Do research interviews cause distress or interfere in management?

Experience from a study of cancer patients

ABSTRACT - Research interviews with seriously ill patients are now often undertaken in quality of life research. Clinicians may be approached by researchers wishing to study their patients, and may be worried at some ethical aspects of interviewing. Concerns may include potential distress which interviews may cause, that they may interfere with the doctor-patient relationship, and perhaps, a scepticism that techniques addressing psychosocial concerns produce only 'soft' data. However, interview methods are a valuable tool for medical sociologists, nurse researchers and others.

We discuss here some reflections following a study that involved interviewing severely ill patients with incurable malignant cerebral glioma. We use our observations to answer concerns and to discuss problems that arose. We suggest areas researchers and clinicians might consider before embarking on such collaboration.

Patients' views about their care are now recognised as an important component of outcome assessment following medical intervention. Increasingly, therefore, research on quality of life seeks to interview patients, and in some situations their relatives or carers. These studies necessarily involve contact with seriously ill patients, and interviewers may ask about difficult and sensitive topics. The ethical issues raised by such research have been considered most often in relation to cancer patients. Fallowfield, for example, found women with breast cancer welcomed participation in research. Eardley and colleagues suggest that research interviews with cancer patients may have a positive impact, providing an opportunity for patients to discuss concerns they have been unable to raise elsewhere, but that patients should have control over how topics are discussed. Plant has summarised potential problems, including an undue pressure on patients to participate, the possibility of disrupting coping strategies and problems arising when matters are disclosed that need advice or intervention. However, in a different vein, Grimley Evans has questioned the merit of much interview research, which, he argues, may be poorly designed and unable to answer the questions it poses. He points out that patients co-operate with research interviews because they feel that knowledge will be increased; to interview them unnecessarily may therefore be unethical, particularly if the interview is an intervention with possible negative consequences.

In this paper we illustrate some of these tensions in the light of research we conducted with patients suffering from malignant cerebral glioma. During the study we considered the ethics of the project and the effect of research on management. Here we attempt to discuss these issues openly, if retrospectively and anecdotally, and to comment on our involvement. We consider whether patients and their relatives seemed distressed by in-depth questioning, whether data collection by tape-recording seemed acceptable, whether patients and relatives or carers could be interviewed separately and questions asked of the interviewer. We then consider the nature of the research relationship and whether it is possible to study a clinical situation without influencing it in some way. Issues that clinicians might consider before agreeing to collaborate with research are also suggested.

A brief description of our research study

Between 1990 and 1994, based at St Bartholomew's Hospital, London, we studied 105 patients with malignant cerebral glioma recruited from Barts itself and five other hospitals. We considered patients with malignant cerebral glioma because of their poor prognosis. Six weeks of radiotherapy increases the median survival of patients after biopsy from 14 to 36 weeks, but two years from diagnosis only 5–15% of patients remain alive. For many patients, therefore, radiotherapy takes up a considerable portion of their limited survival. Because side-effects can be severe, some clinicians have reservations about the trade-off between radiotherapy and the quality of the survival achieved. We aimed to interview patients and their relatives on several occasions over the course of their disease, to explore their experiences and to obtain their views about the value of treatment.

In our study of patients with a uniformly poor prognosis, we considered our approach to patients carefully. We decided to question patients and relatives using a semi-
structured interview schedule – a method whereby the areas to be covered are clearly defined but which allows the interviewer scope to encourage respondents to talk freely, and take cues from them in deciding on the pace and depth at which to explore difficult issues. Thus, although suggested questions are given, the interview is not a rigid sequence of standard questions administered to all respondents. For example, the initial interviews showed that most patients were unaware of their poor prognosis, whilst relatives tended to be more aware. To assess this awareness of prognosis we would ask a patient or relative to describe how they first came to suspect that something was wrong. Questions might then be Do you remember exactly what that doctor said?, or Were the doctors able to find out any more about the outlook in your own case ... or your relative's case? However, we would never assume that respondents understood the prognosis, nor would we volunteer information if it became clear they had an incomplete picture. In each topic area the interviewer was guided by an associated rating scale which indicated the level of detail required and how the data should be coded. These scales were tested for inter-rater reliability.

