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Developing a Model American Indian Intergenerational Youth Health Messenger Program to Promote Breast Cancer Screening

Shannon M. A. Sparks, Lisa L. Tiger, and Alexandra A. Tiger

Disparities in health have existed for American Indians and Alaska Natives (AI/ANs)[1] in the United States for more than five hundred years, a consequence of disparities in power and wealth that have prevailed since colonization.[2] Today, AI/ANs continue to experience significant disparities in morbidity and mortality for many health conditions including diabetes, liver disease, influenza and pneumonia, mental health disorders, and injuries, and they have a lower life expectancy than the United States population as a whole.[3] For some other health conditions, such as cancer, AI/ANs experience lower morbidity and mortality overall than non-Hispanic whites (NHWs), yet those with the disease often have poorer health outcomes and lower five-year survival rates.[4] The roots of these disparities are multiple, a consequence of

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poor socioeconomic conditions, inadequate education, cultural differences, historical trauma, distrust of the Western medical system and providers, inadequately funded health care, and a limited focus on preventive care.[5]

For AI/AN women, breast cancer is generating increasing concern and attention. It is the most common cancer for AI/AN women and a significant cause of mortality, largely due to low rates of screening and more advanced stage at diagnosis.[6] In an effort to address such disparities in cancer screening and outcomes, in recent years AI/AN communities have increasingly turned to community-engaged and participatory approaches to identify culturally appropriate, strength-based solutions. From these efforts have emerged a variety of initiatives, including community-based, culturally embedded cancer health education and navigation programs, as well as AI/AN grassroots groups designed to create forums to promote breast cancer awareness in culturally sensitive ways. While these have had positive impacts on cancer knowledge and behavior, disparities in AI/AN cancer screening and health outcomes persist. In an effort to improve survival rates, communities have been looking to innovative ways to increase awareness of breast cancer in AI/AN communities and motivate women to access screening.

In 2009, AI/AN youth working with the Wisconsin Pink Shawl Initiative (WPSI) in Milwaukee, Wisconsin came up with an innovative idea to help motivate women to follow through with breast cancer screening. Since family and their role as caregivers are of high importance to many AI/AN women, these youth reasoned that they could leverage their relationships with their mothers and women in their extended families to encourage them to get screened. Out of this idea grew Junior Pink Shawls (JPS), a youth-led AI/AN community organization, and the intergenerational youth health messenger concept. Youth health messengers function as health change agents, delivering breast health education across generations and leveraging their relationships with women in their families to encourage them to access screening.[7] It builds upon community-based, culturally appropriate models of cancer health education being successfully utilized in AI/AN communities, and simultaneously works to empower youth to make positive changes in their own lives as well as their families and communities.

In this article we describe the origins of JPS and the development of the youth health messenger project through a community-academic partnership with AI/AN youth in Milwaukee, Wisconsin. As background, we discuss the issue of breast cancer in AI/AN communities, culturally embedded cancer education programs, and review models of youth as agents of change. Next, we describe the organic development of JPS out of a recognized community need to motivate women to get screened for breast cancer. Finally, we detail the development of the intergenerational youth health messenger model through a community-based partnership between JPS, WPSI, and university partners, highlighting the role of AI/AN youth in its development and implementation.

Breast Cancer in AI/AN Communities

Cancer is the leading cause of death today for AI/AN women.[8] Breast cancer is the most common cancer among AI/AN women and the second leading cause of cancer death.[9] While incidence rates of breast cancer overall are lower for AI/ANs than

non-Hispanic whites (NHWs) (100 vs. 131.3/100,000),[10] AI/AN women tend to be diagnosed at a younger age, have more advanced disease at diagnosis, and have the lowest five-year survival rate of any ethnic group.[11]

Late stage at diagnosis and subsequently high mortality from breast cancer among AI/AN women are at least partially explained by low screening rates.[12] National surveillance data and multiple studies have documented rates of clinical breast exams and mammography that are consistently and significantly below those of women in the United States overall.[13] In 2013, for example, only 61 percent of AI/AN women age forty-five or older had received mammography screening within the past two years, which was notably lower than the NHW rate of 69 percent and the lowest of any racial/ethnic group in the United States.[14]

