Lightening Can Strike Twice: A National Partnership Promoting Breast Health among Women with Disabilities

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ABSTRACT

Background: Women with disabilities are less likely to receive recommended screenings for breast cancer, which is often related to lack of knowledge about screening. *Lightening Can Strike Twice* was a project aimed at understanding barriers and improving knowledge about breast cancer screening among this population in the National Capital Region (NCR).

Objectives: We describe a partnership between national organizations and an academic institution that provided educational workshops and coaching sessions to increase knowledge of breast cancer screening among this population in this region.

Methods: Twenty-two workshops and 56 coaching sessions were offered from 2017-2019. Pre-session surveys were used to collect data on participant demographics and barriers and post-session evaluations were used to determine improved knowledge and likelihood of scheduling a future screening.

Conclusions: A total of 299 women attended the workshops and 56 women were coached over the two-year project period. Pre-workshop surveys assessed demographics and barriers among workshop participants and highlighted the need for education on obtaining a screening. Post-workshop evaluations showed that most participants strongly agreed that their understanding of the benefits of screening had increased and that they were more likely to schedule a screening. The national partners were able to address the lack of knowledge of breast cancer risks and screening among this population and identify future opportunities within the targeted community.

KEY WORDS: Partnership, mammography, women, disability, health education, coaching, nursing, advanced practice nursing.

Breast cancer is the second most common cancer in the U.S. with greater mortality among black women.[1] From 2008-2017, overall mortality from breast cancer declined but remained 39% higher among black women.[2] Screening and early detection can reduce mortality but is limited by barriers such as low income and lack of health insurance, access to care, recommendation from a provider to get a mammogram, and knowledge of breast cancer risks and screening methods.[2] Women with disabilities are at risk for greater mortality from breast cancer and are less likely to receive a clinical breast exam (CBE) and recommended mammogram screenings which can lead to late-stage diagnosis impacting survival.[3] System-level factors such as inadequate training, knowledge, and ineffective communication among health care professionals can further contribute to disparities among persons with disabilities.[4] Health care providers may also make assumptions about those with disabilities, limiting their options for preventive care.[4]

Breast cancer screening recommendations from the American Cancer Society (ACS), National Comprehensive Cancer Network (NCCN), and U.S. Preventive Services Task Force (USPSTF) vary, with the only CBE recommendation from NCCN being every one to three years beginning at age 25 and a mammogram beginning at age 40 (NCCN and USPSTF) or age 45 (ACS) for women at average risk[5].

The American Association on Health and Disability (AAHD), a national cross-disability organization that promotes the health and wellness of persons with disabilities partnered with the Susan G. Komen For The Cure (Komen) to advocate for outreach to women with disabilities. In 2012, they launched *Project Accessibility USA: Removing Barriers for Women with Disabilities* to provide on-site mammography facility assessment and technical assistance to improve mammography screening accessibility for women with disabilities. They also created

interactive, on-line training modules to increase mammography staff awareness, and access to materials on an online Breast Health Resource Portal.[3] Although this project ended in 2014, it provided AAHD with experience working with women with disabilities and foundational data and resources for continued work with this population in the National Capital Region (NCR). This region had the highest rates for breast cancer incidence and mortality than any other region, with the incidence rate in DC alone being 15% higher than the national average.[6] The NCR includes the District of Columbia (DC), Montgomery and Prince Georges County in Maryland, Prince William, Loudoun, Arlington and Fairfax Counties and the cities of Arlington, Fairfax, Falls Church, Manassas and Manassas City in Virginia.

In 2016, AAHD launched *Breast Cancer Awareness for Women with Disabilities: Lightening Can Strike Twice.* This project title was crafted to dispel a common misconception that women living with a disability cannot have other health issues[7,8]. This project supported Komen's NCR Community Health Survey that encompassed a focus on the continuum of care among women with disabilities, highlighting the importance of early detection and motivating women to be screened. AAHD was aware from community health survey data that women with disabilities may not seek a CBE or mammogram, limiting access to timely care. Therefore, the aim was community education on CBE and mammography screening for this population.

