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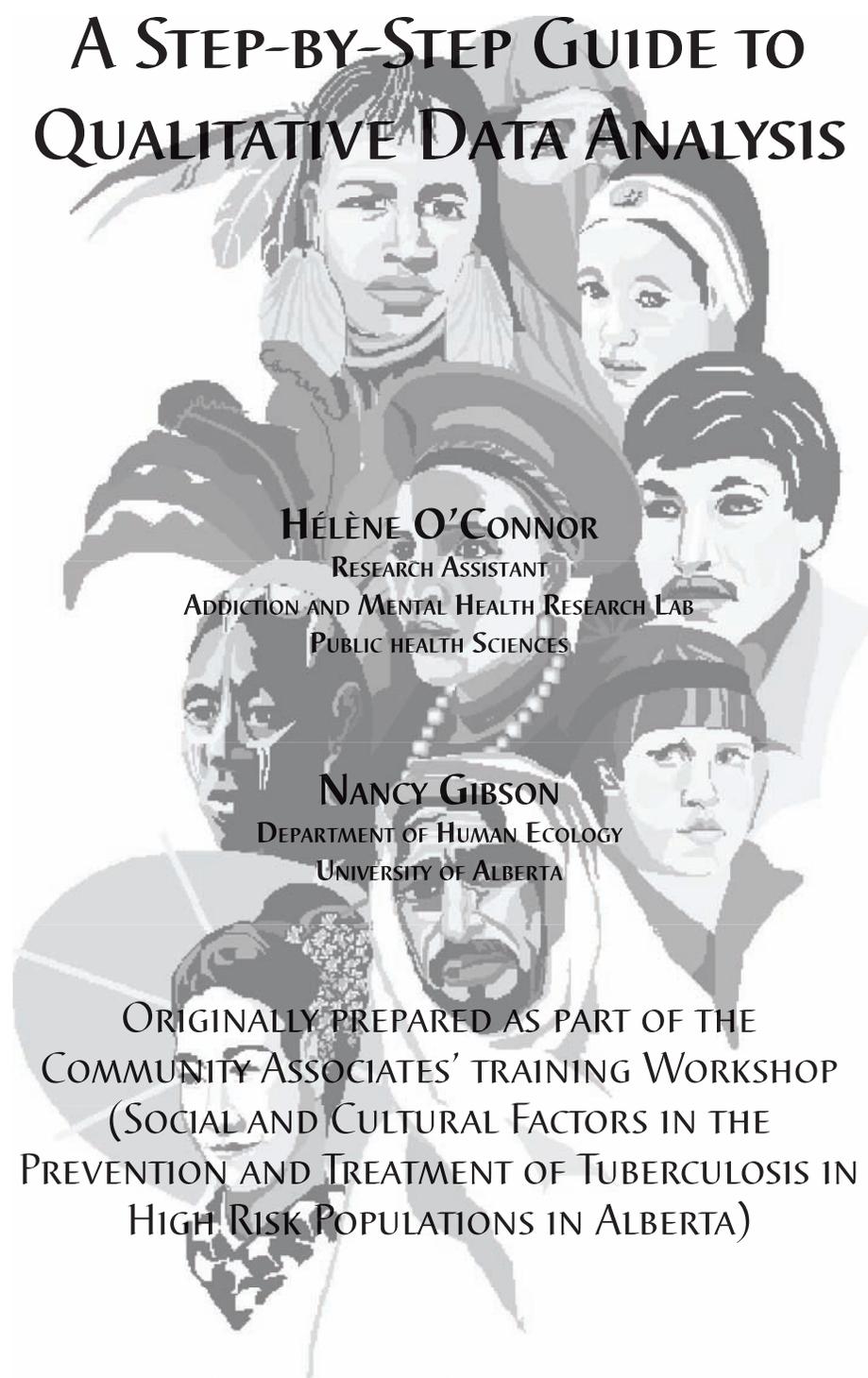
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A STEP-BY-STEP GUIDE TO QUALITATIVE DATA ANALYSIS



HÉLÈNE O'CONNOR

RESEARCH ASSISTANT
ADDICTION AND MENTAL HEALTH RESEARCH LAB
PUBLIC HEALTH SCIENCES

NANCY GIBSON

DEPARTMENT OF HUMAN ECOLOGY
UNIVERSITY OF ALBERTA

ORIGINALLY PREPARED AS PART OF THE
COMMUNITY ASSOCIATES' TRAINING WORKSHOP
(SOCIAL AND CULTURAL FACTORS IN THE
PREVENTION AND TREATMENT OF TUBERCULOSIS IN
HIGH RISK POPULATIONS IN ALBERTA)

INTRODUCTION

Collecting information, which researchers call *data*, is only the beginning of the research process. Once collected, the information has to be organized and thought about. Quantitative analysis uses data to provide answers which can be expressed numerically. Qualitative analysis, which this paper discusses, is more concerned with meaning. Data is a word which describes valid information that can help a researcher answer his/her question(s). It can come from many different sources:

Notes/observations



Interview tapes and transcripts



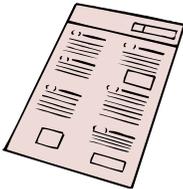
Newspaper clippings



Personal journal



Surveys/questionnaires



We'll be focusing on analyzing data from one-on-one individual interviews.

