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Cervical Cancer Screening: Exploring Appalachian Patients' Barriers to Follow-Up Care

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Abstract

This article describes a community-based Patient Navigation (PN) project conducted to identify potential barriers to seeking follow-up cervical cancer care in southeastern Kentucky. Patient navigators (PNs) were placed in cervical cancer programs within county public health departments where they interviewed patients about their perceived barriers to seeking follow-up care after receiving a positive Pap test result. Participants identified various potential barriers at three levels:

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the individual/personal level, the health care system level and the community/environmental level. One identified barrier that was unique to this study was a lack of consistency between follow-up recommendations and follow-up guidelines for patients under age 21. Implications are discussed.

Keywords

cervical cancer; pap test; follow-up care; patient navigators; Appalachian patients

INTRODUCTION

Appalachia has long been a region associated with tight knit communities and camaraderie as well as an area characterized by geographic isolation, high rates of poverty, significant health disparities, and poor health outcomes (Lengerich et. al., 2006). Fifty-four of the 120 counties in Kentucky are designated as Appalachian (Appalachian Regional Commission, 2013). The socioeconomic indicators for these counties are considerably lower than those for non-Appalachian counties as a whole, and the overall health disparities that exist in these communities are excessive (McGarvey et al., 2011). While formidable efforts to address these health disparities are ongoing, these disparities remain, especially in the area of cancer prevention.

The question of what facilitates the continuation of health disparities in Appalachia persists. In terms of cancer screening and care, cost is often identified as a barrier to seeking services. In response to this concern, screening and follow-up for cervical cancer is provided through local health departments and federally qualified health centers at minimal cost, and by health care providers in private practice, yet cervical cancer mortality rates remain elevated in Appalachian counties (Freeman & Wingrove, 2005). Additional research is needed to identify and consider barriers that may be interfering with cancer screening-related health behaviors in Appalachian populations. Approaches sensitive to the Appalachian culture are needed so that once identified, those barriers can be more effectively addressed.

One unique approach to addressing health disparities that is being used of late is the addition of patient navigators to health care teams. Patient navigators (PNs) are trained lay community health workers who assist patients to navigate barriers to accessing health care (Cohen, Scott, White, & Dignan, 2013). The National Cancer Institute suggests that PNs can be effective at providing guidance and support to patients with abnormal cancer screening results living in medically underserved communities (Cohen et al., 2013). The use of patient navigators also reduces the practice burden of more highly trained health professionals, including social workers. Patient navigators interact with patients extensively and at-length, so they are also uniquely positioned to work with patients to explore and identify barriers to care.

In light of the ongoing need to identify and address barriers related to follow up care in medically vulnerable populations, the purpose of this paper is to describe the barriers detected during a patient navigation intervention in Appalachian Kentucky.

REVIEW OF THE LITERATURE

Appalachia is a unique geographic region that encompasses 410 counties along the Appalachian mountain chain across 13 states (Appalachian Regional Commission, 2013). Cancer disparities are pronounced in the Appalachian region (Paskett et al., 2011b). Cancer mortality rates within the counties of Appalachia are significantly higher when compared to non-Appalachian, in-state counties (Blackley, Behringer & Zheng, 2012). Indeed, the elevated rates of cancer are what motivated the National Cancer Institute (NCI) to recognize the residents of Appalachia as a special population with cancer health disparities (Appalachian Regional Commission, 2002). Rates of invasive cervical cancer in Appalachia are highest in Kentucky, West Virginia, and Ohio (Hopenhayn et. al., 2008). In Kentucky, the cervical cancer incidence difference between Appalachian and non-Appalachian residents is 26.1% (Appalachia Community Cancer Network, 2006). This elevated cervical cancer incidence rate is even higher in rural Appalachia, which suggests that access to health care may be extensively compromised in less populated areas (Lengerich et al., 2006). Low income, Appalachian women are among the groups of women least likely to be screened for cervical cancer (Behringer et al., 2007; Documet et al., 2008).

