

Obtaining the perspective of the TB patient attending diagnostic services in Yemen: A qualitative study employing In Depth Interviews and Focus Group Discussions

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Contributor biographies

Rachel Anderson de Cuevas obtained a PhD in the area of Social Medicine in the Department of International Public Health at the Liverpool School of Tropical Medicine, University of Liverpool, in 2013, for which she was awarded a scholarship from the Economic and Social Research Council. She has undertaken research for the past 10 years, working in programme evaluation research for the UK government's *Sure Start* early years poverty reduction programme, at the Faculty of Education at Liverpool John Moores University and most recently, as a doctoral candidate. Her overriding interest is the effect of health and social policy on marginalised and disadvantaged populations; an interest she has pursued variously as a social work practitioner, advocate and researcher. Her publications appear in peer-reviewed journals in the area of education, international health and the social sciences.

Sally Theobald is Reader in Social Science and International Health in the Department of International Public Health, Liverpool School of Tropical Medicine. She has a Masters in Gender and Development, a PhD in Gender, Health and Development and over 15 years' experience of qualitative research in international health. Her particular research interests include equity, HIV, tuberculosis, sexual and reproductive health and health systems. She teaches qualitative research in health at Masters level at LSTM and supervises PhD students. She has wide ranging experience of designing and implementing gender sensitive qualitative research projects in health and has worked collaboratively on qualitative research projects on HIV, TB, Sexual and Reproductive Health (SRH) and health systems in Thailand, South Africa, Burkina Faso, Malawi, Ethiopia, Kenya, Yemen and Uganda.

Najla Al-Sonboli is associate professor in Paediatrics in the Paediatric Department at the Faculty of Medicine and Health Sciences, Sana'a University. She is also Head of the Paediatrics Department at Al-Sabeen Hospital for Children and Women, Sana'a, Yemen. She has undertaken research for the past 15 years, working on studies of respiratory tract infections in Yemen and diarrhoeal diseases in children in Brazil and Yemen, as part of her Masters and PhD at the Liverpool School of Tropical Medicine (LSTM). Since 2007, she has worked on many projects concerning TB in children and adults in collaboration with LSTM, the World Health Organization (WHO), Tropical Diseases Research (TDR), TB Reach and Stop TB and more recently research into Leishmaniasis in children, in several countries, employing qualitative and quantitative methods. Her main professional interests are nutritional, diarrhoeal and respiratory diseases in children on which she has worked as a paediatrician and a researcher. She has published in peer-reviewed journals in Paediatrics.

Nasher Al-Aghbari is a paediatric consultant in the Paediatric Department at Al-Thawra General Teaching Modern Hospital in Sana'a, Yemen. He is Head of the Paediatric Emergency Department. He is also a member of the Teaching Panel in the Arab Board Membership. He has undertaken research for the past 15 years. As part of his Masters degree and PhD at LSTM he worked on blood diseases in children in Africa and Yemen and pulmonary childhood tuberculosis in Yemen. After 2007 he worked on a range of projects examining TB in children and adults in collaboration with LSTM, WHO, TDR, TB Reach and Stop TB. He is trained in qualitative research methods and has undertaken multi-country research using quantitative and qualitative methods. His dominant interest is nutritional and respiratory diseases in children; an interest he has pursued variously as a paediatrician and a researcher. His publications appear in peer-reviewed journals in the area of Paediatrics.

Relevant disciplines

Health, Sociology, Social Policy

Academic level

Advanced undergraduate and Postgraduate

Methods used

Qualitative research, Focus groups, Interviews

Keywords

Tuberculosis, TB, TB diagnostics, access, access barriers, access to health services, Yemen, qualitative research, in depth interviews, focus group discussions

Abstract

In this entry, we present the qualitative phase of a multi-method, multi-country study exploring barriers and enablers to accessing TB diagnosis. We describe the implementation

of the study in Yemen, of particular interest as little qualitative research has been undertaken in this country and, even less so, studies in the area of health that solicit the views of patients. The lack of a precedent and the distinct cultural context meant that implementing a generic protocol presented a range of practical, budgetary, logistical, sociocultural and ethical considerations. Of particular prominence were normative practices surrounding the freedom of women to work, travel and speak autonomously; religious sensitivities influencing the wording of interview questions; and the organisation of individual and group interviews and a cultural tendency to operate in groups. Reflecting on how these considerations were addressed illuminates the planning and problem solving entailed in managing a research project overseas.