SO NOW YOU'VE GOT SOME DATA...

Start the analysis process by “getting to know” your data. You do this by listening to your tapes, transcribing interviews from tape to paper, and reading over the written transcripts.

- ◇ After doing this, you might have a general feeling or idea of what people are saying and what your results are looking like;

◇ **but**, you'll be surprised at how much more information is contained in your data once you start going deeper and begin a **systematic** and **rigorous** analysis!

Formal systems for the analysis of qualitative data have been developed in order to help researchers get at the meaning of their data more easily. These systems involve:

- ◇ coding techniques for finding and marking the underlying ideas in the data;
 - ◇ grouping similar kinds of information together in categories;
 - ◇ relating different ideas and themes to one another.
- (Rubin and Rubin, 1995).

This manual will guide you, the community researcher, through a step-by-step guide to analyzing qualitative interviews. There are many components to this type of analysis and they include:

- ◇ organizing the data
- ◇ finding and organizing ideas and concepts
- ◇ building overarching themes in the data
- ◇ ensuring reliability and validity in the data analysis and in the findings
- ◇ finding possible and plausible explanations for findings
- ◇ an overview of the final steps.

STEP 1: ORGANIZING THE DATA



“Valid analysis is immensely aided by data displays that are focused enough to permit viewing of a full data set in one location and are systematically arranged to answer the research question at hand.” (Huberman and Miles, 1994, p. 432)

The best way to organize your data is to go back to your interview guide. Identify and differentiate between the questions/topics you are trying to answer, and those that were simply included in the interview guide as important, but for the moment, not essential.

A MODEL FOR PRIORITIZING, REDUCING AND ORGANIZING YOUR DATA

Thinking inside the box

The amount of data generated by one interview (never mind 20 or 30) could answer an incredible number of questions. You could spend the rest of your life trying to analyze all of that information. That's why it is important to go back to the original questions that you are trying to answer. Analyze your data always keeping in mind what you are trying to find out and why you wanted to do the interviews in the first place.



Thinking outside the box

Once you have answered your original questions, look at other ideas and themes that have emerged from your data (surprises). Look at them in terms of how they relate to your questions and in terms of future research considerations.

→ For active and prophylaxis case interviews, the guides are organized by overall theme, information sought and actual questions. This becomes very useful during the analysis and makes organizing the data easier. ←

Data should be organized in a way that is easy to look at, and that allows the researcher to go through each topic to pick out concepts and themes.

One way to do this is to organize all the data from your transcript (see transcript at the end) and make a chart. It might look something like this...

EXAMPLES USING ACTIVE CASE INTERVIEW GUIDELINES

Topics	Interview A	Interview B	Notes
<p><i>History of illness</i></p> <p><i>Treatment</i></p> <p>personal experience with the medicine and treatment</p> <p>Transportation/Nutrition and others</p> <ul style="list-style-type: none"> • problems getting care needed? • suggestions to make it better? 	<p>But sometimes I don't like to have to take so many tablets. They are big and hard to swallow. Also they sometimes make me feel like vomiting — sometimes I do. I have to go to the clinic every month. [To get to the clinic] I sometimes when I am feeling OK I can take the bus, but other times my son or my wife, they drive me. It is inconvenient sometimes — for them. They are very busy.</p> <p>No, my family is helping me a lot.</p> <p>No [suggestions] because the medicines work, so it is worth it even though there are some problems.</p>	<p>write (verbatim) the various answers/responses</p>	<p>make a list of recurring words, ideas, concepts, themes</p>
<p><i>Effects of TB</i></p> <p>(Perceptions of TB in the family and community)</p> <ul style="list-style-type: none"> • who they told • how they acted • how TB has affected their family 	<p>Just my family. Oh, and I had to tell my boss because I was missing days at work so much. My family were concerned. Because they were worried about me and also they were worried that they didn't get sick too.</p> <p>They were worried about getting sick. And they were worried about my health.</p> <p>They had to get tested and even though they aren't sick they have to take the medicines. . . .</p> <p>My boss — he didn't like it. He was worried about the other employees getting sick so he made me take time off until I am better, so that is too bad because I really need the money. I need to help out my kids, it's hard for us.</p>	<p>write (verbatim) the various answers/responses</p>	<p>make a list of recurring words, ideas, concepts, themes</p>

This method of organizing and displaying the data allows the researcher to look at the responses to each topic and specific question individually, in order to make it easier to pick out concepts and themes.

Once the data are organized, the researcher can move onto the next step: picking out ideas and concepts and organizing them into categories.

