Author's Commentary on "Family Decision-Making about End-of-Life Care"

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Ethical Issues and Analysis

Part I of this case study introduces Dr. Luci Menendez as both a researcher and a clinician who seeks to develop an integrative program of research whereby her clinical work informs her research and vice versa. Critical to this case is an understanding of the ways in which general systems theory informs Luci's research and clinical practice. General Systems Theory (von Bertalanffy, 1968), the basis of family therapy and many theories of family process, is most readily epitomized as 'the whole is greater than the sum of its parts.' Individual parts of the system are interdependent and information feedback loops between parts or between the system and the broader environment function to keep the organization of the system relatively stable. "This systemic approach has led to a method of treating psychological problems and of posing research questions that is fundamentally different from the traditional, individually based one"(Copeland & White, 1991, p. 8).

Copeland and White (1991) argue that family researchers, such as Dr. Luci Menendez, not only have the traditionally recognized responsibility to assess the effects of a study on individual research participants, but have a special ethical responsibility to attend to the impact of the study on the family as a whole. Similarly, family therapists are ethically required to attend to *both* the well-being of individual family members *and* the well-being of the family as a whole, a difficult balance to achieve at best.

One may rightly question from the start whether Luci should have recruited families to her study with whom she would eventually have a clinical relationship. Whether or not Luci recruits research subjects from the same population that she will be serving clinically is partially influenced by the availability of palliative care consultation services. These services are still relatively new and not all hospitals or communities have interdisciplinary palliative care teams. The very fact that these services are new may be an argument for the importance of researching currently unexplored issues so as to increase evidence-based clinical practices. However, if Luci's team is the only one of its kind that is readily accessible to Luci for research, she may be at higher risk for unwittingly pressuring her clients to participate.

Only interviewing palliative care patients and families not receiving services from Luci's professional team would *ostensibly* lessen the complexities of this case by reducing the formal fiduciary relationships Luci has with clients/subjects. However it is debatable whether the absence of formal relationships with specific family members *completely* eliminates Luci's more general duty as a socially sanctioned professional to protect the well-being of society's members. In other words, even if Luci interviewed research subjects with whom she does not have formal therapeutic relationships, the fact that she is a clinician with a specialized knowledge and skill set may still have some ethical bearing on her research relationships.

Though others may disagree, I would argue that Luci's two roles are neither 100% separable, nor equally exchangeable. Luci's membership in a publicly recognized and regulated clinical profession with all of its attending benefits (e.g., status), obligates her to give priority to her clinical role over her researcher role. In other words, Luci can be a clinician without assuming a researcher role, but her clinical knowledge *must* inform her research choices. Her clinical knowledge likely makes her more sensitive to the types of harm that may befall individuals and families participating in her research project which may obligate her to take steps above and beyond those required by federal, state, and institutional research regulations.

Recognizing the complexity of her dual role as a clinician/researcher, Luci took precautions in her research design. First, she used a two stage recruiting process, whereby patients and families were first invited to consider participation in research by someone other than the researcher, the physician in this case. Whereas this was intended to increase the autonomy of family members in deciding whether or not to participate in the study, it increased Luci's risk of having nuances of the study misrepresented. Furthermore, Luci failed *fully* to account for perceived power

dynamics in the physician's relationship with the family, leaving them vulnerable to perceived (if not actual) "authoritative persuasion."

Second, when meeting with families to describe the research opportunity, Luci made explicit the dual nature of her relationship with patients and families, stressing that clinical care is a higher priority than research, and that the decision whether or not to participate in research would not negatively affect the clinical services they received. During informed consent procedures, Luci also explained the on-going voluntariness of research participation. While these precautions are commonly required by Institutional Review Boards as means of protecting *individual* research subjects, additional efforts may be necessary to protect the *family system*.

For instance, the case does not specify the exact nature of the informed consent document Luci has each family member sign, but it does say the discussion took place with everyone present. Copeland and White (1991) note that "especially in studies in which families are asked to discuss important, real issues together [e.g., end-of-life care], the promises of anonymity and confidentiality about what they say, usually afforded to research subjects, are limited because the other family members are sitting there and listening" (p.4). Per most IRB requirements, the informed consent document should discuss the limits of confidentiality. This is typically understood as delineating the conditions under which the *researcher* may not keep absolute confidentiality.

Confidentiality is typically understood as the ethical mechanism through which we respect the right of *privacy of individuals*. But does this individual-focused understanding of privacy and confidentiality adequately apply to information about relationships, which by definition involve more than one individual? Family researchers are faced with the dilemma of gathering and protecting information that from the perspective of individual family members may be considered quasi-private. There may be a genuine risk of harm to individuals and/or family relationships if some members of the family disclose relational information that the other members did not want disclosed.

