MAINTAINING THE ANONYMITY OF VULNERABLE SUBJECTS

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Current North American standards for research on human beings assert that the researcher must inform potential participants about the study and, without coercion, obtain their consent to participate. Sometimes, however, nurses initiate research on people who are dependent upon them. The dependent relationship raises questions about whether potential participants are able to consent without coercion. Dependent groups include patients or families of patients. Nurses may also be vulnerable to coercion if the researcher is a nursing administrator studying nursing practice.

The purpose of this paper is to examine the strategy used by researchers who faced the problem of dependency in a study of head nurse stress. Investigators included nursing administrators with managerial responsibility for some of the participating head nurses. The strategy adopted was to keep participants unknown to the researchers. The tactics that were used will be discussed, as will evidence for their importance and effectiveness. Tghe problems that were created by using these tactics will also be examined.

Literature Review

Polit and Hungler (1989) suggest beneficence, justice and voluntariness are the major ethical principles guiding nursing research. Beneficence refers to a judgment about the potential harm of participating in a study, relative to its potential benefits. The principle of justice relates to fair and equitable treatment of those studied, including protection of their privacy. The emphasis on voluntary participation in research stems from respect for human dignity. Researchers attempt to ensure participation is voluntary through the process of informed consent.

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Informed consent has several facets. Among these are ensuring the subject knows and understands the research and the roles of others who may be involved. An initial understanding is established when the investigator explains the study to a potential participant. Studies can go in unanticipated directions, however, particularly during the interchange between the researcher and participants in qualitative investigations (Ramos, 1989). Respondents may exceed the agreed boundaries if they become caught up in relating their experiences to a researcher (Weitz, 1987). Several authors discuss the particular ethical difficulties faced by qualitative researchers (Brannen, 1988; Cowles, 1988; Munhall; 1988; Robinson & Thorne, 1988).

Another facet of informed consent concerns being able to give consent freely. Ethical guidelines of the The Canadian Nurses Association (1983) note that research subjects who are competent should not have their freedom of choice affected by expecting benefits or fearing loss of existing benefits. Ethical guidelines provided by the Canadian Social Sciences and Humanities Research Council (1986) state that, "there should be no coercion, constraint or undue inducement" in obtaining consent. Groups for whom freely given consent may be an issue include students, prisoners, patients and employees.

Patients are the focus of most discussions of ethics in health care research. To minimize coercive influence on them, informed consent can be sought by an individual on whom the potential subject is not dependent (World Medical Assembly, 1975). Strategies to protect nurses who are asked to participate in research on their work have not been described in the nursing literature.

Those who study nurses' work are often asked how they will act if their research reveals a nurse's performance is a threat to patients' well-being. Mirvis and Seashore (1982) discribe ethical dilemmas that they encountered as social scientists studying organizations. The discussion illustrates other ways in which employees face a potential loss of benefits when their work is being researched. They present one case where the researchers had guaranteed confidentiality to employees, and management personnel had also agreed that data would be confidential. Nonetheless, a manager requested information from a researcher when considering an employee for promotion. In the manager's perspective, access to information that might benefit the organization took precedence over the researchers' assurance of confidentiality. The researcher did not provide the information despite feeling that it would support the promotion. The employee was not promoted.

The Study

The research project started because nursing staff and administrators were interested in workplace stress. A review of the literature located many

studies of staff nurse stress, but there were relatively few reports on head nurses. The role of head nurse is important to the organization and was thought to be significantly different from that of staff nurses. Given the importance of this role and the lack of recent research, the investigators decided to focus this project on head nurses.

An exploratory study was designed that would help elaborate the framework for a larger scale investigation. Data were collected with open-ended interviews because of the exploratory nature of the project and the paucity of prior research on head nurses' workplace stress. The investigators wanted to look at coping and, as such, planned to follow Lazarus's paradigm (Lazarus & Folkman, 1984) which uses interviews to obtain data. Generally, the investigators wanted to know about head nurses' experience as they described it in their own words.

Four teaching hospitals were included in the study. A sample of six head nurses was drawn from three hospitals and three from the fourth hospital, for a total of 21. The sample was deliberately diverse. The investigators sought head nurses who varied widely in their job tenure, educational preparation and type of unit as well as other factors. An hour-long tape recorded interview was conducted with each respondent.

