Advances in Nursing Science
Vol. 27, No. 2, pp. 117–128

Methodological Issues Associated With Studying an Illegal Act
Assisted Dying

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The experience of receiving patient requests for assistance in prematurely ending life can represent both an ethical and legal dilemma for nurses in the United States. Similarly, the study of nurses' involvement with such a sensitive topic also poses risks to the study participants, the researcher, and the nursing profession's covenant with society. The purpose of this article is to explore methodological issues and approaches associated with studying an ethically and legally sensitive issue, and to describe application of these approaches to a study of oncology nurses' experiences with receiving requests for assisted dying from terminally ill patients with cancer. **Key words:** *assisted dying*, *ethics*, *illegal act*, *oncology*, *research methodology*

THE experience of receiving a patient request for assistance in prematurely ending life can represent both an ethical and legal dilemma for nurses in the United States, where the right to personal control over the timing and circumstances of one's death remains a controversial issue. Public opinion polls reveal that that most adults favor the right of terminally ill people to euthanasia and physician-assisted suicide.[1] Yet public opinion is at odds with the legal and ethical status of these practices. Euthanasia is illegal in every state; physician-assisted suicide is legal only in Oregon. Furthermore, many professional organizations have published position statements or codes that oppose euthanasia and physician-assisted suicide.[2–5] Survey research findings show that nurses do receive such requests and have prematurely ended terminally ill patients' lives. In Asch's[6] study of 852 critical care nurses, 164 (20%) acted on requests from patients or family members for assisted suicide or euthanasia by hastening patients' deaths. Matzo and Emanuel[7] reported that 30% of their sample of 441 oncology nurses had received requests from patients for assisted suicide; 20 of their respondents admitted to injecting drugs to end a patient's life intentionally. Because little is known about the context of these experiences or the ways in which nurses respond to this ethically troubling situation, research is necessary. Because of the sensitive nature of this topic, the design of such a research study warrants careful consideration.

In all research endeavors, the protection of study participants is paramount. When studying ethically or legally sensitive topics, the investigator must be especially cognizant of all issues that may impact study design. Lee and Renzetti[8] described sensitive research topics as those that pose a substantial threat to the researcher or the researched. Threat may arise because the topic explores an area of social deviance, impinges on powerful social interests, or examines a deeply personal, sacred

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The study cited in this report was supported by an Oncology Nursing Society Foundation grant.

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value held by study participants. The behavior under study is likely to be "intimate, discreditable, or incriminating."[8(pix)] Examples of socially sensitive topics include illegal drug use, domestic violence, alcohol use during pregnancy, and whistle blowing. Because of the potential negative consequences of study participation, research focused on a sensitive topic must be designed with special attention to participant recruitment, data collection, and dissemination of study results.

Issues involving the design of socially sensitive research have been discussed in a wide variety of literature.[8–16] But no information was located on design issues specific to studying an illegal action committed by health care professionals within the context of the professional-patient relationship. Hence, the purpose of this article is to (a) describe methodological issues and approaches associated with studying an ethically and legally sensitive issue, and (b) describe application of these approaches to a study of oncology nurses' experiences with receiving request for assisted dying from terminally ill patients with cancer. (See Table 1 for definitions of terms used in this article.)

METHODOLOGICAL ISSUES AND APPROACHES

Sieber[18] recommended that risks or potential for harm be carefully assessed and anticipated during the planning phase for any study and that "all feasible steps be taken to minimize risk and maximize acceptability."[(p15)] In a study of illegal professional behavior, the potential for risk exists for study participants, the researcher, and society. Once risks are identified, study design decisions can be made to mitigate risk.

Participant risks

The protection of participant privacy is the predominant issue in studying nurses' responses to patient requests for assisted dying. Because of the ethical and legal sanctions against assisted suicide and euthanasia, nurses who reveal personal involvement in assisted dying risk loss of professional licensure, legal actions, imprisonment, and social ostracism. Given these risks, potential study participants may be reluctant to disclose any experience with assisted dying. Nurses' reluctance to participate in ethically sensitive studies has challenged researchers who have studied assessment of patient abuse,[10] effects of professional discipline on nurses,[19] and the experience of head nurse stress.[20] Although these studies addressed sensitive topics, none encompassed illegal activities.

