by myself. (Woman 05, 55 years)

I would for sure not come by myself. (Woman 06, 48 years)

A service provider mentioned a similar situation during the screening campaign:

We met this situation once when we were doing the screening in a town. Several women came together and they learned they need to take off the pants. One said 'This is what it is. Forget it. Let's go'. And all of them felt reluctant and left together. It's a group mentality.
(Provider 03, 43 years)

Inconvenience

Difficulty in scheduling, or otherwise allocating time for screening was considered to be a significant barrier to women's participation. Many women eligible for screening work in

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4 disparate locations throughout the year and may and only return home at the time of Spring
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6 Festival. Such holidays are busy with limited time available for activities such as routine
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8 health checks. One working woman stated that leave is only feasible for actual illness.
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12 *I work elsewhere and only ask for leave when they have an emergency or special*
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14 *occasions at home. It's hard to ask for leave and I lose some salary for that. Usually I*
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16 *come home once a year for only 5 or 6 days. It's not enough. (Woman 21, 40 years)*
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21 *Many rural people go to other places to work and don't come home often. We call them*
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23 *to come back but they can't. They don't get paid if they ask for leave and it's too expensive*
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25 *on the road. So they don't want to come back. (Provider 02, 44 years)*
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29 Women who do not travel for work also report many demands on their time including
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31 family business, child-care, housework and farming duties that are often seasonal. Lack of
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33 time for routine health care is reported as a barrier to cervical cancer screening either. When
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35 asked why not attend the screening, a woman who had never gone through the examination
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37 said:
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43 *I'm always busy with the kids going to school every day and housework never seems to*
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45 *end. Family and housework are the most important for me. So I somehow forget about it*
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47 *(the screening). (Woman 08, 46 years)*
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52 *I tell you we farmers are pretty busy. When we are not, we want to do some small*
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54 *business to make money. So no time for examinations. (Woman 19, 56 years)*
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57 58 59 60 **DISCUSSION**

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4 This study used standard qualitative tools to explore the barriers to attending cervical cancer
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6 screening among rural women in Jining Prefecture of Shandong province in eastern China.
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9 Such in-depth assessments have rarely been reported in Chinese literature. Our study
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11 identified gaps in knowledge of cervical cancer and health awareness, fear of cancer and
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13 screening outcomes, cultural barriers, the influence of close contacts, and inconvenience as
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15 frequently cited barriers.
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21 Our findings on gaps in knowledge or awareness are echoed in studies from other
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23 resource-constrained settings, with specific misconceptions and poor awareness of the
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25 benefits of routine health checks reported from diverse settings including Burkina Faso,
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27 ²⁴Iran,²⁵ Malawi,^{26 27} Nigeria²⁸ and elsewhere. Reluctance to seek care in the absence of
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29 symptoms is a common theme, seen also in high-income settings such as Norway,²⁹ and this
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31 was one of the most important constraints identified in our study. Our finding that there is
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33 very low awareness of the risks posed by cervical cancer is seen elsewhere in China.^{30 31}
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35 Accessible and attractive educational products tailored to rural women are urgently needed
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37 to communicate accurate information about cervical cancer, those at risk, screening methods,
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39 treatments available, and the need for regular checks.
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48 Fear poses a significant psychological barrier to care-seeking for cervical cancer
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50 screening. This includes the general fear of “cancer” as a vicious and intractable class of
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52 disease,³² and the fear that it would not be possible to emotionally cope with a diagnosis,
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54 seen in relation to cervical cancer in our findings and in other high- middle- and low-income
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56 settings.^{33 34 35} A study among Mexican women shows that women reported not attending
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4 cervical cancer screening because of fear of ‘knowing,’ that is, prefer to live with hopeful
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6 doubts instead of facing the possibility of an unfavorable result.³⁶ This poses a key
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8 knowledge challenge to community health education efforts. They must find ways to not
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10 only build knowledge of the risks of an asymptomatic disease, but also address the
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12 misconceptions and emotions aroused by cancer more generally, in order to build trust that
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14 timely screening can render cervical cancer treatable.
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21 The influence of women’s close contacts risks generating clusters of mutually-reinforcing
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23 resistance to screening,³⁷ with partners playing a key role.^{38 39} This suggests some education
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25 initiatives will need to address whole communities and possibly include peer-education
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27 approaches that encourage positive health discussions among friends.
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32 In our study, like other resource-constrained settings²⁷ fears of financial catastrophe
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34 generated by high treatment costs also posed a barrier to screening. In our context this
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36 emphasizes the need for health planners to understand the pragmatic choices families make
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38 when health care costs are seen as unaffordable. Making treatment financially accessible, for
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40 cervical cancer and many other protracted diseases, is a key challenge facing China’s public
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42 health system reformers.
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49 We found culturally based embarrassment to be a key barrier. Such associations with
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51 concepts of conservatism and modesty obstruct access to reproductive health in general and
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53 cervical cancer screening in particular in our and many other settings,^{30 40-42} especially when
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55 providers are male,^{43 44} or women are older.⁴⁵ For such communities in China and Asian
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57 populations elsewhere,⁴⁶ this requires providers of screening to have high levels of cultural
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4 competence, and planners to ensure sufficient numbers of female providers. On the other
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6 hand, inconvenient screening services, in terms of timing and location also posed a major
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8 barrier for the rural women in our study. This applies to those who must relocate for paid
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10 work and those whose family care duties leave little time for health screening, and findings
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12 were seen in a wide range of settings.^{33 47 48} Delivering services at times, even holiday times,
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14 and in places where women already congregate, perhaps through mobile services, may help
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16 overcome this barrier in China, and elsewhere.⁴⁶
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23 These findings have several implications for practice, as noted above in relation to each
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25 key theme. In addition, new methods for screening⁴⁹ using automated nucleic acid
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27 amplification tests may help overcome timing and location constraints by allowing more
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29 rapid screening, and may help overcome cultural constraints by allowing women to
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31 self-collect vaginal swab samples.
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37 The mix of data sources across women, their husbands, and healthcare providers enabled
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39 triangulation of themes and identification of varying viewpoints. The qualitative methods
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41 with data saturation provided detailed and rich responses on barriers to cervical cancer
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43 screening for this group of rural women, available to inform providers and other researchers.
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45 In addition, a policy brief containing findings and implications will be provided to local
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47 policy makers and managers, and to community leaders, to inform future planning. Our
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49 study acknowledges the usual limitations of qualitative research, our purposeful sample may
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51 under-represent some women, and the peer effect in the focus group discussions may have
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53 influenced providers to give answers that they perceive to be more socially acceptable. As a
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4 qualitative study, our findings relate primarily to our study setting, and our recommendations
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6 should be tested with larger studies.
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10 11 **CONCLUSION**

