

## The TAPS Project. 2: Challenges and pitfalls of community interviewing

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From November 1987 until March 1990 I worked as a researcher with the TAPS project. So far this project's task has been to evaluate the reprovision of hospital services for the long-term mentally ill from two hospitals in the North East Thames Region (Team for the Assessment of Psychiatric Services, 1988). My work involved gathering clinical and social data from over 250 patients and their carers after they had spent a year out of hospital. Most of these patients were suffering from schizophrenia. The design and first results (Team for the Assessment of Psychiatric Services, 1990) provide an objective account of this research. In contrast, this paper intends to put forth a subjective view of some of the problems encountered while obtaining these data in the community. This situation faced the researcher with unique and challenging circumstances that are not normally discussed in the scientific presentation of follow-up data. Its aim is to pre-empt similar difficulties for other community research by providing guidelines. I am going to cover three areas: arranging interviews, conducting them safely, and handling situations that necessitate stepping out of the interviewer role.

### *Arranging interviews*

Identification of patients' key-carers in the community is a vital step. We need people, preferably professionals, who have day-to-day knowledge of patients so that we can obtain objective assessments of their behaviour. Also, key-carers can be crucial in gaining patient's cooperation. This is achieved most efficiently by asking key-carers to negotiate with patients on the researcher's behalf to secure their participation in the research.

Until the case management system of care is implemented in the community, it will remain unclear whom to identify as each patient's key-carer. For our purposes the different possible carers were contacted to discuss the extent to which they were involved in the day to day care of the patient. The carer who had most day to day involvement was then designated as the key-carer.

When there is no key-carer, the researcher has to embark on these initial negotiations. The best yield is obtained from sending a brief letter that clearly

explains the purpose of the intended assessment and its duration, and arranges an appointment for the researcher to call, but allows the patient to make alternative arrangements with the researcher if this is inconvenient. This may seem an uncompromising approach; however in our experience open-ended letters that invite the patient to make contact or arrange an appointment never yielded any response.

The telephone has proved to be a poor medium to make arrangements with both patients and carers. Few patients have them and as a means of establishing contact with the patient it can lead to misunderstandings and the forgetting of arrangements. Any arrangements made on the phone or through a key-worker as intermediary need to be confirmed by letter.

In direct negotiations with patients, they usually decide early on whether or not they want to participate. So far, the vast majority have agreed to take part and those who refuse rarely change their opinion despite the researcher's attempts at persuasion. A frustrating problem is respondents who, despite, agreeing to an appointment, repeatedly fail to attend, perhaps indicating their own ambivalence or disorganisation. If they fail to turn up twice it is unusual for any subsequent appointments to be attended.

### *Safe interviews*

In general the precautions that are usual in hospital practice need to be applied in the community, although somewhat more rigorously. The psychiatric history of the patient needs checking for past episodes of violence. The key-carer interview should precede the patient's, so that the researcher may be forewarned of the patient's recent behaviour. The researcher should adopt a positive attitude that avoids showing irritation, anger or fear. The room in which the assessment is conducted must be spacious, with the exit nearest the researcher. The lounge is preferable; bedrooms should be avoided. Colleagues in the research unit must know where you are going and when you plan to return.

During the interview the researcher must be aware of any objective signs of impending violent behaviour, for example, signs of agitation, anger, and growing suspicion. The researcher should be alerted

for any voiced grievances that are becoming attached to himself, since with psychotic patients these may rapidly become delusional during the assessment. Most importantly, the researcher must respect his own feelings in relation to the patient. Strong feelings of fear and alarm should not be disregarded and even in the absence of objective warning signs they should be enough to justify ending the assessment.

If attacked, the only course of action is to flee immediately. A car parked nearby can provide a safe refuge. This should be parked within a short distance of the residence but not so near as to invite pursuit.

Out of 226 first follow-up assessments there has been physical violence on one occasion, and on two other occasions I have felt at risk of violence. All three cases have been single male patients, living alone in flats. In two cases they were unsupervised and had missed their depot injections for some time. In view of this it is now a rule in the unit that researchers visit in pairs patients who lives alone or with family members, as opposed to those in supervised group settings.

Many lessons were learnt from the situations in which violence occurred. In particular, re-evaluating their antecedents threw light on some important points in need of further attention. In retrospect the signs of potential violence were present from the beginning. During the first visit the patient was seen to shut the curtains hastily and then briskly pace the entrance corridor. The glass in the front door was already broken and on inspection the impact had occurred from inside. No professional was in contact with the patient; hence his parents, who lived nearby, provided the key-carer information. They described in an amiable, tolerant way the grossly psychotic, verbally abusive behaviour of their son, failing to recall his past history of violence towards one of them. The father attended a support group for relatives of the mentally ill and felt his son was doing well, considering the seriousness of his illness. His mother worked alongside the long-term mentally ill and as a result described viewing her son more positively. The parents' massive denial was contagious and together with a dedication to achieve a high follow-up rate led to the wrong decision to visit the patient a second time.

