NVivo output file

Overarching theme: Clinical Patterns

Theme 1: Clinical Queries

- § 1 reference coded [0.58% Coverage]

Reference 1 - 0.58% Coverage

Some informants acted in the role of teacher and this caused them no conflict as they perceived it was what they should be providing to the participants. For example, one informant, an academic recalled: I was interviewing somebody about having diabetes and they asked why it was necessary to monitor their blood sugars anyway .. seeing how important it was to try to explain the need for monitoring I moved outside my role as researcher and explained why monitoring was essential.

<- Internals\\Double-checked\\Cartwright and Limandri 1997 WORD version> - § 2 references coded [0.93% Coverage]

Reference 1 - 0.33% Coverage

Others capitalized on the researcher's nursing credentials to seek either advice in specific matters or, as one man indicated, to possibly feel better through the process of talking about a difficult caregiving situation.

Reference 2 - 0.60% Coverage

Depending on one's paradigmatic stance and a study's design, nurse researchers vary in their ways of responding to situations that may benefit from intervention or to participants' requests for nursing information. In this study, participants frequently asked for information related to symptom management or community resources. Essentially, their questions initiated the nurse-client relationship.

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Reference 1 - 1.05% Coverage

As an experienced clinician and a novice researcher, I felt it important to remain mindful of my experience and clinical background, and appreciate the differences between a research interview and a clinical consultation. It was paramount in the research interview that I should avoid commenting on clinical questions raised by the participants, where possible, as this could affect the authenticity of the emerging data. Interestingly, Carolan (2003) suggests that it is acceptable to exchange information with participants as this helps to formulate trust and relationships.

Reference 2 - 0.55% Coverage

Some answered my question with a question, as if they were looking for clarification or prompting me for answers about their condition and/or situation. This process of clarification, Docherty and McColl suggest (2003), helps individuals to make sense of their illness.

Reference 3 - 1.50% Coverage

The Heideggerian approach allows me to draw on my experiences, as well as those of the participants, in order to appreciate their world of LTOT and COPD. Although I believe that I have chosen the right method, there are times when I have experienced internal conflict in relation to my role as a researcher and clinician. Initially, I was confused about this dual role as I felt that I should avoid answering questions that might affect the quality of the data generated. However, as Carolan (2003) advocates, the experience of the clinician can help to build a strong and trusting relationship between the participants and the researcher. I was keen for this to happen during the research interviews as I wanted the participants to have a positive experience and benefit from their involvement.

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Reference 1 - 0.80% Coverage

Holloway and Wheeler (2002) suggest that patients may also not understand the role and will expect empathetic nursing care even from a professional who happens to have the title 'researcher'. I certainly encountered this phenomenon while undertaking my study. Even after careful explanation of my role, participants regularly directly requested specific information, and expected caring, knowledgeable and honest responses from me as a nurse, not a researcher.

Reference 2 - 1.05% Coverage

Following my literature searches I began to recognise that previously I had held a very fixed image of a nurse researcher as being someone who followed rigid rules of an imagined research persona. As I searched for answers to my role conflict it became apparent that self-disclosure or intervention did not equate to high treason and that it need not invalidate the study. Thus, if participants asked me treatment-related questions I could offer answers; if the spouse/partner was desperate for emotional support I could function as a listener and provide details of agencies that might prove helpful.

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Reference 1 - 1.40% Coverage

Professional expert During the course of some of the interviews with the patients and their SOs, direct questions were asked and advice and direction were requested. Obviously, in this situation I was regarded as the 'expert', having professional knowledge (Cotterill and Letherby 1994). These issues at times caused conflict for me in the role of researcher. This was sometimes resolved by advising the respondents to contact the relevant member of the rehabilitation team, but occasionally I felt that this was unlikely to happen if sensitive issues were being discussed or the staff member proved to be unavailable. A quiet word with the relevant staff member could have resolved the issue, but this could have been regarded as a breach of confidentiality. In these instances I was often unsure how to act, but when possible I approached the respondent when he or she attended the hospital and quietly asked if the issue had been resolved.

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Reference 1 - 1.94% Coverage

Experience contextualisation was very explicit when the RA reflected upon the post-discharge interviews. Participants were happy to respond to questions on the interview schedule, but when asked if there was anything they wished to add, they used the opportunity to attempt to make sense of their hospital experience. For example, one patient who had been referred to oncologists for further treatment, wanted to know; 'What does "chemo" involve, and what can you tell me about it?' On further probing, it was clear that information received by this patient had been comprehensive, but that reiterating it helped him to make sense of his experience and emotions. Similar experiences of information-seeking from a researcher were reported by Webb (1986); given developments in patient-information strategies over the past few years, it is interesting to note that the use of researchers as 'information givers' persists.

Reference 2 - 1.52% Coverage

Other respondents used the interview time to reinforce or double-check information they had been given. In some cases, they would reflect upon their in-patient experiences and ask the RA to speculate on why certain things had happened or had been done to them, reflecting the experiences of Wilson and Row (1998). This occurred in spite of the RA making it clear that she had neither access to the patient's hospital records nor any specific insight into the strategy of care employed at the time of the interview. The RA felt these respondents were asking for reassurance from a practitioner they trusted. Respondent-initiated dual roles did not end with the discharge of the patient from hospital, but existed for as long as contact with the RA was maintained.

Reference 3 - 1.47% Coverage

The RA was perceived as contributing to continuity of care, even though she had not formally participated in nursing treatments. The educative and advisory role she had assumed towards some ward staff may have rein- forced this concept for participants. Wilson and Roe (1998) found similar responses from telephone interviews, to the extent that they had to develop a specific management protocol to deal with it. The Wilson and Roe study differs from ours in that researchers had less care-related contact with participants. Participants in our study related to the RA almost as a 'one-stop shop' information source, while Wilson and Roe's advice was limited to suggesting alternate sources of help.

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Reference 1 - 0.38% Coverage

However, if the participant raised concerns about a lack of information or misunderstanding, the researcher usually had a strategy in place for dealing with them. This included explaining potential sources of help and information, and, in some instances, researchers would arrange for participants to discuss their concerns with an appropriate health care practitioner.

<Internals\\Double-checked\\Nicholl 2007> - § 1 reference coded [2.73% Coverage]

Reference 1 - 2.73% Coverage

However, when participants know the researcher is a nurse, 'questions and comments directed to a person in a nurse's role often emerge' (Moch and Gates 1999 p8): 'interviewees may misinterpret the interviewer's role' (Grbich 1999 pioo). During interviews mothers asked for practical advice about their child's care, including management of prolonged seizures and new methods of treatment, particularly as I had identified myself as a practising children's nurse and lecturer in nursing with experience in caring for sick children at home. If I did not know the answer I referred the mother for professional advice from someone who was actively involved in providing medical or nursing care for the family, particularly the public health nurse or general practitioner. This situation causes a dilemma for the researcher in terms of professional credibility and in some cases I chose to give advice as a nurse

- § 2 references coded [1.77% Coverage]

Reference 1 - 0.41% Coverage

and the presence of family members requesting the nurses' assistance in addressing interventions for subjects' needs.

Reference 2 - 1.36% Coverage

An 80-year-old male subject was asked a question from the activities of daily living scale about his ability to eat. As a result of this question, his wife commented about their difficulty locating a place to purchase products to thicken his food. As a result, the interviewer temporarily disengaged from the prescribed data collection procedure to assist the family with this problem.

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Reference 1 - 0.36% Coverage

I made it clear that I was not practising currently. I gave no medical advice; general queries were dealt with at the end of the interview and respondents were referred to their own GP as appropriate.

Reference 2 - 1.02% Coverage

Respondents from all social backgrounds asked clinical questions. For example, with regard to cholesterol, one respondent said: "You might be able to tell me something about that. Somebody was telling me that they've reduced the upper limit from . . . six down to four point six" (male, middle-class, R29). In relation to heart disease and the menopause, a woman asked: "Once that [periods] stops like, you're at higher risk . . . Is this true?" (female, working-class, R31). Respondents frequently gave detailed accounts of hospital appointments and medical treatments.

Reference 3 - 0.89% Coverage

When asked at the end of the interview whether there was anything they would like to add or ask, respondents expanded on their health problems, asked health-related questions and gave their opinions of doctors and other aspects of the health service. One woman said: "Excuse me saying it, I don't think [doctors] realise how frightened people are when having this sort of thing [operations]" (female, working-class, R13). In this case, the respondent apologized for expressing a negative view of doctors.

Reference 4 - 0.66% Coverage

Respondents' preconceptions of the roles of doctors and university researchers also influenced the content of the interviews, particularly the topics mentioned spontaneously by respondents. For example, respondents asked HR health-related questions (including those relating to sexual health), whereas they tended to talk to CE about broader, non-health-related topics.

- § 1 reference coded [0.89% Coverage]

Reference 1 - 0.89% Coverage

Although families accepted the 'scientific and investigational' nature of the study, in their eyes the researchers were seen first as nurses. As a result, they were asked for advice about schools, their child's health status, the health-care delivery system, and/or caregiver/family health-care needs. For example, one researcher brought one participant the requested information about a particular nursing program. Seed (1995) noted that researchers such as Webb (1986) suggest that providing information and assistance for those participating in a study increases rapport between participant and researcher.

NVivo output file

Overarching theme: Clinical Patterns

Theme 2: Agenda Meeting

<Internals\\Double-checked\\Baarnhielm and Ekblad 2002> - § 2 references coded [2.14% Coverage]

Reference 1 - 1.66% Coverage

After one year, according to the design of the study, Gülizar was contacted for a follow-up interview. She was very eager to meet the researcher, the first author (SB), and said that she had been on the verge of calling. The interview was conducted with Gülizar's 4-year-old son playing in the room and trying to get attention. Gülizar reported that the pain had increased and that she had pain in her bones, her stomach and in the soles of her feet. She said: 'Something has accumulated in my knees. I have been to the doctor. They have made a blood test. I don't think it was mental. I don't think so much, I work and run around but I can never forget my pain. I have always worked hard. Now I am alone with a child. Honestly, I can't make it. I need to rest. I have never been able to rest enough.'

Gülizar was now involved in a conflict with her GP. Gülizar considered that rest would be the proper course for improvement and recovery. Gülizar demanded that her GP put her on the sick list. The GP found no grounds for issuing a sick-leave certificate. Talking about this, Gülizar said: 'They don't care. I have told you that they don't care. They don't understand. They think one wants a paper [refers to sick leave certificate]. I have been struggling my entire life. I have not felt well recently.' Shortly after this Gülizar started to cry and said: 'I mean,I have had a hard life, in the end one struggles and struggles, finally you just can't carry on.' The researcher (SB) took Gülizar's statement as a cry for help.

Reference 2 - 0.48% Coverage

During the ethical analysis, the researcher tried but was unable to ground the decision-making with significant knowledge about Gülizar's understanding of the research situation. This included Gülizar's expectations of the researcher who, on the one hand, was exploring her illness experiences alongside the clinical context and, on the other hand, belonged to the health-care system, with professional competence and the capacity to intervene.

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Reference 1 - 0.35% Coverage

The challenges to role boundaries experienced in this setting often occurred when the midwife left the room momentarily. There were a number of occasions when the woman

and/or her partner would use this opportunity to ask what I thought about their situation. Having introduced myself to participants as an outsider midwife there followed a tendency to 'check out' what I thought about whether everything seemed 'normal' or not.

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Reference 1 - 0.51% Coverage

My professional role could also have influenced the decision to take part in the research. Although it was stated in the consent form that participation would not affect future care, fear of reprisal if they did not take part could have been a factor. Also, others may have felt that participation could have resulted in additional support.

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Reference 1 - 1.86% Coverage

M Dr Jones said something. He said, 'We're going to discharge you and you'll be taken over by the Blue Nurses.' Then he said, 'I know you'll be all right but I don't know about your wife.' I started to think 'come on what is he talking about'. Then I started to worry; you come out of hospital and you've got to think about it because you know, it is an infection and I'm worried about my wife and my knee operation.

G So you were concerned about the infection affecting other people in your family? M Mmm ... So because you're a nurse I'd like to ask you does that infection, that bug, lay dormant? I asked Dr Jones this but he said no. But I thought this is just hospital talk because he doesn't want to take any responsibility for something that could happen. What's your feeling about it, with your experience?

G Well, I'm happy to talk to you about it, but I'd like to do that when we finish the interview, then I'll talk to you about the infection and your knee operation. Is that all right with you?

M Oh sure, yes.

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Reference 1 - 0.45% Coverage

It is our contention that research participants build their own stories around their interactions with researchers in the clinical setting and use them to gain significant benefit from the researcher/participant relationship.

Reference 2 - 2.16% Coverage

The unequal power relationship between researcher and participant, usually described as favouring researchers, was being balanced by the use participants were making of the RA. Three main themes that illustrate this were identified.

'Sponsorship' Some study respondents appeared to use the RA as a 'sponsor' to forward their grievances or anxieties to the person in charge of the clinical area. The RA was perceived as an unofficial means of highlighting issues of concern that allowed them to avoid having to lodge a formal request to speak to someone in authority. Some patients extended this sponsorship to include other patients on the ward who were not participating in the research study by asking the RA to talk to them, to sort out a problem for them, or to see if she could find a ward-based practitioner to help them. They also attempted to use the RA to rectify perceived deficiencies in care; during the follow-up interview, participants often cited the RA, more than the ward nurses, as someone who gave excellent nursing care.

Reference 3 - 0.92% Coverage

Many interview respondents used the post-discharge follow up to 'offload' their pent-up emotions about their hospital stay. They were extremely keen to discuss unhelpful staff, strange situations and pleasant and unpleasant experiences, but when offered the opportunity to make formal complaints, all declined. They felt that speaking to someone they knew from their hospital encounter, but who was external to it, helped them make sense of their experience.

Reference 4 - 1.10% Coverage

The theme of 'sponsorship' was identified early in the reflective sessions. Other researchers (Johnson 1997, Stockwell 1972) have commented on how patients use an apparently disinterested party to further their own agenda within a clinical setting. If a patient/study participant can encourage a researcher to articulate concerns or anxieties about care or progress, issues can be brought before the appropriate authorities without the label of 'deviant' being attached to the patient. There were clearly benefits in this for the research participant.

Reference 5 - 0.98% Coverage

This two-pronged interpretation of the researcher's interest - caring/cared for, or friend - was mirrored in the responses obtained during the follow-up interviews. Some respondents used the follow-up exercise to complain about their in-patient experiences, but usually as they would with a friend rather than a representative of the hospital. They neither expected nor wanted the RA to action these complaints formally or informally, but shared them as a part of normal social discourse.

Reference 6 - 1.52% Coverage

Other respondents used the interview time to reinforce or double-check information they had been given. In some cases, they would reflect upon their in-patient experiences and ask the RA to speculate on why certain things had happened or had been done to them, reflecting the experiences of Wilson and Row (1998). This occurred in spite of the RA

making it clear that she had neither access to the patient's hospital records nor any specific insight into the strategy of care employed at the time of the interview. The RA felt these respondents were asking for reassurance from a practitioner they trusted. Respondent-initiated dual roles did not end with the discharge of the patient from hospital, but existed for as long as contact with the RA was maintained.

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Reference 1 - 1.85% Coverage

Discussions about sick leave often caused dilemmas during our research because as physicians we had to keep to certain professional guidelines, sometimes clashing with the participant's wish. Vera was a 38-year-old nursing assistant, divorced, with two preschool children for whom she was carrying most of the parental responsibility. She had planned to begin studying once both children started school. She suffered from back pain for several years and had often been on sick leave. At the time for this interview, she worked full time after a long period of sick leave, but now she said, Honestly, I would like to be sick-listed part time. I can't manage full time. First work a full day, and then fetch the kids at the day-care center... bring them back home in the pram. I'm not a good mother when I've come back home. Here, Vera is challenging the rules for being certified for sick leave, and as physicians, we had objections. In the margin of the transcript we had noted, "She can't be sick-listed because she manages to work fulltime!" However, we were also frustrated due to her frankness and afraid that we had come too close and were not professional enough. In our memos, we had written, for example, "How come she asks me such a bold question?" Kej experienced a dilemma. The aim to obtain trust and closeness in the interview could be a threat to the guidelines of the physician. There was also a risk that the informants were receiving illegitimate "advantages" due to their participation in the study, which raised ethical questions.

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Reference 1 - 0.45% Coverage

Concerns About Confidentiality

Maintaining confidentiality when reporting their study findings was a concern expressed by a number of the researchers. This was particularly true where the location of the inquiry could be identified easily by those having access to the research reports. The issues raised and that fall within this theme include (a) fear of participants' being identified and (b) pressure to "report back" to health professionals.

Reference 2 - 0.61% Coverage

Pressure to "Report Back" to the Health Professionals In one or two instances, there was also concern about maintaining confidentiality when in contact with those involved in the health care of interviewees. One researcher had felt under pressure to report back to the health professional responsible for referring patients to the study. The difficulty is when they give you the names and then they say "Let me know if there are any problems" ...Well that can be a bit difficult because by saying "No... unfortunately I'm not able to do that"... then they might stop referring so many patients.

Reference 3 - 1.05% Coverage

However, what we did not find in the literature is the anxiety expressed by some researchers in this study concerning the request to report to the person referring the participant any concerns or problems the interviewee revealed with respect to their care and health status. This might be peculiar to inquiries where the topic is sensitive and/or where the route of access to participants is via a professional or informal caregiver. An added concern for the researchers was that the refusal to report back might restrict the number of referrals made to their study. However, this latter concern, often referred to as "gate-keeping" (Burgess, 1984), is not uncommon among researchers, particularly those using a qualitative approach, where difficulties vis-à-vis access are inherent in the research design (Ersser, 1996). Nevertheless, although such concerns do not appear to be unique to sensitive research, it is argued that the level of concern is probably linked directly to the level of sensitivity of the topic being investigated.

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Reference 1 - 1.80% Coverage

Initially some of the residents thought I was with "the state" and wished to verbalize all their grievances to me. I offered frequent explanations of my role as a graduate nursing student conducting research. For some of the residents I was simply a person they could talk with. Once family members understood who I was and what my role was, they would seek me out to offer their insight on and opinions about the care of their family member and other residents. One family member stated he was glad I was not employed by the facility because he felt that he was able to talk more freely with me.

<Internalsline | Double-checked | Profitt et al 1993 WORD version | - § 1 reference coded | 1.76% Coverage |

Reference 1 - 1.68% Coverage

The interviewer was told of an incident that took place during a recent dialysis treatment where a small, ceiling-mounted television had fallen on the subject's head during treatment. The subject's daughter indicated that her mother had sustained injuries to her face and that her vision was becoming progressively impaired. The daughter believed that this head injury was an important factor in her mother's rehabilitation. The interviewer was asked at this point to intervene with advice about referrals.