AI/ANs in the Northern Plains region, of which Wisconsin is a part, have both incidence (112.6/100,000) and mortality rates (25.8/100,000) for breast cancer that are significantly higher than the rates for AI/AN women in the United States overall. This is particularly notable when compared to incidence and mortality rates for NHW women in the Northern Plains, which are lower than the United States averages.[15] Even within the Northern Plains, breast cancer rates for AI/AN women vary significantly. The most recent data available from Indian Health Service (IHS) indicates that the Bemidji service area (Wisconsin, Minnesota, Michigan), one of three in the Northern Plains region, had a mortality rate for breast cancer that was the highest of any IHS service area in the nation and significantly higher than the other service areas in the Northern Plains.[16]

Regional variation in mortality rates is at least partially due to disparities in screening. Data from 2008 indicate that mammography rates in the Bemidji service area were only 46 percent,[17] significantly below the national AI/AN mammography rate and the Healthy People 2020 goal of 81 percent. While data are not reported separately for urban areas such as Milwaukee, data from the Urban Indian Health Institute indicate that more than 13 percent of AI/AN women forty to sixty-four in urban Indian health organization service areas within Bemidji have never had a mammogram, a rate more than double the all-races rate.[18] Research from other urban Indian communities have similarly found urban mammography rates to be significantly lower, likely due to the comparative lack of resources allocated to urban Indian clinics.[19]

While resources and access definitely are a factor in AI/AN screening rates, barriers to participation are complex and often involve numerous psychosocial and psychocultural factors related to misinformation, fear, distrust and cultural beliefs. These include a distrust of providers and the Western medical system overall, a lack of AI/AN health providers, the belief that AI/ANs do not get cancer, a lack of knowledge and awareness of breast cancer screening procedures, a lack of culturally appropriate cancer prevention and control materials, the belief that mammograms are painful and cause death, and the belief that cancer is incurable and screening only reveals inevitable death. Preventive cancer screening efforts are also complicated because cancer tends not to be openly discussed in AI/AN families, reinforcing the stigma and fear associated with the disease.[20] Even in contexts where women recognize the importance and value of preventive screenings, they may not prioritize their own

health needs. Family and community are of high importance and their needs take precedence. Thus, AI/AN women attend to their own health care needs—especially preventive care—only after the needs of their family and children are met.[21]

Culturally Embedded AI/AN Cancer Education Programs

Culturally framed interventions, including lay health education, navigation, and peer mentor programs, have been successful in many AI/AN communities in increasing screening rates and improving women's cancer health outcomes.[22] Important to the success of these programs is an understanding of AI/AN illness beliefs as well as the array of structural, social, and cultural factors that inhibit or facilitate the utilization of screening and treatment recommendations.[23]

Common to many successful cancer-prevention intervention programs has been the utilization of community-engaged approaches in assessing community needs and identifying barriers to screening, as well as the development of interventions tailored to the specific culture and needs of the individual community.[24] Many of these programs also utilize lay community members to deliver health information and navigate women to resources. The NAWWA project in Colorado, for example, successfully utilized AI/AN lay health advisers ("Native Sisters") as part of a community-based breast cancer education program to increase mammography screening for urban women.[25] The Pathways to Health program in California created a video promoting the importance of breast cancer screening that included testimonials from local AI/AN women recalling their experiences with screening and breast cancer; they also developed a formal workshop focusing on breast cancer screening techniques, risk factors, treatment options, and provider communication that was staffed by AI/AN trainers who were members of the community and utilized AI/AN professionals as panel members.[26]

While few other programs have specifically focused on breast cancer, other culturally specific community education and navigation/mentoring programs aimed at increasing screening rates for other AI/AN women's cancers have similarly utilized lay community members. The Messengers for Health program on the Apsaalooke Reservation in Montana has increased cervical cancer knowledge and comfort discussing cancer issues by hiring trusted, respected women from the community as lay health advisors (LHAs).[27] Similarly, Dignan and colleagues successfully utilized female lay health educators who were members of the Lumbee tribe to deliver a cervical cancer education program that had a positive influence on knowledge and behavior.[28] Other programs, such as Walking Forward in western South Dakota, utilize community navigators who are recognized community authorities on cancer prevention, screening and treatment resources for multiple forms of cancer, and who actively navigate AI/AN patients through cancer treatment, bridging AI/AN and Western modalities of care.[29] Central to these programs are culturally appropriate materials and methods of communication (such as storytelling and talking circles) as well as attention to AI/AN values and beliefs.[30]