Typically, a researcher addresses the issue of privacy by promising to maintain participant confidentiality within the mechanism of informed consent. As an additional protection, an Institutional Review Board (IRB) may waive the requirement for a signed consent form. However, researchers can be subpoenaed by judicial authorities and legislative bodies, and ordered to disclose information

Table 1. Definition of terms

Assisted suicide: Making a means of suicide available to a patient (eg, providing pills, weapon) with knowledge of the patient's intention. The patient who is physically capable of suicide subsequently acts to end his or her own life.[4(p1)]
Active euthanasia: Someone other than the patient commits an action with the intent to end the patient's life, for example, injecting a lethal dose.[3(p1)]
Assisted dying: Any provision of aid to intentionally end life, including assisted suicide, active euthanasia, advising a patient about specific strategies or available resources for ending one's life, assisting the patient with accomplishing suicide, or refraining from interventions to prevent or dissuade the patient from taking his or her life.[17(p40)]

about research participants and information obtained within the context of a study. For example, DiFranza et al[21] published a study suggesting that cigarette advertisements featuring the cartoon character, "Joe Camel," are recognized by young children and influence purchasing choices by teenagers who smoke. All related study files and data were subsequently subpoenaed by R.J. Reynolds, manufacturer of Camel cigarettes.[22] Because Reynolds was embroiled in a civil lawsuit alleging that Joe Camel T-shirts and other paraphernalia were distributed without the US surgeon general's warning about smoking, the company sought confidential information about DiFranza's study participants. Other examples involving subpoena of research data include civil lawsuits by manufacturers of breast prostheses and diethylstilbestrol.[23] In all 3 cases, however, the study participants were not involved in criminal activity.

The potential for subpoena of study data that contains participant identity must be considered when planning a study design involving nurses and assisted dying. If participants disclose involvement in an illegal act, both state licensing authorities and criminal prosecutors could seek information regarding the nurses' identities in order to pursue punitive actions. In a study of processes used by nurses to live with the dying, Maeve[24] anticipated potential disclosure of "rule bending" regarding titration of pain medication outside of a physician's prescribed parameter. Although Maeve expected this type of professional judgment to be supported by the Colorado Nurse Practice Act, she presented her proposed research and informed consent process to the Colorado State Board of Nursing, who offered no objections. However, Maeve informed both the Board and her participants that reportable incidents such as acts that represented serious bodily harm or death would be reported. A study focused on intentional acts of hastening death would likely invite scrutiny from licensing authorities if participant identity is known. Thus, in addition to protecting study participants from such harm, a study design must also consider the risk that disclosure of identity can have on participant recruitment efforts.

Researcher risks

The researcher's risks are similar to participant risks, including loss of professional licensure, legal actions, imprisonment, and peer ostracism. If a researcher is aware that a nurse engaged in an illegal action such as AS or active euthanasia, does this knowledge obligate the researcher to report the act to legal and professional licensing authorities? The answer to that question lies within state statutes that govern professional nursing practice. For example, the Texas Board of Nurse Examiners[25] Standards of Professional Practice state that the registered nurse must comply with all federal, state, and local laws relevant to one's current area of nursing practice. Further, failure to report violations of the Texas Nurse Practice Act or associated rules constitutes unprofessional conduct. Hence, failure to report a nurse who reveals assisting a suicide (felony) or engages in euthanasia (homicide) is a violation of state law. Both civil and criminal charges could be levied against the nurse researcher who has knowledge of these illegal activities yet refuses to reveal the identity of an involved nurse.

