What do young women living in regional and rural Victoria say about chlamydia testing? A qualitative study

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Abstract. Background: Chlamydia trachomatis is the most commonly notified sexually transmissible infection in Australia, with almost 100,000 cases diagnosed in 2018. Chlamydia is easy to diagnose and treat, but infections are underdiagnosed. Eighty per cent of chlamydia cases are asymptomatic. Without testing, infections will remain undetected. Several barriers to testing have been identified in previous research, including cost, privacy concerns for young rural people, knowledge gaps, embarrassment and stigma. The aim of this study was to investigate young regional and rural women’s understanding of chlamydia and factors that may prevent or delay testing.

Methods: Semistructured interviews were conducted with 11 women aged between 18 and 30 years residing in north-east Victoria, Australia. Interviews were transcribed verbatim and analysed thematically.

Results: Themes were grouped under four categories: (1) chlamydia and stigma; (2) the application of stigma to self and others; (3) factors affecting testing; and (4) knowledge. A chlamydia infection was associated with stigma. The young women in this study anticipated self-stigma in relation to a positive diagnosis, but resisted stigmatising others. Increased knowledge about chlamydia prevalence was associated with reduced self-stigma. The most consistent factor affecting testing decisions was personal risk assessment. Knowledge gaps about symptoms, testing and treatment were also identified, with participants not always accessing information from reputable sources.

Conclusion: Chlamydia testing was viewed as a positive activity among this cohort. However, there is considerable perceived stigma about being diagnosed with an infection. Interventions that communicate prevalence, reduce stigma and provide factual information about testing and risk are still needed. Clinicians have an opportunity to convey this information at consultation. Health promotion workers should continue to develop and run campaigns at a community level to encourage regular screening.

Additional keywords: Australia, perceptions, sexually transmitted infection, STI.

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Introduction

Chlamydia trachomatis is the most commonly notified sexually transmissible infection (STI) in Australia, with almost 100,000 cases diagnosed in 2018.1 Most cases diagnosed each year are among those under 30 years of age, and diagnosis rates tend to be slightly higher in rural areas.2,3 If left untreated, chlamydia can have serious health consequences, particularly in women, causing pelvic inflammatory disease, which increases the risk of tubal factor infertility and ectopic pregnancy.4,5 Increased engagement in behaviours such as illicit and licit drug use, binge drinking, low condom use and multiple sexual partners has been found to contribute to increased risk of chlamydia in young people.6–9

Over 80% of cases of chlamydia are asymptomatic so, without testing infections will remain undetected.10 A previous study in rural Australia showed that among those diagnosed with chlamydia, nearly three-quarters were tested opportunistically and were not attending the clinic that day specifically for a chlamydia test.3 Factors previously identified as being associated with low rates of testing include lack of symptoms, cost,11 privacy concerns for young rural people,12,13 embarrassment and stigma.14–17 Privacy and stigma concerns are important for young Australian people, particularly those living in rural areas. Previous research has shown that young women in rural areas were especially worried about being recognised in health clinics,18 citing this as a significant
deterrent for seeking sexual health care in rural areas. Although knowledge about STIs among young Australian people is relatively high, with secondary school students correctly answering 71% of STI-related questions in a recent national survey, approximately 90% of students believed they were unlikely to get an STI. This belief may also influence young people’s testing decisions.

In Australia, opportunistic screening for sexually active young women is recommended. However, only approximately 15% of young sexually active men and women receive screening despite a high proportion attending a GP clinic annually. The Fourth Australian National STI Strategy (2018–2022) continues to recognise young people as one of seven priority populations in the national response effort to reduce STIs. To increase young rural and regional women’s uptake of chlamydia testing, it is important to understand their beliefs about chlamydia, testing and the factors that influence their testing decisions. This project aimed to investigate young regional and rural women’s understanding of chlamydia and factors that may prevent or delay testing.

Methods
A social constructionist viewpoint informed the framework for this study. From a social constructionist viewpoint, there is no one true ‘reality’; rather, people’s perceptions of reality (their thoughts, knowledge, language, perceptions and beliefs) are socially constructed and shaped by the cultural, historical, political and social norms operating at the time and within that context. From this perspective, each person’s experience or ‘reality’ of being tested for chlamydia will differ and what is important is not the accuracy of their accounts, but rather their lived experiences and personal realities of being tested for chlamydia. People’s ‘reality’ can be greatly influenced by the cultural and social meanings attributed to an illness or condition, particularly if the condition is stigmatised. STIs have considerable negative stigma associated with them, which can, in turn, affect the ways in which people cope with, understand and manage the testing process.