Models of Youth Engagement and Advocacy

While most community-based health education, navigation, and mentoring programs are adult-initiated and -led, there is a tradition of youth action and leadership in efforts to address the collective well-being of their local communities. Examples can be found worldwide in both indigenous and non-indigenous communities.[31] In some instances, youths partner with adults to address concerns of youth themselves such as education, neighborhood violence, or youth health; in other cases, youth engage to address concerns of their larger communities, such as civic engagement, sustainable development, humanitarian challenges, or community health concerns.[32]

Such models recognize youth as active citizens and capable agents, acting in concert with adults to effect change and achieve collective well-being.[33] They are based on the belief that youth have the right to be involved in decision-making and social change projects that affect themselves and their larger communities. Youth are given support to define their own problems and solutions and learn how to achieve systemic change through collective action.[34] They act as behavioral change agents in their own communities, leading by both word and example.

Youth change agent models rooted in such participant-centered, experiential approaches are believed to be particularly beneficial to minority and disadvantaged youth. Youth are encouraged to address the larger oppressive forces affecting themselves and their communities and empowered to actively participate in exploring creative solutions.[35] This process demonstrates and builds the capacity of youth to participate in deliberative democracy as legitimate and competent citizens and respond to community problems, and gives them a sense of agency and control. It also builds identity and self-efficacy by focusing on the capabilities and strengths of youth rather than labeling them by unfortunate or limiting circumstances.[36]

While youth generally engage issues that directly affect their lives or relate to their own needs, they can also serve as an important conduit for creating change in their families or broader communities. Programs such as Youth as Agents of Behavioral Change, for example, work on the principle of the cascading effect: youth start by working on inner change, but then multiply their learning within their local community through outreach and education efforts.[37] Other programs, however, engage issues not as directly or immediately relevant to youth, but instead encourage them to serve as an avenue to influencing adult behavior. Parents or other adults are reached indirectly through "trickle-up" influence, with information or knowledge being passed on to them through their children and influencing their own behavior.[38] It is important to note that while youth in these contexts serve primarily as an avenue for influencing adult beliefs or behavior, youth beliefs or attitudes are also likely influenced which may impact future youth behavior.

Youth as Health Change Agents

While youth have functioned as change agents around a variety of topics and issues, health is one of the most common foci of youth engagement and advocacy. This view of youth as health change agents recognizes youth as individuals who can make things

happen and take an active role in the production of health for themselves and their families. Not merely passive recipients of other individuals' care and interventions, youth can actively engage with health knowledge and skills in their own right, and they are capable of strategizing, manipulating resources, and navigating constraints in the interest of promoting health.[39]

Moreover, youth can function as health change agents within a variety of social environments where they are active, including school, home, and community.[40] Their genuine participation in health issues relevant in their immediate contexts can enable youth to acquire action-competence by trying to influence real life conditions that impact local health.[41] However, it is important to recognize that as social agents, youth are embedded within larger societal structures which can facilitate or restrain their ability to act as change agents.[42] Thus, the extent to which youth are able to successfully function as health change agents, and the forms their work takes, are influenced by the local social and cultural context, and will vary from place to place.

Much of the literature around youth as health change agents centers on peer health education.[43] These models are based on the belief in youth's potential to spread health messages and health practices to younger children and peers, and their capacity to work together with others in their community to solve local health issues.[44] However, youth can also influence health change at the family and community level.[45] As basic health workers, they have the potential to spread health messages and health practices to older family and community members as well as peers.[46] Implicit in this approach, however, is the assumption that parents and other adults are willing to learn from youth and include them in health care decision-making at the family and community levels.[47]

Most such programs address issues directly relevant to the youth and their broader communities, such as healthy living, environmental health, malaria control, or hygiene. In rural Laos, for example, youth successfully improved malaria-related knowledge, attitudes, and practices in the community through family and community-based presentations of a malaria-themed flip chart story.[48] Programs in Kenya and Ghana have similarly utilized youth to communicate health messages and introduce relevant health practices in both school and home environments related to hygiene, diarrhea, and malaria control.[49] There are a few examples of other programs, however, that utilize youth as agents of change for health issues that are not of as immediate or direct concern to the youth themselves. In Tanzania, for example, youth performed skits focused on HIV/AIDS as a way to promote education and openly engage community members in discussions. While this intervention has not been successful in changing adults' information or knowledge, it did demonstrate that youth can effectively open public channels of communication around the disease and related social issues such as stigma and disclosure.[50]