The results of our study showed that only 40% of patients achieved a remission or period of stability following radiotherapy. Severely disabled patients gained little benefit whilst most of those not disabled experienced significant side-effects. However, the dissatisfaction expressed by patients about radiotherapy did not increase and remained at about one-fifth throughout.

The acceptability of interviewing

Do patients and relatives agree to interviews?

The first point about the acceptability of interviewing is the high rate of initial agreement. We approached patients several weeks after the diagnosis, explaining that we wished to interview them about their satisfaction with care and treatment several times over the forthcoming year. We also asked to see a close relative or carer separately, since we expected that they might have a different perspective. We asked patients to discuss a letter repeating these points with a close relative or carer before agreeing to help. A week later, when we telephoned, 92 (88%) of a consecutive series of 105 glioma patients agreed to an initial interview. Eighty-nine had close relatives and of these 85 (96%) also agreed to be seen. It is clear therefore that most patients will talk about their illness to a research team. Although one of the interviewers (ED) was medically qualified she made it clear that she would not be involved in patient care. Her recruitment rate was no different from two other interviewers (SH and MB) from a social science background.

Are patients or relatives distressed by in-depth questionnaire?

Overall we conducted 451 interviews. These interviews, lasting 60–90 minutes, covered many aspects of this distressing situation. We estimate, on the basis of their comments and demeanour, that participants did get some satisfaction or comfort from being interviewed in 63% of the interviews (284/451). Some said that they appreciated the chance to repay the Health Service or to give feedback about unsatisfactory management. When asked at the end of the study how they had found talking about their experiences, some were flattered that their views were valued:

Well, thank you for being interested enough to listen to my story. I do hope you do find it is some use.

Or

Fine. No, no problems at all. No problem. I'm pleased you have contacted me.

Others found the interview an opportunity to reflect privately.

Someone I can talk to, not a relative, a staff member or a friend, but someone outside of the situation whom I can tell things I wouldn't tell anyone else.

In 5% (21/451) of instances, however, it seemed, even though they did not always say so, that the respondent had disliked the experience. They became uncomfortable, would change the subject or ask pointedly whether we had many more questions. They found the subjects difficult, and in trying to encourage them the interviewer had probed too far. The worst of these instances left a strong impression:

I agreed to see you because I was so impressed with the care Dr Brown gave me and I would like to help in any way I can. Maybe it's inevitable, but I must say it's actually been quite upsetting and I feel you've reduced me somewhat.

We judged that in the remaining third of interviews, patients and relatives (32%, 146/451) had no strong feelings and gave their time in the spirit that others might eventually benefit.

Our impression that most patients were happy to cooperate appears to be confirmed by the high follow-up rate we achieved. In instances where we initially saw a relative (85 out of 92 patients; 92%), we were able to see either the patient or another family member subsequently in 95% (81/85) of cases. This suggests that most families did not perceive the interview as so intrusive that they would decline to repeat the experience. Our impression that the research seemed acceptable tallies with findings of other workers who have sent questionnaires to participants after interview research. Funch and Marshall found only 5% wished they had not participated, and Fallowfield and colleagues reported that 85% of women had found interviews helpful.

Do patients and relatives agree to tape-recording?

We asked permission to tape-record interviews so that detailed comments and examples might be retained for analysis. We emphasised that all information given is
confidential ... and will not be written in the medical notes'. We also emphasised that data would be stored and reported anonymously, and we reiterated this at follow-up. All patients and all but one carer agreed to tape-recording.

