A case report: ethics of a proposed qualitative study of hospital closure in an Australian rural community

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**Background.** The GP and qualitative researcher use similar patient-centred approaches, but their roles are different. Guidelines for conducting GP research in small communities are limited. I planned a qualitative study about hospital closure in a small rural Australian town where I worked. Few studies have researched community reaction to hospital closure and this process of change.

**Methods.** I used historical analysis to improve external reliability, and purposeful sampling to develop and pre-test a qualitative semi-structured research instrument. Newspaper articles, minutes and tape recordings of public meetings, annual reports from 1991 to 1997, quality assurance data and interviews with two health professionals were analysed in this process. These sources were coded using content and thematic analysis. Ethical issues arose during early stages of planning. Ethical guidelines and bioethics principles were discussed with colleagues and a member of an ethics committee. I validated my findings with three other community members involved in the hospital closure.

**Results.** Themes of a transition, from resistance to change and divisions between key stakeholders, to a need to appreciate the benefits of change emerged in coding material from 1991 to 1997. The principle of non-maleficence outweighed the principle of beneficence in this study. Existing health services could be harmed by examining the process of change after spending time and resources to reconcile community differences. Individuals could be harmed as confidentiality in a small community was difficult to maintain, and discussions about sensitive issues could produce adverse public criticism. The autonomy of participants to give informed consent was complicated by the author providing clinical services in the community, raising concerns about patients feeling an obligation to participate.

**Conclusions.** A justified case for discontinuing this study was made by the researcher on ethical grounds. Use of bioethical principles and community representatives to validate findings was a useful technique to guide decisions in a small rural community. This discussion has application in planning other small community studies.

**Keywords.** Ethics, general practice, research, rural.

Introduction

The GP and qualitative researcher use similar patient-centred approaches, but their roles are different. The GP uses motivational interviewing to modify patient behaviour and interventions to treat their illness. In contrast, the researcher documents the subject’s viewpoint without wanting to influence their attitudes or change their present state of health.

The close relationship between a patient and GP can bias qualitative research. There is a need to state explicitly the relationship between a researcher and subject, with most papers failing to do this adequately. One method, to avoid this bias, is to use external researchers and recruit subjects outside your practice. Expense limits this method’s application.

Lack of clear research guidelines limit the application of qualitative research in general practice. Disclosing you are a GP/researcher is contentious if subjects are interviewed from outside your practice. Some GP researchers avoid disclosure; however, it may be better
to disclose explicitly and record this in your method. Patients often find out or guess you are a doctor in this setting, altering their response to questions. Explicit disclosure avoids this bias and potential role confusion, particularly if subjects become distressed during an interview and want counselling or treatment. 1

GP researchers using their practice population have the potential problems of limited external reliability and bias. Balint 3 or multi-disciplinary peer groups 2 or historical analysis 7, 8 have been used to plan research and validate findings. Tensions can arise in the multi-disciplinary research team as GPs are trained towards praxis, while other disciplines are more theoretical and descriptive about subjects and their attitudes. 2

Ethical decisions made by GPs in clinical practice often lack a framework. 9 Hoddinnot suggests that a decision to research your own patients depends on the research question and how closely it relates to medical care. 1 An explicit framework for making these decisions is lacking, with some researchers recommending weighing risk and benefits. 10, 11 These recommendations are based on studies in urban areas, where the GP and patient may only interact in the surgery.

The literature fails to explore the implications on conducting qualitative research in a rural area where the GP also lives in a small community. I present a useful framework for ethical decision making about small community research by the researcher and/or research team prior to the project being formally submitted to the relevant Ethics Committee(s), by describing a case study of a proposed study of hospital closure in rural Australia. This has applications to other small community research.