Youth health change agent programs addressing broader community concerns are less common in the United States, but examples do exist. Youth Engagement and Action for Health, for example, has successfully utilized youth to advocate for neighborhood improvements in physical activity and healthy eating opportunities in Southern California.[51] Another successful project in California's Latino community, Proyecto Movimiento, has focused on prevention across multiple generations, training

Youth Health Advocates to deliver health education messages on nutrition and diabetes not only to peers, but to younger children and older family members as well.[52]

Development of an AI/AN Intergenerational Youth Health Messenger Model

The idea of engaging AI/AN youth as health advocates or messengers has been gaining interest in recent years. A central theme of the 2013 Native Youth Summit, for example, was the creation of AI/AN youth health advocates to address cancer and diabetes through youth-developed prevention and educational media.[53] In addition, several examples exist of peer health-education programs that have successfully targeted health issues of concern to AI/AN youth. Examples include Native STAND, a program which utilizes a peer education curriculum to promote healthy decision making for youth;[54] the Native Youth Sexual Health Network, an organization by and for indigenous youth that works across issues of sexual and reproductive health, rights, and justice;[55] and a suicide prevention program that uses digital storytelling to highlight AI/AN youths' assets and emphasize their reasons for living.[56] A central theme of these programs is the integration of tradition and, as Native Youth Sexual Health Network states, "cultural growth specific to today's realities."[57]

What is unique about our intergenerational youth health messenger model is the use of youth to promote preventive health care for the adults in their lives. Lay health education models have demonstrated success in AI/AN communities and, as noted above, examples exist of youth successfully engaging adults around community health issues of concern.[58] We believe that AI/AN youth are well-situated to take action to promote health intergenerationally. Indigenous teachings emphasize the importance of relationships and working between and among different generations.[59] Collectively, the community and each constituent member, including youth, have a responsibility to honor and protect the health and well-being of both current and future generations.[60] Youth autonomy and leadership are culturally valued traits, and thus youth are likely to be respected in a role promoting and protecting the well-being of both their elders and future generations as well.[61] They may also be uniquely positioned to leverage their parents and other elder relations to care for themselves since the health and well-being of youth—physically, culturally and spiritually—is dependent upon the health and well-being of the elder generations.

Below, we describe the Pink Shawl concept and the origins and development of Junior Pink Shawls (JPS) and the intergenerational youth health messenger model. The model was developed through a community-academic partnership between the JPS youth, WPSI leadership, and researchers at the University of Wisconsin-Madison. The project has been youth-organized and led since its inception, with adult representatives from both WPSI and the university providing guidance and assistance with development and implementation of the model.

This project was situated in the urban Indian community in Milwaukee, Wisconsin, home to 11 percent of Wisconsin's approximately 86,000 AI/ANs.[62] Milwaukee has a long history as a diverse urban Indian center with representation from Wisconsin's

nations, including the Oneida, Ojibwe, Menominee, Potawatomi, Ho-Chunk, Stockbridge, and Brothertown, as well as numerous out-of-state tribes. It is also home to approximately twenty tribal and intertribal organizations, including Southeastern Oneida Tribal Services, the Indian Community School, and Gerald L. Ignace Indian Health Center, serving the social, cultural, educational, and health needs of the community.

The Pink Shawl Project/Wisconsin Pink Shawl Initiative

The Pink Shawl Project is a community-based initiative started in Michigan in 2003 by Lorraine "Punkin" Shananaquet, a community health representative for the Match-E-Be-Nash-She-Wish Band of Potawatomi (Gun Lake Tribe). Her vision was to create a multigenerational forum for AI/AN women to raise breast health awareness and education issues in a noninvasive and culturally sensitive manner. The Pink Shawl Project has used two venues to bring attention to the issue of breast cancer in AI/AN communities: mother-daughter healing teas and local powwows. AI/AN women from local communities created traditional shawls in the color pink to be worn at powwows to raise awareness of breast cancer. The shawl is a visual reminder of the sacredness of life and the importance of women in the circle of life; like all regalia, the shawls incorporate stories and messages and are part of the teachings passed from one generation to the next. The idea was that the large number of pink shawls being worn at the powwow would gain attention, and that attention could be focused on breast cancer awareness in the AI/AN community. Today, the pink shawls have become symbols of awareness in AI/AN communities.[63]