The disclosure of different perspectives within families

Many studies suggest that communication between family members about life-threatening illness is difficult and rarely completely open13,14. In our study we needed to ask relatives about personality and cognitive change in the patient, and since we thought it might distress the patient to hear negative reports, we decided it would be best to interview patients and relatives separately. Although most relatives seemed happy with this, 7% (6/85) were unwilling to leave us with the patient. Three remained, as far as we could judge, to help patients with severe speech problems. Three other relatives requested that they be interviewed together. Later in the study, two other relatives admitted having disliked separate interviews, making 6% (5/85) who objected to this approach. One patient complained. Thus, in most cases our request to see relatives separately was accepted. It often seemed that for relatives the request elicited relief that we were interested in the impact of the situation and would allow them to talk freely.

Joint interviews were more difficult to manage, particularly when a couple disagreed. Interviewers would find themselves veering away from sensitive topics, or trying to defuse a situation. Other workers have commented on the unpredictability of joint interviews where one member may disclose issues which the other had not anticipated15. The value of seeing each patient and carer separately was borne out by later findings concerning awareness of the prognosis. Of the 66 cases where both a patient and a relative were seen shortly after diagnosis, relatives were three times more likely than patients to be rated as fully aware of the poor prognosis: 67% (44/66) of relatives, against 21% (14/66) of patients8. Had we conducted joint interviews, this finding would have emerged less vividly, and given that families appeared not to have discussed prognosis explicitly, deliberately raising this in joint interviews would probably have altered the situation. For some families, such discussion might have been a welcome intervention; for others it could have been extremely distressing.

Should the interviewer answer questions about the illness?

One possible objection to in-depth interviewing is that it will prompt people to seek out information which their doctors have decided not to disclose. To assess this objection, we noted the questions we were asked. After interviews, 5% (23/451) of respondents simply wished to know whether their views were typical. A further 10% (24/246) of patient interviews and 11% (23/205) of relative interviews contained straightforward questions about practicalities of treatment. Interviews with relatives were more likely to elicit questions (28%, 57/205) than those with patients (17%, 42/246). Relatives were over twice as likely to ask about prognosis: 11% (23/205), against 4% (9/246) of patients. Generally those who asked had already asked medical staff the same questions. We therefore first reflected these questions back, asking them to consider why they sought alternative views. We encouraged further discussion with their own doctors and indicated that it was not our role to disclose information. However, if a patient or relative was persistent, we felt it would be counterproductive to feign ignorance. No patient to whom we confirmed the poor prognosis withdrew from the study. We did not observe that answering questions during interviews made the situation more difficult for clinicians, nor altered subsequent management. Although we did not formally ask clinicians referring patients about this, we can report that we received no feedback from them that an interview had caused difficulty.

The interviewer as counsellor?

A further objection to in-depth interviewing may be that the interviewer can only elicit sensitive information by adopting the role of counsellor, albeit unwittingly. Undoubtedly, as discussed above, counselling techniques were used in some interviews, but the relationship differs in several basic aspects. First, the interviewer is always a visitor to the home, and, rather than defining the situation, needs to adapt to it. Second, we saw patients every three months, an interval less frequent than outpatient appointments, and far less frequent than is usual during counselling. Third, we did not set out to help individuals come to terms with their situation, as a professional counsellor might do. However, the depth of enquiry and continuity provided by the same interviewer did sometimes mean that respondents placed great importance on a developing relationship. This would sometimes happen after only one meeting, taking us by surprise.

Well it's easy with you because you know where we are, I don't have to start from the beginning and explain everything. I think you know more about us than most people.

One relative16, who has since written about her experience, comments:

A detached but interested observer can bring up aspects of life that are worth evaluating and admitting. The enquiry went beyond consideration that my husband and I could have considered together ... Effectively, this acted as counselling for us both ... I suddenly realised the value of being able to share our thoughts within a professional context. The whole of that period without such back-up would indeed have felt far bleaker.

Thus, whilst we owed our thanks to the participants, we commonly found ourselves being thanked for listening. We were also shown considerable hospitality: at only a handful of over 300 visits were we not offered refreshments. Thirteen percent (11/85) of families gave us small gifts, or wrote to us after the patient's death. Rather than becoming
counsellors, however, we would argue that we were afforded highly privileged access that stemmed from a perceived legitimacy of trying to improve the situation for others. The reward for the respondent was to be able to contribute to this activity in return for the undivided attention and often straightforward sympathy of the interviewer. It is possible that the benefits of professional counselling, both for patients and relatives, would have been greater.