Researchers also run the risk of imprisonment for failure to comply with court orders to supply participant data. For example, ethnographer Scarce[26] was imprisoned for 5 months after refusing to reveal the content of research interviews conducted as a part of a study of the radical environmental movement. In this instance, the researcher was asked by a grand jury to reveal whether he had interviewed individuals accused of engaging in illegal activity. He unsuccessfully argued that revealing such information would break his promise of confidentiality to his participants, violate his professional code of ethics, and preclude future employment opportunities as a researcher. Scarce concluded that there are 3 potential scenarios in which researchers should anticipate potential imprisonment: (a) if participants engage in illegal activity in the

researcher's presence; (b) if participants describe past activity that is illegal, or (c) if the research becomes a component of a legal action and the researcher refuses to testify.[26(p128)]

Certificates of confidentiality

Although threat of imprisonment should not prevent research on sensitive topics, studies must be designed to prevent such threats from becoming realities. Indeed, a researcher must carefully evaluate the risks one is willing to take to advance our understanding of nursing practice. In addition to the usual process of informed consent, a strategy that can reduce both participant and researcher risks associated with the study of a legally sensitive topic is the US Federal Certificate of Confidentiality.[14] If a socially sensitive study is designed such that the researcher must know the identity of participants, use of a certificate of confidentiality may be warranted. Issued by the National Institutes of Health, this certificate helps researchers to protect the privacy of participants in research projects by preventing involuntary disclosure mechanisms (eg, subpoenas) used by others who seek participant identities and study data. Specifically, federal law specifies that the certificate of confidentiality

> May authorize persons engaged in biomedical, behavioral, clinical, or other research (including research on the use and effect of alcohol and other psychoactive drugs) to protect the privacy of individuals who are the subject of such research by withholding from all persons not connected with the conduct of such research the names or other identifying characteristics of such individuals. Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals.[27]

Presumably, the certificate provides the researcher with the ability to assure a potential study participant that one's identity will be kept confidential.[28]

Table 2[29] outlines types of projects both eligible and not eligible for certificates of confidentiality. Examples of study topics that have used the certificates include battered women,[30] alcohol use during pregnancy,[31] genetic testing,[32] and violence.[33]

Although certificates of confidentiality have been used successfully in a variety of situations, they do not provide absolute protection against divulging a study participant's identity. Certificates are granted on the basis of individual review and may not be issued depending on the guidelines used by the review body within National Institutes of Health (NIH). Review time for each application may be lengthy and significantly delay the research project. Also, there is

Table 2. Eligibility criteria for federal certificates of confidentiality.[29]

Projects eligible for a certificate:
- Studies that collect information on HIV, AIDS, other STDs, sexual attitudes, preferences, or practices, alcohol use, drugs, or other addictive products, illegal conduct, or any other information that could lead to social stigmatization or discrimination
- Studies that collect information that, if released, could be damaging to participant's financial standing, employability, or reputation
- Research on psychological well being, mental health, biobehavioral interventions, and epidemiologic studies
- Genetic studies

Projects not eligible for a certificate:
- Projects that are not research-based
- Projects that are not approved by an IRB
- Projects that do not collect sensitive, potential harmful, or personally identifiable information

ambiguity regarding the range of situations covered by certificates of confidentiality. Questions arise regarding the researcher's legal mandate to report situations such as child abuse, partner abuse, suicidality, and homicidality.[34–36] In addition, a certificate of confidentiality is designed to protect the researcher from forced disclosure of a participant's identity; it does not protect the study participant from a researcher's choice to report *voluntarily* an illegal action. Indeed, federal guidelines require that participant consent forms include information about the protections offered by a Certificate of Confidentiality and that they do not prevent voluntary disclosure of participant identity by the researcher.[28] It is vital for a researcher to consider which actions one will not voluntarily disclose and actions that will be reported to authorities. These decisions must be explicitly discussed with potential participants within the informed consent process. Although researchers may intend initially to protect participant identities, they may learn of illegal actions that cause them to rethink this stand. For example, what if the researcher learns that a nurse has engaged in multiple acts of active involuntary euthanasia in which neither patients nor families have requested such action? Such individuals, labeled as "angels of death" by the popular press, may cause researchers to reconsider their promises to maintain confidentiality. Hence, the certificate of confidentiality may not be an optimal choice for protecting participants and researchers in a study of assisted dying.