In 2007, a group of AI/AN women in Milwaukee, some of whom were breast cancer survivors, gathered to discuss how they could raise breast health awareness among AI/AN women in southeastern Wisconsin. The women were interested in starting a local Pink Shawl Project and founded the Wisconsin Pink Shawl Initiative (WPSI) that year. They made their debut with sixty women in pink shawls at the powwow that year at Indian Summer Festival, one of the largest festivals held every summer on the Summerfest grounds in Milwaukee. WPSI's mission is "to reduce breast cancer in American Indian communities through education, advocacy and service and increase the number of American Indian women accessing screening opportunities." The all-volunteer AI/AN nonprofit sponsors a number of educational events including Dream the Cure conversations, small-group educational sessions moderated by specially trained Pink Shawl members. These events are designed to increase breast cancer awareness and likelihood to screen for breast cancer and provide a safe venue where women can talk openly about breast cancer and the impact it can have on their lives. WPSI also engages in ongoing outreach at area powwows and other community events, helps connect women with needed screening services and support, and offers support to AI/AN breast cancer patients and survivors.[64]

Junior Pink Shawls

In late 2009, this article's second author, Lisa Tiger, attended a WPSI educational event with her daughter Alexandra, the third author, who was then twelve years

old. After the workshop, there was a discussion of the gap between the numbers of women showing up at WPSI educational events and the number following up and getting mammograms, and the factors that motivate women to follow through with needed screenings. The consensus of the group was that a major motivator for AI/AN women in their community is their role as caregivers of their family. The third author suggested that women might need someone—such as their children—to inspire them and give them support to get their mammograms.

Out of this discussion emerged the idea for the Junior Pink Shawls (JPS). Together with the WPSI executive board, Lisa and Alexandra Tiger conceived of a group of AI/AN girls who would work alongside the adult WPSI women to further the group's mission while also routinizing breast health behaviors for the youth early in life. It was felt that engagement in this work could also help address other issues facing youth such as low self-esteem, lack of leadership skills, and lack of knowledge of health issues and healthy habits.

JPS was officially organized in the winter of 2010. It functioned as a youth-led community group with three complementary goals: (1) breast health education; (2) youth leadership development; and (3) youth health promotion. The group was open to all self-identified AI/AN youth in the Milwaukee area, although most of the founding members of the group had family connections to WPSI. JPS was led by a youth executive board that utilized a consensus model to make decisions about the group's activities. Meetings took place on a monthly basis and integrated educational and cultural activities centered around quarterly themes reflecting an AI/AN value or teaching. While youth-focused, JPS was not a dropoff program and asked for and expected adult engagement. Mothers, fathers, aunts, grandmothers, and other adults attended meetings and engaged in group activities with the youth, thus strengthening familial and intergenerational relationships and building a sense of community. In addition to monthly meetings, JPS engaged in a variety of outreach and educational efforts aimed at promoting breast cancer awareness, building the self-confidence and leadership skills of its membership, and preparing youth to be adult women taking responsibility for their own health.

As with the Pink Shawl women, the initial focus of the JPS youth outreach was powwows. During the initial JPS meetings, the Pink Shawl women worked closely with the youth to make pink shawls, and the JPS youth debuted during grand entry of the Indian Summer Festivals Mid-Winter Powwow in Milwaukee in March 2010. In addition, JPS staffed tables at Milwaukee-area powwows that provided information about the organization and gave JPS youth opportunities to talk with members of the public and promote health screenings and mammograms. One particularly successful engagement tool has been a whiteboard activity with the prompt, "Tell us your reasons why you will pledge to be screened." This activity provides an opening for the JPS youth to hear AI/AN women's reasons for getting (or not getting) mammograms and engage in conversations about the importance of breast cancer screening. The JPS youth have also engaged in similar outreach and education activities at other public events such as health fairs. By providing opportunities to engage adults in conversations about an important health topic, as well as individuals' concerns and

misperceptions, these activities have also been an important tool for building the self-confidence of the JPS youth.