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Reference 1 - 0.89% Coverage

When asked at the end of the interview whether there was anything they would like to add or ask, respondents expanded on their health problems, asked health-related questions and gave their opinions of doctors and other aspects of the health service. One woman said: "Excuse me saying it, I don't think [doctors] realise how frightened people are when having this sort of thing [operations]" (female, working-class, R13). In this case, the respondent apologized for expressing a negative view of doctors.

- § 1 reference coded [1.38% Coverage]

Reference 1 - 1.38% Coverage

1998). In African American families, it is often the case that several persons perform various roles and functions in both health and illness situations (Manns, 1997). This premise was supported by observations of the families in this study. Often, several family members were involved in the asthmatic child's care. Those persons were interviewed privately and engaged themselves in scheduled and unscheduled family discussions with the researchers. That strategy led to the issue of maintaining privacy among individual family members as they told their stories. Family group discussions were not an issue; they willingly and openly expressed their opinions with the researchers and with each other. During individual interviews, however, a participant would ask something like this: 'What did she tell you?' Reiteration of the study's confidentiality (i.e., not sharing information from individual interview) fostered researcher credibility.

NVivo output file

Overarching theme: Clinical Patterns

Theme 3: Helping Hands

<Internals\\Double-checked\\Arber 2006> - § 1 reference coded [1.30% Coverage]

Reference 1 - 1.30% Coverage

For example, one day the doctor had some sad news for the relatives of a very sick patient. The relatives broke down crying. I felt in a dilemma: 'What should I do? Should I try and offer some comfort to the relatives as a nurse would do?' I was aware that there was no nurse present. The tension between being a researcher and a nurse was arising again, but on this occasion I kept the researcher boundary in place even though I felt very uncomfortable about this. I used my field- work journal to reflect on this experience. I note in my research journal, 'one of the most distressing aspects of observing distress is not being able to have an active role in relation to this'. By this I mean that a nurse would have a part to play in consoling and comforting the relatives, but a researcher can only witness the distress and write about it. For the researcher to become a nurse on this occasion I felt may cause some embarrassment for the team. Conversely, it may have not been a problem for the team at all but a judgement I had made and a boundary I had put in place.

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Reference 1 - 1.23% Coverage

I am still aware of my professional obligation to divulge vital information. As a nurse obliged to stop at a road traffic accident (outside my working day), surely I have a professional, if not personal, obligation to provide vital information in the clinical area? True, I have chosen an extreme example and by no means do I claim to possess more knowledge or expertise than any other member of the emergency team. But there is a possibility that I may have cared for a particular patient before and have knowledge that would direct treatment without delay.

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Reference 1 - 0.33% Coverage

The situation described by the informant occurred as she arrived at a house to interview a woman and could not raise her: 'then the community nurse came and we organised to enter the house and found the woman on the floor having had a stroke. We organised an ambulance etc'.

Reference 2 - 1.40% Coverage

In the stories related by two informants, there was an assumption by health professionals working in a ward where the research project was being conducted, that because the researcher was a nurse she could move into the clinician role if the need arose. An example of this was a story of an informant who was collecting data in a neonatal intensive care unit where she had previously been the Nurse Educator: i was left alone in a room with six ventilated neonates One of the neonates was very unstable and I was forced into the nurse's role.] was ethically obliged to act when a neonate dramatically desalinated ... [a life threatening situation] ... When the nurses returned to the room they were quite happy with the fact that I had had to intervene. However, since then, I make it quite clear that I am not legally covered to take on the nurse role and therefore unable to answer phones or turn off alarms etc. Contrary to this, the other informant who acted in a similar situation, again in a neonatal intensive care unit, answered the phone and the practice questions of the clinical nurses in the area without any reference to the legal issues of doing so.

<Internals\\Double-checked\\Bland 2002> - § 2 references coded [6.47% Coverage]

Reference 1 - 2.52% Coverage

I was very grateful to the management and staff for allowing me to conduct my research in their facilities. Opening up personal practice to the scrutiny of others was not a step to be taken lightly. I was overwhelmed by their encouragement and interest, with one of the homes even making me an honorary staff member. I hadn't expected such a degree of support, and struggled with the sense of obligation this engendered. Was being made an honorary staff member purely symbolic, a handy way of dealing with the legalities of allowing someone access to people and information they would not otherwise be entitled to access, or something more substantial than that? Securing registered nursing staff for nursing homes is currently problematic in many areas of New Zealand. What should I have done when the manager of this particular home was unable to locate a registered nurse for a shift I could have filled? While I was clear that my principal role was that of a researcher, I felt torn by the need to reciprocate the generosity management had extended to me, aware that I could have helped them out of their staffing dilemma.

Reference 2 - 3.95% Coverage

Before starting the fieldwork I had spent some time trying to clarify for myself what my role would be in relation to my status as a registered nurse. I was aware of the registered nurse shortages that existed in nursing homes, and was wary that I could end up spending time undertaking nursing duties, rather than getting on with my research (Kite 1999). Conscious that it was now several years since I had practiced in this area I was, like Kite, concerned that I would be seen as being more capable than I felt. I made it clear to management that I would not undertake any work within their homes that would normally be considered the domain of their registered nurses. I was prepared

though to be a second 'pair of hands', to 'help out' when staff were busy. There were some tasks such as feeding residents, or answering call bells, which I saw as compatible with my role as a researcher, and equally compatible with my role as a human being. The boundaries were less clear when I was asked to assist another staff member with lifting or transferring a resident, especially when this involved toileting or showering - activities that invaded the person's physical privacy and could lead to embarrassment for them (see Higgins 1998). When interacting with residents I tried to keep my researcher role to the forefront. My concern was that helping with activities such as intimate personal care would make it even more difficult for residents to sort out just who they were dealing with the next time I wanted to talk with them about nursing home life. The dilemma was that at the same time I didn't want them to have to wait for something that I was easily able to assist with. It was simply not possible to be solely a researcher and sometimes 'being a nurse' just had to happen (Borbasi 1994).

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Reference 1 - 3.24% Coverage

On many occasions during an observation period, other nurses on the ward shared patient information with me and treated me as a colleague but, unlike Kidd (1992), I was not asked to perform routine nursing activities. Only once was I required to help in an emergency when a patient, who was receiving haemodialysis treatment during an observation period, stated that he was starting to feel faint and I took his blood pressure. The nurse, who I was observing at the time, reduced his blood flow rate and transmembrane pressure to reverse the effects of sudden hypotension.

<Internals\\Double-checked\\Burns et al 2012> - § 5 references coded [3.08% Coverage]

Reference 1 - 0.46% Coverage

As a midwife I was very comfortable relating to midwife participants within this environment. I could relate to their frustration when working shifts with insufficient staff. Whilst at times I felt it important to 'help out' whenever I could this was hampered by my limited capacity, due to ethical and legal requirements, associated with organisational outsider 'researcher' status. Vignette 3 highlights the dilemmas associated with this. Scenarios such as these became common place whilst I maintained a presence within the midwives working station.

Reference 2 - 0.34% Coverage

However, quite unexpectedly, once I had become comfortable interacting with midwifery participants within this 'inner sanctum' I found myself slipping into clinician 'worker' mode at times as indicated below, when the boundary between clinician and researcher became blurred. The nature of this particular ward environment, which was often short

staffed and busy, meant that I often felt a strong desire to 'help out'

Reference 3 - 0.62% Coverage

When call alarms are activated, and at times go unanswered, my natural inclination (or perhaps conditioned response) is to go and answer them. I am finding it unsettling knowing that someone is needing assistance and yet staff are busy and cannot attend. Today I noted a buzzer ringing during a staff member's whole tea break (20 minutes continuously) as none of the other midwives had answered it. I wanted to help out today by answering the call for assistance when staff were busy. However, due to my organisational outsider status, inevitably I needed to find a staff member to assist with the woman's request. This is becoming very frustrating when, with my 'clinician hat' on, I could easily be of assistance to both the woman and the staff member.

Reference 4 - 0.74% Coverage

personnel and resources to assist with their work throughout the day. Midwives seemed to spend most of their time with women and the 'staff-call buzzers' were mostly answered promptly. At times I helped out by fetching things for the midwife, however, while interacting with the midwives at this site, I maintained an 'observer midwife' status and seldom felt the need to engage in 'hands on' help whilst there. I believe this was partly due to my position at the outer perimeter of the work station. When call buzzers would alert I did not feel obligated to answer the call if the midwife was busy. The staffing levels at this site meant that another staff member would invariably leave the central work station to answer the call. I did notice, however, that on evening or night shifts, whilst I was sitting within the work station, I often helped out in more practical ways, such as settling babies.

Reference 5 - 0.92% Coverage

Whilst highlighting the researchers professional 'insider-ness' implied certain desirable 'midwifery' characteristics, it also, unintentionally, entailed some unwanted socially constructed meanings. The socially constructed nature of the identity of 'nurse', 'midwife' or 'researcher' (Allen, 2004) meant that potential participants brought their own preconceived notions about the researcher—clinician role independent of the desired positionality. The implicit understanding that the researcher/ clinician could 'pitch in' if it was busy (Beale and Wilkes, 2001) and work the full shift was an unspoken feature of the clinician—researcher relationship. The balancing act between being a stereo-typical 'good' clinician and/or a 'good' researcher seemed at times an impossible tight-rope to walk (Beale and Wilkes, 2001: 38). This was especially so when colleagues were working with minimal staffing and busy workloads. The tussle between roles experienced here, highlighted the importance of clinical practice to clinician identity and the confusion which arose when this identity was evoked (Allen, 2004).

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Reference 1 - 0.62% Coverage

Nurses traditionally function and are viewed as helping professionals who intervene with clients in response to assessed needs. Confusion and conflict may occur, for both nurse and subject, when the nurse assumes the researcher role and relates to individuals according to formal research protocols.

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Reference 1 - 1.08% Coverage

I, as nurse researcher, will intervene in patient care only in the event that:

- A patient is experiencing a life-threatening event, such as a cardiac arrest and no suitably qualified staff are present.
- A patient/patients are at risk of physical harm from fire, other person/patient and no suitably qualified staff are present.
- A patient's safety is at risk, for example from a fall, maltreatment or inappropriate treatment by a staff member or student and no other suitably qualified staff are present.

(Adapted from Elliot and Wright 1999, Davies et al 2000, Casey 2004)

<Internals\\Double-checked\\Newbury 2011> - § 2 references coded [2.17% Coverage]

Reference 1 - 1.08% Coverage

By creating my front, I used the same defences I would use in my professional work with patients and their carers. This was just one example of how my professional and cultural values and experience were imposed on the study. Part of my performance included saying, 'Oh, that's all right,' when a participant had forgotten our appointment for her bereavement interview and was not at home when I arrived. This happened on a day off from work when I had dressed appropriately and driven 20 miles to her home as far as I was concerned it was not all right. I reminded myself, however, that she was doing me a favour by agreeing to participate. I also had to remind myself constantly that other people's lives did not revolve around my research in the same way that mine did.

Reference 2 - 1.09% Coverage

On another occasion, I helped the carer with immediate nursing needs. Seymour and Ingleton (2005) had concerns about providing hands-on care and other nursing skills while doing palliative care research. They concluded, however, that a researcher's nursing experience meant that she was someone who could understand the participants' situation and who was attempting to shed light on problems about which

they had a shared concern. I found it was ethically and personally essential to be flexible about my roles because of the nature of the research and the need for reciprocity in the researcher-participant relationship (Carolan 2003). However, these situations confirmed that my professional nursing stamp was ever-present in the research setting and therefore in the whole process.

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Reference 1 - 0.68% Coverage

At some times I found that I was faced with the reality of acting as a nurse, especially when the child needed urgent care. This dilemma between being a nurse and a researcher needs careful consideration by novice researchers.

Internals | Double-checked | Patterson 1994> - § 1 reference coded [3.42% Coverage]

Reference 1 - 3.42% Coverage

Although I am a licensed registered nurse, my role was to conduct research, not to render direct nursing care. This goal was challenged several times by different residents requiring assistance, including one who insisted I was lying when I said I was not an employee of the facility. Many times I felt guilty and frustrated because I could not respond to a resident's needs. For example, in my journal I wrote "I feel badly that CS fell. Maybe I should have stayed with him and rang the call light instead of thinking that he wouldn't reach for the object himself. I'm just glad he didn't get hurt." It was equally difficult to handle the many requests from certain residents to run errands for them. I noted in my journal: I said no to a resident today who asked me if I would go to the store to get her a frozen yogurt. I felt so guilty but my time is limited at the home. I really didn't have the time to walk over. I asked WL how she handles personal requests from residents. She said she does them if she has the time. There is a fine line before one gets too involved.

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Reference 1 - 0.62% Coverage

At the conclusion of the session, the interviewer thought it necessary to leave appropriate phone numbers if the subject or family needed further assistance with their situation.

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Reference 1 - 0.78% Coverage

CRNs stated that providing information and supporting nurses about pressure care was an important part of their role. However, CRNs had to distinguish appropriate use of their expertise. Some reported an over-reliance on them to deal with aspects of pressure care that were not within their remit, such as problems with pressure relieving equipment: They seem to think that every problem on their ward about the mattresses is yours, even though we might have one mattress and one patient involved [in the trial]. They're waiting for you when you go on in a morning to tell you that the mattress has bleeped all night long! [Laughter and agreement in the group]. (CRN4)

Reference 2 - 0.32% Coverage

There were also problems associated with taking patients off the mattresses, or 'step-down' care; a decision for ward clinical staff rather than the CRN. CRNs reported that ward staff would leave patients on the mattresses and not reassess to take appropriate care actions.

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Reference 1 - 0.72% Coverage

The illness of another participant who was diagnosed with breast cancer during the course of the study required assistance outside the research role. Specifically, this unfortunate episode mandated that the researcher advocate for the participant so that she could access and receive the medical care needed. These interventions benefited the participant and ultimately the study in that the assistance received strengthened the investigator's relationship and credibility with the family.

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Reference 1 - 1.78% Coverage

This scenario reports a life-threatening episode. All of the participants agreed that the action of the researcher was appropriate. They judged the appropriateness of the researcher's actions from the ANC nursing competency standards perspective, in that the nurses needed to function in accordance with legislation and common law and accept accountability and responsibility for their own nursing practice. Most participants emphasised the fact the researchers were primarily health professionals. One participant stated: 'She has a professional obligation whether or not she is a researcher ... you are first and foremost a healthcare professional', and another: 'when we do

research, we still have a duty of care about participants.' When judging the ethics of the situation, the participants saw beneficence as doing no harm and doing good to the woman primarily from a care perspective. The issue of weighing the benefit of the research against harm did notarise in the scenario. Because of the seriousness of the situation, no scientific/rigour framework or obvious personal-moral valuing of decision making was used.

Reference 2 - 1.19% Coverage

All of the participants agreed that because of the life-threatening nature of the incident, the researcher had acted appropriately within the ethical framework of beneficence and from the ANC nursing competency standards perspective of accepting accountability and responsibility for own action. Five participants, however, qualified their answers, claiming that she should have summoned professional help as she was not in the NICU as a nurse. From the ANC nursing competency standards perspective, she was not functioning in accordance with legislative and common law affecting nursing practice: 'It's a difficult one ... Legally what she should have done was ring the buzzer three times and summoned whoever was supposed to be caring for the neonates.'

NVivo output file

Overarching theme: Clinical Patterns

Theme 4: Research or Therapy

<a href="maistoothe-checked | Baarnhielm and Ekblad 2002> - § 3 references coded [1.81% Coverage]

Reference 1 - 1.09% Coverage

Our professional backgrounds have influenced the research process in terms of the questions we raised and probably also our interpretation of the responses. We also found that there were potentially conflicting roles in being both researcher and clinician, which influenced our opinions about our own responsibilities in different situations. Our dual professional affiliations seemed to be given different meanings by participants at different times. Our background as clinicians could, on the one hand, contribute to making our research interest understandable and meaningful and, on the other hand, contribute to participants' expectations shifting in relation to their own perceived health status and needs, and their current interaction with other health professionals. We found it important to be clear and open about professional affiliations.

Reference 2 - 0.16% Coverage

the dual identity of the first author, as a researcher and psychiatrist, increased the risk of participants misunderstanding the role of the researcher;

Reference 3 - 0.55% Coverage

Whilst conducting the studies, it became evident that the ethical complexities of the impact of the cross-cultural situation, although discussed and analysed before the start of the study, had not been given enough methodological attention. We realized that even though we had given repeated information about the procedure of the research project, we had still underestimated the importance of understanding how each participant made sense of the research situation and its relation to mental health care.

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Reference 1 - 0.87% Coverage

Other' informants felt they should be a counsellor and in some incidents very much the therapist. As one informant, her clinical and research foci being mental health, stated categorically: I wondered if what 1 was doing as a researcher was any different to my usual role of listening empathically and dying to make meaning out of what was being said ... I decided that research interviews were therapeutic and allowed the participants to tell their stories ... So I felt comfortable in combining the roles and ultimately being

able to be empathic towards these people and use my skill that I had developed as a nurse and as a clinician and being with people therapeutically, to actually bring this to the research role.

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Reference 1 - 1.18% Coverage

A disturbing feature of researching the needs of family members of critically ill patients is the intense emotion that is often generated during the course of interviewing. For some the opportunity to talk about the experience of having a loved one in an intensive care unit was therapeutic; for others it meant anguish and despair as they relived the event that resulted in a life-threatening illness. Despite being a reasonably experienced educator and critical care nurse, I was unprepared for the intensity of feelings shown by many of the participants. I found that exposure to this kind of suffering was emotionally draining, experiencing the various roles of confidante, nurse, counsellor and researcher.

Reference 2 - 0.68% Coverage

Methodological and ethical issues that arose included: generating a situation that potentially required therapeutic intervention; the impact on the 'purity' of data of becoming emotionally enmeshed; and the level of investigator preparedness when researching sensitive topics. The issue of walking away from an intensely emotional and intimate interview often leaves one with a sense of 'unfinished business'.

Reference 3 - 1.57% Coverage

The therapeutic effect of the interview on participants appeared in several ways. AB noted previously, the mere act of talking seems to diffuse some of the emotional pressure, and is enhanced by the presence of an accepting and engaged listener. In a particularly lengthy interview, the man I referred to earlier demonstrated a faltering capacity to cope in the face of inadequate social support, his vulnerability expressed in both anger and pleas for help: 'All the friends that I had have long gone, they're retired, dead and gone out of the road, I've got nobody that I'm close to, nobody that I can turn to ..., people in our street don't talk, they don't communicate- to hell with them that's my attitude', He emphasized several times that despite the lack of support, he was 'a man who doesn't need anybody'. But towards the end of the interview he said: 'If you want to see me again later on I'm only too happy'!