To be eligible for participation, young women had to be aged between 18 and 30 years, reside in north-east Victoria and sexually active. Approximately 2.2% of young Victorian women aged 15–34 years reside in north-east Victoria. The area is classified by the Australian Accessibility and Remoteness Index as inner and outer regional. Flyers inviting participation were distributed on the noticeboards at local university and technical and further education campuses. The flyer was also distributed electronically via The University of Melbourne’s Women’s Health Goulburn North East (WHGNE) newsletters and the WHGNE Facebook page. Young women contacted a member of the research team directly to participate. The final cohort included women who were a mix of students and young professionals aged between 19 and 30 years, with a median age of 25 years. Overall, eight women came from regional centres (population >26,000) and three came from rural towns (population <1000).

Semistructured interviews of approximately 30 min took place over the telephone or face to face according to the participant’s preference. The questions about chlamydia experiences and perceptions were informed by research conducted by Balfe et al. and Theunissen et al. Questions explored testing experiences, chlamydia perceptions, factors influencing testing, disclosure and encouraging others to test. Two additional questions were added after the first seven interviews to address themes concerning judgements (of self, others and health professionals). All interviews were undertaken by two authors (EW and JT) and were recorded, transcribed verbatim and analysed thematically.

All interviews were read and analysed independently by two authors (EW and JT), with the third author (JH) reading and analysing a smaller number of randomly selected interviews. Throughout the data collection period, EW and JT met regularly to review and discuss themes identified from the interview data. All three researchers independently read and manually coded the transcribed interviews, primarily using a segmented approach, and grouped the codes into broader themes to develop a coding framework. At this point the researchers discussed and compared the identified themes and interpretations (cross-coding technique). Themes were derived both deductively from current literature, clinical practice and the interview schedule questions and inductively from recurring themes in the data itself. At the completion of 11 interviews, despite some variation in coding frameworks, principally relating to coding language or wording, there was strong consensus among the three researchers around the major themes, subthemes and interpretation of data, with no notable differences evident. At this time, it was agreed that all interview questions had been thoroughly explored, with interviewees reiterating similar ideas. No new themes were identified at this point. EW collapsed the three researchers’ individual coding frameworks into one final agreed version before undertaking a final read of all transcripts and review of the coding and thematic analysis.

Individuals without English proficiency were not eligible for inclusion in the study due to resourcing and time constraints. Participants received a gift card to the value of A$20.00.

The University of Melbourne Human Research Ethics Committee provided approval for this study (No. 1852557).

Results
Identified themes were grouped under four categories: (1) chlamydia and stigma; (2) the application of stigma to self and others; (3) factors affecting testing; and (4) knowledge. These categories are explored in detail below.

Chlamydia and stigma
Participants thought a chlamydia diagnosis was associated with younger, sexually promiscuous, careless or irresponsible people who lacked self-control and education about STIs. When asked who was at risk of chlamydia, one participant responded:

‘I’d be thinking someone who’s pretty – oh what’s the word – not maybe looking after themselves as they should be, who are not thinking about long-term, who aren’t thinking about consequences.’ (Participant 8, 20 years)
Another said:

‘...you just kind of, just think that a person is dirty if they have got it I reckon. I suppose for women it’s the kind of thing if you have got chlamydia then you sleep around a lot, you’re a bit of a slut, and you’re just like, unhygienic, and stuff if you manage to obtain it. Well that’s kind of like my negative reputation of it I think. Well it’s not my reputation, but it’s what I would think about it.’  (Participant 1, 23 years)

Although several participants acknowledged ‘anyone’ could get chlamydia, they did not generally identify themselves as being that person. However, two older participants had more nuanced views:

‘I guess before realising how common it was, I guess it was always like people that slept around, people that were a bit loose, you know, the people that were a bit reckless that didn’t use [unclear] protection... Now knowing family and friends that have had it, I’m just sort of like, well, it’s anyone and everyone and everyone slips up so it could be anyone.’  (Participant 9, 28 years)

Application of stigma to self and others

None of the women who participated in the study reported a current or previous diagnosis. Therefore, fear of stigmatisation was anticipated, not experienced. Participants feared stigmatisation from themselves:

‘[A positive test result] is negative in the way like you know, it’s a sexually transmitted infection, but I wouldn’t judge anyone with that, but it’s a negative – like for me, if I were to get it, I would feel disgusted in myself that I’d got it and I’d feel embarrassed and it’s got negative connotations behind it generally.’  (Participant 3, 19 years)

Participants also feared stigmatisation from others:

‘...I wouldn’t tell anyone if I had it...I wouldn’t go tell my friend “oh, I’ve just been diagnosed with chlamydia” because I don’t want them to – I would feel embarrassed.’  (Participant 11, 23 years)

Participants appeared to believe contracting chlamydia was something within their control, and therefore contracting chlamydia was seen as a personal failure. In contrast, if other people received a positive diagnosis it was perceived as a mistake:

‘I think because [as] a friend you naturally have more sympathy for people you love, so you naturally think, oh, I’m sure it was just a mistake, I’m sure he didn’t mean it and things like that. I have much [the] same feeling with friends of mine because I’d think they just made a mistake, you know, I’m sure they didn’t mean it. For yourself I guess it’s a bit more like, oh, you’re an idiot, you shouldn’t have done it [contracted chlamydia].’  (Participant 9, 28 years)

The participants held themselves and others to different standards. They did not stigmatisate others with chlamydia and all participants stated they would start a sexual relationship with someone who had chlamydia in the past. Despite this, they feared they would be stigmatised. The participants attached a high level of personal responsibility to contracting chlamydia and such an ‘error’ would lead to feelings of ‘shame’, ‘disgust’ and ‘embarrassment’.

Participants differed in their willingness to disclose previous tests with friends and family members. Some participants would not share their experience at all:

‘...because I’ve just never spoken to any of my friends about it, nor will I ever...I’ve just never really felt comfortable to discuss STIs and stuff.’  (Participant 11, 23 years)

In contrast, others were open to telling select friends or siblings that they were getting a test:

‘I’ve definitely shared it with more single friends I guess because I think there’s more of a stigma with people who have been in relationships for a long time and who haven’t had to do it I guess, so they find it a bit more confronting.’  (Participant 9, 28 years)

However, of those who did discuss testing, they rarely discussed results after the test within their trusted network.

Factors affecting testing

Initiating chlamydia testing was viewed by most of the participants as a positive activity:

‘I’d say it’s the right thing to do because you’re taking, you know, a proactive approach to your health and checking yourself out.’  (Participant 6, 22 years)

However, for some participants, positive feelings about testing seemed to be associated with a confidence that they were not at risk of receiving a positive test result:

‘...’cos I have always been fairly sure that I don’t have one [an STI] I don’t feel ashamed to get a test.’  (Participant 1, 23 years)

In contrast, two participants who believed themselves at higher risk delayed testing:

‘I guess [I was] trying to hide myself from what I’d done. If I don’t get the chlamydia test then – I’m fine. I didn’t do anything wrong. I’m totally innocent.’  (Participant 2, 26 years)

These responses seem to suggest the participants’ perception of their risk influenced testing decisions. Those who see themselves as low risk may use testing as confirmation of their belief. In contrast, those who see themselves as high risk may avoid or delay testing because a diagnosis could have negative consequences for identity.

Participants made decisions about chlamydia risk by making personal risk assessments. Information about the number of partners and the features of those partners were used to determine risk. If participants were not currently sexually
active, were in a committed relationship or were sexually active with people they trusted and believed were ‘clean’, they considered themselves low risk.

‘I haven’t really thought anyone I have slept with...I haven’t really thought that they would have it. But, yeah I won’t lie to you there has been a few drunken hook ups, so no, I just kind of go with the thought that if I use a condom I should be right.’ (Participant 1, 23 years)

Several other factors that influenced testing decisions were raised. These factors included embarrassment about asking the general practitioner (GP) for a test:

‘I don’t know how to go about that. I don’t know do I just ask like oh, can I get an STI testing? I feel like that’s – it is embarrassing even though I say that I wouldn’t judge anyone with that – I would feel embarrassed asking.’ (Participant 3, 19 years)

knowledge:

‘I’ve had a pap smear but I don’t know if that’s the same [as a chlamydia test].’ (Participant 10, 25 years)

perceived judgement from health professionals:

‘I was quite uncomfortable going to my GP clinic. I think then – I know, just because this is – I live in a small town, I felt like there might have been a bit of pre-judgement there.’ (Participant 8, 20 years)

cost and geographical location:

‘There’s no other option for us [rural women], we can’t just go to the next suburb and go to a bulk billing clinic.’ (Participant 7, 30 years)

Most participants had overcome these barriers to initiate at least one test. Two participants had not, and one was unsure whether she had been tested before; therefore, knowledge remained a barrier.

