Using qualitative research to explore patient understandings of asthma

Asthma is a common condition, and from the perspective of health professionals, there is a problem in that many patients don't take medication as prescribed: the medication intended to prevent symptoms (the 'preventer') may not be taken at all, and the medication intended to relieve symptoms (the 'reliever') is often over-used. Adams and colleagues note that such apparently irrational behaviour is understandable if we look at the patients' perspectives – how they understand symptoms and medications, and how these are managed within everyday lives. The study used in-depth interviews with a sample of patients on preventative asthma medication. After analysing patients' accounts, the researchers identified three broad groups in their sample.

First were the 'deniers'. These patients, about half of the sample, denied that they had asthma, although they had been identified from general practice records as people diagnosed with asthma and prescribed preventative medication. However, these patients did not see themselves as asthmatic, but saw their problems as 'chest trouble' or bronchitis. They also claimed that symptoms did not interfere with everyday life, despite at times using quite complex or drastic strategies to manage symptoms, such as complete avoidance of going outdoors. This group also hid their medication use to a large extent, reporting only using inhalers out of sight of others, and had negative views of asthmatics – an identity they did not accept for themselves. Most did not use preventative medications at all – partly because of worry that they would become dependent on drugs that have to be taken daily, but also because taking medication regularly, whether there are symptoms or not, relies on accepting an asthmatic identity, which these 'deniers' did not. Given that they didn't see themselves as having asthma, they did not attend special clinics for asthma patients.

A smaller group within the sample accepted both the diagnosis and their doctors' advice completely, using medications as prescribed and taking pride in doing so. For this group, the route to 'normal life' was gaining adequate control over symptoms through

medication. Their definitions of asthma coincided with those of medical professionals. For them, 'asthmatic' was not a stigmatized identity, and they used inhalers in public.

The final group was identified as the 'pragmatists'. This group did use preventative medication, usually not as prescribed, however, but only when their asthma was particularly bad. They also had a pragmatic approach to disclosing asthma diagnosis; for instance, in telling family but not employers in case it prejudiced their employment prospects. This group accepted they had asthma, but usually perceived it as mild, or as an acute rather than chronic illness.

Looking at medication use from the point of view of patients enabled the researchers to see how health behaviour was tied tightly to people's beliefs about asthma and what kind of chest problems they had, as well as social circumstances and the threat of an asthmatic identity to other social identities. For service providers and health promoters, this kind of information is very useful. First it suggests that providing designated asthma clinics may not appeal to the majority of sufferers, since they don't identify themselves as having asthma. Second, professionals can see that what appears to be irrational use of medication, and the result of ignorance, is actually deeply embedded in complex social identities that have to be managed. For patients, health, defined in medical terms, may not be the top priority all the time, and the meaning of symptoms for professionals may be rather different from the meaning of symptoms for patients.

Reflective questions

You might like to reflect on a setting with which you are familiar. Are there seemingly 'irrational' choices made by some of the 'actors' in your chosen scenario (be it work, leisure or study)? Think how you might apply some of the research techniques discussed above to tease out why these seemingly irrational choices are made. For example, people continue to eat 'unhealthy' food even though they are well aware of its negative aspects. What do you think might be the reasons? What might you do differently as a policy-maker hoping to address these negative outcomes?

Feedback

One approach would be to get the perspectives of the 'actor' whose behaviour puzzles you by simply asking them in an open-ended way and then listening carefully to what they say. In the example of 'unhealthy foods' it might be that social norms and expectations (food as celebration) or eating as emotionally satisfying (a discourse of pleasure) outweigh any perceived health impact. Policy-makers might: a) consider how best to take these other perspectives into account; or b) consider whether the health benefits or risks do in fact outweigh the other reasons. This latter would be an example of how taking a 'critical approach' can lead to very different aims and outcomes.

Evaluating an intervention to improve TB care in South Africa

Sources:

Lewin, S., Daniels, K., Dick, J., Zwarenstein, M. and van der Walt, H. (2002) *A qualitative evaluation of the Kopana TB training intervention.* Internal Report, Health Systems Research Unit, Medical Research Council of South Africa.

Lewin, S. and Green, J (2009) 'Ritual and the organisation of care in primary care clinics in Cape Town, South Africa', *Social Science* & *Medicine,* 68: 1464–71.