Strategies for reducing coercion

Stress, as it is experienced by head nurses, is a sensitive issue. The decision to conduct interviews with head nurses on this topic posed problems because two of the investigators were senior administrators to whom head nurses were responsible and accountable. The researchers thought head nurses might not feel free to refuse to participate in such a study if their bosses were making the request. Head nurses might also circumscribe their responses to questions during the interview. Thus, unless care was taken, the study would be ethically unacceptable and scientifically flawed.

The investigators felt that ensuring participants would remain anonymous would address these concerns. They assumed that explaining how anonymity would be achieved to potential interviewees would substantiate the promise of anonymity. It was further assumed that the promise of anonymity would remove coercion to consent and would allow participants to speak freely.

Several tactics were used to create anonymity. One was to employ an interviewer so that investigators would not conduct interviews themselves. The issue was whether to select a nurse as the interviewer. The interviewer had to be independent of the participating hospitals and, upon further consideration, had to be outside of the local nursing community to reduce respondents' concerns about possible "leaks." This was because the local nursing community

is closely-knit and all participating hospitals are affiliated with the same university. Many people were educated at the university, have taught there, or are involved in teaching students on their units. People frequently change jobs from one hospital to another, attend conferences together and sit on inter-hospital committees. Anyone from this group would be known to others and could be seen as having potential to share information from the interviews. The interviewer also had to be someone who was unlikely to become an employee of any of the respondents.

The decision also had implications for the kind of information respondents might give. Respondents might expect a nurse to understand what they were saying, and they might react negatively to probing from a nurse interviewer. Similarly, a nurse interviewer might be less likely to probe presumed understandings because of her own familiarity with the profession. A non-nurse interviewer's probes might be more legitimate to respondents, but the probes would have to be done in a way that communicated understanding and empathy. The decision was made to hire an experienced non-nurse interviewer.

Another tactic was to separate the investigators from the process of selecting subjects and seeking their consent. Purposive sampling was used because the study was exploratory and the sample size was small. The investigators developed criteria for potential respondents. Each participating hospital identified a liaison person who was not otherwise associated with the research project. The liaison person approached head nurses who met the criteria and who might be interested in participating in the study. Names of interested head nurses were given directly to the interviewer. The interviewer then contacted the head nurse and gave a more complete description of the study, answering any questions. If the head nurse was willing to participate, the interview was scheduled at a mutually-agreed-upon time, and in a location preferred by the respondent.

Interviews were tape recorded. Investigators could not hear the tapes, so the third tactic was to give investigators only disguised transcripts. This "disguising" had to go beyond the common methods of removing or changing names of the hospital, the unit and persons. Thus, references to specific illnesses or disease, or to specialized equipment, were also changed or removed. Numbers, such as the number of beds or staff, were changed. The changes did not alter the essential nature of the unit. For example, the number of beds might be changed from 14 to 12 or 16, thus maintaining its small size. Structural features such as the position of assistant head nurse were hospital-specific, and references to them were modified. The term for a nurse who had just graduated and was awaiting licensure was also specific to a hospital; it was altered so the same phrase appeared in all interviews.

The non-nurse interviewer was not familiar with the settings and individuals and so was not sensitive to all the cues that could reveal a respondent's identity. Steps were taken to assure that the disguising would be thorough. Training interviews were set up with people who had been head nurses in the participating hospitals. These interviews were used to sensitize the interviewer to the kinds of disguising that were required. A faculty member at a university school of nursing, who was familiar with the settings but was not employed in any of them, acted as a consultant. She reviewed and made suggestions about the disguised training interviews and indicated whether they still contained revealing information. The interviewer continued to discuss disguising with this consultant during preparation of transcripts for analysis by the investigators. A sociologist affiliated with the university school who had conducted several studies of nurses at the participating hospitals also acted as a consultant.

The disguised interviews were given to the one investigator who was not administratively responsible for head nurses. She made further changes before sharing them with her co-investigators. There were some transcripts that could not be adequately disguised without altering the meaning of the interview. These were withheld from all the investigators and analyzed by the interviewer.

