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Responding to Poor Quality Care during Research in Nursing Homes

Melanie R. Krause, MS, RN[Dissertator],
University of Wisconsin-Madison, School of Nursing

Janice L. Palmer, PhD, RN[Assistant Professor],
Saint Louis University, School of Nursing

Barbara J. Bowers, PhD, RN, FAAN[Helen Denne Schulte Professor and Associate Dean for Research], and
University of Wisconsin-Madison, School of Nursing

Kathleen Coen Buckwalter, PhD, RN, FAAN[Sally Mathis Hartwig Professor of Gerontological Nursing Research and Director]
John A. Hartford Center of Geriatric Nursing Excellence University of Iowa, College of Nursing

A 2001 congressional report entitled, *Abuse of Residents is a Major Problem in U.S. Nursing Homes*, found that over 30% of U.S. nursing homes were cited for an abuse violation during inspections between January 1, 1999 and January 1, 2001 (U.S. House of Representatives, 2001). The report also found that over 9% of all U.S. nursing homes during that period were cited for abuse violations that caused actual harm or placed residents in immediate jeopardy. The actual prevalence of nursing home resident abuse is likely even higher due to underreporting (Hawes, 2003; McCool, Jogerst, Daly, & Zu, 2009; Peduzzi, Watzlaf, Rohrer, & Rubinstein, 1997). Due to the widespread nature of abuse of nursing home residents (Hawes), there is potential for researchers to directly observe or indirectly learn of resident abuse while conducting research in nursing homes.

Many states have mandatory reporting laws for nursing home resident abuse and neglect. Responding appropriately to witnessed resident abuse is straightforward. The abuse must be reported. That is, even in the role of researcher, nurses are typically required to report any activity that meets the state's definition of abuse, although the definitions of reportable abuse vary from state to state. In a study of nursing home employees, McCool et al. (2009) found that one reason for not reporting suspected abuse was difficulty in knowing if the mistreatment of the resident was severe enough to be considered reportable. As definitions of reportable abuse vary from one state to another, it is important for nurse researchers to familiarize themselves with the definition of abuse in the state where they are conducting research. For a listing of state government agencies, state laws, and statewide abuse related resources, see:

http://www.ncea.aoa.gov/NCEAroot/Main_Site/Find_Help/State_Resources.aspx.

Responding to care that is of poor quality, where care practices are problematic, but do not meet the definition of reportable abuse, is not so straightforward. Given the extent of reportable abuse, it is reasonable to expect that witnessing poor quality care might not be a rare occurrence. Examples of such care practices include those that are not responsive to

individual resident preferences or requests, long delays for care, and lack of compassion. Should researchers witness these problematic care practices during their research, they face an ethical dilemma about whether, how and when to respond. Depending on the situation, nurse researchers might also be faced with deciding whether to continue the research. This decision will be influenced by ethical and professional principles as well as a high level of self-interest to complete the research project. The purpose of this article is to provoke a dialogue about a dilemma faced by many researchers conducting research in long term care--responding to poor quality care that does not meet the state's definition of resident abuse. We will do this by illustrating a real life situation faced by a novice researcher conducting her first funded research project, identifying some of the important considerations and possible responses by nurse researchers. A secondary purpose of this article is to prompt additional dialogue about this important issue, actions that could be taken, and the implications of the actions, ethical and otherwise.

A Case Study of Poor Quality Care in a Nursing Home

A nurse researcher conducting a study about certified nursing assistant (CNA) work in long-term care had already interviewed several CNAs and was in the process of conducting field work. The field work consisted of spending several shifts shadowing and being 'schooled' by the CNAs about what it was like to work in the nursing home. The researcher sensed that she had started to blend in with the CNA staff, since they began treating her as 'one of them' and talked openly about their personal lives and about the nursing staff. The CNA being shadowed on that particular day had described, very proudly, during a prior interview how hard she worked and how well she treated all the residents she cared for. She described herself as compassionate, caring, and a very good caregiver. During this shift, the CNA began speaking quite harshly to a new resident. She told the man, sharply, to 'roll over' so she could pull a sheet out from under him, then turned to the researcher and described how this resident had soiled himself. The man, who was evidently very embarrassed, began to cry. The nurse researcher noted that the door to his room was open and that several staff in the hallway, including the nursing supervisor and the charge nurse, overheard the CNA. A few looked in her direction. The charge nurse and nurse supervisor looked over at her, listening to what she was saying. However, when the CNA was finished, the nursing supervisor resumed her conversation with the charge nurse as if nothing unusual had happened. Believing that this incident did not fit the state's definition of reportable abuse, the researcher was uncertain of the best way to proceed.