Reference 4 - 2.80% Coverage

Some participants were extremely emotional and needed to talk about what was happening to them and their family as a consequence of one member becoming critically ill. For others this was apparent from very long interviews, full of details of the incident that resulted in admission to intensive care, their reactions to it, what other

members of the family were doing and how they were dealing with it. Some took the opportunity to work over details of their relationship with the patient, almost always emphasizing what a good person they were and, often, how good the relationship had been and how close the family was. This may have been an attempt to establish the patient as an individual in the care process, or it may have been a plea for their recovery, or a release from suffering, as a deserving individual. One woman, for example, went into great detail, amounting to almost two pages of transcribed text, about how wonderful her critically injured 28-year-old son was. She talked about how good he was at school and how the teachers thought so highly of him, that he was always the most considerate and caring of all her children. She gave details of his intellectual pursuits and sporting achievements, his relationships, and how socially adept and polite he was. I am aware that this kind of data constitutes 'dross', but it revealed her very real need to highlight the positive nature of his character. It was almost an impassioned plea to someone, somewhere, that he deserved to recover. This strong idealization of the person and family was evident in many interviews, and seemed to help participants deal with their perceived injustice of the critical illness event.

Reference 5 - 0.87% Coverage

Another participant said that she had been encouraged by the nature of the research, quoting this as her reason for agreeing to the interview; however, she also identified how useful it had been for her: I'm doing it [the interview] because I'm going to help someone else. But I have to be honest with myself ... who sent you? Believe it or not you have helped me because I haven't been able to talk like this to anyone else ... this is my way of letting everything out that I've been holding in for two days'.

Reference 6 - 0.84% Coverage

It seems the 'Pandora's box dilemma' is not uncommon.2 But one of the benefits of participating in a research interview is the catharsis that often occurs when topics are painful and emotive.7,9 The hour, and .sometimes more, that I spent with some participants seemed to be the tip of the iceberg. My feeling was that, if given the opportunity to talk freely about their feelings and problems in another situation, they would continue what seemed to me to be an emotionally therapeutic catharsis.

Reference 7 - 0.56% Coverage

The life-threatening illness of a loved one is a personally these vulnerable individuals in such circumstances may stimulate what are usually private emotional responses. The nurse as researcher needs to anticipate and be prepared to respond to an emotional catharsis, as well as be aware of the interactional effect on him/herself.

Internals\\Double-checked\\Cartwright and Limandri 1997 WORD version> - § 1 reference coded [0.33% Coverage]

Reference 1 - 0.33% Coverage

Others capitalized on the researcher's nursing credentials to seek either advice in specific matters or, as one man indicated, to possibly feel better through the process of talking about a difficult caregiving situation.

<<u>Internals | Double-checked | Clancy 2007> - § 1 reference coded [0.65% Coverage]</u>

Reference 1 - 0.65% Coverage

However, as Carolan (2003) advocates, the experience of the clinician can help to build a strong and trusting relationship between the participants and the researcher. I was keen for this to happen during the research interviews as I wanted the participants to have a positive experience and benefit from their involvement.

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Reference 1 - 0.75% Coverage

As a nurse, nurse researcher, and human being, my fear when undertaking the qualitative research was that I might unwittingly inflict harm (particularly psychological and emotional harm) on participants. The concept of the role of 'professional friend' appeared a suitable one to adopt to resolve my fears, as it provides the researcher with permission to pull back and initiate emergency care to prevent harm or to ameliorate it.

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Reference 1 - 2.10% Coverage

Researcher or counsellor? Dilemmas of a different nature were raised during interviews with some patients and their SOs. Some of the patients were living with significant losses or residual deficits. The impact of these residual deficits became more apparent over a period of time when the rate of change became slower. During the interviews, some of the respondents expressed great sadness over the situation that they experienced. I was sometimes unsure if it was ethical to focus on these issues, which obviously were the source of distress. I was aware that my role was not that of counsellor and, as other authors have stated, to assume that respondents want something done for them could be patronising (Cotterill 1992). Conducting interviews was not always easy. Although I could have directed the conversation to less painful topics, I felt that I had no right to determine the course of the interview. All the respondents, patients or SOs, would have to find some mechanism for coping with the

difficulties that they experienced and opportunities to discuss these matters could actually assist the process of working through feelings (Cotterill and Letherby 1994). In some cases, the respondents spontaneously discussed their methods of coping, which often involved talking with friends or through contact with professional staff, but during the interviews the course I should take was not always clear.

Reference 2 - 1.14% Coverage

If the interviews were emotional experiences for my respondents, they were often no less so for me. When completing an interview I sometimes felt elated, having shared the achievements that had been discussed. Sometimes, however, I did feel very moved because many of the accounts were deeply personal, and managing personal responses in the research situation was occasionally difficult (a feeling shared by others such as Exley and Letherby 2001). This raised another issue in my mind. All the respondents consented to participate in the study, but in giving consent they might not have appreciated the effect that the interview would have. I certainly did not expect the degree of emotion that the research generated within me, and I was the instigator of the project.

Reference 3 - 0.55% Coverage

Although the interview was not a counselling session, many were glad of the opportunity to talk to someone not directly involved in their care, or in the care of their relative, but who was involved in the establishment that had become a significant part of their lives. This relationship could be described as that of a 'sympathetic listener' (Cotterill and Letherby 1994).

Reference 4 - 1.62% Coverage

I could not know how well I would cope given their circumstances or if it would be possible to focus on gains if the losses still apparent were significant. Nor could I know if my quality of life would be worthwhile if disability prevented participation in valued activities and affected hopes and ambitions. In the context of the interview, I did not know if I caused distress when these areas were discussed. For some individuals the implications of their impairments did not appear to cause distress when discussed, and therefore I felt that I must be wary of projecting my own feelings onto them. With the SOs, too, I asked myself similar questions. I had no knowledge of how I would cope with caring for a loved one who had changed. One SO described the situation as 'living with a shadow', since the qualities she had loved and admired in her husband were so reduced. No one could help feeling a great deal of compassion in this situation, but it was again important to convey the responses and experiences of the respondents, and identify and acknowledge my own for what they were.

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Reference 1 - 0.52% Coverage

We also find evidence that while researchers and subjects often tend to view care and research as conflicting activities, both parties tend to see research as a way of caring for patients. We found no relationship, however, between subjects' perception of caregiving by researchers and the tendency to misunderstand that they are in a research study. Because research, by necessity and inclination, is unlikely ever to be 'care-free', we recommend that the ethical debate surrounding the danger of confusing research with treatment take into account the kinds of care described by respondents.

Reference 2 - 0.89% Coverage

Over the past three decades, a number of empirical studies have shown that subjects in clinical trials are indeed likely to misunderstand the difference between research participation and treatment for their condition, and to overestimate the potential for research to offer them direct medical benefits (Gray 1975, Daugherty et al. 2000, Joffe et al. 2001, Henderson et al. 2006) originally identified as a 'therapeutic misconception' for subjects (Appelbaum et al . 1982). These studies reinforced concerns about the potential for confusion in patients who are considering participation in clinical research. It is unclear whether this confusion is also fuelled by the presence of treatment relationships and a perception of 'care' in the context of a clinical research study, although this is the assumption of the CIOMS guideline.

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Reference 1 - 0.48% Coverage

Often, however, the participant will choose to see the researcher as a therapist; this represents a readily-understood power relationship, but one that may leave the participant less able to protect him or herself in the research situation.

Reference 2 - 0.42% Coverage

They also attempted to use the RA to rectify perceived deficiencies in care; during the follow-up interview, participants often cited the RA, more than the ward nurses, as someone who gave excellent nursing care.

Reference 3 - 0.92% Coverage

Many interview respondents used the post-discharge follow up to 'offload' their pent-up emotions about their hospital stay. They were extremely keen to discuss unhelpful staff, strange situations and pleasant and unpleasant experiences, but when offered the

opportunity to make formal complaints, all declined. They felt that speaking to someone they knew from their hospital encounter, but who was external to it, helped them make sense of their experience.

Reference 4 - 0.90% Coverage

Some respondents chose to re-interpret the researcher's role throughout their hospital stay and the duration of the research study. Although it was abundantly clear that the primary reason for the RA's visit was to collect research data, it would appear that the 'story' patients told to themselves described (in some cases) a social relationship based upon equality and (in others) a relationship contextualised within a caring/cared for framework.

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Reference 1 - 1.35% Coverage

Some researchers expressed guilt at not feeling able to "help" participants because this, they believed, would be in direct conflict with their role as data collector. For some, this concern was compounded by previous training and experience, such as in counseling. For example, "It was very difficult not to do anything about some of the things I was hearing . . . and I felt very bad, very guilty and extremely frustrated especially as I had been programmed to try and help people."

Reference 2 - 0.93% Coverage

Influencing the Course of the Interview

Taken a step further, one or two participants raised concerns about the way they had "handled" some of their interviews and the impact such handling might have had on the research process. In other words, they were concerned about the way in which they might have influenced the course of the interview. For example, one researcher believed that by exploring people's experiences as a counselor, she was generating data that might not otherwise have been produced, either because it did not exist or because it was not of particular importance/relevance to the participant.

I was sort of modeling myself on how I felt a counselor would be in that situation...so I was thinking "Is this what a researcher should be doing?" . . . and this became a methodological problem for me...I found I was exploring ideas with them . . . and I sort of felt I was putting ideas into their heads.

Reference 3 - 1.85% Coverage

Impact of the Interview on Participants

Here, the main issue was concern about the effect of in-depth interviewing on participants. Although the majority of researchers believed that "telling their story" was probably of some benefit to participants, they expressed concern that they could never

be certain some were not harmed by the experience. In comparing the research interview with the counseling interview, some researchers drew a clear distinction between the client who expresses a need to be interviewed and the research participant who is approached and, possibly albeit, unwittingly coerced into being interviewed. The following quotes are examples of the concern researchers felt after reflecting on the impact the interview might have had on their participants:

I was never sure how they really felt... sometimes they said it was the first time they'd been able to talk about it...but I'm not sure....I mean for some of them...the cancer was all behind them and then we come along and open it all up again...one or two were really quite upset by the experience ...it really worries me.

I do remember going back to do the second interview and then she told me that she had been very upset by the first one even though she had said it was fine at the time...so I don't think you ever know what they are really feeling like . . . Funnily enough, I had really impressed upon her to ring me if she had any concerns about the interview—or anything to add.

And looking back . . . sometimes they found it helpful to talk . . . other times it really distressed them...so I don't know...I don't know how you can tell what's going to be OK for them . . . it's like a minefield.

Reference 1 - 0.56% Coverage

However, I was also cognisant of the research literature which suggests participants often experience qualitative interviews as cathartic and therapeutic (Finch, 1993; Murray, 2003), allowing a re-evaluation and changed perspectives (Serrant-Green, 2005) and so I encouraged Ann to continue.

Reference 2 - 2.52% Coverage

My approach must have given Ann legitimacy to continue to disclose her feelings but her distress deepened and her tears and sobs became uncontrollable as she told me that she feared she would die. I was uncertain how to respond. There is little in the research methodology literature which gives specific guidance on how best to handle these highly emotional situations, but Coffey (1999) advised the researcher to acknowledge and accept tears by maintaining eye contact and trying to talk through the issue. However, I experienced a conflict of emotions as to how I should act. I realised the significance of Ann's experiences and feelings, but at the same time I was in the position of power and I was aware of the vulnerability of Ann in this situation. I decided to turn off the tape recorder and stall the interview until Ann had regained composure. However, Etherington (1996) advised researchers not to assume that participants will wish to discontinue, even if they become distressed. I may have acted in haste and denied Ann the opportunity for her voice to be heard. In my mind I was juggling research interests with the responsibilities of being a researcher, a midwife and an empathetic human being. As Gunasekara (2007) suggested, this leads to role and

emotional conflict, which I indeed experienced.

Reference 3 - 1.78% Coverage

Hallowell et al (2005) discussed the importance of maintaining a clear boundary and not adopting a counselling role. I believe I overstepped the boundary, slipped into my midwifery role and in an attempt to reassure Ann, talked to her about the procedure of a caesarean section and tried to give her a balanced perspective of the risks of caesarean section. However, it could be argued that I acted according to my Code of Practice as a midwife (Nursing and Midwifery Council (NMC), 2008) and many other researchers have been obliged to do just this when faced with similar circumstances (Kirkham, 1989; Hunt and Symonds, 1995; Davis, 1996). After some time Ann regained her composure and I felt able to continue. At the completion of the interview I spent some time with Ann, only leaving her when I felt she had regained a sufficient level of calm to be left alone. Ann rejected my suggestion of a referral to a midwife or GP.

Reference 4 - 1.23% Coverage

Arksey and Knight (1999) acknowledged that some interviews can be emotionally draining with participants revealing intimate and personal information and this can also be painful for the researcher. Following this interview my feelings of disquiet continued. I experienced a sense of discomfort and guilt that I had evoked such distress. I was left with a persistent, deep rumbling sense of uneasiness about how I had dealt with the situation. Some researchers have found that the emotional nature of their research has impacted on their physical and emotional health (Dunn, 1991) ' thus it is important to acknowledge and address these emotions.

Reference 5 - 0.44% Coverage

The experience may have been cathartic and therapeutic in nature; perhaps as a stranger I had allowed Ann to reveal that which she would not reveal to those closer to her. Therefore I had not breached my ethical duty to 'do no harm'

Reference 6 - 1.03% Coverage

In undertaking a literature review for this reflection, I am comforted by the writings of others who have reported similar feelings (Lofland and Lofland, 1995; Hand, 2003; Skene, 2007). Through my reading I came to accept that I had not caused Ann's distress but only provided her an opportunity to express it. I had listened to her concerns without judgment and hopefully this way provided support for Ann's feelings and contributed to the therapeutic component alluded to by many qualitative researchers (Finch, 1993; Murray, 2003).

< Internals \ Double-checked \ Newbury 2011> - § 4 references coded [2.04% Coverage]

Reference 1 - 0.27% Coverage

The potential for therapeutic change for research participants was seen as beneficial, but it could cause conflict between my roles as nurse and researcher and risk of exploiting participants.

Reference 2 - 0.40% Coverage

I also debated the tension between the risk of causing distress to Carers as a result of being interviewed (Seamark ef al 2000, Takesaka ef al 2004) versus giving them the opportunity to contribute to research and to tell their stories (Kellehear 1998, Seamark et al 2000, Hudson 2003).

Reference 3 - 0.84% Coverage

Textbooks say that the interviewer should remain neutral (Bowling 2001, Patton 2002) but I found it impossible to avoid giving empathic and affirmative responses to the intensely moving accounts that the participants gave. Morray (2003) emphasised that the role of nurse researcher should not be confused with the role of nurse therapist, but maintaining a clear boundary was difficult. I challenged one carer when she repeatedly said that she should have done more for her husband. I congratulated another when she described how she woke her sister at just the right moment before her father died.

Reference 4 - 0.54% Coverage

I am not suggesting that I necessarily had a therapeutic effect but I believe that a number of the carers benefited from having the opportunity to vent their feelings and tell their side of the story.

Internals | Double-checked | Patterson 1994> - § 1 reference coded [2.11% Coverage]

Reference 1 - 2.11% Coverage

On a deeper level, I listened to the residents' stories, their life histories. I spent time with them. They accepted my presence, answered my questions. I had an effect on the setting and its residents. I undoubtedly had become a source of support for some of the residents. Although none of the residents directly shared their feelings with me regarding my presence in the nursing home, they rendered comments to others on staff that they enjoyed my visits and our talks. I noted in my journal: She chides me if I don't stop in to see her when I come in. She contemplates my return. She asks when I'll be back and frequently jokes that we won't be able to go for a walk that day because it is suppose to rain.

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Reference 1 - 0.24% Coverage

Some interview interactions were common to both researchers; for example, interviews were often regarded by respondents as therapeutic.

Reference 2 - 1.17% Coverage

The similarity between research interviews and therapeutic interactions has been widely discussed.22–25 Qualitative interviews are often described as 'non-directive', a term which originates from psychotherapy, where patients are encouraged to express problems in their own terms "stimulated by an interested and sympathetic listener"26 (p. 111). Some respondents in both studies stated that they found interviews therapeutic. For example, when asked to describe her health problems, one respondent replied: "Oh, I love this. I love it. I think that once you get to a certain age, your doctors are not interested in you" (female, working-class, R31, HR).

Reference 3 - 0.40% Coverage

Both authors found that interviews were described by some respondents as therapeutic. Qualitative interviews are likely to be perceived as therapeutic by respondents regardless of the professional background of the interviewer.

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Reference 1 - 0.53% Coverage

Interestingly, the time spent with the primary caregivers was sometimes perceived as an intervention. Having the opportunity to 'tell their stories,' have their voices heard, and receive personal 'one-on-one' attention from a person whom they believed had a genuine and sincere interest in them during an extended period was perceived by them as being helpful.

<Internals\\Double-checked\\Thompson and Russo 2012> - § 1 reference coded [0.80% Coverage]

Reference 1 - 0.80% Coverage

Role blurring can also be perceived by participants. Thompson has experienced this on several occasions when, in purposively recruiting people who are likely to be experiencing distress, they have actively requested intervention. Where this happens it is important to assess the degree to which the person actually wishes to participate. This is not always clear. For example, Russo was just about to commence an interview

with a mother in her cystic fibrosis study, when the participant disclosed personal difficulties adjusting to her husband's death several years ago, and expressed concern of the impact that this was having on her child. She reported that she was glad to have contact with a clinical psychologist, as she wanted to ask advice on ways forward. Although the mother had consented to the interview, KR made the decision to not go ahead and instead gave priority to these concerns.

<Internals\\Double-checked\\Tuffrey-Wjine et al 2008> - § 1 reference coded [1.07% Coverage]

Reference 1 - 1.07% Coverage

The initial research protocol for the Veronica Project stipulated an involvement of around 4 months. However, as the study progressed, that seemed not only too short to collect all the relevant data; it also seemed unethical to withdraw what had become, in many cases, a supportive presence. While we were always aware that the researcher was not a therapist or indeed a friend in the usual sense, with some people it was clear that the researcher could not suddenly end the relationship. Booth & Booth (1994) state that 'social researchers using biographical methods with vulnerable groups must be prepared to live up to this commitment or risk their field relationship becoming exploitative' (p. 419).