Only one study of assisted dying (specifically, physician-assisted suicide) that cited use of a certificate of confidentiality was located.[37] In this ethnographic study, 20 physicians from California and Washington were interviewed about their experiences with receiving patient requests for a prescription for a medicine to help end life. Data collection for this study was done in 1997. Subsequent actions by the federal government cast doubt on whether the NIH would be allowed to continue to sanction such protection for a study of assisted dying. For example, shortly after Oregon legalized the practice of assisted suicide, the US House of Representatives initiated an attempt to revise the Controlled Substances Act (CSA) to allow the Drug Enforcement Agency (DEA) to revoke DEA registration of any physician who prescribed controlled substances for assisted suicide. Although this attempt was blocked by then-Attorney General Janet Reno, Attorney General John Ashcroft issued a subsequent directive stating that prescribing a lethal medication was contrary to the CSA.[38] The state of Oregon successfully challenged this directive in a district court; the case is now under appeal.[39]

Another concern about usefulness of a certificate of confidentiality is the potential for Food and Drug Administration (FDA) involvement. Although the certificate normally provides for confidentiality, data protected by a certificate may be required to be disclosed to the FDA as required under the Federal Food, Drug, and Cosmetic Act.[29] Hence, even if a certificate were obtained, study participants would have to be told that absolute confidentiality could not be guaranteed. In sum, the potential for FDA or other governmental interest could have a chilling effect on participant recruitment.

Anonymous data collection

Given that a certificate of confidentiality does not confer absolute protection of study participant identity, an anonymous data collection process is an alternative to minimizing participant and researcher risks. The advantage of this approach is obvious: because the researcher cannot link the story to a specific participant, there is no apparent risk that compelled disclosure will result in adverse consequences. Nurses who might otherwise decline to participate due to risk of exposure, embarrassment, or shame, might be more open to telling their stories if they remain anonymous to the researcher. Methods of anonymous data collection could include interviews of participants who do not reveal

their identities to the researcher and participant submission of written accounts of their experiences.

Interviews of anonymous participants can be obtained via "in person" interviews or via electronic interview via the Internet. Personal interviews pose a challenge because recruitment and interview processes must make the study known to potential participants and provide a means for participants to speak with the researcher, all without the researcher having any knowledge of the participant's identity. This could be accomplished via recruitment flyers posted during a professional conference and provision of a private room at that conference for potential participants to be interviewed by the researcher. Participants would be asked to remove name badges or any other personal identifying information prior to entering the interview room. Of course, an exclusion criterion for participation would be any previous contact with the investigator. Although this data collection process provides for an anonymous interview format, it relies on having a sufficient number of conference attendees who have received requests for assisted dying and do not know the researcher, and a willingness of the attendees to take time away from other conference activities. Despite the anonymous format, participants may still be reluctant to reveal their engagement in unethical or illegal activity to another nurse.

The Internet provides another possible means for "electronic interview" of study participants. Use of the Internet as a data collection tool assumes that a sufficient number of potential participants have access to the Internet and are comfortable using this technology. Although electronic mail or live chat venues provide for electronic dialogue between participant and researcher, this approach does not allow the researcher to observe the nonverbal component of the interview process. However, Web-based data collection may yield more information on socially sensitive topics than more traditional methodologies because participants may assume that their responses are more anonymous or secure.[40] Yet this assumption may be erroneous, as preservation of participant confidentiality cannot be guaranteed. Frankel and Siang[41] note that confidentiality can be breeched during Internet-based data transmission and storage. Although the process of encryption (translation into an encoded message) may be used to protect responses, it cannot protect a participant's Internet Protocol (IP) address. Analogous to a personal phone number, an IP address identifies a particular computer on the Internet. Hence, an unscrupulous person could ascertain a participant's IP address (which leads to personal identity) and then its association with an Internet site used to obtain socially sensitive information.[40] Confidentiality could also be compromised if research participants use e-mail systems or accounts that are monitored by employers, linked to computer network file storage systems, or shared by multiple family members. Thus, if the Internet is used for data collection regarding assisted dying, potential participants must be informed that data may not remain confidential.

An alternative to Internet-based data collection is collection of anonymous "pen and pencil" written stories of nurses' encounters with requests for assisted dying. However, disadvantages of the anonymous submission format must be considered. Provision of a written experience precludes any opportunity to probe for additional detail. Again, the researcher has no opportunity to observe the nonverbal component of communication. The emotion of the experience could be lost or diminished, depending on the participant's literary skills. In short, the quality and quantity of information shared rests solely with the participant. Use of a written data collection format may also be a barrier to recruitment, should a potential participant decide that the format is burdensome.

