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Cancer Screening Knowledge Changes: Results From a Randomized Control Trial of Women With Developmental Disabilities

Susan L. Parish,¹ Roderick A. Rose,² Karen Luken,³ Jamie G. Swaine,⁴ and Lindsey O'Hare⁴

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Abstract

Background: Women with developmental disabilities are much less likely than nondisabled women to receive cervical and breast cancer screening according to clinical guidelines. One barrier to receipt of screenings is a lack of knowledge about preventive screenings. **Method:** To address this barrier, we used a randomized control trial ($n = 175$ women) to test *Women Be Healthy*, an intervention designed to promote cervical and breast cancer screening for women with developmental disabilities. Women assigned to the experimental group participated in weekly health education program for 8 weeks. Women assigned to the control group participated in their regular vocational training or educational activities. **Results:** Unadjusted findings indicated modest gains for both groups in knowledge related to cervical and breast cancer screening. Regression results indicated statistically significant but modest knowledge gains for the experimental group related to breast cancer screening. **Implications:** These findings indicate that the *Women Be Healthy* curriculum is promising but needs to better address cervical cancer.

Keywords

disabilities, field of practice, health care, field of practice, RCT, outcome study

Mortality and morbidity associated with both cervical and breast cancer is significantly reduced by early detection. However, the gains promoted by cervical and breast cancer screening have not reached the entire population of U.S. women. The extant research indicates women with developmental disabilities have substantially worse rates of receipt of cervical and breast cancer screening than other women (Gill, 1994; Parish, Moss, & Richman, 2008; Parish & Saville, 2006; Rosenbaum, 2007; U.S. Surgeon General, 2002). Women with developmental disabilities face many barriers to receiving timely and appropriate cervical and breast cancer screening. Challenges come from the women's communication abilities, caregivers' misunderstandings about preventive screenings, health care providers' negative attitudes about people with developmental disabilities, and the women's anxiety or fear about receiving preventive screenings, particularly the pelvic exam required to complete Pap tests (Broughton & Thomson, 2000; Gill, 1994; Krahn, Hammond, & Turner, 2006; Lunsky, Straiko, & Armstrong, 2003; Messinger-Rapport & Rapport, 1997; Parish et al., 2008; Parish & Saville, 2006; U.S. Department of Health and Human Services, 2000).

Women with developmental disabilities also lack adequate knowledge about these procedures and why they are necessary (Parish, Swaine, Luken, Rose, & Dababnah, in press). Such knowledge gaps reduce the chances that these women will perceive the need for such care or seek care. Current practices require patients to be full partners with their doctors (Agency for Healthcare Research and Quality [AHRQ], 2006). There

is also a long-standing theoretical rationale that supports the need to improve the knowledge women with developmental disabilities have about cervical and breast cancer screening. In the Andersen Behavioral Model of Health Care Access (1995), which is commonly used in public health research, patient knowledge is a critical so-called enabling factor that, when combined with other enabling factors (i.e., health insurance) and predisposing factors (i.e., income), determine an individual's receipt of needed health care. However, there is little empirical evidence about what interventions might help women with developmental disabilities gain knowledge about these procedures. The study reported here describes the results of a randomized controlled trial to test an intervention, *Women Be Healthy*, designed to improve women's knowledge of

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cervical and breast cancer screening. Knowledge about cervical and breast cancer screening have been combined because most women receive both screenings during the same well-woman exam from their gynecologist, family practitioner, or internist.

Literature Review

Cervical and Breast Cancer and Women With Developmental Disabilities

Specific risk factors elevate the chances that women with developmental disabilities will develop cervical or breast cancer. Being childless and hypogonadism increase women's likelihood of developing breast cancer (Hulka & Moorman, 2001; Valk, Schupf, & Patja, 2002). There is some evidence that women with developmental disabilities have lower fertility rates than nondisabled women, which increases their likelihood of developing breast cancer (Block, 2002; McCarthy, 2002; Servais, 2006).

The risk of cervical cancer is elevated for some women with developmental disabilities due to their limited understanding of sexually transmitted diseases, poor hygiene practices, obesity (Valk et al., 2002), and exceptionally high rates of sexual assault victimization (Wacker, Macy, Barger, & Parish, 2009). Further, the sexual histories of these women are often unknown to health care providers. If health care providers are unable to obtain accurate sexual histories or assume that women with developmental disabilities are asexual (Block, 2002; McCarthy, 2002), women's likelihood of developing cervical cancer without treatment is elevated. Taken on balance, these factors converge to make preventive screenings critically important for these women (Parish et al., in press; Quint, 2004).

Disparities in Preventive Health Care

The existing research convincingly indicates that women with developmental disabilities do not receive timely cervical and breast cancer screening. Numerous studies have been reported in which these women had low rates of receipt of cervical and breast cancer screening (Havercamp, Scandlin, & Roth, 2004; Kopac, Fritz, & Holt, 1998; Lewis, Lewis, Leake, King, & Lindemann, 2002; Parish et al., 2008; Parish & Saville, 2006; Reichard, Sacco, & Turnbull, 2004).