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15 In summary, our study details important barriers to cervical cancer screening in terms of
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17 gaps in knowledge, fear of cancer and screening outcomes, cultural embarrassment, the
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19 influence of close contacts, and inconvenience. We hope policy makers and planners can
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21 make use of these findings to improve education and service delivery for screening that will
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23 decrease the incidence and mortality rates of cervical cancer in China.
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28 29 **Acknowledgments**

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31
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33
34 collection and recruitment of participants and the study participants for their time and
35
36 contribution to this study. This work was supported by China Medical Board Open
37
38 Competition Grant [Grant number CMB14-195]. Responsibility for any remaining errors lies
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40 solely with the authors.
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46 47 **Author Contributions**

48
49 Huan Yang designed the study, completed the data collection and analyses, and wrote the
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51 manuscript. Shunping Li designed the study, collected and analyzed the data, and edited the
52
53 manuscript. Qing Chen designed the study, collected and analyzed the data. Christopher
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4 Morgan helped design the study, supported interpretation of findings, and edited the
5
6 manuscript. All authors have read and approved the final manuscript.
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9 **Competing Interests**

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13 The authors declare no conflict of interest.
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15

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19 This work was supported by China Medical Board Open Competition Grant [Grant number
20
21 CMB14-195]. Responsibility for any remaining errors lies solely with the authors.
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25 **Ethics approval**

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28 The study was approved by the Medical Ethics Committee of Medical School, Shandong
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30 University (LL-201401048).
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33 **Data sharing**

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37 No additional data are available.
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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	2
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5
Purpose or research question	#4 Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	5-6
Researcher characteristics and reflexivity	#6 Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or	7,9

1		presuppositions; potential or actual interaction between	
2		researchers' characteristics and the research questions,	
3		approach, methods, results and / or transferability	
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6	Context	#7 Setting / site and salient contextual factors; rationale	5-6
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8			
9	Sampling strategy	#8 How and why research participants, documents, or events	6-7
10		were selected; criteria for deciding when no further sampling	
11		was necessary (e.g. sampling saturation); rationale	
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15	Ethical issues	#9 Documentation of approval by an appropriate ethics review	9-10
16	pertaining to human	board and participant consent, or explanation for lack thereof;	
17	subjects	other confidentiality and data security issues	
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21	Data collection	#10 Types of data collected; details of data collection procedures	7-9
22	methods	including (as appropriate) start and stop dates of data	
23		collection and analysis, iterative process, triangulation of	
24		sources / methods, and modification of procedures in	
25		response to evolving study findings; rationale	
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31	Data collection	#11 Description of instruments (e.g. interview guides,	7-9
32	instruments and	questionnaires) and devices (e.g. audio recorders) used for	
33	technologies	data collection; if / how the instruments(s) changed over the	
34		course of the study	
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38	Units of study	#12 Number and relevant characteristics of participants,	11
39		documents, or events included in the study; level of	
40		participation (could be reported in results)	
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44	Data processing	#13 Methods for processing data prior to and during analysis,	9
45		including transcription, data entry, data management and	
46		security, verification of data integrity, data coding, and	
47		anonymisation / deidentification of excerpts	
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52	Data analysis	#14 Process by which inferences, themes, etc. were identified and	9
53		developed, including the researchers involved in data	
54		analysis; usually references a specific paradigm or approach;	
55		rationale	
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1	Techniques to	#15	Techniques to enhance trustworthiness and credibility of data	9
2	enhance		analysis (e.g. member checking, audit trail, triangulation);	
3	trustworthiness		rationale	
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7	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and themes);	11
8	interpretation		might include development of a theory or model, or integration	
9			with prior research or theory	
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13	Links to empirical	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs)	11-17
14	data		to substantiate analytic findings	
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18	Intergration with	#18	Short summary of main findings; explanation of how findings	18-21
19	prior work,		and conclusions connect to, support, elaborate on, or	
20	implications,		challenge conclusions of earlier scholarship; discussion of	
21	transferability and		scope of application / generalizability; identification of unique	
22	contribution(s) to the		contributions(s) to scholarship in a discipline or field	
23	field			
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28	Limitations	#19	Trustworthiness and limitations of findings	20-21
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32	Conflicts of interest	#20	Potential sources of influence of perceived influence on study	22
33			conduct and conclusions; how these were managed	
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36	Funding	#21	Sources of funding and other support; role of funders in data	22
37			collection, interpretation and reporting	
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Keywords:	barriers, cervical cancer, cancer screening, China

