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Measuring Preparedness for Mammography in Women with Intellectual Disabilities: A Validation Study of the Mammography Preparedness Measure

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Abstract

Background

Women with intellectual disabilities have similar breast cancer rates as the general population, but lower rates of regular mammography and higher breast cancer mortality rates. Although prior qualitative work demonstrates that women with intellectual disabilities face unique, disability-specific barriers to mammography, the present authors lack standardized, validated instruments for measuring knowledge of breast cancer screening in this population. In addition, much research related to adults with intellectual disabilities focuses on family or carer perspectives, rather than

involving women with intellectual disabilities, themselves.

Methods

The present authors first pilot tested a general population instrument measuring breast cancer knowledge, and found that it did not perform adequately in women with intellectual disabilities. In response, the present authors developed the Mammography Preparedness Measure (MPM), a direct short interview tool to measure knowledge and preparedness in women with intellectual disabilities, themselves, rather than relying on caregiver or other reports, and using inclusive methodology. The present authors validated the MPM by assessing test–retest reliability.

Results

Average test–retest per cent agreement of 84%, ranging from 74 to 91% agreement per item, with an overall kappa of 0.59.

Conclusion

The MPM appears to be a valid instrument appropriate for measuring mammography preparedness in women with intellectual disabilities. The success of this innovative tool suggests that direct, rather than informant-directed tools can be developed to measure health knowledge and cancer screening readiness in adults with intellectual disabilities, an important measure in studying and reducing disparities.

Background

Although individuals with intellectual disabilities are now living longer, to a mean age of 66 years (Janicki *et al*. **1999**), compared with the general population's life expectancy of 70 in the United States (Mathers *et al*. **2001**), they represent a medically underserved population (Jobling **2001** ; Krahn *et al*. **2006** ; Wisdom *et al*. **2010**). Adults with intellectual disabilities experience significant health disparities in accessing primary care (Langan *et al*. **1993** ; Stein **2000** ; Alborz *et al*. **2005**), routine cancer screenings (Espie & Brown **1998** ; Sullivan *et al*. **2006** ; Wilkinson *et al*. **2007**) and health education and knowledge. Standard patient education materials may not be accessible for people with intellectual disabilities, who have varying levels of literacy (Greenhalgh **1994**). There are also significant disparities in research participation, which in turn leads to difficulties in measuring health inequities (Freedman **2001**). Although notable exceptions exist, research related to the health of people with intellectual disabilities tends to focus on the perspectives of family members and other carers, excluding adults with intellectual disabilities, themselves. In the general population, lack of health knowledge is often a driver of health disparities. Although low health and general literacy is

thought to be associated with health care access disparities in adults with intellectual disabilities, the present authors lack effective and inclusive tools for measuring health knowledge in individuals with intellectual disabilities. Without appropriate measurement tools, the present authors are unable to compare adults with intellectual disabilities with their peers without disabilities, and the present authors lack means of evaluating interventions to improve health knowledge. Therefore, developing inclusive and accessible tools to measure health knowledge in adults with intellectual disabilities is an important step to reducing health disparities in this population.

Adults with intellectual disabilities face disparities in cancer screening rates, and have unique needs related to cancer (Satge & Merrick **2011**). For example, women with intellectual disabilities have equal rates of breast cancer as compared to the general population of women (Patja, Eero & Iivanainen, **2001**), Breast cancer is the second most common cancer among women, impacting approximately one in eight women. Current thinking suggests early detection through regular mammography as a key component of breast cancer control (Women'sHealth.gov,). In the United States, the United States Preventive Services Task Force recommends that all women over age 50 receive yearly mammograms, a screening test involving imaging of the breasts. Other agencies, such as the American Cancer Society, recommend that yearly mammography screening begin at age 40. Standard of care in our community is to offer mammography screening to all women beginning at age 40. It is beyond the scope of this paper to address the controversy in age of mammography initiation, as our concern is health equity among women with and without intellectual disabilities. In the general population, mammography rates are rising, and several successful breast cancer screening initiatives have reduced disparities in mammography rates among ethnic and racial minority groups (Peek & Han **2004** ; CDC **2011**). However, women with intellectual disabilities have very low mammography rates, with rates of regular mammography as low as 12%, and higher breast cancer mortality, thought to be associated with lower rates of early detection (Davies & Duff **2001** ; Sullivan *et al* . **2003** , **2004** ; Parish *et al* . **2006**).