Methods

Rationale for study and my relationship to the research question
From 1996 to 1998, I was a participant observer in a small farming rural community which I will call Adia (population 2000) in Australia. This rural community was adjusting to closure of its hospital in 1993, with subsequent restructuring of health services. During this period, I worked as a GP providing clinical services to the region, working in the Adia rural university teaching unit which had been established in 1995. I observed that some members of the community avoided using local GPs or the local hospital in the neighbouring town Baria, (population 2000), 30 km away. They would access all of their health services in the capital city 250 km away or avoided accessing health care altogether. What were the main reasons for this? How had this community adjusted to health service change? Could this change have been better managed? I wanted to explore this situation further.

Background and history of Adia Hospital closure
There was a long tradition of local town rivalry and competition between Adia and Baria (source: interviews and newspaper articles). Adia District Hospital was initially administered by the local district council in 1885. It was founded by the local community by grants from wealthy landholders and had a long tradition of community support and a “fine local reputation for the delivery of quality services” (Essay about hospital closure written in 1997). The hospital was central to the community; this is reflected by “it was a place to be born and a place to die” (interview with community member).

In 1980, the hospital was incorporated under the state Health Commission Act. As early as 1983, a state-funded report ‘Community health service requirements at Adia’ recommended that:

“the role of Adia Hospital should be orientated strongly towards nursing home care and at the same time the reverse would seem logical at Baria Hospital where acute services should be further developed.” (Executive summary report):

Adia residents strongly rejected the recommendations. In 1992, hospital budgets were reduced due to low occupancy rates at both Adia and Baria hospitals. A joint proposal between the Commonwealth and State health authorities was presented to the Adia hospital board and stated:

“Voluntarily amalgamate with the Baria hospital board, relinquish all hospital acute service and apply to become a nursing home.” (Board minutes)

In return, the State health authority guaranteed ongoing accident and emergency services at Adia and an expansion of community services. Failure to agree to these terms would result in all services being located to Baria. After much community consultation and public meetings resisting this change, a combined area health service was established in 1993; a 25-bed hospital at Baria, a nursing home and emergency unit at Adia, and an expanded community health service providing services not previously available. With these changes, the local doctors of Adia left in 1993.

From 1993 to 1994, up to 30 locums were employed to operate the emergency service at Adia, resulting in a loss of continuity of services. In 1995, Adia rural university teaching unit was established, recruiting two permanent academic GPs including myself. This was based on an agreement between the State health authority, area health service and the university. In 1997, the Adia and Baria local councils were similarly amalgamated to form an area local council. In Australia, local government are responsible for water supplies, roads, environmental health and local town planning.

External reliability and resource implications of this study
Ideally, I wanted to use an external independent interviewer to overcome problems of bias and external reliability; however, I lacked a grant to resource this. Even if I employed an external interviewer, their independence would still be questioned if I continued to
direct this research project. If I did my own interviews, external reliability would be even more difficult to maintain. I questioned whether my patients would tell me what they thought I wanted to hear, rather than their own views. In planning this study, I wanted to develop a research instrument to conduct in-depth interviews with key informants involved in the hospital closure. My considerations included: that subjects had limited choice as to accessing other GPs in this region; that I needed to consider the influence of my doctor–patient relationship with subjects; and that I was not resident in the community when events occurred.

I used historical analysis and interviews to improve external reliability and to develop and pre-test a qualitative semi-structured research instrument. From 1991 to 1997, I reviewed all newspaper articles, minutes and tape recordings of public meetings, quality assurance data from Adia and Baria hospitals, and annual reports, and conducted interviews with two health professionals present during the restructuring. These were analysed using content and theme analysis to develop themes for a research instrument.

This qualitative semi-structured interview research instrument was to be used to explore attitudes to health service restructuring and community participation as part of a larger project. Ethical approval is needed in this type of health service research as: it has implications for health service planning; and resource allocation; and my study would involve direct approaches to patients who used the health service. I planned to submit this piloted research instrument as part of a formal research submission to the local university ethics committee for approval.

An ethical framework for decision making, validation and sampling

Prior to this, ethical issues became evident during these early stages of planning. These issues were analysed using the National Health and Medical Research Council (NHMRC) statement on human experimentation, the Declaration of Helsinki and bioethical principles as a framework for decision making. Colleagues with research experience and a member of an ethics committee were consulted. My findings and conclusions were validated with three other community members involved in the hospital closure who had not already been consulted. I used a non-random purposeful sampling framework to represent both community and health professional staff from the two towns with opposing viewpoints about the hospital closure in the preliminary pilot interviews and validation of findings.