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Barriers to Cervical Cancer Screening among Rural Women in Eastern China: a Qualitative Study

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Keywords barriers; cervical cancer; cancer screening; China

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ABSTRACT

Objectives To explore barriers to free cervical cancer screening among rural women in China from the perspective of women, healthcare providers and women's husbands to inform intervention planning.

Design A qualitative study framed around potential policy and practice options, drawing on the concepts of descriptive phenomenology and implementation research.

Setting This study was carried out at township level within two counties in Jining Prefecture of eastern China.

Participants and data collection Semi-structured in-depth interviews with 21 women and five healthcare providers, focus group discussions with nine healthcare providers, and key informant interviews with 4 husbands of women eligible for screening.

Results Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers including reticence for intimate examinations, (4) influence of close contacts on screening decisions, and (5) inconvenience. These demonstrate key knowledge gaps challenging current community health education. Important barriers, including fear of treatment cost and the time needed for screening, were also raised.

Conclusion Our study details important barriers to cervical cancer screening relating to knowledge gaps, attitudes of fear or embarrassment, and the role of contacts and service models. These provide data for policy and planning to improve the screening that will

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4 decrease the incidence and mortality rates of cervical cancer in China.
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7 **Article Summary**

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10 **Strengths and limitations of this study**

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14 The qualitative methods allowed for detailed and deep responses and triangulation across
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16 providers, clients and their partners.
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20 The findings have direct relevance to policy makers considering the development of
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22 interventions to increase uptake rate of cervical cancer screening in our setting.
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26 Our purposive sampling may bias our findings to those representative of women with lower
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28 educational levels and low uptake of services.
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32 Some social acceptability bias may have influenced focus group discussion findings, which
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34 we attempted to counter-balance with individual interview data.
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38 As a qualitative study, there are limits to generalizability beyond our setting.
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INTRODUCTION

Infection with the human papilloma virus (HPV), which can be transmitted during sexual intercourse, is the most significant risk factor for cervical cancer.¹ The majority of HPV infections resolve spontaneously and do not cause symptoms or disease.² However, persistent infection with specific types of HPV (most frequently, types 16 and 18) may lead to precancerous lesions, which, if not treated, can progress to cancer 10 to 20 years later.³ Cervical cancer is a preventable and treatable disease, and screening of precancerous lesions can reduce its incidence and mortality.⁴ In many high-income countries, the incidence and mortality of cervical cancer have decreased significantly because of the efforts made to detect precancerous lesions early.^{5 6} However, in low- or middle-income countries, cervical cancer remains the most common cause of cancer-related deaths among women.⁷

Cervical cancer is recognized as a major public health problem in China,⁸ both in mortality and morbidity burden, the latter causing protracted economic stress on women, heaviest in rural communities. As part of responses in 2009, a new round of deepening health system reforms intended to integrate the breast cancer and cervical cancer screening programs in rural areas into broader national public health services.⁹ The government's National Cervical Cancer Screening Program in Rural Areas (NCCSPRA) launched in 221 pilot counties and a total of 11.69 million rural women between 35 and 59 years of age accessed this screening program between 2009 and 2011.¹⁰ In one site that is the subject of our study, Jining Prefecture, free breast cancer and cervical cancer screening has been available to rural women over 35 years of age since 2011, with the upper age limit extended

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4 from 59 to 64 years in 2014, with three free screens available to women up until November
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6 2017.⁴ However uptake rate of the free service remains very low.⁴
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10 In China, a number of studies have been conducted into women's knowledge and attitudes
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12 toward cervical cancer screening and related factors,¹¹⁻¹⁴ however most data have been
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14 quantitative in nature.¹²⁻¹⁴ This leaves local gaps in understanding of underlying
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16 determinants of care-seeking, including the reasons why women do not take up free care,
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18 which require more qualitative research approaches.^{15 16} This research aimed to gain a deeper
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20 understanding of the barriers to uptake of free cervical cancer screening by rural women in
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22 Jining Prefecture, using a design that can suggest new policy and practice approaches that
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24 may be able to increase future uptake and reduce the burden of cervical cancer.
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32 **METHODS**

33 **Study setting and design**

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36 This study was conducted in Shandong Province, which is located in eastern China with a
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38 population of more than 100 million.¹⁷ In 2016, the gross regional product of Shandong
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40 Province amounted to CNY6803 billion (US\$1024 billion), ranking it as the third largest
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42 economy within China.¹⁷ Jining Prefecture, located in the southwest of Shandong Province
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44 with a population of 8.35 million and the gross regional product of CNY430 billion (US\$63
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46 billion) in 2016.¹⁸
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56 Our study design drew on descriptive phenomenology,¹⁹ concepts of acceptability and
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58 appropriateness in health implementation research,²⁰ and was framed by options for change
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4 in policy or practice, as identified by local health managers and experts. These helped
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6 identify qualitative tools, and categories of inquiry, deemed useful to understand knowledge
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8 and attitudes affecting women's and family's decision-making in relation to screening. The
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10 qualitative data collection methods included semi-structured in-depth interviews with 21
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12 women eligible for free screening aged between 35 and 64 years, and with five healthcare
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14 providers. These were supplemented by focus group discussions with healthcare providers of
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16 varying disciplines (described below) aiming to use discussion to elicit contrasting
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18 disciplinary perspectives. To gain a partner perspective, key informant interviews were
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20 conducted with husbands of women eligible for screening.
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29 **Study participants and sample**