To provide outreach and education to this population in the NCR, AAHD partnered with the Association of Public Health Nurses (APHN). AAHDs mission is to advance health promotion and wellness initiatives for persons with disabilities with a goal of reducing health disparities between people with disabilities and to support full community inclusion and accessibility blended with APHNs mission to shape the role of public health nursing within the specialty of population health and to educate and advocate for policies and practices that

promotes the public's health. It was important for both organizations to gain trust within communities served, so a nurse practitioner and educator from Howard University in Washington, D.C. was recruited to serve as Project Coordinator. The Project Coordinator was well-suited for outreach to the targeted population because of practice and teaching experience among the population and in the NCR. The Project Coordinator was responsible for identifying community organizations in D.C. that provided services to women with disabilities and conducting educational workshops and one-on-one coaching sessions in D.C. Wards 2, 5, 7 & 8. These Wards were targeted due to death rates from breast cancer that exceeded national rates[6.] The objectives of the educational workshops were to teach women about the benefits of early screening and mammograms, recommended timing for clinical breast exams and mammograms, myths about breast cancer screening, and how to communicate and work with clinic staff about their disability to increase the likelihood of scheduling a breast exam and/or mammogram. Coaching sessions were offered to provide more individualized education for those who had further questions about breast cancer screening.

Methods

Data Collection

AAHD developed a pre-workshop survey and a post-workshop evaluation to assess changes in knowledge, attitudes, and behaviors specific to the continuum of care in breast health. Before the start of each workshop, the Project Coordinator utilized a voluntary, IRB-approved survey developed to assess participant demographics and past experiences with mammography. This survey was developed for another AAHD activity within the Komen grant that provided mammography facility assessment. It was designed for women with disabilities and asked if respondents met one of the two criteria of (1) having a disability and being at least 40 years of

age or (2) having a disability, being younger than 40 years of age, and advised by a health care provider to have a mammogram. If neither of these criteria applied, the survey ended after these questions. Those who met the criteria continued with the full survey, which asked them to indicate their race, functional abilities, health insurance status, time frame of their last mammogram, difficulties in obtaining a mammogram and reasons why they have not obtained one.

Following the educational sessions, participants were asked to complete post-workshop evaluations to assess if the training met its objectives and if the training facilitator was effective. Related to training objectives, participants were asked how much they agree or disagree (strongly agree, agree, disagree, or strongly disagree) that their (1) understanding of the benefits of early screening and mammograms has increased, (2) knowledge about recommended timing for clinical breast exams and mammograms has increased, (3) understanding about some of the myths about breast cancer screening has increased, (4) understanding about how to communicate and work with clinic staff about my disability has increased, and (5) based on what was learned in this presentation, how likely they were to schedule a breast screening exam and/or mammogram. Related to the facilitator effectiveness, participants were asked how much they agree or disagree (strongly agree, agree, disagree, or strongly disagree) that the facilitator was (1) knowledgeable in the topic/area, (2) responsive to participants' questions and needs, (3) well-organized, and (4) able to present the material in an understandable way.

The coaching session evaluation was similar to the workshop evaluation, asking participants how much they agree or disagree (strongly agree, agree, disagree, or strongly disagree) that they knew more about the benefits of early screening and prevention of breast cancer and the risk factors for breast cancer, were more likely to get a mammogram on a regular

schedule in the future, felt more comfortable being an advocate for themselves with their health care providers, that the coach was knowledgeable about breast cancer screening and risks for breast cancer, was able to present material in an understandable way, and overall, was satisfied with the coaching received.

Development of Educational Materials

As a national, cross-disability organization, AAHD works to ensure that all printed materials for all of their programs are accessible to those who are blind or had low vision (e.g. large print, braille, or other alternative formats), deaf of hard of hearing (e.g. ASL interpreters), and that web-based resources are 508-compliant (i.e. section in Rehabilitation Act of 1973). AAHD developed an educational Power Point that was initially created for the *Project Accessibility USA* and updated for *Lightening Can Strike Twice*.

