

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: (a) How to protect the participant's autonomy while ensuring his decision had not resulted from untreated depression or modifiable social factors; (b) How to interpret self-harm; (c) How to protect the research team members' "mandated reporter" status; (d) How to counteract the attractive qualities of pro-euthanasia videos depicting an easy end to personal suffering; (e) 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; (f) How to leverage a participant's trust to address these issues; and (g) Whether researchers should do anything further to help address unmet needs in similar situations.

Keywords

Alzheimer's disease, Euthanasia, Switzerland, adverse events, cognitive impairment, qualitative research, suicide, ethics

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 1 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, Roth, Samus, Yasar, & Wolff, 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, Covinsky, Rubinstein, Halpern, & Johnson, 2018; Portacolone, Johnson, Covinsky, Halpern, & Rubinstein, 2018). This article focuses on the case study of a participant, Mr. David Vine (a pseudonym), who shared with the researcher (E.P.) 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 (E.P.) his plans to undergo euthanasia

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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 (Hiruit Nguyse, 2004; J, 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 paralyzes 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 gray-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 US\$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 Association, a large advocacy organization, 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: (a) 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); (b) How to interpret self-harm: Mr. Vine saw his plan as self-care while the research team interpreted it as a man planning suicide; (c) How to protect the research team members' "mandated reporter" status; (d) 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); (e) 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; (f) How to leverage Mr. Vine's trust with the researcher to address these issues; and (g) 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 understood by the Ombudsman, after 1 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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Commentary I

Researcher Integrity and Contrasting Obligations in Interdisciplinary Research

Winston Chiong¹
and **Tobias Haeusermann¹**

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 and 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. Although 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.

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.

Although 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 (Swedlow, 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 trade-offs, 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.

Although 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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Commentary 2

Two Roads Diverge: Assisted Suicide in Alzheimer's Disease for a Research Participant

Stephen G. Post¹

Mr. Vine is sad about his plight, as anyone would have reason to be. Sadness has its reasons, while depression has none, and the two are not the same. The path to a better future calls Mr. Vine to Switzerland unless his external circumstances and support can be improved, and the primary researcher involved on the team (Dr. Portacolone) has taken a number of steps toward this goal. But even if circumstances are elevated, it is the indignity of living and dying with dementia that Mr. Vine wishes to avoid.

Two roads diverge. "Deeply forgetful people" (Post, 2000) can and do live on in dignity with varying degrees of continuing self-identity. Every case is different, and Alzheimer's disease (AD) is increasingly referred of late as a "spectrum disorder" (Devi, 2017) for which many psychosocial interventions can bring surprising benefits, such as personalized music (see www.musicandmemory.org). But people are biased against this path due to "hypercognitive" values (Post, 1995), which obscure the ways in which

self-identity can be expressed despite dementia, and relies on valuing lives too exclusively on the basis of the “procedural rationality” of *what we do* (proposed future goals and their implementation as “agents”) rather than on the basis of the “symbolic rationality” of *who we are* (the core of self-identity) that can be well stimulated with creative personal care. Mr. Vine seems to prefer to die pre-emptively via suicide while his procedural memory and agency are still sufficiently intact for him to propose suicide and operationalize it with some assistance.

Mr. Vine, however, remains open-minded to psychosocial interventions as suggested by his caring “live alone” investigator who has engaged him in meaningful interactions as a subject. Yet Mr. Vine appears serious about assisted suicide via a flight to the *DIGNITAS* center near Zurich, where assisted suicide is available for a price as can be observed on the web.

Mr. Vine seems to be able to pay the US\$12,000 needed for physician-assisted suicide (PAS) in Switzerland and therefore can implement his wishes when people who are poor could not. Does this make his plan any less worthy of moral support? Is it right that autonomy in this case is related to relative wealth?