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32 Two townships (Tangma and Xingcun) were randomly selected from within the mainly rural
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34 areas of Sishui and Yutai Counties in Jining Prefecture in eastern China. Purposive sampling
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36 was used to focus research on those were representative of women as less likely to take up
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38 screening, identified by local health managers. The selection criteria included: women aged
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40 between 35 and 64 years (those eligible for free screening and at higher risk), resident in the
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42 study townships, not in formal employment, and those who had either never been screened
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44 or who had failed to attend a second or third follow-up screening. Twenty-one women (10
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46 from Xingcun, 11 from Tangma) were recruited in collaboration with township community
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48 partners. Fourteen health care providers (7 from Xingcun, 7 from Tangma) including
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50 hospital managers, public health directors and medical practitioners whose responsibilities
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52 included contact, recording and managing data for screening and screening service
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4 provision, were purposefully selected by discipline mix. Five providers took part in
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6 semi-structured in-depth interviews and nine in two focus group discussions (four in the first
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8 and five in the second group). Four key informant interviews (2 from Xingcun, 2 from
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10 Tangma) were conducted with screening-eligible women's husbands who were purposefully
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12 selected and were not related to the women participants. The numbers of interviews and
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14 focus group discussions were designed to enable a theoretical saturation of qualitative
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16 themes, and data collection ceased at a point when no new information was being obtained
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18 (as assessed by rapid review during field operations).
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26 **Data collection**

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29 All interviews and discussions were conducted over a one-week period in November 2017
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31 by four researchers from Shandong University who had extensive knowledge of cervical
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33 cancer, and were trained in conducting qualitative research and interviews on sensitive
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35 topics. Women participants were interviewed in healthcare institutions identified by
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37 community partners. Individual interviews in private rooms gave participants the opportunity
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39 to speak freely and comfortably. Before interviews, a short questionnaire⁴ including 17 items
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41 was used to assess knowledge on cervical cancer, risk factors, symptoms, and the objectives
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43 and processes of cervical cancer screening. Consistent with earlier studies, responses were
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45 scored as correct (one point), incorrect or "do not know" (zero points), with numbers of
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47 correct scores used to categorize respondents into 2 groups: "high level of knowledge"
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49 (score 9 to 17) or "low level of knowledge" (score 0-8).^{21 22} The semi-structured in-depth
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51 interviews with women used open questions in categories informed by our design, with
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detailed probes to deepen responses (Table 1). Topics covered included sociodemographic characteristics, screening experience, purpose of cervical cancer screening, perception of barriers to screening uptake and suggestions for overcoming barriers.

Table 1 Overview of question categories in semi-structured in-depth interviews

Knowledge of cervical cancer screening
Have you heard about cervical cancer screening?
What do you understand cervical cancer screening?
Why cervical cancer screening is done?
Barriers to cervical cancer screening
Why don't you take free cervical cancer screening?
Why do you think other women don't take free cervical cancer screening?
Suggestions for overcoming barriers
How do you think these barriers could be overcome?

In-depth interviews and focus group discussions with providers were conducted close to the work place and lasted approximately 30 and 45 minutes, respectively. The in-depth interviews and focus group discussions guide (Table 2) explored providers' experiences in providing screening services, perception of barriers to cervical cancer screening uptake for women, and suggestions for overcoming barriers. Key informant interviews with husbands were conducted in their home. Interview guides included questions on their knowledge about cervical cancer, and attitudes towards screening for cervical cancer and potential barriers to uptake for women.

Table 2 Overview of discussion/question categories for focus groups and provider interviews

Experience in providing screening services

How long have you provided screening services?

What are your responsibilities for screening services?

Barriers to cervical cancer screening

Why do you think women don't take free cervical cancer screening?

Suggestions for overcoming barriers

How do you think these barriers could be overcome?

Verbal informed consent using a standard script was obtained from all participants prior to interviews. All interviews and focus group discussions were digitally recorded. Confidentiality was ensured through using code numbers rather than names. Researchers took care to identify and reflect on any bias relating to differential status between themselves and interviewees, using introductory explanations on themselves their neutrality and the study purpose, ensuring simple comprehensible language, and maintaining careful non-judgmental listening, in order to minimize bias during the interview process. Each participant was given a vacuum beverage cup to compensate for their time commitment to the study.

