

Ethics Response

The Online Environment: A Key Variable in the Ethical Response to Complementary and Alternative Medicine for Alzheimer's Disease

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Abstract. Racine et al.'s Ethics Review highlights the challenges associated with the use of complementary and alternative medicine (CAM) in the context of early diagnosis of Alzheimer's disease (AD). As CAM are increasingly promoted and sold on the Internet, the unregulated online environment has the potential to significantly impact the health and well-being of the aging demographic, and in particular of individuals concerned about AD. In this response, the ethical challenges specific to the online environment are discussed and solutions are put forward to empower the aging population to maximize the benefits of the online environment while minimizing the potential harms of misinformation, conflict of interest, and other ethical concerns.

Keywords: Alzheimer's disease, bioethics, complementary therapies, health policy

Racine et al.'s Ethics Review [1] brings to light the challenges associated with the use of complementary and alternative medicine (CAM) in the context of Alzheimer's disease (AD). The authors describe practical challenges from the perspective of different categories of stakeholders and discuss key issues such as whether people with an early diagnosis of AD have a moral obligation to try all available options and how health agencies should regulate the marketing of CAM. Racine et al. [1] raise these questions specifically in the context of early diagnosis of AD, and this

ethics review is timely as AD research is increasingly focused on biomarkers as well as early diagnosis and intervention.

Central to the discussion of the ethical challenges of CAM use in the context of AD is the online environment. Various types of CAM such as dietary supplements and homeopathic remedies are promoted, discussed, and readily available for purchase on the Internet [2, 3]. An increasing proportion of older adults are spending time online and a majority of these Internet users seek health information through this interactive and anonymous medium [4]. As websites about AD are receiving up to several million unique monthly visitors [5], online resources and sales have the potential to significantly impact the health and well-being of the older adult demographic.

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The lack of regulation in the online environment poses important ethical challenges for Internet-based health resources, and in particular in the context of the promotion of resources for AD. As early diagnosis can occur in asymptomatic individuals, the use of CAM could be intended for prevention or to delay the onset of symptoms, rather than for treatment. From this standpoint, the benefits of CAM may be less clear than in applications aimed at ameliorating symptoms, which could lead to misleading narratives. With regards to the online environment specifically, a recent study identified conflicts of interest as an important ethical concern in a sample of online tests for AD [5]. For CAM specifically, predatory marketing strategies may be disguised as health information or services. These types of issues are especially salient when considering the aging demographic, as evidence suggests older adults can experience difficulty discerning trustworthy information and products from fraudulent practices that prey on vulnerable people in particular [6, 7]. Further, Internet users are often required to disclose identifying information, such as credit card numbers and addresses, when interacting in the online environment and purchasing goods such as supplements. This can be problematic if unregulated CAM providers fail to provide adequate safeguards to maintain privacy and confidentiality. Beyond these complex issues, Internet users may suffer negative health outcomes as a result of consulting health information of poor quality. In a review of websites about popular supplements, Walji et al. found that a quarter of these sites contained information that could directly cause physical harm [8]. As well, complications from self-medication with a substance obtained from a CAM website led to the death of a cancer patient in 2000 [9].

Despite these serious concerns, the online environment also has important benefits. For example, Internet users seeking health information may feel empowered [10], and people faced with a diagnosis of AD may find valuable information online to assist with health decision-making. The online environment can raise awareness about AD. Web-based interventions and support groups have shown to be effective to decrease stress and increase well-being in caregivers [11].

Racine et al. [1] call for an increased awareness by clinicians and other stakeholders of the potential for patients to pursue CAM following an early AD diagnosis, and suggest this increased awareness would help prepare proactive ethical responses to minimize

the potential harms of CAM use in the current context of limited evidence-based prevention and treatment options for AD. We should waste no time in implementing this important recommendation to foster a meaningful and multidirectional conversation about the ethical issues associated with CAM use in AD and with the promotion of CAM online.

Alongside efforts to raise awareness of the issues described by Racine et al., clinicians, AD patient groups, and health agencies must also promote educational strategies that equip older adults, people with AD, their families and caregivers with the tools they need to identify reliable online resources about CAM. Broadly disseminated educational interventions aimed at enhancing online health literacy may improve consumers' ability to appraise health information as well as to detect fraudulent or predatory practices. To reach a large variety of stakeholders, these interventions should be delivered both in person, through outreach activities in the community, as well as online, for example through national advocacy sites. The successful development and delivery of these educational tools will empower the aging population to maximize the benefits of the online environment while minimizing the potential harms of misinformation, conflict of interest, and other issues that challenge the full potential of meaningful online resources for AD.

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