

When no-one wants to talk: personal reflections on engaging rural communities in a study about sexually transmitted infections

Karin Fisher^{1,2}

¹University Department of Rural Health, ²Hunter New England Rural Training Unit, Hunter New England Health

Abstract

This paper shares some insights gained from undertaking a mixed methods study examining sexually transmitted infections (STIs) in a rural community. The study specifically aimed to gain an understanding of syphilis notifications in relation to rurality and disadvantage as well as how an individual's construction of rurality shaped the way in which he or she accessed community-based health services for STIs.

In this paper, I outline key concepts perceived to be central to consultation identified from the qualitative component of the study. In-depth interviews were conducted with 24 Aboriginal and non-Aboriginal participants, 18 females and 6 males, aged between 19 and 65 years. Participants were recruited from small rural communities in NSW via multiple media approaches (internet, radio and print media), snowballing, direct contact and word of mouth.

I will use my experiences of undertaking this study to illustrate the negative and positive aspects of talking to rural community members about a sensitive topic like STIs. Challenges highlight issues of stigma, context, reluctance to participate, and issues of trust. Issues such as gender, cultural aspects and social contexts, like being known by the community, can encourage and discourage individuals from participating in rural community-based research. On a personal level, one challenge was the experience of being a health professional who had worked in sexual health, undertaking a research study. Being desensitised to sexual health meant that I needed to be mindful of a range of different responses from community members. The positive aspects included gaining insight and conceptual understandings from differing perspectives of the community. Another positive was the willingness of community members to trust me and share their personal stories.

The complexities associated with undertaking a study with hidden and difficult to reach populations highlight my reflections of the issues that face researchers and practitioners when eliciting information from rural communities. My discussion of these issues reflects the challenging and rewarding aspects of talking to community members, in addition to the importance of representing their story accurately. By reflecting on this research experience and drawing insights, the paper contributes to the discussion about developing and managing effective ways to engage with rural communities, especially in relation to sensitive topics.

Introduction

When no-one wants to talk about Sexually Transmitted Infections (STIs) how do you engage rural communities in discussion? The answer to this question varies according to different perspectives on consultation. I have chosen to use a reflective account of my experiences of undertaking a mixed method study that examined STIs in rural Northern NSW. The study aimed to understand the dynamics of public health surveillance and issues regarding access to health services, in addition to

exploring how an individual's construction of rurality shaped the way in which he or she accessed health services for STIs. The purpose of this paper is to outline key concepts perceived to be central to consultation identified from the qualitative component of my study. Subject matters such as social contexts, social and cultural aspects in conjunction with trust and sensitivity all contribute to the management of the consultation process in rural communities. My experience has shown that undertaking research on sensitive topics required persistence, a repertoire of different approaches and an understanding of rurality. The inhibitions and lack of open discussions associated with the topic of sex contributed to the complexities surrounding recruitment.

Throughout my involvement in the area of sexual health, I cannot deny the emotional response that STIs raise. The taboo, stigma and shame [1-4] that surround STIs ultimately inhibit the discourse necessary for an in-depth understanding of not only the public health impact but also a community perspective. Accurate data is important for care, treatment, prevention and resource distribution. Having the ability to make sense of the data requires that there is an understanding of the experiences of individuals and communities to supplement the data. Consequently engaging with communities or individuals about their experiences provides a human factor to the equation.

Given the historical nature of syphilis and the perception of syphilis as a hidden disease, undertaking research that explores community understandings of sexually transmitted infections create a number of challenges. Some of the challenges in undertaking research about STIs particularly in rural areas include the recruitment of people to studies. Decisions about sampling in rural communities are complex and can be difficult because people may be hard to locate. Minority groups may be reluctant to participate in research. Indigenous people continue to be mistrustful of research [5] and the taboos surrounding sexuality influence which people will participate [6]. Furthermore, people who have been tested for STIs are especially 'invisible' [7].

Geographic barriers and an individual's sense of community group membership can hinder participation. The population disparity and available infrastructure in rural areas compounded with the distribution patterns of STIs increase the difficulties associated with recruitment of people to the study. Physical location and distance to place of research including transportation issues may make it inaccessible for some people. In addition, in rural areas there may be no defined groups or places to draw participants from, such as gay or lesbian groups or specialised STI clinics.

Methods

A mixed method approach was used in this research study. The quantitative component consisted of a sample of 254 syphilis notifications for the Hunter New England Health (HNEH) Northern region over an eleven-year period from January 1994 to December 2004. The study sample comprised 33.5% males and 66.5% females with a median age of 24.7 years (range 15-91 years). Of the total number of syphilis notifications, 75% were identified as Aboriginal. Findings suggested that there was a gender and age differential according to Australian Bureau of Statistics Socio Economic Index for Areas (SEIFA). It was identified that there were differentials in location, gender and age in relation to the syphilis notifications.