The Project Coordinator reviewed the literature for educational and coaching interventions aimed at promoting breast cancer screening behavior among women. The program *Learn, Share & Live* aimed to increase knowledge of breast health and resulted in greater screening among older, African American women who belonged to an urban social service organization.[9] Health care professionals led three, half-day sessions over a period of two years. Findings affirmed the education intervention was effective as a strategy to increase knowledge and change attitudes and beliefs and mammography adherence increased significantly. Church-based educational programs that included culturally-sensitive videos about the role of mammography in early detection of breast cancer and myths related to breast cancer and screening concluded that education increased rates of breast cancer screening significantly when compared to a control group who received no health education materials.[10] The *Telephone Coaching Adherence Project* (T-CAP) was a 10-min coaching intervention by phone offered

among women who were non-adherent to mammography screening appointments.[11] Psychosocial factors and perceptions of barriers were measured by a baseline survey. T-CAP showed that even brief coaching with tailored messages could modify behavior and improve adherence to mammography appointments. These interventions affirmed the need for education and coaching to improve knowledge, self-efficacy, and motivation about recommended screening and follow-up care.

Development of the Coaching Toolkit

AAHD developed a toolkit used for coaching sessions. This toolkit was a binder of resources on breast health from Komen and AAHD that included a list of FDA-approved mammography facilities in the region and fact sheets on screening and the continuum of care. The toolkit was used to guide discussion about the importance of breast cancer screening, risk factors, treatment, follow up and survivorship and was given to each women following the sessions.

Identification of Host Sites

With prior experiences and relationships with key stakeholders, the Project Coordinator was able to identify host sites for the educational workshops in targeted DC Wards known to serve a population of women with disabilities. Sites were chosen based on the likelihood that women with disabilities came to these sites and that they were accessible to those with physical disabilities. Host sites included places of worship, senior wellness centers, adult day care, recreational centers, and shelters for women.

Offering Workshops at Host Sites

The 60-minute interactive workshops included the Power Point presentation and discussion on the importance of breast awareness, for example, what signs and symptoms to look

for and what changes should be reported immediately to a health care provider. The participants were instructed on how to prepare for a CBE and mammogram, what to expect, and how often they should be screened in consultation with their health care provider. Risk factors for breast cancer, types of treatment, and the importance of follow up with a health care provider were also discussed. The participants were encouraged to inform their health care provider of anything that makes them feel uncomfortable during a clinical breast exam or a mammogram and to advocate for their health. Women who reported never having had a mammogram shared personal stories, firmly held beliefs, and myths and workshops provided an opportunity to dispel common myths and misbeliefs.

The Project Coordinator used data collected from pre-workshop surveys and was assisted by Site Coordinators to identify those in attendance at sessions who self-reported hearing, vision or cognitive impairments so that these individuals could be positioned in the room to be able to hear and see the speaker and materials. The Project Coordinator was able to observe those using assistive devices (e.g. glasses, magnifying glass and hearing aids) and spent additional time with attendees with known cognitive impairments to explain content and to answer questions. It was also noted that participants were supportive of each other to ensure content was heard and understood by all in attendance.

Offering One-On-One Coaching Sessions

Beginning in 2018, coaching sessions offered by the Project Coordinator were added. Coaching sessions were voluntary and reinforced education provided in the workshops to support women navigating through challenges they encountered in the process of seeking mammograms and care. The principles of motivational interviewing, a "collaborative conversation style for strengthening a person's own motivation and commitment to change" were used to promote

behavior change and adherence to provider recommendations.[12] All coaching sessions were held in-person immediately after the workshops. All workshop participants were invited to participate in a coaching session, and those who expressed concerns about screening during the workshop were targeted. At the conclusion of the coaching session the participant completed a coaching evaluation and received a $25 grocery gift card that was provided through the Komen grant funds.

Lessons Learned

Educational Workshops and Coaching

A total of 22 workshops in targeted D.C. Wards were provided by the Project Coordinator and 299 women attended the workshops from January 2017 through July 2019. Eighty-five pre-workshop surveys were completed by workshop participants and 66 of those met the criteria. These 66 surveys revealed that the largest percentage of participants were black, had difficulty with walking or climbing stairs, were insured, had difficulty with getting a mammogram in the past, had a mammogram within the last two years, and did not have difficulty accessing the facility. The largest percentage of survey completers who reported that they did not have a mammogram in the past two years specified the reason as it was uncomfortable because of their disability (see Table 1). Although not all women who attended the workshops completed a pre-workshop surveys, the data collected was helpful to the Project Coordinator in showing demographics and barriers among the women who attended. It also highlighted the need for education related to obtaining a mammogram screening and self-advocacy.