Results

Historical analysis and preliminary interviews in developing the research instrument

Themes of a transition emerged. From 1991 to 1993, preceding the hospital closure, meeting records and articles reflected a resistance to change and divisions between key stakeholders in the community. There were expressions of dissatisfaction and anger about change. With time, a need to appreciate the benefits of changes was expressed by some but not all sectors in the region. This included the advantage of one organization managing hospital, nursing home and community health services within the region. This was felt to assist co-ordination and prevented duplication of health services. The restructure resulted in an increased level of community health support services, not previously available, such as community nursing, allowing many elderly residents to remain at home rather than entering institutional care. Interviews and later articles about the health services reflected an emphasis on planning for the future rather than focusing on irreversible changes of the past.

Ethical analysis

Based on these preliminary themes, I began to assess whether the study should continue. The NHMRC statement on human experimentation was relevant to this small community study, stating that the investigator after careful consideration and appropriate consultation must be satisfied that the possible advantages to be gained from the work justifies any discomfort or risk involved. In conducting the research, the investigator must at all times respect the personality, rights, wishes, beliefs and freedom of the individual subject. Before research is undertaken, the free consent of the subject should be obtained. Special care must be taken in relation to consent and to safeguard individual rights in a dependent relationship such as a doctor–patient relationship. Further, the Declaration of Helsinki states that the refusal of a patient to participate must never interfere with the relationship of the doctor with the patient.

Underlying these guidelines are the bioethical principles of non-maleficence (above all, do no harm), beneficence (will it do good?), autonomy (rights and freedom of choice of the individual) and justice (is it fair?).

The principle of non-maleficence

In this study, I concluded that the principle of non-maleficence outweighed the principle of beneficence. Three other community members purposefully selected because of their involvement in the hospital closure concurred with my conclusions. They agreed that this study could be divisive.

Existing health services at Adia and Baria could be harmed by examining the process of change after spending time and resources to reconcile community differences of the past. The area health service had recently passed accreditation and was promoting a need to plan for the future rather than dwell on the past. The Adia university teaching practice had gradually increased its patient numbers, after years of patients travelling elsewhere for services. There was a concern of...
exacerbating divisions between stakeholders which were gradually improving.

Individuals could be harmed as confidentiality in a small community was difficult to maintain and discussions about sensitive issues could produce adverse public criticism. Small amounts of demographic information would result in individuals being readily identifiable, breaking confidentiality. Publication would require subjects to reach consensus and agree to the findings of the study, a situation unlikely to arise as viewpoints were so diverse.

The principle of beneficence
This study had potential to increase understanding about the impact of hospital closure in a small community. This could assist other communities undergoing this change. As a GP working in the community, I hoped that such a study could be used as a means of reconciliation after the restructuring of health services. Through this process, a greater level of community input into health care could be achieved. Unfortunately, these aims could not be guaranteed and there was the potential for the study to be counterproductive to these aims.

The principle of autonomy
Exploring autonomy is problematic. This study demonstrates that rural communities may lack resources and infrastructure to represent their interests adequately. What community organization should decide about involvement in this study? At a community level, the Adia hospital board and district council had both closed. The medical centre where I worked was controlled by a university based in a capital city. It was difficult to locate an appropriate contact in this community with whom to discuss the implications of the research.

At an individual level, I was mindful of the autonomy of participants to give informed consent. This was complicated as I provided clinical services in the community, raising concerns about patients feeling an obligation to participate. Poorer residents had limited access to other local medical services if they did not want their GP researching their community.

The principle of justice
Is this study fair? Certainly, it could provide useful information for other communities and health authorities undergoing change. This has implications for improving utilization of health resources. Fairness to local residents of Adia is more difficult to reconcile.