Learning outcomes

It is hoped the student will obtain:

- An appreciation of the deliberations, negotiations and decision-making inherent in the implementation of a research project.
- An understanding of the influence of the cultural, economic, religious and political context on the management and conduct of research.
- A realisation that adaptations may be necessary to ensure a generic protocol is appropriate for a particular study setting.
- An understanding of the challenges presented by conducting a research method - in this case qualitative interviews and focus group discussions - for the first time in a research setting, from the perspective of staff training, acceptability by the study population and methodological rigour.

Introduction and background

The study aimed to identify and describe the factors which inhibited and facilitated attendance at diagnostic services for tuberculosis (TB) for adults in Yemen. TB is a leading cause of morbidity and mortality, which predominates among disadvantaged populations in low and medium income countries. The diagnosis in adults is mostly achieved through a combination of clinical assessment and low cost, low technology tests, including smear microscopy and X-rays. In some settings, a portion of the cost of the consultation and tests is passed on to the patient. Diagnosis requires access to laboratory facilities and patients are obliged to travel, often some distance from home and to return on one or more occasions. Patients are often unprepared for the need for multiple visits and a proportion leaves without completing the process, before a diagnosis has been reached. The obstacles impeding access to diagnostic services are complex and range from social stigma and belief that traditional remedies can cure the disease, to physical, logistic and economic constraints, through to patterns of behaviour shaped by gender roles. The widespread difficulties experienced in obtaining a correct diagnosis acts as a major constraint to accessing appropriate treatment.

The study was part of a larger study funded by the Economic and Social Research Council in partnership with the Department for International Development. The wider study comprised 2 cross-sectional surveys and qualitative studies and was designed to assess whether accelerated diagnostic schemes would lead to improved completion rates for diagnosis and registration for treatment for adults with symptoms of TB in four high incidence settings.

In this Case, we describe the implementation of the qualitative study phase in Yemen. The factors affecting the ability of adults to attend diagnostic services, complete the diagnostic process and register for treatment had not been studied in Yemen. This study represented the first attempt to use qualitative research methods to explore the views of adults attending

diagnostic services and indeed one of the first to employ qualitative methods to elicit patients' perspectives in the area of TB in the country. The lack of previous research or qualitative fieldwork experience and the distinctive cultural context raised several interesting, sometimes unusual practice dilemmas, which provide rich points of discussion of research practice in action.

Study context

Yemen is the poorest of the Arab states and has a small and mostly rural population clustered in village settlements and cities over difficult and mountainous terrain, with low literacy. Gender roles are strongly delineated, particularly in the north, and many Yemenis live in extended family groups. The population is Arab and Muslim, with a minority of Jews who have settled in the north of the country. The north and south of the country have distinguishing cultural characteristics, having had different political, economic and social histories and been separated for many years. The country has seen various political and tribal tensions, including a southern independence movement and a drive for greater autonomy by a branch of Shia Islam in the north. In 2011, a call for increased democracy led to civil conflict and the resignation of President Saleh.

Methodology

Research design

This study was informed by two research paradigms - positivism and naturalism - since it lay at the intersection of two academic disciplines, the biomedical and the social. This led to a decision to adopt a mixed methods approach. Quantitative cross sectional surveys were chosen to quantify patient costs, the prevalence of beliefs and the most common issues to be explored in qualitative studies. The latter aimed to capture the reasons for patients' behaviour and the meaning that patients attributed to their experiences of healthcare.