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Reference 1 - 0.74% Coverage

Ten participants agreed with the premise that research interviews were therapeutic. This emphasises their personal-moral valuing of the research activity, rather than any other framework. As suggested by one and confirmed by others, interview participants often say to the interviewer: 'a lot of people say [the interview] is healing... no one had spoken to them before about their problems and no one had talked to them before and they thanked me for doing this.'

Reference 2 - 0.85% Coverage

Contrary to the above, all but one felt that the intent of the interview should be research, not therapy, and that the researcher should not attempt to do both (as implied in the scenario): '1 don't think that you should go in there with that as a co-objective of doing the research', and: 'that may be a by-product.' They felt it was important not to cross boundaries between the research and therapy roles: 'as long as listening is the only intervention', and: 'it's a pretty fine line ... being very clear... where your boundaries lie.'

Reference 3 - 0.81% Coverage

'She's lost the plot. She may feel comfortable and all of those things but I think she's

really not seeing what research is about in this type of setting. I don't think you can do it and be totally objective.' The other participant who disagreed with the action of the researcher cited the delineation of the two roles of nurse and researcher from the scientific/rigour approach perspective: 'I think that if you are going in there as a researcher, then that is your principle role ... they are two different roles.'

NVivo output file

Overarching theme: Clinical Patterns

Theme 5: Uninvited Clinical Expert

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Reference 1 - 1.55% Coverage

It was the professional opinion of the researcher, as a psychiatrist, that Gülizar's depressive mood had worsened and that she was socially and mentally impaired and that somatic symptoms were a way of expressing this to a clinician. The researcher interpreted Gülizar's conflict with her GP as being linked to the two parties having different agendas for understanding the current illness.5 They probably also differed in their views of socially accepted ways of expressing distress and acceptable healing strategies. Subsequent to this change in the research situation, and when the taperecorder had been switched off, Gülizar told the researcher about suicidal wishes and that she was worried that she might harm herself if her poor state of health continued. The researcher and Gülizar had a conversation about illness and healing during which the researcher tried to bridge the gap between Gülizar's opinions and the presumed agenda of illness understanding of the caregiver. The researcher suggested that she should try to negotiate with the caregiver about Gülizar's agenda of understanding her illness and that of the caregiver. The researcher was of the opinion that the participant was not able to be her own advocate in a discussion with her caregiver.

<Internals\\Double-checked\\Bailey 2007> - § 1 reference coded [0.70% Coverage]

Reference 1 - 0.70% Coverage

what if I am in a situation as an observer where I notice something that no one else has because I am the only professional in the room? As a practitioner with experience in emergency nursing, I know the things to look for in resuscitation attempts. What if I notice something no one else has yet had the chance to see?

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Reference 1 - 2.06% Coverage

One informant, who was interviewing nurses in a high dependency area in an acute care hospital, stated: Unexpected situations are the most difficult. i see the difficulties more in interpretive and critical paradigm research because you are there and you are ostensibly a researcher but you have, in my case, a nursing background. The difficulty arises when you see problematic interactions with other health care workers. At interview, this nurse researcher described in detail one of these problematic interactions

or 'grey problem areas'. The nurse researcher still remained primarily a researcher even though she utilised her professional knowledge and code of practice of advocacy for the patient. When interviewing a patient for her study an alarm went off and:

... the nurse who came to investigate the alarm appeared cross and talked to the patient in very abrupt manner Her tone and the content of what she said seemed to blame the patient for setting off the alarm... My first emotions were shock at the nurse's level of anger, upset on behalf of the patient and disappointment in the behaviour of the nurse .. After the interview I asked the nurse if she was free and if she would explain something to me. I had not gained written or verbal consent from this nurse to be part of the study. She was not very communicative and later refused to be part of the study ... I went to talk to the Clinical Educator on the ward and without explaining why, I asked her if people were often angry with this patient. This educator, who later became one of the chief informants for the study, revealed a whole infrastructure of control and countercontrol issues that became a major finding of the study

Reference 2 - 0.65% Coverage

She initially acted as a nurse because of the potential life threatening nature of the situation but over time she became a confidant and a friend of the study participant. As she stated herself of the woman she counselled: I thought this woman was almost suicidal ... I thought I cannot justify collecting this information and going off and doing my little research project. I referred her to the General Practitioner and maintained contact with her for a number of years after the project, and remained a friend for 14 years.

<Internals\\Double-checked\\Bland 2002> - § 2 references coded [1.97% Coverage]

Reference 1 - 0.97% Coverage

WAS I A SPY? What should I have told the nursing home managers about what I saw? There were a few staff who never appeared to feel comfortable in my presence, convinced, I thought, that I would be reporting them for helping themselves to the odd spare meal, or some similar misdemeanor. I wasn't interested in that sort of activity, but what should I do when I observed a staff member being short-tempered with a resident, or failing to provide professional care?

Reference 2 - 0.99% Coverage

So was I an advocate? What are the consequences for both my study and other future studies in this kind of environment if I did, or did not let someone know when something inappropriate was going on? Should I intervene, or was my primary responsibility to record my observations truthfully and with as much objectivity as possible 50 "that a deeper understanding might allow me to be more effective in contributing to improved practice in the future" Koch (1994: 980)?

- § 3 references coded [4.60% Coverage]

Reference 1 - 3.49% Coverage

Resistance, as a means of opposing or confronting conflict between duties, was described in a variety of ways. Strategies included: resisting the clinical protocol itself where it is thought not to be in the patient's best interests; resisting pressure from peers, colleagues or the organization to participate in a study; and resisting direct influence by putting the onus on the patient/family to read and understand the protocol themselves; and resisting by not promoting the research study. Several physician—researchers refused to be involved in research studies (despite the fact that the studies were already approved both scientifically and ethically) because they believed the studies were not in the best interests of the patient under their care. These physician—researchers went beyond reliance on the extant guidance documents, standards and ethical policies and took a more personal approach to deciding whether research participation should be offered to their patients:

It was an unpleasant situation when I had to take a stand and say this is not in the patient's interests and I was thinking, must not do this. It stopped. I haven't been popular with this person since but it doesn't really matter to me. It was the wrong thing to do for him and I think it was the right thing to do for me.

There are times when we said or I certainly said, no. I will not participate because I don't feel that this . . . that there is a question that merits randomizing people or applying different techniques or something to them.

I wouldn't participate. I wouldn't have my patients participate in the study where I don't like the protocol and where I'm not very comfortable with the protocol irrespective of what the ethics say you know.

Reference 2 - 0.50% Coverage

Others demonstrate their resistance by failing to promote the research study: I thought it was inappropriate that a person be told, before you go into have your test that your doctor wants, you have to sign a consent form [for research]. So I didn't do that even though I was supposed to and I was going to take the heat for it but the risk was small.

Reference 3 - 0.61% Coverage

In the research group, we discuss new studies because there's then a certain burden to being approached and the consent process and the time all of this takes and so even new studies that the national group is approached with are triaged based on what we think our patient population can handle. If we're trying to do something nationally, we'll agree or disagree as a group whether we can take it so we're not overburdening . . .

Internalsliburns et al 2012> - § 1 reference coded [1.22% Coverage]

Reference 1 - 1.22% Coverage

especially uncomfortable when the practice being observed was causing distress to the woman. Remaining a silent observer when the midwife had left the room was especially challenging. For example, during an observation of a discussion about infant care with a first time mother the midwife continually spoke to the woman as though she was a novice at handling infants. When the midwife left the room (to get a nappy) the woman and I engaged in chit-chat. During this brief interchange the woman indicated that she had a professional background as an early childhood worker. When the midwife returned I was torn between telling the midwife this additional information or continuing to observe the conversation that ensued to determine how far into the interaction it would be before the midwife elicited this information herself. I found it agonising to observe the resultant interaction because the midwife continued to speak to the woman as a novice and did not engage in any 'checking in' with the woman about prior knowledge. Despite my maintenance of an outsider observer positionality the relationship formation, which inevitably occurs between researcher and (in this case midwife) participants, meant that observing this midwife without supplying her with the additional information I had gained felt like 'spying' or what some researchers describe as 'exploitative interloper' behaviour (Adler and Adler, 1987; Gerrish, 1997; Hammersley and Atkinson, 2007: 217; Simmons, 2007: 4).

- § 2 references coded [1.47% Coverage]

Reference 1 - 0.22% Coverage

Particularly when conducting research in the home setting, nurses may recognize clinical situations that may benefit from health-related interventions.

Reference 2 - 1.24% Coverage

In several instances, the researcher, not the family, identified a need for additional health care; in these situations the researcher initiated the nurse-client relationship. In one example, she suspected a care recipient was having undesirable effects from a psychotropic medication that might be managed by adjusting the dosage schedule. In another situation, she thought both the caregiver and care recipient seemed clinically depressed. In each case, the researcher shared her concerns with the caregiver and provided recommendations for dealing with the problems. In two situations the researcher also appraised the primary care gatekeeper of the concerns after relaying her intent to the caregiver.

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Reference 1 - 0.58% Coverage

were not those that arose with easily identified high risk or severely distressed subjects, but rather with sub- jects for whom intervention was not clearly mandated. Some subjects (or the pregnant partners of the expectant fathers) had unmet health needs of a noncritical nature.

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Reference 1 - 1.97% Coverage

During the investigation Finlay (1998) became aware that not only was she observing OTs delivering care, but also that she could not stop becoming involved in the care. This is an area where nurse researchers may need to reflect honestly. For example, as nurses do they have to feel needed; do they gain gratification from being part of a team assisting an individual to an improved health status; do they need that special patient-nurse relationship in order to be motivated; as nurses are they able to let go of the clinical skills and the rewards of a hands-on nurse to become subjective, reflexive nurse researchers? I found it a painful process answering these questions honestly: I experienced difficulty in letting go of my clinical role and hard-earned technical skills. I no longer had the role of a nurse specialist but was a novice researcher, yet I needed to find an alternative to clinical fulfilment. I finally became reconciled to the view that the researcher role was the avenue through which participants could tell their story and, it is to be hoped, effect care in a positive way for other patients in the future.

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Reference 1 - 1.06% Coverage

I often had knowledge of the patients involved in the study through observation and discussions with members of the rehabilitation team involved in their care. However, how much information could or should be included in the data and how far the data used should be confined to those obtained during the formal research situation were sometimes an issue. To use all information available regarding specific individuals and their relatives could have led to inconsistencies, since I did not have this knowledge of all the respondents if they did not return for further treatment at the day unit. Yet it was difficult to omit, since I was consciously aware that personal knowledge did at times influence the interviews.

Reference 2 - 1.40% Coverage

Professional expert. During the course of some of the interviews with the patients and their SOs, direct questions were asked and advice and direction were requested. Obviously, in this situation I was regarded as the 'expert', having professional knowledge (Cotterill and Letherby 1994). These issues at times caused conflict for me in the role of researcher. This was sometimes resolved by advising the respondents to contact the relevant member of the rehabilitation team, but occasionally I felt that this was unlikely to happen if sensitive issues were being discussed or the staff member proved to be unavailable. A quiet word with the relevant staff member could have resolved the issue, but this could have been regarded as a breach of confidentiality. In these instances I was often unsure how to act, but when possible I approached the respondent when he or she attended the hospital and quietly asked if the issue had been resolved.

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Reference 1 - 0.52% Coverage

Subjects who said that care was part of the PI or SC role defined this care as clinical activities, psychosocial support, expressions of concern and close personal relationships with study team members. Many cited monitoring for symptoms and side effects, prescribing medications, discussing medical issues and generally 'performing all of the functions that a doctor would normally do'. Both PIs and SCs primarily supported their care responses with instrumental, clinical activities, though SCs were more likely than PIs to offer descriptions of psychosocial support and relationships.

Reference 2 - 0.60% Coverage

Fourthly, some respondents defined research in opposition to individualised standard care. Several PIs made this distinction: 'this would not be part of my standard care of patients'; 'it's about research, not about patient care'. A few PIs revealed discomfort about this, as expressed by this PI: 'From the study perspective, I'm conducting research. Putting them in the study isn't really taking care of them, [but] it's a conflict, there's a tension when you're the investigator and the physician'.

Reference 3 - 1.84% Coverage

One PI said, 'I'm a clinician and I spend a lot of time seeing patients but this is a study that I'd really like to know whether it will impact on the patient, especially to cure [his] cancer'. Others focused on indirect benefits as a source of care. Some researchers felt that research participation itself (without a prospect of direct benefit) could still be considered a form of taking care of patients because it pro- vided extra monitoring, health education and psychosocial benefits such as hope. Such conviction caused one investigator to strongly resist the question: 'Stupid question . . . clinical trials and patient

care are one and the same. [I think] that being someone's doctor is more than giving them some- thing which makes a tumour get smaller. I think it's helping them cope with their present problem physically, emotionally, helping them look forward to and prepare for the future. I think clinical trials are an integral part of that'. Typically, when SCs and subjects described psychosocial benefits from the study, they talked about the care and concern shown by study personnel. Finally, the 'dual nature' of some research activities made it difficult to separate care and research. Even if no benefit is expected from the experimental intervention, care can arise whenever the subject's data are needed for both care and research. As two SCs explained in categorising care and research, 'it's hard to separate out, but that [study] data also represents how well the patient is doing'; 'I think the two go together. Although we are doing research on patients, we have to do care to get the answers that we need. So, I would have to say it's caring for patients in a research capacity'. One investigator may consider the management and monitoring of patient- subjects as care in research, while others may create distinct spheres of care and research based on the specific purpose of the activity required by the research: '... while getting a CAT scan could be a patient care issue, it's really a research issue if we have to have that CAT scan for this study'.

<Internalsline Double-checked\\Hamburg and Johannson 1999> - § 4 references coded [3.59% Coverage]

Reference 1 - 0.26% Coverage

Furthermore, when Sally spoke about social activities and chores at home, her description of her capacities put the legitimacy of her sick certification in question. Kej became suspicious and afraid of becoming deluded and misled. A

Reference 2 - 1.01% Coverage

We positioned ourselves, and were positioned by the participants, as doctors, women, and researchers. These positions reflected different discourses, and we reacted differently, depending on which position was triggered by a certain statement during the interviews. The reflexive analysis explored shifts between dis- courses, or between positions within a discourse, and their consequences for the interaction and interpretation. We could, for example, change from a patient- centered physician position, where we asked for the patient's experiences and let her describe them in her own words, to a more doctor-oriented position (Byrne&Long,1984; Pendleton et al., 1984), where we questioned and encouraged her to describe her symptoms in ways that suited a diagnostic curriculum.

Reference 3 - 1.11% Coverage

The main duty of the physician is to help others by way of investigating, finding a diagnosis, and suggesting or giving adequate treatment. Therefore, we were pre-pared to try to find out what could improve the health of each single woman in the study. If a participant told us that her low back pain had changed lately, we would immediately

think of new medical investigations, such as laboratory tests, examinations or a referral to X-ray. For instance, during the study, we examined and treated urinary tracts infections, gynecological disorders, and sleeping disturbances. In the Swedish context of family medicine, "patient-centeredness" and "wholeness" are prestigious clinical concepts that express the willingness to see the patient's symptoms in light of his or her biomedical as well as social and psychological circumstances (McWhinney, 1993). To talk about, for example, psychosocial strains at work or in the family was, therefore, appropriate in a family physician-patient relationship.

Reference 4 - 1.21% Coverage

There are also ethical, administrative, and legislative guidelines that regulate what is right and legal to do as physician, and these guidelines had an impact on the research. For example, in Sweden, sickness benefits are paid by the state and the employer as part of general health insurance. To receive sickness benefits for more than 1 week, a person needs a certificate in which a physician confirms that she or he is not able to work due to an illness. Sick leave is granted due to problems associated with paid employment, not for problems associated with unpaid responsibilities in the family or elsewhere. Furthermore, in the shadow of the economical crisis in Sweden and other industrialized countries, there has been an extensive debate about the necessity to restrict sick leave when the diagnosis of the patient's symptoms is in doubt (Spitzer, 1993). This approach permeated the interview passage with Sally. When Sally talked about housework, Kej wanted to know more about her job because Kej saw it as her duty to help Sally return to work or to identify the problems that kept her on sick leave.

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Reference 1 - 0.37% Coverage

Potentially, this could result in the researcher intervening if student-staff conflicts arose or if the students appeared to be experiencing difficulty with aspects of the care that they were giving.

<Internalsline Double-checked\\Johnson and Macleod Clarke 2003> - § 1 reference coded [2.71% Coverage]

Reference 1 - 2.71% Coverage

An ethical dilemma for the researchers who were also health care professionals was the situation whereby participants were obviously either misinformed or had not understood the information given to them about their condition. Clearly, the conflict here lies in the researcher versus health care practitioner role. It would be impossible for such professionals to shed their previous knowledge and experience and enter the "data field" with blank curricula vitae. It is reasonable to assume that training and experience will provoke within the researcher a need to intervene, a need that is likely to be more

problematic when researching sensitive topics. However, if the participant raised concerns about a lack of information or misunderstanding, the researcher usually had a strategy in place for dealing with them. This included explaining potential sources of help and information, and, in some instances, researchers would arrange for participants to discuss their concerns with an appropriate health care practitioner. However, where a participant did not express concern, the researcher was often left feeling extremely anxious about whether confidentiality should be breached in the interest of the participant's welfare. One researcher remained concerned about such an incident long after the study had been completed.

I was really concerned about one person ...in fact it's still unresolved and I don't know what to do . . . she told me she was taking Tamoxifen® . . . and that was OK until later on she talked about starting a family...and I just felt she didn't realize that this drug could... actually probably would stop her from ovulating. She didn't say she was concerned so it was difficult for me to chip in. But then I came away and felt I should mention it to the breast nurse...but how could I? I promised her I wouldn't talk about anything she said to anyone.

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Reference 1 - 2.92% Coverage

As a participating observer, she might have observed with her "nursing glasses" instead of "researching glasses," a situation that might have caused cultural blindness. This was probably the case at first, as it was difficult for her to develop any kind of distance from a situation she knew so well. She dressed like a nurse, and as she assisted the nurses in their work, she might at times have paid more attention to patient care than to research. In some situations, she also felt that keeping a researcher's distance placed her in an ethical dilemma with regard to the well-being of patients. Prior to this project, however, the researcher had also been a practicing teacher of nursing and, as such, was familiar with the clinical field; she had also studied the literature on education. Being a teacher certainly enhanced her understanding of nursing as a practice. Hence, her prior experiences could have caused her to be blind and seeing at the same time. Although the blindness might come about as a result of her familiarity with the nursing culture—from her being an insider—her ability to see might have been enhanced by her life as a teacher or by the fact that she was an outsider. At one point when the researcher assisted a nurse in caring for a patient, she was surprised by the way the nurse performed this chore. According to her "teacher" eyes, the nurse attended to the patient's personal hygiene in a way that was not in accordance with accepted hygienic principles. On noticing this, she realized that this practice was guite common in the unit, a fact that she probably would not have recognized without her experience as a teacher.