STEP 2: FINDING AND ORGANIZING IDEAS AND CONCEPTS



“Identifying salient themes, recurring ideas or language, and patterns of belief that link people and settings together is the most intellectually challenging phase of the analysis and one that can integrate the entire endeavor.” (Marshall and Ross, 1995, p. 114)

WHAT TO LOOK FOR

WORDS/PHRASES USED FREQUENTLY

When looking at the various responses for one particular question, the researcher may find specific words or ideas keep coming up. The researcher should make note of the different ideas (i.e., keep a list) as the different responses are read through.

Example from the TB data (Who they told/how they reacted)



Effects of TB (Perceptions among Family and Community)
Just my *family*. Oh, and I had to tell my *boss* because I was missing days at work so much. My family were **concerned**. Because they were **worried** about me and also they were **worried** that they didn't get sick too. They were **worried** about getting sick. And they were **worried** about my health. My boss — he didn't like it. He was **worried** about the other employees getting sick so he made me take time off work until I'm better, so that is too bad because I really need the money.

There are many ideas here. The participant didn't tell a lot of people about his TB (only those he had to). For his family, their main reaction was concern/worry both for him and for themselves. For his boss, he was worried about the other employees.

FINDING MEANING IN LANGUAGE

Sometimes we can learn about a person's perceptions, attitudes, and feelings about something simply by noticing the words they use to express themselves.

The people who you are interviewing probably have their own way of expressing themselves. The way in which they refer to specific things or events can reflect attitudes or behaviours. The researcher should pick out the words and expressions used frequently by the interviewees that might sound different than how you or others would express themselves. This is particularly important while doing cross-cultural interviews. First, because the researcher needs to make sure he or she understands what is meant by certain expressions and also because it allows the researcher to look at the meaning and underlying implications of those expressions.

Every language and culture has expressions with meanings different than the obvious. This is why it is important, during transcription and translation, not to "clean up" the grammar. We want our translations to be as true to the original speech patterns as possible, and we want our transcripts to give the best reflection possible of how the conversation actually happened.

In many cases, a researcher must ask (either the interviewee or another knowledgeable source) to clarify or verify the meanings of these words or expressions. Community Associates have the advantage of belonging to the same cultural community as the people being interviewed, and are probably familiar with many of the expressions that are used. However, it is still important to pay attention to these expressions; not only what they mean but also where they come from and what they imply.

WATCH FOR THE UNEXPECTED

This is where we learn new things or things we didn't expect to hear. It is important to always follow up when a participant seems to be going in a new

or unexpected direction. These situations are called “rich points” (Asar, 1998) and are often very valuable.

Example: TB information circulated by the participant’s granddaughter.

→ Well, my granddaughter — she is in grade 5. She is also taking the medicines, so she is learning about TB. She decided that she wanted to do her science presentation — everybody in the class has to do one — on TB. So she went with her mother to the library and they got some books. She talked to me, and I told her how I was feeling. She talked to the nurse and doctor at the TB clinic. She is supposed to present next week some time. ←

HEARING STORIES (RUBIN AND RUBIN)

Stories are a way for the interviewee to communicate the point of ideas or symbols indirectly. Many events, themes and meanings can come out of a story. It is important to pay close attention to them and to their meanings.

Example: How do you think people get TB?

Well, I remember when I was a little boy in my village back in Zimbabwe. My sister, she liked playing with this other little girl from the village — she lived only a few houses away. One day my sister came home and said that she couldn’t play with her friend anymore. When my mother asked her way, she said that she had a cough and a fever and was tired. She said her friend had probably caught what was making her mother sick too. My mother became worried, so she asked some of the other villagers when she went to get water. They said the girl had caught TB from her mother. When my mother came back, she sat down with my sister and asked her if she had ever eaten from the same bowl as her friend, or the same cup. So, I guess that is how someone would catch TB from someone who has the disease. And let me just say too that after my mother told my sister not even to go visit her friend anymore. Isn’t that sad? She was sick, and she was all by herself.



→ By telling us a story, the participant has identified what he perceived are the symptoms of TB, how someone can catch TB and how people (from his village and his family) react to someone having TB. ←

CODING AND CATEGORIZING IDEAS AND CONCEPTS

Once you have identified words/phrases used frequently, as well as ideas coming from how the interviewee has expressed him/herself and from the stories that he/she has told you, you have to organize these ideas into codes or categories.

For TB Active Cases

Question/Topic	Responses	Categories
<i>History of illness (emotional reaction)</i>		
How did you feel when you first know you had TB?	I was <i>scared of what was going to happen to me . . . most people I knew who had TB died</i> . I was also scared of what others would think and what their reaction would be – especially my family. Also, I am scared – I don't want to make anyone else sick, so I try not to go places where I might give it to other people.	<i>Concern about not making healthy recovery</i> Concern over other people's reactions
How has having TB affected your life?	<i>My body has been feeling weak. I do not want to eat much and I have lost a lot of weight.</i> <i>I had to miss some work, and when my boss found out I had TB, he made me go on leave for a while.</i> Also, it is difficult because my family – they have to be careful and avoid touching anything that I touch so that they don't get sick. <i>It worries me that maybe I won't get better. . . .</i>	Physical effects Work/financial effects Feeling of being "infectious"

STEP 3: BUILDING OVER-ARCHING THEMES IN THE DATA

Each of the response categories has one or more associated themes that give a deeper meaning to the data. Different categories can be collapsed under one main over-arching theme.