Choice of qualitative research tools

Two qualitative research tools were employed – In Depth Interviews (IDIs) and Focus Group Discussions (FGDs) - with the aim of providing a richer and more complete account of patients' experiences. Individual interviews explored the patient's experience in the context of his/her personal circumstances. Group discussions were conducted after individual interviews and were used to stimulate debate and discussion of issues emerging from the interview phase, to clarify meaning and interpretation of interview data and elucidate social attitudes towards TB healthcare and disease.

Patients were placed into 4 subgroups to allow for comparison of the presence or absence of phenomena within and between groups, as follows: patients **completing** the diagnostic process; those failing to return and **abandoning** the process; and patients diagnosed with TB **registering** or **failing to register** for treatment.

The development of semi-structured interview and topic guides was informed by the experience of conducting the quantitative phase and the data gathered. Individual and group interviews identified barriers and enablers for diagnostic adherence and explored patients' experience of the diagnostic process and ways in which services could be modified to facilitate access. Interviews with defaulters also discussed the reasons for abandoning the process. Interviews conducted with patients registering for treatment explored perceptions of treatment access and identified barriers and enablers for treatment adherence.

Study organisation, planning and training

The project ran from 2008 to 2012 and was conducted in a TB diagnostic Institute in Sana'a, selected because it had a high turnover of patients, belonged to the National Tuberculosis

Control Programme (NTP), predominantly served populations with limited financial resources and had well-established collaborative links with the UK partner.

Yemeni field coordinators attended a workshop in the UK to inform the protocol, the development of research tools and receive training in qualitative methods. Following approval by the Ethics Committees in the UK and Sana'a, a British PhD candidate (registered at a UK university) undertook a familiarisation visit to Yemen in 2008, accompanied by a senior investigator. The candidate used the visit to become acquainted with the TB control programme, met local partners and programme staff, learnt about the cultural, social and religious context, and discussed approaches to data collection and surveillance. A social scientist and 2 social workers were recruited locally to assist with data collection. Local staff was considered more suited to conduct fieldwork given their familiarity with customs, the religious and political environment, their ability to conduct interviews in Arabic and to develop rapport with research participants. The field coordinators, PhD candidate and principal investigator provided on-site training to field staff and piloted and refined research tools.

Data collection

Data collection took place between 2009 and 2010. Forty-eight IDIs and 12 FGDs were undertaken with adults > 18 years old. Research instruments were translated from English to Arabic and interviews were conducted in Arabic. Where research participants spoke another local language, a translator was identified - often the person accompanying the patient - who could provide simultaneous translation.

Interviews were audio-recorded with permission, transcribed in Arabic and translated into English by a professional translator. Field coordinators double translated selected transcripts

to check for accuracy and authenticity and translations were checked by the coordinators for quality control and re-translated as necessary.

Selection of research participants

Our research team established a monitoring system to record and trace patients attending the Institute suspected of having TB. This was used to generate a sample frame from which potential research participants could be selected. Participants continued to be enrolled until little fresh information was elicited.

Interview participants were selected purposively according to their demographic and sociocultural characteristics to ensure inclusion of younger and older participants of both sexes, of different educational levels, work and socioeconomic status, ethnicity and geographical locations.

FGDs of 6 to 10 participants were held with individuals completing diagnosis and individuals registering for treatment. Several companions also took part. Male/female and older/younger participants were separated, to reflect established social hierarchies. Participants did not know each other and differed in relation to their educational background, occupation, relationship status and residence.

Patients were invited to participate by telephone, home visits, or in-person on attendance at the Institute where written informed consent was obtained. Individual interviews took place in discrete locations in the health centre, at the patients' home (particularly for women) or at a mutually convenient setting. FGD participants were grouped geographically, to avoid

extensive travel. Patients and accompanying relatives were offered subsistence and transportation costs and refreshments.