Data analysis

All interviews and focus group discussions were transcribed verbatim and subjected to thematic analysis.²³ We analyzed the data across all stakeholder groups collectively. HY collated interview and questionnaire data across all sites, ensuring consistency supervised by SL for data integrity. HY and SL jointly read all transcripts and developed themes (both pre-determined by our design and emerging), a topic index and code structure. HY, SL and

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4 QC undertook coding and thematic consolidation, with any differences discussed and
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6 resolved through consensus. These analyses were performed in Chinese and then translated
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8 into English by HY for further review by SL, QC and CM. Care was taken to ensure data
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10 validity in the translation of dialect and colloquialisms.
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14 15 **Ethical approval**

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18 This study was approved by the Medical Ethics Committee of Medical School, Shandong
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20 University (LL-201401048), and conforms to the ethics guidelines of the Declaration of
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22 Helsinki.
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26 27 **Patient and public involvement**

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30 Participants were not involved in the study design and conduct, but their experiences and
31
32 preferences will inform the development of the research questions to generate major themes
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34 for analysis. Public involvement including community partners was involved in the
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36 recruitment process. A policy brief containing findings and implications will be provided to
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38 local policy makers and managers, and to community leaders for dissemination to study
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40 participants.
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49 **RESULTS**

50 51 **Sociodemographic characteristics of participants**

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54 There were no refusals of consent or drop-outs during participation, with a total of
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56 twenty-one rural women participating. The mean age of participants was 48.7 ± 6.4 years,
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with a range from 37 to 60 years, and with more than half (57.1%) aged between 46 and 55 years. Most participants (95.2%) were married and most (90.5%) had an education level of primary school or below. About half of the participants (52.4%) had previously been screened once for cervical cancer. Table 3 shows details of the characteristics of participants. The mean knowledge scores were 4.4 ± 2.3 (range from 0 to 10).

Table 3 Sociodemographic characteristics of women interviewees, n (%).

Characteristics	Sishui(n = 10)	Yutai(n =11)	Total(n = 21)
Age (years)			
35~45	6(60.0)	0(0.0)	6(28.6)
46~55	3(30.0)	9(81.8)	12(57.1)
56~64	1(10.0)	2(18.2)	3(14.3)
Educational level			
No school	3(30.0)	5(45.5)	8(38.1)
Primary school	6(60.0)	5(45.5)	11(52.4)
Middle school or above	1(10.0)	1(9.0)	2(9.5)
Marital status			
Married	9(90.0)	11(100.0)	20(95.2)
Divorced or widowed	1(10.0)	0(0.0)	1(4.8)
Ever screened for cervical cancer			
Yes	7(70.0)	4(36.4)	11(52.4)
No	3(30.0)	7(63.6)	10(47.6)

Among the 14 health care providers, the mean age was 42.6 ± 9.0 years and most (64.2%) were aged between 41 and 50 years. They had an education level of junior college and

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4 above. Most providers were medical practitioners (50.0%). The mean age of four husbands
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6 who undertook key informant interviews was 50.7 ± 6.3 years, and all of them were
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8 small-hold farmers.
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11 12 13 **Key themes**

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16 Thematic analysis generated five major themes: (1) gaps in knowledge of cervical cancer
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18 and health awareness, (2) fear of cancer and screening outcomes, (3) cultural barriers, (4)
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20 influence of close contacts, and (5) inconvenience. Each of these is elaborated below,
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22 including quotations from participants with their identification number and age.
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26 27 28 **Gaps in knowledge of cervical cancer and health awareness**

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31 Knowledge gaps and lack of access to reliable information on cervical cancer is reported as a
32
33 major barrier to women's participation in cervical cancer screening. Findings from these
34
35 interviews showed that the majority of women participants had a low level of cervical cancer
36
37 knowledge. Most women indicated that they had heard about cervical cancer from their
38
39 friends or television, however, almost none knew that HPV infection was the cause. Some
40
41 cited inaccurate information and most reported that their knowledge, especially about causes
42
43 and symptoms, was speculative. For example, one reported misconception was that "cervical
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45 cancer will never happen after menopause". Limited knowledge seemed linked to lack of
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47 awareness of being at any personal risk of cervical cancer happening. When asked why she
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49 had not participated in cervical cancer screening, one woman stated:
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58 *I think my health is in a good condition. I've never had anything serious, or any*
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4 *symptoms. No symptoms, no examination. We only go to the hospital when we are*
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6 *uncomfortable or feel sick. (Woman 11, 53 years)*
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10 One of the health provider focus groups also mentioned:

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13 *Cervix is a dumb organ. There are no symptoms nor is it typical in the early stage. It*
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15 *doesn't affect their work or daily life; there is even no bleeding. No symptoms, nothing at*
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17 *all. They don't think they are infected, so there is no need to go through the screening.*
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21 (FGD 2, provider 05, 41 years)
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24 There were gaps in disease prevention understanding, as well as limited knowledge of the
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26 process, cycle, purpose and importance of screening. The importance of early screening prior
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28 to symptoms was poorly recognized. These factors were reported to limit women's
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30 acceptance of or commitment to screening, hindering or postponing their participation in
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32 cervical cancer screening.
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38 A woman who had been notified to attend cervical cancer screening said:

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41 *I was told to do the screening yesterday. Well, I didn't want to. I thought I always have*
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43 *a good appetite and never feel uncomfortable. There's no point doing it. (Woman 04, 48*
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45 *years)*
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49 Another woman who participated only once in cervical cancer screening stated:

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53 *I did the examination once and the doctor said I was good. So I never came back. Why*
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55 *bother when I'm good? (Woman 15, 55 years)*
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59 Health care provider viewpoints echoed this:
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4 *These women have low health care awareness. They wouldn't go to the hospital even if*
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6 *they have other common diseases. All they care about is if they could still do the*
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8 *housework. They don't have much understanding of medicine, so they couldn't know the*
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10 *significance of early screening if they got the disease. (FGD 1, provider 03, 52 years)*
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15 **Fear of cancer and screening outcomes**