Women with intellectual disabilities face unique, disability-specific barriers to mammography utilization, including increased dependency on others, such as family or paid support workers, low levels of support staff knowledge regarding breast health and lack of physician recommendation of mammography to women with intellectual disabilities (Iacono & Sutherland **2006** ; Tuffrey-Wijne *et al* . **2006** ; Barr *et al* . **2008** ; Kirby & Hegarty **2010** ; Tyler *et al* . **2010**). In addition, recent studies have demonstrated that women with intellectual disabilities perceive mammography differently than their counterparts without disabilities (Wilkinson *et al* . **2011**). Women with intellectual disabilities are more likely than their non-disabled peers to have low knowledge about breast cancer and breast cancer screening, anxiety about navigating the various steps of the mammogram process, such as checking in at the clinic, disrobing etc., lack of health education and feelings of unpreparedness for the test itself (Wilkinson *et al* . **2011**). In the past, the present authors conducted a qualitative study asking women with intellectual disabilities about their perceptions of breast cancer and mammography screening using an interview guide focused on barriers and facilitators to cancer screening (removed for review). In this prior study, women with intellectual disabilities felt neutral about the actual clinical mammogram procedure, but expressed frustration with their lack of preparedness for the logistical aspects of the mammography experience.

Although ensuring that women with intellectual disabilities access cancer screenings at the same rate

as their non-disabled peers is an advocacy priority, clinicians, policy makers and researchers currently lack a proven and effective intervention to help increase the rate of mammography uptake in this population (Center for Disease Control **2011**). To effectively develop and evaluate interventions to increase health knowledge and cancer screening rates, the present authors first need instruments that can measure breast cancer knowledge and preparedness for mammography in women with intellectual disabilities. Such instruments would allow researchers to evaluate and demonstrate the effectiveness of future interventions to increase breast cancer knowledge and screening rates. Many instruments used in other studies have been developed for patients with intellectual disabilities. However, these scales were designed for and found to be reliable only when completed by parents, caretakers or the general population (Maas *et al*. **2011** ; Bastiaanse *et al*. **2012** ; Morin *et al*. **2013**). They were not developed for patient self-reported measures (Taylor & Novaco **2013**). In recent years, the present authors have seen a positive trend towards inclusive research, which has been quite successful with people with intellectual disabilities, and so the present authors felt that an instrument based on reports from adults with intellectual disabilities, rather than their carers, was warranted.

In connection with our prior qualitative study, the present authors administered selected questions from the Breast Cancer and Heredity Knowledge Scale (BCHK) (Ondrusek *et al*. **1999**) to a sample of 27 women with intellectual disabilities. The BCHK is a standardized instrument that has been validated as effective in measuring knowledge of breast cancer in the general population. The BCHK using a true/false format asks factual questions related to breast cancer signs and symptoms, treatments and incidence and survival rates, using a true/false format. In the prior study, the present authors choose not to ask questions related to hereditary risks; the questions selected are listed in Table 1. During the course of our prior qualitative study, the present authors noticed that participants with intellectual disabilities found the BCHK too abstract, and answered with great difficulty. In addition, while the BCHK measures factual breast cancer knowledge, it does not address the more logistical and practical concerns raised by women with intellectual disabilities in our qualitative study. So while a woman might theoretically understand the factual knowledge measured by the BCHK, she might still feel unprepared or unable to actually receive screening mammography.

Table 1. Breast Cancer and Heredity Knowledge Scale (BCHK) questions and responses

BCHK pilot test questions	% Correct answers	Representative qualitative comments – when asked what they thought the question meant
Q1: 75% of women with breast cancer are alive and well 10 years later	70	“It would be good to do all the tests.” “You don't get it done, women could die.” “I don't know.” “A lot of women with breast cancer still don't go to doctors and get it checked out and everything.”
Q2: Stress increases the risk of breast cancer.	70	“I don't know what that means.” “Well I don't have breast cancer but I do have stress.”