A grounded theory approach underpinned the analysis. In-depth interviews from 24 participants aged between 19 and 65 years provided the data for the qualitative component. Participants for the study were recruited using snowballing (i.e. asking participants to identify other individuals who may be interested in the research) and self-selection. In order to attract participants different recruitment strategies were utilised. These comprised written material such as pamphlets, flyers, media releases as well as radio interviews and verbal approaches towards individuals. Interviews were conducted with

twenty-four participants, 18 females and 6 males aged between 19 and 65 years, of whom 16% were Aboriginal and 84% non Aboriginal. Participants provided comparisons on a range of postcodes, education levels, and socioeconomic status. Findings indicated that individuals engaged in a process of negotiating and managing the flow of private information about STIs.

Procedures

A number of strategies were required to increase access to participants from hidden or difficult to access populations that are diverse in terms of the research criteria. The strategies need to be flexible and adopt a model that included more than one method [8]. Successful strategies for recruiting people about sexual issues include telephone and postal surveys [6, 9] opportunistic sampling such as kerbside recruiting [10], snowball sampling [11] convenience samples such as people who access specialist clinics [12-14] educational and health facilities (including staff) [15-17] and the use of surveillance data [18]. Time and energy also influences an individual's interest in being part of research. The time taken to complete questionnaires or face to face interviews requires that the person feel comfortable or be able to concentrate for a set period [19]. Building rapport and trust is important to increase participation and also to obtain a deeper understanding of the issues [8].

The following section describes the recruitment strategies, advertising and networking, utilised in my study.

Advertising

Poster and pamphlets were developed in conjunction with local people who provided advice on appropriate cultural specific aspects and language. These were then posted out to all general practitioner medical practices in the area, Aboriginal Medical Services and Specialist sexual health clinics. The message on the posters and pamphlets were aimed towards people who had a story about STIs that were willing to share. This strategy yielded one person who requested further information but did not make any further contact regarding an interview. In hindsight, the taboo surrounding STIs are still so enormous that the mere mention of the words on a pamphlet may have threatened potential participants.

The use of the media in publicising the study encompassed the use of the internet, radio and newspaper advertising. A media release was available on the University website detailing what the study was about and contact details. This yielded one person who was willing to be interviewed. Four radio interviews were conducted over a week which yielded four people interested in the study. Of those four, three agreed to be interviewed and the fourth was deemed inappropriate as he lived outside of the study area.

An article in the local newspaper asked for "volunteers to help university research" [20]. This article attracted no contact with potential participants to date. Use of word of mouth and use of the media hanging raise a number of safety issues for the informants as well as for the interviewer. The resounding silence also reflects the difficulty people have in discussing private issues. Making contact with people who may not want to be found is somewhat difficult. What is in it for them, why should they be involved, and why should they trust you with their information? Are they really going to be anonymous and how confidential is the information going to be? The answers to these questions is an important element of community engagement. For individuals to participate they must feel that they

have something to contribute or can help in some way. For example when some participants were asked to be a part of the study, many individuals stated they 'wanted to help'.

Networking

Consulting key informants or people who have information relating to the target group and potential entry points [21] provide other mechanisms for obtaining potential participants. They can provide you with names of organisations that may be able to help or assist in arranging attendance at appropriate gatherings to discuss your research. This avenue provided a number of opportunities to talk about the research and encourage potential participants to participate. One example is how information was provided about the research to the Division of General Practitioners through the key informant who arranged for the distribution of pamphlets and written information to General practitioners who attended a specific seminar. Another opportunity arose when the researcher was given entry to a group of university students who were gathering as part of their degree to discuss the research and obtain potential candidates for the research.

The use of snowball sampling is recommended as a way to obtain access to participants for sensitive matters [22, 23]. Due to the sensitivity surrounding STIs this study utilised snowball sampling as a way to obtain people who may have come into contact with someone who had been tested, treated or wanted information about the subject. However, the networks of people with STIs are such that, except for the person who they obtained the infection from, they do not know anyone else with an STI. This strategy was not useful in gaining entry to those people who had an STI. However as the research progressed and it was decided to involve people who may not have encountered an STI, then snowballing was a useful strategy. This resulted in obtaining seven participants who agreed to be interviewed.

Having a personal or professional profile within the community in which you wish to engage individuals can have a positive and negative aspect. As some people know you, they are therefore willing to share personal and private information with you as a participant in the research. However, 'being known' by others became a negative concept in terms of recruitment because some people do not want you to know private and personal aspects of their lives.