One national study found that these women were 45% less likely than nondisabled women to receive mammography and 72% less likely to have received cervical cancer screening (Parish & Saville, 2006). This 2006 study corroborates earlier evidence that in comparison to their nondisabled peers, women with a range of disabilities do not receive cervical and breast cancer screening according to recommended clinical guidelines (Altman, 1997; Becker, Stuijbergen, & Tinkle, 1997; Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Deschler et al., 2007; Iezzoni, McCarthy, Davis, & Siebens, 2000; Parish & Huh, 2006). This pattern holds even when the women with disabilities had health insurance through the Medicaid program (Parish & Ellison-Martin, 2007). The weight of the research evidence

clearly indicates that women with disabilities' needs for timely preventive screenings are not met.

It is important to note that significant policy statements in the United States have recently called for implementation of assertive and effective new approaches to end pervasive disability-based health care disparities in receipt of health care. These policy statements include the U.S. Surgeon General's (2002) report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*; the *Long-Range Plan* of the National Institute on Disability and Rehabilitation Research (2007); a major report issued by the National Council on Disability (2009); and *Healthy People 2020* (U.S. Department of Health and Human Services, 2010), which is the nation's public health plan. Despite these policy arguments, there are no interventions that have been demonstrated to be effective in reducing the gap in cervical and breast cancer screening experienced by women with developmental disabilities.

Barriers to Receipt of Cervical and Breast Cancer Screenings

There is compelling evidence that women's lack of knowledge in three areas contributes to nonreceipt of timely cervical and breast cancer screening. These areas include insufficient understanding of their anatomy and reproductive system; inadequate knowledge of sexual health and sexuality; and limited understanding of the need for timely cervical and breast cancer screening (Broughton & Thomson, 2000; Davies & Duff, 2001; Havercamp & Dickens, 2004; Heller & Marks, 2002; Kopac et al., 1998; Marks & Heller, 2003; McCarthy, 2002; Parish et al., 2008). Several research studies have also found evidence that women with developmental disabilities have elevated anxiety and fear related to cervical and breast cancer screening. These fears are particularly acute in relation to the pelvic exam that is necessary for Pap tests (Broughton & Thomson, 2000; Kopac et al., 1998; Messinger-Rapport & Rapport, 1997; Parish et al., 2008; Prevatt, 1998). Equipping women with developmental disabilities with knowledge about the procedures, and how to manage anxiety is therefore likely an important facet of effective interventions.

Standards for the effective delivery of high-quality health care increasingly demand that patients actively partner with their health care providers about treatment options and decision making about their health care (AHRQ, 2006). Practices that promote full patient engagement in health care are fully compatible with the self-determination and consumer-directed support trends that scaffold a significant part of the contemporary developmental disabilities service system. Little has been done, however, to actually enable adults with developmental disabilities to effectively participate in their health care decisions (Heller & Marks, 2002; Marks & Heller, 2003; Shogren, Wehmeyer, Reese, & O'Hara, 2006). To effectively partner with their health care providers, women with developmental disabilities need a basic understanding of what cervical and breast cancer screening are, and why these procedures are important.

Coupled with evidence of the pervasive negative attitudes health care providers hold about adults with developmental disabilities, these factors compel the development and testing of interventions that effectively empower women with developmental disabilities to meaningfully partner with their health care providers. Enabling women with developmental disabilities to receive recommended cervical and breast cancer screenings requires teaching them both about the importance of such procedures, the specifics of the procedures, as well as ways to manage fear and anxiety related to these procedures, and how to effectively communicate with their health care providers. The present study was therefore conducted to address the following research question: Will women with developmental disabilities demonstrate knowledge gains from participating in *Women Be Healthy*, a targeted educational intervention designed to improve women's knowledge about cervical and breast cancer screenings?

Method

We conducted a randomized control trial to test the effectiveness of *Women Be Healthy* (Lunsky, Straiko, & Armstrong, 2002) in increasing the knowledge of women with developmental disabilities about cervical and breast cancer screening. Data about women's cervical and breast cancer screening knowledge were collected via computer-assisted, face-to-face interviews with community-dwelling women with developmental disabilities ($n = 175$ women) in one state. This article reports changes in knowledge from before and after the intervention. This study is part of a larger, mixed-method project to develop new knowledge about why women with developmental disabilities do and do not receive timely cervical and breast cancer screening and to determine what interventions might increase their screening rates. The findings we report here are derived from (a) the results of baseline knowledge surveys that were conducted prior to the women's randomization into treatment and control groups, and (b) interviews collected after women in the experimental group participated in the *Women Be Healthy* intervention. The Institutional Review Board at the University of North Carolina at Chapel Hill approved our research protocol.