Framework for data management and analysis

The analysis followed the Thematic Analysis method described by Braun and Clark, and drew on the Framework Analytic method, conceived by Ritchie and Spencer. We adopted a ‘contextualist’ approach to the analytic process, situated between the essentialist and constructionist traditions. The researcher was regarded as an active player in the analysis, whose decisions and choices had the potential to influence the final interpretation of the data. Our research team occupied the middle ground between an inductive and theoretical thematic analysis, recognising that they arrived at the analysis with specific questions and themes informed by knowledge of the subject area, the surveys and reading of the literature, but took care not to impose these theories on the data. The IDI and FGD guides were semi-structured and required interpretation of the data produced. Patients’ responses were mediated by power and hierarchical relationships (between health staff and patient or service provider and service user); the patient’s level of education and ability to express their ideas; the position of women in Yemeni society; the patient’s social standing, economic position and age. Each of these factors combined to influence the respondent’s ability or freedom to express their ideas, voice criticism and question figures of authority in a government-run health centre that may be considered part of the establishment. The patient’s voice was thus perceived to have been shaped by interpretation during interview, transcription, translation and the meaning assigned by the researcher. Our research team examined and described the entire data set, while giving priority to the specific research questions of interest to the study. This approach is considered appropriate for new research areas, in this case an investigation of patient’s experience of the diagnostic process. Themes were largely identified at a semantic or explicit

level; however we were sensitive to societal influences likely to have affected participants' accounts. Data was reduced to its core meaning, while participants' terminology was retained as much as possible by means of direct quotations or vignettes to illustrate the researcher's narrative.

Following the steps of the Thematic Analysis, data was prepared and managed using the data analysis software NVivo. A period of data familiarisation followed, during which the PhD candidate began to list ideas about the content and noted issues of interest, under a theory-driven approach. A coding framework was developed, in consultation with the Yemeni research team. Data extracts were coded and collated using the Framework Matrix facility within NVivo. Ideas were noted for themes and observations about decisions taken during the analysis and factors affecting interpretation of data were recorded. Themes were developed, reviewed and refined by analysing the data contained against each code and an analysis workshop was held with UK and Yemeni study partners, to check and discuss the meaning and interpretation of the data and formulation of key themes. The latter provided a foundation for the development of broader theories and concepts.

Ethical considerations: Group confidentiality and implicit disclosure

There was a danger that participants' attendance at FGDs would imply positive TB status. This was not felt to be problematic for those FGDs held with patients that had been referred for treatment and were therefore positive, but more so for mixed groups, comprising TB positive and negative patients who had presented for diagnosis. Participants were clearly informed that disclosure to the group was voluntary and of the need to respect the confidentiality of group members. We also made it clear that confidentiality from other participants could not be guaranteed.

Research in context: Methodological dilemmas and points of interest

Implementing a generic protocol presented us with a range of practical, budgetary, logistical, sociocultural and ethical considerations. Of particular prominence were normative attitudes surrounding the *position of women in society*, which restricted women's freedom to work, travel and speak autonomously; *religious sensitivities* influencing the content of questions, the organisation of individual and group interviews and a *cultural tendency* to conduct one's daily affairs with company, which affected travel and attendance. Some of these issues were new to the UK team and were context specific, while others were more common and might be encountered in other environments. An example of the latter was the effect of the economic climate, employment and working practices on project operations, manifest in high staff turnover, short working days and multiple and unstable employment. Here we discuss selected issues that arose and how the group arrived at workable solutions.

Cultural and religious customs and the research interview

Individual interviews were difficult to obtain because Yemenis customarily travel in groups and it is rare for a patient – whether male or female - to attend alone. Most are accompanied by one or more family members or friends. Obtaining the unique perspective of the patient was therefore problematic, as a more senior person, or male accompanying a female patient, would tend to answer on the patient's behalf, as in this example:

Interviewer: "Can you tell us about your experience in the centre? Was it a positive or negative one?"

Male companion: "She is illiterate and can't answer."

[...]

Male companion: “She is illiterate and does not know anything. I am her husband and [should be] asked on her behalf. I treated her in the Republican Hospital.”

Even without gender or age differences, it is commonplace to join in a discussion and to add one’s point of view. Exploring the issue of a woman’s freedom to seek healthcare was particularly problematic, as women are usually accompanied by a senior male or older female family member (and children) and are unlikely to answer the question without interference or moderation. Patients were reluctant to be separated from their companions or to go with their companion(s) into an adjacent room away from the public eye.

