

## EXPLORING BREAST HEALTH EDUCATION AND KEY EDUCATIONAL PROVIDERS FOR WOMEN WITH INTELLECTUAL DISABILITIES IN AUSTRIA

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### Abstract

Women with intellectual disabilities (ID) show lower participation rates in breast cancer screening than the general population. This leads to cancer being diagnosed at a later stage and higher morbidity. Studies previously highlighted the importance of education targeted at women with ID. Being educated on and understanding the importance of leads to higher utilization of breast cancer screening. However, it is yet to be explored what proportion of women with ID received breast health education in Austria. Moreover, it remains unclear who is delivering breast health education. In order to successfully target educational providers when designing educational measures, it is crucial to identify them first. This study aims to explore breast health education in women with ID in Austria. First, we aim to assess the proportion of women with ID who have previously received education on breast health, focusing on breast cancer, mammography and breast palpation. Further we aim to identify who provided them with information on the respective topics. Data collection was part of a larger online survey on breast cancer screening in Austria. We surveyed 113 primary caregivers of women with ID. Given their close connection and importance in facilitating healthcare, they represent a reliable source of information for this purpose. For this study, characteristics of women with ID and their caregivers, as well as information on breast health education was collected. Results suggest that half of the women with ID (49.6%) received education on breast cancer. A majority of the women with ID (63.5%) were provided with information on mammography and approximately 24.8% received education on breast palpation. Education on mammography was significantly associated with characteristics of women with ID. Further, education on breast cancer and mammography was mostly provided by caregivers themselves, medical personnel and social workers. Education on these domains was rarely, to almost never, delivered through educational institutions, media or family members. Comprehensive results will be presented at the conference. The results of this study show a lack of education on breast health in women with ID in Austria. Medical personnel and caregivers seem to be primarily responsible for breast health education. Contrarily, educational institutions seem to represent an underutilised source, which could potentially offer a range of possibilities for providing education. This study offers information on who to target for educational means and lays a foundation on eventually providing a comprehensive breast health education for women with ID.

**Keywords:** *Intellectual disabilities, breast health education, breast cancer, mammography.*

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### 1. Introduction

Women with intellectual disabilities (ID) show lower participation rates in breast cancer screening than women without ID, while invalid screening outcomes occur more frequently (Banda et al., 2025; Horsbøl et al., 2023; Khan et al., 2024). This contributes to the inequalities in cancer care, which people with ID are facing. Cancer is often detected at later stages in individuals with ID, undermining the benefits of early detection and contributing to higher morbidity. Consequently, cancer-related mortality, including breast cancer mortality, is approximately 1.5 times higher among individuals with ID than in the general population (Cuypers et al., 2022).

Education has been recognised as a pivotal factor in shaping screening participation rates among people with ID (Kuper et al., 2024; Power et al., 2024). A deficit of information represents a significant barrier, as insufficient understanding increases distress and limits the capacity for informed decision-making (Wagner et al., 2026). As people with ID have expressed a desire for more information in prior studies, accessible and tailored materials can facilitate higher screening uptake (Kuper et al., 2024; Wagner et al., 2025).

Given the importance of increasing breast cancer screening participation among women with ID, targeted education on breast cancer and mammography is critical. Moreover, literature underscores the value of education on breast self-palpation. As it serves as a valuable additional preventive measure, targeted information may encourage regular practice (Wagner et al., 2026).

To effectively enable education on these aspects, an understanding of the baseline educational situation is needed. However, data on breast health education for women with ID in Austria is lacking. The current study aims to address this gap by investigating breast health education for women with ID from the perspective of caregivers. It aims to provide empirical evidence on the proportion of women with ID who have received education on breast health aspects and to identify educational providers.