Living and working a rural community, I recognised that there were differences and nuances of that community and that each community has its own unique identity. Each community also had a mix of community groups with a diverse range of interests. Using these elements as a basis for community engagement suggests that 'one size fits all' strategy would not work, as capturing the differentiation between rural areas would be difficult to represent in a broad-brush approach. The development of individualised and integrated community strategies may require intensive work but may well improve the responsiveness from community members.

Key concepts

Gender

Reflecting on the difficulties encountered with the recruitment of participants, I now realise that a number of conditions may have contributed to them. These include the role of gender, social conditions of the population and social acceptability of STIs. Being a woman undertaking research into STIs may have contributed to the low number of males participating in the study. Although all efforts were undertaken to engage men in the study, many of the men who were asked to be a part of the

study unfortunately declined despite being offered a male interviewer. Men who participated in the study were asked what they thought about men talking to a woman about sex. The male participants in the study individually agreed that being a woman researcher could be a problem for other men even though they themselves did not have a problem discussing sexual issues. One male participant also stated that Aboriginal men would find it very difficult to talk to women because of cultural taboos associated with sex. Male participants were given the opportunity to speak to a male interviewer; however, the offer was not taken up. This raises questions as to whether a male recruitment person may have made a difference to the men's participation in the qualitative component of the study. Hence some data may not have been collected because of the associated taboos.

Accessing hidden populations

Researching hidden populations and sensitive topics such as sexual issues and STIs raise a number of problems and issues that may arise throughout the research process [22, 23]. These articles point to a number of issues that influence the difficulties associated with accessing hidden populations. The first is where the research poses an intrusive threat to issues and topics that are private, stressful or sacred. The second relates to the possibility that information may be revealed which is stigmatising or incriminating in some way. Given the historical significance of the perceptions of STIs by society, and the associated stigmas and taboos, it is not surprising that this affected recruitment for the present study.

People who participated in my study were willing to share private information about the self. One of the participants stated that the only reason she spoke to me was that I was so approachable. The inhibitions and lack of open discussions associated with the topic of sex contributed to the complexities surrounding recruitment. The silence from potential participants may reflect the difficulty people have in discussing private issues.

One of the strategies I used when accessing people from a different cultural background to me was to talk to individuals who trusted me. These individuals were pivotal to engaging Aboriginal people in the research. They initially participated in the research and recommended me to other Aboriginal people who they felt might be able to help me and were willing to discuss issues of such a sensitive nature.

Occupational stigma

Research can also become problematic for the researcher who is researching sexuality [24]. Occupational stigma may arise. Research work may be trivialised or treated in a joking manner or the researcher may be viewed as subverting traditional values or advocating for particular sexual practices [24]. One of the issues that I constantly came up against was the responses that followed when truthfully answering the question about what I was researching. When stating that I was looking at access to services for STIs, many people became silent and did not know how to respond. Others (there were very few) would jokingly tell me a story about someone they knew, or some would offer themselves to be interviewed or they would offer to ask others if they would be interested in participating; however, there were no participants forthcoming following the offer. As I became aware of these issues I began to control the type and amount of information that I gave, depending on the person whom I was asking, whether I knew the person and their background or on the basis of my initial judgments. Judgments were made through non-verbal communication such as potential participants' age and gender as well as through the verbal interaction entered into. The main reason for controlling the type and amount of information, such as whom to tell about the study, was to avoid the uncomfortable silences that often followed and the lack of positive responses.

Concluding remarks


This paper has raised a number of challenges I experienced when undertaking rural research. While some relate to the research topic, process of recruitment and interactions with the community, others relate to the social structure and processes evident within rural communities. The reflections from this research study indicates that accessing hidden and difficult to reach populations may become problematic for a researcher living and working in a rural community, especially being a woman undertaking research into STIs. Gender, culture, social contexts of the population and social acceptability of STIs can influence participation in research. 'Being known' can have positive and negative aspects in the recruitment of participants to the research and increase the complexities surrounding participation in rural research. Reflecting on this process as a researcher working in the area, particularly the congruency of my experiences with the participants added a new dimension to the conceptualisation of the data. In researching stigmatised topics such as STIs, the importance of trust and understanding of rural contexts cannot be underestimated when engaging people to discuss sensitive topics.

Recommendation

An integrated and individualised approach should be employed when undertaking community engagement in rural and remote communities.

