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Testing the Feasibility of a DVD-based intervention to promote preparedness for mammography in women with intellectual disabilities

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Abstract

Women with intellectual disabilities (ID, formerly mental retardation) have a similar breast cancer incidence as the general population, but they have higher breast cancer mortality and lower rates of regular screening mammography. We conducted a feasibility study evaluating acceptability, demand and limited efficacy of a health education DVD about mammography for women with ID. The DVD was developed in order to address disability-specific barriers to mammography identified in prior studies, such as anxiety related to navigating the logistics of obtaining a mammogram. The DVD was found to be acceptable and feasible, and led to a moderate increase in mammography preparedness in this population. Study results suggest that this DVD-based intervention is an appropriate candidate for further study measuring efficacy and effectiveness in increasing regular mammography in women with ID, a disparity population.

Keywords

breast cancer screening; intellectual disability; cancer screening education; vulnerable populations; cancer screening disparities; media-based education

Background

Adults with intellectual disabilities (ID) face numerous health disparities (1,2), including disparities in access to health promotion and health education (3), and access to primary care (4). There are particularly concerning disparities related to cancer screening in this population, and women with ID have higher breast cancer mortality rates than their counterparts without disabilities, despite a similar overall incidence of breast cancer (5). Women with ID also have lower rates of regular mammography screening as compared to women without disabilities (6), and screening utilization further varies across residential settings (7). Barriers to mammography documented in the literature include lack of mammography-related knowledge (8), limited understanding of general health-related content and lack of health education (9), fear and anxiety-related challenging behaviors that prevent receipt of the exam (10), transportation and other community-level barriers (11), lack of education/comfort with working with patients with ID on the part of health care providers that may prevent referral for mammography (11, 12, 13) and health systems

factors (14, 15). There is a clear need for effective interventions to increase mammography rates among women with intellectual disabilities (2,12).

Evidence-based health education and health promotion interventions are important tools for reducing health disparities (1,2, 16,17). However, there is a paucity of data regarding what constitutes effective health promotion and education in adults with intellectual disabilities (1,3). We also lack evidence-based processes for developing health education for this population (18). For this reason, the development and evaluation of health promotion interventions for people with ID is a public health priority, with particular focus on determining intervention effectiveness.

Effectiveness is defined as the intervention's ability to effect measurable change in real-world conditions (19). However, effectiveness trials are costly and time consuming. Conducting effectiveness trials as a first step would limit the number of interventions evaluated, due to the high cost of these trials. Prior to examining effectiveness, public health researchers first evaluate the feasibility and acceptability of their interventions (20). Feasibility trials determine which interventions are appropriate candidates for more expensive effectiveness trials and ultimate dissemination (20). It is therefore important to develop methods for evaluating feasibility for health promotion interventions that target adults with intellectual disabilities.

Previously, we conducted a qualitative study to explore the mammography experiences and perceptions of women with ID, aimed at identifying barriers and facilitators of regular mammography in this population (8). Our prior study consisted of 27 semi-structured qualitative interviews with women with ID who were eligible for mammography (i.e., over age 40 or younger with a family history of breast cancer) and had sufficient verbal skills to participate in an interview. Participants were asked about their mammography experiences, barriers and facilitators of mammography and health education needs. We used a convenience sample with continued recruitment until saturation (the point at which new themes cease to emerge) was reached. Interviews were audio-taped and transcribed and transcripts were analyzed using line by line coding. Codes were then grouped into larger themes and analyzed using grounded coded theory. The results from that study were used to inform our current study. Going forward, we will report on the current study, which evaluated the feasibility of an educational DVD.