Responsibilities of the research team

So far we have considered the responsibility of the interviewer to collect sensitive data without causing unnecessary distress. We now consider whether the interviewer should intervene in the study. When a study continues during inevitable deterioration, interviewers will often note changes in the patient’s condition. Whilst our primary aim was to study the situation as it evolved, there were 14 instances where we obtained consent from a patient or relative to discuss a problem with the clinical team after an interview. These problems concerned 9 patients and involved 11 instances of aggressive behaviour, cognitive deficit or distress. Three further instances concerned distressed and unsupported relatives. These situations represent only 3% of interviews (14/451) involving 7% (12/177) of patients and relatives. In only 5 of 14 did the clinical team respond with a change in management. We took no further action except in one case which we now describe in some detail to illustrate the tensions that developed.

Case study

Background. Mr H was 32 years old, and when interviewed two years from diagnosis and treatment was exceptionally well, working full-time and suffering only occasional partial complex seizures. At two years and eight months he developed headaches and drowsiness. His wife was told by one doctor (at a centre other than the research base), that ‘the tumour’s appearance on CT scan was unchanged’ and that Mr H would be ‘all right’ after steroids to treat brain swelling. Another doctor said that Mr H was in the ‘final phase of his illness’. Mrs H had always known that the prognosis was poor, but having a young family she had hoped for the longest possible remission. Feeling distressed and confused, Mrs H telephoned the medically qualified interviewer (ED) to ask what she thought was happening. The interviewer discussed the possibility of a recurrence with Mrs H and reassured her that further treatment would probably be considered. She relayed the conversation to the patient’s consultant who agreed to explain the situation again at their next meeting.

The request for help. One month later Mrs H telephoned to ask if she could bring Mr H to be assessed at the centre where the research was based. Mr H was increasingly drowsy, but despite repeated attendance at an accident and emergency department, he had not been admitted or offered an earlier appointment to see the consultant, nor had a further CT scan been performed. Mrs H recounted that a junior doctor had said that her husband’s prognosis might range ‘between one month and ten years’ and that she should contact her GP for symptomatic treatment. The GP in turn had told her that nothing more could be done. The interviewer (ED) explained that the research was not intended to intervene and declined Mrs H’s request for a second opinion at the research centre. The following day another relative telephoned and begged for help.

The decision to intervene. The discussion within the research team about this case was lengthy. The interviewer (ED) and the most senior (medical) member of the team (AH) shared the view that Mr H should be reassessed. ED felt that further treatment should be attempted, whereas AH felt the patient’s plight had to be balanced against other responsibilities. For instance, not only might such an intervention antagonise the patient’s clinical team and jeopardise collaboration, but if it was perceived more generally that clinical judgement had been challenged, other centres might be unwilling to contribute cases. AH decided to attempt a compromise solution which avoided direct disagreement with the clinical team. He spoke to the GP explaining that the family had contacted the research team, indicating that they were desperate to obtain a second opinion. The GP agreed that this might help them come to terms with the reality of the situation which he thought they had difficulty accepting.

Outcome. With the GP’s help, Mr H was assessed by a second team and promptly referred for chemotherapy. Following this, he improved remarkably and was able to attend college and enjoy an active social life. Mrs H appeared much happier with the second team, and their frank explanations about prognosis. She made a formal complaint to the first hospital, but after their initial reply, she took no further action. Mr H’s remission lasted three months and he spent several further months in a hospice. When asked after his death whether the chemotherapy had been justified, Mrs H replied that the quality of her husband’s life had been sufficiently good to make the extra survival worthwhile.