<- Internals \Double-checked \Mitchell 2011 WORD version> - § 1 reference coded [0.36% Coverage]

Reference 1 - 0.36% Coverage

As a mother myself and a midwife, I shared Ann's concerns but I could not reassure her as the anxieties and fears about her forthcoming caesarean section were real (Lobel and DeLuca, 2007).

<Internals\Double-checked\\Newbury 2011> - § 1 reference coded [0.61% Coverage]

Reference 1 - 0.61% Coverage

There was only one instance where I felt that there might be ethical grounds to take the carer's criticisms to the management of the service concerned. I took advice from a colleague who was checking the accuracy of my transcriptions and had therefore read the Carer's complaints. We agreed that the carer reported in the interview that adequate action had been taken to resolve the problems and that I did not need to take it any further.

<Internals\\Double-checked\\Nicholl 2007> - § 2 references coded [4.02% Coverage]

Reference 1 - 2.39% Coverage

In this type of study there is the potential for significant and sensitive information to be divulged by the mother, or situations to be observed by the researcher that could have clinical, legal or ethical implications. Ethical committees often require potential issues such as these to be identified before the study starts and a description of the mechanisms the researcher has in place to deal with emerging situations and dilemmas. Strategies must be in place to manage any issues that are a cause for concern about the mother, child or other members of the family. This includes providing written information advising the mothers about the researcher's professional responsibilities in such situations and being aware of current policies and practices relating to child protection and family care.

Reference 2 - 1.63% Coverage

Often there is a fine line between what is acceptable and what is not and the researcher must be clear about professional codes of practice or conduct, as well as child protection, mental health and domestic violence policies and reporting and referral mechanisms. I observed mothers giving care in their own way and managing drug regimes as required in individual situations. In these situations it may be inappropriate to intervene as the mothers had obviously been doing things this way for some time, often on the advice of other professionals.

<Internals\\Double-checked\\Profitt et al 1993 WORD version> - § 1 reference coded [1.12% Coverage]

Reference 1 - 1.12% Coverage

As evidenced by these examples, interviewers (master's-prepared registered nurses) experienced difficulty in limiting their role to that of a research interviewer. Nurses often found subjects with conditions or circumstances that they thought warranted nursing interventions as a higher priority than data collection.

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Reference 1 - 0.65% Coverage

Are nonlicensed personnel, such as a research assistant, responsible for reporting under mandatory reporting laws? Licensed clinicians are bound to report when the suspicion of abuse is raised.

Reference 2 - 9.60% Coverage

Suspicion of Severe Depression

A potential subject for an exercise intervention trial for chronic stroke reported at initial screening that he was being treated for depression with maximal doses of an antidepressant. Eligibility criteria allowed for the inclusion of subjects with "treated" depression. On the Center for Epidemiologic Studies—Depression Scale (CES-D) screen, he scored 19. (Scores greater than 16 on this screening instrument indicate a need for further investigation for possible depression.) During the interview, the subject also completed a quality of life/ health status assessment instrument. One section of the instrument requires patients to respond using a Likert-type scale ranging from none of the time to all of the time to the question, "In the past week, how often did you feel life is worth living?" The subject responded, "None of the time." This response was reported to the program manager and the principal investigator and was documented in the potential subject's chart. Because the subject did not indicate actual depressive responses on a subsequent clinical interview conducted by a physician, he was permitted to enroll in the study and became an active participant.

At subsequent investigator meetings, questions were raised about how to handle this particular situation. Opinions were divided regarding whether the response indicated a need for further investigation for depression/suicidal ideation. The consent form for this particular study stated, "The results of medical tests will be shared with you and the physician you choose."

The questions raised by this situation include the following: 1. Should consent forms include explicit dis- claimers for making mandatory referrals to mental health services if there is a question regarding extreme mental/emotional dis- tress? It is not uncommon to find a high risk for significant depression in a study population of chronically disabled individuals with stroke. 2. How should differences between inclusion/ exclusion criteria

and clinical judgment be resolved? The consent form addressed the possibility that "the results of medical tests will be shared with you and the physician you choose." This line addresses the issue of follow-up that is essential whenever clinical evaluation and testing are incorporated in the protocol. It is the researcher's responsibility to identify how the results of the examination or test are going to be interpreted and handled, especially when studying a high-risk population. In this case, an explicit cutoff criteria for the depression screen score, indicating the instrument was trusted to identify probable depression, would have excluded the study subject from further evaluation and triggered a clinical interview and a medical hold pending further psychiatric assessment and/ or treatment by qualified provider not associated with the study.

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Reference 1 - 0.32% Coverage

CRNs were supported through regular contact with the CRN Coordinator and team meetings to review trial progress. During these meetings CRNs raised interesting issues relating to ward staff protocol adherence, observed standards of pressure care and experiences of the research role.

Reference 2 - 0.32% Coverage

For example, CRN8 recalls how she observed a patient with a pressure ulcer sitting out in a chair for extended periods of time, without pressure-relieving equipment. She asked the nurses to assist the patient back to bed to ensure the patient was on a pressure-relieving surface.

Reference 3 - 0.87% Coverage

CRNs reported the variability of pressure area care and management across clinical settings. They highlighted that in some clinical areas, such as surgical or orthopaedic wards, the focus was on a procedure (such as hip replacement), rather than considering potential risk factors:

I mean I can think of a gentleman who came in for a knee replacement and he wasn't that old, probably under 60, and the staff were aghast that I wanted to put him in the trial. He had Parkinson disease, he had problems with his medication, he froze postoperatively and he ended up being in bed for three days, so he was an ideal candidate. But nobody had connected that he had other problems other than what he was presenting for, which was a knee replacement. (CRN5)

Reference 4 - 0.52% Coverage

CRNs reported some inadequacies in management of patient pain and discomfort associated with pressure ulceration. CRNs observed ward staff putting a patient on a pressure relieving mattress but not providing any additional care, such as pain relief,

dressings or repositioning:

CRN8: Do you find as well with patients on a mattress, they [ward staff] accept that as fully, well, that'll do for them? CRN6: That they don't need to do anything else.

Reference 5 - 0.59% Coverage

CRNs felt leadership and role modelling in the clinical area were important influences for the delivery of 'good' pressure care. CRNs described areas where they observed good practice but also areas where they were concerned about Charge Nurses' awareness of pressure damage:

Or we've had comments like 'No we have nobody with any pressure damage!' and I think you, well, I have gone onto areas where we've done the [initial] assessments, and that's just not been the case. (CRN7)

Reference 6 - 0.81% Coverage

CRNs identified that resources played a key part in provision of pressure care. Many CRNs reported a lack of suitable equipment, particularly a lack of pressure relieving equipment for chairs. However, rather than leaving patients in bed on appropriate pressure relieving surfaces, ward staff would sit a patient on a chair without appropriate equipment, and then not monitor pressure care because of competing time demands: It's this great denial [by nurses] though – 'She'd [patient] only been there for an hour!' But I knew that she'd been there at 10 o'clock when I went up there, and when I went to recruit a patient at 4 o'clock she was still sitting in the chair. She hadn't moved!' (CRN2)

Reference 7 - 0.54% Coverage

CRNs identified unequal distribution of resources, such as the availability of mattresses; one ward within a centre could have a plentiful supply but would not share the resource with other wards:

I think the thing that came out as well, was that some areas were flush with mattresses and some weren't. And again that was where the territorial came in; they wouldn't allow the ward next door to have them. They would rather have them lying on the bathroom floor. (CRN8)

Reference 8 - 1.36% Coverage

This study demonstrates the additional ways in which CRNs can inform clinical trials. Their engagement in the day-to-day activities of the trial mean that CRNs are useful informal 'participant observers', particularly when employed on trials focusing on a nursing specific topic. These observations may provide contextual detail of the settings being studied and potentially offer insights into trial findings. For example, CRNs on this trial had concerns about the reliability of skin assessments recorded by ward nurses, highlighting examples of poor documentation, which were then explored in more detail by the trial team (Nixon et al. 2005). In addition, their reports that pressure area care can have a low priority in some clinical specialities; that senior staff may be unaware of

patients with pressure damage; that the dangers of leaving at risk patients sitting in chairs for long periods were often not recognized; and that pressure ulcers of Grade 2 (i.e. broken skin) were often not dressed are important for understanding an area of care accorded little clinical importance. Such observations are useful for gaining further understanding of the trial findings.

<Internals\\Double-checked\\Tuffrey-Wjine et al 2008> - § 4 references coded [6.67% Coverage]

Reference 1 - 1.12% Coverage

Professionals could be understandably protective about asking a potential participant and their family or carers to take part and to involve an unknown researcher, at a difficult and worrying time. Life was complicated enough with the huge array of people already involved. We found that 'gate-keepers' tended to agree to take part if they could see some benefit for themselves or the person, with comments ranging from 'it will be nice for him to have someone to talk to' to 'it's good to have an outsider to keep an eye on things'. Our perceived professional expertise in the area of cancer, end-of-life support and bereavement often facilitated recruitment, and we had to be clear about the boundaries of our role as researchers.

Reference 2 - 0.32% Coverage

The Research Ethics Committee agreed, but wanted to be explicitly reassured that we would not reveal any information to the participant about their diagnosis or prognosis. Carers, too, wanted this reassurance.

Reference 3 - 0.30% Coverage

Aspects of the care John and his family received in the weeks leading up to and immediately after his death, after his story went to press, were so shocking that IT wrote a formal letter of complaint

Reference 4 - 4.92% Coverage

At times the participant observer witnessed sub-optimal care. This raised different ethical issues. At what point should the researcher step out of her neutral role and influence the situation? The Veronica Project protocol stated that the researcher could intervene if a (lack of) care and support seemed detrimental to the participant's well-being; and that before intervening, the researcher should seek guidance from certain members of the Research Advisory Group who had agreed to provide 'ongoing' ethical advice. Intervention by the researcher would inevitably lead to a change in the person's situation and would therefore affect the data collected. However, we deemed it unethical to observe seriously inadequate care without intervention: the welfare of the participant had to come before the needs of the researchers. In practice, this was not always straightforward. When is care sub-optimal? There were many occasions where the

researcher, who had many years' experience as a nurse in the fields of both learning disabilities and palliative care and whose expected standards of care were admittedly high, observed practice that may not have been optimal, but that did not warrant intervention. Rather, these observations were simply part of the findings. Examples include participants being patronised or ignored by hospital staff, or participants' wishes not being acted on by support workers. There were a few occasions when, having consulted her Advisory Group. IT intervened. One participant, Nick Ballard, who had no speech, clearly and consistently indicated that he was in pain, but his home manager did not want to give him regular analgesia. IT's suggestions to get a palliative care review were not followed up. She became concerned when Nick began to lose his balance, a possible sign of spinal cord compression which could lead to irreversible paralysis and can be prevented by prompt treatment. After asking advice from the palliative care consultant on her Advisory Group, she spoke of her concerns to the home manager and to Nick's hospital medical team. An observation of abusive behaviour was more challenging. Ursula Smith was very frail when a support worker at her residential care home forcibly poured coffee down her throat, despite Ursula's cries of protest and efforts to push the cup away. IT could not report this immediately, as the home manager was absent. She consulted her advisory group and reported the incident to the home manager some days later, insisting on a report to Social Services under the 'Protection of Vulnerable Adults' structure. The support worker was suspended, the incident was investigated, and this contributed to the support worker's decision to leave her employment. On reflection, IT felt that she should have intervened immediately, but such decisions can be difficult, particularly as a researcher's role is usually explicitly not to intervene. In new research protocols, the authors now include the clause that the researcher may intervene without consulting her Advisory Group if he/she believes that the participant is at immediate risk from harm, working on the principle that it is unethical not to intervene when observing harmful situations.

NVivo output file

Overarching theme: Connection

Theme 6: Clinical assumptions

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Reference 1 - 1.09% Coverage

Our professional backgrounds have influenced the research process in terms of the questions we raised and probably also our interpretation of the responses. We also found that there were potentially conflicting roles in being both researcher and clinician, which influenced our opinions about our own responsibilities in different situations. Our dual professional affiliations seemed to be given different meanings by participants at different times. Our background as clinicians could, on the one hand, contribute to making our research interest understandable and meaningful and, on the other hand, contribute to participants' expectations shifting in relation to their own perceived health status and needs, and their current interaction with other health professionals. We found it important to be clear and open about professional affiliations.

Reference 2 - 0.16% Coverage

the dual identity of the first author, as a researcher and psychiatrist, increased the risk of participants misunderstanding the role of the researcher;

<Internals\\Double-checked\\Bland 2002> - § 1 reference coded [0.33% Coverage]

Reference 1 - 0.33% Coverage

Conscious that it was now several years since I had practiced in this area I was, like Kite, concerned that I would be seen as being more capable than I felt

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Reference 1 - 0.45% Coverage

Some of the nurses felt uncomfortable using a different approach with patients they had known for some time. They thought sometimes this resulted in participants, whom they previously knew as patients, being unsure of how to respond:

...but I think patients struggled a bit with understanding what was expected of them, and they were trying to answer in a way that they were expected to answer... (A205–208)

Reference 2 - 0.48% Coverage

As participants indicated their discomfort with this different approach, at times the nurses felt they had to work hard to keep them engaged in the process: ... I did find sometimes... it was like trying to teach them to suck eggs.... like my one that said 'I was in the army for so and so years do you think I can't'... they'd look at me as if to say 'Are you honestly asking me this?' or you know 'I'm not that stupid!' (E164–168)

Reference 3 - 0.56% Coverage

However, many of the nurses knew the participants in the context of ongoing diabetes care. As a result, SAMS participants were frequently people with whom they already had an established relationship. Equally, as patients, the participants will have had their own expectations and strategies when talking to nurses (Kettunen et al. 2002). This raises the question as to what extent the intervention encounter, despite the protocol script, really was able to alter the established dynamics of communication.

<Internals\\Double-checked\\Clancy 2007> - § 1 reference coded [1.71% Coverage]

Reference 1 - 1.71% Coverage

I was aware that participants would have some knowledge of my professional background from the recruitment letters and the earlier discussions they had had with their clinicians about the study. Thus I believed that if I were to 'bracket' my previous experiences in respiratory nursing, as suggested by Husserl (1964), my knowledge of domiciliary oxygen could affect the relationship between participant and researcher. Bracketing - also known as transcendental phenomenology - is concerned with suspending one's preconceived ideas and attitudes towards the environment and phenomenon under study in an attempt to purify the consciousness, enabling the phenomenon to be studied in its naturalistic form (Hallett 1995). If I had attempted to bracket and not acknowledge my knowledge and experience of domiciliary oxygen therapy, I believed that I would not be true to my own beliefs and in tum this could affect the authenticity of the study

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Reference 1 - 1.07% Coverage

Member checking, where data are fed back to respondents to ensure that the experiences described are recognised, can also increase credibility (Krefting 1991). This strategy was particularly relevant for me, given my knowledge of the hospital environment and my role there. Without checking the meaning of the information that the respondents had given, it would have been easy to form opinions based on my own assumptions. Although the respondents did not receive copies of transcripts to check, at various times during the interview I would feed back or reiterate issues to ensure that I

had understood correctly the meaning of that information. Any misunderstanding or misinterpretation was clarified at this time.

Reference 2 - 0.94% Coverage

One issue very relevant to the study was my role as researcher/practitioner, which gave 'insider status' (Finlay 1998). This was obviously going to be an issue when interviewing the respondents, since all of them had knowledge of my position at the hospital and my professional identity. However, I felt that it was necessary to identify myself in the context of the research and practice in order that the respondents had some means to position me in relation to themselves (Oakley 1988). This made my involvement in the research overt (Abbott and Sapsford 1999) and enabled the respondents to have a clear understanding of my identity.

Reference 3 - 1.08% Coverage

My role as a researcher/practitioner was an influential factor, but did appear to give grounds for a common understanding in that the respondents were able to assume that I was familiar with the establishment that had been a significant part of their recent experience. As such:

... mutual recognition and acknowledgement of common experience makes possible a taken for granted element in the research so that often explicit explanations are unnecessary (Cotterill and Letherby 1994, p116).

Although my experience was certainly different from that of the patients and their SOs – I was an employee and they were the recipients of care – the shared experience of the hospital seemed to give a common ground for understanding.

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Reference 1 - 1.08% Coverage

I suggest that this privileged position is not confined to the immediate nurse-patient situation, and is one that holds significant importance for the nurse researcher in the interpretive research endeavour, particularly in the area of the interview. The person who was once a patient, or may still be a patient in a different healthcare context, holds memory of the nurse-patient relationship and is often willing, if the situation arises, to grant a researcher who is a nurse a privileged relationship: an instant familiarity that results from a shared understanding of health, illness and the body.

<Internals\\Double-checked\\Haigh et al 2005> - § 2 references coded [3.51% Coverage]

Reference 1 - 2.61% Coverage

many participants construed her interest in their progress as friendship, rather than professional curiosity. Comments from in-patients included; 'It's nice to see a friendly

face', and; 'You always have a smile for me.' The continuity of seeing the same person at more or less the same time every day was greatly appreciated, particularly by those participants who did not have many visitors. Post-discharge comments included; 'You came every day, which comforted and helped me.' Qualitative research methodologies acknowledge that the researcher/ researched relationship often develops into one of 'friendship' (for want of a better term). This is often seen as a natural development, given the connection generated between the two participants (Darlington and Scott, 2002). In this study, however, the RA was not seeking disclosure from patients. She was simply visiting to collect pain scores and reports of side-effects. She did not routinely undertake any 'comforting and helping' activities as part of the 'official' ward team, although she did regularly provide information and instruction about pain management to ward staff. Her daily presence and interest nevertheless appeared to be construed as friendship, with patients valuing the continuity she provided.

Reference 2 - 0.90% Coverage

Some respondents chose to re-interpret the researcher's role throughout their hospital stay and the duration of the research study. Although it was abundantly clear that the primary reason for the RA's visit was to collect research data, it would appear that the 'story' patients told to themselves described (in some cases) a social relationship based upon equality and (in others) a relationship contextualised within a caring/cared for framework.

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Reference 1 - 0.24% Coverage

Probably there were situations in which we, due to our preconceptions, did not question or follow up unclear statements but, instead, interpreted them straight off, with the risk of drawing premature conclusions.