Women Be Healthy

The *Women Be Healthy* curriculum addresses key barriers (enumerated above) to receipt of cervical and breast cancer screenings for women with developmental disabilities. To tackle the lack of knowledge women have about cervical and breast cancer screening, *Women Be Healthy* addresses the female body; hygiene; the importance of cancer screening; how and when to schedule screenings; what to expect at medical appointments; how to ask questions and speak with a health care provider, including how to report symptoms.

The intervention is delivered in eight, weekly group sessions of 90 min each, to a group of about 6–8 women with developmental disabilities. Individual sessions include role plays and

other group and individual activities designed to deliver the content and give women opportunities to practice new behaviors (e.g., anxiety-reduction strategies). For one of the sessions, participants visit a physician's office to see the instruments and an examination table. The intervention is designed to be taught by women with experience teaching or otherwise working and communicating with people with developmental disabilities. The curriculum was developed specifically for use with women with mild and moderate levels of impairment, including those with limited or no literacy. The intervention was tested in a small-scale pilot ($n = 39$ women) and in this pilot, women reported enjoying the classes (Lunsky et al., 2003).

We evaluated the fidelity of intervention delivery by having two research team members observe a sample of the classes, and by interviewing a sample of instructors for feedback about the lessons taught. Observers used a checklist to indicate if the instructor delivered the content according to the intervention design for that week. The fidelity analysis showed that instructors largely hewed to the script.

Instructors were trained by a member of the research team with extensive experience conducting train-the-trainer sessions for *Women Be Healthy*. Training sessions took approximately 5 hours and were held onsite at the local partner organization.

Site Recruitment

We recruited community colleges, residential, and community rehabilitation programs from across one state to participate in the project. We initially contacted potential sites by telephone and e-mail, and then had onsite meetings to develop memoranda of understanding for sites that were interested in participating and met the participation criteria. Collaborating sites had three primary responsibilities: (a) identifying women with developmental disabilities within their agency who could participate in the study, (b) identifying at least one staff to receive training and teach the *Women Be Healthy* curriculum onsite, and (c) helping the research team maintain contact with participants over a 3-year period. A total of 45 community rehabilitation, community college, and multiservice developmental disabilities service organizations were initially contacted and 21 (47%) joined the study. A total of 24 sites declined to participate due to factors including a shortage of staff, inadequate staff time, or low numbers of potential participants. Of the 21 that joined the study, 1 was not able to teach the curriculum, and so was dropped from the project, yielding a total of 20 sites. The community college program in this state, Compensatory Education, is free and open exclusively to adults with developmental disabilities. Despite varying terms used to describe these collaborating partner sites, all provide similar educational, habilitation, vocational training, and support services to adults with developmental disabilities. In our extensive experience working with these partner sites, the population with developmental disabilities that is served is generally the same across sites, and many women receive services from more than one of the organizations or change service providers from time to time.

Participant Recruitment

A power analysis demonstrated that a sample of 158 women was required in order to be able to detect a log-odds of 0.50 ($OR = 1.65$), given an expected attrition rate of 20%, power of .80, and a one-tailed test confidence of 95%. We recruited study participants via open sessions held onsite at each partner site. Women were eligible to participate in the study if they had a diagnosis of developmental disabilities, as documented by the service provider; were at least 18 years of age; and were able to provide assent or consent with an understanding of the research project; and lived in the community (as opposed to institutional settings).

Potential participants, parents, guardians, and support staff were invited to attend information sessions that fully explained the project, and solicited informed consent. Women were asked to sign an assent/consent form only if they wanted to participate, regardless of their guardianship status. This procedure was implemented to ensure that each woman actively chose whether or not to participate in the project. When women declined to participate or otherwise expressed their unwillingness to join the study, we did not make further contact with them or with their guardians. We employed this procedure to give the women the first right of consent or refusal, and to take care that they were not pressured into participating by their guardians. Some women who were their own guardians requested that information about the project be given to a family member or staff, which the research team did by mailing information and/or calling identified family and staff. Once women consented or assented to participate, we contacted their guardians, if they had them, for consent. For women who were unable to attend these open information sessions but who expressed interest in participating, research team staff met with them individually at another time. Further details about the recruiting and consent process are available elsewhere (Swaine, Parish, Luken, & Atkins, 2011).