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19 The majority of women in the interviews expressed a deep fear of cancer. Some did not want
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21 to know if they had cervical cancer; a common reason offered for why they were unwilling
22
23 to attend the screening was that they did not want to learn the results. This fear extended to
24
25 any form of cancer terminology. Women wanted to avoid the anxiety and distress that would
26
27 be associated with being told of a cancer-related lesion:
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32
33 *It's a terrible disease. I'm afraid something bad might show. If I don't do the screening*
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35 *I wouldn't know if I had it, I will at least have a good appetite. If the results were bad, I*
36
37 *wouldn't feel comfortable knowing that. Appetites and good sleep would be gone for sure.*
38
39 *I would have more years to live freely if I didn't know it. (Woman 01, 37 years)*
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44 *People become upset whenever they talk about cancer. In the first 2 years of the*
45
46 *screening campaign, we couldn't put 'cancer screening' on the banner and used 'health*
47
48 *examination' instead. People couldn't take it if they saw the word 'cancer'. (FGD 2,*
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50 *provider 01, 47 years)*
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55 A husband also mentioned, during key informant interview:

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58 *They were all afraid they might have it. Older women would say 'why do the screening?*
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4 *I would be upset if I knew I had it*'. (Husband 02, 63 years)
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7 Fear of a positive screening test was also related to the financial implications. Some women
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9 with fewer economic resources reported avoiding screening because they were worried they
10
11 would not have the money for treatment if they were diagnosed with the cancer, noting that
12
13 at present, while screening is free of charge, treatment is not. This suggests that family
14
15 finances are likely to influence their participation, with families weighing up the impact of
16
17 debt against that of the disease:
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23 *We wouldn't afford the treatment even if we found out we had it, so it's better we don't*
24
25 *do it at all. Adults need money and so do children. The money would be wasted if we went*
26
27 *through the treatment and not cured. No need to spend money on a disease that can't be*
28
29 *cured. We don't want to add burden to the family.* (Woman 10, 54 years)
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35 Two focus groups also noticed this:
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39 *People only see nearly 100,000 yuan for the surgery and it's a very heavy burden. The*
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41 *disease would drag the already poor family into debt. They can't take it.* (FGD 1, provider
42
43 02, 44 years)
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47 *There are indeed financial problems, especially for rural families. They think they don't*
48
49 *feel anything right now, if they find out they are infected after the screening they have to*
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51 *go through the treatment and spend money. So it's better not to do the screening at all.*
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54 (FGD 2, provider 03, 41 years)
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57 58 **Cultural barriers** 59 60

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4 A common report, especially among older women, was a reluctance to remove clothing or
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6 allow genital examination, especially being exposed in front of non-family members. It was
7
8 mentioned by nearly all women that they felt embarrassed about this step. Informants related
9
10 this to cultural norms in their rural setting, and among Chinese women more generally.
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15 *Felt like a very private part and I don't want other people to see it. That's the thought.*

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18 *Yes it's embarrassing. I'm too old. Don't want to be a joke. So ashamed.* (Woman 09, 55
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20 years)
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24 *When I went to the gynecology for the screening, I went inside and the doctor told me to*
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26 *take off my pants, and I suddenly didn't want to do the screening.* (Woman 02, 48 years)
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30 Participants were specifically asked about willingness to accept screening by male doctors.
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32 For some participants, the gender of the service provider seemed a barrier; nearly half
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34 indicated that they would not undertake screening if performed by a male doctor.
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38 *I wouldn't go if a man was doing the examination. It's less acceptable than a woman.*
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40 *It's so private and men are so improper for that.* (Woman 14, 41 years)
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44 A female service provider mentioned:
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48 *They are very conservative. Some women with vaginitis go to the clinic. We tell them to*
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50 *take off the pants and they are embarrassed. Some even put up with the disease until they*
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52 *can't. So they would be more uncomfortable if male doctors are here.* (Provider 01, 63
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54 years)
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57 58 59 **Influence of close contacts** 60

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4 It was found that close contacts (such as mothers, sisters or neighbors) were an important
5
6 factor influencing women's participation in cervical cancer screening. Knowing other people
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8 who had been screened or who had been diagnosed with cervical cancer and undertaken
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10 treatment was reported to increase participation in screening. The converse was also true,
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12 with reports that if close contacts were not willing to participate, this reduced women's
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14 acceptance of screening. This was also reported to generate clusters of women who would
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16 refuse screening.
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23 *I wouldn't know it if they (the neighbors) asked me to come along. If the others (the*
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25 *neighbors) don't come, I wouldn't either. It's good to have someone with you. I wouldn't*
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27 *come by myself.* (Woman 05, 55 years)
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31 *I would for sure not come by myself.* (Woman 06, 48 years)
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34 A service provider mentioned a similar situation during the screening campaign:
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38 *We met this situation once when we were doing the screening in a town. Several women*
39
40 *came together and they learned they need to take off the pants. One said 'This is what it is.*
41
42 *Forget it. Let's go'. And all of them felt reluctant and left together. It's a group mentality.*
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45 (Provider 03, 43 years)
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50 **Inconvenience**