There was concern that being unable to interview the patient alone would compromise patient confidentiality and the validity of responses, especially regarding sensitive topics. We decided to consider this phenomenon when interpreting and presenting the data: to note that the viewpoints expressed were likely to be the combined perspective of the patient and companions. Here is an excerpt from the analysis phase to illustrate this point, in which an elderly male patient is asked his experience of diagnostic services and the PhD candidate (heeding the interviewer’s record) notes that his son responds: “There is a shortage in the doctors in this centre. I have seen some patients suffering in [on] the ground and there’s no doctor to see them. Some get upset and leave the centre without being seen by doctors!”
(Son of older, male patient, completed diagnosis, IDI)

In the planning phase, holding a FGD for women was considered problematic by local staff. However, an all-female discussion was facilitated by female research staff. When the discussion started, accompanying men and children were invited into an adjacent room by a male research staff and offered refreshments. Male companions met the research staff, saw

the venue, were informed about the interview process and knew the whereabouts of their relatives. The women were able to talk without being inhibited by their companions.

Subsequent FGDs for women had a festive atmosphere. Children were often present and were provided with activities and women enjoyed the opportunity to assemble, talk together and leave the house. Moreover, the research group provided drinks and food from a restaurant. Men did not seem to enjoy the discussions so much. They did not take much interest in the refreshments and answered questions quickly, so that they could continue their daily business. Nevertheless, male FGDs also elicited information that did not emerge in the IDIs, for example on attitudes to women's access to healthcare, as in this passage from a transcript:

Patient 1: “[...] some [men] do not even believe in medicine and if their sons tell their dads about the importance of the hospitals, they just say: ‘No, let her die at home’.” [...]

Patient 2: “They [men] only realised at a very late stage, when it's too late!”

Patient 3: “Some [men] just do not want to know.”

(Male patients, FGD)

The interview location required careful consideration. Interviews with men could be held in a variety of locations to suit the patient (such as a café, place of work or a car), while interviews with women took place at home or in the clinic, which was regarded as an acceptable public place for women to attend. For the latter, the research team sent 2 female social workers in a car with a driver to collect the patient. When the family of a female patient saw 2 female workers in the minibus, they were happy for women to attend without male company.

Culture, religion, the economy and human resource issues

Work positions in Yemen can be insecure and unprotected by law. Salaries are low and it is common to have more than one job. Employees may leave at short notice for a position offering a better salary. Despite careful selection, project staffing was initially unstable, with a high turnover and interrupted availability. Although this situation partly resulted from limited human resources, other phenomena, such as identifying female workers who had their family's permission to travel to patients' houses, were also common. To minimise the effects of staff discontinuity, the team invested in training the co-investigator and local co-ordinator - experienced biomedical researchers, who had a longstanding working relationship with the UK institution - in qualitative research. This provided a more durable solution, as senior local staff was able to train new team members.

Research personnel were employed in accordance with cultural norms. In Sana'a, a woman does not traditionally travel alone or with a man outside her immediate family, and when travelling with a female companion, does not travel far from home. It was therefore necessary to employ at least one male and two female workers. The team was thus able to interview patients of both sexes in the clinic or in the community. When interviewing in the community, the 3 interviewers travelled together to cover any eventualities, such as a male being present in the household of a female patient. This arrangement was costly in terms of resources, including salaries, travel, work time and other expenses.

Locating patients and securing attendance

There was a high rate of non-attendees, especially for FGDs. Patients tended to accept the invitation, then not attend. When the driver arrived at the house, the household did not open the door, or said the patient was not home, or the patient said s/he was busy (particularly males). Some asked, 'What do you want?' or 'What benefit is there for me?'

Often patients gave the wrong address, or unclear addresses (house numbers and street names are not well developed and there are no maps). In addition, it is not easy to knock on doors and ask local people where a patient lives because residents are suspicious, especially at a time of political uncertainty. To draw a parallel, during public health campaigns patients are sometimes vaccinated in front of the house, as Yemenis may not want to invite in people they do not know. Social workers would sometimes spend several hours looking for a patient's house only to be refused entry.