		"Means it hurts like its painful" "You don't want to get breast cancer or something like that."
Q3: Women over 50 are more likely to get breast cancer than younger women	70	"Yeah. 54, I'm gonna be 54." "Yeah, I don't understand these questions."
Q4: A change in size or shape of one breast could be a sign of breast cancer	78	"They check for cancer in your breast, if you have it in one, you could have it in the other one."
Q5: Over a lifetime, one in nine women will develop breast cancer.	78	"I don't know what you mean by that." "Nope, I'm healthy." "It means that you'll get the cancer. And then if they can't cure it, it will be too late."
Q6: Chemotherapy is always used to treat breast cancer	39	"I thought chemotherapy was for your hair?" "What does [chemotherapy] mean?" "A medicine that brings your hair back?" "When someone has leukaemia they go through chemo."
Q7: Women over 50 should get a mammogram every 2 years	91	"You should have one every two weeks, I mean every month."

At the start of this project, the present authors thoroughly reviewed participant responses on the BCHK questions from our prior study, which had been audio recorded and transcribed verbatim as part of the qualitative interview process. Although per cent of correct responses among our sample of 27 participants were generally high (ranging from 38 to 91% correct responses, with an average of 70.8% correct answer rate on the seven questions the present authors administered), the present authors also reviewed participants' comments in connection with the questions. Representative responses are described in Table 1. In general, participants did not appear to understand the questions, and often appeared to be guessing either true or false. Through this content analysis, it was clear that standardized instruments using a true–false format were ineffective in our sample population of 27 women with intellectual disabilities. In addition, standard instruments measuring breast cancer knowledge are ineffective for measuring preparedness for mammography among women with intellectual disabilities.

Therefore, the present authors have developed a new instrument more appropriate for women with intellectual disabilities called the Mammography Preparedness Measure, or MPM. It focuses on the respondent's (women with intellectual disabilities) desire to be more prepared for the mammography and uses concrete wording and an open-ended format. The MPM was created with our target population in mind and consists of verbally administered questions that use concrete wording and measure mammography preparedness, as demonstrated by concrete knowledge of mammography's

purpose and procedure. The MPM provides a means of measuring the success of future interventions developed for this target population. The MPM measures each participant's preparedness for mammograms directly by having the participant complete the survey without help from relatives or caregivers. The MPM is unique in that it collects information directly from the women themselves, providing a patient-centred measurement of the patient's mammography preparedness, rather than the knowledge of her supporters. The present authors evaluated the MPM's test–retest reliability and face and content validity.

Methods

Evaluating a general population instrument in adults with intellectual disabilities

As described above, the present authors first analysed the performance of prior participants on the BCHK, an instrument designed to measure breast cancer and mammography knowledge in the general population. In our prior study, the present authors administered the BCHK to a sample of 27 women with intellectual disabilities. Results were tape recorded and transcribed. The present authors analysed these transcripts qualitatively using content analysis to determine whether it appeared that participants understood the questions. While participants had a high rate of correct answers on the true–false items, comments made by the participants in response led us to believe that most participants were simply guessing, with a 50% likelihood of guessing correctly on a true–false survey item. For example, when asked if chemotherapy was always used to treat breast cancer, the participant answered no, which was the correct answer, but went on to state that chemotherapy is a treatment for hair. Another participant also provided the correct answer, but then elaborated that chemotherapy is a treatment for leukaemia. Our content analysis demonstrated that participants did not generally understand the BCHK questions, and that the true–false format was inaccessible for many adults with intellectual disabilities, as it seemed to encourage blind guessing with a 50% likelihood of success. This led to the development and evaluation of the MPM, an instrument designed for use in adults with intellectual disabilities.

Developing the MPM

The MPM was developed using focus group interview data from our previous qualitative study (Wilkinson *et al*. **2011**) in which participants were asked what they would like to have known in advance of their first mammography experience and what mammography knowledge they considered essential. An 8-item scale was drafted from this data and tested on a pilot group of 10 women with intellectual disabilities using cognitive interviewing (where the present authors asked what the participant thought the question meant to see if it corresponded to what the present authors wanted it to mean) (Willis **2005**). Based on this pilot data, three questions were removed due to participant confusion, and the final instrument was created.

Materials

The MPM's items include open-ended questions regarding what body part a mammogram is for, the purpose of mammography, whether disrobing is required, how long a mammogram will take to complete, and how often one should have a mammogram. These items were selected because of their practical nature. The MPM uses a standardized introductory script in which the interviewer asks the respondent to pretend that the interviewer is having a mammogram the following day, and informs the participant that she would like her help in understanding the process. This script was developed in response to pilot testing with women with intellectual disabilities, who stated that the questions should be made as concrete as possible, and suggested putting the questions in the context of a story to facilitate comprehension through relationship-based understanding. The script includes language stating that incorrect answers are not penalized and that only the participant's opinions are needed. Guardians and caretakers are allowed to be present to help ensure the participants' comfort, but the MPM's introductory script states that they may not assist the participant in answering the questions.

