



At, with and beyond risk: expectations of living with the possibility of future dementia

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Biomedical research aimed at the development of therapies for chronic and late-onset conditions increasingly concentrates on the early treatment of symptom-less disease. This broad trend is evidenced in prominent shifts in contemporary dementia research. Revised diagnostic criteria and new approaches to clinical trials propose a focus on earlier stages of disease and prompt concerns about the implications of communicating test results associated with the risk of developing dementia when no effective treatments are available. This article examines expectations of the implications of learning test results related to dementia risk, based on focus group research conducted in the UK and Spain. It points to the extended social and temporal aspects of the dementia risk experience. Three key dimensions of this risk experience are elaborated: living 'at risk', represented in efforts to reduce risk and plan for the future; 'with risk', through vigilance towards cognitive health and earlier or prolonged contact with healthcare services; and finally, 'beyond risk' through a cessation of the self in its current social, legal and financial form. A virtual abstract of this paper can be viewed at: https://www.youtube.com/channel/UC_979cmCmR9rLrKuD7z0ycA

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