Several barriers to seeking cervical cancer screening have been associated with women living in Appalachia. Populations of women who experience the greatest cervical cancer burden may not accept or understand the need for cervical cancer screenings, they may not have access to medical care, and they may not be educated to understand the new guidelines that direct the need for preventive cervical cancer screenings (Scarinci et al., 2010). In a group of 345 Appalachian Kentucky women who had either never received a Pap test or had not received one within the last 5 years, identified barriers to screening included a belief that if a woman had cervical cancer she would experience defining symptoms, and a lack of access to regular medical care (Hatcher et al., 2011).

Evidence suggests that interventions to address barriers and improve cervical cancer screening and follow-up compliance need to be examined (Bernard, Lawson, Eheman, Anderson, & Helsel, 2005; Paskett et al., 2010), and that these interventions need to be culturally tailored to the target population (Erwin et al., 2003). Patient navigators, lay health workers, and community health workers have all been used in health care settings to improve care, provide educational interventions, and address barriers to prevention services.

The use of PNs to increase cancer screening and follow-up care is recommended, especially with poor and underserved patients in medically underserved areas like Appalachia (Braun et al., 2012; Dohan & Schrag, 2005). Research indicates that PNs can be effective in assisting medically vulnerable patients with cervical cancer follow-up care (Cohen et al., 2013; Ell et al., 2002). Others suggest that PNs are well situated to guide patients through complex system barriers within fragmented health care systems (Domingo, Davis, Allison & Braun, 2011). Patient navigators are uniquely situated to intervene to increase both screening and follow-up when a Pap test indicates that follow up is necessary (Paskett et al., 2011a). While evidence surrounding PN programs suggests that positive results can be achieved, the literature also suggests that patient navigator research on a variety of patients across the cancer continuum is still needed (Wells et al., 2012).

In light of the need for more research in this area, this article describes the barriers that were identified and documented during a patient navigator project. Implications for social work practice are also discussed.

METHODS

Study Design

A community-based Patient Navigator (PN) program was developed in partnership with local public health departments in Appalachian counties in Southeastern Kentucky. The project was designed as a trial consisting of two groups of county public health departments: an intervention group who received patient navigation services and a comparison group who received the current standard of care. Data were collected from September 2008 through April 2010. Eligible participants included female patients 18 years and older who had an abnormal Pap test result during the study period. Patients under age 18 were excluded. The project was reviewed and approved by the Institutional Review Boards of the University of Kentucky and the Kentucky Cabinet for Health and Family Services.

Health Department Recruitment and Patient Navigator Training

County public health departments serving rural populations in southeastern Kentucky were recruited to participate in the project. The health departments hired the PNs. The qualifications for the position were being female and being familiar with the area served by the health department. The PNs were assigned to work with 2–3 health departments and were based in a “home” health department. The investigators trained these individuals to serve as PNs in health departments’ cervical cancer screening programs. Training focused on providing PNs with strategies to help public health department patients needing follow-up for abnormal Pap tests navigate the health care delivery systems in their rural communities. A manual developed specifically for this project was used to guide project training. The manual covered the following topics: (1) an overview of the project; (2) patient navigation protocol; (3) human subjects protection; (4) information about cervical cancer risks factors, procedures used to detect and diagnose cervical cancer, and treatment methods; and (5) roles and responsibilities as a PN.

Participant Recruitment and Intervention

Health department staff referred patients age 18 and older with abnormal Pap test results to PNs. The PNs then sent letters to the patients introducing themselves, describing the project and inviting patients to participate. If patients were interested, arrangements were made to meet them at a convenient location at which time the PNs obtained informed consent and administered a baseline interview. Participants were offered a $25.00 gift card for their time and travel costs. The interview was designed to collect information about barriers to obtaining follow-up, in addition to demographic characteristics. Navigation varied according to the recommendation but in all cases included education and support to ensure adherence to follow-up recommendations. The PNs documented all follow-up recommendations, barriers, patient needs, and specific actions taken to ensure adherence with follow-up recommendations.