One of the themes that emerges from the TB data is that this participant associated feelings of isolation with TB. The theme of *isolation* emerges from the responses, and the categories from each of the questions/topics discussed.

ISOLATION BECAUSE OF HOW TB IS PERCEIVED

- ◇ He sees how other people with TB have been treated.
- ◇ The story of his sister’s friend.
- ◇ He fears how others will react, so he limits the number of people told in order to avoid further isolation.

ISOLATION AS A RESULT OF BEING INFECTIOUS

- ◇ He was forced to take a leave from work in order not to infect any of his colleagues (isolation by others).
- ◇ Family has to take precautions (limit contact and sharing) in order not to get sick.
- ◇ He avoids going to places where he might infect others (where there are many people) – isolation of himself for others.

STEP 4: ENSURING RELIABILITY AND VALIDITY IN THE DATA ANALYSIS AND IN THE FINDINGS



Validity: The accuracy with which a method measures what it is intended to measure (Schopper et al., 1993) and yields data that really represents “reality” (Goodwin et al., 1987). Validation does not belong in some separate stage of the investigation, but instead as an ongoing principle throughout the entire research process.



Reliability: The consistency of the research findings (Kvale, 1996). Ensuring reliability, requires diligent efforts and commitment to consistency throughout interviewing, transcribing and analyzing the findings.

In the case where there is only one primary researcher, it is important that he/she develop a systematic and consistent way of carrying out and analyzing the research.

In the case where the research is being carried out by an entire team, developing a systematic approach and maintaining consistency throughout the process is essential to having “good data.”

TESTING EMERGENT FINDINGS AND HYPOTHESES

As themes and patterns emerge from the data, it is important to go through the data, carefully searching for negative instances of the patterns. These are sometimes called “outliers” (Miles and Huberman, 1994). It is often too easy to discard these since they don’t fit into the patterns and themes of the data, however it is just as important that these are carefully examined and that possible explanations for these outliers are thought out.



CHECKING FOR RESEARCHER EFFECTS (MILES AND HUBERMAN 1994)

The dynamics of the interaction between the interviewer and the interviewee will be influenced by the personal characteristics of both parties. Differences in age, gender, education, background, and language will all have an effect on the outcome of the interview.



Note: While belonging to the same cultural community helps to reduce researcher effects, since the interviewer is seen as being less of an outsider, many of these other factors still play a very important role and must therefore be recognized and taken into consideration when doing the analysis.

VALIDATING/CONFIRMING FINDINGS



Triangulation: Findings are more dependable when they can be confirmed from several independent sources. Their validity is enhanced when they are confirmed by more than one “instrument” measuring the same thing.

Different types of triangulation

- ◇ Triangulation from *different sources*: for example, interviewing different members of the community who can give different perspectives on a specific question or topic. Personal journals are also an example of this.
- ◇ Triangulation from *different methods*: looking at the same questions/topics but trying to answer them using different research methods, such as surveys, focus groups and individual interviews (often blending qualitative and quantitative methods).
- ◇ Triangulation from *different researchers*: having two different researchers conduct the same interview, for example, or analyze the same data is a good way to test validity.

What can you expect from triangulation?

Corroboration of the findings: they are both valid and reliable.

OR

Inconsistent or conflicting findings: these can elaborate the findings and often lead to more complex and context-respective explanations. Through triangulation it is not uncommon to find things that were missed in the original data collection process. Sometimes it means that our assumptions were off base, and that we need to change our questions or do more research.

OBTAINING FEEDBACK FROM PARTICIPANTS



The best way to examine the validity of the research findings and of the researcher’s interpretation of them is for the researcher to go back and ask those individuals who participated in the study or who can speak on behalf of them.



“local informants can act as judges, evaluating the major findings of a study” (Denzin, 1978).



Focus Groups: After all the interviews have been completed, a series of focus groups will be conducted in order to obtain feedback from community members on the accuracy, the validity and the appropriateness of the research findings. The implications of the research findings and how the dissemination of information should be done will also be discussed.

EXTERNAL VALIDATION OF CODING STRATEGIES

Not only is it important to ensure validity in the research process and findings, but also in the data analysis process. One way to do this is to compare how you (the researcher) have categorized and coded the results into themes with how a colleague would have done it.



Randomly select a few passages from questions/topics that you have already coded and analyzed. Give the list of your codes/categories to a colleague as well as all of the responses for that question/topic. Have them code the responses and you can compare the coding with your own as a measure of validity and reliability of coding strategies. Remember, however, to always protect the identity of your participant, even if you are working with a trusted colleague.