Risk to society and the nursing profession

In addition to risks to the study participants and the researcher, a study of assisted

dying and nurses can pose a risk to society. The ANA states that "nursing has a social contract with society that is based on trust and therefore patients must be able to trust that nurses will not actively take human life."[4(p4)] If a study reveals that oncology nurses have assisted dying patients to end their lives, some individuals might construe these acts as undermining the nursing profession's covenant with society. Further, research on sensitive issues may be misinterpreted or misused by parties with political agendas contrary to the scientific aims that researcher seeks to serve.[18] A case in point is the popular press' interest in Asch's study of critical care nurses' experiences with assisted suicide and active euthanasia.[6] The *New York Times* story headline stated, "1 in 5 Nurses Tell Survey They Helped Patients Die."[42] The coverage was relatively balanced and included an accurate synopsis of the study and quotes from both the researcher and the author of a rebuttal editorial by Colleen Scanlon,[43] Director of the ANA's Center for Ethics and Human Rights. However, other groups with more overt political agendas were more inflammatory in their reporting of the study. For example, the *Catholic World News* headline read "Nurses Say They Have Killed Dying Patients."[44] "Killing patients" is not part of the nursing profession's covenant with society to care for the sick and vulnerable. The word "kill" is not used within Asch's original report. Indeed, Asch stated that "I do not believe the results of this study suggest that patients or the public should fear or distrust critical care nurses."[6(p1378)]

One must also consider the risk to society associated with *not* conducting research of illegal activities. If barriers to conducting such research prevent examination of the social and professional issues associated with assisted dying, the status quo remains. That is, members of the lay public may continue to desire control over the timing of death while the nursing profession espouses ethical mandates against assisted dying. Indeed, the public expects nurses to practice in a scientifically sound manner; as such, conducting and disseminating research addresses that mandate.

Researchers who engage in socially sensitive research must be prepared for scrutiny by diverse professional and lay parties who have varying agendas and interests. Sieber[18] recommended that researchers anticipate such scrutiny and seek counsel from IRBs, professional colleagues, attorneys, ethics committees, and the like. Although a researcher cannot prevent misrepresentation, potential harms can be anticipated and minimized through study design decisions and careful consideration of how findings are reported.

STUDY EXAMPLE

The qualitative study presented here demonstrates application of the methodological concerns associated with studying an ethically and legally sensitive topic. The purpose of the study was to understand the experience of oncology nurses who receive requests for assisted dying from terminally ill patients with cancer who seek to take deliberate action to end their lives.[17] This was accomplished by collecting and analyzing stories anonymously submitted by nurses from throughout the United States.

Original study design

The purpose of the original study design was to ensure capture of a potentially elusive sample of oncology nurses, to collect thick, detailed descriptions of receiving requests for assisted dying, and to protect participant identity. Given that the study focus was on experiences of *receiving requests* for assisted dying, both nurses who had acted on requests and those who had not were included in the study sample. Hence, one's participation in the study did not imply that an illegal action necessarily was carried out. The study method was designed in consultation with dissertation committee members (including nurses, an attorney, and a bioethicist), an institution IRB chairperson, and members from the target population of oncology nurse

colleagues. Given that a federal certificate of confidentiality could not guarantee absolute protection of participant identity, a method for anonymous study participation was devised. Per Sieber's[18] recommendation to use members of the target population to identify participant concerns and to help formulate ways to minimize those concerns, peer input into the study design was invaluable. The oncology nurses strongly advised use of an anonymous format for 2 reasons: fear of legal repercussions (loss of licensure) and potential embarrassment or shame with admitting illegal activity to a nurse researcher. Nurses worried about being negatively judged by a peer for such behavior. Hence, a data collection procedure that excluded personal, "face-to-face" contact was devised and approved by an institutional IRB.