In 2012, the JPS executive board decided they wanted to expand the group's messaging beyond its existing community-based outreach activities. They settled on the idea of producing a public service announcement that could be shared with broader audiences via YouTube. The concept was to create a short video that would present a simple message and be compelling to women who had been resistant to breast cancer screening. To generate the content of the PSA, the youth brainstormed two lists: (1) reasons why women may not get a mammogram, and (2) ways in which youth could inspire women to do so. Using these ideas, the JPS youth wrote and produced a one-minute video entitled "Breast Cancer Screening: Will You Do It for Me?"[65] Their message—"Who's going to take care of me if you don't take care of you? . . . Do it for Me. Do it before my next birthday"—is intended to encourage screening by situating women's health promotion in the context of their relationships to subsequent generations; their children and grandchildren.

Youth Health Messengers

Building upon the success of their approach and the PSA's message, JPS decided they wanted to develop an intergenerational youth health messenger program that would allow youth to communicate to family members one-on-one the importance of screening and encourage them to access age-appropriate screenings. As with the PSA, the model was designed to leverage intergenerational relationships to motivate women to prioritize screening while also adding an educational component providing information about the importance of screening and its role in early detection of breast cancer.

Whereas JPS developed organically out of community-identified needs, strengths, and interests, the intergenerational youth health messenger model and program was developed through a community-based partnership with the first author, a faculty member at the University of Wisconsin-Madison. Community-based approaches to intervention development, similarly to community-based approaches to research, emphasize equitable engagement of all partners throughout the development process and positive social change as an end goal.[66] Community-based approaches are guided by an issue of importance to the community, build upon the community's recognized strengths and resources, and promote co-learning and capacity-building.[67] Such approaches benefit youth by empowering them to use their voices, offer important and unique insights to issues affecting them, and develop skills untapped in other contexts.[68] In addition, by valuing youth for their unique contributions and having their knowledge and experiences legitimated by adults, community-based approaches empower them as agents of change.[69]

The goal of this project was to increase breast health knowledge and improve rates of breast cancer screening in the Milwaukee AI/AN community through the development and implementation of an intergenerational health and wellness messenger program. The youth health messenger model and materials were designed collaboratively by the first and second authors in partnership with the JPS youth. The youth

guided the development of the model, outlining the concept, goals, and content they envisioned. The academic partners examined existing models of youth change agents and AI/AN cancer health education, both local and national, and compiled examples we believed would be age-appropriate for the range of JPS youth involved.[70] The youth provided input and feedback on these examples which were utilized to develop the youth health messenger educational curriculum and materials. The youth also developed health messaging and selected an educational craft activity that were integrated into the project. The academic partners developed a simple evaluation designed to assess the effectiveness of the model in communicating messages about breast health and preventive screenings, and in convincing women eligible and due to access breast cancer screenings. While all JPS youth participated in aspects of the project development, their input varied depending on both age and interests.

The model utilizes a simplified breast health education curriculum modeled after the WPSI Dream the Cure conversations and interactive, culturally relevant activities for youth to engage in with family members. All JPS youth wishing to serve as youth health messengers participated in a one-day training session where they learned about the goals of the youth health messenger program and engaged in an age-appropriate discussion of cancer, the importance of early detection of breast cancer, and the tools doctors use to detect breast cancer early. To help them (and family members) remember recommended screening guidelines, they also came up with a simple mnemonic device: "Under 40—Doctor Exam. Over 40—'Mommy-gram.'"[71] In addition, the youth reviewed all of the materials they would use in their "Breast Health Conversation" with a family member, and practiced these conversations with their peers and adult volunteers.

Once trained, the youth health messengers selected an adult female family member to ask to participate in a Breast Health Conversation with them. These educational sessions are designed to position the youth as the "teacher" and the adult as the "student." Youth start a conversation about breast cancer and screening by reviewing "Breast Health: The What and the Why" with their family member. This illustrated booklet, developed specifically for the project, provides a template for youth to discuss cancer and preventive screenings using simple language and age-appropriate illustrations. To help illuminate the importance of screening and early detection, the youths review with their family member three illustrated flash cards that illustrate the approximate size of breast cancer tumors that can be detected through different screening mechanisms: the tip of a toothpick (mammography); a pony bead (clinical breast exam); and a golf ball (breast self-exam). The youth and their family member then use supplies provided by JPS to create matching bead necklaces using beads representing the three tumor sizes. The purpose of this interactive craft is to leave the family member with a memento of their educational session, the importance of screening to early detection, and the importance of preventive health care in the context of preserving intergenerational relationships into the future, as well as a potential tool for sharing their knowledge with others. At the end of the session, the family member completes an evaluation form assessing screening status and past screening behavior, changes in knowledge and intent to screen, and the effectiveness of the Breast

Health Conversation. Finally, women eligible and due for screening are asked to sign a "Promise Card" to get their appropriate breast cancer screening before their "teacher's" next birthday.