ACKNOWLEDGING FACTORS (BEYOND THE INTERVIEWER'S CONTROL AT THE TIME) WHICH MAY HAVE INFLUENCED THE PARTICIPANT'S RESPONSE

- ◇ Time of day the interview was conducted



- ◇ Were there other people (family members, friends, co-workers) present or within ear shot while the interview was being conducted?



These factors, and others like them, can be taken into consideration when going over possible explanations for the findings. They can and often should be included in the section on Limitations of the Study (in the Final Report).

STEP 5: FINDING POSSIBLE AND PLAUSIBLE EXPLANATIONS OF THE FINDINGS

SO, WHAT DID YOU FIND?

- ◇ Start by making a summary of your findings and your themes.

ASK YOURSELF SOME QUESTIONS

- ◇ Are these findings what you were expecting, based on the literature?
- ◇ Were there any major surprises in the findings?
- ◇ How are they different/similar to what is stated in the literature from other similar studies?

IMPORTANT SOURCES TO ANSWER THOSE QUESTIONS

Literature

Go back to the literature and compare your findings. This may also help you find possible explanations for them.



Personal notes/observations/journal



You've been paying attention and collecting data throughout the research process. Now this information will help you to tie themes together to get a better idea of the results you found and why you found them.

Key Informants/Community Collaborators

If you are not sure why you found the results you did, ask someone you trust and who is familiar with your topic and its context. There might be an obvious answer that only an "insider" would know.



It is important to relate the findings back to the context of the cultural experience within each respective community. This is not only important in terms of finding explanations for the results, but also in terms of findings' implications for that community. The implications of the findings are an important part of the final report.

AN OVERVIEW OF THE FINAL STEPS

WHAT ARE THE IMPLICATIONS OF THE FINDINGS?

Once you have developed your over-arching themes, you need to think about the implications. Why is your work important, why should anyone pay attention to it? What are the implications within each community? How are the partners within the communities reacting to the findings?

This is where the ACTION comes in from Participatory Action Research. The findings from the research should help us not only in identifying strategies to bring about change, or to be more responsive to a community's needs, but also help us find realistic ways of implementing those strategies.

COMMUNICATING THE INFORMATION

Determine (before writing the final report) who will have access to the information and how those people/communities will be affected by it.

Keeping in line with the foundational principles of the research project, we aim to disseminate the results carefully, sensitively, and in conjunction with those affected. It is important to remember that some study results are sensitive to some people and communities. So we ask ourselves, "What is the most appropriate way to let people know of the results of the study?"

There are many options:

- ◇ newspaper
- ◇ newsletter
- ◇ mail
- ◇ radio or video
- ◇ council meeting
- ◇ focus groups
- ◇ community workshops/seminars
- ◇ formal report

These decisions may also have funding implications to be considered.

ORGANIZING THE INFORMATION INTO A FINAL REPORT

This includes not only the results, but how the entire research process was carried out, what went right, what went wrong, highlighting the strengths and limitation as well as what you would do differently and how it could be improved. One of the most important things to take into consideration when

writing the final report is knowing who your target audience is going to be (who is actually going to be reading the report?)

In the final report, you are summarizing why the research question(s) you were looking at was an important one, how you went about answering it (methods), what your findings were, the implications of those findings, recommendations, and strategies, and areas of future research that you were able to identify.

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TRANSCRIPT (TRAINING SESSION - HOW TO DO DATA ANALYSIS)

This is a sample interview transcript for you to use as practice, either for yourself or in a training workshop. So, get out your coloured highlighters and mark the key words. Then, cluster them to find the themes. Remember, although most of us will select similar concepts and themes, we all see things slightly differently. This is why we often ask more than one person to analyze the research data.

I = Interviewer

P = Participant

(Turn on tape recorder)

- I. So, we are sitting in the participant's kitchen, in his home; the time is just after 8 o'clock in the evening.
- I. Good evening. How are you?
- P. Fine thank you.
- I. Last time I spoke to you, you weren't feeling so good.
- P. It's better now.
- I. Oh good, I'm glad. Do you mind if we get started right away?
- P. No, that's fine.
- I. As you may remember, the purpose of this research is to try to find a better way of treating and eventually preventing tuberculosis. We are speaking with people like you, throughout the province, to learn more about your experiences with TB.
- P. Yes, I remember you told me when we talked on the phone before.
- I. Good. Do you have any questions about the research?
- P. No.
- I. Do you understand that your participation is completely voluntary, that you don't have to speak with me if you don't want to?
- P. Yes, I understand that.
- I. And also that you can change your mind at any point during our discussion?
- P. I can?
- I. Yes. If you do not feel comfortable with a particular question or with

what we are talking about, or if you would like to postpone our talk until later.

P. OK.

I. You can also refuse to answer any of the questions.

P. OK.

I. Now, like we agreed before we started, I am going to be tape-recording our discussion so that I can be clear — later on — on what we talked about. Nobody will be able to recognize your voice, and your words will be written onto paper without your name on it. Is that all right with you?

