



METHODOLOGY

How we collect and analyse the interviews for www.healthexperiences.ca

Introduction

This website is exceptional in the field of patients' experiential research and communication, because each collection of stories (or module) about a particular health problem is based on an original research study using rigorous qualitative research methods to collect interviews and analyze what people tell us. Too often, health information sites using patient experiences present only one or two anecdotal accounts, often focusing on heroic or inspiring cases, or exceptional testimonials. The evidence-based medicine movement has revolutionized attitudes to healthcare research. There is now widespread acceptance of the need for thorough and appropriate research methods to improve care. This applies equally to quantitative and qualitative research questions.

For credible research into the effectiveness of medical interventions, well-designed randomized controlled trials and systematic reviews are appropriate. For other questions, such as understanding how patients experience illness and make treatment choices, qualitative research is the method of choice, and should equally conform to rigorous standards. A systematic collection of interviews, carefully analyzed, is just as important in qualitative research as systematic reviews are in quantitative research.

Here we explain our study methods which are modelled on the award-winning Healthtalk website developed by the Health Experiences Research Group at the University of Oxford in the UK. Links are provided to papers that describe these methods in greater detail. In the UK, these methods have recently been recommended by the NHS National Knowledge Service as the 'gold standard' for research into patients' and caregivers' experiences. Our Canadian Health Experiences initiative is closely linked to the UK and several other countries engaged in similar projects through an international collaboration—DIPEX International – with link to the website: <http://www.dipexinternational.org/>)

Research Team

This website is the result of an interdisciplinary and collaborative effort to present people's lived experiences with illness and health conditions, along with useful information and resources that are grounded in evidence-based medicine and best practice. Our research team is composed of qualitative researchers, technical and administrative research assistants, and graduate students from different disciplines such as medicine, anthropology, health services research, management, public health, psychology, and sociolinguistics. The team is based at the Research Centre at St. Mary's Hospital Center in Montréal, which is a McGill University-affiliated hospital. The team meets regularly to monitor progress, share expertise, and provide mutual support. The principal investigator has overall responsibility for ensuring the research process is adhered to, approving any changes to it, and conducts annual performance reviews of individual team members.



Each module is led by an experienced and trained qualitative researcher who specializes in this sort of study. All of the qualitative researchers for the Canadian Health Experiences initiative have undergone intensive training with the Health Experiences Research Group in Oxford on the research methods, and have received a detailed handbook. We have a careful recruitment process to ensure that we appoint excellent and sensitive researchers. Before the researchers start interviewing, they read published books and papers on the subject to help identify both the questions for the interviews and what types of participants should be included in the study.

Their reading includes up-to-date reviews of clinical evidence on the particular topic as well as social science studies, and will include recommendations from the expert advisory panel (see below). A particular strength of the process is that each researcher leading a health experiences module is assigned another researcher who acts as 'buddy'. The buddy supports and advises his/her colleague at all stages.

Modules

Each module focuses on a specific health problem, condition or illness, and presents a collection of individual interviews that includes a wide scope of lived experiences. The idea for which topics to select may come from several different places, and will depend on the funding to do the work (each module is separately funded), as well as the priorities of patients, our community, funders, and other stakeholders.

Expert Advisory Panel

For each module there is an expert advisory panel including participants, health professionals and researchers with a special interest in the condition or topic being covered. The expert advisory panels are very important to the projects, and play a key role in ensuring we produce high quality research-based information. They provide advice to the researcher throughout the project, help us to ensure that we interview an appropriate range of people and have included all of the main treatments and perspectives, check that the material we write is clinically accurate, sensitive and accessible to a lay audience, and promote the project in their own professional and social communities.

Recruiting Participants

We recruit people to take part in interviews in a number of different ways, including with the help of family physicians and hospital specialists, support groups and newsletters, advertising in newspapers, the radio and local media, on websites and by word of mouth. Doctors and nurses hand out recruitment packs (which include a study information sheet, an introductory letter, a reply slip and stamped addressed envelope) to potential participants, who can get in touch with us if they are interested in hearing more.

Sometimes people hear about the study and contact us directly, in which case we send them an information package to help them decide if they want to take part in the study. To make sure that a wide range of experiences and views are included we use a method called purposive (or maximum variation) sampling (Coyle,1997).