RESULTS

A total of 13 public health departments participated in the study. Six PNs were recruited and trained by the investigators. A total of 1,039 potential study participants were referred to the PNs over an 18-month recruitment period and 519 provided informed consent and were enrolled.

Demographic Characteristics

The demographic characteristics of the 519 study participants are shown in Table 1. U.S. Census data describing the populations of the counties where the women resided are also shown in Table 1 (U.S. Census Bureau, 2013). The women enrolled in the study were similar in terms of race, but tended to be younger with more education, were more likely to be unmarried and were more likely to have lower incomes when compared to the overall county population.

Identified Barriers to Obtaining Follow-Up Care

Study participants reported a wide variety of factors that they identified as potential barriers to obtaining follow-up care following an abnormal Pap test. Three levels of factors that might influence a woman to seek follow-up care were identified including individual, health care systems, and community/environment factors (Table 2). Personal factors such as cost and lack of insurance were reported by 46% and 51% of women, respectively; however, over one third reported getting follow-up care was not a problem. Among the health care systems factors, women reported “I am afraid of what they might find” (35%); “I have not had to do this before” (23%); and “It will be painful” (25%). Community and environmental factors seemed to be less of a barrier to getting care as only 15% of women reported they did not have transportation or a way to get to the appointment and only 6% reported the roads made it difficult to get to the appointment.

An important barrier to care that was uniquely identified here was inconsistent adherence to the established guidelines for follow-up care. While, overall, the recommendations were generally consistent with the 2006 Consensus Guidelines (U.S. Department of Health & Human Services, 2013) for women over age 21, for women under age 21, the health departments occasionally recommended follow-up when not indicated by the guidelines.

DISCUSSION

Patient Characteristics

Results of the current study suggest that the characteristics of the women enrolled in the project were generally reflective of the county population. While the women tended to be slightly younger and fewer were currently married, this difference is consistent with the characteristics of the clientele of most public health departments in this geographic area (Behringer & Friedell, 2006).

Identified Barriers

The PNs were very successful enrolling women for the study, indicating a capacity to interact effectively with this vulnerable population, which is consistent with previous research (Braun et al., 2012; Cohen et al., 2013; Dohan & Schrag, 2005; Feltner et al., 2012). Of those eligible, the enrollment rate was nearly 80%. During the baseline interview, the PNs were very successful at getting patients to identify potential barriers for seeking follow-up care, indicating a potential for identifying and addressing barriers that has not been possible in settings without navigation services. PNs were also successful at identifying whether recommendations for follow-up were consistent with consensus guidelines, which was also a barrier. Based on this information and the type of follow-up care recommended, the PNs personalized their navigation efforts to meet the needs of the patient, indicating the flexibility of the PNs to tailor their efforts to the individual based on personal circumstances, something overworked health professionals may not have time to accomplish, given their other responsibilities.

Guidelines

The recommendations of the health departments differed from the 2006 Consensus guidelines to some extent. In particular, medical guidelines for women under age 21who have an abnormal Pap test result differed from the recommendations provided by the health department. Conversely, results from adult patients ages 21 and older suggest that recommendations for this age group provided by the health department were consistent with the consensus guidelines most of the time. These discrepancies suggest lack of adherence to the guidelines, but it remains unclear as to whether such is contributing significantly to cervical cancer follow-up treatment adherence.

This lack of adherence to the guidelines is a barrier not identified in previous studies. In many instances women were requested to do more actions that the guidelines would require, which would involve additional time and perhaps additional cost for the patient. If recommendations are unnecessarily excessive, they could be perceived as insurmountable barriers to these women, and thus potentially interfere with their follow-up care seeking behaviors.