P. Yes.

I. All the information that you share with me today will be kept confidential. Nobody will know that it was you who said these things.

P. OK.

I. Here is a copy of an information sheet that explains the reasons for the study. We can go through it right now if you like.

P. Yes, thank you (reads over information sheet).

I. Do you have any questions about it?

P. No.

I. In that case, when we do a research project like this one, we always ask the participant to sign a release form so that the information from the interview can be used in the study. Here is a copy.

(Participant reads and signs it)

I. Thank you. This form will be filed in the Research Office within the University of Alberta. Any questions before we begin?

(shakes his head to say no)

Now, for the record, my name is xxxx. We are sitting in the participant's kitchen, on today October 12, 1999 and the time is 7:40 PM. The first thing I would like to talk to you about today is your background. For how long have you lived here in Edmonton?

P. I've lived in Edmonton for as long as I've been to Canada, and that's um . . . about 15 years now. Ya 15 years.

I. So, why did you choose to live here?

P. Where in Canada, or in Edmonton?

I. OK, let's say both.

P. Well, we — my wife and I — came to Canada because we wanted a better

life than the one we had back in Zimbabwe and we got the opportunity because my uncle sponsored us as refugees. We came to Edmonton because this is where my uncle lived.

(Phone call . . . turned tape recorder off. The participant answered the phone and told the person he would return their call later).

P. Sorry for the interruption.

I. That's OK. So, How do you feel about living here?

P. It's good.

I. How do you find it compared to Zimbabwe?

P. It's a lot different. It took some time for us to get used to it here, but it's better now. Still . . .

I. What is it?

P. Oh . . . sometimes I think that things were better when my wife was still with me.

I. What happened?

P. She died in a car accident 4 years ago.

I. I'm sorry.

P. It's OK. Things just seem harder without her, that's all.

(Pause: the participant has tears in his eyes as he thinks about his wife. I offer him a tissue and turn off the tape recorder. I wait a few minutes before continuing).

I. So, what other places have you lived in?

P. Do you mean here in Canada?

I. I mean any place other than Edmonton.

P. Only back in my village in Cambodia. Do you mind if we stop for a minute, so that I can go make a phone call? It's very important and I don't want to forget.

I. No problem.

(Turn off tape recorder and resume about 5 minutes later)

I. That was a good time for a break.

P. Yes (some laughter).

I. Let's talk about your TB.

P. OK.

I. For how long have you had TB?

- P. Um, well I went to the TB clinic for the first time about six months ago – that is when they told me.
- I. So, how did you find out? Who told you?
- P. The people over at the TB clinic.
- I. Mhmm. And how did you feel when you first knew you had TB?
- P. I felt a bit scared and I was upset. I was concerned that my family would also have it.
- I. What were you scared of?
- P. I was scared of what was going to happen to me – most people I knew who had it died. I was also scared of what others – my family – would think and how they would react.
- I. Is there anything else?
- P. Also, I was scared because I don't want to make anyone else sick, so I try not to go places where I might give it to other people.
- I. So, where would you not go?
- P. Oh, like to a big mall I guess. Um, I was usually too tired to do a lot of walking, but I still thought it would be a good idea because I wanted to avoid giving it to anyone else.
- I. Can you tell me more about how TB has affected your life?
- P. Well, in my country, we have an expression.
(pause)
We say when the sun rises the lion is full, when it sets he is hungry again and ready to feast.
- I. That's an interesting saying.
- P. Thank you.
- I. Can you tell me a little bit more about it. How this meaning is important to you?
- P. Well, you see, in my country – and in other parts of Africa – the way that man lives . . . I mean that man looks to how the animals live and he observes how they live so that he can better understand how we fit into the universe.
- I. That's very interesting. It's a good way to look at the world. So, you're saying that man can relate to the lion because . . .
- P. Ahhhh, for this one, well, all I am saying is that I am very much like the lion.

I. And how is that?

P. Well, because with the TB I am tired all day and all I want to do is rest and the only time I ever feel like eating a little bit is at night!

(some laughter).

I. Oh, OK, I see. Thank you for sharing that with me. So are you saying that TB has affected how your body feels?

P. Yes it has.

I. Can you tell me more about that?

P. Well, my body has been feeling weak. I do not want to eat much and I have lost a lot of weight.

I. Has TB affected other aspects of your life as well?

P. I had to miss some work, and when my boss found out I had TB, he made me go on leave for a while. Also, it is difficult because my family — they have to be careful and avoid touching anything that I touch so that they don't get sick. And . . .

I. And? . . .

P. Well, sometimes it worries me that maybe I won't get better . . .

I. Can you tell me more about that?

(The participant takes his time to think about the question.)

P. It's just that I would feel so weak. And so many people they die from TB. It's not good. It's not good to have this disease. You never know.