Although the eventual decision by the research team to intervene may appear to have been correct, the way we handled the case can be criticised. For example, the patient was entitled to a second opinion and the interviewer should have clarified this earlier. The research team felt uneasy at handling their difference of opinion with the first clinical team, but could have spoken earlier to the GP. This case shows that future researchers need to consider clearly at the outset situations where interviewers and clinicians will need to discuss cases. Problems may arise when research and clinical teams see patients’ interests in different ways. This is particularly likely when research is undertaken with the object of taking a new look at a clinical problem, and when researchers are able to spend longer with patients and
relatives than doctors. We had not anticipated this issue – but the instances where we wished to intervene were driven by the responsibility we felt towards the patient.

Conclusions

We have considered the acceptability of interviewing cancer patients, the management of family situations and the influence of interviews on clinical management. Our experience confirms that studies of seriously ill patients need to foresee many issues, including the distress an interview may cause or disclose, how to deal with requests for information or help, and situations in which it may be necessary to intervene.1

Acceptability of interviewing

Contrary to concerns that patients and relatives would dislike being interviewed, it has been our experience that an in-depth but conversational style of interviewing seems acceptable. Our impression was that nearly two-thirds found interviews enjoyable or helpful; 5% seemed uneasy. Interviewers do need to remain vigilant for signs that respondents are finding the interview unpleasant or that their coping strategies are compromised. Although it might generally be thought that tape-recording would be found intrusive, only one participant declined. The high acceptance rate to follow-up provided further evidence that the research method was acceptable, adding weight to the view that patients are willing to participate if others may eventually benefit.

Managing conflicts, questions and causing harm

Another issue we considered is how family situations may best be managed. We found that interviewing most patients and their relatives or carers separately was feasible, and this disclosed important differences of opinion, in particular about prognosis. A sizeable minority of respondents, particularly relatives, asked questions about management or prognosis. In general, we answered these directly; we have no evidence that this affected management. We have also made a case that although the interviewer should know when to counsel, in most situations the research relationship is fundamentally different from counselling. We have argued that research interviewers are given a highly privileged access, stemming from a perceived legitimacy of their role of trying to improve the situation for others. Most patients and relatives agree to contributing to this activity in return for an interviewer’s attention and sympathy.

Our interpretation of this generally positive response has to be offset against the considerable distress which may have been produced for a minority. In such projects, therefore, potential harm must be weighed against the potential benefit research may yield in enlightening health professionals to the problems of future patients.2 Critical here are methodologies that are recognised as appropriate and representative, and clinicians need to be aware of the insights that interviewing can bring into complex situations. Researchers, however, need to have sufficient training and expertise to recognise when harm may be done. The context in which this study was performed – that of a severe illness where patients and relatives were highly dependent on the medical staff who clearly supported the study – may have made patients more likely to comply and unwilling to voice misgivings. Our observations cannot therefore be seen as an objective evaluation of our research project, but nonetheless they do provide some further evidence to support the view that there are ethical issues involved in research by interview and underline the care needed in the design of projects.

Influence of interviews on clinical management

Our study attempted to record the patients’ situation as it evolved. Although we thought it preferable not to intervene, in a small proportion of interviews (3%) we judged it necessary to give new information to the clinical team with the patient’s consent. Most of these instances concerned patients’ mental problems or distressed and unsupported relatives. A change in management followed in less than half of these instances (1%); these were mostly minor changes and were clearly to everybody’s benefit.

In retrospect, we do not believe that we meddled too much. It soon became clear how impractical it was for the interviewer to remain impassive to patients’ difficulties. Further, it does not appear fair to use patients’ and relatives’ time, and benefit from their experience, without providing some level of help when an appeal is made. This perspective is similar to that described by Plant17 in relation to patients with terminal illness and by Smith in a study of women with drinking problems.18 This experience needs to be placed within the general context of the impossibility of observing a system without in some way altering it. Perhaps, had we sought more feedback from the clinical teams, they might have had more criticisms about this aspect of the study.

A code of practice

The rights of patients in research are usually considered in relation to physical interventions.19 Similar rights apply to research interviews, despite the apparent readiness of patients to participate. Based on our experience, we are developing a code of practice for research interviews involving seriously ill patients, considering issues of confidentiality, situations where research and clinical teams may need to communicate, and a policy for requests for information and help when patients or relatives need it.