If guardians were unable to attend information sessions, consent forms were mailed to them. Obtaining guardian consent often required several contacts from the research staff by mail and telephone. From this recruitment process, we successfully enrolled 179 women into the study. Attrition was not a significant problem in this study. A total of 4 women (2% of the overall sample) in the experimental group dropped out of the study prior to collection of the second wave of data; none of the women in the control group dropped out. This attrition represents a rate of 2% overall. The *Women Be Healthy* intervention was designed for women with mild and moderate developmental disabilities, which was ascertained from the records provided by the program sites. While an additional 19 women with more significant impairments also participated, their data are not reported here. Notably, we conducted sensitivity tests that compared these women with more significant impairments to those with mild to moderate developmental disabilities, which showed that they differed significantly on all measures except mammogram definition and frequency (women with severe or profound developmental disabilities were less likely to correctly respond. Another test in which we included these women in the analyses

demonstrated that the findings were not different from those reported here (included in the results section).

Randomization Into Experimental and Waiting List Control Groups

As part of the informed consent procedure, we fully explained that about half of the participants would be randomly assigned to the experimental group, and about half would be randomly assigned to the waiting-list control group. Women were randomized into either the experimental or the control group using the random numbers feature in Microsoft Excel. Randomization was completed by one of two members of the research team. Interviewers from the research team were blinded to the woman's status in the experimental or the control group. However, a few of the women told the interviewer during the interviews that she had enjoyed *Women Be Healthy*, thereby disclosing her status. The staff at the partner sites were not blinded; they were informed which women were expected to participate in the experimental group, and which women were wait listed into the control group. We note that there were no unintended results or harms for any of the women in the study.

Women who were randomly assigned to the waiting-list control groups continued to participate in their typical activities at each partner site. Women at the community colleges continued participating in classes; women at the community rehabilitation programs continued to participate in vocational training activities.

Table 1 describes the sample. Nearly half of the participants were Black or African American. However, we were less successful recruiting Native American, Asian, and Latina women with developmental disabilities. The small proportion of the sample from these groups ($\leq 2\%$ of the total sample in each case) is due to their lower representation in the population of this state, and their relatively lower levels of representation in the developmental disabilities service organizations across the study state. The women ranged in age from 20 to 71 years (mean = 41). Approximately equal numbers of women in the sample lived with family caregivers ($n = 81$ or 47%) or in supported residential settings ($n = 79$ or 45%). The remaining women lived alone or with a spouse ($n = 14$ or 8% of the sample). Consistent with the target population for whom the *Women Be Healthy* curriculum was designed, all of the participants for whom data are reported here had mild to moderate levels of cognitive impairment. Table 1 also presents the results of the comparison of the women who were randomly assigned to the control ($n = 84$) and treatment ($n = 91$) group. As delineated in the table, there were no statistically significant differences between the two groups on any of the demographic measures. Not shown in the table are results related to session attendance among only the treatment group women: 50 of 91 women attended all eight sessions; 19 women attended seven of eight sessions; 12 women attended six of eight sessions; and 10 attended fewer than six sessions.

Table 1. Description of Sample

Characteristic at Baseline	Control (n = 84)		Experimental (n = 91)		χ^2
	n	%	n	%	
Race					
White	43	51	47	52	4.018
Black	38	45	41	45	
Asian	2	2	0	0	
Native American	1	1	1	1	
Latino	0	0	2	2	
Has a child or children	13	15	12	13	0.19
Self-rated health is good or okay	76	95	81	95	0.01
Lives with family member	36	43	45	50	0.89
Living arrangement					
Lives alone or with spouse	7	8	7	8	0.91
Lives in residential setting	41	49	38	42	
Lives with family caregiver	36	43	45	50	
Site					
Community college	27	32	27	30	0.15
Community rehabilitation program	24	29	26	29	
Residential-vocational combination	33	39	38	42	
	M	SD	M	SD	t
Age	41.1	13.8	39.6	11.8	0.780

* $p < .10$.** $p < .05$.*** $p < .01$.**** $p < .001$.

Development and Testing of Interview Tool

No single interview instrument has been validated to collect all of the cervical and breast cancer screening knowledge information and demographic information we needed for this study. We identified questions from various established measures that have previously been used with people with developmental disabilities. These measures included the National Core Indicators (National Association of State DD Directors & Human Services Research Institute, 2010), and the Socio-Sexual Knowledge and Assessment Tool-Revised (Griffiths & Lunsky, 2003). We iteratively pilot-tested this interview guide with two women with developmental disabilities to determine if there were questions that were confusing or difficult for them to answer. After pilot-testing the interview guide, we refined the final measure. The final instrument used eight open-ended questions to measure the dependent variables, and one question that was forced choice (women were asked to identify instruments from a picture). The specific questions are delineated in the section below.

Procedure

After obtaining consent from the women (and from their guardians, as necessary), we conducted computer-assisted, face-to-face individual interviews with each woman. All interviews were conducted in a private setting to ensure that the woman's information would not be shared beyond the study team. Each

interview took approximately 15–20 min. Participants received \$15 for each interview. The vast majority of interviews were completed onsite at the participating program but a few interviews were completed at the participants' homes, if this was more convenient or if the woman was no longer receiving services from the initial recruitment site. An average of 31 days passed between collection of the baseline interview data and the beginning of the intervention (range: 1–110 days). An average of 13 days passed from the end of the intervention to collection of the posttest interview data (range: 1–68 days).