<Internals\\Double-checked\\Newbury 2011> - § 1 reference coded [0.53% Coverage]

Reference 1 - 0.53% Coverage

my roles as researcher and nurse. In the 'current carer' interviews, I was always aware of the presence of the patients even though they were usually in other rooms. The patients sometimes interrupted the interview and some carers remained alert to their patients' needs throughout the interview. One interview had to be suspended and rearranged because of the patient's needs.

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Reference 1 - 1.26% Coverage

I was talking to a mother about the management of her child's seizures and what was involved when I used the word 'fit' instead of seizure. The mother corrected me saying: 'We refer to them as seizures'. I had used the word 'fit' to avoid medical jargon, often a barrier to communication, yet in this situation this had been inappropriate and potentially threatened the credibility of the researcher in this field of study.

Reference 2 - 3.04% Coverage

Related to professional credibility is vulnerability of the researcher. There is much literature on the specific ethical concerns when interviewing vulnerable populations such as children, carers and those with age, intellectual or illness-related disability (for example, Gbrich 1999}. However, in this type of research study the vulnerability of the researcher as well as the mothers needs to be considered. Mothers of children in this study were experts in the delivery of care; they knew more than anyone about their child's condition. Some of the children had the rarest of rare conditions or were without a specific medical diagnosis. Knowing that I was an experienced children's nurse may have given the mothers an expectation that I had some knowledge about their child's condition. In fact this was not always so and I made it known to each mother that they were the expert in their child and that I did not have the knowledge that they had, that I was learning about these conditions as the study progressed.

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Reference 1 - 0.49% Coverage

However, some interactions seemed to be related to the researcher's professional background. The GP's perceived higher status led to obscuring of her personal characteristics. The sociologist was often perceived as a 'young woman' rather than defined by her professional role.

Reference 2 - 0.97% Coverage

Many of the working-class respondents were deferential: the title 'Doctor' was often used and I was introduced by several interviewees to family members as 'the doctor'. One respondent apologized for taking up my time, even though the interview took place at my request, and one revealed his view of doctors by saying of his own GP: "He's the same sort of man as a priest type thing . . . they're not far away from the same profession" (male, working-class, R46). Another respondent referred to his GP as "a saint" (male, working class, R56).

Reference 3 - 1.44% Coverage

Deference was not observed among the middle-class respondents who, in contrast, tended to align themselves with me by assuming commonality of opinions and experience. In particular, there were references to friend- ships and insider knowledge which had led to special medical treatment. For example, one respondent who was in a profession allied to medicine said: "There's a waiting list for bypasses obviously but, in a sense, . . . I'm on an inside track" (male, middle-class, R18). Another middle-class man reported how he was able to avoid the GP appointment system by knocking on the surgery door when his GP was working late, and there were several examples of friendships between respondents and their GPs and consultants. The assumed commonality of experience was stronger in male than female respondents.

Reference 4 - 0.84% Coverage

Another example of the interview taking on elements of the consultation was when respondents talked about sexual health problems. One response to the question "Have you had any other sort of health problems?" was: "Ehh, the sexual one are you talking about?" (male, working-class, R49), and a woman, talking about her hysterectomy, said: "Even sexually it's changed me, I can't be bothered to be touched, I just don't have the same urges any more" (female, middle-class, R2).

Reference 5 - 0.62% Coverage

However, the authors found some notable differences in interview interactions. Doctors have a more clearly defined role and higher social status than sociologists. This difference in status led to the more frequent obser- vation by HR than CE of deference amongst working- class respondents and social alignment amongst middle-class respondents. W

Reference 6 - 0.57% Coverage

The professional identity of 'the doctor' is so well known that it became an exaggerated variable in HR's interviews, overshadowing her personal characteristics. In contrast, professional back- ground was much more muted for CE, so gender and age were key variables in identifying her as 'the girl from the University'.

Reference 7 - 0.79% Coverage

Respondents have definite preconceptions about the role of a GP; in contrast, a sociological 'researcher' is an unknown quantity and respondents took more time to place the interviewer. GP researchers must first decide whether or not to declare their professional background. If they do make it clear that they are medically qualified, they should be aware of respondents' possible preconceptions and take care to explain their current role as

Reference 8 - 0.26% Coverage

It has been argued that "who you are affects what you get told" 29 (p. 114); we suggest that who respondents think you are affects what you get told.

NVivo output file

Overarching theme: Connection

Theme 7: Suspicion and holding back

<Internals\\Double-checked\\Baarnhielm and Ekblad 2002> - § 2 references coded [1.65% Coverage]

Reference 1 - 0.68% Coverage

Gülizar's general practitioner (GP) suggested that she should participate in the present interview study. When the first author (SB) phoned Gülizar to inform her about the study she became upset, not about the aim of the study but because the researcher was a psychiatrist. Gülizar said that she was not mentally ill but suffering from back pain. She said that there was nothing strange about this as she had a lot of major problems such as stress, sleeping difficulties and being a single mother. She did not trust the local primary care and said that no one could help her. After a while Gülizar asked: 'What do you want?'

Reference 2 - 0.98% Coverage

According to the design of the study, a psychiatric diagnostic SCID interview (SCID-RV, 1996) for Axis I, according to DSM-IV (American Psychiatric Association [APA], 1994), was conducted in order to confirm the psychiatric assessment of the clinician. The SCID interview confirmed the diagnosis of major depression. Gülizar asked for the result of the diagnostic interview and was informed of the diagnosis of major depression. Upon hearing this, she responded: 'You are not allowed to say that [referring to depression]. I do feel depressed but I don't want anyone to know that. That is our secret. You may not speak about it. No one should know.' Gülizar was given brief information about the clinical significance of the term depression and about possible treatment.

< Internals \ Double-checked \ Colbourne and Sque 2004> - § 1 reference coded [1.49% Coverage]

Reference 1 - 1.49% Coverage

As a purely subjective observation I often wrote in my journal after a participant interview: 'Participant began talking once the cassette recorder was turned off". Ironically, I have documented some of the most revealing data at this point — rapport is greater when the 'official' part of the interview is over. This may be because participants prefer that certain thoughts and feelings are not to be recorded verbatim. Or perhaps, on reflection, it may indicate that the participant responds to the nurse or to 'me' as a person more openly than to the nurse researcher and data gatherer. Conversely, do I, as a nurse researcher, hold back during the taped interview so that when the recording is over the participant perceives an alteration in the nurse researcher- participant relationship. Perhaps I do, subconsciously, have a research nurse persona.

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Reference 1 - 0.51% Coverage

My professional role could also have influenced the decision to take part in the research. Although it was stated in the consent form that participation would not affect future care, fear of reprisal if they did not take part could have been a factor. Also, others may have felt that participation could have resulted in additional support. T

Reference 2 - 0.74% Coverage

It could be argued, however, that the respondents could have been inhibited by the fact that I was a member of the rehabilitation team at the hospital where they as patients had received treatment, especially when they were expressing dissatisfaction with the service as a whole or any part of that service. This was likely to be particularly relevant when aspects relating to my own profession, occupational therapy, were discussed.

Reference 3 - 0.91% Coverage

The comments regarding the occupational therapy service were variable, some being highly complimentary and some equally critical, as were the comments about the service as a whole. I was not aware that the respondents were inhibited by my role, but it certainly was an influence. Despite assurances that the information was confidential, some appeared both to voice their feelings about rehabilitation critically and to compliment, perhaps on the understanding that these issues would be fed back to others at the hospital. Alternatively, the respondents could have accepted that I would hold their confidence.

Reference 4 - 0.24% Coverage

I was much less aware of this when interviewing the patients and their relatives, who appeared to be comfortable with my role and their position within the research.

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Reference 1 - 0.78% Coverage

All the participants knew my professional role and that I was employed by the hospice. Carers ' of patients known to me however were excluded. Although it was uncomfortable to hear, I was relieved that some of them felt able to criticise the services of the hospice. In this respect, I made a particular effort to remain neutral. I resisted all instincts to defend the hospice or any other health and social services the carers expressed problems with, or indeed to confirm their criticisms. I was left, however, with feelings of discomfort and disappointment.

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Reference 1 - 0.89% Coverage

When asked at the end of the interview whether there was anything they would like to add or ask, respondents expanded on their health problems, asked health-related questions and gave their opinions of doctors and other aspects of the health service. One woman said: "Excuse me saying it, I don't think [doctors] realise how frightened people are when having this sort of thing [operations]" (female, working-class, R13). In this case, the respond- ent apologized for expressing a negative view of doctors.

<Internals\\Double-checked\\Thompson and Russo 2012> - § 1 reference coded [0.87% Coverage]

Reference 1 - 0.87% Coverage

It can be difficult to guarantee privacy before an interview, simply because, in explorative qualitative research, both the participant and the researcher are unlikely to know precisely what they will end up discussing. For example, one of Thompson's (Thompson& Broom 2009) explorative studies involved interviews with participants living with a disfigurement, who were self-selected on the basis that they were coping well with the intrusive actions of others, and yet participants actually reported experiencing episodes of distress. Whilst participants need to know the privacy and confidentiality "guidelines," there will be uncertainty about what is actually going to happen. As a consequence, some have argued for an ongoing or "processual" form of consent, which facilitates participants' option to opt out at any point (Rosenblatt 1995). However, this involves problems related to the pressures-to-continue which may be experienced by both the researcher and participant.

NVivo output file

Overarching theme: Connection

Theme 8: Revelations

<a href="mailto:line-checked | Baarnhielm and Ekblad 2002> - § 1 reference coded [1.55% Coverage]

Reference 1 - 1.55% Coverage

It was the professional opinion of the researcher, as a psychiatrist, that Gülizar's depressive mood had worsened and that she was socially and mentally impaired and that somatic symptoms were a way of expressing this to a clinician. The researcher interpreted Gülizar's conflict with her GP as being linked to the two parties having different agendas for understanding the current illness.5 They probably also differed in their views of socially accepted ways of expressing distress and acceptable healing strategies. Subsequent to this change in the research situation, and when the taperecorder had been switched off, Gülizar told the researcher about suicidal wishes and that she was worried that she might harm herself if her poor state of health continued. The researcher and Gülizar had a conversation about illness and healing during which the researcher tried to bridge the gap between Gülizar's opinions and the presumed agenda of illness understanding of the caregiver. The researcher suggested that she should try to negotiate with the caregiver about Gülizar's agenda of understanding her illness and that of the caregiver. The researcher was of the opinion that the participant was not able to be her own advocate in a discussion with her caregiver.

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Reference 1 - 1.46% Coverage

One informant acted clearly as an advocate during a research project investigating the health knowledge and status of young detainees in custody. She described a 'grey problem area' - an interaction with a detainee about how stressed he felt being locked up:

He could not mentally stand confinement any longer and confided in me his plans to escape. At this point J became distressed, [felt the participant needed to have immediate psychological assistance and that he had trusted me, almost appealing to me to help him ... After discussing my concern with the other researchers in the team who understood the dilemma, ! decided to tell the nurse in the centre that in my professional opinion I felt this person should see a psychologist immediately ... I am left wondering what was the eventual outcome for this person, I still reflect my feelings of despair. This situation also reflects an event where the young man saw nurses as caring and trustworthy, and there to help. However, it developed a conflict for the nurse researcher between a principle of confidentially as a researcher and the duly of care of the nurse to prevent harm in an instance where the solution was not immediately

obvious.

Reference 2 - 1.73% Coverage

Advocacy was again the initial impetus for an informant who was involved in a project with the chronically mentlly ill living in boarding houses and who came across an 'invisible problem area' - one- integral to the social context. Her story: I had become concerned about the level of sexual safety of some of the participants who were living in boarding houses ... When interviewing a woman she informed me that the house manager regularly forced her to have sex against her will. He also forced her to have sex with other men who he brought to the house. The woman was resigned to the situation, I stopped the interview and asked the woman what she felt about it. I asked her if she wanted it to stop. I never felt for one moment that it wasn't true. She indicated she did but was afraid of the consequences. The informant continued her story by relating how she talked of the incident with her research team and was told: "You cannot do anything about it ... You should have stayed in the project officer's role." She then felt she had to act, not only as an advocate for the woman, but as a political activist for her and the others in similar circumstances. In this role, she approached the government authorities to try to set up protective measures for women living in boarding houses. She stated on a personal level: "from an ethical point of view I don't think I could have lived with myself if I hadn't done something."

<Internals\Double-checked\\Bland 2002> - § 1 reference coded [1.08% Coverage]

Reference 1 - 1.08% Coverage

One or two residents told me of experiences of treatment that I had hoped never to hear. Their stories were given in confidence, and on condition that I did not intervene in any way. I respected their wishes, but didn't I have some role as a fellow human being here, let alone as a health professional? What would my role have been in these situations if I had been just a casual visitor to the home and become aware of these particular situations?

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Reference 1 - 2.43% Coverage

One woman, for example, had a 22-year-old son in a drug and alcohol detoxification unit, who would phone her several times a day blaming himself for his father's illness. She wept when she was describing how difficult it was travelling long distances to be with her son and participate in a therapy programme, as well as supporting her husband in the ICU. She did not tell her husband about the son's self- blaming because she 'didn't want to worry him', and always 'put on a brave face', saying she would lie to him if necessary. She had kept her emotions contained and not told anyone about her problems. She would not have told e except that she said I seemed to be genuinely

interested in what she was going through. Another participant described how difficult and painful reaching a consensus about the potential withdrawal of his mother's treatment. One woman, a Jehovah's Witness, was distraught and visibly shaken as she talked about seeing her husband's unexpected blood transfusion in progress. Yet another participant, in his sixties, was very lonely and very afraid. He wept when he said that he had 'no support whatsoever' and that:

'For the first time in my life I'm scared witless. I do not know what the hell to do. I don't want to see my wife in pain, I don't want to see my wife a vegetable. It's just cutting me to pieces ... I can handle anything that life dishes up, but I can't handle this'.

Reference 2 - 0.75% Coverage

Furthermore, intervention of this nature had not been negotiated during the research approval process, although common sense prevailed and where appropriate I sought the participant's consent for follow-up. On one occasion, for example, when a man repeatedly said he would shoot himself if his wife died, I asked if he would like some professional help apart from talking to me about how he was feeling. He agreed, and additional help was obtained.

Reference 3 - 0.27% Coverage

I often found myself weeping with these men and women, and this unintended expression of empathy seemed to encourage them to greater levels of disclosure.

Reference 4 - 0.60% Coverage

In addition to the expression of empathy, the 'listening ear' of the researcher has often been said to stimulate dis- closure of many extraneous and intimate details.2 I found this occurred on several occasions where my attention to the participants seemed to give them implicit permission to contribute information that was often not contextually appropriate.

<- Internals\Double-checked\Cartwright and Limandri 1997 WORD version> - § 1 reference coded [1.07% Coverage]

Reference 1 - 1.07% Coverage

The research proposal called for observations of activities where the research team anticipated enrichment might occur, such as bathing, meals, and bedtime. Early, however, while interviewing caregiving dyads, the role of nonparticipant observer became uncomfortable. The researcher felt awkward as a potential intruder in the caregiving home. As a nurse, the researcher was comfortable participating with intimate care of an unknown person. As a guest in the home, she felt intrusive. One does not simply observe in such a private setting. Thus the observational component of the data collection consisted of planned visits to participate in specifically identified activities or arose spontaneously during the interview.

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Reference 1 - 0.48% Coverage

Over the course of time, the developing trust between subject and nurse interview- er fostered subject disclosure that made it more difficult to restrict the focus to the interview questions and not actively pursue additional information.

Reference 2 - 1.06% Coverage

For instance, appropriate intervention, referral, and follow-up procedures were implemented for subjects in severe physical or emotional distress. One situation involved a recovering alcoholic expectant father. He reported experiencing distress due to a strong urge to resume drinking because of marital difficulties which he perceived as pregnancy-related. The staff member made the immediate decision to intervene by encouraging him to contact his alcohol counselor. He was subsequently dropped from the study.

<Internalsline Double-checked\\Johnson and Macleod Clarke 2003> - § 1 reference coded [1.35% Coverage]

Reference 1 - 1.35% Coverage

was really concerned about one person ...in fact it's still unresolved and I don't know what to do . . . she told me she was taking Tamoxifen® . . . and that was OK until later on she talked about starting a family...and I just felt she didn't realize that this drug could... actually probably would stop her from ovulating. She didn't say she was concerned so it was difficult for me to chip in. But then I came away and felt I should mention it to the breast nurse...but how could I? I promised her I wouldn't talk about anything she said to anyone.

Some researchers expressed guilt at not feeling able to "help" participants because this, they believed, would be in direct conflict with their role as data collector. For some, this concern was compounded by previous training and experience, such as in counseling. For example, "It was very difficult not to do anything about some of the things I was hearing . . . and I felt very bad, very guilty and extremely frustrated especially as I had been programmed to try and help people." Other issues around confidentiality included participants' not complying with treatment regimes and, in one instance, threatening to take his or her life.

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Reference 1 - 1.31% Coverage

I asked Ann how she felt about this. Immediately her eyes welled up with tears as she told me of her fears and anxieties regarding her forthcoming caesarean birth. Ann cried as she told me that she felt her needs had been disregarded by the doctors, midwives and her husband, with consideration only being given to the wellbeing of the baby. Tears ran down her cheeks as she told me she had never been ill in her life, that she hated hospitals and was really scared about having an operation. As a researcher, I had not considered my research area to be of a particularly sensitive nature and I had not anticipated such as emotional response in this context, nor fully prepared myself

Reference 2 - 2.52% Coverage

My approach must have given Ann legitimacy to continue to disclose her feelings but her distress deepened and her tears and sobs became uncontrollable as she told me that she feared she would die. I was uncertain how to respond. There is little in the research methodology literature which gives specific guidance on how best to handle these highly emotional situations, but Coffey (1999) advised the researcher to acknowledge and accept tears by maintaining eye contact and trying to talk through the issue. However, I experienced a conflict of emotions as to how I should act. I realised the significance of Ann's experiences and feelings, but at the same time I was in the position of power and I was aware of the vulnerability of Ann in this situation. I decided to turn off the tape recorder and stall the interview until Ann had regained composure. However, Etherington (1996) advised researchers not to assume that participants will wish to discontinue, even if they become distressed. I may have acted in haste and denied Ann the opportunity for her voice to be heard. In my mind I was juggling research interests with the responsibilities of being a researcher, a midwife and an empathetic human being. As Gunasekara (2007) suggested, this leads to role and emotional conflict, which I indeed experienced.