At the end of all educational workshops, paper evaluations were distributed to all participants. These anonymous evaluations were collected by the Project Coordinator, results

were entered into Survey Monkey, and descriptive statistics were compiled. Nearly all participants responded that they were more likely to schedule a breast screening exam and/or and mammogram (see Table 2).

Coaching evaluations were distributed to all women who chose to participate in coaching sessions. A total of 56 coaching evaluations were received from March 2018 through July 2019. These anonymous evaluations were collected by the Project Coordinator, results were entered into Survey Monkey, and descriptive statistics were compiled. Responses showed that most of the women who attended the workshop strongly agreed or agreed that the coaching changed their knowledge and feelings about breast cancer screening (Table 3).

The National Partnership

When the partnership between AAHD and APHN began, there were no known educational or coaching initiatives in D.C. specifically targeting women with disabilities to promote breast health. This provided an opportunity for the partners to use shared expertise to offer education and coaching about breast health. The Project Coordinator's experience working with women with disabilities and relationships with community partners as a trusted source for delivering breast health education was essential. Despite relationships with community partners, the scheduling of workshops was challenging for the Project Coordinator. Some of the sites had prescheduled events which resulted in cancellation or rescheduling of workshops. Presenting community partners with flexible scheduling options proved to be necessary for planning the workshop schedule.

The educational component was seemingly enhanced by adding one-on-one coaching sessions following the 2018-2019 workshops. During these sessions, participants were able to share personal experiences about navigating the health care system and challenges encountered

with seeking a mammogram. Further study is needed to determine the efficacy of coaching related to increasing breast cancer screening or follow-up with a health care provider.

One important lesson learned through this partnership was that there should have been more consideration of how to measure health outcomes. Beyond knowing that knowledge and self-efficacy increased, greater impact could have been achieved had we looked at how the education and coaching influenced health behavior. One of the Site Coordinators voluntarily reported to the Project Coordinator that six of the women who attended one of the workshops had a mammogram and one woman reported that she had a mass and planned to follow up with her provider. These are the outcomes that we hoped to have more of and should be measured in educational programs.

Conclusions

In this project, AAHD chose to tap into the expertise of APHN for community outreach by nurses, but other health professionals should also be considered to provide education and coaching in the community setting. The challenges and barriers experienced by women with disabilities support the need for all health professionals to be more educated about caring for them[4, 7]. This is a call to action for the future of this national partnership between AAHD and health professions organizations.

In academia, one approach could be integrating content on the care and unique needs of people with disabilities into health professions curricula. Community and clinical experiences could offer opportunities for students to work with those with disabilities. These approaches can help close knowledge gaps and change perceptions and attitudes about the disability community. AAHD could partner with academia to help inform curricula development that is inclusive of this content.

In practice, health professionals in community and public health setting should collaborate with those in health care settings to identify and reduce barriers to ensure greater adherence to provider-recommended screening and follow-up. AAHD could develop online training modules for use in practice settings to educate health professionals on barriers and approaches to improve mammography screening and follow-up care among women with disabilities.

The partnership between AAHD and APHN provided a blend of expertise to outreach to a population at-risk for mortality from breast cancer. Inviting APHN as a partner brought the needed clinical and community perspective, while recruiting a Project Coordinator from Howard University provided regional and population-specific experience needed to promote trust among those we intended to reach. Partners at the national level can work with state and local partners to help identify and eliminate barriers and empower women with disabilities to seek recommended screenings that can lead to greater prevention and early detection of breast cancer.