A purposive, national sample of registered professional oncology nurses was recruited via a letter to the editor published in the *Oncology Nursing Forum,*[45] a professional oncology nursing journal with a circulation over 27,000 at that time. Nurses who had experienced requests for assisted dying were invited to participate by contacting the researcher either by collect phone call or by mail. Both nurses who had assisted dying, and those who had received requests to assist but declined, were recruited.

Those interested in study participation were mailed an information packet. Once the packet was mailed, the researcher destroyed all contact information about the packet recipient. The study packet contained a cover letter and instructions for sharing the experience with assisted dying. Potential participants were instructed to select 1 of 3 options for telling their stories. The first option was to submit an anonymous, written account of either receiving a request for assisted dying or engaging in an act to assist a death. An instruction form, demographic data sheet, and self-addressed stamped envelope were provided for this purpose. Respondents were advised that the demographic information would be used as group data only and not linked to individual stories. They were also cautioned to leave no personal identifying information on the return envelope. The second option for sharing one's story was via a tape-recorded account of the experience. Respondents interested in this option were asked to mail back a tape recorder request letter. They then would be mailed a small, hand-held tape recorder, blank tape, instruction form, demographic form, and prepaid envelope for returning the tape. All identifying information about the requesting nurse would be destroyed as soon as the packet was mailed.

The third option for participating was an anonymous telephone interview by the study investigator. Respondents interested in this option were invited to complete a telephone calling card request form and use the card to place an anonymous call for an interview with the investigator. Again, all identifying information for calling card requests would be destroyed after sending the card. Regardless of the option selected, instructions for sharing one's story were the same (Table 3). Within a 4-month time frame following publication of the letter to the editor, only 3 individuals requested study packets. One individual did request a telephone calling card but later

Table 3. Participant instructions for submitting stories

Describe a situation in which you received a request for assisting dying from a terminally ill cancer patient. This can be a situation in which you chose to assist or declined to assist. Assistance could take the form of actions to end life, such as administration of a lethal drug dose, advising a patient about specific strategies or available resources for ending one's life, assisting the patient with an act to end his or her life, or refraining from interventions to prevent or dissuade the patient from taking his or her life. Describe your experience, including your thoughts and feelings at the time and in retrospect, as fully as you can. Please do not include any information or details that could reveal your own or your patient's identity.[17(p42)]

returned the card with a note declining to participate. The other 2 individuals never returned any further information regarding desire to participate in the study.

Study modifications

Given the poor response to the initial plan, a revised recruitment plan was initiated and approved by the institution IRB. Potential participants were recruited by a randomized, sequential direct mailing of study packets to ONS members who identified themselves as patient care providers. The accessible population included 10,265 nurses in the "direct patient care" and 2112 nurses in the "clinical nurse specialist"(CNS) membership demographic categories. The study packet included a cover letter describing the study, a description of how to share one's story using an anonymous, written format, a demographic data sheet, and a self-addressed, stamped envelope. In order to maximize the potential for response, the anonymous written format was specifically requested because the respondent would not have to disclose one's identity in order to receive a tape recorder or calling card. Packet recipients were asked to submit an anonymous, written account or story of receiving a request for assisted dying as outlined in Table 3.

Given the critical need to protect the privacy of participants, anonymity was reinforced by refraining from using a separate consent form that asked for a participant's signature. All elements of informed consent were included in the cover letter. Participant consent was inferred via completion and return of the completed study tools to the investigator. Participants were reminded of the potential illegal nature of assisting death, and apprised of the risk associated with divulging such participation. All stamped, addressed return envelopes had no identifying marks other than a postmark upon return. The returned envelopes were destroyed upon receipt. Participants were requested to not include any identifying information on or within any responses in order to preserve anonymity. Additionally, individual demographic profiles of individual respondents were not linked to their stories.

Three hundred packets were mailed every 3 weeks until data analysis revealed redundancy in submissions from study responders. A total of 1600 packets were mailed out over a 4-month time frame; 1000 went to direct care providers and 600 to CNSs. The CNS group was purposively heavily sampled, as a review of the first 10 stories submitted revealed that Master's-level-prepared nurses provided much more detailed descriptions of their experiences. Ultimately, 40 nurses submitted 48 written stories of their experiences of receiving requests for assisted dying.