Measures

We analyzed nine individual dependent variables, which indicated knowledge of cancer generally (one item); knowledge of breast cancer screening (four items); and knowledge of cervical cancer screening (four items). Participants used diverse terms, including slang and colloquialisms to explain anatomy and health screening procedures. These terms were accepted as correct.

The indicator of general cancer knowledge was obtained from the question, "What is cancer?" Correct responses were those in which participants correctly identified two aspects of cancer (i.e., it is a disease, treatment can include chemotherapy, surgery, mastectomy, it can be fatal or not, identifying cancer types). The first measure of breast cancer screening ("What is a mammogram?"), was coded as correct when participants identified a machine for detecting breast cancer that compresses breasts and/or uses X-ray. Responses to the second indicator of breast cancer screening knowledge ("How often should a woman >40 years old get a mammogram?") were deemed correct if the participant responded every year. The third measure of breast cancer knowledge ("Whose job is it to check a woman's breast for lumps?") was coded as correct for responses of the woman or her health care provider. The final measure of breast cancer knowledge ("What should a woman do if she finds a lump in her breast?") was correct if the participant noted that care should be sought from a health care provider.

There were four measures of cervical cancer screening knowledge. These included "What is a Pap test?" which was coded as correct if the woman indicated a pelvic exam to detect cervical cancer, and/or a medical procedure in which the health care provider examines inside the woman's vagina, and/or otherwise accurately described what occurs during an exam. The second cervical cancer screening knowledge measure ("How often should a woman get a Pap test?") was determined to be correct for responses of annually. For the third indicator, women were showed a single sheet of paper with four large pictures of instruments and were asked to identify which device was used to perform a Pap test. Responses were coded as correct if they indicated either of the correct choices (cytobrush and speculum) or incorrect for either of the other two pictures (blood pressure cuff and otoscope). The final cervical cancer screening knowledge measure asked participants to explain how a woman could be less nervous or anxious about a Pap test or pelvic exam. Correct responses were any action or activity

Table 2. Proportion of Correct Responses at Baseline and Postintervention by Random Assignment into Experimental or Control Group

Knowledge Indicator	Control (<i>n</i> = 84)		Experimental (<i>n</i> = 91)		Odds Ratio	Test Statistic
	<i>n</i>	%	<i>n</i>	%	T:C	χ^2
Definition of cancer	33	39	28	31	0.687	1.40
Definition of mammogram	38	45	37	41	0.829	0.37
Frequency of mammogram	18	22	13	14	0.610	1.54
Whose job is it to do the breast exam	76	90	81	90	0.947	0.01
What to do if you find a lump	60	71	64	70	0.948	0.03
Definition of Pap test	32	38	35	38	1.016	0.00
Frequency of Pap test	16	19	16	18	0.919	0.05
Pap test picture identification	50	60	53	59	0.974	0.01
Identify ways to decrease anxiety for pelvic exam	33	41	38	42	1.043	0.02
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		<i>t</i>
Knowledge composite (nine items)	4.25	2.26	4.04	2.23		-0.642

**p* < .10.

***p* < .05.

****p* < .01.

*****p* < .001.

that would be calming or supportive (e.g., relaxing, holding someone's hand, praying, picturing a calm place, asking the doctor questions).

We also created one knowledge composite, composed of all nine items (pretest mean = 4.1, *SD* = 2.2; posttest mean = 4.9, *SD* = 2.4). Reliability of this composite measure was assessed using the Cronbach α coefficient: .73 for pretest overall knowledge; and .76 for posttest overall knowledge, indicating adequate reliability.

Analysis

Responses to the questions were independently coded by two members of the research team. If they disagreed, they conferred to discuss how responses should be coded. Cohen's κ was calculated to determine interrater reliability in the independent coding of the raters, adjusting for the likelihood of chance agreement (Gordis, 1996). Across all items, κ exceeded 90%, which is considered excellent reliability.

Simple bivariate comparisons were initially conducted to describe the sample and determine if there were any differences between the women who were randomly assigned to the experimental or control groups (see Table 1). Bivariate statistics were also used to describe and compare the women's cervical and breast cancer screening knowledge at baseline (Table 2). To conduct unadjusted comparisons between knowledge at baseline and posttest within the control group and within the experimental group, we used the McNemar chi-square test (for paired, dependent samples) for the knowledge indicators and a paired sample *t*-test for the knowledge composite (Table 3).