Evidence that concerns were well-founded

It was evident to the interviewer that the research team appropriately anticipated participants' reactions to being in this project. All head nurses contacted by the interviewer expressed concern about who she was and where the interviews would take place. Many asked about the purpose of the study. Several head nurses expressed concern as to why the investigators wanted this study done and several asked the interviewer how she was selected for the position. The detail and precision of the questions went beyond the boundaries of general inquiry. Respondents sought detailed information as to the reasons for the research, what would be done with the data and what the implications would be for their position and their work. Several respondents did not want to be interviewed on their unit. One would only participate if the interview was done outside the hospital.

Potential respondents' apprehensions about their anonymity was apparent in their questioning before giving consent. They repeatedly asked "What are you going to do to make sure the researchers will not know who we are?" Respondents wanted assurance that the investigators would not see undisguised transcripts. They also inquired about how the disguising was going to be done. One head nurse gave a hypothetical example and asked how the interviewer would disguise it.

Concerns surfaced during the interview as well. Before elaborating a response, several respondents asked, "This is going to be disguised?" or "No one will see this?" Others were reluctant to go into any detail, even after several probes. One, in particular, gave predominantly "yes" and "no" answers and would respond to much probing with, "Oh, I can't really say." The respondent also sat in a closed, defensive posture. The interviewer felt this head nurse did not really want to be part of the study, even though consent had been given.

Most respondents appeared to participate willingly in the interviews, but the interviewer observed that head nurses who had been in the job longer were more negative, more frustrated and more concerned about confidentiality. Respondents who had been head nurses for less time seemed more relaxed and talked excitedly about their job and what they hoped to accomplish. They laughed more throughout the interview and seemed less caught up in issues of confidentiality. The investigators also saw this relationship between affect and tenure in the job during their analysis of disguised interviews.

Problems raised by the approach

The tactics that were adopted to address ethical concerns raised various problems. Problems arose from the decision to employ an external interviewer, in conjunction with a need to complete interviews in a relatively short time. Investigators conduct their own interviews in most qualitative studies. This gives them the opportunity to modify later interviews, if earlier ones fail to provide desired information, or to change the researcher's perspective on the research questions. In this study, the investigators were, of necessity, second-hand parties to the interviews. The interviewer gained an understanding of the investigators' thinking by participating in the preparatory discussions to refine the research issues and develop the interview schedule. Contact was maintained with the interviewer while interviews were in progress, but the constraints of anonymity limited the information about interview content that could be shared. The turn around time to transcribe, disguise and verify disguising was so long that investigators did not see disguised transcripts until the entire set of interviews was completed. Ideally the investigators would have reviewed and discussed each disguised transcript with the interviewer before the next interview was conducted. This was not possible, so the project lost some of the flexibility that normally characterizes qualitative studies.

Another difficulty in the method of investigation was the need to avoid questions that could explicitly "give away" the identity of the interviewee. For example, while investigators were ultimately interested in how the organization affected employees' experience of stress and coping, questions

that would reveal the respondent's hospital were not included. Similarly, the interview did not test whether settings such as emergency rooms or intensive care areas are more stressful than others. Explicit questions to explore this would have endangered anonymity.

The data analysis may have been affected by the need to ensure investigators did not hear the taped interviews. Often the qualitative investigator's data in a study goes beyond a respondent's words. The researcher notes non-verbal behaviours and patterns of voice tone and inflection in understanding a respondent's meaning. These cues were unavailable to the investigators. While the interviewer punctuated transcripts, the investigators were limited in their capacity to verify different interpretations by reference to cues from the interview or the tape. The interviewer gave investigators general information about her perceptions of an interviewee's affect during the interview and also confirmed or contradicted impressions garnered from the transcripts. Nonetheless, richness was lost.

It is also possible that "disguising" altered interview content in important ways. Nursing experts who were external to the settings were used as consultants to avoid this. They were asked to judge whether a change was significant. The possibility remains that disguising distorted interview content, especially when it required changing an example used to illustrate a point.

Learning from experience

A number of tactics to achieve anonymity were used in recognition of the ethical issue of voluntary participation. Overall, the tactics worked reasonably well. Improvements can always be made, however, even with similar resources and constraints.

The subject selection procedure could be improved. A liaison was used to ensure investigators did not know who was invited to participate. Using individuals familiar with the head nurses facilitated purposive sampling, but the liaison may have been too closely connected to the nursing administration at participating hospitals to minimize potential coercion. An alternative approach would be to send every potential participant a demographic information sheet to be returned to the interviewer. Completion of the sheet would indicate willingness to be contacted, and the interviewer could use the information to select who would be invited to participate in the interview.