While the youth health messenger model is still in the process of being evaluated, based on informal conversations with program participants and community members we know that this framing of cancer screening in the context of intergenerational relationships resonates with many AI/AN women in the community and that it may provide that additional push needed to follow through with breast cancer screening. Improved screening rates are key for improving cancer health outcomes today. However, we also believe that this model can have important implications for the preventive health behavior of tomorrow's AI/AN adult women. Because AI/AN youth are learning important lessons about women's health and breast cancer screening at an early age, the model has the potential to impact the youth's own future health outcomes as they internalize these messages and prioritize preventive health care in the future.

Discussion

Community-based, culturally framed health education interventions have met with success in improving breast cancer knowledge and screening in AI/AN communities, yet disparities persist. Junior Pink Shawls (JPS) and its intergenerational youth health messenger model grew out of recognized challenges in motivating AI/AN women to follow through with breast cancer screenings and the youths' desire to encourage the women in their lives to get screened.

The intergenerational youth health messenger model is premised on the idea that women will engage in health promotion activities for their children or grandchildren that they would not engage in for themselves. As noted by Hodge and Casken, and reiterated by women in Milwaukee, family and community are of high importance for AI/AN women, and they tend to prioritize their family's health needs ahead of their own.[72] To convince women to attend to their own preventive health care, it is necessary to connect it to the health and well-being of themselves and their families in the future. The youth health messengers do this by simultaneously communicating the importance of preventive breast health screenings to the women in their families while utilizing the strength of their intergenerational relationships as both social capital and an inspirational motivator. As the JPS youth emphasize in their PSA, "Who will take care of me if you don't take care of you?" The well-being of the youth, both from a physical and cultural standpoint, is dependent upon the elder women in their family attending to their own preventive health needs and ensuring the maintenance of their intergenerational relationships long into the future.

We see the youth health messenger model and its associated education and outreach activities as having positive impacts on AI/AN women, the participating youth, and the larger community. While evaluation of the model is still underway, we have anecdotal evidence that the message presented by the youth health messengers resonates with women and that for some, this may convince them to follow through

with breast cancer screening. However, we see other benefits as well. Having youth engage one-on-one with family members reinforces intergenerational relationships and bidirectional transfer of knowledge. Even if the message does not result in a change in screening intentions or behavior, the act of engaging in the conversation provides an opportunity to strengthen relationships, reinforces the importance of the elder women in the lives of youth, and offers an opening for sharing knowledge and perspectives.

JPS and the youth health messenger model also have a positive impact on the youth themselves. Participation has led to increased youth self-efficacy and leadership skills. Through this youth-led organization and project, the youth have been empowered to use their voice and offer their own perspectives and insights. As youth health messengers, they have taken on roles that position them as teachers with knowledge to share. In some cases, they have gained experience as cultural brokers, navigating women's fears and misperceptions about cancer screening and Western versus traditional beliefs about cancer. They have also shared their experiences and insights with both members of the community and professional audiences and had their perspectives respected and legitimated by adults. These have all served to increase their belief and confidence in themselves and, for some, develop their skills as leaders within their community. It has also demonstrated to them that as youth they have the power to take action to create meaningful change in their community.

The youth have also had the opportunity to see their value and place in the community recognized. In their inaugural powwow, they were given an honored position in grand entry directly behind the Honor Guard and royalty, and their organization and mission was announced by the emcee to the crowd. JPS youth flanked the WPSI elders, visually reinforcing the intergenerational theme. Through the reception of their organization and message in the community, they have also seen the traditional values of youth autonomy and leadership reflected.

Youth engagement in this project also has the potential to positively impact youth health, both now and in the future. Health and nutrition have been central themes of JPS meetings, and the youth are taught about the importance of healthy eating and physical activity. In addition, the youth health messenger training teaches participating youth important lessons about preventive health care and the importance of screening in early detection of cancer. We are hopeful that these lessons are internalized leading to the prioritization of preventive health care when they reach adulthood.

