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Walking the Tightrope Between Study Participant Autonomy and Researcher Integrity: The Case Study of a Research Participant with Alzheimer's Disease Pursuing Euthanasia in Switzerland

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Abstract

This article addresses ethical issues in the conduct of ethnographic research with vulnerable study participants, such as individuals with cognitive impairment. Seven ethical issues emerged from this case study, in which a participant diagnosed with Alzheimer's disease wished to pursue euthanasia in Switzerland: (**1**) How to protect the participant's autonomy while ensuring his decision had not resulted from untreated depression or modifiable social factors; (**2**) How to interpret self-harm; (**3**) How to protect the research team members' "mandated reporter" status; (**4**) How to counteract the attractive qualities of pro-euthanasia videos depicting an easy end to personal suffering; (**5**) How to find a better alternative to the common practice of reporting self-harm cases to Adult Protective Services and then removing these cases from studies; (**6**) How to leverage a participant's trust to address these issues; and, (**7**) Whether researchers should do anything further to help address unmet needs in similar situations.

Description of the study in which the ethical issues arose:

Drawing from an ongoing study of the lived experience of older adults living alone with Alzheimer's disease and related dementias (ADRD), this article addresses ethical issues related to the conduct of ethnographic research with vulnerable study participants. Older adults with ADRD living alone are an understudied and vulnerable population (Alzheimer's Association, 2012). More than one million older adults (age ≥65) with ADRD, which make up almost one-third of the population with ADRD in the United States, live alone (Alzheimer's Association, 2012; Amjad et al., 2016), but there is limited knowledge about their lived experience. To address this gap, we used qualitative methods to better understand, in depth, the priorities and concerns of older adults with cognitive impairment living alone. Initiated in 2014, the study involves multiple ethnographic interviews and participant observation in Northern California; its design is discussed elsewhere (Portacolone,

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

Covinsky, Rubinstein, Halpern, & Johnson, 2018; Portacolone, Johnson, Covinsky, Halpern, & Rubinstein, 2018). This paper focuses on the case study of a participant, Mr. David Vine (a pseudonym), who shared with the researcher (EP) his plan to seek euthanasia. Sensitized by the unforeseen suicide of a study participant in the same study (discussed in Portacolone, Byers, Halpern, & Barnes, Under review; Portacolone, Covinsky, Johnson, Rubinstein, & Halpern, Under review), the research team grappled with several ethical issues that arose during the researcher's frequent interactions with Mr. Vine, including seven in-person interviews between October 2017 and September 2018.

Case vignette

An energetic 62-year-old professional artist diagnosed with Alzheimer's disease (AD) and depression, Mr. Vine disclosed to the researcher (EP) his plans to undergo euthanasia in Switzerland, to end the suffering he experiences due to the symptoms of AD. Mr. Vine disclosed this information after the researcher inquired about his plans for the future. In his tiny living room, filled by two leather armchairs and a desktop computer, he showed the researcher YouTube videos about a man and a woman who underwent euthanasia in a Swiss facility (J. 2004; Nguyse, 2004). He said, "I'll show you the death part because that's really great to see. It sounds horrible, but I really like how this thing happened." Each video depicts these persons assenting to the question "Are you sure that you want to drink this liquid with which you will sleep and die?" They are filmed drinking a glass of a bitter liquid containing a fatal dose of sodium pentobarbital, which will induce a deep coma in the span of a few minutes. As the organization's website explains: "After some time, the Sodium Pentobarbital paralyses the respiratory centre which leads to death" (Dignitas, 2018). In one video, an elegant and suntanned French woman in her sixties makes jokes and, after drinking the liquid, asks for extra chocolate bars. Mr. Vine mentions that he identifies with her strong spirit: "She looked like she was really feisty." He was also full of praise for the Swiss facility's facilitator, a demure grey-haired woman ready to hug her clients as soon as their consciousness wanes. Mr. Vine said, "She'll be doing it to me. This lady is great!" While explaining his plan to fly to Switzerland with a friend and pay the $12,000 for the procedure, he reflected, "I just see a dead end here. And a painful end. And an undignified end. And it's against my moral system." With his loud voice, locking eyes with the researcher, he further explained that his symptoms of AD make him feel like he is being chased by a monster who is getting ever closer, and that euthanasia is his way to end this chase. In his words:

> If you were being in a horror movie and you're being chased by someone and they say, "You can end this, the monster is probably going to get you." Would you say no? I think I want to end this because I don't want this monster chasing me because this is a spooky film and I don't want to live the film. That's basically what I'm doing.