The results from our prior study (described above) suggested that women with ID perceive mammography differently than their counterparts without disabilities and often lack important information about the mammography process. Though participants expressed feelings of competency and mastery in their day to day lives, women felt unable to manage the logistics of obtaining a mammogram, often leading to considerable anxiety. This confusion was compounded by a lack of explanation from their medical care providers, who often began and ended the discussion with the fact that the woman was being referred for a mammogram. For these reasons, many women experienced their first mammogram as negative, and subsequently did not return for regular mammograms as recommended. Study participants also suggested that they would benefit from education about the logistics of mammography, in order to feel more prepared. The participants' comments suggest that adults with ID may prefer to learn through concrete formats, such as stories (8). Prior research regarding menopause education suggests that women with ID prefer to learn about women's health topics from peers (21).

In response to these data, we developed a DVD-based health promotion intervention to increase "preparedness" for mammography in women with ID, with the ultimate goal of increasing regular mammography screening. We developed our intervention in collaboration

with women with ID, using an iterative, qualitative process. Media based education for adults with ID is growing in popularity and has the potential to effectively deliver health education to people with low literacy skills (22). Using comprehensive feasibility measures developed by Bowen et al (20), we evaluated the acceptability, demand and limited efficacy of the DVD as a health education intervention for women with ID.

Methods

This project was approved and monitored by the Boston University Medical Campus Institutional Review Board.

We conducted a feasibility study of a DVD-based health education intervention designed to increase preparedness for mammography among women with mild to moderate ID.

Making the DVD

Our prior qualitative study (described above) explored barriers and facilitators of mammography in women with ID (8). Themes from the prior study included isolation/lack of support related to mammography, lack of explanation from medical care providers, associated lack of information about the purpose and process of obtaining a mammogram, difficulty with process logistics (e.g., arriving at the facility, putting one's clothes in a locker and putting on a hospital gown) and anxiety associated with lack of mastery of the process. As women wanted to be perceived as competent (and did, in fact, display a significant level of mastery over their daily lives), this last barrier was thought to be particularly important.

Our next step was to develop a brief DVD featuring an actress with ID who surmounts these barriers and takes viewers start to finish through the mammogram process. The PI and the actress developed the script together. In response to study participants' suggestion that they would prefer to learn from peers and receive information in a concrete story format, the DVD tells the story of the actress's first mammogram experience, and the actress is intentionally portrayed as a relatable peer. The DVD was filmed after hours in the mammography clinic, and also features a mammography technician who volunteered her time. The story begins with the doctor informing the actress that she will be referred for a mammogram and explaining the purpose and process of mammography. The actress models positive health care advocacy, including asking the doctor questions. The actress is then shown navigating all the steps of the mammography process, including arriving at the clinic, asking questions, putting on a hospital gown, and so forth. The mammography technician demonstrates the use of the mammography machine and is shown ensuring the actress's comfort. The DVD concludes with the actress back in the doctor's office, receiving her mammography results. The actress is meant to be both relatable and a positive role model.

Feasibility Testing

In order to evaluate acceptability, demand and limited efficacy, we showed the DVD to a sample of women with intellectual disabilities, who were given pre-post tests to measure any changes in mammography preparedness, as well as asked to answer quantitative and qualitative measures. We collected data regarding participants' age, residential setting (independent, group home, with family) and prior mammogram usage. Study activities were conducted over the course of two study visits approximately three to six weeks apart. At visit one, we obtained informed consent, collected demographic data and verbally administered the pre-test. At the second visit, participants were shown the DVD. Immediately after viewing the DVD, participants were asked to verbally complete the post-test, which consisted of the same instrument that had been administered previously. They were then asked to verbally complete an acceptability questionnaire. Though participants

watched the DVD as a group, pre and post tests were administered privately by a research assistant one-on-one to each participant in a separate room, in order to avoid the potential for participants to influence each others' answers. The same research assistant verbally administered both the pre- and the post-test to each participant.