While additional research is needed, medical professionals in health departments may need to pay closer attention to bridging the gap between guidelines and health department recommendations. Perhaps PNs could be trained to compare actual recommendations to guideline recommendations and work closely with health department staff to resolve any identified discrepancies. Alternately, social workers may be needed to address this area of intervention as it may require a more specialized scope of practice than what the PNs would be comfortable delivering.

Additional Barriers

Outside of the guidelines to care, the barriers that were reported by patients to the PNs were varied and complex, as was consistent with extant research (Cohen et al., 2013). Some of the barriers could logically be addressed using PNs. For example, if PNs are trained to educate patients about free and reduced-cost for follow-up services, regardless of insurance, then one of most commonly identified barriers (concern about cost) could possibly be addressed by the PNs on site.

Patient Navigation and Social Work

Some of the barriers to care are complex and may fall more naturally within the scope of practice of the public health social workers (Ely, Miller & Dignan, 2011) who are practicing in these communities. These social workers are already specifically trained in areas such as evidence based counseling techniques that can help patients cope with barriers at all three of the identified levels. For example, counseling for psychosocial stressors such as fear, embarrassment and family interference is well within the scope of practice for a trained social worker. These social workers also have specialized training in the area of coordinating resources that may help patients cope with macro oriented barriers such as lack of access to childcare.

It is also important to consider that one-third of respondents indicate that they do not experience barriers to follow-up care, yet still may not be seeking the recommended care. This is an area where social workers may be needed to further address the potential resistance to follow-up with these women. Counseling and assessment techniques can be provided in order to increase follow-up care with the women who do not identify barriers when working solely with the PNs.

As research begins to support the effectiveness of identifying and addressing barriers using patient navigation services, considerations should be made in terms of adding permanent patient navigation teams to health care settings, especially settings serving medically vulnerable patients. The results of the current study suggest the effectiveness of lay patient navigators in terms of documenting barriers to care. The question then becomes what level of training and education should patient navigators have when they are part of a permanent health care team? Previous study results indicate that pairing lay navigators with master’s level social workers is an effective model for reducing barriers to treatment adherence in medically vulnerable populations (Ell et al., 2002). Another potential approach includes adding trained social workers to primary practice settings as the actual patient navigators., Previous research suggests that using degreed social workers as patient navigators, rather than lay workers, may greatly assist both patients and primary care practices when navigation service needs are varied and more complex (Ferrante, Cohen, & Crosson, 2010). In fact, social workers have functioned informally as navigators in health settings for years (National Association of Social Workers, 2010), so by adding trained social workers with navigation responsibilities to health care teams, patient navigation can be permanently incorporated into heath care delivery systems. In such cases, the social workers can provide services within their scope of practice in addition to patient navigation, and thus offer the patient access to more specialized care than could be provided by lay navigators.

Limitations of the Study

One limitation of the study is lack of generalizability to cervical cancer screening programs beyond those included in this project. In addition, almost a third of the women who were eligible could not be reached by the PNs and offered enrollment in the study. The screening outcomes for these women remain unknown. Because of the way that information about barriers was collected, a more sophisticated statistical analysis was not possible in the current study. Furthermore, employing lay navigators from the community for this study may have introduced social approval bias to the process of collecting information about barriers, as is suggested in research by Adams and colleagues (2005). Such limitations should be addressed in future research.

Directions for Future Research

Additional research is needed to more completely explore the utility of PNs in working with patients with other health-related issues. The barriers detected in this study are also commonly experienced by patients with other diseases such as diabetes. An additional area for future research is the contribution of PNs in controlling health care costs. Research is also needed that pairs PNs with social workers to determine ways in which this type of partnership can best be used to address barriers to follow-up care in medically compromised patients.

The use of key informants to probe for a more complex understanding of existing barriers could improve the ability of researchers to identify and then address such barriers, especially in patients who initially did not report experiencing any. The use of a community advisory board to guide future studies may also improve the ability to understand culturally specific barriers in this community.