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53 Difficulty in scheduling, or otherwise allocating time for screening was considered to be a
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55 significant barrier to women's participation. Many women eligible for screening work in
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57 disparate locations throughout the year may only return home at the time of Spring Festival.
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4 Such holidays are busy with limited time available for activities such as routine health
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6 checks. One working woman stated that leave is only feasible for actual illness.
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10 *I work elsewhere and only ask for leave when they have an emergency or special*
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12 *occasions at home. It's hard to ask for leave and I lose some salary for that. Usually I*
13
14 *come home once a year for only 5 or 6 days. It's not enough. (Woman 21, 40 years)*
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16

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18 *Many rural people go to other places to work and don't come home often. We call them*
19
20 *to come back but they can't. They don't get paid if they ask for leave and it's too expensive*
21
22 *on the road. So they don't want to come back. (Provider 02, 44 years)*
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27 Women who do not travel for work also report many demands on their time including
28
29 family business, child-care, housework and farming duties that are often seasonal. Lack of
30
31 time for routine health care is reported as a barrier to cervical cancer screening either. When
32
33 asked why not attend the screening, a woman who had never gone through the examination
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35 said:
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40 *I'm always busy with the kids going to school every day and housework never seems to*
41
42 *end. Family and housework are the most important for me. So I somehow forget about it*
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44 *(the screening). (Woman 08, 46 years)*
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49 *I tell you we farmers are pretty busy. When we are not, we want to do some small*
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51 *business to make money. So no time for examinations. (Woman 19, 56 years)*
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55 56 **DISCUSSION**

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59 This study used qualitative tools to explore the barriers to attending cervical cancer
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4 screening among rural women in Jining Prefecture of Shandong province in eastern China.
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6 Such in-depth assessments have rarely been reported in Chinese literature. Our study
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8 identified gaps in knowledge of cervical cancer and health awareness, fear of cancer and
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10 screening outcomes, cultural barriers, the influence of close contacts, and inconvenience as
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12 frequently cited barriers.
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18 Our findings on gaps in knowledge or awareness are echoed in studies from other
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20 resource-constrained settings, with specific misconceptions and poor awareness of the
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22 benefits of routine health checks reported from diverse settings including Burkina Faso,
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24 ²⁴Iran,²⁵ Malawi,^{26 27} Nigeria²⁸ and elsewhere. Reluctance to seek care in the absence of
25
26 symptoms is a common theme, seen also in high-income settings such as Norway,²⁹ and this
27
28 was one of the most important constraints identified in our study. Our finding that there is
29
30 very low awareness of the risks posed by cervical cancer is seen elsewhere in China.^{30 31}
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32 Accessible and attractive educational products tailored to rural women are urgently needed
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34 to communicate accurate information about cervical cancer, those at risk, screening methods,
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36 treatments available, and the need for regular checks.
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45 Fear poses a significant psychological barrier to care-seeking for cervical cancer
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47 screening. This includes the general fear of “cancer” as a vicious and intractable class of
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49 disease,³² and the fear that it would not be possible to emotionally cope with a diagnosis,
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51 seen in relation to cervical cancer in our findings and in other high- middle- and low-income
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53 settings.³³⁻³⁵ A study among Mexican women shows that women reported not attending
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55 cervical cancer screening because of fear of ‘knowing,’ that is, they prefer to live in hopeful
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4 uncertainty rather than facing the possibility of an unfavorable result.³⁶ This poses a key
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6 communication challenge to community health education efforts. They must find ways to not
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8 only build knowledge of the risks of an asymptomatic disease, but also address the
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10 misconceptions and emotions aroused by cancer more generally, in order to build trust that
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12 timely screening can render cervical cancer treatable.
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18 The influence of women's close contacts risks generating clusters of mutually-reinforcing
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20 resistance to screening,³⁷ with partners playing a key role.^{38 39} This suggests some education
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22 initiatives will need to address whole communities and possibly include peer-education
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24 approaches that encourage positive health discussions among friends.
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29 In our study, as in other resource-constrained settings,²⁷ fears of financial catastrophe
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31 generated by high treatment costs also posed a barrier to screening. In our context this
32
33 emphasizes the need for health planners to understand the pragmatic choices families make
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35 when health care costs are seen as unaffordable. Making treatment financially accessible, for
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37 cervical cancer and many other protracted diseases, is a key challenge facing China's public
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39 health system reformers.
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45 We found culturally based embarrassment to be a key barrier. Such associations with
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47 concepts of conservatism and modesty obstruct access to reproductive health in general and
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49 cervical cancer screening in particular in our and many other settings,^{30 40-42} especially when
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51 providers are male,^{43 44} or women are older.⁴⁵ For such communities in China and Asian
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53 populations elsewhere,⁴⁶ this requires providers of screening to have high levels of cultural
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55 competence, and planners to ensure sufficient numbers of female providers. Lastly,
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4 inconvenient screening services, in terms of timing and location also posed a major barrier
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6 for the rural women in our study. This applies to those who must relocate for paid work and
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8 those whose family care duties leave little time for health screening; findings also seen in a
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10 wide range of other settings.^{33 47 48} Delivering services at times, even holiday times, and in
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12 places where women already congregate, perhaps through mobile services, may help
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14 overcome this barrier in China, and elsewhere.⁴⁶
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21 These findings have several implications for practice, as noted above in relation to each
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23 key theme. In addition, new methods for screening⁴⁹ using automated nucleic acid
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25 amplification tests may help overcome timing and location constraints by allowing more
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27 rapid screening, and may help overcome cultural distaste for vaginal examinations by
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29 allowing women to self-collect vaginal swab samples.
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35 Our mix of data sources across women, their husbands, and healthcare providers enabled
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37 triangulation of themes and identification of varying viewpoints. The qualitative methods
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39 with data saturation provided detailed and rich responses on barriers to cervical cancer
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41 screening for this group of rural women, available to inform providers and other researchers.
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43 In addition, a policy brief containing findings and implications will be provided to local
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45 policy makers and managers, and to community leaders, to inform future planning. Our
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47 study acknowledges the usual limitations of qualitative research, our purposeful sample may
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49 over-represent women with lower educational levels and low uptake of services, and the peer
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51 effect in focus group discussions may have influenced providers to give answers that they
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53 perceive to be more socially acceptable. As a qualitative study, our findings relate primarily
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4 to our study setting, and our recommendations should be tested with larger studies.
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8 **CONCLUSION**

