

Social Participation and Pain, Fatigue, and Depression in People Aging with Disabilities

Participation and inclusion in society are important for healthy living and successful aging. A person's ability to participate in an activity or in a group can be affected by their physical and mental health. Individuals experiencing a new or worsening illness may not be able to perform or enjoy the same activities they once did. People who have a chronic illness or disability may have symptoms of pain, fatigue, or depression. These symptoms can be barriers to participation in social activities. For example, the severity of a person's fatigue may affect which activities they perform on a given day. Thus, people who manage a chronic illness may not participate in activities or social roles in the same way that healthy individuals, who do not have any experience with prolonged illness or disability, can.

Older adults and persons with disabilities face unique challenges to their health and well-being, which can result in barriers to participation and social inclusion. Studies have investigated ways to improve participation for older adults and people with disabilities. However, more research is needed to understand the relationships between participation and health in a specific subgroup of people with disabilities: *persons aging with disability*. This term includes people who have lived with a disability for many years (e.g., spinal cord disorders, cerebral palsy) and also people who have acquired a disability later in life (e.g., stroke, Parkinson disease). Recent research suggests that the symptoms of pain, fatigue, and depression consistently affect the daily living experiences of people aging with disability. Our goal is to better understand how these symptoms influence social participation.

Therefore, we did a study to explore how personal characteristics and symptoms (pain, fatigue, and depression) influence social participation for people aging with disability. Specifically, we examined how one's symptoms, self-reported physical and mental health, and personal characteristics such as age, race and ethnicity, gender, number of years living with disability, marital status, living arrangement (i.e., whether they live alone or with others), food security, and annual personal income correspond with social participation outcomes.

Our Study

We looked at data from two time points—enrollment and 2-year follow-up—of a long-term study of people aged 45–65 with a physical disability. Each year for 3 years, participants answered a series of questions about their health and their participation in home and community activities. Participants had the option of finishing the survey online or over the phone for both the enrollment and 2-year follow-up surveys. The first survey took place before the COVID-19 pandemic, and the follow-up survey took place after the pandemic had been declared. Therefore, we analyzed the data separately rather than longitudinally. We analyzed data from 474 participants at enrollment and 329 participants at follow-up.

Findings

Participants who reported more fatigue, pain, and depression had lower scores for participation in social roles and activities at both time points. Participants with poorer physical health also had lower social participation outcomes.

Looking at personal characteristics, participants who were older, female, lived with others, or had a higher annual income had lower participation scores. On the other hand, participants who identified as African American/Black and those who reported better physical health had higher participation outcomes.

Overall, we found that health status, fatigue, pain, depression, age, gender, race, income, and living arrangement all influenced social participation. Participants with different personal characteristics and health statuses experienced different participation outcomes.

The findings of this study suggest that the presence and intensity of pain, fatigue, and depression affect social participation for persons aging with disability. Personal characteristics can also influence participation outcomes. These findings could help health and social care providers who work with adults who are aging with disabilities. Consideration of how an individual's personal characteristics and experiences with pain, fatigue, and depression influence their participation and social activity may be helpful for care providers who aim to improve the health outcomes and well-being of their patients who are aging with disability. Participation and social activity are important for all individuals, including those aging with disability, to age well and live healthy lives. The findings of this study may help care providers create new programs and care plans to better support and increase participation among people aging with disability.

Citation: Putnam, M., Morgan, K., Heeb, R., Yan, Y., Chen, S.-W., & Stark, S. L. (2002). Aging with disability symptoms and ability to participate in, and satisfaction with, social participation among persons aged 45–65. *Healthcare, 10*(5), 903. <https://doi.org/10.3390/healthcare10050903>.

The contents of this paper were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DPCP0001-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this paper do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.