Evaluation

Objectives

To evaluate the MPM, the present authors focused primarily on test–retest reliability (the extent to which participants' answers remain stable over time, reflecting that their understanding of the questions' meanings is consistent). This was our primary outcome of interest as the present authors noted a high rate of random guessing on the prior instrument (see above) and also because the present authors thought test–retest reliability would most accurately reflect the suitability of the instrument for the population. The present authors looked, secondarily, at both face and content validity to assess the instrument. Face validity is the extent to which the questions seem to reflect their actual meaning. Content validity is the extent to which the questions ask about a content area that is easily defined and clear from reading the questions. Both of these concepts are relatively straightforward to assess with an instrument as concrete as the MPM, so the present authors used data from preliminary testing and cognitive interviewing to assess this.

Participants

Recruitment

Our goal was to access a cross-section of women with intellectual disabilities who were in the appropriate age for mammography. Adult women over the age of 37 were asked to participate in this study. The present authors initially attempted to recruit participants using the clinical data warehouse at Boston Medical Center. In this strategy, a clinical data warehouse consultant queried the repository to identify female patients with an ICD-9 code indicating intellectual disability who were within or approaching the age range for mammography (ICD-9 codes included 3.17 through 3.19; at the time of the study, our institution had not yet transition to ICD-10 codes. ICD 9 and ICD-10 codes are diagnostic codes used primarily for billing). The clinical data warehouse provided us with an initial list that included 172 patients. This list contained the patient's name, age contact information and name of the primary care provider (PCP) serving that patient. The present authors then attempted to contact each identified PCP. PCPs were asked to verify their patient's intellectual disability and to determine the appropriateness of contacting the patient. The present authors were able to contact PCPs for 96 of

172 patients and were given approval to contact 30 patients. Of these, the present authors were able to contact 17 patients, nine of whom agreed to participate. Eight of these nine patients ultimately participated; one did not attend her scheduled study visit and did not respond to follow-up calls (See Figure 1).