According to some state laws, the case study above would clearly meet the definition of reportable (verbal) abuse, and the appropriate response in that situation would have been for the researcher to report her observations to the appropriate state agency. However, under other state laws, the CNA's actions would not have constituted reportable resident abuse, even though those actions were highly problematic. It is not the purpose of this article to debate the legal definitions of abuse but, rather, to discuss the different options for responding to care that is of poor quality, that which makes the nurse researcher uncomfortable but does not constitute reportable abuse. If the case study presented above makes readers uncomfortable, we invite them to substitute a different scenario for the purposes of this discussion.

Knowing How and When to Intervene

Kayser-Jones, Beard and Sharpp (2009) acknowledged struggling with when and how researchers should intervene in cases of poor quality care. In addition to the concerns for residents, researchers will ideally proceed in a way that allows them to continue the study. Krebs, Denton and Wark (1997), suggest that this will often "involve promoting good social

relations, upholding favorable self-concepts and justifying self-interested behavior” (p. 131). In the case study presented above, the researcher was left trying to balance a high level of self interest (e.g. a desire to move forward with the study) with a commitment to ethical responsibilities as a nurse. It is important to acknowledge the difficulty created by this dual role. In the words of Mayo and Wallhagen (2009):

Role confusion can...be problematic for investigators. The nurse's role is to preserve the patient's health, whereas the investigator's role is to pursue scientific knowledge. In the investigator role, the nurse will act to protect the participant from harm, but the focus is not the delivery of nursing care (p. 108).

The response options presented later reflect an attempt to balance these roles.

When possible, a priori planning for responding to observations of poor quality care will enhance the likelihood of protecting vulnerable nursing home residents, successfully completing the study, and preserving the setting for subsequent studies (Maas, Kelley, Park & Specht, 2002). Having a plan in place for observations that may occur before learning of poor quality care minimizes the ambiguity of the situation and guides the researcher's response in a timely manner.

The researcher's human subjects' protection board and legal department may be able to provide helpful insights for developing a plan about responding to poor quality care. In terms of IRB involvement, according to 45CFR46.111, the IRB must approve that the research plan makes an adequate provision for monitoring the data collected to ensure the safety of subjects (IRB Review of Research, 2005). Therefore, especially when the subject of the research is an elderly nursing home resident, the IRB will be involved in ensuring that there is an adequate plan in place for responding to poor quality care. The IRB can also assist researchers to develop clauses to discuss limitations in participant confidentiality. For example, a researcher might add a clause such as, “Any information from this research that personally identifies subjects will not be voluntarily released or disclosed without consent, except as specifically required by law.” The legal department can help researchers to better understand those situations by which confidentiality must be breached as required by law, such as mandatory reporting of abuse.

The response options discussed below could be seen as important components of a plan for responding to poor quality care. For example, Kayser-Jones included in her research proposal to study the care of terminally ill residents in nursing homes, that research team members would intervene in situations of inadequately treated pain (Mason, 2009; Kayser-Jones et al., 2009). Kayser-Jones did intervene, but only when she ethically as a nurse and personally felt that she had no other option. Other actions that she took included providing pain assessment tools, directly instructing nurses to call doctors for pain medications, and taking fresh fruit to dying patients. In her recent article entitled, *Dying with a Stage IV Pressure Ulcer*, Kayser-Jones (2009) wrote of her personal struggles with knowing when to intervene versus the importance of the potential findings of her research observations. Intervening every time she observed poor care would likely have altered her conclusions. She also noted that after years of experience, much thought on the topic, and consultation with others, she has determined that “it is more important for me to be able to continue to collect and report data that could have a wide impact than to try to improve care on a case-by-case basis” (p. 42). Kayser-Jones' frank discussion of her struggles related to this topic highlight the timely relevance of ongoing discussion on this topic.

Response Options

When poor quality care that does not meet the state's definition of resident abuse is observed, there are several potential response options, including doing nothing, informing upper level management or the worker's supervisor, and delaying action. Each of these response options has implications for the nursing home resident and staff as well as for the researcher.

Do Nothing

Regardless of the study focus, a direct response by the researcher at this time could alter the reports of other staff members, alter her relationship with the staff, or modify staff behaviors in the researcher's presence. This could negatively affect the integrity of the research. Therefore, out of self-interest, researchers may feel pressured to not act on an observation of poor quality care. However, by not responding to poor care, the researcher could contribute to lengthening the time until identification and remediation of care problems or to the perception that the care is acceptable.