References

- [1] Goffman E. *Stigma Notes on the Management of a Spoiled Identity*. New Jersey: Prentice Hall 1963.
- [2] Nack A. Damaged Goods: Women Managing the Stigma of STDs. *Deviant Behavior*. 2000 March 1;21(2):95–121
- [3] Lichtenstein B. Stigma as a Barrier to Treatment of Sexually Transmitted Infection in the American Deep South: Issues of Race, Gender and Poverty. *Social Science & Medicine*. 2003;57:2435-45.
- [4] Newton D, McCabe M. The Impact of Stigma on Couples Managing a Sexually Transmitted Infection *Sexual and Relationship Therapy*. 2005;20(1):51-63.
- [5] National Health & Medical Research Centre. *Values and Ethics—Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research: Commonwealth of Australia*; 2003 10 October 2005 11:51 am.
- [6] Smith AMA, Rissel C, Richters J, et al. Sex in Australia: the Rationale and Methods of the Australian Study of Health and Relationships. *Australian and New Zealand Journal of Public Health*. 2003;27(2):106-17.
- [7] Browne J. Kerbside Recruiting: Issues of rigour in using an innovative technique for recruiting qualitative research participants. "Issues of Rigour in Qualitative Research"; 1999; Melbourne, Australia.: Association Qualitative Research; 1999.
- [8] Liamputtong P, Ezzy D. *Qualitative Research Methods*. 2nd ed. Melbourne, Victoria: Oxford University Press 2005.
- [9] Khan A, Hussain R, Schofield M. Correlates of Sexually Transmitted Infections in Young Australian Women. *International Journal of STD & AIDS*. 2005;16:482-7.
- [10] Nack A. Bad Girls and Fallen Women: Chronic STD Diagnoses as Gateways to Tribal Stigma. *Symbolic Interactionism*. 2002;25(4):463-85.
- [11] Scoular A, Duncan B, Hart G. "That sort of place... where filthy men go..." a Qualitative Study of Womens Perceptions of Genitourinary Medicine Services. *Sexually Transmitted Infections*. 2001;77:340-3.
- [12] Plummer D, Forrest B. Factors Affecting Indigenous Australians' Access to Sexual Health Clinical Services. *Venerology*. 1999;12(2):47-52.
- [13] Wright M, Giele C, Dance P, et al. Fulfilling Prophecy? Sexually Transmitted Infections and HIV in Indigenous People in Western Australia. *MJA*. 2005;183(3):124-8.
- [14] Narouz N, Allan PS, Wade AH, et al. Genital Herpes Serotesting: A Study of the Epidemiology and Patients' Knowledge and Attitude Among STD Clinic Attenders in Coventry, UK. *Sex Transm Infect*. 2003 February 1, 2003;79(1):35-41.

- 
- [15] Trajman A, Belo MT, Teixeira EG, et al. Knowledge about STD/AIDS and Sexual Behavior among High School students in Rio de Janeiro, Brazil. *Cadernos de Saúde Pública*. 2003;19:127-33.
- [16] Fairley. CK , Fehler. G., Lewin. SR., et al. Sexually Transmissible Infection and HIV Management among Men Who Have Sex with Men with and without HIV: Survey of Medical Practitioners who are Members of the Australasian Society for HIV Medicine. *Sexual Health*. 2008 Jun;5(2):155-9.
- [17] Grant. K, Ragsdale. K. Sex and the 'Recently Single': Perceptions of Sexuality and HIV Risk among Mature Women and Primary Care Physicians. *Culture, Health & Sexuality*. 2008 Jun;10(5):495-511.
- [18] Weinstock H, Berman S, Cates Jr W. Sexually Transmitted Diseases among American Youth: Incidence and Prevalence Estimates, 2000. *Perspectives on sexual and reproductive health*. 2004:6-10.
- [19] Schofield. M. Sampling in Quantitative Research. In: Minichiello V, Sullivan G, Greenwood K, R A, eds. *Handbook of Research Methods for Nursing and Health Sciences*. 2nd ed. Frenchs Forest: Pearson Education Australia 2004.
- [20] unknown. Students Seek Volunteers to help University Research. *Northern Daily Leader*. 2005 October 10;Sect. 5.
- [21] Hashagen S. Models of Community Engagement: Scottish Community Development Centre 2002.
- [22] Dickson-Swift V, James EL, Kippen S, et al. Doing Sensitive Research: What Challenges do Qualitative Researchers Face? *Qualitative Research*. 2007 August 1, 2007;7(3):327-53.
- [23] Dickson-Swift V, James EL, Kippen S, et al. Risk to Researchers in Qualitative Research on Sensitive Topics: Issues and Strategies. *Qual Health Res*. 2008 January 1, 2008;18(1):133-44.
- [24] Lee R. *Doing Research on Sensitive Topics*. London, UK: Sage Publications Ltd 1993.

Presenter

Karin Fisher is a Tamworth-based research academic at the University of Newcastle, Department of Rural Health and is currently the recipient of a PHCRED Research Fellowship. Karin completed her PhD in 2007 through the University of New England, supported by a grant from the Hunter New England Health Service. Her research interests include rural health, sexual health, public health and population health issues. Karin also works on a part-time basis as a senior research officer with the Hunter New England Health Rural Training Unit focusing on recruitment and retention of rural health practitioners.