CONCLUSION

The social justice orientation of both public health social workers and patient navigators makes them a natural fit for pairing together (Ely et al., 2011) to address the barriers that prevent patients from seeking follow-up care in light of an abnormal Pap test result. It also makes social workers a natural fit for adding patient navigation to their scopes of practice in health care settings. Interventions need to be developed that pair social workers up with PNs so that the barriers to care can be addressed once patients identify them. In some cases PNs may be equipped to address the barriers on their own while freeing up social workers and other medical staff to focus on counseling and referrals. In other cases, social workers may be needed to provide assessments and counseling techniques while PNs address education and information needs. Additionally, interventions where social workers act as the patient navigators also need to be developed in order to determine which model provides the best range of services to the patients. Such approaches need to be implemented and evaluated if we are to affect cervical cancer mortality rates present in these medically compromised Appalachian communities.

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TABLE 1

Demographic Characteristics (Enrolled Women Compared to All Intervention Counties)

	Enrolled(N)	**All study counties**[a]
Age		
18–24	251 (48.4%)	7, 034 (7.3%)
25–44	206 (39.7%)	32, 628 (33.8%)
45–64	56 (10.8%)	35, 617 (36.9%)
65+	6 (1.2%)	21, 160 (21.9%)
Race		
White	499 (96.2%)	94, 518 (98.0%)
Black/African American	5 (1.0%)	833 (0.9%)
Other	15 (2.9%)	1, 088 (1.1%)
Marital Status		
Married	173 (33.3%)	59, 547 (58.5%)
Not Married	343 (66.1%)	42, 218 (41.5%)
Education		
Less than High School	115 (22.2%)	35, 726 (37.0%)
High School	249 (48.0%)	31, 049 (32.2%)
Vocational School	9 (1.7%)	No data
College /Graduate School	146 (28.1%)	13, 626 (14.1%)
Income		
<$10,000	213 (41.0%)	22, 176 (22.9%)
$10,000–$50,000	241 (46.4%)	57, 761 (59.6%)
$50,000+	18 (3.5%)	17, 045 (17.6%)

[a] Data from U.S. Census Bureau; Age and race data are estimates of women age 20 and over, 2009; Marital status data are women age 15 and over, 2000; Education data are women age 25 and over, 2000; income data are household income levels from 2000.

TABLE 2

Perceived Barriers to Obtaining Follow-Up

	Enrolled (N)
HPV Vaccine Awareness (Heard of HPV Vaccine)	
Yes	408 (78.6%)
No	110 (21.2%)
Barriers to Follow-up Care	
Individual Level Factors	
It costs too much	237 (45.7%)
I don’t have the time	75 (14.5%)
I didn’t realize it was important to get follow-up care	23 (4.4%)
I don’t know what to do to take care of my health	23 (4.4%)
I don’t have insurance	265 (51.1%)
My physical limitations	22 (4.2%)
Getting follow-up care is not a problem for me	185 (35.7%)
Health Care Systems Factors	
There aren’t enough doctors in my community	28 (5.4%)
I do not trust the health care providers	12 (2.3%)
I cannot understand what the health care providers are saying to me because I do not speak English well enough	15 (2.9%)
I have trouble understanding the written information that I have received because I do not read well	18 (3.5%)
Having a male health care provider	74 (14.3%)
Clinic hours	76 (14.6%)
I have not had to do this before	121 (23.3%)
I am concerned about my privacy	51 (9.8%)
I am afraid of what they might find	184 (35.5%)
It will be painful	132 (25.4%)
I’m too embarrassed	81 (15.6%)
I’m afraid that I won’t be treated with respect	25 (4.8%)
I don’t want to go to the place recommended	10 (1.9%)
Lack of childcare	67 (12.9%)
Community/Environment Factors	
The roads make it difficult to get to the appointment	31 (6.0%)
My family/friends don’t think I should	5 (1.0%)
I don’t have transportation or a way to the appt.	79 (15.2%)