To examine differences between women in the experimental and control conditions controlling for preintervention knowledge about breast and cervical cancer, a regression analysis was conducted. We modeled each posttest knowledge indicator and the composite on a linear model consisting of the same knowledge indicator or composite at baseline and the treatment

assignment indicator. Presence of children, living arrangement, marital status, and impairment severity were tested as covariates of the treatment effect but had insufficient variance. In many cases, parameter estimates from these variables or the other variables in the model were very large with large standard errors, indicating that some collinearity was present between these variables. These variables were therefore excluded from the analysis. We note, however, that the experimental and control groups did not differ on any demographic characteristics or in terms of baseline knowledge (Tables 1 and 2).

For each of the individual knowledge items, a logistic regression was modeled. Findings from these models are expressed as odds ratios (with 90% confidence interval; Table 4). For the composite knowledge scores, ordinary least squares regression was modeled. Coefficient estimates and 95% confidence intervals are reported (Table 4).

We conducted intent-to-treat analyses with no adjustments made for attendance or abnormalities in the data (such as unusually influential observations on any participant). Residual normal probability plots were examined after regression to confirm the assumption of the normality of the residuals for the model of the knowledge composites, and studentized residuals of the composite and knowledge items were examined for influence. Sensitivity analyses were subsequently run to indicate whether results would be substantively altered by the exclusion of participants with studentized residuals more than two and a half standard deviations from the mean (either direction). While there were sparse missing values on covariates and dependent variables, a chi-square test demonstrated that we should not reject that these missing values occurred completely at random (Little, 1988). Thus, the missing values were simply deleted.

Results

Table 2 presents the number and percentage of women who (a) correctly responded to each question, and (b) the mean score on

Table 3. Unadjusted Comparison of Women’s Correct Responses at Baseline and Posttest by Control and Treatment Group

Knowledge indicator or index	Control Group (N = 84)					Statistical Test χ^2	Experimental Group (N = 91)					Statistical Test χ^2
	Baseline		Posttest		Odds Ratio (P:B)		Baseline		Posttest		Odds Ratio (P:B)	
	n	%	n	%			n	%	n	%		
Definition of cancer	33	39	35	42	0.999	0.17	28	32	34	39	0.994	1.38
Definition of mammogram	38	45	40	48	0.999	0.67	36	41	48	55	0.994	7.20***
Frequency of mammogram	18	22	17	21	1.003	0.11	13	15	25	29	0.968	9.00***
Whose job is it to do the breast exam	76	90	75	89	1.000	0.09	78	90	79	91	1.000	0.11
What to do if you find a lump	60	71	68	81	0.998	4.00**	62	70	63	72	1.000	0.07
Definition of Pap test	32	38	44	52	0.993	7.20***	35	40	45	51	0.994	3.57
Frequency of Pap test	16	19	24	29	0.982	4.00**	16	18	32	37	0.972	10.67***
Pap test picture identification	49	59	58	70	0.997	5.40**	51	59	61	70	0.997	5.00**
Identify ways to decrease anxiety for pelvic exam	33	41	39	48	0.996	1.64	38	43	51	58	0.994	6.26**
	Mean	SD	Mean	SD		t	Mean	SD	Mean	SD		t
Knowledge composite (nine items)	4.3	2.3	4.8	2.4		3.97****	4.1	2.3	5.0	2.4		5.72****

*p < .10.
 **p < .05.
 ***p < .01.
 ****p < .001.

Table 4. Gains in Experimental Group Knowledge in Comparison to the Control Group, Controlling Baseline Knowledge

Dependent Variable	Intercept	Baseline Score Covariate	Experimental Group ¹
Knowledge Indicator	Odds Ratio (90% C.I.)	Odds Ratio (90% C.I.)	Odds Ratio (90% C.I.)
Definition of cancer	0.35(0.22,0.56)****	5.38 (3.04, 9.52)****	1.00(0.57,1.74)
Definition of mammogram	0.16(0.08,0.30)****	52.03(22.05,122.80)****	2.33 (1.09, 4.98)**
Frequency of mammogram	0.08(0.04,0.16)****	30.89(12.33,77.41)****	3.09(1.36,7.03)**
Whose job is it to do the breast exam	1.27(0.50,3.23)	10.18(3.84,27.01)****	1.26(0.51,3.09)
What to do if you find a lump	0.95(0.52,1.73)	15.99(7.78,32.87)****	0.49(0.24,1.02)
Definition of Pap test	0.53(0.34,0.82)**	8.33(4.52,15.37)****	0.90(0.51,1.59)
Frequency of Pap test	0.23(0.14,0.37)****	10.39(4.87,22.17)****	1.62(0.89,2.96)
Pap test picture identification	0.62(0.36,1.05)	18.32(8.84,37.96)****	1.03(0.53,2.02)
Identify ways to decrease anxiety for pelvic exam	0.42(0.26,0.67)**	7.10(3.91,12.88)****	1.55(0.88,2.73)
	Intercept	Baseline Score Covariate	Experimental Group ^a
Knowledge composite (nine items)	Estimate (90% CI) 1.04 (.63, 1.45)****	Estimate (90% CI) 0.88 (0.81, 0.96)****	Estimate (90% CI) 0.38 (0.04, 0.72)**

*p < .10.
 **p < .05.
 ***p < .01.
 ****p < .001.

