

Successful Aging of Women with Intellectual Disabilities: The Toronto Experience

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Abstract

Older women with intellectual disabilities are a growing population, whose perspective has been traditionally ignored in research. This study aims to identify some key issues in aging for this group from the perspective of the women themselves. Nine women in the Greater Toronto Area participated in 1 to 2 hour interviews addressing personal demographics, economic and personal safety net, health, social roles, and well being. Findings indicate that these women face significant challenges as they age, especially in the areas of health and economic well being. Despite their challenging situations, most women report feeling relatively happy and are satisfied with the support in their lives.

According to the World Health Organization (1995), there will be 800 million older people in the world by 2025, a majority of whom will be women. As life expectancies become higher, it becomes more important to understand issues related to disability, health, and aging from the perspective of these women. Older women with intellectual disabilities constitute a growing population facing a unique set of health and health care access issues (Gill & Brown, 2002). Until recently, older people with intellectual disabilities remained a highly understudied population and gender specific concerns had not been addressed (Fine & Asch, 1988). In recent years, this has changed as a result of an emerging interest in older women with intellectual disabilities (Walsh, Heller, Schupf & Van Schrojenstein Lantman-de Valk, 2000). However, even the recent research has ignored the perspective of individuals with intellectual disabilities themselves, omitting a point of view which Stancliffe (1999) has argued should be considered "the best source of information."

The purpose of this study was to address the current gap in research in the area of aging and women's health by considering women with intellectual disabilities' perspectives on the aging process. Nine older women participated in structured interviews related to health and aging issues as part of a larger international project on healthy aging in women with intellectual disabilities (Walsh & LeRoy, 2002).

Method

Recruitment and participants

Nine women were interviewed for this project. Women were recruited through networking with social service agencies that serve persons with disabilities. Criteria for participation were being a woman in her late forties or beyond and having an intellectual disability. Participants were provided full information about the project and all gave informed consent to participate.

The women in this study ranged in age from 47 to 65, with a mean age of 57. All participants lived in the Greater Toronto Area and were living in either group homes (4/9) or apartments (5/9). Of those women in apartments, 4 lived completely independently, receiving support from a paid worker once a week or less. One woman was unmarried with children, one was engaged to be married, and the remaining women were single.

Procedure

Each participant was interviewed face-to-face in a location of her choice (typically the home) using a structured interview protocol designed by Walsh and LeRoy (2002). The protocol consisted of 103 questions, divided into five sections; personal demographics, economic and personal safety net, health, social roles, and well being. Interviews took place at a time and place chosen by the participant. In most cases (5/9), only the participant and the interviewer were present. In other interviews (4/9), participants chose to have a support worker present. Participants were allowed as much time as necessary to answer questions. Interviews typically took between 1 and 2 hours.

Results

Economic and Personal Safety Net

Questions in this subsection of the measure dealt with supports available both personally and economically. Most women appeared to struggle financially. All participants relied primarily on the government for economic support. Some women were able to supplement this income with monetary contributions by family members or part time work. However, several women (4/9) revealed that they did not have enough money to do the things they wanted to do. When asked if they would like to change anything about their financial situation, most (7/9) women indicated that they would like to have more money. Most (6/9) women said they managed their own money, with support in some cases.

Most of the women interviewed (8/9) identified a paid worker as their primary support person. Support people were reported to help with activities like cooking, cleaning, and housework. Most women (8/9) reported at least partial independence in housework (8/9), laundry (8/9), and shopping (7/9). Most (8/9) felt their primary support person was available when needed and all women felt this person was generally reliable.

Health

In this subsection, participants were questioned about their overall health and any barriers to healthy living. Most women reported at least one chronic health concern, such as arthritis, diabetes, and mobility difficulties. Most women (6/9) felt that their health was preventing them from doing what they wanted to do. For instance, several women had to discontinue or lessen involvement in community activities because their health was preventing them from traveling to or participating in the activity. All participants reported having seen a doctor in the past three months, and most (7/9) women had also seen a dentist in the past year. On a four point scale ranging from excellent to very bad, 5 women rated their overall health as 'good' and 4 women rated their overall health as 'poor.'