Recruitment

Two distinct recruitment strategies were used in order to assemble a convenience sample to evaluate the DVD. Initially, our hospital system's patient database was used to identify women who had received prior medical care (though not necessarily mammography). This method was chosen because patients in the hospital database could be safely presumed to have had at least some previous contact with the health care system. A database employee queried the database system and generated a list of women age 40 and above with a ICD-9 code of intellectual disability. This list contained the name of the patient's primary care physician, who was provided with a description of the study and asked to approve patient contact. Physicians were asked to confirm intellectual disability, if they felt the patient had significant verbal abilities to answer questions designed for adults with ID, and whether they felt the patient was an appropriate candidate for the study. If we were unable to contact the primary care physician after repeated attempts, we excluded the patient from the study. We then contacted "approved" patients and their families/support providers to explain the study, using a script that emphasized the right to decline participation without consequence. If possible, we asked the family member/support provider to initially approach the potential participant, in order to maximize opportunities to decline participation to a familiar person. After explaining the study, the research assistant asked permission to re-contact the potential participant again in 2–3 days, in order to avoid unintentional coercion through the social desirability phenomenon.

In order to reach a diverse sample, we also partnered with five agencies providing services and supports to adults with ID, who agreed to help us with recruiting. We approached four agencies in Massachusetts, and an additional agency in Alabama. These two states were selected because they are economically, geographically and demographically distinct from each other, with vastly different health care systems, and we wanted to ensure a diverse sample. These agencies made information about the study available to women who met the inclusion criteria, and agency staff approached potential participants to explain the study. We then scheduled visits to the agency's facility, where a researcher met individually with potential participants to explain the study and obtain informed consent. The Massachusetts-based research team conducted a data collection visit to Alabama. Study activities were modified in Alabama in that only one study visit was conducted. At this visit, informed consent was obtained, followed by demographic data and a verbally administered pre-test. Participants then watched the DVD and were asked to verbally complete the post-test immediately after viewing the DVD. All study activities were approved by the Boston University Medical Campus IRB.

Inclusion criteria

We included women aged 37 and above with ID, as defined by either an ICD-9 code related to ID identified by the hospital database query or receipt of services from an agency that supports people with ID. Though mammography screening usually begins at age 40, we choose to include women aged 37 and above due to the need for anticipatory guidance for people with ID.

As always, the right to participate in research for people with intellectual disabilities must be balanced with careful informed consent and respect for human rights. Informed consent was obtained using a teach-back method that emphasized the voluntary nature of the study.

Participants were given a verbal explanation of the study's purpose, procedure, risks and benefits and voluntary nature, and were then asked to describe or "teach back" whether they had a choice about participating, the bad things that could potentially happen and what they would have to do. This method of consent was selected because it was the most task-specific and has been used successfully in the past. All participants were asked if they used a guardian for health care decision-making, and informed consent was also obtained from the guardian if appropriate.

Measures

We tested three aspects of feasibility, limited efficacy, demand and acceptability, in the following manner:

Limited Efficacy

We evaluated limited efficacy using the pre and post-DVD scores on the Mammography Preparedness Measure (MPM). The MPM is a validated instrument (23) designed to measure knowledge of mammography purpose and process in women with ID. The MPM was developed and validated by our research group in order to measure mammography "readiness" or concrete knowledge of mammography's purpose and procedure. The instrument is administered verbally and uses a story format that asks the participant to pretend that the interviewer is having a mammogram tomorrow and needs advice regarding practical aspects of mammography, such as how long the mammogram will last and whether she will need to remove her clothes. The MPM has a kappa of 0.59 and high percent agreement when administered approximately one month apart (average percent agreement for all instruments is 84%, with per item percent agreement ranging from 74% to 91%). It is described in Table 1. Participants were also asked if they felt that they knew what to do to get a mammogram after the DVD, and if they intended to get a mammogram. Participants responded using a Likert scale of one to five, with five being very sure they would know what to do/ definitely planned to get a mammogram and one being very unsure/definitely did not plan to get a mammogram (Table 2).