Cape Town, South Africa, has high rates of tuberculosis (TB) and clinics face problems in persuading patients to complete the long course of therapy needed to cure it and bring the epidemic under control. Previous research suggested that one barrier to patient compliance could be poor support from staff, who have a 'task orientation', rather than patient orientation, focus to their work. The Kopana project aimed to deliver a participative, experiential training intervention to clinic staff that would lead to improved communication with patients through patient-centred care and an orientation towards quality improvement. An experimental design, in which clinics were randomly allocated to either receive or not receive the Kopana training package, was used to evaluate the intervention. This used quantitative measures, including TB treatment completion rates, to look at the effectiveness of the intervention, and a qualitative evaluation to look at the process. The aims of the qualitative evaluation were to explore how the intervention was developed and implemented, and what impacts it had on staff, clinic organization and patients.

Simon Lewin and colleagues used ethnographic approaches to study the process of training and its impact on clinic organization. This included observations of TB clinic routines and the Kopana training sessions, interviews with staff, and analysis of transcripts of the training sessions. The findings from this ethnographic study first helped identify why Kopana did not have the anticipated outcomes; that is, it did not reduce TB cure rates significantly in the intervention clinics. A key reason was that in many clinics what the researchers call the 'integrity of the intervention' was difficult to maintain. For various logistical and organizational reasons, it was impossible to deliver the training package (which involved six facilitated sessions with clinic staff leading up to them identifying changes in practice, plus a follow-up session) in line with intention. This is perhaps typical of training interventions: although they may work well with enthusiastic advocates in initial projects, when rolled out as realistic interventions in randomly chosen settings, they are resisted and adapted by recipients in unpredictable ways.

Other findings from the qualitative evaluation were that 'task orientation' was deeply entrenched as a pattern of provision in this setting, and was hard to shift through the process of Kopana training; that a lack of middle management involvement may inhibit change; and that extensive health system restructuring at the same time as the intervention had created uncertainty among clinic staff and a high rate of turnover of experienced nurses. Qualitative interviews enabled the researchers to look in detail at staff concerns. In some clinics, staff fears about local gangsters causing trouble in the waiting rooms, or worries about catching TB themselves, meant that an intervention designed to increase patient-centred care raised concerns about reducing the amount of

control they had over patients. In others, deep-seated interpersonal conflicts between staff members or inadequate management limited the impact of any intervention that relied on building on team-working. Nurses did not necessarily identify themselves as part of a clinic team, so an intervention addressing 'the team' did not resonate with their perspectives.

Ethnographic insights included analysis of the implications of ritualised care in the clinics, which had symbolic functions: changing practice would need to engage with these functions as well as the more instrumental aspects of care. One example was the lack of any ritual that marked the end of the long period of TB treatment: there was no symbolic way in which the 'sick' patient was reintegrated into the healthy social body.

The qualitative study therefore helped unpack the results of the quantitative evaluation, in explaining why the intended outcomes had not occurred. It also suggested some issues to consider in future attempts to change the delivery of care for TB patients in primary level clinics. The ethnographic study also produced findings of wider significance, given the paucity of data on the organization of care in settings such as this one. Detailed accounts of how clinic organization is achieved from the perspective of staff involved, and why apparently irrational organization structures (such as 'task orientation') persist, are useful for building future interventions that take account of the motivations and behaviour of staff, rather than making assumptions about why nurses act in the way they do.

Reflective questions

Consider your own work setting, or somewhere you are familiar with, such as a school or a health clinic. Are there systems in place there that you feel could be improved if only the experiences of workers or users had been taken into account? List the ways in which these views might be made known (e.g. through a questionnaire survey, a suggestion box, one-to-one interviews, participant observation/ethnography). What might be the advantages and disadvantages of each?

Feedback

The relative advantages and disadvantages might relate to: whether the responses are confidential and allow for elements such as tension between staff to be acknowledged; whether the views of the users/practitioner are expressed about the situation as a whole, rather than simply about the issue in question, showing how it is experienced in the overall context rather than as an isolated and perhaps abstract 'issue'. Disadvantages of all methods may be that expectations are raised about issues or difficulties being resolved when this is beyond the power or remit of the research team.