We collect interviews until we are convinced that we have sampled the experiences and views of people within Canada. Often this requires between 35 and 50 interviews.

Interviews

The interviews take place throughout Canada, mainly in participants' homes. However, if people prefer they can be interviewed somewhere else. Interviews are usually sought with people one-on-one, but sometimes a partner or friend may be present during the interview. The interview takes a semi-structured form, i.e. very few questions are directly asked and are often used as prompts, and the interviewee can tell her stories in the way she better prefers. All the interviews are audiotape recorded for analysis. If the respondent is happy to consent, interviews are also recorded on digital videotape. In the first part of the interview, people are asked to tell the story of what has happened to them, perhaps from when they first began to suspect there was a problem. The researcher does not interrupt the person while they are telling their story but, when they are finished, the researcher asks additional questions, which may have been prompted by issues the respondent raised or identified in earlier interviews, or from the review of the literature.

It is usual for qualitative interview studies to have an overlap between collecting and analysing the interviews. Two members of the research team (the main researcher and their 'buddy') discuss the emerging themes after a few interviews have been completed, and new ideas may be suggested. This may lead to changes in the interview guide for subsequent interviews to enable issues that are important in the respondents' stories to be explored more fully.

Consent

The interview recordings are fully transcribed and the transcript is returned to the respondent for review. Participants sometimes decide that there are sections of the interview they would rather did not appear on the website, in which case the researcher removes them from the final version. After reviewing the transcript (if they wish to) the respondent is asked to sign a consent form which allows the interview to be used for research, teaching, broadcasting and on the website.

Analysis

Software is used to help organize the interview transcripts for analysis. Analysis begins soon after the first interview (Tesch 1990). Before analysis starts we draw up a list of categories for analysis. These are identified from the literature and from the first few interviews but, as the analysis progresses, additional categories are added.

During the analysis we group and link all of the sections of the interviews that cover a similar topic. When this coding is finished we can then look at what everyone has said about a particular topic, gathered together in one or more reports. These reports are the basis for the analysis and for writing the topic summaries.



During analysis the researcher and their buddy look at the reports and together they make sure that important points, and every respondent's perspective, have been included in the topic summaries (see below). The role of the buddy is to be a 'critical friend' who takes an independent view of the data collected.

At this stage there may be some discussion about meaning and interpretation of points made during the interviews. (The analysis process is described in more detail in Ziebland and McPherson (2006), see link below.)

Writing the Topic Summaries for the website

Two qualitative researchers from the team look at the interview transcripts for the study and discuss which topic summaries should be written for the website. The list of topics is also discussed with the expert advisory panel.

In writing the topic summaries, the researcher represents the full range of perspectives collected during the interviews, not just a majority view or a few selective opinions. The findings are set in the context of the latest clinical evidence and current best practice.

Each topic summary is drafted by the researcher, checked by their buddy, revised and then sent to at least one appropriate member of the expert advisory panel for additional contextual material and checking.

Finally, the summaries are given a final edit for coherence. The research team is given regular refresher training in writing for a lay audience.

Selecting the Clips for the website

The researcher identifies video clips, audio clips, and texts from the interviews to illustrate the range of views and experiences in the interviews. Only a few clips from each interview appear on the website, however the full interviews are used for the analysis and as the basis for papers for conference presentations, peer reviewed journals and chapters.

Publishing Papers

We aim to publish one or two papers in peer reviewed journals from each of the studies or modules. These will be submitted to social science and specialist and general healthcare journals. We regard this as an important way of disseminating our results widely to all types of professional readers, as well as ensuring that the quality and academic credibility of the studies are maintained.



Secondary Analysis

Researchers in other higher education institutions may, under agreement with the St Mary's Research Centre and Health Experiences Research Team, access the full or partial interview collections for secondary analysis. For more information please contact the project coordinator at info@healthexperiences.ca.

References

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Coyne, I. (1997) Sampling in qualitative research. Purposeful and theoretical sampling: merging or clear boundaries? Journal of Advanced Nursing, 26, 623-630.

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Acknowledgements

This summary of the methodology has been adapted for the Canadian Health Experiences initiative from the methods developed by the Oxford HERG for Healthtalkonline and Youthhealthtalk

See www.healthtalk.org for the DIPEX International collaborating countries.