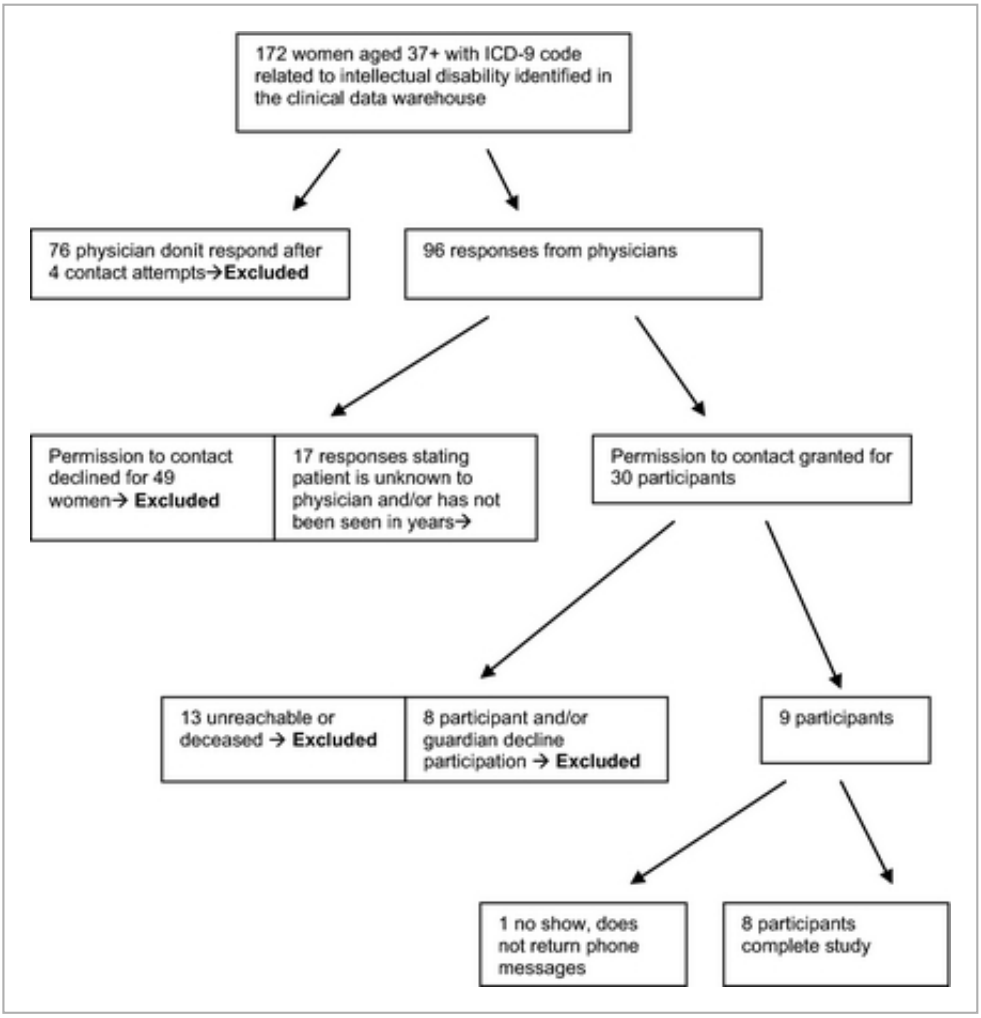

Figure 1.

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Recruitment flow chart.

To expand our participant pool, the present authors then partnered with four local agencies that provided services for people with intellectual disabilities. Partner agencies were asked to approach eligible clients (defined as females with intellectual disabilities over age 37 with sufficient verbal skills to answer questions) and obtain their permission to be contacted by a researcher during a visit to an agency site. Researchers then visited and provided further information and obtained informed consent. The majority of our participants (n = 40) were recruited through these community partnerships, a recruitment strategy that was ultimately simpler and more high-yield than our initial strategy of recruiting through our clinical data warehouse (as described above).

No medical records were accessed, and only information on the patients' PCP and contact information

was provided to the PI. To protect participant confidentiality and privacy, the present authors did not request information about specific intellectual disabilities diagnosis or severity, other diagnoses, disabilities or medical issues, medications used or the presence of mental health disorders. The present authors also did not inquire about participants' marital status, literacy levels, educational attainment or work. While the present authors recognize that these variables might impact access to mammography, the present authors did not feel that our study's aim of validating a survey instrument justified the invasion of patient privacy that collecting additional variables would entail. Functionality was used as the benchmark of enrolment criteria instead and patients who were verbal enough to understand and answer questions read to them in the MPM and could provide informed consent were enrolled in the study. All participants were English speakers, as the present authors did not have a translated version of the MPM. Participants included a wide range of verbal abilities, from highly articulate to communicating solely through the use of a pictorial/alphabetical communication board. While the present authors recognize that a significant amount of the intellectual disabilities population is minimally verbal or non-verbal, these participants were excluded from our study, as the present authors were interested in validating an instrument designed for verbal participants, including those who effectively use adaptive technology to communicate.

Procedure

Test–retest reliability

A research coordinator who is also a family caregiver of an adult with intellectual disabilities visited all participants and administered the MPM on both occasions using the same procedure. While experienced in interacting with adults with intellectual disabilities, she did not have any training in mammography or health care navigation. Once participants were identified and had given their consent for participation, the present authors met them at their homes or workplaces for the preliminary interview and MPM administration. Three to six weeks following the first administration of the MPM, the same research coordinator re-administered the MPM to each participant again. More information (e.g. did the participant get a mammogram between the two interviews?) was gathered from the participant's caregiver to identify any factors that may exclude the data from analysis.

Face validity and content validity: The MPM represents a test for mammogram preparedness; because it measures concrete, objective knowledge, its face validity was easily demonstrated by assessment from women with intellectual disabilities during pilot testing. Staff members were also asked to provide their opinions, to triangulate data from the experts (women with intellectual disabilities). Its content validity was also measured during pilot testing when the present authors interviewed a group of women with intellectual disabilities using cognitive interviewing.

Statistical analysis

The present authors assessed the test–retest reliability using per cent agreement between time 1 and time 2 and calculating an overall kappa for the entire instrument. Validity was assessed qualitatively using the participants' comments during pilot testing.

Consent and human subject protection

The present authors used a careful process of informed consent where participants were given verbal and written information about the study in a private setting and all questions were answered. If a participant identified that she used a legal guardian, consent was obtained from the guardian with assent obtained from the participant. Our study was approved and monitored by the (removed for review) Institutional Review Board.

