(S91) PATHWAYS OF CHANGE EXPERIENCED BY PEOPLE AGING WITH MULTIPLE SCLEROSIS: FOCUS GROUP STUDY
K. McMullen, K. Yorkston, M. Ivan, M. Jensen
Rehabilitation Medicine, University of Washington, Seattle, WA

Background: An increasing number of people with conditions such as multiple sclerosis (MS) are aging with disability; little is known about the changes they experience as they grow older. Objectives: This study examines the experience of people aging with MS and other disabilities. The heterogeneity of the sample allowed comparisons across disability groups, including whether aging differed with type of disability. Methods: Adults near Seattle, WA, with MS and other disabilities participated in four focus groups, with 5 to 7 participants each. Participants were recruited through involvement in research or attendance at clinics at the University of Washington, and through advertisements with groups such as the National Multiple Sclerosis Society. Twenty-six people participated, of whom 8 were diagnosed with MS. Focus group facilitators asked open-ended questions about changes related to aging with disability, accommodations made, and perspectives on the future. Participants, including people with post-polio, muscular dystrophy, and spinal cord injury, were encouraged to share personal experiences. Results: Qualitative analysis suggested five themes related to aging with disability, endorsed by participants in all disability groups: 1) Participant Identity: how participants described themselves and their lives with a disability; 2) Physical Pathways: decline in physical functioning; 3) Psychosocial Pathways: adaptations to disability, the development of emotional well-being and strategies to deal with disability; 4) Changing Health Care: improvement noted over time in health-care services; and 5) Concerns About the Future: uncertainty about the potential course of disability. Conclusions: Aging with MS and other disabilities was characterized by multiple pathways. These were similar for all individuals across disability groups. Some, including positive psychosocial adjustment and medical advancements, were favorable. Others, including physical decline, were not. The coexistence of high quality of life with physical decline is consistent with literature on older adults, and future research should focus on factors that may contribute to buffering the psychological impact of physical decline. Research is also necessary to determine whether there are perceived differences regarding aging with disability by disability type.

Supported by: Department of Education, NIDRR grants H133B080024 and H133B080025

Disclosure: Nothing to disclose

Keywords: psychological issues and MS, psychosocial issues in MS, quality of life in MS