Reference 3 - 1.78% Coverage

Hallowell et al (2005) discussed the importance of maintaining a clear boundary and not adopting a counselling role. I believe I overstepped the boundary, slipped into my midwifery role and in an attempt to reassure Ann, talked to her about the procedure of a caesarean section and tried to give her a balanced perspective of the risks of caesarean section. However, it could be argued that I acted according to my Code of Practice as a midwife (Nursing and Midwifery Council (NMC), 2008) and many other researchers have been obliged to do just this when faced with similar circumstances (Kirkham, 1989; Hunt and Symonds, 1995; Davis, 1996). After some time Ann regained her composure and I felt able to continue. At the completion of the interview I spent some time with Ann, only leaving her when I felt she had regained a sufficient level of calm to be left alone. Ann rejected my suggestion of a referral to a midwife or GP.

Internals | Double-checked | Nicholl 2007> - § 1 reference coded [2.39% Coverage]

Reference 1 - 2.39% Coverage

In this type of study there is the potential for significant and sensitive information to be divulged by the mother, or situations to be observed by the researcher that could have clinical, legal or ethical implications. Ethical committees often require potential issues such as these to be identified before the study starts and a description of the mechanisms the researcher has in place to deal with emerging situations and dilemmas. Strategies must be in place to manage any issues that are a cause for concern about the mother, child or other members of the family. This includes providing written information advising the mothers about the researcher's professional responsibilities in such situations and being aware of current policies and practices relating to child protection and family care.

<Internals\Double-checked\\Richards and Elmslie 2001> - § 1 reference coded [0.49% Coverage]

Reference 1 - 0.49% Coverage

Respondents also disclosed sensitive and confidential information. One respondent who still had chest pain despite a recent coronary bypass operation said "I don't mention it to anyone, if I mentioned it to S (wife), she'd just get excited about it" (male, middle-class, R1, HR).

 - § 2 references coded [9.03% Coverage]

Reference 1 - 8.51% Coverage

A study subject presented to the clinical setting for baseline data collection prior to beginning an exercise rehabilitation intervention trial for per- sons with chronic stroke. During the initial visit, the subject's formal (contracted) caregiver dis- closed information about the subject's behaviors toward her disabled spouse. The reported behaviors included verbal abuse, liquidation of shared assets, and repeated attempts to have him placed in a nursing home because of his "dementia," which was not formally diagnosed. The caregiver was concerned that the spouse had "lost his will to live" because of this mistreatment. The caregiver was sufficiently concerned about the potential of elder abuse that she sought help from the research personnel. The research assistant on the study, a Master's level psychology student, reported this information to the project manager.

Given the report of possible elder abuse, the research assistant and project manager filed a re- port with local adult protective services with careful documentation in the study record. As a registered nurse, the project manager deemed the report mandatory

according to her professional practice act. The study subject was not told the report had been filed. Adult protective services' subsequent communication was limited to confirmation that contact had been made. The language of the study consent form signed by the subject stated that medical information would be protected to the fullest extent allowed by law. The subject withdrew from the study shortly thereafter due to a new onset medical problem that was unrelated to the stroke.

Reference 2 - 0.52% Coverage

What are the responsibilities of study personnel if personal medical information is inadvertently obtained about another person not involved in the study?

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Reference 1 - 0.59% Coverage

In some situations, there was no other choice but to intervene. Ethically, researchers are obligated to protect study participants and promote their well-being. During the course of this study, episodes of family violence, particularly wife abuse were revealed. The participant's safety was of utmost importance, leading to the nursing role to assure that the participant received the help she needed.

<Internals\\Double-checked\\Thompson and Russo 2012> - § 1 reference coded [1.11% Coverage]

Reference 1 - 1.11% Coverage

For example, Russo was faced with a dilemma when her participants in the cystic fibrosis segregation study disclosed "rule-breaking" behaviour. This was particularly challenging due to the multiple roles which Russo held. During the research interviews, both young people with cystic fibrosis and their carers confided that they engaged in behaviours that were "against the rules." For example, carers revealed the use of mobile phones in the hospital setting, which at the time was against hospital policy, and that they encouraged their child to hide their mobiles from staff. Although this caused unease about dual roles, the participants' confidentiality was respected in this matter because there was no direct harm to others, and the information had been provided whilst Russo was in researcher role. Clearly these disclosures were useful to the findings of the research, particularly in relation to the practical recommendations that followed from the study, and could easily have been lost had participants perceived Russo to be acting entirely in her clinical role. Spending time with potential participants to clarify one's role is important in ensuring that there is a shared understanding of the boundaries of the researcher-participant relationship.

NVivo output file

Overarching theme: Connection

Theme 9: Over-identification

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Reference 1 - 0.71% Coverage

The interviews were often conducted in the participants' homes and the researcher became closely acquainted with the participants' daily life. This included their experiences of the gap between participant and caregiver understandings of illness. In working with these issues, the researcher was acting outside her usual clinical and private framework and her professional role as psychiatrist with its formal guidelines for professional behaviour. Becoming acquainted with the participants' illness narratives and suffering had a powerful emotional effect and the researcher experienced the boundaries between her and the participants as permeable.

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Reference 1 - 0.65% Coverage

She initially acted as a nurse because of the potential life threatening nature of the situation but over time she became a confidant and a friend of the study participant. As she stated herself of the woman she counselled: I thought this woman was almost suicidal ... I thought I cannot justify collecting this information and going off and doing my little research project. I referred her to the General Practitioner and maintained contact with her for a number of years after the project, and remained a friend for14 years.

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Reference 1 - 0.50% Coverage

At first, nurses found it particularly challenging to follow a scripted protocol which defined the intervention and that had to be conducted in a specific time frame and audio-recorded for quality assurance by the trial team:

..Well absolutely terrifying. The first two I felt... I just felt quite sick in my stomach. It's like going for a job interview or something. It was horrible. But I did get used to it but I didn't like doing it... (L141–143)

Reference 2 - 0.61% Coverage

Although it was recognized that there was a need to be all singing from the same songsheet (E153), the nurses were particularly uncomfortable with reading from the protocol. One described how she needed to keep her finger on the script to avoid losing her place. They were also concerned about how the participants might feel about its unfamiliar and formulaic nature:

Having to stick to something that didn't sound quite right, I found it repetitive and it made it sound as though the patients were stupid. It was a bit patronizing... (F106–108)

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Reference 1 - 0.33% Coverage

findings might be and there was an undeniable sense of dread from staff about the final analysis (see Vignette 5). This trend towards over-identification with participants represented the commencement of a period of re-thinking the merits of insider positionality. Slowly I began to acknowledge some of the benefits of my organisational outsider status whilst in the field (see Vignette 6).

Reference 2 - 0.23% Coverage

I am beginning to feel like it is a breach of trust to report any negatives about the way midwives conduct their work. I feel that the midwives have generously offered to let me observe their practice and it subsequently feels wrong to highlight the areas of poor practice observed.

- § 1 reference coded [0.68% Coverage]

Reference 1 - 0.68% Coverage

Methodological and ethical issues that arose included: generating a situation that potentially required therapeutic intervention; the impact on the 'purity' of data of becoming emotionally enmeshed; and the level of investigator preparedness when researching sensitive topics. The issue of walking away from an intensely emotional and intimate interview often leaves one with a sense of 'unfinished business'.

<Internals\\Double-checked\\Clinton et al 1986 WORD version> - § 1 reference coded [0.50% Coverage]

Reference 1 - 0.50% Coverage

A major area of difficulty in the expectant father study resulted from the constraints placed on information-gathering activities. Nurses with highly refined interviewing skills

found it difficult to limit their inquiry to a structured format.

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Reference 1 - 1.82% Coverage

By now I was beginning to climb my learning curve. After reading the paper by Frank (1997) I began questioning how I was seeing the data of my own study. Was I analysing participant narrative through the eyes of a researcher or through the eyes of a nurse with a different knowledge base of the healthcare system? I was now aware that my professional socialisation could be getting in the way. I went back to the original data and found that although I was analysing the data from the study participants, I was also slanting them from my perspective as a nurse, and to some extent comparing the data against cancer standards used for peer review visits. I realised I was being more critical of the service experienced by participants than the participants were themselves! Once I realised what I was doing I became more aware of how I was constructing knowledge from the data, and acknowledged the need for greater self-vigilance during data collection and analysis.

Reference 2 - 2.10% Coverage

Not being able to help participants to resolve their problems, merely suggesting other avenues for intervention, made me feel callous, uncaring and awkward. I therefore devised some strategies to assist me in avoiding over-familiarity and to help participants not to see me as a nurse who could offer them care. For example:

- I specifically set participant recruitment criteria timescales for the study to ensure that the patients I had given direct nursing care to during their
- A paragraph in the participant study information sheet described my nurse researcher role
- I did not wear a clinical uniform, so as to reinforce that I was not part of the clinical care setting
- I did not have a base on the hospital site
- On first meeting with a participant I described my nursing background but reinforced the research role
- When appropriate I suggested to the patient avenues other than myself for needs that arose.

Despite these precautions there were still times when participants used me as a nurse and when the nurse in me took over to provide (primarily supportive) care.

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Reference 1 - 1.62% Coverage

I could not know how well I would cope given their circumstances or if it would be possible to focus on gains if the losses still apparent were significant. Nor could I know if

my quality of life would be worthwhile if disability prevented participation in valued activities and affected hopes and ambitions. In the context of the interview, I did not know if I caused distress when these areas were discussed. For some individuals the implications of their impairments did not appear to cause distress when discussed, and therefore I felt that I must be wary of projecting my own feelings onto them. With the SOs, too, I asked myself similar questions. I had no knowledge of how I would cope with caring for a loved one who had changed. One SO described the situation as 'living with a shadow', since the qualities she had loved and admired in her husband were so reduced. No one could help feeling a great deal of compassion in this situation, but it was again important to convey the responses and experiences of the respondents, and identify and acknowledge my own for what they were.

<Internals\\Double-checked\\Gardner 1996> - § 1 reference coded [1.18% Coverage]

Reference 1 - 1.18% Coverage

This relationship can bring an added depth and quality to the interview situation, and can provide nurse researchers with a way to position themselves in relation to the person being interviewed. This repositioning provides the basis for overlapping circles between the interviewer (nurse) and interviewee (patient) where the overlap constitutes a common ground of shared meaning. In this inter- view context, both participants contribute to the production of a discourse where the patient is the expert narrator of his/her experience of illness and the health- care system. Consequently there is no neutrality, objectivity or Othering in this relationship.

<Internalsline | Double-checked | Groenkjaer 2002 ethnography issues | 1 reference coded [1.36% Coverage]

Reference 1 - 1.36% Coverage

For example after the first two weeks I found the days had changed, and I found myself moving more into providing nursing care. I reflected over the change and the following was recorded in the field notes:

...I guess this comes with the fact that I know the ward by now. Things that I paid much attention to in the beginning (organisation, routines etc.) are now 'basic knowledge' to me... there has been a slight change in my role from observing the nurses from the nurses' station and looking through charts to more participation in the nursing care . .. I find that appropriate, since I now have an overview of the ward ... it is therefore easier for me to become immersed into the culture ...

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Reference 1 - 0.22% Coverage

As a doctor, Kej was disappointed when Sally did not complete the rehabilitation

program. Kej considered it to be a professional failure not being able to find a treatment that relieved Sally's pain.

Reference 2 - 1.21% Coverage

There are also ethical, administrative, and legislative guidelines that regulate What is right and legal to do as physician, and these guidelines had an impact on the research. For example, in Sweden, sickness benefits are paid by the state and the employer as part of general health insurance. To receive sickness benefits for more than 1 week, a person needs a certificate in which a physician confirms that she or he is not able to work due to an illness. Sick leave is granted due to problems associated with paid employment, not for problems associated with unpaid responsibilities in the family or elsewhere. Furthermore, in the shadow of the economical crisis in Sweden and other industrialized countries, there has been an extensive debate about the necessity to restrict sick leave when the diagnosis of the patient's symptoms is in doubt (Spitzer, 1993). This approach permeated the interview passage with Sally. When Sally talked about housework, Kej wanted to know more about her job because Kej saw it as her duty to help Sally return to work or to identify the problems that kept her on sick leave.

Reference 3 - 1.85% Coverage

Discussions about sick leave often caused dilemmas during our research because as physicians we had to keep to certain professional guidelines, sometimes clashing with the participant's wish. Vera was a 38-year-old nursing assistant, divorced, with two preschool children for whom she was carrying most of the parental responsibility. She had planned to begin studying once both children started school. She suffered from back pain for several years and had often been on sick leave. At the time for this interview, she worked full time after a long period of sick leave, but now she said, Honestly, I would like to be sick-listed part time. I can't manage full time. First work a full day, and then fetch the kids at the day-care center... bring them back home in the pram. I'm not a good mother when I've come back home.

Here, Vera is challenging the rules for being certified for sick leave, and as physicians, we had objections. In the margin of the transcript we had noted, "She can't be sick-listed because she manages to work full-time!" However, we were also frustrated due to her frankness and afraid that we had come too close and were not professional enough. In our memos, we had written, for example, "How come she asks me such a bold question?" Kej experienced a dilemma. The aim to obtain trust and closeness in the interview could be a threat to the guidelines of the physician. There was also a risk that the informants were receiving illegitimate "advantages" due to their participation in the study, which raised ethical questions.

Reference 4 - 0.77% Coverage

However, we also saw situations in which shared understanding risked blinding us. Bitte, a young participant in the study, did not attend the physiotherapy and work trials

she had agreed to attend. Her reason for not coming was her son: He was not well; therefore, she had to stay at home with him. Her excuses appealed to us as mothers: "You know what it's like." However, when she continued to miss her rehabilitation, her excuses were questioned. Was her son too sick for the daycare center? After a while, it became clear that she had a phobia about new places. We realized that the difficulty in recognizing Bitte's explanations as evasions was the result of an overidentification with her as a mother.

Reference 5 - 0.53% Coverage

As researchers, we were a part of the feminist research discourse. This implied an awareness of the fact that the knowledge produced should be useful to the participants, and the research methods should not be oppressive (Acker, Barry, & Esseveld, 1983; Smith, 1990). According to all this, the first interview passage was shameful. Because Kej stressed the need for rehabilitation and a return to work, Sally was prevented from talking freely about her activities at home.

Reference 6 - 0.56% Coverage

An important aspect of the power asymmetry concerned social and economical status. Sally was a low-paid, unskilled worker, whereas Kej was a well-paid, well- educated physician. Their experience of what it means "to work" was very dissimilar, but Kej's suggestions indicate that she did not take that into account. Instead, she used her social power and preferential right to interpret what was best for Sally. In this part of the dialogue, Sally's values were not stimulated; instead, they were silenced.

Reference 7 - 0.37% Coverage

Our main concern was not to provide intimate details about our private life, restricting such information to descriptive facts, that is, that we had children, were married, and so on. Seen in retrospect, this was due to a fear that our roles as physicians would suffer if we said too much about our private strengths and shortcomings.

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Reference 1 - 2.92% Coverage

As a participating observer, she might have observed with her "nursing glasses" instead of "researching glasses," a situation that might have caused cultural blindness. This was probably the case at first, as it was difficult for her to develop any kind of distance from a situation she knew so well. She dressed like a nurse, and as she assisted the nurses in their work, she might at times have paid more attention to patient care than to research. In some situations, she also felt that keeping a researcher's distance placed her in an ethical dilemma with regard to the well-being of patients. Prior to this project, however, the researcher had also been a practicing teacher of nursing and, as such,

was familiar with the clinical field; she had also studied the literature on education. Being a teacher certainly enhanced her understanding of nursing as a practice. Hence, her prior experiences could have caused her to be blind and seeing at the same time. Although the blindness might come about as a result of her familiarity with the nursing culture—from her being an insider—her ability to see might have been enhanced by her life as a teacher or by the fact that she was an outsider. At one point when the researcher assisted a nurse in caring for a patient, she was surprised by the way the nurse performed this chore. According to her "teacher" eyes, the nurse attended to the patient's personal hygiene in a way that was not in accordance with accepted hygienic principles. On noticing this, she realized that this practice was quite common in the unit, a fact that she probably would not have recognized without her experience as a teacher.

Reference 2 - 2.12% Coverage

cultural blindness was apparent in the beginning of the study, but the researcher felt that this bias diminished as her role as a researcher developed. The uncritical acceptance of routines is an example. At the outset, the researcher did not question the routines that were established at the unit. Patients were, for instance, routinely bathed and dressed before breakfast, which was served at 8 a.m. She was initially somewhat blind to the consequences that these routines might have for the patients. The change in perspective sometimes called for as the fieldwork is in progress can be a source of certain methodological problems, as researchers spend time and effort in attempting to acquire some degree of an insider's view. A field researcher does not necessarily understand the inside workings of a practice just because she has the same professional background and is familiar with the field. A researcher working in a familiar field might possess experiences and knowledge that keep her from seeing the field from alternative perspectives. She has to handle being an insider as well as an outsider, and developing an understanding requires analytical distance as well as relational closeness

Reference 3 - 0.63% Coverage

In the present study, the researcher felt herself becoming emotionally involved in the nurses' reactions to different events at the ward. This involvement was an important part of her understanding. It might, how- ever, have prevented her to some degree from adopting the analytical distance that is necessary to see matters from a different perspective.

Reference 4 - 1.47% Coverage

How can a researcher work on changing his or her perspective while the fieldwork is in progress? Loyalty is a precondition for building trust, which, again, is necessary in the acquisition of available information and experience. There is, however, always a danger of not succeeding in maintaining the necessary distance, resulting in the researcher's "going native," so to speak (Hammersley & Atkinson, 1996, p. 138). The researcher then sees only what the practitioners see. To avoid this, the researcher must develop a critical look at the field and ask critical questions. This, again, might be perceived as

disloyalty, both by the researcher and by those in the field. Striking and maintaining an acceptable balance between such loyalty and disloyalty, thus, become crucial to the attainment of such a change in perspective.

Reference 5 - 0.63% Coverage

In this project, it is quite probable that the researcher was more of a participant than an observer. She did not participate on the same level as the interviewee, but, all the same, her friendliness and her commitment to her profession might have concealed the asymmetric power relationship that is always present between the researcher and the subject.

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Reference 1 - 1.40% Coverage

The example from Nede's interview also reflects a collision of multiple identities for this GP researcher. Rather than containing her clinician identity, she was embarrassed and felt compromised by this story, worrying that Nede's GP's behaviour may have reflected on her profession, generating a reluctance to hear more. Arber, a nurse researcher, has described her own fluid identity, which was constantly being defined and re- defined by herself and the participants during interviews [17]. She suggests the need to carefully distance or bracket ones own experience. The GP researcher, during later interviews, having now experienced these personal feelings and disclosing and discussing them with others, was better able to put the clinician identity aside when required.

