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Family Decision-Making about End-of-Life Care

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Description

A family therapist doing research that seeks families and patients deal with the process of making decisions at the end-of-life also serves as a clinician providing palliative care consultation at a local hospital. When a family who gave their informed consent to participate in her study confesses that they only did so because they thought their family member who is dying would not receive needed treatment with their participation, a number of ethical questions arise.

Body

Part I

Dr. Luci Menendez is a licensed family therapist with years of clinical experience helping families cope with the grief associated with both death and non-death related loss as well as a child and family development researcher at a large university. Luci has been working as part of an interdisciplinary palliative care consultation service at a local hospital. The palliative care team specializes in providing pain and symptom management for patients and families facing chronic or terminal life-limiting illnesses. As a family therapist paid through a contract with the hospital, Luci specializes in “relational pain management,” helping to sort through

emotional and sometimes conflict-laden family dynamics. Physicians refer patients for a consultation with the palliative care team when they believe cure is no longer a realistic treatment goal. All members of the palliative care team then meet with the patient and family to decide if they would like to continue receiving treatment focused on cure or shift care goals to emphasize comfort care.

In addition to clinical work, Luci is interested in research that focuses on the family as the unit of investigation with the goal of eventually developing and testing clinical interventions to assist patients and families through the process of making decisions at the end-of-life. She approaches her research and practice from the perspective of general systems theory. Luci plans to conduct a study using validated measures of family cohesiveness and adaptability, participant observation of family interactions and decision-making processes, and qualitative interviewing.

Questions

1. What ethical issues arise from Luci's dual role as a clinician/researcher?
    a. Could these issues be avoided? Should they be?
    b. How does this dual role facilitate and hinder Luci's clinical work and research?
2. Should Luci be asking dying patients and their families to participate in research at all? Why or why not?
    a. Should dying patients and their families be viewed as "vulnerable populations"? Why or why not?
    b. What additional ethical issues arise if using dying patients and their families is classified as research involving vulnerable populations?

Part II

Luci gains IRB approval for her study. She recruits research subjects through the network of physicians making referrals to her palliative care team. After talking with patients and families about the need for a palliative care consultation, the physicians secured permission for Luci to contact the patient and families about the possibility of participating in a research study. During Luci's first meeting with patients and their families, she explains both her normal clinical role on the palliative care team and her interest in researching the decision-making processes families use related to

palliative care. Luci describes the study and answers all questions. She carefully stresses that receiving her clinical services and that of the rest of the palliative care team is not contingent upon their participation in the research. While everyone is present, Luci then asks the patient and family members to each sign an informed consent document, which includes the statement that research participants are free to stop participating and withdraw consent at any time for the use of any data they have provided.

Thirty minutes prior to the start of each palliative care family conference, Luci meets simultaneously with the patient and his or her family to reconfirm their decision to participate and to administer pre-test measures. After each palliative care family conference, Luci records participant observation data. On separate occasions she conducts qualitative interviews, one with all family members present, then one with each individual, followed by a second, follow-up interview with the entire family. So as to not overly tax the participants, Luci keeps all questionnaires and interviews brief.

These procedures appear to be going well until Luci meets with one particular family. Though the patient and all family members had signed informed consent documentation stating they were freely volunteering for this project, a comment was made by a family member during an individual interview about how strongly the patient's primary care physician urged the patient to participate in the study. When Luci follows up on this comment during the second family interview, the same family member explains that they got the impression that the physician thought the family would benefit from extra interaction with a family therapist. Luci re-explains that receiving clinical services was never dependent upon participation in the research project and the patient and family could have met with her as often as they liked and as time allowed. Then, several family members shyly confess they had only agreed to participate in the study out of fear that the patient would not receive all the treatment the doctor thought best.

Questions

3. Was undue influence or coercion involved in this case? By the physician? By Luci? By family members?
    a. How is *undue* influence defined?

    b. Is some influence okay or is any amount of influence understood to be coercive?
4. If some family members would like to participate in the study while others do not, how should Luci proceed given that her research interests are in collecting family-level data?
    a. Should the desires of any single member of the family carry sufficient moral weight as to override the desires of all others?
    b. If only one person does not want to participate but all other family members do, does that one person have the right to insist that family-level data not be used?
    c. Should Luci have obtained the informed consent of each individual member separately before proceeding with the research project?
5. If Luci uses data only from some members of the family but not others, does this invalidate her quest to gather full family-system data?
    a. Are the data she has collected so far from this family valid, now that she knows some members were reluctant participants?
    b. Can Luci trust the validity of data from other families who were referred by this one physician?

Part III

Although Luci is worried about the loss of data to her study (especially since full family participation was hard to come by), she reminds the patient and family that they are free to withdraw their participation and data from the study at any time. At this point, the dying patient, with whom Luci has developed a close therapeutic relationship, reiterates his interest in participation in the research project and urges his family to “please participate.”

As a family clinician-investigator, Luci has duties not only to see that her research causes minimal harm, but to intervene in harmful family dynamics. Luci is reminded that much of her interest in collecting family-level data is that a dying patient’s decisions about end-of-life care have enormous impact on family members and that in some cultures duty to family carries more moral weight than individual preference. Indeed, it is a holistic focus on the family system that distinguishes family researchers and clinicians from others who study and intervene with individuals. She hopes her research on the family as a whole will lead to clinical

interventions that strengthen family relationships during such a vulnerable time.

Questions

6. How should Luci respond to the dying patient's request that reluctant family members participate in the research?
    a. If she says nothing, is this a neutral response or does it have the effect of helping to insure the inclusion of these data?
    b. Does the fact that a person is dying automatically add moral weight to what a person wants to the neglect of other family member's desires? Is this coercion? Why or why not?

Note on Teaching this Case

This case was constructed with several pedagogical assumptions and goals in mind. First, it is geared toward investigators who are already familiar with the fundamentals of ethical research practice, particularly regulatory standards associated with Institutional Review Boards (IRBs). As such, this case study intentionally focuses on ferreting out and potentially challenging assumptions embedded in traditional research ethics protocols.

Second, it is designed to highlight some of the unique challenges faced in clinical research, which those conducting traditional basic research are less likely to face. Similarly, this case raises issues that are of central concern to family systems researchers, but may *seem* less relevant to social scientists whose unit of analysis is at the level of the individual, or larger social groups whose members may be anonymous to one another or have less intimate connections.

Finally, those unfamiliar with the nuances of clinical research or a systemic (vs. reductionistic) approach to science, may find the myriad issues raised in this case to be so multifaceted that the case loses pedagogical efficacy. While this is a risk, it was decided that the realism associated with simultaneously wrestling with the complexities of this case offered an alternative to case studies frequently found in the ethics literature that make clear philosophical points at the expense of face validity.

Contributor(s)

Brian Schrag

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