Ethical and research dilemmas arising from a questionnaire study of psychological morbidity among general practice managers

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SUMMARY
A questionnaire-based research project enquiring into the psychological health of general practice managers found that 5% of managers admitted to suicidal ideas. This paper explores the moral issues raised when research conducted at a distance uncovers information about participants which indicates that they may be at increased risk of harm. It examines whether the authors of such studies have responsibilities towards their research participants beyond those of analysing and properly interpreting the data supplied to them. The paper is an exercise in self-reflection and self-criticism; not all the questions posed and explored by it can be answered definitively. Implications for planning studies of this kind are discussed.

Keywords: ethics; psychological morbidity; primary care; questionnaires.

Introduction
Practice managers play pivotal roles in the functioning of many British general practices. Organisational changes currently taking place within primary care in the United Kingdom are set to widen their role and to increase their responsibility. Anecdotal observations have pointed to high levels of occupational stress and psychological morbidity among this group of managers. Having failed to identify any previous research enquiring into the psychological health of practice managers, we undertook a survey to enquire about their psychological morbidity in the context of occupation.¹

Method
With Local Medical Committee approval, a postal survey of practice managers was conducted that indicated high levels of self-reported psychological morbidity as revealed by validated and reliable psychological screening instruments. Of particular concern was that 17% of managers achieved scores indicative of depression, with 5% of responders reporting that they entertained suicidal ideas.

All questionnaires were completed anonymously but a coding system was used to allow non-responders to be identified and approached with reminder letters. The letter accompanying the questionnaire assured managers that their responses would remain confidential. No enquiry was made in this survey about whether managers were currently undergoing any medical treatment.

Results
The survey results raised a number of conceptual and ethical concerns for us as researchers. Foremost among these were the following questions:

1. What is the predictive value, in terms of completed suicide, of questionnaire responses revealing suicidal ideas?
2. What sort of relationship exists between us as researchers and our responders? Do we, as clinical researchers, have a moral responsibility to make further enquiries regarding those whom, from their questionnaire responses, we consider to be at significant risk of self-harm?
3. Were the assurances we provided regarding anonymity and confidentiality binding, or are there circumstances in which it would be appropriate to breach such assurances?
4. Could the difficult position we found ourselves in have...
been avoided and what, if any, are the implications of our experiences for further research of this kind?

Discussion

Relationship between questionnaire responses and suicide

The psychological screening instruments used in this study included the Hospital Anxiety and Depression Scale (HADS) and the General Health Questionnaire version 28 (GHQ-28). The HADS contains a specific depression subscale, as does the GHQ-28. Each was chosen for its face validity, content value, and self-completed format. The GHQ-28 depression subscale makes specific enquiries regarding suicidal ideas. It has been suggested that those scoring positively on two or more of its seven questions should be classified as being ‘suicidal’ which suggests an appreciable risk of self-harm. However, despite a comprehensive search of the literature, we were unable to ascertain any estimates of the predictive value for either completed suicide or self-harm, as outcomes of admitting to suicidal thoughts in a questionnaire survey of this sort.

Responsibility and relationships

Other than ensuring the scientific validity of the study design, that appropriate ethical permissions had been sought, that consents had been obtained and confidentiality assured (and ensured), little consideration had been directed during the design stage of the study to considering the moral connectedness that could ensue between researchers and participants in this type of study. However, once we began to ponder the meaning of our findings it soon became apparent that we had in fact developed a study protocol that framed responders as point sources of raw data only.

In contemplating the results of our study and in attempting to draw out its significance, we began to feel anxious. The act of assuming a relationship to disembodied point sources of information deprived us as researchers of any human contexts to which we could relate our findings. We knew nothing about the personality or proclivities of responders and we had not thought to ask about medical care, family, or personal relationships; such information had not seemed initially relevant to the research question. We had conceptualised the research issues being addressed in the study as centring narrowly on stress and occupation and arguably had paid too little attention to broader psychosocial matters, such as the social causes of depression (M Gantley, personal communication, 1999). Therefore, how could we approach knowing whether our findings at individual or group level indicated particular risk? If we were to contact those responders who appeared to be at high risk then we would be acting outside the research protocol without the permission of the participants.

