Family caregivers’ perspectives on barriers to receipt of cervical and breast cancer screening among women with developmental disabilities

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Abstract: Women with intellectual disability do not receive cervical and breast cancer screening at the same number as women without disabilities. Numerous barriers to receipt of screening have been reported by individuals with intellectual disability, paid caregivers, nurses, and other medical professionals. This study utilized semi-structured qualitative interviews to assess barriers to care from the perspective of female familial caregivers (n = 32). Caregivers reported a number of barriers to care including not knowing or not believing the exam was needed for their family member and discomfort during exams. Caregivers also described enablers to screening. The most common response to what enabled the woman with an intellectual disability to receive the exam was preparation prior to the exam. A significant portion of the sample of family caregivers lacked knowledge about the need for cervical and breast cancer screening by women with intellectual disability. Policy recommendations are discussed.

Key Words: family caregivers; barriers; health screenings; women