Ancient Wisdom and Modern Times

Mr. Vine’s autonomy is to be respected so long as he has capacity for the decision making in question. His dilemma is not new. The ancient philosophers justified suicide for the aged when significant decline is imminent, just as they condemned it in the young as lacking in courage. The Dutch are in step with the ancients when they justify AD PAS (physician-assisted suicide) as an alternative to “self-effacement” even though AD is not a “terminal condition” in the imminent sense, although in the broadest sense it is terminal and the Alzheimer’s Association describes it as such. For those who hold “hypercognitive values,” AD is metaphorically terminal in a cognitive sense (de Beaufort & van de Vathorst, 2016). Perhaps Mr. Vine feels this way, and he is not alone in this today or historically. Yet to respect his interest in PAS is also to diminish the gravitas of the disability perspective that cognitive deficits are not the end of a life worth living, and that we should embrace the deeply forgetful as “differently abled.” Indeed, perhaps the researcher involved with Mr. Vine is an advocate for this inclusive view, and we have to ask where his or her conscience should be considered.

In the Netherlands only about 5% of those diagnosed with AD take the path of PAS, even though that nation has what is probably the finest publicly funded long-term care system in the world, including entire parks with state-of-the-art design, wonderful dementia guide dogs, beautiful pathways, and so forth. The 5% are not being forced into AD PAS as a default option. They really do have two paths,

both equally supported. Perhaps the relatively low figure of 5% is an artifact of people with progressive dementia forgetting that they desired to pursue PAS (e.g., in the movie *Still Alice*), but perhaps they come to see that a deeply forgetful life is the only life they’ve got (Dresser, 2017). A very few people with AD are actually euthanized in the Netherlands, and only they have an advanced directive stating that this is what they wish at a certain level of decline. But this is rare because doctors in the Netherlands are generally against killing (Tomlinson & Stott, 2015).

For those who support AD PAS, it seems plausible to assert that *wherever PAS is legal for individuals who are competent to act and are within six months of death, it should also be made legal for people with an early diagnosis of probable AD who are competent even though they are still some years away from dying. As a purely legal matter, to exclude those diagnosed with AD who are still competent to avail themselves of the AD PAS option is to discriminate against them unfairly.* The reason these laws exclude AD PAS is only because they were designed for people with illnesses like pancreatic cancer (and the like) that just so happen to bring about death within months while the patient is still lucid of mind. *At a legal level, despite ethical doubts, equal legal rights of soon-to-be deeply forgetful people while they are still competent to choose are justifiable.* In the United States, where PAS is legalized, AD PAS is not. This restriction against AD PAS will eventually give way to legalization, as it has in the Netherlands and possibly soon will in Quebec.

Two Cautions

Ideally, a society would only allow AD PAS after an excellent and affordable long-term care system is in place, as in the Netherlands. But it is unreasonable to hold people with AD back from PAS on these grounds alone. Nevertheless, there are two major reasons to be cautious of AD PAS.

Caution 1: The Incompatibility Hypothesis

The “incompatibility hypothesis” (Post, 2000) suggests that PAS is incompatible with the development of good long-term care programs, and it is of concern only where good long-term care is not yet available or affordable. Without the full development of affordable long-term care systems in the United States, assisted suicide would become a forced option, especially for people who live alone and have a diagnosis of AD. Legalization of AD PAS may prove incompatible with the development of such care systems. Yet it can be argued that this incompatibility is not applicable to health care matters. For example, acceptance of the right to withdraw or withhold life-sustaining therapy did not preclude the development of new forms of such therapy; indeed, these technologies continue to develop at a fast pace and resources are invested in them. Therefore, the argument

runs, it is unlikely that the legalization of AD PAS will hamper the development of other good options. There is the broad question of the right to die when needed long-term care is not provided by the state.

It can be added that in the United States long-term care is very expensive and covered by the individual and spouse until the “spend down” into relative poverty exhausts savings, at which point Medicaid coverage at last kicks in. This dynamic would incentivize those in the United States to take the cheaper option, which is the flight to Switzerland.