Knowledge

Most participants did not feel they had sufficient knowledge about chlamydia symptoms, testing and treatment, even after a consultation with their GP or sexual health nurse. After having a chlamydia test, Participant 1 (23 years) articulated:

‘All I know about chlamydia is that often symptoms don’t show. So you can have it and not be aware that you’ve got it, but symptoms that do show I’m not even sure what they are. I would assume painful urination or itchiness or something but um, yeah...I mean obviously it wouldn’t be right down there but, yeah I wouldn’t know.’

Participants felt it was the responsibility of the GP to provide them with information and indicated they would wait for the information to be conveyed to them, rather than ask specific questions:

‘I hadn’t been seeing that doctor regularly...so I was a bit – just like overwhelmed with the entire situation and I didn’t feel like I could ask those questions. They weren’t super-approachable about it. Both times I did expect that there would be a bit more communication to me. Or like, if you do have it, here’s where we go...But I think mainly I do expect my doctor to sort of run me through more specifically.’ (Participant 11, 23 years)

Increased knowledge appeared to play a role in reducing the self-stigma associated with chlamydia. As participant 9 (28 years) expressed:

‘Whereas the rare things are always seen as the scary things, where the more common it is you go, oh, well, it’s not that bad, I know three other people that have had it [chlamydia]. So if they’re fine with it I can be fine with it.’

This suggests that knowledge is not only important for managing sexual health, but also for reducing stigma and embarrassment about a positive test result. Participants acquired most of their knowledge about chlamydia from friends, the Internet and mainstream media, rather than school programs, health promotion campaigns or GP consultation:

‘...you see things on TV. You hear things about – your friends talk to you about certain things. So you kind of pick up a few bits and pieces [about STIs] as you go.’ (Participant 2, 26 years)

This knowledge was not always from reputable sources, with Participant 1 (23 years) joking:

‘...my entire knowledge comes from [the 2004 film] Mean Girls when he says if you have sex you will get pregnant and die’.

Although a light-hearted comment, the participant raised this in the context of feeling she not been provided adequate STI education.

Discussion

This study found that chlamydia infection among young regional and rural women is associated with considerable perceived stigma and embarrassment. The participants applied this stigma differently to themselves and others. The most consistent factor influencing testing decisions was personal risk assessments conducted by participants. Knowledge gaps about symptoms, testing and treatment were also identified, with most participants sourcing knowledge from friends and the Internet. Increased knowledge among participants was associated with reduced self-stigma.

Most participants perceived a positive chlamydia diagnosis as a stigmatising condition shaped by the perception that young, promiscuous individuals who exercised poor judgement and self-control are most at risk of infection. This finding has been reported elsewhere, suggesting the stereotype associated with chlamydia remains well defined and pervasive.14,17

Encouragingly, participants acknowledged the contradictions inherent in this stereotype. This enabled them to withhold judgement from others diagnosed, particularly friends and siblings. However, most of the participants could not do this for themselves and expressed concern that others outside their
trusted network would judge them. Although none of our participants reported experiencing a positive test result, they anticipated this would be a shameful and ostracising experience. Anticipated social rejection has been established previously,\textsuperscript{20} and may be worse than the anxiety experienced by those who test positive.\textsuperscript{22} In an Australian cohort study investigating chlamydia incidence, women aged 16–25 years completed a survey detailing actual and anticipated feelings about a positive chlamydia diagnosis. Women who had actually tested positive for chlamydia were significantly less concerned about their result compared with the anticipated feelings of women who tested negative.\textsuperscript{27}

Most participants believed they were at low risk of contracting chlamydia. Participants who had been sexually active with a small number of people, people they trusted or with people they perceived as ‘clean’ did not always initiate testing. When participants did initiate testing, most felt confident they would receive a negative test result. Low risk self-assessments have been reported in other studies.\textsuperscript{28–30} A previous study proposed that low risk assessments are associated with a belief that high-risk people are promiscuous and ‘dirty’.\textsuperscript{28} That study suggested that if participants did not identify with the stereotype of someone who purportedly gets chlamydia, they perceived themselves as low risk.\textsuperscript{29} It has also been reported that young people may feel they are low risk because they make judgements about the risk of their sexual partners based on their reputation, appearance and familiarity.\textsuperscript{28–30} These risk assessment strategies were used by many of the young women in the present study. Participants who were in long-term relationships determined themselves as having no risk if they were monogamous and/or their partner had been tested at the beginning of their relationship. This suggests that it is important to communicate the recommended screening guidelines to young women. Encouraging women to engage in opportunistic screening, rather than waiting until they believe they have chlamydia based on their personal risk assessment, may increase testing among this population.