Inform Upper Level Management or the Worker's Direct Supervisor

When concerns about resident care arise, an important first step may be to report this to a nursing manager, Director of Nursing, or Administrator. This action may be required by the nursing home's administration, the researcher's IRB and the researcher's plan for responding to poor quality care, especially if residents are participants in the research. Researchers may choose or be required to report the incident using generalities or aggregate data. Conversely, if staff are the participants in the research, this option would likely not be available to the researcher as it would expose the worker to potential harm, which would likely violate the IRB protocol to protect subjects. As the CNAs are the subjects in this study, the IRB would be committed to protecting the workers. Although abuse would no doubt be exempt from such protection, poor quality care may not be.

If the researcher elects to inform upper level management of a concern, the management team may elect to take no action or to take action at the facility level (e.g. staff inservice or change to policy and procedures). An advantage of informing upper level management is that it raises awareness of the researcher's concerns to someone who could continue to try to resolve the potential care problem even after the end of the study. A potentially serious drawback to this approach is that management could react negatively to the researcher's concerns, thus endangering future research endeavors by the researcher and others at the nursing home. Additionally, if the researcher identifies specific individuals, staff and/or residents may feel that their confidentiality has been violated. This could be potentially avoided by clearly describing the researcher's reporting requirements in the proposal and consent form and discussing the procedure a priori.

Delay Action

The researcher could elect to delay taking action. Delay might be an appropriate response if the researcher believed the poor care did not equate to reportable abuse and that speaking with staff or upper level management would not result in appropriate action and would only serve to detract from the relationship between the researcher (or other researchers) and the study site. However, this could also make the situation worse by delaying identification and remediation of poor quality care. Three options for delaying action include collecting additional information, providing staff training and filing a report with the local ombudsmen or care review committee (ombuds).

Collect Additional Information

The researcher could elect to postpone deciding whether or how to respond and collect additional data about what happened. This might be an appropriate response option if, for example, the researcher was unclear about what if anything actually happened between the resident and the staff person. By taking this approach, the researcher might also be able to determine whether what she saw was poor quality care and whether this was an isolated event, a pattern by an individual, or a facility pattern. This information could then guide subsequent actions by the researcher.

Speak with the resident—Prior to making a decision about whether or how to respond to concerns about resident care, a researcher may find it useful to talk with the resident. One might begin this conversation by stating what was seen or heard, then asking for the resident's opinion about what happened. By choosing this approach, the researcher might also gain important information about whether the resident feels unsafe as well as the frequency or intensity of poor care. Residents may, however, be unlikely to report poor quality care for fear that such reporting may have negative consequences, such as retaliation (Hayley, Cassel, Snyder & Rudberg, 1996). Additionally, a resident could acknowledge being poorly treated, but request that this not be disclosed to anyone else. Also, the research protocol may prohibit directly interacting with residents since they may not be identified as research participants and therefore have not consented to participation. In that case, speaking with residents about any perceived poor care that was not reportable abuse would violate the study protocol creating a different set of ethical problems.

Speak directly with involved staff—There are many staff members with whom the researcher could elect to speak, including the CNA in question. Who the researcher speaks with will depend, at least in part, on the protocol, IRB policy and the terms described in the consent form. The researcher might use his or her relationship with the CNA to explore whether poor care occurred. An advantage of speaking directly with the involved staff person might be that the researcher could find that this does not reflect usual behavior, rather unusual stress from some source, including possibly having a researcher follow them. An important disadvantage could be that the CNA could become angry or defensive, disrupting the rapport that had been established previously.

If the researcher elected to discuss the observation with the CNA, care should be taken to raise this sensitive issue in a manner that was neither accusatory nor inflammatory. There would be several important considerations in approaching a busy staff member, including timing, how to summon the staff member, and what to say. The best time to approach the staff person may be during a break or immediately after the behavior in question is observed. Another consideration might be how best to summon the staff member, so as to be non-threatening and non-judgmental. One approach might be to speak with the CNA in as private a space as possible, so as not to intimidate or embarrass them. For example, the researcher could say:

“(Staff name), do you have just a minute to talk to me? Let's go into the (select a private location where conversation will not be overheard). I need you to help me better understand what happened in (resident's name) room.”