Acknowledgements

The study described was supported by the Cancer Research Campaign Grant, CP 1017. We are grateful to Professor

410 Journal of the Royal College of Physicians of London Vol. 32 No. 5 September/October 1998
Sheila Hillier for her comments on an earlier draft of this paper. Dr Anthony Hopkins made substantial contributions to this paper but died before the final version was completed. We thank an anonymous reviewer for helpful comments.

References

1. Fallowfield LJ. Quality of life: the objective measurement of subjective responses to cancer and its treatment. Cancer Topics 1987; 6:99–100.
2. Eardley A, Cribb A, Pendleton L. Ethical issues in psychological research among patients with cancer. Eur J Cancer 1991; 27: 166–9.
3. Plant H. Research interviewing. Palliative Medicine 1996; 10: 339–41.
4. Grimley Evans J. The ethics of futile research. British Journal of Medical Ethics 1997; 23: 59–6.
5. Walker MD, Alexander E, Hunt WE, MacCarty CS, et al. Evaluation of BCNU and/or radiotherapy in the treatment of anaplastic gliomas: a co-operative clinical trial. J Neurosurg 1978; 49: 333.
6. Bleehen NM, Stenning SP. A Medical Research Council trial of two radiotherapy doses in the treatment of grades 3 and 4 astrocytoma. Br J Cancer 1991; 64: 769.
7. Wroe SJ, Foy PM, Shaw MDM, Williams IR, et al. Differences between neurological and neurosurgical approaches in the management of malignant brain tumours. Br Med J 1986; 293: 1015.
8. Davies E, Clarke CR, Hopkins A. Malignant cerebral glioma I: Survival and morbidity following radiotherapy. Br Med J 1996; 313: 1507–12.
9. Davies E, Clarke CR, Hopkins A. Malignant cerebral glioma II: Patient and relative perspectives on the value of radiotherapy. Br Med J 1996; 313: 1512–6.
10. Brown GW, Rutter M. The measurement of family activities and relationships: a methodological study. Human Relationships 1966; 19: 370–4.
11. Brown GW, Harris TO. Life events and illness. London: Guildford Press, 1989.
12. Funch PP, Marshall JR. Patient attitudes following participation in a health outcome survey. Am J Public Health 1981; 71: 1396–8.
13. Glaser BG, Strauss AL. Awareness of dying. London: Weidenfeld and Nicolson, 1965.
14. Hinton J. Dying. London: Penguin Books, 1972.
15. Larossa R, Bennett LA. Ethical dilemmas in qualitative family research. Journal of Marriage and the Family, May 1981: 303–13.
16. Chappell J. Breaking bad news: the perspective of relatives. In: Davies E, Hopkins A (eds). Improving care for patients with malignant cerebral glioma. London: RCP, 1997.
17. Smith L. Ethical issues in interviewing. J Adv Nurs 1992; 7: 98.
18. Davies E, Hopkins A (eds). Improving care for patients with malignant cerebral glioma. London: RCP Publications, 1997.
19. Guidelines on the practice of ethics committees in medical research involving human subjects. London: RCP, 1996.

Address for correspondence: Dr Elizabeth Davies, Specialist Registrar in Public Health, Department of Public Health, Merton Sutton and Wandsworth Health Authority, The Wilson, Cranmer Road, Mitcham CR4 4TP.

Medical emergencies for consultants ... the 6th Course

UNIVERSITY COLLEGE LONDON

7–9 December 1998

A didactic approach to the management of the acutely ill patient specifically aimed at consultants in general medicine, geriatrics, A&E, anaesthesia and surgery

- £250 registration fee includes textbook, course notes, meals and refreshments
- CME approval sought

For further details, please contact Alison Owens:

Bloomsbury Institute of Intensive Care, UCL Medical School, University Street, London WC1E 6JJ

Tel: 0171 209 6208 Fax: 0171 209 6258 E-mail: a.owens@ucl.ac.uk

Journal of the Royal College of Physicians of London Vol. 32 No. 5 September/October 1998 411