However, the researcher's numerous interactions with Mr. Vine revealed a series of factors, other than his symptoms of AD, that influenced his decision to pursue euthanasia. These factors include: receiving his diagnosis of AD in a harsh way, feeling stigmatized because of his condition, his limited ability to negotiate transportation, and limitations in both financial resources and affordable assistance for his cognitive impairment. Mr. Vine explained that he misses having someone helping him with the everyday tasks that are made more difficult by his condition: “You need someone that’s just a committed advocate, if that makes any sense.” Because of limited public assistance, he occasionally paid out-of-pocket for an acquaintance to help him make phone calls related to managing his health and other complex matters, take him to appointments, and assist him with money management. The forced retirement from his freelance job gave him less purpose in life and reduced his income. A gifted performer, Mr. Vine longed to give presentations about living with AD. But finding a way to accomplish this goal was harder than he imagined: after contacting the Alzheimer’s he found himself competing with other applicants in a similar condition. Other factors include changes in health plan coverage that eliminated his eligibility to see a psychologist regularly, and his partner, sister, and friends behaving insensitively to his condition.

To receive guidance on how to support Mr. Vine as a study participant, the researcher contacted colleagues and the administrators of the Institutional Review Board. One colleague explained that, were he in this situation, his protocol would require reporting the case to Adult Protective Services and removing Mr. Vine from the study. Other colleagues did not have conclusive answers. The director of the Institutional Review Board suggested that the researchers should seek guidance from the research team members who were clinicians. In the United States, people in certain professions are required by law to report abuse and neglect of vulnerable populations to the proper authorities. As “mandated reporters,” clinicians have the legal obligation to report possible cases of elder abuse and neglect in research participants to Adult Protective Services. In conversations with the research team, seven ethical issues were identified within the researcher’s relationship with Mr. Vine. These issues are discussed below.

Ethical issues arising

The research team grappled with the following issues: (**1**) How to protect Mr. Vine’s autonomy while ensuring his decision was not to the result of untreated depression or modifiable social factors (e.g., limited services, stigma, lack of psychologist); (**2**) How to interpret self-harm: Mr. Vine saw his plan as self-care while the research team interpreted it as a man planning suicide; (**3**) How to protect the research team members’ “mandated reporter” status; (**4**) How to counteract the attractive qualities of videos showing an easy end to personal suffering (i.e., drinking a glass of bitter liquid followed by a chocolate bar and “easing” into death); (**5**) How to find a better alternative to the practice (observed in similar research) of reporting self-harm cases to Adult Protective Services and then simply removing these cases from the study; (**6**) How to leverage Mr. Vine’s trust with the researcher to address these issues, and; (**7**) Whether researchers should do anything further to evaluate situations like Mr. Vine’s and help address unmet needs. This final issue invites a larger question: at what point do we, as researchers, shift our attention from *human subject* issues to *purely human* issues?

Conclusion

Mr. Vine’s case illustrates how researchers must ethically take responsibility for their relationships with vulnerable study participants. This responsibility includes ensuring that study participants' decision-making is not biased by modifiable external circumstances, which in this case was the absence of a therapist or other mental health professional, as well as lack of a subsidized home care aide. Responsibility also includes maintaining the researcher's direct involvement in any intervention related to mandatory reporting. Mr. Vine, for example, understood his responsibility to protect the research team members' mandated reporter status, and interpreted it as an act of service. On the other hand, he also shared concerns that his involvement in the study and disclosing his intention to the researcher might derail his plans to go to Switzerland. He said, "I don't want anyone to stop me … If they have to report it I don't want someone to say,'Okay, we've got to have this guy institutionalized, so stop him from doing it.'" To reassure him, the researcher explained that the research team respected his wishes and did not have the power to stop him in any way. As a result, Mr. Vine agreed to a visit with a Long-Term Care Ombudsman in the researcher's presence. Because Mr. Vine felt understod by the Ombudsman, and after one month Mr.Vine invited the Ombudsman and the researcher to dine with him at a restaurant. In addition, the researcher leveraged her connections with local agencies to arrange for Mr. Vine to be visited regularly by a therapist who accepted his health plan. The researcher accompanied Mr. Vine to the first visit with the therapist and initially reminded him of future visits. Finally, the researcher continues to keep in close contact with Mr. Vine, who has reviewed this piece and given his approval.

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