^aThe reference group is the women in the control group.

the knowledge composite at baseline and at posttest, stratified by whether they were in the control or the treatment group. There were no statistically significant differences in cervical and breast cancer screening knowledge at baseline between the control and the experimental group (Table 2).

Unadjusted comparisons between baseline and posttest knowledge, within each group, are reported in Table 3. Statistically significant gains in knowledge were found for the experimental group on five measures: definition and frequency of mammography, frequency of Pap test, Pap test instrument identification, and ways to manage anxiety

during an exam. Statistically significant knowledge gains were found for the control group on four measures: what to do if you find a lump in your breast, definition and frequency of Pap test, and Pap test instrument identification. It is important to note that these are within-group comparisons only. Table 3 also indicates wide variability in the knowledge of the experimental group. For cancer definition, frequency of mammography, and frequency of Pap test, fewer than 40% of the group correctly responded at posttest. However, 70% or more of the experimental group correctly responded at posttest to questions about whose job it is to

do a breast exam, what to do if you find a lump in your breast, and Pap test instrument identification.

Table 4 presents the posttest knowledge regression models. Using a one-tailed test, we found two breast cancer knowledge items and the knowledge composite on which the participants in *Women Be Healthy* responded correctly to, compared to participants in the control condition: On “definition of mammogram,” the odds that experimental participants gave the correct answer were more than twice that of participant in the control group (OR = 2.33; $p < .05$). On frequency of mammogram, the odds of a correct answer in the treatment group were more than three times that of women in the control group (OR = 3.09; $p < .05$). On the overall knowledge composite, women in the experimental group had a score that was on average 4/10 of a point greater than women in the control group ($\beta = 0.38$; $p < .01$), representing a relatively large effect size (measured in standard deviations of the post-test overall knowledge composite) of 0.70.

Diagnostics showed that residuals (for the linear outcome) were distributed approximately normal. Removal of observations for women having residuals outside of 2.5 standard deviations from the mean changed the result for the knowledge composite but not in a substantive way; it went from 0.38 to 0.33 (both $p < .05$). The binary outcomes were not changed as none of the residuals were of sufficient magnitude. No other findings were substantively altered by unusually influential data. Further diagnostics that include the women with severe to profound disabilities in the analysis demonstrated no substantive changes in the results, when these women were included; definition of mammogram rose from OR = 2.33 to OR = 2.60 (staying at $p < .05$); frequency of mammogram fell from OR = 3.09 to OR = 2.40 (staying at $p < .05$) and knowledge composite went from $\beta = .38$ to $.35$ (also at $p < .05$).

Discussion

To the best of our knowledge, this is the first randomized control trial of the effectiveness of a targeted intervention to advance the knowledge of cervical and breast cancer screening of women with developmental disabilities. We found modest but statistically significant gains in women’s breast cancer knowledge but nonsignificant rates of knowledge gains for women in the treatment group related to cervical cancer. On overall knowledge, the difference of one point represented a large effect of 0.70 standard deviations. The evidence reported here suggests that women’s knowledge about both cervical and breast cancer screening can be improved, which is a significant first step in the development and testing of effective interventions that promote increased cervical and breast cancer screening rates for this population.

Before discussing the study’s implications, we first delineate its limitations. First, this investigation relied on a fairly simple set of questions to understand women’s cervical and breast cancer screening knowledge. It is possible that some women had knowledge beyond that which they were able to express to the interviewers. Most of the women expressed satisfaction

and even delight with participating in the research project, but it is possible that some were nervous or anxious by the questions, and that this anxiety may have biased their answers. Second, several questions required women to provide narrative answers, which requires a degree of verbal sophistication. Therefore, women with more severe impairments may be less able to answer these questions. However, the questions we asked were drawn from a standardized instrument that was developed explicitly for use with adults with developmental disabilities, the Socio-Sexual Knowledge and Attitudes Assessment Tool–Revised (Griffiths & Lunskey, 2003).

Third, this intervention was administered in a classroom setting at sites where women in the treatment group were in some contact with women in the control group. The classroom setting makes it impossible to rule out that the observed effect of the treatment was partly due to participants interacting with each other (a violation of the stable unit treatment value assumption; Morgan & Winship, 2007). Further, it is possible that some of the women in the experimental group shared their knowledge with women in the control group. This is possible because women were randomized at each site, and nearly all sites had an equivalent number of women in the experimental and the control group. We cannot be certain if such spillover effects occurred. The fact that the women in the control group showed knowledge gains may reflect this spillover effect and/or an effect emerging from being interviewed. The interviews collected at baseline may have served as a small intervention of sorts, and may have induced the women to seek information, or otherwise inquire about these issues. However, if there was a significant spillover effect, the resultant bias would make our findings a *conservative* estimate of the differential gains in knowledge that accrued to the women who participated in the *Women Be Healthy* intervention.