If the staff member does not address the researcher's observations, the researcher could ask additional probing questions, such as, “It seemed like you got upset because Mr. Jones soiled the bed. Tell me what was happening.” This approach may help to elicit responses such as, “Well, yelling is certainly not bad care. And besides, he's hard of hearing.” Or, “I told you what I thought you wanted to hear”, or even, “I was afraid to admit I yell at residents when they upset my routine. I thought you would report me to the Director and I

would lose my job.” In some instances the researcher may have actually misinterpreted observations, coming to an incorrect conclusion about the quality of care. To avoid confusing the role of the researcher in the nursing home, researchers may need to forgo talking to staff on these issues, except as agreed upon with nursing home administration as part of the plan for responding to poor quality care. For example, Kayser-Jones' (2009) proposal included plans for notification of nursing administration of concerns regarding patient care that arose during her study. However, there were times that she was instructed by the Director of Nursing to speak directly with the involved staff member.

Provide Staff Training

With the permission of facility administration, the researcher could also choose to offer staff training sessions to address the concerns about resident care without singling out specific participants. There are at least five potential benefits of offering training sessions. Staff training sessions have the potential to: (a) raise awareness about quality of care, (b) change practice within the nursing home, (c) promote open relationships with the staff, (d) protect confidentiality for both staff and residents, and (e) foster future collaborative relationships with the nursing home. Past research has demonstrated that training can be useful for reducing quality problems and improving staff-resident interactions. One study demonstrated that staff training is effective for reducing the frequency of self-reported abusive actions toward residents (Pillemer & Hudson, 1993). Several studies have found that training of nursing home staff, including nursing assistants, can have a positive impact on communication with older adult care recipients, thus improving the nature of the interaction between staff and residents (Bourgeois, Dijkstra, Burgio & Allen, 2004; Burgio, Allen-Burge, Roth, Bourgeois, Kijkstra, Gerstle, et al., 2001; Stevens, Burgio, & Bailey, 1998; Williams, 2006).

File a Report with the Local Ombudsmen

Researchers may also consider sharing their concerns with the local ombuds. The ombuds is a required, state-level advocacy group for consumers of long-term care. Responsibilities of the ombuds include investigating complaints and protecting the rights of nursing home residents (Vladeck & Feuerberg, 1995). Complaints may be made anonymously. The ombuds may provide a helpful alternative to directly acting on quality problems when the researcher is concerned that his or her interventions may not have the desired effect. After conducting an investigation, the ombuds may make referrals to state agencies and/or specific recommendations to the facility.

Implications for the Study

When writing manuscripts about their studies, researchers may need to consider how to describe the response to poor quality care if it is questionable as to whether the data collected subsequently were conflicting or impacted by the researcher's response. Responding or intervening during data collection will likely affect the way staff behave during subsequent field observations. Instead of considering the data as problematic or invalid, the researcher could embrace all of the data as findings and probe more deeply to better understand care in the nursing home. For example, Kayser-Jones (2002) noted discrepancies between ordered care, interview data, and her observations of malnutrition, dehydration and starvation in the nursing home. Her seminal work led to important discussions of the seriousness of the problem in the media and by policymakers. Eventually, Kayser-Jones' research was used to influence nursing home policy and therefore potentially impact care for many nursing home residents.

Conclusion

When possible, a priori planning of methods for coping with observations of poor quality care will minimize the ambiguity of the situation and guide the researcher's response. The optimal response by researchers to poor quality care may involve one or multiple (or none) of the response options discussed. Ideally, the researcher's plan for responding to poor quality care would be developed in concert with individuals from the researcher's legal department, IRB and other stakeholders, such as the administrator or director of nursing from the study site(s), before the study begins. This information can then be integrated into the proposal and consent process, further reducing any ambiguity over whether and how the researcher should respond to poor quality care.

Although researchers have a moral and ethical obligation to respond to poor quality care, they also have an obligation to ensure that they do not close off important study sites and key respondents for other researchers or create a situation that results in unintentional harm to a resident. If staff, management, or resident respondents feel betrayed by the researcher or the research process, they may prematurely end their participation and/or prohibit future investigators access to the facility, employees, and residents. We have explored important considerations and possible response options for researchers who identify poor quality care that does not qualify as reportable abuse during a study. In order to stimulate dialogue on these important issues, we invite readers to respond to this article with their own perspectives on how the researcher should have responded to the real-life situation portrayed in the case study and to support, refute, or suggest alternative responses to those set forth in this article.

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