



HHS Public Access

Author manuscript

J Empir Res Hum Res Ethics. Author manuscript; available in PMC 2020 December 01.

Published in final edited form as:

J Empir Res Hum Res Ethics. 2019 December ; 14(5): 487–489. doi:10.1177/1556264619853198a.

COMMENTARY 1: Researcher integrity and contrasting obligations in interdisciplinary research

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We are members of an interdisciplinary research team examining ethical issues in novel neurotechnologies, and we bring to the project our different disciplinary backgrounds in sociology and clinical neurology. In reviewing this case study, one feature meriting discussion is how this case illustrates both the particular strengths of interdisciplinary research as well as some of the unique ethical challenges faced by research teams comprising different disciplines. In interdisciplinary research, each contributing discipline, informed by its own history, will usually have a distinct conception of ethical standards particular to its work; but each team member must then participate in articulating a shared ethic that can faithfully incorporate these potentially divergent perspectives.

In the case of Mr. Vine, the primary researcher on the team (Dr. Portacolone) is a sociologist employing ethnographic methods to conduct a detailed examination of the attitudes, beliefs, and behaviors of older adults living alone with Alzheimer's disease and related dementias. Ethnographic researchers have traditionally not regarded themselves as mandatory reporters. Meanwhile, the research team also includes a geriatrician (Dr. Covinsky) and a psychiatrist (Dr. Halpern). Over a lengthy and contested history, these clinical disciplines have become regarded in practice and state law as having specific duties to report concerns for elder abuse, neglect, and self-harm to Adult Protective Services (in addition to reporting duties for suspected child abuse and protective duties when identifiable third parties are threatened) (U.S. Department of Health and Human Services, 2016). One of the ethical challenges documented in the case is that, in the course of Dr. Portacolone's ethnographic fieldwork, she learned that Mr. Vine intended to travel to Switzerland for medically-assisted death, which is not legal for patients in Mr. Vine's clinical situation in California. While Dr. Portacolone is not a mandated reporter, two other members of her team are health practitioners and thus (in the state of California) mandated reporters.

For the purposes of this brief discussion we will pass over past controversies regarding mandatory reporting and legal duties to protect third parties in medical care, particularly in psychiatry. While these mandates are recognized to erode the traditional primacy of patient confidentiality and thus have the potential to undermine the therapeutic alliance or even to discourage those most in need of attention from seeking care, they have largely become incorporated into practice. Many patients now enter care with the understanding that absolute confidentiality can no longer be assured.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

This sort of understanding is less compatible with existing practice in ethnographic research, and is at cross-purposes with many crucial research programs in the social sciences. Unlike mental health professionals or other health professionals, ethnographic researchers do not approach research participants from a position of professional authority, and their engagement with participants is not intended as therapeutic (Clifford & Marcus, 1986). In the course of field observations and interviews, research participants may expose potentially unflattering details about their perceptions, attitudes, and practices. Unlike similar exposures in psychotherapy or other clinical encounters, these details are not revealed to facilitate the research participant's own medical care, but instead to advance general knowledge. Truly insightful work thus requires a deeply trusting relationship between the participant and researcher. There are critical topics of public policy and public health importance that would be effectively impossible to examine using these tools if not for a firm commitment to participant confidentiality, for example, peer influence among adolescents, the perpetuation of racial and ethnic privilege, and loyalty within criminal gangs (American Sociological Association, 2018). This commitment is thus partly constitutive of the ethical worldview of ethnographic research, and in our view, it would be a grave mistake to try to assimilate ethnographic researchers to norms appropriate to clinicians.

The case in question illustrates the value of ethnographic research, particularly in an interdisciplinary context. First, the research program addresses individuals who are uniquely vulnerable both on medical and psychosocial grounds: older adults living alone with Alzheimer's disease and related dementias. This population is medically underserved and underrepresented in research, in part because it is uniquely challenging to engage. Here, the involvement of a geriatrician and a psychiatrist with clinical expertise can provide needed context for the interpretation of field work, such as whether some of a research participant's reports reflect the influence of a cognitive or psychiatric disorder.