Participants were also asked about their health in terms of diet and exercise. Five women rated their diet as excellent or good and 4 women rated their diet as poor or very bad. When asked about favourite foods, many women reported that they enjoyed foods such as chicken, hamburgers, fries, and

pasta. Most (8/9) women said they were able to choose their own meals and eat food they enjoyed. Most (5/9) women reported participating in some kind of exercise at least once a week on a regular basis.

Social Roles

This subsection of the interview protocol focused on relationships with family and friends, community involvement, and recreation and leisure activities. Most women (7/9) reported they do not spend time with or speak with family members more than a few times a year. Participants spent time with family members on special occasions more than on a regular basis. Most participants (7/9) reported having lost significant family members, which is characteristic of their age and stage in life. Many women indicated that they missed their parents and that life had changed since their passing.

All women spent time with a friend at least once a month. Most women (7/9) felt they had someone with whom they could do something special. Friendships appeared to be linked with living situations (e.g., having friends in the same apartment building or group home) or service programs (e.g., having friends from the same day program or bingo group). Most women (8/9) stated that their friendships had changed as they grew older, some stating that they saw friends less or had fewer friends, and others reporting that they had more friends now than in the past.

When asked about leisure and recreational activities, most women reported participating in structured activities such as bingo, crafts, and bowling at least once a week. Many of these activities were agency organized but some were more general community based activities. Most women (5/9) reported doing activities with other people more than alone. It should also be noted that despite involvement in such activities, many (5/9) women indicated that they usually or almost always had nothing to do in their spare time.

Well Being & Happiness

When asked to rate their overall happiness, 5 women reported they were "happy" and 4 women said they were "so-so." Women commonly cited the people in their lives (e.g., friends, support workers, family members) as important contributors to their happiness. Many women also said their pets, hobbies, and day-to-day activities were of high importance to them. However, these women also struggled with feeling down at times. One participant stated "I worry about getting through the depression and frustration I'm going through." In terms of coping strategies, most women

(8/9) said that friends or support workers were there to help them through significant life events. One woman said, "To solve problems, I talk with [a social worker]. If I get myself in trouble, she'll be there." These women were generally optimistic about their futures, and were able to identify positive strategies and philosophies of life. As one woman put it, "The secret to my life is being strong, having self confidence, and trying the things I want to do."

Discussion

The purpose of this study was to examine issues related to aging for women with intellectual disabilities. Overall, these women welcomed the opportunity to share their stories and experiences. Interviews revealed they had a lot to say. Generally speaking, it was found that these women faced challenges in several facets of life, but still reported being relatively happy and satisfied with their lives overall.

More specifically, it was found that finances and health are two key areas where these women face difficulties. Many of the women interviewed had also experienced loss of friends or family members as they aged, which supports Lunsky's (in press) finding that the experience of loss is quite common. Paid support from agencies and workers was highly valued by these women, helping them persist through difficult times and cope with challenging circumstances. Supporting parties also played a significant role in these women's participation in recreation and leisure activities, as they did not tend to be active in their communities alone.

It is vital that agencies and support workers continue to provide programming and opportunities for active participation for this population. This will undoubtedly involve a fine balance between provision of support and allowing women the freedom to age as they please and take care of themselves. As noted by Stalker and Harris (1998), the opportunity to make choices is often lacking for people with intellectual disabilities. As more research in this area emerges, findings can be applied to development and practice of more effective programming. It should be noted that despite facing many challenges, women are quite active in their communities and relatively happy overall.

Considering this project's small sample size, it is difficult to draw conclusions about a larger population. Future research could expand its scope and involve a greater number of women with intellectual disabilities. It would be interesting to learn the perspective of women still living with

parents, as well as the perspective of those living in less urban settings. This will be addressed in part in the larger project by LeWalsh and Roy, which will consider cross-cultural issues. Finally, future research could involve friends, workers, and family members of women with intellectual disabilities, addressing differences in perspectives.

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