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12 In summary, our study details important barriers to cervical cancer screening in terms of
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14 gaps in knowledge, fear of cancer and screening outcomes, cultural embarrassment, the
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16 influence of close contacts, and inconvenience. We hope policy makers and planners can
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18 make use of these findings to improve education and service delivery for screening that will
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20 decrease the incidence and mortality rates of cervical cancer in China.
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28
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32
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35 Competition Grant [Grant number CMB14-195]. Responsibility for any remaining errors lies
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37 solely with the authors.
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43 **Author Contributions**

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46 Huan Yang designed the study, completed the data collection and analyses, and wrote the
47
48 manuscript. Shunping Li designed the study, collected and analyzed the data, and edited the
49
50 manuscript. Qing Chen designed the study, collected and analyzed the data. Christopher
51
52 Morgan helped design the study, supported interpretation of findings, and edited the
53
54 manuscript. All authors have read and approved the final manuscript.
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Competing Interests

The authors declare no conflict of interest.

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Ethics approval

The study was approved by the Medical Ethics Committee of Medical School, Shandong University (LL-201401048).

Data sharing

No additional data are available.

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For peer review only

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

	Reporting Item	Page Number
	#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	2
	#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Problem formulation	#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	4-5
Purpose or research question	#4 Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	5-6
Researcher characteristics and reflexivity	#6 Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or	7,9

1		presuppositions; potential or actual interaction between	
2		researchers' characteristics and the research questions,	
3		approach, methods, results and / or transferability	
4			
5			
6	Context	#7 Setting / site and salient contextual factors; rationale	5-6
7			
8			
9	Sampling strategy	#8 How and why research participants, documents, or events	6-7
10		were selected; criteria for deciding when no further sampling	
11		was necessary (e.g. sampling saturation); rationale	
12			
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14			
15	Ethical issues	#9 Documentation of approval by an appropriate ethics review	9-10
16	pertaining to human	board and participant consent, or explanation for lack thereof;	
17	subjects	other confidentiality and data security issues	
18			
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21	Data collection	#10 Types of data collected; details of data collection procedures	7-9
22	methods	including (as appropriate) start and stop dates of data	
23		collection and analysis, iterative process, triangulation of	
24		sources / methods, and modification of procedures in	
25		response to evolving study findings; rationale	
26			
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31	Data collection	#11 Description of instruments (e.g. interview guides,	7-9
32	instruments and	questionnaires) and devices (e.g. audio recorders) used for	
33	technologies	data collection; if / how the instruments(s) changed over the	
34		course of the study	
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38	Units of study	#12 Number and relevant characteristics of participants,	11
39		documents, or events included in the study; level of	
40		participation (could be reported in results)	
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45	Data processing	#13 Methods for processing data prior to and during analysis,	9
46		including transcription, data entry, data management and	
47		security, verification of data integrity, data coding, and	
48		anonymisation / deidentification of excerpts	
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52	Data analysis	#14 Process by which inferences, themes, etc. were identified and	9
53		developed, including the researchers involved in data	
54		analysis; usually references a specific paradigm or approach;	
55		rationale	
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1	Techniques to	#15	Techniques to enhance trustworthiness and credibility of data	9
2	enhance		analysis (e.g. member checking, audit trail, triangulation);	
3	trustworthiness		rationale	
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7	Syntheses and	#16	Main findings (e.g. interpretations, inferences, and themes);	11
8	interpretation		might include development of a theory or model, or integration	
9			with prior research or theory	
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13	Links to empirical	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs)	11-17
14	data		to substantiate analytic findings	
15				
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18	Intergration with	#18	Short summary of main findings; explanation of how findings	18-21
19	prior work,		and conclusions connect to, support, elaborate on, or	
20	implications,		challenge conclusions of earlier scholarship; discussion of	
21	transferability and		scope of application / generalizability; identification of unique	
22	contribution(s) to the		contributions(s) to scholarship in a discipline or field	
23	field			
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28	Limitations	#19	Trustworthiness and limitations of findings	20-21
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32	Conflicts of interest	#20	Potential sources of influence of perceived influence on study	22
33			conduct and conclusions; how these were managed	
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36	Funding	#21	Sources of funding and other support; role of funders in data	22
37			collection, interpretation and reporting	
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