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Table 1. Pre-Workshop Survey Results

Race (N = 66)	
Non-Hispanic Black	63.64%
Non-Hispanic White	21.21%
Other	7.58%
Hispanic	4.55%
Multiple	3.03%
Reported some or great difficulty with: (N = 64)	
Walking or climbing stairs	76.19%
Seeing	39.06%
Remembering or concentrating	34.37%
Self-care	34.38%
Hearing	15.63%
Using your usual (customary) language, do you have difficulty communicating (understanding or being understood	14.06%
Health Insurance (N = 63)	
I have Medicare, Medicaid or other medical insurance	95.24%
I do not have Medicare, Medicaid or other medical insurance	3.17%
I have medical insurance, however it does not cover mammograms	1.59%
Difficulty obtaining mammograms in the past (N = 62)	
Yes	69.35 %

No	30.65%
Last mammogram (N = 62)	
I have had a mammogram in the last 2 years	67.24%
I have NOT had a mammogram in the last 2 years	32.26%
Had a mammogram in the last 2 years and encountered the following difficulties (N = 43)	
I had no difficulties as a result of my disability.	58.14%
The mammogram was uncomfortable because of my disability.	30.23%
I told the scheduling staff I would need accommodations in order to have the mammogram, and the staff said the accommodations would not be available.	11.63%
Other	9.30%
I had difficulty obtaining transportation to the facility.	6.98%
I had difficulty with parking at the facility.	6.98%
There was a lack of alternative format materials.	6.98%
There was not an accessible machine where I receive my mammogram.	6.98%

The staff were unable to accommodate my specific needs.	2.33%
Difficulty accessing (select all that apply): (N = 42)	
None of the above	78.57%
Other	11.90%
Mammogram facility	7.14%
Room in which the mammogram was taken	4.76%
Bathrooms in the facility	4.76%
Changing/dressing rooms of the facility	2.38%
Have NOT had a mammogram in the past 2 years for the following reasons. (Check all that apply) (N = 19)	
Other	57.89%
There was not an accessible machine where I receive my mammogram.	21.05%
I had difficulty with physically accessing the facility.	15.79%
I had difficulty with parking at the facility.	10.53%
I had difficulty obtaining transportation to the facility.	10.53%
I did not know I needed to have a mammogram	10.53%
I told the scheduling staff I would need accommodations in order to have the mammogram, and	10.53%

the staff said accommodations would not be available.	

Table 2. Workshop Evaluation

Most participants agreed or strongly agreed that the training met its objectives. (N = 298)				
Strongly Agree	**Agree**	**Disagree**	**Strongly disagree**	**In response to**
60%	36%	2%	2%	My understanding of the benefits of early screening and mammograms has increased.
58%	38%	4%	1%	My knowledge about recommended timing for clinical breast exams and mammograms has increased.
51%	43%	4%	2%	My understanding about some of the myths about breast cancer screening has increased.
57%	38%	3%	2%	My understanding about how to communicate and work with clinic staff about my disability has increased.
65%	31%	2%	1%	Based on what I learned in this presentation, I'm more likely to schedule a breast screening exam and/or mammogram.
Most participants agreed or strongly agreed that the training facilitator was effective. (N = 293)				
Strongly Agree	**Agree**	**Disagree**	**Strongly disagree**	**The facilitator was:**
74%	24%	1%	1%	Knowledgeable in the topic/area
73%	25%	1%	1%	Responsive to participants' questions and needs
77%	21%	0%	1%	Well-organized
80%	18%	0%	1%	Able to present the material in an understandable way

Table 3. Coaching Evaluations (N = 56)

% of Women	In Response To
56.06% strongly agreed 41.94% agreed	Know more about the benefits of early screening and prevention of breast cancer.
66.67% strongly agreed 30.30% agreed	Were more likely to get a mammogram on a regular schedule in the future.
78.79% strongly agreed 21.21% agreed	Felt more comfortable being an advocate for themselves with their health care providers.
59.38% strongly agreed 40.63% agreed	Knew more about risk factors for breast cancer.
81.82% strongly agreed 18.18% agreed	Felt coach was knowledgeable about breast cancer screening and risks for breast cancer.
72.73% strongly agreed 27.27% agreed	Felt coach was responsive to questions.
72.73% strongly agreed 27.27% agreed	Felt coach was able to present material in an understandable way.
87.50% strongly agreed 12.5% agreed	Overall, was satisfied with the coaching received.