I. That sounds pretty tough. How have you been able to deal with it?

P. With the help and support of my family.

I. How do they help and support you?

P. Well, they do so much. They take me to the clinic if I need to go. My son and his wife — they make sure I don't forget to take my tablets . . . and they make sure that I am taking the right ones. But most of all, I think that they help me because they make me want to get better. I don't want to leave them behind.

I. Where in your body is the TB?

P. Well, I have a cough so it is in my throat and lungs.

I. How do you think you got TB?

P. I don't know.

I. Do you have any idea?

- P. They tell me that probably someone from back home infected me with it before I came here.
- I. Who told you this?
- P. The people over at the clinic.
- I. The TB clinic?
- P. Ya, TB.
- I. Do you think they're right?
- P. Probably . . . I mean there are a lot of people back home who have this disease. But what if I got it here? Maybe that too is a chance? I don't know. People here they. . . .
- I. . . . They what?
- P. They don't like to think that there is such a disease here in their country. That is all.
- I. OK. So, have you noticed any changes in your body with having TB?
- P. Yes, I've noticed some.
- I. Could you tell me more about those changes?
- P. Well, I have lost a lot of weight and I do not feel like eating. Also I am coughing quite a lot.
- I. Did you notice those changes before they told you that you had TB?
- P. Yes, that is why I went to see my doctor.
- I. So, when did you first notice the changes?
- P. I don't know, I can't remember exactly.
- I. Can you think of when you first went for advice or help?
- P. When I started coughing a lot. And then I got a fever, so I went to see my doctor.
- I. And how long ago was that, can you remember?
- P. I think it was about six months ago.
- I. OK, six months. So, what kind of treatment have you been receiving?
- P. Well, at first my doctor thought it might be something else, so he gave me some tablets. I think they were antibiotics. But when I didn't get any better, he did some tests and then sent me to the TB clinic.
- I. So you went to the clinic?
- P. Yes.
- I. Did you get help from other healers?

P. Well, do you mean the healers from my country? There is one here in Edmonton. She gives me herbs for my cough. She sometimes tells me breathing exercises to do. We — my family — visit her every few months.

I. For how long have you been receiving your medical treatment?

P. For the TB?

I. Yes, for the TB.

P. I have been receiving it since I was referred to go there about six months ago.

I. Can you please tell me about your experience with the TB medicines?
(Doorbell rings).

P. Let me just go see who it is.

I. Yes, that's fine.

(I turn off the tape recorder, as the participant answers the door. It turns out that it was just some neighbourhood kids selling some chocolate. He bought some, so now we are sharing some chocolate as we chat. I turn on the tape recorder again).

P. This is good chocolate.

I. Yes, I like it very much!

P. I like to support the kids when I can. I think it was for playing hockey. I do not play because I have never been on these shoes that have blades.

I. You mean skates?

P. Ya, I've never tried that.

I. You should — its fun! I take my kids to skate at the park sometimes — outside, when it's not too cold.

P. But I can't buy a pair.

I. I know a place that you can rent them for not too much money.

P. Hmmm . . . well, maybe I will try that once I am feeling better.

I. Ya. We should probably get back to the questions.

P. Yes, sure. What was the last question you asked?

I. Hmmm . . . let me see. Oh yes. I wanted to know more about your experience with the TB medicines.

P. Oh yes. Well, I take the medicine that they give me. But sometimes I don't like to have to take so many tablets. And they are big and hard to swallow. Also they sometimes make me feel like vomiting — sometimes

I do. I have to go to the clinic every month so that they know that I am taking my pills. .

I. So, are you saying that sometimes you have problems with taking the pills?

P. Yes.

I. Do you have any suggestions about this?

(he pauses to think about it)

P. No, I don't think so. Because, the medicines work, so it is worth it even though there are some problems.

I. Do you think that chocolate will help you get better?

P. Ha (laughter) yes, I think very much this is true!! (we both laugh)

I. OK, so how do you manage to get to the clinic?

P. Sometimes when I am feeling OK I can take the bus, but other times my son or his wife, they drive me.

I. How do you feel about that?

P. It is inconvenient sometimes— for them. They are very busy you know.

I. Yes, I am sure that they are. So would you say that you have any problems getting the care you need for your TB?

P. No, my family is helping me a lot.

I. So your family knows that you have TB?

P. Yes

I. Who else did you tell that you had TB?

P. Just my family. Oh, and I had to tell my boss because I was missing days at work so much. I had to bring him a note from my doctor.

I. And how did they act when you told them?

P. Well, my family — they were concerned. Because they were worried about me and also they were worried that they didn't get sick too. My boss — he didn't like it. He was worried about the other employees getting sick so he made me take time off until I am better, so that is too bad because I really need the money. I need to help out my kids . . . it's hard for all of us.

I. You mentioned your family — how has this affected them?

P. Well, they all had to get tested and even though they aren't sick they have to take the medicines so that they don't get sick in the future.