Results

The present authors administered the MPM to 48 adults with intellectual disabilities over age 37. Characteristics of the participants are described in Table 2. It should be noted that a majority of participants had already undergone mammography on at least one occasion. The present authors were interested in enrolling participants with prior mammogram experience, as the present authors wanted to know how well women understood their experiences, and the present authors wanted to measure mammography knowledge, which often comes from personal experience. One participant was excluded because she had received a mammogram in between tests, potentially biasing her results, as she may have learned new information during her very recent experience, making her answers different from each other, and thereby impacting our ability to measure test–retest reliability. There was a low loss-to-follow-up rate, with only one participant withdrawing from the study per guardian request after the first study visit. The present authors were unable to re-administer the MPM to an additional five participants due to unforeseeable circumstances such as illness/medical appointment/family event and absence from her day programme during the research coordinator's scheduled visit.

Table 2. Participant characteristics

Characteristic	Number	Per cent
Total participants	48	100
Residence type		
Group homes	14	29.1
Independent (with live-out support services)	15	31.25
Supported living	3	6.25
Family	7	14.58
Other or unknown	9	18.75
Lives with other enrolled participants?		
Yes	8	16.6
Previous mammogram?		

Previous mammogram?		
Yes	44	91.6
Age		
37–39	3	6.25
40–49	11	22.91
50–59	13	27.08
60–69	15	31.25
70+	6	12.5

The mean time between the first and second interview was 37 days. After both of the interviews, the participant's answers were taken and marked as either correct or incorrect according to the MPM's scoring guidelines (see Table 3). A per cent agreement was calculated to determine how many of the participants answered each question correctly or incorrectly on both the test and the re-test (Table 3). As shown in Table 3, question 3 has the highest %-agreement. All questions on the survey have a high %-agreement above 70% ranging between 74 and 91%. Mean percentage agreement was 84% with kappa of 0.59. This indicates fair to good test–retest reliability (in general, kappa > 0.8 is excellent, >0.6–0.8 is good, 0.4–0.6 is fair and below 0.4 is poor). Through participants' and staff member's feedback and cognitive interviewing in the pilot study, the MPM demonstrated face and content validity. The participants showed good comprehension of the items, which corresponded well to their intended meaning.

Table 3. Per cent agreement per question

Question	% Agreement
Q1: What part of the body is the mammogram for? Correct = breast (or any reasonable slang term)	88%
Q2: Why would I have a mammogram? Correct = check for cancer, must include cancer and screening (not curing etc.)	86%
Q3: Would I have to take my clothes off for a mammogram? Correct = top only, shirt and bra etc.	91%
Q4: When I have the mammogram how long will I be in the machine? Correct = any answer under 30 min	74%
Q5: How often am I supposed to have a mammogram?	86%

Correct = every year or every other year, annually etc.	
Overall Kappa	0.59

Discussion/Conclusions

In this study, the present authors developed and validated the MPM, a reliable instrument to evaluate the mammography preparedness of adult women with intellectual disabilities. Test–retest reliability was demonstrated over a period of weeks. The MPM also demonstrated face and content validity.

To our knowledge, the present authors are the first to investigate the reliability of an instrument measuring health knowledge and readiness for adults with intellectual disabilities who provide their answers without the assistance of a family member or caretaker. Measurements from these kinds of studies need to come from the participants as well as from their parents or caretakers. Many adults with intellectual disabilities are capable of interviews (Williams **1999**), and inclusive research (Walmsley & Johnson **2008**) is important both in measuring the effectiveness of research and in avoiding the dangers of paternalism towards these adults (Walmsley **2004**). Adults with intellectual disabilities represent a disadvantaged group in terms of health disparities (Walmsley **2011**), and so inclusive research regarding measurement is crucial for disparity reduction. With this population in mind, the present authors have managed to successfully create an instrument that accurately measures the mammography preparedness of women.

The MPM's face and content validity are reasonable. Our experts, the women with intellectual disabilities themselves, helped finalize the instrument and made sure it was understandable and valid for its purpose. Given the concerns about our participants' comprehension of instruments intended for use with the general population, such as the Breast Cancer Hereditary Knowledge (BCHK), the present authors felt that test–retest reliability would be the most helpful measure in demonstrating actual comprehension that remained stable over time (as opposed to random guessing). Therefore, our testing focused on reliability and the stability of answers over time rather than alternate forms of validity (especially given that the meaning of items on the instrument is concrete).