Acceptability

After watching the DVD and completing the post-DVD MPM, participants were asked a series of Likert-scaled questions to determine acceptability of various aspects of both the DVD itself and of the DVD as a learning platform. The acceptability questions were developed through a literature search related to measuring acceptability of health education interventions and an existing, validated mammography self-efficacy scale and validated acceptability questions adapted from a study evaluating informational materials in a clinical cardiology setting. Already validated questions measuring constructs of interest were selected and their language was modified in order to be understandable for people with intellectual disabilities, based on our clinical and personal experience with this population. (Source questions and citations are included in Table 2, which shows our acceptability questions and response averages and standard deviation). As adults with ID can struggle with abstract constructs like Likert scaling, we modified the method in which we asked our Likert questions by first asking the participant whether she agreed or disagreed with a statement. Then she was asked to clarify whether she strongly disagreed/agreed, or just sort of agreed/disagreed. For example, when asking participants to rate the DVD's ease of understanding on a scale of one to five, with five representing very easy to understand, participants were first asked whether they thought the DVD was easy or hard to understand. If they replied that it was difficult to understand, they were asked if it was very difficult (scored as one) or just a little difficult (scored as two).

Qualitative comments were solicited using specific prompts after every Likert question. We then included three additional qualitative questions that collected information regarding participants' impression of the doctor, the actress and the DVD as a whole. Qualitative responses were written verbatim by hand by the researcher as the acceptability questions were asked. The acceptability questions were pilot tested with two women with intellectual disabilities, whose answers are included in the averages presented in the table. They felt that the acceptability questions were effective and easy to understand.

Demand

We offered each pilot tester the option of taking home a copy of the DVD to watch later or share with friends and recorded how many chose to keep the DVD.

This project was approved and monitored by the Boston University Medical Campus Institutional Review Board.

Results

Description of sample

A total of 53 women aged 37 and above participated in this study. Recruitment was stopped after 53 due to limited study resources. Fifteen percent of participants ($n = 8$) were recruited through the hospital database, with the remaining participants recruited through partnerships with five community agencies in Massachusetts and Alabama. Eight of these women did not complete the two study visits. One woman was withdrawn from the study based on her guardian's request to do so. The other seven women were unavailable during the second study visit due to circumstances such as being absent from the day program for a doctors' visit or being away visiting family. The final sample included 46 women who watched the DVD and completed pre and post-DVD MPMs. All participants completed both the pre and post-test verbally in private with the same research assistant for both tests. All women but two were at least minimally verbal; one woman communicated through vocalization and hand signals and another used a communication board to express herself. Participant demographics are included in Table 3. The most common residential setting was group homes, with 33.9% of the participants residing in these supervised settings. An additional 7.5% lived in supported living arrangements. Other participants (13.2%) lived with family members, and 16.9% lived in alternative or unknown settings. The remaining 28.3% of participants lived independently or with their children or spouses/significant others. Participants ranged in age from 37–82, with an average age of 56 (SD 11.5). The vast majority of participants (92.45%) had had at least one prior mammogram, based on participant self-reports.

Limited efficacy testing demonstrated a moderate increase in mammography knowledge post DVD, as shown in Table 1. Women who had not yet had a mammogram scored lower on both pre (2 compared with 3.9 in the previous mammogram group) and post (3.25 as compared with 4.29 in the previous mammogram group) tests than did women with previous mammography experience.

All but four participants elected to keep the DVD. One participant who choose not to keep a copy lived in a supported residence where the staff already had a copy. In addition, when asked the final qualitative acceptability question about whether the participant had any other comments related to the DVD, several women stated that they planned to share the DVD with family members or friends. One woman stated that her sister-in-law had not had a mammogram and needed the education and she was glad to be able to share the DVD with her.

Average scores on the Likert scaled acceptability questions are listed in Table 2. In general, participants gave the DVD high acceptability ratings, with an average score of 4.4 from a potential total of five for interestingness. Ratings for whether or not the participant would recommend the DVD to a friend were consistently high, with all but three women stating that they agreed or strongly agreed with the statement. One of the three, who said that she would probably not recommend the DVD to a friend, stated that she didn't think her friends would be interested in this topic when asked the final qualitative question. A second participant stated that she did not want to recommend the DVD to a friend because she did not want to share her copy. All participants but one also rated highly the statement that they had learned about mammograms from the DVD, with an average rating of 4.4 for this statement. The lowest rated acceptability question was whether the participant wanted to get a mammogram after viewing the DVD, which scored an average of 3.8 out of a potential total of five. This response did not differ significantly among women who were slightly too young for mammography and those who were already eligible.