## **2. Methods**

### **2.1. Materials**

Data for this study represent a subset of data stemming from a large, comprehensive online survey on breast cancer and breast health in women with ID in Austria. The survey was administered through SoSci Survey (Leiner, 2023). After providing informed consent, participants, primary caregivers of women with ID, completed items assessing knowledge and education regarding breast health and breast cancer screening. Given caregivers' close involvement in the health care of individuals with ID, and the study's focus on objective knowledge rather than subjective components, caregivers represent a useful source of information on this matter (Perkins, 2007). To assess breast health knowledge and experiences with breast health education, caregivers were asked to respond from the perspective of the woman with ID they provided care for. If caregivers supported more than one woman with ID aged 45 years or older, they were instructed to answer with reference to the woman they knew best. For each topic on which the woman had received education, participants were subsequently asked to indicate the corresponding educational provider. Sociodemographic characteristics of caregivers and the woman with ID were assessed. Caregivers were asked to rate their own knowledge of breast cancer and breast cancer screening on a 7-point Likert scale. Completion of the entire survey required approximately 10 minutes.

### **2.2. Procedure**

Participants had to be (1) over 18 years old and (2) a primary caregiver of at least one woman with ID, being aged 45 years or older. Participation was voluntary and participants could withdraw from the study at any point without providing a reason. Participants were recruited by distributing invitation links for the online survey to representatives of organizations providing services to people with ID. Additionally, a snowball sampling approach was used to encourage further distribution of the survey to potentially interested individuals. To achieve a broad representation, organizations in every Austrian federal state were contacted. Given the exploratory nature of the study, no a priori sample size was determined and data collection ended on a predetermined date. The study was conducted in line with the Declaration of Helsinki and obtained approval from the Ethics Committee at the Medical University of Vienna (No. 1345/2022; approval date: 13.07.2022).

### **2.3. Statistical analyses**

All analyses were descriptive. Education rates and educational providers were analysed using frequencies. Sample characteristics, including caregiver information and information about the woman with ID, were summarized using measures of central tendency and frequencies. Chi square tests were used to examine associations between breast health education and characteristics of women with ID. Percentages were based on the available responses to each question. All analyses were conducted in IBM SPSS (Version 31.0).

### 3. Results

#### 3.1. Sample characteristics

The final sample size comprised 113 caregivers, each reporting information for one woman with ID. The age of women with ID represented in this study ranged from 44 to 74 years ( $M = 56.3$ ,  $SD = 7.3$ ). Acknowledging that the inclusion criteria required women to be over 45 years of age, we retained data for the women aged 44 ( $n = 2$ ) as they had previously participated in breast cancer screening and were therefore considered relevant for the sample. Further sample characteristics are presented in Table 1.

Caregivers were aged 22 to 63 years ( $M = 41.7$ ,  $SD = 10.6$ ). Most caregivers were female (88.1%), followed by male (11%) and other gender (0.9%). Mean working experience with people with ID was 13.4 years ( $SD = 9.2$ , range = 1 – 34). The majority of caregivers were employed in the social care sector as support workers or care workers in residential homes. The remaining 5.4% reported another role. Examples include psychotherapist and outreach support worker. Caregivers' self-rated breast cancer and breast cancer screening knowledge (1 = none, 7 = excellent) was relatively high ( $M = 5.3$ ,  $SD = 1.3$ ).

Table 1. Socio-demographics of Women with ID.

Characteristic	<i>n</i>	% <sup>a</sup>
Communication mode <sup>b</sup>		
Verbal	98	87.5
Nonverbal (gestures, facial expressions)	13	11.6
Nonverbal (sign language)	3	2.7
Relationship status		
Single	76	75.2
In a relationship	25	24.8
Living area		
Rural	40	35.7
Urban	58	51.8
Suburb	14	12.5
Hearing disability <sup>c</sup>	12	10.8
Level of ID		
Mild	37	33.9
Moderate	56	51.6
Profound	16	14.7
Reading proficiency		
No reading ability	30	26.8
Poor	12	10.7
Somewhat poor	19	17.0
Moderate	17	15.2
Somewhat good	16	14.3
Good	14	12.5
Excellent	4	3.6
Writing proficiency		
No writing ability	26	23.2
Poor	22	19.6
Somewhat poor	20	17.9
Moderate	19	17.0
Somewhat good	13	11.6
Good	8	7.1
Excellent	4	3.6

Note. <sup>a</sup>for calculation of percentages, missing values were excluded. <sup>b</sup>Multiple responses were allowed. <sup>c</sup>Reflects the number and percentage of participants answering "yes" to this question.