### *Ethical dilemmas*

The situations that present ethical dilemmas fall into three categories: patients whose severity of illness is unrecognised, bad practices, and staff who are in need of care themselves. All these exert pressure on the researcher to change from the position of an observer to becoming involved in the situation. This means occasionally taking on the role of doctor or ombudsman for the research subject and counsellor

for distressed staff. Obviously, this affects the data that are being collected and the observed outcome for a minority of subjects; however this is in exchange for maintaining the integrity of the research process as a whole.

As a consequence of adopting an advocacy role for the patient, there can be short-term personal costs for the researcher and longer term costs for future data collection that have to be borne. Alerting carers to unrecognised illness in their patients and acting as the patient's ombudsman can be understood by some members of staff as implying that they have been personally negligent in some way. The researcher may then become the object for their displaced feelings of anger and resentment. The longer term cost can be that future data collection is jeopardised; carers become awkward about providing information as well as facilitating access to their patients.

The most commonly occurring situation is when patients are recorded on their Present State Examination to be more ill than their care staff seem to be aware. In part, this may be due to the researcher having the time to explore the patient's mental state for as long as it takes to complete the PSE, which on average is about an hour.

In general we regard information provided by community patients as confidential. The exception is information from the PSE if this reveals patients to be at risk of harming themselves or others, or reveals them to be distressed by seemingly unrecognised symptoms. In these specific circumstances the information is fed back to staff as a summary of symptom categories. This is done after discussion with patients, who usually appreciate this concern for their welfare. In our experience, this process of feedback facilitates the on-site carers to bring in additional professional help.

During the first period of follow-up of reprovocation patients (September 1987–August 1988) 97 patients were completely or partially assessed using the PSE. Among these, six patients required feedback of their mental states. During the subsequent follow-up period (September 1988–August 1989) 99 patients were completely or partially assessed using the PSE and seven patients required feedback of their mental states. Overall the most common symptoms to be fed back were those of depression with or without psychotic symptoms.

A much less common situation has been to come across bad practice. By way of illustration, I will describe two such situations and the eventual outcome of becoming the patient's ombudsman. One elderly patient had been placed in an adult fostering scheme with a single person as her carer. The carer refused entry to the researcher. When I visited the patient's day centre, staff there unburdened themselves of their worries about the care their client was receiving at home. They described how the patient

was locked in at week-ends and how they needed to unlock the flat in the mornings to allow her to travel to the day centre. Medical staff were contacted by phone. Their immediate response was of indignation that a researcher had seen one of their patients without their direct permission. However, in due course the patient was removed from that setting and adult fostering placements closed in that district.

On one occasion bad practice involved a whole group home. When visited, it had the following characteristics: senior management had lost touch with the on-site managers; interdisciplinary team work had broken down; staff were "burnt-out" and had a high sickness rate; the inside of the home showed unacceptable signs of neglect. The end result was a failure to provide for the needs of the homes' residents and staff. In this isolated case, our response was to send a report to the district general manager. This was followed by an improvement in conditions for everyone living in the home. However, the knowledge that the research team had stepped outside their expected functions and submitted a report, rapidly spread round the district and generated antipathy towards and suspicion of the research project.

The need to act as the patient's ombudsman has rarely occurred. A total of 39 different community settings including the patients' own homes were visited during the first follow-up year of reprovision patients (September 1987 to August 1988). Of these, only three settings necessitated this kind of action. It is noteworthy that during the subsequent follow-up year (September 1988 to August 1989) a similar number (32) of settings were visited and there was no need for this sort of response. This improvement may represent better planning and management of community services. Managers themselves may have needed time to adapt to the smaller and more varied settings in the community.

The last category is when community workers present themselves to the researcher as being in need of support. The emotionally neutral, listening stance of the researcher may in itself unwittingly lead them to unburden their concerns about their work and, rarely, about themselves. In this event, a counselling approach is recommended, encouraging the community worker to deal with the issues themselves

rather than the researcher feeling that they have to act on the carer's behalf.

This type of situation happened often during the first follow-up year when reprovision settings were visited (September 1987 to August 1988) and rarely during the subsequent follow-up year. This may suggest that managers are implementing methods of staff support and development that were initially neglected in the movement of services into the community.

### Conclusion

In this paper I have stepped outside of the usual scientific account and outlined some practical and subjective issues that are at the heart of gathering community follow-up data. At times it can be personally demanding, especially when the obligation of care means dropping the onlooker role in order to act as a patient's advocate, only to incur the antipathy of the staff involved. Hospital training alone may leave the researcher unprepared for important practical and ethical issues encountered in the community. In these circumstances, it is of prime importance to be part of a cohesive and well-led team that can provide support and advice.

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