Confidentiality

On the one hand, having advised managers that their responses would remain confidential, we felt that their privacy should be respected. On the other hand, by inviting practice managers to participate in the survey, we wondered whether we may have assumed something of a duty of care to them and, if so, whether this meant that we had a duty to offer help to responders who prima facie seemed to be at risk.

How ought researchers who perform questionnaire studies to assess the appropriate weight to be given to each of these ethical demands? One way to approach this is by considering arguments in favour of, and against, making contact with the responders in this particular case.

Arguments for contacting responders

It is widely recognised, both by practitioners and by medical ethicists, that in certain circumstances confidences may (and perhaps should) be broken. Is such a circumstance? If it is accepted that questionnaire responses provide convincing evidence that a number of responders are at risk of suicide, do we not as researchers have a responsibility to offer assistance?

Had this research taken the form of a face-to-face interview rather than of a questionnaire, and had we noted during one such interview that a particular interviewee responded to our questions in ways indicating similar suicidal thoughts, we would surely consider it unethical to have allowed him or her to leave without offering some form of support or advice. What justification can be given for acting differently in the case of a questionnaire-based study?

While it is true that we advised responders that their responses would remain anonymous, it is not clear if they participated only on the understanding that this promise would be adhered to in this kind of circumstance. Their consent and understanding of the confidential basis of the study, it could be argued, was only partially informed and, in the circumstances that had arisen, breach of this assurance to make contact with responders who seem at risk would not damage their autonomy.

Arguments against contacting responders

We had assured responders that their responses would remain confidential. There is a clear moral obligation to respect this agreement. Furthermore, while we recognise that there are circumstances under which such agreements may legitimately be breached, the breaking of confidentiality is usually an action of last resort and is not justified by a high score on a psychological screening instrument.

The responsibilities of researchers are different to those of clinicians. Researchers have a responsibility to carry out research ethically. This means that, among many other things, they should adequately inform potential participants of the nature of the research and of its risks and benefits, and must not expose participants to unacceptable risks. In questionnaire-based research, the researcher and responders do not usually enter into a therapeutic relationship. Furthermore, by asking for or agreeing to confidentiality, responders have effectively said that they accept they are not entering a relationship of care. Under such circumstances, it is the responsibility of the research participants (not that of researchers) to seek out help if they need it.

Should all medical research projects be required to provide support and advice to participants? Agreeing to this proposition would decrease the likelihood of such research...
Commentary

Sheikh, Hurwitz, and Parker have done a courageous and valuable thing. They have offered their honest reflection upon their role as researchers in relationship with the anonymous research participants, a minority of whom responded to screening-questionnaires indicating high levels of depression and, in some cases, suicidal ideation.

The authors seem concerned that the relationship between researcher and responder and the rules that structure or guide this relationship (such as ethical approval, informed consent and confidentiality) prevent the authors from changing this relationship to carer and patient, or at least to assessor and client. This is, thankfully, exactly what these rules do prevent. We agree wholeheartedly with their conclusion that there are no grounds to change this relationship. We could go further and suggest that the researchers have no basis upon which to intervene and any attempt to do so is unethical and potentially dangerous. They have made the right decision and should be allowed or permitted to feel no personal, moral or emotional responsibility for the lives or deaths of the responder who have made marks on the questionnaires they were sent. To elaborate, we would like to comment first on (a) the nature and reporting of depression and suicidal ideation, and (b) the importance of supervision or consultation in research.

Depression and suicidal ideation are complex and dynamic processes not well captured by simple screening tools.1 We would like to comment first on (a) the nature and reporting of depression and suicidal ideation, and (b) the importance of supervision or consultation in research.

Depression and suicidal ideation are complex and dynamic processes not well captured by simple screening tools.1 Depression and suicidal thinking often go unrecognised and unreported owing to social and occupational stigma. In addition, these thoughts are often not fully acknowledged by the sufferer. Further, recognising suicidal thinking does not necessarily lead to intent or behaviour. We should also recognise that people do and will successfully commit suicide despite the actions of others to prevent them. The anonymous and brief reporting of distress on a validated instrument is not akin to a cry or request for help. The reporting of this information is not an invitation from a participant for the researcher (or, for that matter, the reader) to cross a clear boundary and adopt a role as a carer or messenger.

