

## CASE STUDY 6.1

### Virtual participant observation: Research on the internet to study patient identities

#### Sources:

Fox, N. and Ward, K. (2006) 'Health identities: From expert patient to resisting consumer', *Health*, 10(4): 461-79.

Fox, N., Ward, K. and O'Rourke, A. (2005) 'The "expert patient": Empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet', *Social Science & Medicine*, 60: 1299-309.

Websites are an increasing source of health care advice, and online communities are a potential field for ethnographic research. Nick Fox, Katie Ward and colleagues were interested in the role of the internet in the consumption of pharmaceuticals, and more broadly in how 'patient identities' might be changing in the light of the proliferation of internet sites which allow the posting, sharing and discovery of information about health, illness and treatments. Sites such as online advice services, discussion forums and email

lists do not just provide information, they also facilitate sharing, offering a space for those who might be physically distant to exchange experiences and social support. The users are therefore 'virtual communities', and through becoming a participant in those communities, the researcher can study social interaction and the presentation of self.

In their study, Fox and colleagues draw on ethnographic work on different sites used in their research on patient identities. These sites included:

- A public web forum called 'X-Online' for people wanting to lose weight and using a drug called Xenical, available on prescription or to buy online. This forum has 495 users from the USA, UK and Australia, with 20–30 messages posted each day. Typically, users discussed the use and effects of Xenical, and offered support and advice to other users.
- Online discussion forums for male impotence, including one called 'V-Board', concerned with the use of Viagra, a drug to treat erectile dysfunction. This was used by participants to share advice on buying the drug without prescription, and its medical and more recreational uses.
- A website/discussion forum, 'Anagrrl', for members living with anorexia, who were resisting medicalized models of anorexia as a 'disease' to be treated or recovered from, and instead sharing advice on how to live a safe and healthy life with anorexia. The users were largely female.

Like most virtual communities, these sites included users from a range of countries, who were using the sites for information-seeking, advice and mutual support. The fieldwork sites were identified from searching the internet using pharmaceutical names, for example as search terms, and following the links from sites identified. Despite having no face-to-face contact with participants, the researchers, as participants in discussion forums and by interviewing site-users, were able to derive first-hand experience of immersion in the online communities.

The methods of data collection and generation for such virtual ethnography are the same as those for more traditional forms: participant observation, interviewing, analysing textual documents and reflexive analysis of the experiences of membership. After a period of participation in the forums to become familiar with the local culture (e.g. of what and how to post), the researchers then became participants as well as observers, posting questions directly to the forums. This also generated contacts willing to take part in in-depth email interviews away from the site. The ethical issues considered by the researchers were also similar to those of ethnographies in physical spaces. 'Lurking' on a site, without letting other users know you are there, is a covert approach which breaches principles of informed consent, so when researching X-Online, for instance, Katie Ward sought permission from gatekeepers (the site organizers), announced her presence, using her real name, and announced her interest in researching the topic. To protect the anonymity of participants, all the sites have been given pseudonyms in published papers, as have any participants' whose postings or interview answers are quoted in reports.

Studying the questions posted by site users, how they were answered by others, and what sources of information were sought, shared and legitimized on the sites enabled the researchers to outline a range of possible identities that were adopted, which arose from particular constellations of engagement with technologies (both pharmaceutical and information), health expertise, and consumerism. Those using X-Online were to some

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extent 'expert patients', using the site to inform themselves about the drug, its effects and how to manage their diet. However, weight loss was understood and discussed largely through a medical model. For the users of V-Board, argue Fox and colleagues, identities were blurred between that of 'expert patient' and 'independent consumer', as some users sought Viagra for non-medicalized uses. Finally, the users of Anagrrl were engaged in an 'anti-medical' movement, rejecting the idea of recovery as a goal. Although these identities relate to biomedicine, argue Fox and colleagues, we cannot simply explain them in terms of traditional 'medical' concepts of health and illness.

### Reflective questions

What effect do you think having a researcher present in an online community might make (if any)? How might this be different to the effects of a researcher's presence in an actual ethnography or observational study?

### Feedback

There may be a social desirability bias affecting the content of what is posted. Alternatively, as the researcher's presence will not be visible, participants may forget they are part of a study and be more liable to 'over-disclose'.

## Applied anthropology in a diarrhoeal disease control project

Source: Scrimshaw, S.C.M. and Hurtado, E. (1988) 'Anthropological involvement in the Central American diarrheal disease control project', *Social Science and Medicine*, 27: 97-105.

Susan Scrimshaw and Elena Hurtado note the importance of a detailed understanding of local health beliefs, culture and language for effective health interventions. In introducing oral rehydration therapy (ORT), for instance, it is vital to know local terms for different kinds of diarrhoea in order to target health promotion effectively, and to understand local health beliefs about both the causes and potential cures. Anthropologists have a large role to play in planning health interventions through presenting data on folk health beliefs to public health specialists. As a contribution to a programme on reducing the morbidity from diarrhoeal disease in Central America, they collated ethnographic information on 'ethno-classifications' of diarrhoea in four communities in Guatemala and Costa Rica. These proved to be complex. One taxonomy, from a highland community in Guatemala, included eight main kinds of diarrhoea, based on the primary cause: for instance, the mother, food, tooth eruption, fallen fontanelle or stomach, evil eye, stomach worms, cold or dysentery. These primary classifications were further subdivided. Different therapies were appropriate for different causes. Thus, if diarrhoea is caused by the mother being overheated (from pregnancy or being out on a hot day) and her milk being spoilt, the remedy would be to abstain from breastfeeding or weaning the baby. The only type of diarrhoea that was seen as appropriate to take to the clinic was that of dysentery, which was the most serious form and distinguished by blood in the stools. Others were seen as amenable to home cures (such as herbal teas, baths and massages) and various traditional healers. The ethno-classifications of other communities differed

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in detail, but all included multiple types of diarrhoea with their own symptoms and preferred remedies. Explanations and therapies often combined biomedical and folk beliefs.

The implications for project planners are: that ORT has to be available widely in the community, through pharmacies and other stores, rather than only from the health clinic; that any information has to stress both the different kinds of diarrhoea in the local folk classifications and terminology; and that the need for rehydration in less serious categories of diarrhoea must be stressed. There is also scope for testing the effectiveness of home remedies identified, so that effective ones can be recommended.

To inform public health interventions, Scrimshaw and Hurtado recommend training project workers to carry out rapid ethnographic assessments in local communities to aid understanding of local health beliefs. They stress the need to present anthropological findings in ways that workers from other disciplines can understand. So rather than producing monographs using anthropological language, they summarize ethno-classifications briefly as taxonomies, with diagrams if possible.

## Reflective questions

How far do you agree that some sort of assessment, however superficial, is better than no assessment at all?

Can you think of an example from your own community of practices or taken-for-granted beliefs that might mislead a visiting ethnographer who had not had time to learn the 'insider' view?

## Feedback

This has been much debated: findings might be so compromised as to be misleading, but, where sound findings can be generated, they might be more readily understood by practitioners from a wide range of disciplines. For applied work, 'some' findings available whilst the issue is still current, not several years down the line, may be essential.

One example might be the practice amongst some mothers in the UK of sucking the dummy a baby has dropped before handing it back to them; this is understood by the mothers as cleansing it of 'unknown germs' and replacing them with 'safe', known germs. An outsider however might observe this and conclude that a mother's saliva was considered 'lucky' and to be passed on to the baby at every opportunity.