Participants considered testing to be a positive activity, but most participants did not engage in regular screening. This could be because participants felt it was unnecessary because they had determined they were low risk. Stigma did not appear to directly influence testing decisions for participants, particularly among those who felt they were unlikely to receive a positive test result. The small number of participants in the present study who believed they may receive a positive test result did engage in delay tactics. However, this tactic appeared to be related to fear of a positive test result, rather than a fear of testing. Participants’ desire to manage their health ultimately outweighed this fear and they initiated a test. For the study participants, testing was viewed as a responsible part of managing their health. This is similar to previous studies that found young male and female participants experienced self-stigma, shame and perceived public stigma in relation to STI testing, but indented to, had initiated or had accepted a test when offered.\textsuperscript{17,31,32} A qualitative study reported that although young people had concerns around testing, they preferred to know whether they had chlamydia.\textsuperscript{17} This suggests that young people would be responsive to screening if offered. Although this is promising, stigma has been cited as a barrier to testing by other studies.\textsuperscript{14,28,33,34} Recent qualitative research among young people in New Zealand found STI testing was seen as a risk to identity because it implied promiscuous and unsafe sexual activity.\textsuperscript{29}

Participants raised a range of factors that influenced testing decisions, including cost, geographical location, time, embarrassment, perceived judgement from health professionals and knowledge. These factors are consistent with barriers reported by other studies.\textsuperscript{11–13} Interestingly, privacy and anonymity were not consistent concerns reported by the participants in the present study. These factors have been found to be important for rural people in other studies.\textsuperscript{12,13} This could be because those studies included adolescents <18 years of age, who may experience these concerns differently. It could also be that although some young women in the present study did not articulate privacy concerns specifically, their anxiety about judgement and embarrassment may have been associated with the lack of anonymity inherent to living in regional and rural locations. However, overall, the most significant factor affecting testing decisions was the participants’ personal risk assessment.

Most participants had not received, or could not recall, information provided by their GP about testing intervals, when they should seek testing or what treatment entailed. This represents an opportunity for clinicians to provide this information at consultation. In addition, participants could not recall STI screening or risk forming part of their school sexual health programs. Major information sources about chlamydia were not always reputable or accurate, such as mainstream media and friends. This led to knowledge gaps about symptoms and testing, and highlights the ongoing importance of directing young women to reputable online sources. Promisingly, participants felt knowledge about the prevalence of chlamydia reduced the self-stigma they anticipated with a positive test result. This indicates that enhancing knowledge about prevalence among this group may help reduce negative feelings about a chlamydia diagnosis.

Limitations of the study include the small sample size and exclusion of women under 18 years of age, who are also at high risk of contracting chlamydia and may experience barriers differently. This may account for the inconsistencies between the results of the present study and those of other studies about privacy concerns for young rural women. In addition, those who agreed to participate in the study may have an interest and experiences in the topic that differ from those who chose not to participate. For example, no participants reported experiencing a positive chlamydia diagnosis and most participants perceived themselves as low risk. Nonetheless, comparisons with other studies reveal consistencies in experiences and beliefs with other populations.

**Conclusion**

This paper provides an insight into young rural and regional women’s understanding of chlamydia, its symptoms and testing and their perceptions of being diagnosed with an
infection. The results can be used to generate interventions that promote uptake of chlamydia testing and regular screening. The findings demonstrate that testing is already viewed as a positive activity, but there is considerable perceived stigma about being diagnosed with an infection. Interventions that communicate prevalence, aim to reduce stigma and provide factual information about testing and risk are still needed. GPs and sexual health clinicians have an opportunity to convey this information at consultation. Health promotion workers should continue to develop and run campaigns at a community level that deconstruct stigma, promote reputable online resources, communicate prevalence and encourage regular screening.

Conflicts of interest
The authors declare no conflicts of interest.

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