The authors are clearly left with a moral uneasiness and a sense of unfinished business. Although the arguments for not being responsible are well made, it would seem that they still in some sense feel responsible for people who are not patients, who have not asked for help, and who are unknown to the researchers. Ironically, it is exactly these no-win situations that lead to burn-out and depression in health care workers who are, after all, in the business of helping. Where research is undertaken with distressed people the researchers will take on (or mirror) some of this distress. This is a completely normal and healthy process but one that should not end with the researcher feeling responsible. In situations where the topic under examination is likely to induce distressing and lingering emotional attachment in the doctor, therapist or researcher, we strongly suggest that appropriate systems consultation or supervision be provided and that ethics committees should be sensitive to this requirement.2

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References


Commentary

When I was first asked to read and referee this paper I judged it well written and argued, and agreed with the conclusion of the writers that there were insufficient grounds to compel them to contact the questionnaire responders. But, I added sourly that I thought the researchers had made too much of the dilemma and had ‘over-egged the pudding’.

The predictive value of the instrument chosen by the researchers, in terms of completed suicide, seems not to have been established. The researchers pray this in part defence of their decision not to contact the responders. But this is to avoid the moral question, which is more sharply posed on the presumption that a valid measure of suicide risk had in fact been used. What then?

The writers state that their questionnaires were completed ‘anonymously’. However, their letter accompanying the questionnaire states that ‘[the] answers will remain confidential to the researchers’. There is a distinct difference between the promise of anonymity and of confidentiality. Anonymity promises that the responder cannot be traced. A breach is technically not feasible. There is no need or room for moral judgement. Confidentiality sets out a rule of relationship between responder and questioner — that the responses will be kept secret. Here a breach is at least feasible and can be argued on moral grounds.

I concluded that the researchers were right not to contact the responders. Had they done so, however, they would not have breached the researcher/subject contract of confidentiality. No third party need have been involved.

What is most interesting in all this is the evidence in this report of the deep pervasiveness of the doctors’ sense of duty to care. This goes beyond the contractual grounds of a specific doctor-patient contract, and has no other mandate than the assumption of overriding professional responsibility shared by doctors and public alike.

At the conclusion of their report the researchers wrote: ‘Nevertheless, we were left with a lingering sense of unfinished moral concern’. This confusion between the nature of researcher/subject and doctor/patient contracts may, as I complained, sometimes result in the too exquisite agonising of the authors’ final sentence. But it ought to be unnecessary, given the pervasiveness of the doctor’s duty to care. In our society, this pervasiveness of the doctor’s duty to care remains the rule and not the exception. In this sense there was not much egg in the writers’ pudding. The egg was on the face of the reviewer.

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naire, nor to the 17% who achieved a score indicative of depression. We could find no objective evidence for or against genuine risk of harm associated with such questionnaire responses in this context. In these circumstances we judged there were insufficient grounds to breach our undertaking of confidentiality to participants, and thereby to transform our settled role of detached research observers into the more complex role of concerned clinicians. Nevertheless, we were left with a lingering sense of unfinished moral concern.

Implications for research

Had the ethical dimensions of the research been more intensively considered at the outset of the project, many of the problems encountered in this study could have been foreseen and, to some extent, minimised. In hindsight, it now appears obvious to us that a study into psychological morbidity is likely to reveal a certain number of subjects to be anxious, depressed or even suicidal. It is also likely that, for some participants, completing a questionnaire of this kind will bring to the surface feelings about which they may have been previously unaware. Given this to be the case, a narrative perspective on the research approach adopted may from the outset have suggested to us that ethical research of this kind should take place in a context capable of offering participants the sort of support they might need. A narrative perspective may have produced methodological tensions with the research paradigm adopted for the study (which was determined by the key questions posed being answered by prevalence estimates of psychological morbidity), but it would have helped us to keep in mind during the study planning phase that potential research participants are people embedded in their own life stories. At most, such a perspective could translate into an offer to provide counselling to those considered to be at risk (logistically difficult and likely to be expensive); at least it would mean putting a warning at the top of the questionnaire pointing out that the questions asked might bring to the surface distress which the participants might wish to discuss in the context of a confidential telephone helpline.

References


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