The picture of the respondents' affect could also be improved. The interviewer gave the investigators her impressions about the tone of an interview. The interviewer could also make detailed notes about the atmosphere and the respondent's reactions after each interview and could be more closely involved in the data analysis. Information about non-verbal behaviours and

patterns of tone of voice and inflection, which are an essential part of interpreting meaning, could be inserted into the transcripts.

Nursing experts were consulted to ensure disguising did not alter the content of interviews significantly. Investigators also had planned to have respondents read disguised interviews to ensure essential features had not changed. This step was not taken because of constraints of time and finances. A summary of results was sent to each participant. All head nurses at participating hospitals were invited to forums at which results were reported back and questions were encouraged. Researchers who have sufficient resources can check back with each respondent to verify interpretations and disguising. This is most useful if it occurs after completing an initial analysis of the interviews.

This was an exploratory study in an area in which there has been little research to date. The researchers wanted to capture the range of head nurse experiences and thus sought a heterogeneous sample. This complicated the disguising of the interviews because unique units, such as emergency, were included and were difficult to mask. Investigators whose research objectives allow selecting a more homogeneous sample will have less difficulty managing this aspect of disguising.

Conclusions

The means by which some nursing administrators addressed the problem of conducting interview research on their staff, while meeting ethical concerns of non-coerced participation, have been discussed in this paper. The reactions of head nurses approached for this study indicate that these members of managerial staff were concerned about being asked to participate. On the whole, the interviewer felt most respondents were comfortable with the guidelines and procedures used to protect participants, although there was still doubt as to whether some respondents felt free to say "No".

The concerns expressed in this paper about ensuring that employees can decide to participate in research without feeling coerced also apply when conducting research with patients or their families. Patients and families are assured that their decision about participating in the research project will not affect the care received by the patient. Is this assurance sufficient? Is it believed? The common observation that patients and family members express high levels of satisfaction with nursing care may be a result of their feeling coerced because they fear the consequences of saying something negative. Investigators who are giving direct care must be particularly careful to ensure that patients and families believe they can freely consent. An independent researcher must also provide assurances because she may be perceived as a representative of the health care facility, therefore someone

with power over the care received by the patient, even if she is not directly involved in giving care.

The strategy described in this paper helped obtain valuable data on a sensitive topic from a vulnerable group, even though it caused some problems in the data analysis. The tactics for ensuring anonymity allowed researchers to collect data through face-to-face interviews, which can produce much richer data than paper and pencil instruments. The measures taken to ensure anonymity enabled most respondents to talk quite openly about the stress they experienced, and how they coped with it. Hindsight suggests how the tactics could be improved. Nonetheless, meaningful data was obtained because investigators anticipated and addressed the potential coercion faced by the dependent group being researched.

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This research was supported by a grant from the Social Sciences and Humanities Research Council of Canada.

RÉSUMÉ

Respecter l'anonymat des sujets vulnérables

On admet généralement que le consentement éclairé est un aspect important de la recherche effectuée dans le respect de la déontologie. Conformément aux directives déontologiques de l'AIC (1983), on ne peut parler de consentement éclairé que si les sujets sont libres de donner ou de refuser leur consentement. Certains groupes - c'est le cas des employés - sont plus exposés que d'autres à la coercition quand on cherche à obtenir leur consentement. Le présent article décrit une stratégie utilisée pour faciliter l'obtention d'un consentement de plein gré alors que des cadres supérieurs de personnel infirmier effectuaient une étude qualitative du stress chez les infirmiers chefs. La stratégie visait à garantir l'anonymat des participants. On a donc fait appel à des intermédiaires pour choisir et interroger les sujets et on a masqué les transcriptions des entrevues avant de les remettre aux chercheurs en prenant soin de retenir celles dont le masquage menaçait d'altérer foncièrement les données. On a la preuve de l'importance et du succès de ces mesures. On examine également l'effet des mesures visant à assurer l'anonymat au niveau de l'analyse des données. Les chercheurs qui étudient les patients et leurs familles doivent aussi atténuer la contrainte pour obtenir un consentement éclairé.