DISCUSSION

The original recruitment method used for this study was unsuccessful. Lack of response to this strategy may have been due to a variety of factors. Perhaps the journal readership did not read letters to the editor, or those who did did not qualify for the study. Given the potential illegal nature of assisted dying, perhaps the step of making direct contact with the investigator in order to obtain a study packet was too threatening. Interested nurses had to either provide their names and addresses in order to receive a mailed packet, or express interest through direct contact and be handed a packet. One of the potential participants who did respond to the letter to the editor left her name and address on my answering machine and stated, "I understand that this information will *not* be passed along, and I'm counting on you for *that*" (italics is used to convey vocal emphasis). Another potential explanation was that making contact to obtain a study packet required more effort than potential participants were willing to expend. Additionally, once a potential participant received a study packet, another step, which entailed contact with the researcher had to occur in order to obtain a calling card or tape recorder. No nurse chose the

anonymous telephone interview method to participate in the study, yet many of the written stories submitted consisted of several pages of typed, single-spaced detailed accounts of their experiences.

Was the risk of talking about assisted dying too threatening despite an assurance of anonymity? Perhaps. Although the study did not reveal whether participants declined to participate on this basis, underreporting is an inherent limitation in all research on euthanasia and assisted dying.[46] In future studies, the use of a different recruitment strategy may be warranted. In the recent study of physicians' responses to patients' requests for assisted suicide,[37] physician participants were recruited from 2 states where assisted suicide is illegal. These individuals were identified using a snowball sampling technique: physician "key informants" who had spoken on assisted suicide in public forums provided names of other physicians thought to have experienced requests for assisted suicide. Perhaps nurses could be recruited in a similar fashion. Ultimately, trust in the researcher to protect participant identity is critical. A snowball recruitment method among professional colleagues who already know and trust the researcher may yield the best results.

Was the lack of nonverbal communication that one otherwise gains in a "live" interview detrimental to understanding the emotions associated with the experience of receiving a request for assisted dying? Certainly some of the study participants had the skill to convey emotion within their written responses. In addition to descriptive phrases, some stories were punctuated with words in all capital letters, double and triple underlining, liberal use of exclamation points, and other devices to convey emphasis of certain points. Others either began or ended their stories with asides or explanatory notes describing their emotions associated with recalling the patient scenarios they shared. Although these techniques differ from the traditional nonverbal cues an interviewee may offer, they did communicate emotion and emphasis beyond the details of the story itself.

The study of socially sensitive issues can have a larger, societal impact. Although studies of illegal actions could have a negative impact on the covenant between the nursing profession and society, the current study did not generate headlines like those prompted by the Asch[6] study. Indeed, the extensive press coverage of Asch's work may reflect wider social acceptance of physician dominance over nursing practice.[47] The lack of press coverage of the current study may have been due to the journal used for dissemination (*New England Journal of Medicine* versus *Oncology Nursing Forum*), media disinterest in reporting nursing research,[47] and the study design: quantitative survey with a large sample (1139) versus qualitative with a small sample (40). Also, the present study did not focus on whether or not nurses reported assisting death. Although some respondents revealed that they had engaged in acts intended to end life, the study focused on the meaning of the experience of receiving an ethically troubling request. Instead of posing a risk to the profession and society, the study benefited both groups because it opened a dialogue about an otherwise surreptitious action, revealed the struggles that nurses engage in when responding to patient requests for help, and demonstrated a professional commitment to improving patient care.

CONCLUSION

The methodological considerations associated with investigating the experience of nurses receiving patient requests for assisted dying were presented in this article. Resolution of the conflict between minimizing participant risks versus advancing knowledge was guided by one simple caveat: ". . . the ethical priorities of nursing lie with the person as respondent rather than the research."[48(p47)] All methodological decisions were guided by consideration for participants and minimizing risk to them. The challenges associated with conducting socially sensitive research are not insurmountable barriers. Careful

attention to study design can yield important insights into otherwise hidden ethical and legal dilemmas, move public discourse beyond polarized views to a more balanced consideration of a divisive topic, and reveal new directions for future research.

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