Our study had several limitations that are important to note. Our research used a small sample of verbal adults, rather than a broader spectrum of adults with intellectual disabilities. While the present authors felt that this enrolment criterion was necessary to accomplish our stated goal of evaluating the validity of the verbally administered MPM, the present authors recognize that the present authors excluded adults who lacked verbal ability and/or who have more serious intellectual disabilities. Our inclusive study design centred around enrolling participants with intellectual disabilities who could speak for themselves. The present authors recommend, however, that research to develop needed breast cancer screening interventions include a more representative range of adults with intellectual disabilities. In addition, the present authors were limited by the amount of information the present authors were able to collect. In all research, the present authors must balance the value of information gained with the risks to participants. While the present authors recognize that factors such as intellectual disabilities type and severity, co-occurring disabilities, health conditions and mental health

disorders, language, education, marital status, medication use and others might impact access to mammography, the present authors did not feel that the information to be gained in this case justified the risks to confidentiality and the intrusion into protected medical records. Trials evaluating the efficacy of interventions would warrant the collection of this personal information, but in our opinion, such personal and protected information would not significantly impact a study evaluating the validity of a measurement tool, and so the present authors opted not to risk participant confidentiality by gathering this additional information. Another limitation is the 91% rate of prior mammography in our study population. The present authors chose to include women with prior mammography experience, as this category was more likely to possess the kinds of knowledge measured by the MPM, thereby facilitating our evaluation of the instrument itself. In a study measuring the test–retest reliability, the present authors were less interested in how the participant acquired her mammography knowledge, as our goal is to evaluate whether the instrument reliably and consistently measures this knowledge.

Although our instrument is proven to be reliable, there are some additional limitations in the use of the MPM. First, the present authors could only test participants who had the verbal ability to complete the MPM. Participants who are not verbal will hypothetically have more logistical barriers to getting a mammogram than those who are verbal. Because the questions were developed for women with intellectual disabilities, our instrument would be more appropriate for participants with limited verbal skills than the instruments currently available. The present authors hope that future interventions will be able to take into account women who are not verbal or who use alternative communication methods, as this represents a significant number of individuals with intellectual disabilities. In addition, the range of intellectual disabilities is extensive. It would be difficult to use the MPM to measure preparedness in individuals with severe intellectual disabilities. While the present authors focused primarily on evaluating the MPM in this study, further research related to adapting the MPM for use with various subpopulations of women with intellectual disabilities, such as non-verbal or hearing impaired individuals, is suggested. It would also be useful to develop versions of the MPM that could be used in various subpopulations, such as a pictorial version that could be used with non-verbal individuals. The MPM is currently only available in English and was tested with English speakers only. The present authors would welcome research translating the MPM into other languages and evaluating its efficacy among non-English speaking populations. The MPM's introductory script assumes a female interviewer who states that she is planning to have her first mammogram the following day. However, a male interviewer could easily use third person and state that his friend is having her first mammogram the following day and ask the participants to provide advice for his friend. The MPM was designed with ease of administration in mind; the interview does not need extensive training or medical experience and need not have personal experience with mammography. Finally, our instrument measures the participants' preparedness, rather than general education levels regarding mammograms and breast cancer. However, the present authors chose to focus the instrument on what was more important to the participants as shown in previous qualitative studies (Wilkinson *et al*. **2011**) rather than focus on knowledge that might be less useful for our target population.

This study shows that the MPM is a reliable and valid tool in assessing the preparedness of women with intellectual disabilities for breast cancer screening. Women with intellectual disabilities experience a higher burden of breast cancer deaths than their counterparts without disabilities, and are much less likely to access routine mammography screening. The development of interventions to increase rates

of cancer screening, including mammography, has long been an advocacy priority. However, without tools such as the MPM, the present authors are unable to measure the success of such interventions. The creation of this instrument allows researchers to develop and evaluate interventions needed to raise mammography rates in this population. While overcoming health disparities will be a long and complex road, the ability to understand and measure the drivers of disparity is an important first step(James **2009**). The present authors encourage future researchers to create, refine and validate tools such as the MPM to further the work of disparity reduction among adults with intellectual disabilities, and the present authors encourage further research using similar processes to develop future instruments to measure different drivers of disparities facing adults with intellectual disabilities and help close these gaps.

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