Caution 2: Will AD PAS Spill Over Into Other “Non-Terminal” Illness Categories?

Indeed, AD PAS probably would spill over into “non-terminal” illness categories, which is a major problem. Derek Humphrey (1991), after all, founder of the Hemlock Society, in his controversial book *Final Exit*, proposes that society accept assisted suicide and euthanasia, not just for the terminally ill but also for the spouse whose loved one is dying and wishes to “go together” or for those who are just getting old. The spillover of AS to other regions of human distress that challenge the will to live is unavoidable and explains why there is much ethical reluctance to legalize AD PAS. Since guidelines were established in 1984, the Netherlands has de facto permitted PAS and euthanasia, although they have limited this practice to terminally ill persons, including persons with progressive dementias. Since December 1993, exclusion of physicians from criminal prosecution for assisted suicide and euthanasia has been established in law, and it has been specified that the patient must be suffering unbearably, be in the terminal phase of illness, and have more than once expressed the will to die. In June 1994 the Dutch Supreme Court went further. It ruled that Dr. Boudewijn Chabot could not be prosecuted for assisting in the suicide of a 50-year-old woman who was suffering after the deaths of her two sons. Chabot’s patient could not cope with life, and he decided, after seeing her for 24 hr in total, that her wish to die was genuine. Subsequently, “He provided her with the lethal preparation, which she drank in his presence and that of a friend and her general practitioner. Chabot then reported the case to judicial authorities as required by law” (Spanjer 1994, p. 1630). The Supreme Court judgment clarified that mental suffering is a legally acceptable reason for assisted suicide.

Conclusion: What Is a Researcher to Do?

Mr. Vine has the meaningful social support of his researcher who is clearly concerned about the possibility of his planned trip to Switzerland being a potential “adverse event.” She could notify the research team’s mandatory reporters (a

geriatrician and a psychiatrist), one of whom could interview Mr. Vine and assess his capacity for choice despite the reasonable sadness that he feels. But this routine required reporting always leaves confidentiality compromised, so the researcher should only report after deep reflection on the seriousness of Mr. Vine’s stated desire for PAS, and as a last resort with something of an apology:

I am sorry, Mr. Vine, because I do not want to harm our relationship, but I may need to report your wishes to a couple of colleagues, and they may want to speak with you about these plans and especially about why you want to pursue them.

There seems to be no reason to assume that he is incapable of meaningful choice. If he wishes to carry out his voyage to *DIGNITAS*, then no one should prevent him although it is fitting to encourage him to entrust his life to caregivers. The fact that he lives alone is highly relevant because he does not have any “near and dear” in the familial sense, and thus his urge to fly to Switzerland may make all the more sense.

The role of the health care professional, clergy, and friends and family of Mr. Vine is not likely to afford an easy consensus. But perhaps the following possibilities are worthy of discussion:

1. Assure him that any medical intervention in the advanced stage of the progression of AD will only be focused on his freedom from pain and discomfort. There will be no use of artificial nutrition and hydration, no overly aggressive efforts to assist swallowing, and little recourse to antibiotics unless for palliative reasons. In essence, a purely hospice approach to care is to be assured in advanced AD and even earlier.
2. Assure him that, while this is a disease that affects cognition, function, and behavior, some of its symptoms can be mitigated mainly through relational, social, musical, and creative arts programs that can enhance quality of life deep into the disease.
3. Assure him that dependence on others is a natural and inevitable aspect of human life and love, and that he or she can entrust himself or herself to those others, although for those living alone this may sound unrealistic.

Many people with a diagnosis of AD, if they know that they will receive the care and respect of others and that their lives will not be held hostage to a technological-mechanical epoch of morbidity protraction, would prefer to die a natural death in the midst of loved ones because they know that they only have one life to live and that small gratifications can be hugely meaningful. But no one shoe fits all, and for

those who live alone, such entrustment takes a lot more faith in the kindness of strangers than would otherwise be necessary.

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