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Reference 1 - 0.78% Coverage

All the participants knew my professional role and that I was employed by the hospice. Carers ' of patients known to me however were excluded. Although it was uncomfortable to hear, I was relieved that some of them felt able to criticise the services of the hospice. In this respect, I made a particular effort to remain neutral. I resisted all instincts to defend the hospice or any other health and social services the carers expressed problems with, or indeed to confirm their criticisms. I was left, however, with feelings of discomfort and disappointment.

<Internals\\Double-checked\\Patterson 1994> - § 3 references coded [4.62% Coverage]

Reference 1 - 1.73% Coverage

One afternoon my fear of being viewed as a spy for administration was realized. I innocently shared something I had observed the evening before with the social worker. She immediately confronted a nursing assistant who had worked the previous evening.

This assistant asked how the social worker knew this information, and I was pointed out as the informant. I was very distressed by this incident, given my efforts to build trusting relationships with the staff. I felt as if I had betrayed them. Fortunately, the nursing assistant did not express similar feelings.

Reference 2 - 2.45% Coverage

Residents frequently asked how my children were or what I did when I was not at the nursing home. They expressed sincere interest in my life. I derived pleasure from interacting and talking with the residents, but to arrive home to two small children after spending several hours at the nursing home engendered conflicting emotional responses, from melancholy to joy. I wrote:

[My husband] tells me I'm getting too close if I say something bothers me or I comment that the day was depressing. I think about how difficult it must be for the cognitively intact elderly person to be in a nursing home-I think I would hate living here. All the things they must tolerate-sharing a room with a stranger, the food, many different personalities, boredom. This nursing home seems above average; still there are so many problems.

Reference 3 - 0.44% Coverage

When the fieldwork was completed, I visited the nursing home intermittently over the next 6 months to say hello and to see how the residents were doing.

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Reference 1 - 4.37% Coverage

Whereas these elements were present in the training of nurse interviewers for the stroke rehabilitation study, salience of the nursing role over the interviewer role was not foreseen. It is important to note that clinical and research interviews differ. Collins et al. (1988) suggest clinical interviews include assessment, with the goal often being intervention (if required). Meanwhile, the goal of research interviews is simply collecting unbiased in formation. Questions used in clinical interviews are more individualized and nonuniform, whereas questions used in structured research interviews are typically uniform. Rapport-building in clinical interviews is established by empathic listening and reflection, whereas rapport-building in research interviews is established by reinforcement of acceptable subject performance. During clinical interviews, elaboration is encouraged by open-ended questions, whereas in re- search interviews, elaboration is discouraged by controlled choices and use of specific probes. During clinical interviews, data is interpreted and summarized by the clinician and may be acted on at the time, whereas in a research interview, a subject's specific response is recorded and few inferences, if any, are drawn.

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Reference 1 - 1.40% Coverage

Data collection ended with each family when no new information was generated, redundancy guiding us to that end. Disengaging with families proved to be a challenge. Reciprocal bond of affection had grown between researchers and families. One way that helped with the termination process was to make it formal and mark it with a ritual. Such rituals need not be elaborate, they should be somewhat formal. During the last visit, for example, time was devoted to review what the family had shared and thank them for the time given to the study. Some families and their children requested to remain in contact with the researchers. Families saw them as researchers and nurses and now had come to see them as friends. To date, some study participants continue to communicate via written cards and voice mail messages to provide updates about their asthma status, school accomplishments, and family activities, especially birthday and holiday celebrations.

<Internals\\Double-checked\\Thompson and Russo 2012> - § 1 reference coded [0.34% Coverage]

Reference 1 - 0.34% Coverage

when Russo started the cystic fibrosis project, she had a view that segregation would be a negative experience and detrimental to the young patients and their families. However, recognition of this perspective allowed consideration of its influence on the emergent data which eventually led to a change in KR's perspective - as most people welcomed segregation despite the difficulties.

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Reference 1 - 1.08% Coverage

The initial research protocol for the Veronica Project stipulated an involvement of around 4 months. However, as the study progressed, that seemed not only too short to collect all the relevant data; it also seemed unethical to withdraw what had become, in many cases, a supportive presence. While we were always aware that the researcher was not a therapist or indeed a friend in the usual sense, with some people it was clear that the researcher could not suddenly end the relationship. Booth & Booth (1994) state that 'social researchers using biographical methods with vulnerable groups must be prepared to live up to this commitment or risk their field relationship becoming exploitative' (p. 419).

NVivo output file

Overarching theme: Connection

Theme 10: Manipulation

<Internals\\Double-checked\\Bland 2002> - § 2 references coded [3.36% Coverage]

Reference 1 - 0.66% Coverage

Kennedy (1999) describes wearing a uniform when undertaking fieldwork in a district nurse setting, as her status as a fellow professional was considered to increase the comfort of the patients concerned. Were residents more likely to talk with a nurse, or a researcher? And what if they didn't see me as either?

Reference 2 - 2.70% Coverage

WAS I A FRIEND? My relationship with the residents was some- thing that I thought about constantly. I enjoy the company of older people - this is a practice environment where I have always felt at home. One of the delights of this study was having time to just sit and talk with residents, to share in their stories and their lives, and not once having to think about the next medication round or the care plans waiting to be updated. Being a friend should have been easy, but in fact was a source of considerable personal discomfort. In line with the reflexivity needed as part of the ethnographic method (Marcus 1998) and my commitment to honesty in my dealing with others, I found myself constantly examining my motives for acting in particular ways. I needed some of the residents to agree to participate in the study in a more formal way, by consenting to take part in interviews that would be tape-recorded for later transcription and analysis. And for that they needed to get to know me reasonably well, and develop a sense of trust. So was I chatting with them simply because I enjoyed their company, or because I was trying to develop a relationship that would lead to their participation in my study? I struggled with the fact that often I could answer 'yes' to both questions.

Internals\\Double-checked\\Cartwright and Limandri 1997 WORD version> - § 1 reference coded [1.35% Coverage]

Reference 1 - 1.35% Coverage

Early in the data collection phase, the researcher experienced profound feelings of indebtedness to the informants. Total strangers, talking for hours at a time, were sharing intimate thoughts, feelings, and experiences. She felt a sense of imbalance at the one-sided giving that occurred, despite her belief that the study findings would benefit other caregivers. To minimize her feelings of overindebtedness, the researcher shared professional information, such as resources or tips on care; brought small gifts such as cookies to follow-up interviews; wrote thank-you notes; selectively shared personal information; and provided a listening ear when the participant wandered beyond the interview's purpose. These actions were consistent with Leininger's (1985) position that

strategies of reciprocal exchange help develop rapport and address the moral obligation of researchers to the groups they study.

<Internals\\Double-checked\\Clancy 2007> - § 1 reference coded [0.65% Coverage]

Reference 1 - 0.65% Coverage

However, as Carolan (2003) advocates, the experience of the clinician can help to build a strong and trusting relationship between the participants and the researcher. I was keen for this to happen during the research interviews as I wanted the participants to have a positive experience and benefit from their involvement.

Reference 1 - 0.61% Coverage

My role within the hospital did not include working with inpatients on the ward or their relatives. My professional responsibilities involved the treatment of those attending as day patients. Once discharged from the ward, the respondents did not become part of my patient caseload. Nevertheless, during the course of the study, the influence of my professional status became increasingly clear and was a necessary consideration with regard to many issues, one of which was that of consent.

<Internals\\Double-checked\\Gardner 1996> - § 5 references coded [8.31% Coverage]

Reference 1 - 1.08% Coverage

I suggest that this privileged position is not confined to the immediate nurse-patient situation, and is one that holds significant importance for the nurse researcher in the interpretive research endeavour, particularly in the area of the interview. The person who was once a patient, or may still be a patient in a different healthcare context, holds memory of the nurse-patient relationship and is often willing, if the situation arises, to grant a researcher who is a nurse a privileged relationship: an instant familiarity that results from a shared understanding of health, illness and the body.

Reference 2 - 1.99% Coverage

An added benefit to the establishment of this relationship is that it achieves what Patricia Benner referred to as a 'familiar communicative context' (p. 108).21 This is an interview situation that is close to the context of the situation of interest. Benner claimed that in the communicative context 'narrative memory and practical knowledge are solicited by our being in the familiar circumstances of performance'. The nurse-patient relationship provides this familiar context. In essence, when the nurse researcher becomes actively conscious of the Self as Nurse, she/he will use the language of nursing. This is a language of permission for the participant to adopt the patient

discourse which enables them to talk about what are for them embarrassing and intimate details of an illness experience. The result is a research context that is comfortable and familiar for the patient, and is based upon a sharing of information and experiences. In this way, an interview situation is established that builds upon intimacy and reciprocity, resulting in quality data and therefore quality research.

Reference 3 - 3.25% Coverage

L Monday night I was lying in bed and it burst in bed. And I couldn't wake Tony and I had to just ... all I had was some sanitary napkins to try and mop it all up, and I got up the next morning and I found some packing.

G What was it like when it burst?

L It felt like buckets came out Sorry.

G It's OK. So a lot came out, was it smelly?

L Oh it stinks, it still does stink, it was green. Very bloody at first and then green. And it's still green today. This T- shirt, I've only had this T-shirt on this morning and see the, mark? ... (pause) ... Did you say you were a nurse?

G Yes. Is that mark a stain from the discharge?

L Excuse me just a sec. Libby went out the back door and down the stairs. She came back moments later holding a garment in her hands. It was a white satin one-piece undergarment (teddy), cut high on the leg and trimmed with delicate white lace. As she held up the garment to me I could see a large greenish stain on the front. Our eyes met as the implications of this stain on this garment of sexual expression was communicated between us without words. Libby just said: 'See what I mean.' She went on to say:

L Now all my nighties are stained at the front because of it. I only put a packing in last night and this morning it stank. I could smell it, I could smell it walking round yesterday, getting out of the car going to people's houses I go, sniff [sic].

As we continued the interview I was aware that a shift had occurred. Libby was talking more about her body, her feelings and about the effect this event had on her life. The data up to this point were more factual, the story of her experience, the chronological events. Her first mention of the characteristics of the wound and the discharge was followed by an apology, 'sorry' as if she were offending me.

Reference 4 - 0.43% Coverage

Libby needed to check out the fact that I was a nurse before she was able to move into this discourse. With this interview I was more conscious of myself as a nurse researcher and so the transition to intimacy and reciprocation was seamless.

Reference 5 - 1.56% Coverage

These two examples demonstrate my progress as a nurse researcher during this phase of my fieldwork. In later inter- views the line between social science and nurse researcher is gone. As I became more certain about my method as a nurse researcher, I was able to enter the level of intimacy and comfort smoothly in response to the level of engagement set by the research participant. The participants felt free to talk about their

bodies; discharging bodies, ugly bodies, problematic bodies, bodies that simultaneously defied and resulted from advances in medical science. It is difficult for a social science researcher to access these and similar topics with this degree of freedom and intimacy. The nurse researcher is in a position to bring this added dimension to qualitative research practice through drawing upon the skills and privileges of nursing practice.

<Internals\\Double-checked\\Groenkjaer 2002 ethnography issues> - § 1 reference coded [3.28% Coverage]

Reference 1 - 3.28% Coverage

Many hours were spent working out how to present myself on the ward and what to wear. Was I a student, a nurse or a researcher? Should I wear a nursing uniform, student nurses' uniform or civilian clothing? In the attempt not to confuse staff or patients I decided, in consultation with the Clinical Nurse Consultant on the ward, to wear neat civilian clothing, such as dark pants and a Simple top, as I was not employed by the hospital. My university student identity card was worn at all times. I presented myself as a registered nurse and a Master of Nursing student. The emphasis was placed on the title as a nurse because being a participant observer would involve actual nursing practice on the same level as the nursing staff; 'I was one of them'. Registration was obtained through the Nurses Board of South Australia for the purpose of the study and I was therefore permitted to work alongside the nurses. However, since I was wearing different clothing than the nursing staff it was obvious that I had a different role, and the title of a Master of Nursing student was used to further distinguish me from other nurses. The word 'researcher' was seldom used when staff were introduced to the study and the purpose of m)' presence. This was not a deliberate choice. Rather, upon reflection, it seemed natural as I quickly became immersed into the culture, and therefore it would have been inappropriate to use the term 'researcher', even though the staff were well aware that I was present to collect data. Additionally, the setting was a 'real ward' and the 'academic' sound of the word 'researcher' did not seem to 'fit in'.

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Reference 1 - 0.70% Coverage

Feminists acknowledge that there is a power asymmetry that the researcher has to deal with in all research, and they seek strategies that allow the informants to assert power, achieve reciprocity, and in that way receive personal, unique, and honest answers to research questions (Oakley, 1993; Ribbens, 1989). Still, in the end it is up to the researcher to decide on interpretations and what to include in reports (Webb,1993). In our study, this hierarchy was reinforced by certain conditions characterizing the patient-doctor relationship—the patient being in a subordinate and dependent position (Davis, 1988; Meeuwesen et al., 1991).

Reference 2 - 0.61% Coverage

When Kej asked Sally why she did not refuse to go to pool training at once, she said, "It's like I just can't say no. I know that you want me to go there and that you think it's good...but if you only knew what I feel inside." According to Ribbens (1989), the empowerment of participants in research has limitations beyond the researcher: "While we may seek strategies to minimize power, groups without power more generally in society are not in a position to assert power over the research process either, which is the essence of vulnerability" (p. 590).

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Reference 1 - 0.93% Coverage

Influencing the Course of the Interview

Taken a step further, one or two participants raised concerns about the way they had "handled" some of their interviews and the impact such handling might have had on the research process. In other words, they were concerned about the way in which they might have influenced the course of the interview. For example, one researcher believed that by exploring people's experiences as a counselor, she was generating data that might not otherwise have been produced, either because it did not exist or because it was not of particular importance/relevance to the participant. I was sort of modeling myself on how I felt a counselor would be in that situation...so I was thinking "Is this what a researcher should be doing?" . . . and this became a methodological problem for me...I found I was exploring ideas with them . . . and I sort of felt I was putting ideas into their heads.

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Reference 1 - 2.92% Coverage

As a participating observer, she might have observed with her "nursing glasses" instead of "researching glasses," a situation that might have caused cultural blindness. This was probably the case at first, as it was difficult for her to develop any kind of distance from a situation she knew so well. She dressed like a nurse, and as she assisted the nurses in their work, she might at times have paid more attention to patient care than to research. In some situations, she also felt that keeping a researcher's distance placed her in an ethical dilemma with regard to the well-being of patients. Prior to this project, however, the researcher had also been a practicing teacher of nursing and, as such, was familiar with the clinical field; she had also studied the literature on education. Being a teacher certainly enhanced her understanding of nursing as a practice. Hence, her prior experiences could have caused her to be blind and seeing at the same time. Although the blindness might come about as a result of her familiarity with the nursing culture—from her being an insider—her ability to see might have been enhanced by her

life as a teacher or by the fact that she was an outsider. At one point when the researcher assisted a nurse in caring for a patient, she was surprised by the way the nurse performed this chore. According to her "teacher" eyes, the nurse attended to the patient's personal hygiene in a way that was not in accordance with accepted hygienic principles. On noticing this, she realized that this practice was quite common in the unit, a fact that she probably would not have recognized without her experience as a teacher.

<- § 1 reference coded [1.91% Coverage]

Reference 1 - 1.91% Coverage

The GP researcher also began to allow herself to respond to direct personal questions from interviewees at times, realising that reciprocity could enhance rapport. She always informed participants during the interview preamble that she was both a GP and a lesbian woman. Kirsti, a bisexual woman, referred to this knowledge during her interview:

Kirsti: Do you worry about the fact that you are a lesbian doctor and people might be worried about that when you examine them or something? Has that occurred to you? Interviewer: It has occurred to me as a boundary issue. In fact I attend lesbian doctor conferences where we all meet together to talk about these things.

Kirsti: And do you tell your patients that you are lesbian?

Interviewer: I work in a practice that is for gay and lesbian patients, so I am often asked by patients whether I'm lesbian and if I am asked I tell them. If I am not asked I don't tell them.

This exchange during the middle of the interview assisted Kirsti to become more open and reveal her own feelings about seeing GPs.

<Internals\\Double-checked\\Newbury 2011> - § 2 references coded [1.22% Coverage]

Reference 1 - 0.63% Coverage

When examining the ethical background to my study, I was aware of the potential vulnerability of the carers. Their vulnerability could lead to exploitation, with carers agreeing to participate in research because they feel obliged, out of gratitude, to please me or because they think that declining my request will affect the quality of professional care they or their family member receive (Richards and Schwartz 2002, Lee and Kristjanson 2003).

Reference 2 - 0.59% Coverage

the feminist interviewer, showing empathy towards the participant, might gain a good rapport and the interviewee might explore and reveal more of her intimate experiences and emotions than she might have wished. Although some carers may have revealed more than they had anticipated about their experience and their emotions, I do not think that I manipulated them into disclosure by being too intimate or faking friendship.

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Reference 1 - 1.11% Coverage

I decided to wear street clothes (no lab coat) and a name tag. The name tag indicated that I was a registered nurse and a graduate nursing student. I did not want to be confused with the nursing staff who provided the direct care to the residents. I hoped my attire would facilitate interactions and the development of trusting relationships with the residents and staff.

Reference 2 - 1.64% Coverage

Reciprocity emerged within our relationships. On one level, the staff and residents would invite me to various social functions. Generally I attended the social functions with my children. The residents enjoyed interacting with them, and the presence of children in the nursing home was always welcomed by the residents. The director of nursing shared anticipated changes within the nursing home that might be of interest to me or perhaps influence my research. I offered copies of journal articles that might be pertinent to resident care.

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Reference 1 - 0.69% Coverage

Participation and cooperation of ward staff was unpredictable and could change over time depending on individual ward staff and wider organizational issues. A strategy deployed by all CRNs to overcome these difficulties was to help out in the ward areas. By doing so the CRNs felt that they gained the co-operation of the ward staff: We would call it diplomacy but it's just manipulating things! If you go and do the [systemic] observations on a ward for them, they do the skin text [trial data]. And I'm [helping out] to get the skin text. And I'm not doing it to help them out! (CRN5)

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Reference 1 - 0.86% Coverage

For the clinical psychology researcher there maybe organisational or academic demands and for the participant (particularly where there is a dual relationship) there may be a sense of duty. For clinical psychologists who undertake research in their area of expertise, it is likely that past or current patients will fulfil the research inclusion criteria. Russo faced this dilemma during her segregation research. Excluding these potential participants would have removed the opportunity for them to have their say about their experiences, and would have effectively silenced those that were struggling

with segregation, the very issue that was being researched. However, Russo was mindful of not taking advantage of the therapeutic trust that had developed in her clinical role for research gain. Russo found supervision to be essential to explore these issues, and careful exploration of roles, boundaries, and confidentiality was required to ensure informed consent.