In this case, a fully ethical approach to informed consent in family research might also include a discussion of the fact that data collected from one individual, even during individual interviews, cannot be completely separated from information about other members of the family because the focus of the research is on *shared* family history and dynamics. One approach is to include a statement on the consent

document stating that agreement to participate in family data collection includes giving permission to other family members to disclose potentially private information about one another.

Having such a statement included in consent procedures allows the researcher to explain the importance of gathering “un-edited” family data, while simultaneously facilitating family members’ discussions about possible limitations on the type of information they will share with the researcher. Of course, research subjects are always free to edit their responses, but by making this process explicit, the researcher may be able to at least gather information directly from subjects about the limitations of the data rather than solely relying on hindsight speculation about missing data.

Explicitly highlighting interest in the family as a whole also gives the researcher an opportunity overtly to discuss family dynamics in the process of consenting to participate in research. Families differ in important ways from other groups studied by researchers (Copeland & White, 1991; Greenstein, 2001). In addition to being interdependent systems of individuals, families “develop private, idiosyncratic norms and meanings about their own activities. . . , [creating unwritten] patterns of, and rules for, behavior” (Larzelere & Klein, 1987, in Greenstein, 2001, p. 11) that are often hidden from public view. Families have ways of restructuring their view of themselves in order fit these family rules and expectations as a means of managing family tensions and maintaining family stability (Copeland & White, 1991). Family members also have multiple statuses and enact multiple roles simultaneously (e.g., father, son, and brother) requiring researchers to be sensitive to the fact that the kinds of responses offered by family members may depend on the role and status the individual is occupying in the context of gathering family data (Gelles, 1978, in Greenstein, 2001).

These systemic considerations are not typically considered in the traditional bioethics or research ethics literatures. Relying on an individualistic approach to research ethics, it is tempting to resolve Luci’s case by simply saying, “If a family member does not want to participate, that’s the end of the story; just collect data from those who agree.” This response is problematic in at least two ways. First, the validity of system-level data is likely to be compromised, thereby altering the risk-benefit analysis used by IRB reviewers. Second, assuming a purely individualized approach to ethics in the context of family dynamics may itself be a morally questionable activity that may increase the risk of harm to the family *system*.

Ivan Boszormenyi-Nagy (1984, 1986, 1987, 1991), a founding family therapy theorist, argues that “relational ethics” is critical to healthy family functioning, such that failure of each family member to give “due consideration” to the interests of other members is seen as the heart of family dysfunction. Nagy (1991) claims that family functioning is enhanced when members of the family can trust that the family system as a whole will facilitate the process of balancing considerations of the well-being of oneself with considerations of the well-being of others.

In this case study, some family members acknowledged during data collection that their motivation for participation had been out of a perceived benefit to the dying patient. From a traditional perspective, subject participation “out of fear” of lost benefits raises questions of voluntariness and possible coercion (both direct and indirect). Superficially, this circumstance arose due to miscommunication. At a deeper moral level, however, it could be argued that the situation is *also* borne of “relational ethics,” in that family members gave “due consideration” to the wishes and interests of other members of the family system.

Luci’s response is in keeping with traditional research ethics: she reminds family members of their individual freedom to withdraw from the study. In her attempt to protect the rights of individuals, however, does Luci risk harming the system by challenging the family’s “idiosyncratic norms. . .[and unwritten] patterns of, and rules for, behavior” (Larzelere & Klein, 1987, in Greenstein, 2001, p. 11), which has demonstrably included “due consideration”? In other words, by highlighting individuals’ rights to withdraw their participation, is Luci, in effect, suggesting that “due consideration” of other family members’ interest in contributing family-level data (e.g., the dying patient) is not relevant? In doing so, does she undermine the *trustworthiness* of the family system to support “due consideration” — a key factor in healthy functioning according to Nagy (1991)? If this line of reasoning holds, then Luci’s adherence to traditional research ethics protocols may violate her ethical responsibilities as a family clinician and researcher to protect (and enhance when possible) the welfare of the family system.

Biomedical ethics and most approaches to research ethics emphasize individual autonomy in decision-making, but this tends to decontextualize people from their social context, a criticism increasingly explored in feminist ethics. Recognizing that human beings have autonomous moral status (i.e., their moral worth is not dependent on external considerations) need not automatically be equated with decision-making that is free from the influence of others. Certainly, the influence of

the researcher on the consent process needs to be kept to a minimum. However, it is morally suspect to presume that decision-making itself must always be free of the influence of others.

While some attention has been given to cultural or societal-level groups (e.g., Native American tribal considerations), little discussion has occurred about the moral relevance to decision-making of intermediate level groups such as the family. Yet in many cultures these more personal groupings impact one's daily life most, and it is not uncommon for loyalty to one's family to be given priority over individual interests. If Nagy's theory of family functioning is correct, it would suggest that being in intimate relationships with others changes the level of influence on ethical decision-making we consider to be appropriate, particularly in contrast to non-intimate relationships.

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