- I. So they had to get tested and now they take the medicines. Did it affect them in any other way?
- P. Well, they were worried about getting sick. And they were concerned about my health. Oh and then. . . oh, you probably don't need to know that.
- I. Maybe I do. Would you like to tell me anyway?
- P. Well, my granddaughter — she is in grade 5. She is also taking the medicines, so she is learning about TB. She decided that she wanted to do her science presentation — everybody in the class has to do one — on TB. So she went with her mother to the library and they got some books. She talked to me, and I told her how I was feeling. She talked to the nurse and doctor at the TB clinic. She is supposed to present next week some time.
- I. Wow, that should be very interesting.
- P. Yes, she is very clever girl. We all learn something from her project. It is very good.
- I. You must be very proud.
- P. Yes, I am.
- I. Can you tell me if any other members of your family have had TB?
- P. My cousin had it when she first came to Canada — thinks she caught it before leaving our country to come here.
- I. So where was she treated?
- P. They gave her medicines here at the TB clinic when she first arrived. She is OK now.
- I. Do you know anyone else who has had TB?
- P. Only people from home. Oh, and some people I met at the clinic.
- I. So what people helped you with your TB?
- P. My family, as well as the nurses and doctors.
- I. Please tell me about your experience at the health centre/unit.
- P. It was good. They — the doctors and nurses — are very polite and very friendly. My visit was very quick . . . (pause) maybe a little fast. But they seem so busy I can see why they want to go so fast.
- I. So are you comfortable with the staff and services at the health unit?
- P. Yes, I am satisfied. They helped me.
- I. Even though you are satisfied, do you have any suggestions to make it better?

- P. No. Well — um — maybe they could take more time.
- I. Let's go back to TB. How do you think people get TB?
- P. Well, I remember when I was in a little boy in my village back in Cambodia. My sister, she liked playing with this other little girl from the village — she lived only a few houses away. One day my sister came home and said that she couldn't play with her friend anymore. When my mother asked her why, she said that she had a cough and a fever and was tired. She said her friend had probably caught what was making her mother sick too. My mother became worried, so she asked some of the other villagers when she went to get the water. They said the girl had caught TB from her mother. When my mother came back, she sat down with my sister and asked her if she had ever eaten from the same bowl as her friend, or the same cup. So, I guess that is how someone would catch TB from someone who has the disease.
- I. Did you get the information you needed when you were told you had TB?
- P. Yes, the nurse explained a lot of things to me.
- I. What do you think people need to know about TB?
- P. They need to know how you can catch it, and how you can stop yourself from catching it. They also need to know where they should go in case they think they might have it.
- I. Maybe they should see your granddaughter's presentation.
- P. Ha (laughter) yes, that would be very good! (more laughter)
- I. What other information do you think would be useful?
- P. I think that is all. Maybe that if you have TB, it's OK because you can treat it and it doesn't mean you have to die. Me, I always thought I would have to die if I had TB because my sister's friend and her mother both died because of it. Still, I think sometimes I am scared. Maybe I don't need to be so scared . . . but I can't help but be like that.
- I. That's OK. So tell me, what do you think are the best ways for people to learn about TB?
- P. Well, I have learned a lot because I have it, and my family has learned a lot because I have it. So maybe to get it, or to know someone who gets it. But I think that more people should be talking about it, like they talk about the flu or about cholesterol. Maybe they don't know there are people who still have it.

- I. Thank you very much. Those are all the questions I have for you right now. Do you have any questions that you would like to ask me?
- P. No, I don't think so.
- I. Do you have any comments or suggestions about this study?
- P. No.
- I. Is there anything else that you would like me to tell you about this study?
- P. I'd like to know when the final report will come out. Do you think I'll be able to get to look at it?
- I. Yes, we're not sure when we'll be done . . . we should be done before a year. You would like to be informed of what we find?
- P. Yes.
- I. All right. I will remember that. Would you like me to call you in a day or two in case you have some further thoughts or suggestions?
- P. No, that is all right. I think I've said everything I can think of.
- I. Here is my phone number, just in case.
- P. Thank you very much.
- I. Are there any other people you know that you think I should talk to about TB?
- (Participant thinks about it).
- P. I'll think about it. Maybe my granddaughter, she is an expert now you know! (laughter) Maybe one day she will be researcher just like you!
- I. (laughter) Yes, maybe I can call you again later.
- P. Yes, that is no problem.
- I. I'd appreciate that very much. Thank you for spending this time with me.
- P. Thank you, I enjoyed talking to you too.
(I give him the gift and turn off the tape recorder).

A COMMUNITY COMMENT

I enjoyed reading it. I kept thinking “Where were all these people all this time?” It would probably be helpful to a community person needing to know how to deal with data. The idea of different cultural approaches is important. I like the boxes setting things off. I like the stick figures. It made me wonder: if two people came to an interview would they hear the same thing? I felt sorry for person who was sick. Felt he was feeling very alone. I like the interview at the end. It reminds me of the research about boarding schools I was in. The man who interviewed me knew me really well but he still had to ask the questions. The questions seemed respectful of someone from another country.