Neurodegenerative diseases, such as Alzheimer Disease, Parkinson Disease, Huntington Disease, Amyotrophic Lateral Sclerosis, and prion diseases pose significant challenges to individuals, their families, and society overall. With the aging of societies around the world, the prevalence of many neurodegenerative diseases will continue to increase in the future. For example, Alzheimer Disease International has estimated that the world-wide prevalence of dementia will increase from 35.6 million in 2010 to 65.7 million by 2030 and 115.4 million by 2050 (Alzheimer's Disease International, 2010).

Despite the tremendous scientific advances of the past decade, effective cures for these diseases remain elusive. An important guiding principle for contemporary research in this area is that earlier identification of disease will result in improved treatment outcomes. This does not come without significant ethical challenges, however. The purpose of this special issue is to examine some of the tensions that are created by increased research efforts to diagnose and treat these conditions earlier than before, and the consequences of such efforts. The initiatives occur in the face of complex juridical situations as interventions are proposed or undertaken before all the strands of immediate and downstream impact can be understood.

The nine papers included in this special issue cover a wide range of topics. Several of these papers are organized around specific neurodegenerative diseases. Peters and colleagues propose a conceptual framework for future prevention trials for Alzheimer Disease and use this framework to examine important ethical issues. Gauthier and colleagues also discuss important ethical issues related to the diagnosis and management of Alzheimer Disease, with an emphasis on how these issues have changed over time and will continue to evolve in the future. Eisen and Krieger review ethical considerations related to the diagnosis and management of amyotrophic lateral sclerosis, and Bechtel and Geschwind examine similar issues with respect to prion diseases.

Two of the papers deal with specific types of interventions that have been used in neurodegenerative diseases. Barker and de Beaufort consider the scientific and ethical issues related to stem cell research and interventions. Woopen and colleagues discuss the clinical and ethical issues associated with the application of deep brain stimulation early in the course of disease, as well as in childhood.

In terms of genetic research, Paulsen and colleagues review the literature on quality of life after predictive testing, and Roberts and Uhlmann discuss important ethical and practical issues related to genetic susceptibility testing for neurodegenerative diseases. de Vugt and Verhey examine the impact of dementia diagnosis and intervention from the perspective of informal caregivers.

We hope that this special issue effectively highlights and unravels some of the ethical challenges that are associated with research on neurodegenerative disease and the clinical management of individuals with these diseases. As a teaching resource, we believe it provides vital new thinking in biomedical ethics, health law, and public policy, and complements other emerging online educational material in this area as well. Overall, by proactively examining and addressing important ethical issues, essential improvements in the ethical quality and rigor of research on neurodegenerative diseases will follow.

Reference

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