Discussion
Ethics comes from the word ‘ethos’ or spirit of the community.14 A justified case for discontinuing this study was made on ethical grounds. The dilemmas of a GP conducting research in a small community are illustrated by this case report and include issues of: the population being identified; maintaining confidentiality of individuals; and delineating research and clinical practice boundaries.

The GP researcher has been likened to being a participant observer or ethnographer when patients within a practice are researched.5 The ethnographer collects both qualitative and quantitative data to describe a community. The forefather of GP research, Pickles, used similar methods describing epidemics of infectious disease in small villages.15 While not directly named, the gender, sex and towns of cases is enough to identify the individuals afflicted by these epidemics, particularly if local villagers read his publications. Pickles describes no consent process in his data collection and publication of findings.15

Compared with the Yorkshire Dales in the 1930s, today’s GP researcher must consider the likely outcomes of their research and consider reasons for non-disclosure of their findings. This includes when the population is identifiable (with the need to consider the stigma of disclosure on a population or individual) and when there will be an infringement of the rights of the individual.16

Confidentiality for the qualitative researcher in a small community is more difficult, particularly if findings are to be published. Descriptive data can lead to most subjects being identifiable. Gaining consent of all participants is recommended; this is problematic if sampled subjects have opposing views and are likely to disagree with findings.10 Some Australian authors have published under a nom de plume to avoid recognition in small community research about hospital closure.17 This limits the accountability of the researcher in a peer review process. Some of these tensions may reflect the limited output of rural research in Australia and a publication bias towards urban-based settings. While the rights of communities are important, rural areas of Australia have much higher morbidity and mortality.18 It is important to facilitate more rural research projects without creating more barriers to this process.

Guidelines for GP qualitative researchers interviewing their own patients are needed to expand research opportunities in this discipline. This case study demonstrates that this question is complex, with the research question being only one of many considerations. It also raises the important question of when does research begin in a small community. Reviewing the literature and developing a research instrument have traditionally been required in order for an ethics committee to assess and approve research. Perhaps a two-stage process is needed, with the initial piloting and larger study requiring separate approvals. This would slow the approval process and require more resources, but would mean more protection for the researcher and community and allow the researcher to explore new
unanticipated ethical issues with a group of peers if they arise. The group best placed to answer these questions, however, is unclear in a small rural community.

This case study found that both the hospital board and council who represented this country town were no longer functional. This limited the community’s autonomy in the research process. A university ethics committee with its mix of urban-based medical and lay members would have limited appreciation of the local issues of this research in this specific country town. Local residents will lack research experience, but will be expert in local implications of research findings.

Internationally, this has been one of the arguments for an expansion of local ethics committees to reflect application of research questions and resource allocation to the local environment. Ethics committees have developed processes to ensure that the interests of vulnerable groups such as indigenous people are represented. Urban-based ethics committees may need to consider other methods of community input to ensure local views are reflected where traditional forms of community representation cease. Community juries have been used to involve the community in resource allocation questions in other research projects.

Historical analysis involves the collection of evidence, and evaluation and interpretation of retrospective data. It is useful in assessing the government and community responses to changes in health systems. As with other qualitative research, the focus of my research changed in response to themes developed. In my case, the ethics of research on a potentially vulnerable population became the main focus. Medical editors report a similar focus when confronted by a manuscript of unethical research.

My preliminary historical analysis is consistent with other studies of hospital closure which have found that rural hospitals sustain rural economies. GPs provide accessible health care to communities in rural hospitals, with residents valuing this more highly than preventive care. Organizational changes to health services in small communities are traumatic, with many residents undergoing a grief reaction, and resisting change imposed from government. The rural hospital is seen as a town’s greatest asset. Similarly to Adia, other towns describe loss of doctors after hospital closure. Economic studies have failed to estimate adequately the impact of closure on vulnerable populations.

Conclusion
The GP researcher needs to consider the implications of small community research, particularly if a clinical and research role are combined. Using a bioethical framework and a group of community members to validate conclusions was a useful guide for my research. This methodology has applications in other communities, particularly those lacking an infrastructure to represent the interests of vulnerable members of society.

References