This sample did not include women who are unknown to the service system. All of the women were recruited from either a community rehabilitation program, residential program, or a community college; most women were receiving at least case management services in addition to residential and/or vocational services, and lived in a single state. Furthermore, the women were not randomly selected to participate in the study (they were randomized into either the experimental or the control group). For both of these reasons, we cannot generalize these results to the entire population of women with developmental disabilities.

Finally, this study reports short-term gains in knowledge as women were interviewed an average of 13 days after the intervention was completed. It is wholly unclear from these results if the women would retain knowledge gains over time or whether the knowledge gains translate into increased rates of cervical and breast cancer screening. Further research to examine these issues is warranted.

Despite these limitations, this study has several important strengths. It employed a relatively large sample of women with developmental disabilities who were from a diverse geographic area across a populous state. These women were enrolled in a

range of employment, educational, and day activities and had a number of different living arrangements. As such, these results are likely to be generalizable to the larger population of women with mild to moderate developmental disabilities who live in community (as opposed to institutional) settings. As a randomized control trial, we were able to eliminate many threats to internal validity (such as selection bias) and reduce other threats (such as differential attrition bias) by randomizing over both observed and unobserved confounders of the treatment effect (Shadish, Cook, & Campbell, 2002).

Implications

Improving women's knowledge about vital cervical and breast cancer screening is doubtless a critical step in empowering them to effectively partner with their health care providers and also for the design and implementation of effective interventions to improve their rates of receipt of cervical and breast cancer screening.

Our findings first show that women with developmental disabilities generally have limited knowledge of cervical and breast cancer screening, offering critical evidence that interventions to teach them about these issues are critically needed. This study makes clear that educational efforts to improve the understanding of women with developmental disabilities about these screenings are imperative. The women's ability to actively participate in their health care and communicate effectively with health care providers requires them to have basic knowledge about cervical and breast cancer screening. Such educational efforts, if they are to succeed, must be geared to learners with limited literacy and cognitive limitations.

This study also indicates that with a short-term intervention, women can achieve modest gains in knowledge even about fairly complex health care screenings. To realize more significant knowledge gains, we speculate that interventions for this population must be of greater duration and intensity, particularly in the content area of cervical cancer. It is also possible that instructors need to develop greater comfort with teaching content related to cervical cancer, further research to understand this issue is warranted. This study provides clear evidence that *Women Be Healthy* is a promising practice. However, our evidence also suggests that it needs to be revised, particularly in the area of cervical cancer, if it is to be more effective in advancing women's knowledge about cervical and breast cancer screening.

Social workers who provide services to women with developmental disabilities should work to improve their knowledge and information about clinically recommended screenings. Such efforts could take several forms. First, social workers could educate their clients with developmental disabilities about the importance of cervical and breast cancer screening and the need to receive such screenings according to clinical guidelines. Social workers could also support women with developmental disabilities in their efforts to be assertive with their health care providers. In anecdotal evidence volunteered by some of the women we interviewed, health care providers

sometimes told women that they did not need Pap tests, in particular. We have no way of knowing which of the women in our study were sexually active and therefore at elevated risk for developing cervical cancer. Notably, one-sixth of the sample reported that they had children. These women offer a conservative estimate of those at least who either were sexually assaulted or were sexually active, further substantiating the urgent need for cervical cancer screening for this population. Health care providers are unlikely to have such intimate knowledge of their patients with developmental disabilities, particularly because widespread beliefs persist that the sexuality of women with developmental disabilities is deviant or absent (Block, 2002; McCarthy, 2002), and women with developmental disabilities may be reluctant to disclose their sexual histories or sexual behavior to their health care providers and caregivers. As such, the clinical guidelines as established by the U.S. Preventive Services Task Force (2009) should be followed for women with developmental disabilities. Social workers, who often work much more closely with their women clients with developmental disabilities than health care providers do, are well positioned to have or acquire this intimate knowledge. As such, they are uniquely able to offer support both in advocacy with health care providers and also in helping women with developmental disabilities to learn about the importance of cervical and breast cancer screening.

Social workers in a range of settings, including residential, day and employment programs, as well as clinical and generic social service venues, could actively pursue efforts to provide training and educational material that increases the women's understanding of the importance of cervical and breast cancer screening, as well as reduces their fear and anxiety about having these exams.

Conclusions

On balance, this study offers new evidence that women with developmental disabilities can benefit from targeted educational interventions to advance their knowledge about cervical and breast cancer screening. However, the modest gains realized with an 8-week intervention suggest that if major knowledge gains are to be realized, an expanded amount of instructional time may be necessary, particularly in the area of cervical cancer.

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