Representative qualitative comments from the last three questions appear in Table 4. In general, participants expressed that they found the actress relatable, and liked that she asked questions and otherwise actively participated in her care. As shown in the table, some comments also relate to the need for the DVD, e.g., comments such as (re: actress), "Was that her first time getting one? Your first time, you don't know what to expect." Participants also expressed satisfaction with the DVD overall, stating that they learned more about mammography, found it interesting, and appreciated the story-based format.

Discussion

This study evaluated the limited efficacy, demand and acceptability of an educational DVD designed to increase mammography knowledge and preparedness among women with intellectual disabilities. The DVD was developed in response to themes identified during a prior qualitative study of mammography experiences, perceptions and needs of this population (8). We found that viewing the DVD led to a moderate increase in mammography knowledge in this population, and was acceptable for participants. Our prior qualitative work suggested a need for mammography education tailored to women with intellectual disabilities. Qualitative comments from participants in this current study and the high rate of wanting to keep the DVD also demonstrated demand for accessible mammography education within this population.

The DVD was developed in response to themes identified by women with ID who were interviewed in a prior qualitative study (8). We found this process effective, and helpful in terms of developing an acceptable intervention. For example, comments by participants in the prior study about anxiety related to lack of mastery of the mammogram process led us to develop an intervention focused on the logistics of obtaining a mammogram, including steps like putting on a hospital gown, waiting in the waiting room, etc. Because prior participants in the previous study expressed that their doctors didn't adequately explain mammography, we worked with the actress to model asking questions in the doctors' office (8). Tellingly, participants in this study commented positively on the aspects of the DVD that were developed in response to participant comments in the prior study.

Our DVD represents an easy to implement and low cost model of health education. Other researchers using more time and resource-intensive interventions have had higher effectiveness in increasing mammography knowledge and preparedness than we were able to demonstrate in this study's limited efficacy measures (24). One such example is the Women Be Healthy curriculum developed by Lunskey et al (25) and disseminated and evaluated by Parish et al. This program trains agency staff to offer a 12 hour curriculum to

small groups of six to eight women with ID at a time; an updated curriculum now recommends 22 hours of training (26). While very comprehensive and effective, Women Be Healthy is also resource-intensive. Our DVD represents an effective and efficient way to meet the pressing need for mammography education and cancer prevention materials for adults with ID without greatly increased time or cost.

Limitations of the current study include limited follow up with participants, who were not contacted again after the second study visit. As we were evaluating feasibility only, we do not know whether participants subsequently obtained mammograms, and, if so, had positive mammography experiences. This limitation suggests the need for a more comprehensive, long-term study, such as a randomized controlled trial evaluating the effectiveness of the DVD in increasing mammography utilization. The high acceptability and feasibility scores found during this current study suggest that this kind of more costly trial is appropriate. In addition, this study was primarily conducted in a state with high health insurance coverage and mandated coverage of mammography. Ninety-two percent of our sample had had a prior mammogram. Women who had not yet had a mammogram scored lower on both the pre and post tests than did women with prior mammography experience. It should be noted that this finding is preliminary, as this study was not powered to analyze differences among subgroups, such as those who had previous mammography experience and those who had never had a mammogram. This represents an important limitation, and we recommend that future research consider possible differences among sub-populations who might have divergent educational needs, for example adults who live in group homes as compared to those who live with relatives. Additionally, though the change in mammography knowledge and comfort was relatively small, it should be noted that post-DVD mammography preparedness measures were administered after a single viewing of the DVD. In real world conditions, such as a woman who lives in a group home or with her family preparing for mammogram, the recipient might choose to watch the DVD multiple times, potentially further increasing her knowledge and comfort through repeated exposure.