Finally, we see this project as having positive impacts on the larger AI/AN community. The youth health messenger model reinforces teachings that emphasize the importance of relationships and intergenerational work. It is also raising awareness at the community level of an important but feared health issue facing AI/AN women, and reframing it in a positive context (preserving intergenerational relationships). Finally, we think that positioning youth as a center-point for creating positive change in communities, as Junior Pink Shawls does, provides an important counterpoint to the boarding school era, a dark chapter in AI/AN history when youth were forcibly removed from their families and communities and unwittingly used as tools of assimilation.

While we believe that the youth health messenger model has the potential to positively impact AI/AN breast cancer screening rates and, consequently, cancer health outcomes, we recognize that there are many other barriers to screening that this project does not address. This model is specifically aimed at encouraging busy or reluctant women to prioritize and follow through with breast cancer screening. While referrals to the Wisconsin Well Women Program[73] were available to women without insurance, other barriers including lack of transportation, child care, and culturally competent care remain.

We also note that the simplified educational messages provided by the youth health messengers are not meant to be a replacement for the more in-depth cancer education curricula offered by WPSI and other successful AI/AN cancer education programs. These programs, as well as associated navigation and peer mentor programs, provide critical culturally appropriate knowledge and tangible assistance that have been demonstrated to be important in improving screening rates and cancer health outcomes. We do, however, believe that this model offers a unique point of entry and motivation for those who may be reluctant to think about, discuss, or prioritize preventive breast cancer screenings.

While we found success with and acceptance of this model, we recognize that not all communities would be as accepting of youth stepping into the role of educator to parents or elders, particularly around topics that may be considered sensitive. Communities must decide if such a model would be considered appropriate and, if so, what topics they would feel comfortable having youth engage. While this model was developed to encourage breast cancer screening, its approach could be applied to a broad range of community health issues or other topics.

Based on our experiences through this project, we offer the following recommendations to others wishing to develop or implement youth health change agent models:

(1) Have youth integrally involved in program development. To the greatest degree possible, have youth guide the foci, goals, and activities of the group. Decision-making processes and roles should be negotiated by the youth, with youth involvement guided by the interests, maturity and capabilities of each individual. This will facilitate youth ownership of the program, help them build confidence and self-efficacy, and empower them to explore creative solutions. Adults should serve in an advisory capacity, providing support, guidance and advice but avoiding a top-down approach.

(2) Design the program to fit with local needs, priorities, and culture. While youth should take leadership in shaping the foci and goals of the group, they should be responsive to local needs and priorities. If these are not clear at the group's inception, the youth can be encouraged to engage in a form of needs assessment as part of their work. This will educate youth as to pressing local issues and help ensure that the program brings concrete benefits to the community; it will also reinforce the value and place of the youth in the community and a sense of purpose through their contributions. In addition, the program, curriculum, and activities should be designed to fit with the shared culture and values of the community. This will help ensure that the program both reflects the community it serves and resonates with those whom it engages.

(3) Promote strong family and community involvement. Include parents, grandparents, extended family, and interested community members and leaders in the program. Collectively, these individuals can help provide a context for the needs, priorities, and history in the community and help provide a strong cultural foundation for the work. Their involvement will also help strengthen the youth's familial, community, and cultural relationships, build a sense of community, and provide a context for intergenerational learning and sharing.

(4) Ensure approach and materials are age-appropriate. A program engaging preteens will look very different from one employing youth in their late teens. Design the approach, materials, activities, and trainings to be appropriate to the age of the youth involved in the program. This will help keep youth engaged in the program, and ensure that they can comprehend the material and communicate it to other audiences. If a range of ages is involved, the approach and materials can either be targeted to the abilities of the younger members or vary by age with older youth taking on more responsibility or more complicated tasks/material. Older youth can also mentor or partner with the younger youth. While there might be some concerns about simplified content, it is important to consider that programming offered by the youth does not necessarily have to be comprehensive. Instead it could be viewed as a steppingstone to other, more comprehensive health education in the community. If simplified curriculum or materials are used due to the inclusion of younger youth, investigate other community resources that could be used to supplement the youth education or advocacy.

(5) Partner with other organizations in your community with complementary missions and interests. Recognize that your youth program cannot (and should not) try to develop all materials and resources from scratch or address all aspects of the issue it is trying to address. Find and partner with other organizations in your community with whom you can build mutually beneficial relationships. These can include other organizations engaging in education or advocacy work on the same issue or topic, clinics providing services, agencies that can provide material or financial resources, etc. It can also include academic institutions that can partner to conduct related research or evaluation, or help youth build capacity to engage in these activities themselves.

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