#### 3.2. Breast health education and educational providers

Results indicate that half (49.6%;  $n = 56$ ) of the women with ID had received education on breast cancer. A majority (63.5%;  $n = 72$ ) of women has been educated on mammography and 24.8% ( $n = 28$ ) had received education on breast self-palpation. In total, 13.8% indicated that the woman with ID had not received information about either breast cancer, mammography, or breast palpation. Chi-square tests indicated significant associations between level of ID and education on both mammography

( $\chi^2(2, n = 109) = 11.85, p = .003, V = .33$ ) and breast self-palpation ( $\chi^2(2, n = 109) = 9.18, p = .01, V = .29$ ). Moreover, education on mammography was associated with relationship status ( $\chi^2(1, n = 101) = 4.64, p = .031, V = .21$ ). and living area ( $\chi^2(2, n = 112) = 6.77, p = .034, V = .25$ ). There were no significant associations between education on mammography or self-palpation and the remaining characteristics. Breast cancer education was not associated with any personal characteristics.

Education on these domains was most commonly provided by caregivers themselves, medical personnel, and social workers. Educational institutions and media were rarely reported as providers. Detailed information on educational providers is presented in Table 2.

Table 2. Educational Providers for Breast Health Education.

Educational provider	Breast cancer (N = 56)		Mammography (N = 72)		Breast self-palpation (N = 28)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Caregivers themselves	27	47.2	42	58.3	8	28.6
Medical personnel	43	76.8	53	73.6	20	71.4
Social workers	20	35.7	26	36.1	5	17.9
Educational institution	1	1.8	2	2.8	-	-
Media (e.g. social media)	4	7.1	5	8.9	2	7.1
Family members	11	19.6	7	12.5	2	7.1

Note. Numbers and percentages indicate respondents who selected each educational provider. Multiple responses were allowed.

#### 4. Discussion

This study examines the current state of breast health education for women with intellectual disabilities (ID) in Austria. The findings indicate a substantial lack of education on breast health among women with ID. Notably, only half of the women had been educated about breast cancer. Given that the sample consists exclusively of women at an age relevant for breast cancer screening in a country with an established screening program, this result is particularly concerning.

Interestingly, education about mammography was more common than education about breast cancer itself. However, the importance of breast cancer awareness has been established (Walsh et al., 2021), and knowledge about cancer should not be omitted. Breast self-palpation was introduced to only a small proportion of women with ID. Yet it has considerable potential, as it can be practiced without a doctor's visit. Future education should incorporate this component as an additional preventative measure.

It is important to note that the sample comprised professional caregivers who reported relatively high levels of breast cancer knowledge for themselves. Consequently, education rates might be even lower among women with ID whose caregivers report lower awareness of breast cancer. Given that personal attitudes and time resources of caregivers can influence participation in breast cancer screening (Sykes et al., 2024), there is a need for systematic educational offers for women with ID.

This study also identifies key educational providers for women with ID. Medical personnel and caregivers themselves are primarily responsible for breast health education. Educational institutions currently play a largely underutilized role. Despite women with ID expressed interest in receiving education, there is a lack of inclusive materials (Wagner et al., 2026). Educational institutions likely have the expertise and resources to develop and disseminate accessible materials and can contribute to improving access to health education. Ultimately, women should be able to decide from whom they prefer to receive information about potentially sensitive topics. However, necessary resources should be established to support these choices, as accessible education is essential to improving screening uptake (Kuper et al., 2024; Power et al., 2024) and ultimately lowering breast cancer mortality.

This study did not assess individuals with ID directly, representing a limitation to these findings. Future research should explore cancer-related education from the perspectives of women with ID themselves.

Overall, the results highlight substantial gaps in breast health education among women with ID and identify key educational providers.

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