Feasibility studies are often used to determine which interventions are appropriate for more costly effectiveness trials (20). As our feasibility study demonstrated limited efficacy, established demand and high acceptability, we conclude that fully powered effectiveness testing, such as a randomized controlled trial is warranted. In addition, our results suggest that an iterative process of interviewing followed by intervention development and pilot testing is appropriate and effective means of developing evidence-based health promotion interventions for adults with intellectual disabilities.

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Table 1

Limited Efficacy Testing-Pre and Post DVD Mammography Preparedness Measure (PMP) Percent of Participants Answering Correctly

Item	Pre-DVD percent correct	Post-DVD percent correct
What body part is a mammogram for?	93.6%	95.5%
Why would I have a mammogram?	70.2%	80%
Do I need to take off my clothes to have a mammogram?	93.6%	91%
When I have my mammogram, how long with I be in the machine?	59.5%	80%
How often should I have a mammogram?	63.8%	75.5%
Total score (average)	3.8/5 (SD 1.34)	4.2/5 (SD 1.39)

Table 2

Acceptability Questionnaire

Source	Original Question	Adapted Question	Average Response (Likert scale of 1–5, 5=positive)
Gwadry-Sridhar F, Guyatt GH, Arnold JMO, Massel D, Brown J, Nadeau L, Lawrence S. Instruments to measure acceptability of information and acquisition of knowledge in patients with heart failure. <i>Eur J Heart Fail</i> 2003;5(6):783–791.	The booklet maintained my interest and attention	The DVD was interesting to watch	4.4
Gwadry-Sridhar et al	I would share this booklet	I would recommend this DVD to my friend	3.9
Gwadry-Sridhar et al	The information in this booklet helped me to better understand my heart condition	This DVD helped me understand more about mammograms	4.4
Gwadry-Sridhar et al	The booklet explained things in terms I could understand	This DVD was easy to understand	4.5
Champion V, Skinner CS, Menon U. Development of a self-efficacy scale for mammography. <i>Res Nurs Health</i> . 2005;28(4): 329–36.	I know how to go about getting a mammogram	I would know what to do to get a mammogram	4.6
Champion et al	I know for sure I could get a mammogram if I wanted one	I could get a mammogram if I wanted one	4.1
Fernandez ME, Diamond PM, Rakowski W, Gonzalez A, Totolero-Luna G, Williams J, Morales-Campos DY. Development and validation of a cervical cancer self-efficacy scale for low-income Mexican-American women. <i>Cancer Epidemiol Biomarkers Prev</i> 2009;18:866–75.	I am planning to get a Pap test in the future	I want to get a mammogram after seeing this DVD	3.8

Table 3

Participant Demographics

Characteristic	N	Percent
Female	53	100%
Age:		
37 to 39 (pre-mammography age)	4	7.5%
40–49	14	26.4%
50–59	13	24.5%
60–69	16	30.1%
70+	6	11.3%
Residence Type:		
With family (i.e. sibling, parent etc)	7	13.2%
Independent (with live-out supports provided)	15	28.3%
Group home	18	33.9%
Supported living	4	7.5%
Other or unknown	9	16.9%
Previous mammogram	49	92.4%

Table 4

Selected Qualitative Comments re: DVD

General:	I liked the story
	It was good to see something like that so you know. I learned things.
	I'm going to bring it (DVD) to my sister-in-law. She never had a mammogram before.
	I watched it straight through. I thought it was interesting
Re: Doctor:	I liked that she went through it step by step. I know the first time I did it (mammo) I was clueless. This would help me do it without any embarrassment
	She was talking a lot of good stuff. Easy to understand
	She seems like she knows what she was talking about. It's good to see this because some people are afraid, especially the first time.
	She was right on point
Re: Actress	She kept asking questions and wanting to know and that's what I would do
	She sounded pretty good, like she understands. Its good to see that, don't be afraid.
	I know her name, I liked her
	She was calm and relaxed