This contrasted with a low refusal rate for the surveys. Possibly because the patients were already in the health centre and the survey seemed to be endorsed by the staff. The questions were less threatening and did not probe into patient's social status or feelings.

Local research staff hypothesised that since Yemeni people are not accustomed to participating in research, they could be wary. The public also associates form-filling with government institutions. In general, people do not have the expectation that a public employee is interested in understanding their experiences and make their life easier. The suggestion that someone was interested in improving health services was met with incredulity.

Religious sensitivities and the taboo of HIV

Yemeni research and health staff informed the steering group that HIV and AIDS are not spoken about in Yemen. Rates of infection are presumed to be low (as is the practice and uptake of HIV testing) and it is considered an affront on someone's honour and moral integrity to ask their HIV status. Yemeni staff emphasised that mentioning HIV would be akin to insinuating promiscuity or lapse as a Muslim, and had the potential to jeopardise the patient's relationship with their spouse or other relatives. The team decided it was not

possible to ask Yemeni patients about their understanding of the link between HIV and TB, as planned.

Discussion

This qualitative study provided a unique opportunity to explore the views of patients on the facilitatory and inhibitory factors for attendance at diagnostic services and treatment registration, in a country in which the perspective of patients on health services has rarely been heard. Northern Yemen is characterised by its conservative and tribal society and the study required adaptations, particularly with regard to the operation of male and female interviewers, the organisation of FGDs and appropriateness of interview questions. The study was successful in interviewing defaulters from diagnosis, thus providing an interesting complement to the survey, which only included patients that returned to complete the diagnosis process. It also provided explanations for the higher expenditure of patients from rural areas or other towns and the detail of cost components; issues which had been left unanswered in the survey. Research participants also voiced criticism of diagnostic services – a perspective that did not emerge in the quantitative phase. As intended, the use of two qualitative tools provided complementary information. FGDs allowed the differential experiences of men and women in accessing healthcare to surface, as well as the impact of disease status on social and work relationships and opinions on public awareness of TB. Some of the barriers for completion of diagnosis (and eventual treatment registration) were unique to the study setting. For instance, females faced particular and multiple barriers to attendance. Restricted female autonomy inevitably impacted on women's ability to participate fully in the research. It is likely that many women do not attend formal health services and studies in the community are necessary to further explore the unique situation of women. An important limitation was that the study only interviewed those individuals who

in one way or another had managed to reach the services. Given that one third of the estimated new TB cases occurring in the world never contact diagnostic services, there is undoubtedly a pool of individuals who did not manage to overcome these barriers. These are likely to include those with terminal illnesses who were too weak to travel, those who did not believe the diagnostic services were of good quality, perhaps proportionally more women (as aforementioned), and those in a precarious economic position. Whether the barriers preventing these individuals from accessing diagnostic services are the same for those who attend remains to be explored.

Conclusion

The cultural, economic, religious and political context shapes the manner in which a study is organised and conducted. The practice decisions taken by the research team and their consequences have been discussed in this Case. In some instances, solutions may be a best-fit, or compromise, against the methodological ideal; a trustworthy approach requires open discussion of these. The challenges and negotiations involved in conducting this research project demonstrate that, despite extensive planning, the research context is dynamic and researchers need to respond to unforeseen eventualities.

Exercises and Discussion Questions

1. Obtaining a one to one interview was difficult to achieve in this research context. What are the possible methodological implications of the presence of multiple voices in the in-depth interviews? Do you consider the presence of multiple voices to be a methodological weakness, or a format which was true to the sociocultural environment?

2. Focus Group Discussions and In Depth Interviews often elicit different types of information, as was the case in this study. What are the possible explanations for this?
3. How could the perspective of women be further explored in a future study?
4. How would you take the sociocultural environment and gender dynamics into consideration in your research particular context?
5. Your research group has been commissioned to conduct a follow up study to explore the barriers to attending TB diagnostic service from the perspective of symptomatic adults in the community. How would you plan this, taking into account the political, sociocultural and religious considerations mentioned in this study?

Further readings

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