The case study also illustrates how the deep relationship fostered by the ethnographic researcher can yield insights that are provocative and profound. Mr. Vine's desire to travel for assisted suicide and his comparison of life with Alzheimer's disease to being chased by a monster are emotionally and professionally challenging. This transmits a visceral understanding of his experience as an older adult living alone with Alzheimer's disease, and is precisely the sort of insight (even if unwelcome) that this research is designed to provide. In addition, the researchers did not simply take Mr. Vine's desire at face value; instead they applied their detailed understanding of his situation to identify other factors besides symptoms of Alzheimer's disease influencing his decision. These findings can help to inform our thinking about why older adults with dementia seek aid in dying, and about what psychosocial supports would help them to live in ways that they value continuing.

At the same time, another strength of ethnography lies in examining the multifaceted nature of power relationships. It can shed light on the pervasive consistency of underlying notions such as "protect", "vulnerability", and "vulnerable" that are generally unquestioned and accepted. For the case at hand, such notions may include concepts of "protection", "vulnerability", "free will", "quality of life", or "autonomy", to name but a few. Dr. Portacolone's ethnographic work could therefore foster a more complex and nuanced discussion of different forms of power embedded in Mr. Vine's various institutional and

personal relationships. By deciding to report Mr. Vine to an authoritative agent, Dr. Portacolone might thus not only risk undermining the delicate relationship that exists between ethnographer and research subject, but also place herself in the very position of professional authority she might have initially intended to study or question.

While interdisciplinary ethnographic work is uniquely positioned to yield such insights, it has the potential to expose clinician members of a research team to professional and legal risks. If this were a situation in which clinician reporting is mandatory (which may depend on specific local statutes), then clinician members of the research team could face legal jeopardy for failing to report the case to Adult Protective Services (Swerdlow, 2018). In our view, this case highlights a potential situation that interdisciplinary research teams involving clinicians or other mandated reporters should anticipate in their research planning: for ethnographic research involving children or older adults, is field work likely to yield reasonable suspicions of abuse, neglect or self-harm? And if so, is reporting of such suspicions or evidence to Child Protective Services or Adult Protective Services consistent with the research design? If such reporting is consistent with the research design, then prospective participants should be aware of situations in which confidentiality cannot be guaranteed at the time that informed consent is sought, and the ethnographic approach will need to be modified. If, however, such reporting is inconsistent with the research design, then internal processes may be needed to obscure identifying data about research participants from clinician members of the research team, so that reporting mandates will not be triggered. To be sure, this design choice carries its own ethical tradeoffs, potentially introducing barriers within interdisciplinary teams that reduce the effectiveness of such collaborations. We must acknowledge that ethical role conflict within such teams does not always admit of ideal solutions.

While our commentary has focused on contrasting obligations within interdisciplinary research teams, the case also highlights other features of researchers' relationships with Adult Protective Services that may elicit confusion. First, in this commentary we have focused on California law, reflecting the actual circumstances of Mr. Vine's case. Researchers should be aware that there is considerable variation among U.S. state laws regarding who is a mandated reporter, what findings require reporting, how reports must be made, and whether these laws apply to older adults living in the community or in institutional settings. In some jurisdictions Mr. Vine's case is one in which reporting to Adult Protective Services would be mandatory for a clinician researcher, while in others this may depend on how local statutes codify notions such as self-harm or self-neglect. As a result, researchers should consult the details of law in their state, and in cases of uncertainty may seek guidance from legal counsel. This applies even more so when considering the diverse legal frameworks and professional practice between different countries.

In addition, in this commentary we have focused on considerations of professional and disciplinary integrity, which may favor designing studies to avoid triggering mandatory reporting statutes. However, there is also a role for discretionary reporting to Adult Protective Services, when such reports are consistent with researcher integrity (and ideally with the consent and involvement of the research participant). Many researchers and clinicians assume that Adult Protective Services have very broad powers similar to those of

Child Protective Services, such as the power to separate families or to remove older adults from their homes. Among other things, older adults with capacity have the right to refuse Adult Protective Services inquiries; so, for instance, if Mr. Vine were judged to have decisional capacity, he need not worry about being institutionalized against his will. (Even for older adults without decisional capacity, the least restrictive alternative should be sought.) In some cases, Adult Protective Services can provide intensive social work and links to needed community supports. Given the researchers' concern that insufficient social resources may have influenced Mr. Vine's suicidality, Adult Protective Services could be viewed a resource and partner for addressing such gaps, and thus potentially as promoting Mr. Vine's autonomy rather than threatening it.

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